

Editorial

What is it like to be diagnosed with bipolar illness, borderline personality disorder or another diagnosis with mood instability?†

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**Summary**

Patients with mood instability represent a significant proportion of patients with mental illness. Important lessons need to be learnt about how current assessment processes do not meet their expectations. Changes at various levels, including medical and nursing education, service provision

and research priorities, appear necessary if we are to help our patients better.

Declaration of interest

None.

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Bilderbeck *et al* present in this issue some much needed qualitative research on how patients referred with mood instability perceive their psychiatric assessment.¹ Although the first contact with secondary care is very influential on later outcome, the literature on how people experience being assessed and diagnosed with bipolar disorder or borderline personality disorder (BPD) is meagre. The patients told Bilderbeck *et al* that they were seeking an explanation for their symptoms, wanted to feel listened to and acknowledged, have consistent support from, and a good relationship with, the clinician and to be involved in clinical decisions.

I still remember how, closer to the beginning of my training, I sometimes came across more senior colleagues who felt unequipped to provide help for BPD patients and/or did not even consider BPD an illness (i.e. a legitimate reason to seek help via the health service). Unfortunately, Bilderbeck *et al* still found that many patients felt rejected and disbelieved. If we are to help our patients better, we will need to adopt a medical approach that is more responsive to expectations from our patients and non-medical colleagues and more effective at handling both the positive and negative consequences of diagnosis.

The need for an enlightened medical approach

Bipolar disorder affects roughly 1% of the population and BPD about 1–6%. Patients with pathological mood instability constitute a significant proportion of all patients with mental illness and it has been argued that directing more of the research effort at this population (see for example Goodwin *et al*² regarding bipolar disorder) would be a worthwhile change in psychiatry. It is important to listen to what this patient group has to say, so that a model of help that is adapted to their needs can be designed.

Our patients can read from our attitude how we view their predicament. Bipolar disorder includes one of the old classical psychoses (then referred to as ‘manic–depressive madness’) and hence its status as a disease has a longer tradition. Consequently, few people would now challenge the view that it is a major mental illness with a strong biological vulnerability. Evidence is slowly

accruing about the biological differences in BPD too, including genetic and imaging studies, leading to better recognition and acceptance. Here, the mind *v.* brain (biological *v.* psychosocial, etc.) dichotomy is not helpful. Our understanding of mental ill health has already been improved through the rejection of received wisdom in favour of hypothesis-testing and openness to alternative explanations. Demonic possession as an explanation for mental and behavioural symptoms has been replaced by the acceptance of an interaction of a variety of factors in the aetiology of most psychiatric disorders, including physical conditions and heredity and psychological and societal factors. Overemphasising the role of any one of these factors to the exclusion of the others seems to have led to stagnation at best and adverse consequences at worst in the past. Not being open to a more pluralistic view risks losing out on much needed synergism. Engaging in a genuine dialogue with our patients and colleagues in cognate fields, such as neurology, psychology, anthropology and philosophy, is more likely to lead to a solution and the time to do this more consciously is now. Conversely, not listening to the voice of the patients, ignoring their needs when designing the health services that are supposed to look after them and not directing enough resources into research that could lead to a better understanding and treatments for these disorders would be a backward step.

The biomedical model (and psychiatry itself) has again come under attack increasingly in recent times. It would be naive (and irresponsible) to think that discrediting a medical explanation and help before considering the scientific evidence (or despite that) has no impact on how people affected by severe mood instability see themselves and how they are perceived by healthcare workers. Similarly, it would also be naive (and irresponsible) for psychiatry to respond with hubris, complacency or inaction. We can argue endlessly about the nature of these phenomena or their putative aetiology; what will not go away, unless we develop effective help, is the enormous suffering of people affected by mood instability in themselves, or in those around them.

The usefulness of diagnosis

Patients do not want labels (perceived by them as preconceived and unfavourable opinions), but they are often well aware that diagnosing has the potential to be helpful.³ The existing classification systems are far from perfect in defining homogeneous groups with shared underlying pathology and similar response to treatment, but they serve important functions, such as aiding communication between clinicians, providing access to treatments that can lead to improved outcome and guiding research.

†See pp. 234–239, this issue.

We often think participating in research is a chore for our patients, but I have met very few other groups as keen on research as some of my patients with BPD. A well-known illustration of what intelligent experimentation based on a far-from-perfect classification system can achieve comes from the story of James Lind. In 1747, he found that two oranges and one lemon a day were 'the most effectual remedies' for scurvy. This had made preventive intervention possible centuries before Albert Szent-Gyorgyi and Charles Glen King developed a more complete understanding of scurvy at a biochemical level.

Important from both a patient and a clinician point of view, correct diagnosis helps in choosing the treatment that is most likely to work. High-quality meta-analytic evidence supports the use of medication in the treatment of bipolar disorder. Although currently there is no similar evidence for specific pharmacological interventions to treat BPD, there is convincing evidence about psychological interventions.⁴ Dialectical behavioural therapy has been studied most intensely, but other modalities, such as mentalisation-based treatment,⁵ are also showing promise.

Crucially, diagnosis offers an explanatory scheme for the patient and their relatives, which can enable the patient to start off on a journey of recovery. Reporting disbelief, shock, denial or anger after a mood disorder diagnosis is not uncommon, but many actually describe relief, especially those who have experienced a long delay before receiving a diagnosis and being able to have a name for the symptoms they have been experiencing.⁶ Uncertainty about the meaning of the diagnosis is also common.⁷ Diagnosis needs to be communicated well, giving enough detail, relating it to the patient's own experience and be followed by post-diagnostic counselling if the patient's goals for the assessment (understanding their problem, getting an explanation, feeling understood, etc.) are to be reached. This way, they will be more likely to accept their diagnosis and do well in treatment, too.⁸ Receiving a diagnosis is an active process and reducing ambivalence about it has a potential for reducing relapse.⁹ Qualitative research also suggests that providing education to family and friends (and the public) is also likely to reduce stigma.⁶

Although there are undeniable differential diagnostic challenges in this group, the problem of diagnosis is substantially complicated and overshadowed by that of stigma that comes with the diagnosis. The subjective view that mental health diagnoses lead to stigma and not seeing the patient as a person but as a label is fairly common among not only lay people but also mental health professionals, and seeing research that studies patients' views on this is refreshing and vital in giving direction to further research and shaping the way healthcare is designed and provided in a scientifically informed way. Stigma is likely to reduce if – through research – ignorance is replaced by an understanding of the pathomechanism and the development of treatments, as it has in the case of many types of cancer or infectious disorders. The alternative of giving no diagnosis when there is illness and the patient is seeking diagnosis is, of course, unacceptable and wrong for many reasons.

This choice of either neglecting a sizeable group of patients on the one side and the harm through medicalising 'normal' emotional suffering, overdiagnosis and stigma on the other side is a false dichotomy: compassion and humanity combined with a scientific approach, which is the true medical approach, should mean staying clear of both.

Future implications for clinical care, research, education and health economics

Understanding better the journey of these patients could contribute to a positive change in attitudes in mental health workers and the

ways mental health services are set up. Acknowledging the importance of continuity of care in this patient group should inform further research into models of service provision, such as the impact of patients needing to re-tell their stories, often under time pressure, as they travel through the multiple stages of the current system on therapeutic alliance, treatment adherence, clinical outcome, patient satisfaction and health economics. Seeing the same health professional whenever possible is important for all of us when we are ill and feel vulnerable, but it is especially so for people who have a fundamental problem developing attachment (BPD). Having a long-term relationship with the service and not having a fixed discharge date was rated very highly, higher than managing risks and crises, or learning to live with the condition by patients with BPD in our service (S. Burt, personal communication, 2013).

Some of the changes in attitude that are needed may not require huge monetary investment but a conscious effort in medical, nursing and public education, and in policy-making. Paying attention to what our patients are saying would be good for them (consistent and continuous care, feeling involved and informed, not feeling dismissed and discredited), could pay off through better clinical outcome, less frequent crises, more time spent in productivity and other health economic gains. Given that developing cures for these disorders may not be round the corner, the way we organise treatment provision should be made as humane as possible. The paper in this issue by Bilderbeck *et al* provides important insights into this.

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