

## **Comparative study of perception of stigma among caregivers of persons with Bipolar affective disorder and Schizophrenia**

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**Abstract:** Many people with serious mental illness struggle with the symptoms and disabilities that result from the disease and are also challenged by the stereotypes and prejudices that result from misconceptions about mental illness. As a result of both, people with mental illness are robbed of the opportunities that define a good quality life: good jobs, safe housing, satisfactory health care, and affiliation with a diverse group of people. There are still attitudes within most societies that view symptoms of psychopathology as threatening and uncomfortable, and these attitudes frequently foster stigma and discrimination towards people with mental illness. Stigma may result in various forms of exclusion or discrimination – either within social circles or the workplace.

Mental health stigma can be divided into **social stigma**, which is characterized by prejudicial attitudes and discriminating behaviour directed towards mental health problems and **perceived stigma** which is the internalizing by the mental health sufferer of their perceptions of discrimination. Perceived stigma can significantly effect in feelings of shame and lead to poorer treatment outcomes.

It is important to understand the aspect of prejudice against mental illness. By addressing this important issue appropriately, it is easier to create a supportive environment for persons with mental illness.

**Key Words:** Caregivers, Stigma, Mental illness.

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### **I. Introduction**

The stigmatization of mental illness is currently considered to be one of the most important issues facing the mental health field <sup>[1]</sup>. An enormous number of persons are affected by mental illness worldwide. It is estimated that 1 in 5 persons will suffer from a mental illness each year, with about 6% showing forms that indicate high levels of severity <sup>[2]</sup> <sup>[3]</sup>. Although individuals with mental illness suffer from a wide range of negative effects and impairments related to the disorder itself. These outcomes are exacerbated by societal stigmatization of their illness.

Stigma is a serious concern for individuals with Bipolar Affective Disorder and their families. Stigma occurs within affected individuals, families, social environments, work and school environments, and the healthcare industry. With stigma often come a loss of social support and occupational success, reduced functioning, higher symptom levels and lower quality of life. Bipolar Affective Disorder stigma is comparable to that of other severe mental illnesses, such as schizophrenia. <sup>[4]</sup>

Families of persons with mental illness face a range of practical and emotional stresses. Studies suggest that burdens could come from the stigmatizing attitudes. Stigma surrounding mental illness is so strong, that it places a wall of silence around this issue. Stigma related to schizophrenia in India is particularly high <sup>[5]</sup>.

Stigmatising attitudes towards people with mental health problems are widespread and commonly held. The most commonly held belief was that people with mental health problems were dangerous – especially those with schizophrenia, alcoholism, and drug dependence. People believe that people with mental health problems were generally hard to talk to. People tend to hold these negative beliefs regardless of their age, regardless of what knowledge they have of mental health problems, and regardless of whether they knew someone who had a mental health problem.

The impact of stigma is twofold. Public stigma is the reaction that the general population has to people with mental illness. Self-stigma is the prejudice which people with mental illness turn against themselves. Both

public and self-stigma may be understood in terms of three components: stereotypes, prejudice, and discrimination. Although stigmatizing attitudes are not limited to mental illness, the public seems to disapprove persons with psychiatric disabilities significantly more than persons with related conditions such as physical illness<sup>[6] [7] [8]</sup>.

Individuals with mental illnesses are highly stigmatised. Many people who might benefit from these services do not obtain them, or do not fully adhere to treatment regimens once they have begun. Treatment adherence plays a vital role in psychiatric rehabilitation<sup>[9]</sup>

Poor adherence to medication and psychosocial treatment is prevalent among individuals with schizophrenia, which increases their likelihood of relapse and re-hospitalisation<sup>[10] [11] [12]</sup>. While stigma does not affect quality of life, it sharply affects the self-esteem and personal growth of mentally ill. Self-esteem and personal growth are more affected by stigma of mentally ill patients than physically ill patients.

Stigma has been argued to be a major determinant of outcome of severe mental illness across cultures<sup>[13]</sup>. Studies on stigma and mental illness in the Indian setting have focused both on measurement of stigma and on locally important socio-cultural factors shaping stigma<sup>[14]</sup>.

The cultural dimension and cross-cultural comparison of stigma related to depression has been studied which measured illness experience, symptom prominence and indicators of stigma among 80 outpatients from mainly urban backgrounds<sup>[15]</sup>. The study concluded, amongst other findings, that patients reporting somatic symptoms had lower stigma scores than those reporting psychological symptoms.

Another study examined perceptions of stigma among caregivers in a sample of 159 urban patients attending outpatient clinic and fulfilling DMS-IV criteria for schizophrenia. Findings suggested that female sex of the patient and a younger age of both patient and caregiver were associated with greater stigma. An interesting conclusion that emerged from analyzing illness attributes of study subjects was “a lack of an explanation” for the illness among the high-stigma group of families.<sup>[5]</sup>

Stigma and discrimination linked to schizophrenia was found to have a significant impact on the lives of these individuals from a study investigating the patients’ perceptions of stigma. It was reported that with respect to perceived causes of stigma, a strikingly large percentage of participants (97%) believed that stigma was caused by a lack of awareness about schizophrenia, followed by the nature of the illness itself (73%). Behavioural symptoms associated with schizophrenia were also thought to cause stigma, whereas drug-related complications were seen as playing a less influential role in stigma. Sixty nine percent of patients felt that stigma came from attitudes from the general community, 46% from co-workers and 42% from family members<sup>[16]</sup>.

It is evident that stigma leads to negative outcomes for those with mental illnesses. Specifically, it means because of it, the mentally ill avoid seeking treatment because they fear being discovered and in turn shunned from society. Consequently, they increase their duration of untreated illness, continue to experience debilitating symptoms and as a result face the very stigma they were attempting to avoid in the first place.

## **II. Material and Methods**

**Aim -** The aim of the present study was to assess the perceived stigma of the caregivers of persons with Bipolar Affective Disorder as compared to Schizophrenia.

### **Objectives**

- To assess the stigmatizing beliefs among Caregivers of persons with schizophrenia.
- To assess the perceived stigma in relation to the clinical variables like duration of the illness as well as medication compliance.
- To study the relationship between stigma and various socio-demographic variables between two groups, i.e., Schizophrenia and Bipolar Affective Disorder.

This study was a cross-sectional hospital based, carried out at the Institute of Human Behaviour and Allied Sciences (IHBAS) in Delhi. For the purpose of study 30 caregivers of persons having the diagnosis of Bipolar Affective Disorder and 30 patients of Schizophrenia were selected purposively as per the inclusion and exclusion criterion of the study. After selection of the samples instruments like Socio-Demographic and Clinical Data Sheet, and Devaluation and Discrimination Questionnaire were used for data collection. A written as well as informed consent was taken from the samples of either group before starting data collection.

### **Inclusion criteria for patients**

Persons aged between 18 – 60 years, fulfilling the ICD criteria for schizophrenia/ Bipolar Affective Disorder, and who were clinically stable at the time of the study.

**Inclusion criteria for caregivers**

Caregivers of persons with Schizophrenia / Bipolar Affective Disorder, aged between 18 – 60 years who were living with the patient since the past 2 years.

**Exclusion criteria for Care givers**

Caregivers who had any major physical /psychiatric illness were excluded from the study.

**Tools**

**Social Demographic proforma with clinical details**

Socio-demographic schedule was used to elicit socio-demographic profile of the subjects. This schedule had covered domains like age, gender, education, occupation, socioeconomic status, income.

**Devaluation & Discrimination Questionnaire**

This is a 12-item rating scale measuring perceived public stigma. Responses are obtained on Likert Scale ranging from strongly agree = 1 to strongly disagree = 6. Higher scores indicate greater perceived stigma. The scale yields internal consistency of .81 and split-half reliability of .69 among clinical and community samples. This scale was aimed to measure subjective perception of stigma, which also records the respondents’ assumption of how the general population, i.e., “the others”, presumably thinks about mentally ill people.

**III. Results**

**Table I - Socio-demographic details of the patients**

Variables	BPAD (n=30) Mean±SD/ n (%)	Schiz (n=30) Mean±SD/n (%)	t/ □2	df	P Value
Age ( In years)	35.10± 10.36	37.13 ± 9.98	.774	58	0.442
Education (yrs.)	9.93 ±3.85	10.68 ±4.60	.639	58	0.525
Gender					
Male	19 (63.33)	18 (60)	.071	1	0.791
Female	11(36.67)	12(40)			
Religion Hindu					
Muslim	23(76.7)	22(73.3)	1.44	3	0.695
Sikh	6(20.0)	5(16.7)			
Others	1(3.33)	2(6.7)			
Domicile					
Rural	4(13.3)	4(13.3)	4.33	2	0.115
Urban	26(86.7)	22(73.3)			
Semi urban	Nil	4(13.3)			
Family Type					
Nuclear	15(50)	15(50)	4.658	2	.097
Joint	14(46.7)	9(30)			
Extended	1(3.3)	6(20)			
Compliance					
Good	15(50)	12(40)	.606	1	.436
Average	15(50)	18(60)			
Poor	Nil	Nil			

In the above table, persons with Bipolar Affective Disorder are found to be having mean age of 35.10 where as in Schizophrenia mean age is 37.13. Around 63.33% male and 36.67% female respondents were reported in BPAD, where as 60% male and 40% females were reported in Schizophrenia group.

It was found that, majority of the respondents belonged to the mean age group of 35 to 37 years in the schizophrenia and bipolar affective disorder respectively. Majority of the caregivers were male in both the groups. Majority of the caregivers belonged to the urban areas.

It was also observed that most of the persons visiting to the hospital were from Urban or semi urban background i.e. 86.7% each in BPAD and Schizophrenia. Compliance to the treatment in both the groups was quite encouraging i.e., 50% each good and average in Bipolar disorder; and 40% having good and 60% average compliance in Schizophrenia.

**Table II – Comparisons of DDQ with Socio Demographic details of the Caregivers**

Socio Demo Graphic Variables	n (%)	Mean Score of DDQ	Std. Dev.	T value/ F value	P value
Gender					
Male	37(61.7%)	38.08	5.82	0.511	0.611
Female	23(38.3%)	37.26	6.40		
Age (Yrs.)					
18-20	1(1.7%)	38.00	-		

<b>21-40</b>	31(51.7%)	37.55	4.74	0.041	0.960
<b>41-60</b>	28(46.6%)	38.00	7.34		
<b>Years of Education.</b>					
<b>0-5</b>	12(20%)	39.50	9.05	1.264	0.296
<b>6-10</b>	13(21.7%)	38.69	6.12		
<b>11-15</b>	32(53.3%)	36.44	4.54		
<b>16 &amp; above</b>	3(5%)	41.00	2.00		
<b>Domicile</b>					
<b>Rural</b>	8(13.3%)	41.88	8.81	2.139	0.037*
<b>Urban</b>	52(86.6%)	37.13	5.30		

The above table shows the comparison of Devaluation and Discrimination Questionnaire (DDQ) with socio demographic details of the caregivers. Marginal difference could be seen in the mean score of both the genders.

Variation could also be seen in the mean score of the education category. People with lesser education could be seen having less mean score as compared to the more educated people. It can be interpreted that less education has no role in understanding or acceptance of mentally ill persons in the society.

Statistically significant difference could be seen in the rural and urban category, the details are discussed in table III.

Among the caregiver respondents, 20 % caregivers were parents and another 20% were siblings; 42% persons caregivers were spouses, only 6% caregivers were children and 12% were other relatives in Bipolar affective Disorders. In the Schizophrenia group, 45% caregivers were parents and siblings, 25% were spouses, 10% were children and rest i.e. 20 % was other relatives.

**Table III - Stigma among Rural and Urban Population**

Domicile	Level of Stigma		
	Low	Medium	High
<b>Rural</b>	33.3%	66.7%	—
<b>Urban</b>	56.1%	41.5%	2.4%

In the above table it was found that, 33.3 % of the caregivers from rural areas expressed low stigma, 66.7% caregivers expressed medium stigma and no caregivers expressed high stigma. Alternately, 56.1 % of the caregivers from urban areas expressed low stigma, 41.5% caregivers expressed medium stigma and only 2.4% of the caregivers expressed high stigma. In contrast to the general opinion, findings related to stigma have been encouraging. Stigma among rural and urban population also seems to be varying from low to medium level. Stigma among rural and urban population also seems to be varying from low to medium level. Major international studies suggest that schizophrenia has better prognosis in low income nations and in rural settings [17] [18] [19].

**Table IV - Item wise Analysis of Devaluation and Discrimination Questionnaire (DDQ)**

Details of the questions	BPAD(%)	SCHIZ(%)	t/□2	df	P Value
<b>As a Close Friend</b>	10(33.3) Somewhat Disagree	15(50) Somewhat Agree	17.389	4	.002**
<b>As intelligent as others</b>	15(50) Agree	17(56.7) Agree	.313	5	.997
<b>Trustworthy</b>	11(36.7) Agree	18(62.1) Somewhat Disagree	10.99	5	.052
<b>Accept as Teacher</b>	9(30.0) Agree	17(65.4) Somewhat Agree	8.914	5	0.113
<b>Take it as personal failure</b>	12(40) Agree	15(50) Disagree	19.467	5	.002**
<b>Consider as caretaker of the child</b>	9(30) Agree	14(46.7) Somewhat Agree	4.567	5	.471
<b>Don't think about mentally ill</b>	9 (30) Somewhat Disagree	11 (36.7) Disagree	6.727	5	.242
<b>Don't employ despite suitability</b>	16(53.3) Agree	19(63.3) Somewhat Agree	11.577	5	.041
<b>Overlook the application</b>	13(43.3) Agree	14(46.7) Somewhat Agree	7.64	5	.177
<b>Behave like any other</b>	13(43.3) Agree	14(46.7) Agree	6.037	5	.303

<b>Girls will not prefer to interact</b>	9(30) Agree	9(30) Somewhat Agree	8.482	5	.132
<b>Don't take opinion</b>	17(56.7) Agree	9(30) Disagree	17.381	5	.004**
<b>Total Score</b>	35.83	39.70	2.612	58	.011**

In the above table, statistically significant difference could be found in the mean score of the Schizophrenia and Bipolar Affective Disorder group. Statistically significant difference also could be found on the 3 responses amongst the caregivers of persons with Schizophrenia and Bipolar affective disorders, which was mainly relating to acceptance of a former mentally ill person as a close friend, take it as a personal failure and not taking opinions of persons with earlier mental illness seriously.

The response to the questions pertaining to considering former mentally ill person as close friend has been found statistically significant between the two groups. It can be interpreted that the acceptance of persons with BPAD is much easier as compared to the persons with Schizophrenia. The response to the question as to whether the former mentally ill persons can be accepted as teacher has also received mixed reaction. Caregivers seem to have very less difference while perceiving stigma across male and female patients. The same is the case with male and female caregivers. Stigma observed among the two groups was found to be having very less difference on most of the domains, and are statistically not found to be very significant. Questionnaire used for evaluating the Stigma has its limitation, as all the questions pertaining to stigma was possibly not found suitable for the Indian culture.

#### IV. Discussion

Considerable research has documented the stigmatization of people with mental illness and its negative consequences. Recent literature further suggests that stigma seriously affects families of psychiatric patients<sup>[20]</sup>. Families with more education and whose relative had experienced an episode of illness within the past 6 months reported greater avoidance by others<sup>[21]</sup>. Psychiatric labels themselves can elicit stigmatizing responses above and beyond those attributable to symptomatic behaviour. Burden perceived by the family members were related to stigma and lack of mental health and rehabilitation services. Consequences included social isolation of the families<sup>[22]</sup>. As compared to the western literature, in the current study it was found that irrespective of the nature of mental illness or its severity, the relatives or caregivers' perception of stigma did not vary significantly.

In the current study, statistically significant difference could be found between the stigma towards Schizophrenia and Bipolar affective disorders. In the area of acceptance of the persons with mental illness in the stigma scale, it has been found that because of stigma attached with mental illness, patients are not accepted by the people in the community. Studies suggest that mental health patients' experiences are still not taken enough into account, neither by mental health professionals nor by their social networks<sup>[23]</sup>.

Statistically significant difference also found in the rural and urban population. Indian families, because of their rich values and high tolerance level are able to cope with the stigma. Most families were thought to be supportive and there was an impression that caring had made better family emotional ties. The DDQ scale has been primarily used in Western set up; some of the questions in the scale cannot be generalized in the Indian context. The study can be further planned within college, school or any other professional setting, where perception of the stigma about mental illness can be measured in the community set up.

There is enough evidence to suggest that stigma is a clinical condition; it is related to the phenomenology and symptom constellation of an illness. However, it remains poorly understood, investigated, and treated. To address the issue of stigma in the treatment setting, it is necessary and likely to offer the best possible anti-stigma program at an individual level. In order to achieve this goal, it needs to be demonstrated whether or not stigma associated with mental illness can be quantified, and whether such quantification can help clinicians in dealing with stigma.

#### V. Conclusion

It is clear that stigma leads to negative outcomes for those with mental illnesses. Specifically, it means, because of it, the mentally ill avoid seeking treatment because they fear being discovered and in turn shunned from society. Consequently, they increase their duration of untreated illness, continue to experience debilitating symptoms and as a result face the very stigma they were attempting to avoid in the first place. The mental health awareness of caregivers and their attitudes towards mentally ill can be important factors in the early initiation of the treatment of persons with Schizophrenia. If stigma is one factor that delays treatment seeking and continuation, then specific measures to reduce stigma in a variety of mental illnesses may prove to be of great value to achieve better outcomes. This will also allow for better patient integration into society as social

barriers due to prejudice are reduced. However, integrating stigma coping strategies in treatment in routine clinical practice remains a challenge.

Improving community attitudes by increasing knowledge and understanding about mental illness is essential if people with a mental illness are to live in, and contribute to the community, free from stigma and discrimination. Reducing stigma may represent a cost-effective way to reduce the risk of relapse and poor outcome occasioned by chronic exposure to stigmatising environments. In addition, significant gains in quality of life may result if all patients with schizophrenia routinely receive information about stigma and are taught to use simple strategies to increase resilience vis-à-vis adverse, stigmatising environments.

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