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Title: *A Qualitative Investigation into the Reciprocal Relationships between Social Factors and the Experience of Bipolar Disorder*

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Abstract

Background: Evidence suggests that social support can influence relapse rates, functioning and various clinical outcomes in people with bipolar disorder. Yet ‘social support’ is a poorly defined construct and the mechanisms by which it affects illness course in bipolar disorder remain largely unknown. Key aims of this study were to ascertain which facets of social interaction affect mood management in bipolar disorder, and how symptoms of bipolar disorder can influence the level of support received.

Method: Semi-structured qualitative interviews were conducted with 20 individuals with bipolar disorder. Questions were designed to elicit: the effects of social interaction upon the management and course of bipolar disorder; and the impact of bipolar disorder upon social relationships. An inductive thematic analysis was used to analyse the data.

Results: Empathy and understanding from another person can make it easier to cope with bipolar disorder. Social interaction can also provide opportunities to challenge negative ruminative thoughts and prevent the onset of a major mood episode. The loss of social support, particularly through bereavement, creates a loss of control and can trigger mania or depression. Hypomanic symptoms can facilitate new social connections, whereas disinhibited and risky behaviour exhibited during mania can cause the breakdown of vital relationships.

Conclusions: An in-depth clinical formulation of an individual’s perceptions of how their illness affects and is affected by social interaction is crucial to understanding psychosocial factors which influence mood management. These results have clear application in interventions which aim to promote improved wellbeing and social functioning in bipolar disorder.

Key Words: Bipolar; family, social; caregiver; psychosocial.

Introduction

Previous research suggests that social support can influence clinical outcomes in people with a bipolar disorder diagnosis. Poorer symptomatic profiles (i.e., higher relapse rates) have previously been associated with lower levels of social support (Kulhara et al., 1999; Romans & McPherson, 1992); a greater number of future mood episodes (O'Connell et al., 1985); and more severe self-reported depressive symptoms (Johnson et al., 1999). A prospective follow-up study also found that higher levels of stress and lower levels of social support independently predicted the recurrence of depression over a one year period (Cohen, Hammen, Henry & Daly, 2004).

There is evidence that specific characteristics of the family environment can play a role in determining the clinical course of bipolar disorder. A longitudinal study demonstrated that a critical and hostile family atmosphere, known as high expressed emotion (or high EE), significantly predicted the rate of relapse into acute mood episodes (Miklowitz et al., 1988). Other studies have suggested that the presence of high EE in the family is associated with more frequent relapse and worse symptomatic outcomes (Honig et al., 1997; Kim & Miklowitz, 2004; Miklowitz et al., 2000; O'Connell et al 1991; Yan et al., 2004). Moreover, psychosocial interventions which focused upon educating family members about bipolar disorder, facilitating better communication, and optimising problem-solving have been associated with better global functioning (Clarkin et al., 1998), fewer relapses and greater improvements in depressive symptoms (Miklowitz et al., 2000).

The negative impact that bipolar disorder can have upon the family environment has been fairly well documented (e.g., Dore & Romans, 2001; Miklowitz, 2010; Post, 2004). However, this issue tends to be examined from the perspective of the carer, usually the significant other or a close family member. Individuals with bipolar disorder tend to receive less social support than non-clinical populations (Beyer et al., 2003; Cohen, Hammen, Henry & Daly, 2004). This may be partly due to the disruptive impact that major mood episodes can have upon social networks (Dore & Romans, 2004). Several studies found that the families of individuals with bipolar disorder reported a high level of caregiver burden (see Reinares & Vieta, 2004 for a review). A qualitative investigation revealed that the acute stages of bipolar disorder created considerable difficulties, including negative effects on the caregiver's own employment and the caregiver's other social relationships (Dore & Romans, 2001). A cross-sectional study assessing sources of family burden reported that caregivers' distress was associated with the individual's behaviours when they were unwell, including hyperactivity, anger, sadness and withdrawal behaviours (Reinares et al., 2006). Higher levels of perceived caregiver burden have in turn been associated with more adverse clinical outcomes in individuals with bipolar disorder (Perlick et al., 2004).

A more comprehensive understanding of the reciprocal relationships between bipolar disorder, social relationships and general social interaction, psychological wellbeing and day-to-day functioning, is necessary to develop feasible and effective psychosocial interventions. To our

knowledge, no study has examined the impact of bipolar disorder upon social relationships from the perspective of the individual with bipolar disorder. The aim of the present study was to redress this gap by using semi-structured qualitative interviews to generate a comprehensive examination of the relationship between bipolar disorder, perceived functioning and social interaction. Qualitative methodology offers an in-depth, flexible, service-user informed approach in an area where there is a paucity of previous work.

Method

Design

The present study used a series of one-to-one semi-structured qualitative interviews to collect data from participants with a diagnosis of bipolar disorder. The data was analysed using thematic analysis.

Recruitment

This study was given approval by the University of Manchester Ethics Committee and NHS Research Ethics Committee (Ref: 13/ NW/0846). 20 participants were recruited from the North of England using a range of recruitment methods. Members of staff in NHS services, such as community mental health teams, were contacted to aid recruitment. Study advertising materials were distributed amongst voluntary mental health organisations, such as Bipolar UK, to allow self-referral. Advertisements were also placed in local newspapers and online social media. Based on the information provided, participants were able to contact the first author (RO) directly. Thematic saturation was reached after 20 participants had been recruited and hence study recruitment was ceased.

Participants

Participants were consented into the study providing that they met the following inclusion criteria:

1. A primary diagnosis of bipolar disorder (I or II) according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV research criteria (First, Gibbon, Spitzer, Williams & Benjamin, 1997). Participants were in a euthymic mood state according to SCID criteria (four weeks free from clinically significant mood symptoms), when they took part in the qualitative interview.
2. In regular contact with a care-coordinator or an equivalent named health professional who could be contacted in the event of risk issues.
3. Aged 18-65 years.
4. Sufficient English language skills to comprehend the interview schedule and take part in the interview.

Measures

The Structured Clinical Interview for DSM-IV Axis I Disorders, Research Version (SCID; First et al., 1997)

The first author (RO) conducted the SCID interview which assessed criteria for the Major DSM-IV Axis I disorders. It remains the gold standard for confirming psychiatric diagnoses in clinical research trials (First et al., 1997). Modules A (Mood Episodes), B (Psychotic and Associated Symptoms), C (Psychotic Disorders), D (Mood Disorders), E (Substance Use Disorders) and F (Anxiety Disorders) were administered to all participants. RO was fully trained and experienced in administering the SCID interview.

The Semi-Structured Qualitative Interview

The interview topic guide was developed based upon a systematic review of the research literature (Owen, Gooding, Dempsey & Jones, 2015; in press), discussion amongst the research team and consultation with a service-user advisory panel. Questions were designed to elicit (1) appraisals of positive and negative social experiences, (2) positive and negative effects of bipolar disorder on social experiences, (3) positive and negative effects of social experiences upon the symptoms of bipolar disorder (including mood fluctuations and other symptoms the participant associated with bipolar disorder).

There were a number of key open-ended questions which were asked of every participant, e.g., to elicit appraisals of positive specific social experiences, “Can you tell me, in your own words, about a time when you have got on well with another person?” To elicit the perceived impact of these experiences upon functioning in bipolar disorder, “What effect, if any, do you feel these sorts of social experiences have on symptoms of bipolar disorder, such as, mood changes?” However, the topic guide was sufficiently flexible to account for variation in responses and allowed the inclusion of personal experiences which were not anticipated in the original interview outline (the corresponding author can be contacted for a copy of the interview topic guide).

It should be noted that all participants who took part in the current study had experienced suicidal ideation at some point during their lifetime. The second half of this qualitative interview (not analysed as part of the present study) asked participants about the ways in which social experiences have impacted upon any past experience of suicidal feelings (see Owen et al., 2015).

Procedure

Potential participants were first provided with a participant information sheet. After considering the information sheet for at least 24 hours, potential participants were invited to take part in a face-to-face structured clinical interview (SCID; First et al., 1997) to confirm diagnostic eligibility for the study. Informed consent procedures took place in person at the first appointment. The first author (RO)

explained each point on the consent form, checked understanding and gave the opportunity for participants to ask questions before providing their written consent.

A separate appointment was arranged for the qualitative interview. Both interviews took place either at the participants' home or at the University of Manchester. Interviews were audio recorded to permit transcription and analysis of the data. During transcription, interviews were anonymised by removing any personally identifiable data, such as, names and places. All participant information was stored securely in accordance with the Data Protection Act (1998).

Data Analysis

Participant responses were analysed using an inductive thematic analysis (Braun & Clarke, 2006). Within the current study, thematic analysis was used as a realist method which allowed us to report participants' true experiences. This allowed the identification of key themes or topics which were repeated across the transcripts. The initial coding system was developed by the first author (RO). The codes and preliminary themes were presented to the academic and clinical research team (PG, RD and SJ) for discussion, during which theme content and provisional labels were agreed upon. Themes were discussed at monthly research team meetings until the team were satisfied that the themes had captured participants' subjective experiences (the corresponding author can be contacted for a copy of the coding manual).

Stages of Data Analysis

(1) Familiarisation: Transcripts were read and re-read by the first author (RO) in order to develop a high level of familiarity with the data.

(2) Coding System: The initial coding system was based upon the identification of common experiences across the transcripts. Each experience was assigned a brief label or 'code'.

(3) Indexing: The coding system was applied to the data. The wider academic and clinical team discussed the coding system and agreed upon provisional theme headings and theme content.

(4) Charting: Theme headings were used to create charts of the data. Thematic saturation was reached when no new themes began to emerge.

(5) Mapping and Interpretation: Finally, the team searched for patterns and associations both across themes and within the data. This process was partly guided by the original research aims and by themes which were fully grounded in the data.

Results

Participants

The mean age of participants was 45.6 (range 26-60). There were 7 males and 13 females (see Table 1 for sociodemographic information). Fifteen participants met criteria for bipolar I disorder and five participants met criteria for bipolar II disorder. There was considerable range in terms of patterns of

mood episodes, with 0-200 self-reported depressive episodes (mean = 27 depressive episodes), and 2-50 self-reported manic or hypomanic episodes (mean = 16 manic/hypomanic episodes).

Thematic Analysis

Overview of Key Findings

Themes were grouped into, (1) positive effects of bipolar disorder on social experiences, (2) negative effects of bipolar disorder on social experiences, (3) positive effects of social experiences on bipolar disorder, (4) negative effects of social experiences on bipolar disorder. Positive effects of bipolar disorder on social experiences included the sub-themes, 'bipolar disorder provides a social advantage', 'a bipolar diagnosis facilitates understanding', and, 'bipolar disorder changes social perceptions'. Sub-themes relating to the negative effects of bipolar disorder upon social experiences were identified as, 'bipolar disorder damages relationships', 'bipolar disorder triggers a loss of social control', 'bipolar disorder provides a social disadvantage', 'mental health stigma', and, 'mood symptoms impair social functioning'. Positive effects of social experiences on bipolar disorder included the sub-themes, 'understanding facilitates coping', 'social support', 'changing unhelpful thought processes', 'recovery aids social control', and, 'social anonymity aids recovery'. The negative effects of social experiences on bipolar disorder were identified as, 'separation of the person from the illness' and, 'social experiences trigger acute mood episodes'.

Positive Effects of Bipolar Disorder on Social Experiences

One way in which participants reported that bipolar-related experiences had a positive effect on social interactions was by providing them with a social advantage. Five participants indicated that this could be a direct effect of bipolar-related experiences, for example, by using elevated self-esteem during a high mood phase to make a positive first impression.

Participant 10: "I can just walk in a room and get the attention I need to fulfil whatever business endeavours I need to cope with that day".

Nine participants reported that receiving a clinical diagnosis of bipolar disorder helped to facilitate their family and friends' understanding of their problems. This in turn facilitated more open communication and enhanced the participant's level of coping.

Participant 9: "I think it was like a relief when they found out I got the diagnosis of bipolar, it was like yes it is something, there's a reason for all these problems, there's a name for it and then they found out all about it, so it's made us get on even better now".

Four participants reported that bipolar-related experiences enhanced their ability to cope with negative social experiences. Two participants talked about how a specific experience relating to overcoming depression helped them to see that they were capable of coping with a negative social experience, such as, bereavement.

Participant 18: "There's nothing worse than depression, there really isn't anything worse, I don't think there is anyway, like when my dad died it was nothing, I didn't care, well I cared obviously but it didn't bother me like other people would have been bothered, cos I'd had worse than that already and there just isn't anything worse".

Negative Effects of Bipolar Disorder on Social Experiences

All 20 participants were able to recall at least one negative effect of bipolar-related experiences upon some facet of their social network. This included the direct damaging effects upon relationships, such as, the individual exhibiting unreasonable behaviour leading to the breakdown of friendships.

Participant 4: "I didn't recognise it as an illness and they couldn't see it as that, so it's not really their fault, but it impacted because I was behaving ... I was coming in at all hours, I was bringing people back to the flat, and it was just everything was getting faster and faster and faster, and they just lost it with me and it ruined those friendships for life".

Participants also talked about bipolar-related experiences causing a loss of social control, such as, being in a high mood phase and not perceiving any threat or danger within certain social situations.

Participant 18: "I think there's a problem for girls with bipolar, they have a real problem when they're high, because they can get into dangerous situations a lot easier, if a girl goes into a bar and sits there on her own, if she goes and chats to a guy, which they do when they're high, then they're not gonna get no for an answer are they, so for a woman it's very easy to get into trouble when they're high".

Fifteen participants stated that bipolar-related experiences gave them a social disadvantage. An example was when other people perceived bipolar disorder as a weakness.

Participant 1: "People are like, 'don't give him anything to do, he'll get unwell', it's frustrating, and I think people kind of forget, because I've got this label of being bipolar, they forget that I can function quite normally like everybody else".

A further way in which 11 participants explained that bipolar-related experiences created social difficulties was through the experience of social stigma.

Participant 2: “People judge us because of the media, because their only experience of a bipolar person is Jean from Eastenders who was a lunatic, or the only thing that they’ve ever associated with bipolar is Kerry Katona snorting coke off the bathroom floor, that’s their experience of it”.

Seven participants reported that bipolar-related experiences created barriers or challenges in terms of social functioning.

Participant 5: “It almost kills me when I’m low because I know that I am snappy and irritable and I don’t mean I’m not nice with the children but I’ve no time for them, I don’t want to do their homework with them, I just want to go to bed because I just can’t cope with them when I’m low”.

Participant 16: “When I’m like this [stable], I get on well with everyone, but when I feel at my most euphoric or most happy, I’m so annoying ... I feel good but people distance themselves from me, I irritate them, it’s like an exasperation, they become exasperated, so when I feel at my best I lose that structure around me”.

Positive Effects of Social Experiences on Managing Bipolar Disorder

Participants reported that when other people showed empathy and understanding for their bipolar-related experiences, it facilitated better personal coping.

Participant 1: “Having friends and family being very close to me and understanding about bipolar disorder is important, I can freely talk about how I feel if something is bothering me within the comfort and the security of that friendship or that relationship”.

Social support was a key factor in helping participants to manage the challenges of accepting a bipolar disorder diagnosis.

Participant 5: “I’ve got a really good network of friends who are really supportive who know about my diagnosis and they kind of, I think without them I wouldn’t have got through the crisis of when I was diagnosed, that made all the difference”.

Eight participants reported that certain individuals within their social networks had helped them, e.g., by communicating their positive qualities to them. The authors interpret the example below as friends helping the participant to challenge their negative thoughts, for example, by interrupting negative self-focussed rumination and reinforcing more positive self-appraisals.

Participant 1: “It helps when your friends remind you that you *are* a good person, that it’s just your illness talking and it’s not you talking and come on let’s get back to reality, and this is how it really is and this is what you need to mentally focus on”.

Six participants reported that aspects of their bipolar-related recovery, such as, feeling more emotionally stable, were associated with regaining control over some aspect of their social environment, such as, carrying out usual activities with friends.

Participant 8: “I know I’m getting better when I feel confident enough to go out and socialise again, it takes a lot but once I’ve done it I know I’m well on the road to recovery which is reassuring”.

Another factor which aided recovery from major mood episodes was being able to temporarily gain social anonymity. Two participants reported that feeling socially invisible helped to enhance their self-confidence.

Participant 8: “It helps with recovery because in a city I can feel invisible, because nobody’s interested in strangers because they’re just busy getting on with their own lives, it makes me feel a bit more confident, you can like do things and achieve what you want in life”.

Negative Effects of Social Experiences on Managing Bipolar Disorder

Twelve participants stated that other people often mistook behaviour they exhibited as being attributable to symptoms of bipolar disorder or as being indicative of an imminent acute mood episode, rather than benign behaviour. This was perceived as other people using bipolar disorder to explain their behaviour or finding it difficult to separate the person from the illness.

Participant 1: “She thinks, ‘oh well he’s just bipolar,’ it’s used as an excuse to explain a whole range of behaviours that might be nothing to do with being bipolar, it’s just my personality. I find that hard to deal with and it can create stress which is obviously no good for me”.

Participant 12: “It’s like you’re living on the edge because if you’re starting to feel a bit happy, you know just like a normal person would, I can see it in my kids, like my son will say, ‘are you alright mam? What are you cleaning that for? What are you doing that for? Why don’t you sit down?’ and it’s like I know he’s thinking in his head, ‘is my mam going high?’”.

Three participants also reported that social experiences, such as, those involving bereavement, could trigger negative bipolar-related experiences, such as, a loss of control.

Participant 9: “I always think ‘I’ll crack it this time, I’ll crack it this time’ but it’s things like if my mum was to die or something happens, I know it could affect me, I know an event can make me lose control, like [*sister passing away*], you know”.

Discussion

The aim of this study was to explore positive and negative appraisals of the reciprocal relationship between symptoms of bipolar disorder, perceived functioning and social interaction.

There are a number of novel features of the present study. First, it explores relationships between characteristics of social experiences and bipolar disorder from the perspective of the individual with bipolar disorder. Research investigating the impact of bipolar disorder on social factors has tended to elicit the main caregiver’s perspective, usually a spouse, partner or family member (e.g., Dore & Romans, 2004; Reinares & Vita, 2004). Although the current qualitative study identified three positive themes relating to bipolar disorder and social interaction, all participants reported that bipolar disorder has a negative effect on social experiences. These included damaged or broken relationships, a loss of social control, social disadvantages, the experience of mental health stigmatisation and poorer social functioning. Previous research has documented that caregivers perceived bipolar disorder as having created significant problems within the relationship (Dore & Romans, 2001) and the symptomatic experience of bipolar disorder, such as behavioural hyperactivity and social withdrawal, was difficult to cope with (Reinares & Vieta, 2004). This is somewhat consistent with the current work; however there were also clear differences. For example, caregivers have previously reported that their loved one’s experience of bipolar disorder had significantly impacted on the caregiver’s own employment and other social relationships (Dore & Romans, 2004), whereas this was not identified as a theme within the present study. This finding highlights the importance of taking into account both family and individual perspectives of the quality of social relationships, with a particular focus upon any discrepancies, in order to comprehensively inform family-based psychosocial interventions which aim to facilitate better understanding and effective communication.

Previous research investigating the social networks of individuals with bipolar disorder has tended to exclusively consider the negative impact that social factors, particularly low levels of social support, have upon the clinical course of bipolar disorder, (e.g., Cohen, Hammen, Henry & Daly, 2004; Kulhara et al., 1999; Romans & McPherson, 1992; Vieta et al., 2006). The adverse clinical impact of psychosocial stressors in bipolar disorder has been highlighted, such as, physical and verbal abuse in childhood, (Alvarez et al., 2011; Carballo et al., 2008; Garino et al., 2005), or negative life events (Antypa, Antonioli & Serretti, 2013; Azorin et al., 2009). These studies found that such stressors were significantly associated with severe negative clinical outcomes, including suicidal ideation and suicide attempts. The present study is novel in that it considered both positive and negative appraisals, hence presenting a more complete picture of social functioning in bipolar disorder.

Indeed, there is evidence that certain aspects of bipolar-related experiences can be highly valued by some individuals (e.g., Lobban, Taylor, Murray & Jones, 2012). People with a diagnosis of bipolar disorder have identified several perceived benefits of mood fluctuations, including, occupational and educational achievements (Murray & Johnson, 2010). A recent review of the literature focusing upon service user perceptions of the positive aspects of bipolar disorder found empirical evidence for the augmentation of five positive psychological facets, which were, (1) spiritualism, (2) empathy, (3) creativity, (4) realism, and (5) resilience (Galvez, Thommi & Ghaemi, 2011). Qualitative work focusing on perceived positives has also revealed themes relating to the intensification of perceptions and emotions, more effective communication and connectedness with other people, and an increased ease in the ability to undertake complex tasks (Lobban et al., 2012; Michalak et al., 2006). The present study both corroborated and extended this work by investigating social factors in more depth and demonstrating that individuals with bipolar disorder perceived some aspects of the disorder as having provided them with a definite social advantage. First, participants perceived that high mood enhanced their self-confidence and facilitated more effective social interactions. Second, being given a diagnosis of bipolar disorder was perceived to have helped family members to gain a better level of insight and understanding of the individual's problems. Third, bipolar-related experiences were said to have made participants more resilient to negative social experiences. Encouraging individuals to focus upon and enhance the positive aspects of bipolar disorder may help to protect against feelings of hopelessness which are commonly experienced in those with serious mental health problems (e.g., Hor & Taylor, 2010; Tarrier et al., 2013) and inspire both positivity and psychological resilience in the face of negative life stressors.

Studies which have examined the positive effects of social experiences upon bipolar disorder, such as social support, have tended to evaluate these experiences according to quantitative assessments which are constrained to dimensions pre-defined by clinicians or researchers (e.g., Jenkins et al., 2005; Rickwood & Braithwaite, 1994). By asking individuals with bipolar disorder which types of social experiences they perceived as being valuable in terms of helping them to

manage their mood, the present study ensured that key factors which were deemed important to the individual were not overlooked. Moreover, the present study enhanced current understanding of the ways in which social support impacts on mood in a clinical population, by providing information regarding the specific characteristics of social networks which service users valued in terms of facilitating better mood management. For example, when other people listened to and understood their bipolar-related experiences, or how reassurance from a friend changed negative thought processes. This type of information has clear applicability in psychosocial interventions which aim to target and reduce relapse rates in bipolar disorder.

Interestingly, twelve participants reported that other people were unable to differentiate their everyday behaviour from bipolar-driven behaviour. Participants reported that they often felt forced to censor their behaviour or to act in ways that their family or friends would perceive as non-bipolar related, e.g., Participant 20: “You have to withhold your emotions because if you react like someone normal, like you want to, then its ‘oh she’s going off her head!’, but you’re not”. Previous research investigating the psychological impact of monitoring and censoring behaviour have emphasised that maladaptive self-regulation or the repression of emotion can lead to poorer psychological wellbeing (Sheldon & Kasser, 1995). There is a clear need for interventions which promote more effective emotion regulation strategies and help to educate families to effectively distinguish between everyday behaviour and illness ‘early warning signs’.

There are two limitations which must be taken into consideration when interpreting the findings. The study had a fairly small sample size, which means that the findings may not be applicable to all individuals with bipolar disorder. However, qualitative interviews were necessary to conduct an in-depth investigation into the complex reciprocal interactions between characteristics of social relationships and functioning in bipolar disorder. It also ensured that the research was entirely service-user informed, because there is a paucity of research in this area.

The second limitation was that despite having 15 participants with bipolar I disorder and five participants with bipolar II disorder, the data was grouped together and analysed collectively. This may have meant that key differences between bipolar I and bipolar II may have been overlooked. This is particularly relevant because negative effects on social or occupational functioning constitutes part of the diagnostic criteria for bipolar I disorder but not for bipolar II disorder. Future work should aim to ascertain whether there are differences between bipolar I and II regarding these areas of investigation.

The present study highlights the importance of considering the reciprocal relationship between social factors and bipolar-related experiences. Future research should aim to, (1) identify the presence of each theme in larger samples of people with bipolar disorder and in different mood states, (2) ascertain the extent to which each social factor predicts prospective bipolar-related experiences longitudinally to elucidate cause and effect relationships, (3) investigate the hypothesis that enhancing feelings of authenticity in people with bipolar disorder would increase psychological wellbeing, (4)

explore the effects of factors such as stigma, locus of control and social anonymity in individuals with a bipolar disorder diagnosis.

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