

PERCEIVED STIGMA AMONG PATIENTS WITH SERIOUS MENTAL ILLNESSES AND THEIR FAMILY MEMBERS IN RURAL SOUTH INDIA

Sreelakshmi Sharma¹, Prashanth Peethala², G. Gopalakrishnan³

¹Junior Resident, Department of Psychiatry, MVJ Medical College and Research Hospital, Hoskote, Karnataka.

²Senior Resident, Department of Psychiatry, MVJ Medical College and Research Hospital, Hoskote, Karnataka.

³HOD, Department of Psychiatry, MVJ Medical College and Research Hospital, Hoskote, Karnataka.

ABSTRACT

BACKGROUND

Stigma is defined as stereotypes or negative views attributed to a person or a group of people, when they are viewed as being different from or inferior to societal norms. Stigma associated with mental illness has chronic, devastating effects. The Centre for Mental Health Services (CMHS) defines serious mental illnesses (SMIs) as those that result in functional impairment that significantly interferes with or limits one or more major life activities. They are schizophrenia, schizoaffective disorder, other psychotic disorders, bipolar disorder and severe depressive disorder.

The aim of the study is to determine as to whether perceived stigma levels are more among patients with severe mental illnesses or their family members. The objectives were to measure stigma levels among patients with severe mental illnesses, and their attenders, and then to compare the two levels in order to arrive at a reasonable conclusion.

MATERIALS AND METHODS

Semi-structured socio-demographic proforma was used to assess the patients' age, sex, socio-economic status, occupation and relationship with the caretaker. The Stigma Questionnaire was then administered to both patients and attenders in order to assess their perceived stigma level.

Settings and Design- This was a cross-sectional, comparative, observational study conducted on fifty patients and their primary caregivers at a tertiary care center in rural Karnataka.

Statistical Analysis- Comparisons were made, patient vs. attender group, using mean scores.

RESULTS

The study concluded that the caretakers of the patient perceived much higher stigma than the patients. The patients perceived maximum stigma in the respect domain, whereas the attenders perceived maximum stigma in the marriage domain.

CONCLUSION

The patients faced higher levels of self-stigma whereas the attenders perceived public stigma.

KEYWORDS

Stigma, Serious Mental Illness, Family.

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BACKGROUND

The word stigma is derived from a Latin word, which means a scar, a tattoo or a mark. Mental illness is typically seen as a scar, which sets one apart, and this stigma has chronic and devastating psychosocial consequences. In psychological terms, stigma is defined as stereotypes or negative views attributed to a person or a group of people, when they are viewed as being different from or inferior to societal norms.¹

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Corresponding Author:

Dr. Sreelakshmi Sharma,

Junior Resident,

Department of Psychiatry,

MVJ Medical College and Research Hospital,

Hoskote, Bangalore- 562114, Karnataka.

E-mail: sree7491@gmail.com

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The US Surgeon General (1991)² and the WHO (2001) cite that stigma is a significant barrier to treatment-seeking among those with mental disorders.³ Even after recovery from illness, stigma can affect the quality of life of the patient. Though it is a socio-cultural phenomenon, the impact of stigma across different cultures is similar. They include a decline in the quality of interpersonal relationships, discrimination at workplace, difficulty in leisure activities etc. The Centre for Mental Health Services (CMHS) defines serious mental illnesses (SMIs) as those that result in functional impairment that significantly interferes with or limits one or more major life activities. They are schizophrenia, schizoaffective disorder, other psychotic disorders, bipolar disorder and severe depressive disorder.

Most of the existing studies on stigma have attempted to measure it in the community rather than the patients. Very few studies have attempted to compare the stigma levels among patients and attenders. The present study was

carried out against the above background, in order to measure and compare stigma perceived stigma levels of the patient as well as the attender.

Aim of the Study

To establish whether perceived stigma levels are more among patients with severe mental disorders or their family members.

Objectives

- To measure stigma levels among patients with severe mental disorders
- To measure stigma levels among attenders of patients with severe mental disorders
- To compare the two levels, in order to arrive at a reasonable conclusion

MATERIALS AND METHODS

Type of Study:

- Hospital-based cross-sectional observational study

Study Population:

- Patients attending psychiatric OPD at MVJMC&RH, which is a tertiary care hospital based in rural South India.

Sample Size:

- 50 patients and their primary caretakers.

Inclusion Criteria

- ICD-10 criteria, manifesting as severe mental disorders, as diagnosed by consultant psychiatrist.
- Age above 18.
- Patients accompanied by primary caretaker.
- Those giving written informed consent.

Exclusion Criteria

- Co-morbid medical/psychiatric disorders.
- Those already on family therapy, interfering with responses.
- Age below 18.
- No consent.

Sample Selection:

Samples were selected in a serial consecutive manner, without randomization, from among those meeting the eligibility criteria.

Data Collection

Patients were recruited and data was collected over a period of six months (Apr-Oct 2018). There was no randomization and selection were made in a serial consecutive way, from among those who met the inclusion criteria. The population consisted of the patients, attending Psychiatry OPD at MVJ Medical College and Research Hospital, Hoskote, Bangalore, which is a Tertiary Care Referral Hospital. On evaluation by a senior psychiatrist, if their diagnosis was indicative of any

severe mental disorder as per ICD-10 criteria, written informed consent was taken from all of them, as well as their caretakers. Semi-structured socio-demographic pro-forma was used to assess the patients' age, sex, socio-economic status, occupation and relationship with the caretaker. The Stigma Questionnaire was then administered to both patients and attenders in order to assess their perceived stigma level. Comparisons were made, patient vs. attender group.

Instruments

1) Semi-structured socio-demographic proforma- All participants were first administered this proforma in order to record the socio-demographic variables, such as age, sex, occupation, socio-economic status of the family, and the relationship with the primary caretaker.

2) Stigma Questionnaire (2011)⁴ - It is an 8-item scale, developed in 2011 by Mahajan & Bannerjee. The scale was developed for the Indian population and has been standardized across India. It is a clinician-administered scale, designed to assess the extent to which stigma is present amongst individuals with mental illnesses. It has adequate reliability as well as good face and construct validity. For ease of analysis and comprehension of results, the scale has been further divided into eight domains as follows:

- I- Concealment
- II- Avoidance of social contacts
- III- Self-pity
- IV- Ridicule
- V- Respect
- VI- Impact on marriage or marriage prospects
- VII- Job discrimination
- VIII- Job prospects

Each domain is scored on an ordinal range from 0-3, 0 meaning no perceived stigma, 1 meaning uncertain stigma, 2 meaning possible stigma and 3 denoting definite stigmata. The maximum score on the scale is 24 and the minimum is 0.

Method of Administration

The scale was administered to all participants, i.e., patients and attenders, in the same manner. Informed, written consent was taken from all the participants, before their enrolment in the study. Before administration of the questionnaire, it was emphasized that there were no 'right' or 'wrong' answers, and that all the items should be answered frankly without inhibition. Since many items were highly personal to the families under study, participants were assured of the confidentiality of their responses. Questions were translated into the local languages for the benefit of the participants of the study who did not follow English. For illiterate participants, the scale was administered by reading out the questions and asking them to indicate their response.

Statistical Analysis

Responses were summarized in the form of tables, and the central tendencies such as the mean score was calculated for ease of comparison.

Ethical Clearance

Ethical clearance was obtained from the Institutional Ethical Committee. Besides, informed consent was taken from the participants of the study, which included patients as well as their next of kin. It was an observational study, which meant that no interventions would be carried out on any of the participants. Confidentiality of responses was assured to all participants.

RESULTS

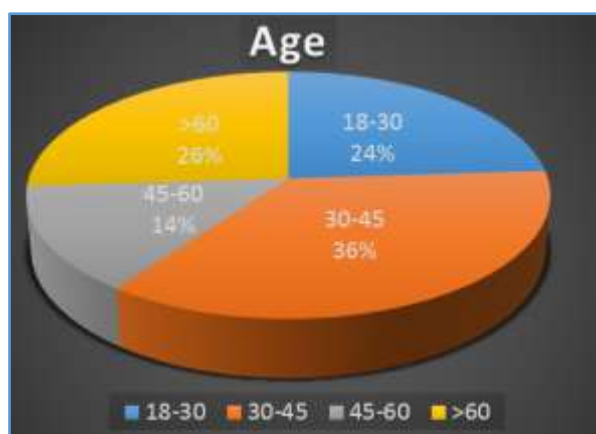
The data collected over the period of the study is summarized in the form of tables and charts in the following pages of this section.

I) Socio-Demographic Data

A) Age

Age	No. of Patients	Percentage
18-30	12	24
30-45	18	36
45-60	7	14
>60	13	26

Table 1



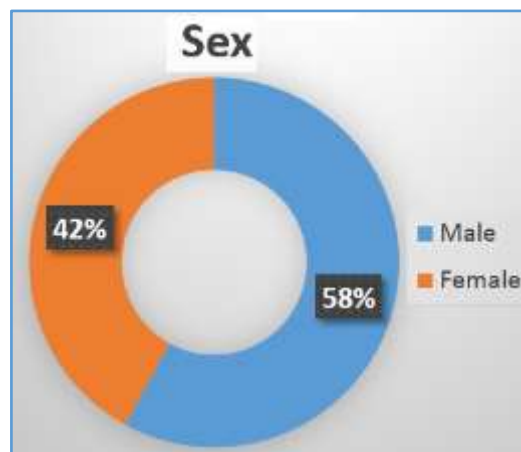
Graph 1

Most of the patients (36%) belonged to the age group 30-45, followed by the age group >60(26%). Next most common was the age group 18-30 (24%), lastly followed by 45-60(14%).

B) Sex

Sex	No. of Patients	Percentage
Male	29	58
Female	21	42

Table 2



Graph 2

58% of the study population consisted of males and the rest (42%) were female.

C) Occupation

Occupation	No. of Patients	Percentage
Unskilled	38	76
Semi-skilled	10	20
Highly skilled	2	4

Table 3



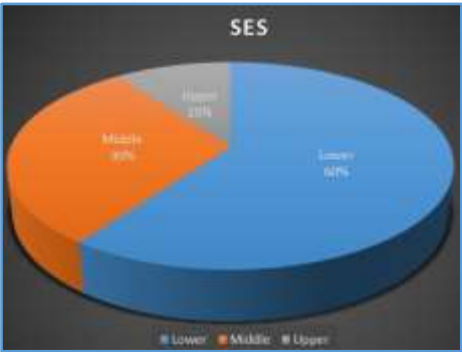
Graph 3

Most of the participants were unskilled labourers (76%), followed by semi-skilled workers (20%). Only a few of them were highly skilled workers (4%).

D) Socio-Economic Status

SES	No. of Patients	Percentage
Lower	30	60
Middle	15	30
Upper	5	10

Table 4



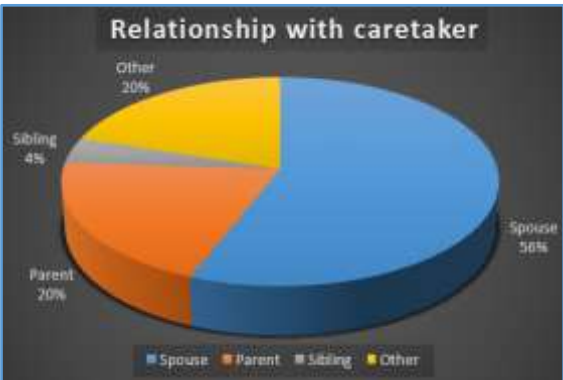
Graph 4

Most of the participants were from the lower socio-economic strata (60%), followed by the middle classes (30%) and the upper class (10%).

E) Relationship with Primary Caretaker

Relationship	No. of Patients	Percentage
Spouse	28	56
Parent	10	20
Sibling	2	4
Other	10	20

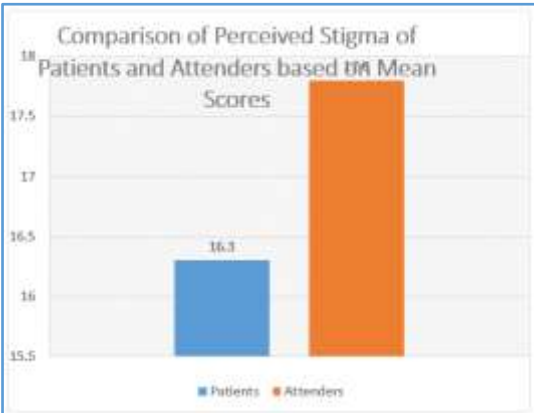
Table 5



Graph 5

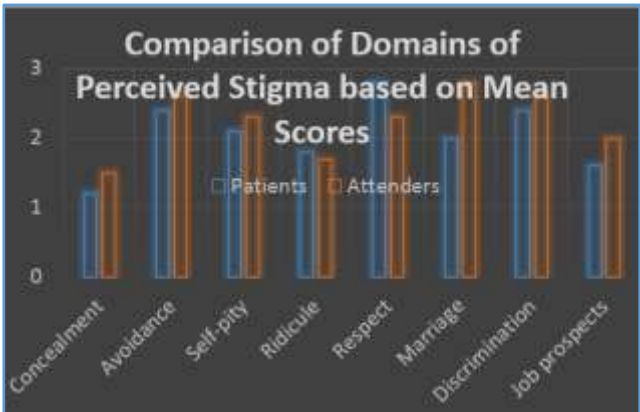
In most cases, the primary caretaker was the spouse (56%), followed by the parent (20%). About 4% caregivers were siblings and the remaining 20% consisted of other relatives.

II) Survey Data



Graph 6

The mean stigma score of the patients' attenders was higher (17.8) than that of the patients (16.3).



Graph 7

In most of the domains the attenders perceived higher stigma levels than the patients. The patients scored higher than the attenders only in the respect and ridicule domains. The patients perceived maximum score in the respect domain, whereas the attenders perceived it in the marriage domain.

DISCUSSION

This observational study set out to measure perceived stigma levels among patients and attenders, using the Stigma Questionnaire. Using the same questionnaire, different domains of perceived stigma could be compared as well. Thus, there are two major perspectives of this study.

1) Comparative Stigma Levels among Patients and Attenders

From the above results, it is seen that in most cases, the attenders perceived higher stigma levels than the patients. Corrigan et.al highlighted the difference between public stigma and self stigma.⁵ Public stigma refers to a sense of awareness about stereotypes held by the general public. Self-stigma refers to internalized feelings of shame and guilt. The attenders of the patients with SMIs are likely to suffer from both public stigma as well as self-stigma. Judd et.al (1993) showed that a lack of insight among patients would lead to a difficulty in assessing their condition.⁶ Kreuger et.al (1996) note that most patients with SMIs have poor social cognition, which would imply their relative resistance to public stigma.⁷ Hilton et.al (1996) observed that stigma levels are much higher in collectivistic rather than individualistic societies.⁸

2) Domains of Perceived Stigma

The caregivers perceived maximum stigma in the public domains, such as marriage, workplace discrimination and job prospects. Attenders perceived the maximum level of stigma in the marriage domain. Patients were much more concerned about the personal domains of stigma such as ridicule and respect. Moreover, the patient scored higher than the attender in these two domains.

Limitations

- 1) A larger sample size would allow for more homogeneity of population.
- 2) The sample population consisted of homogeneous population from a single center.
- 3) Blinding of participants as well as investigators would have eliminated any risk of bias.

Future Directions

A larger sample size for the same research would allow for more homogeneity of population. Other associations, such as age and stigma, sex and stigma etc. can be explored in detail.

CONCLUSION

This was a cross-sectional comparative study conducted on fifty patients and their primary caregivers at a tertiary care center in rural Karnataka. The study concluded that the caretakers of the patient perceived much higher stigma than the patients. The patients perceived maximum stigma in the respect domain, whereas the attenders perceived maximum stigma in the marriage domain.

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