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Stigma and its correlates among patients with bipolar disorder: A study from a tertiary care hospital of North India

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ABSTRACT

This study aimed to assess stigma and its sociodemographic and clinical correlates among patients with bipolar disorder while in remission. 185 patients currently in remission were assessed on Internalized Stigma of Mental Illness Scale (ISMIS) for internalized stigma, Explanatory Model Interview Catalogue Stigma Scale for perceived stigma and Participation scale for restriction of activities. About 28% patients reported moderate to high level of self stigma as assessed by ISMIS total score. Discrimination experience (38.9%) was reported to be the most commonly experienced self stigma followed by alienation (28.6%) and social withdrawal (28.6%). On the participation scale, about two-fifth (42%) of the participants had severe restriction of activities. Internalized stigma was higher among those with lower age and lesser income. Higher level of stigma was associated with shorter mean duration of remission, income, mean duration of depressive episodes, higher severity of residual depressive symptoms and current level of functioning. Higher internalized stigma was associated with greater restriction in participation of activities. To conclude, present study suggests that self stigma is highly prevalent among patients with bipolar disorder in India and is associated with clinical variables like duration of depressive episodes and level of functioning.

1. Introduction

Bipolar disorder is a chronic relapsing condition characterized by episodes of depression, hypomania, mania and mixed episodes (Goodwin and Jamison, 2007). Depending on the severity of illness in the long run, it has been shown to be associated with unemployment, lost productivity, poor social functioning, poor quality of life, disability, marital failure and high treatment costs (Simon et al., 2007; McMorris et al., 2010; Miller et al., 2014; Somaiya et al., 2014). Additionally the illness is associated with significant family burden, distress among the caregivers and poor quality of life (Beentjes et al., 2012; Pompili et al., 2014; da Silva Gdel et al., 2014).

Because of the nature of the symptoms, relapsing and remitting course, residual symptoms in between the episodes, associated unemployment, lost productivity, poor social functioning, poor quality of life, disability and negative attitude of the society towards mental disorders, bipolar disorder is also associated with stigma (Ellison et al., 2013; Hawke et al., 2013). Stigma is understood as “a deeply discrediting attribute” that reduces the bearer “from a whole and usual person, to a tainted discounted one” (Goffman, 1963). From the mental illness perspective, Elliott et al. (1982) considered stigma as a form of deviance that leads others to judge an individual as not having legitimacy to participate in a social interaction. According to Elliott et al. (1982), this is because of a perception that person with mental illness lack the skills or abilities to carry out such an interaction. This is possibly influenced by judgments about the dangerousness and unpredictability of the person.

In the context of mental illnesses, stigma experienced by the patients is recognized as public or personal stigma (Corrigan et al., 2006). Public stigma is the prejudice held by the general population against the patients with mental illness and it is reflected as discrimination towards people with mental illness (Corrigan et al., 2006). Personal stigma is categorised into 3 categories, i.e., perceived stigma, experienced stigma and self-stigma. Perceived stigma is the perception or anticipation of stigma by the mentally ill person. It is influenced by the person's own beliefs about attitudes of others in the society towards their condition and towards themselves as members of a potentially stigmatized group (Lebel, 2008). If persons with mental illness have internal cultural stereotypes prior to onset of their illness, they tend to apply these stereotypes to themselves after the onset of illness, and feel stigmatized (Watson and Philip, 2005). Simply stating, self stigma involves self-attribution of others' negative attitudes, whereas perceived stigma is the perceived attitude of others. Experienced

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stigma is the actual discrimination or restrictions faced by the persons affected with a stigmatized illness (Corrigan et al., 2006). Self-stigma or internalized stigma is understood as internalization and adoption of stereotypic or stigmatizing views of others by the stigmatized individual (Yanos et al., 2008). Self-stigma is also understood as a type of identity transformation that might lead to the loss of previously held (positive) beliefs about the self. The identity transformation leads to negative consequences for the person such as diminished self-esteem and self-efficacy (Corrigan and Rusch, 2002). Self-stigma is *the product of internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with mental illness* (Corrigan, 1998). It leads to negative feelings about oneself and maladaptive behavior related to anticipation of negative social reactions (Livingston and Boyd, 2010).

As compared to the number of studies across the world which have assessed stigma among patients with schizophrenia (Thirthalli and Kumar, 2012; Ellerby, 2015) and depression (Latalova et al., 2014), there are fewer number of studies on stigma experienced by patients with bipolar disorder (Ellison et al., 2013; Hawke et al., 2013).

In a recent review, Ellison et al. (2013) identified 25 publications arising out of 22 studies which assessed public and professional stigmatizing attitude or internalized stigma as perceived by patients with mania or bipolar disorder. Of the available studies, 11 publications evaluated the public or professional stigma and followed a qualitative design. Remaining 14 publications focused on internalized stigma among patients with bipolar disorder and their caregivers; of these 11 publications followed quantitative study design. Comparison of these studies becomes difficult because of the differences in the scales used for assessment of internalized stigma. These studies used the internalized stigma for mental illness scale (ISMIS) (Ritsher et al., 2003), Inventory for stigmatizing experiences (ISE) (Mileva et al., 2013), Sense of stigmatization subscale of Bipolar Disorder Functioning Questionnaire (BDFQ-Stigma) (Aydemir et al., 2007), Self-Esteem and Stigma Questionnaire (SE/SQ) (Hayward et al., 2002) and perceived discrimination and devaluation scale (Link, 1987). Data from these studies suggest that patients with bipolar disorder who are in remission experience moderate level of stigma (Cerit et al., 2012) and those in family oriented treatment programs experience lower level of internalized stigma (Lee et al., 2011).

A recent multicountry with a large sample, which used ISMIS, suggested moderate to high level of stigma perceived by patients with bipolar disorder (Brohan et al., 2011). Studies based on ISE scale suggest high level of stigma among patients with bipolar disorder (Lazowski et al., 2012; Vazquez et al., 2011), which did not differ from that experienced by patients with depression. However, those with bipolar disorder experienced more psychosocial impact (Lazowski et al., 2012). Studies based on other scales also have reported moderate (Meiser et al., 2007) to high stigma among patients with bipolar disorder (Aydemir and Akkaya, 2011; Hayward et al., 2002). Qualitative studies have also concluded that patients with bipolar disorder experience their illness as highly stigmatizing (Michalak. et al., 2006; Sajatovic et al., 2008; Proudfoot et al., 2009; Ward, 2011; Suto et al., 2012).

Available studies on internalized stigma in bipolar disorder are limited by their small sample size, heterogenous study population (bipolar disorder type-1, bipolar disorder type-2 and Bipolar disorder NOS), inclusion of patients in various phases of illness or not specifying the phase of illness at the time of assessment (Ellison et al., 2013). Available reviews on stigma among patients with bipolar disorder highlight lack of research from developing countries and this limits cross cultural comparisons (Hawke et al., 2013; Ellison et al., 2013).

There is limited data from Indian on stigma experienced by patients with bipolar disorder. A study which included patients with bipolar disorder, schizophrenia, obsessive compulsive disorder and substance abuse showed that those with better insight experienced higher level of stigma, however, this study did not specifically report the findings for patients with bipolar disorder (Mishra et al., 2009).

Stigma is postulated to be shaped by cultural and historical forces. Hence, it is essential to evaluate stigma in different societal and cultural contexts. In India, most often than not, family is involved in the whole treatment process and it plays an important role in seeking treatment from a particular source, type of treatment, supervision of medications and rehabilitation. Although patient's own wish is given due consideration, yet the final decision is to a large extent influenced by others. In European countries, patients with mental illnesses are very much autonomous in decision taking regarding their treatment and future goals. Since, there are no social security schemes for mentally ill in India, but for some disability benefits, families tend not to disclose about the mental illness to others as being mentally ill can severely compromise matrimonial and employment prospects. It is not known whether greater family dependence and involvement influences perception of stigma are not in the Indian context. It can be hypothesized that higher dependence on family members or family members not allowing the patient to take independent decision about their life, can lead to higher self devaluation and may lead to higher perception of stigma. Further, higher involvement of family may also lead to exposure to higher expressed emotions, which can further increase the distress, self-devaluation and stigma. Keeping these issues in mind, present study aimed to assess the internalized stigma, perceived stigma and stigma in the form of participation restriction in various spheres of life by patients with bipolar disorder while in remission. Additional aims were: 1. to evaluate the relationship of stigma with socio-demographic variables and clinical variables; and 2. to study the relationship of internalized stigma, perceived stigma and restriction in participation. We considered the hypothesis that patients with bipolar disorder will experience different level of stigma as reported in studies from other parts of the world and stigma experienced by patient would be influenced by socio-cultural factors.

2. Methodology

This study was carried out in the outpatient unit of Department of Psychiatry at Postgraduate Institute of Medical Education & Research, a tertiary care hospital in North India. Institute Ethics Committee approved the study and all the participants were recruited after obtaining written informed consent.

One hundred and eighty five (N = 185) participants were recruited by purposive sampling. To be included in the study the participants were required to meet the diagnosis of Bipolar disorder-type 1 (F31) as per the Diagnostic and Statistical Manual, fourth revision (DSM-IV), aged 18–65 years and currently in euthymic state. Euthymia was defined as having Young Mania Rating Scale (YMRS) (Young et al., 1978) and Hamilton Depression Rating Scale (HDRS) (Hamilton, 1960) scores of < 7. Those with comorbid intellectual disability were excluded.

Stigma was assessed by using following instruments:

2.1. Internalized Stigma of Mental Illness Scale (ISMIS)

It is a 29-item scale which assesses subjective self-stigma/internalized stigma experienced by the person. Each item is scored on a four point scale (strongly disagree-1, disagree-2, agree-3 and strongly agree-4), with higher scores indicating greater stigma. Various items of the scale are combined into five domains - alienation, stereotype endorsement, perceived discrimination, social