

A qualitative investigation into the experience of parenting with a severe mental illness

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Rebecca Murphy

School of Psychological Sciences

Table of Contents

Word Count.....	3
Thesis Abstract.....	4
Declaration.....	5
Copyright Statement.....	5
Acknowledgements.....	7
Section 1: Literature Review	
The experience of parenting with a severe mental illness: a meta-synthesis of qualitative research.....	8
Abstract.....	9
Introduction.....	10
Method.....	13
Results.....	18
Discussion.....	41
References.....	46
Section 2: Empirical Research	
A qualitative investigation into the experience of parents with bipolar disorder.....	57
Abstract.....	58
Introduction.....	59
Method.....	61
Results.....	68
Discussion.....	93
References.....	100
Section 3: Critical Reflection	
Navigating internal worlds and qualitative methodology: a critical reflection.....	108
Introduction.....	109
Critique of qualitative methodologies.....	110
Interpretative Phenomenological Analysis.....	114
Process of carrying out an IPA.....	116
References.....	128
Appendices.....	132
Appendix 1:Submission guidelines for the British Medical Journal.....	133
Appendix 2:Quality Appraisal Summary of Included Studies.....	137
Appendix 3:Participant Information Sheet & Consent Form.....	139
Appendix 4:Interview Schedule.....	144
Appendix 5:Family Background Questionnaire.....	147
Appendix 6:Interview Transcript - Coding Sample.....	153

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Thesis Abstract

Rebecca Murphy
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A qualitative investigation into the experience of parenting with a severe mental illness

This thesis explores the experience of parenting with severe mental illness, using qualitative methodologies. It is presented in three parts: a literature review, a report of the empirical research, and a critical reflection of the process undertaken.

The literature review provides both a systematic review of qualitative studies exploring the experience of parenting with a severe mental illness (SMI), and a meta-synthesis of the findings from the included studies. The findings demonstrated six overarching themes that were central to the parents' experience. The themes were interlinked and often conflictual in nature and a model of the relationship between the themes is provided. The synthesis revealed how the additional and conflicting pressures faced by parents with SMI can interact with their symptoms to affect parenting behaviours and decisions about engagement with services. The model of themes elicited by the synthesis provides a broad conceptual framework in which parenting with SMI can be considered across the age range of children, parental symptoms and parenting roles.

The empirical research provides a specific focus on the views and experiences of parents with Bipolar Disorder (BD). Interpretative Phenomenological Analysis was used to explore the lived experience of parenting with BD, to provide insight into the parents' perspective and the influence that this may have on outcomes for parents as well as their children. The analysis resulted in six overarching themes, each of which consisted of a number of sub-themes. There were important interactions between the themes and these are illustrated for the reader. It was found that the parents identified a number of challenges in being a parent with BD and experienced feelings of inadequacy, guilt and worry relating to the impact that their illness had on their children and family. Strategies for managing these feelings and limiting the impact of BD could have an inadvertent negative effect on their own well-being, and that of their child. Learning to accept their diagnosis and developing strategies for managing their symptoms were crucial for positive parenting, although the changing needs of their children often presented new challenges. Contextual factors, including the stigma associated with mental illness, could also either mediate or exacerbate the challenge of parenting with BD. The clinical implications of these findings are discussed.

The critical reflection provides a consideration of qualitative methodologies and a personal reflection on the qualitative process in relation to the empirical research. It details the critical debates around qualitative methodology, the application of qualitative methodologies, and the challenges this presented for the researcher. The report was written on completion of the investigation and reflects the process by which, as a novice, the author was able to develop an understanding of qualitative methodology and carry out an insightful piece of research.

Declaration

No portion of the work referred to in the 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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The experience of parenting with a severe mental illness: a meta-synthesis of qualitative research

Rebecca Murphy

The University of Manchester

Prepared in accordance with submission guidelines for the British Medical Journal

(See Appendix 1 for submission guidelines)

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Address for correspondence:

Rebecca Murphy
Department of Clinical Psychology
School of Psychological Sciences
University of Manchester
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
rebecca.murphy@postgrad.manchester.ac.uk

Abstract:

Objective: To synthesise the views and experiences of parents with severe mental illness (SMI), to understand parents' own perspectives and the influence this may have on outcomes for the parent and their child.

Design: A systematic review of qualitative studies exploring the experience of parenting with SMI, and a meta-synthesis of the findings from the included studies.

Data Sources: CINAHL Plus, EMBASE, Medline, PsychINFO, Wilson Social Science Abstracts, Web of Science and AMED were searched to identify empirical literature that used qualitative methodology.

Review Methods: Eligible studies were critically appraised using the CASP appraisal tool to ensure credibility and facilitate translation of the results. Findings were synthesised using Noblit & Hare's approach.

Results: 14 studies reporting the experience of 222 parents were included in the synthesis. The sample comprised mothers and fathers recruited from community and inpatient settings and included those who had lost access to their children, as well as those continuing to parent. Six major themes were identified as being central to the parents' experience: Stigma and negative judgement due to mental illness; desire to be a good parent; the negative impact of mental illness on children and parenting; stress associated with parenting; the positive aspects of parenting and the importance of support. The themes are interlinked and conflictual in nature. A model of the relationship between the themes is provided.

Conclusions: The additional and conflicting pressures faced by parents with SMI can interact with their symptoms to affect parenting behaviours and decisions about engagement with services. The model of themes elicited by the synthesis provides a broad conceptual framework in which parenting with SMI can be considered across children's age, parental symptoms and parenting roles.

Introduction

There is a well established relationship between parental mental illness and adverse outcomes in children. The literature in this area is wide ranging and a number of detailed reviews have been published¹⁻³. However, research has focussed on risk to children and parental deficit, and there is a lack of clarity with regard to the subjective needs and experiences of parents who have a mental illness. Given the known importance of user views for the development of effective policy and service provision⁴⁻⁷, this is a significant limitation of the literature. Here we present an overview of the literature and a meta-synthesis of findings from qualitative studies that have explored the experience of parents with severe mental illness (SMI). The significance and contribution of these findings is discussed.

Overview of the literature:

Whilst mental illness in parents does not necessarily constitute a protective concern⁸, the risks to child development and mental well-being are substantial in some cases. Children of parents with mental health difficulties in general, are at greater risk of social, emotional and behavioural problems during childhood and adolescence⁹⁻¹², and are at substantially greater risk of developing mental health problems throughout life¹³⁻¹⁸. There is however ongoing debate with regards to the mechanisms determining progression towards either favourable or adverse outcomes for these children. Whilst there is evidence for genetic risks in some forms of mental illness¹⁹, child outcomes are not necessarily linked to specific parental diagnoses. Rather, it is the persistence of the disorder and its effects on a parent's ability to function that has been found to have the greatest impact on child well-being²⁰⁻²⁴. As such, children of parents with SMI have been found to be at significantly greater risk of adverse outcomes than children of parents with less severe difficulties²⁵⁻²⁷. The experience of parents with SMI will therefore be the focus of the present synthesis.

Children of parents who have a SMI are more likely to be exposed to parents' maladaptive affect, behaviour and cognitions which may be the result of symptoms, medication or co-occurring substance use²⁸⁻³¹. Children may also experience the indirect effects of SMI, such as stigma, separation from parents, and other adverse life experiences³²⁻³³. There is also an increased risk of contextual stressors such as poverty, unsatisfactory education and poor social support³⁴⁻³⁸. So whilst some of the mechanisms have features that are specific to mental illness, many are essentially the same as those operating in the case of other vulnerable children and families. There is ongoing debate regarding the degree to which genetic factors interact with environmental context to affect child outcomes³⁹⁻⁴⁰.

Limitations of the literature:

The UK's Social Exclusion Unit has identified parents with mental health problems and their children as a group likely to experience difficulties in getting their needs met⁴¹. Interventions specifically for children and families affected by SMI are limited and the evidence for the effectiveness of such interventions is weak⁴². Although prevalence rates for parents with SMI have not been established, Parker and colleagues⁴³ estimated that approximately 1 in 10 women and 1 in 20 men will be a parent with a mental health problem at any given time in the UK. There is therefore a clear need for investment in good quality interventions and service development to improve the life chances of children whose parents have mental health difficulties. Preventative interventions for children usually involve working with parents. However, there has been much less focus in the literature on the needs and experiences of parents with SMI. Given the increasing appreciation of the need to understand the subjective experience of people who make up clinical populations in order to identify opportunities for and barriers to change⁴⁻⁷, this is an important limitation of the literature. Studies have identified what they describe as inadequate parenting skills in mothers with SMI⁴⁴⁻⁴⁵ and the influence that parenting beliefs and perceptions have on parenting practices⁴⁶. However, these studies have been based on structured questionnaire measures to test out theoretically based

hypotheses about parental attributes. They do not provide insight into the ways in which parents with SMI perceive and make sense of their experience.

A number of studies have explored the lived experience of parenting with SMI using qualitative methodology to enable a more in depth understanding of parents' experience. These studies have provided important insight into parents' own perspectives and the influence this may have on outcomes for themselves and their children. However, due to the small sample sizes necessary for in-depth qualitative research, the findings from these studies are rarely collated to inform the evidence-base. The Royal College of Psychiatry provided a short, narrative review of qualitative findings in their report 'Patients as Parents'⁴⁷. However, this did not capture the richness and complexity of the experiences that were revealed in the studies. It is argued that a meta-synthesis of findings from the qualitative studies will enlarge the interpretative possibilities offered by the studies and facilitate a fuller understanding of the experience of being a parent with a SMI⁴⁸. Whilst preserving the integrity and holism of individual studies, inductive and interpretative techniques are used in a meta-synthesis to sufficiently summarise the findings into a product of practical value⁴⁹. This results in a greater degree of insight and conceptual development than is likely to be achieved in a narrative literature review or indeed an individual empirical study⁵⁰.

The aim of the current research was therefore to carry out a meta-synthesis of findings from qualitative studies that explored the experience of parenting with a SMI, in order to establish the main experiences that characterise parenting in the context of SMI. Given the larger interpretative context, it was hoped that the synthesised results would have a greater impact on direction for service planning and future research.

Method

The plan for the research was to a) search the literature for studies exploring the qualitative experience of parenting with a SMI; b) review the journal articles; and c) develop an understanding of the key themes that capture the experience of parenting with a SMI.

Selection Criteria and Literature Search

Inclusion & Exclusion Criteria:

Detailed inclusion and exclusion criteria are reported in Table 1. Qualitative studies that were written in English and used interviews, focus groups or observations to explore the experience of parents who had SMI were included in the review. For the purpose of this investigation, SMI was defined by clinical diagnosis and receipt of mental health services. The included diagnostic categories were: psychosis, schizophrenia or schizoaffective disorder; bipolar disorder and severe depression. The decision to only include studies of parents with SMI was due to the enhanced risk of adverse outcomes for their children, and the potential for difference in the experience of those with less severe difficulties.

Studies that focussed solely on the experience of parents with post-natal depression (PND) were excluded from the synthesis as these studies have been synthesised elsewhere⁵¹. It is also likely that there would be differences between the experience of parents with PND and those with SMI, due to the nature, onset and duration of PND.

Studies that did not elicit data from parents themselves were excluded. Where research used mixed methods, or included data from participants other than the parents themselves, results that met the inclusion criteria were included in the synthesis only if they were reported separately and were readily extractable without influence from other sources.

Table 1: Inclusion and Exclusion Criteria

	Inclusion Criteria	Exclusion Criteria
Language	Studies written in English.	Studies not written in English.
Population	Studies which sample mothers and/or fathers with severe mental illness.	Studies which do not include parents with severe mental illness. Studies which review experiences of post-natal depression.
Outcome	Studies that focus on the experience of being a parent whilst also having a severe mental illness.	Studies that do not include parents' own account of their lives. Papers that focused a priori on specific aspects of severe mental illness (such as dissociation) or narrow areas of parenting (such as custody loss).
Study Type	Primary research which reports on findings that use qualitative methods for both data collection & analysis.	Studies which do not include qualitative methods of data collection and analysis. Research that only resulted in quantitative data. Single case study designs. Book reviews, opinion pieces, literature reviews, policy documents.
Quality	Studies of sufficient quality, with a rating of A-C during the quality assessment phase.	Studies with inadequate information to establish the quality of the research. Studies of poor quality as identified during the quality assessment phase.

Database Search:

Terms relating to the following three areas were combined in a systematic search strategy: a)

Parent (*mother, father, parenting, parents, parental*); b) **Mental illness**

(*mental/psychiatric/psychological illness/condition/disorder*, as well as disorder specific:

depression, psychosis, schizophrenia, bipolar disorder, and affective disorders); c) **Qualitative**

research (methodological terms, such as: *focus group, interview, grounded theory, IPA*, and

words that are likely to occur within a description of qualitative research, including *experience,*

perception, perspective).

Database searches were carried out in CINAHL Plus (1938 to April 2011), EMBASE (1980 to Week 13 2011), Medline (1948 to March Week 4 2011), PsychINFO (1806 to March Week 4 2011), Wilson Social Science Abstracts (1983 to March 2011), Web of Science (1945 to March 2011), AMED (1985 to April 2011).

For the vast majority of papers the titles indicated that they were not relevant to the study or were not qualitative research papers. These titles were excluded. Where this was not clear, the abstract was reviewed. Studies that appeared to include relevant data or information were retrieved and their full text versions analyzed and examined for study eligibility. The citations included in all papers meeting the eligibility criteria were also checked and reviewed for eligibility⁵².

After reviewing the literature, 17 studies appeared to be relevant to the current synthesis. However, two articles^{53,54} reported on findings from the same piece of research so these will be reported together for the purpose of this review. One study focused on substance misuse and custody loss, rather than the overall experience of parenting⁵⁵, and one study focused on how dissociation impacted on parenting⁵⁶. Both studies were excluded. Fourteen studies were eligible for inclusion.

Quality Assessment

The Critical Appraisal Skills Programme criteria⁵⁷ was used to assist the quality assessment of the remaining studies. The appraisal tool covers three areas: rigour, credibility and relevance, using ten prompt questions. It was used in conjunction with Walsh and Downe's⁵⁸ guidance for appraising qualitative research to ensure in-depth theoretical as well as technical appraisal. Walsh and Downe's criteria includes consideration of the appropriateness and coherence of the study scope and purpose, design, sampling strategy, analysis, interpretation, researcher

reflexivity, ethical dimensions, relevance and transferability. A summary score was then allocated to each study⁵⁹. Box 1 explains the quality ratings key. In accordance with the guidance of Walsh and Downe⁵⁸, it was agreed that any studies rated as having significant flaws (i.e. quality rating D) should be excluded from the synthesis because studies that do not meet at least a minimum level of credibility, transferability, dependability and confirmability are unlikely to contribute to a significant reduction in uncertainty in the area. However, all studies received a quality rating of A-C and therefore did not require exclusion. Appendix 2 provides a summary of the quality appraisal of each study.

Box 1: Quality Rating Key

<p>Key to Quality Rating:</p> <p>A - No or few flaws: The study credibility, transferability, dependability and confirmability is high.</p> <p>B - Some flaws, unlikely to affect the credibility, transferability, dependability and/or confirmability of the study.</p> <p>C - Some flaws, which may affect the credibility, transferability, dependability and/or confirmability of the study.</p> <p>D - Significant flaws, which are very likely to affect the credibility, transferability, dependability and/or confirmability of the study.</p>
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Synthesis of findings

The findings were synthesized using Noblit and Hare's⁶⁰ approach to the synthesis of qualitative research. The analysis involved the following phases:

1. Reading each study several times, noting the key themes, concepts, phrases and relationships that had been elicited from the data.
2. Translating the studies into one another using a two stage process:
 - a) Reciprocal Translation: Searching for themes, concepts, phrases and relationships that occurred repeatedly across the included data and translating these into each other. This process is idiomatic rather than exact translation. The purpose is to try to derive concepts that encompass more than one of the studies being synthesised. Synthesised concepts may not have been exactly

identified in any of the original empirical studies. They resemble second-order constructs in the analysis of primary qualitative research data but would in effect be third-order constructs⁶¹.

b) Refutational Translation: Searching for themes, concepts, phrases and relationships that would contradict or refute the emerging patterns. Examining refutations and making attempts to explain them.

3. Synthesizing the translations arising from the preceding steps in a way that most completely expresses the emerging patterns across the included studies. Noblit and Hare⁶⁰ term this the 'line of argument' synthesis.

This is a highly iterative and revisionist process, closely aligned to qualitative constructionist epistemologies⁴⁹. As such the phases detailed above were not distinct but overlapped and repeated as the meta-synthesis progressed. In line with standards for carrying out good quality qualitative research^{62,63}, discussions about emerging themes and models of interpretation were discussed within the research group to ensure transparency and to verify the judgement of the lead researcher in relation to higher order themes and categorization.

Noblit and Hare's approach was chosen because it is one of the most well developed and successfully utilized methods of synthesizing qualitative research findings^{50-51,64-65}. It has potential as a method to preserve the interpretative properties of primary data, and acknowledges that the resulting findings are partial and positional on the part of the researcher performing the synthesis.

Results

Characteristics and Quality of the Included Studies

See Table 2 for a summary of the key characteristics of each study. Fourteen studies were included in the synthesis^{53-55, 66-78}. The studies were carried out in the USA, Australia, United Kingdom, Canada, New Zealand and Brazil.

The studies varied with regards to the characteristics of their participants. The majority explored the experiences of parents with dependent children (n=9), although within these studies, some focussed on pre-school/early childhood (n=3) and middle childhood years (n=2), whilst others explored a broader age range, specifying that at least one child must be under the age of either 16 or 18 (n=4). The remaining five studies included parents of either dependent or young adult children. The family circumstances of the parents also varied both within and across studies, with most studies also including parents who no longer lived with their children. Nine studies involved participants who were living in the community at the time of the interview, although due to the nature of SMI, many of the parents had experienced one or more hospital admissions. Two studies included parents recruited from inpatient as well as community settings and only study 2 included parents from a community-based residential rehabilitation programme.

Parental diagnoses differed across studies, although the majority of parents had a diagnosis of either severe depression, bipolar disorder or a psychotic disorder. Study 5 also included two parents diagnosed with personality disorder and one parent diagnosed with PND. Study 2 also included a parent diagnosed with having a personality disorder. Whilst the majority of studies included parents with a variety of diagnoses, three of the studies focussed on specific types of SMI: two studies explored the experience of parents with bipolar disorder and one study explored the experience of fathers with psychosis.

The studies elicited data from over 222 participants in total. One study did not detail the number of participants and therefore this total cannot be exact. Eight studies explored the experience of mothers only; two looked solely at the experiences of fathers and four combined experiences of both mothers and fathers with SMI. Only 33 of the participants were fathers.

There were also methodological differences between the studies. Each study used either focus groups and/or semi-structured interviews to elicit data, and analysis was carried out using a range of methodologies. The quality of the studies was generally good although there were particular weaknesses in the transparency of the analysis and in reflexive accounting (Appendix 2: Quality Appraisal Summary).

Table 2: Characteristics of included studies

Study Details			Sample Characteristics				Methodology		Quality Rating ^a	
Authors	Year	Country	Description	No of Participants	Mothers/ Fathers	Ethnicity	Recruited From	Data Collection	Analysis	
1 Mowbray, Oyserman & Ross	1995	USA	Mothers with long term SMI with at least one child under the age of 16. Custody of the children is not stated.	24	Mothers Only	Diverse Sample Details not provided	Community & inpatient settings	Interviews	Not stated	C
2 Sands	1995	USA	Single low-income mothers with SMI with at least one pre-school child either living with them or awaiting reunion.	10 ^a	Mothers Only	Diverse Sample 7 African American; 3 White American	Community residential rehabilitation on setting	Interviews	Not stated	C
3 Nicholson, Sweeney & Geller	1998	USA	Mothers with long term SMI with at least one child under the age of 13, either living with them or not.	42 ^b	Mothers Only	Diverse Sample 35 White American; 5 African American; 1 Hispanic; 1 Native American	Community setting	Focus Groups	Not stated	B
4 Bassett, Lampe & Lloyd	1999	Australia	Mothers with mental illness with custody of at least one child under the age of 5.	Not stated	Mothers Only	Not stated	Community setting	Focus Groups + Interviews	Not stated	B
5 Thomas & Kalucy	2002	Australia	Parents with long term SMI with dependent or young adult children either living with them or not.	35	28 Mother 7 Fathers	Not stated	Community & inpatient settings	Interviews	Not stated	C+
6 Ackerson	2003	USA	Parents with SMI with dependent or young adult children either living with them or not.	13	12 Mothers 1 Father	Not stated	Community Setting	Interviews	Constant Comparative Analysis	B+
7 Diaz-Canjela & Johnson	2004	UK	Mothers with long term SMI with at least one child under the age of 16, either living with them or not.	22	Mothers Only	Diverse Sample 13 White British; 3 White Other; 2 Asian; 1 Black UK; 1 Black Caribbean; 1 Black African; 1 Mixed	Community Setting	Interviews	Thematic Analysis	A
8 Montgomery Tompkins, Forchuk, French	2006	Canada	Mothers with SMI with at least one child aged between 2-16 years, either living with them or not.	20	Mothers Only	Not stated	Community setting	Interviews	Grounded Theory	A

9	Boursnell	2007	Australia	Parents with mental illness with at least one child aged between 0-18 years, either living with them or not.	10	7 Mothers 3 Fathers	Not stated	Community setting	Interviews	Not stated	C
10	Evenson, Rhodes, Feigenbaum & Solly	2008	UK	Fathers with Psychosis with dependent or adult children, either living with them or not.	10	Fathers Only	All White British	Community setting	Interviews	Interpretative Phenomenological Analysis	A
11	Venkataraman & Ackerson	2008	USA	Mothers with Bipolar Disorder with dependent or adult children. Custody of the children is not stated.	10	Mothers Only	All White American	Community Setting	Interviews	Constant Comparative Analysis	B
12	Reupert & Mayberry	2009	Australia	Fathers with mental illness with either dependent or adult children. None had full-time custody of their children.	11	Fathers Only	Diverse Sample 9 White Australian; 1 Indian/Fijian; 1 White European	Community setting	Interviews	Interpretative Phenomenological Analysis	A
13	Soares & Carvalho	2009	Brazil	Mothers with long-term mental illness with at least one child aged between 7-12 years. Custody of the children is not stated.	10	Mothers Only	Not stated	Community setting	Interviews	Grounded Theory	B-
14	Wilson & Crowe	2009	New Zealand	Parents with Bipolar Disorder with young children. Custody of the children is not stated.	5	4 Mothers 1 Father	Not stated	Not stated	Interviews + Expert & popular texts ^c	Critical Discourse Analysis	A

^a Sands also elicited data from 8 single low-income mothers without SMI to compare mothers' experiences. However, this data will not be included in the meta-synthesis.

^b Nicholson et al also elicited the views of 55 case managers working with mothers with mental illness. However, this data will not be included in the meta-synthesis.

^c Expert and popular texts used by Wilson & Crowe were not included in the meta-synthesis.

Synthesis of findings

The literature was not in a position to enable a synthesis of findings according to variables such as parents' gender, diagnosis, or the age of their children. A reciprocal translation of the overall experiences of parents with SMI was therefore produced. However, any nuances in the data will be discussed in relation to each of these variables, as appropriate.

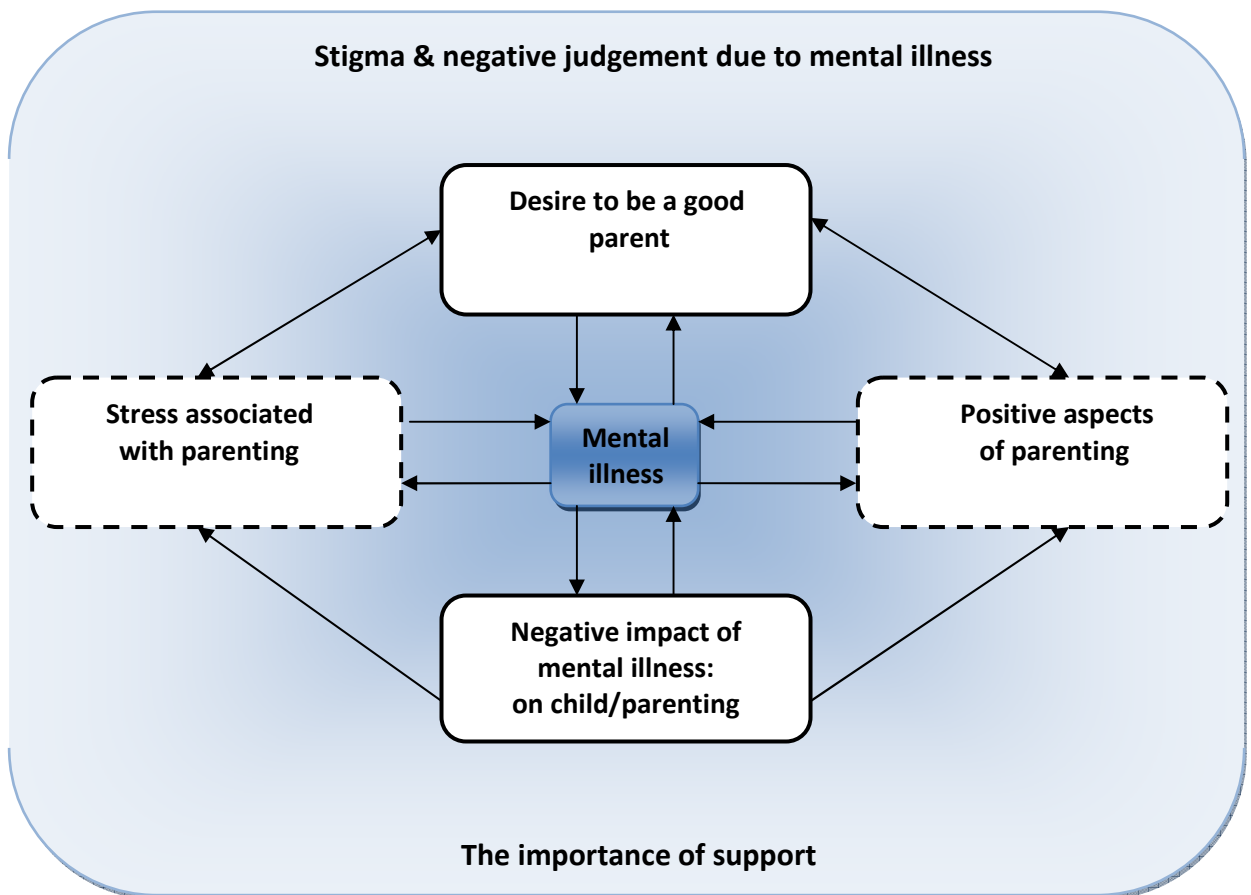
The synthesis highlighted six major themes that characterise the experience of parenting with a SMI. These were:

1. Stigma and negative judgement due to mental illness
2. Desire to be a good parent
3. The negative impact of mental illness
4. Stress associated with parenting
5. Positive aspects of parenting
6. The importance of support

Table 3 lists the studies that reported or discussed each theme. There was significant across-study agreement of the themes elicited, irrespective of study quality or sample characteristics. Where a theme was not found in a study, this was most often due to the absence of a theme (illustrated by '-' in Table 3) rather than a contradiction (illustrated by 'No' in Table 3). Where differences were observed, potential reasons for the difference were examined and will be discussed throughout the results.

Inevitably, due to the nature of experience, the themes often overlapped and were interlinked. This has been illustrated in Figure 1.

Figure 1: Diagrammatic illustration of themes



Stigma and negative judgement due to mental illness had an overarching influence on the parents' experience. All parents wanted to be a good parent but the negative impact that their SMI could have on their parenting and their child often had the potential to undermine their parenting abilities. This resulted in a number of internal and external conflicts for parents which could impact on their mental well-being in various ways. Stress associated with being a parent and having a SMI also had a negative impact on parents' well-being. However, there were a number of positive aspects of parenting that had a mediating effect on the parents' mental illness that, in combination with a desire to be a good parent, provided incentive for parents to manage their symptoms and stay well. The presence or absence of support also had an important influence on the overall experience of being a parent with a SMI. These links will be discussed in further detail throughout the description of the individual themes below.

Table 3: Summary of parenting experiences identified in each study

Themes	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Stigma and negative judgement due to mental illness	-	Yes	Yes	Yes	-	Yes	Yes	Yes	Yes	-	-	Yes	Yes	Yes
2. Desire to be a good parent	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- To prioritise and meet their children's needs	Yes	Yes	Yes	Yes	-	Yes	Yes	Yes	-	Yes	Yes	Yes	-	-
- To have a good relationship with their child	-	-	-	Yes	Yes	-	-	Yes	-	-	-	Yes	-	-
- To have a normal life	-	Yes	-	-	Yes	-	-	Yes	-	-	-	Yes	-	-
3. The negative impact of mental illness	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- On parenting	Yes	No	Yes	-	Yes	Yes	Yes	Yes	-	Yes	Yes	Yes	Yes	Yes
- On children	Yes	No	-	-	Yes	Yes	Yes	-	Yes	Yes	Yes	-	Yes	-
- The trauma of hospitalisation	-	-	-	Yes	Yes	-	-	-	-	Yes	-	-	-	-
4. Stress associated with parenting	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- Managing dual demands of parenting and mental illness	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- Fear of child developing mental illness	Yes	-	-	Yes	Yes	-	Yes	Yes	Yes	Yes	Yes	-	Yes	-
- Fear of becoming ill again	-	-	-	Yes	-	Yes	Yes	Yes	-	-	-	-	Yes	Yes
- Fear/experience of losing custody of or access to children	-	Yes	Yes	Yes	-	Yes	Yes	Yes	Yes	-	-	Yes	-	-
5. Positive aspects of parenting	Yes	Yes	Yes	Yes	-	Yes	Yes	Yes	Yes	Yes	Yes	Yes	-	-
- Importance of parenting role, personal growth and development	Yes	Yes	-	Yes	-	Yes	Yes	Yes	Yes	Yes	Yes	Yes	-	-
- Children provide an incentive to stay well	Yes	Yes	Yes	-	-	-	Yes	Yes	-	Yes	Yes	Yes	-	-
- Love and joy gained from being a parent	Yes	Yes	-	-	-	Yes	Yes	Yes	Yes	Yes	Yes	Yes	-	-
6. The importance of support	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	-	-	Yes	Yes	-
- Complex relationships with sources of support	-	Yes	Yes	-	Yes	Yes	-	-	-	-	-	Yes	Yes	-

Key to table:

Yes = Theme/sub-theme was present in the study; '-' = Theme/sub-theme was not mentioned in the study; No = Theme/sub-theme was refuted in the study

Theme One: Stigma and negative judgement due to mental illness

“We have a mental illness, and people consider that we’re going to abuse our children. We’re going to take it out on them” (Mother, Study 3a)

A pervasive part of the parents’ experience, as elicited by parents in ten of the studies was the experience of feeling stigmatized as a parent, because they had a mental illness. There was a sense that the usual stigma associated with psychiatric diagnoses was heightened for parents. Parents frequently perceived that they would be judged negatively by friends, family, professionals and the general public, with many having experienced such judgement. Parents perceived that the overall assumption by others was that parents with SMI were essentially bad parents, and the cause of any difficulties that their child experienced.

“I felt like he was blaming me – I was sitting there with this child that I had deliberately ruined – and I didn’t take kindly to that. I don’t think I have ruined her, I have done my very best to make sure of that” (Parent, Study 14)

This may in part reflect the known difficulties encountered by some parents with SMI; however the accounts suggested a prevailing negative assumption despite alternative evidence in individual cases. Parents also described an overemphasis on pathology resulting in the judiciary system, and many described living in fear of losing their children because they felt judged by their diagnosis rather than their parenting ability. They often felt scrutinized by others and feared others’ perceptions of their parenting and the relative impact of SMI. This theme remained present even for those who had achieved a high level of recovery.

“If you say a little thing, they’re so quick to jump to the conclusion that you’re defective mentally. A lot of judgements are made, a lot of accusations” (Mother, Study 3b)

“Well I’m frightened of saying the wrong thing to... the children’s father or something like that because I fear that he is going to turn it around and use it against me and put me in again. I’m scared. I’m scared. I’m so scared” (Mother Study 4)

Parents also worried that the stigma associated with SMI would impact on their children in other ways too. They worried that their children would be rejected, or would experience abuse or discrimination because they had a ‘mentally ill’ parent.

“If other mothers knew I had a mental illness, they might not allow their children to play with mine” (Mother, Study 7)

“People are so narrow minded...Because society will always label and at school they say your dad’s got bipolar you know and the other kids go ‘ha ha your dad’s a nutter’ you know and he has gone and got suspended for punching some kids” (Father, Study 9)

Thus, not only does stigma increase parental stress, it would often lead parents to try to hide their illness, prevent them from talking about any difficulties they might experience and impact on their willingness to seek help and engage in treatment.

For some parents, the sense of negative judgement from others served to undermine their confidence as a parent; for others, it could reinforce their desire to be a good parent and to prove themselves as such.

“I think sometimes we make the better parents because it is so hard to be like this and we have to try twice as hard” (Mother, Study 3)

In three of the four studies that did not elicit themes of stigma, this appeared to be due to a more narrow focus in their interview schedules, for example, a focus on parents’ perceived

strengths and challenges (Study 11), or a focus on the meaning of children to parents (Study 1). However, this was not the case in the Study 10, which was rated highly in terms of quality and explored the experience of fathers with psychosis. This does not appear to be a gender difference, as fathers in Study 12, which was of an equally high standard, expressed concerns about the impact of stigma. Some of the fathers in the latter study were also diagnosed with schizophrenia. This difference could still reflect an experience specific to fathers with psychosis, although it could be that fathers in the Study 10 had more positive fathering experiences that they wished to reflect upon. They may have felt more supported by the services that they were recruited from, as they also did not express any concerns about losing access to their children. Alternatively, this difference could also reflect the nature of the interviewer in this study.

Theme Two: Desire to be a good parent

The desire to be a good parent was elicited to various degrees in each of the fourteen studies. Prioritizing and meeting their children's needs, having a good relationship with their child and providing a 'normal' life for themselves and their children (i.e. one without mental illness), were all identified as important aspects of being a good parent.

"I missed a lot of things with her [when she was in foster care]. I now stay home, even if she is away, I stay home. See, right now I have to be there for her... It feels good 'cause I missed that when she was young, and I want to take care of her"

(Mother, Study 2)

"When I have them I make sure all of their needs are met, and I look after them properly... I play with them, read to them, just all the normal things I suppose"

(Father, Study 12)

Although social desirability may have influenced parents' responses in this domain, many parents reflected upon less socially desirable times when they believed that they had not been a good parent, especially when acutely unwell, as discussed in the next theme. Although parents could not always be a good parent, the majority of the sample maintained a desire to be a good parent when insight prevailed.

For many parents, their perception of a 'good parent' was influenced by societal expectations of parenthood as well as their own experience and upbringing. This is commonly found in the parenting literature⁷⁹⁻⁸⁰. Two of the studies highlighted how this could also be a direct response to parents' negative experiences of being parented, as several of their participants wanted to raise their children in a different manner than their own upbringing:

"I had an idea, from an early age, from the age of 16, I thought if I ever have a son, I'm going to treat him totally different to the way my [step-] dad treats me. He's never going to be punched, kicked, beaten, sworn at, nothing. He's going to have it nice and easy and a better chance than I got started with in life" (Father, Study 10)

"Well, my dad... he would leave me at home at the middle of the night...having food in the house was very sporadic. It was just not a safe place....and so for [daughters name], I have tried to provide her with like a really safe place to be that is clean and I always there" (Mother, Study 11)

Given that there is a significant relationship between adverse parenting experiences and the emergence of SMI in later life⁸¹⁻⁸², it seems important that this context should be taken into account, despite not arising as a separate theme within this synthesis. Unfortunately, the role of positive parental experiences in the parents' childhood was not elicited within any of the synthesised studies. A qualitative exploration of the influence of the parents' upbringing on the parenting styles of parents with SMI may therefore be an area for future research.

Parents' desire to be a good parent could serve to motivate parents to minimize the impact of their symptoms on their children, through symptom management and engagement in treatment programmes. Thus, motivation to be a good parent could potentially work against fear of stigmatization and custody loss to facilitate engagement. One father said it was the fear of being a bad parent that had forced him to do things with his children even when his symptoms were overwhelming:

"I was finding it really hard to get through the swimming lesson. I had to get into the pool with them you know – and then I had to interact with other people. I was finding it really hard, and then I was thinking that I just have to push through this for her and it gave me something to focus on rather than focussing on myself" (Father, Study 9)

However, a parent's desire to be a good parent could also conflict with their mental health in other ways, resulting in tensions about how to respond. For example, parents could experience guilt when having to prioritize their own needs, or parents may deny themselves treatment and neglect their own needs in order to attend to their family, thus resulting in a deterioration in mental health.

"They don't like me going into hospital ... Once when I went to hospital they all cried...so I went home again" (Parent, Study 5)

As such, some parents perceived their illness as undermining their efforts to be a good parent, which could lead them to question their ability to parent whilst having a SMI, and result in a sense of hopelessness. This theme therefore has an interactional relationship with theme three - the way in which parents perceive their illness to have an impact on either their parenting and/or their children.

Theme Three: The negative impact of mental illness

Thirteen of the studies clearly indicated how parents perceived their SMI to have an impact on either their parenting or their child. Only the parents in Study 2 refuted this, frequently not perceiving that their mental illness would impact on their children. However, this was in the context of what were perceived as a number of defensive responses, which could be related to the study's setting; this research was carried out within a rehabilitation programme for parents with SMI. Due to the severity of difficulties that parents in this study were experiencing in managing the dual roles of parenting and SMI, it could also be that they had little insight into the potential for SMI to affect child development. In general however, parents in the remaining studies recognised the impact that their symptoms or medication could have on their ability to meet their children's practical, social or emotional needs, particularly during more acute episodes of illness. This was in contrast to desire to be a good parent, as discussed.

"I wasn't able to look out for their common welfare. Not able to be the mother I really wanted to be" (Mother, Study 1)

"I think I wasn't always a good parent, I neglected them a bit. Sometimes I would forget to bath them for 4 or 5 days and things like that. Sometimes I was short tempered with them. I probably ignored them at times" (Mother, Study 5)

"Well because you alienated them from your mind...they're my children but they're not my children... it's a horrible feeling. You know to believe they weren't my children... I was...a bit offish with the kids, because I'm thinking they know what I'm going to say, and things like that... knowing that they can read me brain. Thinking that they can read me brain" (Father, Study 10)

Some parents acknowledged the more subtle impact of living with SMI.

“I know there were days, times, periods that I was depressed enough so that I just kind of went through life. I didn’t feel anything, I just you know, did the grocery shopping, did the cooking, took care of their needs but I wasn’t happy. I wasn’t enthusiastic about anything... I just went through the steps of living the way I had to but I didn’t have any joy, and I am sure that affected [the children]...” (Mother, Study 11)

Some described the more indirect and long-lasting effects that SMI could have on parenting.

For example:

“I used to discipline them when I was sick and it was wrong... So now I don’t punish when I’m sick... I shy away from it because I’ve done it in the wrong way before” (Parent, Study 6)

“Yes he has a lot of friends, but we have become isolated lately because I don’t always feel like doing things” (Mother, Study 5)

Less commonly discussed but nevertheless prominent was the parents’ perception of the impact that their parenting and behaviour had on their child. A number of parents described their children’s concern and distress associated with their parent’s SMI, as well as the additional responsibilities that some of the children had taken on.

“From the ages of 8 and 10 my children developed a mother-watch program... if my husband had to go to work, one of them would feign sickness and not go to school. They felt I had to be watched 24 hours a day” (Parent, Study 5)

“That was difficult for my daughter... During the week I would sit [my son] beside me and I would watch cartoons or whatever, a lot times my head was really out of it... My daughter had to help; she still thinks that was the pits. [At other times when her symptoms became worse] they would tell me. I would tell them to tell me; I would say, “Tell me if I am not making sense, because I need to know, it is important.”

(Mother, Study 6)

Another way in which parents perceived their SMI to impact on their children was through the trauma of hospitalization. For many, hospitalization meant separation from children for potentially long periods of time, leading to disruptions in family relationships and distress for both parents and children.

“For them it was a trauma, my daughter became very worried that I wasn’t coming back, and even now doesn’t like it when I leave her” (Parent, Study 5)

“I miss out, and my son misses out on my contact...not seeing my son when I’m on section 3, maybe 4 months in hospital. And that really hurts, but I do keep phone contact and writing letters twice a week” (Father, Study 10)

Few parents discussed the long-term impact of SMI on their children. However, it was not clear whether this was due to lack of belief, consideration or knowledge, or whether this was to prevent further distress. Indeed, some parents appeared to minimise the impact that SMI had on their child and it is possible that this was a way that parents attempt to mediate feelings of guilt.

“The impact on them has not been so great, though they react differently. When I am unwell, one of them thinks it is funny, the other is embarrassed” (Father, Study 12)

Where parents did perceive their SMI as having an impact on their parenting or their child, many experienced feelings of shame, guilt or inadequacy which would further impact on their mental well-being. Parents often felt that they had let their children down and many parents struggled with a problematic identity as a parent because of this – wanting to be a good parent, but feeling as though they could not be because of their illness.

“...and when it relates to my kids, that makes it hard to be a dad. I feel ashamed of having fallen short of my standards...in what I should be doing” (Father, Study 10)

Theme Four: Stress associated with parenting

It was recognised across all of the studies that being a parent and caring for children can contribute to stress. Accomplishing routine tasks associated with parenting, managing behaviour, and parenting anxieties, for example, about the child’s well-being, were frequently stated as important stressors. Many also acknowledged how lack of sleep, increased noise and increased activity levels due to children could also increase symptoms.

“When I am really ill I wish the children were not there so I wouldn’t have that burden to bear. I can’t cope with them; their demands are too much for me. And I keep on struggling until eventually I just break down” (Mother, Study 7)

“Four young children... all under 5 and that and they’re flying about, large as life all the time. You know, as soon as I got home, after coming out of a quiet hospital, you know it was too much for me. I had to go back in” (Father, Study 10)

Parents also described experiencing stress and guilt in trying to accomplish the competing demands of being a good parent whilst also managing symptoms and services relating to SMI.

“I need to get out, you know, but in the back of my mind I feel guilty that I need time alone” (Mother, Study 3a)

“I had a long time in those early days when I felt really useless as a parent, really, really useless” (Parent, Study 14)

“I wasn’t at his birthday party and I felt so bad... I locked myself in my room and cried and cried...” (Mother, Study 1)

Parents also had to manage specific fears relating to parenting and SMI. Many parents worried about the impact of SMI on their child, and this included a fear of their child developing a SMI.

“I have a great fear that they too will suffer from mental illness, either genetically (my mother also had mental health problems) or socially because of what they have been through” (Mother, Study 7)

“It was like, just don’t get the schizophrenia that I got, cause you know, I wouldn’t like to bring another person into the world to have to go through what I’ve been through” (Father, Study 10)

Parents also feared new crises and becoming ill again; not only because of the potential impact this had on their child but also due to worries about who would care for their child should they require hospitalization. However, this latter fear appeared to be more prominent for mothers with SMI, who were the sole carers of their children.

“There’s that fear of ...am I going to be okay today?” (Mother, Study 4)

“They have to go into foster care, which is quite sad for me and for them because they are not in their own environment. They are with strangers... I did not really like it because I had never met these people before. Even though they have been checked through social services I have never met them and I am not happy...” (Mother, Study 7)

Parents also feared loss of custody or access to their children. For a number of parents this was more than just a fear, and parents had experienced struggles to maintain or obtain custody of their children. Some had to suffer the emotional trauma associated with custody loss.

“That’s another fear that I have. That... the loss of my children. I worry about that every day” (Mother, Study 4)

Each of these stressors served to undermine parental well-being and cause further conflict for parents in terms of service use. Furthermore, stressors were heightened during psychiatric crises as parents struggled between being a good parent, maintaining their parenting role and minimizing the impact of SMI on their children.

*“I started off feeling that I wasn’t a really good parent. I remember thinking to myself that he would be better off without me and that I should put him up for adoption”
(Parent, Study 9)*

Some blamed themselves for problems in their children and some would misinterpret normal problems of childhood or adolescence as being related to mental illness. Parents acknowledged how normal stresses were exacerbated by illness related issues and many parents struggled to distinguish what was normal stress of caring for children, and what was due to their SMI.

*“I feel guilty a lot of the time because I get irritable with them, I get impatient, and I don’t know whether that is my illness or whether that is normal at times, it is hard to work out”
(Parent, Study 14)*

Theme Five: Positive aspects of parenting

There were also a number of positives associated with parenting that served to improve mental health and provide motivation for maintaining parenthood and being a good parent. The positive aspects of parenting were described in eleven of the studies. The three studies that did not elicit this experience appeared again to be due to the scope of the study, for example study 5 focussed on parental perceptions of the effects of SMI on their family, whilst

studies 13 and 14 were more concerned with the way in which parents perceived themselves as parents.

The majority of parents described how being a parent gave them a purpose and focus in life. Parents described personal growth and development through the parenting role. They described a sense of pride, fulfilment and value in raising their child which served to reinforce a more positive sense of identity.

“I felt like a mother that was there for him – I just felt good about that. I was happy”

(Mother, Study 1)

“Well I feel proud like... I feel that I've achieved something... that's worth achieving. To be a family man and to have a family” (Father, Study 10)

Their children were significant in helping them to make positive changes in their life and an incentive to remain well.

“It gave me responsibility. It gave me something to live for, something to hope for...they give you a reason to face the day and get up in the morning because you have to take care of that child” (Mother, Study 1)

“My kids keep me focussed and directed...Before I had kids, I didn't really have any goals, but when I had kids, I wanted to buy a house, settle down. Before my son was born, I had attempted suicide, but afterwards I felt that now I had something to live for, even when I was feeling bad” (Father, Study 12)

Parents also described the positive impact of the love and joy they gained from parenting their children.

“Having your children with you is a form of therapy because they give you so much love” (Mother, Study 7)

“...she’s such a happy child, sort of quite life affirming. It jogs me out of the depression that used to get me so down” (Father, Study 12)

For some, there was evidence that the children themselves provided a rescuing and supporting role to their parents. However, some authors wondered about parents’ over-dependence on their children in some cases, and it is likely that for some parents, the positives associated with parenting may enhance fear of custody loss.

“I think that it has helped a lot with my mental health because I am able to get love from them and this really has a calming effect to know that they are there for me and I am there for them, so this makes me very happy” (Mother, Study 7)

“I keep them very close to me through my depressions... I needed them because they were my reason for wanting to live because I felt so bad. They were the only reason I wanted to live” (Mother, Study 8)

The positives associated with parenting could also become vulnerable to the impact of the illness as parents along with others questioned the value of their parenting practices, and reflected on their child’s well-being and on their own ability to manage. The way in which parents perceived their children would often equate to their success as parents. So whilst there was a positive sense of self gained from having children, this could also become negative if parents were experiencing difficulties with parenting or problems with their children. Furthermore, where parents lost custody of their children and lost many of the positives associated with parenting, many also lost their motivation to get better.

“In the past when I was in hospital I would have a picture of my daughter and work towards getting well... This time round I wouldn’t be going back to full-time parenting, and I was in hospital a long time... I didn’t have that focus, as I wasn’t getting my daughter back. In fact I felt destitute, like I’d lost everything in the world”

(Mother, Study 7)

Theme Six: The importance of Support

A prominent theme for parents in ten of the studies related to social support. Parents frequently emphasised the importance of social support and the difficulties associated with a lack of support. Complex relationships with sources of support were also reported in six of the studies.

Many parents reported difficulties associated with a lack of social support. This included a lack of practical help with childcare resulting in a lack of time for themselves, and a lack of emotional and material support, thus increasing parental stress.

“I can’t cope with it 7 days a week... I mean for the first year of her life she never went to my mothers for more than a couple of hours so I was just looking after her 365 days, just no break and it’s really hard and I think if there was a group out there where I could mix with single mothers, you know, that have a mental illness, it would help me, you know, cause at the moment I just feel like I don’t know” (Mother, Study 4)

It is possible that parents’ lack of support may be related to the nature of their SMI, for example, due to social withdrawal or difficulties with interpersonal functioning. Indeed, some parents described difficulties in maintaining long-term relationships. Many mothers were single parents and the majority of fathers were separated from their children’s mother. Those who did have strong support networks were able to cope with crises better than those who were socially isolated, and there was a sense that this mediated the impact of SMI on children and families too, especially during stressful times such as hospitalization. Practical support

reduced stress when parents were finding it difficult to manage, as it allowed time for parents to meet their own mental health needs and consider the needs of their children. Emotional support also helped them to cope with their illness and the challenges of being a parent with SMI.

“If it hadn’t been for [wife’s name], I am not sure I would have been a father to my kids at all... She made it all happen, the doctor’s appointments, the medication. She took over the parenting for a long time and involved me when I could. Not sure if the kids would even know me now if it hadn’t been for her” (Father, Study 12)

“Whenever I go into the hospital, then my daughter goes and spends time with my parents, so that’s really good, and that’s just like a second home for her”

(Mother, Study 3b)

However, the benefits of support were often complicated by the complex relationships that parents had with their source of support. Parents described the additional pressures placed on them by other family members, or the tendency for others to undermine their parenting role. They often struggled to negotiate more helpful ways of managing the challenges that they faced.

“My mom feels that I should do everything that my children want me to do. I tried lying down the other day in the afternoon and my mother insisted that I get up and take my kids swimming because they wanted to go.” (Mother, Study 3b)

“I hear about some problems after it is sorted out. I suppose they are trying to protect me, but sometimes when I find out later it upsets me” (Parent, Study 5)

The parents’ behaviour and the way in which mental illness was perceived by family members had a significant impact on relationships. This could also impact on the relationship the parent

had with their child. Parents were faced with the distress that this could cause and the challenge of having to manage this.

“The family talks and a lot of the family members are ignorant about mental illness. Their ignorance speaks a lot of malicious stuff and my children have to listen to that about their mother” (Mother, Study 3b)

Some parents also experienced conflict around the relationship their children had with sources of support.

“My daughter favours her [the grandmother] more than me because when I used to be in the hospital for weeks, my mother took care of her, so I think that she’s really attached with my mother; she’s very close. It makes me a little upset because I’m her mother” (Mother, Study 3b)

A sense of burdening others also complicated relationships with sources of support and could mitigate against parents’ use of support.

“Well, she is getting kind of old. She babysits all the other grandkids. I think it’s too much for her” (Mother, Study 3b)

Of the studies that did not report on the support needs of parents, this appeared to be due to the focus of the study for two of the articles. However, the importance of support was also not elicited in Study 10, which explored the experience of fathers with psychosis. Again, this may be due to the particular sample included in this study, or it may be related to the focus and interpretations made by the researchers in this IPA investigation. However, it could be that there are unique differences in the experience of fathers with psychosis, in contrast to other forms of SMI. This may therefore need further exploration.

Discussion

To our knowledge, this is the first study to carry out a meta-synthesis of the findings from qualitative research exploring the experience of parenting with SMI. The results illustrated six important themes, the relationships between these themes and the conflicts they may present to parents who have a SMI. Some of the themes verify, from the parents' perspective, what has been illustrated elsewhere in the literature. In particular, the harmful effects of stigma on persons with SMI have been well documented⁸³⁻⁸⁴ and the indirect effects of stigma on the children of parents with SMI have also been recognised³²⁻³³. The synthesised findings from a large number of parents clarify the ways in which stigma and negative judgement provide an additional challenge for parents through the influence they have on parental confidence, relationships with others and decisions around service use. This finding also highlights the degree of insight that parents have into this process. The importance of support for the well-being of parents both with and without mental illness⁸⁰ has also been well researched, and family conflict in the lives of parents with SMI is recognised³²⁻³³. Furthermore, the literature around expressed emotion and family conflict has illustrated the negative effects that this can have on individuals with SMI⁸⁵ and their children⁸⁶⁻⁸⁷. The parents' perspectives reported here contributes to this knowledge, as it has shown how children can add complexity to family relationships and support that can maintain a negative cycle of difficulties and heighten the impact on mental illness. The two broad aspects of stigma and support have resonance with what is known about the impact of the wider societal and familial context on parenting practice⁸⁸⁻⁸⁹.

However, the more intra-personal aspects of the parents experience are rarely recognised in the review literature. The conflict between parents' desire to be a good parent and the ways in which SMI can undermine this parenting emerged as a particularly important aspect of the parents' experience. Whilst the literature recognises the ways in which SMI can impact on parenting practice and child development, the importance of being a good parent for parents

with SMI, and striving to do the best by their child is less frequently reported. Furthermore the potential for this conflict to destabilise parents is poorly recognised. Indeed, when parents' attempts to be a good parent are undermined by their symptoms, this impacts on parental self-efficacy, which is known to have a further impact on parenting and mental health⁹⁰⁻⁹¹, thus resulting in a perpetuating cycle. Parents recognise a number of ways in which SMI can impact on their parenting and their child and attempts to minimize this are likely to reflect a defence rather than a lack of insight or care. The additional stress associated with parenting that parents with SMI face is likely to have significant effects on their perception of their parenting role, their well-being and the difficulties they experience. As well as the normal stress associated with parenting⁹², parents with mental illness have to manage their illness, the additional worries pertaining to being a parent with a SMI, and the conflict between trying to be a good parent and feeling undermined in their attempts to do so by their illness. These experiences are rarely validated for parents with SMI in the empirical literature.

It is well known that parenting can increase mental health difficulties¹⁷ and it is recognised that increased distress makes it more difficult to be able to consider the needs of others⁹³⁻⁹⁴. Parental cycles of distress can lead to negative cycles of interaction with children that increase child behaviour difficulties and further impact on parental mood⁹⁵. However children could also have a positive impact on parents' mental health in a number of ways. Whilst the importance of children to parents with SMI has received greater attention in the literature, the positive influence that children have on parental mental health is rarely reported. Overall it seems that there is a constant battle for parents with SMI to maintain the balance between a number of competing factors. In order for parents to maintain the balance, their view of themselves as parents needs to not be undermined (i.e. by their symptoms, by stigma or through difficulty with support) to such a degree that they become hopeless about their ability to parent. The positive gains of parenting need to balance out the stress of parenting, and the

ability to seek help when required needs to not be overruled by fear of negative judgement and potential for custody loss.

The parents' perspectives that have been reported here have provided insight into the lived experience and challenges that parents with SMI often face; and the ways in which the conflicting pressures on parents, as well as their symptoms, can interplay to affect parenting behaviours and responses, and decisions with regards to engagement with services.

Strengths & Limitations

The reported findings should be considered in the context of the strengths and limitations of the synthesis that was carried out. This synthesis incorporated the experiences of parents with SMI from a variety of backgrounds and circumstances. Rigorous methods for systematic review were used that included a comprehensive search of published studies using pre-determined criteria. Previously applied methods were used to synthesise the parents' experience and perspectives, emphasising transparency in the development of themes⁶²⁻⁶³. Comprehensive details of the primary studies were also provided, as reported by each study. Some of the older studies did not state the analytical procedure that was used, thus casting doubt on the reliability of the findings as a representation of the participants' views. However, the synthesis showed significant overlap between the themes elicited in studies of the highest quality and those in which flaws were identified, thus facilitating confidence in the overarching themes produced by the synthesis.

The themes elicited were however limited to the experiences of participants in the included studies. It was noted that fathers in particular were under-represented and the synthesis results may therefore be biased towards the experience of mothers with SMI. A potential consequence of the lack of specificity reflected in the studies (for example in the grouping of mothers and fathers, various diagnoses, and ages of children) is that there may be important

factors pertaining to these areas of difference that may have been overlooked. Furthermore, due to the nature of the synthesis approach, the identification of the strongest themes means there is an inevitable loss of more marginal areas which may still be of importance. However, there needs to be a balance between analyzing the studies in sufficient detail to preserve the integrity of each study and yet not become so immersed in detail that no useable synthesis is produced⁴⁸. The analytical themes provided in this synthesis therefore offer a conceptual model for thinking about parenting with a SMI that may be applicable across different contexts. Due to the interpretative nature of the synthesis however, the resulting findings are positional on the part of the researcher performing the synthesis. Thus, the interpretation of the data may or may not have resonance with others in the field. A useful future step would be to test the relevance and ultimately the quality of the synthesis findings by presenting them to a group of parents with SMI and related professionals, to test out whether this interpretation fits with their overall experience.

Implications of the review

The model of themes elicited in this synthesis provides a broad conceptual framework in which parenting with SMI can be considered across a range of children's ages, parental symptoms and parenting roles. Consideration of the parenting stressors and positive aspects of parenting that children present at different ages; the ways in which these interact with the specific symptoms of the parent, and how this is interpreted as undermining their ability to be a good parent will be useful for professionals working with parents with SMI. Indeed, parental perceptions of what a good parent is or does may differ dependent on the age of their child, parents' gender and also parents' own experiences of being parented. It is hoped that this framework can be used to complement quantitative literature on parenting with SMI.

If further empirical studies verify that the identified domains are essential aspects of the experience of parenting with SMI, then education and care delivery systems need to be designed to allow consideration of each aspect of experience and the conflicts they present.

Healthcare professionals have a role in dispelling harmful myths about mental illness and parenthood that are prevalent in society and exacerbate risk to parental well-being. Educating clinicians to help them to acknowledge and differentiate the many fears, anxieties and conflicts that parents may be grappling with, and the interaction between the child's behaviour, the parents' symptoms and their parenting will also be useful to help parents develop strategies that enable them to effectively manage the dual demands of parenting with SMI. Interventions and delivery systems specifically designed to maximise good parenting skills in this context is also important.

Further research should explore parenting with specific diagnoses in further detail so that experiences can be compared and contrasted. Research into the experiences of parenting across the different age groups of children, and gender roles of parents will also be beneficial. As more research is conducted in the area, it is hoped that future reviews may be able to discriminate between gender, diagnosis and age of the children to develop understanding about whether the experiences and needs differ in relation to such variables. As none of the studies focussed specifically on the experience and perspectives of mothers with psychosis, parents with severe depression, or parents with personality disorder, future research would also be beneficial in each of these areas.

Conclusions

This synthesis has provided insight into the needs and perspective of parents with SMI, which is often neglected in the literature. As recognised by Göpfert and colleagues⁹⁶, the separation of parent and child services makes it hard to encompass the needs of both the parent and the child, especially when the expert knowledge about parenting resides in the children's service. It is hoped that this synthesis of qualitative studies will help adult professionals appreciate the issues of parenting faced by parents with SMI, and help child professionals better manage the conflicting needs of the parent with SMI.

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A qualitative investigation into the experience of parenting with Bipolar Disorder

Rebecca Murphy

The University of Manchester

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Address for correspondence:

Rebecca Murphy
Department of Clinical Psychology
School of Psychological Sciences
University of Manchester
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
rebecca.murphy@postgrad.manchester.ac.uk

Abstract

Objective: To explore the lived experience of parenting with Bipolar Disorder (BD) to provide insight into the parents' perspective and the influence this may have on outcomes for both the parent and their child.

Design: A qualitative design using semi-structured interviews and Interpretative Phenomenological Analysis.

Participants: Six mothers and two fathers with BD, each of whom had at least one child aged between 4 and 12 years.

Setting: Participants were recruited via a national organization for people whose lives are affected by BD. Interviews were carried out in participants' homes.

Results: Six themes were identified: 'BD stops me from being the parent I want to be – the impact of BD on parenting'; 'Worry, guilt and denial – the impact of BD on family'; 'Managing guilt, limiting worry – strategies for coping'; 'Parenting highs and lows - the impact of parenting on personal well-being'; 'The domino effect - the influence of contextual factors'; 'Improvement over time – important temporal factors'. Each theme consisted of a number of subthemes and there were important interactions between the themes. The themes were discussed in relation to the literature on parenting, mental illness and BD.

Conclusions: Parents with BD recognise a number of challenges in being a parent and experience feelings of inadequacy, guilt and worry about the impact their illness has on their children and family. Strategies for managing these feelings and limiting the impact of BD can have an inadvertent negative effect on the parent's well-being, and that of their child. Learning to accept the diagnosis and developing strategies for managing symptoms were crucial for positive parenting, although the changing needs of their children often presented new challenges. Contextual factors, including stigma associated with mental illness, could either mediate or exacerbate the challenge of parenting with BD. Clinical implications are discussed.

Introduction

Children who have a parent with Bipolar Disorder (CPBD) are at substantially greater risk of developing psychiatric disorder, and recent advances in the literature have illustrated a clear need to develop preventative interventions for this vulnerable population. The present research was devised to advance the development of appropriate services.

Bipolar Disorder (BD) is one of the leading causes of disability worldwide, affecting approximately 1-1.5% of the general population in the US and UK¹. It is a recurrent, episodic and severe mental illness characterised by extreme fluctuations in mood, thought and behaviour which can impact on functional domains such as work, family and social relationships²⁻⁴, even during periods of relative stability⁵⁻⁶. In addition to the personal impact of mood disturbance, there is the potential for impact on others. Research has illustrated negative effects on the physical and psychological health of those who care for people with BD⁷ and there is extensive evidence illustrating poorer outcomes for CPBD. Several studies indicate that CPBD have an elevated risk of developing BD, as well as other psychiatric conditions, such as anxiety, depression, ADHD and sleep disorders⁸⁻¹⁰. Increased rates of problem behaviours, such as aggression and rule breaking¹¹⁻¹², and difficulties with psychosocial functioning¹³⁻¹⁵ have also been shown in CPBD. Although hereditary influences are important in the aetiology of BD¹⁶, the literature also indicates an important role for environmental factors in the developmental trajectories of CPBD¹⁷. Research indicates elevated difficulties in the family environment¹⁸⁻²⁰ and communication styles of parents with BD²¹⁻²³, and that such problems are prospectively related to transition to BD and other emotional and behavioural difficulties in their children.

Furthermore, it is well known that parenting confers risk to mental illness²⁴, and there is extensive evidence which indicates the reciprocal relationship between maternal mood and emotional and behavioural difficulties in children²⁵⁻²⁹. The stressors associated with parenting

therefore have the potential to maintain or exacerbate symptoms in parents with BD, resulting in a negative cycle within which risk to both parent and child is increased. There is therefore a need to develop services that will minimize risk and improve outcomes for children and families in which there is a parent with BD. To do this effectively, it is crucial not only to understand the needs and experiences of parents with BD from their own perspective, but also to increase understanding of the influence that these perspectives may have on outcomes for parents and their children.

Qualitative research methods are particularly suited to the exploration of lived experience as they are able to explore issues that are difficult to access using more structured, statistically based techniques. They provide the opportunity to explore novel or complex phenomena and develop rich understandings of these phenomena as they occur³⁰⁻³¹. A limited number of studies have explored the experience of parents with severe mental illness³²⁻³⁴ (SMI), which often include but are not specific to parents with BD. These studies have illustrated important aspects of the parenting experience for parents with SMI, however given the variety of symptoms and relative difference in the various forms of SMI, exploring whether there are experiences that are more specific to parents with BD would assist the design and delivery of appropriate preventative services. Two studies have explored the views of parents with BD previously. In 2008, Venkataraman & Ackerson³⁵ carried out a thematic analysis of the strengths, challenges and service needs of mothers with BD. Whilst this highlighted the potential strengths and difficulties in the parenting abilities of parents with BD, it did not facilitate understanding of what these experiences were like for parents, or the meaning that parents attributed to these experiences. In 2009, Wilson & Crowe³⁶ used critical discourse analysis to investigate how parents with BD constructed their role as a parent. This provided insight into the way in which societal expectations of parenting, particularly the importance of emotion regulation, influenced the confidence and behaviour of parents with BD. However, there is a need for a broader understanding of the internal worlds of parents with BD. The

current research was designed to fill this phenomenological gap; to provide greater clarity regarding the lived experience of parents with BD and the influence that this may have on outcomes for themselves and their children.

Method

Ethical approval for the study was granted by the School of Psychological Sciences Research Ethics Committee at the University. BD service user groups were consulted on all aspects of the design.

Design

A qualitative design, using semi-structured interviews and Interpretative Phenomenological Analysis (IPA)³⁷ was chosen as the most appropriate research methodology for this study. IPA is particularly concerned with identifying the personal perceptions of individuals, rather than producing an objective record of an experience or state: 'Meaning is central, and the aim is to try to understand the content and complexity of those meanings, rather than measure their frequency' (Smith & Osborn³⁸; p66).

IPA requires researchers to engage in an interpretative relationship with the data to make sense of participants' personal, emotional and psychological worlds. It is therefore useful to be aware of the general stance and background of the researcher to enable readers to understand the potential biases that may be brought to the analysis. Undertaking doctoral training in clinical psychology alongside this research facilitated broad awareness of a range of psychological models and theories. However the primary researcher is particularly affiliated with systemic approaches and the bridge between cognitive and dynamic viewpoints. This orientation was reflected within the research team.

Recruitment & Participants

Participants were recruited via an advertisement in a newsletter of a national user-led organisation for people whose lives are affected by BD. The inclusion criteria for participation in the study were: Participants must a) have a diagnosis of BD; b) be a parent/guardian of at least one child aged between 4 and 12; and c) either live with or regularly care for their child(ren). Specification of the child's age was due to the authors' desire to capture the experiences of parents currently living with younger children to facilitate the development of early, preventive interventions. Conversations with parents about their diagnoses facilitated confidence in the validity of parents' BD; however, diagnosis was not verified by other sources. The homogeneity of the sample was defined by the participants' shared experience of being a parent with BD. Thus, specifications around age, gender, and demographic/socio-economic profiles were not set.

The final sample consisted of eight White British parents including six mothers and two fathers, aged between 33 and 50 years. Parents were recruited from locations across England and had a range of socio-economic backgrounds. The number of children in each family ranged from one to four. Five parents were currently married and living with their partner, and the remainder were single parents. Further details are included in Table 1. The sample size was guided by Smith & Osborn³⁸ and deemed sufficient given the in-depth analysis required for the purpose of this study.

Interview Procedures

Data collection consisted of semi-structured interviews followed by demographic and questionnaire data. Informed consent was obtained from each participant before the interview (Appendix 3: Participant Information Sheet and Consent Form) and all interviews were conducted by the primary researcher in the participants' homes. Interviews lasted

between 65 and 143 minutes. The mean interview time was 89 minutes. All interviews were digitally recorded and transcribed.

Interview Schedule:

The interview schedule was developed following reflection on relevant literature and through discussion with service user consultants. The interview schedule was piloted on two parents with BD who did not meet study eligibility criteria, and adjusted according to feedback from the interviewees and the research team (Appendix 4: Interview schedule). Questions were open ended and a non-directive approach was adopted to encourage parents to develop and elaborate on their experiences. The schedule covered three broad areas: impact of BD on family; impact of BD on parenting, and impact of parenting on BD. Participants were encouraged to describe their thoughts and feelings concerning their experience, and emphasis was placed on facilitating discussion of the positive as well as negative experiences. Reflection on past and present experiences was also encouraged.

Questionnaire Data:

In order to provide sufficient context for parents' views and experiences^{30, 39}, qualitative data were supplemented by questionnaire data regarding socio-demographic details and current mood, which may have influenced the parents' perspective. Participants' responses are detailed in Table 1. Questionnaires were completed following the interviews so that they did not influence the flow of the interview.

- *Family Background Questionnaire (FBQ)*⁴⁰

Demographic data were collected using an adapted version of the FBQ (Appendix 5), used in previous parenting research with a UK sample⁴⁰. This questionnaire was extended to include details of parental diagnosis and management of BD.

- *The Internal States Scale (ISS)*⁴¹

The ISS is a 15-item self-report questionnaire assessing manic and depressive symptoms for the preceding 24 hours. This measure is widely used and has good internal reliability and validity. Parents are asked to rate themselves on each item using a visual analogue scale that ranges from 'Not at all/Rarely' to 'Very much so/Much of the time'. This results in a description of current mood state which indicates high possibility of either 'Depression', 'Mania', 'Euthymia' or 'Mixed state'.

Reflective Diary:

Following each interview, the interviewer completed a reflective diary recording thoughts and ideas arising from the interview, including observations and researcher feelings which may have contributed to how the data were collected or analysed.

Data Analysis

Data were analysed using the procedures outlined by Smith & Osborne³⁸ for conducting IPA. A multi-level analysis was undertaken that tried to capture an insider's viewpoint through open questioning but also a more critical, 'outsider's' position by questioning what was being said and searching for nuances in the data that could reveal a more covert agenda. An idiographic approach was used, for which detailed examination of one transcript was completed before moving onto the next. Variations as well as commonalities within the data set were also identified.

Individual transcripts were read repeatedly and notes were made of utterances of particular significance. The transcripts were then re-read and an initial list of preliminary themes identified which were subsequently translated into emergent themes (see Appendix 6: Interview Transcript- Coding Sample). Emerging themes were grouped into associated clusters and master lists of themes were compiled for each interview. Analysis was then conducted

across the interviews. Themes were compared from all interviews and recurrent themes were assembled together as sub-themes within higher order categories. The emergence of a theme in the majority of transcripts was considered as appropriate for inclusion in the list of higher-order themes⁴². The researcher took an iterative stance and revisited the transcripts throughout the process to ensure the analysis remained close to the data. The process was aided by analytical memos and reflections recorded throughout data collection and analysis.

As the analysis progressed, a range of processes became particularly apparent both within individual interviews as well as across participant interviews, and associations between themes became clear. Following completion of the analysis, these relationships were explored further by revisiting transcripts, constructing diagrams and discussing ideas within the research team. These are techniques that are more commonly associated with Grounded Theory but can be applied to IPA following the initial analysis⁴². A model that appeared to explain the relationships between themes was developed.

Validity and Reliability

As IPA is contingent upon the interpretation of the primary researcher, it is vital to ensure that interpretations are as trustworthy as possible and fit with the participants' experience. The study was therefore conducted using established validation standards for the conduct of good qualitative research³⁰. Validation methods included regular meetings between researchers to ensure transparency in procedure; close supervision to provide an ongoing critique of the work; and the detailed examination of similarity and difference, convergence and divergence among cases and themes. An experienced IPA researcher oversaw the analyses at all stages and conducted credibility checks on the data. Data and analysis audits were carried out during which codes and themes were tested by returning to the original data. The analysis of the transcripts was judged to be coherent. Final themes were agreed on following discussion

within the research team. Themes have been supported by participants discourse throughout the results to allow the reader to assess the reliability and validity of the interpretations.

Table 1: Participant characteristics

Parent	Age	Years since diagnosis	Parent when diagnosed	No. of children	Age of children	Additional Needs of Children ¹	Marital Status	Level of Education	Current Employment	Receipt of Benefits ²	Ethnicity	Prescribed Medication	Mood at Interview ³
1. Mother	44	17	No	1	5	Child has epilepsy, cognitive and emotional difficulties.	Married	University Degree	Part-time	Yes	White British	Yes	Depressed
2. Father	40	0	Yes	4	21 20 12 6	Two youngest children have a diagnosis of Autism	Married	Post-Graduate Degree	Full-time	Yes	White British	Yes	Mixed State
3. Mother	39	2	Yes	2	9 6	One child has Asperger's Syndrome. Second child is showing delay in social and emotional skills	Married	Masters Degree	Self-employed Part-time	Yes	White British	Yes	Euthymic
4. Mother	33	3	Yes	3	7 6 4	One child has a hearing impairment	Married	University Degree	Unemployed	Yes	White British	Yes	Depressed
5. Mother	41	10	No	2	8 5	One child has ADHD, poor communication and social skills.	Single	University Degree	Unemployed	Yes	White British	No	Euthymic
6. Mother	50	4	Yes	1	10	None	Single	GCSE / O-levels	Unemployed	Yes	White British	Yes	Depressed
7. Father	35	3	Yes	3	9 5 2	One child has emotional difficulties. No formal diagnosis.	Married	University Degree	Part-time	No	White British	Yes	Euthymic
8. Mother	36	11	No	1	4	None	Separated	GCSE / O-levels	Unemployed	Yes	White British	Yes	Euthymic

¹ As reported by parents on completion of the Family Background Questionnaire

² Excluding Child Benefit.

³ According to the Internal States Scale, completed by participants at the time of the interview based on the previous 24 hours

Results

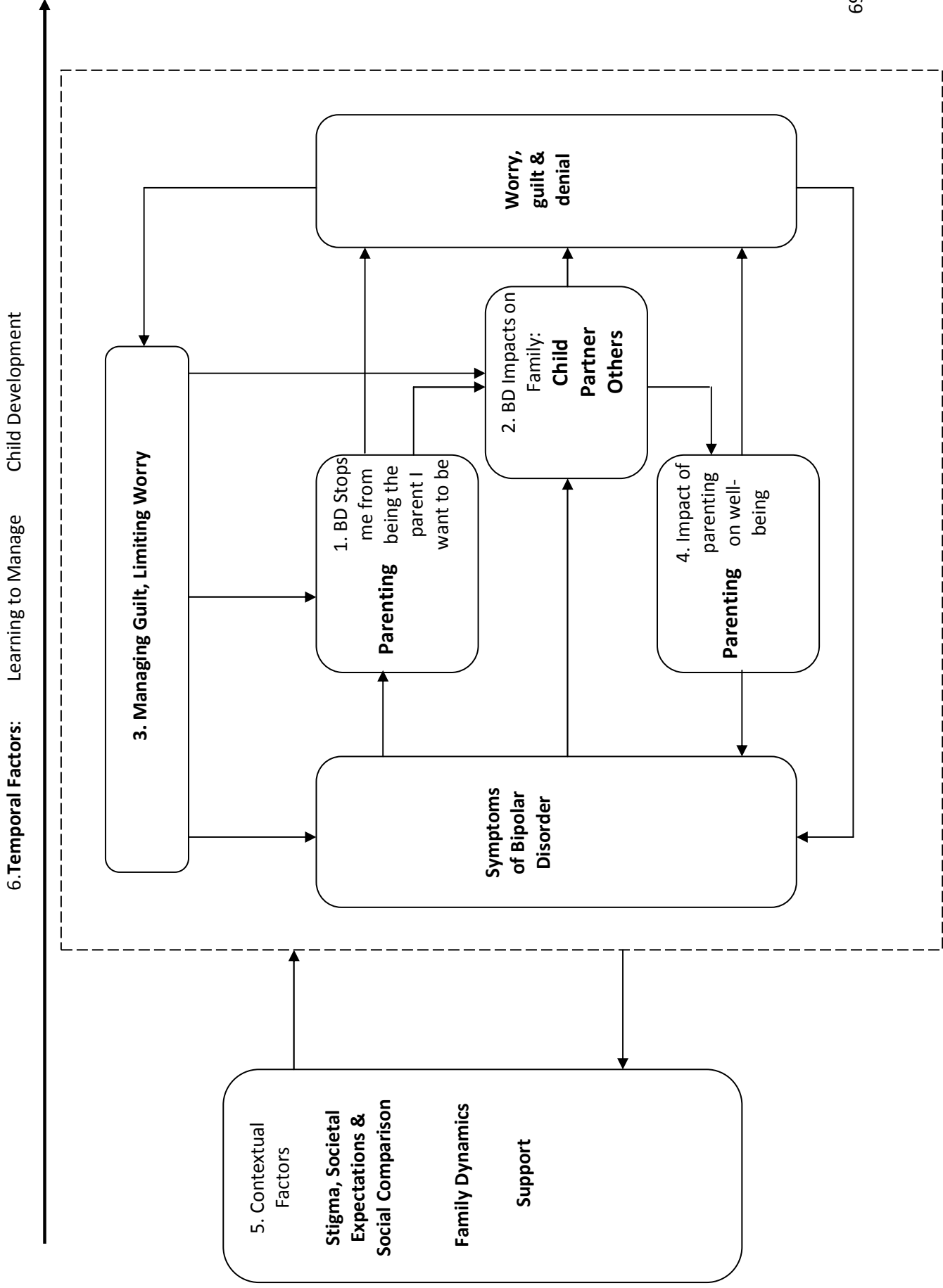
Results are presented to illustrate the key components of the participants' accounts. IPA facilitated the development of six core themes that illustrate important aspects of the experience of parenting with BD. These were:

1. 'BD stops me from being the parent I want to be' – the impact of BD on parenting.
2. Worry, guilt and denial – the impact of BD on family.
3. Managing guilt, limiting worry – strategies for coping.
4. Parenting highs and lows - the impact of parenting on personal well-being.
5. 'The domino effect' - the influence of contextual factors.
6. Improvement over time – important temporal factors.

Each theme consisted of a number of subthemes which will be discussed in detail below.

There was significant overlap and interaction between the themes and this will be explored within the results and discussion. Figure 1 provides a diagrammatic summary showing how the themes and sub-themes fit together. It should be noted that the arrows linking the themes are speculative but are based on the accounts of participants.

Figure 1: Diagrammatic illustration of themes



Theme 1:

'BD stops me from being the parent I want to be' -the impact of BD on parenting

"I feel a terrible mum on a daily basis" (Participant 3)

Each of the parents had ideas about how they would like to be as a parent and this often included unrealistic or idealised views about how they believed they should be. However, parents felt that they were unable to parent the way they wanted to, because of their BD. The discrepancy between parents' idealised view of themselves as parents, and the reality of themselves as parents often resulted in self-criticism and a lack of confidence in their parenting ability. Parents frequently experienced feelings of inadequacy and failure which were heightened when parenting difficulties were highlighted. This could maintain or escalate low mood. Similar effects have been found in parents without mental illness who feel inadequate in their parenting role^{26, 27, 43}.

As BD was seen as the cause of the discrepancy between parents' idealised and real view of themselves as parents, this could either motivate parents to overcome their symptoms or leave them feeling hopeless about their ability to do things differently. This can be seen in the language that was used throughout the text. The sense of hopelessness was especially apparent when parents believed that their symptoms were out of their control, which mirrors the experience of others' with BD^{44, 45}. However, locating the cause of parenting difficulties with BD could also absolve the parents' responsibility for their parenting behaviour, and therefore be protective for parents. Indeed, to believe in the ability to gain control over symptoms could result in further criticism from both self and others when symptoms were not well managed.

"All the time that the daily awfulness was going on there was a part of me that kept saying this is not you, this is not you, you are an intelligent and capable woman,

you're not some benefit, useless, druggy mum. What the hell is going on?...Why have your symptoms gripped you so much that, that me can't get through? And the difficulty of trying to stop it in its tracks and make the decision that it wasn't going to slide any further was about saying to myself that I am more than my symptoms. I can go one of two ways now, I can lose my kids and I can give up and say who I was before is gone, I am now a set of bipolar symptoms... and I wasn't prepared to do that...not with my little boy starting school" (Participant 5)

In line with the results of Venkataraman & Ackerson³⁵, parents described a number of ways in which they believed BD prevented them from being the parent that they strived to be. This included parenting difficulties inherent in the changeable nature of their mood, as well as particular difficulties associated with high or low mood. These will be discussed in the subthemes below. Whilst many of the difficulties described are similar to the challenges parents without mental illness face, for example, being consistent, managing behaviour, discipline and making time for themselves and their children⁴⁶⁻⁴⁸; the difficulties appear to be heightened for parents with BD, due to their mood.

Subtheme 1.1: Impact of depressed mood-'too hard to bear'

"Well it's just motivation and what-have-you...I am one for getting out and doing things... [but] when I do get low I tend to not engage with [name of child] as much. It-it's easier for me to put him the telly on more, give him the DS to play with, and I just tend to sit there and think [sighs] I'll sit on this chair and look out the window [sighs]..."
(Participant 8)

Parents generally believed that the greatest impact on their ability to parent came from low mood and episodes of depression. Parents described how the biological, psychological and social effects of depressed mood could impact on their parenting. Parents described increased stress, anxiety and irritability and a lack of enjoyment which would impact on the interactions

they had with their children. They reported being less emotionally available for their children, spending less time with them and a difficulty responding appropriately to their children's demands when low.

"...you know, if [name of third child] comes at me shouting, which he does sometimes, if I'm feeling agitated, I'll shout back despite intellectually knowing that that's not going to help because it'll just escalate his behaviour, it's just like I'm so short tempered and so tense I can't do anything but.." (Participant 2)

Some parents were also aware that their ability to problem solve diminished with increasingly low mood, and this impacted on their ability to manage difficult situations. Reduced awareness of their children's needs could also occur during depression, and in some cases parents described difficulty developing an emotional connection with their children.

"Sometimes I've felt like I'm there doing all the hugging but I feel that there's this, a bit of a barrier between me and them when I'm not feeling up to it, but I'm still trying to go through the motions of doing the mothering bit..." (Participant 4)

Practical tasks such as cooking and housework could become more difficult to achieve, but there was a general sense that parents would attempt to meet their children's most basic needs for as long as possible. When depression was very severe however, parents described a complete inability to function as a parent.

"When I've become depressed, I just can't manage any of the role... really... I,[sighs] I just withdraw myself from the family and I can't, you know, although I have the feelings of responsibility towards the children I can't do anything to, to... I'll let one of them come and lie on the bed with me or something like that but I can't, I can't do much more than that when I'm very down and... I mean I would go as far to say that if

I'm on, in a depressive episode, I'm really quite disabled, I can't, can't seem to muster the will to do much of anything at all" (Participant 2)

As is evident from the breaks and hesitations used by the participant in this extract, parents experienced a lot of guilt, anxiety and embarrassment when admitting the extent of the impact that their symptoms could have. This was very hard for participants to bear.

Subtheme 1.2: Impact of elated mood – a lack of concern?

"I never worry that I'm getting high, I worry when I'm low because [name of child] is quite energetic and you know I need a lot of energy for him..." (Participant 8)

Most parents were not concerned about the impact that mania or hypo-mania had on their parenting. Parents described how they were a very different parent when elated, having more energy, being more creative, fun, and less anxious. Parenting was experienced as more enjoyable during these times, and importantly parents described feeling more capable as parents during periods of elated mood. Parents made positive comparisons of themselves to other parents when reflecting on episodes of elated mood, and this was in stark contrast to the negative associations of themselves as parents when suffering low mood. This could therefore be positively reinforcing for parents, serving to combat negative identities of themselves as consistently 'bad' parents. This may have made it difficult for parents to acknowledge some of the negative consequences that elated mood had on their parenting. However, parents did acknowledge a number of risks associated with elated mood. In particular, parents described a tendency to become overambitious during these periods, leading to exhaustion and an increased likelihood of depression. Parents also described how decisions made during manic and hypo-manic episodes could have long-lasting and negative effects on their lives. As such there was a sense that even the positive aspects of their symptoms were tainted.

“Then I’m busy and lots of energy and stuff which is very different from the depressed mum that’s got no energy and no motivation to do anything, but it’s dangerous, because after every high comes a low” (Participant 3)

Two parents described how they could be hurtful, irritating or embarrassing to their children when their mood became elated and acknowledged the potential to become insensitive to their children’s needs during these periods. Whilst most parents stated that they never lost their sense of responsibility to their children during periods of mania, others stated that they did. It was not clear whether it was a lack of insight or experience of the negative consequences of elated mood that prevented their acknowledgement of such, or whether it was a defensive strategy to protect their self-esteem as a parent. Again, as illustrated in the extract below, it was difficult for this parent to share her experience.

“It probably came evident to the family because, I was very focused on work only and if anybody interrupted me I was really angry and irritable, erm, I really, I suppose at that point, so this is like probably 2 or 3 months after I started work, erm... I just completely disregarded the family, I’d go to work, come home, have a bowl of soup and, and then work. Err [name of husband] became a househusband because there was nobody there to look after the children” (Participant 3)

It is important to note however, that the extent of the impact appeared to depend on both severity of elated mood and the availability of other forms of support for the children. The parents’ descriptions suggested that knowledge of alternative and sufficient support for children reduced parental responsibility to their children when unwell.

Subtheme 1.3: The changing nature of BD - Unpredictable, inconsistent and interrupted parenting

“[I have] guilt... that she’s on her own ... and... that she’ll never know what mood I’m gonna be in” (Participant 6)

Many parents described how difficulties with emotion regulation and the changing nature of their moods led to inconsistencies in their parenting. This made discipline and boundary setting particularly difficult. Parents also described difficulty in modelling appropriate behaviour to their children due to inconsistent and sometimes exaggerated responses to environmental stimuli. Preoccupation with their own difficulties also meant that it was often difficult for parents to hold their child’s needs in mind and this could lead to changing expectations of their child.

“So those children occupied their day pretty much the whole day. And then we have to remember to come together in the evening and have some us time, watch a film or cuddle up on the sofa so they’re not being little adults as a way of helping me manage my stresses, which is what I ended up doing as a child. I have to try and remember; I don’t always do it successfully” (Participant 5)

Parents found that their unpredictability could be confusing and unsettling for their children, and changes to routines and pre-arranged plans due to parent’s mood could be upsetting.

“I can’t make commitments...erm... so I think me daughter suffers in that respect...I’ll have to say to her, ‘I’ll have to see how I feel if you want somebody to sleep over ‘ or something... last couple of days I’ve felt alright, she’s had two friends to sleep over,[and] I took four of ‘em to a play centre... but if I’m low, I won’t go out hardly at all” (Participant 6)

Parenting could also be interrupted by time spent away from children, for example when parents were hospitalised. Changing carers added to the inconsistency of care that their children experienced and it could take a long time to re-establish their parenting role following a period of separation.

Theme 2: Worry, guilt & denial – the impact of BD on family

Although parents were able to talk, albeit with difficulty, about the impact that BD had on their parenting behaviours, it was much more distressing for parents to consider the long-term consequences of those behaviours on their child. Parents did not always associate the impact of BD on their parenting with the impact of BD on their child, and for this reason these aspects of parents experience are portrayed as distinct themes. It was interesting to note that the parents were clear about the effects that BD had on their partner and other family members, as will be discussed in the subthemes below.

“Its affected [name of husband] you know massively, massively, massively, erm....But with [name of child], I think it is diff- difficult to quantify it, because I haven’t been as...unstable, erm... so... I’m not sure, but I think our family you know...[sighs] I think it still does impact on us now, even though...[very quietly] I’m not always ill”

(Participant 1)

Subtheme 2:1 Impact of BD on children - a worrying uncertainty

“I’d like to think, I suppose I’d like to think that my children haven’t been disadvantaged by it, you know” (Participant 4)

Parents initially denied that BD had any impact on their child, but later would acknowledge the observable and immediate effects that BD had on their child. Some parents described a social impact, such as a child being unable to take part in an activity or event due to their parent’s

symptoms. Others acknowledged emotional and behavioural responses, for example, a child's emotional distress in relation to their parent's behaviour.

However, the less obvious, long-term consequences for children were rarely discussed. Most parents maintained an important level of uncertainty when considering this. There were often a number of reasons reported as to why they believed their children were unaffected by their BD, and these frequently related to strategies for managing guilt and worry, as discussed in theme three. Even where distress may have been communicated through behaviour, there were often a number of other possible explanations for the behaviour. It was therefore difficult for parents to establish cause and effect, thus enabling parents to avoid feelings of self-blame and guilt.

" [Name of eldest child] started poo smearing, and I'm quite happy for that to be on the tape because, to this day, we'll never know whether that was ADHD coming up, a reaction to extreme stress or whether that was just toddlerhood... I've known other children who have just done it, they're not, you know they're not damaged in any way, nothing else has been going on, they have just done it because they were interested"

(Participant 5)

It appeared too painful for parents to consider the impact that BD might have on the child's long-term well being, and parents varied in the extent to which they were able to acknowledge the potential for this occur. All parents worried about the possible impact but hoped that their difficulties did not influence their child's development. One parent who did acknowledge the potential impact on her child experienced greater feelings of guilt and self-blame which appeared to exacerbate depressed mood.

“But there’s already been damage done and I’ve seen it, like I said with [name of youngest child]...so we’ve now got to go back and repair all the damage that I’ve done in the meantime” (Participant 3)

Thus it is likely that the sustained uncertainty around the impact of parental BD on their child serves as a protective function for some parents to refute impact and avoid further distress. This seems particularly the case given that almost all parents referred to the impact of parenting on the long term well-being of children in different contexts, throughout their discourse.

Subtheme 2:2 Impact on partners & other family members – the undeniable effects

“It was awful for him to see, even if he chose to stand away from it, he said ‘I couldn’t reach you, I couldn’t help, I didn’t feel like there was anything I could do, the only thing I could do was run away” (Participant 5)

Parents’ clarity around the impact that BD had on other family members appeared to be related to the communication of this between family members, resulting in an inability to refute the effects. All parents believed that the symptoms of BD placed additional strain on their partners or other family members due to the additional parenting responsibilities that they had to adopt, as well as their concern and need to care for the parent with BD.

“I’d be unwell and unable to do anything and, [the children’s] behaviour was difficult... wouldn’t do as they were told, getting out of bed, tidying up, getting in the bath that sort of thing. My wife could see that it went with when I was feeling low ... my wife was being very understanding about it but it was very tough for her I’m sure, trying to look after me and trying to keep the children in, in control” (Participant 7)

Parents also described how partners and other family member were fearful of the BD, even when their mood was stable, and they worried about the parent becoming ill again. Parents experience significant guilt in relation to the perceived impact that BD had on their family and this enhanced the difficulties they faced. Thus, a number of strategies were implemented to reduce guilt and worry, as will be discussed in Theme 3.

Theme 3: Managing guilt and limiting worry – strategies for coping

Like parents with other forms of SMI³²⁻³⁴ all of the parents experienced guilt and worry about the impact that BD had on their parenting and their family. This led parents to develop ways of minimizing guilt and limiting worry. Parents made attempts to refute the impact of BD, whilst also seeking to improve outcomes for their children. The extent to which parents engaged in these activities appeared to be contingent upon the degree of worry and guilt they experienced. However, it appeared that the strategies used also had the potential to enhance parenting difficulties and distress. Strategies have been illustrated in the subthemes below. They do not appear to have been identified previously in the literature.

Subtheme 3.1: Normalizing

Normalizing parenting experiences and difficulties appeared to be a protective strategy for many parents. Whilst most of the parents' experiences did appear to be 'normal' and this was helpful for parents who were anxious about their performance, there was the potential for some parents to minimize difficulties to the extent that this would reduce motivation to change.

"I had to write down when she had a feed, coz everything just wouldn't sink in and I ... when the midwife used to come I'd forget what times she'd had a feed and how much she'd had and then me mum went to bath her, I think she were 2 week old, and she'd lifted her chin up and I'd forgot to lift her chin up to clean... and it were all dried... er so I

think the first couple of months were just... I mean, I think everybody's same adjusting to a new baby but... at the baby clinic she were always a good weight, never any problems" (Participant 6)

As illustrated by the contradictions in this mother's account, parents' fear of being a 'bad' parent resulted in the normalization of difficulties and the justification of this perspective in an attempt to reduce the resultant distress that acknowledging this might cause.

Subtheme 3.2: Searching for evidence

In a similar way, all of the parents used their children's behaviour and other people's appraisals of their children as evidence of their parenting abilities and the impact that BD was having on their children. The absence of any difficulties and praise about their children was reassuring for parents.

"He's good fun, he's a good laugh, he's sociable, he's certainly not withdrawn or anything like that, there's nowt wrong with him" (Participant 8)

However, research has shown that children's reactions can be very difficult to judge. For example, children may be very distressed but may deal with the situation by becoming detached or adopting adult responsibilities⁴⁹. Thus, parents may be falsely led into believing that their children are unaffected by their symptoms. Few parents acknowledged this possibility.

"I'm surprised that she's such a well adjusted child. I let her be independent in the fact that she can use a microwave, make a cup of tea and she's doing very, very, well at school...no problems whatsoever...very polite ... she even picked the iron up to do something herself, I have never had to say, I think it's about time you tried a bit of ironing or this or that, she always wanted to. I know, I'm lucky, very lucky"

(Participant 6)

Where children were showing difficult behaviours, these were either attributed to alternative causes as discussed above, or serve to reduce confidence in parenting abilities and increase guilt and self-blame. Parental worry about their child developing BD meant that parents became particularly watchful of signs of BD in their children. Indeed, three of the parents believed that at least one of their children was displaying signs of BD. Although this was upsetting for parents, there appeared to be some solace in this knowledge. Emerging BD could serve to reduce guilt about parenting behaviours, when BD was perceived to be due to genetic factors that were out of parental control. Parents also indicated a 'special bond' with the child they perceived to have BD, due to a sense of shared understanding and experience. It is likely that these are additional ways in which parent seek to reduce dissonance in their views of themselves as parents.

Subtheme 3.3: Seeking to minimize impact

Parents also developed strategies in an attempt to minimize the impact that their BD had on their children. This was often dependent on other forms of support and contextual factors. For example, when mood deteriorated, some parents would try to keep going for as long as possible to continue to meet their children's needs, although this often led to further deterioration in symptoms.

"Even when I'm quite unwell I still try for as long as I can before it gets too bad, to keep going as normal and getting, you know made sure they're fed, you know, sometimes it's just doing the basic functioning, making sure they've clothes to wear, making sure they've food, you know, coz I do isolate myself in the house sometimes weeks on end and I don't move, so everything that goes on outside of the house, you know [name of husband] has to do all that" (Participant 4)

Other parents would avoid their children when they were unwell in order to minimize the impact that their symptoms had. Some parents chose not to inform their children of their diagnosis to avoid burden or worry, whilst others chose to share their diagnosis to prevent children from perceiving themselves as the cause of their parent's behaviour and facilitate their understanding. Many of the parents would also ensure that their children were engaged in lots of extra-curricular activities to minimise the effects of BD. Parental knowledge and beliefs about what would cause the most or least impact on their child were therefore important in guiding conscious decisions about their parenting behaviours.

Subtheme 3.4: Making amends

Parents also described a pressure, when well to make amends for not parenting the way they would like to at other times. Parents experienced a pressure to do more with the children, be a better parent and be more helpful as a partner. However, this could heighten inconsistency in parenting and thus impact on their children in other ways. This strategy also increases the likelihood of exhaustion for parents with BD.

"When I am feeling well, or if I'm feeling even a bit high, I can be quite creative in what I plan for them to do, like through the holidays you know...I try and do things with them that are a bit unusual for, from sort of other mums you know, it's nice sometimes, just the impulsive side of it... I mean I do try to be a bit over ambitious about things... if I try and cram a lot into a week and I've got all these activities planned and you know, people'll say to me, oh god you know I couldn't bother to do that...I suppose in a way that has its pros and cons coz it's alright as long as my mood stays the same the whole time, but if I suddenly drop coz I'm knackered then I can't always do everything that I planned and I feel disappointed with myself" (Participant 4)

Furthermore, some parents would almost develop a split in their identity as a parent as a result of this pressure to make amends. They would consider themselves to be a 'good' parent

when well, and an incapable parent when unwell, mostly when low in mood. However, this led to the BD being blamed for any lapses in parenting (e.g. irritability towards the children), and further reinforced beliefs about being unable control the BD and its effects on parenting.

Subtheme 3.5: Working hard to stay well

Awareness of the impact that BD had or could have on their child, or their parenting was a significant motivator for staying well. Some parents deeply feared the consequences of BD; some believed that they were unable to parent if their symptoms were out of control.

“Because that impulsivity would come out of the blue...that is to me my most dangerous trait and I accept it...with two children in the car I had collected a prescription, parked up, swallowed the lot, driven back to my mum’s seven miles away...So that is why I have to guard against ever being that ill again” (Participant 5)

In addition to medication, parents described how awareness and understanding of the ways in which BD affected them, monitoring mood and reducing triggers were essential in staying well.

“I think I’m generally more aware of my mood, on a daily basis because I know that I, I need to identify slight changes in my mood in order to perhaps prevent a major episode happening. And then look at what’s going on in my life and think, well I need to cut down on that, I planned to do that in 2 months but maybe I’ll cancel it...” (Participant 4)

Parents sometimes became rigid in their management of BD and established set routines for their family, negotiating roles with their partner and seeking to avoid stress. However, as children could be a source of stress, this could lead some parents to avoid their children at times too. Furthermore, the constant focus on monitoring mood could make it difficult for parents to differentiate between what were normal fluctuations in mood, normal parenting responses and what was due to the BD. Wilson & Crowe³⁶ found a similar finding in their study

of parents with BD, in which they described how the constant focus on self-surveillance maintained focus on problems and deficits. Indeed, many of the parents were dissatisfied with the way in which managing their mood impacted on their lives, and there was a sense across all of the parents that their lives should not have to be this way. The following extract illustrates how this can relate back to parents idealized views of how they would like to be as parents, as discussed in theme one.

“I am more rigid than I would like to be to manage the bipolar I have to be more rigid and less flexible than I wish I could be as a yummy mummy. I really do wish I could be a yummy mummy; it not only doesn't work for me it doesn't work for [name of eldest child] either” (Participant 5)

When parents were unable to keep themselves well, this could lead to significant distress and feelings of failure. For example, one parent reflected on a time when she had suffered an episode of mania due to poor psychiatric care following a general hospital admission for medical reasons:

“It was the most horrendous experience...coz I'd always, you know over the years, obviously you didn't at first, you know, but over the years I'd worked really really closely with all the services...and really good understanding of my illness, and to be let down so badly was, was awful...throughout that period[name of child] really didn't see me very much – it took so much time away from my relationship and my time, I kind of went through a hell of a lot to have [child], you know I came off everything [medication] and they took a lot of time away from my, my time with [child]” (Participant 1)

Theme 4:

Parenting highs and lows - the impact of parenting on personal well-being.

Parents described the positive and negative influence that being a parent had on their mood and well-being. Although the strain of parenting was clearly evident for the parents, they were keen to point out the positive impact that children had on their well-being.

Subtheme 4.1: Parenting as a positive influence on mood

Parents described how positive experiences with their children could lead to a sense of achievement and hope. Children also led to increased activity, socialisation and enjoyment for parents and could provide a good source of distraction from their own distress.

“When [name of child] came along, he sort of... he put a stop to me just sat, sitting there and analysing me” (Participant 8)

“...in one respect it keeps me going, coz I always say I don't think I'd be here if it weren't for [name of daughter]. Erm, in another, it is an extra worry and more work, but I think the positives outweigh the negatives” (Participant 6)

Being a parent could also motivate parents to manage their moods more effectively, as previously discussed, and a few parents described family life as a “natural moderator” of mood as it often prevented escalation into manic and hypo-manic episodes.

Subtheme 4.2: Parenting as an additional strain in a difficult life

Most parents perceived that parenting had an impact on their symptoms due to the additional strain that being a parent placed on them as individuals. This has also been shown for parents with other forms of SMI^{34, 50}. For many of the parents in this study, it was the sense of responsibility for their children's well-being and development, coupled with the constancy of parenting that they found overwhelming. Parents acknowledged the stress and demands

inherent in being a parent including a constant pressure to meet children's needs, manage their behaviour and manage the emotions related to being a parent. Parenting also resulted in greater physiological stress for the parents, such as increased noise, sleep disturbance and a greater need for energy.

However, parents were keen to point out other stressors that had a greater influence on their symptoms and increased the strain of parenting. Parents described pressurised jobs, difficulties in relationships and significant life events in this context, as well as other factors associated with parenting, such as financial difficulties, single parenthood and having a child with additional needs as increasing the strain of parenting. It was often the context of too many pressures that impacted on parents' symptoms rather than the children or parenting per se. Whilst this may have been a way in which parents minimised the challenges of parenting, many of the parents did have very complex lives.

"I can remember when he started nursery, just before he turned three that I was starting to lose functionality because I just couldn't cope with the hyperactivity and the prospect of a long, the first summer of him not being in nursery and being pregnant with [name of youngest child] And thinking I've, I've got no money, selling the house, I've got nothing done and I can't cope with the thought of him bouncing off the walls, made me start to shut up shop and I was getting more and more lethargic, less and less as he was getting more hyperactive I was actually taking a down turn" (Participant 5)

Theme 5: 'The domino effect' - the influence of contextual factors

In accordance with what is known about the impact of the wider social context on family practices^{51,52}, there were also a number of factors that could have either a mediating or exacerbating influence on the participant's experience of parenting with BD. The influence of stigma, support, and family dynamics are described below.

Subtheme 5.1: Stigma, societal expectations and social comparison – a sense of difference

Consistent with the findings of Wilson & Crowe, and the wider literature on parenting and mental illness⁵³⁻⁵⁵, the parents with BD in this study described how the stigma associated with mental illness impacted on the way that others perceived and responded to them as parents. There was a sense that some forms of mental illness were more acceptable than others, but that BD was less acceptable and led to negative judgements from other people. This often had a negative impact on parents' desire to discuss their illness or parenting experiences with others, including professional services. When others knew about their diagnosis, the majority of parents perceived that their emotions and behaviour were monitored by others, and their parenting abilities questioned.

“If you do phone your health visitor and you have concerns...they'll be looking at you, they'll be watching and you, you, and especially because not many people understand bipolar disorder and mental health, so you say you've got a mental health problem and people do automatically start questioning your abilities as a parent. Which isn't right. You know, so that, I suppose that's put me off asking for help” (Participant 8)

The parents were conscious of how they were perceived by others, often fearing negative judgement. For some, this increased self-surveillance and made them question their parenting ability to a greater extent; parents often made negative comparisons about themselves to other parents, including their partners. Parents also experienced pressure to conform to societal norms of parenting and to ultimately prove themselves as parents. Whilst at times this could be beneficial for their child, it sometimes prevented parents from doing what they believed was best for their own and their child's well being. Reflecting on her time spent in hospital, one mother said:

“To have them keep coming up and visiting every weekend was harder, but had I said that I didn’t want to see them that wouldn’t have been showing that I was recovering enough to take on my role as a parent, so I couldn’t do that” (Participant 5)

Pressure to meet the social expectations of others, comparison to other parents and feelings of failure are frequently experienced by parents without mental illness⁴⁸. However, this appeared heightened for parents with BD, as having BD increased their sense of difference from other parents. Parents’ experience of judgement and social comparison could have important effects on social relationships. Some tended to withdraw from social contact whilst others actively sought out support and reassurance.

Subtheme 5.2: Support

“We have the benefit of an extended family who have rallied round to some extent... we live in this house as an extended family... so she has always had the recourse to fall back on some support that way” (Participant 2)

All parents believed that the presence of support mediated the impact of BD on their children and helped them to manage more effectively. This is consistent with the experiences of parents with other forms of SMI. Parents often relied on the support of their partner or other family members to take responsibility for their children’s care at times when they were unable to parent. Where parents had little support, they tended to struggle more, and needed to manage their symptoms more rigidly in order to sustain parenthood. The transfer of responsibility to others could however create further difficulties. Some parents became over reliant on support, which served to undermine confidence in their own abilities as a parent, and their ability to manage their symptoms.

Parents also reported the benefits of social support from other parents to help normalize parenting difficulties. For the participants in this study, this was effective in helping to reduce guilt and concern with regards to their parenting and their child's well being.

"I had a couple of parenting classes when she were younger...and it's helped me to cope as a person, if you think, well you're confidence [is] not very good and the parenting groups, somebody else'll say, 'yeah I've felt that as well', you don't feel so bad" (Participant 6)

Subtheme 5.3: Family Dynamics

All parents described how BD had an impact on relationships with partners, and other family members due to increased tensions, worry and sometimes resentment. There was a sense that BD could either create distance or improve connection with family members. If another family member had a mental health difficulty, parental BD could be perceived as enhancing the relationship with this person as it enabled a shared understanding. However, for many, the differences highlighted by the symptoms of BD and the reliance on others for support placed a strain on relationships.

"I need him to take the initiative sometimes, because when I'm low, erm, what will happen is the boys will sit in and say play on the Wii all day, and I don't like that but because I'm low and I haven't got the energy and motivation to do anything different and because [husband's name] quite happy just to sit and read his book or whatever, he doesn't feel the need to do anything, so like there's me sort of just like bubbling with resentment, feeling depressed anyway" (Participant 3)

BD influenced family dynamics in other ways too. Parents could become associated with specific roles and parenting tasks within the family with distinct differences being noted between parents in dual parent families. This could maintain some of the difficulties parents experienced in their parenting role, and exacerbate family tensions.

“Because I find the functional tasks easier to deal with than the emotional tasks, and [name of husband] is actually quite happy-go-lucky and enjoys the emotional tasks, he will go off and do the enjoying and be with the boys which then actually makes it harder, so they associated daddy with fun and me with functional tasks and they then put the pressure on me because they then come for me, oh mummy I can’t do my homework or I can’t...all the stuff that I find, you know, more of an obligation and then I start to think, well hang on I’m, I’m having to do all the work here and they’re getting all the fun”

(Participant 3)

Parents also spoke about how BD could impact on communication within families, which could lead to further problems. Children and other family members would not talk to the parent about certain things for fear of upsetting the parent. Sometimes the parent’s communications were attributed to the BD and therefore ignored by others. This made negotiations around parenting and other family issues particularly hard. It served to undermine the parent, intensify difficulties in relationships and increased the parents’ frustration and distress.

Theme 6: Improvement over time – the importance of temporal factors.

Parents also described a number of factors that reflected changes in experience over time.

These are reflected in the sub-themes below. The nature of the parents’ experiences in relation to these themes was evident in parents’ different stages of recovery at the time of interview and also in parents’ own reflections on their experiences to date.

Subtheme 6.1: Learning to manage - a process of acceptance and adjustment

Throughout their discourse, parents reflected on periods of extreme suffering, where it felt too hard to manage their own distress and function as a parent.

“You know when I first had the breakdown, the first thing I wanted to do was escape, all I could think about was wanting to drive to [place] and just get away from everybody, erm...if [husband] hadn’t, I wanted to erm, give the children up, because they just, they-they were more stress than what I could cope with. [Husband] would never let that happen...” (Participant 3)

Beyond this, parents struggled to know how to manage the dual demands of being a parent whilst also living with BD, especially when their children’s needs conflicted with their own. Parents described feeling overwhelmed and hopeless about their ability to carry on in the future. Parents found that accepting their diagnosis and learning to manage their symptoms over time made their situation easier. Parents in this study who had gained a good level of control over their symptoms prior to having children did not find parenting as de-stabilizing as those who had to learn to manage their symptoms whilst also having children. Parents also described a process of adjusting to the demands of parenting and developing strategies that fitted with their experience of BD. This often required making adjustments to previous expectations of themselves, as individuals and as parents, to be able to attend to their own mental health needs, accept help, and negotiate a change in role or responsibility with others.

“By the time [wife] was pregnant with [youngest child] I had accepted that I was unwell and I was able to ask [wife’s] mum to come and stay with us for the last part of the pregnancy, and after he was born as well for a while, quite a few months altogether...so that was about accepting that I was unwell and not able to do everything that err, I wanted to do. I knew I was a good father when I was well but when I was unwell I wasn’t able to, yeah...” (Participant 7)

This finding is similar to a qualitative study exploring the lived experience of BD, in which hope for the future was only gained once individuals gained insight into the ability to feel well, and

manage their symptoms; to accept the illness and assume responsibility for managing it⁵⁶.

However, research has shown that acceptance of BD can be a lengthy process⁵⁶⁻⁵⁷.

Subtheme 6.1: Child Development - changes and challenges

Parents generally perceived that their child's stage of development had an impact on their ability to cope and manage. Most parents described periods of increased difficulty during their child's pre-school years but generally reported that the process became easier to manage as their children got older, particularly as they became more independent and as communication and mutual understanding increased.

However, the need to continually adapt to the changing needs of their children could also be a challenge. Some parents experienced anxiety about new situations and developmental tasks, such as toileting, or transition to secondary school, and life-cycle markers and transitions could also trigger reactions in parents. This fits with what is known with the family life-cycle model⁵⁸, however emotional responses may be heightened for parents with BD for a variety of biological and psychological reasons.

"He's starting school on Monday, and I'm terrified about it, you know, people saying to me, yeah but he's got to go to school and he's got to do this and you need to just chill out a little bit, but I'm, I'm devastated, I'm losing me little man 5 days a week"

(Participant 8)

"I remember turning up at his third birthday and thinking this is awful and this is not the way my little boy's birthday should be, and the following year thinking I'm still here, I am not going to have, I might be shaky, but this is going to be the start of the recovery because I'm not having yet another birthday ruined, and that was enough, of a thing to start pulling it back" (Participant 5)

Discussion

This is the first study to investigate the views and experiences of parents with BD to understand how parents perceive and make sense of their parenting experience, and the influence this may have on outcomes for parents and their families. The themes generated confirm and extend findings from previous studies exploring parenting with BD, offering insight into the lived experience of these parents.

Parents were aware of the ways in which the specific features of BD impacted on their parenting. BD was perceived as preventing parents from being the parent that they wanted to be. Parents often held idealised views about how they should and/or wanted to be as parents and their inability to be this parent often led to self-criticism, a lack of confidence and feelings of inadequacy. As BD was seen as the cause of the discrepancy between how they perceived they were and how they would like to be as parents, beliefs about the ability to control the symptoms of BD played an important part in parents' ability to make changes to their parenting behaviours. Parents were surrounded by feelings of guilt and worry. Parents did not always associate the impact of BD on their parenting to BD having an impact on their children. However, they often worried about the effects on their children. Thoughts about the impact on their children were accompanied by guilt, and for some it appeared more protective for them to sustain uncertainty around the effects that their BD had on their children. This fits with cognitive dissonance theory⁵⁹. Parents developed cognitive strategies to reduce dissonance, or discrepancy between idealised views and reality. When they were unable to reconcile such discrepancy, this would lead to destabilisation. This could be important in terms of engaging parents in support services or interventions.

Parents also developed a number of other ways in which they could manage guilt and limit worry, including normalizing parenting responses, searching for evidence to prove their parenting capacity, and expressing the positive attributes and influence of their children.

Parents also sought to improve outcomes for their children by making attempts to minimize the impact BD could have, making amends for any perceived failures and working hard to stay well. The extent to which these strategies were effective varied, as they could also heighten parents' analysis of their own behaviour, increase anxiety and guilt, and exacerbate parenting difficulties. In addition to the normal stresses of parenting, the guilt and pressure to make amends and manage symptoms increased the strain of parenting, which could have a significant impact on parental well-being. This fits with social information processing models which highlight the importance of parental cognitions such as attributions, expectancies and beliefs as factors which contribute to self-efficacy, decision making and behaviour⁶⁰. The way in which parents with BD managed guilt and worry in conjunction with bipolar symptoms may therefore be an area in which targeted interventions are helpful. Indeed, parents' experiences were not static and changed over time. In general the challenge of being a parent with BD reduced as parents learned to manage their symptoms and adjust to their situation, thus illustrating the potentially important influence that early interventions could have in supporting parents and improving family relationships. The age and development of children was also important. Whilst children presented new challenges at different stages, improved communication and understanding was often beneficial in parents' ability to manage the dual demands of parenting and BD. There were also a number of contextual factors that affected the experience of parents with BD. Parents' experience of stigma, societal expectations and social comparison had a further impact on parental confidence and feelings of inadequacy, whilst the way in which families responded to the parent with BD could exacerbate parental difficulties and distress. The experience of practical and social support from friends and family was particularly helpful for parents and often mediated the effects of BD. However, there was potential for parents to become over-reliant on support and this would serve to further undermine parental capabilities.

A significant number of the experiences described were those commonly experienced by parents without mental illness, and individuals with BD who were not parents. Thus they were not all unique to being a parent with BD. However, it is likely that these experiences may be compounded for parents with BD, especially feelings of inadequacy, guilt and worry, and the meaning of these experiences to parents appears to be important.

Strengths & Limitations

The interpretation of the results must be considered within the context of the limitations of the research. The main limitation concerns the characteristics of the sample. The sample size was necessarily small and self-selected. Although participants varied in social and demographic characteristics, all of the parents were White British and therefore do not present a representative sample. As the aim of the research was to develop preventative interventions, parents who had lost custody of their children were not included. However, this also limits generalizability of the findings. The results may also be biased by the context and self-selecting nature of the recruitment strategy. Given that parents were recruited from an organization for people with BD, parents may have been more likely to accept their diagnosis and look for ways of resolving difficulties through the use of support organizations. Those who chose to participate may have had more positive parenting experiences and been interested in reflecting on their parenting. The experience of shame and social desirability may have also made it difficult for parents to disclose certain aspects of their experience. However, a good level of rapport was developed during the interviews and participants often shared distressing experiences with the researcher. Finally, the process of qualitative analysis is inherently subjective and influenced by the investigator's interpretations of the accounts given. It is therefore acknowledged that some interpretations may be left uncovered. Nevertheless, the methodology employed was appropriate to the study aims and systematic and rigorous approaches were taken to data collection and analysis. The results offer valuable insights into the way in which parents with BD perceive their experiences and there are similarities

between the findings presented here and the findings of other research on parenting and BD, thus strengthening the findings. Conclusions may be tentatively accepted to offer a basis for further research that will increase understanding of the experience and perspectives of parents with BD and the ways in which this may influence outcomes for parents and their children.

Clinical Implications

If verified by future research, the results will have important implications for developing appropriate support services for parents with BD. Education and care delivery systems will need to be designed to allow consideration of the parents' experience and the additional challenges faced by parents with BD. There will be a need for early interventions to prevent the escalation of difficulties within families, specifically:

1. **Symptom management programmes that take into account the parenting and family context of parents with BD.** The findings suggest that helping parents to gain control of their symptoms is crucial in helping them manage their parenting responsibilities. However, symptom management programmes would need to take into account:
 - a) The additional barriers to engagement. Clinicians should be aware of how a parent's fear of being judged negatively in relation to their parenting, and parental attempts to manage guilt and limit worry may prevent them from offering insight and wanting to engage with services. Clinicians should also be mindful of how parental beliefs about BD and the ability to control symptoms may serve an additional function in relation to their parenting, specifically in terms of reducing feelings of blame and guilt.
 - b) The additional pressures of parenting, particularly in relation to the child's current stage of development, and the influence of contextual factors on family life.

- c) The possibility that parents may have more invested in recovery, and experience greater distress should relapse occur, due to feelings of guilt and worry in relation to the impact that their symptoms may have on their child and wider family.

Services may therefore need to adapt ways in which they work with parents.

2. Parenting programmes that take into account the additional challenges faced by parents who have BD. The findings also suggest that interventions designed to increase parenting confidence and maximise good parenting skills in the context of BD will help to improve outcomes. This should be facilitated through:

- a) The provision of accurate information about the reality of parenting which may help to reduce unrealistic expectations and guilt, and prevent the attribution of all undesirable parenting behaviours to BD.
- b) Naming the known pressures and common cycles that parents with BD are drawn into, and drawing attention to the effects that these patterns of behaviour have on the parent, child and wider family, in order to also increase parents' awareness and facilitate the development of preventive strategies.

3. Partnership working between child and adult services.

In order to achieve the above outcomes, it will be important for child and adult services to work in partnership to facilitate a mutual appreciation of the systemic impact of BD, parenting and family dynamics for both the parent and the child. This would need to be facilitated in terms of both generic education and training, but also through joint working on a case-by-case basis. Services will need to work with the needs of the whole family, as advocated by the literature on BD⁶² and UK public policy around parenting and mental health, specifically the 'Think Family' documentation published by the Social Exclusion Task Force^{63, 64}.

Implications for future research

This study has also highlighted a number of areas for further exploration:

- 1. In depth exploration of specific aspects of the parenting experience:** The present research presented a breadth of issues around parenting. Future research may benefit from exploring specific aspects of this experience in more detail. For example, a focus on the experience and perception of elevated mood would be beneficial given the remaining queries surrounding parents' perspectives on this aspect of their mood. Exploring relationships between parents may also be helpful in understanding processes that may influence outcomes for families.
- 2. Exploration of similarities and difference between sub-groups of parent with BD:** Further research is needed into the experience of parents with BD from other ethnic backgrounds and those who have adolescent children in order to facilitate understanding of any differences in the parenting experiences that may be important when intervening with different populations of parents with BD.
- 3. Enhance understanding through exploration of alternative family perspectives:** Researching the experience and perspectives of children, partners and other family members will be useful to understand the broader experience of families who have a parent with BD, to test out the accuracy of parental perspectives on family impact and to increase understanding of the processes that may influence the developmental trajectories of children and the mental well-being of parents and carers.

Conclusion

Parents with BD recognise a number of challenges in being a parent and experience feelings of inadequacy, guilt and worry about the impact their illness has on their children and family. Whilst this aspect of their experience was similar to other parents with SMI, strategies for managing these feelings and limiting the impact of BD, in combination with the fluctuating

mood characteristic of BD, could have negative consequences for parents and children. Learning to accept the diagnosis and developing strategies for managing symptoms were crucial for positive parenting, although the changing needs of their children often presented new challenges. The findings therefore have implications for the development of interventions and appropriate services to support parents and improve outcomes for their children. They indicate a role for early interventions to facilitate symptom management and positive parenting, and to improve family relationships.

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Navigating internal worlds and qualitative methodology: a critical reflection

Rebecca Murphy

The University of Manchester

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Address for correspondence:

Rebecca Murphy
Department of Clinical Psychology
School of Psychological Sciences
University of Manchester
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
rebecca.murphy@postgrad.manchester.ac.uk

Introduction

The aim of this paper is to provide a consideration of qualitative methodologies and a personal reflection on the qualitative process in relation to an empirical investigation exploring the lived experience of parents with Bipolar Disorder (BD). This is not intended to be an exhaustive list of the process and challenges of qualitative methodology, but an account of the critical debates around these approaches, the application of qualitative methodologies to a particular research question, and the challenges this presented for the researcher.

The report was written on completion of the investigation and reflects the process by which, as a novice to qualitative research, I was able to develop an understanding of the methodology and carry out an insightful piece of research. As this project was embarked upon as part of my training in clinical psychology, this is likely to be reflected throughout the account.

Why use qualitative methodologies?

Qualitative methodologies were devised to understand and represent the experiences and actions of people from their own perspective. In discussing the difference between quantitative and qualitative research, Elliot¹ argues that qualitative research lends itself to understanding participants' perspectives, to defining phenomena in terms of experienced meanings and observed variations, and to the development of theory from field work. It can therefore be particularly useful when there is little or no research in an area. In contrast, quantitative methods lend themselves to testing hypotheses about relationships or causal effects and measuring the degree of generalizability across samples.

For the purpose of the research undertaken, gaining the perspectives of parents with BD was particularly important. The impetus for the empirical research was driven by a recent move to develop preventative interventions for children at risk of developing BD and other psychiatric

disorders²⁻³, because they had a parent with BD. Research had begun to recognise the importance of psycho-social factors in the development of BD⁴ and in particular, differences in the home environment and parenting styles of parents with BD⁵⁻⁶. In the context of considering how parenting programmes that were already well established could be tailored towards the needs of parents and families with BD, there was a clear need to understand the experience of these parents, from their own perspective.

Consideration of the implications of this research led the researcher to reflect upon the experience of other parents with mental illness, as well as those without mental illness. Would the experience of parents with BD be different from other parents who were diagnosed with severe mental illness? And indeed, would it be possible to identify differences between the experiences that were common reflections of parenting in general and those that may be qualitatively different for parents with BD? An initial scan of the literature identified research describing the common challenges of parenting, and this included occasional qualitative descriptions⁷. However, there was less pertaining to the experience of parents with mental illness. Importantly, the qualitative studies that had been completed, whilst eliciting highly valuable information, were often lost in literature reviews, which focussed on the risk that parents with mental illness confer to their children and deficits in their parenting abilities. A review and meta-synthesis of qualitative studies exploring the experience and perspectives of parents with severe mental illness was therefore carried out alongside the empirical research, not only to place the results of the empirical research into context, but also to facilitate greater impact of the findings from qualitative studies to inform professionals and contribute to service development.

Critique of Qualitative Methodologies

Although the benefits of qualitative methodologies have been acknowledged and received an increase in popularity over the last 20 years⁸, qualitative methods have been and continue to

be subject to a number of criticisms. Mays and Pope⁹ identify three common criticisms of qualitative research. Firstly it has been argued that qualitative research tends to comprise anecdotal, personal accounts; the interpretation of which is subject to researcher bias. Secondly, qualitative research has been criticised for lacking reproducibility, since the interpretation of one researcher may be very different from another. Thirdly, qualitative research has been considered to lack generalizability, since it generates large amounts of detailed information about a narrowly defined topic or population. Some common difficulties arising in qualitative research have fuelled these criticisms. For example, not all qualitative researchers provide explicit descriptions of their methodology, or they claim to use a specific approach but fail to describe the methodology or interpret the data in a manner which is consistent with the approach¹⁰. This creates difficulty when evaluating the quality of the research. In addition, Carter & Little¹¹ cite frequent failures to adequately describe the epistemological assumptions that underpin the methodology.

Indeed, qualitative research is argued to be generalizable (or transferable; the preferred term for qualitative researchers) by a different logic to that of a quantitative approach. Yin¹² describes these as "analytic generalization" and "statistical generalization" respectively (pp 31-33). Analytic generalization is not generalization to a defined population that has been sampled, but to a theory of the phenomenon being studied; a theory that may have much wider applicability than the individual cases that are studied. There is a call for qualitative researchers to make this argument for the generalizability of their research¹³. Failing to do so can limit the value of qualitative research to "exploratory" studies that only prepare the way for more "rigorous" investigations¹³.

A number of guidelines have been produced to maintain the integrity of qualitative studies. However, the development of guidelines for qualitative methods created debate among researchers. Some believed that having explicit guidelines was at odds with the spirit of

qualitative research¹⁴. However, Elliott and colleagues¹⁵ among others have argued that there is a need for evaluative guidelines to increase reflection about the conduct and reporting of qualitative research, and to enable wider recognition and acceptance of the methodology. Furthermore, Elliott and colleagues¹⁵ propose that evaluative guidelines can facilitate 'more valid scientific reviews of qualitative research' (p217) given the propensity for some quantitative researchers to evaluate qualitative investigations using standards for quantitative research (for example, necessity of experimental controls), and potentially overlook criteria that are central to qualitative traditions (for example, owning one's own perspective). This is now well recognised within qualitative research and the valuable contribution of qualitative studies is better established¹⁶⁻¹⁷. Nevertheless, scepticism does remain and there continues to be a need to justify the value and reliability of qualitative research¹⁸.

Reliability and validity of qualitative data

Elliott and colleagues¹⁵ devised a set of evolving guidelines for the production of good quality research via a rigorous process in which all previous attempts to articulate standards for good quality research were collated. Feedback was sought from experts of diverse theoretical persuasions over a series of stages, whereby revisions were made on the basis of feedback and further opinion sought after each revision. These standards are widely recognized and were chosen specifically as an outline for conducting the empirical research.

The final guidelines include guidelines shared by both qualitative and quantitative approaches and guidelines especially pertinent to qualitative research. These are detailed in Table 1. The guidelines are meant to be tentative so as not to stifle the emergence of qualitative research. My ability to adhere to these standards will be reflected upon throughout the paper.

Table 1: Evolving guidelines for publication of qualitative research studies

Publishability guidelines especially pertinent to qualitative research	
Reproduced from Elliott et al (1999) ¹⁵	
1. Owing one's perspective	Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.
2. Situating the sample	Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.
3. Grounding in examples	Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.
4. Providing credibility checks	Researchers may use one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include a) checking the understandings with the original informants or others similar to them; b) using multiple qualitative analysts, an additional analytical auditor, or the original analyst for a 'verification step' of reviewing the data for discrepancies, overstatements or errors; c) comparing two or more varied qualitative perspectives; or d) where appropriate 'triangulation' with external factors (e.g. outcome or recover) or quantitative data.
5. Coherence	The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fit together to form a data-based story/narrative, 'map', framework or underlying structure for the phenomenon or domain.
6. Accomplishing general vs. Specific research tasks	Where a general understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a specific instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances.
7. Resonating with readers	The manuscript stimulates resonance in readers/reviewers, meaning that the material is presented in such a way that readers/reviewers, taking all other guidelines in to account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation of it.

Choice of qualitative methodology: Interpretative Phenomenological Analysis

Whilst there are a range of qualitative approaches, each have overlapping but different theoretical and/or methodological emphases, which can be confusing when first approached - not least because of the theoretical language that is often used. I expect that it is only through a process of engaging in each type of analysis that the differences will be truly understood. In the absence of this experience, supervision and active discussion with other researchers facilitated some degree of insight.

As the aim of my research was to capture the lived experience of parents with BD, it was particularly suited to a phenomenological approach, for which the central concern is to generate a rich description of lived experience¹⁹. Whilst there are a number of phenomenological approaches, Interpretative Phenomenological Analysis²⁰ (IPA) was chosen because, in addition to the phenomenological emphasis, it also involves an interpretative requirement to contextualise and 'make sense' of these claims and concerns from a psychological perspective²¹. IPA therefore identifies more strongly with hermeneutic traditions²² which recognise the central role played by the researcher in making sense of participants' personal experience. Smith²³ describes how for IPA, research involves a double hermeneutic: 'The participant is trying to make sense of their personal and social world, whilst the researcher is trying to make sense of the participant trying to make sense of their personal and social world' (p53).

Although other qualitative methods explore participants' lived experience, the way in which they do this differs. For example, some approaches would seek to place participants' experience within a socio-political context (e.g. narrative methodologies) whilst a Grounded Theory approach would seek to understand the theoretical processes that would explain why

for example, participants experienced parenting in a certain way. Furthermore, they would seek confirmation on the resultant theory through methods of triangulation and participant validation. Whilst IPA may contribute to theory this is more of a secondary aim²⁴. As the goal of the research was to provide a rich description of, rather than explanation for, participants' experience of parenting with BD, IPA was chosen as the most appropriate methodology.

Critique of IPA

IPA has become well established in qualitative psychology, particularly in the UK, and is being used with increasing frequency in published studies. However, there are a number of limitations to this method that are acknowledged. In particular, it is recognized that access to 'experience' is both partial and complex²⁰. Thus, the analytic process cannot ever achieve a genuinely first person account. The account is always constructed by both the participant and the researcher. It is reliant on the ability of the participant to be able to verbalise their experience²⁵ and it is also dependent on and complicated by the researcher's own experiences and meanings of the world²⁰. Neither of these limitations are unique to IPA, yet an important strength of IPA is the ability to engage with other forms of knowledge in interpreting insight offered by participants, including consideration of what may not be offered, for example due to shame or desire to convey responses in a way that is deemed socially desirable.

The actual degree of interpretation that is used in IPA studies has however come under scrutiny from experts in the field. Larkin and colleagues²¹ describe how 'like so many qualitative methods, IPA can be easy to badly and difficult to do well' (p103). They describe how many researchers employing IPA have tended to be over-cautious in their analyses, summarizing participants' concerns but not developing them further into an interpretative or conceptual level, thus undermining the potential for IPA to properly explore, understand and communicate the experiences and viewpoints offered by its participants.

I tried to remain mindful of these limitations and potential flaws throughout the research process; my attempts to manage the tensions are reflected upon throughout the next section.

Process of carrying out an IPA

Data collection

Semi-structured interviews are described as the exemplary method for IPA²³ as this allows the participant and researcher to engage in a conversation whereby questions can be modified and the interviewer is able to explore interesting and important areas as they arise. Smith²⁶ expresses caution about the use of focus groups, due to the commitment necessary in IPA to the detailed exploration of personal experience. Indeed, researchers who have used both interview and focus group data within the same study have noticed potential differences in the elicited data^{27, 28}.

In addition to the above, semi-structured interviews were deemed the most appropriate technique for the purpose of our particular research, due to the sensitive nature of the subject area being explored. On reflection, this was an extremely effective approach. I expect that it would have been very difficult for participants to have shared the same experiences in a focus group. Shame and guilt were important themes for the parents in the study, and comparison to other parents was raised as a particularly difficult aspect of their experience. I can also imagine that some of the participants would have struggled to have their voices heard in a focus group. Thus, the semi-structured interviews were believed to have provided greater insight into the parents' experience than other forms of data collection would.

Developing an interview schedule, developing interview skills

The interview schedule was developed following guidance by Smith & Osborn²³ and in conjunction with both the research team and service-user consultants. Whilst certain

qualitative methodologies advise that researchers should enter into qualitative projects relatively 'blind' to the subject literature, other approaches use the literature to guide the development of the schedule in order to develop understanding of experiences pertinent to a theoretical model. There is no reason why either approach is incompatible with IPA²⁹. However, given the recognition of the dynamic role of the researcher in IPA, the approach taken should be reflected upon throughout. For the purpose of my research, the literature was not specifically searched prior to developing the interview in order to minimise external influence on data collection and subsequent analysis. However, prior knowledge of parenting experiences and mental illness was unavoidable due to both the professional and personal experience of the lead researcher and the research team. Indeed, the schedule was particularly helpful in making explicit the assumptions I held about what I thought might be elicited. For example, the key questions in the interview schedule were around the impact that BD had on parenting, and the impact that parenting had on BD. This was a clear reflection of my knowledge and assumptions about the reciprocal relationship between parenting and mental health.

I was especially concerned about the way in which the questions asked would shape the answers elicited. However, recognizing that this would be unavoidable, I focussed on:

- a) Devising a schedule that would generate a broad discussion of parents' experience.

Thus, questions were open-ended and were revised to ensure that they were not loaded or leading in any way. At the beginning of the interview I asked parents to try and reflect upon both positive and negative experiences, as well as current and past experiences when answering the questions. And at the end of the schedule, I asked parents if there was anything that they believed was important that we had not covered throughout the interview. In line with the semi-structured approach, prompts were devised to encourage parents to develop and elaborate on their experiences.

- b) In line with guidance around the importance of owning one's perspective¹⁵ the background of the research team and the approach to data collection was made transparent in the reporting of the study and attempts were made to remain mindful of this influence throughout the analysis.

Nevertheless, it is acknowledged that the way in which the schedule was constructed would have influenced the data. For example, some of the themes elicited were related to the impact of child development on parents' experience and a process of adjustment over time. It is possible that this had only been elicited due to the way in which the interview was initially shaped to encourage reflection on parents' experience over time. Whilst this was clearly an important facet of the parents' experience, it is not known whether this would have been expressed if my initial request had not been stated. For me, this was a clear illustration of how an individual's given account of their experience is always constructed by both the participant and the researcher.

Two pilot interviews were carried out on parents who had shown an interest in participating in the study but did not meet the eligibility criteria: one a service-user consultant who had lost custody of their child many years previously, and one who had a daughter above the specified age-range. Both were keen to contribute to the project and provided informed consent to participate in the pilot stages of the interview. Both were aware that their data would not be included in the final study. As a lot of thought went into developing the schedule (e.g. sensitive wording and a structure that would gently ease parents into topics that could potentially be more emotive), few changes were required to the overall structure or wording of the questions as a result of feedback from the pilot interviewees .

The pilot interviews were however invaluable in facilitating the development of my interview skills. This was something that I had not been concerned about given my training in clinical

psychology and extensive experience in carrying out clinical interviews as part of my job.

However, this was precisely the problem. The role of the research interviewer and the role of the clinical interviewer are very different. My clinical experience led me into three important traps: 1) justifying my questions prior to asking them; 2) empathising with the interviewee; and 3) summarizing what the interviewee had said. Without realizing, each of these strategies had an important influence on the data elicited. For example, by justifying the questions prior to asking them, this increased the likelihood of demand characteristics as the participants were given greater insight into the prior assumptions of the research. Showing empathy influenced the way in which participants experienced and reported information, and hearing the information summarized back could help parents to make sense of their experience in a different way.

The role of the interviewer in generating the account is not always made clear in the literature but through discussion in supervision and in line with social constructivist thinking, it was agreed that my influence on the interview should be as minimal as possible. As a clinician whose overall aim is to facilitate a resolution of distress, this was a difficult adjustment to make. Whilst a non-judgemental stance could be presented through non-verbal strategies and parents could be made to feel at ease in similar ways, I particularly struggled with not overtly empathising with parents (*“that must have been a really difficult time”*), and with not normalizing struggles or identifying particular strengths in parents. I therefore developed a preamble to make this transparent to parents, thus facilitating their understanding and reducing my own internal pressure to decrease distress and facilitate psychological understanding:

“As this research is focussed on really capturing your experience, I want to try to do that with as little influence from me as possible. I will ask you a few broad questions, and at times I might follow these up with additional questions but in general I try not to

comment on your experience. This is not because I am not understanding or empathizing with your experience but more because I don't want my feedback to impact on what you were planning to say next, or the way in which you make sense of your experiences. I try to stay as quiet as possible and let you do all the talking!"

It was particularly helpful to have gained insight into these processes prior to the participant interviews and my awareness of and confidence in myself as a research interviewer was then able to grow and develop throughout the remaining interviews. This experience also increased my awareness of myself and the language I use as a clinician as well.

Interviews

The interviews themselves were particularly emotive experiences for both myself and the participants. I became impassioned by their experience and felt an intense pressure to do their narratives justice in the literature, and develop ways of supporting similar parents in the future. The interviews were also exhausting experiences. Parents were often fatigued afterwards and this was not anticipated. On days where I had booked two interviews in on the same day, I noticed that my technique was not at its best by the time of the second interview. I therefore avoided doing this again.

I used a reflective diary to record any information that appeared to be important, and whilst this felt rather strange at first, I was able to see the benefits of this during the analysis, particularly when I struggled to make sense of what parents were indicating. The reflective diary was particularly helpful in confirming my understanding of specific utterances or the parents' described behaviours.

Participants

The need for a homogenous and small sample in IPA means that it is often subject to more criticism as a qualitative method, for its relative lack of statistical generalizability. The detailed case-by-case analysis of transcripts takes a long time and the aim of IPA is to say something in detail about the perceptions and understanding of a particular group rather than prematurely making more general claims. IPA studies have been published with samples on one, to over fifteen participants. However, more recently there has been a trend for some IPA studies to be conducted with a very small number of participants³⁰ as it is recognized that the most detailed interpretative accounts can only be realistically done on very small sample. Thus, researchers in effect sacrifice breadth for depth. However, for the purpose of my particular study, we hoped to achieve a balance between breadth and depth and it was agreed that a sample size of between 8 and 12 participants would be satisfactory. However, following the recruitment of 8 participants, it was agreed that no further participants would be necessary due to the extensive and rich data that had been elicited during the interviews. On reflection, any further data is likely to have been too much for me to manage given the time constraints that I was operating under.

The homogeneity of the sample for the purpose of my research was based upon the shared experience of being a parent of child between the ages of 4 and 12, and also having BD. Thus both mothers and fathers were recruited. However, the participants also varied on a number of other factors, for example, length of time since diagnosis, and whether or not they were a parent prior to receiving their diagnosis. Thus, there may be important differences between the experiences of the parents pertaining to these different variables that were not captured during the analysis. However, as much as possible, I tried not to lose sight of the differences apparent in the group and tried to reflect these differences when discussing the themes in the empirical paper. Furthermore, the results of the study enable understanding of the shared experiences across the diversity of this group of parents, and whilst it is true that some facets

of experience unique to these specific groups may have been missed because of these differences, relating the findings back to the initial purpose of the study, it would be impossible to devise interventions for parents that solely met the needs of individual groups of parents with BD. Thus, it is argued that the sample was appropriate to the aims of the study, and whilst they may not be generalizable to all groups of parents with BD, the findings offered valuable insight that could be verified with by further research, and that may be cautiously generalised across similar contexts.

Data Analysis

Although Smith and colleagues offer practical and accessible guidelines to using IPA²³, what determines the quality of the outcome in IPA is the personal analytic work done at each stage of the analysis. This process presented a number of specific challenges for me which are reflected in the following questions: What do I code? What does this mean? How far should I interpret this? And when do I stop?

Smith and colleagues begin by encouraging researchers to note down what is interesting or significant about what participants said. However, it seemed to me that almost all of what the parents said was important. I was so immersed in the parents' data that I quickly became overwhelmed by the amount of information generated. It took a long time for me to code the initial transcript and the perfectionist in me sought the most fitting understanding and ultimately the most fitting way of coding the parents' utterances. I was ultimately aware of the potential for my own state of mind to influence what was seen as important and had concerns about how I could analyse each of the transcripts fairly without only seeing what was of interest, and what I was most aware of on that particular day. Whilst the use of a reflective diary was helpful in verifying understanding generated throughout both the data collection and analysis stage, it was only on progressing through the entire process that I became reassured by the iterative and cyclical nature of the process. As transcripts are analysed

repeatedly in light of insights obtained – either in other transcripts or during generation of higher order themes - the analyst's previous omissions or lack of insight during 'off' days can be mediated.

However, the very nature of this process led me into my final dilemmas relating to the extent of my interpretations and knowing when it is appropriate to stop the analytical process.

Whilst I felt I had met the first aim of IPA, which is to try to understand the participants' world and describe 'what it is like', I found the second more interpretative aspect of IPA more difficult. Larkin and colleagues²¹ describe this as a 'more overtly interpretative analysis, which positions the initial 'description' in relation to a wider social, cultural and perhaps even theoretical context' (p104). This second-order account aims to provide a critical and conceptual commentary upon the participants' personal 'sense-making' activities²³. Although I was able to do this at the level of individual participants, it was initially difficult to detach sufficiently from the idiographic analysis to identify shared aspects of experience. Once these were identified, it then became even more difficult not to lose the initial areas of divergence, and to prevent themes from becoming over-generalised.

Although in theory the analytical process could continue *ad infinitum*, in reality the researcher has to decide when the analysis is sufficiently complete to stop. In their guidance, Elliott and colleagues¹⁵ state that qualitative research should strive to achieve 'understanding represented in a way that achieves coherence and integration, while preserving nuances' (pp222-223). Given the constraints of time placed on the analysis due to submission deadlines, it was agreed that the analytic process could cease once this goal was achieved. However it is acknowledged that there was the potential to further the analysis to a higher level if time had allowed.

The issue of process

An important dilemma that I was faced with during the analysis was what to do with the processes that became apparent throughout data collection and analysis. Parents frequently talked about patterns or cycles that they experienced and I had made a number of notes in my reflective diary about various processes that occurred due to the nature of the parents' BD and their interactions with their children. Formulation is an integral part of my profession and I was again concerned that it was the clinical psychologist in me impacting on the data. Whilst this is likely to have been true to some extent, on reviewing the data, these processes were clearly detailed in the participants' accounts. Thus, process was an important part of parents' lived experience and parents had been able to make sense of this to some degree: the processes identified were not solely the result of my interpretation. Whilst it is more typical of a Grounded Theory approach to explore theoretical processes, through discussion and supervision, it was decided that the development of process is not necessarily at odds with the theoretical underpinnings of IPA. As discussed, many participants described this as part of their experience and this was interpreted further using psychological knowledge and through convergence and divergence of themes across participants. It was believed that it would be important to illustrate the participants' experience to the best of my ability, rather than to be constrained to the norms of a particular methodology. Indeed, Smith and colleagues encourage analysts to make use of their own 'interpretative resources'³¹(p223) and to adapt and develop the guidelines given, rather than stagnate the development of the approach²⁶. Thus, relationships and interactions between themes were discussed and illustrated in a diagrammatical format.

Although a Grounded Theory approach would have been better suited to establishing theory as it uses theoretical sampling to develop and elucidate the analytical categories, and places greater focus on attending to the variability and context of phenomena³², IPA was nevertheless able to manage this well. IPA provided rich descriptions of the parents'

experience as well as potential explanations for interactions and process. However, it would be interesting to explore how a Grounded Theory approach to the experience of parenting with BD would compare to the findings elicited by my IPA.

Evaluating the analysis

As a qualitative research method, IPA is inevitably subjective and no two analysts with the same data are likely to come up with an exact replication of the others' analysis. Although this is something that is recognised and welcomed by advocates of the approach, for others it may raise questions of reliability and validity, as previously discussed. The subjective nature of the analysis was also particularly difficult for myself, as a novice qualitative researcher, as I frequently sought to verify that what I was doing and the way I was interpreting the data was 'correct'. Somewhere along this journey I read a brief article by Jonathon Smith who advised analysts to remember the role of the 'I' in IPA – not only in terms of the interpretative element of IPA, but also in terms of the individual analyst, 'I', 'Me'. I had to remember that this was my interpretation of my in depth knowledge of the participants' accounts. I tried to be mindful of this throughout the remainder of the evaluative process.

The aim of the validity checks within the context of IPA then is not to prescribe the 'singular true account' but to ensure the credibility of the final account. Credibility checks were therefore carried out through discussions with the research team, to ensure clarity in the decisions I had made and the procedures that I had gone through; to verify my interpretation, and to ensure that these were grounded in the parents' accounts. This process continued throughout the writing of the report where verbatim extracts were provided to allow the reader to make his or her own assessment of the interpretations made.

Writing the report

The writing of the report presented the final challenge. As a team, we were passionate about sharing the parents' perspectives with as broad an audience as possible. As a profession, we were also passionate about sharing a psychological understanding with as broad an audience as possible. Whilst the majority of qualitative studies that had explored parenting and mental illness had been published in nursing and social work journals, we were keen for the medical profession to also gain insight into the experiences and challenges faced by this particular group. The high impact factor of the British Medical Journal (BMJ) and the open access and availability of articles published online were particularly appealing. It was also noted that the BMJ had begun to publish more qualitative articles and thus, not only was this an opportunity to promote a psychological interpretation of parents' experience, it was also an opportunity to further promote the utility of qualitative research.

However, despite the opportunities, this also presented a number of challenges. The preference for concise and precise information, and the language used in medical journals can be very different from that which is usually used in psychological writing, and is also at odds with the underpinnings of qualitative methodology to some extent. My writing style therefore had to be adapted accordingly, whilst theoretical and methodological underpinnings of IPA had to be presented in such a way that would ensure confidence in the approach but did not alienate a reader who was perhaps more comfortable with qualitative methodologies. This was no easy feat, and one for which only feedback will tell how successful I have been in achieving.

Reflective summary

The title of this paper reflects how I would summarise my experience of trying to understand and make sense of the participants' internal worlds, and also the 'internal world' of qualitative methodology. It has been a constant process of having to decide what to do and which way to go; where to take certain lines of enquiry and when to acknowledge that I have come to a

dead end! My experience has been characterised by a lot of uncertainty and it has definitely been more challenging than I had anticipated. It is only now, having experienced the entire process that I have been able to achieve clarity, and consolidate my initial theoretical learning about IPA. It is hoped that this will free me up to improve my interpretative potential in the future. I have found IPA to be an incredibly powerful approach, with the potential to provide important insights into the lived experience of others. I particularly enjoyed the flexibility of this approach, and I believe it has enhanced my training in clinical psychology by emphasising a greater need for self-awareness and acknowledgement of what I bring to interactions with others. I have been able to adapt my clinical skills in response to what I have learned. Indeed, it would seem that in exploring the internal world of others, I have also gained greater awareness of my own internal world.

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Appendices

Appendix 1:
Submission Guidelines for the British Medical Journal

Submission Guidelines for the British Medical Journal

The following information has been taken from the BMJ Website as there is no single document detailing guidelines for submission. Please note additional information is available across various pages of the BMJ website:

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, a structured discussion, and a succinct introduction that focuses - in approximately three paragraphs - on the background to the research question.

This [video slideshow presentation](#) gives more detailed advice on writing each section of a BMJ research paper.

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.

If the standard headings do not suit the type of study, substitute something sensible such as "population" as a heading instead of "participants" in an economics article. Please do not simply delete the heading.

Abstracts for meta-analyses and systematic reviews should have these headings but should also include all the items required (as recommended in the [PRISMA](#) statement):

- **objective** – what the review set out to determine
- **design** – type of meta-analysis, systematic review and study appraisal and synthesis methods
- **data sources** - where included studies were retrieved from
- **eligibility criteria for selecting studies** - inclusion and exclusion criteria (specifying participants and interventions, as appropriate)
- **results** - main findings with 95% confidence intervals
- **conclusions** - primary conclusions and their implications
- **systematic review registration** - registry and number (if registered)

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

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

Structured discussion

Please ensure that the discussion section of your article comprises, on average five paragraphs and follows this overall structure, although you do not need to signpost these elements with subheadings:

- statement of principal findings
- strengths and weaknesses of the study
- strengths and weaknesses in relation to other studies, discussing important differences in results
- meaning of the study: possible explanations and implications for clinicians and policymakers
- unanswered questions and future research

References

- Authors must verify references against the original documents before submitting the article.
- References should be numbered in the order in which they appear in the text. At the end of the article the full list of references should follow the Vancouver style (www.nlm.nih.gov/bsd/uniform_requirements.html).
- Please give the names and initials of all authors (unless there are more than six, when only the first six should be given followed by et al).
- The authors' names are followed by the title of the article; the title of the journal abbreviated according to the style of Index Medicus; the year of publication; the volume number; and the first and last page numbers.
- References to books should give the names of any editors, place of publication, editor, and year.
- For material published online, give the authors, title, name of website, date of publication as given on the web page, and URL.
- Please add the URL if material (such as official reports) is available online as well as in print.
- Information from manuscripts not yet in press or not yet published online, papers reported at meetings, or personal communications should be cited only in the text, not as a formal reference.
- Authors should get permission from the source to cite personal communications.

Tables

- Tables should be simple and should fit on one page, and they should not duplicate information in the text of the paper.

Appendix 2:

Literature Review:

Quality Appraisal Summary of Included Studies

Quality rating summary of the studies included in the meta-synthesis

CASP Criteria	Studies													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Is there a clear statement of aims?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Appropriate research design	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
4. Sampling	✓	✓	✓	Minor Flaws	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5. Data collection	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓
6. Reflexivity	X	X	X	X	X	X	✓	Minor Flaws	X	Minor Flaws	X	✓	X	Minor Flaws
7. Ethical Issues	✓	X	✓	✓	X	✓	✓	✓	X	✓	X	✓	✓	✓
8. Data Analysis	X	X	Minor Flaws	X	X	✓	✓	✓	Minor Flaws	✓	Minor Flaws	✓	✓	✓
9. Findings	✓	✓	✓	✓	Minor Flaws	✓	✓	✓	✓	✓	✓	✓	X	✓
10. Value of the research	Minor Flaws	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Minor Flaws	✓
Quality Rating	C	C	B	C+	C	B+	A	A	C	A	B	A	B-	A

Table Key: ✓ Indicates that the study fulfils this aspect of the quality criteria;

x Indicates that the study is flawed in this aspect of the quality criteria;

'Minor Flaws' indicates the presence of some minor flaws in this aspect of the quality criteria.

Appendix 3:

Empirical Research:

Participant Information Sheet & Consent Form

SCHOOL OF PSYCHOLOGICAL SCIENCES

Participant Information Sheet

Parenting and Bipolar Disorder**Introduction**

Parenting can be a rewarding but potentially stressful role. Being a parent can have a considerable impact on a person's mental health. For parents who experience significant mental health difficulties such as Bipolar Disorder, the stress of being a parent can be greater as they are faced with the dual demands of managing their symptoms, as well as meeting the needs of their children. Research has shown that there can be negative outcomes for both the parent with Bipolar Disorder and their children. So far, the parent's perspective on being a parent with Bipolar Disorder has tended to be missed in research.

This study will explore the views and experiences of parents who have Bipolar Disorder, to build up a picture of the parents' actual experiences - both the positive and negative - to be able to contribute to the research literature and inform the development of appropriate support and interventions for families who may wish to access this in the future.

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

- 1) An initial meeting will be arranged for the researcher to meet with you to answer any questions you may have about the research and to arrange a time and place for the interview to take place.
 - ❖ At this meeting, you will be asked to provide the details of your G.P. It is a requirement for researchers to hold these details to ensure the safety of everyone involved in the research. We will only contact your G.P should you disclose information that could suggest potential harm to yourself or others, and we will always discuss this with you prior to contacting your G.P. Your G.P will not be contacted for any other reason, nor will he or she be informed of your involvement in the research.

- 2) On the day of the interview:
 - ❖ The researcher will phone you on the morning of the interview to confirm your availability.
 - ❖ The interview should last approximately one hour.
 - ❖ The interview will be tape recorded.
 - ❖ Following the interview, you will be asked to complete 3 brief and standardized questionnaires about your child's strengths and difficulties, your perspectives on parenting and your current mood. Socio-demographic information will also be gathered as well as information about your diagnosis and management of Bipolar Disorder. The information given on the questionnaires will be used to provide a background for your views and experiences.
 - ❖ Please aim to allow up to 2 hours for the interview and questionnaires to be completed.

Will my current mood influence whether I can take part?

Because we know that the way we feel can affect the way we view our experiences, it is better for the interviews to take place during a period of mood stability, rather than

during a manic or depressed episode. This is so that a balanced view of your experience of being a parent can be presented. We will therefore ask about your mood when we phone you on the day of the interview and check whether you think it is a good day to carry out the interview. If you wish to go ahead with the interview then the interview will go ahead as planned. If you think it will be best to rearrange the interview then this will be arranged.

Will my data be anonymous?

Yes, all information collected from the interview and the questionnaires will be anonymous. All personal information will be removed so that others cannot identify you from the data. All information you provide us with will be kept securely and in keeping with the Data Protection Act. Any data that we show to other people in the field will be anonymous.

No researchers outside of the immediate team will have access to your personal information. The only time such information would have to be shared would be if you indicated that you have or might hurt yourself, your child or someone else. In that case, the interviewer would have to pass that information onto the relevant authorities. We will always discuss this with you prior to contacting any of the authorities.

Do I have to take part?

You do not have to take part in the study. If you decide to take part and then later change your mind, either before you start the study or during it, you can withdraw without giving your reasons, and if you wish your data will be destroyed.

Where can I obtain further information if I need it?

If you have any questions about this research, please contact either:

Researcher:

Rebecca Murphy rebecca.murphy@postgrad.manchester.ac.uk

Research supervisors:

Dr Rachel Calam rachel.calam@manchester.ac.uk

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

If you are concerned or upset by any of the issues raised in this study, please contact one of the research supervisors on the above email addresses.

Thank you for taking the time to read this information sheet.

**This project has been approved by the
School of Psychological Sciences Research Ethics Committee**

Parenting and Bipolar Disorder

Consent form

Please answer the following questions: (Delete **and initial** as necessary)

1. Have you read the Participant Information Sheet?	YES / NO Initials:.....
2. Have you received enough information about the study?	YES / NO Initials:.....
3. Do you consent to being audio taped as detailed in the Participant Information Sheet?	YES / NO Initials:.....
4. Do you understand that you do not need to take part in the study and if you do enter you are free to withdraw:- * at any time * without having to give a reason for withdrawing * and without detriment to you?	YES / NO Initials:.....
5. Are you aware that you do not have to answer a question that is asked of you if you do not wish to do so?	YES / NO Initials:.....
6. Are you aware that the researcher may have to share the information you disclose if there is a potential risk to yourself, your child or another person?	YES / NO Initials:.....
7. Do you agree to take part in this study?	YES / NO Initials:.....

Name of participant:**Signed:****Date:**.....

Name of researcher:**Signed:****Date:**

This project has been approved by the

School of Psychological Sciences Research Ethics Committee

Parenting and Bipolar Disorder

G.P Contact Details

Please complete the following contact details for you current G.P:

G.P Name:.....

G.P Address:.....

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

G.P Telephone Number:.....

Name of participant: **Signed:** **Date:**

Name of researcher: **Signed:** **Date:**

Appendix 4:
Empirical Research:
Interview Schedule

Parenting and Bipolar Disorder: Interview Schedule

Initial Brief:

There are no right or wrong answers, and you do not have to answer every question if you do not feel comfortable to do so.

All illnesses tend to create new challenges in people's lives, but they can also have a positive impact; so throughout the interview when I'm asking about impact, I would be really interested in hearing about both sides of the story so if you tell me about the positives I'll ask about negatives and vice versa. I'm not here to make any judgements or to present a particular point of view through the research. The purpose of this research is simply to present the reality of your experience of being a parent with Bipolar Disorder.

It will be really good if you can talk not only about your current situation, but also about how things have been in the past, and where appropriate what you anticipate for the future. I will ask further questions if it seems important to do so, to make sure we are able to capture the complete account of your views and experience. Throughout the interview we will be looking at how having Bipolar has affected you and your family, and also how being a parent has affected your Bipolar. So to start...

Could you tell me briefly about how Bipolar Disorder affects you?

The impact BD has on the family:

Who in your family is aware that you have Bipolar Disorder?

How do you think you having Bipolar Disorder affects your family?

Prompts:

If needed: How do you think the times when you have been depressed/manic (depending on the information given above) have affected your family? Does the way you manage

The impact your bipolar affect your family in any way? How did you diagnosis affect your family

Do you think having Bipolar Disorder has impacted on your role as a parent?

Could you tell me more about that?

Prompts:

If needed: How do you think the times when you have been depressed/manic (depending on information given above) have affected your parenting? What about when your mood is stable? Does the way you manage your bipolar affect the way you parent?

The impact being a parent has on BD.

Have you found that being a parent can affect your Bipolar Disorder?

Could you tell me more about that?

Prompts:

If needed: Have the demands of being a parent ever impacted upon your Bipolar symptoms? Do you think your role as a parent has ever triggered an episode for you? Have there been any positive influences?

General Prompts:

For all questions, the following prompts will be used as appropriate:

- How?
- Can you give me an example?
- Why?
- Are there any other positive/negative experiences you can think of?

- Has this always been the case? / Does that still have an impact now?

To end the interview:

- Is there anything else that you'd like to add to what you've said during the interview?
- Are there any issues you thought we should have talked about today but haven't?
- What do you think is the most important message that I get across from what we've discussed today?
- Have you any questions for me?

Appendix 5:

Empirical Research:

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

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

Name:	1.	2.	3.	4.	5.
Gender:					
Age:					
Ethnicity:					
Your relationship to this child:	Mother	Mother	Mother	Mother	Mother
	Father	Father	Father	Father	Father
	Step-mother	Step-mother	Step-mother	Step-mother	Step-mother
	Step-Father	Step-Father	Step-Father	Step-Father	Step-Father
	Foster Mother	Foster Mother	Foster Mother	Foster Mother	Foster Mother
	Foster Father	Foster Father	Foster Father	Foster Father	Foster Father
	Other:	Other:	Other:	Other:	Other:
	_____	_____	_____	_____	_____

6. Do you currently live with your child(ren)? Yes No

If not, how often on average do you see your child(ren)?

.....

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

Name	Age	Gender	Relationship to child
1.			
2.			
3.			
4.			
5.			
6.			

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**

- | | |
|---|---|
| <u>Over the past 6 months:</u> | <u>Prior to the last 6 month:</u> |
| <input type="checkbox"/> Not at all supported | <input type="checkbox"/> Not at all supported |
| <input type="checkbox"/> Slightly supported | <input type="checkbox"/> Slightly supported |
| <input type="checkbox"/> Moderately supported | <input type="checkbox"/> Moderately supported |
| <input type="checkbox"/> Very Supported | <input type="checkbox"/> Very Supported |
| <input type="checkbox"/> Extremely Supported | <input type="checkbox"/> 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**

	You	Partner	If yes, please specify:
Psychologist			
Psychiatrist			
Counsellor			
Social Worker			
Other professional			

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**

	You	Partner	If yes, please specify:
Psychologist			
Psychiatrist			
Counsellor			
Social Worker			
Other professional			

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 6:

Empirical Research:

Interview Transcript - Coding Sample

Parenting & Bipolar Disorder: Interview Transcript

Participant No: 5

Date of Interview:

Length of Recording: 01:22:10

Comments	Transcript	Themes
<p>Interplay of many other factors, not just BD/parenting</p> <p>Financial difficulties</p> <p>Pressures associated with age of child</p> <p>What is BD, what is due to other cause? Is PND seen as more “normal”?</p> <p>Periods of difficulty – sounds more than just difficult</p> <p>Difficulties in relationships</p> <p>Child behaviour problems</p> <p>Child with additional needs</p> <p>Knock on effects?</p> <p>Distressing life events</p> <p>Difficulties financially Distressing life events</p> <p>Having to keep going, tried to keep going, feels very hard to manage</p> <p>“shut up shop” Too many stressors =inability to function - ?understandable</p>	<p>P: And I started to struggle financially, you know relationship wise, everything as well as having a four moth year old baby that was now moving and weaning and not just sleeping and eating, it was brilliant! Erm no one could isolate between which was the depressive elements of bipolar or postnatal</p> <p>INT: Right</p> <p>P: So that, that was difficult and the same thing happened with [name of youngest child]. When erm just in the last few months of the pregnancy with [name of youngest child], his father decided he could no longer sustain the relationship with us because [name of eldest child] was going through a difficult patch of child development stuff which as probably the onset of the ADHD stuff erm my first part, well the partner I had been with when [name of eldest child] was born who was probably but has never been established committed suicide.</p> <p>Int: Oh</p> <p>I was in the process of having my house re-possessed, I had managed to that keep going to court appearances throughout the pregnancy and I did just completely shut up shop, I managed to get as far as the house sale and the exchange of contracts and [male name], but I was already getting to the none functioning point, I was just</p>	<p>Importance of contextual factors</p> <p>Child’s stage of development</p> <p>Uncertainty re: symptoms</p> <p>Importance of contextual factors – complex life: child, relationship, life events</p> <p>Motivation to keep going vs. impact of depression --BD undermines ability to keep going?</p>

<p>Continued to meet child's basic needs despite difficulty</p> <p>Exhaustion Minimum functioning Unable to care/make decisions</p> <p>BD is dangerous. BD causes me to do things - ?that wouldn't normally do/like to do Impulsivity</p> <p>Sense of exhaustion – too many things to manage Overdoses</p> <p>Experience of hospitalisation Others fear her taking an overdose – impact of others perceptions?</p> <p>Conflict – BD leads me to overdose, but also some control, or insight – knowing when things will happen??</p> <p>Importance of family Influence of family Family perceptions – how does this make her feel?</p>	<p>about feeding the baby, I was just about doing things. How I, how I even know how we moved from [place name] to a house he had found us in [place name] down here because I was no longer in a position, I just you know just find us a house I don't care what, if you're going to stick around for that long just do that, get the move done but I got into that house in [place name] and shut up shop completely</p> <p>INT: Mmm</p> <p>P: and it was a terribly terribly dangerous time... because the depressive element of my bipolar leads me to impulsivity.</p> <p>INT: right</p> <p>P: so leave me alone with a handful of tablets especially the ones that are going to knock me out and let me sleep, which is what I want to do in the depressive stage and its instant overdose time, which then lead to when I was hospitalised and them refusing to give me the right anti-depressants medication in case the impulsivity caused me to overdose.</p> <p>INT: yeah ok</p> <p>P: even though I wasn't going to do that with those, two to three hospital err emergency admissions and then we moved back down to [place name] because the family put their foot down and said we can't have this happen we need to know where you are, here's a house you</p>	<p>Ensuring basic needs are met, responsibility to children</p> <p>Impact of depression Loss of ability to function with depression</p> <p>Beliefs about BD: Dangerous</p> <p>Impact of depression: impulsivity</p> <p>Impact of depression: exhaustion</p> <p>Family influences: Protective?</p>
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<p>Long periods of time in hospital Chose to go – why, best for her or for her children?</p> <p>Frustration with services for not helping – again is this for herself or her children</p> <p>Allowed to return home to children despite not being better</p> <p>Sense that she shouldn't have got the children back Children lead to anxiety/panic – fear of causing harm or nature of the children? Unhelpful coping mechanisms – likely to heighten difficulties? In parenting and in symptom management</p> <p>Experience of almost losing custody – Emphasising just how close she came – admitting how bad things were Why is primary school significant?</p>	<p>need to be here now. Erm and I grumbled along until I voluntarily asked to be admitted thinking it would be a couple of weeks, but 15 weeks later</p> <p>INT: a long time</p> <p>P: they discharged me but I was in no better state because I hadn't been put on any medication.</p> <p>INT: right</p> <p>P: well not the right medication, it's its effects of it, its venlafaxine that takes the anxiety symptoms away for me in conjunction with the mood stabiliser so on the discharging the [date] I went straight back into a home environment in exactly the same state</p> <p>INT: right</p> <p>P: Got the children back, major panics you know, major anxiety and I was self medicating with alcohol</p> <p>INT: yeah</p> <p>P: to calm the anxiety symptoms</p> <p>INT: yeah</p> <p>P: and I came very very close to losing the kids just as [name of eldest child] was about to go into primary school</p> <p>INT: so he was about 4 at that time?</p>	<p>Hospital admissions</p> <p>Impact of children on symptoms? Unhelpful coping mechanisms</p> <p>Potential to lose children</p> <p>Child's developmental stage: Life-stage transition</p>
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<p>Illustrates how grateful she is for recovery – was important for her to get well.</p> <p>Importance of relapse prevention plan Dedication to recovery process Sharing with others - despite earlier sense of not wanting to share – Are her children the reason for this discrepancy? – Hard to bear others judgement but motivation to be well for children is more important maybe?</p> <p>Dedicated to staying well V focussed on this, why? Fear of becoming ill again? Fear of consequences for children</p> <p>Sense of achievement - reinforcing</p> <p>Perceived others negative response was due to stigma of mental illness</p>	<p>INT: mmm</p> <p>P: Lenquits, anyway very valuable book we drew up a relapse prevention plan for both the hyper manic and the depressive episode highlighting all the triggers, possible outcome plus a list of contacts and you know a friend networks for emergencies</p> <p>INT: wow</p> <p>P: and that's now gone with me every where we've moved</p> <p>INT: sounds brilliant</p> <p>P: it has been the best thing I ever did, because loosing the house meant I lost my permanent roots I was dependant on rentals until the money ran out. We fell foul of rented neighbour who decided they didn't like my lifestyle as a musician made complaints to, its its so common, so common with people with mental health issues</p>	<p>Motivated to recover</p> <p>Importance of staying well</p> <p>Importance of staying well: very focused on this</p> <p>Importance of staying well: Sense of achievement</p> <p>Impact of (perceived) stigma</p>
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