A qualitative investigation into the experiences of children who have a parent with a mental illness

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Medical and Human Sciences

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Abstract

This thesis investigated the experiences of children who have a parent with a mental illness, using qualitative methods. It is divided into three separate sections, the first two written as standalone journal papers. Paper 1 is a systematic review and synthesis of qualitative studies exploring children’s experiences of having a parent with a mental illness. The review used specific databases, a search of qualitative journals and a general internet search to identify relevant studies, and the subsequent application of inclusion/exclusion criteria and a quality appraisal assessment. 14 studies meeting inclusion and quality criteria were identified exploring the experiences of 163 children and young people aged between 5 and 22 years, from a range of countries, with a variety of parental mental health diagnoses. The review then involved synthesising the findings of these studies to generate five overarching themes which were found to influence children’s experiences. Children who had some knowledge and understanding of their parent’s mental illness were more likely to use effective coping strategies, have a more positive relationship with their parent, and experience fewer negative effects on them as a child.

Paper 2 is an original research study which explored the experiences of children who have a parent with bipolar disorder, to see how this might impact on the child’s emotional wellbeing. This qualitative study used ‘In My Shoes’, a computer assisted interview tool, to explore the experiences of ten children from England aged between 4 and 10 years. Subsequent comparison with their parent’s accounts enabled greater insight into family life. Child and parent interview data was analysed using thematic and content analyses. The four main themes that emerged from the child interviews were: knowledge and awareness of bipolar disorder; perception of parents; managing family life with a ‘bipolar’ parent; and living in a family with bipolar disorder. The study concluded that further research was needed to understand children’s perspectives, which should be taken into account when developing appropriate services and
interventions to support children and parents with mental illness, including bipolar disorder.

Finally the third section of the thesis was a critical appraisal of the literature review, research study and research process as a whole, including methodological reflections, implications for future research and clinical practice, and the researcher’s personal reflections in undertaking the research. The findings were deemed vitally important for the future of families in which a parent has bipolar disorder.
Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Acknowledgements

I would like to thank my supervisors Rachel Calam, John Fox and Fiona Ulph for their support and guidance throughout the research process. I would also like to thank my fellow researcher Rebecca Murphy who worked alongside me on the associated research study. I could not have got through this without your encouragement during those ‘stressful times’!

I would like to thank my close friends, colleagues and fellow trainees for their constant support and patience, especially in the last few months prior to thesis submission.

Thank you to family, specifically my mum and dad, who have always believed that I could do it. I hope that I have made you proud and I appreciate everything that you do for me.

Finally to Paul and our beautiful daughter Emily; I know I must have been a ‘pain’ to live with during this process, and I thank you for your love and support. Emily, you can now have your mummy back!
The experiences of children who have a parent with a mental illness: A review and qualitative synthesis

This is paper 1 and has been prepared in the format of a journal article to be submitted to The British Medical Journal (BMJ). The style and format, including references, reflects the BMJ's guidance for submission (see Appendix 17). The paper is a literature review using the meta-synthesis approach reviewing the experiences of children who have a parent with a mental illness.

Word Count: 9266
The experiences of children who have a parent with a mental illness: A review and qualitative synthesis
Abstract

Objective
To synthesise the views and experiences of children who have a parent with a mental illness.

Design
Systematic review of qualitative studies exploring children’s experience of having a parent with a mental illness and a synthesis of study findings.

Data Sources
Databases: AMED, CINAHL, Embase, Medline, Ovid MyJournals, PsychINFO, PubMed, SSCI, Web of Science (search period up until March 2011); search of qualitative journals; general internet search.

Review Methods
The literature search involved the application of inclusion/exclusion criteria and a quality appraisal assessment. The synthesis involved: identifying key themes, concepts and phrases from each study; looking for similarities and differences; determining whether there were reciprocal or refutational translations; and synthesising the translations to create overarching themes to explain the phenomena in all of the included studies.

Results
The review identified 14 studies that reported experiences of 163 children and young people aged between 5 and 22 years from a range of countries. Parental diagnoses ranged from affective/mood disorders, to schizophrenia and personality disorder. Five major themes were identified which influenced children’s experiences: knowledge and understanding of parental mental illness; coping strategies and support; parent-child relationship; social, emotional and behavioural effects on the child; and the role of other people & society.

Conclusions
Children who had some knowledge and understanding of their parent’s mental illness were more likely to use effective coping strategies, have a more positive relationship with their parent, and experience fewer negative effects on them as a child. Children who struggled to understand and had little or no information were more likely to use maladaptive coping strategies, experience a range of negative effects and have a more problematic relationship with their parent.
Introduction

Background

Estimates suggest that there are over two million children living with a parent with a mental illness in England and Wales. Between 50% and 66% of parents with a severe and enduring mental illness live with one or more children under 18, which amounts to approximately 17,000 children and young people in the United Kingdom. There have been a number of published review articles and narrative papers focusing on the impact on children of having a parent with a mental illness. Many families do not have any difficulties, and children who have remained ‘healthy’ and seemingly unaffected by their parent’s illness have been labelled as ‘resilient’ or ‘superkids’. However the majority of research suggests that children with a parent with mental illness are at a significantly greater risk for multiple problems such as: developing a mental illness themselves, developmental delay, lower academic competence and difficulties with social relationships. Most research studies have been quantitative in nature, often exploring the pathological effects on children and risk and resilience factors. An extensive literature review was commissioned in Australia by the NSW Department of Community Services. This review explored consequences for children of parents with mental illness and the effectiveness of interventions designed to assist children and their families. It extended on the findings from a similar review produced by the United Kingdom’s Social Care Institute for Excellence. The Australian review found that parental mental health issues were a significant reason for the reporting of children to child protection services. There was also strong evidence of a link between parental mental illness and child maltreatment. Finally the review found that children whose parents had a mental illness were at an increased risk of adverse consequences other than maltreatment, including: developing mental health problems as they get older; perinatal complications and other health problems; social and behavioural problems in childhood and adolescence; and suffering the consequences...
of stress associated with caring for parent with a mental illness. In terms of vulnerability and resilience, the review highlighted important factors such as: the level of parental awareness of their illness and insight into the effects on themselves and their children; the severity and chronicity of the mental illness and the age of the children at illness onset; and whether or not the illness has been diagnosed and being appropriately treated.

Due to the increased risk to children of parents with mental illness, resources have been designed and are available within the ‘grey literature’ to help children and families in which a parent has a mental illness. Leaflets, information packs and web resources have been developed by charities such as MIND, Barnados and The Mental Health Foundation to help families understand and manage crises and difficulties relating to the impact of parental mental illness. Organisations such as the National Health Service (NHS) and The Royal College of Psychiatrists have also designed resource packs and information to help support families, and there are specific websites primarily targeting children of parents with a mental illness containing a range of downloadable resources. However, it is acknowledged that all these resources are available in isolation, have not been formally evaluated for effectiveness and are not readily accessible unless children and families have been signposted by professionals.

Despite the overwhelming evidence that children of parents with mental illness are at greater risk, what is apparent is the lack of focus from the child’s perspective, and many of the resources referred to above have been designed without consultation with children and young people to see what they would find useful. It is widely acknowledged that research about families often centres on parents and parenting issues and overlooks the experiences and views of the children. It has been argued
that children are often excluded from the social and political contexts in which their problems occur\textsuperscript{23}. Children are often viewed as objects of research rather than active participants, and the views of others such as parents, teachers and professionals are more often sought than the perspectives of children themselves\textsuperscript{24}. With the increasing recognition and acknowledgment that qualitative research can offer rich and important information about health and mental illness, as well as people's unique experiences and insights, more recent research has begun to explore children's generic understanding of mental illness. Wahl's (2002) review found that younger children do not show a clear concept of mental illness but their understanding becomes more sophisticated with age\textsuperscript{25}. The early research suggested that younger children confuse mental health problems with physical illnesses and learning disability, whereas older children were more able to understand the link between mental health problems, emotions, cognition, as well as the observed behaviour. Roose & John (2003) suggested that the sophisticated understanding of mental illness by children in their study meant that young people should be involved in discussions about developing services for their age group\textsuperscript{26}. This perspective was taken in Australia, where young people were consulted about service guidelines relating to parental mental illness\textsuperscript{27}. It has been suggested that a better balance needs to be achieved by focusing on the family as a whole, as well as the individual needs of the parent and child\textsuperscript{28}.

Young people's perspectives have also been sought about their personal attitudes towards mental illness and the factors which influence this, for example the media\textsuperscript{25, 29}. More recently some studies have begun to explore the direct experiences, understanding and attitudes of children actually living with a parent with mental illness. Some of these focus on children in the caring role\textsuperscript{30-31} or retrospective accounts from adult children\textsuperscript{32-34}, but little attention has been paid to children's views of what might be useful to them in coping with their families' circumstances. Gathering information about
children’s experiences is vital if effective services are to be designed which are both beneficial to these children and also cost effective for the National Health Service.

**Aim**

Given the emerging qualitative research exploring children’s perspectives and the fact that this type of research is not traditionally included in systematic reviews, the purpose of this paper was to review and synthesise the qualitative research exploring children’s experiences of parental mental illness. The specific research question was ‘What are the experiences of children who have a parent with a mental illness?’ Without reviewing qualitative studies, knowledge development and implications for clinical practice are hindered unless the important findings from these studies are explored and synthesised.
Methods

Meta-synthesis

A meta-synthesis was considered the most appropriate review technique for the research aims. These have become increasingly utilised in recent publications due to the increase of qualitative research and the move towards evidence-based practice. Unlike meta-analysis which aggregates research findings, meta-synthesis involves synthesising qualitative research evidence by translating and interpreting themes from studies and discussing the links between them, to provide a more holistic interpretation of the evidence\textsuperscript{35-38}. Although not as well-advanced as methods used in quantitative reviews, qualitative synthesis methods have been under considerable development to create a more transparent, consistent approach\textsuperscript{39}. There were four stages to this review: searching the literature; applying inclusion/exclusion criteria; a quality assessment of studies; and synthesis of the study findings.

Literature search and selection criteria

An initial scoping exercise was carried out to establish whether any recent reviews had been published in the area of children and parental mental health. It was found that there was an abundance of quantitative studies and reviews discussing the negative impact on children of parents with mental health problems. What was lacking was a review of children’s actual experiences i.e. a qualitative review. Therefore it was decided that a meta-synthesis in this area would be an important additional to the literature.

The following online databases were searched: AMED, CINAHL, Embase, Medline, Ovid MyJournals, PsychINFO, PubMed, SSCI, Web of Science. Key qualitative journals were either hand or electronically searched, for example Qualitative Health Research, Qualitative Research, Qualitative Research in Psychology; and a general
internet search using Google and Google Scholar. Finally reference citations from relevant research were followed up for further potential research studies.

As many electronic databases have only recently began to index qualitative research with a specific subject heading, literature searching was found to be problematic and often free text words as opposed to MeSH terms yielded higher recall and specificity. Search terms were therefore divided into four categories to try and identify the unique sample of studies: 1) the study design term (for example qualitative, interview, focus group, grounded theory); 2) terms related to experience (for example experience, perception, attitude); 3) terms based on perspective (for example children’s, parent’s, parental; and 4) terms related to mental health (for example mental illness, mental health problems, depression, affective disorder). This enabled a very broad approach to capture all potential studies, and quantitative as well as qualitative studies were still retrieved. This approach is routinely used at the Evidence for Policy and Practice Information Centre (EPPI-Centre) when carrying out linked systematic reviews of qualitative and quantitative studies. Flemming & Briggs (2007) suggest that using broad free text terms e.g. ‘qualitative’, ‘findings’, ‘interviews’, in conjunction with topic specific thesaurus terms, may be adequate to identify qualitative studies.

Studies were included if they used qualitative methods, for example interviews and focus groups to explore children’s experiences of parental mental illness and used a form of qualitative analysis. Studies were excluded if they used structured questionnaires as the only method of data collection, or if they reported only quantitative data. Mixed method studies were only included if the results from the qualitative method were reported separately and could easily be attributed to the children’s experiences. Studies that did not generate data from children themselves were also excluded, including retrospective studies of adult children. Studies with
multiple perspectives, i.e. interviews with children and parents, were only included if the child experiences were reported independently. Studies were only included if they were published in an English Language Journal prior to March 2011, when the search took place.

Quality assessment

The quality of studies was assessed using guidance from the Critical Appraisal Skills Programme\textsuperscript{42}. Studies that appeared eligible were assessed using the CASP for rigour, credibility and relevance (see Appendix 1). Following this, a more detailed assessment on the studies was applied using the checklist devised by Walsh & Downe (2006)\textsuperscript{43}, which explores issues such as: the appropriateness and coherence of the study scope, design, sampling strategy, analysis and interpretation and studies are rated on these criteria from A-D (where A equates to little or no flaws and D equates to major flaws; Appendix 2). Although studies were not excluded on the basis of the quality assessment, it enabled the author to weigh up how reliable and transferable the results were, which aided the synthesis of findings.

Synthesis of findings

This review adhered to the guidance from Noblit & Hare (1988)\textsuperscript{44}; the most widely used and well developed method of synthesising qualitative research, and criteria developed more recently by Walsh & Downe (2005)\textsuperscript{38} (Appendices 3 & 4). The analysis involved several phases: identifying the key themes, concepts and phrases from each study; looking for similarities and differences; determining whether there are reciprocal or refutational translations; and synthesising the translations to create overarching themes to explain the phenomena in all of the included studies. The researcher (CB) carried
out the initial synthesis and discussions with the research team allowed for further refinement of themes and a consensus on final results.
Results

Characteristics and quality of included studies

Seventeen studies were retrieved which appeared relevant to the review. Of these, two were later excluded as they had a case study design, and the methods used to elicit information from the children were unclear, and one study was excluded as the emphasis was on children as their parent’s carers. Of the 14 remaining studies, no more were excluded on the basis of the quality checklists. The quality of studies ranged from average to good and the reporting of key domains was variable across studies, particularly with regards to the type of qualitative analysis used. All 14 studies were rated A-C and deemed as robust and relevant to the review. As none of them were judged to be of poor quality with major flaws, all studies were treated equally in terms of their findings due to the acceptable level of methodological rigour.

Of the 14 included studies, 12 of them were separate studies, and 2 studies used the same participants but reported the findings in a different way. The studies were split across nationalities: UK, USA, Canada, Scandinavia and Australia, and were predominantly from Nursing, Social Work and Clinical Psychology perspectives. There were 163 children in total, and the ages of the children interviewed ranged from 5-22, with the majority focusing on adolescent’s experiences of parental mental illness. Parents’ diagnoses ranged from mood/affective disorders to schizophrenia and personality disorder (see table 1).
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| Buckwalter et al<sup>45</sup>  
(Study 1) | 1988 | USA     | Nursing    | Children (12 to 20)                    | 9                      | Affective Disorder              | Semi structured in-depth interview | Qualitative analysis (not specifically stated) | Children’s experience of having a parent with an affective disorder; their recurrent problems and coping mechanisms |
| Cogan et al<sup>46</sup>  
(Study 2) | 2005 | Scotland | Clinical Psychology | Adolescents (aged 12-17)            | 20                     | Affective Disorder              | Multi-Method; Psychometric and semi structured interview | Huberman & Miles interactive model | Adolescent’s coping styles; experiences of family life |
| Cogan et al<sup>47</sup>  
(Study 3) | 2005 | Scotland | Clinical Psychology | Adolescents (aged 12-17)            | 20                     | Affective Disorder              | Multi-Method; Psychometric and semi Structured interview | Huberman & Miles interactive model | Adolescents understanding of MHP’s and their own family experiences |
<p>| Study 5 | Garley et al | 1997 | Canada | Nursing | Adolescents (11-15) | 6 | Mood disorder (depression &amp; manic depression) | Focus groups | Qualitative analysis (not specifically stated) | Needs, cognitions and perceptions of children with a parent with a mood disorder |
| Study 6 | Handley et al | 2001 | Tasmania | Nursing | Children (11-15); Parents &amp; Service Providers | 4 children | Major Affective Disorder | Multi-method: Questionnaire &amp; Interviews | Thematic analysis | The types of supports perceived to be needed by parents, children and service providers |
| Study 7 | Maybery et al | 2005 | Australia | Social Science | Children (6-16) | 17 (reducing to 12 part way through) | Mood disorder; anxiety disorder; personality disorder &amp; psychotic disorder | Focus groups &amp; Questionnaire | Not stated | Differing viewpoints regarding issues faced by children whose parents have a mental illness |
| Study 8 | Meadus &amp; Johnson | 2000 | Canada | Nursing | Adolescents | 3 | Mood disorder (2 bipolar &amp; 1) | Interviews | Giorgi’s (1985) guidelines | Living with a parent with a mood disorder |</p>
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<td>Mordoch &amp; Hall</td>
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<td>Canada</td>
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<td>Riebschlege</td>
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<td>Clinical Psychology</td>
<td>Children (6-17); Parents</td>
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<td>Depression; psychosis; eating disorder; chronic fatigue &amp; personality disorder</td>
<td>Interviews</td>
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Synthesis

Through the process of synthesising and translating the study findings, five overarching themes were identified which were deemed important and reflected the essence of what was being reported in the literature. These were: 1) knowledge and understanding of parental mental illness, 2) coping strategies and support, 3) parent-child relationship, 4) social, emotional and behavioural effects on the child, and 5) the role of other people and society (see figure 1). In general findings indicated that knowledge/information about mental illness, how the child understands their own parent’s illness and how it impacts on them can mediate how the child copes and accesses support, how they view their parent and the quality of their relationship, and the social, emotional and behavioural effects on them as a child. The other important mediators were the role of other people, encompassing their attitudes towards mental illness and the associated stigma of having a parent with a mental illness. The child’s age and stage of development was also crucial to a child’s understanding and affected how they experienced their parent’s illness. The next section will explain these links more thoroughly, with examples from the research studies and quotes from the children being interviewed. Table 2 lists the studies that discussed each theme.

Summary of themes and sub-themes

1) Knowledge and understanding of parental mental illness

- Lack of knowledge & difficulty understanding

What was apparent from the majority of studies was the importance of information and knowledge about mental illness and the child’s subsequent understanding of their parent’s illness and how it affects them. Many children described a basic lack of knowledge, for example that it had never been discussed properly within the family, feeling excluded and not knowing what was happening to their parent, and feeling like
they had nobody to talk to about what was going on. Children stated that they did not know about illness symptoms, as well as issues such as treatment, and often felt confused and uncertain about ‘not knowing,’ especially when there was disruption and a perceived ‘loss of parenting.’

Some children described how mental illness was more difficult to understand than physical health problems because mental health problems are ‘in the mind’, ‘in the head’, and ‘your thoughts.’ Some children experienced fear, frustration, confusion and loneliness as they struggled to make sense of the situation:

“I could tell that she was sick or something…Cause…she usually would get mad at me…or sometimes she’d cry or something. That was hard for me to understand cos I didn’t know what she was crying about.”

(Study 5 - boy, age unknown)

“I was about 10 or 11 when these episodes happened…I sort of realised something was strange. Well, I just kinda, like I knew the police were at our house a lot and I knew my dad wasn’t there. I didn’t know he was in hospital for a long time.” (Study 8 - Adolescent girl, age unknown)

Some of the younger children worried about their parents dying and going into hospital because they did not know about mental illness, and found the whole situation difficult to manage. Many children highlighted the difficulty understanding their parent’s illness due to receiving little or conflicting information, which lead to confusion, uncertainty and worry, especially about the future:
“I was really upset when nobody explained it to me for ages…and the fact that she had just gone when I needed her…”

(Study 6 - Age and gender unknown)

“Nobody said ‘Oh she will get over it, she will get better.’ I mean if somebody had said that, I probably wouldn’t have got quite so angry with her…It was just going to go on forever as far as I knew.”

(Study 6 - Age and gender unknown)

“It’s better for kids to know…you’ll ask what’s happening and your parents don’t tell you…They don’t want to cause you any stress. I don’t think parents realise, it causes more stress not knowing what’s going on…You’re lost as to what’s happening.”

(Study 10 – age and gender unknown)

-Wanting more information/explanation

In over half of the studies children explicitly stated that they wanted more information about mental illness to help them understand what their parent was experiencing, for example about the causes of mental illness, the symptoms, how they could help and cope better, and the treatment available. Many children, specifically adolescents who wanted to be involved more, made reference to wanting more information from professionals (for example the doctor), and had little consultation about their parent’s illness from the mental health worker. Children also stated that they would like more information about mental illness at school, stating that having more information helped you cope.
"I think the doctor should try and explain more in the best way possible what has happened ... I think schools should give more education about it cos we have only ever had like one lesson about it and I don't think that's enough, no one really understood it all."

(Study 2 - Age and gender unknown)

Only one study made reference to some children not wanting more information because they found it overburdening and confusing.

- Finding out about their parent's mental illness

In eight of the studies children discussed issues associated with finding out about their parent's illness. Some children made reference to them not being told and a general lack of communication about the subject. This linked to the general lack of knowledge and understanding and the children's desire for more information and to understand what was going on. Children in three of the studies had been told by their parents, "I know about it just through experience with my dad," or found out bits of information, but generally the ways in which children found out about mental illness were varied, for example from the media, overhearing conversations, reading written materials, finding out by chance, by comparing themselves to other families and seeing a 'difference'; and having conversations with friends/family or with a professional (for example a school counsellor). Most children described how they preferred to be included in family discussions about mental illness, because overhearing things by chance, or not knowing what to read about, increased their confusion and worry about what was going on.
- **Knowledge about their parent’s mental illness**

Children who had been told about their parent’s illness, or had access to information demonstrated a greater understanding of their parent’s illness. Those who had been given information stated that it helped them understand and cope better with the situation:

“I knew what was happening then, that it wasn’t my fault.”

(Study 3 – age and gender unknown)

“Once I understood, things were better.” (Study 9 – Girl aged 16)

Some older children could identify potential causes, for example genetics, abuse, social and environmental factors etc:

“I think it’s probably you are born with it…like it will come out if…from stress or something.” (Study 5 – adolescent, age and gender unknown)

They used different terms to describe the illness, largely determined by their age, i.e. older children used more diagnostic labels, whereas younger children used more behavioural terms to describe their parents, for example ‘looking stressed’ or ‘unwell’ and “you act real weird”. Many children, even without knowledge and understanding, could describe the basic symptoms of their parent’s mental illness. Some children made reference to their parent’s emotions and behaviour for example: sleep problems,
sadness, crying, stress, shouting, anger, yelling, irritability, less attentive, routine changes, disruption and inconsistent parenting:

“they (parents) lose interest in things they used to like and they get sadder and sadder.” (Study 9 - Girl aged 10)

“I could tell when she’s getting upset, because…she’d drink and start saying really depressing things.” (Study 9 – Girl aged 16)

Some children drew a distinction from physical health problems, for example ‘it’s not like having a broken leg or being in a wheelchair.’ The changeable nature of their parent’s symptoms was also referred to:

‘my mum has good days and bad days.”

(Study 3 – age and gender unknown)

‘sometimes things are alright but then my dad gets depressed again.” (Study 4 – age and gender unknown)

“it can make my mum grumpy and tired so she goes to her bed but other times she’s a bit better.” (Study 3 – age and gender unknown)
Children often described changes in their parent’s behaviour as a result of mental illness as unpredictable and frightening. Older children who had knowledge and awareness were more likely to understand what was happening and adjust accordingly:

“Well, we know right away what’s happening…we notice that he tends to give out money when he’s sick, so we just stop everything like credit cards.” (Study 5 – boy aged 15)

Some children described how having knowledge and understanding about the signs and symptoms of their parent’s illness was actually reassuring and enabled them to make sense of their parent’s behaviour:

“When my mum is nice, she says that she really doesn’t mean to get…yelling at us. (It’s) just…the illness…that’s how I know when she’s …getting her illness…I know that she doesn’t mean it.”

(Study 5 – boy, age unknown)

- Adjustment to their parent’s mental illness

What was apparent was the children who had some knowledge, awareness and understanding of mental illness and how it affected their parent were in a better position to adjust to the illness. Adjustment was also mediated by time, age and development, and more specifically the age of the child when the parent developed the illness. Children spoke about needing to adjust to the changes in their environment, the general behaviour of their parent and how they interacted with them. Children also
spoke about needing time to get used to the changes and accepting the parent’s illness:

“It has been an important step for me to get as far as this. To talk about it.” (Study 4 - Girl aged 22)

“The worst thing is, I can’t understand why, I got used to it, because it had been like this since we were toddlers, so I did not really see that there was something wrong, before quite late” (Study 4 - Girl aged 15)
Figure 1: Model of themes

- Knowledge & Understanding of parental mental illness
- Coping Strategies & Support
- Parent-Child Relationship
- Social, emotional & behavioural effects on the child
- Role of other people & society
- Child’s development & adjustment over time
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2) Coping strategies & support

- Coping strategies

Children of all ages described using a variety of ways of coping with their day-to-day life. Some children referred to school, or activities and hobbies such as reading, watching television, playing sports and cooking/cleaning as a way of distracting them from the effects of their parent’s mood and behaviour on them. Older children with more independence reported that they could go round to their friends and go shopping or to the cinema. Younger children were more limited to remaining in the family home and keeping busy. Children’s hobbies helped them forget what was happening in order to try and be normal:

“I was always visiting the others, all the time…and I was the one never crying, always laughing, and playing football with the boys”

(Study 4 – Girl aged 15)

Some children cited positive ways of coping such as using humour, positive thinking, talking to people, getting comfort/attention from elsewhere, and having their own lives and interests which were not dominated by the parent’s mental illness. These older children were more likely to have a greater understanding of mental illness, and could recognise the most effective coping strategies to help them. In general it was found that coping was much more difficult for children if they were not told anything about the parent’s illness, or if they were told conflicting information.
- Avoidance

Other children talked about avoidance of their parent, for example ‘getting out of the way’, ‘pretend it’s not happening’, ‘ignoring what was going on’, and removing themselves from the situation. These were often the children with less knowledge and awareness, and they therefore struggled to understand why their parent was behaving in a certain way. Sometimes the younger children, who could not leave the family home, avoided their parents by seeking solitude, often withdrawing to their bedrooms:

“I used to spend a lot of time in my own room. I didn’t like to stay downstairs at that time. Keep quiet most of the time, not do anything wrong.” (Study 4 – boy aged 17; speaking retrospectively).

Withdrawal was also seen in other forms, for example not going to school. Avoidance as a coping strategy is often seen as unhelpful, and this was applied by the many of the children who lacked an understanding of why their parents were behaving in a certain way.

- Importance of friends/siblings

Four studies made reference to the role of friends and siblings. Many children who preferred to keep their parent’s illness a secret from their friends (see later theme), or did not want to burden other people chose not to discuss these issues with friends. However, the older children who did wish to talk about it spoke highly of the support they felt they received from friends and that they felt less isolated. Sometimes friends were just seen as a distraction, for example going to their houses after school:
“My friends helped me a lot, even if they did not know they were helping me. They helped me by acting just like they acted towards others…They did not know they were helping me and they did not know that my mother was mentally ill.” (Study 4 - Girl aged 16)

However, other children spoke explicitly about the importance of telling their friends what was going on with their parents, as this made it easier for the child to explain how they were feeling:

“I just sort of you know, tell my friends about it you know. Just sort of joke about it and stuff, I talk about his (father's) illness to people in school just the same as I talk about anything else.” (Study 8 – Girl aged 17)

Children across the age range spoke of the support that having siblings gave them, whether they were older siblings to rely on, or younger siblings to look after.

- Other sources of support

The children in four other studies spoke of the valuable support they sought from people other than their friends and siblings. Those in two-parent families talked of the importance of the support of the ‘well’ parent who often took on child rearing responsibilities whilst the other parent was unwell. Some children talked about the emotional support they got from other family members and even teachers, which helped them to cope with often upsetting events, and disruptions to their school and homework:
“My grandma helps us. Talks to us about it. That he’s gonna get better, but he might have to stay in there (hospital). It’s just his illness, don’t worry, it’s just his illness, it’s not him talking.” (Study 10 – age and gender unknown)

Three studies discussed accessing professional support, and the benefit of talking to someone external outside the family unit. Some of the older children in these studies talked about attending support groups and seeking counselling.

Two separate studies made reference to the active avoidance of support from outside agencies, mainly due to the children’s fear of being removed from the family home, and subsequently hiding problems from professionals. These children were in single parent families and did not have the support of another parent to rely on.

3) Parent-Child relationship

-Responsibility & Role reversal

Eight studies discussed the issue of children taking responsibility and their changing role within the family. Some studies labelled this as ‘role reversal’, ‘parentification’, taking on a parent role, or carrying out extra roles. Often the children with some knowledge and understanding that their parent was unwell wanted to take responsibility for some of the practical tasks around the house, to ease the pressure on the parent. These often included cooking, cleaning, looking after siblings and even looking after the parent themselves:

“It’s kind of difficult to distinguish who’s the parent and who’s the child sometimes. Um (pause), just because my mother has a lot of needs it’s difficult
for her to be (pause) the caregiver, and I tend to be more of the caregiver. She can't be there emotionally for me.”

(Study 8 - age and gender unknown)

“When my Mom gets sick, I'm responsible for (younger brother) so he doesn't get in trouble…and that he heads right home.”

(Study 13 – age and gender unknown)

They talked about the role reversal as a positive characteristic, for example being self-reliant and independent, ‘growing up faster’, being ‘mature and able to manage the ups and downs’, and ‘feeling like an adult’. Generally this theme applied to the older children aged 10 and above, and was more common amongst adolescent girls:

“My mother was very dependent on me. I grew up early (laughing)…the first time I went to withdraw money from the bank was at age 5. And I went shopping…and so on…But I did not think about it. That was my life… (Study 4 – Girl aged 21)

“In comparisons with my friends who have lived in a secure environment with healthy parents with no difficulties I have had the opportunity to mature.” (Study 11 – Adolescent, age and gender unknown)

These children often perceived their parent in a positive light due to their understanding about what the parent was experiencing and the child’s desire to make things easier for them. Two studies involved children who saw the need to take on extra roles as a
‘burden’, and felt like their parent was not taking care of them properly, so they had to take the responsibility themselves. In these cases although the children were older, they appeared to have less understanding of their parent's illness and lacked the ability to make sense of why their parent was unable to maintain the family home and 'look after them properly.'

-Loyalty/Positive regard for the parent

In another eight studies, (some different from the ones discussed above), children perceived their unwell parent in a positive light. They described the love they had for them and a generally positive parent-child relationship. These children could recognise the impact of the mental illness on their parent, and wanted to protect them, for example:

“I don't like to ask him about that (hospitalisation) because I'm not sure if it will make him uncomfortable.” (Study 5 – Adolescent girl, age unknown)

Some older children with knowledge about mental illness talked about how monitoring their parent’s moods and behaviour patterns was helpful in preparing them for how they should adjust. ‘Monitoring’ enabled children to be prepared and could access appropriate coping strategies and support to help them when their parents were having a particularly bad time. The changeable nature of the illness meant that those children whose parents had ‘good days’ could appreciate when there was increased communication in the family, more attention from the parent, and doing activities with their parent. Children who experienced this positive side and appreciated it could often make sense of and manage the situation when the parent had ‘bad days’:
"(Mental illness) is not 24/7…it’s not all bad, you know."

(Study 9 – age and gender unknown)

Some children described how they helped their parent out in order to ‘keep the peace’ and ‘keep things normal’. Feelings such as joy, pride, love, trust and hope were identified by some children of all ages in response to their relationship with their parent:

“it’s not like we don’t love her cause she’s got a mental illness…her heart’s still there and she cares about me and K (sister) more than anything.” (Study 9 – Boy aged 13)

Linked to role reversal, children were more likely to take on extra responsibility if they had positive regard, a good relationship with their parent and a general understanding of the impact of mental illness. Some older children had a wider world view and discussed how having a parent with a mental illness was not the main problem in their lives, and could identify factors such as poverty, divorce, death and moving house as things which they would experience as ‘worse’ than having a parent with a mental illness. Finally in one of the studies, some children expressed a wish for their parent to be better and for general relationships within the family to be improved.

4) Social, emotional & behavioural effects on the child

-Self blame

Children in five of the studies talked about a feeling of responsibility for their parent being unwell. Some children blamed themselves as the cause of the illness, whereas
others felt like they were to blame for not managing properly. Some children reported that they had heard people saying it was their fault, and they felt bad about it, but others still felt a sense of responsibility even when told it was not their fault:

“I sometimes think it’s my fault, I blame myself for the way my dad is feeling, even though he tells me it’s not”

(Study 2 – age and gender unknown)

“I thought I had made my mum ill” … “I thought it was my fault.”

(Study 3, age and gender unknown)

Often the children who felt to blame were the ones who lacked understanding about mental illness, had little knowledge of the origins and causes, and were generally the younger children, who had egocentric perspective appropriate for their developmental stage.

- Fear

In ten studies children of all ages named fear as one of the most prominent emotions they felt about having a parent with a mental illness. Fear arose as a consequence of a variety of illness related factors such as: a lack of understanding; a fear of violence (either against them or between both parents); and fear of the parent committing suicide or self-harming:
“I remember Mom talking a little about it (suicide) when she was in hospital to us, my sister and I. It was a concern for me, but it was good she was able to talk about that. When she came home, I was thinking about it, like when she was in the bathtub or if she had a razor or whatever. You just wanted to ask, Mom are you okay in there, or with whatever she was doing.” (Study 8 – girl, age unknown)

Younger children felt a general fear of losing the parent, being separated from them, and a fear of having to move house. Some children spoke of a fear of the parent being in a chronic episode of illness and the fear of managing these severe episodes:

“…the days when she was severely ill it was spooky to wake up.”

(Study 4 – girl aged 18; speaking retrospectively)

Hospitalisation was also a big influence on children. Children in six of the studies talked about the fear of their parent being admitted into hospital. This was worse when the child was younger and lacked understanding about their parent’s condition and they described their concern about death:

‘hospital is where people die”. (Study 12 – age and gender unknown)

“Sometimes it may kill you. What I know about mental illness is when you get real sick, you have to go to the hospital and then you die.”

(Study 13 – age and gender unknown)
Children spoke of being separated from their parent when they went into hospital, and experienced this as worse when they were not informed about it, for example:

“I got really upset when I found out my mum wouldn’t be there (for a birthday) and started crying and then no one to tell you. I think it would have been better to have been told…to know that I wasn’t going to see mum.” (Study 6 – age and gender unknown)

Fear, worry and confusion about their parent being in hospital was influenced by other factors such as the disruption it caused the family, practical issues such as having difficulty visiting or not liking visiting the hospital, ‘it’s not a nice place’, and an overall feeling of being unsafe whilst the parent was away. Only one study discussed the positive impact of hospitalisation, where some children, namely adolescent boys, described it as a sense of relief when the parent was admitted, and having time away from the ill parent meant it was less stressful.

Children in five studies discussed a different type of fear, the fear of getting the illness themselves. These children were afraid and stated they were worried due to genetics and inheriting the mental illness:

“I think it could be hereditary …like it runs through the family, cos my dad’s mum had a mental health problem…she was in the mental hospital for most of her life.”

(Study 3 – age and gender unknown)
“Ah, first when she was ill in hospital I was wondering if it was heredity then, because if I felt down or something or the other, then I was worrying. Well am I going to be like that too, so…”

(Study 8 – age and gender unknown)

Often these were older children who did have some understanding and access to information about mental illness, and had been told or had read about heritability. Only a few children in one study stated explicitly that they were not worried about getting the illness.

- Other emotional/behavioural effects on the child

As well as feelings of blame, responsibility and fear, children from the majority of studies talked about a wide array of emotions they experienced as a result of their parent's mental illness. Worry, stress and anxiety were common for children of all ages, for example about their parent’s health, risk and suicide, school, the 'uncertainty', being able to cope (e.g. in terms of money), and generally about being looked after:

“I worry about, like, lots of things. What’s going to happen and things like that, to everybody. Sometimes my mom’s up, sometimes my mom’s down, sometimes she’s normal. I’m always nervous.”

(Study 10 – age and gender unknown)

Children also described feeling sad, hurt and a sense of grief about losing a part of their parent due to the mental illness. Some children felt very angry and frustrated,
sometimes at the parent, but often at the mental illness itself which was impacting on their parent:

“I’ve had so many mixed emotions. I was so mad sometimes. The difference is that I’m not mad at her. I’m just frustrated. I wake up in the morning, no one is here. I come home no one is here.”

(Study 10 – age and gender unknown)

Older children in four of the studies admitted to feelings of shame and embarrassment, for example about the home situation, or about the parent’s inappropriate behaviour. Shame could also arise from the associated stigma of mental illness (see later theme). Some of these children and others also reported feeling guilty for thinking badly of their parent and feeling ashamed. Children from one specific study stated that they were not ashamed of their parents, as having a mental illness was not their fault. Loneliness had a major influence on some children, who described a lack of communication and having little attention paid to them. Those who did not have people to share the experience, for example siblings, or friends they could confide in, described ‘feeling alone’, and ‘not coping well’. Often these children were the ones who ‘bottled things up’ and used avoidance to try and cope with stressful experiences by themselves.

In terms of physical and behavioural effects, some children spoke about the influence of their parent’s behaviour or the child’s own mood on their sleep patterns. Some children had problems sleeping due to worry, and others could not sleep due to disruption in the household. This then impacted on their daily functioning due to fatigue, for example at school:
“I was falling asleep in school and all that cos of my dad’s illness. We (family) had been up the night before.”

(Study 2 – age and gender unknown)

Only one study made reference to children being abused by their ill parents. Abuse in this case was described as physical and psychological, but was not the norm amongst the sample of children recruited for the studies.

In general, those children who had knowledge and understanding, could access support, and used appropriate coping mechanisms were less likely to experience as many negative emotional and behavioural effects, as they had learned how to adjust to their parent’s mental illness. Time, age and developmental level of the child also had an impact on this and the older the child and the longer the illnesses duration, the better equipped the child was to cope.

-Effects on school

In addition to the effect of fatigue on school performance, adolescent children in four of the studies discussed how their parent’s illness meant they had difficulties with their schoolwork:

“When I’m trying to do my (school) work I’m worried cos my mum can’t go out her house and she doesn’t like being by herself, I can’t concentrate on my (school) work.” (Study 2 – age and gender unknown)
“It’s hard to listen to the teacher when I’m thinking about if my mum is ok.” (Study 2 – age and gender unknown)

Some children spoke about having difficulties completing their homework due to the disruption at home:

“when I was going through my exams, doing my studying and everything, everyone (family members) was arguing all the time, I could never get homework done.” (Study 2 – age and gender unknown)

In two studies the children talked about being bullied and made fun of because their parent had a mental illness. Bullying was not a common theme, as children tended to keep their parent’s illness to themselves (see secrecy sub-theme) and avoiding telling people unless they were really close friends. Other children spoke of the disruption of having an ill parent, for example changing schools, and missing or being late for school:

“I can’t get up to go (to school) sometimes ‘cos there isn’t anyone else getting up in the morning.” (Study 2 – age and gender unknown)

In one study, the children who were not being bullied perceived school as a distraction and a chance to think about something else other than mental illness. They valued school as an opportunity to see friends and socialise:
“school gives me a chance to think about something else and see my pals.”

(Study 2 – age and gender unknown)

-Secrecy

Some children chose to keep their parent’s illness a secret from people outside of the family. Five studies made reference to children covering up, hiding problems and avoiding telling friends and professionals:

“Some of my pals have asked me “what’s happening in your house?” but I can’t tell them. I just say “can you leave it,” I don’t want anyone to know about my dad’s (mental health) problems.”

(Study 2 – age and gender unknown)

“I don’t like talking to teachers about my family, about what’s going on in my house and all that…it just gets to me.”

(Study 2 – age and gender unknown)

Older children talked about keeping things a secret to protect their parents, “It’s a private experience,” (Study 3 – age and gender unknown) “a family secret” (Study 13 – age and gender unknown), and younger children for fear of ridicule and bullying at school. Some children described how they ‘bottled things up’, kept things to themselves and often denied there was anything wrong:
“I just bottled it all up and then one day I just lost my temper…I just totally burst my top! It’s the worst thing you can ever do, is just let it all build up inside.” (Study 2 – age and gender unknown)

This was linked to how they chose to cope with the situation, which was discussed earlier. One study made reference to the parent as hiding the illness rather than the child:

“My parent “pretends nothing wrong.” “…tries and not show me when she’s upset.” (Study 3 – age and gender unknown)

“My dad stays in his room when he’s depressed, he doesn’t want us seeing him when he’s like that.” (Study 3 – age and gender unknown)

Secrecy was also linked to stigma and the role of other people, which will be discussed in the following theme.

5) Role of other people & society

-Stigma

The final overarching theme concerned the role of other people outside of the family unit. Stigma was discussed in many of the studies, and the attitudes of other people impacted on the way the child coped with having a parent with a mental illness, how it affected the parent-child relationship and the subsequent social, emotional and behavioural effects on the child. Even though children often did not use the term
stigma, some of the older children were aware that having a mental illness was seen
less favourably by society than having a physical illness. Some children referred to
mental illness as an ‘invisible illness’ which people found difficult to understand.
Adolescent children who were aware of the negative perception of mental illness
expressed fear about their friends not understanding, and a general worry about
negative attitudes towards themselves and their family, which left them feeling
vulnerable:

“I have no problem talking about my mother’s illness; it’s not something that I’m
ashamed. Ah (pause), I don't think it is something that my mother should be
ashamed. The only thing is other people’s reactions.”
(Study 8 – age and gender unknown)

“I think it (psychiatric disability) is something that other people think bad
about...Lots of people get teased. Like in my mom’s case, she was made fun of.”
(Study 13 – age and gender unknown)

Children often avoided inviting their friends back to their house:

“cos of my mum and that I don’t want to invite them (friends) back...cos I think
“I'm not inviting them back they'll think that I'm a weirdo!” so I don't.” (Study 3 –
age and gender unknown)
These children were more likely to ‘bottle things up’, and stigma therefore prevented open discussion, leading to isolation for many children. Some older children talked about negative attitudes from friends, acquaintances and strangers, and impacted on how they also perceived their own parent, for example feeling ashamed:

“I did not want to be identified with mum’s illness.”

(Study 4 – girl aged 22; retrospective thoughts about being aged 12-14)

In general, children who were aware of stigma and other’s negative attitudes were more likely to use maladaptive coping strategies such as avoidance and keeping things to themselves; were more likely to be ashamed of their parent’s illness or try to distance themselves from it; and were more likely to experience negative effects for example painful emotions and bullying. Stigma in effect, prevented these children from seeking the support they really needed.

‘Difference’

Many children talked about their parent with a mental illness as ‘different’ to others:

“For quite a while I knew (Dad) had a problem, but I just didn’t know about it. I didn’t know if it was normal or not normal, but I knew it was different.” (Study 13 – age and gender unknown)

The terms ‘difference’ and ‘normality’ were often used when describing how other people and society referred to having a mental illness or not. Some children stated that
their parent was seen as ‘bad’, ‘different’ or ‘not normal’ because they had a mental illness, and that other people were afraid of them, due to their lack of understanding about mental illness:

“People are afraid of persons with a mental illness.”

(Study 11 – age and gender unknown)

Some children described how their ill parent was ‘different’ to other parents without illness and examples of difference were given, for example a mother being ‘different’ to other mothers in public (e.g. talking loudly in a shop and talking too much), which made the child feel embarrassed. Awareness of ‘difference’ appeared to depend on the age of the child, the severity of the parent’s mental illness and the parent’s behaviour (i.e. how strange or unpredictable it was). Older children appeared better able to see ‘difference’ as related to stigma and other people’s attitudes towards mental illness, and had a clearer understanding of the negative influence that a lack knowledge and understanding from others could have on people with a mental illness and their families.
Discussion

Summary

To our knowledge this is the first review to systematically explore the qualitative literature on the experiences of children who have parents with a mental illness. Five overarching themes emerged and a model was developed in order to explain how children experience parental mental illness. Children who had some knowledge about mental illness and an understanding of how it impacted on their parent were more likely to be able to cope with the effects of mental illness, see the illness as separate to their parent and have a positive relationship with their parent. This appeared to limit the negative social, emotional and behavioural effects associated with having a parent with a mental illness. Conversely, those children with limited or no knowledge and understanding struggled to make sense of their parents ‘difference’ and often unavailability. These children were more likely to use maladaptive coping strategies such as avoidance and experience negative social, emotional and behavioural effects, for example blame, shame and anger at the parent for being ‘different’; and this had a negative effect on their parent-child relationship. The role of other people and society also impacted on children’s experiences, especially if they experienced negative attitudes and stigma.

The findings highlight some of the risk and resilience factors identified in the extensive literature on the impact of parental mental illness on children. The review found that children often lacked knowledge and wanted to know more about their parent’s illness, as they felt this helped them to manage more effectively. This is consistent with Fudge and Mason’s (2004) consultation with children, which informed a key document for the Australian Government regarding good practice principles and guidelines for services and people working with young people and their families. They found that children also wanted more information about their parent’s mental illness, and identified ways of
accessing the information, for example from parents, family members, school and mental health professionals. Similar findings were also highlighted in other research not included in this review. This is consistent with the research on child carers, where children expressed a need to be informed and consulted by professionals, who often focus exclusively on the parent’s needs and ignore the child.

In this review, children who identified supportive relationships found this a great help in having someone with whom they could talk. This was more important for older children, and is consistent with previous research suggesting that supportive relationships and good parenting predicted resilient outcomes in children and young people; and social and emotional connections with others significantly moderated the effects of mental illness. The older children in Fudge & Mason’s (2004) consultation also identified having someone to talk to as a significant protective factor. The review findings on coping strategies identified the ways in which children positively cope with their experiences which helped them adjust to their parent’s mental illness. Older children with some awareness had learned to monitor their parent’s symptoms, enabling them to access appropriate strategies to help them cope. Research supports this, suggesting that children who use strategies to accept or adapt to the stress of parental mental illness have fewer adjustment problems than those unable to disengage. In contrast, the review also identified many children who used maladaptive coping mechanisms, such as avoidance. This was consistent in another study, where many children adopted problematic coping styles, withdrawing, avoiding and distancing themselves from their parent who had a mental illness. This was more common in younger children with restricted social networks and less independence. The synthesis examined the relationships between knowledge and understanding, coping strategies, the parent-child relationship and the subsequent effects on the child. Other research offers support for these links, where it has been found that resilient children possess self-
understanding, the ability to view parental illness realistically, and the ability to build the resources necessary to survive despite parental dysfunction⁶⁶-⁶⁷.

**Strengths and limitations of the review**

This review not only identifies the key issues, but provides an explanation and interpretation of how some children experience their parent’s mental illness. What is different about this synthesis is that the perspectives explored are directly from children. This enables us to know how children experience their parents’ mental illness in order to understand how their unique perceptions might affect the development of resilience or their own emotional and behavioural problems. The review incorporated the views of 163 children and young people aged between 5 and 22 years from a range of countries. Parental diagnoses were varied with many focusing on affective/mood disorders. Therefore this broad sample allows for more reliable generalisability to other contexts more reliable. However, it is acknowledged that for the families who consented to their children being involved, the parent was more likely to be seeking treatment for their mental illness, therefore the children’s experiences in these studies may differ from those of children whose parents do not want input from mental health services, are not accepting treatment, or parents who have an undiagnosed mental illness.

The synthesis adhered to rigorous methods for literature searching; appraising the quality of included studies⁴²-⁴³; and synthesising the study findings⁴⁸, ⁴⁴. Although a contentious issue in qualitative research, in the present review the application of quality appraisal criteria was useful in screening out inappropriate papers, enabling the researcher to become very familiar with the data prior to beginning the synthesis. While the appraisal was time consuming, partly due to the variable nature of how some studies reported their qualitative methods and analysis, the researcher began to collate
important emerging concepts and ideas prior to the synthesis. Despite this, the quality was average to good across all studies, and they were only excluded if they did not fit the inclusion criteria. The review only included studies published in peer reviewed journals, as this was seen as a marker of quality. However, during the search the researcher identified relevant book chapters, grey literature and unpublished dissertations/PhD theses, all of which might have provided a valuable insight. It is also acknowledged that by limiting the review to English language journals, the review may also have missed some potentially relevant studies, which would have aided generalisability across countries and cultures.

**Implications of the review**

Important insights about the unique experiences of children who have a parent with a mental illness have been highlighted. Findings were predominantly consistent across all studies, and although further research would enable children’s perspectives to be generalised more widely, what is urgently needed is intervention to address the issues identified. What is clear is the need to involve children in all aspects of research into parental mental illness, including asking about their experiences, as well as information about what support they feel they require. It is not adequate to only ask parents and professionals about children’s experiences, as this excludes potentially crucial information about how children develop and make sense of their experiences. Children should be consulted about issues which directly impact on them, for example when developing policies and services to benefit them. Numerous papers have highlighted the need for the involvement of children in this process, and research evidence that informs policy and practice needs to achieve a better balance between focusing on the needs of the parent, the child, and the family as a ‘whole’.[28, 68].
Although risk and resilience factors have been highlighted in research over the last few decades, this review of the emerging research on children’s experiences has highlighted some of these factors from the child’s perspective. Therefore interventions need to be designed to take account of this. By identifying protective factors and knowing what children actually want and need from services, we can begin to foster resilience in children, for example by providing information to children and families about mental illness, encouraging and teaching effective coping strategies and promoting effective communication between all family members. While this does not necessarily have to come from specialist services, but more research is needed to evaluate existing prevention programs and interventions designed to help children and families coping with mental illness.

**Conclusion**

This review and synthesis of qualitative studies has identified the key issues involved when children grow up with a parent who has a mental illness, and explained the relationship between these factors in order to provide an understanding of children’s unique experiences. The findings highlight the importance of involving children and considering children’s experiences when developing policies and designing services to help children and families.
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Stallard P, Norman P, Huline-Dickens S, Salter E, Cribb J. The Effects of Parental Mental Illness Upon Children: A Descriptive Study of the Views of


“It's like being on the other side of the world with mummy”: A qualitative study exploring children's experiences of living with a parent with Bipolar Disorder

This is paper 2 and has been prepared in the format of a journal article to be submitted to The British Medical Journal (BMJ). The style and format, including references, reflects the BMJ’s guidance for submission (see Appendix 17). This paper follows on from the literature review, and reports on a qualitative study exploring the experiences of children who have a parent with bipolar disorder. This study is one of two studies from the research team exploring bipolar disorder and the family. Recruitment was shared with another researcher, who interviewed parents about parenting and bipolar disorder, and the study reported here interviewed the children. Throughout the paper the research team are referred to by their initials, and will be named as authors on the journal article. The research team are:

Clare Backer (CB) – main researcher
Rebecca Murphy (RM) – researcher on associated study
John Fox (JF) – new qualitative supervisor
Fiona Ulph (FU) – old qualitative supervisor
Rachel Calam – Academic supervisor

Word Count: 9988
“It’s like being on the other side of the world with mummy”: A qualitative study exploring children’s experiences of living with a parent with Bipolar Disorder
Abstract

Objective
To explore the experiences of children with parents who have bipolar disorder, and how this might impact on their emotional well being. To contrast children’s accounts with the parents’ perceptions of the impact of their bipolar disorder and to gain insight into children’s narratives, to increase understanding of the child perspective.

Design
Qualitative study using ‘In My Shoes’, a computer assisted interview. Thematic and content analyses were used.

Participants
Ten children aged between 4 and 10 years and their six parents who had bipolar disorder.

Setting
Home based interviews with parents and children in England.

Results
The four main themes that emerged from the child interviews were: knowledge and awareness of bipolar disorder; perception of parents; managing family life with a ‘bipolar’ parent; and living in a family with bipolar disorder. Children as young as four years of age were able to participate in the ‘In My Shoes’ interviews and could discuss their parent’s mood and behaviour. Children aged seven and above could have candid and insightful discussions about their parent’s bipolar, with knowledge of symptoms, and about how having a parent with bipolar disorder impacts on them emotionally as well as practically. Age mediated the process of adjustment, and older children were better at making sense of their parent’s illness and its impact, rather than seeing it as their fault. Parents were often unaware of how much their children knew, or they overestimated the knowledge and understanding of their child.

Conclusions
This exploratory study represents an important first step in exploring the experiences of young children who have parents with bipolar disorder. More research is needed to understand children’s perspectives, and this should be taken into account when developing appropriate services and interventions to support children and parents with mental illness, including bipolar disorder.
Introduction

Bipolar Disorder has a worldwide prevalence of between 1 and 4%\(^1\,^2\) and can have a debilitating effect on people if not diagnosed and managed effectively. Evidence suggests that bipolar disorder runs in families\(^3\,^4\), and much research has focused specifically on the impact on the child of having a parent with bipolar disorder. The majority of these studies have been quantitative, reporting that children of bipolar parents are vulnerable and at an increased risk of developing psychiatric problems such as mood disorders, anxiety disorders, Attention Deficit Hyperactive Disorder, disruptive disorders and co-morbidity\(^5\,^9\). Increased rates of behaviours like aggression, rule breaking and attention problems have also been reported\(^10\,^11\). More recent research has explored psychosocial functioning in children of bipolar parents. Findings suggest that children of bipolar parents do not function as well as children of ‘healthy’ parents in areas such as satisfaction, recreation, work, school, and interpersonal relationships\(^12\). However, it is unclear whether there is a causal relationship between having a parent with bipolar disorder and these problems, as these difficulties might emerge in the presence of parental impairment and existing child psychopathology. As with the mental health literature, there is also little emphasis on positive outcomes for children, although one small study found that children of bipolar parents scored higher on a creativity test than the controls\(^13\).

It is widely acknowledged that research about families often centres on parents and parenting issues and overlooks the experiences and views of the children\(^14\). Children are often not regarded as the primary source of knowledge on their experience, and their experience is often filtered through their parents, distancing the researcher from the child’s unique world and denying children the opportunity to speak about situations concerning them\(^15\). This is true in relation to mental health literature and more specifically bipolar disorder. To our knowledge there have been 14 qualitative studies exploring the direct experiences of children living with a parent with mental illness (see
paper 1 for a review), but these have focussed mainly on adolescents and adult children. Findings suggested that, dependent on age; children/adolescents lacked understanding about their parent’s illness, experienced a range of emotional, behavioural and social effects and accessed support to help them cope with difficult situations. These studies often included a mixture of parental psychiatric diagnoses, with only a small number using parents with bipolar disorder in their sample. There do not appear to be any studies to date that have focussed explicitly on exploring the experiences of children who have a parent with bipolar disorder and how this might impact on their emotional wellbeing. Similarly there is a lack of research exploring parenting with a diagnosis of bipolar.

Recent legislation such as the Think Family Review, Department of Health (2008)\textsuperscript{16}, emphasises the need for adult and child services to be integrated and address the wider needs of the individual and the family. Therefore to develop appropriate support for children and their parents with bipolar disorder, and to help fill an important gap in the literature, a qualitative study was conducted to explore the experiences of children with parents who have bipolar disorder, and how this might impact on their emotional well being. The younger age group of 4-12 years was chosen as it was identified as least represented in the existing studies exploring children’s experiences of parental mental illness. It is argued that this research is timely and of particular relevance. Both positive and negative experiences were explored to highlight areas of resilience and potential difficulties experienced by the children. Children were also asked to comment on their support needs. The main research question explored was ‘How do children with parents who have bipolar disorder experience family life and how does this impact on their emotional wellbeing?’ Parents were interviewed in a separate study (not reported here) about their experience of parenting with bipolar disorder, and some of their accounts about the direct impact on their child were used in this study to gain
insight into children’s narratives, adding an important level of understanding to the child data.
Methods

This qualitative study used ‘In My Shoes’, a computer assisted interview for communicating with children and vulnerable adults. ‘In My Shoes’ provided the framework for the interview to help generate data about children’s emotions and their experience of their parents and family life. The interview is divided into eight modules: The Introduction, Emotions, Emotions and Scenes, Places, Emotions and People, Somatic Experiences, and Subjects. All modules except Somatic Experiences and Subjects were initially used for the interviews. Using the computer assisted interview and qualitative methods enabled exploration of the research question and provided opportunities for the children to describe their experiences in their own words. Qualitative methodologies are highly effective in understanding a phenomenon from the perspective of the research participant within the context of their everyday lives, and are useful when little research in the area exists. They also encourage children to express their perceptions and provide an understanding of the context of their lives.

Recruitment

The study used purposive sampling, and eight parents with bipolar disorder were recruited via a national user-led organisation and charity for people whose lives are affected by bipolar disorder. A research advert was placed in the Spring 2010 edition of their quarterly publication sent to all group members (see Appendix 5). Parents were targeted if their children were between 4 and 12 years of age, as this age group are often neglected in research and their experiences are often ignored or not sought at all. Given the young age of the participants and depending on their level of understanding and knowledge, in order to obtain a homogenous sample, it was envisaged that a minimum of 12 computer assisted interviews would be necessary.
To recruit the child participants, parents with bipolar disorder who had agreed to participate in an associated parent study were asked to consent to their children being interviewed. Of the eight parents, six agreed, equating to 10 children overall. There were a number of challenges with recruitment, and the researcher would have liked more participants given the nature of the study. However, it was recognised that the sample was unique and this was a novel approach which had not previously been researched.

On receiving confirmation that both the parents and children met inclusion criteria, information packs were sent out containing information sheets and consent forms (see Appendices 6, 7, 8 and 9 for child and parent documents). The inclusion criteria for child participants included being a child of a parent who has a diagnosis of bipolar disorder; be between 4 and 12 years of age; and live with or be regularly cared for by the parent with bipolar disorder. The parents needed to have a diagnosis of bipolar disorder, have children in the above age group, and live with or regularly care for their children.

Children aged 7 to 12 years had their own information sheets and consent forms. After giving their assent, children could only participate with written consent from the parents. A convenient time and location for the interviews was then arranged.

**Interviews**

Interviews were initially piloted on two children prior to the research interviews, and changes were made to the modules used in ‘In My Shoes’. The Emotions and Scenes module was removed as it was deemed too long and did not add to children’s descriptions of their families. All child research interviews took place in the family home.
at the same time as the parent interviews. These were conducted in a separate room by another researcher (RM). An initial meeting with the parents prior to the commencement of the interviews enabled the researcher (CB) to briefly discuss issues such as the child’s insight into their parent’s illness, and to find out the terminology used by the child and parents, for example whether the child knew their parent had bipolar disorder, and whether it was referred to as an illness, or not referred to at all. This terminology was then reflected in the computer interview. It was made clear in the information sheets and prior to the interviews that if the parent did not feel comfortable, then there would be no specific questions about bipolar disorder, just about family life, and the children did not need to be aware of their parent’s diagnosis to be involved in the research.

All child participants were interviewed by the researcher (CB), a trained, registered user of ‘In My Shoes.’ The computer programme was run on a laptop, and the variety of settings, people and emotions, allowed the children to describe their experiences with family members, on different occasions and in different settings (see Appendix 10 for examples of questions from the modules). After initially choosing pictures to represent themselves, their home, and their family members, children were also asked to label line drawings of faces to describe different emotions (for example a very happy face, sad face, sad face with tears, scared face). This was called the emotions palette. The computer screen was then split into two sections (the top half with pictures of the family, and the bottom half with the child in front their home). Children were able to allocate an emotion face to themselves on the screen from the palette, and were then asked if they had ever felt that way and if they had they were encouraged to describe these times. Using the computer mouse, children were able to ‘drag down’ the family members that were present at those times and allocate emotion faces to them too. The use of thought, speech bubbles and text boxes also allowed the children to expand on
their descriptions of family life and the emotions they experienced in connection to family members and events that occurred in the home.

The nature of the ‘side by side’ interview enabled a warm rapport to be established between both child and researcher as they worked together on the computer. Interviews lasted between twenty minutes and eighty minutes depending on the age of the child and their level of engagement in the interview process. Older children used a separate mouse on the laptop to move people and objects around the screen and were encouraged to take charge of the typing if they wanted to. It was made clear before and during the interviews that the child could withdraw at anytime. Of the 10 children, eight were seen individually and two of the younger children chose to be interviewed with an older sibling present.

If during the interview the child began to talk about their parent’s illness or symptoms, the researcher followed up on this with more bipolar specific questions provided the parent had consented to this. If however, the child made no reference to their parent’s illness during the interview, and the researcher knew that their parent had discussed their illness with them, they asked for the child’s permission to discuss this subject at the end of the computer modules. Only two parents did not consent to the researcher asking bipolar-specific questions, as they did not think their young children were aware of their illness.

The parents of the child participants completed a questionnaire to gather socio-demographic information and information regarding the diagnosis and management of their bipolar disorder (See Appendix 11). Two standardised questionnaires were also administered to provide background information on a) the level of child difficulties (The
Strengths & Difficulties Questionnaire, SDQ\textsuperscript{21}; see Appendix 12); and b) parental symptoms of bipolar disorder (The Internal States Scale\textsuperscript{22}; see Appendix 13). All questionnaires were completed by the other researcher (RM) following the parent interviews so that they did not influence the discussion and analysis.

**Analysis**

Interviews were video recorded, digitally audio-recorded and transcribed verbatim (see Appendix 14 for coded transcript). The video recorder filmed the computer screen and did not capture footage of the child or researcher. Identifiable information was removed from the transcripts and child participants were allocated pseudonyms. Child data was analysed using thematic analysis\textsuperscript{23-24} to explore how the children experienced family life and their parent’s illness. In analysis the researcher looked for themes about the overall descriptions that children gave of what family life was like and how they experienced it, and did not look for comparisons to other children.

Thematic analysis was used as it is a flexible analytic tool which can provide rich, detailed and often complex accounts of data\textsuperscript{23}. The researcher (CB) looked for emerging codes and themes in the data, under guidance from an experienced qualitative researcher (JF). Themes were coded inductively at the semantic level\textsuperscript{23}, and it was a systematic and iterative process. The coding framework was continually refined and this continued until both researchers (CB and JF) were satisfied that the themes were representative of the data. Themes were also discussed regularly during research meetings (CB, JF, and RM) every 2-3 weeks. To ensure consistency a codebook was developed by the researcher (CB) with descriptions of the themes and two independent researchers were given transcript excerpts and asked to code them using the themes. This is a method often used in qualitative methodology to ensure reliability\textsuperscript{25}.  

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Content analysis was then used on the parent data from the related study and analysis was performed at the manifest level\textsuperscript{[26]}. Only the six transcripts from the parents who allowed their children to be interviewed were analysed. Themes and information generated from the child data guided the analysis. The parent transcripts were systematically read and data related to each child theme was extracted. Summaries were developed and specific comparisons were made between each parent-child pair.

To demonstrate rigour of analysis, an audit trail documented decisions made during the analytic process, and a reflective journal was kept by the researcher (CB) to document the researcher’s influence on the research process as a whole and on the construction of data.
Results

Eight families participated in the research as a whole. Some families contacted the researchers to participate, but either geographical distance was too far, or the parent did not have a formal diagnosis of bipolar disorder from a psychiatrist. Of these eight families, six parents agreed for their children to be interviewed for this study and these will be the focus of this paper. Therefore in total, ten children took part in this study.

Family structures were equal in terms of single and two parent families (three of each type); were predominantly White British and all from England. Apart from one father; all parents with bipolar disorder were mothers. The sample of children consisted of nine boys and one girl. The median age was seven years (range 4 to 10 years). Seven out of ten children scored in the ‘normal’ range on the SDQ, suggesting their difficulties were average when compared to children of their age. Three children scored in the ‘abnormal’ range, but two of these children already had existing diagnosed conditions (Asperger's Syndrome and ADHD); and one child had already been identified by services as having a delay in emotional and social skills.

From the codebook, there was greater than 70% agreement for all themes, which is deemed the acceptable level of reliability in qualitative research. The four main themes that emerged from the child interviews were: knowledge and awareness of bipolar disorder; perception of parents; managing family life with a ‘bipolar’ parent; and living in a family with bipolar disorder. These were grouped into sub-themes and will be discussed in relation to children’s developmental stages, with quotations from children to demonstrate reliability. Pseudonyms are used for the child participants. Comparisons will also be made with the parent’s data to facilitate insight into their children’s experiences.
**Table 1: Socio-demographic and difficulties information for parents and children**

<table>
<thead>
<tr>
<th>Parent</th>
<th>Age</th>
<th>Children at time of diagnosis</th>
<th>Ethnicity</th>
<th>Marital Status</th>
<th>No. of Children</th>
<th>Level of education</th>
<th>Currently employed (Y/N)</th>
<th>Child pseudonym, age, additional needs and SDQ overall stress score</th>
<th>Professional Agencies Involved (Y/N)</th>
<th>Parental medication and mood state (ISS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>39</td>
<td>Yes</td>
<td>White</td>
<td>Married</td>
<td>2</td>
<td>University Degree, Mphil, MBA</td>
<td>Self-employed Part-time</td>
<td>Jake (age 9) Asperger's Syndrome 18 (High)</td>
<td>Children Yes</td>
<td>Euthymia</td>
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<td></td>
<td></td>
<td>Harry (age 6) Delay in emotional and social skills 31 (Very High)</td>
<td>Participant Yes</td>
<td></td>
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<tr>
<td>2</td>
<td>33</td>
<td>Yes</td>
<td>White</td>
<td>Married</td>
<td>3</td>
<td>University Degree</td>
<td>No</td>
<td>Michael (age7) None 3 (Average)</td>
<td>Children No</td>
<td>Depression</td>
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<td>Connor (age 6) None 12 (Average)</td>
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<td>Daniel (age 4)</td>
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<td>Jordan (age 8)</td>
<td>ADHD, Poor communication &amp; motor skills</td>
<td>31 (Very high)</td>
<td>Children</td>
<td>Participant</td>
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<td>Not interviewed (age 4)</td>
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<td>Euthymia</td>
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<td>Alice (age 10)</td>
<td>None</td>
<td>2 (Average)</td>
<td>Children</td>
<td>Participant</td>
<td>Yes</td>
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Knowledge and awareness of bipolar disorder

- Description of illness

Children’s knowledge and awareness of their parent’s bipolar disorder often depended on the child’s age. Some older children (aged 7-10), knew that their parent had a mental illness called ‘bipolar’. Some of these children referred to it as simply ‘an illness’, ‘being ill’ or ‘unwell’ and only referred to it as ‘bipolar’ when asked if they knew what the illness was called. One child referred to physical symptoms such as headaches and stomach aches that her mother experienced, and only later in the interview linked these to her mother’s bipolar. Some of the younger children (aged 4-6) did not know about their parent’s bipolar and so were not questioned directly on this, but information was elicited where the children described aspects of their parent and family life which alluded to bipolar symptoms without their explicit awareness.

Children varied on how much they knew about bipolar, and being unsure was common, for example knowing it was bipolar but being unsure about what it was; being unsure about the frequency of their parent’s symptoms; or knowing that their parent was ‘different’ but not knowing how to explain it. One child explained about bipolar:

“Yeah it’s like a mental illness”… “Quite complicated to understand” (Michael aged 7).

Another discussed her mother’s bipolar symptoms in the context of it not being her fault:
“Erm when my mum feels irritable, but I know it’s not her fault” … “she possibly sat on the sofa cos she … um I don’t know if she thinks it’s her fault but I don’t think it is” (Alice aged 10)

Alice’s perception differed to that of some of the younger children, as she was older, less egocentric and able to empathise with her mother despite the impact of bipolar on her.

A few of the children stated that they knew their parent had bipolar, but that they could not remember any more, or had forgotten about it. It was unclear whether this was the case and it was hypothesised that some or all of these children might have been trying to avoid a discussion about the impact of bipolar on their parent and family, or that maybe ‘forgetting’ about it was a defence. Only one child stated explicitly that he did not want to talk about his mother’s illness. The children that were aware of bipolar differed in their knowledge about how long their parent had been diagnosed. Two children talked about how their mother and father had bipolar before they were born so they did not know any different. In one family the mother had been diagnosed whilst her children were young, and two siblings from this family were able to make comparisons between their mother before and after bipolar:

“Erm she erm there wasn’t a single problem with her”, “Erm basically she was just normal” (Michael aged 7)
The families with more than one child highlighted the importance of age and developmental level. Older siblings (aged 9) commented how it was more difficult for their brothers to understand as they were too young and it affected them differently due to their age (aged 5 and 6). Although an only child, one of the children made reference to her age and adjustment to her mother’s bipolar:

“Mmm I’ve probably got used to it when I turned ten” (Alice aged 10)

Some parents discussed their child’s awareness of their bipolar disorder and they highlighted that the extent of their awareness depended on the child’s age and level of understanding. This was consistent with the older siblings above, and it was unclear whether this was children’s actual perception, or whether they had heard their parents discussing it and were using their parents’ own words. For the children who had grown up with an unwell parent, parents recognised that children needed to adjust to the changeable nature of moods and that children’s understanding increased over time. Parents also discussed how physical aspects of the illness were easier for children to understand, and this was consistent with the younger children’s descriptions. Often parents thought that children were more aware of their depression symptoms, however children were aware of a variety of emotions expressed by their parents (see later theme-perception of parents). Therefore in these incidences, children had more awareness than their parents perceived.

Some parents discussed how they referred to their bipolar disorder with their children. This differed between families, as some parents wanted their child to know about the term
‘bipolar’ and its effects to increase children’s understanding of the ‘unpredictability’; whereas others worried about burdening their children with knowledge, so kept details to a minimum. Generally there was a belief that children’s awareness of bipolar disorder was important to reduce children’s anxieties, partly to protect them so they did not blame themselves, but also to reduce blame on them as a parent. This however, was not always successful, as despite having knowledge, some children still perceived their parent negatively and often younger children continued to either blamed themselves or their parent (see later theme-perception of parent).

- Communication about illness

Some of the older children discussed finding out about their parent’s bipolar from their parent. As previously discussed, some children stated they could not remember and others made reference to being told but then forgetting:

Int: “Yeah, aah, do you know what Bipolar is?”

P: “Err she’s told me a tiny bit about it but I’ve forgotten”

Int: “So how do you think Bipolar affects your mummy?”

P: “Err makes her walk around the house erm with making a funny face”

Int: “And what sorts of things was she ill with, how did you know she was ill?”

P: “Well I didn’t know she was ill but she started acting funny one day”

Int: “Aah right can you tell me a bit more about that?”
P: “Mmm I’ve forgotten most I’ve forgotten nearly all of it, I can’t remember anything else about it”

Int: “So you could just tell that there was something a bit different?”

P: “Yeah and dad and daddy thought I erm that dad erm thought I was lying but one day then he noticed”

Int: “Ah ok, and what sorts of things was your mum doing?”

P: “Erm I’ve forgotten now” (Michael aged 7)

As previously discussed, it was unclear, whether ‘forgetting’ was about avoidance, for example not wanting to display their parent in a negative light and appear critical; or whether it was a defence and uncomfortable or upsetting to talk about. It is certainly possible that children may have ‘forgotten’ for different reasons.

Another child discussed how his father only talked to him about his bipolar when he became worried that the child had bipolar too:

Int: “When did he talk to you about it?”

P: “Well erm he thought I had it”

Int: “Mmm

P: “Cos I was getting more and more… I was having more and more things to do with Bipolar and he’s told me that I might have it”
Int: “Mmm

P: “And that’s when he told me about what it does” (Thomas aged 9)

For the older children that were aware of their parents’ bipolar, some of them discussed having explicit conversations with their parents about bipolar symptoms and how it affected them, for example whether they were feeling happy, angry or sad. The parents also reflected on discussing the illness with their children. Some parents had sat their children down and discussed it; others had asked their partner to discuss it with them; and other parents had not explicitly discussed it, but thought that the children might have picked up information, becoming more aware as they got older. In these incidents, parents sometimes assumed that the child had more awareness and understanding than they actually had. Parents with more than one child discussed how explanations were given at a level they could understand, and adapting the language used for younger children.

Some children referred to finding it helpful for their parents to discuss their symptoms, for example knowing their parents moods so they could be prepared. Only one child discussed not liking these bipolar-specific conversations because she did not like how bipolar made her mum unwell and not able to do what she wanted:

Int: “Has she ever talked to you about it?”

P: “Um sometimes but I don’t really listen cos I don’t like it”

Int: “So how do you know when your mum’s feeling ok?”
P: “Erm… By her face

Int: “Ok”

P: “Like if she’s happy she’s smiling but if she’s not she’s either got a straight face or like a sad face”

Int: “And how do you know whether it’s going to be a good day or a bad day?”

P: “Err when she tells me how she’s feeling or what she’s doing”

(Alice aged 10)

Two of the younger children (aged 5 and 6) who did not know about bipolar but were aware that their parents were unwell, stated that they had not been talked to and had not heard conversations within the family about this. This did not appear to worry them and they did not express a desire to know more. However, the older children seemed more curious, and although some stated their knowledge and understanding was limited, their descriptions of bipolar symptoms suggested a more sophisticated level of awareness. This will be discussed in the next theme.

Perception of parents

Half of the families were single parent and half were two parent families. This theme has been classified into ‘Bipolar’ parent and ‘Well’ parent as there were distinct descriptions of both parents, and the accounts given by children in both family structures were similar. The child’s perception of the parent without bipolar disorder was important and enabled insight into family adjustment.
- ‘Bipolar’ parent

All children were able to describe their parent with bipolar whether they knew about the illness or not. As the focus of the computer interview was labelling emotions and discussing times they had felt emotions and who was with them, this enabled insightful discussions about their parent’s moods throughout the interview. Children of all ages used a variety of terms to describe their parent: depressed, sad, happy, giddy, irritable, angry, worried, stressed, ‘funny face’ and ‘naughty’. The two latter terms were used by the youngest child (aged 4).

_Int: “Ah ok erm and so Bipolar makes your mum irritable a bit, yep, are there any other things that it makes your mum?”_

_P: “Um happy, sad, erm, angry… and lots of different emotions”_

(Alice aged 10)

_Int: “Yeah so Bipolar makes your mum angry, how else does it affect your mum?”_

_P: “Erm stressed… makes her worried about things she shouldn’t be. Makes her worried about the future and not enjoy the present”_

(Jake aged 9)
Some children discussed reasons why they thought their parent was experiencing a particular mood. One child (age 4) blamed himself for making his mother angry, and another stated his mother’s mood was angry and sad for no reason:

P: “because she just cries for no reason, I don’t know, she just told that to me once”

(Harry aged 6)

Younger children particularly, in terms of developmental level, were in the stage of egocentricity, and attributed much of their parent’s mood and behaviour to either themselves, for example because they had been naughty, or to there not being a reason, due to lack of awareness of their parent’s illness.

Children of all ages could describe frequency of their parent’s moods, often stating that their parent was more happy, ‘normal’ or ‘ok’ than sad and angry. Only one child made reference to his father’s insight into his moods:

“Well when he’s erm sad and depressed he erm tells us…but when he’s giddy I don’t think he can really tell… We can, but he can’t”

(Thomas aged 9)
Although the interview prompted children of all ages to reflect on emotions and their parent’s moods, younger children were better at describing their parent’s behaviour. A range of behaviours were described, for example angry parents shouting, over-reacting and telling their children off more. One child referred to her mother being irritable and not liking people to go near her. Sad parents were described as tired, sleeping lots during the day, resting and generally not doing very much:

“It’s the same when she’s unwell she gets she sleeps for the whole day…and then she gets more sleep at night” (Connor aged 6)

Another child compared his mother to others without bipolar:

P: “Err she’s tell off she’d tell off [brother’s name] but she wouldn’t entire entirely be too comforting to me, she’d still comfort but not as much as maybe another mother would. I don’t mind that cos I don’t like too much comforting, it makes me feel uncomfortable”

Int: “So what would other mums do do you think?”

P: “They’d probably do it a bit more maybe and they might tell off [brother’s name] a bit more but I’m alright I’m alright with that cos I don’t I don’t like comforting too much it makes me feel uncomfortable”

(Jake aged 9)
Some parents discussed affection and comforting their children and had insight into their difficulties showing affection and empathising with their children. Some parents also stated that it was difficult to have their children near them when they were feeling depressed.

Only two siblings referred to their mother being in hospital due to being unwell, and only one child reported that her mother took medication. This was surprising given the majority of parents had been in hospital and all but one took prescribed medication. Some parents discussed their hospital admissions and the impact of being away from home. However, children either had forgotten this, or did not want to talk about it.

One child’s perception of his mother and her bipolar was expressed in a single sentence: “It’s like being on the other side of the world with mummy.”

(Connor aged 6).

Adolescents interviewed about parental mental illness often state that communication within the family helped them to understand the condition, consequently making them perceive their parent more positively. For the present study with younger children this was not consistent. Even children that had some knowledge and awareness still described their parent’s moods negatively and were more egocentric, describing the direct impact it had on them and how it made them feel (see next theme). This is not surprising given their developmental level. These findings suggest that the younger children still viewed themselves as the ‘centre of the world’ and anything that affected their routine was considered an inconvenience, unfair, or their fault.
-‘Well’ parent

The children in two parent families often described their perception of the parent without bipolar and their role within the family. One child described how his father was different to his mother who had bipolar disorder:

P: “and daddy and dad’s just in dreamland

Int: “Right so mum and dad are quite opposite are they?”

P: “Yeah sort of in a way”

Int: “How would you describe your dad?”

P: “Erm freefalling

Int: “Hmm and what does that mean?”

P: “Oh he’s not a care in the world he’s, he enjoys what’s happening now and doesn’t worry about the future…which is what me and mummy do”

(Jake aged 9)

Jake described his worry about the future like his mother, which is atypical for a boy of his age. This will be discussed later.

Having a supportive ‘well’ parent appeared to have a ‘buffering’ effect on children, enabling them to cope with the ‘bipolar’ parent’s symptoms in a more manageable way.
Having a consistent parent was a reassurance, offering a sense of routine and predictability alongside an otherwise ‘unpredictable illness’. Often the ‘well’ parent was more prominent in the child’s life, for example looking after them, playing and disciplining them in the absence of their partner.

*Int:* “How is it different since your mum got Bipolar?”

*P:* “Erm daddy’s normally erm with us looking after us by his self…especially when she went in hospital” (Michael aged 7)

Principally with fathers taking on extra roles within the family, children’s perceptions often differed depending on the role. When discussing their father generally, two siblings described a positive relationship and positive regard, for example “my daddy makes me happy…makes me laugh” and “I want me to have a happy face…and my daddy to have a happy face” (Daniel aged 4). However as the father took sole responsibility for disciplining the children, this elicited negative reactions from the children:

*Int:* “What makes you sad?”

*P:* ‘When my daddy gets cross’

*Int:* “Right…And what does he get cross about?”

*P:* “He does…He tells me off…all the time” (Daniel aged 4)
The father at other times was also described as ‘angry and stressed’, which reflected his attempts to support the family whilst his wife was unwell. The interviews highlighted how the descriptions of the ‘well’ parent were mediated by the severity of the ‘bipolar’ parent’s illness. When children gave descriptions which resembled manic or depressive episodes, the role of the ‘well’ parent changed accordingly as they took charge of the family, trying to cope without their partner.

All parents with partners discussed the impact on their relationship. Specifically when discussing their children, some parents spoke about the distinct roles of both parents. Parents perceived that their children favoured the ‘well’ parent as they were emotionally available and could play and ‘do fun things’. Whereas the parents with bipolar often saw themselves as ‘spare parts’ when they were depressed, and could not help with practical tasks, such as getting ready for school, cooking, and helping with homework. This is consistent with children’s experiences and was reflected in descriptions of the ‘well parent’.

Managing family life with a ‘bipolar’ parent

- Emotional effects on child

Children described a variety of emotions they experienced as a result of family life, and many were in direct response to their parent with bipolar. The two prominent emotions were ‘sad’ and ‘anger’. Over half of the children expressed sadness that their parent was ‘ill’ or ‘unwell and described feeling upset:
Some children described feeling sad when their parent was in a particular mood, for example when their parent was angry, irritable or annoyed, and one of the youngest children said that his mum made him cry when she was sad. Some older children reflected on the impact of their parent’s moods and how it affected them on a daily basis:

*Int:* “Describe your dad to me when he’s feeling like that”

*P:* “Well he gets all angry and sometimes he gets sad and doesn’t do much…just sits and sleeps…or rests. He can’t get to sleep but he rests”

*Int:* “And how does that make everyone else in the house?”

*P:* Well… it does make us a little bit um sad that he’s not doing anything”

(Thomas aged 9)

Many children discussed feeling angry at the parent for their moods (e.g. being angry or sad), but generally younger children kept this to themselves. It was hypothesised whether these children expressed their anger through behaviour (e.g. fighting and ‘being naughty’) as these were apparent throughout the interviews with the boys. This will be discussed in the next theme. One older child described his father laughing at him when he told him he...
felt angry, and the oldest child described feeling angry when her routine was disrupted due to her mother’s illness:

“…and if we plan to go a place and all of a sudden my mum gets stomach ache or irritable…I get quite angry cos we’ve already planned it and I’ve been looking forward to it” (Alice aged 10)

Other emotions children expressed were: feeling annoyed when the parent was ‘giddy’, and scared when the parent was angry. When asked directly if they thought having a parent with bipolar affected them, one older child had difficulty describing what he meant:

*Int:* “How do you think that affects you?”

*P:* “Erm, well of course it makes her angry more so…I don’t get as much…erm…

*Int:* “Get as much what?”

*P:* “Of any…erm…err…I’m not sure I said that actually [laughs] really. I sort of know but…” (Jake aged 9)

The oldest child did not believe that her mother’s bipolar had a big effect on her:
“Mmm I don’t think it really affects me except that I don’t really get to do much if she’s feeling down. But if she’s feeling happy then I get to do quite a lot and do lots of things when she takes me out” (Alice aged 10)

Earlier Jake (aged 9) discussed his worry about the future and linked this to his mother:

P: “Makes her worry about the future and not enjoy the present”

Int: “Ah and how does that affect you?”

P: “Err well I do it as well now…and from what I’ve heard I didn’t use to”

Int: “Since finding out about your mum’s illness?”

P: ‘No I think I’ve just copied it naturally with…not me wanting to…it’s just happened naturally”

This was not apparent throughout the other interviews and did not represent the views of the other children. Worrying in this context does not appear to be age appropriate and might reflect the child’s developmental difficulties, rather than due to the experience of having a parent with bipolar.

Parents reflected on their worries about how their bipolar disorder had impacted on their child’s development. They discussed how bipolar had impacted on their parenting style, making it difficult to be consistent, especially with regards to discipline. One mother
reflected on her inability to teach ‘right from wrong’, given that she often ‘screamed’ at her child for no reason. Thus, parents reflected on their own turbulent, chaotic and unpredictable moods and behaviour, and how this frightened and upset their children. Consequently some parents were worried they had ‘damaged’ their children and whilst stable felt the need to try and repair the damage. Children did not express that they had been severely affected by their parent’s bipolar disorder, but were able to recognise the unpredictability of moods, and the ‘unfairness’ of being shouted at for no reason.

- ‘Independent’ child

Older children (aged 7-10) displayed a mature attitude when adjusting to family life. They discussed doing tasks independently in the absence of their parent when they were either in bed or not feeling well. A few children discussed getting up early before their parent(s) and playing/watching TV, before making breakfast and waiting for their parent(s) to wake up:

“I go I go downstairs, play for a little bit, decide when I have my breakfast, make the breakfast. If I want some more I just make as much as I like…and when I’ve done that I normally wait until daddy’s down, then most of the time playing”

(Michael aged 7)

Some children referred to looking after themselves and the oldest child referred to looking after her mum and helping her, for example making tea and going to the local shop:
“Mmm erm I feel happy because I like helping her... so and I help her like make things and make my own tea... and if she wants something I'll go fetch from the shop, I'll go and fetch it” (Alice aged 10)

Parents also referred to their children’s maturity when helping out and taking on extra responsibility. One mother referred to their child as being ‘like a carer’, who looked after them when they were feeling unwell. Some children were perceived as being very considerate to their needs, and helping out in order to make them feel better. Some parents also expressed guilt that their children had to grow up faster and take on these ‘adult roles’ when they should be playing and enjoying themselves. However, children did not perceive this extra responsibility as a burden; rather they appeared to enjoy helping out and being independent.

- Support Networks

Children rarely discussed the concept of ‘support’ and were unable to talk about what support they felt their family required, often stating that they did not know or that they did not need any help. This may reflect the young age of some children and their inability to think reflectively around their family issues as a whole. However, almost all children discussed the importance of having other extended family members, specifically grandparents, who they saw frequently and the children valued. Children did not say whether they discussed their parent’s illness with wider family, however going to stay with grandparents or visiting them was seen a distraction and the opportunity to receive positive attention, for example being taken shopping or to nice places:
“And I’m having dinner at grandad’s and I had a lolly…and there was an ice cream and I ate it all. And grandma was reading stories for me”

(Luke aged 4)

Although children struggled to identify the support they needed, parents spoke a lot about the support they needed as a family. Some parents had identified problematic behaviour in their children and worried that they needed professional help. Consistent with the children, all parents discussed the importance of wider extended family for supporting them and their children, especially in times of crisis. Parents discussed this as a protective factor against the effects of their illness, and felt reassured to know that their children had other attachment figures to counteract the symptoms of bipolar disorder.

In terms of other support, many children discussed their friends, stating they had lots of friends at school, and referred to their best friends. Children described how friends made them happy, and one boy explained how having friends meant he was not lonely. With most children, the discussion of friends was not in the context of having a parent with bipolar, and they did not talk about whether they had told their friends about this. Alice, the oldest child was the exception. She discussed how only her closest friends knew that her mum was unwell and described how both she and her mum told them about bipolar disorder:

Int: “Did you think it was important for them to know?”
Alice wanted her friends to know so that she did not have to ‘bottle things up’ when she was feeling upset, and could explain the reasons why she could not play out if her mum was unwell. Age was clearly important and Alice showed maturity, understanding and could reflect on the impact of her mother’s mood and behaviour. It is unclear whether other children of the same age would perceive this, and as the only female interviewed it is also unclear whether gender differences would also be present.

Finally, a major influence for some children was their pets. Pets were a great source of amusement, love and played a key role in the interviews. During the interview children were asked to choose and label pictures of their pets, and pets were frequently represented when the children described feeling happy. Children felt like they could talk to their pets and played with them:

*Int:* “What makes you happy?”

*P:* “Err when my mum’s feeling ok, I get to see my best friend, and my pet wants to come out and play” (Alice aged 10)

Only one child discussed professional help that he had accessed as a result of having symptoms similar to his dad’s bipolar disorder:
"Yeah they took me to um CAM things"

“Oh the CAMHS team?”

“Yeah”

And what did they do?”

Erm they talked me through what I my motions and what I feel like when it happens…and I think we did it for over…about maybe…6 weeks or something”

“Did you see a psychologist or psychiatrist or something?”

“Erm I think he was I don’t know really by the helped me with um problems and I don’t go anymore”

“What sorts of problems?”

“How to not get angry and …how to not get too giddy…I feel a lot better”

(Thomas aged 9)

This was also an exception, although it was clear from the demographic information and questionnaire data that some other children were experiencing difficulties, but not all had received professional input.

-Avoidance & Coping

Many children talked about their active avoidance of their parent, for example when they were angry, sad or irritable:
“Erm it makes, if she is angry then I know to try and kind of avoid her slightly…of course not entirely but just be wary that it’s happening that she is…” (Jake aged 9)

“Yeah I just get on with it and sometimes I just ignore her when she’s acting funny”

(Michael aged 7)

Children described different ways of avoidance, for example going upstairs to their bedrooms to play, or visiting friends and relatives who lived nearby. One child discussed how when angry, she did not discuss it with her mum, but went off somewhere to be alone. Parents often had insight into their child’s avoidance strategies, often stating how children had learned to modify their behaviour as a direct result of their behaviour. When stable the parents were able to reflect and feel guilty about this, but when feeling unwell, were glad of the quiet time away from their children, as noise was often an irritant which worsened parental stress.

In terms of how children spent their time, children discussed their hobbies, which they often used as a distraction whilst avoiding the parent. For all boys, playing Lego and on computer consoles were the main hobbies, followed by watching TV. Some children talked about their love of sports such as playing tennis and going swimming. One pair of siblings were also musical and played instruments. Children also discussed school, however half of them liked it and did very well, and the other half described feeling angry at going to school. Nevertheless school served an important function in providing routine, consistency and a chance to see friends.
Some parents were aware that they could not meet their children’s needs in terms of emotional availability and entertainment, for example due to fatigue, lack of motivation or irritability. Parents therefore organised lots of extra-curricular activities to keep their children occupied, to divert attention away from them and to reduce their sense of guilt.

Living in a family with bipolar disorder

The interviews highlighted the importance of general family life in the context of bipolar. Everyday occurrences such as spending time together, arguments, and mundane activities were all discussed. Children described both positive and negative experiences about living in their family, unrelated to having a parent who was unwell.

Almost all children with siblings discussed fighting with their brothers and sibling rivalry. Many described their fights, often in the context breaking or stealing toys and getting revenge. Children discussed the punishments which followed this, for example being told off, smacked, or not being allowed to play on the computer/watch TV. Younger children often discussed how the punishments were unfair, and they appeared unable to put themselves in other’s positions and recognise that they had done wrong and needed to be disciplined. This reflected their developmental level and egocentricity. Some children described quite graphic accounts of fighting with their brothers and how angry it made them feel:

“Then I say stop it or I’ll punch you with my knuckle…I start to get a bit violent”

(Michael aged 7)
Children gave a variety of responses about family life, for example: stressful and challenging; happy; nice because of the people, house and garden; and good because friends and extended family lived close by. Only one child said he did not like living in his family, and two others struggled to say what was nice or the best thing about their families. Despite this the rest of the children spoke highly of their relationship with their parent(s). They discussed love and affection and despite arguments, most children stated that they mostly got on with their parent(s) and were happy when they spent time together. One child expressed that there was nothing bad about his family.

Children valued activities and days out with the whole family spending quality time together, for example going on holiday, to the park, to theme parks, and enjoying birthdays and Christmases:

*Int:* “Do you ever spend time together altogether?”

*P:* “Yeah when we go out…we have fun” (Connor aged 6)

They also listed a variety of other things that made them happy, for example playing with their siblings and doing well at school.

Parents also discussed general family life, which was often associated with being stable in mood. When unwell, parents reflected that bipolar took over their lives and they could not appreciate their children and families. But during times of stability, they were able to
function as a ‘normal’ family and spend time together, as well as experiencing the everyday stressors of taking the children to school, sibling arguments and fighting, which is consistent with the children’s narratives. Parents reported that these positive and negative experiences were both difficult to tolerate when unwell, as they preferred to be alone, especially when experiencing depression. This reflects the child’s perspective and when the parent’s symptoms were manageable and stable, children could enjoy living in a family where a parent has bipolar disorder.
Discussion

To our knowledge this is the first study to focus explicitly on the experiences of young children who have a parent with bipolar disorder. This study builds on previous research exploring children’s understanding of mental illness and the experience of having a parent diagnosed with a psychiatric disorder. By interviewing young children about a specific mental illness i.e. bipolar disorder, we have found that children as young as four years can be interviewed using age appropriate and novel methods and can discuss their parent’s mood and behaviour. Young children aged seven and above can have candid and insightful discussions about their parent’s bipolar, with knowledge of symptoms, and how having a parent with bipolar impacts on them emotionally as well as practically.

From a historical perspective, when thinking about children’s age, developmental level and their knowledge and awareness, Piaget’s theory of cognitive development has influenced more recent research into children’s understanding of physical illness. Cognitive changes which occur between seven and eleven years old are said to be fundamental in understanding abstract aspects of illness, with a more mature understanding of illness evident from around twelve years old\textsuperscript{27-28}. This is consistent with the study findings, with children aged seven and above showing some knowledge, awareness and understanding of their parent’s mental illness. The findings are also consistent with the literature exploring children’s generic views of mental illness. In a review, Wahl (2002) found that younger children do not have clear knowledge of what mental illness is and their understanding becomes more sophisticated as they progress in age and development\textsuperscript{29}. Younger children were unable to describe specific traits, and they confused mental illness with physical illness and learning difficulties. The review found that older children were better
able to understand mental illnesses as disturbances of thoughts and emotions rather than just behaviour and showed a broader conception of the causes and treatments of these disorders. A more recent study found similar results with children aged 6 to 11\textsuperscript{30}. At all ages, children held coherent causal–explanatory ideas about the causes, consequences, curability, and timeline of both mental and physical illnesses. However, while younger children tended to rely on knowledge of common physical illnesses when thinking about mental illnesses, older children demonstrated differences in their thinking about mental and physical illnesses. They argued that children hold coherent conceptions of mental illness at all ages, but that mental illness only emerges as a distinct conceptual domain by the end of middle childhood. This was consistent with some children in the present study, although having a parent with a mental illness like bipolar disorder is likely to influence children’s knowledge and understanding, which may differ to children who have no personal experience of mental illness in the family.

It was clear that age and developmental stage of children was important. However, in terms of gender, with only one girl, it is difficult to attribute whether some of the differences were representative. As the only female interviewed, Alice’s perception differed to that of the younger male children, as she was older, less egocentric and able to empathise with her mother. However, research is consistent with this, suggesting that girls tend to exhibit more compassion and acceptance of mental illness compared to boys of a similar age\textsuperscript{31}. Girls are also known to confide in their friends more than boys\textsuperscript{32}, which is what Alice discussed, when referring to telling her friends about her mother’s bipolar disorder. What was evident was the importance of support for children, whether that be in another parent, extended family members or friends. Pets were also important in young children’s lives, which is consistent with the literature suggesting children often include pets and important
family objects in their kinship schemas. For children, having someone to talk to, support them, distract them and be consistent in their lives was a major protective factor. Although children described the emotional effects of having a parent with bipolar disorder, many of them were functioning well in school and were average when compared to their peers in terms of difficulties experienced. Therefore this suggests that support and children’s own coping strategies helped to mediate the effects of their parent’s illness, so that they could function and be well-adjusted. Related to this, research suggests that children’s functioning may not be so impaired at younger ages, but may only begin to deteriorate from mid to late adolescence as social and academic demands increase, and children experience more consequences of their own problems, parent’s mental illness, and subsequent life disruptions. Similar findings have also been reported in which children of parents with bipolar were observed to develop psychosocial competencies early on in life, only to lose them by early adolescence. However, it is also possible that younger children, such as in the study above, are more well-adjusted due to receiving early psychosocial and/or pharmacological interventions.

In the present study support did not necessarily mean professional support and intervention from services, but the children who were accessing mental health services themselves and the benefit they described suggests that early intervention is crucial in addressing children’s needs and may prevent them developing further problems as they get older. Although the majority of children in this study were doing well, some were struggling, and it does suggest that if difficulties are experienced within families, then a way of optimising children’s development and experiences should involve early identification and access to support and treatment for children as well as in their parents. As hypothesised earlier, there could be a link between children’s behavioural problems
and the expression of negative emotion. Research does suggest that younger children struggle to adjust to challenging environments and often display increased aggression and challenging behaviour as they struggle to make sense of their surroundings. The findings from this study alone cannot confirm this, as it is unclear whether this behaviour was ‘normal’ sibling rivalry, exaggerated accounts by the children, or an accurate reflection of increased behavioural problems in children of bipolar parents.

Parents were often unaware of how much their children knew, or they overestimated the knowledge and understanding of their child, suggesting that parents would benefit from further discussion with their children, with consideration of the ways that children at different developmental stages might react and interpret information. Revisiting discussions about illness at different intervals and providing explanation about events in age appropriate language would be useful in adding to their existing and still developing schemas about bipolar and mental illness. This would be helpful for younger children, to help them adjust and make sense of the fact that the problems are not theirs or their parent’s, but just a consequence of living in a family with bipolar disorder.

Although it is recognised that the clinical implications are limited due to the small sample size of this research study, if verified by future research, the current findings, and the research from generic parental mental illness studies, indicate that interventions which involve the whole family would be effective in facilitating shared communication and shared problem-solving, with a collaborative emphasis and shared responsibility within the family. This would help children to understand about their parent’s problems, help them to cope with difficult events, which would subsequently reduce the distress caused by not
understanding about mental illness and not having the knowledge about effective coping strategies. This would also help to improve parental functioning and reduce their distress in trying to manage alone without involving their family, which should also be a priority. The neglect of children’s needs by both children’s and adults’ services\textsuperscript{37-38} has lead to key policy and legislative changes in the UK, which has underlined the need for more holistic family based approaches to service provision\textsuperscript{39}. This is consistent with the recommendations from the present study, however joined up services for both children, parents and families are virtually non-existent in the UK, and approaches such as family therapy which have been found to be effective are often lead from either child or adult mental health services and not from specific services tailored to meet the needs of all parties equally. In terms of interventions currently available, parenting skills programmes and psychological therapies such as Cognitive Behavioural Therapy have been found to be effective for some parents in the short term in managing their own personal mental health difficulties. Those interventions that focus on both parent and child are often designed for mothers experiencing post-natal depression to improve attachment with very young children. Educational programmes do exist in other countries such as Australia to help adolescents (12-18 years) with a parent with a mental illness. These are groups which provide the opportunity for young people to access peer support and information, and to develop helpful coping strategies. However, little is available for children in middle childhood to help them cope with their parent’s mental illness, and nothing is available which relates specifically to the impact of bipolar disorder on children and families. Therefore it is proposed that this is an area that requires further exploration to decide how best to design services or interventions tailored to the needs of all family members to help them manage the systemic impact and changeable and often chaotic nature of bipolar disorder. This might be through specialist services or partnership working between child and adult services to facilitate education and training, but also joint working on referrals to
meet the needs of the whole family. Families would benefit from interventions on either on a case by case basis with sessions involving the whole family or through programmes which involve group work with other families, depending on the choice and individual needs of the family. The results from this research suggested that a lack of knowledge and understanding about mental illness and bipolar disorder contributed to a variety of negative emotions for the children. Therefore to address this, sessions in either format (individual family or group) would provide age appropriate information to children and families about mental illness (in this case bipolar disorder), and parents, children and partners would be encouraged to describe their own experiences, which would promote effective communication between all family members. This would help to avoid confusion, frustration and would facilitate a shared understanding, which was sometimes lacking in this study, where some parents either under or over-estimated their child’s knowledge, or did not discuss with their child at all. Providing information and having a shared understanding might also have a positive influence on the child’s perception of their parents, improving family relationships. Consistent with the theme around managing family life and the importance of coping and support networks, sessions would also encourage and teach effective coping strategies for family members, as well as promoting and enhancing the skills and resources that families already possess. Group work or education and skills programmes run with other families would also provide peer support for both the children and parents, as hearing other people’s stories and getting advice from people with similar experiences can be effective in increasing engagement, confidence and can improve outcomes.

Preventive interventions would also be useful to help the detection of problem areas in functioning, especially for younger children. Areas of Australia do have early intervention
programmes designed to prevent mental health difficulties in at risk children, by providing information, support and activities to children and parenting support to parents. These have been found to be effective for younger children and other countries such as the UK might benefit from this approach if evaluated and designed correctly, with children’s views in mind. Although the younger children in this study found it difficult to reflect on what types of support would be beneficial for themselves and their families, future research should also try to address this, for example asking older children about what they needed. Day (2008) recommended that children, particularly those who are socially excluded, require support and consideration in service development. Therefore it is crucial that children’s perspectives are understood and taken into account when developing appropriate services and interventions to support children and parents with mental illness, including bipolar disorder.

The use of qualitative methods proved beneficial in eliciting children’s experiences of their parent’s bipolar and family life. The use of ‘In My Shoes’ was successful in engaging children, especially the youngest ones, and even four year olds could retain concentration and interest in the interview for between twenty and thirty five minutes. The non-threatening ‘side by side’ nature of the interviews meant that children were able to discuss potentially sensitive and upsetting information, whilst focussing on the computer screen. ‘In My Shoes’ also facilitated discussion about general family life, enabling children to participate even if they had no awareness of their parent’s diagnosis. It was hypothesised that more information may be elicited using ‘In My Shoes’ than with a standard semi-structured interview, or alternative methods for interviewing children, such as the ‘write and draw’ technique, however this is an area which would benefit from further exploration. Given the relatively small sample size of the present study and the skewed
nature with regards to gender and ethnicity, more research is needed to explore children’s experiences of parental bipolar disorder, both with younger children and adolescents. This would enable a comparison to see if it impacts on children and adolescents differently, or if there is an overall shared experience. During the present study there were some difficulties in recruiting additional parents and children, which is understandable given the unique sample inclusion criteria. Alternative methods for recruitment were tried but to no avail. Given that this study recruited via a self-help organisation, it would also be interesting to repeat this study again by recruiting via other channels, for example the National Health Service. It was hypothesised there might be a difference between the families in this study, where the parents had accessed support via the registered charity, as well as mental health services, and parents who had only recently been diagnosed, or had not accessed services and undergone any pharmacological or psychosocial interventions.

This requires further exploration to expel any potential bias, as the parent participants who self-recruited into the study might be parents who are coping more effectively with their bipolar disorder and parenting. Consequently, it is also possible that the current findings are indeed too optimistic regarding growing up with a parent with bipolar disorder. In addition, the sample was based on parents who self-reported their diagnoses, which were not verified by a mental health professional. However, the researcher’s clinical experience with mental illness and the use of the Internal States Scale\textsuperscript{22} suggested that the self-report diagnoses were accurate. The majority of families in the present study were also from similar social backgrounds, and most parents had been educated to university degree level. Therefore this sample of parents might not have represented the norm, and they may have agreed for themselves and their families to participate in the research as they
had above average communication skills and were able to reflect on their own experiences and adjustment to being diagnosed with bipolar and how it affected their parenting. Nevertheless that is not to say that the children themselves were a sample outside the norm, but more research is needed to explore the experiences of children of all ages and backgrounds to fully understand how they experience family life living with a parent with bipolar disorder.

To conclude, this exploratory study represents the first important step in exploring the experiences of children who have parents with bipolar disorder. Children discussed the stresses and struggles as well as positives of being a young child growing up in a family, albeit ‘different’ to that of many of their peers. The core concepts of family life remain the same, but in the context of having a parent with bipolar, these children are trying to adjust to a different way of being, whether this be learning about bipolar disorder and how to access support and coping mechanisms to help; or whether it be taking on additional responsibility and independence. Age mediates the process of adjustment, and older children are better able to make sense of their parent’s illness and its impact, rather than seeing it as their fault through ‘egocentric eyes’. Researching children’s perspectives illuminates the voices of a previously neglected group, and only their inclusion in this process can identify children’s difficulties and facilitate the development of intervention and support tailored to meet their unique needs.
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Ethical approval

The University of Manchester, School of Psychological Sciences Research Committee granted approval for this study to be conducted.
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Paper 3 - Critical Appraisal

A qualitative investigation into the experiences of children who have a parent with a mental illness

This is paper 3 and is an appraisal of the research process as a whole. It has not been prepared in the format of a journal article and is not intended for publication. The paper reviews the work carried out in both papers 1 and 2 and discusses the researcher's reflections on the thesis.

Word Count: 5743
Paper 3 - Critical Appraisal

A qualitative investigation into the experiences of children who have a parent with a mental illness

Overview
The following paper is a critical appraisal and evaluation of the research process as a whole, including the researcher’s own personal reflections. An examination of the findings and process of conducting the literature review discussed in paper 1 of this thesis will be followed by a more thorough and detailed examination of the research study (paper 2) that the researcher devised and carried out as part of her Doctorate in Clinical Psychology. The paper will conclude with a discussion and integration of both papers 1 and 2.

**Paper 1: The experiences of children who have a parent with a mental illness: A review and qualitative synthesis**

1) **Summary and interpretation of findings**

The researcher completed a meta-synthesis to review and synthesise the existing qualitative research exploring the experiences of children who have a parent with a mental illness. From the synthesis, five themes emerged which reflected the overall experience of children growing up with a parent who has a mental illness. One of the key mediators was children’s knowledge and understanding of their parent’s mental illness, and the amount and level of knowledge and understanding influenced children’s perceptions of their parents and how it impacted on them as a child. The researcher was struck by the importance of this issue, as parents are often worried about discussing sensitive issues with their children and it is a common assumption that they can protect them by shielding them and not telling them about things. From the literature, the child’s perspective tells us that by not being informed and involved in family discussions, this actually has the opposite effect, often making children more worried, upset, confused and angry as they
attempt to make sense of and adjust to their parents ‘different’ moods and behaviour. This is supported in the literature, where protecting children from factual information about mental illness was identified as a barrier preventing parents from discussing their illness. Children, however, state that they know something is wrong and shielding them causes more concern (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). Research on physical illness also supports this, suggesting that parents newly diagnosed with serious conditions find communicating the news to their children stressful (Barnes et al., 2000). For children not told about parental illness, for example cancer, they often draw meaning from observing changes within the family, their parent’s visits to surgeries and hospitals, and from their parent’s mood and facial expression (Bluebond-Langner, 1978). This is also supported by strong evidence that children are affected by changes in their parent’s facial expressions from early years of life and particularly by parental depression (Murray & Cooper, 2003). What was apparent from the review findings from parental mental illness and from physical illness research is that although children cannot be protected from adverse events, the quality of relationships and communication between family members are important for preventing longer term consequences (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999).

2) Methodological Reflections

2.1 Strengths and rationale for decision making process

2.1.1-Choice of review: Meta-synthesis

The researcher chose to conduct a meta-synthesis, a relatively new technique for examining qualitative research (Jensen & Allen, 1996). It has been applied in diverse areas, for example experience of chronic illness (Thorne et a.l, 2002); diabetes (Campbell
et al., 2003); adaptation to motherhood (Beck, 2002); and midwifery care (Kennedy et al., 2003). Meta-synthesis is the most effective type of review for qualitative research, and can deepen understanding of the contextual dimensions of healthcare (Walsh & Downe, 2004).

In keeping with the ethos of qualitative research, as in the research study, the researcher decided that a review of qualitative research would be very appropriate and thought that a systematic or more narrative review would not have been as effective. Personally, for the researcher, a review of more quantitative research on psychopathology of children did not feel appropriate to sit alongside a study exploring children’s experiences, particularly as the aim was to explore positives as well as the negative aspects of having a parent with bipolar disorder. When the researcher explored the literature on the impact on bipolar disorder and other mental illnesses on children, it was striking how children were pathologised and their own views and experiences were very much neglected. Since this was the focus of the research study, the researcher searched for literature relating to children’s experiences of mental illness and there did not appear to be a review published which solely explored children’s unique experiences. Studies exploring people’s experiences are predominantly qualitative in nature, using methodologies such as interviews and focus groups, therefore the researcher decided to use a meta-synthesis to review qualitative studies exploring children’s experiences of parental mental illness.

The use of ‘synthesis’ within a meta-synthesis review has been a contentious issue in qualitative research. However, qualitative research is not traditionally included in systematic reviews, and without reviewing qualitative studies there is the risk of marginalisation from policymakers and clinicians if their work remains isolated, esoteric,
and incapable of influencing either strategy or practice (Silverman, 1997). Therefore without drawing together the literature on the experiences of children and parental mental illness, knowledge development and implications for clinical practice are hindered unless the crucial findings from these studies are reviewed and synthesised.

2.1.2 - Synthesis methodology

There are as yet, no set guidelines or common agreements on the most appropriate methods to combine and synthesise qualitative research findings (Britten et al., 2002). There is often discussion around whether researchers should attempt to synthesise qualitative studies using different methodologies or analytic techniques; however it seems implausible to think that all studies must be the same, and the use of guidance on conducting a meta-synthesis helps to address this. The decision about which method to employ is in part driven by the aim of the synthesis itself (see paper 1 for review methods).

2.1.3 - Quality Appraisal

The quality assessment of qualitative research is another highly contested debate, although many accept the need for clear and transparent approaches for judging the quality or credibility of research. As with synthesis methodology, there are also no agreed quality criteria and numerous quality checklists/guidance being used. However, some researchers argue that blindly following guidelines does not necessarily equate with good research (e.g. Barbour, 2001). Conversely, others argue for more rigorous use and reporting of analytical approaches which improve reliability and validity (Seale & Silverman, 1997).
The researcher used guidance from the Critical Appraisal Skills Programme (CASP, 2006), and a more detailed assessment using the checklist devised by Walsh & Downe (2006). The CASP was chosen as it is a quick and easy method involving 10 questions relating to rigour, credibility and relevance, to help screen out inappropriate or irrelevant studies. The CASP is referenced as a good appraisal tool in the NHS Quality Improvement Scotland document-'A guide to synthesising qualitative research' (Ring, Ritchie, Mandava, & Jepson, 2010) and in chapter 6 of the Cochrane Handbook-'Critical Appraisal of Qualitative Research' (The Cochrane Collaboration, 2011). It is also cited in many reviews and one of the most widely used. Walsh and Downe’s (2006) checklist was also used, as alongside the CASP, it is one of the few to be developed explicitly for use in systematic reviews, and was designed as a result of their literature review on the use of meta-synthesis.

2.2 Weaknesses and difficulties encountered in the review process

2.2.1 - Literature search

Only 14 studies were included in the review, but these were the only ones found that matched the inclusion criteria. The researcher carried out the search to the best of her ability (see paper 1 for details), mindful of well known challenges in searching for qualitative research. The methods and tools available to identify qualitative studies, especially from electronic databases are much less well developed than those available for identifying quantitative studies, especially RCTs (Dixon-Woods & Fitzpatrick, 2001). There are as yet no registers of qualitative studies, nor do existing RCT registers record whether qualitative data were also collected; as discussed in paper 1, limiting the inclusion
criteria to English language peer reviewed journals and publication bias, which may limit identification (Dickersin, 1990).

2.2.2 - Potential Bias

In addition to publication bias, meta-synthesis reviews could be questioned for incorporating confirmation bias or biases in interpretation (Plous, 1993). As a creative process is involved in synthesising findings and translating them into each other to create overarching themes, it is possible that the researcher's own attitudes or preconceptions influenced the findings. The researcher tried to remain objective, and selected and adhered to the appropriate guidelines for conducting a meta-synthesis. Discussion of the synthesis also took place within the research team, and the researcher's supervisor monitored the process to avoid this happening. The researcher acknowledges that she was experienced in quantitative and systematic reviews, with little prior experience in reviewing qualitative research; however through extensive reading and supervision from an experienced qualitative researcher, the researcher is confident that the findings from this meta-synthesis are representative of the studies and add significantly to the literature on children and parental mental illness.

2.2.3 - Writing for a medical journal

The research team decided to publish this review in the British Medical Journal (BMJ). Given the significance of the findings, the aim was to reach a wide professional population and the BMJ is accessed by the professions who authored the review studies (specifically
psychiatry, nursing, psychology and social work). By limiting this review to either a nursing or psychology journal, for example, there is the risk that the review might not reach its target audience. On reflection the researcher found adapting her style to adhere to a medical journal challenging, and the terms ‘mental illness’, and ‘psychiatric disorder’ which have been used throughout both papers 1 and 2 might not have been chosen in publishing elsewhere.

3) Conclusions: Paper 1

This review is the first of its kind, and highlighted key issues facing children living with a parent with a mental illness. Although only 14 studies were included, they all shared similarities across themes, suggesting generalisability to other children in this unique sample. Therefore, on the basis of the child perspective, services must now act and intervene to help children with the problems they are facing. By amalgamating and interpreting research from wider disciplines and reaching a shared understanding, it is hoped that this will guide the way for future interventions based on a holistic principle, rather than a more disjointed approach. As paper 1 emphasised, more research is needed to evaluate existing interventions and to design and pilot new approaches.

Overall the review was successful in exploring children’s experiences of parental mental illness, and the researcher enjoyed the process, the novelty, and the challenge of learning a new technique. The researcher was pleased with the results, and as someone already experienced in working with children of parents with mental illness, felt that the review added a great deal in illuminating the voices of previously neglected children within research.
Paper 2 – “It’s like being on the other side of the world with mummy”: A qualitative study exploring children's experiences of living with a parent with Bipolar Disorder

1) Summary and reflection on findings

The aim of the research was to explore the experiences of children, and it was hoped that both positive and negative examples would be found. Given the wealth of negative literature focussing on the problems of being a child of a bipolar parent, the researcher was transparent about her hope to find a more balanced perspective, especially given the researcher’s personal experience of family members experiencing problems with their mental health. The researcher was aware of this during the analytic stage, and was mindful not to let this influence the process of coding and collating emergent themes. This was discussed in research meetings to enable the researcher to try and remain neutral and detached from her background and theoretical stance.

On reflection, the researcher did think that a balanced perspective emerged from the interviews and was pleased with the themes that represented the data. Normal family life was often described, including the ‘ups and downs’. The child’s age, developmental stage, support and coping strategies mediated the effects of their parent’s illness, which could be minor or more severe in terms of emotional effects, and the extra responsibilities that they took on to help out in the family. The child’s knowledge and awareness of their parent’s bipolar disorder and the communication within the family also depended on age, but did
not affect the perception of their parents. This may be explained by the young children’s egocentricity, often blaming themselves or their parents for negative incidents within the family.

Some of the interviews evoked strong emotional reactions in the researcher, which was reflected on during research meetings. The researcher was moved by some of the upsetting accounts of the children’s experiences, but remained professional at all times. In contrast, the researcher also gained a lot of enjoyment from the interviews and often found the children very likeable and funny, and enjoyed spending time talking and working together on the computer. Overall the researcher was very pleased with the results and their contribution to the literature, and the research process as a whole had been a very positive experience, accompanied by high quality, supportive supervision.

2) Methodological Reflections

2.1 Strengths and rationale for decision making process

2.1.1 - Research topic

Research exploring children’s experiences of living with a parent with bipolar disorder is a novel, interesting, insightful and important area for further research and service development, which has not previously been explored. Research involving children’s
experiences of parental mental illness tends to focus primarily on adolescents and adults who were children of parents with bipolar disorder. Although some studies did report that children as young as five and six years were interviewed, these younger ages were under-represented compared to older age groups. Therefore in being specific and focussed on a single clinical presentation like bipolar disorder, this can advance the field by identifying issues that are unique to these families, and we can begin to understand how children experience different parental illnesses. Therefore with this knowledge and insight, services and interventions can be tailored to meet their distinctive needs. The present study therefore is one of a kind and the first stage in this process.

2.1.2 - The use of ‘In My Shoes’

The research used ‘In My Shoes’ (IMS; Calam, Cox, Glasgow, Jimmieson, & Groth Larsen, 2000), a computer assisted interview divided into eight modules: The Introduction, Emotions, Emotions and Scenes, Places, People, Emotions and People, Somatic Experiences, and Subjects (see Appendix 10 for a summary of the modules). The research study was designed using all the modules except somatic experiences and subjects, which did not explore family life, but after the pilot interviews, emotions and scenes was cut out as the researcher felt the interviews were too long and this module did not add to children’s descriptions of their families.

The researcher chose IMS as there are very few approaches designed for interviewing very young children about their experiences and this study intended to use IMS to see if it was feasible and effective in exploring young children’s experiences of issues such as parental mental illness. The research team did not know whether it would work and were
unsure of what to expect. However we predicted it might work based on prior experiences of using IMS to explore other issues, for example in cases of suspected abuse. Therefore it was seen as the ideal method to pilot with young children.

On reflection, the use of IMS was indeed a success, and children as young as four could indeed engage meaningfully with the interview, giving clear and insightful descriptions of family life and relationships. In terms of engagement, the researcher was able to develop a rapport with the children quickly, as the focus of both child and researcher was on the computer working together. Having prior experience in interviewing and assessing children, the researcher was not surprised that children found it much easier to ‘open up’ and discuss upsetting and emotional events via the computer. On reflection this was likely to be due to the external focus on the computer screen, rather than being asked direct questions with the researcher sitting opposite, which is potentially more threatening and ‘off-putting.’ Computers also place fewer demands on children’s verbal abilities as children can engage and provide information without needing to talk. This helped to engage and overcome the initial shyness of a few of the children. The researcher found the computer useful as a distraction so that the child did not pick up on emotional cues or the researcher’s facial expressions.

It was apparent that all children enjoyed the IMS interview and felt comfortable. Although some of the younger children did sometimes find it difficult to find the words to describe their experiences, IMS still enabled information to be collected, and the child’s words were used throughout the interview. Therefore for the purpose of this study IMS proved to be
flexible, adaptable, engageable, and applicable to interviewing young children about family life with a parent who has bipolar disorder.

2.1.3 - Qualitative Analysis

When designing the study the research team discussed the most appropriate forms of analysis. Given that this was a feasibility study in using IMS to explore younger children’s experiences, the research team were unsure of what to expect in terms of content and richness of data. The initial aim was to use Interpretative Phenomenological Analysis (IPA) to analyse the data, which aims to explore how people perceive their social situations and how they make sense of the world around them (Smith, 2008). IPA is thought to be very useful when people are dealing with complex and novel situations. (Smith, 2008). It was therefore deemed appropriate for this study. IPA was chosen over other analytic techniques such as grounded theory (Glaser, 1992; Strauss & Corbin, 1998) as the researcher’s supervisor at the time was a qualitative researcher very experienced in the use of IPA, and the initial aim was not to generate theory, but to gain insight into a unique group of children’s experiences, which has never been done before to the best of the research team’s knowledge.

Given the young age of the participants, if the data was not deemed rich enough to warrant the use of IPA, then thematic analysis (TA) was planned as an alternative qualitative analysis. After the first half of the interviews had been transcribed, the researcher met with the team to discuss the content of the interviews. Although some very interesting and insightful information had already been generated, the volume of data did not appear sufficient to conduct a detailed IPA, therefore the research team decided to proceed with TA.
TA was used as it results in a rich, yet accessible account of the data, rather than a theoretic approach, and the researcher seeks to make sense of the data and the patterns inherent within the data collected (Braun & Clarke, 2006; Boyatzis, 1998). Braun & Clarke (2006) tried to address criticism of the absence of clear guidance on theory, application and evaluation by striking a balance between providing guidance on how to do it to increase reliability, but also retaining the flexibility in how it is used in research. The researcher used this guidance in conjunction with guidance from her research supervisor, and TA was deemed successful in providing a rich description of the children’s overall experiences, which is useful when investigating an under-researched area, or with participants whose views on the topic are not known, like in the present study (Braun & Clarke, 2006).

With the parent’s data, content analysis (Graneheim & Lundman, 2004) was chosen as the aim was to take the existing themes from the child data and look for specific reference to them in the parent interviews. Therefore TA or other alternative analyses were not used as the researcher did not need to code the whole interviews and did not want to generate themes from the parent’s experience. Rather, it was to extract very specific information about their reference to their children and compare parent and child dialogue to illuminate the overall child experience. This was deemed very useful for all ages of child, especially the older ones (to compare their knowledge and awareness of their parents’ bipolar disorder with what the parent actually discussed with them); and for the younger children who did not seem to be aware (to find out if the parent had ever discussed it with them and how they felt their illness impacted on their child). As exploration of the parent data was not an initial objective, the researcher considered the ethical implications of this, and gained ethical approval. Parents were also consulted and were asked to sign an opt-out
form if they did not wish their data to be used in this way. None of the parents objected. With both analyses a careful balance was required, as it was not possible or desirable for the researcher not to assume a particular perspective; however it was also important to not input meaning that was not there (Graneheim & Lundman, 2004).

2.1.4 - Reflective Journal

The researcher completed a reflective journal/diary to record her thoughts about the interviews, including important observations, reflections on the findings, the research decisions made, and her own feelings which may have contributed to how the data was collected or analysed. This was to try to avoid bias and to make the thought and decision making process transparent, to make sure the researcher’s own feelings and attitudes did not cloud her objectivity. The journal was completed as soon after the interviews as possible, and throughout the research process as a whole and was discussed regularly within team meetings. On reflection the researcher found the use of a reflective journal invaluable in keeping a record of these principles, the key events and how they impacted on the research process. Many of the issues discussed in this paper were initially written in the journal.

2.1.5 - Ethical considerations

The researcher was aware of the sensitive nature of the research and took considerable efforts to ensure that the parents were informed about the research aims and that any concerns were addressed. Children were not informed initially that the aim was to research their parent’s bipolar disorder, but were informed that the interview would involve
exploring their experiences of general family life (which is what happened as facilitated by IMS). This was reflected in the information sheet and consent form intended for the children aged 7 and above. The researcher developed a narrative to explain IMS and the study to children aged 4-6 years (see Appendix 15).

It was made clear that if children felt uncomfortable about any part of the interview, then IMS would move on to the next topic or discontinue if the child wanted to withdraw. This did not happen in any of the interviews, as the children enjoyed taking part, despite discussion of sensitive issues. The researcher was also aware of the power dynamic between the researcher and the child participants, and tried to overcome this by making the interview as collaborative as possible, and letting the child take the lead in operating the computer.

2.2 Weaknesses and difficulties encountered in the research process

2.2.1-Sample

Purposive sampling was chosen as the researcher needed to target a unique group of children via their parents (Patton, 1990). More specifically, within purposive sampling the study intended to use a homogeneous sample selection, i.e. a small group of participants for intensive study (children of bipolar parents).

It was envisaged that a minimum of 12 computer assisted interviews would be necessary; however, the researcher was only able to recruit ten children. Smaller
samples are less of an issue in qualitative research, and the aim was to explore their lived experiences and not to compare them to other children. The sample was skewed, with nine boys and one girl. The researcher had hoped to get a more equal number in terms of gender, however as the sample selected itself through parent’s volunteering through a national advertisement, the researcher had no control over this, which could have caused potential bias. The researcher wondered whether a larger numbers of girls would have enabled a comparison of the experiences of males and females to see if they perceived things differently. Research on gender differences is mixed with regards to children’s attitudes and understanding of mental illness. While some studies report differences between girls’ and boys’ conceptions of mental illness, with girls tending to normalise the behaviour (Marsden & Kalter, 1976), and showing greater compassion and social acceptance towards those with a mental illness compared to boys (Ross & Ashok, 1983), other studies have failed to find any gender differences in understanding or attitudes (e.g. Coie & Pennington, 1976; Fox, Buchanan-Barrow, & Barrett, 2010; Novak, 1974).

The sample did not appear representative in terms of ethnicity and educational background, so therefore cannot be generalised to other social groups and ethnic backgrounds. However, given the nature of the unique sample and the sensitive issues involved, it would have been very difficult to have a wholly representative sample. The more sensitive or threatening the research topic, the more difficult sampling is likely to be, because potential participants have greater need to hide involvement (Renzetti & Lee, 1993). Within the present sample however, there was a good range of ages, and the sample consisted of children between four and ten years, although the findings cannot be represented to other age groups or children whose parent’s have other illnesses or diagnoses.
2.2.2 - Recruitment

The researcher was aware that the recruitment of her child participants was reliant on contacting parents with bipolar disorder and getting their consent to allow their children to take part in the study. Two parents consented to their involvement in the associated study but did not consent to their children taking part. Therefore the researcher missed out on the opportunity of interviewing three further children in the correct age range from these families. Following this the other researcher (RM) stopped recruiting as the information she had collected from eight parents was deemed rich enough to begin IPA, so this then hindered the present study’s recruitment. The researcher struggled to recruit independently, as parents did not wish their children to take part if they could not be interviewed also.

The research team decided to recruit via self help groups and not via the National Health Service. The team thought this would make recruitment easier and pose less of an ethical challenge. The Manic Depression Fellowship (MDF) were interested in facilitating recruitment, and in addition to placing an advert in their national magazine they agreed to forward a recruitment email to the self help group leaders (see Appendix 16). The emails were sent out a number of times and the researchers agreed to attend meetings to provide additional information to try and engage potential participants. Despite these efforts, all eight parents and their children were recruited solely from the magazine advert. The researchers also contacted two other large self help organisations, but they were not interested in facilitating recruitment. The researchers placed adverts on the student research and parents/family web-pages on the university website, but with no success. Similar issues with recruiting vulnerable, difficult to access groups when have
been discussed by researchers examining children of parents with alcohol and/or drug misuse problems (e.g. Barber & Robyn, 1999), and ‘young carers’ of parents with a mental illness (Aldridge & Becker, 2003).

2.2.3 - Potential Risk Issues

There are a number of risks and other difficulties associated with home visits. However most parents and children find interviews in the home environment more accessible, and children are more likely to be comfortable talking to someone within their own homes. This was consistent with the present study, and although participants were given a choice of interview location, they all chose their home. Given the personal nature of the interviews, the researcher wondered if this level of information would have been collected if the interviews took place at an external location, for example at a clinic or university setting. At times the interviews were disrupted, for example pets wandering in and out, parents coming to check on their children, and other siblings distracting the child being interviewed. The researcher tried to manage these disruptions professionally and timely so the interviews could proceed.

At times the researcher did gain advice from the research team about potential child protection issues, such as physical abuse and some unusual events described by some younger children, which left the researcher with a sense that ‘something was not right’. There was little direct evidence for this, but was just a feeling evoked in the researcher. It was often difficult to distinguish between factual accounts and fantasy with some of the younger boys, some of who described graphic violence, and unusual disjointed stories.
This was discussed in research supervision and audio tapes were reviewed again to get a sense of what was going on for the child.

3) Implications for future research, theory and practice: Paper 2

- This study is the first to interview very young children about their experience of living with a parent with bipolar disorder.
- The results offer an important contribution to the literature, in an under researched population.
- Both positive and negative experiences have been found, creating a more balanced perspective, which is under-reported and not currently represented in existing research.
- The findings in terms of children’s experiences across different ages and developmental stages contribute to child development theories and support existing research exploring children’s experiences and understanding of other areas such as physical illness and mental illness.
- IMS is a useful and effective method for exploring children’s experiences about parental mental illness and bipolar disorder in children aged 4-12. IMS engaged children, aided communication and all children remained focussed throughout the interview. The engaging nature of the interview made it easy to explore children’s
experiences of family life and the open dialogue allowed children to talk about wider factors not directly asked by IMS.

- The limitations of the study associated with the sample should be addressed by having future research using:
  - similar studies with a larger group of children from a wider age range (both younger children and adolescents) and from different ethnic and social backgrounds, to increase one's knowledge of this novel area.
  - studies that use a range of interview techniques e.g. IMS, ‘write & draw’ techniques, semi-structured interviews, and focus group designs, to compare the findings and highlight similarities and differences or an overall shared experience despite the method used;
  - studies with different designs, for example having two groups of children (control and children of bipolar parents) and comparing the themes generated;
  - different recruitment methods e.g. via the NHS to compare findings.

- Interventions should be designed to focus on the family as a whole to enable a shared understanding and collaborative nature with regards to change and problem solving.

- There should be a focus on early intervention of child problems to stop them escalating.
Children should be involved in the consultation process when designing services and interventions to see what they want and need.

Summary and Integration of papers 1 and 2

Table 1: Themes from the review and research study

<table>
<thead>
<tr>
<th>Paper 1 themes</th>
<th>Paper 2 themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and Understanding of parental mental illness</td>
<td>Knowledge and awareness of Bipolar Disorder</td>
</tr>
<tr>
<td>Coping Strategies and Support</td>
<td>Perception of parents</td>
</tr>
<tr>
<td>Parent-Child Relationship</td>
<td>Managing family life with a ‘Bipolar’ parent</td>
</tr>
<tr>
<td>Social, emotional and behavioural effects on the child</td>
<td>Living in a family with Bipolar</td>
</tr>
<tr>
<td>Role of other people &amp; society</td>
<td>N/A</td>
</tr>
</tbody>
</table>

The themes that emerged from both papers were similar, but with some subtle differences. On reflection it is difficult to make comparisons between the two sample groups, as the review incorporated the views of 163 children and young people aged between 5 and 22 years from a range of countries, whereas the research study interviewed 10 children aged 4 to 10 years from England. However, one of the main similarities was the importance of
knowledge, understanding and awareness of parental mental illness/bipolar disorder. The review and research study demonstrated the importance of children knowing some information, and the content of this and the way it was portrayed was dependant on the age and developmental level of the child. An important finding was that although parents tried to protect their children by shielding them from knowledge, this often had the opposite effect, creating worry, confusion, sadness and anger in the child.

The main difference was the lack of a theme around stigma and the role of other people/society, in the research study. A possible explanation was the younger age group of participants, as they were less likely to be aware of wider societal attitudes towards mental illness, and due to their developmental level, children tended to hold insular attitudes, and in this study blamed themselves, their siblings or their parents for negativity within the family. As children approach adolescence, they are more inclined to be aware of their peers, other people and wider society’s attitudes towards mental illness.

The other themes, although labelled differently, encapsulated similar topics, such as: the impact on the child in terms of emotional effects; taking on extra roles and responsibility within the family; and reference to their parents (whether that be the parent-child relationship or perception of parents). A strength of the interview study was giving children the chance to explore and describe general family life, which was missing from some of the review studies. The theme ‘living in a family with bipolar’ demonstrated that although children have to adjust to ‘difference’ and additional demands upon them, they still have ‘normal’ family life to contend with, including positive and negative experiences unrelated to having a parent with bipolar disorder. This is important to highlight, as one could get too
caught up in attributing all negativity to parental bipolar disorder. Families are complex and dynamic systems and it is difficult to tease apart which parts of the child’s experience are as a result of the bipolar. However, this is not the aim of qualitative research, and the researcher did not intend to ‘measure’ causality, but rather explore the overall experiences of children living with a parent with bipolar.

Conclusion

The research carried out for this thesis was extremely challenging, interesting, and vitally important for the future of families in which a parent has bipolar disorder. Personally it impacted on the researcher as a clinician, and hearing children’s experiences was insightful, fascinating and the researcher felt privileged to be one of the first to investigate such a neglected and unique group of children. It is hoped that the research will soon be published and will offer a great deal to the research and clinical field, in terms of implications for future research and practice. Now children’s voices have been heard, services must take action!
References


Appendix 1-

Critical Appraisal Skills Programme (CASP, 2006)
Critical Appraisal Skills Programme (CASP)

making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is not a definitive guide and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

• Rigour: has a thorough and appropriate approach been applied to key research methods in the study?
• Credibility: are the findings well presented and meaningful?
• Relevance: how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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Screening Questions

1. Was there a clear statement of the aims of the research?  
   Consider:
   – what the goal of the research was
   – why it is important
   – its relevance

2. Is a qualitative methodology appropriate?  
   Consider:
   – if the research seeks to interpret or illuminate
   the actions and/or subjective experiences of
   research participants

Is it worth continuing?

Detailed questions

Appropriate research design

3. Was the research design appropriate to address the aims of the research?  
   Consider:
   – if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Sampling

4. Was the recruitment strategy appropriate  
   Write comments here
to the aims of the research?

Consider:
– if the researcher has explained how the
  participants were selected
– if they explained why the participants they
  selected were the most appropriate to provide
  access to the type of knowledge sought by the
  study
– if there are any discussions around recruitment
  (e.g. why some people chose not to take part)

Data collection

5. Were the data collected in a way that addressed the research issue?

Consider:
– if the setting for data collection was justified
– if it is clear how data were collected (e.g. focus
  group, semi-structured interview etc)
– if the researcher has justified the methods
  chosen
– if the researcher has made the methods explicit
  (e.g. for interview method, is there an indication
  of how interviews were conducted, did they
  used a topic guide?)
– if methods were modified during the study. If so,
  has the researcher explained how and why?
– if the form of data is clear (e.g. tape recordings,
  video material, notes etc)
– if the researcher has discussed saturation of
  data

.................................................................
Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?
   Consider whether it is clear:
   – if the researcher critically examined their own role, potential bias and influence during:
     – formulation of research questions
     – data collection, including sample recruitment and choice of location
     – how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Ethical Issues

7. Have ethical issues been taken into consideration?
   Consider:
   – if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
   – if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
   – if approval has been sought from the ethics committee

Data Analysis
8. Was the data analysis sufficiently rigorous? Write comments here

Consider:
– if there is an in-depth description of the analysis process
– if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
– whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
– if sufficient data are presented to support the findings
– to what extent contradictory data are taken into account
– whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Findings

9. Is there a clear statement of findings? Write comments here

Consider:
– if the findings are explicit
– if there is adequate discussion of the evidence both for and against the researcher’s arguments
– if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
– if the findings are discussed in relation to the original research questions

..................................................
**Value of the research**

10. **How valuable is the research?** Write comments here

   Consider:
   – if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
   – if they identify new areas where research is necessary
   – if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
Appendix 2-

Quality Appraisal Checklist (Walsh & Downe, 2006)
Quality Appraisal Checklist (Walsh & Downe, 2006)

- Summary criteria for appraising qualitative research studies

<table>
<thead>
<tr>
<th>Stages</th>
<th>Essential Criteria</th>
<th>Specific prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope and purpose</td>
<td>Clear statement of, and rationale for, research question/aims/purposes</td>
<td>• Clarity of focus demonstrated</td>
</tr>
<tr>
<td></td>
<td>Study thoroughly</td>
<td>• Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing</td>
</tr>
<tr>
<td></td>
<td>contextualised by existing</td>
<td>• Link between research and existing knowledge demonstrated</td>
</tr>
<tr>
<td></td>
<td>literature</td>
<td>• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both</td>
</tr>
<tr>
<td>Design</td>
<td>Method/design apparent, and consistent with research intent</td>
<td>• Rationale given for use of qualitative design</td>
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</table>

• Were data collection methods appropriate for type of data required and for specific qualitative method?
• Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?
<table>
<thead>
<tr>
<th>Data collection strategy</th>
<th><strong>Apparent and appropriate</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Was triangulation of data sources used if appropriate?</strong></td>
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<table>
<thead>
<tr>
<th>Sampling strategy</th>
<th>Sample and sampling method appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Selection criteria detailed, and description of how sampling was undertaken</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Justification for sampling strategy given</strong></td>
<td></td>
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<tr>
<td><strong>Thickness of description likely to be achieved from sampling</strong></td>
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<tr>
<td><strong>Any disparity between planned and actual sample explained</strong></td>
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<table>
<thead>
<tr>
<th>Analysis</th>
<th>Analytic approach appropriate</th>
</tr>
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<tbody>
<tr>
<td><strong>Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</strong></td>
<td></td>
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<tr>
<td><strong>Was it appropriate for the qualitative method chosen?</strong></td>
<td></td>
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<tr>
<td><strong>Was data managed by software package or by hand and why?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Discussion of how coding systems/conceptual frameworks evolved</strong></td>
<td></td>
</tr>
<tr>
<td><strong>How was context of data retained during analysis</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Evidence that the subjective meanings of participants were portrayed</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Did research participants have any involvement in analysis (e.g. member checking)</strong></td>
<td></td>
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<tr>
<td><strong>Evidence provided that data reached saturation or discussion/rationale if it did not</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Evidence that deviant data was sought, or discussion/rationale if it was not</strong></td>
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<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Context described and taken account of in interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description of social/physical and interpersonal contexts of data collection</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Evidence that researcher spent time ‘dwelling with the data’, interrogating it for competing/alternative explanations of phenomena</strong></td>
<td></td>
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<tr>
<td><strong>Sufficient discussion of research</strong></td>
<td></td>
</tr>
<tr>
<td>Clear audit trail given</td>
<td>Data used to support interpretation</td>
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<table>
<thead>
<tr>
<th>Reflexivity</th>
<th>Researcher reflexivity demonstrated</th>
<th>Discussion of relationship between researcher and participants during fieldwork</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• Demonstration of researcher’s influence on stages of research process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Evidence of self-awareness/insight</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Documentation of effects of the research on researcher</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Evidence of how problems/complications met were dealt with</td>
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<table>
<thead>
<tr>
<th>Ethical dimensions</th>
<th>Demonstration of sensitivity to ethical concerns</th>
<th>Ethical committee approval granted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</td>
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<tr>
<td></td>
<td></td>
<td>• Evidence of fair dealing with all research participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Recording of dilemmas met and how resolved in relation to ethical issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Documentation of how autonomy, consent, confidentiality, anonymity were managed</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Relevance and transferability</th>
<th>Relevance and transferability evident</th>
<th>Sufficient evidence for typicality specificity to be assessed</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Discussion of how explanatory</td>
</tr>
<tr>
<td>Propositions/emergent theory may fit other contexts</td>
<td>Limitations/weaknesses of study clearly outlined</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Clearly resonates with other knowledge and experience</td>
<td>Results/conclusions obviously supported by evidence</td>
<td></td>
</tr>
<tr>
<td>Interpretation plausible and ‘makes sense’</td>
<td>Provides new insights and increases understanding</td>
<td></td>
</tr>
<tr>
<td>Significance for current policy and practice outlined</td>
<td>Assessment of value/empowerment for participants</td>
<td></td>
</tr>
<tr>
<td>Outlines further directions for investigation</td>
<td>Comment on whether aims/purposes of research were achieved</td>
<td></td>
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</tbody>
</table>
Appendix 3-

Guidance for meta-synthesis (Noblit & Hare, 1988)
Guidance for metasynthesis (Noblit & Hare, 1988)

This approach consists of a series of seven phases that overlap and repeat as the metasynthesis progresses:

(a) Getting started and deciding on a phenomenon of study.

(b) Deciding what qualitative studies are relevant to the initial interest.

(c) Reading the qualitative studies.

(d) Determining how the studies are related to each other. In this phase, the synthesizer makes a list of the key metaphors in each study and their relations to each other. The term metaphor refers to themes, concepts, or phrases. Three different assumptions can be made about the relationships between the studies to be synthesized. These key assumptions are: “(1) the accounts are directly comparable as ‘reciprocal’ translations; (2) the accounts stand in relative opposition to each other and are essentially ‘refutational’; or (3) the studies taken together present a ‘line of argument’ rather than a reciprocal or refutational translation” (Noblit & Hare, 1988, p. 36).

(e) Translating the studies into one another.

(f) Synthesizing translations. This involves creating a whole as something more than the individual parts imply. The translations as a group are one level of a metasynthesis. Next, the translations can be compared to decide if the same metaphors/themes or concepts can be encompassed into those of others. This is a second level of synthesis.

(g) Expressing the synthesis through the written word, plays, art, videos, or music.
Appendix 4-

Guidance for meta-synthesis (Walsh & Downe, 2005)
Guidance for metasynthesis (Walsh & Downe, 2005)

Practically, this process begins with the first reading of the studies and is completed with the creation of a grid of key concepts. These findings are then juxtaposed to both identify homogeneity of categories/codes/themes and, crucially, to note discordance and dissonance. Jensen and Allen (1996) identify two processes here. The first, or hermeneutic, aspect consists of accurately capturing individual or cultural constructions. This is the art of respecting and representing context as intended through the original research. Second is the dialectic aspect, which relates the studies to each other. This can be achieved through juxtaposition of the parameters identified by the compare and contrast exercise.

Reciprocal translation

The next phase begins the translation of one study's findings into another, using metaphors and concepts that could be applied to both. Sometimes commonalities will be only too apparent and reciprocal translations are relatively straightforward. At other times they will stand in opposition as a

‘refutational translation’ (Noblit & Hare 1988), or they may overlap without being substitutional. Refutation and overlap may contribute to another, emergent, category or understanding which has not been identified in the original accounts. It is crucial to the method that differences are not glossed over or subsumed. Deviant data may be the raw material of another perspective, making a new space for understanding. In fact the absence of divergent or deviant data may arouse suspicion as to the rigour of the reciprocal translation, as qualitative inquiry rarely results in complete congruence of meaning.

Synthesis of translation

The final phase is synthesizing the translations to elucidate more refined meanings, exploratory theories and new concepts. Clusters of metaphors become progressively more refined and a consensus emerges as to core themes or explanatory, mid-level, or substantive theory (Sherwood 1997b, Strauss & Corbin 1998, Campbell et al. 2003). The synthesis needs to reflect the tension between contradictory or alternative explanations if reciprocal translations suggest a lack of congruence. Ultimately, the final synthesis will be the grounds on which the value of meta-synthesis is judged and it therefore needs to convey explicitly how the whole is greater than the sum of the constituent parts.
Appendix 5-

Recruitment advert
Parenting and Bipolar

As we all know parenting can be both a rewarding and stressful experience. For parents who also have Bipolar Disorder, their symptoms can sometimes make parenting even more of a struggle.

If you are a parent with Bipolar Disorder and you have children between the ages of 4 and 12 years then we would like to offer you the opportunity to take part in our research.

Background: A lot of previous research looking at parenting and mental health highlights the negative outcomes for both the parent with Bipolar Disorder and their children.

Our research:

1. We feel it is important to recognise the strengths of parents with Bipolar Disorder as well as any difficulties; the positive experiences they have as well as the negative, in order to provide a more balanced perspective.
   - This will be done by carrying out interviews with parents who have Bipolar Disorder.

2. We also hope to gain children’s experiences of family life. This can provide useful and important information, which is often forgotten in research.
   - This will be done via a computer package designed for children which is regularly used by health professionals to interview children.
   *Please note* children will not be asked any specific questions about their parent’s Bipolar Disorder. Therefore children do not need to be aware of their parent’s diagnosis to be involved in this research, nor will they be informed about Bipolar Disorder during the interview.

Aims: The aim of this research is to develop an understanding of the experience of families where a parent has Bipolar Disorder, in order to contribute to the development of support and interventions for future families who might need it.

Contact: For further information or to express an interest in one or both parts of the research please contact:

Rebecca Murphy: rebecca.murphy@postgrad.manchester.ac.uk
Clare Backer: clare.backer@postgrad.manchester.ac.uk
Telephone: 07554387014

This research will be completely confidential and if you wish to take part we can arrange this at your convenience. We are happy to visit you at home or a preferred location and will fit around school/childcare arrangements.

This research has been approved by the School of Psychological Sciences Ethics committee.
Appendix 6-

Parent Information Sheet
Title of project

The experiences of children with parents who have Bipolar Disorder.

Introduction

The aim of this study is to explore children’s experiences of family life living with a parent who has Bipolar Disorder. An interview will be carried out with your child using ‘In My Shoes’, a computer-based interview designed to help children talk to health professionals about their emotions and experiences.

A lot of previous research looking at parenting and mental health has indicated that there can be negative outcomes for both the parent with Bipolar Disorder and their children. We want to study both positive and negative views and experiences, and strengths and difficulties, in order to provide a more balanced view. Gaining children’s experiences can provide useful and important information, which is often forgotten in research.

There will be no specific questions about Bipolar Disorder. The interview is made up of a series of modules exploring children’s experiences and emotions with different people in home, educational and other settings. Therefore children do not need to be aware of their parent’s diagnosis to be involved in this research, nor will they be informed about Bipolar Disorder during the interview. We are not here to provide information to your child and will follow your guidance about what the child already knows. We are only here to hear your child’s views and experiences.

This research will work alongside another study investigating the experiences of parents with Bipolar Disorder in relation to their parenting role and the ways in which Bipolar Disorder has affected their family. It is hoped that the findings from both studies will inform the development of appropriate support and interventions for families who may wish to access this in the future.
**What will my child be asked to do if they take part?**

Your child will be asked to take part in an ‘In My Shoes’ interview and the trained researcher will sit alongside your child and talk with them through a structured, yet child friendly, interview process. On average, ‘In My Shoes’ takes about 45 minutes, and is an excellent and enjoyable way of helping children feel at ease and talk about their lives. To help make sure the researcher collects accurate information, a video recorder will be set up to show what is happening on the computer screen. Although we will be able to hear your child’s voice on the recording they will not be shown on the recording. All identifiable information will be removed when the interview is analysed. There are no known disadvantages or risks in taking part in an ‘In My Shoes’ interview. Indeed people often report enjoying being interviewed.

**What will I be asked to do if I take part?**

An initial meeting will be arranged for the researchers to meet you and your child, to provide further information about the research, to answer any questions and to arrange a time and place for the interview to take place.

On the day of the interview, you will be asked to complete some standardised questionnaires regarding child difficulties and parenting issues, and supplementary information about socio-demographic details, and management of Bipolar Disorder, in order to provide the context for child and parents’ views and experience. If you are taking part in the parent study, this will be done in another room at the same time as your child’s interview.

**Will the data be anonymous?**

Yes, all information collected from you and your child will be anonymous and will be kept strictly confidential. All information will have personal details removed after the interview, so that you and your child cannot be recognised from it, and the rest of the information will be shared in the research team only. Video recordings will be kept secure in keeping with the Data Protection Act.

The only time that information would have to be shared would be if it became apparent that there were issues of personal safety to you or your child that were not previously known. In that case, the interviewer would have an obligation to share that information with the appropriate service, such as social services. As with any research involving children, if a researcher has any concerns that a child may be at risk of harm they are bound to pass this information on, which is inline with child protection procedures.

**Does my child have to take part?**
Your child does not have to take part in the study. If you decide to allow your child to take part and then later change your mind, either before the study starts, during it or afterwards, then you can withdraw your child without giving your reasons, and, if you wish your child’s data will be destroyed.

**Where can I obtain further information if I need it?**

Please contact the researcher for further information or if you wish to take part in one or both of the studies.

**Researcher:**

Clare Backer clare.backer@postgrad.manchester.ac.uk

**Research supervisors:**

Rachel Calam rachel.calam@manchester.ac.uk

Dr Fiona Ulph Fiona.Ulph@manchester.ac.uk

This project has been approved by the

School of Psychological Sciences Research Ethics Committee
Appendix 7-

Child Information Sheet
Participant Information Sheet

Invitation

You are being invited to use a computer interview called ‘In My Shoes’, to help explore your experiences of family life.

What is ‘In My Shoes’?

‘In My Shoes’ is a computer game that will ask you questions and help you to talk about your feelings and experiences.

What will I have to do?

If you take part in the study, you will sit next to Clare and answer questions from both the computer and Clare. The interview usually takes about 45 minutes, and most children who have used it in the past enjoy taking part. A video recorder will record what is happening on the computer screen to help Clare remember your answers. We will be able to hear your voice on the video, but you will not be seen.
Do I have to take part?

No, it is up to you and your parent(s) to decide.

If your parent(s) agree, but then change their minds, they can stop you taking part in the study at any time.

You can also ask to stop the study without giving Clare a reason, and ask for your information to be thrown away.

Will my information be private?

Yes, all information that you tell Clare will be kept strictly private and confidential. Your information will have your name and other personal details removed after the interview, so that you cannot be recognised from it, and the rest of your information will be shared in the research team only.

Sometimes if you say something interesting, we might want to share this with people who work in that area, but don’t worry, they will never know who you are.

All your information will be stored in a secure place at the University of Manchester.

The only time that your information would have to be shared would be if you told Clare about any safety issues affecting you or your family that were not known before. In that case, Clare would have to share that information, for example with your parent(s) and GP.
Where can I get further information if I need it?

Please contact Clare for further information and to ask any questions.

Interviewer:

Clare Backer clare.backer@postgrad.manchester.ac.uk

This project has been approved by the

School of Psychological Sciences Research Ethics Committee
Appendix 8-

Parent Consent Form
Title of Project: The Experiences of Children with parents who have Bipolar Disorder

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you read the Parent Information Sheet?</td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>Initials:……</td>
</tr>
<tr>
<td>2. Have you received enough information about the study?</td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>Initials:……</td>
</tr>
<tr>
<td>3. Do you consent to your child’s interview being video recorded as detailed in the Parent Information Sheet?</td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>Initials:……</td>
</tr>
<tr>
<td>4. Do you understand that your child/children do not need to take part in the study and if you wish you are free to withdraw them:-</td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>Initials:……</td>
</tr>
<tr>
<td>* at any time</td>
<td></td>
</tr>
<tr>
<td>* without having to give a reason for withdrawing</td>
<td></td>
</tr>
<tr>
<td>* and without detriment to you?</td>
<td></td>
</tr>
<tr>
<td>5. Do you understand that your child/children will be free to withdraw from the study at anytime?</td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>Initials:……</td>
</tr>
</tbody>
</table>
6. Do you agree to your child/children taking part in this study?

<table>
<thead>
<tr>
<th>YES/NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initials:……..</td>
</tr>
</tbody>
</table>

Name of parent: …………………… Signed: ……………………… Date:…….. 

Name of researcher: ……………….. Signed: ……………………… Date: ……..

This project has been approved by the

School of Psychological Sciences Research Ethics Committee
Appendix 9-

Child consent form
I have read/my parent has read me the information sheet about the 'In My Shoes' interview □

I have been able to ask Clare any questions about the study □

I know I am going to be asked questions about myself and my family □

I know that if there is a question I don't want to answer I can not answer it and Clare won't mind □

I know I can stop taking part at any time and I don't have to tell Clare why □

I know that if I get very upset during the interview that is fine and Clare will not mind, but Clare will have to tell my parent(s) □

I know that Clare will not tell anyone outside the research team what I tell her □
I know that Clare will video what we say but that she won't play
the video to anyone outside the research team

Name: ___________________________  Date: __________

Name of researcher: ______________________  Date: __________
Signature: ________________________

Name of parent: ______________________  Date: __________
Signature: ___________________________

This project has been approved by the

School of Psychological Sciences Research Ethics Committee
Appendix 10-

‘In My Shoes’ modules and example questions
‘In My Shoes’- computer-assisted interview

Example of Interview questions and related modules

Module 1- Introduction

The child is able to choose a person to represent them by scrolling through the ‘people chooser’ and looking at different sets of families.

- “Hello I am Erica the talking bird/Mary and I am here to help you”
- “Choose a picture that looks most like you”
- “Type your name and click the OK box”
- “How old are you?”

Module 2- Emotions

The child is shown an emotions palette and asked to label faces with the name that they use for that emotion. For example, a very happy face, smiling face, confused face, sad face, sad face with tears and a scared face. The faces are transferred to a figure on the screen which is not meant to represent the child. For example:

- “Click on the face and see what happens”,
- “What is he feeling?”,
- “Now try this one”

Module 3- Emotions & Scenes

This module consists of a ‘slide show’ of scenes in which the child is asked to select an emotional expression for the key figure. The figure isn’t meant to be the child, but is the same gender.

Girl on a bike

- “Choose a face for the girl in the picture”
- “You can choose a different face, but if it’s ok click the ok box”
- Example prompt- “Why do you think she feels sad?”

Birthday girl

- “Choose a face for the girl in the picture”
- “You can choose a different face, but if it’s ok click the ok box”
Girl stroking a cat

- “Choose a face”
- “Click the ok box or choose a different face”

Dog barking at girl

- “Choose a face”
- “Click the ok box or choose a different face”

Girl at school

- “Choose a face”
- “Click the ok box or choose a different face”

Girl alone on a seesaw

- “Choose a face”
- “Click the ok box or choose a different face”

Girl fallen off skateboard

- “Choose a face”
- “Click the ok box or choose a different face”

Girl with spider

- “Choose a face”
- “Click the ok box or choose a different face”

Girl watching TV

- “Choose a face”
- “Click the ok box or choose a different face”

**Module 4- Places**

The child is able to choose from a number of pictures representing different types of building e.g. detached/semi/terraced houses, flats, caravan etc.

- “Click a picture that looks most like the place you live now”
- “Do the same again”
- “Is this alright?”
- “Type the number or the name of this place and click the OK box”
- “What do you call this place?”

The child is able to name a number of care settings such as childminder, nursery, school, mum/dad’s house etc.

**Module 5- People**
The child is able to choose family members and other people/pets they live with from the people chooser they used in the Introduction module.

- “Choose a person who lives in this place”
- “Type the name of this person and click the OK box”
- “Choose a person who lives in this place”

Continue until every person is named

Module 6- Emotions and People

From the emotions palette, the child is asked to state whether they have ever felt any of the emotions before. The computer goes through the list they labelled in the emotions module.

- “Have you ever felt like this?”
- “What happened?”

The interviewer asks the child to think of a time when they have felt a particular emotion and to say who was with them. The child is encouraged to add think and speech bubbles to the child and their family members and the interviewer asks the child what they were thinking and what they said, and the same for the other people. For example:

- “Here’s you in front of your home with a smiley face and here are the people that live in your home. Tell me about the last time you felt happy with one of these people.”
- “What happened?”
- “Was anyone else there?”
- “What were you thinking?”
- “Did they say anything to you?” Etc.

The interviewer can capture any important information that the child says by bringing up a text box and typing it in front of the child. If the interviewer wants to make a mental note of something without informing the child, they can apply an event marker at that stage and can fill out the details when they close the program.

The same process then happens for every labelled emotion.

The interviewer will use open questioning to enable more detailed information to be heard e.g.
• “what did that involve?”,
• “how did that make you feel?”,
• “what did you think about that?”

**Module 7- Somatic Experiences** (this is optional and will not be used in the interview)

**Module 8- Subjects** (this is also optional and may not be used)

The child can describe school and associate emotions with different aspects of school including teachers, classmates and subjects taught. A list is drawn up, and then a board appears and the child can place each item on a continuum- ‘good’, ‘ok’, ‘bad’ and anywhere in between.

**Module 9- Training**

This is a practice module to introduce the computer program to the child. It asks the child to guess which magician’s hat the rabbit will pop out of.
Appendix 11-

Family Background Questionnaire
Family Background Questionnaire

This questionnaire collects information about yourself and your family. Please read and answer every question. All information provided will be treated in strict confidence and will not be made available to anyone outside the research team.

**Yourself:**

1. How old are you? ...............................................................

2. a) How old were you when you were diagnosed with Bipolar Disorder? ..............

   b) Did you have children at this time?    ☐ Yes    ☐ No

   If yes, how old were your children when you were diagnosed?

.................................................................................................................................

3. How would you describe your ethnic background? Please tick one ☑

   ☐ Bangladeshi  ☐ Black African  ☐ Black Caribbean  ☐ Chinese  ☐ Indian

   ☐ Mixed  ☐ Other Asian  ☐ Other Black  ☐ Pakistani  ☐ White

   ☐ Other Please specify: ..........................................................................................................

**Your Family:**

4. Your current marital status: Please tick the most appropriate box. ☑

   ☐ Married  ☐ Divorced  ☐ Separated  ☐ Living with partner

   ☐ Single  ☐ Widow/er

<table>
<thead>
<tr>
<th>Name:</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Please complete the following information about your child(ren):

6. Do you currently live with your child(ren)? Yes [ ] No [ ]
   If not, how often on average do you see your child(ren)?

6. Please complete the following information about your child(ren):

7. At present, who else lives at home with your child?

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship to child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. Which best describes your household?

Please tick the most appropriate box. ✔

☐ Original family (both biological or adoptive parents present)
☐ Step-family (two parents, one being a step-parent)
☐ Single Parent Family
☐ Other: Please describe: ...........................................................................................................................

Your Education and Employment:

9. Your highest level of education: Please tick one ✔

☐ No qualifications  ☐ GCSE’s, CSE’s or O-levels  ☐ A-levels / BTEC
☐ Trade/Apprenticeship  ☐ University Degree
☐ Other qualification Please specify: ...........................................................................................................................

10. Your partner’s highest level of education (if applicable): Please tick one ✔

☐ No qualifications  ☐ GCSE’s, CSE’s or O-levels  ☐ A-levels / BTEC
☐ Trade/Apprenticeship  ☐ University Degree
☐ Other qualification Please specify: ...........................................................................................................................

11. Are you currently in paid employment?  ☐ Yes  ☐ No

If yes, a) Do you work part-time or full-time? ......................................................................................................................

b) Occupation? .................................................................................................................................................................

12. Is your partner currently in paid employment (if applicable)?  ☐ Yes  ☐ No

If yes, a) Does he/she work part-time or full-time? ..............................................................................................................

b) Occupation? .................................................................................................................................................................

13. Does your family receive any government benefits (excluding child benefit)?  ☐ Yes  ☐ No

14. How would you describe your family finances? Please tick one ✔

☐ Good  ☐ Managing to get by  ☐ Struggling
Your Children’s Health:

15. Do any of your children experience the following:

a) A vision or hearing impairment?  □ Yes □ No
If yes: Please indicate which child/children:..............................................................................................................
   Please specify their difficulty:.................................................................................................................................

b) A severe or chronic illness that results in regular hospitalisation?  □ Yes □ No
If yes: Please indicate which child/children:..............................................................................................................
   Please specify their difficulty:.................................................................................................................................

c) A physical disability?  □ Yes □ No
If yes: Please indicate which child/children:..............................................................................................................
   Please specify their difficulty:.................................................................................................................................

d) An intellectual disability?  □ Yes □ No
If yes: Please indicate which child/children:..............................................................................................................
   Please specify their difficulty:.................................................................................................................................

e) A developmental delay?  □ Yes □ No
If yes: Please indicate which child/children:..............................................................................................................
   Please specify their difficulty:.................................................................................................................................
f) A restrictive/therapeutic diet prescribed by a health professional?  Yes  No

If yes: Please indicate which child/children:.................................................................

Please specify their difficulty:........................................................................................

16. Do any of your children have regular contact with a professional or agency for emotional or behavioural problems?

Yes  No

If yes, please specify........................................................................................................
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

Social Support:

17. How much support do you feel you’ve had from family, friends or neighbours to help you in your role as a parent: Please tick one for each timescale 

Over the past 6 months:

- Not at all supported
- Slightly supported
- Moderately supported
- Very Supported
- Extremely Supported

Prior to the last 6 months:

- Not at all supported
- Slightly supported
- Moderately supported
- Very Supported
- Extremely Supported

18. Do you access any other kind of support? (For example, self-help groups)

Yes  No

If yes please describe: .....................................................................................................
.................................................................................................................................
.................................................................................................................................
Please detail how often you access this kind of support..........................................................
..........................................................................................................................................
..........................................................................................................................................

Professional Support:

19. In the last 6 months have either you or your partner sought professional assistance from any of the following? Please tick all that apply

<table>
<thead>
<tr>
<th></th>
<th>You</th>
<th>Partner</th>
<th>If yes, please specify:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counsellor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other professional</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Prior to the last 6 months, have either you or your partner sought professional assistance from any of the following: Please tick all that apply

<table>
<thead>
<tr>
<th></th>
<th>You</th>
<th>Partner</th>
<th>If yes, please specify:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counsellor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other professional</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Are you currently taking any medication to help manage the symptoms of Bipolar?

☐ Yes  ☐ No

If yes, please detail the medication you are currently taking:
...........................................................................................................................................
...........................................................................................................................................

Thank-you for taking the time to complete this questionnaire.
Appendix 12-

The Strengths and Difficulties Questionnaire (SDQ); Goodman, 1997
Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child’s behaviour over the last six months or this school year.

Child’s Name .............................................. Male/Female
Date of Birth......................

<table>
<thead>
<tr>
<th>Item</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people’s feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restless, overactive, cannot stay still for long</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often complains of headaches, stomach-aches or sickness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shares readily with other children (treats, toys, pencils etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often has temper tantrums or hot tempers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rather solitary, tends to play alone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generally obedient, usually does what adults request</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many worries, often seems worried</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpful if someone is hurt, upset or feeling ill</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constantly fidgeting or squirming</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has at least one good friend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often fights with other children or bullies them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often unhappy, down-hearted or tearful</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Generally liked by other children □ □ □
Easily distracted, concentration wanders □ □ □
Nervous or clingy in new situations, easily loses confidence □ □ □
Kind to younger children □ □ □
Often lies or cheats □ □ □
Picked on or bullied by other children □ □ □
Often volunteers to help others (parents, teachers, other children) □ □ □
Thinks things out before acting □ □ □
Steals from home, school or elsewhere □ □ □
Gets on better with adults than with other children □ □ □
Many fears, easily scared □ □ □
Sees tasks through to the end, good attention span □ □ □

Signature ................................ Date ................................

Parent/Teacher/Other (please specify:)

Thank you very much for your help © Robert Goodman, 2005
Appendix 13-

The Internal States Scale; Bauer et al, 1991
INTERNAL STATE SCALE

Name: ..............................................................................................................

Date: ..............................................................

For each of the following statements, please blacken the circle on the line that best describes the way you have felt over the past 24 hours. While there may have been some change during that time, try to give a single summary rating for each item.

Over the past 24 hours...

My mood was changeable

0  ○  ○  ○  ○  ○  ○  ○  ○  ○  100

I felt irritable

0  ○  ○  ○  ○  ○  ○  ○  ○  ○  100

I felt like a capable person

0  ○  ○  ○  ○  ○  ○  ○  ○  ○  100

I felt like people were out to get me

0  ○  ○  ○  ○  ○  ○  ○  ○  ○  100
I felt great inside

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100

I felt impulsive

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100

I felt depressed

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100

My thoughts are going fast

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100

It seemed like nothing would ever work out for me

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100

Not at all/.................................................................Very much so/
Rarely..................................................................Much of the Time

I felt overactive

0 ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ 100
I felt as if the world was against me

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|

I felt sped up inside

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|

I felt restless

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|

I felt argumentative

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|

I felt energized

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|

Today I felt...

|   |   |   |   |   |   |   |   |   |   |   | 100 |
|---|---|---|---|---|---|---|---|---|---|---|
Depressed    Normal    Manic
Down         High
Appendix 14-

Coded transcript sample
<table>
<thead>
<tr>
<th>Interview text - Extract from participant transcript (7 year old boy)</th>
<th>Coding (Potential Themes)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Int:</strong> So I know that you’ve got mum and dad, and you’ve got 3, 2 brothers</td>
<td>Family structure</td>
</tr>
<tr>
<td><strong>P:</strong> Yeah</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> and there’s 3 of you, and it sounds like things can get a bit hectic at times, when you’re all trying to play with the same thing and stuff and you don’t like it when they take your things, yeah?</td>
<td>Chaotic family</td>
</tr>
<tr>
<td><strong>P:</strong> Yeah</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> and it sounds like erm sometimes it can be a bit tough when erm other people are in different moods to you, so when it sounds like you’re angry, and they’re laughing and sometimes when other people are laughing do you know, other people are crying and stuff</td>
<td>Family moods</td>
</tr>
<tr>
<td><strong>P:</strong> Yeah</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah … it sounds hectic and you mentioned about erm your mum like having Bipolar erm and you wasn’t quite sure what that was</td>
<td>Child unsure about bipolar (knowledge of bipolar)</td>
</tr>
<tr>
<td><strong>P:</strong> Mmm nah</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> Does it mean that that your mum’s ill?</td>
<td>Bipolar like a mental illness (knowledge of bipolar/Description of illness)</td>
</tr>
<tr>
<td><strong>P:</strong> Yeah it’s like a mental illness</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> Oh right ok, so how else do you think that affects</td>
<td>Bipolar difficult to understand (understanding about bipolar)</td>
</tr>
<tr>
<td><strong>P:</strong> Quite complicated to understand</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah it sounds quite complicated. So you told me before that sometimes it makes her quite sleepy yeah?</td>
<td>Tired mum (Effects on parent-behaviour)</td>
</tr>
<tr>
<td><strong>P:</strong> Yeah</td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> Erm how else do you think it makes her?</td>
<td><strong>P:</strong> Erm … … I don’t know really</td>
</tr>
<tr>
<td><strong>Int:</strong> How how is it different since erm</td>
<td><strong>P:</strong> Erm</td>
</tr>
<tr>
<td><strong>Int:</strong> since your mum got Bipolar?</td>
<td><strong>P:</strong> Erm daddy’s normally erm with us looking after us by his self</td>
</tr>
<tr>
<td><strong>Int:</strong> Aah</td>
<td><strong>P:</strong> especially when she went to hospital</td>
</tr>
<tr>
<td><strong>Int:</strong> Aah ok so she went to hospital</td>
<td><strong>P:</strong> Yeah</td>
</tr>
<tr>
<td><strong>Int:</strong> How was that, how did that make you feel?</td>
<td><strong>P:</strong> Mmm … kinda erm</td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah a bit you’re not really sure</td>
<td><strong>P:</strong> Yeah</td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah. Did you know what was going on back then?</td>
<td><strong>P:</strong> Yeah</td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah, can you remember when it was that when she went in hospital?</td>
<td><strong>P:</strong> No</td>
</tr>
<tr>
<td><strong>Int:</strong> Was it it recently or was it</td>
<td><strong>P:</strong> Erm quite a long time ago</td>
</tr>
<tr>
<td><strong>Int:</strong> Over a year ago?</td>
<td><strong>P:</strong> Yeah</td>
</tr>
<tr>
<td><strong>Int:</strong> Yeah, ok so had she been quite ill before she went in hospital?</td>
<td></td>
</tr>
</tbody>
</table>
**P:** Erm yeah

**Int:** And what sorts of things was she ill with, how did you know that she was ill?

**P:** Well I didn’t know she was ill but she started acting funny one day

**Int:** Aah right can you tell me a bit more about that?

**P:** Mmm I’ve forgotten most I’ve forgotten nearly all of it, I can’t remember any anything else about it

**Int:** Yeah, so she was acting a bit funny?

**P:** Yeah

**Int:** So you could just tell that there was something a bit different?

**P:** Yeah and dad and daddy thought I erm that dad erm thought I was lying but one day then he noticed

**Int:** Ah ok, and what sorts of things was your mum doing?

**P:** Erm I’ve forgotten now

**Int:** What was different, so usually she’d be in the kitchen or whatever

**P:** Yeah

**Int:** So what were the funny things she was doing?

**P:** Erm she was staying in bed longer

**Int:** Mmm

**P:** And she wasn’t going out that she wasn’t going out

**Int:** Yeah

**P:** side

**Int:** Yeah

---

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mum ill</strong></td>
<td><em>(Description of illness)</em></td>
</tr>
<tr>
<td>Didn’t know mum was ill</td>
<td>Mum behaving different?</td>
</tr>
<tr>
<td>Child forgotten about illness</td>
<td><em>(Avoidance/Defence?)</em></td>
</tr>
<tr>
<td>Mum behaving different</td>
<td><em>(Effects on parent-behaviour)</em></td>
</tr>
<tr>
<td>Child aware before dad; Dad didn’t believe child about the difference</td>
<td><em>(Awareness of bipolar/perception of well parent?)</em></td>
</tr>
<tr>
<td>Child forgotten about mum’s illness</td>
<td><em>(Avoidance/Defence?)</em></td>
</tr>
<tr>
<td>Difference- can’t use??</td>
<td></td>
</tr>
<tr>
<td>Tired mum staying in bed</td>
<td><em>(Effects on parent-behaviour)</em></td>
</tr>
<tr>
<td>Not going out</td>
<td><em>(Effects on parent-behaviour)</em></td>
</tr>
</tbody>
</table>
P: Erm she normally staying inside lying on the sofa
erm sitting on the sofa watching some TV

Int: Yeah

P: Something like that

Int: So she sounded like she was quite tired

P: Yeah

Int: and

P: [points to photograph of mum on the desk] Back
back when that picture was taken

Int: Mmm

P: Erm she erm there wasn’t a single problem with
her

Int: Ah right so that was before things changed?

P: Yeah

Int: And how how was she different then then?

P: Erm basically she was just normal

Int: Ah ok ... So if your mum was normal then
how would you describe mum now?

P: Erm … … not really sure

Int: Yeah, just a bit different?

P: Yeah

Int: Yeah and does she sometimes does her
mood sometimes change?

P: Yeah sometimes it sometimes it’s quite
depressed

Int: Mmm

P: Sometimes it’s happy, sometimes it’s worried

Int: Mmm, so she changes emotions quite a bit?

P: Yeah
| Int: Yeah and do you know why her moods change? | Changeable moods-can’t use??  
(Effects on parent-moods) |
| Int: Cos we know why, your moods change don’t they when the boys have done something or whatever and we know why you get angry and upset | Child doesn’t know why moods change  
(knowledge of bipolar) |
| P: Yeah | |
| Int: Do you know why your mum does? | |
| P: No | Child doesn’t know why moods change  
(knowledge of bipolar) |
| Int: No, and how is that, cos that must be must be quite hard for you when you never know what mood mum’s gonna be in? | Hard for child- can’t use??  
(Effects on child) |
| P: Yeah | Child ignores mum when behaving different/funny  
(Avoidance/Coping?) |
| Int: Yeah, it sounds like you just get on with it don’t you? | Mum fine at present  
Child forgotten  
(Avoidance/Defence?) |
| P: Yeah I just get on with it and sometimes I just ignore her when she’s acting funny | |
| Int: Yeah, does she erm act differently with you kids? | |
| P: Erm | |
| Int: Is there any ways that she | |
| P: At the moment she’s erm fine but erm … … can’t really erm remember what I was gonna say | |
| Int: Just about if she acts | |
| P: Yeah | |
| Int: differently with you than when she would do then? [points to photo] | |
| P: Yeah | |
| Int: But you can’t really think? | |
| P: No | |
Int: Ok thank you for that, that was really interesting. Is there anything else erm that you think’s really important that I should know abut you and your family?

P: Nah

Int: No. Do I know everything?

P: Yeah

Int: Shall I go and ask your brother’s now?

P: Yeah

Int: Yep, alright we’ll stop this [tape recorder]

P: [brother’s name] next

Int: It is, let’s stop this. [interview ends..]
Appendix 15-

Script for explaining the ‘In My Shoes’ Interview to children aged between 4 and 6 years
Script for explaining the ‘In My Shoes’ Interview to children aged between 4 and 6

“I am going to show you a computer game on my laptop. It’s called ‘In My Shoes’ and is about you and your family. The computer will ask you to choose pictures that look like you, your family and where you live.

The computer will ask some questions and I will also ask you things too, about you and your family. I will help you with the computer and we will sit next to each other. There will be a video camera recording the computer, but don’t worry, it will not be recording you or me.

Your mum/dad had said that it’s ok to do this together, but if you don’t want to you can say ‘no’. If we start and you don’t want to carry on, that’s ok too and we can switch it off.

Is that ok? Do you want to ask me anything before we start?”
Appendix 16-

Recruitment email
Parenting and Bipolar Disorder Research

We are two researchers from the University of Manchester who are interested in experiences of families where a parent has Bipolar Disorder.

We will be carrying out two studies, the first looking at the experience of being a parent with Bipolar Disorder, the second exploring the children’s experience of family life. Please see advert attached.

We wondered if your group members would be interested in hearing more about our research and consider taking part in order to have their important views and experiences reflected in the outcomes of the research.

We would be happy to attend one of your meetings, if you think that will be beneficial, or alternatively we can provide you with information packs to hand out to the members of your group.

Please feel free to contact either Rebecca or Clare as detailed below:

Rebecca.murphy@postgrad.manchester.ac.uk

Clare.Backer@postgrad.manchester.ac.uk

Tel: 07554387014

Many thanks

Clare Backer and Rebecca Murphy
Appendix 17-

BMJ’s guidance for journal submission
How to prepare BMJ original research articles (full versions)

Here is all the information you need:

No word limit

We do not set fixed limits for the length of BMJ research articles and can be flexible. Nonetheless, please try to make your article concise and make every word count. Think hard about what really needs to be in the paper to get your message across accurately and what can be left out. You will be prompted to provide the word count for the main text (excluding the abstract, references, tables, boxes, or figures) when you submit your manuscript.

IMPORTANT! The manuscript should include the structured abstract and all tables, figures, boxes, and appendices that are essential to reporting the study design and findings. We may suggest later that you separate out some material into web extras to make the main manuscript clearer for general readers, but for peer review (including editorial and statistical review), the manuscript should be a complete document that fully reports the study.

Overall style

Original research articles should follow the IMRaD style (introduction, methods, results and discussion) and should include a structured abstract (see below), a structured discussion (on average five paragraphs), and a succinct introduction that focuses—in approximately three paragraphs—on the background to the research question.

Structured abstract

Please ensure that the structured abstract is as complete, accurate, and clear as possible—but not unnecessarily long—and has been approved by all authors. We may screen original research articles by reading only the abstract. For randomised controlled trials please provide all the information required for a CONSORT style abstract.

Please note the general rules for abstracts in the BMJ:

- should be 250-300 words long: you may need up to 400 words, however, for a CONSORT or PRISMA style abstract. Medline can now handle up to 600 words
- use active voice but avoid “we did” or “we found”
- numbers over 10 do not need spelling out at the start of sentences
- sentences starting with a number do not require a capital letter
- p values should always be accompanied by supporting data and denominators should be given for percentages
- abstracts do not need references

The first few items (objective, design, setting) may be note-like and need not form full sentences. The results and conclusions sections should be written properly. Do not mix notes and full sentences in one section.

Abstracts for qualitative research articles should follow the standard style but may need fewer headings:

- objective
- design
- participants
- setting
- results
- conclusions

Nb: Please see the BMJ website for more extensive guidance situated across several web-pages.