# Staying well with bipolar disorder

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**Objective:** The research aimed to investigate how people diagnosed with bipolar mood disorder avoided episodes of illness and managed to stay well. The research also examined the role that personal, social and environmental factors played in helping people with bipolar mood disorder to stay well.

**Method:** This project used a combination of qualitative research methods. The design contained three (3) components: recruitment from general community, preliminary written questionnaire and semistructured interviews. To meet the criteria for inclusion, the participant must have stayed well for the past 2 years. The two main analytical categories were 'stay well concept' and 'strategies to stay well'. The main category 'strategies to stay well' contained a number of subcategories. These subcategories were acceptance of diagnosis, mindfulness, education, identify triggers, recognize warning signals, manage sleep and stress, make lifestyle changes, treatment, access support, and stay well plans.

**Results:** 100 people were eligible for inclusion in the study. The sample included 63 women and 37 men. The ages ranged from 18 to 83 years, with 86% over the age of 30. Duration of time since last episode of illness ranged from 2 years to >50 years. In the sample, 76% of participants were in paid employment. In addition, 36% of participants were parents. Participants actively managed bipolar disorder by developing a range of strategies to stay well. These strategies were based on participants' individual needs and social contexts. The strategies included acceptance of the diagnosis, education about bipolar disorder, identifying both triggers and warning signals, adequate amounts of sleep, managing stress, medication and support networks.

**Conclusion:** Staying well involved participants being mindful of their illness, which enabled them to develop an individual stay-well plan, including intervention strategies to prevent episodes of illness.

**Key words:** bipolar disorder, health promotion, mental health, qualitative research.

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Bipolar mood disorder is an episodic illness. Although bipolar mood disorder is a common cause of disability [1], some people develop strategies to stay well and avoid relapses of mania and depression [2]. These strategies enable people with bipolar mood disorder to identify early symptoms of relapse and take action to prevent an episode of illness [3].

The aim of the current research was to focus on the collective expertise of one hundred people who lived well with bipolar mood disorder. The National Health and Medical Research Council (NHMRC) *Statement on Consumer and Community Participation in Health and Medical Research* referred to 'those most affected and intimately acquainted with the issues' as providing important insights into health research [4]. The expertise of people who stay well with bipolar mood disorder may also provide new insights for practice.

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Using standard qualitative methods, our research explored the diverse range of strategies that people with bipolar mood disorder used to stay well. The research was designed to answer specific questions about living with a mental illness that could not be accessed through quantitative analysis. Although qualitative research does not have the statistical power of quantitative research, nor the generalisability, qualitative research has its own value. In this instance, qualitative methods identified *how* people with bipolar mood disorder stayed well. The research also examined the role that personal, social and environmental factors played in helping people with bipolar mood disorder to stay well.

According to the World Health Organization, health is not merely the absence of disease or infirmity. Health is a state of complete physical, mental and social well-being [5]. This research explored the concept of 'health' and 'staying well' for people with bipolar mood disorder. In addition, participants identified a range of strategies used to prevent episodes of illness. Although the individual strategies for staying well differed among the participants, common themes were identified.

Like others who experience incurable chronic illnesses such as heart failure, diabetes mellitus, asthma and HIV [6–9], people with bipolar mood disorder developed strategies to manage the symptoms of their illness. The strategies identified were based on participants' individual needs and social contexts [10]. Some people used their own life experiences and circumstances to document their 'stay well plans'. Others used a verbal plan of action. These personal stay well plans were developed with others – partners, family, close friends, and health care professionals. The stay well plans were adapted and revised as required during the course of their illness in response to changing needs.

## Background

A critical review of the literature indicates that mental health research often relies on a convenience sample. Recruitment by convenience sampling limits the sample to those informants who can be easily recruited through mental health organizations, rehabilitation programs and consumer groups. People recruited via convenience sampling often provide different stories to those recruited in the general community [11].

By failing to include people with bipolar mood disorder who are not involved with mental health groups, positive accounts of living with bipolar mood disorder remain largely absent from the research literature. Instead, most social research into the experience of living with bipolar mood disorder focuses on the high rates of suicide, substance abuse, criminal behaviour, unemployment and divorce. For example, a recent study found that people with bipolar mood disorder are '4 times more disabled than the general population' [12]. Another study found people with bipolar mood disorder experienced social isolation, the failure of support networks and the breakdown of relationships [13].

To redress the balance, several autobiographical accounts have been written from a more positive consumer perspective [2,14,15]. Although these published accounts acknowledged that episodes of illness were often traumatic and disruptive, they also demonstrated that it was possible for people with bipolar mood disorder to lead fulfilling lives, including successful professional lives [15].

Bipolar mood disorder affects each person differently [16]. There are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder. Increasingly, researchers are pointing to the importance of individual differences in resilience and vulnerability as key determinants of the intensity and duration of episodes of illness. In a risk-protective model of resilience, a protective factor interacts with a risk factor to mitigate the occurrence of a negative outcome [17]. For example, high levels of sociopolitical control were found to limit the negative consequences of helplessness on mental health [17].

A number of studies have examined the role of specific personality variables in episodes of mental illness. Some studies suggest that personality variables such as high self esteem may play a role in moderating the effects of bipolar mood disorder [18]. In contrast, it has been shown that individuals with feelings of low self esteem, insecurity, lack of personal control, and alienation from others were more likely to experience higher levels of depression [19,20]. It has also been shown that social and environmental factors, such as social support, may also moderate the effects of bipolar mood disorder [21–23].

Determining the relative influence of individual predictors is important for the development of intervention strategies that are sensitive to individual differences [19]. However, it is also important to examine how these personality variables interact with life events such as stress [24]. A number of empirical studies show an interaction between stress and personality variables such as dysfunctional attitudes [25], depression prone personality [26], sense of humour [27], self esteem [28] self complexity [29] and perceived competence [30]. However, the relationship between life event and personality variable is dynamic. It has been shown that the impact of a particular stressor may decrease with time [31]. This may suggest that a life stress that initially triggers episodes of illness may enhance long-term resilience. It

also suggests that self understanding may play a role in developing individual resilience [32].

With bipolar mood disorder, stress can trigger both hypomania and depression, particularly stress that causes disruption to sleep [33,34]. Family stress is also a common trigger for people with bipolar mood disorder [33]. Other events that may contribute to increasing levels of stress include personal relationships, employment issues, and environmental factors. It is often difficult for people with bipolar mood disorder to avoid these day-to-day stresses. It is important therefore that people with bipolar mood disorder develop strategies to deal effectively with stressful events.

Research has shown that people with bipolar mood disorder can learn to both identify factors that may trigger episodes of illness and recognize early warning symptoms [3,35]. These early warning symptoms (prodromes) are idiosyncratic to both the patient and to the type of relapse (mania or depression). Once people learn to identify their early warning signs, they are often able to intervene early to prevent relapses of mania and depression. For example, research indicates that teaching people to recognize early warning signs of mania and seek early treatment significantly increased time to the next manic relapse and reduced the number of relapses [3].

## Method

To explore the types of strategies that people used to manage bipolar mood disorder, the focus of the research was only on people diagnosed with bipolar mood disorder who stayed well. Although the sample was not representative of all people who experience bipolar mood disorder, the current research fills an important gap in mental health research. By focusing on people who had developed strategies to manage stress and stay well, the research focused on a group of people who are often absent from research into bipolar mood disorder.

To recruit people with bipolar mood disorder who stayed well, it was necessary to use innovative recruitment methods to actively recruit people from the general community rather than mental health organizations. In November 2003, a media release was circulated to major Australian newspapers and radio stations. As a result, articles appeared in several major newspapers and 'Staying Well with a Mental Illness' was broadcast on national radio. In addition, a flyer was disseminated via professional colleagues and published on the internet. The recruitment strategies invited people diagnosed with bipolar mood disorder who stayed well to share their story about: the changes people make in their lives to stay well; the early signs of things going wrong; and what they do to prevent an episode of illness.

Within one month of launching the 'Stay Well' study in the media, 163 enquiries were received. Over a quarter of the initial enquiries came from those with bipolar mood disorder, family and friends seeking some sort of assistance. These people were unaware of support and information services that currently existed. They were given the contact details of appropriate support organizations.

From the 163 enquiries, 100 people self selected for inclusion in the study. The sample included 63 women and 37 men. The ages ranged from 18 to 83, with 86% over the age of 30. Duration of time since last episode of illness ranged from 2 years to >50 years. In the sample, 76% of participants were in paid employment. In addition, 36% of participants were parents.

Data were either written by the participant or collected through a personal interview with the researcher. To facilitate a detailed examination of the data, transcripts were entered into a computer software package designed for qualitative research [36]. The computer package, NVivo, was used to store and manage the data. Using NVivo, the transcripts were coded according to main themes that were identified in the data. The main categories were primarily determined by the interview schedule, though some new subcategories were identified from the data. The two main analytical categories were 'stay well concept' and 'strategies to stay well'. The main category 'strategies to stay well' contained a number of subcategories. These subcategories were acceptance of diagnosis, mindfulness, education, identify triggers, recognize warning signals, manage sleep and stress, make lifestyle changes, treatment, access support, and stay well plans. Data were compared and contrasted within and across categories and subcategories.

## Results

Consistent with other qualitative research articles, the results and discussion are presented together. The discussion is required to provide a context for the data.

### Stay well concept

In this study, 'staying well' meant different things to each participant. For some, it meant being free of symptoms and behaving 'normally'. For others, it meant being able to make choices and take control of their illness. A 29-year-old university student described how managing her symptoms had given her a sense of control over her illness.

> One of the best things I can say about my illness now is that I am not scared of it anymore. I believe that I have the power to control it. I have learnt how to manage my symptoms.

By gaining greater control over the illness, many participants became less fearful of the illness. With time, experience and insight, they described learning to minimize the impact that the illness had on their lives. Although they were all aware that the illness could not be cured, participants felt able to prevent relapses of illness.

For many participants, staying well involved separating themselves from their illness. A 54-year-old general practitioner was mindful that the medical diagnosis described only the illness. It did not describe him as a person.

> I see the problem as the manic depression and not me. I separate the two and see the need for me to be in control of the manic depression, so that it doesn't influence my life too much.

Although several participants stated that the illness was not a character flaw, personality trait or sign of personal weakness, they were aware that the diagnosis of bipolar mood disorder was perceived

negatively within the community. They felt that community attitudes were largely influenced by the way the diagnosis was applied. When participants were described as 'manic depressive' or 'bipolar', the medical diagnosis became a label that defined the whole person, not just the illness. A 40-year-old lawyer rejected this labelling.

> At some point I must loosen the tag on my forehead that says 'bipolar' and just get on with it. Otherwise I become obsessed about my illness and then I become my illness.

## Strategies to stay well

The data indicate a range of strategies that were used to stay well. The individual stay well strategies were based on participants' specific needs and social contexts.

### *Acceptance of diagnosis*

The first step in learning to stay well was receiving the correct diagnosis, and then accepting it. Unfortunately, many participants initially received an incorrect diagnosis. For them, the misdiagnosis of manic depression, and the subsequent mistreatment with incorrect medication, had serious implications for their quality of life. The most common misdiagnoses were clinical depression, schizophrenia, anxiety disorders, borderline personality disorder, and attention deficit disorder. A 35-year-old social worker felt health care professionals needed to take more care when taking a history.

> Unfortunately, the initial diagnosis and treatment was for schizophrenia, which was a bit of a nightmare only because the medication was all wrong and the doctor was not open to changing it. I needed to change doctors to get the correct diagnosis. My new doctor took a proper history, not just the presenting symptoms. With the correct diagnosis and treatment, I took more control over my illness.

Those participants who received the wrong diagnoses found the diagnosis of bipolar mood disorder a relief. Once he was correctly diagnosed, a 47-year-old librarian educated himself about bipolar mood disorder.

> Once you know what it is, you can deal with it. I've had bipolar mood disorder all my life, but it was not until I knew what it was that I could deal with it.

For many other participants, the diagnosis of bipolar mood disorder came as a shock. Data indicate that there was often a period of denial in which the diagnosis was not accepted. A 72-year-old retired judge had remained in denial for 20 years. Although he did not accept the diagnosis, he accepted the need to take lithium.

> It is 20 years since I have seen a psychiatrist and other than being told by my local GP that I should continue taking lithium each day as a precaution, I have not sought nor, in my opinion needed, any medical treatment.

### *Mindfulness*

The data indicate the importance of participants remaining 'mindful' that they have bipolar mood disorder. 'Mindfulness' involved participants being aware of themselves and how they were responding to their physical, mental, emotional, social and physical environment. By maintaining a degree of vigilance, participants were able to recognize when they needed to intervene with strategies to prevent episodes of illness. Mindfulness helped the following participant, a 52-year-old school teacher, to control the illness and minimize its impact on her life.

> I now understand the illness and its impact on my body. I move swiftly to intercept a mood swing.

According to the data, health care professionals often advised people with bipolar mood disorder to 'take their medication and forget about the illness'. Participants described this as 'bad advice'. Data indicates that people with bipolar mood disorder benefit from maintaining an awareness of the illness' presence. A 57-year-old parks and gardens superintendent believed his mindfulness assisted his wellness.

> I am able to assist in my wellness by being aware and observing what is happening to me. Sometimes I need to make changes to stay well.

Participants made many different changes to their lives in order to stay well. Data indicate that there was often a period of 'trial and error' in which participants learnt what strategies worked for them and what did not work.

### *Education*

Data indicates the importance of people with bipolar mood disorder learning about the illness. Participants learnt about bipolar mood disorder through books, health care professionals, mental health organizations, seminars, support groups, internet and talking with people. Participants felt that the sooner they accepted their illness, and learnt about it, the better chance they had of managing it.

In addition to being educated about bipolar mood disorder, participants described the importance of learning about their own individual response to the illness. Participants described the value of life experience, including episodes of illness, as a learning process. A 39-year-old mother and factory worker accepted her limitations.

> Many people hope for instant recovery. It takes time to learn how to control it. We learn to monitor ourselves and accept what our bodies can do.

Participants described the importance of time and life experience in learning to recognize their individual trigger and warning signs.

### *Identify trigger factors*

Insight into bipolar mood disorder involved participants knowing what factors trigger episodes of illness. Participants were able to identify specific things that triggered their episodes of bipolar mood disorder. According to the data, the most common triggers were stress and sleep deprivation. The relationship between stress and sleep was complex. In some cases stress caused disruption to sleep. In other cases, a lack of sleep caused a low resilience to stress.

Participants also identified a number of other factors that may trigger an episode of illness. These included fatigue, jet lag, hormonal fluctuations, change of seasons, all night partying and recreational drugs.

### *Recognize warning signs*

Participants described health care professionals advising them to watch for expansiveness and undue enthusiasm, involvement in excessive numbers of projects, poor judgement and changes in sexual and financial behaviour. However participants felt that these were late signs of an impending episode of mania. Participants felt it was much better for them to recognize their early warning signs.

Participants described the importance of observing small changes in their physical, mental and emotional status. Participants were particularly mindful of small changes in sleep, mood, thoughts, and energy levels. They felt it was important to take small changes seriously. Several participants relied on close friends and family to help them to monitor their moods and behaviour.

When participants experienced *early* warning signals, they implemented interventions to ensure they avoided episodes of illness. According to the data, there were many different types of interventions. Responses to early warning signs included canceling work and social engagements, exercise, sleep, yoga and meditation. In some cases participants increased/changed medication and made an appointment with a health care professional. Participants had developed strategies that worked best for them.

### *Managing sleep and stress*

Data indicates that managing stress and sleep were crucial to staying well. Most participants were vigilant about their sleeping patterns. They kept regular bedtimes and avoided intellectual stimulation at night. Participants described trying to avoid situations likely to disrupt their sleeping routine. However, disruptions were sometimes hard to avoid. When sleep was disrupted, participants did not hesitate to take medication to help them to sleep.

Participants developed various strategies to minimize the impact of stress. Many of these strategies were related to managing workplace stress. These included regular holidays, changing jobs, part-time work and regular counselling. Some participants increased their medication during periods of increased stress. A 42-year-old chief executive officer learnt to manage his work stress. As a result, he also managed his illness.

> Stress is a big trigger for me. To a large extent, managing my illness is about managing my stress.

### *Make lifestyle changes*

Participants identified a number of lifestyle factors that helped them to stay well. They included eating healthy foods, exercising, drinking less alcohol/caffeine, sleeping well, spending time with loved ones, having quiet times, managing stress, and laughing. These lifestyle factors help all people to stay well, not only people with bipolar mood disorder. In addition to trying to maintain a healthy lifestyle, participants described making specific changes in their lives to stay well. Some lifestyle changes were small such as remembering to take medication and being mindful about sleep. Others made significant lifestyle changes such as adopting a quieter lifestyle in a rural community and changing to a less stressful job. A 30-year-old woman left a stressful job in the corporate sector to work part time in community health.

> I had to make huge changes in my life to stay well. Taking medication religiously would be the smallest of these changes. I now lead a different but full life.

### *Treatment*

Several participants described being prescribed incorrect medications. Their lives improved once they were prescribed the correct medication. In this study, 85% of participants took prescribed medication to help them control bipolar mood disorder – 80% took a mood stabiliser every day; 2% took a low dose of lithium and increased the dose during stressful life events; 3% only took lithium when they felt warning signals.

Many participants used both prescribed medication and complementary therapies. The most commonly cited complementary treatments were cognitive behavioural therapy (CBT), nutritional supplements, naturopathy, psychotherapy, traditional Chinese medicine, massage, tai chi, meditation and yoga. Data indicate that health care professionals were often not supportive of people with bipolar mood disorder using complementary therapies. A 36-year-old academic was discouraged from exploring other options.

> I wanted to explore alternative therapies. However, my psychiatrist was not supportive. He was very dismissive of other options. He just believes in pumping me with drugs.

Fifteen participants in the current sample did not take any prescribed medication. This included three participants who had ceased taking lithium on the recommendation of their psychiatrist. The remaining 12 participants treated their bipolar mood disorder with complementary therapies instead of medication. One participant had stayed well for the past 5 years with only orthomolecular treatment while another had remained well for over 30 years by taking only brewers yeast. She felt that one teaspoon per day of brewers yeast had the same effect on her as lithium. Ten participants stayed well by using only psychological treatments such as cognitive behavioural therapy (CBT).

### *Access support*

Participants relied on a range of support networks to stay well. This included partners, parents, children, brothers, sisters, friends, colleagues, pets, churches, community and mental health groups and health care professionals. With assistance from their support networks, participants described learning to set limits and boundaries, establish safety nets and set up harm minimization strategies. In particular, many participants enlisted the help of their personal support networks to help them to recognize early warning signs.

Participants in this sample joined local community groups such as writing groups, book clubs, music groups and sport clubs. They rarely joined mental health support groups. A 50-year-old accountant disapproved of mental health support groups.

> You mix with the same people as in hospital. You drink coffee, smoke and talk about the same things – hospital admission, drug reactions and Centrelink. These groups do not encourage you to get on with your life and get back to work.

Most participants received some sort of professional psychiatric support, though the quality of the professional psychiatric support

varied enormously. Many participants shopped around to find the type of professional support that best suited them. Many participants found the process of choosing their own psychiatrist affirming.

In addition to shopping around for the most suitable health care professionals, several participants preferred to work with a number of different mental health professionals (GPs, psychiatrists, case managers, psychologists, social workers and counsellors). A 26-year-old speech pathologist acknowledged that psychiatrists and psychologists had different expertise.

> My visits with the psychiatrist are quick and infrequent. I see him twice a year. He just prescribes medication and arranges blood tests. My psychologist is more instrumental in helping me to get well. We talk things through.

Several participants in this sample saw their psychiatrist only once or twice a year. Their appointments were for routine matters such as prescriptions and/or blood test requests. Participants were generally happy with this arrangement. The data indicated that taking control of bipolar mood disorder often involved knowing when to ask for help. It also required knowing who to ask for help.

### *Stay well plans*

The main finding from this research was the importance of stay well plans in preventing episodes of illness. All participants described their own stay well plan. Participants developed, adapted and revised their stay well plans as their circumstances required. These plans identified their trigger factors. They also identified their early warning behavioural changes and outlined strategies for themselves and others to ensure that the participant stayed well.

In some cases, stay well plans were a verbal understanding with partners, family, friends and health care professionals. In other cases, stay well plans were an informal written document. Having a documented stay well plan enabled participants to clearly identify their own triggers and warning signs. It also helped partners, family and friends to feel comfortable with any intervention that may be required.

## Conclusion

This research focused on people with bipolar mood disorder who stayed well. Although participants do not represent all people who experience bipolar mood disorder, this research fills an important gap in our understanding of bipolar mood disorder. The data demonstrated that people with bipolar mood disorder could manage their illness and stay well.

This research may provide important new insights for health care professionals. Currently, the professional perspective focuses on people with bipolar mood disorder when they are unwell. The professional focus is on ‘patients’, ‘clients’ and ‘consumers’, rather than ‘people’ with bipolar mood disorder who stay well. It is important that health care professionals realize that people with bipolar mood disorder can get well, especially when diagnosed early and treated appropriately.

Once correctly diagnosed, participants actively managed bipolar mood disorder. Although no universal solutions were identified, participants learnt what worked for them. For many participants, controlling bipolar mood disorder involved adequate amounts of sleep; insight into their triggers and warning signs; manageable levels of stress; suitable medication for them; and compassionate social and professional support networks.

The research identified the importance of stay well plans. These stay well plans involved participants remaining mindful of their illness. Degrees of ‘mindfulness’ depended on the circumstances. For example, when participants were feeling well, the illness was in the back of their minds. It did not play a large role in their lives, but they knew it was there. On the other hand, when participants encountered triggers and felt ‘early warning signals’, it was necessary to become more vigilant. In some instances, participants needed to intervene to prevent an episode of illness. Intervention may simply involve a few good sleeps and a long walk along the beach with a dog. Alternatively, intervention may involve making an appointment with a health care professional and altering medication. With experience, participants learnt what worked best to keep them well.

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