



Stigma in Bipolar Affective Disorder: A Systematic Quantitative Literature Review of Indian Studies

Arghya Pal¹ , Vrinda Saxena², Priyaranjan Avinash² 

ABSTRACT

Background: Bipolar affective disorder (BPAD) is one of the most common severe mental illnesses that cause morbidity. Stigma can negatively influence the disease experience in patients with BPAD. Significant differences are observed in the attributes of stigma across the various sociocultural milieus. The current review was thus conducted to compile the evidence regarding the burden and correlates of various forms of stigma in BPAD in India.

Methods: An exhaustive literature review was conducted in PubMed, MedIND, and Google Scholar to identify Indian studies conducted on stigma in BPAD. The broad themes in various forms of stigma were identified (qualitative analysis). Quantitative analysis of measures of stigma was done, calculating the effect size in BPAD and comparator groups (schizophrenia and anxiety disorders) using standardized mean difference.

Results: Overall, 12 studies could be identified for qualitative analysis, and 5 were used for quantitative analysis. Overall, the current evidence points out that the stigma in BPAD is less than that in schizophrenia but more than that in anxiety

disorders. Internalized stigma in BPAD is correlated with poor self-esteem, reduced community participation, and low quality of life. Caregivers of patients with BPAD also experience significant stigma.

Conclusions: The review shows that stigma in BPAD is substantial. It also draws attention to the fact that the research regarding stigma in BPAD is lagging behind. This review also provides a platform to develop an intervention in the Indian scenario, where further research should be carried out.

Keywords: Stigma, bipolar affective disorder, Indian studies, systematic review, quantitative analysis

Key Messages:

1. Stigma in bipolar affective disorder is substantial, however research regarding the same has been limited and mostly restricted to internalized stigma.
2. In comparison to the western countries, research has been limited from India.
3. Overall, available evidence suggests that internalized stigma in bipolar disorder is lesser than that in schizophrenia.

Bipolar affective disorder (BPAD) is an episodic psychiatric disorder that causes unusual shifts in mood, energy, activity levels, and the

ability to carry out day-to-day tasks. It has a lifetime prevalence of 1%¹ and usually starts in the late second decade or the early third decade of life. The chronic episodic course of the disorder, with such early onset, usually means that it negatively affects several aspects of one's life, like the interpersonal relationships and occupational functioning, and can also lead to severe outcomes like suicide.²

The concept of stigma has been a research interest for long, with mixed results. In spite of multiple studies being conducted in this field, researchers have not been able to provide one definition of consensus. According to our current understanding, there are mainly three types of stigma.³ The most well-studied concept is the internalized stigma that explains the subjective appreciation of the negative experiences and perceptions of the patients themselves, leading to identity transformation and stereotype endorsement. The second entity is that of perceived stigma. It is the subjective experience of the patients about being stigmatized by other agencies. This is mostly contributed by endorsement of

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various discriminatory traits deep-rooted in the disease process. The third and probably the least studied entity is the structural stigma. It refers to institutional policies and practices—the structures that surround a person—that create inequality by restricting opportunities for people with mental illness.

Some advances have been made regarding understanding stigma in BPAD. It is well documented that stigma poses a significant obstruction in help-seeking for patients and also causes marginalization and decrease in integration of the patients in the community. Stigma also involves perceiving patients with BPAD with negative outlook and attributing stereotypes, thus further leading to interference in community participation.⁴ But, in spite of that, we have not been able to develop any effective intervention to attenuate this menace. On the other hand, although this phenomenon is global, various subtle differences have been seen in patients across the various geographical locations. It has been advocated that unless we are able to study the nuances of the various indigenous factors that fuel the machinery of biopsychosocial factors contributing to the process of stigma, any attempt to reverse the machinery may not be worthwhile.⁵ India, being the second most populated country in the world, deals with a significant burden of patients with BPAD and the effects of stigma.⁶ Thus, it is important to understand the dynamics of the factors that contribute to stigma in this country. In this background, the current systemic review was conducted to accumulate the evidence of Indian studies regarding stigma in BPAD.

Materials and Methods

Scope

The current review was conducted to get answers to the following questions:

- What is the burden of stigma in patients with BPAD in India?
- What are the correlates of stigma in patients with BPAD in India?

Search Strategy

A literature search was conducted in PubMed, MedIND, and Google Scholar to extract studies. No restriction was put regarding the time frame of the studies included in this review. The search was concluded on September 20, 2020. The

studies were chosen based on the following inclusion criteria:

- Original studies conducted in India on stigma in BPAD
- For studies that had multiple groups of subjects, inclusion mandated a defined separate group of subjects with BPAD (or caregivers of patients with BPAD)
- Only articles whose full text could be accessed and were in the English language were included in this review

The search terms used were “‘bipolar affective disorder,’ ‘bipolar disorder,’ ‘affective disorder,’ ‘mood disorder,’ ‘depression,’ ‘mania,’ ‘stigma,’ ‘internalized stigma,’ ‘perceived stigma,’ ‘social stigma,’ ‘India.’” Similar search was also repeated in Google Scholar and MedInd. Appropriate medical subject heading (MeSH) terms were identified, and a search was conducted in PubMed using the terms {“Social Stigma”[Mesh]} AND “Bipolar Disorder”[Mesh]. After an initial assessment, references of the initially accumulated studies were screened to identify further studies. **Table S1** depicts the number of results obtained using various search terms.

The abstracts of the studies were initially screened, and full texts of the selected studies were accessed. All the authors were involved in the selection and verification of the studies. Differences in opinion that arose were sorted out by mutual discussion.

Data Management

The studies were classified based on the broad themes (e.g., internalized stigma in patients and caregivers). The studies were further arranged on the basis of the sub-themes identified. For the purpose of the quantitative analysis, studies with data available for analyzing pooled estimates were identified. The quality of the studies included in the quantitative analysis was assessed using the Newcastle–Ottawa Scale.⁷ Studies where stigma measures were studied using a validated tool and descriptive statistics (mean and standard deviation of stigma measures and sample size) were available and used for quantitative analysis. The data from such studies were entered into the Review Manager (RevMan 5.3), and emerging trends were observed. The effect size was calculated for stigma in each disorder; this allowed a comparison of the burden of stigma

in various disorders across studies with disparate designs. The effect sizes were calculated using the standardized mean difference. In the current study, we used the random effects model, which is superior to the fixed effects model in cases of disparate studies. The I^2 test was used to study the heterogeneity in the studies.

Results

The summary of the screening and selection of the studies is depicted in **Figure 1**. Overall, 12 studies were identified that were abided by our inclusion criteria. These 12 studies were used for systematic review, of which 5 were included in the quantitative analysis. The summary of the included studies is depicted in **Table 1**. The assessment of the quality of the studies included in the quantitative analysis using the Newcastle–Ottawa Scale is depicted in **Table S2**.

The selected studies are arranged in the following outline.

Internalized Stigma in BPAD

Sociodemographic and Clinical Correlations

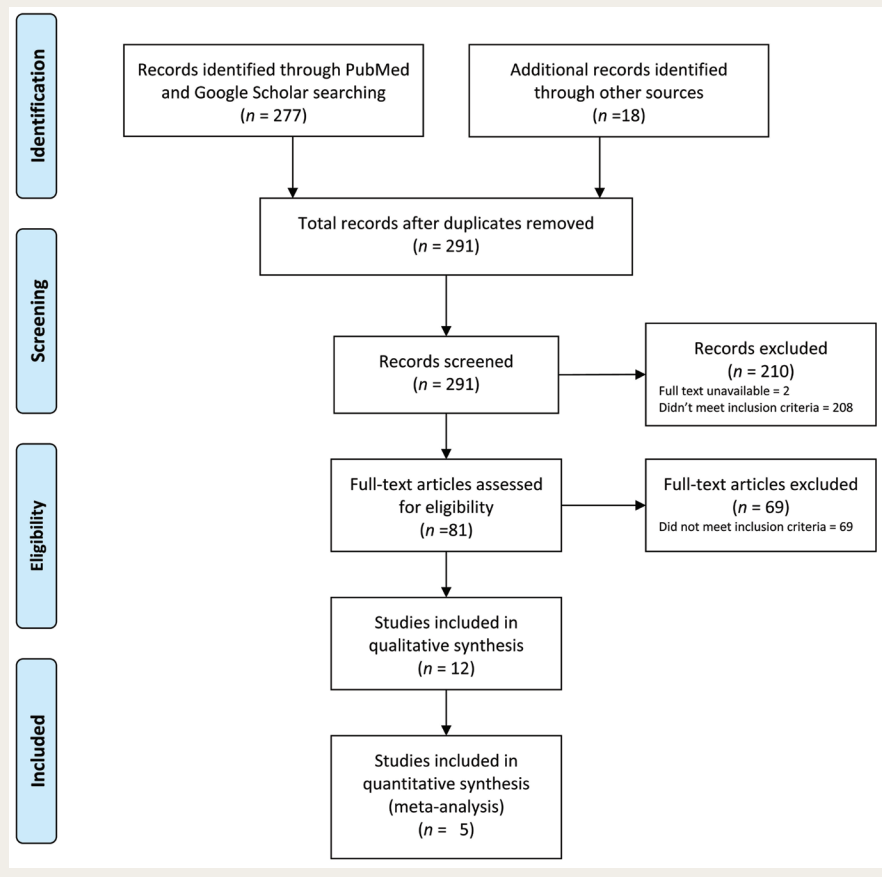
Most of the studies have been very rigorous in obtaining and correlating socio-demographic and clinical details to the measures of internalized stigma.^{8–10} The study by Grover et al. found that internalized stigma tended to be higher when the patients had a lower age, an earlier onset of the disease, or lower socioeconomic status.¹⁰ Concerning other clinical parameters, internalized stigma was positively correlated to a shorter mean duration of remission¹⁰ and the presence of residual symptoms in remission.⁹ Another study¹¹ that compared the internalized stigma across the predominant polarity (two-thirds predominance) of BPAD found no differences among the various predominant polarities on the measures of internalized stigma. However, patients with manic predominant polarity and indeterminate predominant polarity showed more difficulty disclosing than those with depressive predominant polarity.

Correlation of Internalized Stigma in BPAD and Community Participation

The studies were unanimous in the findings that internalized stigma played

FIGURE 1.

Flowchart of Screening and Inclusion/Exclusion of Studies



a detrimental role in the community participation of patients with BPAD.⁸⁻¹⁰ The participation scale¹² was the most common scale that has been used to measure community participation. Correlation measures of the various domains of Internalized Stigma of Mental Illness Inventory (ISMI) (i.e., alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance) and scores on participation scale showed a significant correlation in all studies.^{8,10}

Correlation of Internalized Stigma in BPAD, Self-esteem, and Quality of Life

Two studies^{8,13} showed that remitted patients of BPAD continued to report low self-esteem and quality of life. Both the studies used the Rosenberg Self-Esteem Scale for measuring self-esteem. One study⁸ reported that self-esteem was directly correlated to all domains of ISMI as well as the total score, whereas the other study¹³ showed that the scores on Rosenberg Self-Esteem Scale correlated to only ISMI discrimination and not to its other domains.

Both the studies used the World Health Organization Quality of Life Scale Brief

TABLE 1.

Summary of Studies Included in the Review

Study	Design	Participant Characteristics	Scale	Findings
Bhattacharya et al. (2019)	Cross-sectional	BPAD (N = 62)	Cross-sectional Assessment with ISMI, RSE, and WHO-QOL-Bref.	Patients of BPAD in remission have low self-esteem, experience mild stigma, and have low QOL
Grover et al. (2017) (IS, MC)	Multicentric, Cross-sectional	Schizophrenia (N = 707), BPAD (N = 344), and RDD (N = 352)	Comparison of scores on ISMI	Patients with schizophrenia had higher stigma than the other two groups
Grover et al. (2016) (C)	Cross-sectional	Remitted patients of BPAD (N = 185)	Cross-sectional assessment on ISMI, EMIC, and PS	High level of internalized stigma present in patients with BPAD, which affects functioning negatively
Grover et al. (2016) (R)	Cross-sectional	Remitted patients of BPAD (N = 185)	Assessment on RAS, ISMI, RCOPE, DUREL, HDRS, YMRS, and GAF	RAS scores were positively correlated to discrimination experience, stereotype endorsement and alienation domains of ISMI, level of functioning, residual depressive symptoms, and occupational status
Grover et al. (2017) (CG, MC)	Multicentric, cross-sectional	Caregivers of patients with schizophrenia (N = 707), BPAD (N = 344), and RDD (N = 352)	Assessed on stigma scale for CPMI and GHQ	Caregivers of patients with schizophrenia experience higher stigma than the caregivers of patients with BPAD and RDD
Grover et al. (2019)	Cross-sectional	Caregivers of patients with BPAD-I (N = 103)	Assessed on CPMI and EMIC	Caregivers of patients with BPAD experience significant affiliate and courtesy stigma, and higher stigma is associated with lower income of the caregivers and lesser time spent in care-giving
Karambelkar (2016)	Cross-sectional	Schizophrenia (N = 22) and BPAD (N = 28)	Interviewed on a semistructured scale	Despite having longer remissions and a milder course than schizophrenia, patients with BPAD experienced as much stigma as patients with schizophrenia

(Table 1 continued)

(Table 1 continued)

Study	Design	Participant Characteristics	Scale	Findings
Kumar et al. (2020)	Cross-sectional	Schizophrenia (N = 50) and BPAD (N = 50)	Interviewed on Discrimination and Stigma scale (DISC-12)	Patients with schizophrenia had significant internalized stigma as compared to patients with BPAD.
Pal (2020)	Cross-sectional	75 euthymic patients with BPAD were recruited and classified into their PP using criteria of two-thirds predominance	Assessed on SS, RSES, and WHOQOL-Bref	Although the patients with manic predominant polarity, depressive predominant polarity, and indeterminate predominant polarity did not differ in terms of internalized stigma, patients with manic predominant polarity and indeterminate predominant polarity showed more difficulty in disclosure compared to depressive predominant polarity.
Pal et al. (2017)	Cross-sectional	BPAD (N = 60), schizophrenia (N = 33) and anxiety disorders (N = 30)	All patients assessed on ISMI and SS. Patients with BPAD also assessed on PS, RSE, and WHOQOL-Bref	Patients with BPAD experience substantial stigma, which was intermediate between that experienced by patients with schizophrenia (higher) and that experienced by patients with anxiety disorder (lower). Internalized stigma has significant impact on self-esteem, socio-occupational participation and functioning, and quality of life in patients with BPAD
Pingali et al. (2018)	Cross-sectional	BPAD (N = 34), schizophrenia (N = 61), and anxiety disorders (N = 25)	Comparison on ISMI scores	Patients with anxiety disorders had the highest internalized stigma followed by BPAD, followed by schizophrenia
Sharma et al. (2017)	Cross-sectional	BPAD (N = 38) and schizophrenia (N = 50)	Scores on BAS, Brief COPE, and PDD	The level of burden for caregivers of patients with schizophrenia is more as compared to BPAD

BAS: burden assessment schedule, BPAD: bipolar affective disorder, C: correlate study, CG: caregiver, CPMI: caregivers of people with mental illness, DUREL: Duke University Religiosity Index, EMIC: Explanatory Model Interview Catalogue, GAF: Global Assessment of Functioning, GHQ: General Health Questionnaire, HDRS: Hamilton Depression Rating Scale, IS: internalized stigma, ISMI: Internalized Stigma of Mental Illness Scale, MC: multicentric, PDD: Perceived Discrimination Devaluation Scale, PS: Participation Scale, R: recovery study, RAS: Recovery Assessment Scale, RCOPE: Brief Religious Coping Scale, RDD: recurrent depressive disorder, RSE: Rosenberg self-esteem scale, SS: stigma scale, WHOQOL-Bref: World Health Organization Quality of Life Scale Brief, YMRS: Young Mania Rating Scale.

Version. It has four subscales (physical, psychological, social, and environment). Both the studies showed a significant correlation between the quality of life, especially its psychological domain, and ISMI.

Internalized Stigma and Recovery

In light of the above findings that internalized stigma can negatively affect various domains of the patients' mental state, it can be speculated that it can also negatively affect the recovery of patients with BPAD. It becomes imperative to reiterate that recovery in BPAD is not synonymous with remission but more

about "enabling persons with mental illness to regain control over their lives."¹⁴ One study¹⁵ conducted on 185 remitted patients of BPAD found that recovery, as assessed by Recovery Assessment Scale, was significantly affected by discrimination experience, stereotype endorsement, and alienation domains of ISMI. The study also reported a robust correlation between recovery and level of functioning as assessed by the Global Assessment of Functioning Scale.

Burden of Internalized Stigma in BPAD

The most common approach to study the burden of internalized stigma has been

to compare the burden of stigma with other disorders. In the studies that we had selected, a comparison of internalized stigma has been done with two disorders, namely schizophrenia and anxiety disorders. We conducted a quantitative analysis of the studies (Figures 2 and 3).

Comparison of Internalized Stigma in BPAD and Schizophrenia. We found four Indian studies that compared the internalized stigma in BPAD and schizophrenia.^{8,9,16,17} The quantitative analysis of the studies showed significant heterogeneity in the studies (I squared=86%). Overall, the quantitative analysis compared internalized stigma between 488

FIGURE 2.

Forest Plot of Studies Comparing Internalized Stigma in Bipolar Disorder and Schizophrenia

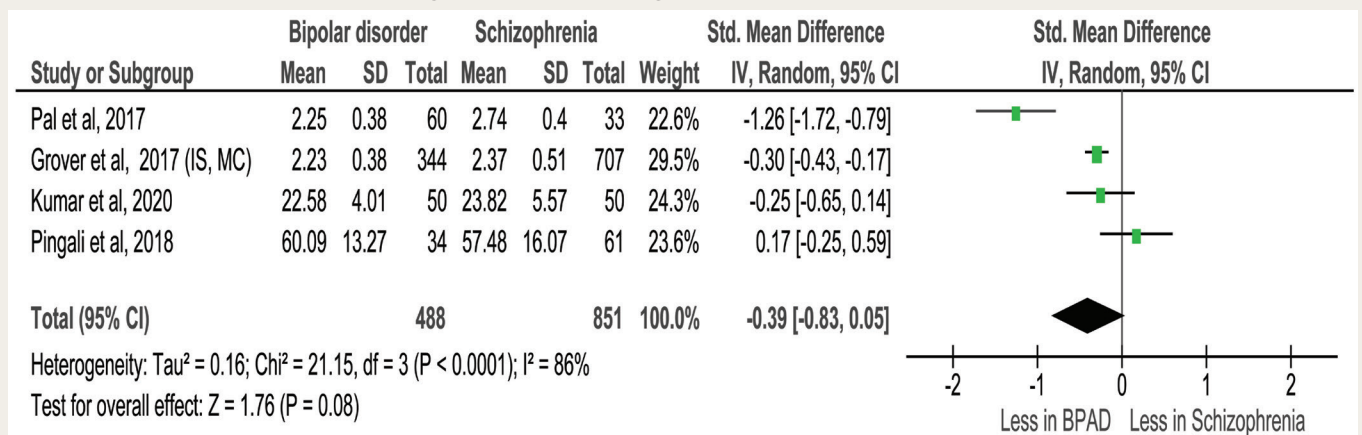
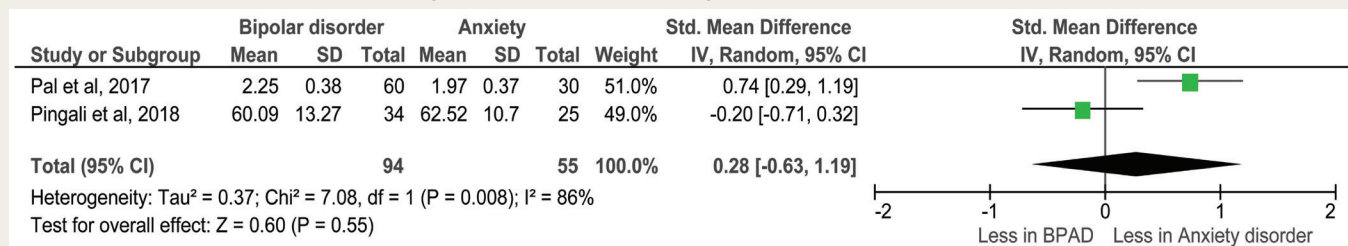


FIGURE 3.

Forest Plot of Studies Comparing the Internalized Stigma in Bipolar Disorder and Anxiety Disorder



euthymic patients of BPAD and 851 remitted patients of schizophrenia. All the patients of both the arms and all the three studies had used ISMI¹⁸ scale to assess internalized stigma. The mean effect size was -0.39 (less in BPAD) (confidence interval of -0.83 to 0.05). It was found that internalized stigma was less in BPAD as compared to schizophrenia (Figure 2). However, another study by Karambelkar et al.,¹⁹ which was not included in the quantitative analysis because it was conducted using a semi-structured interview schedule and a semiquantitative approach, had found no significant difference in the internalized stigma between the two groups.

Comparison of Internalized Stigma in BPAD and Anxiety Disorders. Two studies had compared internalized stigma between BPAD and anxiety disorder, using ISMI.^{8,17} The quantitative analysis was conducted between 94 euthymic patients of BPAD and 55 patients with anxiety disorder in clinical remission. The studies showed significant heterogeneity (I squared—86%). The mean effect size was 0.28 (more in BPAD) (confidence interval of -0.63 to 1.19). It was found that internalized stigma was more in BPAD than anxiety disorders (Figure 3).

Stigma Experienced by Caregivers in BPAD

Comparison of Stigma in BPAD with Schizophrenia and Other Disorders

Two studies compared the stigma experienced by caregivers in BPAD and other disorders. Sharma et al.²⁰ compared the stigma experienced by caregivers in BPAD and schizophrenia. Grover et al.²¹ compared the stigma in caregivers in patients with BPAD, schizophrenia, and recurrent depressive disorders (RDD). A quantitative analysis could not be done,

due to the unavailability of the raw data. However, both the studies were unanimous with the verdict that the stigma experienced by caregivers in cases of schizophrenia was more than that in the case of BPAD. The stigma in caregivers was, however, more in BPAD than RDD in most domains.

Correlates of Stigma Experienced by Caregivers in BPAD

Grover et al.²² evaluated the correlates of stigma experienced by caregivers in BPAD. The important findings were that the stigma experienced by the caregivers tended to be higher if the patients were females, showed poor functioning in the socio-occupational domain²², or had early onset of the illness or presence of residual symptoms in the period of remission. The studies also concluded that the presence of stigma in the caregivers tended to add to their psychological morbidity,²¹ and, in turn, burden. It also increased the odds of resorting to maladaptive coping strategies to deal with the crises of patient care.²⁰

Discussion

This systematic review was conducted to review the body of research that has been done in India regarding stigma in BPAD. The most important observation that we could make is the dearth of research in this regard. It is, however, worth mentioning that the studies included in this review were only from PubMed, MedInd, and Google Scholar. Stigma is often considered to be a well-studied area of social psychiatry. But contrary to this belief, this review makes it apparent that there are many areas of the stigma that should be studied. If we can compare studies conducted on stigma across major psychiatric disorders, schizophrenia has been the focus of the researchers.^{23–25}

BPAD, being a major contributor to the morbidity arising out of severe mental disorders, has been much less studied. Another importance of this review is that it has compiled the evidence base from India. Stigma, in its various forms, is very sensitive to the sociocultural and economic milieu of patients. Thus, evidence from one country may not be successfully extrapolated to others. Thus, it becomes imperative that we take stock of the evidence present in our country. A systematic review of systematic reviews²⁶ had reiterated that stigma shows considerable differences across centers.

Amongst the 12 studies we reviewed, nine of them dealt with internalized stigma in the patients. There is no doubt about the fact that internalized stigma causes the brunt of the damage that the patients deal with. The most common mode of investigation in the studies was the comparison of internalized stigma in BPAD with other disorders (most commonly schizophrenia and anxiety disorders). The most probable reason for choosing schizophrenia as a comparator could be that both BPAD and schizophrenia are classified as severe mental disorders. On the other hand, anxiety disorders may have been chosen considering their high prevalence. Only one of these studies was multicentric,⁹ whereas the rest were single-center studies. Comparing our data with the evidence from other countries^{27–31} makes it clear that internalized stigma in BPAD is less than that experienced in schizophrenia. Only one study³² did not find any difference in the level of internalized stigma in BPAD and schizophrenia. The reason behind comparatively lesser internalized stigma in BPAD could be that BPAD has an episodic course, and in many patients, complete interepisodic remission is achieved. Thus, concealing stigmatizing

attributes are comparatively easier in BPAD.⁸ Thus, to sum it up, the quantitative analysis of Indian studies portrays that the stigma in BPAD is less than that in schizophrenia. However, considering some evidence on the contrary, further research should be employed for a robust answer.

The review concluded that internalized stigma in BPAD is correlated to many socio-demographic and clinical variables. These correlations have also been found in studies conducted elsewhere.^{33,34} If this finding could be interpreted in the light of the theory provided by Link and Phelan,³⁵ we can find important clues in our fight against stigma. Stigma involves the first attribution of labels mainly arising out of features that have high social salience (e.g., residual symptoms). This is then further linked to the undesirable characteristics in the mind of other persons, thus creating “stereotypes.” For example, such stereotypes may arise from symptoms of illness (e.g., big talks made due to delusion of grandeur) or side-effects of prescribed psychotropics. Due to these stereotypes, persons with mental illnesses are separated from society, often hindering their participation in various community activities (e.g., delay in promotion or loss of status in family or community). Along with that, arbitrary creation of “us & them” groups leads to the display of negative emotional reactions (like anger, fear, or pity) to the patients (and often to caregivers) by others (this often includes caregivers). This self-propelling machinery further leads to a status loss and discrimination in the patients (e.g., difficulty in employment and marriage) and finally creates a power differential between attributors and sufferers. In our studies, we have been mostly measuring the most evident part of stigma (i.e., the power differentials) and its immediate complications (status loss and discrimination). But the important clues in developing an intervention targeted at stigma can only be developed when we will be taking into account the factors contributing in the background (like labeling, stereotyping, separating, and negative emotional reactions). The various clinical and socio-demographic correlates that we have been able to identify are probably the points of intervention. The studies,

by their designs, could only provide us with various correlates. Due to the lack of longitudinal studies, we have not been able to attribute the direction of causality to these factors. Thus, further endeavors are required to find out the causal association and identify the prime points of intervention. These factors should also be very important aspects of our clinical decisions so that iatrogenic contributions to the stigmatizing attributes can be minimized.

A very important component of this jigsaw puzzle is the role of the caregivers. Based on our review, it is clear that the caregivers are both perpetrators and sufferers of stigmatizing behavior. Literature often points out that the above two phenomena are not mutually exclusive but often coexist.^{36,37} It is further speculated that caregivers who experience a high amount of stigma tended to pass on the stigmatizing behavior to the patients. The caregivers thus play a role in both perceived stigma and public stigma. Research in this regard, specifically in BPAD, is lacking and should be conducted in the future.

A valid question that might arise is that what does this study add to the existing literature? Multiple systematic reviews have been conducted in this theme in the past.^{38,39} Most of the studies recruited in these reviews were from non-Indian centers. Most of the Indian studies reviewed here have been conducted after the publication of those reviews. The Western studies had primarily studied stigma in BPAD using a descriptive approach. In comparison, the approach of the Indian studies has been comparative. To a large extent, our findings have been in sync with those reviews. Both our review and a previous review³⁸ concluded that stigma in BPAD is less than in schizophrenia. Also, stigma in BPAD negatively affects the patients and their caregivers and can reduce social support, occupational success, and quality of life. However, this review points out the glaring lacunae in the research in this field. Despite the severe burden of stigma in BPAD, we have been lagging in developing strategies to reduce stigma, which has largely been the focus of research in the west.³⁹ One important reason could be that conducting intervention studies on stigma is a resource-intensive task.

The most important strength of our study is that this is the first study according to our knowledge that has accumulated the evidence regarding stigma in BPAD from India in a systematic manner. Also, all the studies have used similar tools with good psychometric properties, thus allowing us to compare the data. Also, because all the studies were conducted in India, the information generated can be reliably generalized to the country.

But our findings should be interpreted with caution. Firstly, all the studies that we could review had a cross-sectional design. As a result, the derived information only presents with correlations, and all the causal associations are merely speculative in nature. Secondly, the tools that have been used by most studies were developed in the Western countries and were translated into local vernacular languages. Thus, the applicability of these scales in this population remains a matter of concern. Furthermore, the possibility of bias arising out of purposive sampling and self-report can also not be ruled out. Another major concern about our study is the fewer number of studies that we could accumulate. There is a possibility that many such studies have been already conducted but not published. This could contribute to publication bias. Making generalized statements based on these studies may be difficult.

Further studies should involve using a qualitative methodology to understand the difference between various stigmatizing attributes across the sociocultural milieu. A mixed-method approach should be considered for this purpose. Also, more multicentric studies should be conducted, involving intranational and international collaboration, for better understanding. A better network needs to be grown across various research centers to collaborate, develop, and implement interventions against stigma.

Conclusion

BPAD is one of the most important disorders that come under the purview of severe mental disorders. BPAD is associated with significant morbidity and leads to restriction in functioning of the patients, even when the acute symptoms of the disorder are in remission.⁴⁰ One major reason behind this is the

stigma that is attached to the patients with BPAD. This study showed that Indian studies on stigma in BPAD had been limited and mostly focused on internalized stigma in patients and caregivers. Stigma in its various forms has been detrimental to the patients' socio-occupational functioning and quality of life. The results of these studies have been mostly in sync with the results from the Western centers. But, unlike the other countries, there is no study from India that has studied intervention measures in stigma in BPAD. Since our current understanding of stigma is limited, our attempts to reduce it and decrease the morbidity have been unsuccessful. Further research is the need of the hour to solve this enigma. To conclude, stigma as a research prerogative seems to have fallen out of favor in the current times, but it should not be forgotten that it remains a devastating machinery for our patients and their caregivers.

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Supplemental Material

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