

## Experiences of Stigma among Outpatients with Psychotic Illnesses in a Tertiary Hospital

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### ABSTRACT

**Background:** Studies in most parts of the world, which have included persons with a mental illness in general and those with psychotic illnesses in particular conclusively show that they experience being stigmatized. These responses are seen as a major obstacle to recovery limiting opportunities and undermining self-esteem of people with mental illnesses. There is a conspicuous absence of this in the Indian context. This study assessed the nature and degree of stigma experienced by the persons with a psychotic disorder and examined its relationship with various clinical and demographic characteristics. **Methods & Materials:** The sample comprised of 100 consecutive remitted adults with a psychotic disorder as per DCR, ICD-10 attending outpatient services. Stigma was assessed using Wahl's self-administered stigma questionnaire. After computing a composite score, groups experiencing 'high' stigma were differentiated from those having 'low' stigma scores on the basis of the median. **Results:** Results showed that participants tend to conceal their disorders, worry of being treated unfavorably, were treated as less competent and experienced offensive media portrayals of mental illness. Lower educational levels and history of psychiatric illness in the family significantly related with higher degrees of stigma. **Conclusions:** The findings of this study may be seen as a serious call for sustained attention to issues related to stigma as a central and powerful experience among those with a psychotic illness in the Indian context. Those who have another family member suffering from a psychiatric illness, and having lower levels of education should be particularly assessed and managed for stigma during routine outpatient evaluations.

**Keywords:** Stigmatizing experiences, psychosis, outpatients, tertiary hospital

Stigmatizing responses to people who have been identified as having a mental illness are seen as a major obstacle to recovery limiting opportunities and undermining self-esteem.<sup>[1]</sup> For example, research has shown that many people with severe mental illness experience discrimination at work,<sup>[2-4]</sup> when leasing

apartments<sup>[5]</sup> and in the criminal justice system<sup>[6,7]</sup>. Moreover, studies have indicated that people with psychosis in general, and among those with schizophrenia in particular<sup>[8,9]</sup> experience being stigmatized primarily because of the visible nature of its symptoms that are manifested during acute

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exacerbations of their illness.<sup>[10,11]</sup>

Though in most parts of the globe, studies on the stigma of mental illness have essentially examined attitudes among the general public (and among sub-groups in them), a noticeable shift towards including perspectives of the mentally ill person is seen in contemporary literature.<sup>[8,12-14]</sup> The earlier notion may have been because of the reckoning that one can draw close to real inferences from the apparent conclusions of these studies, what could be the experiences of those with mental illness. Stigma experienced by family members of persons with a psychiatric disorder has also been studied given the “associative”<sup>[15]</sup> or “courtesy”<sup>[10]</sup> effects of stigma.

Absent from the explorations of mental illness stigma is the person with the mental disorder who is presumably the recipient of stigma. This becomes all the more conspicuous when one weighs the evidence among studies conducted in the Indian setting. However, the relatively few studies that have sought information directly from persons with a mental disorder provide evidence that they experience themselves as stigmatized,<sup>[16-18]</sup> expect to be treated poorly by the public,<sup>[4,19]</sup> encounter rejection and discrimination,<sup>[18,20]</sup> suffer demoralization and reduced life satisfaction connected to stigma,<sup>[4,21]</sup> and employ specific strategies to protect themselves from expected rejection and discrimination.<sup>[18,22,23]</sup> These studies focused on general impressions and expectations of stigma rather than on specific experiences.

The concept of empowerment that is growing in importance in discussions of treatment of mental illness demands that people with a mental disorder be included in research about their lives.<sup>[9]</sup> Rapp and colleagues,<sup>[24]</sup> for example, have noted that “one of the reasons for the dominance of person-blaming interventions and research is that the people (whom clinicians) seek to help have not been judged to be important informants”. The current study, therefore, was undertaken to explore and examine mental illness stigma particularly from the perspective of persons with a diagnosed psychotic disorder, where the nature and degree of stigma was assessed and its relationship seen with various clinical and demographic variables. Till date and as far as the authors of the present study are aware, there is almost no study in India that has looked into this aspect among such a group.

## METHODS AND MATERIALS

### *Sample*

The sample consisted of 100 consecutive persons attending routine follow-up services at the outpatient department of Central Institute of Psychiatry. The inclusion criteria were as follows: age above 18 years; diagnosed having a psychotic disorder as per DCR, ICD-10;<sup>[25]</sup> absence of clear organic etiology for psychosis; currently in remission (i.e. relatively asymptomatic for two months); and absence of mental retardation. Given the nature of psychotic disorders, individuals who were currently somewhat asymptomatic and some degree of communication could be established were recruited in the present study.

### *Measures*

Stigma was assessed using nine questions about people's interpersonal experiences as mentally ill persons. Questions addressed such topics as specific treatment by others (e.g., being shunned or rejected), negative things seen or heard about mental illness (e.g., in mass media), and fears and behaviors related to disclosure of status having a mental illness. These items were adapted from a nation-wide survey conducted by Wahl O.F.<sup>[9]</sup> and respondents were asked to rate the extent of each experience on a five-point scale from 'never' to 'very often'. These set of questions asked have so far not been used among the Indian population, and thus there are no established norms and standards. In the absence of any standardized measure to assess stigma experienced by people with mental illness, the authors found it prudent to adapt items from the above mentioned survey.

### *Analysis*

Descriptive statistics were employed to examine the nature and degree of stigma. A composite stigma score was calculated by adding the scores of the nine items; thereafter the total stigma score was computed for the sample. Persons experiencing 'high' stigma were differentiated from those having 'low' stigma if their total stigma score was above the median. Chi-square tests for categorical variables and t-tests for continuous variables were used to find out significant relationships among clinical and demographic variables, and low and high stigma groups. The level of significance (i.e. p value) was set at 0.01. Data collected was analyzed with SPSS (11.0).

## RESULTS

*Demographic Characteristics*

The age of the respondents ranged between 19-66 years, with the average age being 34.6 years. There was a preponderance of married respondents in comparison to unmarried respondents (64:36%), while there was a slight preponderance of males compared to female respondents (59:41%). Respondents belonging to the general category were 33%, whereas 46%, 14%, and 7% were from the other backward classes, scheduled castes, and schedule tribes respectively. An almost equal number of respondents were from a rural and urban domicile (54:46%). The educational level of the respondents ranged between 0-19 years, with the mean being 8.8 years. Unemployed respondents comprised 80%, while the rest were employed. Sixty three percent (63%) of the respondents were living with their parents

and other family members like elder siblings, uncle or aunts, and cousins, while the 37% were living independently at home (See Table 1A and Table 1B).

Three-fourth of the sample (i.e. 75%) comprised of respondents with a mood disorder and the rest had schizophrenia. The age of the respondents at the time of the onset of their illnesses ranged from 9-59 years, with the mean being 27.8 years. The total duration of illness ranged from six months to 21 years with the mean being 5.6 years. Forty three percent (43%) had a family history of a psychiatric illness, while 42% had a history of being hospitalized in the past (See Table 1A and Table 1B).

*Nature and Degree of Stigma*

The most commonly reported experiences were avoiding telling others outside their immediate family about their mental illness, worrying others will view study participants unfavourably because I have a

Table 1A.

Relationship of Demographic and Clinical Characteristics with High and Low Stigma Groups (Continuous Variables)

Characteristics	Range	Mean (SD)	Low Stigma	High Stigma	<i>p</i> -value
Age in years	19 - 66	34.5 ( 11.9 )	34.2 (13.4)	35.2 (10.2)	0.676
Education years	0 - 19	8.8 ( 4.5 )	10.7 (3.8)	6.9 (4.5)	<b>0.000*</b>
Age of first onset	9 - 59	27.8 ( 11.7 )	28. (12.8)	27.3 (10.5)	0.683
Duration of illness in years	0.5 - 21	5.6 (5.8 )	4.6 (5.2)	6.6 (6.2)	0.076

Table 1B.

Relationship of Demographic and Clinical Characteristics with High and Low Stigma Groups (Categorical Variables)

Characteristics		%	Low Stigma	High Stigma	<i>p</i> -value
Gender	Male	59	34	25	0.103
	Female	41	16	25	
Marital Status	Married	64	27	37	0.060
	Unmarried	36	23	13	
Category	General	33	19	14	0.395
	Others	67	31	36	
Domicile	Urban	46	20	26	0.316
	Rural	54	30	24	
Employment Status	Employed	20	9	11	0.803
	Unemployed	80	41	39	
Current Living Situation	Independently living	37	16	21	0.408
	With parents/ relatives	63	34	29	
Diagnosis	Mood Disorders	74	37	37	1.000
	Schizophrenia	26	13	13	
Family History	Present	43	14	29	<b>0.004*</b>
	Absent	57	36	21	
Past Hospitalization	Yes	42	21	21	1.000
	No	58	29	29	

mental illness, being treated as less competent by others once their illness was known, and experiencing offensive media portrayals or depictions of mental illness. (See Figure 1). Throughout the article, only events that occurred at least sometimes were considered to have a frequency worth noting and have been reported. Ninety three percent (93%) indicated that they had avoided telling others outside their immediate families about their mental illness; such experiences occurred often or very often among 42% of the respondents. Eighty three percent (83%) worried that others would view them unfavorably if their status as a mentally ill patient were disclosed; among which 37% said they worried about this often or very often. Seventy eight percent (78%) experienced being treated as less competent by others once their illness was known. Seventy five percent (75%) experienced stigmatizing media depictions of mental illness, of which 38% reported such experiences were often or very often.

Seventy percent (70%) reported that they had had the experience of sometimes being shunned or avoided and being told to lower their expectations in life. Fifty five percent (55%) reported witnessing unfavorable or offensive comments about mental illness. Twenty two percent (22%) never or seldom experienced being

treated fairly by others after coming to know about their mental illness, while 32% never or seldom experienced support from friends who learned they were mentally ill (See Figure 1).

#### Factors Associated with High and Low Stigma Groups

The median stigma score for the sample was 27.50. Apart from the relationship of different clinical and demographic variables that were examined with high and low stigma groups in the present study; educational level and family history showed statistically significant associations (See Table 1A & Table 1B).

#### DISCUSSION

Interpreting the results of this study may depend upon one's degree of optimism. It is possible, for example, to look at these reports as encouraging. Almost four in five experienced being treated fairly by others after coming to know about their mental illness, while almost seven in ten experienced support from friends who learned they were mentally ill. That may have been spared some of these stigma experiences may be seen as a positive result.

However, the most troubling result is that people with a psychotic illness avoided disclosure of their mental illness outside their immediate family. This, however, appeared to provide only some relief from stigma as more than one in three feared that others would view them unfavourably if their status as a mental patient was disclosed. Such experiences have led many people with a psychiatric disorder to maintain a secrecy that not only is uncomfortable but may also contribute to the very symptoms-anxiety, depression, paranoia-from which they are struggling to recover producing conditions antithetical to the goals of recovery. Additionally, results suggest that this group of people may still find themselves being shunned, avoided, and treated as less competent; may have witnessed themselves being the object of humour, intolerance, and insensitivity. Findings of the present study are somewhat similar to what has been reported in the existing literature.<sup>[4,16-20]</sup>

However, this study exclusively reports on specific experiences of stigma among an Indian population of individuals suffering from psychosis.

Results suggest furthermore, that the experiences of "indirect" i.e., negative remarks and media portrayals of mental illness that are not directed toward any

Figure 1.

The Nature and Degree of Stigma Experienced (N=100)

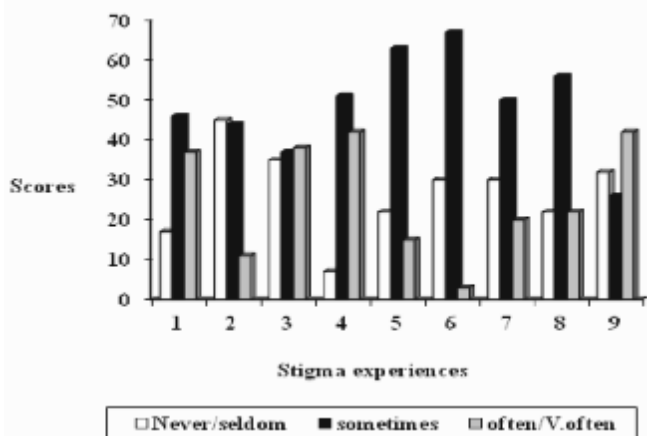


Figure 1. The Nature and Degree of Stigma Experienced (N=100)

Note: 1=Worried others will view me unfavorably, 2= Situations where I have heard others say offensive things, 3= Seen or read things in the mass media that I find hurtful or offensive, 4=Avoided telling others outside my immediate family, 5= Treated as less competent, 6= Shunned or avoided, 7=Advised to lower expectations in life, 8= Treated fairly by others, 9=Friends have been supportive and understanding.

particular individual or that do not directly express opinions about persons with psychiatric disorders is the most common. The sources of such comments and depictions probably do not consider that their audiences might include people with mental illness who could be affected by such remarks. Results suggest that people with mental illness are sensitive to such remarks, which serve as constant reminders of the low esteem in which they are held.<sup>[9]</sup>

Another result that points to communications that people may not be aware are stigmatizing is the degree to which mentally ill individuals were sensitive to advice about lowering their expectations in life; one in two said this occurred at least sometimes. Moreover, more than three in five reported that they were sometimes treated as less competent. The increasing success of consumer run groups is demonstrating that assumptions about the limited potential of people with severe mental illnesses may indeed reflect negative and inaccurate, though lingering stereotypes of incompetence and limited recovery potential. Though there is a lack of reportage on issues related to this in the Indian context, mental health consumers are increasingly rejecting these stereotypes as offensive and harmful in many other countries.<sup>[26,27]</sup>

Findings that are of concern are that positive family history of psychiatric disorder and lower educational attainment among the mentally ill individuals significantly showed higher degrees of stigma. Individuals with another member in the family also having a psychiatric disorder experience greater stigma may be because of the associative or courtesy effects of stigma.<sup>[10,15]</sup> Lower educational levels are associated with poorer functioning in the community as this sample too showed that individuals with higher educational attainment were mostly employed. Poorer levels of functioning in the community further elicit negative responses.<sup>[8]</sup> Stigma research in the future needs to consider both the apparent nature of psychotic symptoms<sup>[10,11]</sup> as well as employment status as an indicator of socio-occupational functioning to better examine stigma experienced by people with psychotic disorders.

#### LIMITATIONS AND CONCLUSION

The major caution in considering results of the present study concerns the nature of participants. Respondents

are not completely representative of the population of people with psychoses attending outpatient services. Firstly, people with substance induced psychotic disorders; delusional disorders; acute and transient psychotic disorders, obsessive-compulsive disorders were left out. Whether or not similar stigmatization occurs for those with the above disorders seeking outpatient treatment is not addressed by these data. A broader sample that includes people with all kinds of psychotic illnesses would be useful in determining the extent to which these diagnoses would lead to similar stigma experiences. Measures like sources of stigma, coping strategies employed, and effects on individual self-esteem and life satisfaction were not examined. Previous studies have indicated that these variables have strong implications in reducing stigma experienced by people with psychiatric disorders.

These cautions, however, do not negate the conclusion that people with psychotic illnesses experience being stigmatized in their life. These results may still be seen as a call for continued attention to stigma as a central and powerful experience of mental illness. Therefore, individuals with psychosis, and particularly those who have another family member with a psychiatric disorder and with lower educational attainments should be thoroughly assessed and managed for stigma during routine outpatient evaluations.

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