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

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Supporting a relative with bipolar disorder poses significant challenges for family members. Clinical guidelines emphasise the importance of addressing family members' needs. This thesis explores family members' experiences, and how they can be most effectively supported.

Part I is a systematic review and meta-analysis of psychological interventions for caregivers of people with bipolar disorder. Nine studies comparing psychoeducational interventions to a control group met inclusion criteria. The review provides tentative evidence for the efficacy of psychoeducation in improving caregiver burden and knowledge. However, included studies were diverse and had methodological limitations, making it difficult to draw firm conclusions.

Part 2 is a qualitative study of the challenges of supporting a relative with bipolar disorder, and the personal impact of providing support. Semi-structured interviews were carried out with 18 family members; transcripts were analysed using the Framework approach. Family members faced challenges pertaining to the nature of the disorder, their relative's responses to their attempts to help, and the limitations of professional support. Providing support had wide-ranging emotional and relational consequences, both positive and negative. The findings suggest the need for an individualised approach to supporting family members.

Part 3 is a critical reflection on the research process. It addresses methodological and conceptual issues which arose when carrying out the empirical study. It also reflects on how the findings of the empirical study could inform thinking about the strengths and limitations of the research designs, interventions, and outcome variables evaluated within the literature review.

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Part 1: Literature Review

Psychological interventions for caregivers of people with bipolar disorder: a systematic review and meta-analysis

Abstract

Aims: Clinical guidelines currently recommend psychological interventions be offered to caregivers of people with bipolar disorder. However, there is little clarity about the efficacy of such interventions. This review aimed to examine the efficacy of psychological interventions in improving caregiver-focused outcomes, including burden, psychological symptoms and knowledge.

Method: A systematic search for controlled trials was conducted using a combination of electronic database searches and handsearches. Risk of bias was assessed using the Cochrane Collaboration tool and outcomes were meta-analysed using Review Manager (RevMan).

Results: Nine studies met inclusion criteria. There was considerable diversity in terms of study methodology and risk of bias. All meta-analyses compared psychoeducation to a control. At post-treatment there was a large effect of psychoeducation on burden (g = -0.8, 95% CI: -1.32, -0.27). However, there was high heterogeneity, confidence intervals were wide, and the effect was not maintained at follow-up. The apparent effect of psychoeducation on psychological symptoms was driven by a single outlying study. There was a very large effect on knowledge at post-treatment (g = 2.60, 95% CI: 1.39, 3.82) and follow-up (g =2.41, 95% CI: 0.85, 3.98). It was not possible to meta-analyse other outcomes.

Conclusions: This review provides tentative meta-analytic evidence for the efficacy of psychoeducation in improving caregiver burden at post-treatment, and knowledge at post-treatment and follow-up. Services could consider offering psychoeducation to caregivers of people with bipolar disorder as part of a multi-disciplinary package of care. However, given the diversity and methodological limitations of the included studies, it is difficult to draw firm conclusions. More methodologically rigorous research is needed before clinical recommendations can be made with confidence.

Introduction

Caregivers[1] of people with mental health difficulties can experience high levels of burden and significant psychological distress (Caqueo-Urízar et al., 2014; Steele, Maruyama & Galynker, 2010; van der Voort, Goossens & van der Bijl, 2007). Although caregiving can bring some benefits, many have difficulties managing the demands associated with it (Ohaeri, 2002; van der Voort et al., 2007). Over six million people in the UK currently provide unpaid care, and around 13% of these care for someone with a mental health problem (Buckner & Yeandle, 2015; NHS Information Centre, 2010). While government policy and clinical guidelines emphasise improving the experience of caregivers, there is a lack of clarity about the most effective ways to provide psychological support (Department of Health, 2014; National Institute for Health and Care Excellence [NICE], 2014; National Collaborating Centre for Mental Health [NCCMH], 2014a).

Bipolar disorder is a severe, cyclical mood disorder defined by episodes of mania or hypomania and, for the majority, episodes of depression (American Psychiatric Association [APA], 2013; World Health Organisation [WHO], 1992). There is some heterogeneity in diagnostic criteria, with bipolar disorder increasingly being conceptualised as a spectrum of mood disturbance (Angst, 2007). However, the distinction between Type I (characterised by mania) and Type II (characterised by hypomania) is often made (APA, 2013). Symptoms and difficulties associated with bipolar disorder such as unpredictable changes in mood, high risk of suicide, risk-taking and irritability can place substantial demands on caregivers (Bauer et al., 2011; Beentjes, Goossens & Poslawsky, 2012; Chessick et al., 2007; Perlick et al., 1999; Reinares et al., 2006). Many people with bipolar disorder also experience

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[1] The term caregiver can be controversial, as often caregivers are family members, and may be preferred to be referred to as such (Henderson, 2001). However, as the literature on interventions often uses the term caregiver, for the sake of succinctness it will be used to mean both caregiver and family members in this review.

sub-syndromal symptoms and functional impairment between episodes (NCCMH, 2014a). It can be a significant challenge for caregivers to distinguish between symptoms and ‘difficult’ or deliberate behaviour, which can have a very negative impact on family relationships (NCCMH, 2014a).

Much of the literature on caregiving focuses on caregiver burden. This is a multidimensional concept, and there is considerable diversity in definition and operationalisation (Vella & Pai, 2012). Some definitions and measures are based on a concept of global burden, defined as the emotional, social and financial stresses that caregiving imposes on the caregiver (Hoenig & Hamilton, 1967). Others distinguish between objective burden, which comprises the symptoms and behaviour of the patient and their consequences such as disruption of social, financial and occupational functioning; and subjective burden which refers to the psychological consequences of caregiving, such as distress and burnout (Cuijpers & Stam, 2000; Schene, 1990). The majority of caregivers of people with bipolar disorder report at least a moderate level of burden, with around 90% reporting high subjective burden in relation to their relative’s symptoms (Perlick et al., 1999, 2007a). Caregiving is also associated with increased risk of mental health problems, with up to 46% experiencing anxiety and depression and up to 32% reporting mental health service use (Steele et al., 2010). Burden and psychological symptoms are associated, with highly burdened caregivers reporting higher levels of depressive symptoms (Perlick et al., 2008).

Caregiving in bipolar disorder has been conceptualised within a ‘stress-appraisal-coping’ model (Chakrabarti & Gill, 2002; van der Voort et al., 2007). The level of burden and psychological symptoms experienced by caregivers may be linked to the severity of the patient’s symptoms and the caregiver’s level of social support (Perlick et al. 1999, 2007a, 2007b). However, caregiver appraisals, for example perceptions of their and the patient’s capacity to control or manage the illness and perceived stigma, may moderate the relationship between patient symptom severity and caregiver burden or psychological symptoms (Perlick et al., 1999; Steele et al., 2010). The impact of appraisals on burden and psychological symptoms may in part be due to how appraisals influence coping style (Chakrabarti & Gill, 2002; Perlick et al., 2007b). High perceived stigma and lack of illness awareness (defined as the understanding that the patient's symptoms are attributable to a mental illness requiring treatment) are associated with more frequent use of maladaptive coping strategies such as avoidance or resignation, and less frequent use of adaptive strategies such as positive communication and seeking support (Chakrabarti & Gill, 2002; Perlick et al., 2008). Appraisals of controllability are also linked to 'expressed emotion', defined as the expression of critical attitudes, hostility or emotional over-involvement (Leff & Vaughn, 1985; Wendel, Miklowitz, Richards & George, 2000). This in turn is associated with negative patient outcomes such as increased relapse and symptom severity (Hooley, 2007; Kim & Miklowitz, 2004). However, existing research is predominantly cross-sectional, and the direction of causality between caregiver responses and illness severity is unclear (Hooley, 2007).

Interventions involving caregivers

The 'stress-appraisal-coping' model implies the potential for interventions to reduce caregiver burden and psychological symptoms, through modification of appraisals and coping strategies and increasing social support. In accordance with this, NICE guidelines for bipolar disorder recommend interventions to improve the experience of caregiving, including group psychoeducation and support groups (NICE, 2014). Psychoeducation may involve providing basic information about the nature, treatment and management of the condition, or may involve more complex components such as increasing coping strategies, teaching problem-solving and communication skills, and improving self-care. Support groups involve caregivers providing mutual support, and may be led by a peer or professional who facilitates interaction between group members. However, the guidelines do not explicitly recommend a particular type of intervention, as NICE describe the evidence that the recommendations are based on as of low to moderate quality (NCCMH, 2014b). It is also important to note that the guidelines are based primarily on studies involving caregivers of people with psychosis and schizophrenia (NCCMH 2014a, 2014b).

To date, the majority of trials and reviews of interventions involving caregivers have focused on patient outcomes, and have evaluated psychoeducational interventions (Oud et al., 2015; Reinares et al., 2016). There is some variation in how interventions are categorised in the literature (Oud et al., 2015; Reinares et al., 2016). However, a broad distinction can be made between interventions involving caregivers alone, such as group psychoeducation, and interventions involving caregivers and patients. Interventions involving caregivers and the index patient can be further sub-divided into those delivered in a group format, such as multi-family group psychoeducation and those delivered to individual families or dyads, such as family-focused therapy (Miklowitz & Goldstein, 1997). Family-focused therapy is a modification of the Falloon model of behavioural family therapy for schizophrenia (Falloon, Boyd & McGill, 1984; Miklowitz & Goldstein, 1997). The primary aims are the reduction of expressed emotion and modification of associated appraisals, in order to reduce relapse (Miklowitz & Chung, 2016). However, there is a substantial overlap in the content of all interventions, with many involving communication skills and problem-solving skills training, as well as basic psychoeducation (Reinares et al., 2016).

Recent reviews have found that there is limited evidence that both family-focused therapy and group psychoeducation delivered to families or caregivers alone can improve patient functioning, adherence, relapse and symptomatology (Oud et al., 2015; Reinares et al., 2016). However, methodological weaknesses and diversity in terms of interventions, participants and outcomes means that further research is needed to reach firmer conclusions about treatment efficacy (Oud et al., 2015; Reinares et al., 2016). Despite the fact that interventions often aim to improve caregiver outcomes through promoting coping strategies (Reinares et al., 2016), these are often not reported or included in reviews of the literature (e.g. Oud et al., 2015).

Previous reviews

To date there have been no reviews exclusively evaluating the impact of interventions aiming to improve the experience of caregiving in bipolar disorder. In a wider review of family interventions for bipolar disorder, Reinares et al. (2016) reported that four trials of psychoeducation involving caregivers alone and one pseudo-randomised trial of family-focused therapy showed positive effects on caregiver knowledge, burden, and psychological symptoms. One intervention also reduced avoidance coping (Perlick et al., 2010). An earlier review reported similar results for two trials involving caregivers alone, and one trial of a family intervention (Justo, Soares & Calil, 2007). Neither review meta-analysed trial effects due to the nature of one review (Reinares et al., 2016) and an insufficient number of studies included in the other (Justo et al., 2007).

A systematic review of trials of interventions reporting outcomes for relatives of people with psychosis found that 60% of studies reported positive effects on at least one outcome (Lobban et al., 2013). The proportion of studies showing effective outcomes was greater for outcomes related to knowledge, beliefs, and family functioning compared to relatives’ needs or emotional responses. It was hypothesised that this might be due to family interventions being based predominantly on the expressed emotion construct. Other differences such as the components of the intervention or whether the index patient was included in the treatment did not discriminate between effective and ineffective interventions. It was difficult for clear conclusions to be drawn from the review, as there was considerable heterogeneity in terms of interventions and participants, and study methodology was generally poor.

A more recent systematic review and meta-analysis of interventions aimed at improving the experience of caring for people with severe mental illness found some evidence to support the efficacy of psychoeducation and support groups in improving the experience of caregiving (primarily operationalised within individual studies as burden) and reducing psychological symptoms, although the majority of evidence was of low quality (Yesufu-Udechuku et al., 2015). However, the review only evaluated interventions provided to caregivers alone, and was based predominantly on interventions for caregivers of people with schizophrenia or psychosis. Only five of the 19 studies included involved caregivers of people with bipolar disorder, and two were mixed groups where the majority had a diagnosis of schizophrenia. Although subgroup analyses were carried out based on diagnosis, there were insufficient numbers of studies to meta-analyse findings for bipolar disorder.

The current review

The aim of the current review and meta-analysis is to critically evaluate and synthesise the impact of interventions aiming to improve the experience of caregiving in bipolar disorder. The experience of caregiving is defined broadly as encompassing any carer-focused outcome, including burden, psychological symptoms or knowledge. This is the first review to focus exclusively on outcomes for caregivers of patients with bipolar disorder, and to use meta-analytic methods to synthesise study findings. Although there have been recent reviews in this area, new trials have been published since this time, which enable the use of meta-analytic methods. As outlined above, both interventions involving caregivers alone and caregivers with the index patient may improve the experience of caregiving. Therefore, in contrast to the most recent meta-analysis of caregiving (Yesufu-Udechuku et al., 2015), both types of intervention will be included in the meta-analysis, thus increasing completeness and transparency of findings. The review therefore aims to clarify whether psychological interventions should be offered to caregivers in order to improve their experience of caregiving.

In line with the literature on caregiving in bipolar disorder, the primary outcome variable will be caregiver burden. However, other relevant carer-focused outcomes, including psychological symptoms and knowledge of bipolar disorder, will also be synthesised. No reviews to date have evaluated the impact of interventions on caregiver knowledge. Given that improving knowledge of bipolar disorder is a primary aim of psychoeducational interventions, and there has been found to be a relationship between illness awareness and coping style (Chakrabarti & Gill, 2002), this seems an important gap in the literature that will be addressed by the current review. A further aim of the review is to assess the quality of the studies included in order to highlight possible areas for further research.

In summary, the review will address whether psychological interventions for caregivers are effective in:

1. reducing burden
2. reducing psychological symptoms
3. increasing knowledge of bipolar disorder

Method

Inclusion criteria

Studies were selected based on the PICOS framework (Petticrew & Roberts, 2006):

(1) *Population*. Informal caregivers of adults with a diagnosis of bipolar disorder. Caregivers included relatives, spouses, partners, friends or neighbours. Caregivers could be living with the person with bipolar or not. Where the study included caregivers or index patients under the age of 18, over 75% of caregivers and patients had to be over the age of 18. Studies where the

population had significant comorbidities, for example substance misuse, were excluded.

(2) *Intervention*. Psychological interventions, including a psychological therapy, psychoeducational intervention, or support group aimed at improving the experience of caregiving. Interventions could involve the person with bipolar disorder as well as their caregiver, or caregivers alone. They could be delivered to individuals, couples, families or groups. They could be administered by any healthcare professionals, such as psychologists, psychiatrists, family therapists and nurses.

(3) *Comparator*. ‘Treatment as usual’, a waitlist control, or an alternative intervention, where this was clearly intended to be a control for the intervention of interest.

(4) *Outcomes*. At least one quantitative caregiver-focused outcome, including caregiver burden, psychological symptoms or knowledge. For studies where more than one diagnostic group took part, studies were included if disaggregated data were reported for caregivers of those with bipolar disorder.

(5) *Study design*. Randomised and pseudo- randomised controlled trial design, with pre- and post- measures.

(6) *Publication characteristics*. Primary research published in English in a peer-reviewed journal at any time up until the end of August 2016.

Search strategy

Four strategies were used to identify relevant studies:

(1) The Ovid PsycINFO and Ovid MEDLINE databases were systematically searched. Search terms were developed for three main concepts: ‘caregiver or family member’, ‘bipolar disorder’, and ‘psychological intervention’ (see Table 1). These were combined with Cochrane’s highly sensitive search strategy for identifying randomised trials in Ovid Medline (Higgins & Green,

2011). Terms referring specifically to drug trials (‘placebo’ and ‘drug therapy’) were removed. There is no equivalent Cochrane strategy for Ovid PsychInfo, so the Medline strategy was adapted. Illness stage specific and illness subtype terms such as ‘manic’ and therapy subtype terms such as ‘family therapy’ were initially included in the search but did not produce further relevant studies, and were therefore excluded. Searches were conducted separately for each concept as both a text word and medical subject heading (‘MeSH’) search, and then combined using the Boolean operator ‘AND’. Studies were limited to those published in English in peer-reviewed journals.

(2) A broader search was conducted on the Cochrane Central Register of Controlled Trials (CENTRAL).

(3) Existing systematic reviews and meta-analyses were searched for further papers (Justo et al., 2007; Oud et al., 2016; Reinares et al., 2016; Yesufu-Udechuku et al., 2015). Reviews were identified from the electronic searches and through searching the Cochrane database.

(4) The reference lists of identified studies were reviewed to identify any further papers.

Data collection and analysis

Selection of studies

Studies were initially included or excluded based on relevance of title and abstract. Remaining studies were then included or excluded after reviewing the full text. Eligibility was judged by the present author. Where there was doubt over eligibility this was discussed with her supervisors, and a consensus reached.

Table 1.

Electronic Search Filters

	Bipolar disorder filter	**Caregiver or family member filter**	**Psychological intervention filter**	**Randomised trial filter**
Psychinfo	exp bipolar disorder/ OR bipolar OR manic depress*	exp family OR exp family members/ OR exp caregivers/ OR carer* OR caregiver* OR spous* OR partner* OR couple* OR marital OR family OR sibling* OR parent* OR relatives OR multi-family OR multifamily	exp intervention/ OR exp treatment/ OR exp counselling/ OR exp support groups/ OR intervention OR treatment OR counsel?ing OR psychotherap* OR therap* OR support group* OR psycho-education* OR psychoeducation*	exp clinical trials/ OR trial.ab,ti. OR randomi?ed.ab. OR randomly.ab OR groups.ab
Medline	exp bipolar disorder/ OR bipolar OR manic depress*	exp family/ OR exp caregivers/ OR carer* OR caregiver* OR spous* OR partner* OR couple* OR marital OR family OR parent* OR sibling* OR relatives OR multi-family OR multifamily	exp psychotherapy/ OR exp counselling/ OR self-help groups/ OR intervention OR treatment OR counsel?ing OR psychotherap* OR therap* OR support group* OR psycho-education* OR psychoeducation*	randomi?ed controlled trial.pt OR controlled clinical trial.pt OR randomi?ed.ab OR randomly.ab OR trial.ab OR groups.ab

Note /denotes a Medical Subject Heading (MeSH) term
* and ? denote truncation; ? replaces 0 or 1 characters, * replaces any number of characters
ab. denotes a word in the abstract
exp denotes exploded MeSH term
pt. denotes a Publication Type term
OR is a Boolean operator that locates records containing any of the specified terms
All filters were combined using the Boolean operator AND. This locates records containing all of the specified terms.

Figure 1 shows the number of studies identified, examined and excluded at each stage. The combined electronic searches yielded 776 references; 27 duplicates were removed. A total of 749 references were screened and 735 excluded based on title and abstract. Fourteen references were screened and six excluded based on full-text screening. Reasons for exclusion at each stage are detailed in Figure 1. The most common reasons for exclusion were that bipolar disorder was not the main focus of the study, the study did not evaluate an intervention, or the study evaluated a drug treatment. Many studies were excluded based on multiple reasons. One additional eligible study was identified from the Cochrane database of randomised controlled trials. Hand searches of identified reviews and studies did not yield further eligible studies. The final number of studies included in the review was nine.

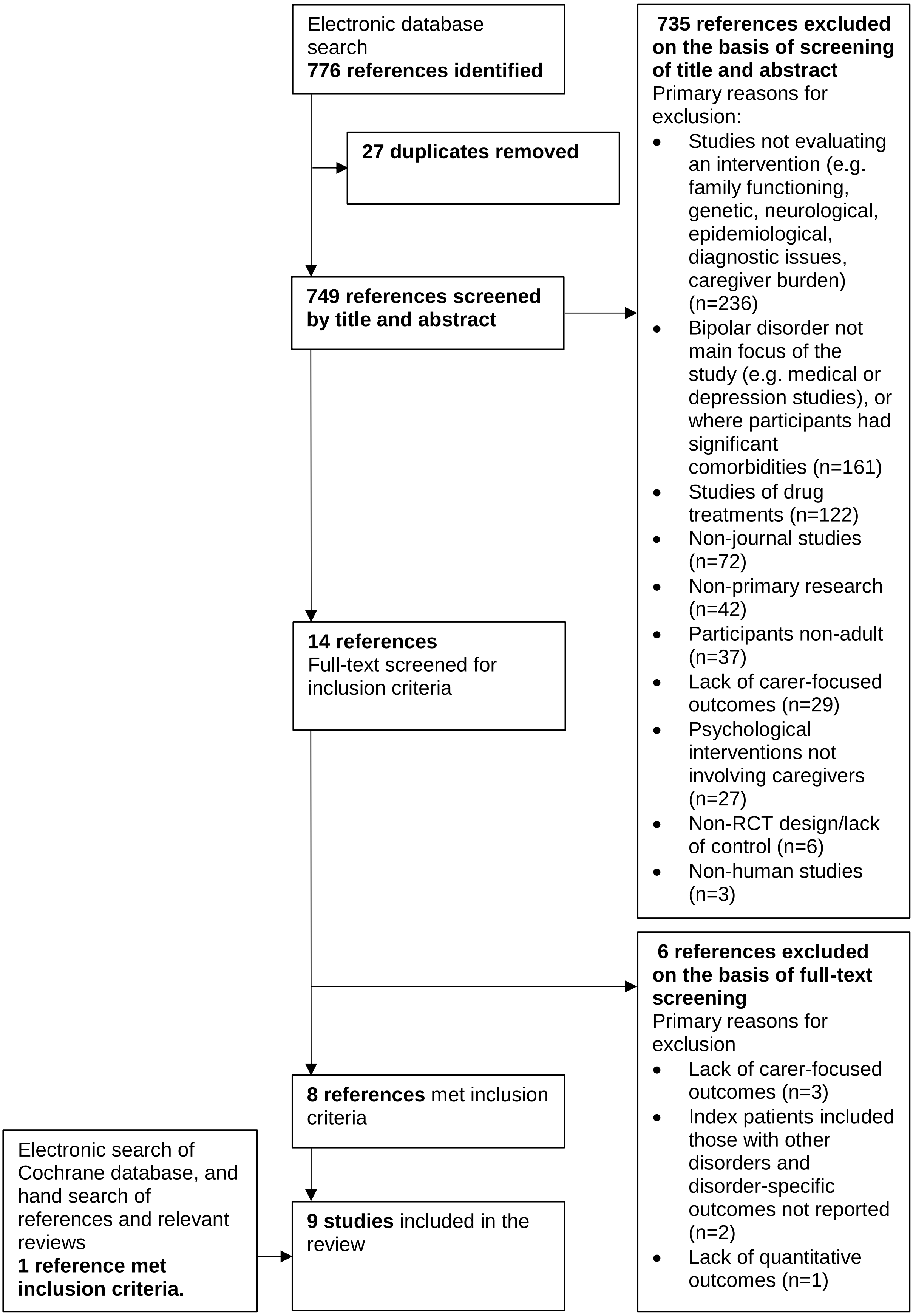
Data extraction

Data were extracted from the full text of studies that met inclusion criteria, and recorded in a data extraction form. Information extracted included study location, inclusion and exclusion criteria, participant characteristics, sample size, setting, nature and duration of the intervention, nature of the control, outcome measures, length of follow-up, and outcomes at post-treatment and follow-up. Where there were insufficient data reported to include studies in the meta-analysis, this was requested from study authors.

Assessment of risk of bias

Risk of bias was assessed using the Cochrane Collaboration’s tool for assessing risk of bias (Higgins & Green, 2011), which assesses selection bias, performance bias, detection bias, attrition bias, and reporting bias. Selection bias refers to the risk of systematic differences between the baseline characteristics of groups, and covers randomisation methods and allocation concealment. In line with recent recommendations (Corbett, Higgins & Woolacott, 2014), baseline imbalances

Figure 1*: Flow Diagram of Study Selection*



between groups were also considered, both in terms of statistically significant and substantive differences. According to this approach, trials that would be rated at higher risk of bias on the basis of randomisation methods and allocation concealment may be rated at low risk if groups are shown to be comparable on variables that may be prognostically important. Conversely trials may be rated at high risk if important baseline imbalances are reported, despite adequate randomisation and allocation concealment methods. Variables considered included demographics, caregiver-focused variables such as burden, knowledge and psychological symptoms, and patient-focused variables such as clinical severity and current treatment.

Performance bias refers to the risk of systematic differences in the treatment of groups, aside from the intervention of interest, and covers blinding of participants and study personnel. Detection bias refers to systematic differences in how outcomes are determined, and covers blinding of assessors. Attrition bias refers to systematic differences between groups in withdrawals from the study, and how missing data is handled within analyses. Reporting bias covers selective outcome reporting.

Review Manager (Revman) Version 5.3 was used to collate results. Each domain was assessed as either ‘high risk’, ‘low risk’ or ‘unclear risk’. A rating of high risk of bias was given when there was plausible bias that was likely to have a significant impact on the study’s results. A rating of low risk of bias was made when plausible bias was unlikely to significantly affect the results. A rating of unclear bias was made where insufficient detail was reported to make a clear judgement (Higgins & Green, 2011).

Measures of treatment effect

RevMan was used to synthesise data and calculate overall estimates of treatment effect with 95% confidence intervals. Due to the heterogeneity of measures used, the standardised mean difference (SMD; Hedges' adjusted *g;* Hedges, 1981) was used to standardise effect sizes using the following formula:

$$SMD_i = \frac{m_{1i} - m_{2i}}{s_i}\left(1 - \frac{3}{4N_i - 9}\right)$$

Hedges' *g* was used rather than Cohen's *d* (Cohen, 1988), as it adjusts for small sample bias (Borenstein, Hedges, Higgins & Rothstein, 2009).

Effects were weighted by the inverse of variance, with 0.2 interpreted as representing a small effect, 0.5 a moderate effect, and 0.8 a large effect (Cohen, 1988).

Random effects models were used to calculate composite effects. This approach takes into account the possibility of variability in population parameters among studies. Compared to fixed effects models, random effects formulas generate more accurate confidence intervals when population parameters vary, thus allowing more robust conclusions to be drawn (Hunter & Schmidt, 2000). Given the likelihood of heterogeneity of behavioural, social and health science data, this approach also allows generalisation of meta-analytic findings (Field & Gillett, 2010; Hunter & Schmidt, 2000).

Separate post-treatment comparisons were carried out for the three categories of outcome. It was planned that, if sufficient data were available, separate comparisons would be carried out for follow-up data.

Unit of analysis issues

Given the research question, data from outcome domains that were not directly relevant to the experience of caregiving were not analysed, for example index patient symptomatology and functioning. In three-armed trials that included two active interventions and a control, the intervention that was more clearly focused on improving the experience of caregiving was treated as the intervention of interest, and included in the meta-analyses.

Where studies reported results for subscales measuring different aspects of burden, which were not intended to be combined into a global burden score, it was decided that the subjective burden subscale scores would be used in the meta-analysis, as this could be most reasonably be expected to change following an intervention**.**

Assessment of heterogeneity

Visual inspection of forest plots and the associated chi-squared test were used to assess heterogeneity. Where confidence intervals have poor overlap and there is a low *p* value for the chi-squared test, this indicates heterogeneity. As the chi-squared test has low power when studies have small sample sizes or are few in number, a threshold of .10 was used to determine statistical significance (Higgins & Green, 2011). As it can be argued that, due to methodological and clinical diversity, statistical heterogeneity is inevitable within a meta-analysis (Higgins, Thompson, Deeks & Altman), inconsistency was also assessed using the I^2 statistic. This describes the percentage of the variability in effect estimates that is due to true heterogeneity rather than sampling error, and assesses the impact that heterogeneity is likely to have on a meta-analysis. An I^2 value of over 50% represents substantial heterogeneity and 75% high heterogeneity (Higgins & Green, 2011). In these cases reasons for heterogeneity were explored qualitatively. Reasons considered included clinical diversity, for example differences in participants and interventions, and methodological diversity, such as outcome measures and risk of bias. Where substantial heterogeneity was present, interpretation of results was based on confidence intervals rather than the average effect.

Sensitivity analyses

The following sensitivity analyses were conducted in order to assess whether findings were robust to the methodological decisions made.

1. Separate comparisons were carried out for global burden, subjective burden, and objective burden, in order to assess the validity of combining global and subjective burden scores.
2. The influence of each study on the combined effect was assessed. It was reported where an outlying study had a substantial impact on heterogeneity, and reasons for this were considered.

Assessment of publication bias

As the meta-analysis included fewer than 10 studies, it was not appropriate to use funnel plots and associated significance tests and correction methods to assess publication bias (Higgins & Green, 2011). This is because when there are fewer than 10 studies the power of these tests is too low to distinguish real asymmetry from chance (Higgins & Green, 2011). Calculation of Fail-safe N, or the calculation of the number of additional studies in which the intervention effect was zero needed to make the results of the meta-analysis non-significant, was not used as this is not recommended in the Cochrane guidance (Higgins & Green, 2011). This is due to methodological issues, and the principle within systematic reviews of focusing on effect sizes and confidence intervals, rather than statistical significance.

Results

Description of studies.

Details of the nine included studies are summarised in Table 2. Studies were conducted in the United States (k=2), Europe (k=5), Brazil (k=1), and Australia (k=1). Six (67%) had been conducted since 2010. The most common constructs assessed were caregiver burden, psychological symptoms, and knowledge of bipolar disorder. Five of the studies also evaluated patient-focused outcomes, such as symptomatology and functioning.

Study design

Eight studies were randomised controlled trials. One had a pseudo-randomised design (Fiorillo et al., 2010), whereby participants were consecutively allocated to the intervention and control group. Eight had a two-arm trial design with one intervention arm and one control. One (Madigan et al., 2012) had a three-arm design, with two intervention arms and one control. In line with the data analytic strategy outlined above, the intervention that was more clearly focused on improving the experience of caregiving (psychoeducation) was treated as the intervention of interest. Four studies reported outcomes at post-treatment and follow-up, three at post-treatment only, and two at follow-up only.

Sample characteristics

For the majority of studies (k=7), only caregivers took part in the intervention. In two studies both caregivers and the index patient participated (Clarkin et al., 1990; Fiorillo et al., 2015). In three, index patients' outcomes were reported, but they did not participate in the intervention. Four recruited from hospital or clinic settings only; the remainder recruited from community populations (k=2), or from a combination of community, student and clinical populations (k=3).

The number of caregivers taking part ranged from 26 to 155 (median=46). The number of index patients participating or providing data ranged from 21 to 137 (median=40). One study did not report the number of caregivers participating or demographic features (Clarkin et al., 1990), and another did not report the number of patients participating (Madigan et al., 2012). A weakness in the included studies was that only one (Hubbard, McEvoy, Smith & Kane, 2016) reported a power analysis, and the study may have been under-powered. Given the relatively small sample size of the majority of the studies, it is likely that others were also under-powered.

Table 2

Study Characteristics

Author (year) and country	Participant characteristics	Therapist characteristics	Intervention	Control/comparative treatment	Outcome: post-treatment	Outcome: follow-up
Clarkin et al. 1990 USA	**Caregivers and patients** (voluntary inpatients and their families) Characteristics of caregiver not reported. Patients: N = 21 Female = 67% Age: *M* = 32.3 Diagnosed according to DSM-III criteria.	One family therapist/social worker and one psychiatric resident/psychology intern	Psychoeducational inpatient family intervention plus standard multimodal hospital treatment **Duration:** At least 6 x 45-60 mins *n* = 12	Standard multimodal hospital treatment *n* = 9	Not reported	**6 months:** No between-group differences for burden, attitude to the patient or quality of life **18 months:** Small improvement in attitude towards treatment in the intervention group
de Souza et al. 2016 Brazil	**Caregivers only** (volunteers from allied research study) Total *N* = 53 Female = 79% Age: *M* = 44.1 Patients diagnosed using the Mini International Neuropsychiatric Interview 5.0 (MINI; Amorim, 2000) and the Structured Clinical Interview for DSM-IV (SCID; Del-Ben et al., 2001)	Not reported	Individual psychoeducation. **Duration:** 6 x 90 minutes. *n* = 25	TAU: caregivers could be given information through their relative's psychiatrist, but no caregiver appointments took place *n* = 28	No between-group differences in subjective, burden, objective burden, self-esteem or quality of life	**6 months:** No between-group differences.

Fiorillo et al. 2015 Italy	**Caregivers and patients** (clinic attendees) Caregivers: *N* = 155 Female = 54% Age: *M* = 51.9 Patients: *N*= 137 Female = 63% Age: *M* = 47.1 Type I BD = 100% Diagnosed according to DSM IV criteria	Psychiatrists, nurses, psychologists and psycho-social rehabilitation technicians	Psychoeducational family intervention (individual assessment and family sessions) plus treatment as usual (TAU) **Duration:** 12-18 x 90 minutes. Caregiver *n* = 85*.* Patient *n* = 70	Wait list/TAU (psychiatric assessment, pharmacological treatment). Caregiver *n* = 70 Patient *n* = 67	Greater improvement in subjective burden, objective burden and social support in the intervention group compared to the control.	Not reported.
Hubbard et al. 2016 Australia	**Caregivers only** (recruited through radio, clinics and university.) Total *N* = 32 Female = 58% Age: *M* = 48.1	Master's level clinical psychologist and registered clinical psychologist	Group psychoeducation **Duration:** 2 x 150 minutes *n* = 18	Wait list *n=14*	Greater improvement in burden, knowledge and self-efficacy in the intervention group compared to the control. No improvement in psychological symptoms.	**One month** Greater improvement in burden and knowledge from pre-intervention to follow-up, but not from post-intervention to follow-up in the intervention group compared to the control.
Kolostoumpis et al., 2015 Greece	**Caregivers only** (recruited from a nongovernmental organisation) Caregivers *N* = 80 Female = 69% Age: *M* = 53.3 Patients: Type I BD = 64% Patients diagnosed through clinical interview according to DSM-IV criteria	A psychiatrist and psychologist	Group psychoeducation plus standard pharmacotherapy **Duration:** 7 x 120 minutes *n* = 40	Standard pharmacotherapy *n* = 40	Greater improvement in knowledge, burden, and psychological symptoms in the intervention group.	**Six month.** Greater improvement in knowledge, burden, and psychological symptoms in the intervention group.

Madigan et al. 2012 Ireland	**Caregivers only. Patients provided data** (recruited through media and mental health services.) Caregivers: *n* = 47 Female = 53% Age: *M* = 52.0 Patient numbers not reported Female = 65% Age: *M* = 42 Type 1 BD = 100% Diagnosed using the SCID for DSM IV (First, Spitzer, Williams & Gibbon, 1997)	Psychiatric nurse and social worker	Group psychoeducation **Duration:** 5 x 120 minutes *n* = 18	1. TAU (care from a multidisciplinary service). *n* = 10 2. Solution focused group psychotherapy **Duration:** 5 sessions (length not stated) *n* = 19	Not reported	**1 year and 2 years.** There was a greater improvement in burden, knowledge and psychological symptoms[2] in the psychoeducation group compared to the control. No differences between the two intervention groups.
Perlick et al. 2010 USA	**Caregivers only. Patients provided data** (recruited from mental health services and support group.) Caregivers: *n* =43 Female = 84% Age: *M* = 52.8 Patients: *n* = 40 Female = 63% Age *M* = 34.7 Type 1 BD = 80% Diagnosed using the SCID for DSM IV	Two experienced clinicians trained in Family Focused Therapy and Cognitive Behavioural Therapy	Individual psychoeducation **Duration:** 12-15 x 45 mins *n* =24	Caregiver health education intervention delivered via DVD. **Duration:** 8-12 x 20-25 minutes. *n* = 19	Greater reductions in burden, psychological symptoms, and health risk behaviour in the intervention group. The greater decrease in depressive symptoms in the intervention group was partially mediated by a decrease in avoidance coping.	Not reported

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[2] Although Madigan et al. (2012) reported a statistically significant effect for psychological symptoms, the direct calculation of the confidence intervals for the effect within this meta-analysis showed that they overlapped zero (see figure 7).

Reinares et al. 2004 Spain	**Caregivers only** (recruited from outpatient clinic.) Total *N* = 45. Female = 76% Age: *M* = 48.5 Patients: Type 1 BD = 79% Diagnosed according to DSM-IV criteria	A psychologist	Group psychoeducation **Duration:** 12 x 90 minute sessions. *n* = 30	Standard pharmacological treatment. *n* = 15	Greater improvement in subjective burden and knowledge in the intervention group. No differences in objective burden, patient relatedness or family relationships.	Not reported.
van Gent & Zwart 1991 The Netherlands	**Partners only. Patients provided data** (recruited from outpatient clinic.) Partners: *n* = 26 Age: *M* = 48.5 Patients: *n*=26 Age: *M* = 33.16 Gender not reported. Diagnosed through clinical interview according to DSM-III criteria.	A psychiatrist and social worker	Group psychoeducation. **Duration:** 5 sessions. Session length not reported. *n* = 14	No intervention. *n* = 12	Greater improvement in knowledge in the intervention group compared to the control. No differences in relationship problems or psychosocial problems.	**6 months**. Greater improvements in knowledge in the intervention group compared to the control were maintained.

All studies recruited adult samples (mean age range of carers: 44.1- 53.3; mean age range of patients; 32.2- 47.1), aside from one (de Souza et al., 2016) which recruited caregivers aged 16 years or older and patients aged 16 to 35 years. The authors confirmed that all index patients and 52 (98%) of 53 caregivers were 18 or over. In all studies the majority of caregivers and patients were female (caregivers' range: 53%- 84%; patients' range: 63%- 67%). In the seven studies where the relationship between the caregiver and index patient was described, it was most common for caregivers to be parents (range: 28%- 71%) or spouses/partners (range: 6%- 100%) of the index patient. Eight studies reported that patients were diagnosed with bipolar disorder according to DSM-III or DSM-IV criteria (diagnostic methods are reported in Table 2). For the five studies which reported whether patients were diagnosed with type I or II bipolar disorder, the majority were diagnosed with type I bipolar disorder (range: 64%- 100%).

A strength of the included studies was that they all reported exclusion criteria. However, only five reported the percentage excluded (range: 0-16%) (Fiorillo et al., 2015; Hubbard et al., 2016; Madigan et al., 2012; Perlick et al., 2010; Reinares et al., 2004). Reasons for exclusion included hospitalisation or lack of clinical stability in the index patient (k=3), and severe mental or physical health problems (k=4), learning disability (k=3) or illiteracy in the caregiver (k=3). However, for one study (Perlick et al., 2010) caregivers had to demonstrate current depressive symptoms, high burden or physical health risk behaviours. Inclusion criteria for caregivers included having an active involvement with the patient's care (k=3) or living with the patient (k=3).

Intervention characteristics

The extrinsic features of interventions were diverse with the number of sessions ranging from 2 to 18, with durations ranging from 45 to 150 minutes. Five were delivered in a group format involving caregivers only, two through individual sessions with caregivers (de Souza et al., 2016; Perlick et al., 2010), and two through family sessions (Clarkin et al., 1990; Fiorillo et al., 2015). One intervention took place in an inpatient setting (Clarkin et al., 1990); the remainder took place in the community. Although seven studies reported that the intervention was manualised, only two reported carrying out adherence checks (Hubbard et al., 2016; Perlick et al., 2010).

The nature and aims of the interventions were fairly consistent; all were described as psychoeducational. Common components included education about the nature of bipolar disorder, triggers and warning signs, treatment, management, and the impact on and role of caregivers. Interventions aimed to teach coping strategies, communication skills, and problem-solving skills. The intervention reported by Perlick et al. (2010) placed a greater emphasis on reducing health risks associated with caregiving, and was more explicitly based on cognitive-behavioural principles, aiming to modify dysfunctional appraisals. The psychoeducational family intervention reported by Fiorillo et al. (2015) was based on family-focused therapy (Miklowitz & Goldstein, 1997), adapted for Italian non-tertiary settings.

Therapist characteristics

A strength of the included studies is that the majority (k=8) reported therapist characteristics and discipline. These included psychologists, psychiatrists, family therapists, and nurses. Seven interventions were delivered by qualified clinicians, and two by qualified and trainee clinicians (Clarkin et al., 1990; Hubbard et al., 2016). Only two studies reported that therapists had received training and supervision (Fiorillo et al., 2015; Perlick et al., 2010).

Control or comparative intervention characteristics

A weakness of the included studies was that the majority (k=8) compared the intervention to a non-active control or an intervention intended to be a control, where the ‘dosage’ or therapeutic contact was lower than in the active arm. It is therefore possible that any effect found was due to increased clinical contact, rather than the nature of the intervention. Studies compared the active intervention to treatment as usual (k=5), a wait-list control (k=1), a wait-list control receiving treatment as usual (k=1), and no intervention (k=1). Treatment as usual included multidisciplinary care, pharmacological treatment, and informal contact between the caregiver and clinicians. Five studies reported that the intervention arm also continued to receive treatment as usual.

The control group reported by Perlick et al. (2010) was a caregiver health education intervention, delivered via DVD over thirteen sessions lasing 20 to 25 minutes. A clinical research associate reviewed information to ensure understanding, but refrained from discussion of the material. Madigan et al. (2012) was the only study to include two active interventions, as well as a control. The comparative intervention was ‘solution-focused group psychotherapy’, delivered to caregivers over five sessions. Intervention details and duration were not reported.

Outcome measures

Outcome measures used are summarised in Table 3. The majority of measures were self-report. All studies aside from one (van Gent & Zwart, 1991) evaluated the impact of the intervention on caregiver burden. As shown in Table 3, burden was operationalised in diverse ways, with three studies reporting separate objective and subjective burden sub-scale scores, one reporting only subjective burden scores, and four reporting a global burden score. One study (Clarkin et al., 1990) used a measure developed specifically for the study and information on reliability and validity was not reported.[3] All other measures had adequate to high reliability and validity, both in their original form and in translation where applicable.

Four studies evaluated the impact of the intervention on caregiver psychological symptoms; all measures had good reliability and validity. Six studies evaluated the impact of the intervention on caregiver knowledge. Measures covered knowledge of bipolar disorder, treatment and management. Five were developed for

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[3] The authors were contacted for this information, but were unable to provide it within the necessary timeframe.

the study, and one study used a measure developed for caregiving in schizophrenia (Madigan et al., 2012). One study reported high reliability (Hubbard et al., 2016) and one adequate reliability (Kolostoumpis et al., 2015) of the knowledge measure. The remaining four did not report reliability or validity.

Other outcomes evaluated by individual studies included caregiver quality of life and self-esteem (de Souza et al., 2016); health risk behaviour (Perlick et al., 2010); psychosocial problems (van Gent & Zwart, 1991); social support (Fiorillo et al., 2015) attitudes (Clarkin et al., 1990) and family relationships (Reinares et al., 2004; van Gent & Zwart, 1991). These outcomes are reported in Table 2, but were not meta-analysed due to there being an insufficient number of studies. One study (Perlick et al., 2010) investigated the role of avoidance coping as a mediator of the intervention effect on caregiver depressive symptoms.

Table 3

Outcome Measures

Study	Measure of burden (subscales/global measure)	Measure of knowledge	Measure of psychological symptoms
Clarkin et al. 1990 USA	Burden subscale of the Family Attitude Inventory (FAI). (Haas et al., 1986) Global burden (assessor rated)	NA	NA
de Souza et al. 2016 Brazil	Family Burden Interview Schedule. Portuguese translation. (Bandeira, Calzavara & Castro, 2008) Subjective and objective subscales	NA	NA
Fiorillo et al. 2015 Italy	Family Problem Questionnaire. Italian translation (Morisini, Roncone, Veltro, Palomba & Casacchia, 1991) Subjective and objective burden subscales.	Knowledge of bipolar disorder questionnaire (developed for study)	NA

Hubbard et al. 2016 Australia	Burden Assessment Scale (Reinhard, Gubman, Horwitz & Minsky, 1994) Global burden	Knowledge of bipolar disorder questionnaire (developed for study)	Depression, Anxiety and Stress Scale (DASS-21) (Lovibond & Lovibond, 1995)
Kolostoumpis et al., 2015 Greece	Family Burden Scale. Greek translation (Madianos et al., 2004) Global burden	Knowledge questionnaire	GHQ-12 Greek translation. (Garyfallos et al., 1991)
Madigan et al. 2012 Ireland	Involvement Evaluation Questionnaire (van Wijngaarden et al., 2000) Global measure	Knowledge of Illness Questionnaire (Smith & Birchwood, 1987)	GHQ-12 (GHQ; Goldberg & Blackwell, 1970)
Perlick et al. 2010 USA	The Social Behavior Assessment Schedule (Platt, Weyman, Hirsch & Hewett, 1980) Subjective burden subscale (assessor rated)		Quick Inventory of Depressive Symptomatology (QIDS; Rush et al., 2003)
Reinares et al. 2004 Spain	Social Behaviour Assessment Schedule (Otero, Navascues & Rebolledo, 1990) Subjective burden, objective burden and patient relatedness subscales (assessor rated)	Knowledge of bipolar disorder test (developed for study) (assessor rated)	NA
van Gent & Zwart 1991 The Netherlands	NA	Knowledge of bipolar disorder questionnaire (developed for study)	NA

Note All measures are self-report unless otherwise indicated

Risk of bias

Figure 2 summarises risk of bias for individual studies. Figure 3 summarises risk of bias for all studies by domain.

Selection bias

Six studies were rated as at low risk of selection bias. Of these, one described an adequate method of randomisation and allocation concealment, and reported

comparability between groups at baseline on a number of clinical, caregiver-focused and sociodemographic variables (Perlick et al., 2010). Two reported an adequate method of randomisation and allocation concealment, and comparability on a limited number of variables (Hubbard et al., 2016; Madigan et al., 2012). One employed a consecutive allocation pseudo-randomised method but demonstrated baseline comparability on a number of variables (Fiorillo et al., 2015). Two did not report randomisation method or allocation concealment in detail, but demonstrated baseline comparability on a number of variables (Kolostoumpis et al., 2015; Reinares et al., 2004). The remaining three were rated as at unclear risk of bias as they did not adequately describe the method of allocation and demonstrated comparability on a limited number of variables.

Performance bias

All studies were at high risk of performance bias *per se*, as blinding of participants and personnel is not possible within psychological interventions.

Detection bias

Blinding of outcome assessors was clearly described in four studies (Clarkin et al., 1990; Kolostoumpis et al., 2015; Perlick et al., 2010; Reinares et al., 2004) and five used only self-report measures (de Souza et al., 2016; Fiorillo et al., 2015; Hubbard et al., 2016; Madigan et al., 2012, van Gent & Zwart, 1991), and so were rated at low risk of bias.

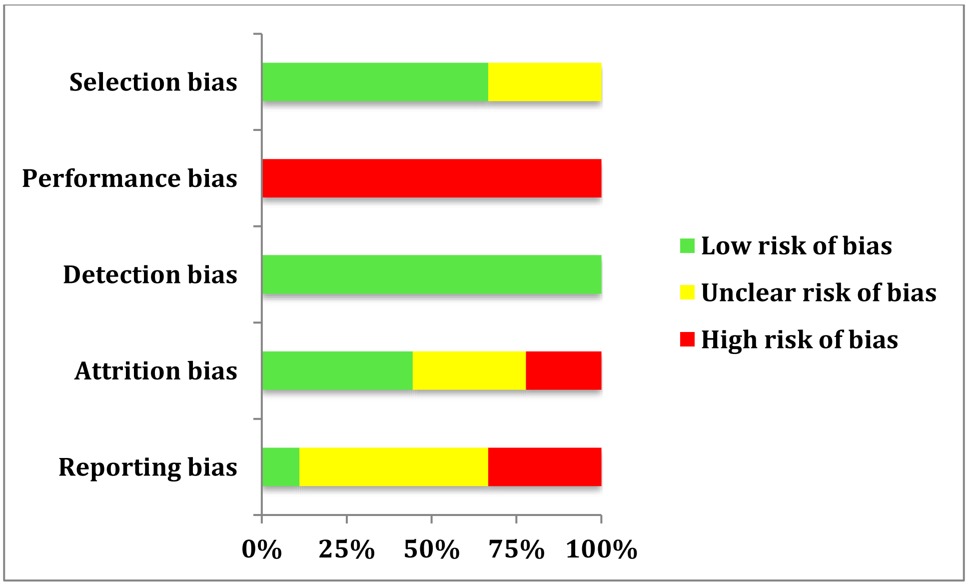
Figure 2

Risk of Bias for Individual Studies

	Selection bias	Performance bias	Detection bias	Attrition bias	Reporting bias
Clarkin 1990	?	-	+	?	-
de Souza 2016	?	-	+	-	?
Fiorillo 2015	+	-	+	+	?
Hubbard 2016	+	-	+	+	+
Kolostoumpis 2015	+	-	+	?	?
Madigan 2012	+	-	+	-	?
Perlick 2010	+	-	+	+	-
Reinares 2004	+	-	+	+	?
van Gent 1991	?	-	+	?	-

Figure 3

Risk of Bias Summary



Attrition bias

Studies were rated at low risk of bias if the level of attrition was unlikely to impact on the observed effect size (set at less than 20%) (Greenhalgh & Brown, 2014); if broadly equal numbers were retained in each group, reasons for attrition were given and were judged to be unlikely to be related to the true outcome; or if intention to treat (ITT) analyses were carried out (Higgins & Green, 2011). Four studies were rated as at low risk of bias. Three were rated as at unclear risk of bias. Two did not report whether attrition occurred (Kolostoumpis et al., 2015; van Gent & Zwart,1991) and for one it was not clear which diagnostic group attrition rates applied to (Clarkin et al., 1990) The remaining two were rated at high risk of attrition bias for several of the above reasons.

Reporting bias

The research protocol was only available for one study, which was rated at low risk of bias due to reporting all pre-specified outcomes (Hubbard et al., 2016). Three studies were rated as at high risk of bias. Clarkin et al. (1990) excluded the data of participants who did not meet a diagnosis at eighteen-month follow-up and did not report descriptive statistics, thus precluding inclusion in the meta-analysis. One study measured caregiver anxiety, but did not report this outcome or statistics for non-significant findings (van Gent & Zwart, 1991). One measured both objective and subjective burden, but only reported subjective burden scores (Perlick et al., 2010). The remaining studies were rated as at unclear risk of bias as the research protocol was not available, and no clear statement was made that all measured outcomes had been reported. Across studies there was inconsistency in how outcomes were measured and the length of follow-up data provided. The possibility of selective reporting was therefore high.

Intervention effects

All meta-analyses were for psychoeducation compared to a control. One study did not report sufficient data to allow inclusion in the meta-analysis (Clarkin et al., 1990).[4] Only three studies reporting outcomes at follow-up between 6 months and one year were included in the relevant meta-analyses. The remaining follow-up periods of 1 month (Hubbard et al., 2016) and 2 years (Madigan et al., 2012) were thought to be too diverse to be meaningfully combined in the analyses. Unless otherwise stated estimates favour the intervention over the control where the standardised difference is negative (g<0). Individual effects for a comparison between psychoeducation and an active intervention are summarised below.

Psychoeducation vs control: burden at post-treatment

The first meta-analysis examined the effect of psychoeducation on caregiver burden at post-treatment. Six studies were included, comprising 379 participants (see Figure 4). Overall, there was a large combined effect of the intervention, g = -0.8 (95% CI: -1.32, -0.27). However, confidence intervals were wide, ranging from a small to large effect, and there was evidence of high heterogeneity, $\chi2$ (5) = 26.18, $p < .001$, $I^2 = 81\%$.

The confidence intervals for four studies ranged from a small to large effect of psychoeducation, while one showed no effect (de Souza et al., 2016). Kolostoumpis et al. (2015) reported a substantially larger effect size than the other studies, and this appeared to be due to very small standard deviations for both the intervention (SD =1.93) and control (SD = 2.16) (for example, compared to the values reported by Hubbard et al. (2016) for a scale with a similar range) [intervention SD = 9.12; control SD = 8.57].[5] Excluding this study reduced heterogeneity to $I^2 = 43\%$, g = -0.56 (95% CI: -0.90, -0.22), although confidence intervals remained wide.

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[4] The authors were contacted for this information, but were unable to provide it within the necessary timeframe.

[5] The authors were contacted for clarification about possible reasons for this, but did not respond. Other possible methodological reasons for the outlying effect are explored in the discussion section.

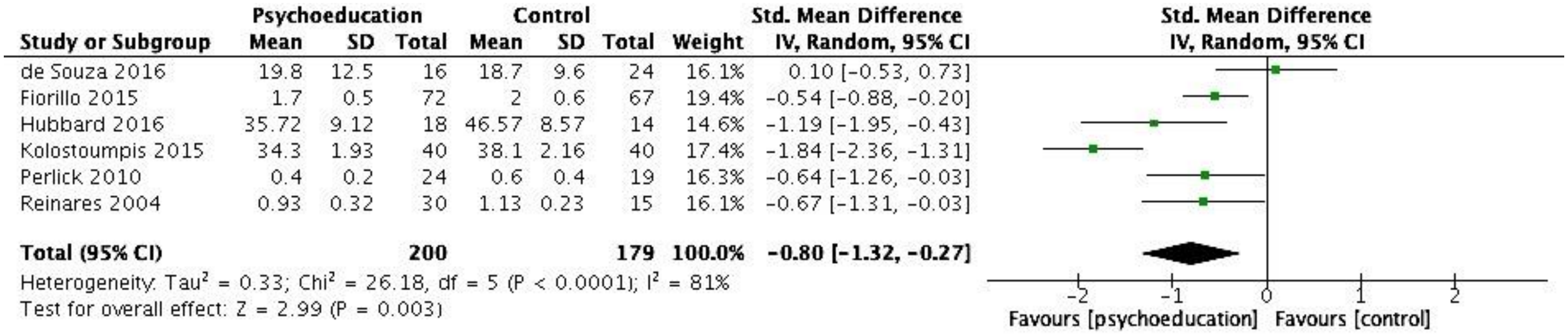
As shown in Table 4, sensitivity analyses showed that the combined effect size differed quite substantially depending on the type of measure of burden used. The combined effect for global burden was large, with evidence of moderate heterogeneity. Confidence intervals were large but the lower bound was still compatible with a large effect. The combined effect for subjective burden was small to moderate, with low evidence of heterogeneity. Confidence intervals for objective burden were compatible with both a reduction and increase in burden, and there was evidence of substantial heterogeneity.

Psychoeducation vs control: burden at follow-up

Three studies were included in the meta-analysis of the effect of psychoeducation on caregiver burden at follow-up, comprising 137 participants (see Figure 5). Overall there was a large combined effect of the intervention, $g = -1.22$ (95% CI: -3.19, 0.75). However, confidence intervals were compatible with a reduction and increase in burden, and there was evidence of high heterogeneity, $\chi 2$ (2) = 43.01, $p < .001$, $I^2 = 95\%$.

Figure 4

Post-treatment Comparative Efficacy for Burden



Study or Subgroup	Psychoeducation Mean	Psychoeducation SD	Psychoeducation Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
de Souza 2016	19.8	12.5	16	18.7	9.6	24	16.1%	0.10 [-0.53, 0.73]
Fiorillo 2015	1.7	0.5	72	2	0.6	67	19.4%	-0.54 [-0.88, -0.20]
Hubbard 2016	35.72	9.12	18	46.57	8.57	14	14.6%	-1.19 [-1.95, -0.43]
Kolostoumpis 2015	34.3	1.93	40	38.1	2.16	40	17.4%	-1.84 [-2.36, -1.31]
Perlick 2010	0.4	0.2	24	0.6	0.4	19	16.3%	-0.64 [-1.26, -0.03]
Reinares 2004	0.93	0.32	30	1.13	0.23	15	16.1%	-0.67 [-1.31, -0.03]
Total (95% CI)			**200**			**179**	**100.0%**	**-0.80 [-1.32, -0.27]**

Heterogeneity: Tau² = 0.33; Chi² = 26.18, df = 5 (P < 0.0001); I² = 81%

Test for overall effect: Z = 2.99 (P = 0.003)

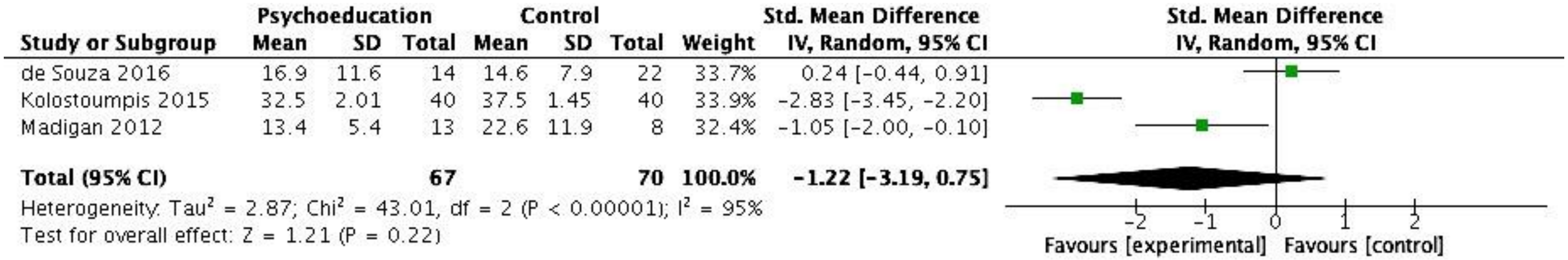
Table 4

Sensitivity Analysis for Measures of Burden at Post-treatment

Measure of burden	Number of studies (author names and date)	Combined effect	95% Confidence Interval	Heterogeneity effect $\chi 2$ (*p*)	Inconsistency *I*²
Global burden	2 (Hubbard et al., 2016; Kolostoumpis et al., 2015)	-1.58	-2.20, -0.95	1.87 (p=0.17)	46%
Subjective burden	4 (de Souza et al. 2016; Fiorillo et al., 2015; Perlick et al., 2010; Reinares et al., 2004)	-0.47	-0.77, -0.16	3.96 (p=0.27)	24%
Objective burden	3 (de Souza et al. 2016; Fiorillo et al., 2015; 2010; Reinares et al., 2004)	-0.03	-0.46, 0.51	5.16 (p=0.08)	61%

Figure 5

Comparative Efficacy for Burden at Follow-up



	Psychoeducation			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
de Souza 2016	16.9	11.6	14	14.6	7.9	22	33.7%	0.24 [-0.44, 0.91]
Kolostoumpis 2015	32.5	2.01	40	37.5	1.45	40	33.9%	-2.83 [-3.45, -2.20]
Madigan 2012	13.4	5.4	13	22.6	11.9	8	32.4%	-1.05 [-2.00, -0.10]
Total (95% CI)			**67**			**70**	**100.0%**	**-1.22 [-3.19, 0.75]**

Heterogeneity: $\text{Tau}^2 = 2.87$; $\text{Chi}^2 = 43.01$, df = 2 ($P < 0.00001$); $I^2 = 95\%$

Test for overall effect: Z = 1.21 (P = 0.22)

Psychoeducation vs control: psychological symptoms at post-treatment

Three studies were included in the meta-analysis of the effect of psychoeducation on caregiver psychological symptoms at post-treatment, comprising 155 participants (see Figure 6). Overall there was a large combined effect of the intervention, g = -1.76 (95% CI: -4.21, 0.70). However, again this was largely driven by the effect for Kolostoumpis et al. (2015). Confidence intervals were compatible with both a reduction and increase in symptoms, and there was evidence of high heterogeneity, $\chi 2$ (2) = 70.78, p < .001, I^2 = 97%.

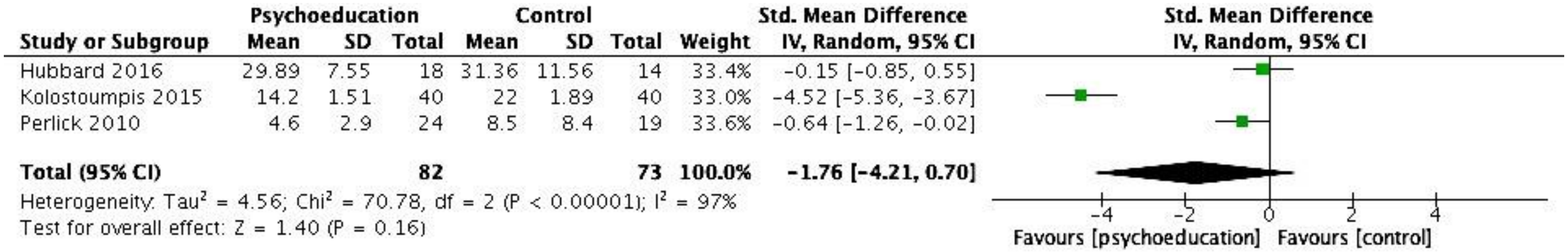
The substantially larger effect size reported by Kolostoumpis et al. (2015) may again have been due to very small standard deviations (intervention SD =1.51; control SD = 1.89). Excluding this effect reduced heterogeneity to I^2 = 5%, g = -0.42 (95% CI: -0.90, 0.05). However, confidence intervals ranged from no effect to a large effect of the intervention.

Psychoeducation vs control: psychological symptoms at follow-up

Two studies were included in the meta-analysis of the effect of psychoeducation on caregiver psychological symptoms at follow-up, comprising 101 participants (see Figure 7). Overall there was a very large combined effect of the intervention, g = -2.44 (95% CI: -5.91, 1.03). However, again this was driven by the large effect reported for Kolostoumpis et al. (2015). Confidence intervals were compatible with both a reduction and increase in symptoms, and there was evidence of high heterogeneity, $\chi 2$ (1) = 32.94, p < .001, I^2 = 97%.

Figure 6

Post-treatment Comparative Efficacy for Psychological Symptoms

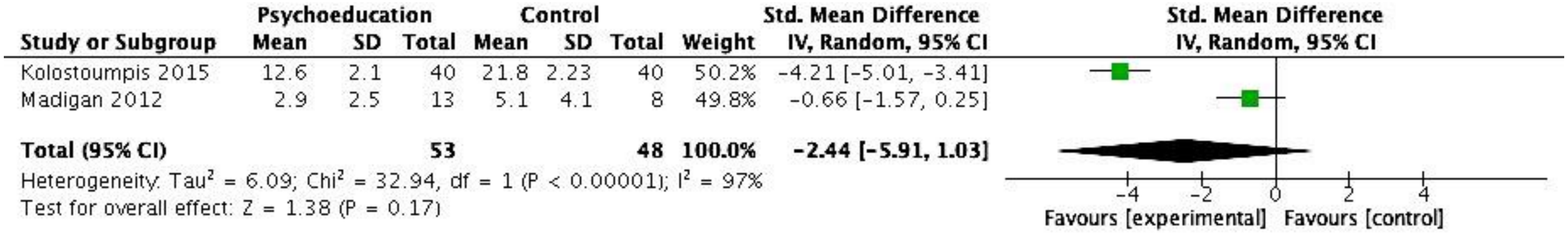


Study or Subgroup	Psychoeducation Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Hubbard 2016	29.89	7.55	18	31.36	11.56	14	33.4%	-0.15 [-0.85, 0.55]
Kolostoumpis 2015	14.2	1.51	40	22	1.89	40	33.0%	-4.52 [-5.36, -3.67]
Perlick 2010	4.6	2.9	24	8.5	8.4	19	33.6%	-0.64 [-1.26, -0.02]
Total (95% CI)			**82**			**73**	**100.0%**	**-1.76 [-4.21, 0.70]**

Heterogeneity: $\text{Tau}^2 = 4.56$; $\text{Chi}^2 = 70.78$, df = 2 ($P < 0.00001$); $I^2 = 97\%$
Test for overall effect: $Z = 1.40$ ($P = 0.16$)

Figure 7

Comparative Efficacy for Psychological Symptoms at Follow-up



Study or Subgroup	Psychoeducation Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Kolostoumpis 2015	12.6	2.1	40	21.8	2.23	40	50.2%	-4.21 [-5.01, -3.41]
Madigan 2012	2.9	2.5	13	5.1	4.1	8	49.8%	-0.66 [-1.57, 0.25]
Total (95% CI)			**53**			**48**	**100.0%**	**-2.44 [-5.91, 1.03]**

Heterogeneity: $\text{Tau}^2 = 6.09$; $\text{Chi}^2 = 32.94$, df = 1 ($P < 0.00001$); $I^2 = 97\%$
Test for overall effect: $Z = 1.38$ ($P = 0.17$)

Psychoeducation vs control: knowledge at post-treatment

Four studies were included in the meta-analysis of the effect of psychoeducation on caregiver knowledge at post-treatment, comprising 183 participants (see Figure 8). All studies reported a combined score, with the exception of one study (van Gent & Zwart, 1991), which reported separate scores for knowledge of the illness, lithium and management strategies. For the purpose of the meta-analysis these were combined into a single mean and standard deviation for each group. Effect estimates favour the intervention over the control where the standardised difference is positive ($g>0$).

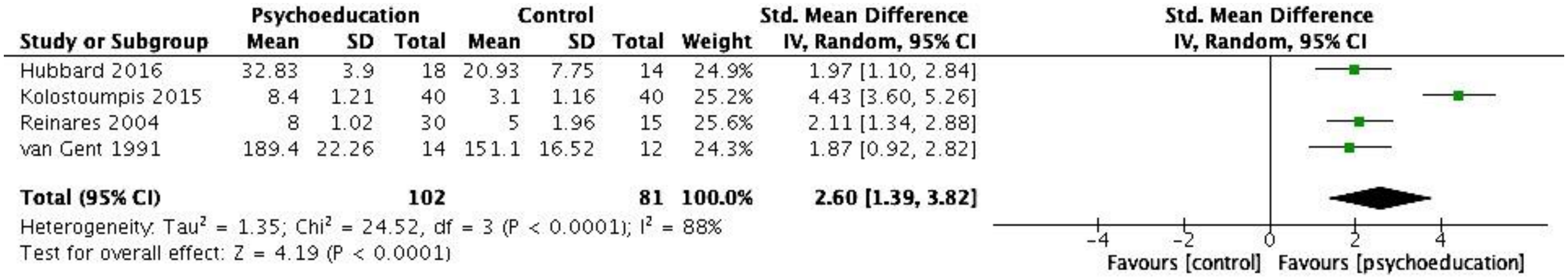
All studies reported large effect sizes. There was a very large combined effect of the intervention, $g = 2.60$ (95% CI: 1.39, 3.82). Confidence intervals were wide, but the lower bound was compatible with a large effect. However, there was evidence of high heterogeneity, $\chi2$ (3) = 24.52, $p < .001$, $I^2 = 88\%$. Excluding the substantially larger effect of Kolostoumpis et al. (2015) reduced heterogeneity to $I^2 = 0\%$, and the combined effect remained very large $g = 2.00$ (95% CI: 1.51, 2.49). However, reasons for the larger effect reported by Kolostoumpis et al. (2015) were unclear, as standard deviations were similar to those reported in another study for a scale with the same range (Reinares et al., 2004).

Psychoeducation vs control: knowledge at follow-up

Three studies were included in the meta-analysis of the effect of psychoeducation on caregiver knowledge at follow-up, comprising 127 participants (see Figure 9). Overall, there was a very large combined effect of the intervention, $g = 2.41$ (95% CI: 0.85, 3.98). Although confidence intervals were wide, the lower bound was compatible with a large effect. There was evidence of high heterogeneity, $\chi2$ (2) = 18.31, $p < .001$, $I^2 = 89\%$. Excluding the substantially larger effect of Kolostoumpis et al. (2015) reduced heterogeneity to $I^2 = 0\%$, and the combined effect remained very large $g = 1.66$ (95% CI: 0.97, 2.34).

Figure 8

Post-treatment Comparative Efficacy for Knowledge



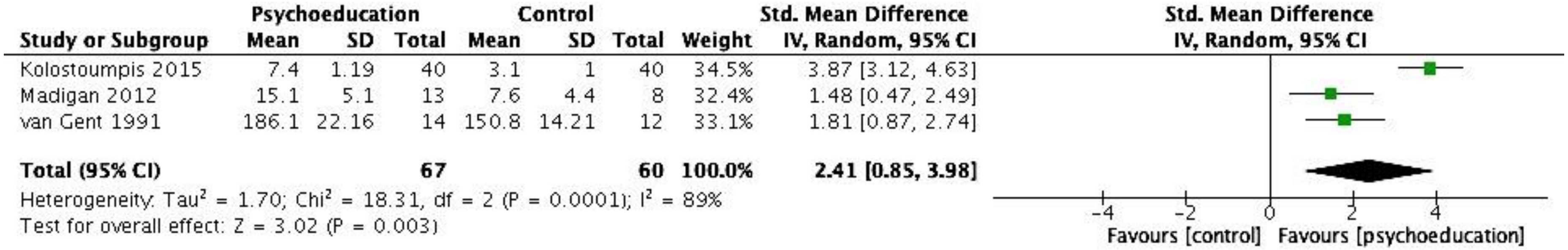
Study or Subgroup	Psychoeducation Mean	Psychoeducation SD	Psychoeducation Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Hubbard 2016	32.83	3.9	18	20.93	7.75	14	24.9%	1.97 [1.10, 2.84]
Kolostoumpis 2015	8.4	1.21	40	3.1	1.16	40	25.2%	4.43 [3.60, 5.26]
Reinares 2004	8	1.02	30	5	1.96	15	25.6%	2.11 [1.34, 2.88]
van Gent 1991	189.4	22.26	14	151.1	16.52	12	24.3%	1.87 [0.92, 2.82]
Total (95% CI)			**102**			**81**	**100.0%**	**2.60 [1.39, 3.82]**

Heterogeneity: $Tau^2 = 1.35$; $Chi^2 = 24.52$, df = 3 ($P < 0.0001$); $I^2 = 88\%$

Test for overall effect: $Z = 4.19$ ($P < 0.0001$)

Figure 9

Comparative Efficacy for Knowledge at Follow-up



Study or Subgroup	Psychoeducation Mean	Psychoeducation SD	Psychoeducation Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Kolostoumpis 2015	7.4	1.19	40	3.1	1	40	34.5%	3.87 [3.12, 4.63]
Madigan 2012	15.1	5.1	13	7.6	4.4	8	32.4%	1.48 [0.47, 2.49]
van Gent 1991	186.1	22.16	14	150.8	14.21	12	33.1%	1.81 [0.87, 2.74]
Total (95% CI)			**67**			**60**	**100.0%**	**2.41 [0.85, 3.98]**

Heterogeneity: $Tau^2 = 1.70$; $Chi^2 = 18.31$, df = 2 ($P = 0.0001$); $I^2 = 89\%$

Test for overall effect: $Z = 3.02$ ($P = 0.003$)

Comparison between psychoeducation and an active intervention

Madigan et al. (2012) was the only study to compare two active interventions: psychoeducation and solution-focused group psychotherapy. At one year follow-up, for knowledge confidence intervals ranged from no effect to a large effect in favour of solution-focused group psychotherapy, *g* = 0.80 (95% CI: 0.01, 1.59). For burden, *g* = -0.40 (95% CI: -1.17, 0.36) and psychological symptoms, *g* = -0.37 (95% CI: -1.13, 0.39), confidence intervals were compatible with both a superior and inferior effect of psychoeducation relative to solution-focused group psychotherapy.

Discussion

Summary of results

The review included nine studies, although only eight could be included in the meta-analyses. All interventions were psychoeducational. Seven were delivered to caregivers without the index patient; five in a group format, and two to individual caregivers (de Souza et al., 2016; Perlick et al., 2010). The remaining two studies evaluated family interventions, one in an inpatient setting (Clarkin et al., 1990) and one in an outpatient clinic (Fiorillo et al., 2015). One of these (Fiorillo et al., 2015) was an adaptation of family-focused therapy, based on the Falloon model of behavioural family therapy (Falloon et al., 1984; Miklowitz & Goldstein, 1997).

The current review provides some meta-analytic evidence for the efficacy of psychological interventions, specifically psychoeducation, in reducing caregiver burden and improving knowledge of bipolar disorder. For psychoeducation compared to a control, there was evidence of a small to large effect on burden at post-treatment, but this was not maintained at follow-up. There was a very large effect on knowledge at post-treatment and follow-up. The effect of psychoeducation on psychological symptoms at both post-treatment and follow-up was large, but these effects were primarily driven by a single outlying study, and due to the small number of studies included in these analyses it is difficult to interpret these results. Overall there was substantial heterogeneity between studies, confidence intervals were wide, and many of the included studies had substantial methodological limitations. It is therefore difficult to draw firm conclusions from the results of the meta-analyses.

Burden

The overall effect for burden at post-treatment was large, with four of the six studies included in the meta-analysis reporting a small to large effect and one reporting a large effect. When the outlying effect for Kolostoumpis et al. (2015) was removed from the analysis the combined effect remained moderate, although confidence intervals ranged from a small to large effect. This suggests that psychoeducation is effective in reducing burden compared to a control at post-treatment. However, sensitivity analyses showed that the effect size varied according to the type of measure used. The effect for studies using a global burden measure was large, the effect for subjective burden was small to moderate, and there was no effect for objective burden. The relative consistency between the results for subjective and global burden does support to some extent the validity of combining these measures in the main meta-analysis. The results for burden at follow-up are inconclusive, as only three studies were included in the meta-analysis, and the large combined effect was predominantly driven by the effect reported by Kolostoumpis et al. (2015).

Knowledge

The effect for knowledge at post-treatment and follow-up was more robust than that for burden. All studies reported a large effect and, although confidence intervals were wide, the lower bound was compatible with a large effect. The effect remained large when Kolostoumpis et al. (2015) was removed from the analysis, which removed any heterogeneity. However, due to lack of information about reliability and validity for the majority of measures used, these results should be interpreted with caution. Clinically, it is also not clear how much gaining knowledge enhances the experience of caregiving. However, theoretically within a stress-appraisal-coping model it seems plausible that greater knowledge could lead to more adaptive appraisals and coping strategies, and there is evidence to suggest that increased awareness of the illness is associated with more adaptive coping (Chakrabarti & Gill, 2002).

Further findings and methodological issues

For all the meta-analyses, heterogeneity reduced substantially when the results of Kolostoumpis et al. (2015) were removed. Possible reasons for the outlying size of the effects are misreporting of standard errors as standard deviations, or that the intervention was compared with pharmacotherapy alone rather than multi-disciplinary care. The comparatively higher number of patients with a less severe Type 2 bipolar diagnosis (37%) could also have made it more possible for caregivers to assimilate and implement new strategies and information. The study was also at unclear risk of attrition bias, which could have led to overestimation of effects (Higgins & Green, 2011).

Only one study showed no effect on burden (de Souza et al., 2016). This study included caregivers of adults aged 16 to 35, and caregivers aged 16 or older. Although only one caregiver was below the age of 18 and the average age of caregivers was similar to that of other studies, it is likely that the average age of patients was considerably lower.[6] It may be that the sample was representative of a different population to that of other studies. There is some evidence to support the efficacy of family-focused therapy for adolescents on patient outcomes (Frias, Palma & Farriols, 2015). It may be that interventions with a greater emphasis on improving family functioning are also more effective in improving the experience of caregivers of young adults. The study was also one of the lower quality studies, and

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[6] This information was requested but was not available.

was rated at unclear or high risk of bias in three of five domains. This may have influenced findings, although bias is more commonly associated with over-estimation of effects (Higgins & Green, 2011).

The results summarised above are derived principally from comparisons between psychoeducation and a non-active control. It is important to note that one study (Madigan et al., 2012) found that when psychoeducation was compared to an active intervention (solution-focused group psychotherapy), there was no effect for burden or psychological symptoms, and a large effect for knowledge in favour of the comparator, although the lower bound of the confidence intervals was compatible with no effect. It may be that, although psychoeducation brings some benefits compared to a control, it is not superior to an intervention with a similar level of therapeutic contact. Given that this is the finding of a single study and few details were given about the comparative intervention, it is difficult to draw clear conclusions.

The findings of this review are in line with that of the most recent meta-analysis of caregiving in severe mental illness (Yesufu-Udechuku et al., 2015), which found a large effect of psychoeducation on the experience of caregiving (largely operationalised as burden) at post-treatment, but no effect for psychological symptoms. However, the current review found no effect for burden at follow-up, whereas large effects were reported by the previous review. This may be a function of the different diagnostic groups included, or differences in how follow-up periods were combined. The finding that there was a more robust combined effect for knowledge compared to burden or psychological symptoms is in line with a previous review of interventions for caregivers of people with psychosis (Lobban et al., 2013). This may reflect the fact that the majority of interventions appeared to place a greater emphasis on management of the illness and improving family-functioning, rather than improving caregiver distress or self-care. It may be that interventions continue to be informed predominantly by the expressed emotion and relapse-prevention literature, even when caregiver outcomes are reported within studies as primary or of equivalent importance to patient outcomes.

Study quality

The studies included in the review had significant methodological weaknesses, and there is a substantial risk of biased findings. The majority were at high or unclear risk of reporting bias, and five were at high or unclear risk of attrition bias. Three were rated as at high or unclear risk of bias in four of the five domains, although one of these was not included in the meta-analysis. There was no clear link between individual study bias and effect size, aside from two studies at higher risk of bias reporting outlying effects, although these were in opposite directions.

Other methodological weaknesses included the small sample size of the majority of studies and probable lack of power, which may have led to lack of precision of estimates and increased heterogeneity. Lack of therapist fidelity may have influenced results; the majority did not report manualisation, adherence checks, or therapist training and supervision. The majority of measures of psychological symptoms and burden were reliable and valid, but this was not reported for the majority of measures of knowledge. Most studies reported exclusion criteria, but only three reported the percentage excluded and exclusion reasons. If caregivers were excluded based on reasons other than pre-specified criteria this could have biased outcomes. The control condition was not well-specified for several studies, and four did not report whether the intervention arm continued to receive treatment as usual. Effects may therefore have reflected the influence of concurrent interventions. Overall, the results of the review should be approached with caution due to these limitations.

Methodological limitations of the review

There was considerable statistical heterogeneity within the meta-analyses, and although this seemed to be primarily driven by one study (Kolostoumpis et al., 2015), there were also many other sources of diversity between studies. Notable differences included study quality, intervention duration, the nature of the comparator, caregivers’ relationship to the service-user, and the severity and type of bipolar disorder. There was also diversity in terms of the measures used, for burden in particular. The length of follow-up was inconsistent, making it difficult to draw clear conclusions about long-term efficacy of interventions. However, there was fairly high consistency in terms of the nature of the intervention, demographic features of caregivers and patients, and exclusion criteria. Aside from those reported by de Souza et al. (2016) study effects were consistently positive for burden and knowledge, although confidence intervals were wide.

Three studies differed in particularly substantial ways, and difficult methodological decisions had to be made about their inclusion in the meta-analyses. The possible difference of the study population for de Souza et al. (2016) is outlined above. For one study (Perlick et al., 2010), the inclusion criteria differed in that only caregivers showing mental or physical health problems were included, and the comparator group was basic psychoeducation delivered via DVD, which could be conceptualised as a comparative intervention or control group. Due to the nature of the delivery of the intervention this was conceptualised as a control group rather than comparative intervention for the purposes of the review, but it is worth noting that the effect may have been under-estimated. Another study (Fiorillo et al., 2015) was the only study to evaluate a family intervention and have a pseudo-randomised design. In order to increase transparency and completeness, these studies were included in the review, and it is also worth noting that the effects reported by two of these (Fiorillo et al., 2015; Perlick et al., 2010) were relatively consistent with that of other studies.

The inclusion of a pseudo-randomised trial is in line with Cochrane guidance (Higgins & Green, 2011). As argued by Herbison (2016), some trials reported as randomised may be pseudo-randomised or not randomised at all, and thus exclusion of pseudo-randomised trials is usually arbitrary. Relatedly, the approach taken to assessment of risk of allocation bias in this review reflects recent thinking about trial methodology, which proposes that trials should be assessed on the outcome of randomisation as well as randomisation method (Corbett et al., 2014). A pseudo-randomised trial may therefore be judged as similarly free from risk of bias as one that is reported to be randomised with unsatisfactory details about randomisation methods, as was the case in this review. The inclusion of a pseudo-randomised trial could therefore be seen as strength of the review, which enhanced completeness.

Other limitations of the review include the fact that only published studies were included, and it was not possible to assess publication bias. Given the wide confidence intervals for the majority of results, it may only have taken a few null findings to make the effects non-significant. The review as a whole may have been underpowered due to the small number of studies and small samples sizes, or conversely large effect sizes may have been due to chance small-study effects. Only English-language studies were included, which may have reduced generalisability, although studies were carried out in diverse locations. Generalisability may also be limited in that five of the studies used community samples, which could differ in significant ways from clinical populations. However, the inclusion of a quasi-randomised study carried out in mental health clinics (Fiorillo et al., 2015) may have increased external validity.

Implications for research and clinical practice

One of the key findings of the review is that the existing literature has considerable methodological limitations. Future research would therefore benefit from increased methodological rigour in terms of randomisation methods and allocation concealment, post-randomisation checks on important variables, clear reporting of numbers and reasons for exclusion and attrition, and appropriate use of intention to treat analyses. It would also be helpful for the nature of intervention and control conditions to be reported with greater clarity, and for trial protocols to be published and outcomes specified in advance. Studies with greater power and the use of reliable and valid measures are also needed in order to improve precision of findings.

In terms of addressing diversity between studies, it would be helpful for a consensus to be reached about the most meaningful outcomes to be targeted by interventions and the most valid measures, particularly in terms of burden. For example, it may be that interventions are unlikely to substantially improve objective burden, and measures of subjective burden should be used to evaluate efficacy. Qualitative research could be useful in exploring the needs of caregivers and their experiences of interventions. In particular, it could be helpful to explore how caregivers perceive the balance struck within interventions between improvement of illness-management and family functioning versus caregiver well-being and coping. Greater homogeneity in terms of the length of follow-up would allow more robust conclusions to be drawn about long-term efficacy.

Future studies might compare family with caregiver-focused interventions. Trials of other interventions recommended in clinical guidelines (NICE, 2014), such as support groups, would help to increase understanding of the most effective support for caregivers. Given the finding that there was no effect of psychoeducation when compared to another psychotherapeutic intervention, further studies are needed which compare psychoeducation to an intervention with an equivalent level of therapeutic contact.

Despite the most prominent models of caregiving using a stress-appraisal-coping framework, only one study (Perlick et al., 2010) assessed the role of coping style as a mediator of treatment outcome, and found that change in caregiver depression was partially mediated by changes in avoidance coping. Future research could assess the role of appraisals, knowledge and coping style as mediators or moderators of treatment effect on burden and psychological symptoms. Other moderator variables could also be explored, such as patients' clinical severity and age, and whether the intervention is delivered in an individual, group or family format.

This review provides tentative evidence that psychoeducation is effective in reducing caregiver burden at post-treatment and improving knowledge at post-treatment and follow-up. Services could therefore consider offering psychoeducation as part of multi-disciplinary care for people with bipolar disorder and their families. Due to diversity in terms of the format of interventions and the small number of studies, it is not possible to recommend interventions involving patients over those involving caregivers alone, or a particular duration of treatment. The majority of interventions were delivered in a group format, although family psychoeducation was also shown to be effective. The lack of an effect for psychological symptoms could suggest that more targeted interventions are needed to address the needs of caregivers experiencing greater levels of distress. Despite the lack of clarity about the most effective support for caregivers, the review certainly raises the importance of assessing caregivers' needs, and offering appropriate support where this is required.

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Part 2: Empirical Paper

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

Abstract

Aims: Clinical guidelines emphasise the central role of family members in supporting people with bipolar disorder, and the importance of addressing their own support needs. However, there has been relatively little focus within the qualitative literature on the challenges family members face in supporting their relative, and how they attempt to manage these challenges. This study therefore explored both the challenges and personal impact of providing such support.

Method: Semi-structured interviews were carried out 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, their relative's responses to their attempts to help, and the limitations of professional support. They described both positive and negative consequences of supporting their relative. Although participants were resourceful in managing difficulties associated with supporting their relative, they strongly valued informal and professional support.

Conclusions: Family members supporting a relative with bipolar disorder face significant challenges, and experience wide-ranging emotional and relational consequences. The findings underline the importance of professional and informal support, both in helping family members to effectively support their relative, and also to manage the significant impact on themselves. Given the diversity of family members' experiences, an individualised approach to support seems essential.

Introduction

Supporting a relative with a severe mental health problem can pose significant emotional and practical demands, and place family relationships under considerable strain (Kuipers & Bebbington, 2005; Reinares et al., 2016; van der Voort, Goossens & Van der Bijl, 2007). As a result of the move to community-based care, family members now often play a central role in supporting people with mental health problems, and their role is increasingly recognised in legislation and clinical guidelines (Department of Health, 2008; National Institute for Health and Care Excellence [NICE], 2014a, 2014b). A recent update to NICE guidelines for bipolar disorder emphasises that caregiver and family involvement can improve outcomes, and recommends their participation in assessment and management where possible (NICE, 2014a). Family members' needs should also be assessed, and where appropriate they should be offered interventions such as psychoeducation or peer support groups, in order to enhance their capacity to support their relative and improve their own wellbeing. However, there remain significant variations in service provision, and relatively little is known about family members' experiences and needs, and the type of support they value (National Collaborating Centre for Mental Health [NCCMH], 2014a; Pompili et al., 2014).

Bipolar disorder is characterised by recurrent episodes of mania or hypomania and, for the majority, depression, with some experiencing mixed episodes (American Psychiatric Association [APA], 2013; World Health Organisation [WHO], 1992). Given the significant heterogeneity in presentation among those with a diagnosis, there is increasing recognition that a dimensional model may be more appropriate than one of discrete diagnostic entities (Angst, 2007; British Psychological Society [BPS], 2014; NCCMH, 2014a). Lifetime prevalence in the UK is estimated at 1.3% (Smith et al., 2013). Bipolar disorder is chronic and recurrent for most, with a four-year risk of relapse of 68% (Simhandl, König & Amann, 2014).

It is associated with high levels of distress and difficulties in functioning, both during and between episodes, with as few as 33% making a full recovery of social and occupational functioning (Huxley & Baldessarini, 2007; NCCMH, 2014a).

Social support and the presence of close relationships is associated with a range of positive outcomes in bipolar disorder, such as reduced relapse, inter-episodic remission, and lower depressive symptom severity (Cohen, Hammen, Henry & Daley, 2004; Johnson, Lundström, Åberg-Wistedt & Mathé, 2003; Weinstock & Miller, 2010). More broadly, people with psychological difficulties tend to seek support from close relationships prior to, and alongside, professional support (Barker & Pistrang, 2002; Barker, Pistrang, Shapiro & Shaw, 1990). Researchers have drawn attention to common processes underpinning both formal and informal helping relationships, such as empathic involvement, enabling others to make new meaning, and promoting change (Barker & Pistrang, 2002). However, there is a lack of clarity about the challenges and benefits of providing informal support in the context of bipolar disorder, and what helps or hinders family members' efforts.

There is evidence from outside the bipolar literature that the support process can involve significant difficulties for the support provider and recipient. In their studies of supporting a spouse following a heart attack, Coyne and colleagues conceptualise illness as a stressor on both parties, with the supporting partner struggling to manage their own needs while supporting their spouse (Coyne, Ellard & Smith, 1990). What is helpful for one may not be helpful for the other, giving rise to various 'dilemmas of helping'. For example, the supporter's distress and concern may lead them to behave in ways which impinge on the support recipient's autonomy. Viewed from this perspective, it is unsurprising that providing support can be a fraught process. The supporter's intention may not correspond to the impact of their actions on the support recipient, with attempts to offer advice or support change potentially being experienced as intrusive or critical (Barker & Pistrang, 2002; Goldsmith, Lindholm & Bute, 2006; Trief et al., 2003). Providing support can therefore pose significant challenges for the support provider (Harris, Pistrang & Barker, 2006).

Features of bipolar disorder may mean that it poses distinctive challenges and dilemmas for family members. The cyclical nature of the disorder, and rapid and extreme changes in mood, may mean that family members are put in a position of containing risk before services can be involved (Chatzidamianos, Lobban & Jones, 2015). Symptoms of mania such as risk taking and aggression, and the high risk of suicide associated with depressive episodes, are extremely challenging for family members to manage, and can place family relationships under substantial pressure (Bauer et al., 2011; Beentjes et al., 2011; Clements et al., 2013; Fletcher, Parker, Paterson & Synnott, 2013). During hypomanic or manic episodes people with bipolar disorder may have limited insight into the impact of their behaviour and not see themselves as in need of help, potentially making it more difficult for family members to prevent the negative consequences of more severe episodes (Beentjes et al., 2011; BPS, 2014; NCCMH, 2014a). Family members may struggle to strike a balance between supporting their relative while not impinging on their autonomy, particularly around monitoring signs of relapse (Doherty & McGeorge, 2014). Doherty and McGeorge (2014) found that, although young adults with bipolar disorder sometimes found family members' involvement in monitoring their mood helpful, this could also be experienced as controlling.

Despite the distinctive features of bipolar disorder, research about family members' experiences is less developed than that concerning relatives of those with schizophrenia or dementia (Chatzidamianos et al., 2015; Ogilvie, Morant & Goodwin, 2005; Van der Voort et al., 2007). As a result, there have been calls for further research, in order to enhance understanding of how interventions and services can best support family members and caregivers (Pompili et al., 2014; van der Voort et al., 2007).

Quantitative studies have tended to focus on a limited number of inter-related aspects of caregiving in bipolar disorder, particularly caregiver burden and expressed emotion. The majority of caregivers experience moderate to high levels of burden, and this is associated with increased physical and mental health difficulties, and health service use (Perlick et al., 1999; Reinares et al., 2006; Steele, Maruyama & Galynker, 2010). Expressed emotion comprises criticism, hostility and ‘emotional over-involvement’, which refers to inappropriate emotional responses, levels of self-sacrifice, and intrusiveness (Leff & Vaughn, 1985). High burden and expressed emotion are associated with poorer patient outcomes, such as increased relapse and symptomology (Reinares et al., 2016). However, these associations may be moderated by other factors such as caregiver coping style, appraisals, perceived stigma, and social support (Chakrabarti & Gill, 2002; Perlick et al. 1999, 2007a, 2007b). Interventions such as family-focused therapy and psychoeducation are based on these constructs, and aim to modify caregiver appraisals, enhance coping and communication skills, and reduce expressed emotion, as well as providing information about treatment and management (Miklowitz & Goldstein, 1997; Perlick et al., 2010).

Although quantitative studies have been useful in identifying important aspects of caregiving, they have been criticised on the basis that the outcomes studied are defined by health professionals and researchers, and may not capture important aspects of family members’ experiences (Ogilvie et al., 2005; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015). Qualitative research can be invaluable in understanding the experiences of family members of those with a severe mental health problems, and the aspects of providing support that are most important to them (Wainwright et al., 2015). Qualitative studies have also highlighted family resilience, and positive aspects of providing support often not captured by quantitative studies (Maskill, Crowe, Luty & Joyce, 2010; Stein & Wemmerus, 2011; Veltman, Cameron & Stewart, 2002).

A small body of qualitative studies has focused specifically on family members' experiences of supporting a relative with bipolar disorder. These studies have predominantly explored the impact of providing support on family members, and have highlighted the complexity of their emotional responses, including feelings of anger, depression and loss (Granek, Danan, Berudsky & Osher, 2016; Tranvag & Kristoffersen, 2008; van der Voort, Goossens & van der Bijl, 2009). Family members also report a sense of strain and isolation as a result of the social and practical effects of caregiving, and struggle to balance their needs with that of their relative (Jönsson, Skärsäter, Wijk, Danielson, 2011; Maskill et al., 2010; Tranvag & Kristoffersen, 2008; van der Voort et al., 2009). However, positive aspects of family members' experiences have also been described, such as developing an increased sense of compassion, and growing closer to their relative (Granek et al., 2016; Maskill et al., 2010). Some ways in which family members manage the difficulties have been elucidated, such as coming to an acceptance of the situation and making time for themselves (Rusner, Carlsson, Brunt & Nyström, 2012; Tranvag & Kristofferson, 2008; van der Voort et al., 2009).

The majority of studies have not explored experiences of professional support in detail, but have found these to be predominantly negative, with family members describing a lack of adequate support available for them and their relative, and being excluded or overlooked by services (Maskill et al., 2010; Tranvag & Kristofferson, 2008; van der Voort et al., 2009). Where family members have been involved in service-users' care, this can have substantial benefits for the service user and family member (Peters, Pontin, Lobban & Morris, 2011). However, numerous barriers to family members' involvement have been identified, including the service-user's desire for autonomy, the culture of mental health services, staff training and workload, and rules around confidentiality (Chatzidamianos et al., 2015; Peters et al., 2011).

Although these studies have been useful in elucidating important aspects of family members' experiences, their focus is predominantly on the impact of providing support, rather than the challenges family members face when attempting to help their relative, and how family members endeavour to overcome these challenges. Furthermore, the majority have focused on the experiences of spouses or parents, thus neglecting the experiences of other close family members such as siblings and adult children. Studies focusing exclusively on the experiences of family members of a person with bipolar disorder have all been carried out outside the UK, in areas such as Scandinavia (Jönsson et al., 2011; Tranvag & Kristofferson, 2008) and the Netherlands (Van der Voort et al., 2009); experiences of mental health difficulties and services in these countries may differ significantly to those within the UK.

Existing studies also have some methodological limitations, such as a lack of a detailed description of the methodological approach employed (Granek et al., 2016; Maskill et al., 2010), and poorly articulated or unelaborated themes (Granek et al., 2016; Rusner et al., 2012). Some aspects of good practice guidelines (Barker, Pistrang & Elliott, 2016; Elliott, Fischer & Rennie, 1999) do not seem to have been adhered to, such as disclosure of the researcher's perspective (Granek et al., 2016; Jönsson et al., 2011; Maskill et al., 2010; Rusner et al., 2012; Tranvag & Kristokkerson, 2008); and the carrying out of credibility checks through 'analytic auditing' (Rusner et al., 2012 Tranvag & Kristokkerson, 2008) or 'testimonial validity' (Jönsson et al., 2011; Maskill et al., 2010; Rusner et al., 2012). These limitations reduce the confidence that can be placed in their findings.

Aims of the current study

In summary, there are few in-depth qualitative studies focusing on both the challenges and impact of supporting a relative with bipolar disorder, and none carried out among a UK population. Despite recent updates to clinical guidelines emphasising the centrality of family members to the management of bipolar disorder, there remains a lack of clarity about family members' needs and experiences of professional support, with guidelines being based predominantly on studies of the experiences of those supporting a person with a diagnosis of schizophrenia or psychosis (NCCMH, 2014a, 2014b). Whilst there may be commonalities in experiences, the symptoms of bipolar disorder are likely to place distinctive demands on family members.

Qualitative methodologies are particularly valuable in gaining an in-depth understanding of personal experience and meaning, and can help give voice to under-represented populations (Pistrang & Barker, 2012). Qualitative methodologies are also valuable in understanding experiences of mental health services (Centre for Reviews and Dissemination, 2009). Furthermore, an inductive approach can allow unexpected findings to emerge, and thus may be useful when investigating a relatively under-researched area (Barker et al., 2016). This study therefore used a qualitative approach to understand the challenges of supporting a relative with bipolar disorder, and the impact on the supporting family member. Factors that help or hinder family members' efforts to manage the difficulties associated with supporting their relative were explored, including experiences of professional support.

The main research questions were:

1. What challenges do family members face in supporting a relative with bipolar disorder, and how do they attempt to manage them?

2 What is the impact of providing support on family members?

Method

A note on terminology

In the following sections, participants will be referred to as 'family members' and the person with bipolar disorder as their 'relative'.

Ethical approval

The study received ethical approval from University College London Research Ethics Committee (see Appendix A).

Service-user involvement

During the design phase of the study a family member of a person with bipolar disorder, recruited from a voluntary sector organisation, commented on the information sheet and interview schedule in order to ensure they were comprehensive and relevant. They were refined in light of their comments.

Recruitment

Eligibility criteria were:

1. Close family member of a person with a diagnosis of bipolar disorder. Eligible family relationships included parents, adult children, partners, spouses, and siblings. Only one family member per index person could take part.
2. The family member perceived themselves as providing substantial support to their relative.
3. Aged 18 years or older.
4. The family member was not experiencing a major crisis in their circumstances, e.g. a bereavement.

Participants were recruited through voluntary sector mental health and carers' organisations and support groups, advertisement for the project on the university website, and word of mouth. Organisations were asked to publicise the study through email, newsletter, or by giving out information at support groups. The researcher attended a carers' workshop and a support group in order to inform potential participants about the study. Initially a consecutive sampling approach was employed. However, as recruitment progressed efforts were made to recruit greater numbers of male participants and people from minority backgrounds in order to obtain a more representative sample. Recruitment ceased when the data-set seemed sufficiently rich to capture both commonalities and diversity in family members' experiences.

Procedure

A recruitment flyer was circulated by participating organisations, with information about the study and the researcher's contact details (see Appendix B). Once family members expressed an interest in participating, an initial phone call was arranged to screen for eligibility, give further information about the study, and provide the opportunity for the individual to ask questions. Interviews took place either at the participant's home, the university, or the voluntary sector organisation they had been recruited from, according to preference and availability. Participants were given an information sheet and gave written informed consent prior to the interview (see Appendices C and D). After the interview participants were asked to fill out a demographics sheet about themselves and the relative with bipolar disorder, and were given a £10 voucher of their choice.

Participant characteristics

Of the 31 family members who expressed an interest in participating, 18 (58%) took part, seven (23%) declined, five (16%) were excluded due to the need to recruit a more diverse sample, and one (3%) did not meet inclusion criteria. Reasons for declining to participate included lack of time, or the relative with bipolar disorder being opposed to the family member's participation. Sixteen of the final participants were recruited through voluntary sector organisations and support groups, one through the UCL website, and one through word of mouth.

Of the 18 family members who participated, 14 were women and four men. Six were parents, five partners or spouses, three adult children, three siblings, and one both a partner and parent of two relatives with bipolar disorder. The mean age was 48 (range: 31 to 67). Eight were white British, four were from other white backgrounds, four were Asian or Asian British, and two were from a mixed background. The majority (n=13) had degrees or higher qualifications. The most common sources of support accessed by participants were voluntary sector mental health and carers' organisations or support groups. Nearly half (n=8) had accessed individual therapy, counselling or family therapy.

The mean age of the relative with bipolar disorder, as reported by the participating family member, was 43 (range: 20 to 79). Ten had a diagnosis of Type I bipolar disorder, two had Type II bipolar disorder, and two Type I with rapid cycling; the remaining four participants were unsure of their relative's diagnosis. Two had had the disorder for over 30 years, seven for between 20 and 30 years, three for between 10 and 20 years, and six for under 10 years. Most (n=16) had no other mental health problems. The majority had taken medication in the last few years (n=17), accessed community mental health services (n=15), and been hospitalised in the past (n=14). Other sources of support included voluntary sector mental health organisations or support groups (n=7), and private mental health services or therapy (n=4).

Semi-structured interview

A semi-structured interview schedule was developed for the study, drawing on published guidelines (Barker et al., 2016) (see Appendix E). It was piloted with three participants, and refined after reading of research transcripts and discussion with the author's supervisors. The preliminary section of the interview covered background information about the relative with bipolar disorder. The main interview then explored the participant's experiences of supporting their relative, including how they attempted to support them and the challenges associated with this, the impact of supporting their relative on them, how they managed supporting their relative, and their experiences of services and support for themselves. Participants were initially asked broad questions, with follow-up questions and probes used as needed. The interview schedule was used flexibly with no fixed structure, thus enabling participants to speak about the aspects of their experiences that were important to them.

The mean length of interviews was 1 hour and 40 minutes (range: 60 to 194 minutes). All interviews were recorded and transcribed verbatim using Express Scribe software (V5.77, NCH Software, 2015). Three interviews were transcribed by the researcher, two by a professional transcription company and thirteen by volunteer research assistants (who were undergraduate psychology students recruited through the university department). Research assistants were given an example excerpt from a transcript and guidelines for transcribing adapted from Barker et al. (2016). These covered confidentiality; the level of detail required within transcripts; and how to indicate paraverbal features and utterances, special emphases, silences, and incomplete sentences. Any identifying information was removed from transcripts.

Analysis

The analysis was approached from a phenomenological perspective, in that it aimed to understand participants' subjective experience. The transcripts were analysed according to the Framework approach (Ritchie & Spencer, 1994; Spencer, Ritchie, O'Connor, Morrell & Ormston, 2014). This is a form of thematic analysis developed for use in applied policy research. It involves a systematic process of identifying key themes in the data. The approach is data-driven, while allowing the incorporation of *a priori* questions or theoretical issues into the analysis. NVivo data analysis software (V11.4, QSR International, 2017) was used to assist in the analysis.

The analysis proceeded through several stages, following the guidelines set out by Spencer et al. (2014). The first stage involved familiarisation with the data, both through transcription, listening to the recordings, and close reading of transcripts. Initial annotations were made, noting key ideas in the data. A summary sheet was compiled for each transcript, recording the initial ideas identified. The second stage involved developing initial codes for the data which captured the ideas expressed in phrases, sentences or larger sections of text, where possible using participants' words to label codes. The third stage involved the synthesis of the initial codes into a coding framework. Codes were organised into preliminary thematic categories, which were informed by the research aims and areas of questioning, but also by emergent issues and themes arising from the data. In the fourth stage, the framework was applied to each transcript. Single passages or phrases could be assigned to more than one code and thematic category.

The fifth stage involved compiling a set of charts which summarised the relevant data extracts for each category. The different 'elements' or units of meaning present within each code were also summarised in a Word document. The sixth stage involved the synthesis of the data into a final thematic map comprising a number of themes and sub-themes. Codes were collated or divided as appropriate in order to achieve internal consistency and distinctness across themes. Themes were continually checked against the data and further refined. While some remained similar to those identified in the preliminary framework, others cut across the initial categories. The frequency of themes across the data set was considered within this process. While some occurred across the majority of transcripts, others were highly prominent for a sub-set of participants. Once the thematic map was finalised, the final stage involved compiling charts for each theme, which recorded the quotations indexed for each participant. This facilitated further checking that themes were supported by, and captured the diversity of, the data. See Appendix F for examples of the framework analysis.

Credibility checks

In line with good practice guidelines for qualitative research (Barker & Pistrang, 2005; Elliott et al., 1999; Santiago-Delefosse, Gavin, Bruchez, Roux & Stephen, 2016), a number of methods were used to ensure the credibility of the results. A consensus approach was employed throughout the process of data collection and analysis. The author's supervisors read a selection of transcripts and initial interpretative ideas were discussed. The preliminary coding of selected transcripts and the coding index were reviewed, and different possible interpretations or refinements discussed. Different ways of organising the thematic map were also considered. Participant quotations were used throughout the process of data analysis, in order to ensure that the themes identified were grounded in the data. An audit trail was also kept and reviewed by the author’s supervisors, in order to ensure the process was transparent and logical. Testimonial validity checks were carried out, whereby each participant was invited to review a summary of the main themes of their interview, and comment on its accuracy and completeness. Summaries were sent to 16 participants, and 11 gave feedback. Of these, 10 said they felt the summary accurately reflected their interview, while one suggested minor amendments. See Appendix G for the respondent validation invitation letter. A sample of an interview summary is not provided in order to preserve confidentiality.

Researcher perspective

In accordance with good practice guidelines (Barker & Pistrang, 2005; Elliott et al., 1999), the author’s perspective is outlined, in order to aid the reader in evaluating the conclusions of the research. I am a white woman in my early thirties. I have personal experience of supporting a person with bipolar disorder. I also have some experience of supporting family members of people with bipolar disorder as a trainee clinical psychologist, as well as knowledge of the theoretical literature around supporting someone with a severe mental health problem. As a result, I did have some preconceptions about the nature of family members’ experiences. For example, I imagined that participants would find it difficult to support their relative, and that manic episodes might be particularly challenging.

In line with good practice guidelines I attempted to ‘bracket’ my assumptions as far as possible, in order to avoid imposing meanings on the data (Fischer, 2009). Throughout the research process I used a research journal and supervision in order to reflect on how my assumptions might influence data collection and analysis. I also reflected on how my earlier interpretations of the data might influence the ongoing process of analysis, in order to prevent this obscuring alternative readings. Despite this, I acknowledged that my prior experience and knowledge could also aid interpretation. I therefore did not entirely discount these, but attempted to actively engage with how my experiences and preconceptions might be impacting on the research process. (Ahern, 1999).

Results

The analysis generated 12 themes, which were organised into two domains corresponding to the research questions: (1) The challenges of supporting a relative with bipolar disorder and; (2) The impact of providing support on family members. Domains, themes and subthemes are summarised in Table 1. Themes are presented below with illustrative quotations.

Domain 1. The challenges of supporting a relative with bipolar disorder

Participants faced numerous challenges in their efforts to support their relative. The themes in this domain concern participants' experiences of these challenges, how they attempted to manage them, and what helped or hindered their efforts.

1.1 Not knowing: "like being in a minefield"

Participants described a sense of shock, fear and uncertainty when their relative initially became unwell. They struggled to comprehend the changes in their relative, and to know how to support them.

> *We would feel like, you know, what's happening to her, why is she being, behaving like this, you know? And, um, we couldn't sort of, we couldn't deal with it because we didn't really understand, um, what was going on.* (P18, father)

> *I wasn't really aware of bipolar as an illness…and I'd just never seen anybody having a manic episode, so I didn't actually know what was happening and it's really quite terrifying.* (P17, daughter)

This sense of uncertainty was exacerbated by a lack of explanation from professionals, and difficulties in gaining information. Participant 10 described *'not knowing what questions to ask'*, and professionals being unforthcoming with

Table 1

Summary of Domains, Themes and Subthemes

Domains	Themes	Subthemes	Prevalence
(1) The challenges of supporting a relative with bipolar disorder	1.1 Not knowing: "like being in a minefield"		14
		Not knowing or understanding at first	6
		Lack of explanation and information	5
		Professional support helped understand, gain information and strategies	12
		Bipolar is different for everyone	3
	1.2 It's out of my control: "Sitting waiting for the next thing to happen"		16
		Sitting waiting for the next thing to happen	11
		Upheaval when relapses	7
		Unpredictability and lack of control in mania	8
		Fear of suicide	7
		Hard to influence relative's mood; waiting for the episode to pass	11
	1.3 "It's all of us in it together"		14
		Ability to work together	14
		Lack of acceptance and openness of relative, leads to anger and hurt	6
		Ability to communicate when notice warning signs	8
	1.4 "Treading on eggshells"		11
		Treading on eggshells	8
		I try to slot these little ideas into place	6
		Addressing the impact of relative's behaviour	7
	1.5 Times of crisis: "between a rock and a hard place"		12
		Relative engages in risky or aggressive behaviour	8
		Dilemma of whether to involve services	4
		Responsiveness of services	8
		A shared plan	6
	1.6 "I have to make my voice heard"		14
		Professionals' lack of openness to involvement, dismissing perspective	9
		Barriers to involvement	5
		Working with professionals, giving feedback	8

(2) The impact of providing support on family members	2.1 It dominates my life		16
		It dominates my life, putting things on hold	10
		Impact on wellbeing	9
		Taking a step back	15
	2.2 Feeling alone: “nobody else knows what it’s like”		18
		Feeling alone, lack of support	12
		Not able to tell others	7
		Others not understanding	11
		Support from people who understand	9
		You’re not alone (support groups)	8
		Differences to others in support group	5
	2.3 “Caught in the middle”		14
		Caught in the middle of conflict	7
		Differences/conflict with other family members	10
		Impact on other family members and relationship with them	6
		Closer to other family members	5
		Talking together	6
	2.4 “A loss of him”		18
		Loss of person and relationship when unwell	9
		Separating the person and the illness	8
		Lasting changes in relative and relationship	11
	2.5 “It's brought us closer”		7
		Closer together	5
		Talked about things wouldn’t have talked about	5
		Talk more openly when relative unwell	2
	2.6 Acceptance and hope		17
		Acceptance	8
		Positive personal changes	9
		Hope for the future	7

information.

> *No, they never made a point of like approaching us…you had to search them out and you know, "How is she doing?", but they never explained anything…Again just not knowing, especially the first time, not knowing what to expect even. And nobody telling us what to expect. It was like being in a minefield.* (P10, mother)

A minority felt that doing their own research gave them a sufficient understanding of the disorder and how it could be managed. However, it was more commonly felt that this understanding was only gained from contact with professionals involved in their relative's care, or obtaining their own support. Participant 11 described how speaking with professionals reduced his sense of fear, and helped him feel more optimistic about the future.

> *It helps us, because if they hadn't, we would've been completely in the dark. And what some people don't seem to understand is that if you don't know, it makes you more worried and more stressed than if you know… 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)

Professional support or attending support groups helped participants gain practical strategies, for example how best to support their relative and communicate with them when they were unwell. Some emphasised gaining an understanding of their relative's behaviour, and how they might be thinking and feeling.

> *You do just kind of think things like, "Am I making it worse by not contradicting him, or is contradicting him making it worse?" and that kind of thing. So it was helpful to have those guidelines.* (P2, sister)

> *And [mental health professional] was able to explain it…she behaves like that because, as far as she's concerned she's having a wonderful time, she's on a high…All the time there's pain and destruction all around her, but because of the way she's feeling, she can't see that.* (P11, father)

For some, a sense of uncertainty persisted, as it took months or years to gain support. Three participants also reflected on it being difficult to have clear cut guidelines about how to manage the difficulties, due to bipolar manifesting differently in different people. Learning to manage it was therefore to some extent a process of *'trial and error'* (P11).

> *I think every case is different so nobody, you know, even if you speak to other people who've um had experience of bipolar it'll be different for them. So it's something you have to work out for yourself.* (P7, mother)

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

A sense of instability and unpredictability pervaded participants' accounts, partly due to the cyclical nature of the disorder, but also the severity of their relative's changes in mood and behaviour. Participants described a constant sense of uncertainty and tension as they would not know when their relative might relapse, and felt they lacked control or influence over their relative's moods and behaviour. They emphasised the sense of upheaval when their relative became unwell, with many having to cancel plans or take time out of work to support them.

> *I mean 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, and probably not sleeping, and then feeling bad again. So I'm just sort of sitting, waiting for the next thing to happen, kind of thing.* (P7, mother)

> *It's a physical gut reaction, um you know, what's he going to come back like, is he going high, is he going low, have we got to go to the doctor, have I got to sort of put everything on hold…your life changes, your daily pattern of life changes.* (P8, wife)

Some emphasised the unpredictability of their relative's behaviour during manic episodes. Participants had a heightened sense of uncertainty and worry, as their relative was more likely to go out and potentially engage in risky behaviour, leaving them unable to intervene and not knowing what might happen.

> *And I think mania in and of itself is just like, you know, it's like the human equivalent of a rollercoaster ride…it makes you feel really out of control.* (P17, daughter)

> *He'd go off, like he wouldn't answer his mobile…So I'd worry about that, 'cos he was vulnerable as well...* (P9, daughter)

Several highlighted the difficulty of coping with the possibility that their relative might attempt suicide during depressive or mixed episodes, and being unable to guarantee their safety.

> *The most, the most difficult thing is when she's suicidal. It's the most scary because you, you um, you know 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, you know, you thank God in the morning when you see her, she's still breathing.* (P18, father)

Participants struggled to make a difference to their relative's mood, both during depression and mania, and had a sense of lacking control over the situation.

> *In that situation, it's all out of my control really. Um I can do the same things, I can reassure her if she's getting anxious or scared...But I don't think she listens to me as well then. I think her mind is just like flicking away and it's so active, that it's very hard for her to hold on to something…* (P10, mother)

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

Given the difficulties in helping their relative, some felt the most they could do at times was to wait for the episode to pass. 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 and instability of their relative being unwell.

> *It's almost like a huge storm… the storm's going to come whether you like it or not. But you can take precautions to protect yourself and ride it out.* (P16, partner)

> *I always tell myself, "Look, you know, I know she's going to come out of this and she'll feel better. Whether it's tomorrow or the day after or whatever, she will feel better." Um, you know, so I kind of look forward to that and I, I, I um, I just feel like ok this will, we will get through this…* (P18, father)

1.3. "It's all of us in it together"

Participants had diverse experiences in terms of how much they were able to work with their relative to manage the difficulties. Some described their relative communicating to them ways they could support them, and managing the challenges together. Others found it difficult to have open discussions with their relative, making it hard to know how to help.

> *He kind of knows what he needs so he can instruct me… he can guide me and tell me, and support me to support him, if that makes sense.* (P15, partner)

> *Many times we've found we couldn't talk to her…she didn't want to talk about things…So we just felt like we couldn't help her in any way…* (P18, father)

Some felt it was difficult to communicate with or support their relative because they did not fully accept they had a problem.

> *If I suggest something to do…she just won't…I think she's probably only starting to accept that she has this condition.* (P7, mother)

Given the impact the situation had on them, some felt a sense of anger or hurt due to their relative's failure to accept and manage the difficulties, or their lack of involvement in decisions around this. Participant 17 reflected on the difficulty of balancing her mother's right to privacy with the need to accept the impact of her difficulties on family members.

> *[Relative with bipolar disorder] needs to accept that they have family members who are also hugely affected by it and therefore, in an ideal world, that they would…manage it in a way that wouldn't hurt you so much…I just feel pretty angry about it…I find it hard to understand why somebody would [stop their medication] without really kind of, um, well just discussing it. But then it is a tension…one should have aspects of one's life that one feels are private to oneself, but this is difficult part of an illness like this you know? It's never just going to be you, it's all of us in it together…* (P17, daughter)

The extent to which participants were able to work together with their relative became particularly important when they showed warning signs of becoming unwell. Around a third were able to discuss this openly to some extent, and take steps to prevent things escalating, for example supporting their relative to access help or adapt their lifestyle. Participants spoke about needing to pick up on warning signs early; if their relative had become too unwell they might be resistant to receiving help, particularly during manic episodes.

> *And it was about monitoring, so things like um picking up on signs when he was slightly going into manicness… I'd encourage him, we'd have an appointment… 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)

Some described their relative recognising when they were becoming unwell, and being actively involved in managing this. Two participants in particular felt they were able 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 when they noticed warning signs of relapse, 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 and for him to convince me that really no he isn't going high, or the other way round……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 [medical professional]…Before that stage um we'll both look at his lifestyle...* (P8, wife)

However, others struggled to communicate with their relative about fluctuations in their mood. Participant 17 felt that raising the possibility her mother might be becoming unwell could lead her to feel *'criticised'* or as if she was *'under a glass bowl'*, and it was therefore difficult to work together to manage her moods.

> *For me it would be better if there was a way that we could talk more openly about it. Um, we could use some kind of tools or some kind of indicators, or some markers or something that we were all ok with…But at the moment it's nothing like that, it's all just amorphous and ambiguous.* (P17, daughter)

1.4. "Treading on eggshells"

Participants described a sense of *'treading on eggshells'* (P11) when trying to help their relative, and it being difficult to know what might inadvertently anger them or exacerbate their mood.

> *We don't know how to help her, we don't know what to say because sometimes, um, something you say actually turns out to be the wrong thing to say, and if, you know, she gets upset, makes her feel worse.* (P18, father)

> *When she's down I'm thinking, "Now how must I be when she goes up?" so that I don't antagonise her, or upset her, or say, or refer to her being down. You know it's like um having to be careful what you say.* (P7, mother)

At times their relative would react angrily or irritably when participants made suggestions about how they might manage the difficulties.

> *She gets irritable and gets impatient with me. Because I'm kind of… concerned that she's going to go over the top and go out and drink, or spend too much money um. So if I'm reminding her of those things, you know, "Be careful", she's like, "Oh yes Mum, no don't worry, don't worry it's alright!"* (P7, mother)

Two participants avoided raising issues or making suggestions around their relative's difficulties, as they feared this might lead to the relationship breaking down, and therefore being unable to support their relative at all.

> *I really can't make any um good suggestions…So a lot of it is just listening to her…and not challenging her actually at the moment. … she's just ostracised [other family member], and I don't want that to happen… You know I think I need to stick in there to be a support.* (P3, sister)

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

Participants also described it being difficult to address their relative's behaviour, and the impact this had on them, as they feared this would negatively impact on their mood.

> *I don't want to say it because I don't want him to feel awful. It's a really hard thing to do because I'm worried about him going down...* (P6, daughter)

As a result of these challenges, participants tried to find ways to make suggestions or address difficulties that might be better received. They described '*picking their moments'* (P1), for example waiting until their relative was calm, or for issues to come up in conversation.

> *…if we can, very rarely things crop up in conversation with our daughter. We can sort of slip a little gem in, you know. Why don't you try this or, you know…?* (P11, father)

They described choosing their words carefully, trying to be *'more subtle*' (P7) about how they made suggestions, and focusing on *'maybe one or two things* (P2), rather than a number of issues. Attending a workshop for family members had helped participant 1 adapt her communication style.

> *I've kind of used those sort of strategies…rather than saying "I really think you should take [medication]", saying, "You know, you could consider". Offering it as something, you know, he might choose to do.* (P1, sister)

Some felt it was also important to address the impact of their relative's behaviour on them, but chose carefully how and when to do this.

> *I mean I'm not saying that I am totally walking around on eggshells because, I also feel that um my feelings are important, and I will express them to her. Um it's just putting them in a slightly gentler way I guess… I try to sort of just like slot these little ideas in when I feel they'll be received.* (P7, mother)

Others found it helpful to express their emotions more openly, and in some instances felt this led to a change in their relative's behaviour.

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

1.5 Times of crisis: "between a rock and a hard place"

During crises participants faced numerous challenges in terms of how best to support their relative, particularly during manic episodes. As well as engaging in risky behaviour some could become aggressive, but did not perceive themselves as being unwell or needing services' involvement. Suggesting they might need support or attempting to keep them safe could lead to conflict or, for a minority, violence.

> *When he's in that manic state it becomes impossible to talk to him because he will just be in denial about any kind of problem. And, he will also get very angry if any kind of, if you mention contacting any of the professionals.* (P1, sister)

> *He was out at like two o'clock in the morning, like high. Anyway, and he went to me, he said um, "If you make this stop…I'm gonna be really upset…" He's so angry, this time he didn't want to go to the doctor…* (P5, wife)

Four participants in particular described difficult dilemmas in terms of whether to risk the situation escalating further, or whether to act without their relative's knowledge and involve services, which could anger them or damage their relationship.

> *You're basically, you're between a rock and a hard place. If you call the police, you know, they might do something that might help, but your brother will hate you and be really angry at you. And if you don't, you know, you might find your brother dead in the morning, you know…So, it's, it is very difficult.* (P1, sister)

Decisions about how to respond in a crisis were made harder by the fact that participants were aware that being hospitalised could be unhelpful, and had had the painful experience of witnessing their relative becoming very distressed or violent when they were sectioned or hospitalised.

> *I think that never leaves you. You know, 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)

> *We got him to the hospital, the doctors started to talk to him and he completely flipped and they had to restrain him. Um and those times were hard…it does kind of pull you in different directions…* (P9, daughter)

Acting without their relative’s knowledge ran the risk of the relative feeling there had been a *‘conspiracy’* (P1) against them. Two participants felt the steps they had taken to manage crises had damaged their relationship, and led to their relative excluding them from involvement in their care, leading to a sense of frustration and fear for the future.

> *It’s just frustrating, ‘cos I know from my side…I know that I wasn’t doing anything to try and make his life any worse.* (P1, sister)

> *Because she won’t let me have anything to do with her mental care…I don’t know what I could do if it happens again, so...I feel pretty helpless…* (P11, father)

Although some had had positive experiences of services such as crisis teams, others described lacking support, and felt they were left deciding whether the situation was serious enough to call the police or have their relative sectioned.

> *You know, when you call them up if there’s actually a crisis, the irony is they’ll do absolutely nothing…So we are left with deciding, is this serious enough to contact the police?* (P1, sister)

Participants expressed their desire for better communication with professionals, and a shared plan with them and their relative about how to respond in a crisis. The minority who did have a shared agreement felt this reduced their sense of uncertainty and could prevent crises escalating.

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

> *He has an um advance directive which was agreed with all the people involved…So that’s really good for me, I’m not scratching around, you know, “Who do I phone?”* (P8, wife)

1.6 “I have to make my voice heard”

Participants’ experiences were diverse in terms of how far they were able to work together with professionals to manage the difficulties in the longer-term.

Around half felt that professionals did not encourage their involvement or could be dismissive of their views, and had a sense of having to fight to have their perspective listened to. Participant 9 felt that professionals failing to listen to her concerns about her father becoming unwell led to the difficulties escalating.

> *I found them quite dismissive of my concerns… and lo and behold (laughs) one of the first phone calls was saying my father's taken off… I thought, "Why wouldn't you just take the clues?"* (P9, daughter)

> *They still just want to see him, and they ask him all the questions, and that. And I go, "Excuse me, don't you want to ask from the carer's point of view as well?" I have to make my voice heard, otherwise we're not taken into consideration.* (P4, wife)

Some felt that the main barrier to their involvement was their relative's lack of openness to this. Others felt that rules around confidentiality were used inflexibly, and prevented their involvement or input. Participant 12 felt this had been a significant factor in her son not receiving a diagnosis earlier.

> *But this patient confidentiality thing is getting in the way I think. Because I know [son] more than anybody else, my husband knows him and we know he, it's not him… they should, maybe speak to us, you know the people that live with him…It should have been dealt with a lot sooner.* (P12, mother)

Despite these difficulties, 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 join meetings in order to gain feedback and discuss their concerns.

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

Domain 2: The impact of providing support

Supporting their relative had both positive and negative consequences for participants. The themes in this domain concern the impact of the situation on participants, and what helped them to manage the more difficult aspects.

2.1. It dominates my life

Participants felt that their relative's difficulties had *'dominated their life'* (P3) at times, and had a sense of prioritising supporting them above their own needs. Some had put other aspects of their life *'on hold'* (P10), such as pursuing their interests and maintaining other relationships.

> *That strain on me, it came out in my relationship. And I think for me the hardest part of all of this has been that loss, because I don't think I prioritised myself or my relationship at all, in any of this.* (P9, daughter)

Participants carried a constant sense of worry and strain. Around half felt that supporting their relative had had a significant impact on their wellbeing, with a third having experienced depression.

> *I have a tendency of getting a bit down as well 'cos it's draining. It's really, it's like when he was ill, it was taking me three hours to get him out of bed, and go for a walk. That was really exhausting. And now that he's manic, he's so happy, it's like "Oh what's he going to do next?" So that it, it gives me anxiety.* (P14, wife)

The majority felt it had been necessary to *'take a step back'* (P9) from their responsibilities in different ways. Professional support or attending support groups had helped several participants to accept the need to prioritise themselves, both for their own wellbeing and to be able to continue to support their relative.

> *I think what I've realised, I think through the [psychological support] as well, about trying to put myself first as well. 'Cos as a mother you just put yourself on like the back burner, and what you think and feel isn't important, and you've got to be there, you've got to support your daughter. But I've learnt that you have to think about yourself. Because if I fall apart then I'm no help to anybody, so I've got to do things that are going to keep me in a better frame of mind...* (P10, mother)

Some took time for themselves, and did things they enjoyed. Others had put in place boundaries in terms of how often they spoke to or saw their relative, and felt this prevented them from becoming burnt out or resentful. Some described a more psychological process of taking the difficulties *'on board a little bit less'* (P3). Some felt this had been beneficial for their relative, for example in increasing their ability to support them or reducing their relative's sense of guilt.

> *I have to be realistic and know um that I can't be with her, I can't be responsible for her all the time. Um and for me to have a life is better for her. Otherwise when she's down, she'd feel really guilty…* (P7, mother)

However, taking a step back from the situation was not without complications. Some described feelings of guilt or sadness, despite feeling it was necessary to have a greater distance from their relative.

> *Then there's just this constant feeling that, you know, one should give one's life to be, to you know, to provide a safe place for this person…but you can't do that, can you? Because then it'll just cripple me. It would make me very resentful* (P17, daughter)

> *Um, it's sad, I mean I could cry about it a lot if I sat down and really thought about it. About what our relationship was like, and what it is now. And, although maybe in some ways it's better now…it's with me all the time but it doesn't dominate my life…* (P3, sister)

2.2. Feeling alone: "nobody else knows what it's like"

A sense of isolation was a common theme across participants' accounts, with several feeling that it was difficult for others to understand their situation. Around half were the only person substantially involved in supporting their relative. Other family members or friends were often unable to provide as much support as they could, or had distanced themselves due to their view of the relative with bipolar disorder's behaviour, or conflict with them.

> *I'm the only one that's there for her. You know, her friends will be around but, you know, they're not going to be looking after her when she's just staying in bed all day.* (P7, mother)

> *[Participant's parents] have not been supportive really…My mum's like, "Well [son]'s just rude."…So I do feel a bit on my own.* (P12, mother)

Several felt they or their relative lacked consistent professional support. Participants described services being unreliable or unresponsive, as well as frequent changes in staff, thus increasing their sense of being alone in managing the difficulties.

> *…it means that all the caring comes down to me. And I can't rely on them for support, and you basically just have to get on with it and manage the best you can.* (P10, mother)

At times, participants had felt unable to confide in friends or extended family, in some cases due to a sense of stigma carried by themselves, their relative or other family members.

> *We just felt completely alone. And, you know again because our daughter doesn't want anyone to know, it was, you know, I felt quite constrained as to who I could talk to.* (P11, father)

Participants also felt that it was difficult for those who had not experienced anything similar to understand their situation, and had a sense that "*nobody else knows what it's like*" (P17, daughter). Friends and family sometimes lacked an understanding of mental health problems, and struggled to know how to talk with them about their situation, or inadvertently implied there was an easy solution to the difficulties.

> *We don't have any support from friends…I mean, nobody else has got similar issues so we don't really know how to, if they would really understand or know how to support us anyway.* (P18, father)

> *You know what's unhelpful is somebody who just doesn't understand and says, "Well you know, tell him to pull his socks up," or um, "Why don't you just do this…?"* (P8, wife)

Given these difficulties, participants particularly valued the support of those who had a good understanding of the challenges and constraints they faced, for example others who were involved in supporting their relative.

> *I don't always have to explain my feelings, I can just tell [other family members] what happened, and they can just exactly understand…they'll kind of give advice that's realistic*. (P1, sister)

External support could also reduce participants' sense of isolation. Although some spoke about the value of professionals understanding and recognising the impact of the difficulties on them, the sense of feeling less alone was most strongly related to attending support groups. A minority described a sense of difference to others within support groups, and felt that groups of different types of family members or those also comprising people with bipolar disorder did not directly address their concerns. However, the majority felt other group members had an implicit understanding of their situation, and found this to be a unique and moving experience. Hearing how others had managed the difficulties also gave participants a sense of perspective and hope for the future.

> *It was just amazing to be in this place where everybody else there knew what you were going through…* (P2, sister)
>
> *Up until then, I think I felt very isolated that it's happened to us…But in that group people were happy to talk about it, you know, how they dealt with it, what things they'd gone through, and so you didn't feel so alone... 'Cos it just gives you a better perspective, that other people have been down this road…* (P10, mother)

2.3. "Caught in the middle"

Participants experienced positive and negative changes in their relationships with other family members as a result of their relative's difficulties. Some found themselves '*caught in the middle'* (P3) of conflict between other family members and the relative with bipolar disorder, and attempted to mediate between them or help other family members respond differently to their behaviour. The majority also described other family members holding differing perspectives to them, for example a lower level of acceptance of the difficulties, which in some cases led to conflict.

> *I feel as if my parents…they are waiting for her to get better or change…I feel, you know, angry with them 'cos they haven't really dealt with it as much as they, I think they could…it's very difficult for me, because I am mediating between them all the time* (P3, sister)

Participants expressed concerns about the impact of the difficulties on other family members and their relationship with them, particularly those who had children. Some felt they had been less available to other family members. Participants who were parents described having to treat the child with bipolar disorder differently, and this leading to difficulties in their relationship with their other children.

> *It has affected [other children], in that [other child] does feel that I've paid all my attention to [child with bipolar disorder], and therefore ignored [other child] you know, which is very difficult to deal with 'cos I don't see what I could have done different.* (P10, mother)

However, others felt the situation had brought them closer to other family members, as they came together to support their relative.

> *Um, and it certainly, one of the positive things in [year] was it definitely brought us closer together as a family.* (P1, sister)

Participants had mixed experiences of talking together about the impact of the situation as a family, for example in family therapy. For some, this led to distress or conflict.

> *It was too difficult because people's feelings were really raw, and on the other hand they didn't want to talk about things in front of somebody else, and then everybody got upset and everybody felt bad…* (P10, mother)

For others, having professionals present created a calmer space where they were better able to communicate and understand one another's perspective. Participant 1 felt that family therapy both increased understanding between her brother and the rest of the family, but also allowed discussion of different approaches to supporting him, enabling her to feel *'more hope about the situation.'*

> *I could see there were definitely moments where it was like a light was being switched on, and my brother heard things that he hadn't really heard before. And we heard things from him that we probably hadn't heard before…It was helpful because discussions can get so heated about what to do…* (P1, sister)

2.4. "A loss of him"

A sense of loss was prominent across participants' accounts. Some described lasting changes in their relative and relationship with them, while for others this was more confined to changes when their relative was unwell. Their relative seemed to become a different person, particularly during manic episodes, leading to a sense of temporarily losing them.

> *It's a completely different person. So you lose your trust and your relationship and everything, it's just not there. That's not the same person; they are completely different. That's hard (becomes audibly emotional). Yeah, that's a big thing.* (P8, wife)

> *It's almost like she was a different person, a possessed person.* (P16, partner)

During manic episodes some experienced dramatic changes in their relationship and felt they became *'the enemy'* (P5) and the focus of their relative's aggression or paranoia, leading to feelings of fear, anger and hurt. Others described subtler changes, both during depression and mania, such as their relative becoming colder or more distant. They struggled to adapt to this, and experienced feelings of rejection and resentment.

> *He's a bit cold…but when he's manic he'll be even more. Before he, I was just, I was his only focus…Whereas now, he's got so many interesting new things to deal with, that I'm not anymore. I don't feel important anymore…* (P14, wife)

Some found it helpful to remind themselves that their relative's behaviour was part of the illness, or that they were not themselves when unwell.

> *When he gets really bad he has a totally different look in his eyes, and it doesn't, he doesn't seem like it's him… I get angry with him about it but I think, I know it's not him being really himself, wanting to do these horrible things.* (P6, daughter)

However, others felt their relative's behaviour when unwell had done lasting damage to their relationship. One spoke about a sense of uncertainty as to whether they could continue the relationship, while others described finding it hard to forgive or regain trust in their relative.

> *I mean, some of the things that she's said to me…I find very difficult, even now, to come to terms with…I find, even though I know that she was ill, I find it very hard to forgive… On the surface, it's repaired, at the moment. But inside it's not the same, it will never be the same.* (P11, father)

Several participants described a more permanent sense of having lost the person their relative was before. Some had become more *'volatile'* (P18), while others were more withdrawn due to the effects of the condition and medication.

> *I felt like she is not my daughter, she's just like somebody totally alien. Um her moods were so volatile…she was a very effervescent person…and then all of a sudden there was this like, really weird person, we couldn't recognise her…* (P18, father)

> *He was a very sociable, vivacious personality and not seeing that as much…so I think in a way, there's a massive loss of, a loss of him.* (P9, daughter)

The dynamics of some participants' relationship with their relative had fundamentally shifted in different ways. Two described a sense of discomfort and resentment at becoming a 'carer', as this was something they had not chosen, and did not fit with how they had seen their previous relationship. Two others felt their relationship with their parents had been inverted.

> *There's a huge level of anger and resentment towards him…I end up being a carer, and I didn't choose to be a carer.* (P14, wife)

> *Your mother in particular is such a figure of kind of security… And then suddenly having that turned up and it was like, no actually she won't always be able to take care of me and I'm going to have to take care of her quite a lot. So I think grief about that, a lot of grief, and a lot of anger about that.* (P17, daughter)

Siblings and parents struggled to accept that their relative might be unable to fulfil the expectations they had had for them. Siblings in particular felt they had lost the relationship they had always imagined they would have with their relative.

> *To stop studying at such a young age, and not going higher, and yet he had the brain. I mean I found it very difficult, you know.* (P13, father)

> *You've like lost this person that you had and that you thought you were going to have. You know, when you're growing up you think, "Oh well I've got an elder brother and he'll always be my elder brother and, it's going to be like this…" And that all gets taken away.* (P2, sister)

2.5 "It's brought us closer"

Despite many participants experiencing negative changes in their relationship with their relative, some felt the difficulties had brought them closer together, strengthened their relationship, and enabled them to gain a greater understanding of one another.

> *It is an achievement and I'm very proud of our relationship. I think it's made us stronger. I think we've overcome something…* (P8, wife)

> *But I think I've got a different understanding, me and my dad have a different understanding of each other because of it…So yes, I think that's, kind of, brought us closer in a way.* (P6, daughter)

Participant 9 felt that the situation had enabled her and her father to talk about his past in a way that they otherwise would never have done. Psychological support had helped him to become more reflective, and this had enabled her to gain a new understanding of him.

> *We had a conversation about emotions that we hadn't spoken about before… it was quite overwhelming, it was quite an experience, seeing my*

> *dad in a different light. Seeing him as a person, as opposed to just my dad.* (P9, daughter)

Two participants were able to talk more openly with their relative when they were unwell. Participant 7 felt that her daughter's depression '*brought out something different'* in both of them, and they were able to communicate better without becoming annoyed. Participant 17 described the moving experience of her mother sharing memories she would otherwise never have discussed during a manic episode.

> *She often has flashes of memory as well of things that she's forgotten or she's not, doesn't discuss. And when she's having a kind of episode, it all kind of comes up… and it was very moving to have that conversation with her, it was really very beautiful and touching. And that is, you know, that is something I really kind of treasure.* (P17, daughter)

2.6 Acceptance and hope

Participants described a process of coming to an acceptance of the situation, and the changes in their relative. Professional support or attending support groups helped some to reach this acceptance.

> *I went through many years of looking for answers…And I've learnt you've just got to learn to live that way, there are no answers. It's something for life, you can't cure it. You learn to live with it, and deal with it in a better way.* (P8, wife)

> *I think that's what going to the [mental health support group] helped with in some way…it was just, it was just realising that this is how she is, and it may never change… you have to let go of what you thought your sister was going to be like, your relationship with your sister was going to be like…* (P3, sister)

Accepting the difficulties improved some participants' relationship with their relative, and helped them to better support them, for example through modifying their expectations or supporting their need for ongoing treatment.

> *And so there was a lot of denial…And, and we weren't very keen on her having medicines in the beginning so we were resisting the idea…You know, so initially our reaction was very sort of, actually unsupportive. Um, but then, you know, gradually we realised, we realised it's not going to go away, you know. It is actually here to stay. Um, and that we, you know, that acceptance finally came.* (P18, father)

Some described an increased sense of strength and confidence as a result of managing the difficulties, and reflected on positive changes in themselves the situation had brought about, particularly a greater sense of empathy.

> *Made me stronger, stronger in me, knowing that I can do it.* (P4, wife and mother)

> *I think that it's given me empathy for people…you know it shows that, that not, life's not always easy. And I'd say that's all quite positive.* (P5, wife)

Although a minority had become less optimistic about the situation improving, it was more commonly felt that it was important to retain a sense of hope that their relative could recover to some extent, or that they would be better able to manage the difficulties. Participants valued services conveying this message.

> *And actually there is hope, and people can get better…to me that, that was really helpful to have that sort of message.* (P1, sister)

> *So I decided to stay because I love him. And I have hope. [Interviewer: So your hope is an important thing?] Yeah. Yeah. Quite essential, I would say.* (P14, wife)

Discussion

This study investigated the challenges of supporting a relative with bipolar disorder, and the impact of providing support on family members. Participants experienced a variety of challenges, which pertained to the nature of the disorder, their relative's responses to their attempts to help, and the limitations of professional support. Providing support had wide-ranging emotional and relational consequences. Family members showed significant resourcefulness in managing the difficulties they faced, and valued informal and professional support where it was available. Participants also described positive changes in themselves and their relationships as a result of their supporting role.

The challenges of supporting a family member with bipolar disorder

Participants struggled to understand the difficulties when their relative first became unwell, and experienced an acute sense of uncertainty about how best to help. Although professional support reduced uncertainty, some were unable to access this for months or years. These findings are consistent with previous studies of family members' experiences of bipolar disorder and other mental health problems (Nystrom & Svensson, 2004; Tranvag & Kristoffersen, 2008; Wainwright et al., 2015), although the need for professional support early in illness onset has perhaps been under-emphasised in studies of bipolar disorder. Participants in this study also highlighted how, given the diversity of difficulties experienced by those with a diagnosis of bipolar disorder, the support process was to some extent a matter of 'trial and error'. This is consistent with the increasing conceptualisation of bipolar disorder as a spectrum of mood disturbance, requiring individually tailored support (Angst, 2007; BPS, 2014).

Despite the heterogeneity of bipolar disorder, aspects of the challenges participants faced were to some extent specific to the nature of the condition. Fear of relapse and rapid changes in mood engendered a sense of instability. Previous qualitative studies have highlighted fears of relapse, while quantitative studies of burden have emphasised disruption to caregivers' daily lives, but have said less about specific experiences of mania or depression (Granek et al., 2016; Tranvag & Kristoffersen, 2008; Van der Voort et al., 2007). Participants in this study experienced increased anxiety during manic episodes due to the unpredictability of their relative's behaviour, and within depressive and mixed episodes due to the threat of suicide. The literature is inconsistent as to whether manic or depressive symptoms are more burdensome for family members (Dore & Romans, 2001; Post, 2005; Van der Voort et al., 2007). Although participants in this study tended to emphasise the difficulties associated with mania, they struggled to affect their relative's mood in both illness phases. This sense of lacking control over their relative's mood is consistent with the finding that a sense of helplessness and hopelessness is the most common type of burden experienced by caregivers (Bauer et al., 2011), and suggests that family members may benefit from interventions which empower them to support their relative within different illness phases.

The results highlight the importance of family members' capacity to work with their relative to manage the difficulties, particularly when they show signs of becoming unwell. Family participation in relapse prevention can be highly valued by family members and service-users, and improve outcomes (Doherty & McGeorge, 2014; Peters et al., 2011). However, service-users can also oppose family members' involvement, and experience their input as hypervigilant or controlling (Doherty & McGeorge, 2014; Peters et al., 2011). The results of this study are consistent with these findings, but also elucidate the sense of anger and hurt family members may feel when excluded from involvement. Participants also had a sense of 'walking on eggshells' when trying to help their relative, as they could react irritably or angrily to their interventions. This is consistent with the finding that irritability and aggression are some of the most distressing symptoms for family members, and communication often the most problematic area of difficulty (Dore & Romans, 2001; Reinares et al., 2006).

These challenges could be conceptualised as 'dilemmas of helping' (Coyne et al., 1990). Family members' distress and desire to prevent relapse, and the negative consequences this has for themselves and their relative, may lead them to seek a level of involvement in illness management which conflicts with their relative's desire for autonomy, or to intervene in ways their relative finds unhelpful. There is some overlap here with the concept of emotional over-involvement. However, Coyne et al.'s (1990) conceptualisation highlights the extent to which the illness acts as a stressor for both parties, with their needs sometimes conflicting. It is therefore unsurprising that, in line with previous studies of informal helping, participants felt that some of their support attempts 'failed' or were not received as intended (Barker & Pistrang, 2002; Goldsmith et al., 2006; Trief et al., 2003).

From this perspective, participants' resourcefulness in managing the challenges of the support process was striking, for example adapting their communication style in order to increase their relative's receptivity to their input.

Those who were most successful at working with their relative to prevent or reduce the severity of episodes cited professional support and their relative's awareness of the difficulties as important factors. As argued by Doherty & McGeorge (2014), conveying concern or offering advice around changes in mood in a way which will be positively received involves considerable skill, and families may require support to develop effective communication skills. Interestingly, some participants in this study 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 is multi-dimensional, comprising both appropriate and inappropriate levels of intrusiveness, self-sacrifice and emotional distress (Fredman, Baucom, Boeding & Miklowitz, 2008). In the context of bipolar disorder, it may be adaptive for family members to express distress around their relative's functioning, particularly if this leads them to better manage their difficulties (Fredman et al., 2008). It could be that a certain level of emotional disclosure motivates behaviour change where self-responsibility has failed (Coyne et al., 1990).

Family members' experiences of being excluded or over-looked by services have been well- documented (Rowe, 2012; Rusner et al., 2012, Tranvag & Kristoffersen, 2008). Studies of severe mental health problems carried out in the UK have also highlighted issues raised in this study, such as confidentiality being used inflexibly, and an absence of crisis planning, suggesting these difficulties are particularly pertinent to the British system of care (Chatzidamianos et al., 2015; Wainwright et al., 2015). The results of this study support Chatzidamianos et al.'s (2015) assertion that UK services may be better equipped to support those with chronic, rather than episodic difficulties, with participants reporting a lack of responsiveness from crisis services. Participants' accounts also highlight how the nature of mania may pose significant challenges for family members, in that sufferers may not perceive themselves as unwell or in need of support, thus increasing their opposition to services' involvement (BPS, 2010; Doherty &

McGeorge, 2014). Participants described a sense of being caught between their relative's wishes, and their fears for their safety and that of others. The fact that people with bipolar disorder can value some aspects of their experiences (Lobban, Taylor, Murray & Jones, 2012), highlights the complexity of the task facing family members, whose aims may be to some extent fundamentally at odds with those of their relative.

The impact of supporting a relative with bipolar disorder

The difficulties dominated participants' lives at times, and many felt significantly under strain, with a third having experienced depression. Although it was beneficial to 'step back' from their responsibilities, this was sometimes emotionally challenging. This is consistent with the quantitative literature, which reports moderate to high levels of burden, and elevated rates of depression among caregivers of people with bipolar disorder (Perlick et al., 1999; Reinares et al., 2006; Steele et al., 2010). Qualitative studies have also highlighted the complexity of negotiating boundaries, with family members experiencing feelings of guilt and uncertainty (van der Voort et al., 2009). Drawing on the informal support literature, a sense of responsibility may lead family members to take on a role that is highly burdensome, despite this sometimes having negative outcomes for themselves, and at times their relative (Coyne et al., 1990). Participants in this study felt that external support helped them to realise the importance of honouring their own needs, partly so that they could continue to support their relative.

As in previous qualitative studies, a sense of isolation was prominent in participants' accounts, with many feeling it was difficult for others to understand their situation (Jönsson et al., 2011; Tranvag & Kristofferson, 2008). While previous studies have emphasised more overt experiences of prejudice (Tranvag & Kristoffersen, 2008), participants in this study largely described a more internalised sense of stigma, which prevented some from seeking support. This is consistent with the finding that the association between perceived stigma and depressive symptoms may be partly mediated through lack of social support (Perlick et al., 2007b). Given the difficulties in accessing support from those in their network, support groups were invaluable in reducing participants' sense of isolation, and offering a sense of hope. The value of support groups perhaps reflects core processes underlying psychological helping, including conveying empathy and 'making meaning' or framing the problem from a new perspective (Barker & Pistrang, 2002).

Although the experience of loss is well-substantiated in the literature (Tranvag & Kristofferson, 2008; van der Voort et al., 2009), this study highlighted how family members may experience different types of loss based on their relationship, for example adult children experiencing a loss of security. Family members also experienced a more transient sense of loss when their relative was unwell, and described complex emotional responses to the changes in their relative such as feelings of anger and resentment. These findings are consistent with Jones' (2004) concept of complex loss, whereby family members may experience emotions such as anger, due to their relative being visible but fundamentally altered. From a family systems perspective, changes in roles and relationships may be more distressing due to being 'off time' in the family life-course, thus carrying a greater sense of injustice and ambiguity (Marsh & Lefley, 2010; Pickett, Greenley & Greenberg, 1995). Some found it helpful to view their relative's behaviour as part of the illness, which is consistent with the emphasis on the importance of caregiver appraisals (Chakrabarti & Gill, 2002). However, for others this perspective was more difficult to sustain, with participants describing difficulties forgiving their relative's behaviour. These findings perhaps raise questions about psychoeducational approaches (evaluated in Part 1 of this thesis), which may address the cognitive and behavioural aspects of caregiving, but pay less attention to the more complex emotional responses of family members.

This study adds to a small body of literature highlighting the positive aspects of providing support (Granek et al., 2016; Maskill et al., 2010). Some participants had grown closer to their relative and other family members, and discussed things they otherwise would not have done, with a minority feeling it was easier to communicate when their relative was unwell. There was also a strong sense of participants' resilience in coping with the difficulties, with family members describing an increased sense of strength and confidence, and positive personal changes such as a greater sense of empathy. Participants described coming to an acceptance of the difficulties, which in some cases enabled them to better support their relative. However, it was also important to maintain hope for the future. These findings are consistent with a growing emphasis, both in the literature and service delivery, on the need to enhance family strengths and deliver a positive message about recovery (Aldersey & Whitley, 2014; Becvar, 2013; NICE, 2014a).

Limitations

This study has a number of limitations. Although qualitative methodologies do not aim for generalisability, the nature of the sample may limit the transferability of findings. Only four men took part, although this may reflect the tendency for women to play a greater role in providing support. People from minority groups were under-represented, and educational attainment was higher than average. The concerns of other demographic groups may therefore not have been captured. The majority of relatives had a diagnosis of type one bipolar disorder, and so issues pertinent to other types of bipolar disorders may have been missed. Participants were largely recruited through voluntary sector organisations and support groups, and may have differed in significant ways to those who do not access this type of help, for example in being motivated to improve their capacity to cope with the situation, or experiencing greater difficulties. Similarly, those who volunteered for the study may have been motivated to share their experiences due to experiencing higher levels of distress.

The research only captured one side of the support process, thus limiting what can be said about the success with which participants negotiated the challenges of supporting their relative. However, the research was explicitly phenomenological in its perspective, and aimed to capture the subjective reality of family members, rather than necessarily obtain an ‘accurate’ picture of the support process. Interviewing family members separately from their relative may also have enabled them to discuss the more difficult aspects of their experience more freely.

Clinical and research implications

An overarching theme running through participants’ experiences was the extent to which they valued professional support. Where appropriate, support should be offered to family members that addresses both the challenges of supporting their relative, but also the impact on them. Given the diversity of family members’ experiences, support should be tailored to individual needs.

The findings emphasise that family members’ role and perspective should be respected, and where possible they should be involved in their relative’s care. As this is in line with pre-existing guidelines, it may be that staff training or increased resources are needed (NICE, 2014a). It seems particularly important that family members receive support and information early in illness onset, and be involved in relapse prevention and crisis planning. Although confidentiality and the preferences of the service-user are complex issues, in line with clinical guidelines, the findings highlight the need for professionals to engage with service-users and family members around these issues, and where necessary share information in ways that meet family members’ needs without breaching guidelines (NICE, 2014a.). Professionals should also have an awareness of the challenges family members face at times of crisis, and offer appropriate support with risk management and decision-making.

Structured interventions, such as psychoeducation or family-focused therapy may help address ‘dilemmas of helping’, such as balancing family members’ desire to protect their relative with their need for autonomy, as well as enhancing communication skills and empowering family members' to support their relative within different illness phases. It seems essential that professionals adopt a normalising, non-blaming stance, which takes account of the interdependence and challenges of the supporter-supported relationship. However, as alluded to above, it may also be helpful for family members to have a less directive therapeutic space to process complex emotional experiences such as loss.

In contrast to previous research, this study highlights the extent to which family members of people with bipolar disorder experience difficulties in the wider family system, thus suggesting the potential value of systemic approaches in addressing changes in family dynamics. However, given the mixed experiences of family therapy described by participants, individual needs should be assessed. The findings also lend some weight to the tentative recommendations that family members be offered mutual support groups (NICE, 2014a). However, given some participants' sense of difference to others within support groups, separate groups for particular family members may be helpful in addressing the unique challenges they face.

This study highlights the resilience of family members in negotiating the difficulties associated with supporting their relative. It therefore seems vital that interventions are strengths-based, and look for ways to enhance family resilience (Becvar, 2013). In line with NICE guidelines (NICE, 2014a), a positive message about recovery also seems to be an important component of helpful support. Public campaigns would also be helpful in reducing the internalised stigma family members may experience, enabling them to seek support more widely.

Future research could explore the experience of specific family members in more detail, particularly those under-represented in the literature, such as siblings and adult children, as well as the experiences of male family members and those from minority backgrounds. Triangulating the experiences of family members, service-users and professionals would afford a greater understanding of how the challenges of helping are experienced by different members of the system. Observational designs, for example analysis of helping conversations, could help clarify which behaviours are experienced as helpful or unhelpful by people with bipolar disorder. Quantitative or mixed-methods designs could also explore what type of support is most beneficial for family members at different stages of the caregiving trajectory, and whether these effects are sustained over time. Further research is also needed to clarify the factors which enhance the resilience of family members and the extent to which they experience benefits of their supporting role.

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Part 3: Critical Appraisal

Critical Appraisal

Introduction

This critical appraisal considers methodological issues I encountered while carrying out the empirical study, including reflexivity, carrying out semi-structured interviews, and conducting 'insider' research. I will also discuss wider conceptual issues raised by the research, including the implications of constructions such as 'carer' and the bipolar diagnosis. I will then reflect on how the empirical study informed my thinking about the strengths and weaknesses of the interventions, outcome variables, and research designs evaluated in the literature review.

Reflexivity

Reflexivity addresses the reciprocal influence between the researcher on the one hand, and the research process, findings and participants on the other (Hofmann & Barker, 2016; McLeod, 2011). It involves exploration of one's assumptions, experiences, thoughts, feelings, values, and theoretical leanings, and how these may impact on, and be impacted by, the research process (Berger, 2015). Within the phenomenological tradition, reflexivity can enhance the researcher's capacity to understand participants' experiences, and is a means of increasing the rigour of the research endeavour (Hofmann & Barker, 2016; Tufford & Newman, 2012).

One means of safeguarding against the imposition of personal meaning on the research process is through 'bracketing'. Although there are many definitions of this process, broadly the researcher attempts to explore in detail and then 'bracket' or suspend their assumptions, while holding them in awareness (Ahern, 1999; Fischer, 2009). This is not a one-off occurrence, but an ongoing process from the formulation of the research question, through data collection, analysis and interpretation (Ahern, 1999; Tufford & Newman, 2012). There is a clear recognition that total objectivity is neither possible or necessarily desirable; the researcher's experiences can be a source of insight, but our impact on the research process should be actively engaged with and openly acknowledged (Ahern, 1999; Fischer, 2009; Tufford & Newman, 2012).

Reflexivity may become particularly important when one has personal experience of the topic under research, as there may be a greater danger of imposing one’s own assumptions on participants’ accounts, or attending to certain issues at the expense of others (Barker, Pistrang & Elliott, 2016; Berger, 2015; Hofmann & Barker, 2016). As I have personal experience of supporting a person with bipolar disorder, and experience of supporting family members as a trainee psychologist, I was mindful of the impact this could have on the research process. I therefore used a number of methods to reflect on and bracket my preconceptions. At the outset of the research, I assumed that supporting a relative would be challenging. Explicitly building in questions into the interview schedule about the positive aspects of participants’ experiences helped to guard against an over-focus on the negative aspects. I used a research journal to reflect on my thoughts and feelings after an interview, and how participants’ experiences both converged with and differed from my preconceptions. I also read interview transcripts, and considered which issues I tended to follow-up and those I neglected.

Discussion with my supervisors was invaluable in facilitating reflection. For example, drawing on my experiences, I felt that periods of crisis would be particularly difficult to manage, but was concerned that I might over-emphasise the more negative accounts of these periods within the analysis, and was aware that difficulties during crisis periods were central to only a sub-set of participants’ accounts. I was able to discuss this with my supervisors, and as a result ensure minority perspectives were represented within the write-up. I also felt that the rigorous structure provided by the framework approach helped militate against the tendency to impose meanings on the data. In particular, the final stage of charting helped me to reflect on how far my interpretations were grounded in the data and represented the diversity of participants’ perspectives. Finally, compiling participant summaries and eliciting feedback also helped to ensure I had accurately understood and represented participants’ experiences. Despite these measures, I did feel there were times during the interviews when I assumed I understood participants’ perspectives, or perhaps imposed my own meaning, when it would have been more helpful to explore this from a ‘not-knowing’ stance. On the other hand, I felt that in some ways my own experiences facilitated my capacity to understand and empathise with participants’ experiences, and to maintain a non-judgemental and curious approach.

In terms of the impact of the research on me, I found the process to be personally and professionally meaningful. Listening to participants’ stories was emotionally affecting, and I was sometimes surprised by the aspects of participants’ accounts that resonated most with me. Hearing others’ experiences helped me to better understand some of my own experiences, and also to recognise some aspects I had not fully considered, particularly the positive aspects of providing support. Professionally, knowing more about the struggles that family members face has helped me to take a compassionate approach, and enhanced my capacity to hold in mind differing perspectives, for example when difficult dynamics play out between families and team members. I have found the concept of ‘dilemmas of helping’ particularly helpful in maintaining a non-judgemental and empathic stance in my work with families of people with bipolar disorder and psychosis. In particular, the idea that mental health difficulties act as a stressor on all family members helps me to normalise and empathise with family members’ responses, for example behaviour around relapse that might be perceived as ‘over-involved’ or hypervigilant.

I was also mindful of the impact of taking part in the research on participants of the empirical study. Although the discussions that took place within the interviews were often highly emotive, some commented that they found it helpful to tell their story. One participant found the summary of the interview particularly helpful, and felt this contributed to the process of coming to terms with the changes in her relative. Some also said that they were pleased to have contributed to research which could potentially help others in their position, as many felt family members' experiences and needs tended to be neglected.

Carrying out semi-structured interviews

Throughout the research process, I was also aware of the potential impact of my clinical training, particularly the way in which this might affect interactions within the semi-structured interviews. I endeavoured to hold in mind the differing aims of the research interview as opposed to a clinical interview, and resist the pull to try to change participants' thoughts or feelings or come to a coherent formulation (Barker et al., 2016). However, a particular dilemma arose when participants directly asked for advice, or for me to comment on whether their experience was typical. In general I tried to defer questions until the end of the interview in order to place boundaries around the research process, and sign-posted participants to appropriate resources, rather than offering extensive advice (Thompson & Russo, 2012). However, there were times when in the interests of rapport, and perhaps due to a desire to reciprocate participants' contribution to my research, I found myself answering participants' queries briefly during the interview. When reading over transcripts I also noticed there were occasions when I perhaps highlighted participants' strengths or normalised their experiences in a way which might have been more appropriate to a clinical interaction.

A particularly difficult issue to negotiate was how to elicit the challenges participants faced in trying to support their relative, without leaving them feeling overly discouraged or reducing their sense of efficacy. After discussion with my supervisors, I decided to adapt the introduction to the interview to make it clear that many faced considerable difficulties in trying to help their relative. Although this drew on clinical techniques such as normalising, I felt this was an appropriate measure which took into account the duty of care one has to research participants.

Despite experiencing some conflict between my clinical and researcher roles, I also found my clinical skills aided the research process. For example, I felt able to explore the emotional impact of participants' experiences, and also to manage the impact of discussing highly emotive content on both myself and participants.

Another challenge I faced when carrying out the interviews was my capacity to use the interview schedule flexibly. Initially I found that I tended to stick broadly to the order of the subject areas, and to attempt to cover all the questions in the schedule. I would sometimes return later in the interview to areas participants had touched on, rather than following them up as they arose. However, as the interviews progressed I found I was able to use the schedule more flexibly, and to follow up lines of enquiry as they came up, giving the interviews a better sense of flow. Another challenge was how far to follow up participants' comments and probe for further information. Initially I found I tended to sometimes follow up in too much detail, thus leading to some very long interviews. However, as time progressed I felt I was able to gauge more effectively which issues were particularly pertinent, and the interviews became more succinct.

On reflection, I felt that the initial section of the interview schedule, which asked for brief background details, might have been reduced or interspersed more within the main body of the interview schedule. Participants tended to provide a substantial amount of detail when asked for background information, perhaps reflecting their understandable desire to tell their story, and I sometimes wondered whether this meant they had less energy for the latter parts of the interview. On the other hand, this portion of the interview often yielded highly relevant information, which might otherwise have been neglected. For example, participants' experiences when their relative first became unwell formed the basis for one of the final themes. Throughout the data-collection process I found it helpful to reflect with my supervisors on how the schedule was working, and to adapt it and incorporate key ideas or language used by participants. For example, following the first few interviews I added specific questions about illness phases, and also replaced the word ‘support’ with ‘help’ in some places, as some participants tended to use this terminology more frequently. Overall, I found carrying out the interviews to be extremely interesting and rewarding, and valued being able to bring together my clinical and research skills within the research process.

Conducting ‘insider research’

‘Insider research’ refers to conducting research with populations with which one shares an identity or experience (Dwyer & Buckle, 2009). As well as the potential impact of one’s experiences on the research process, a further dilemma facing ‘insider’ researchers is whether to disclose one’s position to participants. This may have advantages, for example potentially increasing trust and rapport. However, it could also compromise the researcher’s ability to maintain a sufficient level of critical detachment, and lead the participant to falsely assume similarity or knowledge, thus not fully explicating their perspective (Hofmann & Barker, 2016; Valentine, 2007). Initially I had felt I would not disclose my position to participants for this reason. However, I quickly realised that withholding this information from someone who had shared with me in-depth personal experiences felt uncomfortable or even unethical (Valentine, 2007). I therefore decided I would be open with those who directly asked about my motivations for the research (without providing extensive detail), but if asked before the interview would defer this until the end, explaining that I wanted to avoid my experiences or background impinging on our discussion. However, this situation did not arise, as those participants who enquired tended to do this at the end of the interview. On balance, I felt more comfortable with not withholding my position, as this fitted better with the spirit of collaboration with which the research was carried out.

The research process also led me to question the dichotomy of the ‘insider’ or ‘outsider’ position. As Dwyer and Buckle (2009) have argued, this distinction may be simplistic and neglects the multiple similarities and differences that may exist between those with a shared experience, identity or label. Although I noted some commonalities with participants' experiences, there were also many differences. This was probably for a variety of reasons, such as the diversity of relationships participants had with their relative, and the differences in clinical presentation of their relative. To some extent I felt that my researcher position and clinical training meant that I simultaneously occupied an 'insider' and 'outsider' perspective, or perhaps a 'space in between' (Dwyer & Buckle, 2009; p1), where I was both involved in the subject matter, but also endeavoured to maintain a critical distance. As a result of carrying out the research, I increasingly identified with the perspective that it is difficult to make a hard and fast distinction between 'insider' and 'outsider' within an approach that aims to capture diversity and complexity, and emphasises the extent to which any researcher will shape and be shaped by the research process (Breen, 2007; Dwyer & Buckle, 2009).

The concept of 'carer'

Although the research was carried out from a phenomenological perspective, the research process also led me to reflect on the nature and impact of the constructions used by myself, participants, and in the literature. As outlined in Part 1, the terms 'caregiver' or 'carer' can be controversial, but are used extensively in the literature, and in services and policy (Henderson, 2001; Molyneaux, Butchard, Simpson & Murray, 2011). Although the concept was originally intended to promote recognition and support of family members' needs, it has been criticised, in terms of both its validity and helpfulness for supporting family members (Eifert, Adams, Dudley & Perko, 2015; Molyneaux et al., 2011).

While the focus of my research was not family members' level of identification with the role of 'carer', some participants touched on this during their interviews or raised it implicitly. As outlined in Part 2 of this thesis, some saw the 'carer' role as unwanted, and at odds with their pre-existing relationship, while others failed to refer to themselves as 'carers' at all. This is consistent with

Henderson’s (2001) finding that couples in which one had a diagnosis of bipolar disorder failed to identify with the term ‘carer’ and found it to be mutually exclusive to their sense of shared partnership. One participant in the present study expressed concern about how her daughter might feel if she was being ‘cared for’, perhaps reflecting the perspective that the carer concept may disempower service-users, and keep relatives’ roles fixed, thus constraining change (Molyneaux et al., 2011). Taken as a whole, participants’ accounts made me wonder whether defining relationships in this way might mask the mutual support that can be provided within a relationship where one person has a mental health problem. As one participant put it when discussing her motivations for supporting her husband, ‘I’m quite happy to support him, he’s supported me in stuff.’

On the other hand, a minority of participants seemed to identify strongly with the role of carer, and several referred to themselves in this way, if only in passing. This is consistent with the finding that some feel that the concept accurately reflects the significant shift in roles and responsibilities that occur when a family member has a severe mental or physical health problem (Eifert et al., 2015). Due to the nature of the organisations I recruited through, several participants had accessed support as a carer, and valued having a shared understanding of their experiences with other carers. However, some spoke about being marginalised or unsupported as a carer, while one spoke about not receiving support due to not being the ‘main carer’.

The fact that participants in this study provided differing levels of support to their relative made me question the extent to which a valid definition can be reached, and if the term could sometimes be used to deny resources to some family members who are less intensively involved in supporting their relative. I also questioned whether defining family members in a way which implicitly professionalises their role might act as a barrier to the provision of adequate resources and support for people with mental health problems and their families

(Molyneaux et al., 2011). While not wishing to detract from the struggles that family members face, the process made me conclude overall that it may be more beneficial for family members to be able to define their relationship in a way that fits for them and their relative, without this potentially impacting on the accessibility of services or support.

The diagnosis of bipolar disorder

The research process and findings also led me to reflect on the validity and utility of the diagnosis of bipolar disorder, and wider issues around psychiatric diagnosis. As outlined in Part 2 of the thesis, family members faced diverse challenges and experienced different aspects of their relative's difficulties as more challenging, with the support process being to some extent a matter of 'trial and error'. Although it is increasingly recognised that there is a spectrum of bipolar disorders, some are also critical of this model, and argue it would make more sense to talk in terms of a spectrum of depressive and hypomanic traits (British Psychological Society [BPS], 2014). The BPS's (2014) recent report, 'Understanding bipolar disorder' questions the validity of the diagnosis, raising questions about its reliability, predictive power in terms of treatment response and course, and overlap with other mental health problems. The report also criticises the illness model in terms of limiting acknowledgement of the positive aspects of hypomanic experiences, which service-users may value and not wish to eliminate. The diversity with which participants in this study described their relative's difficulties also led me to question how far it can be meaningful to talk of a discrete diagnostic entity. However, there were some clear commonalities to participants' experiences, for example a fear of relapse and difficulties in adjusting to extreme changes in mood, that did seem to be more specific to what is termed bipolar disorder.

The dominant model of understanding for participants seemed to be one of their relative having a 'mental illness', and this did have some benefits. For example, participants spoke about acceptance of their relative having a long-term condition being an important way of managing the difficulties. They also found it helpful to see their relative's behaviour as part of the illness, or that they were not themselves when unwell. However, for some this model clearly broke down to some extent in the face of their relative's behaviour, and they struggled with feelings of anger and hurt. This led me to question how far framing the behaviours shown by people with this diagnosis as 'part of the illness' may close down discussion of the significant and complex impact this can have on family members and relationships, and place unrealistic demands on family members to suppress or manage their emotional responses. For example, cognitive conceptualisations of caregiving emphasise appraisals of 'controllability' of behaviour, and interventions seek to modify these in order to reduce criticism or hostility (Falloon, Boyd & McGill, 1984; Kuipers, Onwumere & Bebbington, 2010; Miklowitz & Goldstein, 1997). Although these are clearly important targets for intervention, if applied in a simplistic way these approaches may prevent family members from processing the distressing, and in some cases traumatic, experiences they may have had as a result of their relative's difficulties.

Family members in this study also cited the importance of having hope for recovery or positive change, leading me to question to what extent a life-long illness model enables positive change for service-users and their families. There was also clearly a divergence in conceptualisation between some participants and their relative, with participants feeling their relative had not yet accepted their diagnosis. This perhaps speaks to the importance of service-users and their families having the opportunity to think through which model or understanding of their difficulties makes sense for them, rather than services unquestioningly imposing an illness model (BPS, 2014). On the other hand, I also wondered whether a non-diagnostic model, which may emphasise the positive aspects of elevated mood states, risks minimising the struggles family members experience, for example if their relative is in denial of the need for support but exhibiting aggressive behaviour. Although it is difficult to reach definitive conclusions about these complex questions, I feel it will be helpful in my future clinical work to be able to think critically around these issues and consider how needs and understandings may differ between different families and individual family members.

Psychological interventions for family members

Carrying out the literature review and empirical study led me to reflect on the strengths and weaknesses of the psychoeducational interventions evaluated in Part 1. Unfortunately none of the participants who took part in the empirical study had taken part in a formal psychoeducational intervention, although some had taken part in unspecified family interventions and workshops for family members, with mixed experiences. Participants also spoke about the value of informal contact with professionals involved in their relative’s care. As argued by Lobban et al. (2015), interventions included in the literature review were evaluated as a stand-alone treatment. However, clinical approaches to supporting families of people with severe mental health problems are increasingly moving towards a more integrated approach where family support is embedded throughout services and is tailored to meet their individual needs (Reed, Peters & Banks, 2011; Seikkula et al., 2006).

In line with this, participants in the empirical study had diverse experiences of services, and expressed varying levels and types of need. It is likely that services will be able to support families more effectively by incorporating interventions such as psychoeducation into a broader pattern of personalised care. These approaches are not easily evaluated within the current research paradigm, which prioritises the results of randomised controlled trials, and it may be that observational or quasi-experimental designs are more appropriate (Craig et al., 2008; Lobban et al., 2015). These research designs may also be helpful in evaluating support groups, which were the most widely reported intervention participants of the empirical study had taken part in, and were valued by many.

Relatedly, carrying out the empirical study led me to reflect on the meaningfulness and appropriateness of the outcome variables meta-analysed in Part 1 of the thesis. Some aspects of participants' accounts suggested that knowledge, burden and psychological distress may be important targets for interventions. Participants valued information about their relative's difficulties, and felt that inadequate information at the onset of their relative's difficulties increased their fear and distress. Participants also spoke about experiencing depression, anxiety, and a sense of strain, as well as the disruption to their lives and relationships when their relative was unwell, thus supporting the appropriateness of burden and psychological distress as targets for intervention. However, other areas of difficulty were clearly important, such as a sense of loss, stigma, and difficulties in their relationship with their relative. Several felt that the most valuable aspects of attending support groups was reducing their sense of isolation. Interventions could therefore address and evaluate these areas, as well as aiming to enhance family members' sense of resilience and hope.

Carrying out both sections of the thesis highlighted for me the extent to which both qualitative and quantitative research involves carefully thought through, but ultimately subjective decisions. Although it was challenging to employ both qualitative and quantitative methodologies, I felt that this enriched my perspective, enabling me to think more critically about the strengths and weaknesses of the assumptions, methods and findings of both parts of the thesis. This speaks to the value of methodological pluralism, where a combination of different methodologies may advance clinical understanding more than any one approach alone (Barker et al., 2016).

Conclusions

Carrying out the literature review and empirical study was challenging and rewarding, leading me to reflect on a number of methodological and conceptual issues, from the standpoint of a researcher, clinician and as a family member.

Ultimately the research made me appreciate the scale of the challenges family members can face. Despite their resourcefulness in managing these challenges, the overarching message of the research is the need for family members to be supported, respected and valued for the vital role they play in supporting people with bipolar disorder.

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Appendix A:

Confirmation of Ethical Approval

Pistrang, Nancy

From: John King <John.King@ucl.ac.uk>
Sent: 15 October 2015 10:00
To: Pistrang, Nancy
Subject: Supporting a relative with bipolar disorder: family members' experiences.
Attachments: Ethics_CEHP_2015_530_Pistrang_Amendment_Baruch.zip

Dear Nancy,

I am writing to let you know that we have approved your recent amendment to CEHP_2015_530.

I have attached a copy of your documents, please keep this email as a record of the approval.

I will keep the approved forms on file, and a copy has been lodged with the UCL Research Ethics Committee. Please notify us of any further amendments, in line with guidance on the PaLS Intranet.

Best Wishes,

John King
Chair of Ethics, CEHP

--
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Appendix B:

Recruitment flyer

Supporting a relative with bipolar disorder: family members' experiences.

Research participants needed!

Do you have a relative with bipolar disorder? If so we'd like to hear about your experiences of supporting them, and the impact this has had on you. Your views may help increase understanding of the support relatives and carers need, and shape future services.

I am a Trainee Clinical Psychologist at University College London and am undertaking a research project looking at family members' experiences of supporting a relative with bipolar disorder. If you are a close relative, partner or carer you may be eligible to take part.

Taking part in the research would involve meeting to discuss your experiences for around an hour and a half. We can meet at UCL or a location of your choice. People who take part will be given a £10 voucher as a token of our appreciation. All identifying information will be changed so neither you or your relative can be identified in the write-up of the research.

If you would be interested in taking part please contact me:

Ella Baruch, Trainee Clinical Psychologist
Email: [redacted]
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place
London
WC1E 7HB

Further details about the project can be found at:
https://www.ucl.ac.uk/dclinpsy/traineeresearch/Research_documents/res_participant_invite

Thank you for considering taking part in this study.

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair
Project ID No: CEHP/2015/530

Appendix C:

Participant Information Sheet

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Supporting a relative with bipolar disorder: family members' experiences.

Information Sheet for Participants

We would like to invite you to take part in this research project. You should only take part if you want to. Before you decide whether you want to take part it is important for you to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information.

What is the project about?

We are interested in family members' experiences of supporting a relative with bipolar disorder. We are also interested in family members' experiences of receiving support for themselves, for example from family, friends, support groups, voluntary services or mental health services.

Who is being invited to take part?

We are inviting close family members who support a relative with bipolar disorder to participate. Family members may be parents, adult children, partners, spouses or siblings of a person with bipolar disorder. The support you provide and receive might include a range of things, such as practical, financial or emotional support.

Do I have to take part?

It is up to you to decide whether to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you do decide to take part you are still free to withdraw at any time and can do so without giving a reason. Withdrawing from the study has no consequences for any support you may be receiving.

What will I be asked to do?

If you decide to take part we will ask you to meet with a researcher to discuss your experiences of giving and receiving support. The interview will be recorded so that we have an accurate record of what was said. The whole meeting will last about an hour and a half, and will either take place at UCL or somewhere that you choose. People who take part will be given a £10 voucher as a token of our appreciation.

What will happen to the information that is collected?

The recordings of the interview will be transcribed (written up). We will then delete the recordings. The transcriptions will be made anonymous; names and any identifying information will be removed so that you cannot be identified.

All written information will be stored securely and will be destroyed five years after the study has ended. All data will be collected and stored in accordance with the Data Protection Act 1998. If for any reason you decide to withdraw from the study, all information you provided will be deleted.

Everything that you tell us will be kept confidential; only the research team will have access to what has been said. The only time confidentiality would be broken is if we became concerned that you or another person were at risk of serious harm. If we did need to tell someone else then, where possible, we would discuss this with you first and it would be managed as sensitively as possible.

Once the project is over, the results will be written up as part of a postgraduate thesis and may be submitted for publication in an academic journal. Reports will not reveal the identity of anyone who took part. An anonymous summary of the findings will be given to those who took part in the project and will be sent to any participating organisations.

Are there any risks of taking part?
It is possible that the interview might touch on areas that are distressing. If this were to happen, the researcher will be able to talk this through with you and discuss any support you might need, and you will have the option of stopping the interview.

What are the possible benefits of taking part?
Participants in previous similar studies have reported that the process of talking about their experiences in detail can be interesting and helpful. We hope that the information we obtain from this study will advance knowledge about family members' experiences, and the type of support they need.

Further information and contact details:
If you have any questions about this study, please contact the researchers:

Ella Baruch, Clinical Psychology Trainee <ella.baruch.14@ucl.ac.uk>
Nancy Pistrang, Professor of Clinical Psychology <n.pistrang@ucl.ac.uk>
Chris Barker, Professor of Clinical Psychology <c.barker@ucl.ac.uk>

Research Department of Clinical, Educational and Health Psychology
University College London
Gower St
London WC1E 6BT
Telephone: 020 7679 5962

Thank you for considering taking part in this study.

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair
Project ID No: CEHP/2015/530

You will be given a copy of this information sheet to keep

Appendix D

Consent Form

**Research department of clinical,
educational and Health Psychology**

UCL

Supporting a relative with bipolar disorder: family members' experiences

Informed Consent Form for Participants

Please complete this form after you have read the Information Sheet and listened to an explanation about the research.

Title of Project: **Supporting a relative with bipolar disorder: family members' experiences**

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair
Project ID No: CEHP/2015/530

You will be given a copy of this Consent Form to keep.

Participant's Statement

I ....
agree that:

- I have read the Information Sheet and the project has been explained to me orally;
- I have had the opportunity to ask questions and discuss the study; and
- I have received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.
- My interview will be audio recorded and I consent to use of this material as part of the project.

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as confidential and handled in accordance with the provisions of the Data Protection Act 1998

I agree to take part in this study.

Signed: Date:

Investigator's Statement

I ……………………………………………………………………..
confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:

Appendix E

Semi-structured Interview Schedule

Interview Schedule

Supporting a relative with bipolar disorder: family members' experiences

So just to remind you, in this study I'm interested in finding out about your experiences of supporting your relative. I'm also interested in your experiences of receiving informal and formal support for yourself. This could be from family, friends, support groups, voluntary services, or mental health services. The help you provide and receive might include a wide range of things, for example practical or financial help, or emotional support such as talking. Some people say it can be quite hard to know how to help, so it might be more relevant to talk about the difficulties around supporting your relative, although for some people there are positive aspects too, which I'm also interested in hearing about.

I have some areas I want to cover, but I'm interested in hearing about your experiences, and what's most important to you in these areas. There might be things you feel are important that I haven't covered, so do feel free to raise them. Some of my questions might seem obvious but I really want to try and understand your experiences, and what things have been like for you.

I am aware that discussing these things may be distressing, so please do let me know if you'd like to skip any questions, take a break, or stop the interview at any time. Are you happy to continue? Do you have any questions before we start?

I'd like to start by asking you some brief background information about you and your relative, and their difficulties.

1 Context

Could you tell me briefly about who is in your family?
Do you currently live with x [relative with bipolar disorder]? If not who does x live with?
How often do you speak to or see x?
Who else is involved in supporting x
Do you have any other family members with bipolar disorder?

2. Brief history of bipolar disorder

What type of bipolar disorder does X have?
When did you first notice x's difficulties?
How long did it take until x received a diagnosis of bipolar disorder or treatment?
How has x been since then (e.g. chronicity, number of episodes)?
How has x been recently?

Could you tell me briefly about what x is like when she/he is in a manic/hypomanic episode?

Could you tell me briefly about what x is like when she/he is depressed?

How is x between episodes?

3. Brief outline of contact with formal or voluntary services

Could you tell me briefly about any services x has been involved with?

Did you have any involvement with those services?

What kind of treatment or services does x use at the moment? (for example medication, mental health services, social services, support groups)

Ok, so I'd like to move on and talk in a bit more depth about your experiences if that's ok.

4. Experiences of providing support

Could you tell me about your experiences of supporting x?

Follow-up questions:

Could you tell me a bit about how you try to help or support x?

How do you try and help x during manic/depressive/between episodes?

What do you do in crisis periods (if that applies to you)?

Would you do anything when you think you've noticed early warning signs of x becoming manic or depressed?

Could you tell me about a recent time when you tried to help x? What did you do? How did x respond? How did you feel?

What kind of impact on x do you think your support has? Is it helpful?

Does it lead to any problems or difficulties? In what ways?

Has the way you try to help or support x changed over time? In what ways?

What kind of impact does supporting or helping x have on you? (e.g. practical, financial, emotional)

Follow-up questions:

Could you tell me about any positive or rewarding aspects of supporting x?

Could you tell me about any negative aspects?

What are the most difficult aspects to cope with?

Has it affected your relationship with x?

Has it affected other family relationships?

Has the impact on you changed over time? In what ways?

5. Coping

What kinds of things help you to cope with supporting x?

Follow-up questions:

Has your way of coping changed over time? In what ways?

How do you make sense of the situation and x’s difficulties?

Has this changed over time?

Has that affected how you cope with supporting x?

6. Support from others

Do you receive support or help from friends or family in relation to x’s difficulties?

Follow-up questions

What do you they do to try and support you?

In what ways is this helpful or unhelpful?

Could you tell me about a particular time when a friend/family member tried to help? What did they do? What impact did that have on you?

Do you feel you have enough support or help from family and friends? Do you have any ideas about what gets in the way (if not)?

7. Support from services

Could you tell me about any interactions with services you have had in relation to x’s difficulties? (e.g. mental health services, support groups, voluntary sector)

Did this involve you receiving any support or help?

In what ways was this helpful or unhelpful?

Did it have any impact on x?

(If had informal support and formal intervention) which type of support did you value most?

Overall do you feel you’ve had enough support from services?- now or in the past?

Was there anything that got in the way of you accessing support? (prompts- institutional, stigma, views of person with bipolar)

How did x feel about your involvement with services?

What kind of attitudes did services/professionals have towards you and your role?

In an ideal world, what type of support from services do you think would be most helpful for you?

What aspects of services would it be most important to change?

Probe questions

In what way/s?

Can you tell me more about that?

Could you give me an example?

How did that affect you?

How did you feel about that?

What did you think about that?

Debrief

I’ve asked all the questions I wanted to ask, is there anything important that we haven’t covered?

How did you find the interview?

Thank you very much for taking the time to talk to me. I will be asking all participants to look over my summary of their interview to see if they think I’ve missed anything important or misunderstood anything. Would this be something you would be interested in doing?

Once the study is written up I will also send a copy to all participants if they would like one.

Appendix F

Framework Analysis Examples

Framework analysis examples

This appendix gives excepts from the different stages of data analysis. Figure 1 illustrates the development of the initial codes, applied to an excerpt of a transcript. Figure 2 is an excerpt from the coding framework developed in the third stage of the analysis. Table 1 is an excerpt from a chart compiled in the fifth stage of the analysis, summarising the relevant data extracts for one category of the coding index. Table 2 is an excerpt of a chart developed in the final stage of the analysis, summarising quotations for one of the final sub-themes.

Figure 1 *Example of development of codes*

Excerpt from transcript of interview 10	**Initial annotations**	**Initial codes**
I: And you didn’t feel like [inpatient staff] kind of tried to involve you?		
P: No, they never made a point of like approaching us and sitting down and saying what progress there had been or not. It was really, you had to search them out and you know, “How is she doing”, but they never explained anything.	*Professionals didn’t explain* *Lack of contact with staff*	*Lack of explanation*
I: And what effect did that have on you?		
P: Again just not knowing, especially the first time, not knowing what to expect even. And nobody telling us what to expect. It was like being in a minefield. And no information, nobody’s helping really and it’s just like…I think we were just worn down with it ‘cos we went every day. We noticed most patients didn’t get visitors every day, but I didn’t feel like we could just leave her there and not visit her. Um and that was stressful especially when they put her into [name of hospital] because that was so much further to go and you had to go up after work.	*Just not knowing, nobody telling us what to expect- like being in a minefield.* *No information, nobody’s helping really.* *We were just worn down with it- visiting.* *Hospital was far away- stressful.*	*Not knowing/ understanding at first (like a minefield)* *Lack of explanation* *Supporting leads to stress/draining/tiring*
I: So there was just a real feeling of nothing being communicated to you?		
P: I feel there was definitely a lack of communication. And it’s also, you know, that if you’ve not been involved in mental health in any way, you don’t know what questions to ask. You know, you’re not sure, and you’re waiting for them to tell you or give you information and they’re not very forthcoming. And then, you know, it’s. It’s really, really difficult.	*You don’t know what questions to ask.* *Professionals aren’t forthcoming*	*Not knowing/ understanding at first (like a minefield)* *Lack of explanation*

Figure 2 *Excerpt of Coding Framework*

Knowing/not knowing
- Not knowing/understanding at first (like a minefield)
- Lack of explanation
- Support/research helps understand/know what to expect
- Gained practical strategies/information from support/research

Unpredictability/uncertainty
- Mania is more unpredictable/dramatic
- Sitting waiting for the next thing to happen
- Hard to adjust when switches from high to low
- You don't know what they're doing (when manic)
- Bipolar is different for everyone- trial and error
- Worrying what their future will be like

Looking for signs
- Looking out for warning signs/triggers
- Acting when notice them
- Catching it in time/not

Doing it together
- Managing it together/being shut out
- Able to communicate when notice warning signs vs not able to
- Relative communicating what they need/asking for help/involved in managing
- Relative gives permission to act when unwell

Getting help in a crisis
- Calling services
- Positive experiences of services in crisis
- Need for more support in a crisis/negative experiences

Dilemmas- caught between a rock and a hard place
- Going behind back when unwell
- Balancing safety/wellbeing with person's wishes
- Calling services/attempts to help lead to anger, irritability
- Calling services leads to mistrust, being 'barred' from care

Danger
- Worried about safety/behaviour (of relative and family members)
- Relative becomes aggressive/violent

Hard to help
- Whatever you do is wrong
- Not much you can do
- Sometimes you just have to ride it out
- Relative denies is a problem/doesn't want help

Table 1 *Excerpt of chart developed in fifth stage of analysis for thematic category "Knowing/not knowing and its four sub-codes*

Case	Not knowing/understanding at first (like a minefield)	Lack of explanation	Support helps understand/know what to expect	Gained practical strategies/information from support/research
10	Not knowing what questions to ask. Not knowing what to expect and no-one telling us. Like being in a minefield.	Lack of information when in hospital about diagnosis and medication, no feedback about how daughter was doing. Was a number of years before were able to speak to a professional. Most important thing to change about services is having someone explain things and give answers when relative first becomes unwell.	Consultant sat us down and we could ask questions. He put things into perspective. Helped us know what to look for, and what you can expect to see.	
11	'When it all happened, we hadn't a clue what bipolar was. All we knew, it was a mental illness. And, you know, we were quite frightened by it.' 'We had no knowledge of the illness, we didn't know why she was behaving this way.'	Difficult to get information and understanding about bipolar. Doing your own research doesn't tell you enough. Needed information about how it's treated and managed, but also advice about how to repair relationship and communicate with daughter when unwell.	Support helped recognise signs of relapse, and understand why she behaves the way she does when unwell. Having an understanding helps you feel less afraid, and see a way forward.	Got information from professionals involved in daughter's care and support group about how to manage condition and rebuild relationship.

Table 1 *Excerpt of chart developed in final stage of data analysis for subtheme "Not knowing, understanding at first" of Theme 1.1 Not knowing: "like being in a minefield"*

Case	Example quotations
10	*'Again, just not knowing, especially the first time, not knowing what to expect even…It was like being in a minefield.'* *'And it's also, you know, that if you've not been involved in mental health in any way, you don't know what questions to ask.'*
11	*'When it all happened, we hadn't got a clue what bipolar was. All we knew, it was a mental illness. And, you know, we were quite frightened by it…We had no knowledge of the illness, we didn't know why she was behaving this way, we didn't understand anything…'*
12	*'Having bipolar, we know what it is. And we know what's coming. The not knowing was the worst. You know we, it was about [over a year] before I found out that we could get [psychiatric appointment for son]. I was looking before online. But it was like, who do you trust, where do you go...So then I'm thinking, you know, "I just wanna know what's wrong with him."'*
14	*'At the beginning, I didn't understand. I was like, "What's going on here. Why is he behaving so weird?" And I don't have any relatives or don't know anybody that suffers depression, so I didn't know what it was really. Um and then, and then you know probably the six, the first six months was I went through shock to very sad and depressed. Not depressed, but upset myself about, can't believe this is happening. It's just crazy. It's really weird, really, really very strange illness. Cos he looks well. It's not that you have a broken bone. And I'll be like, "Let's go for a walk." "No." "Why not?" "I don't feel like it" "Come on, just a walk" "No I can't, no I can't," and that's like three hours of pushing, pushing and then we end up going for a walk but it takes ages. And it's really hard to understand.'*
17	*'So I hadn't ever, ever seen anybody, and I wasn't really aware of bipolar as an illness, well you know, especially if you come from [ethnic group] families you're not really…Nobody talks about mental health, um, and I'd just never seen anybody having a manic episode, so I didn't actually know what was happening and it's really quite terrifying.'* *'But I think also, with my case, I just didn't know what bipolar was. So it's not like, "Oh ok she's got pneumonia,"…and that, that really increases you know, your fear. Cause you're just like, "I don't know anything about this, what is this?"'*
18	*'We would feel like you know, what's happening to her, why is she being behaving like this, you know? And, um, we couldn't sort of, we couldn't deal with it because we didn't really understand, um, what was going on.'*

Appendix G

Respondent validation invitation

Dear x,

You recently took part in a research interview with me about your experiences of supporting your relative. Attached is the summary of your interview, with what I think were the main themes. The document is password protected, I will send the password in a separate email.

I would like to invite you to give feedback on the summary, but there is no obligation to do so if you would prefer not to. If you would like to give feedback I have outlined three broad questions below, and you are welcome to send any feedback via email.

1. How accurate do you feel the summary is?

2. Is there anything that needs changing?

3. Is there anything you think should be added?

If you have any questions do let me know. Thank you very much again for contributing to my research.

Yours Sincerely,

Ella Baruch

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