

Internalized Stigmatization in Bipolar Patients: Relationship with Clinical Properties, Quality of Life and Treatment Compliance



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SUMMARY

Objective: This study aimed to investigate the impact of the internalized stigmatization on bipolar disorder (BD) patients.

Materials and Methods: The study included 100 BD patients that provided written informed consent to participate. Diagnosis of the BD patients that were in remission and receiving outpatient treatment was performed using the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I) and patient data were recorded using SKIP-TURK. In addition, the patients were administered the Internalized Stigma of Mental Illness Scale (ISMI), Mood Stabilizer Compliance Questionnaire (MSQC), and World Health Organization Quality of Life Assessment, abbreviated form (WHOQOL-BREF).

Results: Internalized stigmatization was observed in 46% of the BD patients; these patients had higher functionality scores, shorter regression periods, and more depressive episodes than those without internalized stigmatization. Although internalized stigmatization occurred more frequently in seasonal and rapid cycling patients, both attributes were prodrome of internalized stigmatization. Internalized stigmatization was observed more frequently in patients with low socioeconomic status, low level of education, rural residence, lack of work, and more children. There was a strong correlation between ISMI score, and WHOQOL-BREF and MSQC scores.

Conclusion: The clinical features of the BD and internalized stigmatization were observed to affect each other. Furthermore, stigmatization affected treatment compliance and quality of life.

Key words: Bipolar disorder, internalized stigmatization, quality of life, treatment compliance

INTRODUCTION

The subjective experience of stigmatization was first investigated in the 1980s in homosexuals (Malyon et al. 1982). Internalized stigmatization is the acceptance of negative stereotypical judgments of oneself as a consequence of withdrawal from the community with negative emotions such as worthlessness and shame (Corrigan 1998). In the struggle against stigmatization internalized stigmatization was reported to be a target, that can be reached and studied more easily (Corrigan and Watson 2002). The awareness of stigmatization by a stigmatized individual leads to social withdrawal, low self-esteem, the feeling of being different, and shame; comorbid

depression in such cases exacerbates stigmatization (Camp et al. 2002). There is an inverse relationship between self-esteem and stigmatization (Howard et al. 2002).

It can be assumed that the perception of stigmatization will negatively affect quality of life (QoL). In fact, Marcussen et al. (2010) investigated the effect of the perception of stigmatization on QoL in people with chronic and severe psychiatric disease, and reported that stigmatization negatively affects QoL. Insight is a variable that has an inverse relationship with QoL; however, some studies reported that there isn't a relationship between insight and QoL (Yen et al. 2008). The perception of stigmatization has a negative effect on the treatment of chronic psychological diseases and patient

Received: 11.07.2012 - Accepted: 18.02.2013

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doi: 10.5080/u7123

rehabilitation, further eroding QoL. The above-mentioned studies indicate that efficient drug treatment is a prerequisite for improving QoL and that the prerequisite of efficient drug treatment is compliance with treatment (Olusina and Ohaeri 2003). As such, internalized stigmatization should be addressed and overcome during the treatment process.

Among psychiatric disorders, schizophrenia is the most susceptible to stigmatization; however, stigmatization is also a factor in patients with bipolar disorder (BD) a recurrent and chronic disorder (Oral et al. 2002). BD patients with early onset find it difficult to distinguish some aspects of their personality from disease symptoms. Among BD patients in remission, the difference between normal and disease becomes difficult to differentiate; such patients attempt to strictly control their lives, perceiving each fluctuation in mood as a potential trigger for stigmatization (Aydemir 2004).

The aim of the present study was to investigate the effect of internalized stigmatization in BD patients on clinical characteristics, QoL, and treatment compliance.

MATERIALS and METHODS

Sample

The study protocol was approved by the Erenköy Mental Diseases Training and Research Hospital Ethics Committee, İstanbul, Turkey. The study included 100 consecutive BD patients (diagnosed according to DSM-IV criteria) in remission that were referred to the Erenköy Mental Diseases Hospital outpatient clinic between April 2010 and May 2010, and provided informed consent to participate. Patients diagnosed with any physical disease for which they began treatment were excluded from the study.

Tools

Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)

BD was diagnosed using the Turkish version of SCID-I (Özkürkçügil et al. 1999; First et al. 1997).

Mood Disorders Diagnosis and Following Form (SKIP-TURK)

Data on age at disease onset, duration of disease, age at initiation of treatment, history of physical and sexual abuse, academic and social functioning, premenstrual syndrome, type of first disease episode and its severity, postpartum onset, seasonality, subtype of depression, psychotic symptoms, suicidal ideation, number of hospitalizations, dominant course pattern, sudden onset and end, chronicity, rapid cycling, and switch, and tobacco, alcohol, and substance use were collected using SKIP-TURK (Özerdem et al. 2004). Functionality was evaluated via the general assessment of functionality (GAF) within the framework of SKIP-TURK.

Internalized Stigma of Mental Illness (ISMI) Scale

ISMI is a 29-item scale developed by Ritsher et al. (2003) for the evaluation of internalized stigmatization in patients with mental disease. The scale utilizes the following 5 subscales for evaluating the subjective experience of stigmatization: alienation, stereotype endorsement, perceived discrimination, social withdrawal, and resistance to stigmatization. ISMI items are answered using a 4-point Likert-type scale, as follows: 1. I strongly disagree; 2. I disagree; 3. I agree; 4. I strongly agree. The resistance to stigmatization subscale is scored inversely to the others. The overall score (range: 4-91) is calculated by adding the 5 subscale scores. Higher ISMI scores indicate a greater level of internalized stigmatization.

The Turkish version of the scale was reported to be valid and reliable for use in Turkey by Ersoy and Varan (2007). In the present study Cronbach's alpha coefficients for the 5 subscales varied between 0.63 and 0.87, and was 0.93 for the total scale. Examination of the scale's construct validity showed that the total ISMI score was strongly correlated with Beck Depression Inventory, Rosenberg Self-esteem Scale, Sociotropy-Autonomy Scale, Short Symptom Inventory, Multidimensional Social Support Scale, Clinical Global Impression Scale, and General Assessment of Functionality Scale scores, as expected. In the present study Cronbach's alpha coefficients for the 5 subscales varied between 0.72 and 0.85, and was 0.83 for the total scale.

WHO Quality of Life Scale, abbreviated version (WHOQOL-BREF)

WHOQOL-BREF is a 26-item scale with 4 subscales used to measure physical, psychological, social, and environmental well being. Our country participated in the preparation of this scale (Eser et al. 1999a, 1999b; Fidaner et al. 1999). In the present study the inner consistency coefficient (Cronbach's alpha) was 0.86.

Mood Stabilizer Compliance Questionnaire (MSCQ)

MSCQ was developed by Demyttenaere et al. (2004) as mood stabilizer treatment compliance form. It includes 33 items, each of which is scored between 1 and 4. Higher total scores are indicative of more positive attitudes and beliefs about antidepressants. The scale has 4 subscales: 1. Perceived doctor-patient relationship; 2. Beliefs about mood stabilizers; 3. Preserved autonomy in general; 4. Preserved autonomy in mood stabilizer dosage. Kesebir and Üstündağ (2012) reported that the Turkish version was valid and reliable for use in Turkey. In the present study the inner consistency coefficient (Cronbach's alpha) calculated for each subscale was 0.88, 0.85, 0.63, and 0.57, respectively.

Administration

Diagnostic interviews were performed using SCID-I and disease data were collected using SKIP-TURK. Subsequently, the BD patients were administered ISMI, WHOQOL-BREF, and MSCQ.

Statistical analysis

For ISMI a score was calculated according to distribution of the standard deviation of the sample (+3.55) and a score of 81 corresponding to it was accepted as the cutoff point; patients with a score >81 were considered to have internalized stigmatization. Accordingly, numerical variables were compared using the t test and categorical variables were compared using the chi-square test between the patients with and without internalized stigmatization. For this comparison the level of education a variable that differed between the 2 patient groups and can affect other variables was controlled for via ANCOVA. Pearson's correlation test was used to analyze the relationship between ISMI, WHOQOL-BREF, and MSCQ scores. Clinical variables assumed to predict internalized stigmatization ($p < 0.05$) were subjected to logistic regression analysis. All tests were 2-tailed and the level of statistical significance was set at $p < 0.05$.

RESULTS

Characteristics of the sample

Of the 100 BD patients in remission, 60 were female and 40 were male. Mean age of the patients was 39.62 ± 12.14 years and mean level of education was 9.01 ± 4.33 years. Mean age at disease onset was 24.42 ± 9.98 years and mean duration of disease was 15.2 ± 7.24 years. In total, 46 of the 100 patients had internalized stigmatization. In all, 49% of the patients had psychotic symptoms, 20% had a chronic disease course, 10% had rapid cycling, and 24% attempted suicide at least once. Among the patients, 77% were hospitalized at least once, 51% were married, and 31% were employed. Lastly, 87% of the patients had social security and 25% considered their social support to be adequate.

Comparison of the BD patients with and without internalized stigmatization

The BD patients with internalized stigmatization had a lower level of education (7.61 ± 3.84 years versus 10.20 ± 4.40 years) ($t = 4.3$, $p = 0.002$) and more of them lived in rural regions (37% versus 18.5%) ($\chi^2 = 7.844$, $p = 0.038$), as compared to those without internalized stigmatization. There wasn't a significant difference in terms of gender distribution, marital status, socioeconomic level, or social support between the patients with and without internalized stigmatization.

There wasn't a significant difference between the groups of patients with respect to age at BD onset, time from onset to diagnosis, the presence of a stressor prior to the first episode, history of abuse, or family history of mental disease, whereas a family history of physical disease was more common in the patients with internalized stigmatization (87% versus 66.7%) ($\chi^2 = 9.165$, $p = 0.018$). The patients with internalized

stigmatization had lower functionality scores (62.78 ± 5.52 versus 69.80 ± 6.50) ($p < 0.001$) and shorter periods of remission ($p = 0.01$) (Table 1). The difference between the 2 patient groups in the level of functioning persisted after the level of education was controlled for ($p = 0.001$). The patients with internalized stigmatization had more depressive episodes than those without internalized stigmatization ($p = 0.006$). Among the patients with internalized stigmatization the rate of seasonality and rapid cycling was higher than in the patients without internalized stigmatization ($p = 0.002$ and $p = 0.005$).

Total ISMI and ISMI alienation, social withdrawal, stereotype endorsement, and perceived discrimination subscale scores were higher in the patients with internalized stigmatization ($p < 0.001$, $p < 0.001$, $p < 0.001$, and $p < 0.001$, respectively) (Table 2). ISMI resistance to stigma subscale scores did not differ between the 2 patient groups. All 4 WHOQOL-BREF subscale scores (physical health, psychological health, social relationships, and environment) were lower in the patients with internalized stigmatization than in those without internalized stigmatization (respectively $p < 0.001$, $p < 0.001$,

$p < 0.001$, and $p < 0.001$, respectively). Patients with internalized stigmatization had higher MSCQ preserved autonomy in general and preserved autonomy in mood stabilizer dosage subscale scores ($p < 0.001$ and $p < 0.001$); the difference persisted after the level of education was controlled for.

Predictors of internalized stigmatization

In the patients with and without internalized stigmatization the level of education, place of residence, number of children, family history of physical disease, duration of remission, functionality score, number of depressive episodes, seasonality, and rapid cycling were and subjected to regression analysis, and seasonality, rapid cycling, functionality, and the WHOQOL-BREF psychological health subscale score were observed to be predictors of internalized stigmatization ($p = 0.007$, $p = 0.039$, $p = 0.001$, and $p < 0.001$, respectively) (Table 3).

The relationship between internalized stigmatization and treatment compliance

There was a strong inverse relationship between internalized stigmatization and QoL (Table 4). The component of internalized stigmatization that most strongly affected QoL was alienation, followed by social withdrawal, stereotype endorsement, and perceived discrimination ($r = -0.63$, $r = -0.58$, $r = -0.55$, and $r = -0.49$, respectively). Resistance to stigmatization was weakly associated with MSCQ beliefs about mood stabilizers and perceived doctor-patient relationship subscale scores ($r = 0.26$ and $r = 0.25$). Internalized stigmatization had a strong relationship with autonomy in treatment, which was observed most markedly in stereotype endorsement, social withdrawal, and perceived discrimination components of internalized stigmatization ($r = 0.55$, $r = 0.53$, and $r = 0.47$, respectively).

DISCUSSION

To the best of our knowledge the present study is the first from Turkey to investigate internalized stigmatization and evaluate the relationship between internalized stigmatization, and QoL and treatment compliance in BD patients. In the present study functionality, seasonality, and rapid cycling were observed to be predictors of internalized stigmatization. In addition, there was strong correlation between internalized stigmatization, and QoL and treatment compliance. Among the BD patients in the present study, 46% had internalized stigmatization. A recent study reported that 14.8% of patients with severe mental illness had internalized stigmatization and that 53% of patients reported that they experienced discrimination (Alonso et al. 2009). In another study that included both unipolar and bipolar patients, internalized stigmatization and perceived discrimination were present in 20% of patients (Brohan et al. 2011).

It was reported earlier that stigmatization is associated with a low level of education, being single or living alone, and unemployment (Alonso et al. 2009). In the present study the higher frequency of internalized stigmatization among the patients living in rural regions may have been due the fact that in such regions in Turkey social relationships are stronger and more meaningful. Higher rate of internalized stigmatization in lower education level has so far been demonstrated in other mental diseases, which is consistent with the literature (Alonso et al. 2009). Employment, education, and a high socioeconomic level appear to be factors that decrease the incidence of internalized stigmatization, which might be because they increase self-esteem. Having been educated and employment are indicative of a good level of functionality, which has been observed to be a variable that was predictive of internalized stigmatization in the present study; however, the low level of education level in present study's BD patients with internalized stigmatization might have affected their functionality, independently of internalized stigmatization. On the other hand, the difference in functionality between the 2 groups of patients persisted after the level of education level was controlled for.

Interestingly, patients in the present study with internalized stigmatization had more children than those without internalized stigmatization, which is a novel finding. The effect of having children on self-esteem is open to cultural and social interpretation. Meiser et al. (2007) reported that reluctance or little desire to have children was a predictor of internalized stigmatization among unipolar or bipolar schizoaffective disorder patients. Whereas the frequency of a family history of mental disease did not differ between the present study's 2 patient groups, a family history of physical disease was more common among the patients with internalized stigmatization. Although the literature does not include any studies on this issue, a consideration of physical diseases shows us that they are chronic and lead to disability. The reason why a history of

mental disease did not create the expected difference in internalized stigmatization may be that chronicity and disability were not considered in mental disease. At this point, it should be stressed that excluding the patient with chronic physical diseases was a reasonable choice of criterion.

In the present study GAF functionality scores were lower in the BD patients with internalized stigmatization. Similarly, it was reported earlier that among individuals with mental illness that could not return to their pre-illness level of functioning, internalized stigmatization was more marked, independent of disease or disability (Link et al. 2001). In patients that cannot return to their pre-illness level of functioning disease has left its trace. Even if the patient has recovered from the disease, the sign of the disease experience is still there. It was reported that there is a relationship between the current level of functionality, and current mood symptoms and internalized stigmatization. In addition, current functionality scores and mood symptoms were observed to be predictive of internalized stigmatization (Vazquez et al. 2010).

In BD patients the severity of psychopathology and cognitive impairment effect QoL (Brissos et al. 2008); however, psychotic symptoms have no effect on QoL (Macqueen et al. 1997). Indeed, psychotic symptoms are usually not residual, and respond well and rapidly to treatment (Goodwin and Jamison 1990). In terms of stigmatization and QoL, it is thought that the chronicity of psychopathology rather than its severity is important. Similarly, in the present study there wasn't a difference in episode severity or the presence of psychotic symptoms between the BD patients with and without internalized stigmatization, whereas periods of remission were shorter in the patients with internalized stigmatization. A recent study reported that internalized stigmatization was common in patients with psychotic symptoms (Lolich et al. 2010); however, that study included first-episode BD patients and the findings are not indicative of the effect of disease chronicity.

In the present study there wasn't a difference in the number of manic, hypomanic, or mixed episodes between the 2 patient groups, whereas the patients with internalized stigmatization had more depressive episodes. The perception of stigmatization does not differ between different subtypes of depression, and functionality deteriorates as the number of depressive episodes increases in BD patients (Goodwin and Jamison 1990). Marcussen et al. (2010) reported that among patients with chronic and severe mental illness internalized stigmatization was most strongly associated with self-esteem. In addition, when depression is controlled for a defensive reaction against stigmatization is involved (Rüsch et al. 2008); therefore, it might be considered that depressive episodes play a role in increasing the occurrence of internalized stigmatization. In another study depressive episodes and residual depressive symptoms were associated with impaired QoL (Gazalle et al.

2007). Among these depressive symptoms, sleep disorders especially hypersomnia are stressed (Giglio et al. 2009).

In the present study internalized stigmatization was more common in BD patients with a seasonal disease course and rapid cycling, both of which were predictive of internalized stigmatization. The fact that both seasonality and rapid cycling are independent of life events and stressors renders the disease less associated with a reactive nature. In addition, both conditions are difficult to resolve in BD patients (Goodwin and Jamison 1990) and lack of response to treatment is common in such patients. These 2 conditions may lead to the perception of disease as a seasonal or personal characteristic. Statements such as, “you are always like this during this season” or, “this has become your character”, are comments made by friends and relative that our BD patients with rapid cycling and a seasonal course often complain about. In rapid cycling, developmental periods are interrupted in young patients and differentiating the disease for personality becomes more difficult, which makes stigmatization more severe, as commented previously (Sajatovic et al. 2008).

In the present study WHOQOL-BREF physical health, psychological health, social relationships, and environment subscale scores were lower in the BD patients with internalized stigmatization. Impaired QoL in BD patients is a common finding. Marcussen et al. (2010) investigated the effect of internalized stigmatization on QoL in patients with chronic and severe mental disease, and reported that the effect was quite negative. In the present study there was a strong inverse relationship between internalized stigmatization and QoL; however, it should be kept in mind that the relationship is reciprocal. As the level of internalized stigmatization increases QoL may decrease, and vice versa. When the components of internalized stigmatization were considered individually in the present study, alienation had the most negative effect on QoL, followed by social withdrawal, stereotype endorsement, and perception of discrimination. The resistance to stigmatization component had a very weak relationship with QoL, which may be because resistance to stigmatization has no effect on functionality.

BD patients in the present study with internalized stigmatization had higher MSCQ preserved autonomy in general and preserved autonomy in mood stabilizer dosage subscale scores. These patients were opposed to external control and demanded an active role in their treatment. This means that, if this fact is disregarded, the tendency of not complying with treatment will be more pronounced in patients with internalized stigmatization. A study that included patients with major depressive disorder reported that internalized stigmatization had a markedly negative effect on treatment compliance (Sirey et al. 2001). There wasn't a difference in MSCQ perceived doctor-patient relationship or beliefs about mood stabilizers subscale scores between the 2 patients groups in

the present study, indicating that the beliefs and opinions in both BD patient groups concerning treatment compliance were similarly positive.

Internalized stigmatization had a strong relationship with the MSCQ autonomy in treatment subscale score in the present study. This relationship is observed most markedly in terms of ISMI stereotype endorsement, social withdrawal, and perceived discrimination subscale scores, indicating that as the level of internalized stigmatization increased, compliance with treatment decreased. The ISMI resistance to stigmatization subscale score was correlated with MSCQ perceived doctor-patient relationship and beliefs about mood stabilizers subscale scores, according to analysis of treatment compliance. These findings indicate the importance of a good physician-patient relationship and therapeutic cooperation in combating stigmatization.

The relation between antipsychotic drug use and stigmatization has not been adequately studied in BD patients. The belief that such drugs are essentially schizophrenia drugs creates some risk both for stigmatization and poor compliance with treatment (Sajatovic et al. 2007). Actually, many times when BD patients report that they do not want to use schizophrenia drugs, they are in essence reacting more to the stigmatization associated with these drugs than to their reported side effects. In Turkey compliance with antipsychotic treatment was reported to vary between 11% and 80% (Çobanoğlu and Aker 2003). Among BD patients, compliance with mood stabilizers for 2 years was <50% (Scott and Colom 2005). In particular, during the initiation of treatment physicians should seriously consider patients' opinions regarding self, their disease, and their treatment.

Another factor associated with stigmatization is the patient's family and friends. Internalized stigmatization is actually experienced by both patients, and their family and friends. In addition, relatives may also stigmatize and alienate a patient. Internalized stigmatization and depressive symptoms in a caregiver are associated (Perlick et al. 2007). Impaired QoL was observed in 60% of the spouses of BD patients, which is higher than that in the general population (Ellouze et al. 2011). A recent study reported that a caregiver's psychological state affects treatment compliance in BD patients (Kesebir 2009). As such, research that examines the perception of stigmatization in the relatives of BD patients is required.

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