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Doctorate in Clinical Psychology

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Doctoral Thesis

An Exploration of Experiences of Bipolar Disorder within Couples

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Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology Course at Lancaster University, from June 2011 to August 2016. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of higher degree elsewhere.

Name: Anna Clancy

Signature:

Date: 15th August 2016

Acknowledgements

I would like to thank my research and field supervisors for their continuous support and guidance. I know at times this project has felt never-ending and I am grateful for your continued patience. Thank you also to my participants for their willingness and openness in talking to me about something so personal. I am also grateful to the organisations that helped me with recruitment.

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Word Count

	Text Only[1]	**Appendices**	**Total**
Abstract	265	0	265
Literature Review	7989	10336	18325
Research Paper	7982	14801	22783
Critical Analysis	3999	0	3999
Ethics Documents	5702	0	5702
Total Word Count	**25937**	**25137**	**51074**

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[1] Excluding tables, figures and reference lists

Abstract

The literature review section of this thesis explores the experiences of partners of individuals with a diagnosis of severe and enduring mental illness (SMI). A comprehensive literature search identified 15 papers which were critically appraised before narrative synthesis was undertaken to integrate their findings. A preliminary conceptual framework for how a person experiences a diagnosis of SMI in their partner was developed. The results suggested partners experience considerable emotional strain, but that this can be mediated by several factors; highlighting areas for intervention. Recommendations were made regarding how healthcare teams should offer support to these individuals by remaining mindful of the specific difficulties they can encounter as a consequence of this unique care-giving relationship.

The research paper section of the thesis presents a qualitative study investigating the experiences of couples in which one partner has a diagnosis of Bipolar Disorder (BD). Couples were interviewed together to gain a co-constructed view of the relationship and transcripts were analysed using Interpretative Phenomenological Approach (IPA). Analysis yielded four super-ordinate themes which demonstrate how a diagnosis of BD impacts upon both partners and some of the ways in which they cope with this, predominantly by demonstrating flexibility within their reciprocal roles. The study findings are discussed with reference to recommendations for service provision and future areas of research.

The critical analysis presents some of the major decisions made during completion of the research study, with the aim of supporting others conducting similar research. It discusses the use of joint interviews, the decision to incorporate diagnosis as part of the inclusion criteria and the researcher’s personal reflections on the process.

Contents

Section 1: Literature Review

Section 2: Research Paper

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Final SHMREC Documentation

Section One: Literature Review

Living with another's severe and enduring mental illness: A narrative synthesis of spousal experiences

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Word Count (excluding tables, figures and reference list): 7,989

Prepared for submission to *Family Process*[1]

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[1] Guidelines for authors presented in Appendix 1-A

Abstract

The aim of the review was to examine the experiences of partners of individuals with a diagnosis of severe and enduring mental illness (SMI) in order to identify their support needs. The experience of partners is a relatively under-researched area, yet evidence suggests their needs are different to other caregiving individuals, such as parents. A comprehensive literature search was undertaken which identified 15 original papers. The papers were critically appraised and narrative synthesis was undertaken to integrate their findings. A preliminary conceptual framework for how a person experiences a diagnosis of severe and enduring mental illness in their partner was developed. This comprised of six superordinate categories; three of which were process variables (characteristics of individuals with diagnosis; characteristics of caregiving partner and external influences) and three of which were outcomes (burden and emotional wellbeing; impact on relationship; increased responsibility). Limitations relate to the methodological limitations of current literature, including the small number of studies in this area and the heterogeneity between studies. The results suggest partners experience considerable emotional strain, but that this can be mediated by several factors; highlighting areas for support and intervention. Clinical teams should endeavour to support partners by being aware of the particular difficulties that can impact upon these pivotal relationships. They can help by teaching effective coping strategies, increasing social support networks and helping reduce feelings of isolation.

Keywords: Bipolar Disorder, Schizophrenia, Severe and Enduring Mental Illness, Carer, Spouse, Partner

Living with another's severe and enduring mental illness: A narrative synthesis of spousal experiences

Caring for a person with a diagnosis of severe and enduring mental illness (SMI) can be challenging (Bland, 1996; Jeon & Madjar, 1998). As the provision of mental health care has moved from predominantly inpatient to mainly community care, family is a major support system for persons with a diagnosis of SMI. Therefore, it is essential we research and learn about their needs and experiences in order that they can be best supported in this role.

Diagnosis

This review will consider together the experiences of partners of individuals with a diagnosis of bipolar disorder (BD) or schizophrenia. A number of studies have combined these groups previously (e.g. Chadda, Singh & Ganguly, 2007; Ganguly, Chadda & Singh, 2010) as the experiences of caring within these two illnesses have been found to have common features (Chadda et al., 2007; Hill, Shepherd & Hardy, 1998; Nehra, Chakrabarti, Kulhara & Sharma, 2005). Burden within a number of areas has been identified, including family functioning, social isolation, financial problems and health (Ganguly et al., 2010).

Relationship of the carer

The majority of literature investigating the experiences and effects of SMI on carers has considered all types of carers together, for example, parents, spouses and friends. This lack of distinction between different relationships hasn't allowed for the possibility that different carers may experience diverse needs. This review will consider only the needs of partner carers of individuals with a diagnosis of SMI. It has been suggested that psychiatric disorders are associated with a higher rate of divorce (Kessler, Walters & Forthofer, 1998;

Kogan et al., 2004), although causality in these studies could not be determined. Therefore, factors associated with higher levels of mental illness, for example childhood adversity or stressful living conditions, may also contribute to marital problems.

SMI can result in major changes within a relationship including increased responsibility in one partner (Crowe, 2004). This intimate relationship is central to a person's environment and therefore a partner will be both affected by and effect the course of the illness. Relationship factors have been found to be important in relation to the initiation, maintenance and outcome of depression (e.g. Hicks & Li, 2003; Parker & Ritch, 2001). This demonstrates the need for the experiences of partners to be understood, in order that they can be supported both for their own mental wellbeing and for the wellbeing of the individual with a diagnosis of SMI.

Although this review uses the term carer in order to avoid confusion, it should be noted that this label can be a source of contention, particularly within spousal relationships. Individuals with a diagnosis of BD have disagreed with the use of the word, because within a partnership, such as marriage, there is reciprocity of care-giving (Henderson, 2001). Within relationships the identity of who is the 'carer' and who is 'cared for' can change and is adaptable depending on the current needs of each partner. Professionals working with individuals who have a diagnosis of SMI can have certain expectations of the partner whom they place in the carer role, i.e. the one without a mental health diagnosis. Henderson (2001) explains that it is possible for people to reject the carer role. She advises professionals to work with individuals within their own experiences and meanings.

Outcome Measures

The experiences of carers have been studied using a range of methodologies and outcome measures. Caregiver burden is a common outcome measure within the literature. Burden tends to encompass all the effects of caring, including the physical, psychological, socioeconomic and coping abilities (Ohaeri, 2003) and a distinction has been made between objective and subjective burden (Hoenig & Hamilton, 1966). Objective burden refers to the practical demands placed upon the carer, whilst subjective burden refers to the way in which the carer appraises their situation. A systematic review of burden experienced by carers of individuals with a diagnosis of BD demonstrated that high subjective and objective burden was experienced (Van der Voort, Goossens & Van der Bijl, 2007). Severity of symptoms, lack of support and factors within the relationship were associated with higher levels of burden and a variety of coping strategies were utilised. Similarly, high levels of burden were experienced by relatives supporting those with a diagnosis of psychosis (Lobban et al., 2013).

The dominance of the term burden within the carer literature means other family experiences may be overlooked, in particular, the potential for family carers to experience positive outcomes, such as building resilience (Marsh et al., 1996). Positive aspects of care-giving have been identified and are associated with better quality of life (Kate, Grover, Kulhara & Nehra, 2013). Hunt (2003) argues that if caregiving is to be looked at from a holistic perspective, both negative and positive experiences should be considered. Heru and Ryan (2004) included reward as an outcome measure in their study and found that for carers of individuals with depression, perceptions of rewards were high, however, carers of individuals with BD reported low levels of reward. The use of qualitative methods has led to more diverse findings within the carer literature. Indeed, qualitative research appears to allow for more identification of the positive aspects of caring (Hunt, 2003).

A further outcome used in the literature is psychiatric symptoms within carers. Steele, Maruyama and Galynker (2010) completed a review of studies investigating this in carers of individuals with a diagnosis of BD. Their results showed that the majority of papers reported psychiatric symptoms within carers, such as depression, anxiety and an increased use of mental health services. However, a number of methodological limitations within the studies reduced the reliability of the results and further research was recommended.

The difficulties associated with measuring outcomes for carers of people with a diagnosis of SMI have been acknowledged in a review by Harvey et al (2008). They state that over 200 different measures have been used to assess outcomes in carers and data regarding their relative reliability and validity is commonly lacking. Their review looked at 64 of these, with the results concluding that 26 had good psychometric properties.

The Current Review

The aims of this paper are to review the literature regarding the experiences of partners of individuals with a diagnosis of either BD or schizophrenia and identify the needs of this population. It hopes to identify both the challenges and positive outcomes experienced by partners as a result of their caring role. Research in this area has utilised diverse methodologies, incorporating both quantitative and qualitative analysis. Due to the broad nature of the research questions and in order to address them in as much depth as possible, all research in this area was taken into account. Therefore, a systematic mixed methodologies review was conducted. It utilised a narrative synthesis methodology (Popay et al., 2006) to amalgamate existing knowledge about the needs of partners in order to direct further research within this relatively under-researched area and to make recommendations for the support of these individuals. A similar approach has been used successfully in other areas such as to develop a conceptual framework of personal recovery in mental health (Leamy, Bird, Le Boutillier, Williams & Slade, 2011) and to evaluate the effectiveness of music therapy in dementia (McDermott, Crellin, Ridder & Orrell, 2013).

Method

Aims of Review

The review aims to understand the experiences of partners of individuals with a diagnosis of SMI, with a view to identifying their needs. The research question asks what difficulties they may experience in order to identify the ways in which they may be better supported within services.

Study Selection

For inclusion in this review studies had to meet the following criteria: published in peer-reviewed journals; written in the English language; and include data regarding the experiences of partners of individuals with a diagnosis of BD or schizophrenia. Both qualitative and quantitative studies were included. To be identified as a partner, studies stated that participants must live with and be in a romantic relationship with a person who had a diagnosis of either BD or schizophrenia. Diagnosis was either confirmed by the researchers against ICD-10 criteria or determined via the person's current involvement with mental health services.

The following criteria excluded studies from this review: where results were reported for caregivers in general and no separate data for partners was given; where data for partners of individuals with a diagnosis of BD or schizophrenia were not given separately from other diagnoses; and where no analysis of the data had taken place.

Search Strategy

The literature search was carried out in July 2016. The databases searched were psycINFO (1884 – 2016), Medline (1923 – 2016), CINAHL (1980 – 2016), AMED (1986 –

2015) and Web of Science (1945 – 2016) using pre-determined search terms. These search terms were generated by hand, utilising the thesaurus in the databases in order to ensure that similar sounding terms were not missed. The search terms used were (Bipolar disorder OR manic depression OR manic depressive disorder OR schizophrenia) AND (spouse OR partner OR wife OR husband OR significant other) AND (experiences OR support needs OR burden OR coping). Following the removal of papers which had not been peer-reviewed and which were not written in the English language, this search yielded 2278 results. The titles, and abstracts where necessary, of these papers were read and the above inclusion/exclusion criteria were used to identify the final 15 papers which would be included in the review. In situations where the lead researcher was unsure of whether a paper should be included this was discussed with their supervisor and a joint decision made. This process can be seen in Figure 1.

In addition, a web-based search was conducted using popular search engines in order to identify further papers and the reference sections of the final 15 papers were searched by hand. However, neither of these methods identified any further papers which met the criteria to be included in the review.

Insert Figure 1 Here

Methods of Synthesis

Data synthesis adopted a narrative approach as this allowed for consideration of a broader knowledge base from a variety of methodological approaches. This method of synthesis is becoming more common within systematic reviews and involves adopting a narrative, as opposed to statistical, summary of findings (Rodgers et al, 2009). The guidance of Popay et al

(2006) was used[2]. This guidance was created to improve the quality of narrative synthesis and reduce bias by describing specific tools and techniques to use. It describes the ultimate aim of such a method to be, "telling a trustworthy story" (Popay et al, 2006, pp 5) and is recommended for summarising the current state of knowledge in relation to a particular question. The guidance is particularly aimed at those who want to review how current knowledge can inform policy and practice. The steps suggested by Popay et al (2006) are described below:

1) Developing a primary synthesis

Each paper was read a number of times and an initial description of the method and results summarised in textual descriptions. This enabled information to be extracted in a systematic way. The following data were then taken and tabulated: country of origin, research question, methodological approach, data collection method, participant information and summary of findings to allow for easier comparison between studies. Patterns related to the experiences of partners of individuals with a diagnosis of schizophrenia or BD were identified across the studies using an inductive thematic approach. This involved reading the papers several times and identifying concepts which were present in multiple studies[3]. Findings from quantitative studies were included in this thematic analysis by extracting variable labels from the outcome measures and using them as themes (for example when an outcome measure was looking at burden, this was extracted as a theme).

2) Exploring the relationships between studies

The preliminary synthesis resulted in a number of themes emerging across the studies. Concept mapping was used to link pieces of evidence extracted from individual studies in

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[2] Synthesis process presented in Appendix 1-C
[3] Development of themes presented in Appendix 1-D

order to highlight key concepts relevant to the aims of the review. A more rigorous interrogation of these was then completed using reciprocal translation to try and understand one study's findings in terms of another's. To do this, specific details regarding recruitment, diagnosis and form of analysis were compared and contrasted in order to identify factors which may explain the existing similarities and differences. This would allow a new interpretation of the data to be made which would ‘fit’ all the studies.

3) Assessing the robustness of the synthesis

Finally, the robustness of the synthesis was considered. Search criteria, selection of studies and choice of quality assessment tools had been discussed with the research supervisor to ensure they were appropriate. The quality of papers was reviewed and the results of the better quality studies were given more prominence within the synthesis than those of lower quality studies. Furthermore, the author reflected critically on the methodology of synthesis and any discrepancies that were identified. The research supervisor reviewed and gave feedback on the initial development of themes to enhance validity. The lead researcher also remained mindful of and reflected on her previous experience working with carers and how this had the potential to impact upon her findings.

Appraisal of Studies

Each of the 15 papers included in this review were subjected to quality appraisal. Different quality assessment tools were used for the studies dependent on whether they were qualitative or quantitative. The mixed methods paper was assessed using the quantitative measure as this formed the main part of the paper.

Qualitative papers were reviewed with the Critical Appraisal Skills Programme (CASP)[4] using guidance from Duggleby et al. (2010). The first two questions from the CASP were eliminated as the purpose of these was for inclusion/exclusion criteria which had already been completed. Therefore, eight questions on the CASP were answered with each question yielding a score of 1 – 3, allowing for a maximum total score of 24. The eight questions covered research design, data collection and analyses, ethics, reflexivity, and implications of qualitative studies. One point was assigned to articles that offered little to no justification for a certain area. Two points was given to articles that addressed a point but without further elaboration or complete description. Three points was assigned to articles that extensively explained the issue. For the seven qualitative papers included, the mean CASP score was 16.57 with a range of 13 – 20.

Choosing a quality assessment tool for the quantitative papers was more challenging as they were all cross sectional case series studies. Due to the lack of a control group, case control series studies are often considered to be poor in terms of the reliability of the evidence. However, it is acknowledged they are sometimes the only form of research available within an area and therefore their inclusion in systematic reviews may be required (Moga, Guo, Schopflocher & Harstall, 2012). A lack of a reliable instrument with which to assess their quality, however, has meant that their inclusion in Cochrane Reviews has been prohibited (Yang, Li, Costa, Reece & Changli, 2009). A review by Moga et al. (2012) identified 36 papers including information regarding the development or use of quality assessment tools for case series studies. Of these, only three provided details of the methods by which the tools were developed and data regarding internal validity (Downs & Black, 1998; Nichol et al., 1999; Yang et al., 2009). Unfortunately none of these assessment tools met the exact requirements of the current review, however, due to the lack of suitable tools it

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[4] Presented in Appendix 1-E

was decided to use the instrument devised by Yang et al (2009)[5]. It was necessary to amend some of the questions in order to obtain scores that could be used as a guide to inform opinions on quality. It incorporated nine questions, each of which could achieve a yes or no answer (scoring 1 or 0 points respectively) and covering the areas of clear study aims, appropriate study design, replicability, clear inclusion/exclusion criteria, appropriate recruitment, objective assessment, complete data collection, appropriate data analysis and clearly reported outcome measures. For the eight papers in this review the mean score was 6.13, with a range of 4 – 8.

Following this, all studies were included in the synthesis, but in line with recommendations from Popay et al (2006), different weight was given to each study dependent on its quality score. The inclusion of lower quality papers allowed for limitations in the research to be discussed and recommendations for future research to be highlighted.

Results

The studies used various approaches to investigate the experience of being the partner of a person with a diagnosis of SMI. Qualitative studies used interviews to ask partners about their support needs; the impact of the diagnosis on their relationship; the burden they felt and how they coped. The quantitative studies used outcome measures which looked at burden, general health, coping and expressed emotion.

Characteristics of included studies

A total of seven papers included in the review were of a quantitative design, seven were qualitative design and one used a mixed design. Within these sub-categories, a number of different methodologies were used. Within the qualitative papers, four used a grounded

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[5] Presented in Appendix 1-F

theory approach, one used content analysis, one used thematic analysis and one used a phenomenological hermeneutic method. The quantitative papers, meanwhile, were all cross sectional case series studies, but used a variety of different scales and analysed the results using ANOVA (two papers), t-tests (four papers) and correlation coefficients (one paper). The mixed design study did not appear to use a qualitative analysis technique, but instead described the results. It also used t-tests for the quantitative date. Details of these studies are provided in Table 1. Six of the papers interviewed partners of individuals with a diagnosis of schizophrenia and nine were concerned with BD. Four studies were carried out in India; two in Australia; two in Germany; two in Poland, one in Japan; one in Israel; one in the Netherlands; one in Norway and one in the United Kingdom. The 15 studies included in this review had a total sample of 707 spouses of individuals with a diagnosis of BD (291) or schizophrenia (416). The sample sizes in the quantitative studies ranged from 37 to 120 and in the qualitative studies ranged from 8 to 52. The mixed methods paper had 13 participants. All studies aimed to explore the experiences and impact of being married to a partner who has a diagnosis of schizophrenia or BD.

Insert Table 1 Here

Conceptual Framework

A preliminary conceptual framework for how a person experiences a diagnosis of SMI in their partner was developed and can be seen in Figure 1. This comprises six superordinate categories; three of which are process variables (characteristics of individuals with diagnosis; characteristics of care-giving partner and external influences) and three of which are outcomes (burden and emotional wellbeing; impact on relationship; increased responsibility).

Insert Figure 2 Here

Process Variables

All 15 papers discussed concepts that influenced the experiences of being the partner of an individual with a diagnosis of SMI. Through thematic analysis these were grouped into three superordinate categories: characteristics of individuals with diagnosis; characteristics of care-giving partners and support.

Individual characteristics within either the partner or the person with a diagnosis were discussed in 12 of the papers. This included all eight of the papers using quantitative methodology, which would be as expected given the research aims of these tended to be associated with identifying specific predictors of burden. Ten papers discussed the support needs of partners and how the availability or absence of support impacted upon experiences.

Characteristics of individuals with a diagnosis of SMI.

Characteristics associated with the individual with a diagnosis of SMI were discussed in five papers; three studying BD and two looking at schizophrenia. These were mainly related to the impact that severity and course of illness had on burden in partners. Kumar, Rani, Jain & Mohanty (2009) identified that increased psychosocial dysfunction within individuals who have a diagnosis of schizophrenia was correlated with increased subjective and objective burden in spouses. Similarly, Jungabauer and Angermeyer (2002) and Jungbauer, Wittmund, Dietrich & Angermeyer (2004) found that in schizophrenia subjective burden reported by partners fluctuated with illness curve and that more was reported during periods of acute illness. Similarly, in their study of BD, Arciszewska, Siwek & Dudek (2015) identified that more burden was reported by spouses during depression and manic phases as opposed to remission. Additionally, a diagnosis of BD1 was associated with higher partner burden than BD2. It is clear, therefore, that level of burden experienced by care-giving partners is a dynamic concept, fluctuating with the changing needs of their partner and associated demands that are placed upon them.

In addition, Van Der Voort, Goossens, & Van Der Bijl (2009) reported that personality traits and behaviours in the person with BD can impact upon level of burden reported by their spouse. For example, the ability to take the feelings of their partner seriously was helpful in lowering burden. Therefore, it is not just symptoms of illness, but also behaviours that may be open to change.

Characteristics of the care-giving partner.

11 papers discussed factors associated with the spouse that were found to influence their experiences. Kumar and Mohanty (2007) recruited equal numbers of men and women and found that female spouses of patients with a diagnosis of schizophrenia reported more burden than males suggesting there may be a gender differences in the experience of burden. Females also felt they got less external support and reported higher burden in the areas of routine, patient behaviour and care-giver strategy. Arciszewska et al. (2015) also identified that female partners reported higher burden and that women provided more supervision to their partners and were also less accepting of the diagnosis. Other studies, meanwhile, found no significant differences in level of burden experienced by males and females whose partners had a diagnosis of BD (Borowiecka-Karpiuk, Dudek, Siwek & Jaeschke, 2014; Kumar, Singh, Mohanty & Srivastava, 2004). Lack of a control groups within these studies mean comparison with other groups isn't possible. In one study, despite fewer burdens being reported by men, there were no significant differences in levels of distress experienced by men and women (Arciszewska et al, 2015). This suggests men do find being the partner of an

individual with a diagnosis of SMI to be difficult, but they may experience and describe this in different ways to females and in a way which does not correlate to high levels of burden as measured by these scales. It is unclear from the results of this review whether differences in the experiences and coping of male and female partners exist. Although some papers suggest they do, this is contradicted by other papers and the overall participant numbers mean that reliable conclusions cannot be made. If differences do exist this may be due to societal assumptions that caring is a more acceptable role for a woman and therefore less support being offered or to the different profiles of BD in men and women, meaning that male and female partners are needing to cope with different challenges. Further study in this area would be useful.

Van der Voort et al. (2009) and Tranvag and Kristofferson (2008) both discussed the impact of coping abilities and appraisal on partner burden in BD. Characteristics such as having the capacity to persist during difficult periods, having a sense of humour, loving the spouse and being able to share feelings with them appeared to be beneficial. Acceptance of the diagnosis could happen with time, and with it new hope for the future (Tranvag & Kristofferson, 2008). Engagement in task-orientated coping as opposed to emotion-focused coping was also found to result in lower levels of experienced burden (Borowiecka-Karpiuk et al., 2014). Lam, Donaldson, Brown and Malliaris (2005), meanwhile, found that it was not merely symptoms that were influential, but the ways in which they were viewed by the spouse that affected their burden. Behaviours viewed as internal caused more stress. Furthermore, higher levels of expressed emotion (EE) correlated positively with burden of care. As indicated by the arrows in the conceptual map, these individual characteristics within the care-giving partner are thought to interact with one another, as has been identified in previous research investigating the relationships between appraisals of illness coping and levels of EE in schizophrenia (Amaresha & Venkatasubramanian, 2012).

External influences.

The impact of the provision or absence of support was discussed in ten papers; concluding that support was lacking for partners, which had negative consequences for their well-being.

With respect to family support, Kumar and Mohanty (2007) found that partners living within nuclear family systems as opposed to joint family systems reported more burden associated with external support. This study was carried out in India where it is more common for extended families to live together in a joint family unit (Kumar & Mohanty, 2007). This finding suggests that this arrangement increases the amount of support available to partners of individuals with a diagnosis of schizophrenia, which is beneficial to their mental wellbeing.

Meanwhile, Kumar et al (2004) identified gender differences within the experience of social support. In their study, female spouses reported more burden in social support than male spouses. However, limitations in this study design mean that impartial data regarding the amount of support is unavailable. It is unclear as to whether females actually received less support than males or whether they received similar amounts but wanted more. Mizuno, Iwasaki & Sakai (2011), meanwhile, only interviewed male partners and found that reports of social support varied between participants, which again may highlight the different expectations and needs of different individuals.

Tranvag and Kristofferson (2008) reported a lack of social support related to perceived stigma of SMI. Participants reported a reduction in social contacts, which in turn led to social withdrawal in themselves. Gaskill and Cooney (1992) also identified a lack of support for partners, who all expressed appreciation at being given the opportunity to tell their stories when taking part in the research. Van der Voort et al. (2009) identified social support to be an important mediating factor in levels of burden experienced by care-giving partners. In this study, those who had separated from their partners reported virtually no social support.

A further aspect of support considered in these studies was that provided by health professionals. The majority of papers identified this as seriously lacking and reported consequential negative ramifications for partners. In particular, at the point of diagnosis it was found that partners experienced a lot of burden associated with a lack of communication and support from professionals (Jungbauer et al., 2004; Lam et al., 2005). Participants expressed disappointment in the lack of support as they thought it would be useful in helping to decrease their burden and feelings of loneliness, mobilise protective factors and promote successful coping (Tranvag & Kristofferson, 2008; Van der Voort et al, 2009). Furthermore, Gaskill and Cooney (1992) reported that partners found it difficult to be taken seriously by health professionals; it was rare that they were involved in discussions regarding care. Partners needed to be assertive in order to be heard and felt their ability to cope improved as they gained experience of the system and learned where to ask for professional help (Gaskill & Cooney, 1992; Jungbauer et al, 2004).

Outcomes

The experience of being the partner of an individual with SMI is impacted upon by the above process variables. Thematic analysis of the 15 original papers also identified three superordinate categories to describe the major impact outcomes for carers. These outcomes are thought to interact with one another and feed back into the process variables and are described below:

Burden and emotional wellbeing.

All studies discussed the emotional wellbeing of partners; however they differed in their terminology. Quantitative papers were more likely to use the term burden as these papers used questionnaires which specifically assessed this. Qualitative papers allowed the participants to describe their experiences within their own terminology, meaning the term burden was not used as frequently. In order to decide whether burden and emotional distress could be clustered together in this review, the specific assessment questionnaires used in quantitative studies were examined to understand what experiences contributed to the concept of burden.

For assessing burden, four papers used the Burden Assessment Schedule by Thara, Padmavati, Kumar and Srinivasan (1998; Gupta & Mohanty, 2016; Kumar et al., 2004; Kumar & Mohanty, 2007; Kumar et al., 2009); two used the Involvement Evaluation Questionnaire (Arciszewska et al., 2015; Borowiecka-Karpiuk et al., 2014); one used a semi-structured interview designed by Fadden et al (1987; Dore and Romans, 2001) and the final paper used the Relative's Burden Schedule (Lam et al., 2005). All of these included components of emotional distress, such as worrying, loneliness and depression. Furthermore, in the majority of papers, the results discussed scores on these aspects of the assessments separately allowing for the emotional distress components of burden to be extracted for the purposes of this review. Three studies also assessed distress using the General Health Questionnaire (GHQ, Goldberg & Hillier, 1979; Arciszewska et al., 2015; Dore & Romans, 2001; Lam et al., 2005).

All papers demonstrated that burden was associated with being the partner of an individual with a diagnosis of BD or schizophrenia. Kumar et al. (2009) and Kumar et al. (2004) both reported high levels of subjective and objective burden in their participants, with few further details. Lam et al. (2005) meanwhile, broke the burden experience down and reported feelings of being overwhelmed, conflicted, bitterness and loss. Furthermore, Borowiecka-Karpiuk et al. (2014) found the highest levels of burden to be associated with worrying and experiencing fear for the future and the health of their partner.

Scores on the GHQ varied between studies, despite all researching BD. Lam et al. (2005) and Arciszewska et al. (2015) found that 46% and 88% respectively of partners obtained scores suggestive of mental ill-health. These results were not replicated in the Dore and Romans study (2001) who found that only 17% of participants reached the cut-off score for psychiatric morbidity. Low participant numbers and less detailed inclusion criteria mean this result is treated with more caution, however.

All qualitative papers reported emotional distress in participants. This methodology allowed for a temporal description of emotional wellbeing to be developed as participants described how their feelings changed at different points of the illness. Fear and despair at the point of diagnosis, or first acute episode, was often felt by partners (Jungbauer et al., 2004; Tranvag & Kristoffersen, 2008). Emotional wellbeing could also change in relation to illness stability and improve with increased experience and knowledge or with increased acceptance of the diagnosis (Jungbauer et al, 2004; Tranvag & Kristoffersen, 2008; Van der Voort et al., 2009). However, when partners took steps to put their own needs first, in order to reduce stress, they could experience feelings of guilt (Van der Voort et al., 2009).

Even during periods of stable health participants could experience a constant feeling of threat hanging over the family and anxiety about the future (Granek et al, 2016; Jungbauer et al, 2004; Mizuno et al, 2011; Tranvag & Kristoffersen, 2008). This was the case for partners of individuals with both a diagnosis of schizophrenia and BD. Loneliness was also a common feeling expressed by participants (Gaskill & Cooney, 1992; Granek et al., 2016; Tranvag & Kristoffersen, 2008; van der Voort et al., 2009) as they did not feel they had anyone to share their experiences with. Not knowing anyone else in a similar situation to themselves added to this (Gaskill & Cooney, 1992; Mizuno et al., 2011).

No papers reported positive emotional well-being as a consequence of being married to a spouse with a diagnosis of SMI. This is to be expected from the quantitative papers as participants were specifically asked about burden and the challenges in their relationships. However the more unstructured methods utilised in the qualitative studies may have allowed for positive experiences to be discussed. One limitation of the majority of qualitative studies included in this review was their omission to consider and discuss the potential bias and influence of the researchers when completing the interviews and analysis. It is therefore possible that their pre-existing ideas regarding the challenges of being a spouse may have impacted upon the results. Alternatively it is possible the findings are accurate and that spouses do experience a lot of emotional distress with little or no joy.

Impact on relationship.

The impact of a diagnosis of SMI upon the marital relationship was discussed in eight of the papers (Borowiecka-Karpiuk et al., 2014; Dore & Romans, 2001; Granek et al., 2016; Jungabauer & Angermeyer, 2002; Jungabauer et al., 2004; Lam et al., 2005; Mizuno et al., 2011; Van der Voort et al., 2009), including the ways in which partners were able to maintain the relationship and the factors that affected this. Furthermore, six papers specifically discussed the impact of the illness on sexual relations (Borowiecka-Karpiuk et al., 2014; Dore & Romans, 2001; Granek et al., 2016; Jungabauer & Angermeyer, 2002; Jungabauer et al., 2004; Lam et al., 2005). It is these findings that are specific to the experiences of care-giving partners, as opposed to other carers.

Challenges within the marital relationship were present, although not insurmountable. Dore and Romans (2001) reported that 92% of partners found the relationship hard to keep going and that 62% had separated at some point. Furthermore, 62% thought that they would not have entered into the relationship had they known more about the illness. Conversely, Lam et al. (2005) reported that 84% of participants had accepted the situation and 92% were happy to remain within the relationship. Both these studies were quantitative; capturing opinions of participants for the specific moment in time they were asked about their relationship.

These differences of opinion may be attributable to the changing views of partners through the illness course. Jungbauer et al. (2004) described feelings of solidarity at the beginning which weaken with time, particularly if personal sacrifices are needed. Nevertheless, all partners interviewed were still in a relationship with their partner, demonstrating that even though their feelings of solidarity may have weakened, they had not left the relationship. Conversely, Tranvag and Kristoffersen (2008) reported an alternative cumulative process where early days were more challenging, as the realisation the relationship had forever changed caused loneliness, but then got better with increased acceptance over time. Although these results appear contradictory, this may be partly attributable to fluctuating feelings within individuals even at single points of time. Within one study, participants spoke about thoughts of divorce associated with reduced feelings of trust in their partner but also how they felt a strengthened bond and feeling of commitment following successful navigation through difficult periods (Granek et al., 2016).

Beliefs about the permanence of marriage and a sense of duty towards the spouse were found to be influential in the continuation of relationships (Jungbauer et al., 2004; Mizuno et al., 2011). Thoughts of separation were hindered by religious beliefs regarding the sanctity of marriage; feeling that if things were reversed their partner would stand by them and a sense of responsibility. It is possible these findings may have cultural influences. In particular, the Mizuno et al. (2011) study was carried out in Japan and the participants spoke about having a sense of duty to their wives. Furthermore, not all studies included participants who were married and such a sense of duty may not exist within co-habiting partners who are not married.

All studies which explicitly enquired about the sexual relationship reported difficulties**.** Dore and Romans (2001) reported that 77% of participants experienced problems within the sexual relationship and Borowiecka-Karpiuk et al. (2014) found that sexual satisfaction was lower following the diagnosis of SMI than before. Jungbauer et al. (2004) also identified challenges within the sexual relationship, caused by physical changes and lack of interest caused by medication, as did Granek et al. (2016) who identified a lack of physical intimacy as weakening the bond within relationships. Lam et al. (2005), meanwhile, looked at how sexual satisfaction fluctuated with different phases of BD and found it was significantly lower during manic and depressed phases. They identified a link between sexual satisfaction and marital satisfaction, but could not identify causality. Therefore, it is not clear whether lower sexual satisfaction caused lower marital satisfaction or vice versa.

Increased responsibility.

The changing of roles and increased responsibility felt by partners was discussed in six papers. This increase in responsibility was on both a practical level, in terms of doing more around the home, as well as on an emotional level, in terms of feeling responsible for looking after their partner. The increased responsibility had an emotional impact upon participants, making them feel increased burden, and impacted upon relationships.

For participants who were parents, responsibility for childcare was affected. Dore and Romans (2001) interviewed 10 couples who were parents and found that six of them believed the illness impacted upon parenting. Lam et al. (2005) found that half of participants reported more domestic duties and that 61% of those with children said that the illness meant that they had more responsibility for childcare. Partners spoke about taking on additional duties within the home (Granek et al, 2016; Jungbauer & Angermeyer, 2002; Jungbauer et al., 2004; Mizuno et al., 2011). Increased levels of responsibility led to feelings of self-sacrifice; found to be a factor in separation (Granek et al, 2016; Jungbauer et al., 2004). In addition, pressures could evolve from being the sole financial provider in the home, if the partner with a diagnosis of SMI was unable to work (Granek et al, 2016). Van der Voort et al. (2009) identified that feeling solely responsible led to feelings of loneliness and increased burden. It was instinct for partners to put the needs of their spouse first, however with time they worked to find more of a balance between self-effacement (keeping oneself in the background) and self-fulfilment. Mizuno et al. (2011), found this sense of responsibility acted as a protective factor against divorce, which again may be related to cultural factors and sense of duty.

Discussion

This narrative synthesis focused exclusively on the experiences of partners living with a person with a diagnosis of BD or schizophrenia. A preliminary conceptual framework to describe what is currently known in this area was developed.

The research shows that living with a partner who has a diagnosis of BD or schizophrenia puts strain on individuals and relationships. This is moderated by a number of variables, associated with the person who has the diagnosis of SMI, their partner and what external support is available to them. Burden experienced by partners fluctuates with the mental state of the person with a diagnosis of SMI and more is reported during acute episodes. However, there are things that can be done by both partners to help reduce this. Individuals with a diagnosis of SMI can support their partners by taking into account how they feel about the diagnosis. Meanwhile, partners can adapt the ways they appraise and cope with their situation. Engaging in task-orientated coping, as opposed to emotion-orientated is beneficial and those who display less expressed emotion report less burden. It is possible female partners experience more burden than male partners, although results in this area are mixed. Distress levels are similar between sexes suggesting all partners experience difficulties, but that the nature of these may be dependent on sex. Lower levels of social and professional support also increase isolation and reported burden.

Some of these findings are generic and applicable to all carers; however, the following findings are specific to the challenges of the partner care-giving relationship and highlight the need for targeted interventions. Partners report high levels of burden and distress, with a number meeting criteria for mental health support themselves. They describe feelings of loneliness and guilt as well as anxiety over the future. There is an increased sense of responsibility felt by partners, who do not feel as though they are in equal partnerships. They sacrifice their own needs which increases feelings of burden and distress. Feeling solely responsible for family life and unable to share this with their partner also increases loneliness. SMI impacts negatively upon intimacy and sexual relationships. The majority of partners had thought about ending the relationship at some time, although these thoughts fluctuated over time. There seemed to be complex thoughts associated with being a partner of someone with a diagnosis of SMI in that they felt very negatively about and feared the diagnosis and what it brought, but loved the person.

Although this review was interested in both the positive and negative outcomes of being a partner, the synthesis of literature identified solely negative consequences and experiences. This may be due to the nature of the research questions of the included studies, which may not have allowed for participants to express any positives and this would therefore make an interesting area for future study.

Impact of Diagnosis

This review included papers researching schizophrenia and BD. The rationale for this was that clients with these diagnoses are seen in the same services and both are considered to be SMI. Previous research has suggested that the experiences of carers for these two diagnoses are broadly similar (e.g. Chadda et al., 2007; Hill et al., 1998; Nehra et al., 2005). The results of this review support this finding. The quantitative studies suggest that burden is high for partners living with both diagnoses. Furthermore, the qualitative studies identified increased feelings of responsibility, fluctuations in emotional wellbeing associated with illness course, difficulties within the marital relationships and a lack of social support in partners of individuals with both BD and schizophrenia. However, it should be acknowledged that, although the burden levels of partners may appear broadly similar, given the different behaviours and symptoms that are seen in BD and schizophrenia, it is likely that their partners are coping with different challenges to one-another. The low number of papers available for review means that subgroup analysis to identify these potential differences was not possible, although this would be an area of consideration for future study.

Clinical Implications

The results of this review clearly demonstrate that partners of individuals with a diagnosis of SMI are at risk of emotional distress; however this can be mediated by several factors which highlight potential areas for intervention.

Some factors are generic to care-givers in general and the healthcare team working with clients should be aware of fluctuations within a carer's ability to cope, often in line with fluctuations within the illness. There may be periods of time when external support is not necessary; however, it should be available again when required. At the point of diagnosis information regarding the diagnosis and prescribed medication should be shared and time taken to discuss the implications of this for the family. There should also be a named contact available for care-givers to talk to regarding their anxieties and fears. Advice regarding effective coping strategies, communication skills and how to reduce expressed emotion in the home may all help to enhance the emotional wellbeing of care-givers.

Specific findings related to being the partner of an individual with a diagnosis of SMI were also evident and these need to be better understood by healthcare teams. In particular feelings of loneliness may be more enhanced as partners feel they have lost the person in whom they are usually able to confide and share their worries. They are also likely to feel burdened by increased responsibilities around the home, financial pressures and feeling solely responsible for childcare. It would be beneficial for partners to be introduced to other partners, possibly though support groups. Connecting with others who have lived experience of a similar situation could prove helpful in reducing feelings of isolation. It would also create opportunities for shared problem-solving and support within areas specific to these relationships, such as sexual relations and intimacy; something that may be difficult for partners to talk about in the presence of other care-givers, such as parents.

Difficulties in relation to intimacy and sex are prevalent, yet support regarding this is currently lacking within carer and family interventions. Fear of embarrassment may make this a difficult area for staff to talk about, so further training to assist them in this would be required. The risk of relationship breakdown may be reduced if appropriate support is given to the partner. Furthermore, it is clear that individual differences exist between needs of partners, meaning that support offered should be done on a needs-led basis.

Limitations

It is challenging to synthesise data from papers grounded in different epistemological viewpoints and there is some debate in the literature as to whether this is a valid approach

(Jenson & Allen, 1996). The decision was made to incorporate papers with different methodological approached in this review for a number of reasons. Firstly, the review has broad aims due to the relatively under-researched nature of the topic. It was thought that excluding papers on the basis of their methodology would limit the conclusions that could be reached. This decision was also made for pragmatic reasons as the number of papers published in this area are limited. Such an approach is possible as long as the various philosophical assumptions behind each approach are acknowledged and considered (Zimmer, 2006).

The wide range of methodologies also incorporated further differences between papers. Different inclusion criteria were used between studies meaning the definition of what determined a partner varied. Furthermore, the aims of the different studies were quite wide ranging which may be viewed as a limitation. In order to counter this, detailed descriptions of the studies have been included in order to allow readers to make their own judgements[6].

Robustness of Synthesis

The robustness of the synthesis was evaluated by considering the quality of original papers, as well as the methods by which they were combined. The quality scores attributed to each of the papers in this review can be seen in Table 1. Overall the quality of quantitative papers was relatively low and consideration of this was taken when themes were developed. The major limitation of these papers was a lack of control groups and only brief descriptions of outcome measures and results. This made it difficult to ascertain the implications of the findings. However, it should be noted that the results of these studies did appear broadly similar to each other, with each one reporting high levels of burden in partners. The inclusion

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[6] Presented in Appendix 1-G

of these papers also means that their limitations can be discussed and recommendations for future research identified.

Overall the quality of the qualitative papers was higher, although there was variability. More weight was given to the findings of these papers within the synthesis. Participants explained their experiences in their own words which created a richer data set. The most prevalent limitation present in these papers was a lack of consideration for the role of the researcher within the collection and analysis of data. Qualitative research is dependent on the interpretation of the raw data by the research team (Jootun, McGhee & Marland, 2009). Therefore, any biases or pre-held opinions need to be stated and considered prior to analysis taking place. This was lacking within these studies, thereby limiting the validity of their results.

Directions for Future Research

The main area of discrepancy uncovered within this review was whether male and female partners have different experiences to one another. This would be a good area for future research, so that support could be targeted in the most effective way. Future research focusing on the benefits of marriage for people with a diagnosis of SMI would also be beneficial as current research is focused on the challenges faced by their partners. In addition, methodologically sound studies investigating the effectiveness of psychological interventions for supporting the relationships of these individuals would help to direct future support.

Furthermore, although this review identified important factors involved in the experience of partners, it could not be explored within these data how these related to each other. Further work using a grounded theory methodology could move this forward.

References

Amaresha, A. C., & Venkatasubramanian, G. (2012). Expressed emotion in schizophrenia: an overview. *Indian journal of psychological medicine, 34*(1), 12-20. Retrieved from doi:10.4103/0253-7176.96149

Arciszewska, A. I., Siwek, M., & Dudek, D. (2015). Caregiving burden and psychological distress among spouses of bipolar patients-comparative analysis of subtype I and II. *Psychiatria polska*, *49*(6), 1289-1302. Retrieved from doi: 10.12740/PP/OnlineFirst/32177

Bland, R. (1996) Episodic Care of People with a Mental Illness. In *Towards A National Agenda for Carers: Workshop Papers.* Australia Government Publishing Services Aged and Community Care Division, DHSH, Canberra, Australia

Borowiecka-Karpiuk, J., Dudek, D., Siwek, M., & Jaeschke, R. (2014). Spousal burden in partners of patients with major depressive disorder and bipolar disorder. *Psychiatr. Pol, 48(4),* 773-787.

Chadda, R. K., Singh, T. B., & Ganguly, K. K. (2007). Caregiver burden and coping. *Social Psychiatry and Psychiatric Epidemiology*, *42*(11), 923-930. Accessed online at doi: 10.1007/s00127-007-0242-8

Crowe, M. (2004). Couples and mental illness. *Sexual and relationship therapy, 19*(3), 309-318. Accessed online at doi:10.1080/14681990410001715436

Dore, G., & Romans, S. E. (2001). Impact of bipolar affective disorder on family and partners. *Journal of affective disorders, 67*(1), 147-158. Accessed online at doi: 10.1016/S0165-0327(01)00450-5

Downs SH & Black N. (1998) The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health, 52(6),* 377-84. Accessed online at doi: 10.1136/jech.52.6.377

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158. Accessed online at doi: 10.1177/1049732309358329

Fadden, G., Bebbington, P. & Kuipers, L. (1987) The burden of care: the impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry, 150,* 285–292. Accessed online at doi: 10.1192/bjp.150.3.285

Ganguly, K. K., Chadda, R. K., & Singh, T. B. (2010). Caregiver burden and coping in schizophrenia and bipolar disorder: a qualitative study. *American Journal of Psychiatric Rehabilitation*, *13*(2), 126-142. Accessed online at doi: 10.1080/15487761003757009

Gaskill, D. & Cooney, H. (1992). Coping with schizophrenia: what does the spouse need to know? *Australian Journal of Advanced Nursing, 9,* 10–15.

Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine*, *9*(01), 139-145.

Granek, L., Danan, D., Bersudsky, Y., & Osher, Y. (2016). Living with bipolar disorder: the impact on patients, spouses, and their marital relationship. *Bipolar disorders*. 18 (2), 192-199. Accessed online at doi: 10.1111/bdi.12370

Gupta, N., & Mohanty, S. (2016). Relationship of Burden and Social Support with Expressed Emotion in Spouses of Persons with Schizophrenia. *Journal of the Indian Academy of Applied Psychology*, *42*(1), 172. Accessed online at doi: 10.1111/j.1600-0447.1990.tb03060.x

Harvey, K., Catty, J., Langman, A., Winfield, H., Clement, S., Burns, E., ... & Burns, T. (2008). A review of instruments developed to measure outcomes for carers of people with mental health problems. *Acta Psychiatrica Scandinavica*, *117*(3), 164-176. Accessed online at doi: 10.1111/j.1600-0447.2007.01148.x

Henderson, J. (2001). 'He's not my carer—he's my husband': Personal and policy constructions of care in mental health. *Journal of Social Work Practice*, *15*(2), 149-159. Accessed online at doi; 10.1080/02650530120090601

Heru, A. M., & Ryan, C. E. (2004). Burden, reward and family functioning of caregivers for relatives with mood disorders: 1-year follow-up. *Journal of Affective Disorders*, *83*(2), 221-225. Accessed online at doi: 10.1016/j.jad.2004.04.013

Hicks, M. H. R., & Li, Z. (2003). Partner violence and major depression in women: A community study of Chinese Americans. *The Journal of Nervous and Mental Disease, 191*(11), 722-729. Accessed online at doi: 10.1097/01.nmd.0000095124.05023.e1

Hill, R., Shepherd, G., & Hardy, P. (1998). In sickness and in health: The experiences of friends and relatives caring for people with manic depression. *Journal of Mental Health, 7(6),* 611–620. Accessed online at doi:10.1080/09638239817761

Hoenig, J., & Hamilton, M. W. (1966). Elderly psychiatric patients and the burden on the household. *European Neurology, 152*(5), 281-293.

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship, 35*(1), 27-32. Accessed online at 10.1111/j.1547-5069.2003.00027.x

Jensen, L. A., & Allen, M. N. (1996). Meta-synthesis of qualitative findings. *Qualitative Health Research, 6*(4), 553-560. Accessed online at doi: 10.1177/104973239600600407

Jeon Y. & Madjar I. (1998) Caring for a family member with chronic mental illness. *Qualitative Health Research 8(5),* 694–706. Accessed online at doi: 10.1177/104973239800800509

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, *23*(23), 42-46. Accessed online at doi: 10.7748/ns2009.02.23.23.42.c6800

Jungbauer, J., & Angermeyer, M. C. (2002). Living with a schizophrenic patient: a comparative study of burden as it affects parents and spouses. *Psychiatry*, *65*(2), 110-123. Accessed online at doi: 10.1521/psyc.65.2.110.19930

Jungbauer, J., Wittmund, B., Dietrich, S., & Angermeyer, M. C. (2004). The disregarded caregivers: subjective burden in spouses of schizophrenia patients. *Schizophrenia Bulletin*, *30*(3), 665-675. Accessed online at doi: 10.1093/oxfordjournals.schbul.a007114

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Positive aspects of caregiving and its correlates in caregivers of schizophrenia: a study from north India. *East Asian Archives of Psychiatry*, *23*(2), 45.

Kessler, R. C., Walters, E. E., & Forthofer, M. S. (1998). The social consequences of psychiatric disorders, III: probability of marital stability. *American Journal of Psychiatry*. Accessed online at doi: 10.1176/ajp.155.8.1092

Kogan, J. N., Otto, M. W., Bauer, M. S., Dennehy, E. B., Miklowitz, D. J., Zhang, H. W., ... & Calabrese, J. (2004). Demographic and diagnostic characteristics of the first 1000 patients enrolled in the Systematic Treatment Enhancement Program for Bipolar

Disorder (STEP-BD). *Bipolar Disorders, 6*(6), 460-469. Accessed online at doi: 10.1111/j.1399-5618.2004.00158.x

Kumar, S., & Mohanty, S. (2007). Spousal burden of care in schizophrenia. *J Indian Acad Appl Psych, 33*(2), 189-94.

Kumar, S., Rani, U., Jain, A., & Mohanty, S. (2009). Contribution of chronic schizophrenic patients' psychosocial dysfunction in spousal burden. *Indian Journal of Community Psychology, 5,* 191-197.

Kumar, S., Singh, R., Mohanty, S. & Srivastava, A. (2004). Spousal Burden of Care in Bipolar Affective Disorder, *Social Science International, 20 (1),* 69-75.

Lam, D., Donaldson, C., Brown, Y., & Malliaris, Y. (2005). Burden and marital and sexual satisfaction in the partners of bipolar patients. *Bipolar Disorders, 7*(5), 431-440. Accessed online at doi: 10.1111/j.1399-5618.2005.00240.x

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry, 199*(6), 445-452. Accessed online at doi: 10.1192/bjp.bp.110.083733

Lobban, F., Postlethwaite, A., Glentworth, D., Pinfold, V., Wainwright, L., Dunn, G., et al. (2013). A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. *Clinical Psychology Review*, *33*(3), 372-382. Accessed online at doi: 10.1016/j.cpr.2012.12.004

Marsh, D. T., Lefley, H. P., Evans-Rhodes, D., Ansell, V. I., Doerzbacher, B. M., LaBarbera, L. et al. (1996). The family experience of mental illness: Evidence for resilience. *Psychiatric Rehabilitation Journal*, *20*(2), 3. Accessed online at doi: 10.1037/h0095390

McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: a narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, *28*(8), 781-794. Accessed online at doi: 10.1002/gps.3895

Mizuno, E., Iwasaki, M., & Sakai, I. (2011). Subjective experiences of husbands of spouses with schizophrenia: An analysis of the husbands' descriptions of their experiences. *Archives of Psychiatric Nursing*, *25*(5), 366-375. Accessed online at doi: 10.1016/j.apnu.2011.03.001

Moga C, Guo B, Schopflocher D, Harstall C. (2012) *Development of a Quality Appraisal Tool for Case Series Studies Using a Modified Delphi Technique*. Edmonton AB: Institute of Health Economics.

Nehra, R., Chakrabarti, S., Kulhara, P., & Sharma, R. (2005). Caregiver-coping in bipolar disorder and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, *40*(4), 329-336. Accessed online at doi: 10.1007/s00127-005-0884-3

Nichol G, Stiell IG, Laupacis A, Pham B, De M, V, Wells GA. (1999). A cumulative meta-analysis of the effectiveness of defibrillator-capable emergency medical services for victims of out-of hospital cardiac arrest. *Annals of Emergency Medicine, 34(4- 1),* 517-25. Accessed online at doi: 10.1016/S0196-0644(99)80054-7

Ohaeri, J. U. (2003). The burden of caregiving in families with a mental illness: a review of 2002. *Current Opinion in Psychiatry*, *16*(4), 457-465. Accessed online at doi: 10.1097/01.yco.0000079212.36371.c0

Parker, G., & Ritch, J. (2001). The influence of an uncaring partner on the type and outcome of depression. *Journal of Affective Disorders*, *66*(2), 207-214. Accessed online at doi: 10.1016/S0165-0327(00)00311-6

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Britten, N., Rodgers, M., Roen, K. & Duffy, S. (2006) *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: Final Report*. Swindon: ESRC Methods Programme.

Rodgers, M., Sowden, A., Petticrew, M., Arai, L., Roberts, H., Britten, N., et al. (2009). Testing methodological guidance on the conduct of narrative synthesis in systematic reviews effectiveness of interventions to promote smoke alarm ownership and function. *Evaluation*, *15*(1), 49-73. Accessed online at doi: 10.1177/1356389008097871

Steele, A., Maruyama, N., & Galynker, I. (2010). Psychiatric symptoms in caregivers of patients with bipolar disorder: a review. *Journal of Affective Disorders, 121*(1), 10-21. Accessed online at doi: http://dx.doi.org/10.1016/j.jad.2009.04.020

Thara, R., Padmavati, R., Kumar, S., & Srinivasan, L. (1998). Instrument to assess burden on caregivers of chronic mentally ill. *Indian Journal of Psychiatry*, *40*(1), 21.

Tranvåg, O. and Kristoffersen, K. (2008), Experience of being the spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time. *Scandinavian Journal of Caring Sciences, 22,* 5–18. Accessed online at doi:10.1111/j.1471-6712.2007.00562.x

Yang, A. W., Li, C. G., Da Costa, C., Allan, G., Reece, J., & Xue, C. C. (2009). Assessing quality of case series studies: development and validation of an instrument by herbal medicine CAM researchers. *The Journal of Alternative and Complementary Medicine*, *15*(5), 513-522. Accessed online at doi: 10.1089/acm.2007.0806

Van der Voort, T. Y. G., Goossens, P. J. J., & Van Der Bijl, J. J. (2007). Burden, coping and needs for support of caregivers for patients with a bipolar disorder: a systematic review. *Journal of Psychiatric and Mental Health Nursing*, *14*(7), 679-687. Accessed online at doi: 10.1111/j.1365-2850.2007.01158.x

Van Der Voort, T. Y., Goossens, P. J., & Van Der Bijl, J. J. (2009). Alone together: A grounded theory study of experienced burden, coping, and support needs of spouses of persons with a bipolar disorder. *International Journal of Mental Health Nursing*, *18*(6), 434-443. Accessed online at doi: 10.1111/j.1447-0349.2009.00634.x

Zimmer, L. (2006). Qualitative meta-synthesis: a question of dialoguing with texts. *Journal of Advanced Nursing*, *53*(3), 311-318. Accessed online at doi: 10.1111/j.1365-2648.2006.03721.x

Figure 1. Selection of Studies

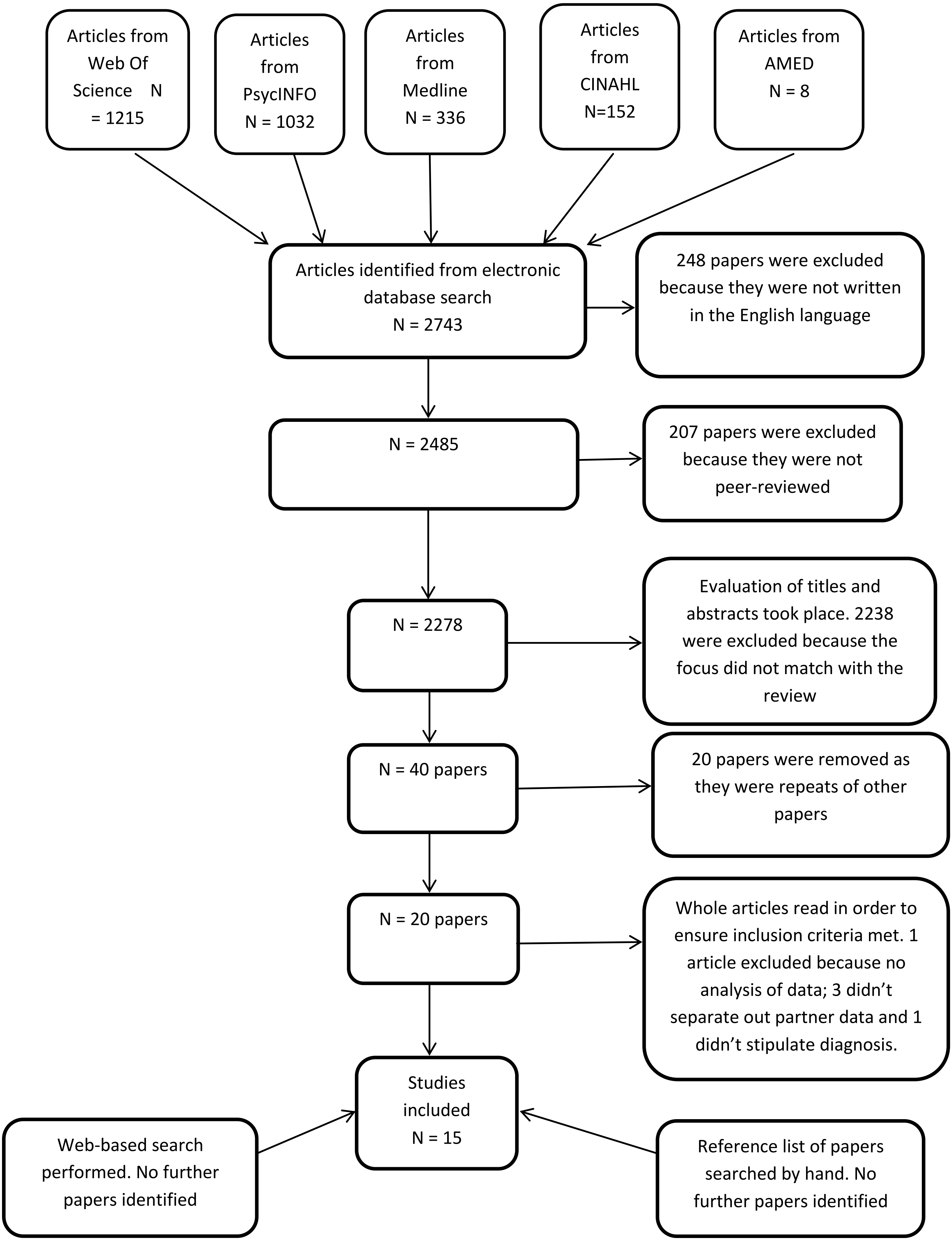


Table 1. Details of Included Studies

Source/Country	Aims/Research Question	Method/Data Collection	Key Findings	Quality Score
Quantitative				
Arciszewska, Siwek & Dudek (2015) Poland	To assess the impact of BD1 and BD2 on the burden experienced and levels of psychological distress reported by partners.	Quantitative – Involvement Evaluation Questionnaire and General Health Questionnaire analysed using ANOVA 44 spouses of individuals with a diagnosis of BD1 and 33 spouses of individuals with a diagnosis of BD2	• In BD1 mania is more burdensome than depression. • In BD2 depression is more burdensome. • Female spouses reported more burden than males and were less accepting of illness. • Both male and female spouses experienced significant distress	Yang et al score – 5/9
Borowiecka-Karpiuk, Dudek, Siwek & Jaeschke (2014) Poland	To investigate the relationship between the burden level of spouses of patients with BD or major depressive disorder in remission and their coping styles.	Quantitative – Involvement Evaluation Questionnaire and Coping Inventory for Stressful Situations analysed using t-tests and Chi squared test 65 spouses of individuals with a diagnosis of BD	• Significant burden experienced by spouses • Burden was significantly higher in spouses who engaged in emotion-orientated coping as opposed to task-orientated coping • Sexual satisfaction in partners had significantly decreased since diagnosis of BD	Yang et al score – 8/9

Gupta and Mohanty (2016) India	To investigate the relationships between burden of care experienced by spouses, expressed emotion and social support?	Quantitative – Burden Assessment Schedule, Family Emotional Involvement and Criticism Scale and Social Support Questionnaire analysed using correlation 100 spouses of individuals with a diagnosis of schizophrenia	• Significant association between high expressed emotion (EE) and burden of care. • Significant association between lower social support and higher burden of care. • Significant association between higher social support and lower EE	Yang et al Score – 8/9
Kumar and Mohanty (2007) India	To assess the effects of socio-demographic variables on spousal burden of schizophrenia	Quantitative – Burden Assessment Schedule analysed using t-tests 70 spouses (35 male and 35 female) of individuals with a diagnosis of schizophrenia	•Females experienced greater burden than male partners •Females received less external support than male partners	Yang et al score – 5/9
Kumar, Rani, Jain and Mohanty (2009) India	To explore to what extent psychosocial dysfunction in patients produces burden in spouses of individuals with a diagnosis of schizophrenia	Quantitative – several measures used and data analysed using regression analysis 120 spouses of individuals with a diagnosis of schizophrenia	•Marked psychosocial dysfunction found in individuals with a diagnosis of schizophrenia •Patient's psychosocial dysfunction was a significant contributor to spousal burden	Yang et al score – 4/9
Kumar, Singh, Mohanty & Srivastava (2004) India	To explore spousal burden of bipolar disorder and compare this across gender of the spouses	Quantitative – Burden Assessment Schedule analysed using factor analysis 70 spouses of individuals with a diagnosis of BD	• Both male and female participants reported high levels of perceived burden • There was no statistical difference between genders on overall burden • Female spouses reported significantly higher burden related to physical and	Yang et al score – 6/9

			mental health and external support.	
Lam, Donaldson, Brown, Malliaris (2005) UK	To provide a description of the burdens faced by partners and contribute to the understanding of relationship dynamics	Quantitative – several measures used and analysed using ANOVA and linear regression analysis 37 partners of individuals with a diagnosis of bipolar disorder	•Majority of partners reported disruptions to their households, increased domestic responsibilities, financial worries and disruptions to social life •Majority of partners had accepted illness and felt happy •Significant differences in sexual satisfaction and marital satisfaction during manic and depressed and euthymic episodes	Yang et al score – 7/9
Qualitative				
Gaskill and Cooney (1992) Australia	To explore the information needs and education of partners of people with a diagnosis of schizophrenia	Qualitative - largely unstructured interviews analysed using ethnograph software 14 partners of people with a diagnosis of schizophrenia	•Partners found it difficult to get information and be included in discussions about care •Their understanding of schizophrenia was variable •Partners felt very alone and appreciated the chance to talk	CASP – 13/24
Granek, Bersudsky & Osher (2016) Israel	To explore the impact of BD on the patient, spouse and their marital relationship?	Qualitative – semi-structured interviews analysed using grounded theory 11 individuals with BD and 10 spouses	• Spouses reported large self – sacrifice; burden and burnout linked to	CASP – 14/24

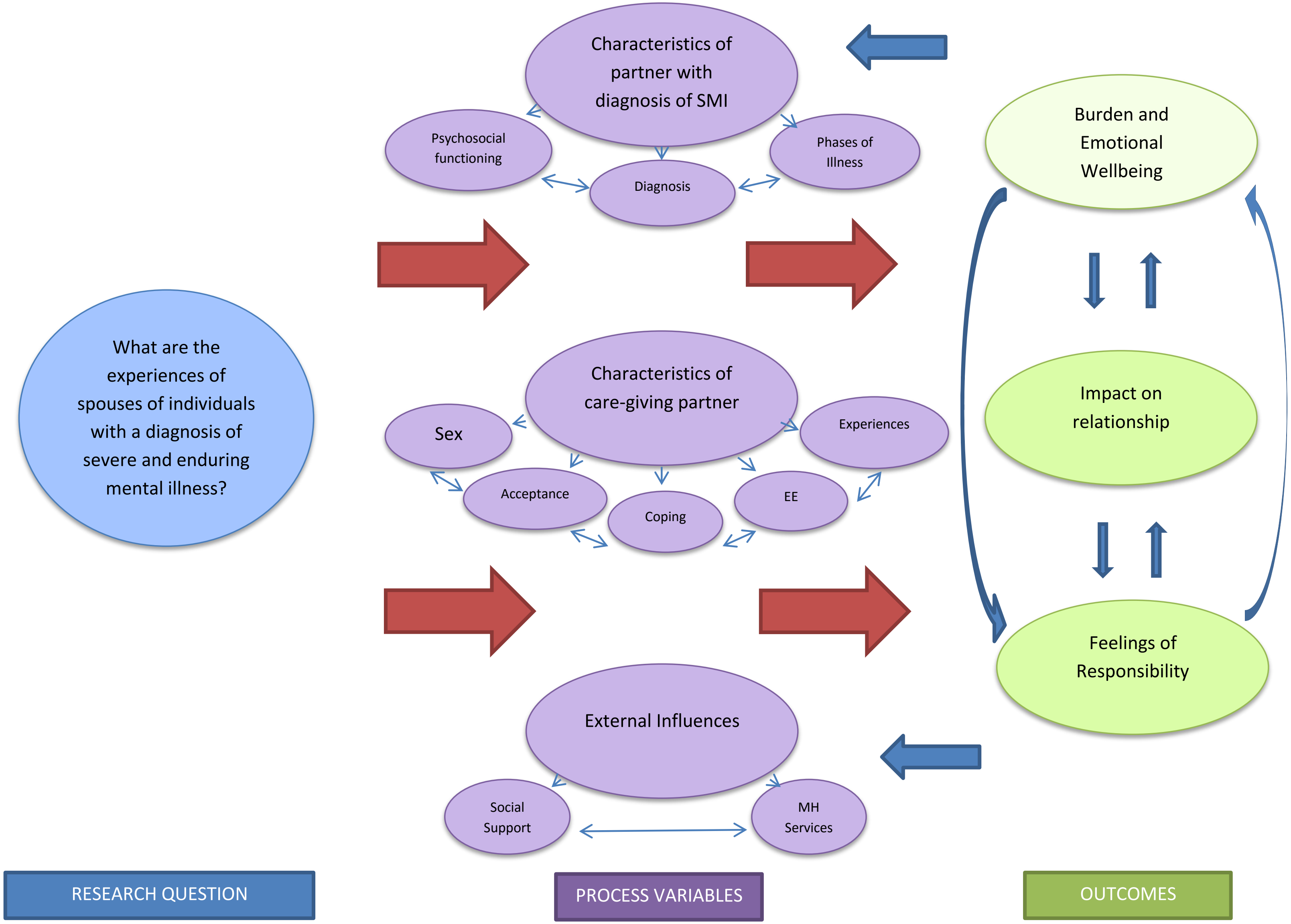
		interviewed individually	responsibility; helplessness and loneliness; personal evolution and increased resilience, empathy and compassion. • Impact on relationships - Volatility and contemplating divorce; strengthening of relationship and deepened bond and commitment; weakening of relationship due to doubt and lack of trust from partners; feelings of loss due to not having children due to illness. • Neither patients or spouses were accurate at describing the experiences and concerns of the other when discussing the impact of BD	
Jungbauer and Angermeyer (2002) Germany	To compare the burden experienced by spouses and parents of individuals with a diagnosis of schizophrenia	Qualitative – narrative interviews analysed using thematic field analysis and grounded theory 52 spouses of people with a diagnosis of schizophrenia	•A number of specific burdens associated with partners were identified •Emotional estrangement may occur between spouses •Tasks within the partnership may need to be redefined •Separation is often considered •Amiable qualities in the spouse can outweigh the impairments associated with their diagnosis.	CASP – 17/24

Jungabauer, Wittmund, Dietrich & Angermeyer (2004) Germany	To explore the burdens of spouses of individuals with a diagnosis of schizophrenia	Qualitative – narrative interviews analysed using grounded theory 48 spouses of individuals with a diagnosis of schizophrenia	•Onset of illness extremely burdening •Schizophrenia is experienced as a constant threat hanging over the spouse •Increased potential for conflict, reduced sexuality and loss of social contacts •Great variability in burden experienced between spouses •Need for redefinition of familial tasks and future plans	CASP – 18/24
Mizuno, Iwasaki & Sakai (2011) Japan	To describe and understand the caregiving experiences of husbands living with spouses who have a diagnosis of schizophrenia	Qualitative – semi-structured interviews analysed using content analysis 12 husbands of women with a diagnosis of schizophrenia	Participants found out about their wives' illness at different points and in different ways. •Acceptance of illness •Increased roles around house •Responsibility of being the 'caregiver'. None considered divorce - sense of duty but also affection. •Varied support obtained •Hopes for the wives for the future but also anxiety about uncertainty	CASP – 16/24
Tranvag & Kristoffersen (2008) Norway	To explore the experiences of spouses/cohabitants who live with a partner with a diagnosis of bipolar affective disorder	Qualitative – semi-structured interview analysed using phenomenological and hermeneutic interpretations 8 spouses of individuals with a diagnosis of BD	•Participants who had lived with their partner for a long time had similar experiences to those with shorter relationships •Their experiences formed part of a cumulative process containing up to 14	CASP – 20/24

			experiences •Each experience was affected by the ways in which previous experiences had been perceived •This pre-understanding affected the ways in which new challenges were managed.	
van der Voort, Goossens, van der Bijl (2009) the Netherlands	To greater understand the experienced burden, coping mechanisms and support needs of these spouses	Qualitative – semi-structured interviews analysed using grounded theory 11 spouses and 4 ex-spouses of individuals with a diagnosis of BD	•Core concept was the feeling of being alone even though they lived with their partner •3 categories of burden described – being solely responsible, being alone with one's feelings and consequences for their spouse's life •Development of coping was not linear and different strategies were used •Lack of professional support was identified	CASP – 18/24
Mixed Methods				
Dore and Romans (2001) Australia	To examine the impact of bipolar disorder on the caregiver in terms of objective and subjective burden.	Mixed methods - GHQ and semi-structured interview 41 caregivers of people with a diagnosis of BD. 13 were partners	•Partners more likely to experience reduced income than other carers •Majority of partners stated it was difficult to keep the relationship going and 62% had separated at some point	Yang et al score – 6/9

			•Majority of partners identified sexual problems •Changes in parenting reported due to illness	

Figure 2. Conceptual Mapping



Appendices

Appendix 1-A. Instructions for Authors

Family Process

Author Guidelines

Submission of Manuscripts

All submissions to Family Process are electronic. Authors should submit manuscripts to the Family Process submissions website at http://mc.manuscriptcentral.com/fp and follow the directions there for submitting manuscripts. By accessing this website you will be guided stepwise through the creation and uploading of files. For assistance, contact Scholar One technical support at 888-503-1050 (US based number) or 434-964-4100, or via email at mcsupport@thomson.com. The submission form requires the name, mailing address, email address, telephone number, and Fax number of all authors including the corresponding author. The letter that accompanies the manuscript submission should include the total word count of the paper including references.

All correspondence, including Editor's decision and request for revisions, will be by email. Manuscripts must be in English and submitted with the understanding that they are not being submitted simultaneously to another publication or have not already been published in whole or substantial part elsewhere. All case reports should protect patient confidentiality. If accepted, papers become copyright of the Family Process. Authors must give signed consent for publication by submitting a license agreement, but permission to use material elsewhere (e.g., in review articles) will normally be granted on request.

Manuscripts—Family Process follows the Publication Manual of the American

Psychological Association (6th ed.).

Additional information is available at www.apastyle.org. Specifically:

- Electronic manuscripts must be double spaced in 12 point font throughout, including the abstract and references. Pages should be numbered consecutively with the title page as page one and include abstract, text, references, and visuals.
- **Manuscripts should not exceed 30 pages or 6,000 words, including title page, abstract, text, references, tables, and figures.**
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- A separate title/cover page must include full names of authors in order of their contribution, author affiliation and location, title, author note, byline, and grant support. Because Family Process uses a masked review system, the cover page should be used to provide identifying information about the authors. The authors' names should not appear on subsequent pages and every effort should be made in the text for the authors' identity to remain anonymous.
- Abstracts should be approximately 200-250 words in length.
- Headings must be short. Three levels of headings are used within the text, as follows:
- Main heading: **Centered, Boldface, Uppercase and Lowercase Heading**
- Main subhead: **Flush Left, Boldface, Uppercase and Lowercase Side Heading**
- Minor subhead: **Indented, Boldface, lowercase paragraph heading ending with a period.**
- **Tables and Figures**—Limit the use of tables to data that correlate specifically to article content or communicate large amounts of data efficiently. All tables and figures should be submitted on a separate page, have a separate title, and be cited within the text with placement indicated. For figures, EPS, TIFF or PDF formatting must be used. Type title, legend, and notes for figures double-spaced on a separate page. Please note that it is the

policy of *Family Process* for authors to pay the full cost for the reproduction of their color artwork in print. Color figures will be reproduced at no cost to the author in the online version of the author.

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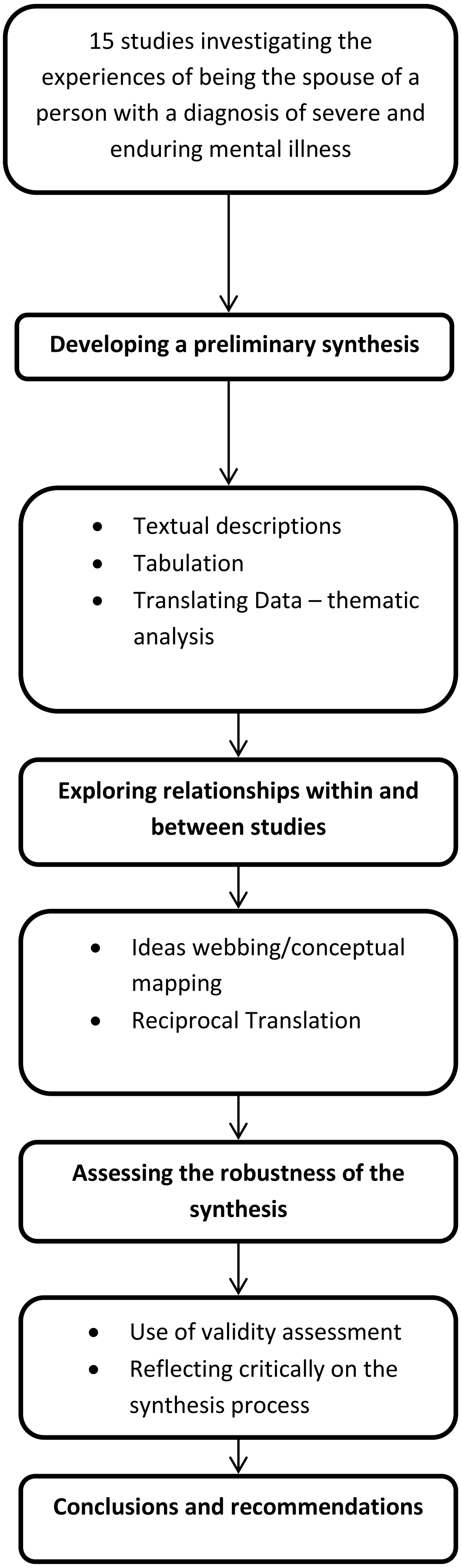
Appendix 1-B. Narrative Synthesis Process (taken from Popay et al, 2006)



Appendix 1-C. Development of Themes

	Emotional Wellbeing	Individual Factors	Social and professional support	Marital relationship	Sense of responsibility
Arciszewska, Siwek & Dudek (2015)	**Distress** 88% of spouses of individuals with BD reported significantly high levels of distress on the GHQ-12 which would qualify them to receive mental health support via counselling.	**Phases of illness** More burden was experienced by spouses in depression and mania phases as opposed to during remission (asked retrospectively). **Diagnosis** Spouses of people with diagnosis of BD1 reported more burden than those of individuals with BD2. **Sex** Female partners reported more burden than male. Specifically, women felt they supervised their partners more **Spouse Acceptance** Men had a more accepting attitude towards their wives' diagnosis than women, and also reported less burden			

Borowiecka-Karpiuk, Dudek, Siwek & Jaeschke (2014)	**Burden** Highest levels of burden were associated with 'worrying'. This sub-dimension was associated with fear for the future and the health of their partner	**Coping** Spouses who engaged in emotion-orientated coping styles experienced higher levels of burden than those who engaged in task-orientated coping styles. **Sex** No significant differences between level of burden experienced by men or women		**Sexual Relationship** Current levels of sexual satisfaction and retrospectively their sexual satisfaction before the diagnosis of BD rated. The results revealed a substantial decrease in the quality of their sexual relationships	
Dore and Romans (2001)		**Type of relationship** Partners report more burden than parents		**Relationship Stability** 92% of partners found the relationship hard to keep going and that 62% had separated at some point. Furthermore, 62% thought that they would not have entered into the relationship had they known more about the illness. **Sexual Relationship** 77% of participants experienced problems within the sexual relationship.	**Family Life** Interviewed 10 couples who were parents and found that 6 of them believed that the illness impacted upon parenting, although further explanation of this impact was not given

Gupta and Mohanty (2016)		**Expressed Emotion** They found a positive and significant correlation between EE and burden of care.	**Social Support** Perceived social support was significantly inversely correlated with burden, meaning those who identified themselves as having little social support also reported more burden of care. Furthermore, social support had a negative correlation with EE, but was not identified to regulate EE to the full extent.		
Kumar and Mohanty (2007)		**Sex** Female spouses of Sz patients reported more burden than male (gender bias in reporting?)	**Social Support** Partners living within nuclear family systems as opposed to joint family systems reported more burden associated with external support – less family around to help share caring role?		
Kumar, Rani, Jain and Mohanty (2009)		**Diagnosis** Increased psychosocial dysfunction within Sz patients was correlated with increased subjective and objective burden in			

		spouses.			
Kumar, Singh, Mohanty & Srivastava (2004)		**Sex** No significant differences in level of burden experienced by males and female partners in BD Females experience significantly higher levels of burden in relation to their own mental health than males	**Social Support** Female spouses reported more burden in social support than male spouses – is this because they receive less support or because they want more?		
Lam, Donaldson, Brown, Malliaris (2005)	**Emotional Wellbeing** Breaks the burden experience down even more and reported a variety of difficult emotions experienced by spouses. These included feelings of being overwhelmed, conflicted, bitter and feelings of loss. In addition, 46% obtained scores on the GHQ which suggested they were psychologically unwell.	**Illness Attributions** Behaviours viewed as internal in bipolar disorder caused more stress.	**Professional Support** Partners experienced a lot of burden associated with a lack of communication and support from professionals	**Sexual Relationship** Looked at how sexual satisfaction fluctuated with different phases of bipolar disorder and found that it was significantly lower during manic and depressed phases than when well, however there were no differences between manic and depressed phases. They identified a link between sexual satisfaction and marital satisfaction, but could	**Family Life** Half of participants reported more domestic duties and that 61% of those with children said that the illness meant that they had more responsibility for childcare

				not identify causality	
Gaskill and Cooney (1992)	**Loneliness** Report feelings of loneliness and uniqueness and most participants did not know of any others in a similar situation.		**Social Support** Lack of support for patients, who all expressed appreciation at being given the opportunity to tell their stories when taking part in the research **Professional Support** participants found it difficult to be taken seriously by health professionals – it was rare that they were involved in discussions regarding care and they felt their views were not listened to. They reported a need to be assertive in order to be heard. No participant in this research felt that they knew enough about the medication their partner was taking – old study (improvements since?)		

Granek, Bersudsky & Osher (2016)	**Loneliness** They reported feeling lonely in coping with the effects of caring. **Loss** Partners also spoke about their decisions not to have children due to the diagnosis of BD and this was felt as a significant loss. **Emotional Wellbeing** Shame at the BD, anxiety and fear over relapse and the future		**Social Support** Spouses of individuals with BD spoke about self-sacrifice and feeling as though they had given up their own pleasures in life, which included going out with friends and having hobbies, which in turn is likely to have reduced their social support.	**Relationship Stability** The spoke of increased volatility in the person with BD's mood impacting on the security of the union and resulting in thoughts of divorce. Partners also found the trust they felt for the person with BD to be lessened which led them to doubt whether they could stay in the relationship. **Strengthening bond** Conversely, however, both partners also spoke about the ways in which BD had strengthened their bond and feelings of commitment to one another which each episode they successfully navigated together. **Sexual Relationship** lack of physical intimacy weakening the bond within their relationship	**Family Life** Self-sacrifice linked to increased responsibility and feelings of being "tethered to their homes". This increased feelings of burden as their responsibilities felt like a full-time job and included medical appointments, ensuring treatment compliance and sometimes being sole financial provider.

Jungbauer and Angermeyer (2002)	**Emotional Impact** The feelings present at the point of illness onset, such as powerlessness, fear and despair. Even when acute periods of illness are over they explain how participants experience a constant feeling of threat hanging over the family.	**Type of Relationship** Type of relationship affected burden, not necessarily in terms of total amount, but in terms of source. The difficulties experienced by partners were different to those experienced by parents in bipolar **Course of illness** Changing views of partners regarding the relationship, throughout the course of the illness Stability within the illness can lead to a more satisfying relationship and core aspects, such as respect, mutual understanding and affection can help.		**Relationship Stability** They describe how at the beginning there are feelings of great solidarity, but that this can weaken with time, particularly when the spouse feels they must make huge personal sacrifices or that they have concerns regarding their own health. Furthermore, thoughts of separation can be hindered by religious beliefs regarding the sanctity of marriage and a belief that if things were reversed their partner would stand by them. **Strengthening Bond** In addition, some participants believed that dealing with the illness had in fact strengthened their marriage. **Sexual Relationship** Identified challenges within the sexual relationship, which can be caused by physical	**Inequality** Inequality that can develop within the relationship at the tasks within a family need to be redefined and the healthy spouse take on a more supportive role

				changes and lack of interest caused by medication	
Jungabauer, Wittmund, Dietrich & Angermeyer (2004)	**Emotional Impact** Feelings present at the point of illness onset, such as powerlessness, fear and despair. Even when acute periods of illness are over they explain how participants experience a constant feeling of threat hanging over the family	**Diagnosis** In Sz burden fluctuated with illness curve **Health of partners** Where the partner also had disgnosis of MI, burden in sz was found to be lower **Experience** As participants gained experience, learned new information and found out where to turn for professional help, their ability to cope improved.	**Professional Support** partners experienced a lot of burden associated with a lack of communication and support from professionals – particularly at the point of diagnosis	**Sexual relationship** Challenges within the sexual relationship, which can be caused by physical changes and lack of interest caused by medication	**Family Life** Spouses needed to take on additional duties within the home, some of which may be unfamiliar to them. This can lead to partners cutting back on their own needs, which in turn, in they feel they are making large personal sacrifices can result in separation
Mizuno, Iwasaki & Sakai (2011)	**Emotional Wellbeing** Reports feelings of anxiety about the future,		**Social Support** Only interviewed husbands found that their reports of social support varied. One discussed the limitations of receiving support from other carers as they tended to be parents who had different experiences to partners	**Relationship Stability** No participants had considered separation as they felt a responsibility to their wives and reported unchanged affection for them (cultural issues?)	**Family Life** Husbands experienced a shift in roles and responsibility which they found to be difficult – this was with respect to more household chores as well as a sense of responsibility for supporting their wives treatment. However, this sense of

					responsibility acted as a protective factor against divorce.
Tranvag & Kristoffersen (2008)	**Loneliness** Acknowledgment that the relationship had forever changed and become more difficult, resulting in feelings of loneliness **Emotional Impact** Many feelings of emotional distress experienced by participants throughout the duration of the illness. These change with time, forming part of a cumulative process and include fear in the beginning, followed by loneliness, anger and despair, feelings of there being a persistent threat and grief over the loss of the partner they had	**Coping** Discussed impact of coping and appraisal of situations of level of burden experience in bipolar disorder **Acceptance** A cumulative process that resulted in acceptance of the illness and with that a reconciliation which brought new hope for the future and ideals for a life together. However, prior to this there had been acknowledgment that the relationship had forever changed and become more difficult, resulting in feelings of loneliness	**Social Support** Partners felt talked about by family and friends and stigma that added to their burden. They reported that many social contacts began to reduce their contact, which in turn led to social withdrawal in the participant **Professional Support** some participants felt very disappointed in their lack of professional support, whilst others reported positive experiences of the health system.		
van der Voort, Goossens, van der Bijl (2009)	**Loneliness** partners experience burden due to being alone with their feelings and unable to	**Patient Factors** Patient factors can act as mediators of burden in the spouse, for example the ability to	**Social Support** Identified social support to be an important mediating factor in levels of	**Relationship Stability** Interviewed partners who had separated as well as those who remained together.	

	share. They also experience guilt when deciding to out their own needs above those of their partner **Burden** partners experience burden due to being alone with their feelings and unable to share.	take the feelings of their partner seriously was helpful. **Partner Factors** characteristics in the participants, such as having the capacity to persist during difficult periods, having a sense of humour, loving the spouse and being able to share feelings with them helped lesson burden	burden experienced by partners. In this study, those who had separated from their partners reported virtually no social support **Professional Support** Participants had little professional support, although they thought that it would be useful in helping to decrease their burden and feelings of loneliness, mobilise protective factors and promote successful coping	They identified differences within the process of resignation between these groups. Those who stayed in the relationship resigned themselves to the situation as an active choice, whereas those who separated did this in an extreme form of self-fulfilment. Amount of social support mediated this process.	

Appendix 1-D. CASP (with questions 1 and 2 omitted)

©Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 31.05.13

<u>Detailed questions</u>

3. Was the research design appropriate to address the aims of the research? ☐Yes ☐Can't tell ☐ No

HINT: Consider If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research? ☐Yes ☐Can't tell ☐No

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

5. Was the data collected in a way that addressed the research issue? ☐Yes ☐Can't tell ☐No

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

6. Has the relationship between researcher and participants been adequately considered? ☐Yes ☐Can't tell ☐No

HINT: Consider If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location ☐ How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? ☐Yes ☐Can't tell ☐No

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

8. Was the data analysis sufficiently rigorous? ☐Yes ☐Can't tell ☐No

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

9. Is there a clear statement of findings? ☐Yes ☐Can't tell ☐No

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

10. How valuable is the research?

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

Appendix 1-E. Assessing quality of case series papers from Yang et al (1999)- amended

Factor 1: Study aim and design

1) The rationale/aims of the study are clear
2) The study design is appropriate for the aims of the study

Factor 2: Descriptions of protocol

3) n/a as no treatment being given
4) n/a as no treatment being given
5) n/a as no treatment being given

Factor 3: Descriptions of methods

6) Details of methods/procedures are adequate to allow the study to be repeated
7) n/a as no therapeutic intervention given

Factor 4: Conduct of the study

8) Inclusion/exclusion criteria are clear
9) Methods of recruitment are appropriate
10) Subject assessment was independent and objective
11) Data collected are relevant and complete
12) Data analysis is appropriate for the design of the study
13) The results of all outcome measures have been clearly reported

As with the original each question can be answered with a yes (score = 1 point) or a no (score = 0 points). A total score out of 9 will then be yielded for each paper, although this score will be used as a guide to quality only.

Appendix 1-F. Description of Studies

Quantitative Papers

Kumar, Rani, Jain & Mohanty (2009)

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: How is the burden experienced by spouses affected by psychosocial dysfunction in patient?
- PARTICIPANTS: 120 – spouses for at least 2 years where partner has had diagnosis of schizophrenia. No diagnosis of mental illness in participant.
- QUALITY RATING: 4/9 – Clear description of aims and explanation of method and data set, however, it is not clear exactly how participants were recruited or who administered the measurements. Therefore decisions regarding the potential bias cannot be made. Also, the results section is very brief and conclusions are made regarding causation following the use of bivariate regression. Although this may demonstrate a correlation between burden and psychosocial dysfunction, it does not indicate that increased dysfunction = increased burden. It is possible that spouses who subjectively report more burden may behave in a way which increases symptoms within their partner.
- FINDINGS: Patients with schizophrenia experience marked psychosocial dysfunction – this includes difficulties working, maintaining social relationships and taking care of their personal needs. A medium effect size (20.5%) of psychosocial dysfunction was found to be related to level of spousal burden. Spouses experienced both objective and subjective burden and this was higher when psychosocial dysfunction scores were higher.
- SUMMARY: Methodological flaws in paper mean that conclusions can only be tentative – there is a correlation between psychosocial dysfunction in patients and the level of burden reported by their spouse.

Kumar & Mohanty (2007)

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: What are the effects of socio-demographic variables on spousal burden?
- PARTICIPANTS: 70 – 35 men and 35 women. Living with patient and no diagnosis of mental illness
- QUALITY RATING: 5/9 – Aims of study are clear and method well explained to allow for replication. No discussion of who undertook assessment or exactly how participants were chosen (i.e. how equal number of gender selected?) meaning that bias cannot be properly assessed. Few socio-demographic factors actually discussed in results – only gender of carer and family type (joint or nuclear – no definitions given). The aims of paper appeared much

broader than this. Data regarding rural or urban location of partners taken, but not discussed in results – due to lack of findings?

- FINDINGS: Significant differences found between scores on burden assessment scale overall scores between male and female spouses. Females reported greater burden. Females felt they got less external support and also reported higher burden in the areas of routine, patient behaviour and caregiver strategy. It should be noted that these scores are a reflection of subjective reported burden – therefore possibility of gender bias in reporting as opposed to in actual burden experienced (but is burden just a subjective concept anyway?). There were also significant difference between family type on burden. Joint family systems (i.e. grandparents, parents, children all together) is associated with higher reported spouse related burden. Meanwhile, nuclear family systems (i.e. parents and children) were associated with more burden in areas of external support and caregiver strategy. There was no difference in total burden scores. Duration to exposure had no effect on burden – however, the comparison was between <5 and >5 years. A more sensitive scale may have found differences. Better description of scale items needed to understand implications of results.

- SUMMARY: Lack of description of items on scale and methodological flaws mean that conclusions are broad and tentative. Overall females reported more burden. Overall burden in nuclear and joint family systems same, but some differences on specific areas of burden. No difference in burden between those living with illness over 5 years and those living with it under 5 years.

Dore & Romans (2007)

- DIAGNOSIS: Bipolar Affective Disorder

- RESEARCH QUESTION: What is the impact of bipolar disorder on the primary caregiver in terms of objective and subjective burden? (included all caregivers, but only results for partners reported in this review)

- PARTICIPANTS: 13 - 11 current partners and 2 separated. Patients underwent assessment to confirm diagnosis of BPD

- QUALITY: 6/9 – The method and aims of the study are clear allowing for replication. The results are well explained and data for all measurements are reported. The analysis appears good, although it would have been beneficial to have compared results to a control group. However, there is no clear information regarding inclusion/exclusion criteria, i.e. who qualifies as a carer? And who administered the questionnaires. Therefore potential bias in participant selection and data collection could not be evaluated.

- FINDINGS: Partners were more likely to experience a reduction in income compared to other carers. 92% of partners said they found it hard to keep relationship going and 62% had experienced periods of separation. 77% had experienced problems within the sexual relationship. 62% felt they would not have entered into relationship if they had known more about the illness. Ten of the couples were parents – 60% of these felt that the illness affected the parenting. Partners also experienced significantly more disruption to social activities than other carers.

- SUMMARY: The needs of partners of individuals with BPD are different to those of other carers in a number of ways.

Kumar, Singh, Mohanty & Srivastava (2004)

- DIAGNOSIS: Bipolar Affective Disorder
- RESEARCH QUESTION: Is there a difference in level of burden reported by male and female spouses?
- PARTICIPANTS: 70 – 35 male and 35 female spouses who did not have a psychiatric condition themselves and partner met ICD-10 criteria. No minimum amount of time together or experience of illness required.
- QUALITY: 6/9 – the aims of the study were clear and the design met these aims and was well explained to allow for replication. However, it is not clear how the participants were recruited or who administered the questionnaires, meaning that potential bias cannot be assessed. Also, the description and implications of the results is limited.
- FINDINGS: Initial differences between groups – males significantly older and women married significantly longer – were these controlled for? High level of burden in both genders – no significant difference. Female spouses reported significantly higher burden in physical and mental health and social support. No control group to compare findings to.
- SUMMARY: High level of burden found in all participants, but no control group to compare them to. No gender differences found, but not control for confounding factors undertaken.

Lam, Donaldson, Brown & Malliaris (2005)

- DIAGNOSIS: bipolar disorder
- RESEARCH QUESTION: What are the burdens faced by partners of bipolar patients and what are the relationship dynamics during different phases of the illness?
- PARTICIPANTS: 37 partners of people with bipolar 1 diagnosis who were not in acute stage of illness. Must have been married or cohabiting for last 3 years during which at least one manic and depressed episode had occurred.
- QUALITY: 7/9 – Aims were well explained and design appropriate. Method and inclusion/exclusion criteria clearly described and analysis appropriate with well explained results. No mention of possible researcher independence or recruitment strategy so cannot assess potential bias in these areas.
- FINDINGS: Slightly more than 2/3 of Ps reported disruptions to their household routines since diagnosis and 1/2 said they had more domestic duties. Over 1/2 said there had been

an impact on their social life and over 1/2 had reduced their working hours. More than 1/2 experienced financial worries. 49% of Ps had children - of these 61% said they had more childcare responsibilities, 50% reported emotional problems in their children and 44% reported difficulties functioning as a parent. Lists patient behaviours viewed as most problematic by spouse. Majority of Ps considered behaviours to be due to external factors, although some were considered to be internal by some Ps. Majority of Ps said their partner had a MI and that there was a biological/genetic cause. 70% were concerned about it being passed to their children. The amount of control Ps thought their partners had over their illness varied, with most thinking some control. Over half though their lives had been altered by the illness and felt overwhelmed. 65% felt conflicted, 40% felt bitter and 38% expressed feelings of loss. However, 84% said that they had accepted the situation and 92% said they were happy to stay as a couple. 46% had scores on the GHQ which indicated they were psychologically unwell. Sexual satisfaction was significantly lower during manic and depressed phases than well. No difference between manic and depressed. There were gender differences however. Marital dissatisfaction was higher when patients were manic than depressed. It was related to an increase in domestic responsibilities, the belief that the mental illness could be controlled or sexual dissatisfaction.

- SUMMARY: A significant number of partners experienced strain. Partners experience a lot of burden associated with lack of communication and support from health professionals. Behaviours viewed as internal caused most stress. Levels of sexual satisfaction were lower during periods of illness, but there was no difference between manic and depressive phases. Marital dissatisfaction was worse during mania, than depression and then stable periods. Also a link between sexual satisfaction and marital satisfaction , but no causality found.

Borowiecka-Karpiuk, Dudek, Siwek and Jaeschke (2014)

- DIAGNOSIS: Bipolar Disorder
- RESEARCH QUESTION: What is the relationship between the burden level of spouses of patients with BD or major depressive disorder in remission and coping styles.
- PARTICIPANTS: 65 patients with a diagnosis of BD and 65 spouses
- QUALITY RATING: 8/9 – Clear description of aims and explanation of method and data set, Recruitment strategy clear although who administered the measurements not indicated. Therefore decisions regarding the potential bias cannot be made. Results clearly explained and findings given.
- FINDINGS: Level of perceived burden by spouses was significant – highest levels associated with worrying and urging around things such as concern for the future and safety and a need to check on medication compliance and diet. Burden was significantly higher in spouses who engaged in emotion-orientated coping as opposed to task-orientated coping. Sexual satisfaction in partners had significantly decreased since diagnosis of BD, although this rating was based on retrospective scoring.

- SUMMARY: Increased burden in spouses of individuals with BD – associated to more emotion focused coping. Possible decrease in sexual satisfaction although scoring was retrospective which means the results should be considered with caution.

Gupta and Mohanty (2016)

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: What are the relationships between burden of care experienced by spouses, expressed emotion and social support?
- PARTICIPANTS: 100 spouses of individuals with a diagnosis of chronic schizophrenia
- QUALITY RATING: 8/9 – Clear description of aims and explanation of method and data set so can be replicated. Clear criteria for recruitment and appropriate sampling. Questionnaires completed by one of the researchers so not independent and potential for bias. All data reported, analysis appropriate and clear outcomes.
- FINDINGS: Significant association between high expressed emotion and burden of care. Significant association between lower social support and higher burden of care. Significant association between higher social support and lower EE
- SUMMARY: Correlation between higher EE and higher burden. Correlation between increased social support and lower EE. Even when social support is controlled for still EE as a result of burden.

Arciszewska, Siwek and Dudek (2015)

- DIAGNOSIS: Bipolar Disorder
- RESEARCH QUESTION: To assess the impact of BD1 and BD2 on the burden experienced and levels of psychological distress reported by partners.
- PARTICIPANTS: 77 spouses – 44 BD1 and 33 BD2
- QUALITY RATING: 5/9 – Clear description of aims of study and appropriate design for meeting these. No explanation of recruitment, how participants were selected, inclusion/exclusion criteria, or who completed assessments so bias unknown and replicability limited. Assessment tools used are appropriate and analysis meets aims. All outcome data reported clearly
- FINDINGS: Women experience higher burden than men during depressive episodes and generally more burdened during mania. More burden experienced during mania in BD1 than BD2. During remission more burden experienced by women than men except for in worrying which was non significant. Spouses of individuals with BD1 experienced more burden than in BD2. Women partners more burdened than men. More burden in mania and depression than remission. Tension higher in women than men, in BD1 partners rather than BD2 and in mania than depression. Higher worrying in women than men and during depression/mania than remission. Spouses of individuals with BD1 had to provide most supervision during

mania, followed by depression. Urging higher in women than men and was higher during depression than mania or remission. Qualitative data showed men more accepting of illness than women especially in BD1. Spouses of individuals with BD2 reported more coping during mania than in BD1. Scores on GHQ had no significant differences between groups as all groups indicated serious health consequences.

- SUMMARY: in BD1 mania more burdensome than depression, whilst in BD2 depression more burdensome. Women spouses reported more burden than male and were less accepting of illness. Both men and women experienced significant distress – therefore there is burden present for all, but sources are different between gender.

Qualitative Papers

Jungbauer, Wittmund, Dietrich & Angermeyer (2004)

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: What burden is experienced by the spouses of individuals with schizophrenia?
- METHOD: Grounded theory
- PARTICIPANTS: 52 – living with a spouse who had diagnosis (28 male & 24 female). Not excluded if had own diagnosis of mental illness
- QUALITY: 18/24 – The use of qualitative methodology was appropriate to meet the aims of the study. There was an adequate description of recruitment and reasons why participants chose not to take part plus the implications of this for the reliability and generalisability of the study. However, there was no discussion of the role of the interviewer and potential bias that may affect results or ethical issues that may have arisen regarding consent. Explicit description of results and analysis and clinical implications discussed, but no discussion of areas for future research.
- FINDINGS: 7 developmental types constructed –
    - **Onset of illness** Extreme burden of onset – frightening and feelings of powerlessness, fear and despair. Prior to diagnosis there is no explanation for symptoms and a lack of information and support available. Forced admission to hospital can elicit feelings of guilt, shock and failure – first impression of psychiatry is one of shock and disconcerting feelings. If partnership begins after onset, spouse not necessarily aware of burdens associated with it and underestimates them. Therefore relapse can be just as burdening as initial onset. If partner had diagnosis themselves, relapse is less threatening. Spouses continue to feel burden at subsequent relapses, but as they gain experience, learn new information and know where to turn for professional help they are able to cope better.

  - **Everyday Life** New aspects of burden present when acute episodes have ended. Constant threat hanging over the family and the ill person is scrutinized for signs of a relapse, which can demand a lot of the spouse's strength. They are also likely to have taken on additional duties which may be unfamiliar to them. Often view that spouse is permanently changed and impaired and the person may cut back on their own needs. Also increased potential for conflict, particularly if the spouse can be violent. Lack of interest or physical changes due to medication can lead to problems with sexuality and both partners can experience a loss of social contacts. Marriages in which both partners experienced mental ill-health reported mutual understanding and support.

  - **Development of Burden on 12 months** 7 different types of developmental burden identified – shows a great degree of variability among spouses. Correlation noted between patient's illness curve and spouse's experience of burden – e.g. deterioration in patient health was accompanied by increased burden.

  - **Separating or maintaining partnership?** Immediately following onset of illness partners showed great solidarity and strongly rejected ideas of separation. However as the illness progressed and thoughts of recovery reduced, this solidarity could weaken. When spouse feels they are making large personal sacrifices or fears for their own health thoughts of separation can develop. This can be especially pronounced when there is violence. However, where there are long periods between acute episodes, the spouse can be more inclined to think a satisfying relationship is possible. If core aspects of the relationship remain – respect, mutual affection and understanding – then compromises that need to be made for the illness are not thought of as such a serious problem,

  - **Biographical Interpretation and Partnership Concepts** Many spouses take time to integrate the illness into their own biographies as reality. Some viewed the schizophrenia as an 'emergency' in which there exists a mutual promise of solidarity. This is related to social norms connected to religious beliefs regarding the insolubility of marriage and the belief that is things were reversed their partner would stand by them. Some believed that the illness had strengthened their relationship. When the partner is viewed as severely impaired the partnership has to be completely redefined in a number of areas with the spouse often taking on more responsibility. However, where both partners have a diagnosis of mental illness there is less change perceived within the relationship – more emphasis is placed on the positive aspects of living together.

- SUMMARY: Some experiences of spouses are similar to those of parents, but others are different – particularly those related to partnership, intimacy and responsibility. However, successful partnerships are possible albeit with various sources of burden. The burden experienced can vary between couples and is influenced by course of illness, whether or not both partners have experience of mental illness and point of time.

Mizuno, Iwasaki & Sakai (2011)

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: What are the caregiving of husbands living with a spouse with schizophrenia?
- METHOD: Content analysis
- PARTICIPANTS: 12 husbands of women treated at outpatient department
- QUALITY: 16/24 – Use of qualitative methodology was suitable, however no discussion of why content analysis was chosen. No discussion of consent procedure or ethics of interviewing spouses or potential bias of researchers performing interview and analysis. Generally good description of results, but no discussion regarding possible reasons why some discrepancies between different participants experiences existed.
- FINDINGS: Six major themes identified –
    - **Onset of Illness** Before marriage – Most participants were told about the illness, however one was not and one did not realise significance due to her stability. After marriage – Variance in experiences. 2 husbands noticed changes in behaviour and were involved in seeking treatment. Others attributed the changes to different things (e.g. menopause) and are not clear when illness started. Participants spoke of needed patience when thinking about recovery.
    - **Past and present experience** Most husbands tried to accept their wife's illness and appreciate their remaining abilities. Experienced a shift in roles and responsibilities though which they found difficult, but discussed the need not to push their wives.
    - **Roles and burdens** Showed compassion and sympathy for their children seeing their mother in such a way. Responsibility to support wife's treatment – particularly with respect to monitoring medication. Burden and negative impact of relapses on husband's work life and need to take on more household chores.
    - **Marital Relationships** Only one participant described himself as a caregiver to his wife. No husbands had considered divorce and talked about feeling responsible for their wives. All reported that their affections for their wives remained the same, although two described feeling uncomfortable around her when she was unwell.
    - **Social Resources** One participant discussed the limitations of mutual support from parent carers as felt their experiences were very different to those of a spouse. Support gained from different participants varied.
    - **Perspectives on Future** Participants expressed hope for stability of the illness in the future - however there were anxieties about the uncertainty.
- SUMMARY: Feelings of burden and increased sense of responsibility, but a general sense of responsibility and maintained affection for their wives – may be cultural (Japanese). Various amounts of external support received.

van der Voort, Goossens & van der Bijl (2009)

- DIAGNOSIS: Bipolar Disorder
- RESEARCH QUESTION: What burdens do spouses of people with bipolar disorder have, how do they cope and what are their support needs?
- METHOD: Grounded Theory
- PARTICIPANTS: 15 spouses or ex-spouses, atleast 5 years relationship with 3 episodes, diagnosis of bipolar 1 or 2 according to DSM IV
- QUALITY: 18/24 – excellent rationale for use of grounded theory and description of data collection. Good description of findings and clinical implications, but no discussion of generalisability or future research. Lack of discussion regarding potential bias of researcher and methods of limiting this. No information regarding ethical approval or considerations of ethical issues when interviewing spouses.
- FINDINGS:
  - Core concepts: burden and difficulties coping – feeling 'alone together'
    - Burden related to not being able to share important aspects of their lives together – being solely responsible, being alone with feelings and consequences for their own lives, e.g. problems with work, within relationship and being exhausted.
  - Development of coping was not linear and involved alternating between different strategies.
    - Appraisal of situation
    - Searching for a balance between self-effacement (putting needs of others first) and self-fulfilment (putting own needs first). Search for balance was lonely and usually began with putting spouse's needs first as instinct. Those who decided to try and put their needs first experienced guilt. Those who divorced had virtually no social support.
  - Mediating Factors – several factors mediate feelings of burden
    - Characteristics of patient
    - Characteristics of spouse
    - External support
  - Resignation – outcomes of described processes differed:
    - Some resigned selves to situation as an active choice and a step towards self-fulfilment

    - Some ended the relationship – a more extreme form of self-fulfilment
    - Some continued to search for balance between self-fulfilment and self-effacement and experience fluctuations in burden
  - Support Needs- most participants had no professional support, but expressed desire for some. They wanted it to decrease burden, loneliness and mobilise protective factors and to promote successful coping. They wanted it to be continued support rather than short and intense and reported that professional support should help them find the balance between self-fulfilment and self-effacement.
- SUMMARY: Describes a model of stress and coping specific for spouses of people with bipolar. Highlighted the lack of support experienced by these spouses.

<u>Tranvag & Kristofferson (2008)</u>

- DIAGNOSIS: bipolar affective disorder
- RESEARCH QUESTION: What are the experiences over time of spouses/cohabitants who live with a partner who has bipolar affective disorder?
- METHOD: Phenomenological hermeneutic
- PARTICIPANTS: 6 spouses and 2 co-habitants using strategic selection to get wide variety of experiences. Had to have been together during at least 2 episodes of illness and 1 hospital admission.
- QUALITY: 20/24 – Highest scoring paper. Excellent description of methodology and why it meets aims, detailed description of results, clinical implications and ideas for future research. Discussion of need for researchers to be aware of pre-ideas, but not further thoughts on ease/implications of this and no information regarding consent procedure or exactly how participants were chosen. Finally, no discussion of areas where findings may have gone against those which were expected.
- FINDINGS: Participants who had longer relationships had same experiences as those with shorter relationships, but also some additional ones. 3 major aspects characterized these experiences:
  - Experience formed part of a cumulative process containing up to 14 experiences – number of experiences reported depending on duration and severity of illness
  - Each experience created pre-understanding which affected how subsequent experiences were perceived
  - This pre-understanding affected how they were able to manage and master new illness-related challenges
      1. Fear and the incomprehensible
      2. Accusations

3. Self-doubt
4. Information v being turned away by professionals
5. Stigma and loss of social networks
6. Uncertainty, powerlessness and hope
7. Loneliness
8. Anger and despair
9. The persistent threat
10. Own health problems
11. Grief over loss
12. Dawning acceptance
13. Reconciliation
14. New hope

- SUMMARY: Participants experienced a number of challenges, most of which were perceived as burdensome. These experiences formed part of a cumulative process over time, where each one was dealt with and perceived dependent upon past experiences. Previous experience of burden created a basis for future experiences to be experienced as burdensome and vice versa. This pre-understanding also affected how they mastered future challenges.

<u>Jungbauer & Angermeyer (2002)</u>

- DIAGNOSIS: Schizophrenia
- RESEARCH QUESTION: What is the burden of parents of individuals like compared to the burden of partners?
- METHOD: Thematic field analysis and grounded theory
- PARTICIPANTS: 52 spouses – married or lived with patient
- QUALITY: 17/24 – Good justification for methodology and valuable research findings with clinical implications and discussion of future research. Good explanation of recruitment and consent. No discussion of how interview schedule was devised or examples of questions and no discussion of potential for research bias.
- FINDINGS: Broad spectrum of burdens described. Some similarities between spouses and parents - described illness in phases. Burden changes according to phases. Themes of shock and helplessness at diagnosis and burden in everyday life described for all participants - not separated for spouses (similar to other spouse studies). *Specific Burdens of Spouses* - Original

definition of relationship called into question - lead to withdrawal and conflict. Sexual relationship can diminish as well as interest in joint activities. Tasks within family need to be redefined as spouse needs to become more supportive (unequal roles). Joint perspective in life called into question, although separation is not thought of as an option shortly after diagnosis. This can change further on when spouse experiences more burden or concerns for own health. Physical threat can heighten this. Partnerships can be thought of as manageable- depends on illness course!

- SUMMARY: Caregivers also affected by illness. Burdens experienced can be specific to the relationship – therefore partners and parents report different challenges

Gaskill & Cooney (1992)

- DIAGNOSIS: schizophrenia
- RESEARCH QUESTION: What are the everyday experiences of partners living with schizophrenia and what are their information and education needs?
- METHOD: Thematic Analysis
- PARTICIPANTS: 12 spouses and 2 ex-spouses. Had lived together for atleast 2 years, no hospitalisation within last 6 months
- QUALITY: 13/24 – Qualitative methodology fits but no discussion of why thematic analysis. Explicit description of results and clinical useful. However, no discussion of why interviews appropriate, possible bias/influence of researchers or consent.
- FINDINGS: 7 themes identified:
    - Obtaining information – Major and consistent difficult for participants to gain access to information.
    - Knowing the diagnosis – All but one participant could articulate their partner's diagnosis. All found it helpful to know diagnosis, although in some cases the patient had not been told which led to difficulties relationship
    - Understanding of schizophrenia – Understanding of Sz was variable – some used own experiences to construct understanding, some went to a lot of effort to find information and others tended to blame themselves for not being more proactive.
    - Obtaining other information – No participant thought they knew enough about medication or side-effects.
    - Being Taken seriously – It was rare for participants to be involved in discussions about care and they felt their views were not listened to. Felt need to be assertive which made them uncomfortable and on occasion felt as though information as deliberately withheld.

  - The need to unburden – All expressed appreciation at being able to tell their stories. For many this was the first opportunity they had been given.
  - Uniqueness and aloneness – Most participants did not know of anyone else in their situation.
- SUMMARY: Partners struggle with being left out of discussions about care. They needs more support, information and to feel less alone

Granek, Bersudsky and Osher (2016)

- DIAGNOSIS: Bipolar Disorder
- RESEARCH QUESTION: What is the impact of BD on the patient, spouse and their marital relationship?
- METHOD: Grounded theory
- PARTICIPANTS: Eleven patients and ten spouses
- QUALITY: 14/24 – The use of qualitative methodology was appropriate to meet the aims of the study, although no rationale for specific use of grounded theory. There was an adequate description of recruitment but no discussion of those who declined participation and the impact of this on results. No discussion of the role of the interviewer and potential bias that may affect results or ethical issues that may have arisen regarding consent. Explicit description of results and analysis and clinical implications discussed, but no discussion of areas for future research.
- FINDINGS: Impact on spouse from spouse perspective – self –sacrifice; burden and burnout linked to responsibility; emotional impact and helplessness and loneliness; personal evolution and increased resilience, empathy and compassion.

  Impact on patient from spouse perspective – difficulty accepting diagnosis; emotional impact or helplessness, shame, guilt and fear

  Impact on spouse from patient perspective – emotional impact of helplessness, shame and loneliness. Generally able to accurately assess impact on their partner

  Impact on patient from patient perspective – shame, sadness, self-doubt, regret, self-blame, empathy for spouse; responsibility for self-care; struggling socially and problems with relationships; struggling developmentally and problems with jobs and life tasks

  Relational impact – more overlap between answers. Volatility and contemplating divorce; strengthening of relationship and deepened bond and commitment; weakening of relationship due to doubt and lack of trust from partners; family planning and loss due to not having children due to illness.

- SUMMARY: Neither patients or spouses were accurate at describing the experiences and concerns of the other when discussing the impact of BD, mainly due to omission. Lack of bilateral empathy. However, perceptions on impact upon relationship similar.

Section Two: Research Paper

An Exploration of Experiences of Bipolar Disorder within Couples

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[1] See Appendix 2-A for Instructions for Authors

Abstract

Objectives

There are challenges associated with being the partner of an individual with a diagnosis of bipolar disorder (BD). Clinical guidelines recommend support and psychosocial interventions for carers where appropriate. However, there is currently a lack of understanding of the specific ways in which BD affects pivotal partner relationships. Here, the co-constructed views of the relationship from both partners together are investigated.

Methods

Four individuals with a diagnosis of Bipolar 1 Disorder and their partners participated in this study. Couples were interviewed together using a topic-guided interview. Responses were analysed using interpretative phenomenological analysis (IPA).

Results

Analysis resulted in four themes: (1) Negotiating Roles; (2) Challenges of Communication; (3) Externalising the Diagnosis and (4) Keeping Positive.

Conclusions

A diagnosis of BD impacts both partners, particularly in relation to communication and intimacy. In order to help manage the fluctuating nature of BD, partners must negotiate their reciprocal roles, adapting behaviours in order to meet current needs. Participants found it hard to access and communicate with mental health services and this research promotes the need for a wider systemic support system in which both individuals within the partnership are acknowledged as being integral to the course of BD.

Limitations

Future research should ascertain whether similar experiences are reported by individuals whose relationships have broken down as all those in this research study remained together. This piece of research was an initial explorative study so further work investigating generalisability with larger participant numbers would be beneficial.

Keywords: bipolar disorder, carers, couples, interpretative phenomenological analysis

An Exploration of Experiences of Bipolar Disorder within Couples

Bipolar Disorder (BD) is often conceptulised within a medical framework as a serious mental illness with a long course including episodes of depressed and elated mood (mania or hypomania). In its most severe forms, BD can be associated with significant impairment of personal and social functioning (NICE, 2014).

Psychosocial factors play an important role in BD and when individuals perceive themselves to have high levels of social support their relapse rates are reduced (Alloy et al, 2005; Cohen et al, 2004; Sanchez-Moreno et al, 2010). Specifically, individuals who have more assistance from others and increased feelings of self-worth report reduced depressive symptoms (Weinstock & Miller, 2010; Cohen et al, 2004). However, individuals with a diagnosis of BD perceive themselves to have less social support than community control groups (Romans & McPherson, 1992).

An important source of social support is family, although relationships with family members are often adversely affected by BD and negative family attitudes and behaviour, such as stigmatization and rejection are reported (Elgie & Morselli, 2007). Conversely, in families where relatives are well informed and supportive, recovery process is enhanced. Expressed emotion (EE) is a measure of the extent to which family members are critical, hostile or overinvolved in their attitudes (Amaresha &Venkatasubramanian, 2012). Higher relapse rates in BD are associated with high-EE relatives (Miklowitz & Johnson, 2009).

The marital relationship can be a valuable source of social support and where individuals perceive their partner to engage in supportive behaviours, lower levels of depression are found (Dehle et al, 2001). Furthermore, marriage was found to have a greater positive impact upon mental health than less formal unions, such as co-habiting (Braithwaite & Holt-Lunstad, 2017). Lieberman et al (2010) found that being married benefits the mental health of women with a BD diagnosis more than men. Their study identified that married women reported lower episodes of depression than those who had never been married. No effect of marriage on episodes of mania was identified for either gender. However, Walid and Zaytseva (2011) found that individuals with a diagnosis of BD are more likely to either be divorced or never have been married than those without the diagnosis.

Crowe (2004) discusses the changes that mental illness can cause within relationships, including the need for partners to take on more responsibility. He emphasizes that partners can be both affected by and have an effect on the illness. Partners of individuals with a diagnosis of BD report feeling burden and strain due to restrictions in their social life (Kumar et al, 2004); increased responsibilities; worries about finances and difficulties with the sexual relationship (Dore & Romans, 2001; Lam et al, 2005). Some partners of individuals with a diagnosis of BD stated they would not have entered into the relationship if they had known more about the illness (Dore & Romans, 2001). Most recently, Perlick et al (2016) found caregiver burden to be the largest predictor of caregiver depression among those caring for people with a diagnosis of BD.

Qualitative research on BD suggests that burden in partners is related to not being able to share important aspects of their lives, such as raising children, and feeling solely responsible and alone with their feelings (van der Voort et al, 2009). Partners experience a number of challenges, such as accusations; stigmatization and lack of support, which are perceived as burdensome (Tranvag and Kristofferson, 2008). These experiences form part of a cumulative process over time, where each one is perceived dependent upon past experiences. Therefore, previous experience of burden creates a basis for future experiences to be perceived as burdensome. Learning from past behaviours also affects how future challenges are mastered.

For couples where one partner has a diagnosis of BD, marital satisfaction is influenced by a number of factors. It can fluctuate with phase of illness, being lowest during manic phases, highest when the individual is well and in-between during periods of depression (Lam et al, 2005). Marital satisfaction was also influenced by how much control the spouse believed their partner had over their symptoms. Those that perceived their partner to be more in control reported lower levels of satisfaction (Lam et al, 2005).

There is an increased use of family systems approaches in the management of BD, which focus on the family system and not just the individual with a diagnosis (Hyde, 2001). Positive effects on spouse knowledge, coping strategies and personal distress have been found following participation in psychoeducational and support groups for families (Mannion et al, 1994). Alloy et al (2005) concluded that family-focused psychoeducation (FFP) is more effective at managing depression than mania and that this may be associated with changes in social support and expressed emotion constructs. Fredman et al (2015), meanwhile, showed that when families demonstrated medium and high levels of emotional over-involvement, those receiving FFP experienced less mania over time, whilst those receiving crisis management experienced an increase in mania. In their review, Reinares et al (2016) concluded that family intervention is beneficial for the person with BD and the wellbeing of caregivers. If interventions are to be facilitated in a way which involves the family, it seems imperative to involve family members in our research and further develop our understanding of the ways in which BD affects these important relationships.

The current study aims to explore the impact of BD on romantic relationships using joint interview methodology. This approach has been used when researching other health conditions (e.g. Molyneaux et al, 2012; Sakellariou et al, 2013) but never before within BD literature. Previous research utilising individual interviews has not captured the shared experience and how partners make sense of their lives together.

Method

Design

This study explores couples' shared experiences where one partner has a diagnosis of BD using Interpretative Phenomenological Analysis (IPA; Smith et al, 2009; Smith & Osborn, 2008). This methodology has been used previously to analyse joint interview (Harris et al, 2006; Robinson et al, 2005). It allows for detailed exploration of each couple's experiences and meaning making within the context of their social worlds.

Data were collected via semi-structured interviews with couples so that they could share the telling of their story and their mutual understanding could be explored. IPA is phenomenological and concerned with the lived experiences of participants and how they make sense of their experiences (Smith & Osborn, 2008). It is strongly idiographic and requires the use of small, homogenous samples so that each case can be analysed in great detail; sample sizes are usually between three to 10 participants. Both the convergences and divergences between the experiences of participants are explored. It acknowledges the double hermeneutic of the analysis, meaning two interpretations are involved in the process; firstly when the participant makes sense of their own experience and secondly when the researcher interprets the participant's account (Smith & Osborn, 2008). It is therefore necessary to acknowledge that the encounter between the researcher and the participants will have shaped and influenced the final interpretation of the data.

Ethical approval was sought and granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC) before conducting the study [2].

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[2] See Section 4: Ethics Documentation

Participants were provided with information sheets[3] and both partners had to give informed consent and sign a consent form prior to participation[4].

Sampling and Participants

Couples were recruited through a participant group for people who have expressed interested in being involved in BD research and two charitable organisations for individuals with a diagnosis of BD. In addition, an advert was placed in relevant publications[5]. Invitations to participate[6] were emailed or posted to all members of the research interest group living within the North West of England (150 members) initially and then within the United Kingdom (500 members) in a second wave of recruitment. Participants opted in by contacting the lead researcher and were provided with more information and the opportunity to ask questions. The two charities were asked to hand out participant information sheets at their support meetings in North West England (34 meetings). As attendance at these support meetings was variable, the exact size of the sample pool is unknown. Inclusion criteria were: (1) One partner must have a diagnosis of bipolar 1 disorder; (2) both partners must be over the age of 18 years and able to give informed consent; (3) each couple must have been together through at least one major mood episode and for at least six months; (4) the individuals with a diagnosis of BD must not be in an acute episode of illness at the time of interview, and (5) each participant must be able to speak English to a level that allows their participation in a semi-structured interview. Only participants with a diagnosis of bipolar 1 disorder were included so that the homogeneity of the sample group was increased, a requirement of IPA (Smith et al., 2009).

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[3] Presented in Appendix 2-B
[4] Presented in Appendix 2-C
[5] Presented in Appendix 2-D
[6] Presented in Appendix 2-E

Ten couples expressed interest in the study, however, four were unable to take part due to the partner with a diagnosis of BD being in an acute episode of illness and two had a diagnosis of bipolar 2 disorder. Therefore, a total of four couples were recruited; three from the research group and one from a charity. The mean age of participants with a diagnosis of BD and their partners was 38 and 38.25 years respectively. All couples lived together and relationship length ranged from two and a half years to 34 years with a mean of 15 years and four months. Two couples had been together at the time of diagnosis and two couples met following diagnosis. In order to maintain confidentiality, each participant has been given a pseudonym by which they are referred to. These pseudonyms are then followed by (BD) to indicate the person has a diagnosis of BD or (P) to indicate the person is the partner. Table I details the characteristics of each couple.

Procedure and Data Collection

In order to determine eligibility, participants took part in an initial screening process. This involved a telephone interview in which they were asked their marital status and The Mood Disorder Questionnaire[7] (MDQ), a screening tool for BD (Twiss et al, 2007). Those who achieved a positive score on this measure were then invited to discuss the study and consent process. Once consent was obtained, the person with a diagnosis of BD then completed Sections A to D of the Structured Clinical Interview for DSM-IV Disorders (SCID-I/P; First et al, 2002) to confirm their diagnosis and that they were not in an acute phase of illness. Following this, couples who met eligibility criteria were invited to take part in interviews.

Semi-structured joint interviews were arranged at the convenience of participants. They were given the choice of attending the university, being visited in their own homes or

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[7] Presented in Appendix 2-F

being interviewed via Skype. All home visits were conducted in accordance with the Lone Worker Policy of the researcher's employing NHS Trust. Three couples chose to be interviewed at home and one couple travelled to the university. Interviews were digitally audio-recorded and typed up verbatim by the interviewer within two months. An interview schedule was devised to guide the interview flexibly; however, participants were encouraged to take the lead in selecting the experiences they viewed as important to the research topic. This is consistent with the approach of IPA. The interview schedule[8] was developed following a review of relevant literature and discussion with the researcher's field supervisor and a service-user researcher who had a diagnosis of BD. The topics covered were: (1) demographic details, including age, length of relationship and time since diagnosis; (2) impact of diagnosis on the relationship; (3) how they described themselves as a couple; (4) what challenges they faced and how they were able to support each other; (5) sources of happiness in the relationship; (6) how mood fluctuations affected the relationship, and (7) what support they received. As it was important to explore the shared constructions of experience, attention was paid to ensuring the views of both partners were elicited during each topic of conversation. The length of interviews ranged from 76 minutes to 111 minutes with a mean length of 89.25 minutes. Following interviews all couples were given debrief sheets[9] and offered a follow-up telephone call from the researcher to discuss any issues that may have arisen due to the interview.

Joint Interviews

Previous research has interviewed carers and individuals with a diagnosis of BD separately, but a joint perspective has never been obtained. Joint interviews would highlight themes within the dynamics of the couples regarding their shared journey that cannot be

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[8] Presented in Appendix 2-G

[9] Presented in Appendix 2-H

obtained from interviewing participants alone. The aim of this research was to gain understanding of the couple as a system comprising of two partners. With focus groups, caution is advised due to the potential difficulty in developing the phenomenological aspects of IPA (Smith et al, 2009) as a result of the presence of multiple voices. In using joint interviews, this project treated each couple's interview as one transcript, using IPA to analyse how each couple experienced and made sense of their world as a unit; recognising that illness is lived and understood within the particular social contexts that people inhabit (Kleinman, 1988). It therefore obtained idiographic couple accounts, adopting a family systems perspective , as has been done previously with couples where one partner has a diagnosis of dementia (Robinson et al, 2005) and depression (Harris et al, 2006)

A further concern about joint interviews may be that partners will work together to provide a consistent story, thereby not providing an accurate reflection of their views. However, research looking at the validity of using joint interviews and focus groups (Bjornholt & Farstad, 2014; Wilkinson, 2011) suggests that such a context may actually promote personal disclosures. Furthermore, attention was paid by the researcher to ensure that both partners participated in interviews so that a joint perspective was obtained.

Analysis

Interpretative Phenomenological Analysis (IPA) was adopted to analyse the interview data using flexible guidance (Smith et al., 2009; Smith & Osborn, 2008). Initially, the first interview was listened to and transcribed by the researcher. The transcript was then read several times whilst ideas were noted on it through detailed line by line analysis regarding what was being described and some initial interpretations of this[10]. These notes were then transferred into a separate document so they could be visually conceptualised into meaningful

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[10] Extract presented in Appendix 2-I

clusters (Smith et al., 2009). This process was repeated until the best fit was made of the data and the final emergent themes had been created[11]. This same process was repeated for interviews two, three and four, taking an idiographic approach to analyse each individually. A narrative for each individual theme from these four transcripts was written. Each transcript was then coded so that all instances of each of the themes could be identified. This also allowed for another check that themes were represented in the verbatim transcript so as to reduce the possibility of researcher bias. Frequency and content of themes were compared across each transcript to produce a final set of four super-ordinate themes across the whole dataset[12].

Although each interview took place with two interviewees, during data extraction each transcript was viewed as one single unit in order to obtain a co-constructed understanding of the experience of each couple. Within this, attention was paid to where the views of each partner were similar or disparate. Themes were developed using dialogue from both partners and presented using quotes to support this in order to focus upon the collective construction of their experience of bipolar disorder.

Ensuring rigour

A number of steps were taken by the researcher to ensure the methodological rigour of this research. Guidance regarding this was obtained from Elliott et al (1999) and Yardley (2007). The researcher kept a reflective diary to acknowledge and reflect on how her previous experiences may have influenced her interpretation of the data[13]. Possible effects of researcher influence can be reduced through bracketing and reflexivity. Bracketing refers to the researcher's acknowledgement of possible influences and an intentional setting aside of

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[11] Example presented in Appendix 2-J
[12] Presented in Appendix 2-K
[13] Extract presented in Appendix 2-L

conscious thoughts influenced by their particular perspective. Reflexivity is the thinking process that helps us to identify potential influences and involves examination of the values and interests of the researcher that may impinge upon research (Chan et al, 2013). The researcher was aware when devising the semi-structured interview that her previous role of supporting caregivers biased her towards thinking that being the partner of a person with a diagnosis of BD would be difficult. It was important to be aware of this to ensure questions allowed participants to describe their experiences in their own way.

The, ‘double hermeneutic’ of IPA means as, “participants are trying to make sense of their world, the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008. p.53). A cyclical approach of bracketing meant that participants and their experiences could be focused on, whilst attention was also paid to researcher’s preconceptions and the influence they would have on interpretations made of the participants’ stories.

Credibility checks were conducted with research supervisors to check analysis was warranted and represented the original data; one supervisor listened to original recordings to check that initial coding was appropriate and another helped create the themes through discussion and visually mapping concepts.

Results

Analysis yielded four main themes: (1) “It’s not a partnership of equal adults” – Negotiating Roles; (2) “That just became the safe thing to do, just not tell anybody and then it is like it is not really there” – Challenges of Communication; (3) “My mind is damaged” – Externalising the Diagnosis and (4) “It’s crap at the moment, but you will get through it” – Keeping Positive. In order to ensure the development of themes from the original transcript is transparent to the reader, themes are presented alongside verbatim quotes from participants (as advocated by Smith, 2008).

“It’s not a partnership of equal adults” - Negotiating Roles

All couples spoke about the significant impact BD had on their respective roles within the relationship. The partner without a diagnosis of BD took on more responsibility for household tasks; including raising children; managing finances and overseeing the health of the person with BD. They felt pressure to keep their partner well so tried to minimise the stress they experienced:

KATIE (P): *She couldn’t really, you couldn’t really handle any kind of stress.*

LUCY (BD): *Anything*

KATIE (P): *Any stress, any change, any difference. Everything has got to stay as smooth as possible, so what I was doing was I was acting as a buffer for life, you know?*

This was a lot to cope with as partners tried to manage things at home as well as maintain performance at work:

KATIE (P): *I was worried about her not being able to work, that was a big worry and...I was sort of thinking okay well I might have to come out of my job...Like I was having conversations with my manager about things are easy at the moment and if you just give me a bit of leeway... really trying to pull away from non-essential things and trying to focus on what I needed to focus on*

This increased responsibility was not always taken on willingly and there was a strong sense of duty and obligation expressed. Partners longed for the person with a diagnosis of BD to contribute more, but also felt concerned about the potential negative consequences of pushing them too much. They didn't know how much they should be doing, as they didn't feel knowledgeable about BD. They tried to follow their instincts and hoped what they did would not trigger relapse:

SUE (P): *Sometimes think do I make things worse for Steve because I'm making some demands from him?*

STEVE (BD): *Which aren't unreasonable*

SUE (P): *Which aren't unreasonable*

The changing needs of the person with BD determined how the roles in the relationship fluctuated as they required different things from their partners depending on their mood. This could be difficult for partners to manage and their flexibility was key in maintaining the relationship. When the person with BD was unwell partners took on increased levels of responsibility. Noticing this, at times subtle, change acted as a warning sign for relapse and could feel overwhelming for partners, particularly when they were required to make decisions regarding healthcare:

TOM (P): *Sometimes they [NHS staff] were turning to me and, "well what do you think is the best?" and it's quite a difficult decision, because a lot of the time they are like, "oh do you think we should keep her here? Do you think she'll be alright?" and I'm well, because at the end of the day I want to do what's best for her, so it's a bit of a tough decision. I didn't want her to be in hospital at the same time I wanted her to be safe so. It's a bit of an awkward one.*

Often the person with BD recognised they took on less responsibility, leaving more for their partner:

STEVE (BD): *I think I avoid responsibility. I don't want to make a decision because I don't want to be wrong. I might be wrong*

SUE (P): *Yes you don't want to be criticized for it*

STEVE (BD): *And that makes me feel very uncomfortable, the thought that I could be wrong*

However, when the person with BD's mental health was more stable, they would try to make amends to their partners and regain control. This could involve doing practical things around the home:

LUCY (BD): *I knew I couldn't give as much emotionally as she needed, so I would try and make up for that in other ways like making sure there was always food in and clothes were clean and the washing was done... Just trying to keep on top of all these things so as I was getting better but was still not well I recognised that she had been having to take up a lot of that kind of thing when I was really ill. Just trying to take bit by bit trying to take back control of different parts of my life... I think for a long time that was how I felt I could give to the relationship, via really practical things, because I just didn't feel able to emotionally connect with anybody a lot of the time. So I think that was my way of showing my love. Making sure you had clean pants and socks*

In this way, the roles within the relationships were continuously changing, influenced by the stability of the BD. Both partners were aware of this. The person with BD couldn't always understand why their partner had stayed through the bad times and, when able, wanted to demonstrate their gratitude in a way they couldn't when experiencing a relapse in their mental health:

JAMES (BD): *It's my turn now to give back. I want to give my wife a life really, to say thank you in way. It's like, without her ...there is no two ways about it, the same scenario I wouldn't be here, because anyone else would have ran down the road away from me. Why has she stuck by me, why is she still here?*

This unequal distribution of responsibility and need for frequent evaluations of what each partner was doing contributed to a blurring of roles within the relationships. It was hard to be a partner and carer simultaneously, making it difficult for participants to understand how this part of their relationship worked:

STEVE (BD): *Part of the carer role is blurred between being a carer, being a partner and actually being a mother*

SUE (P): *Yes*

STEVE (BD): *Because when I'm depressed in a way, I'm a kid and certainly in some respects in a childlike state…but you feel like a sister sometimes, a sister rather than a partner carer.*

Partners felt there was a lack of intimacy within their relationships, particularly when the person with BD was experiencing low mood. This further compounded their confusion over roles, making them feel less like romantic partners, and was one of the most difficult things to cope with:

KATIE (P): *She would get in from work and I would be at home and you know as you do in a couple, you look forward to someone coming home don't you? And a lot of the time it was just straight upstairs and straight doing something and there wasn't a hug and there wasn't a hey how are you doing? How was your day or any kind of engagement on that level...that was difficult*

This theme highlights the changing roles in the relationships made necessary by the changing needs of the person with BD and made possible by the willingness of partners to adapt how they behaved. The responsibility felt by partners to keep the person with BD well was the driving force behind their flexibility, although at times they found this difficult, resulting in feelings of stress. However, it was this flexibility, recognised by both partners, which was pivotal to the continued success of the unions.

“That just became the safe thing to do, just not tell anybody and then it is like it is not really there” – Challenges of Communication

All couples expressed concern the impact of BD may be too much for their relationship. This affected their communication as the participants with BD did not always reveal the full extent of their difficulties to their partners. They wanted to be open, but were worried they may burden their partner too much. One participant compared the conditional love she felt from her partner to the unconditional love from her parents. Her parents would cope with everything, because they had to, but with her partner there was a concern he may not cope and therefore leave if things got too much for him. This impacted on how she communicated with him about her BD, as she felt unable to share full details:

HANNAH (BD): *When I was younger it would always be mum and dad who were involved and then all of a sudden he was there instead and whereas mum and dad have been through it all before, they know what the inside of a psych ward looks like, they know what the rules are and all the rest of it. I knew he didn’t, hadn’t had any of that before, so I suppose part of me was worried whether he would cope and part of me not wanting him to be involved because I didn’t know what he would think.*

These fears meant partners had to prove themselves and show they could cope through difficult times. Therefore, although a first relapse within a relationship was something faced with apprehension, it also had the potential to open up channels of communication:

HANNAH (BD): *It is almost a relief to have a really crappy episode... I can go into getting married knowing he has seen it at its worst and coped really well with it. Last year was shit basically, but in a weird way it's sort of nice to have that in the back of the mind thinking it's not like I'm getting married thinking oh god, you know, what will happen when I get ill and how will he cope with that and worry about it because I don't really have to anymore because it has already happened.*

In one couple the partner with BD withheld her diagnosis until following their marriage due to concerns regarding the stigma of BD:

LUCY (BD): *That became the safe thing to do, just not tell anybody and then it is like it is not really there.*

Despite the intentions of the person with BD to hide things however, partners knew something was wrong and expressed frustration that they were not fully informed of what was happening:

KATIE (P):	*I got hints that you weren't right at certain things you said and certain ways of dealing with things I could sense that and I could tell that there was something but I didn't really know what it referred to and I thought well maybe I just don't understand depression very well.*

This had implications for how well partners were able to offer support. They were expected to hold the responsibility of providing care and make decisions regarding treatment, without being aware of full details which felt frustrating and made their role more challenging.

This also impacted upon access to support. Participants spoke about their struggle to access appropriate mental health services and the need for them to unite together to get help. For the person with BD, feeling as though they had to fight to receive support created further feelings of helplessness at times of already heightened vulnerability. They needed their partners' assistance:

STEVE (BD):	*Because people with mental health difficulties and their spouses are so knocked out by their symptoms and it*
SUE (P):	*It's hard to fight*
STEVE (BD):	*It's hard to be assertive enough*

In order to fully help, partners needed to know what difficulties were being experienced, but these were not always shared with them.

Challenges with communication were prominent when the person with BD was depressed. At these times, partners missed having someone to share their lives with. One couple spoke of managing this by adapting their form of communication to texting rather than talking on the telephone:

LUCY (BD): *We started communicating better, because we weren't having an argument every other time we spoke...we just found a different way for me to be able to initiate conversations that way didn't we?*

KATIE (P): *Uhm*

LUCY (BD): *So that felt a lot better, obviously it felt a lot better for her, but it felt a lot better for me as well, so it almost felt like I had a bit more control over my life again*

Another couple used joint sessions with a psychologist to think about ways to maintain good communication, demonstrating how important it was to them:

SUE (P): *One of the things we have seen the psychologist together about the last time ... is to try and keep communication going. But I think Chris just finds it so difficult.*

To summarise, fear of abandonment and associated reluctance to disclose full details about their illness was a challenge for the participants with a diagnosis of BD. In order to feel reassured their partner would stand by them and support them they had to expose themselves, but the potential risk of losing their partner made this difficult. This was also hard for partners who wanted to respect the choice for privacy but felt their role would be easier the more they knew. Ultimately, however, couples felt effective communication was important and finding ways to improve this helped their relationships.

“My mind is damaged” – Externalising the diagnosis

How participants made sense of the diagnosis of BD was important for managing the impact upon their relationship; predominantly because the diagnosis provided an explanation and reason for why the person with BD acted as they did. The diagnosis was absolution and an indication that things were not their fault:

STEVE (BD): *The label doesn’t bother me, it’s just the fact it is abnormal, you know… I felt relief…that it wasn’t just me being a wuss*

For partners too, it was easier for them to accept and deal with behaviours they attributed to being out of the person with BD’s control:

TOM (P): *I’d go and visit the ward and speak to the nurse and she’d say she has been banging her head against the wall to the extent it* *was bleeding or something like that ...it's quite difficult in the beginning to comprehend but then you've just always got to go back to the fact that it is a terrible condition and she's not thinking straight at this moment in time, but she will come out of it.*

Difficulties arose when partners couldn't differentiate between which actions were due to BD and which were not. Participants were unclear as to what things they should challenge and what things they should excuse:

KATIE (P): *I was like what do I do here? I understand that she's not very well, but what do I do? To what extent do I take this shit and to what extent do I put my foot down?*

Here, there was potential for externalisation to cause friction within couples. Katie spoke about how useful she found support groups to help with this. Meeting other carers and finding out more about BD helped her to better decide what was illness related.

Predominantly, however, externalisation was a useful approach that helped couples support one another and create a united front against BD. No individual was to blame; it was a shared problem they faced together. This created closeness and a sense of resilience; if they can get through this together they can get through anything. This sense of closeness was needed, as other aspects of BD reduced their feelings intimacy. It was hard for partners to not take this personally, but externalising the problem and thinking of it as a symptom helped with this:

SUE (P): *You get no feedback, or getting something back from the relationship, so it definitely, the illness definitely plays a big part in the relationship*

The diagnosis also gave hope that if there was a name there may be a cure:

LAURA (P): *I was relieved in a way when he was on the ward and they finally said this is what it could be and we'll try and help him so I felt relieved that he had been diagnosed with something and something was going to be hopefully getting done about it*

As well as externalising the challenging aspects of BD, participants also externalised their ability to feel better. They felt reliant on a mental health system which was difficult to navigate. Externalisation of difficulties reduced feelings of control and participants expressed fear for what the future may hold. Even during good times, thoughts of relapse were never far away:

STEVE (BD): *Even though you enjoy some of the side of it, it is tempered by the reality that*

SUE (P): *That it can go wrong*

STEVE (BD): *That it can go wrong*

Ultimately, having a diagnosis was helpful for both partners. It provided an explanation for how they were feeling, making it easier to cope with the more difficult symptoms, but also gave hope for successful treatment.

“It’s crap at the moment, but you will get through it” – Keeping Positive

Couples coped with difficult times by remaining optimistic things would improve. Their shared histories and memories of good times got them through bad times:

SUE (P): *We’ve been together 30 years, we’ve got 4 great kids and that in some way probably helps*

STEVE (BD): *Helps you weather the storm*

SUE (P): *Cement you and weather the storm, but, I would certainly say there are times when I have thoughts can I carry on like this?*

STEVE (BD): *This is too much*

SUE (P): *It’s just too much, but then things seem to pick up when we get back and you get the old chatting back and feeling closer again.*

Thinking of their shared histories reminded participants how much they had already invested in the relationship and how much adversity they had overcome. They did not want this to be in vain and it was motivation to keep on battling together. Focusing on better times enabled participants to remember that difficult times were short-lived and, although extremely distressing at the time, would eventually pass:

> *TOM (P):* *Just reassure her that you know it's crap at the moment, but you will get through it and things will get better and you could also refer to past incidences as well and think right I've been in this situation before and come out of it. So you know yourself you are going to come out of it at some point*

Knowing that similar challenges had been overcome in the past gave hope that provided strength to keep on going. In this way a shared past helped create a vision of a shared future.

Couples also used humour during the interviews, demonstrating a shared coping strategy. They spoke about highly traumatic times in a jocular manner which worked effectively to ease tension:

> *JAMES (BD):* *Just laugh, have a laugh. If you can pick a laugh out of something, pick it out. We haven't got long here, so you know, that's how I see it. Just try and be happy. Being happy takes everything away I think. Takes a lot of bad away*

LAURA (P): *Yeah, laughing does, It gets you through a lot*

It is not clear from this study whether the use of humour was present within couples before the diagnosis of BD or had developed since, however, all couples were synchronised in their use of it. There were no occasions when one partner laughed about something that appeared inappropriate to the other. They were unified in this approach, making eye contact and laughing together:

STEVE (BD): *I was in casualty this last time...there was a policeman in the room with me and I said to him I'm worried I'm going to do something to injure you or my wife and he said, "I'm 20 stone lad, you're not going to injure me" (laugh)*

SUE (P): *He was a big chap*

STEVE (BD): *It was really funny in retrospect (laugh)*

SUE (P): *Yeah (laugh)*

This theme highlights the ways couples coped with challenges by keeping positive, recalling memories of good times to get through bad times and using humour. The cyclical nature of bipolar disorder facilitated optimism through bad times that things would be better again in the future.

Discussion

This study is the first to interview couples in order to provide an in-depth co-construction of the experience of being in a relationship where one partner has a diagnosis of BD. Couples spoke about the how their relationships were affected, with particular emphasis on the impact upon their roles and levels of responsibility. The themes also highlighted the fragility of these relationships due to concerns BD was too much to deal with and the ways participants coped with this. As BD is characterised by, “episodes of mania...and episodes of depressed mood” (NICE, 2014) the dynamics could be constantly changing. Participant accounts demonstrated the flexibility required to cope with this. This is similar to results of a previous study of couple interactions where one partner has a diagnosis of BD (Treves et al, 1999). However, while flexibility is viewed as a positive coping strategy in the current study, Treves et al (1999) considered it to be potentially detrimental as couples could never, “find a stable equilibrium”. The difference in these findings may be because couples involved in the Treves et al (1999) study were engaged in “intensive treatment”, which may indicate the presence of difficulties within the relationships not present for couples in the current study.

Partners without BD often held more responsibility; something they did not necessarily take on willingly or feel skilled to do. They managed by following their instincts and learning from past experiences. Previous studies have identified that feelings of responsibility are associated with increased burden in partners (Tranvag & Kristoffersen, 2008; van der Voort et al, 2009). The novel finding of the current study is the response to this shift in responsibility by the participants with BD and their attempts to address this balance when feeling well.

The unique challenges of being a ‘partner-carer’ and how these threatened the partnerships were highlighted. As found in previous studies, partners felt alone as they tried to cope with responsibilities of family life (Lawn & McMahon, 2014; Tranvag &

Kristoffersen, 2008; van der Voort et al, 2009). Generally partners did not identify themselves as ‘carers’ due to the reciprocal role implication their partner would therefore be a patient and the partner with BD reinforced this by increasing their role within the household when feeling well. This is in accordance with previous research identifying the different needs of partner carers from other caring relationships (Henderson, 2001).

The stress of living with BD put strain on relationships, as identified previously (e.g. Dore and Romans, 2001; Kumar et al, 2004). In addition, the current study obtained the perspective of the partner with a diagnosis of BD and their feelings of guilt at the impact of their illness. Social support has a positive effect on relapse rates within BD (e.g. Cohen et al, 2004; Johnson et al, 2003) so it is important to support both partners. Research into interventions designed specifically for partners is lacking, however, there have been positive results for the effectiveness of family psycho-education on improving relapse rates (Miklowitz et al, 2003; Reinares et al, 2016). Family-focused therapy incorporating psycho-education, communication skills training and problem-solving skills training was found to lower rates of relapse in individuals with BD when compared to those who had individual therapy (Geddes & Miklowitz, 2013). In addition, positive results were seen when family members attended educational sessions, even in the absence of the person with the diagnosis. A preliminary study analysing the effects of a psychoeducation intervention for individuals with BD and their spouses suggests it was effective in reducing overall functioning, but not symptom levels although small participant numbers means this requires further investigation (Clarkin et al, 1998). Studies with other carer groups suggest psychoeducation helps in reducing distress and subjective burden felt by carers (Reinares et al, 2004) and further study into whether this result is replicated with partners would be useful.

A number of ways of managing BD were identified. Couples spoke about uniting to face challenges together. This helped when coping with the symptoms, which they externalised and viewed as a separate entity from the person. Therefore, in the current study having a medical view of BD, in which the symptoms were attributed to a medical as opposed to psychological problem, was helpful for participants. This was a similar finding to Mechanic et al (1994) in their study of schizophrenia. However, externalising the BD limited the sense of control felt by participants, a theme previously linked to feeling overwhelmed, flawed and lacking autonomy in individuals with a diagnosis of BD (Crowe et al, 2010). Although participants in the current study did not express thoughts of wanting to be more in control, an increased sense of control has been found to enhance a persons' ability to manage their symptoms (Crowe et al, 2010).

It is also useful to consider the use of externalisation in the context of theoretical models devised to understand how people manage health problems. The Self Regulation Model (SRM; Leventhal et al, 2001; Leventhal et al, 1984; Lobban et al, 2003) suggests a person's coping strategies are influenced by their interpretation of the illness. Those who attribute their mental illness to biological factors (in accordance with a "medical model") report greater self-esteem and score more highly on quality of life measures (Mechanic et al, 1994).

The cyclical nature of BD means difficult times are interspersed with good times and focusing on the latter helped couples. They shared an overall positive outlook on life, displaying humour. Humour as a coping strategy has been identified before in partners of individuals with a diagnosis of mental illness (Lawn & McMahon, 2014) and found to be therapeutic in relieving tension (Kuiper & Martin, 1998; Lefcourt et al, 1995; Moran, 1996; Moran & Massan, 1999). Humour is thought to facilitate more positive cognitive appraisals (Kuiper et al, 1993).

Although interviewing couples made recruitment challenging and resulted in lower participant numbers, their use revealed valuable findings and provided new insights into the impact of BD upon relationships. The researcher had anticipated that living with BD would be challenging; however, the acknowledgment of this from both partners and the ways in which they worked together to re-adjust power imbalances was unforeseen. Joint interviews allowed insight into this collaborative approach to coping. There were also advantages to having a small participant number; it allowed for the analysis of a homogenous sample who all spoke about their positive experiences and demonstrated great unity. We can learn from this more about coping strategies that work and how supportive relationships can nurtured to improve outcomes for individuals with a diagnosis of BD and their partners.

Further Clinical Implications

These findings suggest couples in which one partner has a diagnosis of BD would benefit from joint support from services, given the impact of the diagnosis on both their lives. This support should be tailored to the needs and clinical presentation of individual couples, but could incorporate information on effective communication, managing changing roles, effective coping strategies and psycho-education. Current NICE guidelines (2014) promote support for carers; however the experiences of participants in the current study found this to be lacking. One key challenge for services is a lack of therapist skills in working with couples. Few trained couples therapists and no current evidence base for this approach makes it difficult to deliver in the NHS (Lobban and Barrowclough, 2015). One approach may be to train mental health workers already trained in CBT in how to involve a significant other in the work they are already doing (Lobban and Barrowclough, 2015). Furthermore, it can be difficult for clinicians to prioritise time with family members when they are working in already stretched services, hold a large number of clients on their caseloads and do not feel supported by management to provide family interventions (Askey, Holmshore, Gamble &

Gray, 2009). There can also be worries about client confidentiality and research has shown that mental health workers can be concerned about collaborating with relatives due to this (Askey et al, 2009; Wynaden & Orb, 2005). This is a topic that should be discussed with clients and their relatives so that negotiations can be made and informed consent obtained to share information where applicable and helpful.

Use of the term carer should also be reviewed as partners do not identify themselves in this way. This term fails to reflect the complexities of the relationship and may prevent partners from accessing support. Support services need to be offered in the context of a person’s relationship and services directed at carers may not always be the most appropriate if they do not accommodate the changing nature of this relationship. Concern about the potential instability of conditional love and stigma associated with mental illness can impact upon communication between partners and potentially access to support.

Future Research

Our understanding of the experiences of couples with BD could be further developed by interviewing couples who have separated. Furthermore, couples could be interviewed together and then individually to identify whether additional information is revealed in the second interview that could not be shared when together. Research is also needed to understand the impact of BD on relationships over time using a longitudinal design.

Limitations

This paper does not represent the views of all individuals with a diagnosis of BD and their partners. The small participant number allowed for in-depth analysis of the data, in line with IPA, but restricts generalisability. However, it is the first research paper to interview couples together and acts as a starting point for further research in this area.

All couples within the study were self-selecting and willing to talk openly in front of each other. This provided useful data in terms of what helps maintain a supportive relationship. However, it is possible they are not representative of all individuals with BD in the general population.

The impact of BD on sexual relationships was only discussed by one couple who stated the person with BD's interest in sex was increased during mania; a finding supported by previous research (Kopeykina et al, 2016). The larger impact of this on the relationship was not explored further and would be an interesting topic for further study. This may be an area that participants find difficult to discuss in front of each other and/or a third party, so consideration of how to manage this sensitively would need to be made.

Conclusion

This research has revealed the impact a diagnosis of BD can have on both partners and the ways in which they are able to adapt and support one another. Of particular interest are the ways in which they negotiate their reciprocal roles together, adapting their behaviours in order to meet current needs. It has highlighted ways in which participants feel let down by mental health services and promotes the need for a wider systemic support system in which both individuals within the partnership are acknowledged as being integral to the course of BD.

References

Alloy, L.B., Abramson, L.Y., Urosevic, S., Walshaw, P.D., Nusslock, R., Neeren, A.M., 2005. The psychosocial context of bipolar disorder: Environmental, cognitive and developmental risk factors. Clinical Psychology Review. 25, 1043-75. doi: 10.1016/j.cpr.2005.06.006

Amaresha, A. &Venkatasubramanian, G. 2012 Expressed Emotion in Schizophrenia: An Overview. Indian Journal of Psychological Medicine, 34 (1), 12 – 20. doi: 10.4103/0253-7176.96149.

Askey, R.,Holmshore, J., Gamble, C. & Gray, R. 2009 What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. Journal of Family Therapy, 31 (3), 310-331. Doi: 10.1111/j.1467-6427.2009.00470.x

Braithwaite, S., & Holt-Lunstad, J., 2017. Romantic relationships and mental health. Current Opinion in Psychology. 13, 120-125.

Bjørnholt, M., Farstad, G., 2014. ‘Am I rambling?’ on the advantages of interviewing couples together. Qualitative Research. 14. 3-19. doi: 10.1177/1468794112459671

Chan, Z. C., Fung, Y. L., Chien, W. T., 2013. Bracketing in phenomenology: only undertaken in the data collection and analysis process? The Qualitative Report. 18(30), 1-9.

Clarkin, J.F., Carpenter, D., Hull, J., Wilner, P., Glick, I., 1998. Effects of psychosocial intervention for married patients with bipolar disorder and their spouses. Psychiatric Services. 49(4), 531-3

Cohen, A.N., Hemmen, C., Henry, R.M., Daley, S.E., 2004. Effects of stress and social support onrecurrence in bipolar disorder. Journal of Affective Disorders. 82(1), 143-7. Doi: http://dx.doi.org/10.1016/j.jad.2003.10.008

Crowe, M., 2004. Couples and Mental Illness. Sexual and Relationship Therapy. 19(3), 309-17. doi:10.1080/14681990410001715436

Crowe M., Whitehead, L., Wilson L., Carlyle D., O'Brien, A., Inder, M., Joyce, P., 2010. Disorder-specific psychosocial interventions for bipolar disorder – a systematic review of the evidence for mental health nursing practice. International Journal of Nursing Studies. 47, 896–908.

Dehle, C., Larsen, D., Landers, J., 2001. Social Support in Marriage. The American Journal of Family Therapy. 29(4), 307-24. doi: 10.1080/01926180126500

Department of Health., 1983. Mental Health Act. London: HMSO

Dore, G., Romans, S.E., 2001. Impact of bipolar disorder on family and partners, Journal ofaffective disorders. 67, 147-58.

Elgie, R., Morselli P.L., 2007. Social functioning in bipolar patients: the perception and perspective of patients, relatives and advocacy organisations – a review. Bipolar Disorders. 9, 144-57.

Elliott, R., Fischer, C. T., Rennie, D. L., 1999. Evolving guidelines for publication of Qualitative research studies in psychology and related fields. British Journal of Clinical Psychology. 38, 215-229.

First, M. B., Spitzer, R. L., Gibbon M., Williams, J. B.W., 2002. Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Patient Edition. (SCID-I/P). New York: Biometrics Research, New York State Psychiatric Institute.

Fredman, S. J., Baucom, D. H., Boeding, S. E., & Miklowitz, D. J., 2015. Relatives' emotional involvement moderates the effects of family therapy for bipolar disorder. Journal of consulting and clinical psychology. 83(1), 81-91.

Geddes, J. R., Miklowitz, D. J., 2013. Treatment of bipolar disorder. The Lancet. 381(9878), 1672-82. doi: http://dx.doi.org/10.1016/S0140-6736(13)60857-0

Harris, T. J., Pistrang, N., & Barker, C., 2006. Couples' experiences of the support process in depression: A phenomenological analysis. Psychology and Psychotherapy: Theory, Research and Practice. 79(1), 1-21.

Henderson, J., 2001. 'He's not my carer – he's my husband': Personal and policy constructions of care in mental health. Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community. 15(2). 149-59. DOI: 10.1080/02650530120090601

Hyde, J.A., 2001. Bipolar Illness and the Family. Psychiatric Quarterly. 72(2). 109-18.

Johnson, L., Lundström,O., Åberg-Wistedt, A. and Mathé, A. A. (2003) Social support in bipolar disorder: its relevance to remission and relapse, Bipolar Disorders, 5(2):129-37 DOI: 10.1034/j.1399-5618.2003.00021.x

Kleinman, A., 1988. The illness narratives: Suffering, healing, and the human condition. Basic books.

Kopeykina, I., Kim, H. J., Khatun, T., Boland, J., Haeri, S., Cohen, L. J., Galynker, I. I., 2016. Hypersexuality and Couple Relationships in Bipolar Disorder: A Review. Journal of Affective Disorders.. Doi: http://dx.doi.org/10.1016/j.jad.2016.01.035

Kuiper, N.A., Martin, R.A., Olinger, J. L., 1993. Coping Humour, Stress and Cognitive Appraisals,. Canadian Journal of Behavioural Science. 25(1). 81-96

Kuiper, N. A., Martin, R. A., 1998. Laughter and stress in daily life: Relation to positive and negative affect. Motivation and Emotion,. 22(2). 133-53

Kumar, S., Singh, R., Mohanty, S., Srivastava, A., 2004. Spousal Burden of Care in Bipolar Affective Disorder. Social Science International. 20(1). 69-75.

Lam, D., Donaldson, C., Brown, Y., Malliaris, Y., 2005. Burden and marital and sexual satisfaction in the partners of bipolar patients. Bipolar Disorders. 7. 431-40

Lawn, S., McMahon, J., 2014. The Importance of Relationship in Understanding the Experience of Spouse Mental Health Carers. Qualitative Health Research. 24(2). 254-66. doi:10.1177/1049732313520078

Lefcourt, H.M., Davidson, K., Shepherd, R., Phillips, M., Prkachin, K., Mills, D., 1995. Perspective-taking humor: Accounting for stress moderation. Journal of social and clinical psychology. 14(4). 373-91.

Leventhal H., Leventhal E., Cameron L., 2001. Representations, procedures, and affect in illnessself-regulations: A perceptual-cognitive model. In Baum A., Revenson T. A., Singer J. E . (Eds.), Handbook of health psychology. pp. 19–47. Mahwah, NJ: Lawrence Erlbaum Associates.

Leventhal H., Nerenz D. R., Steele D. J., 1984. Illness representations and coping with health threats. In Baum A., Taylor S. E., Singer J. E . (Eds.), Handbook of psychology and health: Volume IV Social psychological aspects of health. pp. 219–252. Mahwah, NJ: Lawrence Erlbaum Associates.

Lieberman, D.Z., Massey, S.H., Goodwin, F.K., 2010. The role of gender in single Vs married individuals with bipolar disorder. Comprehensive Psychiatry. 51 (4), 380-5. doi:10.1016/j.comppsych.2009.10.004.

Lobban, F., Barrowclough, C., 2015. An interpersonal CBT framework for involving relatives in interventions for psychosis: Evidence base and clinical implications. Cognitive Therapy and Research. 40(2), 198-215.

Lobban, F., Barrowclough, C., Jones, S., 2003. A review of the role of illness models in severe mental illness. Clinical Psychology Review. 23(2). 171-96.
DOI: 10.1348/0144665042388955

Mannion, E., Mueser, K., Solomon, P., 1994. Designing psychoeducational services for spouses ofpersons with serious mental illness. Community Mental Health Journal. 30(2). 177-90.

Mechanic, D., McAlpine, D., Rosenfield, S., Davis, D., 1994. Effects of illness attribution and depression on the quality of life among persons with serious mental illness. Social Science and Medicine. 39(2). 155-64. doi: http://dx.doi.org/10.1016/0277-9536(94)90324-7

Miklowitz, D. J., George, E. L., Richards, J. A., Simoneau, T. L.., Suddath, R. L., 2003. A randomized study of family-focused psychoeducation and pharmacotherapy in the outpatient management of bipolar disorder. Archives of General Psychiatry. 60(9). 904-12. doi:10.1001/archpsyc.60.9.904

Miklowitz, D.J., Johnson, S.L. 2009. Social and familial factors in the course of bipolar disorder:Basic processes and relevant interventions. Clinical Psychology Science and Practice. 16, 281-96.

Molyneaux, V., Butchard, S., Simpson, J., Murray, C., 2012. The co-construction of couplehood in dementia. Dementia. 11(4), 483-502. DOI:10.1177/1471301211421070.

Moran, C. C., 1996. Short-term mood change, perceived funniness and the effect of humor stimuli.Behavioral Medicine. 22(1). 32-8. doi: 10.1080/08964289.1996.9933763

Moran, C. C., Massan, M.M., 1999. Differential influences of coping humor and humor bias on mood. Behavioral Medicine. 25, 36–42

National Institute for Health and Care Excellence, 2014. Bipolar disorder: assessment and management: NICE Guidelines CG185. London: National Institute for Health and Care Excellence. https://www.nice.org.uk/guidance/cg185 (accessed 13.7.2016)

Perlick D., Berk L., Kaczynski R., Gonzalez J., Link B., Dixon L., Grier S., Miklowitz D., 2016. Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. Bipolar Disorders. 18. 183–191

Reinares, M., Bonnin, C.M., Hidalgo-Mazzei D., Sánchez-Moreno J., Colom F., Vieta E., 2016. The role of family interventions in bipolar disorder: A systematic review. Clinical Psychology Review. 43, 47-57. doi: 10.1016/j.cpr.2015.11.010

Reinares M., Vieta E., Colom F., Martínez-Arán A., Torrent C., Comes M., Goikolea J.M. , Benabarre A., Sánchez-Moreno J , 2004 . Impact of a Psychoeducational Family Intervention on Caregivers of Stabilized Bipolar Patients, Psychotherapy and Psychsomatics. 73, 312–319. DOI: 10.1159/000078848

Robinson, L., Clare, L., & Evans, K., 2005. Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. Aging & mental health. 9(4). 337-347.

Romans, F.E., McPherson, H.M., 1992. The social networks of bipolar affective disorder patients.Journal of Affective Disorders. 25, 221-8.

Sakellariou, D., Boniface, G., Brown, P., 2013. Using joint interviews in a narrative-based study on illness experiences. Qualitative Health Research. 23(11), 1563-70 Doi: 10.1177/1049732313508014

Sanchez-Moreno, J., Martinez-Aran, A., Gadelrab, H.F., Cabello, M., Torrent, C., Del Mar Bonnin, C., Ferrer, M., Leonardi, M., Ayuso-Mateor, J.L., Vieta, E., 2010. The role and impact of contextual factors on functioning in patients with bipolar disorder. Disability and Rehabilitation. 32(S1). 94-104. doi: 10.3109/09638288.2010.520810

Smith, J.A., 2008. Qualitative Psychology: A Practical Guide to Research Methods (2nd ed). London: Sage.

Smith, J.A., Osborn, M., 2008. Interpretative phenomenological analysis. In J.A. Smith (Ed.),Qualitative Psychology: A Practical Guide to Methods. 2nd Edition. London: Sage.

Smith J, A., Flowers, P, Larkin, M., 2009. Interpretative Phenomenological Analysis: Theory,Method. Research. London: Sage.

Tranvag, O., Kristofferson, K., 2008. Experience of being the spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time. Scandinavian Journal of Caring Science. 22, 5–18.

Treves, I., Fennig, S., Levkovitch, Y., Elizur, A., 1999. Couple dynamics of bipolar patients: “The Switch Process”. Family Therapy. 26(3). 191-6.

Twiss, J., Jones, S., Anderson, I., 2007. Validation of the Mood Disorder Questionnaire forscreening for bipolar disorder in a UK sample. Journal of Affective Disorders. 110 (1-2). 180-4. doi: http://dx.doi.org/10.1016/j.jad.2007.12.235.

Van der Voort, T.Y.G., Goossens, P.J.J., van der Bijl, J.J., 2009. Alone together: A groundedtheory study of experienced burden, coping and support needs of spouses of persons with a bipolar disorder. International Journal of Mental Health Nursing. 18, 434-43. doi: 10.1111/j.1447-0349.2009.00634.x.

Walid, M., S, Zaytseva, N., V., 2011. Which Neuropsychiatric Disorder is more associated with divorce? Journal of Divorce and Remarriage. 52 (4). 220-4. doi: 10.1080/10502556.2011.556976

Weinstock, L.M., Miller, I.W. 2010 Psychosocial predictors of mood symptoms 1 year afteracute phase treatment of bipolar 1 disorder. Comprehensive Psychiatry. 51, 407-503, doi:10.1016/j.comppsych.2010.02.001

Wilkinson, S., 2011. Analysing focus group data. In D. Silverman (Ed.). Qualitative research (3rd ed.). London, England: Sage.

Wynaden, D., G. & Orb, A. 2005 Impact of patient confidentiality on carers of people who have a mental disorder. International Journal of Mental Health Nursing, 14, 88-95.

Yardley, L., 2007. Demonstrating validity in qualitative psychology. In, Smith, Jonathan A. (eds.) Qualitative Psychology: A Practical Guide to Research Methods. SAGE Ltd. 235-251.

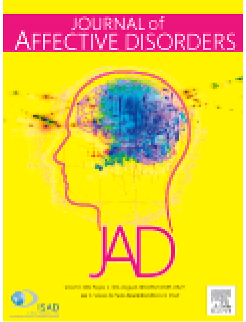
Table I. Summary of participant couple characteristics*

Couple	*Participants*	*Gender*	*Length of Relationship (years)*	*Age*	*Number of children*	*Occupation*	*In relationship prior to diagnosis?*
Couple 1	**Steve**	**Male**	34	**52**	4	**Retired Professional**	Yes
	Sue	Female		54		Housewife	
Couple 2	**Hannah**	**Female**	2.5	**30**	0	**Professional**	No
	Tom	Male		29		Semi-professional	
Couple 3	**James**	**Male**	18	**35**	2	**Unemployed**	Yes
	Laura	Female		38		Housewife	
Couple 4	**Lucy**	**Female**	7	**35**	0	**Professional**	No
	Katie	Female		32		Professional	

*Names highlighted in bold indicate partners with a diagnosis of bipolar disorder

Appendices

Appendix 2-A: Instructions for authors submitting to Journal of Affective Disorders



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Appendix 2.B. Participant Information Sheet

An Exploration of Experiences of Bipolar Disorder within Couples

Participant Information Sheet

> You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

This study is being undertaken as part of my Doctorate in Clinical Psychology thesis. I am interested in finding out how bipolar disorder is experienced within couples and the ways in which partners are able to support one another. It is hoped that this information will help to promote the wellbeing of other individuals who have been diagnosed with bipolar disorder and their partners and to identify ways in which couples can be best supported by services.

Why have we been invited to take part?

You have been invited to take part because you (or your partner) have a diagnosis of bipolar 1 disorder. We would like to speak to couples who have been together through at least one major mood episode and for at least six months. We hope to interview between 8 – 12 couples.

Do we have to take part?

You do not have to take part in the project if you do not want to. If you do decide to take part you will be given a copy of this information sheet to keep and you and your partner will be asked to sign a form giving your permission. You are both allowed to stop taking part at any time during the interview without giving a reason.

What will happen if we take part?

If you are interested in participating please phone the interviewer on the number given below. She will explain the study and ask you some questions to check your eligibility. The partner with bipolar disorder will then be asked to meet the interviewer and take part in a screening interview called the SCID. This will ensure that they meet criteria for the study and will take about 45 – 60 minutes. Those who do meet criteria will be invited to meet again with the interviewer, along with their partner, for about one and a half hours. You will be asked to talk about your experiences of bipolar disorder together and how it may have impacted upon your relationship. The interview will be recorded to help the researcher remember what has been said. You may change your mind about taking part and withdraw your consent up to 2 weeks following your interview, when all information collected about you will be destroyed. If one partner wishes to withdraw from the study, then both will need to.

Will taking part in the study be kept confidential?

All information that is collected about you will be kept strictly confidential. Direct quotes may be used in the report, although your names will not appear and any information which may identify you will be removed or changed. However, if you or your partner tell the researcher something that may suggest you or another person were at risk of harm, the information may need to be discussed further with you and passed onto my research supervisors. Anonymised transcripts of your interview and consent forms will be kept separately and securely at Lancaster University for 5 years following completion of the project.

What will happen to the results of the study?

The results will be written up as part of my Doctorate in Clinical Psychology thesis. If you would like, you can be sent a summary of the results once the study has been completed. It is also anticipated that the study will be written up for publication in a journal.

Are there any potential risks from taking part?

It is possible that you may find talking about your relationship and bipolar disorder upsetting. If you do become upset the interview can be stopped for a short period, until you feel able to continue, or ended immediately. You will also be provided with the contact numbers for some local support organizations.

Are there any potential advantages from taking part?

The main advantage of taking part in this research will be to help increase our knowledge about how people with a diagnosis of bipolar disorder and their partners can be supported. However, there will not necessarily be any direct advantages to you or your partner from taking part.

Who has reviewed the study?

This study has been reviewed by the School of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee, Lancaster University.

Further information and contact details

If you would like more information about the project or think that you would like to take part please contact Anna Clancy.

If you are unhappy about the project, or if there is a problem with the research, please contact Anna Clancy. If you remain unhappy or have a complaint which you feel you cannot come to Anna with then you should contact Dr Jane Simpson (Research Director and Senior Lecturer, Lancaster University) using the details below.

Anna Clancy
Trainee Clinical Psychologist,
Clinical Psychology Programme,
Division of Health Research,
School of Health and Medicine,
Whewell Building
Lancaster University,
Lancaster,

a.clancy@lancaster.ac.uk
[insert research phone number here]

Jane Simpson
Research Director,
Clinical Psychology Programme,
Division of Health Research,
School of Health and Medicine,
Whewell Building,
Lancaster University,
Lancaster, LA4 4YT
LA4 4YT
j.simpson2@lancaster.ac.uk
(0)1524 592858

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme you may also contact:
Professor Paul Bates: Tel (01524) 593718
Associate Dean for Research: Email p.bates@lancaster.ac.uk
Faculty of Health and Medicine
Division of Biomedical and Life Sciences
Lancaster University
Lancaster
LA1 4YD

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

Appendix 2.C. Consent Form

LANCASTER UNIVERSITY

Researcher's Name: Anna Clancy

Title of Study: An Exploration of Experiences of Bipolar Disorder within Couples

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw up to two weeks following my interview, without giving any reason. ☐

3. I understand that any information given by me may be used anonymously in future reports, articles or presentations by the research team. This may include the use of direct quotations. ☐

4. I understand that my name will not appear in any reports, articles or presentations. ☐

5. I am aware that the interviews will be audio recorded and that these recording will be kept for a maximum of 2 months before being transcribed. ☐

6. I am aware that consent forms and anonymised interview transcripts will be stored securely for 5 years following completion of the study ☐

7. I agree to take part in the above study. ☐

Name of Participant Date Signature

____________________ ____________________

Researcher Date Signature

Appendix 2-D. Advert

An Exploration of Experiences of Bipolar Disorder within Couples

The above study is looking to recruit couples in which one partner has a diagnosis of bipolar 1 disorder to talk about how they experience bipolar disorder together as a couple.

To be eligible to take part couples must live in North West England and have been together through at least one major mood episode and for at least 6 months.

We would like to interview couples together in order to obtain a shared view of the ways in which partners are able to support one another as well as the areas which may be more challenging.

We aim to build on previous research investigating the potential sources of satisfaction or stress within the relationship. It is hoped that the results may help clinicians to support both clients and their partners more successfully.

If you would like to find out more about the study and what participation would involve please contact Anna Clancy on [insert research phone number here] or a.clancy@lancaster.ac.uk

Thank you.

Appendix 2-E. Participant Letter

Anna Clancy
Clinical Psychology,
Division of Health Research, Lancaster University, Lancaster,
LA4 4YT

Dear [insert name],

Thank you for volunteering with [redacted]. We are currently recruiting for a research project that you may be interested in participating in. This research is entitled „An Exploration of Experiences of Bipolar Disorder within Couples‟ and I have enclosed a participant information sheet for your consideration.

Research suggests that people with a diagnosis of bipolar disorder benefit from good social support; an important source of which can come from their partner. This study in interested in interviewing couples together in order to obtain a shared view of the ways in which partners are able to support one another as well as the areas which may be more challenging. It aims to build on previous research investigating the potential sources of satisfaction or stress within the relationship. It is hoped that the results may help clinicians to support both clients and their partners more successfully.

This research project is being carried out by Anna Clancy, a Trainee Clinical Psychologist at Lancaster University, under the supervision of [redacted]).

If you are interested in participating in this study, or would like to find out more information, please contact Anna on [insert research telephone number here] or via email at a.clancy@lancaster.ac.uk. Participation in this project is completely voluntary. It is up to you whether you choose to take part or not. We will send out a reminder letter in two weeks time, but will make no further contact with you regarding this project if you choose not to participate.

Thank you for taking the time to read this letter. Yours

Sincerely,

Anna Clancy
(Trainee Clinical Psychologist)

Appendix 2-F. MDQ questionnaire

1. Has there ever been a period of time when you were not your usual self and...

...you felt so good or so hyper that other people thought you were not your normal self or you were so hyper that you got into trouble? Yes No

...you were so irritable that you shouted at people or started fights or arguments? Yes No

...you felt much more self-confident than usual? Yes No

...you got much less sleep than usual and found you didn't really miss it? Yes No

...you were much more talkative or spoke much faster than usual? Yes No

...thoughts raced through your head or you couldn't slow your mind down? Yes No

...you were so easily distracted by things around you that you had trouble concentrating or staying on track?

Yes No

...you had much more energy than usual? Yes No

...you were much more active or did many more things than usual? Yes No

...you were much more social or outgoing than usual, for example, you telephoned friends in the middle of the night? Yes No

...you were much more interested in sex than usual? Yes No

...you did things that were unusual for you or that other people might have thought were excessive, foolish, or risky? Yes No

...spending money got you or your family into trouble? Yes No

2. If you answer YES to more than one of the above, have several of these ever happened during the same period of time? Yes No

3. How much of a problem did any of these cause you - like being unable to work; having family, money or legal troubles' getting into arguments or fights?

No Problem - Minor Problem - Moderate Problem - Serious Problem

How to Interpret the MDQ Score

- Question 1: 7 or more yes responses
- Question 2: Yes- i.e. these symptoms will have occurred together at the same time.
- Question 3: Yes- i.e. they must have caused some problems in aspects of your life.

A score of 7 or more with yes responses to Q2 + Q3 certainly suggests bipolar disorder is a possibility and should be considered and discussed with a professional.

A score of less than 7 and negative responses to Q2 and/or Q3 makes bipolar disorder unlikely but cannot exclude it entirely.

•Hirschfeld, R.M.A. et al. Development and Validation of a Screening Instrument for Bipolar Spectrum Disorder: The

Mood Disorder Questionnaire Am J Psychiatry 2000 157: 1873-1875

Appendix 2-G. Interview Schedule

Interview Schedule (To be used as a guide, although the interview will be led by participants and so not all of these questions may be asked)

Thank you for agreeing to participate in this research project. As you are aware, I would like to ask you some questions about your experiences of bipolar disorder and the effects upon your relationship. Previous research suggests that people with a diagnosis of bipolar disorder benefit from good social support; an important source of which can come from their partner. This study in interested in interviewing couples together in order to obtain a shared view of the ways in which partners are able to support one another as well as the areas which may be more challenging. It aims to build on previous research investigating the potential sources of satisfaction or stress within the relationship. It is hoped that the results may help clinicians to support both clients and their partners more successfully.

You do not have to answer any questions that you do not want to. If you would like to stop the interview at any point, or take a break, that is fine. Please let me know.

I am interested in finding out about your shared views, as a couple. Please only talk about things that you are happy to say in front of each other. I would like to hear from both of you and it is important that I try and keep to the topic of the research question. Therefore, it may be necessary for me to interrupt or change the topic of conversation at times. I hope this is OK?

We will start with some questions about each of you, your diagnosis of bipolar disorder and basic details about your relationship. We will then move on to talk about your broader experiences.

Do you have any questions? Are you ready to begin? Is it okay for me to start the recording?

Initial Questions:

How old are you?

When did you first

meet? How did you

meet?

Are you married? If yes, how long for?

Do you live together? If yes, how long for?

Do you have any children? If yes, how many and how old are they?

Have you ever separated from each other? If yes, please may you tell me a little bit about

this? When were you first given a diagnosis of bipolar disorder? Were you a couple at this

time?

Can you briefly tell me a bit about your bipolar disorder? Have you ever been hospitalised? How much does it affect you on a day to day basis?

What support (if any) do you receive from services?

Intermediate Questions:

If a couple before diagnosis of bipolar given:

How would you describe yourselves as a couple before receiving the diagnosis of bipolar disorder?

Can you tell me about what it was like around the time when you received the diagnosis?

How, if at all, has your relationship changed since then?

If not a couple before diagnosis of bipolar given: When

did you share the diagnosis of bipolar disorder? **All**

couples:

Can you tell me about how you met?

How would you describe yourselves as a couple?

What have been the most important events in your relationship?

Can you tell me about the happiest moments that you have shared together?

What are the biggest challenges that you face as a couple?

What helps you at these times?

What impact do these challenges have on you as a couple?

How are you able to support one another through these challenging times?

Are there any times when you find it particularly difficult to support one another? Why?

How does bipolar disorder affect your relationship (e..g mood episodes, stigma, financial, finding work, burden....)?

What are the sources of satisfaction/happiness from being in this relationship?

How much support do you as a couple, receive from others?

Is there any additional support that you think would be useful?

What advice would you give to other couples who are in your situation?

Ending Questions

Is there anything else that I have not asked about that would help me to understand more about your relationship and experiences of bipolar disorder?

Is there anything that I have asked you about today that you had not thought about before? How have you found our discussion today? Do you have any questions you would like to ask ?

Appendix 2-H. Debriefing Sheet

An Exploration of Experiences of Bipolar Disorder within Couples

Debriefing Sheet

Thank you for taking time to participate in the above study.

The aim of this study was to explore in detail how bipolar disorder is experienced within couples and the ways in which partners are able to support one another.

We hope that participating in this study was not upsetting for you. However, it is possible that you may have found some of the topics that we talked about today difficult. If so, the following organisations may be able to offer you support:

MDF The Bipolar Organisation - 020 7931 6480 or www.mdf.org.uk

Mind - 08457 660163 or www.mind.org.uk

Rethink - 0845 456 0455 or www.rethink.org

Making Space - 01925 571680 or www.makingspace.org

Carers UK - 0207 490 8818 or www.carersuk.org

I would also like to offer you a support telephone call in 2 days time, to see how you are and answer any questions that you may have following the research. Please let me know if you do not want to receive this.

If you are interested in taking part in further research about bipolar disorder, please visit The Spectrum Centre website at www.spectrumconnect.co.uk

Finally, if you have any questions regarding this research please telephone Anna Clancy on [insert research phone number here] or email me at a.clancy@lancaster.ac.uk

Appendix 2-I. Excerpt of interview transcript with notations

Notations	Int: Okay and can you briefly tell me a little bit about it, as much as you want really, about when you were diagnosed	Emergent Themes
Laughing – unsure, coping mechanism, playing it down – relieves tension Repeated use of word abnormal. He is different, there is something wrong with him – how does this feel? How does he cope with this? Diagnosis is meaningful – gives a reason and explanation	**Steve:** Yes, um, I think as I said at the beginning it was always depression with psychotic episodes erm and then after periods of depression I would feel an episode of elation or euphoria. That's what I called it, I called it post depression euphoria. When I felt ooh great the depression has gone, I feel wonderful (laugh) You know? And I think it was a psychiatrist who after, you I used to describe this to him, he said well I actually I think that's abnormal as well (laugh) you know given..so he said I think you're getting episodes of abnormal low mood, but I think this post depression euphoria as you have labelled it is actually abnormally elevated. So he said really I think that means you are bipolar and I think it is type 1, I think type 1 means that you do get episodes of mania or hyper mania where as I think type 2 I don't know (laugh)	Humour as coping strategy Diagnosis as validation/externalisation
	Int: Yes, it is kind of lower hypo	
Use of word obviously – nothing out of the ordinary, matter of fact about symptoms. This is just what bipolar is, he can't help it	**Steve:** Yes you don't actually have any true sort of totally manic episodes. And I don't have many, you know, I don't have many, sort of, episodes of ultra mania I don't think. Well obviously when I am psychotic I think I am excessively important and the whole universe revolves around me and I am very important, so that's mania and I do get that, but only when I'm psychotic	Diagnosis – externalising
	Int: Yes	
Self-blaming – my fault. Thought I was the problem, I was doing something wrong. Diagnosis gave a reason	**Steve**: Erm, so yeah. How do I feel about it? I mean, I think at the beginning I was always, I think, I just thought I wasn't very good at handling stress	Diagnosis – gave a reason. Not to blame anymore

Appendix 2-J. Example of theme development from one transcript – Lucy and Katie

Notations on Transcript	**Narrative Theme Summary**
Emergent Theme 1: Shame of diagnosis v needing it to get support	
• L kept diagnosis of BD hidden from K even when they got married • Admitted to depression but not BD • Stigma • K just assumed depression – some sort of breakdown – no real understanding of MI • Dropped in diagnosis very casually in front of friends – why? Ease pressure, concern about reaction • L's experience of stigma and losing friends following diagnosis – decided not to tell people. Protect self • Denial – don't tell people and it's not really there • Dragged self through lows without support. Highs easy to get through (drinking – looked normal) • Harder to cope with depression alone – opened up to K about his, but not full extent • Mania more stigma? Easier to cope with? • K accepted what she was told and thought she probably just didn't understand depression – it was new to her and a confusing world. Didn't question it • Depression is so common it is more accepted – mania has more stigma. Risks of revealing it are more • BD diagnosis is isolating, people don't understand. Depression can lead to understanding and identification. More support • Trigger to disclosure of BD = suicide of friend and reaction of others. They wished they had known so they could help • Broke down stigma barrier – people weren't appalled, unsympathetic, cruel - they wished they could help • Suicide highlighted vulnerability	This theme describes the complicated views on diagnosis held by the participants. This couple were unique to the others in the study as L already had a diagnosis of BD when they met, however, she kept it secret from K. L's decision to withhold her diagnosis was related to the stigma of mental illness and her concern about K's reaction. Her previous experience had demonstrated to her that people leave when they find out. It was also associated with her shame and attempt at denial – if it wasn't spoken it wasn't real. However, K was aware there was something not okay with L. Despite L's attempts to keep it secret, K knew she was suffering from mental illness, assuming it to be depression and something she didn't understand. Without open communication and information regarding a diagnosis of BD she was unable to research and find out how best to support L. In her eyes it would have been better for her to have known a diagnosis straight from the start as she would then have understood more – the same symptoms and behaviours would have been evident, but she would have been more informed to help support L with them. Both participants described how it was the tragic suicide of a mutual friend who had a diagnosis of BD which led L to reveal her diagnosis, not only to K, but to their whole circle of friends. This suicide brought the topic of BD into the open and allowed L to see how empathic and understanding her partner and friends were. They spoke of their regret they didn't know and weren't able to help more and this provided L with the reassurance that she could reveal her own diagnosis. She felt safe and secure that she would continue to be accepted. This suicide also highlighted her vulnerability and her need for support. K found things easier once she knew of the diagnosis. She was not longer 'blind' and was able to research properly and access the correct support for L. The diagnosis of BD which had brought so much shame and fear for L, brought

• Following friend's death the extent of the strategies he had taken to hide his BD was revealed. • Had a suspicion something was wrong, but didn't know what • Before she knew diagnosis was trying to support L 'blind' – not able to research as didn't have anything to research. Just thought she was 'going mental' • L's fear of not being believed • Knowing diagnosis helped K to support L – knew more about what she was dealing with • Able to research • Diagnosis would lead to right treatment, therefore important • Spent years trying to manage without knowledge of diagnosis – didn't know what was happening or what to do • No reason for behaviours. • More you know about it more prepared you are as a carer • Increase knowledge and can increase support • Can be more understanding of things if know BD related. • Easier to deal with things when you understand them – less hurt	some relief and clarity for K – it meant she was better able to understand some of the behaviours displayed by L and therefore feel less hurt by them
Emergent theme 2: Impact on daily lives	
• Rigid with medication – same time every day • Impacts upon social lives – anxious if out. Don't want to miss medication • When unwell don't want to go out and see people – impacts on both of their social lives • Groggy mornings – impacts upon both of them – need to plan days around best times for L • Effects everything – needs to come round before ready to socialise • K has to fit in with this • Concern from K that L wouldn't be able to work • Knock on effects for her – would she have to leave job to care for her? • Had to speak to manager to get some leeway to cope with supporting L • Pressures of working on L – need right job. Not too stressful with unsocial	This theme highlights the ways in which BD affected the daily lives of both partners. They spoke about the allowances that needed to be made by K to support L, particularly with her anxieties. Routines are very important. They spoke about L's lack of interest in socialising, particularly when feeling low in mood and how this impacts on both their social lives as K does not want to always go out alone. L encourages H to go out without her, but K wants to share things with L. It's not just about going out, it is also about sharing experiences with her partner. L's diagnosis of BD also has large financial implications for them both. She has learned that a stressful job is bad for her mental health and so works part-time in a job below her skills level. K is very supportive of this decision, encouraging L at one point to resign from a highly paid but stressful job. They are both in agreement that L's mental health is the priority, even though it

hours. • The right job can be stabilising – repetitive, not too many hours: able to do it even when unwell. • Tough when L doesn't want to socialise – impacts on K who wants to go out with her, not on her own • Routine – required to help contain L's anxiety. K not always aware what she has to do • Need to be sensitive to L's routine and sensitive of things that cause her anxiety, even if don't really understand them • Financial impact – L only able to work part –time • Need to prioritise mental health and work less hours, even though less money	causes financial difficulties for them.
Emergent Theme 3: Changing /adapting over time	
• K has tried different strategies to support L – was super loving but now steer clear • No right way to do things, just got to try best • Learning things all the time – phone calls. Learned not to communicate via them • Tried out different strategies – just trying to do the best she could • Adapted way of communicating – text and L's choice if phone. Eased pressure and reduced arguments • Changes helped L feel she had more control and K feel less rejected • Changes not easy – middle ground • L has found ways to adapt to in order to make situations better for her anxiety – i.e. lying about time. Means they aren't late • Good planning – keeping to routine • K more aware of when L is getting irritated and ways to help manage that. • Normalising – like any relationship – adapt to make things better • Through discussion with other carers able to think about best way to support L • Some days and weeks are better than others but things generally moving in right direction	This theme describes the ways in which both K and L have changed and adapted over the length of their relationships as they have learned more about each other and more about BD. It centres around their belief that there is no right way to do things, that they can only try their best and learn from previous experiences. They spoke about trying different strategies and both gave specific examples of things they had learned to do to help cope. L has started to lie to K about times when they need to be at places to ease her anxiety about being late and ensure they set off earlier than necessary. K, meanwhile spoke about how she had to alter her methods of communication with L and text more as opposed to speak on the telephone – this is something she finds difficult and she misses the telephone conversations but has found it minimises arguments. With time, K is also becoming better at detecting when L may be getting irritated and is therefore better able to manage it. Both normalised the way they adapted to meet the needs of the other, as being something done in all relationships – compromise is important for harmony. However, in the case of their relationships, the adaptations appeared to be mainly to improve the situation for one partner – L who has the diagnosis of BD – rather than for both of them equally. This was not

• Difficult trying to navigate everything – just do best you can and learn • With support of third sector learned what can do individually and what can do together to make things easier – work as a team • Reflective – think back about things to identify triggers etc. Learn from experiences.	viewed as something K felt discontent about, however, but something she accepts as a necessity to make their relationship better.
Emergent Theme 4: Navigating the mental health system together – joint fight	
• Not clear on set up of mental health system – just have to go along with it • Seeing psychologist now which is useful • Seen psychologist in past which wasn't helpful – group not useful or supportive – being used for research • Group organised for midweek – ridiculous. Comes with assumption people attending don't work. Not practical • Both accessed support from third sector • Need for both of them to have professional support • Notes in NHS lost – bad experience • Had to work together to get L the right support • K didn't know system or about MI but had to help access support because L not up to it on her own • K felt anxiety about this role – important, out of her depth • K just kept on trying – didn't know what she was doing but gave it a go. • Priority was to get L support – didn't know how to do this but just kept on trying • Agreement about what services were good and what were bad • One psychiatrist bad – didn't listen to either of them. • Walked out of session – no empathy and not listening • Telling professionals your story is emotionally hard – worse when it's a battle • Battle to get seen and then not listened to when there • Power imbalance – what can you do when not heard? • Attended medical appointments together – this was their fight. • L not well enough to go alone – K had to help her fight (what do people with no carer/family do?)	The fourth theme describes the way in which L and K have had to fight together to get L the appropriate support from the mental health system. This was very much described as a joint journey with a shared aim – it was not K helping L with her battle, it was them working together in a shared battle. They described a mixture of good and bad experiences with professionals, but it was the bad ones which generated more animated discussion. It was evident that L required the help of K, she would not have been able to sustain the energy to get the required help on her own. Despite this, however, it was rare for K to be invited in to appointments and they spoke of their frustration at this and the fact that K's views were important in gaining appropriate support or L. Their experiences with the Mental health system highlighted a power imbalance present within services. They described not feeling listened to and how frustrating this was, particularly for K, whilst for L it increased her anxieties about reaching out for support and telling her story. Accessing support was made more difficult by their lack of knowledge about the system and that trial and error was required to get support. They were greatly helped by third sector services and it was about one particular charity that they spoke with the most praise.

• K not invited into the clinic room- awful appointment. L not heard • Bad experience with one psychiatrist made things even harder – L's anxiety increased. Bigger battle for H to get her to the doctor. • Gp really supportive and listened • Joint appointment from then on • K needs to be an advocate for L - help her to be heard • Getting diagnosis is priority – then right support can follow • Professionals should invite partner in for support! • K has more insight and helpful for her to know the strategies being discussed to help L • K helped L to access support from third sector – set up initial meeting and went to see if they could help. Scoped it out first to avoid bad experience for L	
Emergent Theme 5: Responsibility/unequal roles	
• K took on responsibility for sorting out L's work situation • No support for her at work, working more about more hours – detrimental to her mental health • No safety net • Worried about own job, but helping L manage hers • Providing emotional support for L's mum – not handling things well • L not interesting in engaging helping out the situation – K had to do it all or it wouldn't be done • L's strategy over the years was just keep working – K saw the dangers of this and tried to support her in other ways. • L wanted to use avoidance, K tried to get her to handle it straight on • L driven by anxiety – felt something bad was going to happen and desperately trying to stop it • No idea why – not informed of diagnosis. Just trying to manage spiralling situation that L was hiding from. • K initiated L handing in notice from one job – too stressful and L was avoiding it • L didn't fight it, but aware it was led by K	This theme describes the shift of responsibility evident in the relationship during L's relapses. At her times of low mood they spoke of her lack of interest in engaging in life and inability to deal with her responsibilities. She would continue with her job, but everything else would pass to K. This was different from their usual roles within the relationship and a signal that things were not quite right. This holds mixed feelings for K – she feels sad that L is obviously so unwell, but comforted by the fact she is trusting her to manage things. It makes her feel closer in the relationship. L, meanwhile, is unaware of the significance of this change in roles to K. She is just trying to get by and to do this shuts herself off from the world. K also spoke of her dilemma when L is unwell about how much she should be doing for her – this relates to her admission that she knows little about how to care for someone with BD and is just trying her best. She is not sure whether by doing everything for L she is in fact prolonging her relapses, but is simply guided by instinct. L is not able to advise on this. Her anxiety at these times means she shuts herself off from the world and K can see and wishes to do all she can to help with this – therefore she sets herself up as a buffer from the world, intercepting all potential stressors before they reach L. This takes

• Relapses change roles – generally L is the leader, but when un well she lets K take over • Indicator to K that L is not well when she lets her take control. • L letting K take control is sad and a relief – makes her worried as not like her, but relieved she trusts her and lets her care for her. • Indicator of trust within relationship • L not aware of these changes within relationship – these things that are significant to K do not even register to L as she is too unwell • Feels like she is observing rather than being part of reality • L carried on going to work – this helped her. Remained a constant, but everything else passed to K – no living going on • Tried to get her to go out for 10 mins a walk etc, but caused too much anxiety – trying to help her feel better but not knowing how • L didn't want to engage with outside world – K's responsibility to keep that going • Appreciation that K does more when she is ill, so tries to pay her back when well by doing more household chores • Tries to get back control when well – take on more responsibility around the home • K's concern she does too much for L – will it delay her recovery? • Sheltering L from stress – acting as a buffer from the world. Taking on all the responsibility. • Concern about making things worse – enabling • How much to interfere in L's affairs? Dilemma	its toll on her and at times she has been worried about her ability to sustain her own employment. Although it is not a conscious decision of L to let K take over during times of relapse, she is aware of it when well and tries to make amends. Even when not feeling well enough to connect emotionally with K, she demonstrates her love in other ways – by doing laundry and cooking K meals. K is aware of the message behind these tasks and appreciates it, although it is not able to replace the intimacy she misses when L is unwell.
Emergent Theme 6: Relationship	
• L impressed that K able to keep up with job even when feeling unwell • Rejected when L didn't want to talk etc • L feeling K was being rude – not understanding • Arguments • Dilemma – how much to take and when to put foot down • Is it illness? What to do about it? • During periods of low mood E didn't want affection and didn't miss it – L felt	This theme discusses the specific challenges BD places on the relationship and the things K and L do to help minimise them. They spoke about the lack of intimacy and how difficult K finds this and alternative ways that L tries to demonstrate her love. Despite this it is tough for K and she feels rejected. They acknowledged that at times it is difficult to see the viewpoint of the other. K also missed the companionship she craves and doing more activities with

rejected. Tough - Hard to see other's viewpoint - L aware when being difficult and tries ways to compensate – cooking food. - Finds alternative ways to show her love when communication/intimacy is not an option for her - Not what K needs completely, but she recognises and appreciates L's effort. - Thinking of really good times helps get through the bad - K misses companionship – doesn't want to do things alone - Main difficulty – K so social and L likes to stay home alone - Make up for lack of socialising/intimacy in other way – cooking and laundry. - Appreciation that K does more when she is ill, so tries to pay her back when well by doing more household chores - Give to the relationship in practical ways rather than emotional - Need to be clear on what is bipolar and what is L – helps with boundaries of what is okay in relationship. Got to be flexible. Can be more understanding of things if know they are BD related	her partner. L is aware she feels this, but does not miss these things herself. When feeling low she is happy without the intimacy and without socialising, although she can recognise it is difficult for K. It helps K to cope with this difficult aspects by thinking of the good times in their relationship and the fact that the bad times are time limited. She also finds it useful to consider what is related to the BD and what is related to L herself – she can make more allowances for symptoms of BD
Emergent Theme 7: Communication	
- Vastly reduced when L was ill - Text messages - L didn't want to communicate with anyone - K needed information from her to sort things out, bills etc - Tough for K, but what L needed, she didn't want to communicate with her - Appreciation from L now that it must have been tough for K - No hugs, no communication when in to work, straight up to bedroom – difficult for K - L didn't want to engage in outside world, but K had to keep that going - K wanted to share her life with L – phone her from work etc. L hated phone calls. - Feeling rejected - Use of text – made communication better again. - Difficult for K, she wanted to phone but knew she had to make allowances for L and texting was better than arguing	This theme centres around communication – something that has been a challenge within their relationship from the very beginning with L hiding her diagnosis of BD from K. It is also something that was heavily affected during a relapse. At times of feeling low in mood L did not want to engage socially with anyone, including K. This was difficult for L to cope with and although K understood this, she did little to change it. It was up to K to change her expectations and feel happy with what L could offer her.

Emergent Theme 8: Peer Support	
• L benefited from attending group with others with diagnosis of BD • Huge positive to share experiences with those who know and understand • Helped their relationship – K more able to understand what L is going through by talking to others • Good for K to meet other carers – less clinical than what you read in books. Useful to share experiences • Helped K to differentiate between what was L and what was BD • Helped K to think about her role and how she could best support L- was she doing too much for her? • Able to discuss role as carer and how to support autonomy with others who have been there • Needed this support – helped them learn better how they can help each other. • K would like to have met more partner carers – different to parent. Different relationship • Other friends didn’t understand as L able to present as fine when out for a few hours but a nightmare when home with K. K would like someone who understands to talk to about that • L found it helpful to chat with peers – realise it isn’t you being mental. Different to how she was originally when withheld diagnosis. Find out that coping strategies are normal and not crazy,.	The final theme discusses the benefits of peer support felt by both K and L. They accessed this through support groups organised by a mental health charity and spoke about the benefits of sharing experiences and learning from others. It allowed K to learn more about BD and how to support L, as well as identify what things were symptoms of the illness and what things were L’s personality. She found this beneficial when deciding what she could cope with and what things she felt needed to change. It also allowed her to discuss the practicalities of her role as ‘carer’ and share ideas about how best to be supportive. Similarly, L found it helpful to talk to peers with a diagnosis of BD and discover shared experiences. This helped her to realise she wasn’t mental and feel less fearful of the stigma of her diagnosis. The only aspect of this support that was felt to be lacking, was that K would have liked to meet with more partner carers. The other carers she met with were parents and she felt this relationship was categorically different and therefore she was not able to completely identify with them. L was in agreement with this, stating it would be nice to know another couple where one has a diagnosis of BD.

Appendix 2-K. Development of final super-ordinate themes

Participants	Emerging Theme from individual transcripts			
	Negotiating Roles	**Challenges of Communication**	**Externalising The Diagnosis**	**Keeping Positive**
Sue and Steve	The emotional impact Changing Roles Flexibility and Adaptation	The emotional impact	Making Sense of the Diagnosis Joint fight to access support	Keeping positive and feeling thankful Maintaining their relationship
Katie and Lucy	Impact on daily lives Shifts in responsibility – managing relapse	Shame of diagnosis V needing it to get support Changing/adapting over time	Shame of diagnosis V needing it to get support Navigating the MH System together Maintaining their relationship Peer Support	Maintaining their relationship
Hannah and Tom	Responsibility/Decision Making – power imbalance within the relationship	Unconditional v Conditional Love – the difference between being a partner and a parent carer	Fight together to get support Creating a united front against BD	Complementary Personalities
James and Laura	Wider impact of BD		Alcohol use/violence Impact of diagnosis Externalising of symptoms/blame	Maintaining a relationship through adversity Adapting over time

Appendix 2-L. Extract from Reflective Diary

Reflections following interview with Steve and Sue (First Interview)

Couple have been together a long time – over 30 years. Very comfortable and jovial together. No awkwardness and seem eager and happy to talk about experiences. Spoke with great warmth – caring interactions. Wanted to make each other feel better. Reassured each other. Sue particularly provided reassurance and support to Steve when he spoke negatively about himself, complimenting him. Is this mirror of what happens in everyday life – Sue always the carer, but Steve wanting to support her too?

Diagnosis very significant event for them – prior to this Steve had tried to explain it himself and thought it was due to imperfections in himself – i.e. he couldn't handle stress (Note the way he says he couldn't handle stress, not the fact he was working in stressful job) – made it about his own weakness. Hard on himself, therefore diagnosis was a relief. It told everyone he wasn't weak, he had something biologically wrong with him and this is better. Very animated and passionate discussion about this – obviously a significant event for both. Steve comes from a medical background so understandable he would feel comfortable and assured by a medical diagnosis?

Incongruence between content of interview and way it was communicated. Spoke about difficult events, such as attempted suicide, using words like traumatic and horrific, yet laughed as they spoke. Why is this? Coping strategy? Embarrassment? Trying to minimise events?

Very open discussion about the challenges of BD – particularly the strain of being a partner. Both aware of stress on Sue. Steve states her mental ill-health is due to him and she doesn't contradict. This is one area she doesn't try to make him feel better. It is a fact between them, no need to try and sugar coat it. Feelings of guilt in Steve for this, but at same time sense that he knows there is nothing he can do about it – linked back to diagnosis. It isn’t his fault.

Both Steve and Sue spoke at length, no concerns about getting equal contributions from both. Frequently spoke about things between themselves with no prompts required from me – benefit of joint interviews. Good to see their interactions. Often seemed to finish each other’s sentences or stories – sense they were ‘on the same page’. At times this did mean the conversation moved away from questions on interview but does this matter? Can lead to other areas of interest that are relevant. Research question is to learn about their experiences so okay to let them talk – may lead to novel findings.

Section Three: Critical Analysis

An Exploration of Experiences of Bipolar Disorder within Couples

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Word Count (excluding tables, figures and reference list): 3,999

Introduction

This appraisal will critically explore a number of methodological issues present during the completion of the research project documented in section two. The project interviewed couples in which one partner had a diagnosis of bipolar disorder (BD) using joint interview methodology. The findings identified that flexibility was required in relation to the roles of each partner within these relationships. These changes in roles were instigated by how well the person with BD was feeling and driven by the desire of their partner to help them feel better. Furthermore, vulnerabilities within the relationships were identified, associated with difficulties in communication. The challenges of being a partner as well as a ‘carer’ were highlighted along with difficulties in accessing support. A common coping strategy utilised by couples was humour, which helped them cope with adversity. Participants also found it helpful to externalise the diagnosis of BD and viewed themselves as a united force against it.

This appraisal will discuss the research design and decision to conduct joint interviews. The challenges and benefits of this methodology will be considered. Furthermore, the decision to use diagnosis within the inclusion criteria and the limitations and strengths of such a method will be discussed. How these methodological decisions were made in reference to the use of Interpretative Phenomenological Analysis (IPA) will be considered.

Diagnosis as an Inclusion Criterion

Deciding upon inclusion and exclusion criteria for a research study can be complex and there are reasons for and against using diagnosis. This research paper utilised inclusion criteria that incorporated one partner having a diagnosis of Bipolar 1 disorder (BD1). This decision was made for a number of reasons, despite the fact that using diagnosis does not generally fit with a psychological model of working. In fact, my epistemological position within clinical work is that a client's difficulties should be understood in terms of how they describe and experience them using formulation as opposed to according to a diagnostic label. Guidelines written by the British Psychological Society (BPS) state that when using diagnoses clinical psychologists, "will be cognisant of the limitations in reliability and validity of diagnostic systems...They will recognise the benefits that may accrue from a diagnosis for some people... but will also be mindful of the potential harm that can result from the use of diagnostic labels, particularly the risk of "pathologising" the individual" (British Psychological Society, 2012).

Following consideration of the issues surrounding the use of diagnosis, it was felt using diagnostic criteria within this research was advantageous for a number of reasons. This was primarily because IPA was used to analyse the interviews. Guidelines for IPA specify the use of a homogeneous sample and purposive sampling (Smith & Osburn, 2008) so that the findings of a particular study can provide greater detail about the particular community being researched. As a result, common themes identified within the research can be more reliably attributed to commonalities within the group as opposed to coincidence. It, therefore, seemed appropriate to enhance the homogeneity of the sample in this project by specifying they should have a diagnosis of BD1. This meant all couples were talking about their experiences of living with similar symptoms to one another, although some variability within the population of people with this diagnosis would exist. It was also specified that couples should have lived together through a certain number of mood episodes, again to maximise homogeneity.

It was also thought the use of diagnoses within the inclusion criteria would increase access to and likelihood of publication in medical journals thereby increasing the potential audience. As the medical model remains highly influential in the planning and commissioning of mental health services it is important that psychological research is viewed as credible within this so that the findings are acknowledged.

Whilst conducting this research it was important to also remain mindful of the limitations of diagnoses and the ongoing concerns regarding their validity and reliability which restrict their clinical utility (Division of Clinical Psychology, 2013). These limitations can be viewed as making the diagnostic criteria for BD “excessively restrictive” (Smith et al, 2008, p. 397) and mean that people who are experiencing significant symptoms may not be formally diagnosed with BD. Berk et al (2006) discuss these limitations, concluding that there is considerable controversy over the boundaries of the diagnostic definition of BD which requires further research.

Assessing for Diagnosis

Once it was decided that diagnosis would be used within inclusion criteria, attention turned to how this would be assessed. I was mindful of the possibility a participant may be told they met criteria for a different diagnosis to what they thought, or even told they did not meet criteria for BD1, when they had previously been told they did. How this situation would be managed was carefully considered during planning and it was decided that participants would be clearly informed this assessment was related to their eligibility to take part in the research project only and not their wider mental health care. It would be made clear that the assessment, and I as a researcher, were unable to make a clinical diagnosis. If they had concerns regarding this, they were advised to speak to their clinical team. This issue never occurred during the research study.

This study used The Structured Clinical Interview of DSM-IV-TR Axis 1 Disorders (SCID-I/P; First et al, 2002) to determine that participants met the criteria for BD1. The main concern regarding this assessment was the time is takes to administer. It would have taken less time to ask participants to self-confirm or to use a shorter screening questionnaire, such as the Mood Disorders Questionnaire (MDQ; Hirschfield et al, 2000). However, solely relying on self- confirmation of BD1 has limitations. It relies on the accuracy of the diagnosis given by the individual's clinician and the individual's interpretation and understanding of their diagnosis. When recruiting for the research study described here, a number of interested individuals were unclear as to whether they had a diagnosis of BD1 or BD2, confirming the limitations of depending on self-confirmation. Furthermore, although the ease of administration makes the MDQ an appropriate tool for helping clinicians in primary care identify individuals who are more likely to have a diagnosis of BD and therefore refer them for further assessment (Hirschfield, 2003), it has lower specificity and sensitivity than longer assessment tools, which makes it less useful for the purpose of identifying participants who meet strict inclusion criteria for a research study.

As the SCID-I/P takes around one hour to administer, there was concern that if it was completed directly before the semi-structured interview participants may become disinterested and not engage as fully, providing less reflective and detailed responses. This was explained to participants and they were offered the opportunity to either meet on one occasion to complete both the SCID-I/P and research interview in one session with a break in the middle, or to have two separate appointments within a few days of each other in order to complete each interview separately. All participants chose to complete the full assessment in one session. The richness of data and detailed answers given in the semi-structured interviews held following the SCID-I/P suggest their engagement in the process was not adversely affected by completing both in succession.

Excluding participants experiencing an acute mood episode

Utilising the SCID-I/P also allowed participants who were currently experiencing an acute mood episode to be identified. It had been decided that participants could only be interviewed when their mood was stable as during mania people can experience difficulties concentrating and an abundance of thoughts (American Psychiatric Association, 2000), which may make it difficult for them to participate in an interview. Alternatively, when experiencing depressed mood and negative cognitions this may have negatively biased the data obtained. It was thought that interviewing participants who were currently in stable mental health would allow for a collection of a broader range of experiences. Individuals with a diagnosis of BD often do experience periods of stable mood in-between episodes of mania and depression (American Psychiatric Association, 2000).

The exclusion of individuals experiencing a current mood episode meant that several participants who expressed interest in the study were not eligible to take part. Potential participants who were identified as experiencing a current acute mood episode were advised of the length of the recruitment stage and that they could contact the researcher in the future to review eligibility again if they still wanted to take part when their mood was more stable. As a number were disappointed they were unable to take part they were also given information of further research studies they may be interested in taking part in.

Sample Characteristics

The use of joint interviews meant that participants had to be prepared to talk about their experiences in front of their partners, which affected recruitment and impacted upon the generalisability of the results.

It is difficult to ascertain what proportion of relationships involving a person with a diagnosis of BD result in separation. This was explored by Walid and Zaytseva (2011) who used the results of the 2004 National Nursing Home Survey to look at the marital status of residents. They found residents who had a diagnosis of BD were more likely to be divorced than those who did not (18%). Furthermore, 85% of residents with a diagnosis of BD were allocated “lonesome status” indicating they were divorced, separated, never married or widowed. The authors concluded that individuals with a diagnosis of BD are likely to either get divorced or never married in the first place. It is, therefore, possible that some potential participants chose not to take part in the current research study because they were experiencing difficulties within their relationship. Consequently, a set of data that would lead to different findings may be missing. It could be said that couples experiencing difficulties in their relationship are a ‘hard-to-reach’ group in terms of recruitment to research. ‘Hard to reach’ is a term used to describe sub-groups of the population who are difficult to engage in research due to their location or social or economic situation (Shaghaghi et al, 2011). This should be considered for future research projects.

The research aimed to recruit a sample of between 8 and twelve couples. This was an appropriate number for a study using IPA as it allows for rigorous analysis of high quality data. IPA studies, “usually benefit from a concentrated focus on a small number of cases” (Smith, et al, 2009, p.51) as it allows for a more in depth analysis of each interview. Due to the need to interview a homogenous sample, owing to the research aims of obtaining meaningful insights into a specific phenomenon, and the characteristics of the population being recruited it was anticipated that the potential sample was limited. Practical issues associated with recruiting couples were evident in this research and participant numbers were not as high as they would have been had individual interviews been used. For example, there were a number of times during the recruitment stage when individuals expressed interest in the project, but were unable to participate as their partner was unwilling to be interviewed. However, the potential benefits in terms of the uniqueness of data obtained when compared to previous research made this a worthwhile compromise to make. Furthermore, data analysis identified similar themes arising within each interview and given the quantity and quality of information obtained it was felt that interviewing four couples allowed for good theme consistency and was therefore appropriate for IPA.

Conducting Joint Interviews

The research paper was focused on exploring the joint experience of couples where one had a diagnosis of BD. This was a novel area of research, as carers and individuals with a diagnosis had been interviewed separately before, but a joint perspective had never been obtained. As joint interviews would highlight themes within the dynamics of the couples regarding their shared journey that could not be obtained from interviewing participants alone, this methodology best complemented the research question. As highlighted by Willig (2008), the research question, method of data collection and form of data analysis are inter-dependent. Semi-structured interviews were chosen as they enabled the researcher to guide the interview in the area of the research question, but also allowed for flexibility so that substantial and detailed accounts of experience could be elicited (Smith & Osborn, 2008).

IPA aims to explore the lived experiences of participants and how they are able to make sense of their world (Smith, 2004). IPA is primarily used when analysing individual interviews so consideration about its appropriateness for this project was important. With focus groups, caution is advised due to the potential difficulty in developing the phenomenological aspects of IPA (Smith et al, 2009) as a result of the presence of multiple voices. In using joint interviews, this project treated each couple’s interview as one transcript, using IPA to analyse how each couple experienced and made sense of their world as a unit; recognising that illness is lived and understood within the particular social contexts that people inhabit (Kleinman, 1988). It therefore obtained idiographic couple accounts, adopting a family systems perspective , as has been done previously with couples where one partner has a diagnosis of dementia (Robinson et al, 2005) and depression (Harris et al, 2006). This fits with the phenomenological theoretical position of IPA of exploring personal lived experience.

Care was taken to ensure the voices of both partners were heard during interviews. To achieve this, participants were told that it was important to hear both their views and advised that if I noticed one partner was talking significantly more I would specifically ask the other partner for their thoughts. All participants indicated they understood this, which made it easier for me to manage the interviews and achieve equal contributions from both partners. Furthermore, in his 2004 paper, Smith acknowledged there was, “scope to push the boundaries in terms of populations and data collection methods” (p 51) and advocated the extended use of IPA away from just individual semi-structured interviews with English speaking adults, as this research paper has done.

Recruiting couples to take part in joint interviews regarding something as personal as how they experienced their relationship was challenging. It was important to be mindful of how much participants would feel able to reveal in front of one another and the potential ramifications within the relationship if sensitive and difficult things were discussed or disagreements arose. This was acknowledged from the initial stages of planning when ethical considerations regarding interviewing couples were acknowledged. Sufficient information was given to participants to ensure fully informed consent was obtained. It was emphasised to couples at the start of each interview they should only speak of things they felt comfortable and able to in front of their partner. Participants were placed under no pressure to take part and made aware they could withdraw at any time if the interview became too difficult. All couples were offered a support telephone call following their interview to enquire as to whether any difficulties or questions had arisen following participation.

Participants spoke freely and at no time did it appear they were struggling to speak in front of their partner or holding back. Furthermore, there were times in the interviews when one participant said something that their partner had been previously unaware of:

Susan: *You say you are not often actually suicidal*

Steve: *No*

Susan: *You just get so fed up of feeling*

Steve: *I have had, I must be honest, and you probably, maybe this is something I haven't told you Sue before, but there are times when I feel sort of suicidal, not very strongly, not like I have when I am psychotic, but I have felt so shitty that I've really thought…but normally I can think I will feel better, it make take a while, but I will do in time.*

Interviews flowed well and were full of data as partners interacted with one another; adding detail to each other's experiences and triggering memories. This 'cueing phenomenon' was described by Morgan and Krueger (1993) as participants help each other to divulge information. Patterns of communication could also be observed within couples, an advantage of joint interviews as suggested by Bjornholt and Farstad (2014). At times, as the interviewer, I was able to just observe as participants interacted with each other to describe events and experiences in their lives. These advantages are similar to those attributed to focus group research, a strength of which "lies in its ability to mobilise participants to respond to and comment on one another's contributions" (Willig, 2008). In this way a collaborative interpretation of experiences is obtained as responses are given in relation to the other person present. The following example demonstrates this process for one couple, Laura and James, who spoke about the impact of James not being able to work:

James: *It gives you respect doesn't it?*

Laura: Everybody is working, like his mum and his step-dad, and going oh I am so tired from work and you feel guilty all the time because

James: Yeah

Laura: And it is a horrible feeling, you feel worthless

James: You do

Laura: You feel worthless

James: You feel that size don't you?

Laura: You can't take the kids on holiday, I would love to take them on holiday

James: They've not been away in ages

In this example Laura is able to confirm that she recognises the impact that not working is having on James' self-esteem and then further expand on the financial consequences of this and wider impact upon their children.

One concern about joint interviews may be that partners will work together to provide a consistent story, thereby not providing an accurate reflection of their views. However, this did not appear to be the case in the present study, where disagreements and discussions did arise, or in previous research looking at the validity of using joint interviews (Bjornholt & Farstad, 2014). In fact, Wilkinson (2011) suggests that in focus group research such a context may actually, "facilitate personal disclosures" (Wilkinson, 2011, p.187). The example below demonstrates how one couple, Hannah and Tom spoke about their different coping strategies that have caused tension in the past:

Tom: *We have different ways of thinking about things. I think that's the main difference between us…at the beginning it was like a bit of a clash between two personalities. We sort of meet in the middle now I think. Yeah just different ways of thinking about things and I think that is the biggest thing really.*

Hannah: *Yeah*

Tom: *I just always have the attitude that everything will be fine and everything will be for the best*

Hannah: *I have the opposite attitude. It's not going to be fine*

Tom: *Hannah will go into specifics and I won't. I'm not saying that I'm right and she's wrong …but it's just a different way of looking at things*

Previous research has shown that sexual relationships are impacted by a diagnosis of BD (Dore & Romans, 2001; Kopeykina et al, 2016; Lam et al, 2005); however, this was only mentioned by one couple in the current study. This may be because the other couples felt uncomfortable to do so in the context of a joint interview, or may be because they did not experience difficulties in this area. Alternatively this may be a topic that participants would have found difficult to discuss in a research interview whether on their own or with their partner. Upon reflection I think this is an area of potential difficulty I could have explored in more detail with participants and is something that should be considered further in future research with couples.

The use of joint interviews was in line with the aims of the study which were to investigate the shared experiences of couples. Although this is not the traditional methodology for analysis using IPA it does fit within the appropriate theoretical framework as it was investigating how participants made sense of their experiences and conducted detailed analysis of each couple's experience as one unit. However, joint interviewing did have implications for recruitment and the characteristics of participants.

Personal Reflections

When planning this research I was interested to investigate how couples made sense of and managed a diagnosis of BD together. My previous role as a carer support worker had shown me that people with a diagnosis of mental illness do not manage and cope with their diagnosis in isolation and that the influence of friends and family can have significant impact. In particular I was interested in the experiences of partners and how the dynamics of this particular relationship were affected, due to the shifts in responsibility and potential reciprocal role development of carer and cared for.

In the planning stages I had some apprehension about interviewing couples and how it would feel to ask them about their relationships. I addressed this by ensuring potential participants were fully aware of the interview process and the nature of topics they would be asked about. I knew then that they had given informed consent to be asked about their relationship and this removed some of the potential awkwardness from the situation. It also helped that the first couple I interviewed were extremely relaxed, talkative and open about their experiences. This first interview felt very positive and gave me confidence in my interview skills. It also demonstrated to me the benefits of utilising joint interviews as I was able to observe first-hand the interactions and experience the warmth and care with which they talked about one another. This was evident in all four interviews. Even when couples spoke about difficult times, the challenges they faced and the disagreements that arose, there remained a feeling of mutual respect and love.

Suggestions for Future Research

This study interviewed couples who were currently happy within their relationships. Future research may want to target couples experiencing difficulties by focusing the research question and recruitment methods more specifically to this group in order to promote engagement. This may be achieved by utilising individual interviews and targeting the research question more purposely towards what challenges exist within a relationship. Furthermore, individuals who are no longer in a relationship could also be invited to participate in order to further understand the difficulties that preceded the break-up and whether or not these were associated with the diagnosis of BD.

As this research project formed an initial look at a novel area, it can hopefully be built upon in future by expanding inclusion criteria to investigate whether the findings generalise to wider definitions of bipolar disorder. Limiting the inclusion criteria to individuals whose mood was currently stable meant the experiences shared regarding the impact of different mood states on the participants' relationships were retrospective and dependent on accurate recall. To gain further understanding of this, it may be useful in future to explore the inclusion of individuals with fluctuating mood states. The management and ethics of this would need to be carefully considered in the planning stages of such a study.

Conclusion

This paper has discussed some of the decisions that need to be considered when planning research into the impact of mental health diagnoses on relationships. Holding joint interviews can make recruitment more difficult and limit participant numbers and therefore needs to be considered carefully. For this research project joint interviews provided a unique perspective not captured before and allowed for exploration of the dynamics and shared story of the couples interviewed. Throughout the planning, recruitment and analysis stages much thought and reflection had taken place regarding how to maintain the welfare of participants and the quality and robustness of the data obtained.

Careful consideration had also been given to the eligibility criteria for inclusion in the study and how this would be assessed. I reflected on the different approaches utilised in psychological research when compared to clinical work and made the decision to follow a more medical model within this research. The limitations and advantages of this approach were discussed and ideas for future research identified.

References

American Psychiatric Association , 2000. Diagnostic and Statistical Manual of Mental Disorders, 4th edition, revised. Washington. DC: American Psychiatric Association.

Berk, M., Berk, L., Moss,K., Dodd, S., Malhi, G., 2006. Diagnosing Bipolar Disorder: How can we do it better? The Medical Journal of Australia. 184 (9). 459-62.

Bjørnholt, M., Farstad, G., 2014. 'Am I rambling?' on the advantages of interviewing couples together. Qualitative Research. 14. 3-19. doi: 10.1177/1468794112459671

British Psychological Society, 2012. Diagnosis – Policy and Guidance (Accessed from http://www.bps.org.uk/system/files/documents/diagnosis-policyguidance.pdf)

Division of Clinical Psychology, 2013. Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift DCP Position Statement (Accessed from http://www.bps.org.uk/system/files/Public%20files/cat-1325.pdf)

Dore, G., Romans, S. E., 2001. Impact of bipolar affective disorder on family and partners. Journal of affective disorders. 67(1). 147-158.

First, M. B., Spitzer, R. L, Gibbon M., Williams, J. B.W., 2002. Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Patient Edition. (SCID-I/P). New York: Biometrics Research, New York State Psychiatric Institute.

Harris, T. J., Pistrang, N., Barker, C.,2006. Couples' experiences of the support process in depression: A phenomenological analysis. Psychology and Psychotherapy: Theory, Research and Practice. 79(1). 1-21.

Hirschfeld, R.M., Holzer, C., Calabrese, J.R., Weissman, M., Reed, M., Davies, M., Frye, M.A., Keck, P., Mcelroy, S., Lewis, L., Tierce, J., Wagner, K.D., Hazard, E., 2003. Validity of the mood disorder questionnaire: a general population study. American Journal of Psychiatry. 160. 178–180.

Hirschfeld, R.M., Williams, J.B., Spitzer, R.L., Calabrese, J.R., Flynn, L., Keck Jr., P.E., Lewis, L., Mcelroy, S.L., Post, R.M., Rapport, D.J., Russell, J.M., Sachs, G.S., Zajecka, J., 2000. Development and validation of a screening instrument for bipolar spectrum disorder: the Mood Disorder Questionnaire. American Journal of Psychiatry. 157. 1873–1875

Kleinman, A., 1988. The illness narratives: Suffering, healing, and the human condition. Basic books.

Kopeykina, I., Kim, H. J., Khatun, T., Boland, J., Haeri, S., Cohen, L. J., Galynker, I. I., 2016. Hypersexuality and couple relationships in bipolar disorder: A review. Journal of affective disorders. 195. 1-14.

Lam, D., Donaldson, C., Brown, Y., Malliaris, Y., 2005. Burden and marital and sexual satisfaction in the partners of bipolar patients. Bipolar disorders. 7(5). 431-440.

Morgan, D. L., & Krueger, R. A., 1993. When to use focus groups and why? In D. L. Morgan (Ed.), Successful focus groups: Advancing the state of the art, pp. 3-19. Newbury Park.

CA: Sage.Robinson, L., Clare, L., Evans, K.., 2005. Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. Aging & mental health,. 9(4). 337-347.

Shaghaghi,A., Bhopal, R., Sheikh, A., 2011. Approaches to Recruiting 'Hard-To-Reach' Populations into Research: A Review of the Literature. Health Promotion Perspectives. 1 (2). 1 – 9.

Smith, J. A., 2004. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qualitative research in psychology. 1(1). 39-54.

Smith J, A., Flowers, P., Larkin, M. 2009. Interpretative Phenomenological Analysis: Theory, Method. Research. London: Sage.

Smith, D, Ghaemi, S., Craddock, N., 2008. The broad clinical spectrum of bipolar disorder: implications for research and practice,. Journal of Psychopharmacology. 22 (4) . 397 – 400.

Smith, J.A., Osborn, M., 2008. Interpretative phenomenological analysis. In J.A. Smith (Ed)Qualitative Psychology: A Practical Guide to Methods (second ed). London: Sage.

Walid, M., S, Zaytseva, N., V., 2011. Which Neuropsychiatric Disorder is more associated with divorce? Journal of Divorce and Remarriage. 52 (4). 220-4. doi: 10.1080/10502556.2011.556976

Wilkinson, S., 2011. Analysing focus group data. In D. Silverman (Ed.). Qualitative research (3rd ed.). London, England: Sage.

Willig, C., 2008. Introducing qualitative research methods in psychology. Maidenhead, England: McGraw Hill.

Section Four: Ethics Documentation

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Word Count (excluding tables, figures and reference list): 6097

School of Health and Medicine Research Ethics Committee (SHMREC) Lancaster University

Application for Ethical Approval for Research

Instructions

1. Apply to the committee by submitting
   - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form). This is available on the Research Support Office website: http://www.lancs.ac.uk/depts/research/lancaster/ethics.html
   - ✓ The completed SHMREC application form
   - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
   - ✓ All accompanying research materials such as, but not limited to,
     1) Advertising materials (posters, e-mails)
     2) Letters of invitation to participate
     3) Participant information sheets
     4) Consent forms
     5) Questionnaires, surveys, demographic sheets
     6) Interview schedules, interview question guides, focus group scripts
     7) Debriefing sheets, resource lists
2. Create a **single** PDF document of all application materials. Instructions for creating such a document are available on the SHMREC website.
3. Submit one **signed** paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website http://www.lancs.ac.uk/shm/research/ethics. Applications must be submitted at least 14 days beforehand, to:

Helen Donnelly
School of Health &
Medicine A71 Physics
Building Lancaster
University
LA1 4YD
h.donnelly@lancaster.ac.uk

5. Attend the committee meeting on the day that the application is considered.

1. Title of Project:
Experiences of Bipolar Disorder within Couples

2. If this is a student project, please indicate what type of project by ticking the relevant box:

☐ PG Diploma ☐Masters dissertation ☐MRes ☐MSc ☐ DClinPsy SRP

☐ PhD Thesis ☐D Pall. Care/Pub. Hlth/Org. Hlth & Well Being ☐MD ☐**DClinPsy Thesis**

For office use only. SHMREC Ref ____________________

☐ original ☐ resubmission

3. Type of study

☐ **Involves direct involvement by human subjects**

☐ Involves existing documents/data only: Contact the Chair of SHMREC before proceeding.

☐ Other: Contact the Chair of SHMREC before proceeding.

Applicant information

4. Name of applicant/researcher:
Anna Clancy

5. SHM Division

☐ Biomedical and Life Sciences (BLS) ☐ Centre for Training and Development (CETAD)

☐ **Health Research (DHR)** ☐ Medicine

6. Appointment/position held by applicant: Trainee Clinical Psychologist

7. Contact information for applicant:

E-mail: a.clancy@lancaster.ac.uk Telephone [redacted]

Address: [redacted]

8. Project supervisor(s), if different from applicant:

Name(s): [redacted]

E-mail(s): [redacted]

9. Appointment held by supervisor(s) and institution(s) where based (if applicable):
[redacted]

10. Names and appointments of all members of the research team (including degree where applicable)

n/a

The Project
NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

11. Summary of research protocol in lay terms (maximum length 150 words).

Individuals with a diagnosis of bipolar disorder (BD) benefit from good social support; an important source of which can come from their partner. Furthermore, spouses of individuals with a diagnosis of BD are known to experience high levels of burden. This suggests that although social support within relationships is important for the well-being of individuals diagnosed with BD, this may be hard to achieve, due to the strain experienced by their partner. This study aims to interview approximately 10 couples in order to discover more about the dynamics within their relationship and the ways in which they are able to support one another. Participants will be recruited through third sector support groups and via The Spectrum Centre.

For office use only. SHMREC Ref ___________________

☐ original ☐ resubmission

Data will be analysed using Interpretative Phenomenological Analysis (IPA). It is hoped that the findings will help identify ways in which these couples can best be supported within services.

12. Anticipated project dates

Start date: September 2012 End date: June 2013 (due to maternity leave taken by the researcher, commencing November 2011, recruitment for the study will take place on her return to work)

13. Please describe the sample of participants to be studied (including number, age, gender):
Inclusion Criteria:

- One partner must identify themselves as having a diagnosis of bipolar 1 disorder, confirmed through administration of relevant sections of the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I).
- Both partners must be over the age of 18 year and able to give informed consent.
- Each couple must have been together through at least one major mood episode and have been together for at least 6 months.
- The individuals with a diagnosis of bipolar disorder must not be in an acute episode of illness. This will be confirmed through the administration of the SCID-1.
- Each participant must be able to speak English to a level that allows their participation in a semi-structured interview.
- Couples must live within the North West England, so that travel to interviews is possible.

The study will aim to recruit between 8 and 12 couples. This number is appropriate for the level of analysis that is to be completed and the time period available within which to complete it.

14. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited from the participant mailing list held by The Spectrum Centre. These individuals have already expressed an interest in participating in research and those who appear to meet criteria will be written to with details of the study and asked to contact the researcher if they would like to take part. The researcher will not have access to details of potential participants unless they contact her regarding the study. A follow-up letter will be posted two weeks later, which will be mentioned in the first letter.
Additionally the project will be advertised via local third sector organisations and support groups, including Making Space, MIND and MDF The Bipolar Organisation. The lead researcher will request permission to attend these groups and talk to members about the research. Advertisements will also be placed in local relevant publications.

15. What procedure is proposed for obtaining consent?

The researcher will explain the project and provide all individuals who are interested with a participant information sheet. Potential participants will be given an opportunity to think about the research and ask the researcher any questions that they may have. If they agree to take part in the research they will be asked to complete a consent form, initialling boxes to confirm that they understand the project and have had an opportunity to ask questions. They will then sign and date the consent form, along with the researcher. Participants will be informed that they can change their minds about participating and withdraw from the study up to 2 weeks following their interview, when all relevant materials would be destroyed. They will also be informed that they do not have to answer any questions that they do not want to.
In order to participate, both partners would need to read the participant information sheet and sign a consent form. All potential participants will be assured that participation is voluntary.

16. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

It is possible that participants may find it upsetting to talk about their relationship and the impact of their diagnosis of bipolar disorder. Potential participants will be advised of this prior to consenting to participate. They will also be provided with the telephone numbers for local organisations that could offer support on a debrief sheet. If the participants do become upset or do not wish to carry on with the interview at any point, the interview will be terminated and support offered by the interviewer.

In addition, due to the nature of joint interviews, it is possible that couples may become upset or angry with each other. Again, the potential for this will be discussed prior to participation and participants will be advised that they only need to talk about issues that they feel able to in front of their partner. If either or both members of the couple do become upset then the interview can be terminated. All participants will be provided with details of relevant support organisations on a debriefing sheet. The interviewer will also offer to follow-up the interview with a support call 2 days later in order to check on the welfare of participants.

Finally, the time commitment required for participation will be up to 3 hours, over two meetings. Therefore, potential participants will be informed of this clearly prior to their participation.

17. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

Interviews will take place either at Lancaster University or at participants' homes. When interviews are at participants' homes the interviewer will follow the lone worker policy. She will ensure that another named person is aware of her whereabouts, car make and registration number and agree to telephone them at an agreed time following the interview. If the other person does not receive the phone call then they will try to contact the interviewer. If no contact can be made then the police will be informed. The named person will have details of the name and address of the participant in a sealed envelope, with the agreement that it will only be opened if contact with the researcher cannot be made. Following contact, the sealed envelope will be returned to the researcher and destroyed.

18. What are the anticipated benefits from completion of the study?

There are no direct benefits to participants from taking part in this study. It is anticipated that the results of the study will be written up and submitted to a relevant journal to ensure that the findings are disseminated to an appropriate audience. It is hoped that the findings will provide further information regarding both the strengths and support needs identified by couples within which one person has a diagnosis of bipolar 1 disorder. This may then provide guidance for how these individuals can be best supported by services.

19. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Participants will be provided with travel expenses up to the value of £10 if they choose to be interviewed at Lancaster University.

20. Briefly describe your data collection and analysis methods, and the rationale for their use

Data will be collected via joint interviews with both partners. Previous research has interviewed partners individually and this method will allow for a shared understanding of the experience of bipolar disorder within a relationship to be developed. The interviews will be recorded and transcribed verbatim before being analysed using Interpretative Phenomenological Analysis (IPA). This will allow for an exploration of the experiences of the participants and the meanings that these experiences hold for them. Qualitative methods are appropriate as this area of research is not well developed and it will allow for un-anticipated findings to be revealed.

IPA methodology had been used when interviewing other couples together in previously published work.

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21. Describe the involvement of users/service users in the study

The interview schedule will be piloted on a service-user researcher who has agreed to give feedback on the process.

22. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

The digital audio recordings will be stored in a password protected file on the researcher's password protected computer and deleted once they have been transcribed. Transcription data will be stored electronically in a password protected file on the researcher's password protected computer and will be deleted once analysis is complete. Interviews will also be accessed by the research supervisor in order to assist with analysis. Paper information will be stored securely on University premises for 5 years following completion of the study. Identifiable information (i.e. consent forms) will be stored separately.

23. Will audio or video recording take place? ☐ no ☐**audio** ☐video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews will be audio recorded. Audio recordings will be stored in a password protected file and will be deleted after transcription, which will be within two months of the interview

24. What are the plans for dissemination of findings from the research?

The findings will be used in my DClinPsy thesis and presented at a thesis presentation day at Lancaster University. In addition, it is anticipated that they will be written up for a suitable journal for publication.

25. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study?

Due to the small number of participants, it will be important to maintain confidentiality of individuals. Therefore, although participants will be informed that direct quotes may be used, no identifying information, such as names, locations etc will be used in the write-up. Pseudonyms will be used.

Participants will be made aware of the screening process and the fact that only those who meet criteria following the SCID-I interview will be invited to interview. This may cause concern for individuals who have previously received a diagnosis of Bipolar 1 disorder, but do not meet criteria from this assessment. I will ensure that I provide reassurance to participants that this screening process is for eligibility to this research project alone and does not have implications for diagnoses received from clinicians previously.

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Signatures: Applicant: ………………………..……………………......................................

Date: ……………………………………………………..

Project Supervisor (if applicable): ……………………………………..................

Date: ……………………………………………………..

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☐ original ☐ resubmission

Research Protocol

Title

An Exploration of Experiences of Bipolar Disorder within Couples.

Researchers

Anna Clancy (trainee)

[redacted]

[redacted]

Introduction

Bipolar disorder has been described as a serious mental illness in which people experience episodes of low mood and elated mood (mania or hypomania) that can be associated with significant social and personal functioning difficulties (National Institute of Clinical Guidance (NICE), 2006). A distinction is made between bipolar I disorder and bipolar II disorder. Bipolar I disorder is characterised by episodes of both depression and mania, whilst a diagnosis of bipolar II is dependent upon episodes of depression and hypomania (NICE, 2006). NICE guidelines recommend the use of psychotropic medications in order to reduce the severity of symptoms and prevent relapse. However, the utility of such medications will vary dependent on individuals and a number of psychological and psychosocial interventions are also recommended (NICE, 2006). These include psychoeducation, mood monitoring and enhancement of general coping skills as well as family-focused intervention. The importance of psychosocial support is also emphasised and befriending schemes are recommended.

Psychosocial factors have been found to play an important role in bipolar disorder. More specifically, social support has been identified as influential, although its role is not well understood. Adults with a diagnosis of bipolar disorder have been identified as receiving less social support than the general population (Speer, 1992). Social support incorporates social interactions with others, particularly friends and family. Adults with a diagnosis of bipolar have reported receiving less family support and were more likely to live in residential care than adults with a diagnosis of major depressive disorder (Doi, 1986). A number of studies have investigated the impact of limited social support and the results suggest it may be associated with increased mood symptoms and may be the most important predictor of change in symptoms of depression (O‟Connell, May, Flatow, Cuthbertson & O‟Brien, 1991; Johnson, Meyer, Winett & Small, 2000). One important source of social support comes from an individual‟s partner and mental illness has been found to be strongly associated with the quality of the marital relationship (Whisman, Sheldon & Goering, 2000). Specifically, a strong association has been found between self-reports of marital distress and bipolar disorder as reported by individuals with a diagnosis of bipolar disorder (Whisman, 2007), although the extent to which marital distress was a cause or consequence of the diagnosis could not be determined. This study did not investigate reports of marital satisfaction in the spouses of individuals with a diagnosis of bipolar disorder. Furthermore, Lieberman, Massey and Goodwin (2010) found that marriage is associated with lower levels of depression in women with a diagnosis of bipolar disorder, but not for men, leading to the suggestion that woman may be more sensitive to the positive effects of social support available within the marital relationship.

In addition, relatives of individuals with a diagnosis of mental illness have been found to experience high levels of distress, burden and psychological morbidity (Baronet, 1999). However, this has been less widely researched within the marital relationship. Specifically with respect to marital relationships, Horesh and Fennig (2000) found that partners of individuals with a diagnosis of affective disorder were more likely to rank their spouses lower on positive qualities and higher on negative qualities than the control group. Furthermore, they reported receiving less emotional and practical support from their partners.

However, the responses of partners of individuals with a diagnosis of bipolar disorder were not statistically different from the control group. It is possible that the selection process of the study resulted in the participation of couples who had managed to survive the difficulties of the illness and therefore had a stronger relationship as a result. The authors also tentatively suggested that partners of individual with a diagnosis of bipolar disorder may gain satisfaction from their role within the relationship and feel stronger levels of affection for their partners, although this requires more research. This was related to the “switch process” proposed by Treves, Fennig, Levkovitch and Elizur (1999). These authors aimed to explore the dynamics of couples in which one individual had a diagnosis of bipolar disorder, with particular attention on the relationships between couple dynamics and relapse. They suggested that two types of spousal behaviour can be identified, over controlling and passive, and that couples switch between the different affective states without finding a stable equilibrium. Although this was a small study, the authors suggested that the behaviours of the spouses changed in response to the phase of illness experienced by their partner, i.e. through manic or depressive phases. They illustrated this by analysing transcripts of therapeutic sessions held with the couple, in which the wife of a gentleman with a diagnosis of bipolar disorder described feeling frightened by his behaviour when in a manic phase causing her to act critically towards him before withdrawing. However, when he was feeling depressed she described acting more supportively, wanting to take care of his needs. From these results the authors emphasised the importance of psychosocial factors on the course of bipolar disorder and recommended that interactions between spouses should be observed in order to identify psychological reasons for relapse. They also suggested that there may be differences between couples depending on the gender of the spouse with the diagnosis of bipolar disorder; however, the small number of participants makes this conclusion tentative.

A number of studies have explored the marital relationships of individuals with a diagnosis of bipolar disorder and their partners by interviewing the partners alone (e.g. Donaldson, Brown & Malliaris, 2005; Tranvag & Kristofferson, 2008). These studies were focused on the burden and sexual satisfaction experienced by partners, finding that marital disharmony in these areas was common and that partners received little support. Van der Voort, Goossens and van der Bijl (2009), meanwhile, conducted a grounded theory study in order to explore the coping and support needs of spouses. Their results suggested that spouses feel a heavy burden, particularly associated with feelings of responsibility and not being able to share important aspects of their life with their partner. Amongst those who were divorced, participants described not being able to share their feelings with their spouses, whilst protective factors for a successful marriage appeared to be having a sense of humour, love for their partner, being able to share feelings and experiencing positives within the relationship. In accordance with other studies, spouses reported receiving little support for themselves from professionals and added that trying to find support increased stress, as they did not know what was available. The authors also identified a link between the spouses‟ appraisals of their situation and the amount of burden that was felt. This finding supports Folkman and Lazarus‟s (1984) stress, appraisal and coping theory which described a cognitive approach to coping, in which an individual‟s level of stress and subsequent coping strategies are determined by how they appraise particular events. The impact of spouses‟ attributions and experience of bipolar disorder was also investigated in a qualitative study by Lam, Donaldson, Brown and Malliaris (2005). They interviewed 37 partners and found high levels of strain within the relationships, predominantly due to socioeconomic and household changes. In addition, their results suggested that attributions were a mediating factor, with marital disharmony becoming more prominent when participants believed that their partners could control their illness. The results also indicated that marital disharmony could fluctuate with the illness and that it was reported to be worse during manic phases than depressed phases.

The current study aims to interview couples together in order to develop a more thorough understanding of the dynamics of the relationship and the ways in which the partners are able to support one another. This method is similar to studies of „couplehood‟ typically carried out in the field of dementia. It acknowledges the person with the diagnosis as being an „active subject‟ as opposed to a „passive object (Meisen, 1997) in the relationship and hopes to develop a shared understanding of the strategies undertaken to maintain the relationship and the particular strengths and weaknesses that exist within it. It aims to build on previous research investigating the potential satisfaction or burden gained from being in the relationship. It is hoped that developing a greater understanding of the dynamics of these relationships may help clinicians to support both the client and their partner more successfully. As recommended by NICE guidelines (2006) psychological interventions can be beneficial for individuals with a diagnosis of bipolar disorder and family therapy is recommended. This involves providing support to the family together and it is hoped that joint interviews will help to identify how strengths and weaknesses within the relationships are defined together, thereby identifying how couples can be supported as a unit, as opposed to individually.

Method

Design

This research will use qualitative methods and the data will be analysed using interpretative phenomenological analysis (IPA), as described in Smith, Flowers and Larkin (2009). Qualitative methods are appropriate for this research as they are concerned with meaning, sense-making and subjective experience. More specifically, IPA is able to explore in detail the experiences of participants and the meanings that these experiences hold for them. This approach involves the researcher taking an active role in the process as they try to understand the view point of the participants. The data will be collected through joint interviews. Joint interviews have been used in a number of studies where the aim has been to explore the dynamics within relationships (e.g. Connolly, 2005; Fingerman, 1998). It involves the researcher interviewing two people together with the aim of collecting information about how they perceive the same events and is therefore useful in the context of marital relationships. In addition, joint interviews have been used when looking at illness and disability for interviewing both the patient and the carer together (e.g. Gerhardt, 1991; Piippo and Aaltonen, 2008). Joint interviews help with the development of rapport and reveal information about the discrepancies in knowledge held by each person. In addition, more in depth data can be retrieved as participants are able to compensate for one another‟s memory lapses and insights into interactions and power relationships can be observed (Arksey, 1996).

Participants

Inclusion Criteria:

- One partner must identify themselves as having a diagnosis of bipolar 1 disorder, confirmed through administration of relevant sections of the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I).
- Both partners must be over the age of 18 year and able to give informed consent.
- Each couple must have been together through at least one major mood episode and have been together for at least 6 months.
- The individuals with a diagnosis of bipolar disorder must not be in an acute episode of illness. This will be confirmed through the administration of the SCID-1.

- Each participant must be able to speak English to a level that allows their participation in a semi-structured interview.
- Couples must live within the North West England, so that travel to interviews is possible.

The study will aim to recruit between 8 and 12 couples. This number is appropriate for the level of analysis that is to be completed and the time period available within which to complete it.

Materials

In order to ensure participants are eligible to participate, they will be asked to take part in an initial screening process. This will involve a short telephone interview in which they will be asked about their marital status and questions from The Mood Disorder Questionnaire (MDQ), a screening tool for bipolar spectrum disorder. Those who achieve a positive score on this measure will be invited to meet with the interviewer in order to discuss the study and the consent process. The person with a diagnosis of bipolar disorder will then be asked to participate in Sections A to D of the Structured Clinical Interview for DSM-IV Axis I Disorders in order to confirm their diagnosis and determine whether or not they are in an acute phase. Following this, couples who meet eligibility criteria will be invited to interview.

This study will utilise qualitative methodology, the data will be collected through joint interviews with participants. A semi-structured interview schedule has been developed specifically for this research project and will be used as a flexible guide for the interviews. A semi-structured interview lists the questions or topics that the researcher wants to explore during each interview. It ensures that similar information is obtained from each participant. However, there are no predetermined responses and so the researcher is able to question and explore as much or as little as required, within each predetermined area (Patton, 1990). The use of an interview guide also helps to ensure that the limited interview time can be used efficiently and that the interviews are kept focused. However, they also allow for the participants to shape the interview and tell their own story. The interview schedule will begin with demographic questions and direct inquiries about the couple‟s relationship (nature, length etc) and the bipolar diagnosis (years diagnosed, course of illness etc). It is hoped that the straightforward nature of these questions will help to put the participants at ease. The interview will then ask participants more in depth questions about their experience of bipolar disorder in the context of their relationship.

Procedure

Participants will be recruited via a number of strategies. All individuals within the North West who appear to meet inclusion criteria from [redacted] Research mailing list will be written to with details regarding the study and asked to contact the researcher for more information if interested in participating. In addition, the main researcher will attend local support groups held by [redacted] to explain the study and answer any questions. Finally, permission will be sought to display flyers and posters in relevant locations and publications (for example [redacted]).

Once a potential participant contacts the researcher, she will talk to them and their partner about the project together (either over the phone or in person), answer any questions that they may have and confirm their initial eligibility, as detailed above. If both partners agree to take part the researcher will arrange a time and place to meet with them to conduct the screening interview. This will take about 45 – 60 minutes. In order to gain informed consent, potential participants must read the participant information sheet (see appendix F) and will be given an opportunity to ask questions. Both partners must then sign a consent form if they understand the study and agree to take part.

Those eligible will then be invited to take part in the research interview. Interviews will most likely take place at participants‟ homes, although a room at Lancaster University may be available if preferred. The researcher will arrange to meet participants for around one and a half hours. Due to the nature of the research, participants will be interviewed together in order to obtain a joint account of their relationship. The interviews will be digitally recorded on a recording device and transcribed verbatim at a later date.

Proposed Analysis

The data will be analysed using interpretative phenomenological analysis (IPA) in order to identify the key themes (using the guidelines of Smith, Flowers and Larkin, 2009). The literature recommends that the interview transcripts should be read and re-read in order to immerse oneself in the data. This should help to make the participant the focus of analysis. The next stage involves making notes on the transcript and considering the language and context of what the participant has said. It is also advised at this stage to identify more abstract concepts in the data, which can help to make sense of the patterns of meaning in the transcript. It is then necessary to identify emergent themes within the data before mapping how they fit together. This needs to be done for each individual participant before then looking for patterns across cases.

In order to enhance the validity and reliability of the analysis recommendations by Yardley, 2008 (in Smith, 2008 pg 239) will be followed. This will include comparing early analytical interpretations of the data with the research supervisor in order to triangulate the perspective. This should ensure that the analysis is not only from the perspective of one person, but will make sense to others. The analysis will also include consideration of disconfirming cases. This means that any data which may not fit the identified themes will be discussed. This should reassure the reader that all data has been accounted for. It may also highlight areas for future research. Finally, a „paper trail" of analysis will be kept (Flick, 1998). This will include the coded transcripts and a description of the codes and their interpretation, allowing the stages of analysis to be retraced.

Practical Issues

Audio recording equipment will be borrowed from the University, which will also cover administrative costs, such as photocopying and printing/posting of information sheets.

Interviews may take place in participants" homes. Therefore, the researcher will be mindful of the Lancaster University and Lancashire Care NHS Trust lone worker policies and ensure appropriate guidelines are followed.

It is also important to consider the practical difficulties that may occur when facilitating a joint interview, as one partner may attempt to dominate the conversation. In order to practice for this the researcher will carry out a pilot interview on a couple in order to practice technique and to receive their feedback about the process. This interview will not be included in the analysis.

Ethical Concerns

It is important to be mindful of the potential for participants to become upset when talking about their relationships. The interviewer will remain mindful of this and ensure that participants are aware of the potential for this before participating. Participants will be provided with a debrief sheet at the end of the interview which will include the contact telephone numbers of local organisations that can provide support and offered a support call after 2 days. The nature of joint interviews also means that couples may become upset or angry with one another as a result of what is being said. This again will be discussed beforehand and participants will be assured that they are only obliged to talk about things that they are comfortable discussing in the context of a joint interview.

Participants will be made aware of the screening process and the fact that only those who meet criteria following the SCID-I interview will be invited to interview. This may cause concern for individuals who have previously received a diagnosis of Bipolar 1 disorder, but do not meet criteria from this assessment. I will ensure that I provide reassurance to participants that this screening process is for eligibility to this research project alone and does not have implications for diagnoses received from clinicians previously.

Due to the relatively low number of participants, it is important that potentially identifying data is not revealed in the write-up. Therefore, pseudonyms will be used and the confidentiality of participants maintained. However, participants will be informed that if they were to say anything that indicates the potential of harm to either themselves of others, it may be necessary to follow safeguarding procedures and potentially break confidentiality.

Finally, participation in the study will require a time commitment of up to three hours over two meetings and it will not be possible to provide monetary compensation to participants (with the exception of travel expenses if appropriate). The participants will be clearly informed about the length of time required for participation prior to obtaining consent.

Time Scale

An ethics application will be made in May/June 2011. The researcher will be taking maternity leave from November 2011. Recruitment will take place upon her return to work in September 2012. Submission will be in May 2013.

References

Arksey, H. (1996) Collecting data through joint interview, *Social Research Update, 15. Winter.* Retrieved from http://sru.soc.surrey.ac.uk/SRU15.html.

Baronet, A. (1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. *Clinical Psychology Review, 19,* 819-841

Connolly, C. M. (2005) A qualitative exploration of resilience in long-term lesbian couples, *The Family Journal, 13,* 266 – 179. Doi:10.1177/1066480704273681.

Fingerman, K. L. (1998) Tight lips? Aging mothers‟ and adult daughters‟ responses to interpersonal tensions in their relationships, *Personal Relationships, 5,* 121 – 138. Doi: 10.1111/j.1475-6811.1998.tb00163.x.

Flick, U. (1998). *An Introduction to Qualitative Research.* London: Sage.

Gerhardt, U. (1991) 'The Roles of the Wife and Marital Reality Construction in the Narrative Interview: conceptual models in qualitative data interpretation', *Sociology of Health & Illness* 13 (3): 411-28. Doi: 10.1111/1467-9566.ep10492405.

Horesh, N. & Fennig, S. (2000) Perception of spouses and relationships: a matched control study of patients with severe affective disorder in remission and their spouses, *The Journal of Nervous and Mental Disease, 188 (7),* 463-466. Doi: 10.1097/00005053-200007000-00012.

Johnson, S. L., Meyer, B., Winett, C., & Small, J. (2000). Social support and self-esteem predict changes in bipolar depression but not mania. *Journal of Affective Disorders, 58,* 79–86. Doi: 10.1016/S0165-0327%2899%2900133-0.

Lam, D., Donaldson, C., Brown, Y. and Malliaris, Y. (2005) Burden and marital and sexual satisfaction in the partners of bipolar patients, *Bipolar Disorders, 7,* 431-440. Doi: 10.1111/j.1399-5618.2005.00240.x.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.

Lieberman, D., Z., Massey, S. H. & Goodwin, F. K. (2010) The role of gender in single Vs married individuals with bipolar disorder, *Comprehensive Psychiatry, 51,* 380 – 385. doi: 10.1016/j.comppsych.2009.10.004.

Meisen, B.M.L. (1997). Awareness of dementia patients and family grieving: A

practical perspective. In B.M.L. Miesen, & G.M.M. Jones (Eds.), *Caregiving in dementia: Research and applications* (Volume 2) (pp. 67–79). London: Routledge.

National Institute for Health and Clinical Excellence (2006) *Bipolar disorder. The management of bipolar disorder in adults, children and adolescents, in primary and secondary care.* Retrieved from http://www.nice.org.uk/nicemedia/pdf/CG38niceguideline.pdf

O‟Connell, R., May, J., Flatow, L., Cuthbertson, B. & O‟Brien, B. (1991). Outcome of bipolar treatment on long-term treatment with lithium, *The British Journal of Psychiatry, 159,* 123 – 129. Doi: http://dx.doi.org/10.1192/bjp.159.1.123.

Patton, M. Q. (1990). Qualitative Evaluation and Research Methods (2nd ed.). Newbury Park, CA: Sage Publications, Inc

Piippo, J. & Aaltonen, J. (2008). Mental health and creating safety: the participation of relatives in psychiatric treatment and its significance, *Journal of Clinical Nursing, 18,* 2003 – 2012. doi: 10.1111/j.1365-2702.2008.02650.x.

Smith, J., Flowers, P. and Larkin, M. (2009). IPA: Theory, method and research. London: Sage.

Tranvag, O. & Kristofferson, K. (2008). Experience of being the spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time, *Scand J Caring Sci, 22,* 5 – 18.

Treves, I., Fennig, S., Levkovitch, Y. & Elizur, A. (1999).Couple dynamics of bipolar patients: “The switch process”, *Family Therapy, 26 (3),* 191 – 199.

Van der Voort, T. Y., Goossens, P. J. & van der Bijl, J.J. (2009). Alone together: A grounded theory study of experienced burden, coping and support needs of spouses of persons with a bipolar disorder, *International Journal of Mental Health Nursing, 18,* 434 –

443. Doi: 10.1111/j.1447-0349.2009.00634.x.

Whisman, M. A. (2007). Marital distress and DSM-IV psychiatric disorders in a population- based national survey. *Journal of Abnormal Psychology, 116*, 638-643. Doi: http://dx.doi.org/10.1037/0021-843X.116.3.638.

Whisman, M. A., Sheldon, C. T. & Goering, P. (2000). Psychiatric disorders and dissatisfaction with social relationships: does type of relationship matter? *Journal of Abnormal Psychology, 109(4),* 803-808. doi: 10.1037//0021-843X.109.4.803.

Yardley, L. (2008). Demonstrating Validity in Qualitative Psychology. In Smith, J. (Ed), Qualitative Psychology A Practical Guide to Research Methods, Second Edition (pp

235 – 251. Sage Publications Ltd

LANCASTER
UNIVERSITY

Ms Anna Clancy and [redacted]
Division of Health Research

10 October 2011

Dear Miss Clancy and [redacted],

Re: An Exploration of Experiences of Bipolar Disorder within Couples

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

SC

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Professor T McMillan (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

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Research and Enterprise services

Lancaster University
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LANCASTER
UNIVERSITY

Applicant: Anna Clancy
Supervisors: [redacted]
Department: DHR

12 February 2013

Dear Anna, [redacted],

Re: An exploration of experiences of Bipolar Disorder within couples

Thank you for submitting your amendment for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The amendment was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee {UREC), I can confirm that approval has been granted for this amendment.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight {01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours Sincerely,

Yvonne Fox
Research Support Manager

Cc Professor T McMillan (Chair, UREC); Sarah Taylor {Secretary, University Research Ethics Committee); Professor Paul Bates (Chair, FHMREC)

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