Experience with treatment services for people with bipolar disorder

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The lifetime prevalence of bipolar disorder (previously known as manic-depressive illness) is estimated at 1.2%,[1] and the annual financial costs of this disorder in Australia are estimated to be $1.59 billion.[2,3] Typically, the disorder has a single spectrum of severity, and clinical manifestations include episodes of both elevated mood as well as depression. The high costs of bipolar disorder reflect not only the severity of the condition but the considerable delays between onset of symptoms and provision of appropriate care. Further, those who access treatment may not be receiving optimal care.[2] Indeed, it has been suggested that people with severe affective disorders (eg, bipolar disorder and major depression) are more likely than those with chronic psychotic disorders to receive disjointed and poorly coordinated care.[4]

To complement research with people with severe depressive disorders[5-7] and other people who use mental health services in Australia,[8] we chose to explore the healthcare system experiences of people with bipolar disorder. Our report focuses on their experiences with healthcare services, as distinct from the wider social barriers or psychosocial aspects of their daily experiences.

METHODS

Participants and questions

Focus groups with people with documented and often extensive experience of bipolar disorder were held in seven Australian capital cities between July 2002 and April 2003. We did not select people whose diagnosis was unclear or whose condition was of very recent onset. Further, we did not focus on which section of the healthcare system (eg, primary care, emergency care, public mental health services, private services or hospitalisation) they had mainly encountered.

Participants were recruited through contact with the website of *beyondblue: the national depression initiative* (www.beyond-blue.org.au), and/or participation in local illness support groups (ie, Association of Relatives and Friends of the Emotionally and Mentally Ill, and Even Keel Bipolar Disorder Support Association). Each focus group involved two sessions (except Sydney, which had one), with the same participants invited to attend each session. All 13 focus group sessions consisted of five to eight participants, and lasted about 2 hours. One-hour indepth interviews were also

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ABSTRACT

Objective: To describe the experiences of people with bipolar disorder with primary care and specialist mental health services.

Design and setting: Focus groups and indepth interviews were conducted in seven Australian capital cities between July 2002 and April 2003. Thematic analyses were conducted using the QSR NUD*IST software package for qualitative data.

Participants: Forty-nine people with bipolar disorder participated in the focus groups and four participated in the interviews.

Results: Thematic analyses highlighted eight key themes. Most notably, respondents identified a lack of awareness and understanding about bipolar disorder within the Australian community, which contributed to apparent delays in seeking medical assessment. The burden of illness was exacerbated by difficulties experienced with obtaining an accurate diagnosis and optimal treatment. The healthcare system responses were described as inadequate and included inappropriate crisis management, difficulties accessing hospital care, inappropriate exclusion of carers and families from management decisions, and frequent discontinuities of medical and psychological care.

Conclusions: People with extensive experience of bipolar disorder report barriers to optimal care because of lack of community understanding and healthcare system shortcomings. These barriers exacerbate the social, interpersonal and economic costs of this illness.

MJA 2004; 181: S47–S51

conducted with four of the participants. Participants were paid a nominal fee for their time and travel expenses.

The sessions were conducted by one of two experienced facilitators (N J H or B G McN) and followed a structured format whereby six stem questions were asked and then openly discussed with the group (Box 1).

Analyses

Responses from each session and interview were collated from transcripts of audio recordings and subjected to thematic analyses using the QSR NUD*IST software package for analysing qualitative data (QSR N6).[9] To be considered a key theme, the subject matter was required to

• have spontaneously and consistently arisen across all focus groups and interviews; and

• reflect the experiences of at least a third of all participants.

Univariate data analyses were conducted with the Statistical Package for the Social Sciences (SPSS).[10]

Ethical approval

Institutional ethics committee approval was obtained from the University of New South Wales Committee on Experimental Procedures Involving Human Subjects.

1 The six stem questions asked during each focus group and supplementary interview

- What were the first signs that something was not right?
- How would you describe the impact of bipolar disorder on you, your family and/or carer?
- What factors make this experience worse than it already is?
- What factors make it less severe?
- What do you consider to be the main areas of need for people who experience bipolar disorder, their families and/or carers?
- As a consumer, what do you need from the healthcare system and the wider society?

RESULTS

Participants

Focus groups

Thirteen focus group sessions (49 participants; mean attendance, 7; range, 5–8) were held in seven Australian capital cities — Adelaide (8/49), Brisbane (7/49), Canberra (7/49), Hobart (7/49), Melbourne (5/49), Perth (7/49) and Sydney (8/49). Participants' ages ranged from 22 to 58 years, and 30 were women. At the time of our study, all participants had obtained a documented diagnosis of bipolar disorder, with the duration of diagnosed illness ranging from 4 months to 35 years. Most participants were single or divorced, or, if they had a partner or spouse, they had had periods of separation.

Indepth interviews

Indepth interviews were conducted with two women and two men. Their ages ranged from 37 to 54 years.

Themes (Box 2)

Eight key themes emerged relating to accessing and receiving treatment for bipolar disorder in both primary care and specialist settings. While a lack of awareness and understanding about the illness initially delayed presentation, other barriers within the healthcare system also prevented access to timely and appropriate interventions.

DISCUSSION

Our study of the healthcare experiences of people with documented bipolar disorder highlights key barriers to access to appropriate treatments. To date, much of the work on healthcare experiences of people with mental health problems has focused on people with chronic psychotic disorders, rather than those with episodic conditions, such as bipolar disorder or severe depression.[4] Consequently, many of the priorities for service reform (eg, increased acute hospital beds, increased long-stay services, increased provision for those with chronic or residual disability), particularly in the publicly funded and state-based mental health services, do not appear to address specifically the needs of this group. Although the number of people in our study is small, our results are consistent with reported research in bipolar disorder.[2] Qualitative research, such as ours, is not necessarily enriched by adding more people. Instead, it should be judged by whether it has captured the essential elements experienced by people who live with this illness.

We focused on those with documented bipolar disorder. Our work does not answer the question of whether the same core experiences are shared by people with less evident or less severe forms of the illness, or by those who preferentially rely on one particular section of our healthcare system. However, the barriers reported by participants are consistent with the patterns of less than optimal treatment reported in quantitative studies of people with bipolar disorder.[2] Failure to provide appropriate treatments for people with documented disorders results in large direct and indirect economic costs.[2]

The first major theme (Theme 1) — delayed or inaccurate diagnosis of bipolar disorder — has also featured in quantitative research and can be attributed to a lack of awareness of and education about the illness in the general community and among healthcare providers. People with bipolar disorder share this difficulty with those who experience depression alone, or who have other forms of mental illness.[5] This indicates a need for more extensive community education about the nature of these disorders. Families who have members with these disorders cannot be expected to encourage presentation for care, and at earlier stages of illness, unless they are aware of the clinical signs, and confident that their relatives will receive competent medical care. Earlier clinical presentation offers the hope of reducing delay to accurate diagnosis and provision of effective treatment. Ideally, education for the community and for healthcare professionals should emphasise the personal experiences of people who have lived with and learned to manage their illness.

An alternative tradition in primary care and specialist mental health services has been to delay specific diagnosis or drug prescribing until the clinician is very confident of the diagnosis. While this may prevent unnecessary exposure to stigma or to the adverse effects of medication, such concerns need to be balanced by the potential benefits of early intervention, even when diagnostic specificity is lower.[11]

Our study also exposes unmet needs in primary care (Theme 2) and specialist mental health services (Theme 3). While working to increase opportunities for earlier and more accurate diagnosis, there is also a need to emphasise the range of effective medical and psychological therapies available, with particular focus on promoting collaborative treatment relationships and appropriate self-care strategies. Furthermore, the lack of continuity of medical care in public mental health services (particularly those involving rotating registrar placements) requires attention. The capacity to provide continuity across both inpatient and community outpatient settings also needs to be addressed.

Some people recounted adverse experiences with hospitalisation (Theme 4) and health professionals (Theme 5). In particular, the impact and debilitating nature of bipolar disorder can result in involuntary hospital admissions, compounded by negative experiences with inpatient and outpatient treatment and management practices. Further, feelings of vulnerability, coupled with perceptions of premature discharge (which may result from healthcare providers viewing bipolar disorder as a less-threatening illness than other forms of psychosis), emphasise the need for effective discharge planning, home help, outreach support and continuity with primary care services.

Theme 6 highlights discontinuities of medical and psychological care. People with bipolar disorder move frequently across the whole range of primary care, specialist and hospital-based services. While such movements may contribute to major discontinuities in

2 Themes from focus groups exploring experiences of people with bipolar disorder with healthcare services

Theme 1: Delayed or inaccurate diagnosis of bipolar disorder

One of the most striking findings was the perceived difficulty in receiving an accurate or timely diagnosis. Participants reported that their condition was unrecognised and/or misdiagnosed for many years. This occurred both in primary care and specialist mental health services. The most common alternative diagnoses included schizoaffective disorder, attention deficit hyperactivity disorder, unipolar depression and/or psychosis, with some participants reporting that they received several diagnoses over time. In turn, delayed or inaccurate diagnoses frequently resulted in no intervention, less appropriate treatments being implemented, and/or repeated hospital admissions. For consumers (and their carers) this process only served to reduce their faith and confidence in the wider healthcare system.

- *I was first diagnosed as being borderline psychotic. Then I think schizophrenia . . . then with bipolar, and a little while ago my psychiatrist thought I had schizoaffective disorder . . . but, I have since been rediagnosed and I have bipolar.*
- *I still didn't have a diagnosis but I'd been seeing a psychiatrist for a couple of years, and the thought was that I had schizophrenia . . . but nobody knew. I was on medication, but it wasn't treating my problems, it was just suppressing my personality.*
- *I was regarded as schizophrenic. For some reason they decided, "No, he's not schizophrenic . . . we've been giving him the wrong medication for the last 29 years. This is why he's having relapses even though he takes his medication".*

Theme 2: Unmet needs in primary care

When people first identified that something was not right, they reported that they were most likely to approach their general practitioner. There was general consensus, however, that many GPs had been unable to make the specific diagnosis or had not had the skills to manage the condition. As a result, people with bipolar disorder approached several doctors to find someone who was not only competent but also empathic or willing to take on such a "difficult" case long term.

Participants also commented on the restricted range of treatments offered in primary care, with most interventions limited to medication. There were several people who, with persistence, found a GP with whom they were satisfied. Key elements for a successful relationship included GPs being not only competent to diagnose and provide effective treatment, but also being non-judgemental, flexible and accommodating (particularly in times of crisis), and willing to spend time with the patient.

- *I had an episode 18 months ago when I dropped one tablet out of my regimen on the advice of a GP. I had two hospitalisations in 2 months because of that.*
- *I've got a very good GP now, but I had to shop around for her. It took a while.*
- *I go to a large clinic and see any one of several doctors there, and it's a clinic I've been going to for 5 years. They write out a script, end of story . . . they do not want to know. They don't even want to say "How are you?" in case you start . . . and that's rather disappointing.*
- *My GP was really good because she would see me for a longer consultation, which was 20 minutes rather than the standard 5 to 10. She was willing to do that . . . I didn't actually ask for it, she just instigated it when I first went there.*

Theme 3: Unmet needs in specialist mental healthcare

Accessing a suitable psychiatrist can be almost as difficult as accessing a suitable GP. Long waiting times for specialist mental healthcare leave many consumers with little choice but to try and manage their illness through primary care alone. Further, consumers reported dissatisfaction after their clinical interactions with psychiatrists. Some of these related to management issues, while others focused on the additional and ongoing costs associated with specialist mental healthcare. Psychiatrists were also perceived to offer a limited range of treatments, with a predominant focus on medication.

- *I didn't have a very decent [psychiatrist] to start with, which was very unacceptable for me . . . So for me, it's actually now easier to just not have a psychiatrist at all. I only see my GP once every 6 months like I'm supposed to, and I also use community support in my own local area. I created support around me which is 24 hours a day, 7 days a week . . . this is my preferred method of self-treatment.*
- *By the time I could get the appointment, I didn't need it. So I never was sure what I was doing there. It ended up being a pointless exercise talking about everything I did . . . I can do that with my friends.*

Theme 4: Adverse experiences with hospitalisation

People with bipolar disorder raised a whole series of issues relating to hospitalisation, ranging from difficulties with access in a crisis, over-reliance on involuntary detention, inadequate care during hospital admissions and premature discharge. Consumers felt that hospitalisation was often overwhelming, impersonal and dehumanising. Treatment was perceived to be essentially monitoring the effects of medication, with little regard, care or respect given to individual treatment needs. The impact of these very short and chaotic periods of hospitalisation on family members and carers was highlighted.

- *In the last 12 months I had the problem of wanting to be admitted for depression . . . I was screaming out for help . . . but I was not able to be admitted. They don't want to detain people . . . they want to keep people in the community.*
- *I was regulated by my psychiatrist until I got to hospital, where they unregulated me and then tossed me out. Within 6 months I had made two suicide attempts. Both times I had to be revived. Both times I was only in hospital for 24 hours.*
- *I don't go to hospital anymore . . . I don't feel comfortable . . . I don't trust the system. The system has failed me miserably.*
- *I always come out of hospital feeling resentment and a lot of remorse.*

Theme 5: Frustrating interactions with health professionals

Consumers related that health professionals play a significant role in perpetuating stigma, largely through their failure to manage care in an individualised, collaborative and respectful manner.

- *Fifteen years ago I was treated with a great deal of regard, consideration and respect . . . I can't say the same in more recent times. Today, you're very much a number . . . you're just the illness.*
- *I bitterly resent the doctor that said people would treat me whether I wanted them to or not.*
- *Every time I've got to see the senior specialist at the hospital for something, I get so churned up and really scared because I think they're going to judge me . . . you go to hospital and say I've been having all these problems, and you just feel they're not going to believe you . . .*

2 Themes (continued)

Theme 6: Discontinuities of medical and psychological care

Participants noted that long waiting lists and costs associated with seeing private psychiatrists, coupled with the frequent rotation of psychiatrists in the public system, all combined to prevent them from forming more stable long-term care relationships. Likewise, the community-health-based systems of case management were often chaotic, associated with frequent changes in personnel or a lack of access to more specialised forms of medical or psychological care. Consumers frequently returned to the care of their GP without receiving adequate ongoing support from specialist mental health services.

- *At the outpatients clinic where I am in the inner city, because the rotation of registrars is 6 monthly, and you wait 5 months between appointments, the maximum you'd ever see the same person would be twice . . . at the very maximum.*
- *The problem with having bipolar disorder is that in order to access the case management system in a public hospital, you have to maintain a level of illness to keep that going. So the instant you become well enough, that gets taken from you and then you can never ever get that case manager back, and the therapeutic relationship is taken from you. You go right back to the beginning again, and even if you start you're not guaranteed the same case manager.*

Theme 7: Inadequate community-based crisis management

Typically, people with bipolar disorder will have acute episodes of illness requiring crisis intervention. Consumers not only reported significant delays, but also a strong tendency for health professionals to enlist the assistance of non-clinical services such as police and medical emergency services. This reinforces notions that people with bipolar disorder are frequently dangerous, unpredictable or reluctant to seek care.

- *For me it took three separate phone calls to track down the right crisis assessment team (CAT) for that area.*
- *You don't ring CATs in a crisis; you ring the cops and the ambulance . . . because if you ring the CAT they think "You're well enough to ring us, we're not going to come out to you." [They say] "what medication are you on? what are you doing tonight? see you later."*
- *My husband and a lot of my friends were at absolute total desperation point. And it wasn't until about four of them all rang the CAT at the same time that they actually responded. And yet I'd been to a private psychiatrist who'd said weeks earlier, "She's definitely manic". So why did it have to reach the point where everybody was put at so much risk? . . . I'm talking real risk. I'm talking the end of possibly several lives . . . that's the point it had reached.*

Theme 8: Exclusion of carers and families from management decisions

Distress to family members and carers is further compounded by the apparent lack of information, and exclusion from the treatment and management process. A common story was:

- *The other element is the extreme you have to go through as a relative . . . the relatives know nothing. The relatives can be ringing up and saying "Look, my wife's suicidal" . . . but they leave it very close to people being dead on the floor before they step in. And quite often . . . it's just too late.*

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care,[4] the potential impact of this on patients and their families affirms the need for innovative and collaborative care systems.

Healthcare services should also respond to the issue of crisis management (Theme 7). These services were perceived to be unresponsive and inappropriate, and current crisis management practices were also considered to contribute to negative community perceptions and stigma. In turn, this exposed the need for prompt and improved access to crisis care during the early phases of acute relapse.

The final theme — exclusion of carers and families from management decisions (Theme 8) — was the perception that these key people were ignored or not actively included in management decisions. In keeping with recent mental health reforms in Australia,[12] we need to recognise the important role played by carers and family members.

In the future, we will need to rely less on our study's style of ad hoc or episodic evaluation of consumers' and carers' experiences. More systematic and ongoing processes have been developed elsewhere in the health sector[13] and are being extended to the mental health sector internationally.[14] Under the auspices of the Mental Health Council of Australia, this effort is being enhanced in Australia.[15-17] The qualitative work we report here is being used to develop appropriate instruments for tracking changes in healthcare experiences for people with bipolar disorder or severe depression.

To improve the situation rapidly, we need not only to attend to service innovation and financial and workforce investment,[10] but also to respond directly to the specific complaints raised here. More extensive community education about the nature of bipolar disorder is required. *beyondblue* has begun to respond to this challenge. A targeted form of this general education, however, clearly needs to focus on health professionals in both primary and specialist care systems.

In Australia, it is clear that, despite a decade of national mental health reform, people with bipolar disorder or people with other disorders who need integrated primary care and specialist mental health services frequently encounter service failures,[9] and this is conceded by government bodies.[16] Rather than being defensive about critiques of mental health services, we should welcome the active input of consumers and carers as an essential part of providing better-quality health services.

COMPETING INTERESTS

None identified.

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