

**‘Between a rock and a hard place’: family members’ experiences of supporting
a relative with bipolar disorder**

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Abstract

Purpose: Clinical guidelines emphasise the central role of family members in supporting people with bipolar disorder. However, there has been little focus on the challenges family members face in supporting their relative. This qualitative study explored the challenges of providing support to a relative with bipolar disorder, and how family members attempted to meet these challenges. Factors that helped or hindered their efforts were also explored, including experiences of professional support.

Methods: Semi-structured interviews were conducted with 18 family members (partners, parents, adult children, and siblings). Transcripts were analysed using the Framework approach.

Results: Participants faced numerous challenges pertaining to the nature of the disorder and specific illness phases, their relative's responses to their attempts to help, and the limitations of support from healthcare professionals. Although participants were resourceful in managing these challenges, they strongly valued professional input. Six themes were identified: 'Not knowing: like being in a minefield', 'It's out of my control: sitting waiting for the next thing to happen', 'Treading on eggshells', 'Picking up on signs', 'Times of crisis: between a rock and a hard place', and 'I have to make my voice heard'.

Conclusions: Family members supporting a relative with bipolar disorder face significant challenges, but show considerable resourcefulness in managing them. The findings underline the importance of input from healthcare professionals to help family members effectively support their relative and manage the challenges they face. Professional support should be strengths-based, and tailored to family members' needs.

Keywords bipolar disorder; qualitative; carers; family members

Introduction

Family members² frequently play a central role in supporting people with bipolar disorder, and social support is associated with a range of positive outcomes, such as reduced relapse [3, 4]. However, supporting a relative with a severe mental health problem can place significant emotional and practical demands on family members [5, 6]. NICE guidelines for bipolar disorder recommend family participation in service-users' care, and provision for family members' own support needs [7]. Despite this, little is known about the experience of providing support to a relative with bipolar disorder, and the challenges this may pose.

Bipolar disorder is characterised by episodes of mania, hypomania or mixed episodes and, for the majority, depression [8, 9]. It is recurrent for most; the risk of relapse within four years is 68% [10]. It is associated with high levels of distress, with as few as 33% making a full recovery of social and occupational functioning [11, 12].

Quantitative studies of caregiving in bipolar disorder have focused predominantly on caregiver burden and the impact of 'expressed emotion' on patient outcomes. Most caregivers experience moderate to high levels of burden, which is associated with increased physical and mental health difficulties [13–15]. High burden and expressed emotion are associated with poorer patient outcomes [6], although these associations may be moderated by factors such as caregiver appraisals and coping style. Interventions such as family-focused therapy and psychoeducation are based on these constructs, and aim to modify appraisals, enhance coping and communication skills, and reduce expressed emotion [16, 17].

Quantitative studies have been criticised because their outcomes are pre-defined, and may not capture important aspects of family members' experiences [18]. Qualitative research has been valuable in understanding the experiences of family members of people

² The term 'carer' is often used to describe those who provide informal support. However, carers are predominantly family members [1], and the term can be perceived negatively by people with mental health problems and their families [2]. The term 'family member' will therefore be used where possible, and the person with bipolar disorder referred to as their 'relative'. Family members include parents, partners, adult children and siblings.

with severe mental health problems [18, 19]. A small body of studies has focused exclusively on experiences of bipolar disorder. These have primarily explored the emotional impact of providing support, with family members describing feelings of anger, loss, stress and isolation [20-23]. The majority have not investigated experiences of healthcare services in depth, but have predominantly reported a lack of adequate support [21, 23]. Although family involvement in service-users' care can have substantial benefits, barriers to this include confidentiality, service culture, and professional workload [24, 25].

While these studies elucidate important aspects of the impact of providing support, they say less about the challenges family members face when attempting to help their relative, and how they endeavour to manage these challenges. Evidence from outside the bipolar literature indicates that providing support can involve significant challenges. Illness has been conceptualised as a stressor on both parties with their needs often conflicting, giving rise to various 'dilemmas of helping' [26]. The supporter's concern may lead them to behave in ways which impinge on the support recipient's autonomy. Their intentions may not correspond to the impact of their actions, with attempts to offer advice or support change being experienced as intrusive or critical [27, 28]. Studies of depression have revealed similar difficulties, with family members' attempts to help being at odds with their relative's wishes [29, 30].

Features of bipolar disorder may pose distinctive challenges for family members. Risk taking, aggression, and high risk of suicide are extremely difficult for family members to manage [31, 32]. During manic episodes, a lack of insight may make it difficult for family members to intervene, and rapid changes in mood may leave them containing risk [24, 32, 33]. Attempts to support their relative to manage their mood may be experienced as controlling [34]. However, few studies have explored these issues from family members' perspectives, meaning that clinical guidelines are based predominantly on studies of psychosis [12].

Study aims

Despite the central role of family members in providing support, and the clear links between family members' behaviour and patient outcome, little is known about how family members experience the challenges of supporting a relative with bipolar disorder. This study used a qualitative approach to explore the following question: What challenges do family members face in supporting a relative with bipolar disorder, and how do they attempt to manage them? Factors that help or hinder family members' efforts to manage the challenges associated with supporting their relative were explored, including experiences of professional support.

Method

Participants

Participants were recruited through voluntary sector mental health and carers' organisations, the university website, and word of mouth. Eligibility criteria were: (1) close family member of a person with a diagnosis of bipolar disorder (parents, adult children, partners, spouses, and siblings), (2) aged 18 years or older, (3) the family member perceived themselves as providing substantial support, and (4) not experiencing a current crisis in their circumstances. Initially a consecutive sampling approach was employed, but as recruitment progressed efforts were made to recruit greater numbers of men and people from minority ethnic backgrounds. Recruitment ceased when the data-set was sufficiently rich to capture commonalities and diversity in family members' experiences. Thirty-one family members expressed an interest in participating. Eighteen participated; seven declined, five were excluded in order to recruit a more diverse sample, and one did not meet inclusion criteria. Characteristics of participants and their relatives are summarised in Table 1.

Procedure

An interview schedule was developed for the study, drawing on published guidelines [35]. The content was informed by the specific research question, the literature on informal helping [26] and family members' experiences of bipolar disorder and other mental health problems [23, 29], as well as by the researchers' clinical knowledge. It was piloted with three

participants, and refined after discussion of transcripts. The schedule covered: (1) background information about the relative with bipolar disorder, (2) how the participant attempted to support their relative and the associated challenges, (3) the impact of supporting their relative on the participant, (4) how they managed difficulties associated with supporting their relative, and (5) experiences of support from healthcare professionals. Semi-structured interviews were conducted by the first author at the participant's home, the university, or voluntary organisations. The mean length of interviews was 1 hour and 40 minutes (range: 60 to 194 minutes). Interviews were recorded and transcribed verbatim, with identifying information removed.

Analysis

The analysis was approached from a phenomenological perspective, aiming to understand participants' subjective experience. Transcripts were analysed according to the Framework approach [36], using NVivo software. Framework is recommended for healthcare research as it is a systematic, data driven form of thematic analysis, which also allows the incorporation of *a priori* questions [37].

The analysis involved several iterative stages: (1) data familiarisation through transcription, reading transcripts, and making initial annotations; (2) developing codes capturing key ideas; (3) organising codes into a framework, comprised of preliminary thematic categories; (4) applying the framework to transcripts; (5) compiling charts summarising data extracts for each category; (6) synthesising codes (collated or divided as required) into a final thematic map; (7) compiling charts recording the quotations indexed for each theme, facilitating further checking against the data.

Quality checks

In line with good practice guidelines [38, 39], 'credibility checks' were carried out. Coding of selected transcripts was reviewed by the co-authors, and different interpretations discussed. Different ways of organising the coding index and thematic map were considered. Participants were invited to comment on the accuracy and completeness of a summary of their interview. Eleven gave feedback; ten said the summary was accurate, and one

suggested minor amendments.

Researcher perspective

All authors had clinical and academic backgrounds in psychology. The first author had personal experience of supporting a person with bipolar disorder, and professional experience of supporting family members. As a result, she had some preconceptions about family members' experiences, for example that it would be particularly difficult to provide support during manic episodes. In line with good practice guidelines she attempted to 'bracket' her assumptions [40], and used a research journal and discussion with co-authors to reflect on how her assumptions might influence data collection and analysis.

Results

Participants experienced a variety of challenges in supporting their relative, relating to the nature of bipolar disorder, their relative's responses to their attempts to help, and the limitations of professional support. The analysis yielded six themes:

1. Not knowing: "like being in a minefield"
2. It's out of my control: "Sitting waiting for the next thing to happen"
3. "Treading on eggshells"
4. "Picking up on signs"
5. Times of crisis: "between a rock and a hard place"
6. "I have to make my voice heard"

1. Not knowing: "like being in a minefield"

Participants experienced shock, fear and uncertainty when their relative initially became unwell. They struggled to comprehend the changes in their relative and to know how to help.

We would feel like, what's happening to her, why is she behaving like this? And we couldn't sort of deal with it because we didn't really understand. (P18, father)

For some, this sense of uncertainty was exacerbated by a lack of explanation from healthcare professionals. Participant 10 described '*not knowing what questions to ask*', and professionals being unforthcoming with information.

No, they never made a point of approaching us... they never explained anything... Again just not knowing... and nobody telling us what to expect. It was like being in a minefield. (P10, mother)

Although a minority felt that doing their own research gave them a sufficient understanding of the disorder, the majority felt that this was only gained through contact with professionals involved in their relative's care, or obtaining their own support. Gaining practical strategies and information, for example how best to communicate with their relative when they were unwell, reduced participants' sense of fear and uncertainty.

You do think, "Am I making it worse by not contradicting him, or is contradicting him making it worse?" So it was helpful to have those guidelines. (P2, sister)

It helps us, because if [professionals hadn't spoken to us], we would've been completely in the dark... You have the chance to start understanding and start seeing a way forward in terms of treatment. And you begin to understand that, well, there is life after this. (P11, father)

2. It's out of my control: "Sitting waiting for the next thing to happen"

A sense of instability and unpredictability pervaded participants' accounts, due to the cyclical nature of the disorder and the severity of their relative's changes in mood and behaviour. They described a constant sense of uncertainty and tension as they would not know when their relative might relapse, and felt they lacked control over this.

On the one hand I'm pleased that she's not in that awful negative state, but then I have the other worries of her overdoing something... So I'm just sort of sitting, waiting for the next thing to happen. (P7, mother)

Some highlighted the unpredictability of their relative's behaviour during manic episodes, likening mania to '*the human equivalent of a rollercoaster ride*' (P17, daughter). Participants had a heightened sense of worry, as their relative was more likely to engage in risky behaviour outside the home, leaving them unable to intervene. Others emphasised the difficulty of coping with the possibility their relative might attempt suicide and being unable to guarantee their safety.

It's like having your heart in your mouth all the time... you can't watch her twenty-four hours, but at the same time you just thank God in the morning when you see she's still breathing. (P18, father)

Participants struggled to make a difference to their relative's mood when they were unwell, and this could make them feel '*despondent*' (P7) or '*useless*' (P6). During manic episodes it was often difficult to communicate; Participant 10 described her daughter's mind being so active that it was hard for her to '*hold onto*' anything she said. During depressive episodes participants' attempts to help their relative see things differently often had little impact. They felt that it was often helpful to encourage their relative to be more active, although it could be difficult to persuade them.

There's nothing you can do to cheer him, because his mind doesn't work that way.
(P8, wife)

Every single time we went, out after a couple of hours he said, "Ah, I'm so glad we made it."...to get him out though was really hard. (P14)

Given the difficulties in helping, some described '*just being there*' (P3), and providing practical support or being available to listen. Although the episodic nature of the disorder was difficult to cope with, the flip side of this was that participants had the knowledge their relative would recover. This helped some manage the uncertainty of their relative being unwell.

I always tell myself, "Look, I know she's going to come out of this and she'll feel better"...so I kind of look forward to that and I just feel like, we will get through this.
(P18, father)

3. "Treading on eggshells"

Participants had a sense of '*treading on eggshells*' (P11) when trying to help their relative. Their attempts to help could inadvertently exacerbate their relative's mood, and they worried about saying the '*wrong thing*' (P18). Several described their relative reacting angrily or irritably when they made suggestions about how they might manage their difficulties. In some cases, participants felt their relative's opposition to their suggestions was because they did not fully accept they had a problem. Participants also struggled to address the impact their relative's behaviour had on themselves, in case this exacerbated low mood or provoked anger.

When I have suggested doing something like him speaking to a doctor or him maybe taking something...the worst thing that will happen is that he'll get really angry. (P1, sister)

There are things that we can't talk about, in case it gets too sensitive or she loses her temper... And it's like treading on eggshells really, because I don't want the relationship to break down. (P11, father)

As a result of these challenges, some attempted to address difficulties in ways that might be better received. Support from carers' or mental health organisations had helped some to adapt their communication style. They described '*picking their moments*' (P1), for example waiting until their relative was calm, choosing their words carefully, and attempting to be '*more subtle*' (P7) about how they made suggestions. However, others felt that expressing their emotions more openly sometimes led to a change in their relative's behaviour.

I've used those strategies...rather than saying "I really think you should take a sleeping pill", saying, "You could consider". Offering it as something he might choose to do. (P1, sister)

Many times I couldn't stop crying. I didn't protect him in showing my feelings...And then because I was really low we somehow will reverse position...he was looking after me in a way, which made him feel good. (P14, wife)

4. "Picking up on signs"

Participants had diverse experiences in terms of how far they were able to effectively communicate with their relative when they showed warning signs of becoming unwell. Some were able to discuss this openly, and take steps to prevent things escalating, for example supporting their relative to access support or adapt their lifestyle. They described needing to pick up on warning signs early, as if their relative had become too unwell they might be resistant to receiving help, particularly during manic episodes.

And it was about monitoring, so picking up on signs when he was slightly going into mania... And I think if I could catch him early enough he's fine. If I didn't catch him early enough he would be really resistant. (P9, daughter)

Two participants in particular felt they were able to work with their relative to prevent episodes or reduce their severity. Participant 8 felt it had taken her and her husband a

number of years to be able to communicate effectively, and that having professional support had helped them to do this.

The biggest thing is us being able to communicate...To actually listen and talk to each other...So now, because he believes me and I believe him, if we both feel that something's not right it's straight through to the GP...Before that stage we'll both look at his lifestyle. (P8, wife)

By contrast, others struggled to communicate openly, and felt that raising the possibility of relapse could make their relative feel criticised, or that their autonomy was being intruded upon.

Nobody wants to feel that they're always under a glass bowl or being watched...but then it's difficult because obviously at times you have to overstep a boundary and say, "I think, it's really not ok", and they're going, "I'm fine"... I think it makes her feel vulnerable, or castigated or criticised in some way. (P17, daughter)

5. Times of crisis: "between a rock and a hard place"

Participants found it extremely challenging to support their relative during periods of crisis, particularly during manic episodes. As well as engaging in risky behaviour, some could become aggressive, but did not perceive themselves as being unwell. Suggesting they needed treatment or attempting to keep them safe could lead to conflict or, for a minority, violence. Participants faced the dilemma of whether to risk the situation escalating, or act without their relative's knowledge, which could damage their relationship.

You're basically between a rock and a hard place. If you call the police they might do something that might help, but your brother will hate you and be really angry. And if you don't you might find your brother dead in the morning. (P1, sister)

Decisions about whether to have their relative hospitalised were made harder by participants' awareness that this could be unhelpful, and previous painful experiences of witnessing them becoming highly distressed when they had been compulsorily admitted.

I think that never leaves you, whether it's the wrong or right thing to do... whether it's going to be beneficial, or if it's going to make things worse. (P5, wife)

Although some had had positive experiences of crisis services, others lacked support and felt they were left deciding whether the situation was serious enough to call the police. Participants expressed a desire for better communication with healthcare professionals, and

a shared crisis plan. The minority who had a shared agreement felt this reduced uncertainty, and could prevent crises escalating.

The hardest thing is about the lack of interaction with professionals... We should all have some kind of ongoing thing so that when there's a crisis, we can all leap into action. (P2, sister)

6. "I have to make my voice heard"

Participants' experiences were diverse in terms of how far they were able to work with healthcare professionals to manage the difficulties. Some found services unreliable or unresponsive, leading to a sense that *'all the caring comes down to me'* (P10). Around half felt that professionals did not encourage their involvement or could be dismissive of their concerns. This could lead to difficulties, for example their relative becoming increasingly unwell or not receiving appropriate treatment. Participants felt that important barriers to their involvement were their relative's opposition to this, and rules around confidentiality being used inflexibly.

They still just want to see him, and they ask him all the questions... I have to make my voice heard, otherwise we're not taken into consideration. (P4, wife and mother)

Some were able to work together with professionals, and felt that services' openness to their involvement had improved over time. Participants played a particularly important role when their relative was less able to communicate, and found it reassuring to discuss their concerns. They valued the involvement of professionals who knew their relative well, and understood the difficulties they faced in supporting them.

I had to go to the meetings because when he was depressed he was hardly talking. So I was in a way an interpreter... I was looking forward to each of them really... Cos you want to hear what the doctor said. (P14, wife)

Discussion

Family members experienced a variety of challenges in supporting their relative, pertaining to the nature of bipolar disorder, their relative's responses to their attempts to help, and the limitations of professional support. They showed considerable resourcefulness in managing the challenges they faced, but valued support when it was available.

Participants reported a strong sense of instability, and a lack of control over their relative's changes in mood. Previous studies of bipolar disorder and other mental health problems have highlighted fear of relapse [29, 41, 42]. However, this study explored in more detail specific experiences of mania and depression. Family members experienced increased anxiety during manic episodes due to the unpredictability of their relative's behaviour, and during depressive episodes due to the risk of suicide. They struggled to influence their relative's mood in both phases. It was difficult to communicate during mania, and to help their relative see things differently during depression, although encouraging them to be more active was felt to be helpful. This is consistent with the finding that helplessness and hopelessness are the most common type of burden experienced by caregivers [31], and suggests that family members may benefit from interventions which empower them to support their relative within different illness phases.

The accounts highlight the importance of family members' capacity to work with their relative to manage the difficulties. Participants stressed the importance of together picking up on warning signs of relapse, particularly manic episodes. However, in line with previous studies of bipolar disorder, family members reported that their efforts to prevent relapse could sometimes be experienced as critical or intrusive [25, 34]. They also described their relative responding angrily or irritably to suggestions about illness management, leading to a sense of 'walking on eggshells'. This is consistent with previous studies of bipolar disorder, which highlight the challenge of coping with irritability and aggression [43], and has similarities with family members' fear of 'getting it wrong' when supporting a relative with depression [29]. However, participants also appeared to encounter these difficulties when their relative was higher in mood and between episodes.

These challenges can be conceptualised as 'dilemmas of helping' [26]: family members' distress and desire to prevent relapse may lead them to seek a level of involvement which conflicts with their relative's desire for autonomy. There is some overlap here with the concept of expressed emotion. However, Coyne et al.'s [26] conceptualisation highlights the extent to which illness acts as a stressor on both parties, with their needs

sometimes conflicting. From this perspective, participants' resourcefulness in managing these challenges was striking, for example adapting their communication style in order to increase their relative's receptivity to their input. Some cited support from healthcare professionals as an important factor in enhancing their ability to communicate. Conveying concern in ways which will be positively received involves considerable skill, and family members may require help to develop this. Interestingly, some felt that expressing their feelings openly had a positive impact on their relative's behaviour. There is some evidence to suggest that the construct of emotional over-involvement in the context of bipolar disorder is multi-dimensional, comprising both appropriate and inappropriate emotional distress [44]. It may be that a certain level of emotional disclosure is adaptive, and can help motivate behaviour change [26, 44].

Family members' experiences of being excluded or over-looked by services are well-documented, both in bipolar disorder and other mental health problems [22, 45], although the need for support early in illness onset has been under-emphasised in studies of bipolar disorder. Although many described the shock associated with their relative's first manic episode, some struggled to comprehend the changes in their relative when they initially became depressed. Studies of severe mental health problems in the UK have also highlighted issues around confidentiality and crisis planning, suggesting these are particularly pertinent to the British healthcare system [18, 24]. Participants' accounts in the current study also highlight the significant challenges mania may pose, in that sufferers may not perceive themselves as unwell, leaving family members caught between their relative's wishes, and fears for their safety.

Limitations

Transferability of findings may be limited by the sample size, and several characteristics of the sample. People from minority ethnic backgrounds and men were under-represented (although this may reflect the tendency for women to play a greater support role). These groups may have differing norms and expectations for providing support, and thus encounter different challenges. The majority of relatives had a diagnosis of

type one bipolar disorder, and so issues pertinent to other bipolar disorders may have been missed. Participants were largely recruited through voluntary sector organisations, and may have differed from those who do not access this support, for example in being motivated to improve coping, or experiencing greater difficulties. Furthermore, only family members who perceived themselves as providing a substantial degree of support were recruited; this may have contributed to the lower number of children and siblings taking part, and thus limits the transferability of the findings.

Clinical and research implications

This study builds on existing literature in highlighting the extent to which family members value support for themselves but feel this is often lacking [18, 22, 45]. Family members may value both informal support from healthcare professionals involved in their relative's care, and from mental health and carers' organisations. The importance of family members' role should also be recognised, and where possible they should be involved as collaborators in their relative's care. As this is in line with clinical guidelines [7], increased training or resources may be needed. This study also highlighted the importance of family members receiving information about their relative's condition early on. In line with previous studies of severe mental illness [18, 24], crisis periods were found to be particularly challenging, and families should therefore be involved where possible in crisis planning. Crisis planning may need to address how family members could respond when their relative does not perceive themselves as in need of help, particularly during manic episodes.

Communication is often the most problematic area of difficulty for family members [6], and interventions such as psychoeducation and family-focused therapy may be useful in addressing this. However, interventions could be targeted to address specific challenges faced in bipolar disorder, including communication around relapse prevention, how to make suggestions or express concern effectively, and how to provide support within different illness phases. Interventions should be strengths-based, building on the resourcefulness family members show in supporting their relative [46].

Future research could explore the experiences of siblings and adult children, as well as of men and people from minority ethnic backgrounds, all of whom are under-represented in the current study and in the broader literature. Triangulating the experiences of family members, service-users and professionals and using observational designs could enhance understanding of the challenges of helping, and clarify which behaviours and communication styles are experienced as helpful or unhelpful. Future research could also investigate what defines adaptive emotional disclosure, and how this may help motivate behavioural change.

Ethical standards

All persons gave informed consent prior to their inclusion in the study. The study was approved by the university ethics committee, and therefore has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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Table 1

Demographic and clinical characteristics of participants and relatives

Participants	
Gender	<i>Female</i> n=14 (78%) <i>Male</i> n=4 (22%)
Ethnicity	<i>White British</i> n=8 (44%) <i>Other White background</i> n=4 (22%) <i>Asian/Asian British</i> n=4 (22%) <i>Mixed background</i> n=2 (11%)
Relationship to relative with bipolar disorder	<i>Parent</i> n=6 (33%) <i>Spouse/partner</i> n=5 (28%) <i>Child</i> n=3 (17%) <i>Sibling</i> n=3 (17%) <i>Spouse and parent</i> n=1 (5%)
Age	M= 48 (range: 31 to 67)
Relatives (as reported by participants)	
Gender	<i>Female</i> n=8 (42%) <i>Male</i> n=11 (58%)
Age	M= 43 (range: 20 to 79)
Diagnosis	<i>Type I bipolar disorder</i> n=10 (53%) <i>Type II bipolar disorder</i> n=2 (11%) <i>Type I with rapid cycling</i> n=2 (11%) <i>Participant unsure of diagnosis</i> n=5 (26%)
