What happens after diagnosis? Understanding the experiences of patients with newly-diagnosed bipolar disorder

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Abstract

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Bipolar disorder is chronic condition involving episodes of both depression and elevated mood, associated with significant disability and high relapse rates. Recent estimates suggest a lifetime prevalence of 5%. Little is known about the subjective experiences of patients after receiving a diagnosis of bipolar disorder, and the impact of these experiences on patients' willingness and ability to work with their health professionals to find the most effective combination of treatments and to set up self-management plans.

Objective This paper describes a qualitative study exploring the experiences and difficulties faced by patients after they have received a diagnosis of bipolar disorder, as expressed online to expert patients trained to provide informed support.

Design Qualitative study.

Setting Online communication within a public health service setting.

Participants Twenty-six participants with recently-diagnosed bipolar disorder communicated online with 'Informed Supporters', people who had been managing their bipolar disorder effectively for 2 years or more, as part of an online psycho-education programme.

Results Participants cited unwanted side-effects of medication, coping with unpleasant symptoms, positive and negative reactions to the diagnosis, identifying early warning signs and triggers of the illness, the loss of a sense of self, uncertainty about their future and stigma as issues of major importance after diagnosis.

Conclusions Personal concerns and difficulties following diagnosis can undermine effective treatment, thwart self-management efforts and interfere with effective functioning. Such data are important for clinicians to take into account when they work in partnership with their patients to fine-tune treatments and help them set up self-management plans.

Bipolar disorder is a chronic condition characterized by periods of both mania/hypomania and depression, with a lifetime prevalence rate of 1.3% and more recent estimates suggesting a lifetime risk of 5%.^{1,2} It has been rated the sixth leading cause of disability in the world and individuals with the disorder are four times more disabled than the general population.^{3,4} Bipolar disorder can be difficult to detect, because of its varied and often subtle presentation, and while onset is typically in adolescence and young adulthood, accurate diagnosis can take 10–20 years.⁵ Little is known about the concerns patients face after receiving a diagnosis of bipolar disorder and how these issues impact on their ability and willingness to work with their health professionals to find an optimal treatment regimen and to set up effective self-management strategies to control the condition. What is known is that poor treatment adherence and inadequate self-management are common in bipolar disorder,⁶ with 40% of patients relapsing within 1 year, 60% over 2 years and 73% over 5 years.³ Recurrent episodes of mania and depression, as well as associated anxiety, alcohol and drug abuse, relationship difficulties and employment problems, all contribute to the disease burden. Approximately 25% of patients attempt suicide and 10–20% complete suicide: the suicide rate is the highest of all psychiatric conditions.⁵

Patient-centred education, self-management training and support after diagnosis assist patients to develop helpful illness perceptions (e.g. of being in control of the illness, rather than it controlling them), which in turn, enhance treatment adherence and self-management.⁶ However, the challenge for health professionals lies in understanding the personal and psychological issues experienced by patients after diagnosis, and providing targeted education and support in a sensitive, timely and non-stigmatizing manner. Much research to date, such as that on medication non-adherence in bipolar disorder, has focused on demographic and clinical predictors of the non-adherence. Recently, however, the need for research that considers patient-centred ‘active processes’ has been high-

lighted.⁷ More broadly, there is a need to examine patients’ subjective and lived experiences of the disorder, to understand the personal issues and difficulties they face at and after diagnosis which may undermine treatment adherence, thwart self-management efforts and interfere with effective functioning.

However, many patients are reluctant to discuss their more personal issues with their clinicians, fearing that their situation is atypical, and that their clinician will either be judgmental or not understand them. Other patients with a longer duration of diagnosed bipolar disorder have spoken of the need to approach several doctors to find one who was not only competent, but also empathic and prepared to take on a ‘difficult’ case long term.⁸ Such experiences mould patients’ conceptualizations of their illness, which in turn can interfere with effective functioning.

Whilst there is an extensive research literature on patients’ experiences of mental illness more broadly, there is a shortage of research on the experience of living with bipolar disorder. Furthermore, to our knowledge, there has been no previous research on patients’ experience following the diagnosis of bipolar disorder, which is especially salient seeing that this is a critical time in the illness trajectory of a patient with this condition. The earlier patients accept their condition and learn how to control ‘it’, the better the long-term outcomes. Yet for reasons not fully understood, many patients ignore or deny their illness, thereby delaying the take-up of effective treatments. Two reasons include patients having suffered many years of incorrect diagnoses and treatments with associated disability and distress before being correctly diagnosed; and secondly having medication as the main treatment for the condition – a long-term proposition and where side-effects can be distinctive. More subtle reasons for patients taking up the reins of self-control, or not, following diagnosis are less ready to be identified.

The aim of this study was to investigate the subjective experiences of patients after they have received a diagnosis of bipolar disorder. Using a qualitative methodology, we aimed to explore

the question: What issues and concerns are experienced by people who have been diagnosed with bipolar disorder in the previous 12 months, as expressed via email to expert patients (individuals who have been managing their bipolar disorder effectively for 2 years or more and have received training to provide support)?

Methods

This study was part of an ongoing randomized controlled trial evaluating the effectiveness of an online bipolar disorder psycho-education programme in helping recently diagnosed patients adjust to their diagnosis and gain control of their illness.

Participants

Participants were recruited through the Black Dog Institute clinic; the Black Dog Institute website (<http://www.blackdoginstitute.org.au>); community mental health organizations; advertisements in the media; and information distributed to general practitioners and psychiatrists, and their support organizations, throughout Australia. To be eligible for the study, participants needed to be 18+ years of age; diagnosed with bipolar disorder by a general practitioner or psychiatrist within past 12 months; currently seeing a health professional for the treatment of their bipolar disorder; had access to internet, email, and printer; computer literate; living in Australia; able to read and write English; prepared to take part in the 6 month study and scored 22+ on the Mood Swings Questionnaire, which confirmed their diagnosis of bipolar disorder.⁹

Interventions and sampling

Within our randomized controlled trial, participants were randomly allocated to receive the online Bipolar Education Programme (Table 1) or to an attention control condition consisting of online information about bipolar disorder. All participants received one education module per week for 8 weeks. The online education

Table 1 Content of the online bipolar education programme

Module	Topic
1	Diagnosing bipolar disorder
2	The causes of bipolar disorder
3	Medications
4	Psychological treatments
5	'Stay Well' plans
6	Carers and support networks
7	Omega-3 as a treatment of bipolar disorder
8	'Person First, Illness Last' and conclusion

program was delivered in two formats: (1) on its own or (2) with the addition of email support from Informed Supporters (people with bipolar disorder who have been effectively managing their condition for at least 2 years and who are trained to provide support to those newly-diagnosed with the condition). This study reports data from the email exchanges between participants and their Informed Supporters about their lived experience of bipolar disorder. Our participants constituted a convenience sample from our larger randomized controlled trial.

Procedure

Before commencing the trial, the four Informed Supporters (one female and three males) completed an 8-h manual-based training program, which was followed by supervised email support of at least two pilot participants over 8 weeks. As part of the study protocol, participants were invited to write to their Supporters weekly to discuss their subjective experiences, difficulties or issues of concern about bipolar disorder. No limit was placed on the number of emails from participants, nor were any constraints imposed on the type of issues raised by participants. Supporter contact was limited to two emails of 300 words maximum each per week per participant. Regardless of whether they received a response, Informed Supporters emailed their participants at least once weekly, raising issues associated with the modules of the online education programme (Table 1) and providing comment, advice, first-hand

experience on how they had dealt with issues raised by participants, or the advantages to be gained from a certain course of action. All emails were copied to the first author. Those from Informed Supporters to participants were assessed for fidelity with good practices, whilst emails from participants were monitored by the first and last authors for adverse events or indications of severely low mood. If either of the latter occurred, an email was sent to the participant advising him/her to contact his/her health practitioner immediately. (As the study was not a treatment study, we were unable to offer clinical treatment. This was outlined clearly in the consenting process and it was an inclusion criterion that participants continued to see their mental health professional throughout the study.) Supervision meetings attended by all Informed Supporters were held monthly during which specific issues and concerns raised by participants in the preceding month were discussed. Ethics approval for the study was gained from the Human Research Ethics Committee of the University of New South Wales.

Analysis

Participants' emails were analysed and coded for themes utilizing the Phenomenology and Lived Experience framework.¹⁰ Developed by Edmund Husserl, this approach aims to explore how individuals make sense of the world in terms of the meanings and classifications they employ – 'the essence of consciousness as experienced from the first-person point of view'.¹¹ Applied to illness, the model proposes that by capturing patients' subjective experiences (in this case, of bipolar disorder immediately following diagnosis) a deeper understanding of the way the disorder is experienced can be gained. Consistent with the approach, the use of a conceptual framework to inform or interpret participant responses was avoided as being too constraining, and instead data were analysed inductively using the method outlined by Pope & Mays (2006).¹² This five-step approach involves familiarization with the data, identifying key issues, concepts

and themes, charting and distilling data for each theme, and finally interpretation. Two levels of analysis were undertaken: first, the data were reviewed for each participant and recurrent themes were identified and coded; and second, common themes and areas of divergence were identified through constant comparison across participants and emails. The data were analysed by the third author and the reliability of the analysis was checked by the first author. Where discrepancies were found, they were resolved through discussion and consensus. In keeping with the emphasis of phenomenological studies, our approach was not to generate wider explanations, but to provide research accounts of individuals in a specific situation and setting.¹³ The most prevalent themes are reported in this paper.

Results

Consistent with other qualitative studies, the results and discussion sections in this paper are amalgamated to provide context for the data. Twenty-six participants (54% female, age range 18–59 years), who were randomly allocated to the Informed Support arm of the study within the randomized controlled trial, were invited to participate in email communication with an Informed Supporter for 8 weeks, in addition to receiving the online modules. According to the number of emails each participant sent to their Informed Supporter throughout the 8-week programme, participants were categorized into high (4), medium (7), low (12), and nil (3) responders, with 12 emails as the most sent by a participant over the 8-week programme. Analysis of participants' emails identified seven major themes in the data. Because of space constraints, the narrative data reported here are illustrative rather than exhaustive.

Ambivalence about taking medication

As bipolar disorder is a biological condition with a strong genetic component, treatment primarily involves the long-term use of medications with regular monitoring, including

blood tests. Side-effects can be severe and a significant proportion (some studies suggest 40%) of patients do not adhere to prescribed medication. Typically patients receive their first prescription for medication on diagnosis. Many participants in our sample were troubled by their medication. Significant concerns were expressed about the negative side-effects and the impact of medication on other areas of their lives, such as blunting their creativity, reducing their energy levels, increasing their weight. Some participants also expressed frustration associated with trialling different medications to find the right combination for them, and the wait they had to endure to ascertain if the 'cocktail' was correct for them.

I have tried many different medications already and am wondering if there really is one that will work for me...how well it will work...will I still have highs and lows?

Generally, however, it was thought that the negative side-effects were bearable if they felt the benefits from the medications.

The impressions I will always carry with me from when I was first medicated 9 months ago are, first, 'so this is what a zombied-out mental patient feels like'. But it was also fantastic to realise what a 'normal' person felt like. I felt so happy and alive; so different from the past 30 years.

Nevertheless, a proportion of patients initially refuse to take medication, either preferring other forms of treatment or none at all.

When I first went to my GP about my symptoms, she asked whether I wanted to see a therapist or a shrink. I chose a therapist because I was afraid of the drugs. I ended up a drugged out zombie anyway, but I'm glad I chose the therapist first as I believe that talking about my situation helped me immensely to come to terms with it, instead of just being loaded up with a showbag of colourful drugs and sent on my way.

While pharmacotherapy is the primary treatment for bipolar disorder, patient adherence is a central problem, leading to the high rates of relapse.¹⁴ The medication concerns expressed by participants in our study draw attention to some of the reasons for low

compliance. Assisting patients to understand that it might take some trial and error and a significant amount of time to experience the full benefits of medication, as well as encouraging them to also pursue psychological treatment may result in better adherence to medication.

The impact of bipolar symptoms

The occurrence of bipolar symptoms was of great concern for participants when it came to management and the experience of the highs vs. the lows. A few participants even went so far as to assert that the thought of an oncoming episode was terrifying to them.

About a fortnight ago, I started to feel really good but became scared that a high was coming on and it would only be followed up with another bout of depression, and it is that that scares me the most.

Several participants commented on how they enjoyed their manic symptoms, however, one participant described the opposite, reporting that she preferred the lows to the highs as the depression gave her a sense of control.

My depression makes me feel good. I feel that I am totally in control of everything when I am depressed. The mania terrifies me, the thoughts run through my mind like a speed train and I hate it.

As well as describing their symptoms, both physical and emotional, participants wanted to know how their Informed Supporter experienced and managed his/her symptoms.

I am currently in a mixed episode and it feels strange. I feel wired and have a racing mind but also depressive thoughts. Have you experienced a mixed episode?

Positive and negative reactions to diagnosis

Bipolar disorder is frequently misdiagnosed and often people remain untreated or are given incorrect treatments for many years. Several participants reported feeling disbelief, shock, denial and anger at their diagnosis.

I was diagnosed about 8 months ago and I feel I am partly in denial, even though I know that my moods are extreme, I can see myself in what I read about bipolar and I trust my doctor.

Alternatively, some participants who had experienced a long delay before receiving a correct diagnosis reported relief at finally having a name for the symptoms they had been living with for years.

It was such a relief to know what was wrong with me was 'fixable' and I wasn't crazy.

Others still spoke about the process of 'coming to terms' with or 'confronting' their diagnosis of bipolar disorder. Acceptance of the diagnosis has been shown to be a contributing factor to patients' staying well.¹⁵ Effective treatment regimens are more likely to be followed, and patients are more able to identify triggers or early warning signs prior to an episode. Failure to accept diagnosis, in contrast, has been related to medication non-adherence.¹⁶

The challenge of identifying early warning signs and triggers

The ability to recognize triggers and early warning signs of an approaching episode is important clinically and was considered by our participants to be central to controlling their bipolar disorder. Some expressed distress that they found the triggers and signs so difficult to identify.

I know what I'm like when I'm depressed and when I'm high, however the triggers are really difficult for me to identify. I generally feel myself going downhill but it's so quick.

Other participants struggled with what the recognition of triggers and early warning signs implied:

It's a lot to ask of ourselves, to identify and then try to modify behaviour that is deeply ingrained in our minds.

Personal triggers nominated by our participants included change in season, changes in sleep, work related stress, family stress, hormones and

caffeine. Daily mood charting has been found to be an effective strategy to help patients identify triggers and early warning signs as it allows them to recognize patterns over time.¹⁷

Questions of identity: who am I?

For some, existential questions such as what their diagnosis means for them and their sense of self were a major concern.

My biggest issue is coming to terms with the loss of who I am, and that I sometimes feel I cannot be the person I once thought I was.

I am continually wondering whether I am really sick or is this just my mind? I hate it that I don't know my own mind and don't know when to trust my feelings!

Medication was also linked to the loss of identity for some participants in that they felt it robbed them of their fundamental feelings of normality.

.....Then there are the middle times thanks to the medication. The times where I can be productive, friendly and social. The times where I show interest and am vibrant. But at the same time, I never actually feel like myself.

Participants reported not knowing whether to trust themselves and questioning whether or not what they were experiencing was real. They understood that while they were depressed they were ill, but they found it harder to comprehend that while they were 'happy' they were also unwell. Bipolar symptoms, especially those associated with elevated moods, can be attributed to other causes such as personality traits (for example, 'creative' or 'energetic'). Yet the illness can cause employment problems, financial difficulties and relationship breakdowns⁵ – and which may have been previously conceptualized and integrated into the person's sense of self in a certain way. After diagnosis, such experiences require re-thinking, re-casting and re-attributing. Helping patients to develop an identity apart from someone who is ill is a priority in psychiatric rehabilitation.¹⁸ Therefore clinicians can benefit from knowing about the feelings of confusion

and loss of self that many patients experience when diagnosed with bipolar disorder.

Uncertainty about the future

Participants questioned what the diagnosis of bipolar disorder meant in terms of the rest of their life, and whether it was possible to ever lead a normal life. Understanding that bipolar disorder is a recurrent and chronic mental illness raised significant concerns.

The only thing I don't like, working through this, is the feeling of inevitability that bad times will happen again.

Participants also questioned what bipolar disorder diagnosis meant in terms of employment, relationships and family and whether or not they could make the necessary changes in their lives.

Thoroughly miserable week. I was having big issues about bipolar and how I hate the person I've become.

The image and effect of stigma

The stigma associated with having a serious mental illness was both distressing and frustrating for participants.

I don't know who to tell that I have bipolar disorder. I told a friend over a week ago and I have not heard from her since. I feel really angry about this because I expected to have her support.

Other participants discussed the fear they held of losing support people if they told them about their illness.

There are others I would like to share things with, but I don't want to lose anyone else at the present time and it's a risk I'm not willing to take.

Stigma was also viewed as contributing to the isolation of the illness.

I am not so good at asking for help from my family and friends. And their response is they tend to retreat, leaving me alone – a bit of the social stigma coming out. And they don't want to 'say the wrong thing'. People don't know what to do and this can make the episodes of illness more isolating.

Much of the stigma reported by participants involved family members and close friends, which reinforces the importance of information and education for family and friends to maximize opportunities for the person to receive support in times of need. Those with strong support systems are also more likely to adhere to treatment and better manage their illness.¹⁹ Stigma frequently results from a lack of understanding of the illness, not only by the general community but also by some health professionals, and it can be exacerbated by the health care system and practices.²⁰ Our participants reported that having access to an informed supporter was helpful in decreasing stigma and reducing the sense of vulnerability and social isolation associated with the illness. Nevertheless, extensive community education about the nature of bipolar disorder is needed to reduce stigmatizing social expectations and actions.

Discussion

This study explored patients' subjective experiences when newly diagnosed with bipolar disorder, as expressed to 'expert patients' who had been trained to provide structured email support. Participants described having to exert significant day-to-day toil to deal with unwanted symptoms and medication side-effects, to manage illness triggers and prodromal states, and they seemed to use a biomedical model to frame their experience of those aspects of their illness. However, they also placed a subjective meaning on the diagnostic label of 'bipolar disorder' and they questioned in an existential way what the diagnosis meant about them as a person and its implications for their future. Of particular concern to participants was the stigma associated with the label. Health care system pressures can cause significant treatment delays, which together with the tendency of health professionals to involve police and emergency services for crisis intervention, can reinforce stigmatizing notions that people with bipolar disorder are dangerous, unpredictable or reluctant to seek care.⁸ At the

same time, lack of understanding about the illness by friends, family and the community can lead them to the creation of social distance, and so a downward spiral is set up: stereotypes are internalized, reducing the self-esteem and self-efficacy of those who have been labeled mentally ill and causing unintended changes in behaviour, such as social withdrawal and reduced engagement with services.²¹

Both clinical experience and research suggest that gaining a diagnosis legitimates a person's illness, both to the self and the wider social world, and it gives meaning to the illness experience, which is often uncertain and confusing.²² Unlike many physical illnesses and some mental illnesses (such as mild to moderate depression), bipolar disorder tends to be visible and so the legitimacy of the diagnosis is not called into question (cf Sim & Madden, 2008²³). However, our participants were divided as to whether they placed a positive meaning on their recent diagnosis (for example, it allowed them to change their attribution for past events from 'characterological defect' to 'neurochemical imbalance') or a negative meaning (for example, it implied they were mad).

Our participants provided rich illness narratives to their Informed Supporters, but what is not known is the degree to which their conceptualizations of their experiences were moulded by social expectations, by their healthcare professionals, by the healthcare services with which they had engaged, or indeed by the Informed Supporters themselves. What is clear, however, is that, if left unresolved, concerns such as those expressed by our participants can undermine take-up of effective treatments or lead to premature discontinuation, which, in turn, can result in exacerbation of symptoms, relapses, poor functioning and reduced quality of life.¹⁴ To pre-empt such negative outcomes, health professionals need to be aware of the issues commonly experienced by patients after diagnosis. Our research findings can be used as a springboard for discussions with patients, to assist them to develop suitable self-management plans and gain a sense of control over their condition.

This raises a question as to whether patients' illness experiences, such as those described in this research, should be treated at face value, or whether health professionals should help patients to re-conceptualize their illness so that they might experience it differently. The advantage of accepting patients' experiences at face value is that it ensures that treatment, education and support which are appropriate, collaborative and respectful can be provided. The alternative course of action – researchers or health professionals helping patients to re-conceptualize their illness – runs the risk of alienating patients, perpetuating stigma and adding to the burden of the disease. Our participants reported that learning from their Informed Supporter that others with bipolar disorder have felt a similar way after diagnosis 'normalized' their experience, reduced their feelings of isolation and facilitated their coping.

The online setting for the research also provided advantages. Online social and self-management support applications offer anonymity and privacy, and people are more willing to self-disclose online than face-to-face.²⁴ There is growing evidence of the acceptability of online applications,²⁵ with many people reporting that they actually prefer communicating via computers, rather than face-to-face, when their problems are of a sensitive nature.²⁶ The opportunity to communicate online with a person who is effectively managing the same illness offers further advantages, in that the online supporters can provide empathy, share real-life experiences, offer credibility and provide practical information and advice. Such 'virtual community care' highlights emergent issues for health and social policy about the place of lay knowledge and experience viz. a viz. the 'expert' knowledge of health professionals, and the changing nature of client-professional relationships^{27,28} These issues were evident in our research. Participants viewed the opportunity to discuss concerns with and ask questions of another person with bipolar disorder as particularly helpful, and they acknowledged the expertise of the Informed Supporters, especially in respect to their lived experience of the disorder.

Online communication also has disadvantages, such as creating an illusion of privacy and exerting limits on probing for elaboration. Mindful of these disadvantages, we took added steps to protect participants' anonymity, such as communicating only their first name and age to their Informed Supporter. We also encouraged the Informed Supporters to seek elaboration via their emails.

Illness narratives have an established place in the study of patients' illness experiences, and some of the themes that emerged from our data analysis reinforce those that have been identified in patients' narratives about other mental illnesses. For example, a study of how people with schizophrenia embody their illness found three primary themes: the illness as a catastrophic experience, illness mediating social relationships and medication side-effects as burdensome.²⁹ In a different study, Judge *et al.*¹⁸ found that people with emerging psychosis described the subjective experience of 'coming to terms with psychosis', for example realizing that past experiences that they believed to be authentic (e.g. delusions) were actually symptoms, questioning what was real and what was their illness.

Within the study of the experience of bipolar disorder, our research extends the limited though important qualitative work conducted to date, by targeting a broader range of issues beyond those relating to reasons for medication non-adherence¹⁵ or to patients' experiences with treatment services⁸, and by including any issues arising in patients' lives after diagnosis, a time when issues are often most salient and can be most distressing. We also extend previous research³⁰ by conducting our study with community-based, rather than hospital-based, participants.

Limitations of this study include the use of a convenience sample which may have prevented the capture of important perspectives from more difficult-to-reach people, and the fact that not all participants who were offered the online Informed Support utilized it fully. Furthermore, because the sample consisted of participants who met eligibility criteria for the randomized

controlled trial, it was not possible to sample to saturation. It is also entirely possible that the involvement of expert patients, with their intimate knowledge of bipolar disorder, as the 'data collection agents' rather than researchers, may have resulted in different data being collected. Similarly, the method of data collection via email within a randomized controlled trial may have constrained the extent to which particular issues or lines of enquiry could be probed. Despite these limitations, however, our results show that email support from non-clinicians within the context of an online psycho-educational program can assist patients to communicate a rich narrative about their experiences, meanings, issues and concerns following the diagnosis of bipolar disorder. Not only was the experience helpful, as reported by our participants, the information gained is of particular relevance for health care professionals when they develop treatment plans and assist their patients to gradually take control of their condition.

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