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Mixed-methods analysis of internalized stigma correlates in poorly adherent individuals with bipolar disorder

Molly Howland[a], **Jennifer Levin**[a,b], **Carol Blixen**[a], **Curtis Tatsuoka**[b,c,d], and **Martha Sajatovic**[a,b,d,e]

[a]Case Western Reserve University School of Medicine, 2109 Adelbert Rd, Cleveland, Ohio, 44106

[b]Neurological and Behavioral Outcomes Center, University Hospitals Case Medical Center, 10524 Euclid Avenue, Cleveland, Ohio, 44106

[c]Department of Epidemiology and Biostatistics, Case Western Reserve University School of Medicine, 10900 Euclid Ave, Cleveland, Ohio, 44106

[d]Department of Neurology, Case Western Reserve University School of Medicine, 11100 Euclid Ave, Cleveland, Ohio, 44106

[e]Department of Psychiatry, Case Western Reserve University School of Medicine, 10524 Euclid Ave, Cleveland, Ohio, 44106

Abstract

Background—Internalized stigma, which occurs when stigmatized individuals accept society's assessment and incorporate this assessment into their sense of self, is prevalent in individuals with bipolar disorder (BD). This study explored the correlates of internalized stigma in a research sample of patients with BD who were poorly adherent to their medications.

Methods—Both quantitative and qualitative analyses were performed. Scores of 115 individuals with BD on the Internalized Stigma of Mental Illness (ISMI) scale were correlated with scores on the General Self-Efficacy (GSE) Scale, Brief Psychiatric Rating Scale (BPRS), Montgomery-Asberg Depression Rating Scale (MADRS), and Young Mania Rating Scale (YMRS). Regression was run for GSE (dependent variable) and ISMI (independent variable). In-depth qualitative interviews were conducted on a representative subsample (N=21).

Results—Internalized stigma levels were moderately high. Internalized stigma and self-efficacy correlated, and internalized stigma related to self-efficacy after adjusting for demographic variables (age, gender, years of education), comorbidities, and symptom severity (BPRS and MADRS). Internalized stigma was also associated with the BD symptoms of depression, anxiety,

Address correspondence to: Molly Howland, Neurological and Behavioral Outcomes Center, University Hospitals Case Medical Center, 2103 Cornell Rd, Cleveland, OH 44106, Tel: 216-844-2808. Fax: 216-844-2742. molly.howland@case.edu.

guilt feelings, suspiciousness, and hallucinogenic behaviors. No association was found with mania.

Conclusions—Because internalized stigma has strong psychosocial and psychiatric symptom associations, it is recommended that clinicians address both societal stigma and internalized stigma. Strategies such as cognitive-behavioral therapy may help modify BD patients' internalized stigma.

Keywords

Bipolar disorder; stigma; self efficacy; qualitative research; self concept

1. Introduction

External or public stigma can be defined as a society lacking knowledge about a specific condition or status, having prejudices against individuals because of that condition or status, and acting in discriminatory ways toward individuals who have that condition or status [1] and [2]. Internalized stigma, or self-stigma, occurs when stigmatized individuals accept society's assessment and incorporate this assessment into their sense of self [3]. Self-stigmatization can be conceptualized as a series of steps: 1.) individuals becoming aware of societal stereotypes, 2.) agreeing with the stereotypes, 3.) applying the stereotypes to themselves, and 4.) consequently suffering lower self-esteem [4]. Individuals with serious mental illness (SMI) may be particularly susceptible to internalized stigma. To quantify internalized stigma in people with SMI, scales such as the Internalized Stigma of Mental Illness (ISMI) have been developed [5]. In one study, one-third of individuals who took the ISMI reported moderate to severe internalized stigma, and an additional 46% reported mild internalized stigma [6].

Internalized stigma has negative psychological consequences in patients with psychiatric conditions. Even after accounting for baseline "morale," a concept that comprises self-esteem and depression, high ISMI scores predicted lower morale scores four months later [7]. According to a meta-analysis by Livingston and Boyd, internalized stigma is related to lower levels of hope, empowerment, self-esteem, self-efficacy, quality of life, and social support, and higher psychiatric symptom severity in patients with various mental health conditions [3]. Moreover, higher internalized stigma is associated with lower functionality in social and work situations [8] and [9]. Social dysfunction related to internalized stigma results in further discrimination, perpetuating a vicious cycle of social stigma, internalized stigma, and social dysfunction [1]. Finally, internalized stigma is correlated with a history of suicide attempts [6].

Studies report a moderate to high degree of internalized stigma among patients with bipolar disorder (BD) [10], [11] and [12]. A Turkish study found that 46% of BD patients experienced internalized stigma [13]. Another recent report found that individuals with BD had more self-stigma than individuals with psychotic disorders, depressive disorders, and anxiety disorders [14]. However, reports on the relative extent of internalized stigma in people with BD are not consistent, as two other recent studies found that, while internalized

stigma was substantial in people with BD, levels were lower than those seen in people with schizophrenia [11] and [12].

While internalized stigma is common in BD, only a few studies have reported BD-specific clinical and psychosocial correlates of internalized stigma. The limited studies on this topic found a negative relationship between internalized stigma and functional impairment, social adjustment, and self-esteem [10]. Two of the three studies identified in a review by Ellison et al. [10] reported a positive association between internalized stigma and BD symptom severity, highlighting the need for further research on these relationships [15], [16], and [17]. To our knowledge, no study has explored the relationship between stigma and self-efficacy in individuals with BD, a psychological variable central to quality of life and self-management of BD [18], [19], and [20].

Being able to characterize a patient's internalized stigma can help in treatment planning, which is reflected in the emerging literature on interventions to address self-stigma [3]. To elucidate the relationship between patient characteristics and internalized stigma in BD, we used both quantitative and qualitative methods to explore the correlates of stigma in a research sample of participants who were poorly adherent to their medications. We hypothesized that self-stigma would inversely correlate with self-efficacy and positively correlate with psychiatric symptoms such as depression, anxiety, and suspiciousness. Understanding the relationship between internalized stigma and its clinical and psychosocial correlates may inform interventions to reduce internalized stigma in high-risk subgroups.

2. Methods

2.1. Methods overview

This analysis used baseline data from an ongoing National Institute of Mental Health (NIMH)-funded study testing a novel psychosocial intervention intended to improve medication treatment adherence in poorly adherent individuals with BD. After participants were screened for eligibility and provided informed consent, demographic variables were gathered. Between one and two weeks after the screening visit, baseline assessment evaluated BD symptoms and psychosocial variables. Additionally, focused in-depth interviews were performed on a subsample of participants (N=21) selected via a purposive quota sampling design. This sample size is within the recommended number for qualitative research of 5–25 individuals who have all experienced the same phenomenon, such as living with BD [21]. The local Institutional Review Board confirmed that all study procedures were in accordance with the Helsinki Declaration as revised in 1989.

2.2. Sample

Participants were recruited from academic and community clinical practices in Ohio. Inclusion criteria included a type I or type II BD diagnosis as confirmed by the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID); BD of at least 2-year duration; receiving treatment with at least one evidence-based mood stabilizer for at least 6 months; and missing ≥ 20% of prescribed BD medication doses, which was measured using the self-report Tablets Routine Questionnaire (TRQ). Mood stabilizers included lithium,

anticonvulsants and antipsychotics prescribed by participants' regular providers. Exclusion criteria were minimal and included the inability to participate in psychiatric interviews or give informed consent, being younger than age 18, and being at immediate risk for suicide.

2.3. Quantitative assessment

2.3.1. ISMI—The ISMI scale is a 29-item measure of internalized stigma that is scored according to an anchored four-point Likert scale (Strongly Disagree, Disagree, Agree, or Strongly Agree). The test features 5 subscales: Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal, and Stigma Resistance. The ISMI scale was originally validated in a population of 127 Veterans Administration patients, for whom the scale produced an internal consistency reliability of α=0.90, a test-retest reliability of 0.92 (N=16, p<0.05), and concurrent validity with the Devaluation-Discrimination scale (r=0.35, p<0.01) and Center for Epidemiologic Studies Depression scale depressive symptoms (r=0.53, p<0.01) [5]. Multinational studies have tested the psychometric properties of the ISMI, finding an internal consistency reliability of α>0.90 and a test-retest reliability of between 0.62 and 0.90 [22]. For BD patients specifically, the items means range was 1.61–3.50 (SD range 0.54–1.03) and the internal consistency reliability was α=0.80 (N=18) [14].

2.3.2. General Self-Efficacy (GSE) Scale—A 10-item scale that assesses general and social self-efficacy using a four-point Likert scale. A multicultural meta-analysis determined validity by associating the GSE with other psychological variables [23]. Studies on the GSE-10 have found Cronbach's alpha of 0.82 and 0.90 [24] and [25].

2.3.3. BD Symptoms—Symptoms were measured using the Brief Psychiatric Rating Scale (BPRS) [27], Montgomery-Asberg Depression Rating Scale (MADRS) [28], and Young Mania Rating Scale (YMRS) [29]. Higher scores on the BPRS indicate more severe psychiatric symptoms. The test can be divided into five factors: Affect, Positive Symptoms, Negative Symptoms, Resistance, and Activation [30]. The MADRS has a three-factor structure: Dysphoria, Retardation, and Vegetative Symptoms. MADRS scores can be categorized as follows: 0–7 normal, 8–15 mild depression, 16–25 moderate, 26–30 severe, and 31+ very severe [31]. Total YMRS scores >12 denote BD mania [29].

2.3.4. Tablets Routine Questionnaire (TRQ)—TRQ is a self-report measure that identifies the proportion of days in the past month with a missed medication dose, with higher scores indicating worse adherence. TRQ has been shown to correlate highly with lithium blood levels [26].

2.3.5. Data Analysis Plan—Mean ISMI, MADRS, and YMRS scores were calculated as were means and standard deviations of each ISMI subscale. Pearson correlations and one-way analyses of variance (ANOVAs) between demographic variables and mean ISMI score were then performed. Next, participants were categorized using the stigma levels delineated by several studies (<2 minimal stigma, 2–2.5 low stigma, 2.5–3 moderate stigma, 3+ strong stigma) [32], [33], and [34]. Within these groups, TRQ adherence scores were calculated. Participants were also dichotomized into "high" self-stigma with an average score of greater than the midpoint of 2.5 and "not high" (below the midpoint) [5] and [7].

Pearson correlations were performed between the ISMI and its subscales, GSE, MADRS and its subscales, BPRS and its subscales, and YMRS. Because of the non-normal distribution of the YMRS and the Activation subscale scores of the BPRS, these associations were verified using Spearman correlations. Regression was conducted between GSE (dependent variable) and stigma (independent variable) while also adjusting for demographic variables (age, gender, years of education), medical comorbidities (reported as Charlson Comorbidity Index score), and symptom severity (BPRS and MADRS). To conduct item-level analysis for the BPRS, Mann-Whitney U-Tests were performed for "not high" versus "high" stigma groups. All statistical analyses were conducted using SPSS Version 22 (Armonk, NY).

2.4. Qualitative assessment

Data on internalized stigma were collected as part of a qualitative analysis of perceived barriers to BD self-management. In qualitative data collection, coding and analysis occur simultaneously rather than sequentially. Emerging insights can be incorporated into later stages of data generation, enhancing the comprehensiveness of the results [35]. Interview audiotapes were transcribed verbatim and analyzed using the classic method of content analysis with an emphasis on dominant themes [36]. Themes were identified by a descriptive label, which facilitated organization and comparison of transcripts [37]. A coding manual was modified iteratively. After descriptive coding, all transcripts were reviewed using the final coding manual to ensure that all possible codes had been applied. The significant statements and themes attached to the codes were then used to texturally describe participants' experiences [38].

3. Results

3.1. Sample characteristics

The mean age of the sample (N=115 for participants who completed the ISMI) was 46.5 years (SD=9.8) with 72% (N=83) women and 71% (N=82) African American participants. 49.6% of participants were single, 32.2% were divorced or separated, 15.7% were married, and 2.6% were widowed. 54.4% of participants were unemployed with disability, 30.7% were unemployed but expected to work, while only 8.9% were employed gainfully (7.0% responded "Other"). Participants had a mean education level of 12.2 years (SD 2.2), a mean age of onset of BD of 21.0 (SD=10.3), and a mean number of years with BD diagnosis of 25.5 years (SD=11.0). The mean MADRS score was 20.4 (SD 9.2), and the mean YMRS score was 8.5 (SD 4.9). Seventeen and a half percent of participants were currently under the care of a psychologist. Common medications included quetiapine, aripiprazole, and valproate. The majority of participants were taking only one medication (66.1%), while 33.9% were taking 2 or more medications. Comorbid substance use or mental health issues included a history of alcohol abuse or dependence in 65.7% of participants, cocaine abuse or dependence in 52.7%, cannabis abuse or dependence in 36.1%, and opioid abuse or dependence in 10.2%, as well as a history of sub-threshold or above threshold posttraumatic stress in 49.5% of participants, panic disorder in 40.9%, specific phobia in 16.5%, social phobia in 14.7%, generalized anxiety disorder in 13.0%, and obsessive-compulsive disorder in 12.2%.

3.2. ISMI score distribution

Based on a four-point Likert scale, the mean ISMI total score was 2.22 (SD 0.48). The means for the ISMI subscales were 2.33 (SD 0.70), 2.11 (SD 0.53), 2.27 (SD 0.75), 2.30 (SD 0.68), and 3.06 (SD 0.46) for Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal, and Stigma Resistance, respectively. Based on cutoffs established by Brohan et al. [33] we categorized participants' internalized stigma levels (Table 1). Using the midpoint of 2.5 to categorize internalized stigma [5] and [7], 26% of study participants experienced "high" internalized stigma.

3.3. ISMI relationship with demographic variables

Pearson correlations and ANOVAs between the ISMI and demographic variables including age, gender, race, years of education, age of onset of BD, and years since BD diagnosis were not statistically significant.

3.4. ISMI relationship with self-efficacy and adherence

Pearson correlations revealed that higher levels of self-stigma corresponded to lower levels of self-efficacy, illustrated by a negative correlation coefficient (Table 2). The correlations of the ISMI subscales generally mirrored those of the total ISMI score. In a linear regression, ISMI score correlated with GSE score after accounting for age, gender, years of education, medical comorbidities, BPRS, and MADRS (B=−0.13, SE=0.04, $p<0.001$). Mean TRQ scores for each of the four internalized stigma categories, from minimal to strong self-stigma, were as follows: 51.3 (SD 28.8), 55.5 (SD 25.6), 61.2 (SD 27.9), and 44.4 (SD 20.7) (Table 1).

3.5. ISMI relationship with clinical measures, their subscales, and items

Higher self-stigma was correlated with higher overall psychiatric symptom severity on BPRS (r=0.32, $p<0.001$) and higher levels of depression on MADRS (r=0.32, $p<0.001$), and each ISMI subscale similarly correlated with BPRS and MADRS (Table 2). Subscale analysis revealed that the Affect and Resistance subscales of BPRS positively correlated with total ISMI score (r=0.36, $p<0.001$; r=0.24, $p=0.009$), whereas the Activation subscale negatively correlated with ISMI (r=−0.26, $p=0.006$; Spearman correlation=−0.19, $p=0.048$). Specific BPRS items within these three subscales that were significantly greater for the "high" compared to the "not high" stigma subgroup were anxiety ($p=0.005$), guilt feelings ($p=0.025$), depressive mood ($p=0.022$), suspiciousness ($p=0.013$), and hallucinogenic behaviors ($p=0.004$). All three MADRS subscales (Dysphoria, Retardation, and Vegetative Symptoms) positively correlated with total ISMI score ($p<0.01$). ISMI and YMRS did not correlate (r=−0.10, $p=0.324$; Spearman correlation=−0.08, $p=0.391$).

3.6. Qualitative results

Stigma was a major concern for half (N=10) of the respondents who were interviewed. Some felt that the BD diagnosis caused others to perceive them as different or crazy:

> "It's kinda weird. People look at you differently. When you say, well, I have bipolar disorder, it's like you're crazy or something. Stay away from her." Respondent #2015

Some participants felt that taking BD medications was stigmatizing:

> "It took a long time for me to take the medicine because I didn't want to be classified as having a mental illness because I thought I'd be ostracized… If my friends knew that I was taking medicine because I was bipolar, they'll say I am crazy." Respondent #2006

One participant avoided taking medications while in a relationship:

> "If I start a relationship, I stop taking medication because I don't want them to know what I got (BD)." Respondent #2007

Another participant explained how the stigma of BD affected his or her sense of self:

> "I feel different from other people. Sometime I feel God gave me a bad hand. If I can't think like most people or you know do stuff like other people, it gets to me." Respondent #2004

4. Discussion

This mixed-method analysis of internalized stigma in a poorly adherent sample with BD found levels of self-stigma that were moderately high compared to other studies that addressed this construct [12], [15] and [39]. Many participants were unmarried and unemployed, which could signify that these participants' lack of social support and workplace dysfunction has engendered self-stigma [1], [3] and [10]. Conversely, anticipated stigma could discourage people with BD from seeking a partner or employment [17]. Further, few participants were under the care of a psychologist, which may have contributed to internalization of stigma [3].

The negative relationship between internalized stigma and self-efficacy in BD—a relationship that persisted after adjusting for psychiatric symptom severity, comorbidities, and demographic variables—has not been previously reported, although our results support the finding by Livingston and Boyd [3] that self-efficacy is low in stigmatized individuals with mental illness in general. One participant's comment that he or she felt "different" and could not "do stuff like other people" illustrates the notion that individuals with internalized stigma due to BD may feel helpless in managing stressors such as their mental illness [18]. This low self-efficacy may be associated with poor medication adherence and less care-seeking behavior [19] and [20]. Another respondent's comment about stopping their BD medication use to hide their illness from their romantic partner may represent the anticipation of stigma, which is a component of self-stigma, as a factor in non-adherence behaviors of some individuals. In addition, with the exception of the small (N=5) "strong" stigma category, non-adherence appeared to increase as internalized stigma increased. These qualitative and quantitative findings suggest that self-stigma may be a barrier to adherence. However, more research is necessary to establish the directionality of the relationships between self-stigma, self-efficacy and medication adherence in individuals with BD.

In accordance with the recovery model of mental illness [18], one strategy to improve patients' self-efficacy, medication adherence, and eventual health outcomes may be to address internalized stigma. Livingston and Boyd [3] identified two stigma interventions that

successfully reduced self-stigma in people with various serious mental illnesses such as major depression. One intervention involved Internet modules for psychoeducation and cognitive behavioral training, and the other involved group cognitive therapy sessions [3]. Future research should ascertain whether these formats could decrease self-stigma in individuals with BD.

This analysis found that internalized stigma was associated with specific BD symptoms. Ellison et al. [10] similarly reported on associations between depression and internalized stigma in BD [15], [16], and [17]. Our findings suggest that general anxiety and guilt feelings may play a role as well. Additionally, higher levels of suspiciousness and hallucinatory behavior correlated with higher levels of internalized stigma. This finding is consistent with higher anticipated stigma relating to higher suspiciousness in individuals with SMI [40]. Anticipating stigma implies that one is aware of societal stereotypes and has applied these stereotypes to oneself. This process is likely important in the formation of internalized stigma [4]; the relationship we found between suspiciousness and internalized stigma makes sense in this context. Experiencing hallucinations is what society often defines as mentally abnormal or “crazy,” and this could explain the relationship between hallucinations and internalized stigma in individuals with BD [41]. This finding may suggest that clinicians should “normalize” hallucinations or other BD symptoms as common components of a biological illness.

Consistent with Ellison et al. [10], our analysis did not find that increased mania correlated with increased internalized stigma. Because the overall mania severity in our sample was low, findings need to be interpreted cautiously. The negative correlation between the Activation subscale of the BPRS and the ISMI may imply that certain aspects of mania are related to decreased self-stigma, which is a novel hypothesis. Perhaps the excitability people experience during mania distracts individuals in these states from feelings of stigmatization. Our cross-sectional design does not permit us to see if internal stigma changed when these same individuals cycled into a depressive phase.

ISMI did not relate to age, gender, race, years of education, age of onset of BD, and years since BD diagnosis, supporting the results of most studies on internalized stigma and demographics [10], [13], [15], [16], [42], and [43]. The five ISMI subscales demonstrated similar correlations with psychosocial and clinical variables, providing support for the subscales being a single construct [5].

The qualitative analysis illuminated the mechanisms by which internalized stigma affects the lives of people with BD [44], providing a poignant look into a key feature of self-stigma: incorporation of society’s stereotypes into one’s sense of self. One participant spoke of feeling “different,” which was distressing to them (“it gets to me”). Another participant described hiding their BD medication use from their partner. These qualitative results support previous findings that internalized stigma is connected to relational anxiety with intimate partners and social anxiety in general in individuals with BD [12] and [45].

Limitations of the study include its relatively small sample size, especially in the “high” stigma subgroup (N=31); the single-site setting; and the cross-sectional design, which

precluded conclusions about directionality. It is recommended that future longitudinal studies establish causal links between self-stigma, self-efficacy, adherence, and psychiatric symptoms. Another limitation is that our poorly adherent sample, which had a large proportion of African-American women, may not generalize to samples with fewer minorities. Nevertheless, minorities tend to be over-represented in non-adherent samples [46], so our findings may inform the care of marginalized subgroups. A third limitation is the use of a general self-efficacy scale rather than a health-related self-efficacy scale, as our results may apply more to general problem solving than health management. Finally, in face-to-face interviews, social desirability bias may influence participants' responses, especially when discussing a sensitive topic such as stigma. In such cases, participants may have misrepresented their experiences to better align with social norms [47].

5. Conclusions

Because internalized stigma has strong psychosocial and psychiatric symptom connections, it is recommended that clinicians discuss both societal stigma and self-stigma with BD patients and consider using strategies such as cognitive-behavioral therapy to challenge the accuracy of patients' perceptions of stigma [6]. Further, effective interventions that target internalized stigma are needed [3]. Future research should evaluate internalized stigma over time in people across the BD spectrum to inform BD-specific stigma reduction strategies.

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Table 1

Distribution of stigma levels according to Internalized Stigma of Mental Illness total score

Stigma category	Percentage (Frequency)	Mean (SD) TRQ score, past month
Minimal (<2)	22.6% (28)	51.3 (28.8),
Low (2–2.5)	45.2% (56)	55.5 (25.6)
Moderate (2.5–3)	21.0% (26)	61.2 (27.9)
Strong (3+)	4.0% (5)	44.4 (20.7)

Table 2

Pearson correlations for Internalized Stigma of Mental Illness total Score and subscales

	BPRS	MADRS	YMRS	Self-efficacy
ISMI Total Score	0.42** (p=0.005)	0.32** (p<0.001)	−0.10 (p=0.324)	−0.39** (p<0.001)
Alienation	0.28 (p=0.052)	0.24** (p=0.008)	−0.06 (p=0.505)	−0.28** (p=0.002)
Stereotype Endorsement	0.28* (p=0.049)	0.25** (p=0.005)	−0.14 (p=0.146)	−0.29** (p<0.001)
Discrimination Experience	0.44** (p=0.002)	0.23* (p=0.012)	0.02 (p=0.861)	−0.31** (p<0.001)
Social Withdrawal	0.36* (p=0.013)	0.27** (p=0.003)	−0.11 (p=0.242)	−0.39** (p<0.001)
Stigma Resistance	−0.35* (p=0.015)	−0.25** (p=0.006)	0.13 (p=0.174)	0.29** (p=0.002)

* significant at p<0.05,

** significant at p<0.01

ISMI = Internalized Stigma of Mental Illness; BPRS = Brief Psychiatric Rating Scale; MADRS = Montgomery-Asberg Depression Rating Scale; YMRS = Young Mania Rating Scale.