Recoding Past Experiences

A Qualitative Study of How Patients and Family Members Adjust to the Diagnosis of Bipolar Disorder

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Abstract: Few studies have investigated the processes associated with patients’ reactions to the diagnosis of bipolar disorder, yet assisting patients to develop an acceptance of the condition is a core component of effective psychosocial interventions. This study explored the views and experiences of patients and family members about receiving a diagnosis of bipolar disorder and its implications for the future. We interviewed 17 people with bipolar disorder (7 diagnosed within the previous 12 months, 10 diagnosed 3–5 years ago), as well as 9 family members. Using the Phenomenology and Lived Experience framework to analyze the interview transcripts, we identified 3 key themes: (1) Misdiagnosis and growing awareness; (2) Accepting the diagnosis; and (3) Factors that may have facilitated an earlier acceptance. From the findings, we draw implications for clinicians.

Key Words: Bipolar disorder, diagnosis, acceptance.

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Aproximately 40% of people with bipolar disorder do not adhere to prescribed treatments (Lingam and Scott, 2002) and relapse rates are high. Treatment adherence is influenced by demographic, clinical, and treatment-related factors including age, gender, ethnicity, marital status, comorbidity, and adverse side-effects of medication (Colom et al., 2000; Sajatovic et al., 2007). Difficulties in accepting the diagnosis of bipolar disorder also compromise treatment adherence (Scott and Pope, 2002). Patients who accept their diagnosis and make a decision to take control of their condition achieve better outcomes, and the period immediately following diagnosis is particularly crucial in this regard (Newman et al., 2002). Further, a core component of most effective psychosocial interventions for bipolar disorder involves developing an acceptance of the illness (Crowe et al., 2010), yet few studies have explored the processes associated with patients’ reactions to the diagnosis of the disorder.

The family’s reaction to the diagnosis can also influence treatment adherence and illness management, by altering the patient’s attitudes to their illness and its treatment (Berk et al., 2010). Yet, we failed to find any studies exploring the views of family members following the patient’s diagnosis and, in particular, family members’ own experiences in accepting the diagnosis.

The aims of this study were first to explore, using qualitative methodology, the factors and processes surrounding the adjustment to a bipolar disorder diagnosis from the point of view of the patient and, separately, of individual family members, and second to compare patients’ and family members’ perceptions of the diagnosis and its implications for the future.

METHOD

Participants

Patients with bipolar disorder at 2 different points along the illness trajectory and family members were recruited through websites of the Black Dog Institute (http://www.blackdoginstitute.org.au) and the School of Psychiatry, University of New South Wales (http://psych.med.unsw.edu.au); community mental health organizations; the Black Dog Institute Community Programs; and a newspaper advertisement. Eligibility criteria included: either (1) diagnosis of bipolar disorder received within the past 12 months or 3 to 5 years ago or (2) having a family member who was diagnosed with bipolar disorder within the past 5 years; 18 or more years of age; able to read and write English; and currently living in Australia. To confirm diagnosis, participants with bipolar disorder were screened with the Mood Swings Survey (Parker et al., 2006).

Instruments

Interview Schedule

The study formed part of a larger project exploring the psychosocial needs of people with bipolar disorder and family members before and after diagnosis. A semistructured interview schedule was developed, with questions drawn from clinical experience and the literature on illness experience. Interview topics focused on the events prior to the diagnosis, the experience of the diagnosis, and postdiagnosis impacts. The interview was piloted with 4 people with bipolar disorder and adjustments were made on the basis of their feedback.

Mood Swings Survey

The Mood Swings Survey is a 30-item self-report screening questionnaire for bipolar disorder (Parker et al., 2006). Three items probe for depressive and manic/hypomanic episodes, while the remaining 27 items assess, on a 3-point Likert scale, the presence and intensity of symptoms associated with manic/hypomanic episodes. Scores range 0 to 54 with a score of 22 or more suggesting the presence of a bipolar I or II disorder.

Demographic information was collected about participants’ gender, age, marital status, area of residence, and current employment status. Participants with bipolar disorder were also asked about the nature of their illness including the duration of episodes and pattern of cycling.

Procedure

After providing written informed consent, participants took part in the interviews which were audio-recorded and later transcribed verbatim. Consistent with qualitative research methods, we...
used a purposive sampling strategy and we sampled to saturation. Participants were reimbursed for their time and travel expenses. Ethical approval for the study was granted by the University of New South Wales Human Research Ethics Committee (HREC 09219).

Analysis
Transcripts were analyzed and coded for themes using the Phenomenology and Lived Experience framework (Todres and Holloway, 2004) which explores the essence of individuals’ experiences and the meanings they use to make sense of them. Primary identification of themes and areas of divergence was carried out by the first author and reliability was checked by the second author. Discrepancies were resolved through discussion.

RESULTS
Seventeen individuals diagnosed with bipolar disorder and 9 family members participated in the study. Participants were recruited from 3 Australian states and 2 territories, covering both metropolitan and rural areas. The family members were not related to the participants with bipolar disorder. Seven participants with bipolar disorder had been diagnosed within the past 12 months (71% female; age range = 28–62 years; mean age = 42.0 years, \( SD = 11.2 \); 86% married/de facto relationship; 57% employed) and 10 had been diagnosed 3 to 5 years ago (70% female; age range = 26–49 years; mean age = 42.3 years, \( SD = 7.2 \); 60% married/de facto relationship; 60% employed). Clinical information about the participants is presented in Table 1. The 9 family member participants were 78% female, with an average age of 39.6 years (SD = 42.3 years, \( SD = 11.8 \)), age range = 23–56 years; 56% were married; 78% were employed. Five were siblings of a person with bipolar disorder, 2 were parents, 1 was a spouse, and 1 was an offspring.

<table>
<thead>
<tr>
<th>Variable</th>
<th>( n )</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis</td>
<td>Mean (SD), 39.65 (9.03)</td>
<td>Range, 21–62 yr</td>
</tr>
<tr>
<td>Age at first depressive episode</td>
<td>Mean (SD), 23.29 (11.74)</td>
<td>Range, 4–49 yr</td>
</tr>
<tr>
<td>Age at first (hypo)manic episode</td>
<td>Mean (SD), 26.20 (13.64)</td>
<td>Range, 7–59 yr</td>
</tr>
<tr>
<td>Most frequently experienced episode</td>
<td>Depression</td>
<td>14</td>
</tr>
<tr>
<td>Average length of depressive episodes</td>
<td>&lt;1 wk</td>
<td>4</td>
</tr>
<tr>
<td>1–4 wk</td>
<td>4</td>
<td>23</td>
</tr>
<tr>
<td>1–2 mo</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&gt;2 mo</td>
<td>9</td>
<td>54</td>
</tr>
<tr>
<td>Average length of (hypo)manic episodes</td>
<td>&lt;1 wk</td>
<td>5</td>
</tr>
<tr>
<td>1–4 wk</td>
<td>6</td>
<td>37</td>
</tr>
<tr>
<td>1–2 mo</td>
<td>2</td>
<td>13</td>
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<tr>
<td>&gt;2 mo</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>No. hospitalizations</td>
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<td>8</td>
</tr>
<tr>
<td>1–2</td>
<td>7</td>
<td>41</td>
</tr>
<tr>
<td>&gt;2</td>
<td>2</td>
<td>12</td>
</tr>
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Interviews lasted 19 to 98 minutes and transcript analysis identified 3 broad themes: (1) Misdiagnosis and growing awareness; (2) Accepting the diagnosis; and (3) Factors that may have facilitated an earlier acceptance.

Theme 1: Misdiagnosis and Growing Awareness
After several episodes of depression or mania/hypomania, many participants (both those with the disorder and family members) described a growing realization that they needed help. Consultations with health professionals were described as unhelpful, mainly because they resulted in misdiagnosis (predominantly unipolar depression if participants presented during a depressive episode, or either a psychotic disorder or anxiety if they presented during a hypomanic/manic episode). Reasons for misdiagnoses varied. Some participants did not report all their symptoms, particularly those associated with manic/hypomanic episodes, because they found them pleasurable or, in the case of family members, they felt relief that their loved one was active and happy. In other cases, doctors failed to recognize the disorder, even when participants drew attention to the symptoms or a familial history of mental illness. Some participants sought second opinions or tried different medications without relief and with increasing levels of disability. Others described how they came to view themselves as “defective,” feeling guilty about their behavioral excesses and being debilitated by crippling periods of depression. They also described the negative impact on their families and the struggle to manage jobs, homes, and relationships. Some referred to a growing awareness during these years that they might have bipolar disorder.

Theme 2: Accepting the Diagnosis
The second theme consisted of 2 parts:

Subtheme 1: Initial Reaction to the Diagnosis
Participants generally reacted more positively to the diagnosis if they had suspected that they or their family member had bipolar disorder, or they had access to information about the disorder which fitted their life experiences.

Participants Diagnosed With Bipolar Disorder
Two levels of acceptance were highlighted. The first involved accepting the diagnosis as a means of explaining their symptoms and current life experiences. The second concerned not only accepting the label of bipolar disorder, but coming to terms with the implications of having the condition, both at present and in the future. The majority of participants with bipolar disorder reported achieving the first level of acceptance on diagnosis. Some described a sense of relief because the diagnosis validated previous feelings and experiences. However, most participants did not accept the full implications of the diagnosis for some time after diagnosis. Reasons included an unwillingness to accept the long-term treatment or lifestyle changes necessary to effectively manage the illness, such as having to take medications for the rest of one’s life, and needing to learn a new “framework” for living life.

“It felt like a totally new framework, like you had always been speaking English and now you will be speaking Chinese and you’ve got to write in Chinese and everything you read will be in Chinese. It’ll be the same you, same experiences, same job, but everything is now Chinese. It’s always been Chinese you just thought you spoke English. I’ve had to recode all my past experiences.” (female, aged 39, diagnosed 7 months ago).

Several reported that their inability to accept their diagnosis restricted the number of people to whom they disclosed their illness out of fear of being stigmatized, which in turn affected the amount of support they received at a time when they needed it most. Of note, many reported that, despite not accepting their diagnosis, they took...
the medication that was prescribed to them on diagnosis. One participant explained the apparent contradiction: "I'm very compliant because I know I don't ever want to get sick, to what I was before." (female, aged 49, diagnosed 4 years ago).

**Family Member Participants**

The majority of family members reported accepting the patient’s diagnosis when it was made. Many felt relieved because it confirmed their suspicions; however, 2 family members (whose adult children had bipolar disorder) reported finding it difficult because they were concerned about the burden on their offspring of having a mental illness.

**Subtheme 2: Adjusting to the Diagnosis**

**Participants Diagnosed With Bipolar Disorder**

The majority told how they adjusted to their diagnosis by learning more about the disorder and its impact on their own symptomatology and life experiences. Some participants reported that time was the key factor in coming to accept their diagnosis. For others, symptom reduction from the medication, telling other people about the diagnosis, receiving support from family members, confirming the diagnosis with a second opinion, attending support or education groups, and processes such as mourning the loss of the “prediagnosis” self facilitated acceptance.

**Family Member Participants**

Similar to participants with bipolar disorder, the majority of family members reported that learning more about the illness and understanding its effects helped them to accept the diagnosis. One participant described how she accepted her husband’s diagnosis: “I was informed, I had a lot of information. I’ve been with him for 30 years and everything was fitting too perfectly. The more you understand the illness, the more you can actually see it.” (female, aged 49, family member).

Another described how her daughter’s acceptance of her diagnosis helped her accept it. Yet, several family members still held concerns about their loved one having a mental illness and what the future held.

**Theme 3: Factors That May Have Facilitated an Earlier Acceptance**

**Participants Diagnosed With Bipolar Disorder 3 to 5 Years Ago**

Participant reaction was divided. About half reported that nothing would have facilitated an earlier acceptance of their diagnosis, because they needed to undergo their life experiences to reach an acceptance. The remaining participants felt that they may have accepted the diagnosis sooner if there were increased societal awareness and decreased stigmatization and labeling associated with bipolar disorder, or if they had had greater support from family and friends, more education and information on the illness immediately following diagnosis, and earlier access to treatment.

**Family Member Participants**

About half reported that nothing would have facilitated their earlier acceptance of the diagnosis, because their information gathering and previous experience with mental illness (either personally or within their family) were the keys. The remaining relatives proposed a range of factors, including increased public awareness of the disorder to make it more easily identifiable; having the illness explained to family members; and being more involved in treatment planning with doctors and other mental health professionals.

**DISCUSSION**

The diagnosis of bipolar disorder came as a relief for many participants and this fits with other research. For example, in one of our previous studies (Proudfoot et al., 2009), newly-diagnosed participants reported that the diagnosis legitimized their illness and provided meaning for their experiences. In contrast, some participants in our current study—both those with bipolar disorder and family members—reported finding the diagnosis anxiety-provoking and disturbing, primarily due to the implications of having a chronic illness and the need for life-time treatment. Of particular concern was the stigma associated with bipolar disorder, which is consistent with other research involving patients and caregivers (Gonzalez et al., 2007; Hayward et al., 2002).

Psychoanalytic and grief theories utilizing the constructs of acceptance and denial have been proposed to explain patients’ responses to the diagnosis of a chronic illness (Telford et al., 2006). However, while bipolar disorder is a chronic illness, staged models of adjustment do not fully capture the dynamic outlined by our participants. Kubler-Ross (1969) proposes that individuals move through 5 sequential stages of emotional adjustment: denial, anger, bargaining, depression, and finally acceptance. Certainly our participants talked about denial and acceptance, and some who did not accept the diagnosis described how they subsequently became depressed, but it is not known whether their depression was related to nonacceptance of the diagnosis or to the chronic recurring nature of the condition. Furthermore, the experiences of our participants in coming to accept the diagnosis did not fit within the sequential pattern.

Our data support an alternative model, similar to the Shifting Perspectives Model of Chronic Illness proposed by Paterson (2001). People experience changing perceptions, expectations, needs, and attitudes in relation to their chronic illness as they interact with others, experience an exacerbation of symptoms, or perhaps are subject to stigma, whether public or internalized (Corrigan et al., 2005). Rather than following a series of stages, the salience of the illness ebbs and flows in patients’ lives and those of family members. Paterson suggests that the implication for health professionals is to understand and support their patient’s current perspective as a valid response to their specific situation.

Our qualitative data do not support previous research which found that diagnosis acceptance was related to treatment adherence (Scott and Pope, 2002). Some of our participants reported that they were compliant with their prescribed medication, even if they did not fully accept the diagnosis of bipolar disorder, because they preferred to do whatever was prescribed to avoid relapse. Thus, while treatment nonadherence is an ongoing problem in bipolar disorder, our data suggest that the reasons are more complex than nonacceptance of the diagnosis.

Our study is unique in that it also explored the experiences of family members. To date, research involving family members has focused primarily on those in a caregiving role and has been restricted to the burden on, and support needs of, caregivers (e.g., van der Voort et al., 2009). While important, this research fails to consider the noncaregiving members of a patient’s family, their reactions to the diagnosis and their influence on the patient’s adjustment to diagnosis. In our research, 5 of 9 of the family member participants were siblings, not caregivers, and their stories provided a different perspective. On the one hand, they were relieved to have a diagnosis that provided an explanation, but on the other, they feared the debilitating and stigmatizing implications of the illness over the long-term.

The study had a number of weaknesses. First, the sample was self-selected and therefore the risk of bias cannot be overlooked. While we did not advertise the study as focusing on acceptance of the diagnosis, it is conceivable, for example, that we attracted participants who had particularly extreme or negative experiences of the diagnosis process. Second, we did not assess comorbidity with other disorders, which may have affected participants’ reaction to...
their diagnosis and to their medication compliance. Third, our sample was small. Further research is therefore needed to confirm our findings.

Despite its limitations, our study provides implications for health professionals. Significant advantages can be gained from taking time to explore the initial reactions of patients and family members to the diagnosis of bipolar disorder, helping them to understand the condition, clarifying the role the family can play, and supporting the varying perspectives they may hold as they journey along the illness trajectory.

CONCLUSIONS

Taken together, these results contribute to the nascent qualitative literature, providing insights into the experience of bipolar disorder from the perspective of the patient and their family members.

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REFERENCES


