STIGMA EXPERIENCED BY PATIENTS WITH SCHIZOPHRENIA AND THEIR CAREGIVERS AMONG RURAL POPULATIONS OF CENTRAL INDIA

Dr. Amey Chandrashekhar Joshi[1]* and Dr. Pradeep S. Patil[2]

[1]Junior Resident, Department of Psychiatry, Jawaharlal Nehru Medical College, Sawangi (Meghe), Wardha, Maharashtra, India.
[2]Professor, Department of Psychiatry, Jawaharlal Nehru Medical College, Sawangi (Meghe), Wardha, Maharashtra, India.

*Corresponding Author: Dr. Amey Chandrashekhar Joshi

Junior Resident, Department of Psychiatry, Jawaharlal Nehru Medical College, Sawangi (Meghe), Wardha, Maharashtra, India.

ABSTRACT

Background: The stigma experienced by patients of schizophrenia and their caregivers have harsh emotional impact upon them and serve as a obstacle to the treatment procedure. **Context**: This study made an effort to measure the stigma experienced by the patients of schizophrenia and their caregivers plus the relationship of measured stigma to their socio-demographic and clinical variables. **Aims**: To study the stigma experienced by patients of schizophrenia and their caregivers. **Settings and Design**: The study design was cross-sectional analysis study. It comprised 100 patients and 100 caregivers to analyze the stigma faced by the patients of schizophrenia with their caregivers. **Methods and Material**:
1)   Semi structured proforma for socio demographic and clinical variables.
2)   Internalized stigma of mental illness Scale (ISMIS) to assess self-stigma.
3)   Stigma scale which is used for the caregiver of person of mental Illness, abbreviated as CPMI.
Results: Overall 42% patients reported high internalized stigma on ISMI scale. On CPMI   scale, the score indicated high level of stigma. None of the demographic characteristics of patients were associated with ISMI or its subscale scores i.e. internalized self-stigma was present equally among all the patients, overall as well as on all the five subscales. Among socio-demographic variables of the caregivers, genders of the caregivers were associated with behavioral component of the CPMI scale (P < 0.05). Women caregivers had higher scores on CPMI scores as well as on behavioral component subscale (P < 0.05). **Conclusions**: The intensity of stigma experienced as a consequence of having mental illness is quite high. Considerable level of self-perceived stigma among caregivers of people with mental illness was observed. For that reason, there is a necessity to take specific interventions to improve overall quality of life and reduce stigma.

KEYWORDS: Stigma, schizophrenia, mentally Ill, caregivers.

INTRODUCTION

A severe mental disorder, like schizophrenia, devastates the lives of the patients along with their family members.

This is due to chronic nature of the illness and the long term it often involves. Person with schizophrenia experiences problems associated with positive symptoms for example hallucinations, aggressive behavior, delusions in addition to negative symptoms for example reduced motivation and insufficient care of himself. Job opportunities get reduced and the capacity to form and maintain social relationships also gets difficult.[1,2]

Modern approaches of treatment have tried to help a great amount of patients with schizophrenia to recuperate or improve considerably, however a lot of continue to suffer shortfalls in various extents of functioning. As a result, long-lasting mental illnesses pose a substantial burden to the ill person as well as his family members and the community.

Patient's family member experiences diverse sentiments, which comprises grief, loss, anger and guilt. Similar to the patient, they too feel the adverse effects of the stigma and isolation.[3,4] Family members who live with the patients with mental illnesses have adverse effects on their lives because they have to provide more care, spend more time for the patient in comparison to the other normal people. It is observed that the families in which the coordination and relations between different members in the family are not good, then the one who cares for the patient has to give extra amount of care to

the patient, the consequence of which can be that he will have to become the sole caregiving person. Burden of playing caregiver role in addition to their already existing personal roles becomes stressful economically, psychologically and physically.[5]

In the west, the engagement of the family as the primary locus of care for a mentally ill relative has been one of the consequences of the deinstitutionalization movement.

Nevertheless, in the Indian scenario, family members have acted as caregivers by tradition for their mentally ill kin. The reason for this setting in India can be attributed to the ideas, customs and social background apart from the existing insufficient mental health infrastructure.[6] In India, family members are seen to be involved in most features of caregiving for people with numerous mental illnesses. They have to play prominent role in various settings for example, to decide whether to start taking the treatment, to continue or discontinue the treatment procedure, providing uninterrupted care, supervision of medication and emotional care for the person with mental illness.[7,8]

The demands of caring for a person with a chronic illness like schizophrenia have both an emotional and practical impact on the caregiver. The consequences of the illness for the patient's family members have been subsumed under the rubric of family burden.[9]

Burden has two components i.e. subjective and objective. Subjective burden has been viewed as the emotional expenditures of the illness for the family whereas in objective burden, disruption of everyday lives of family members occurs such as altered social relationships, loss of free time and financial costs.[10,11]

A stress and coping outline can be helpful to mental health experts for understanding the range of adaptation responses developed by family members to the stress of caregiving for their mentally ill relatives.[12,13] This outlook views the individuals as dealing to situations that are perceived as challenging or as beyond their ability to cope with them.[14] Caregiving for a kin with schizophrenia is seen as a chronic stressor, because of the long term disability, lack of controllability above the situation and endless course of the illness. To the family members, coping comprises continual adjustments to deal with frequent crises and disruptions in their lives[15]. Due to the availability of scanty resources the problem can get more compounded which may result in financial and other hardships.[16] Caregivers experience significant amount of suffering as a result of their caregiving role and are vulnerable to develop minor psychiatric disorders like depression and anxiety.

It is of significance that how the caregiver reacts to the problem, how he defines, plans and makes use of the coping methods to deal with the situation. Because these coping methods will ultimately have an effect on caregiver's own health, patient's health and his future relations with the patient.[17] Coping denotes to the individual's continuously altering behavioral and cognitive strategies to tackle an experience judged as difficult and traumatic.[18] Coping strategies are of two types i.e.; problem focused and emotion focused.

In problem focused policies, the stress is observed to be on discovering answers to the problems, whereas the emotion focused policies denote to the means in which the person manages the emotional reaction to the problematic situation.[19] It is observed that in the cases where the tenure of the illness gets extended and becomes more stressful, then usually it is likely that family members will go for emotion based methods to cope with the problems.[20,21]

Schizophrenia is known as a heterogeneous entity, which involves both positive and negative symptoms. Positive symptoms include hallucinations, thought phenomena and delusions while negative symptoms include anhedonia, alogia, avolition and apathy. Various studies have revealed that negative symptoms are found to be more stable as compared to positive symptoms and are less likely to improve over the course of the illness.[22]

Among patients with various mental illnesses, evidence has shown that those with schizophrenia experience more stigmas as compared to other psychiatric conditions like eating disorders and depression.[23,24] The stigma leads to restricted opportunities for education in addition to employment, plus impaired, unsatisfactory quality of life and social exclusion. It has been reported that people have a tendency to refrain from the use of mental health facilities just for the reason that they dread for the label of being attached to them as "mentally ill patient". In this way they feel that they are avoiding negative consequences associated with the stigma of mental illness.[25] These incidences of self-stigmatization are reported to cause discrimination and low self-esteem which has been shown to contribute to failure to pursue work in the community. There is increasing evidence of stigmatization of people with mental illnesses globally around the world and experience of stigma has been found to vary across different sociocultural backgrounds.[24,26,27,28]

The negative impact of schizophrenia like the stigma is not only restricted to the patients as such, but also the caregivers, particularly the closer relatives of them. "Courtesy stigma" was the term designated by Goffman.[29] He stated it as the stigma experiences of significant others. In addition to being felt uncertain regarding the fate and consequences of mental illness, the family, friends and closer relatives of persons with schizophrenia have experience of shame and embarrassment.[26]

Family members are every so often the primary caregivers of persons with mental disorders. They give

emotional and physical care, and often have to endure the monetary expenditures related to mental health treatment and care. It has been found that families have reported 'stigma by means of association' causing in discriminatory and hurtful behavior towards them. Family members of the patients believe that stigma associated with mental illness brings indignity to the family and has negative impact on the marriage prospects of other family members; therefore they try to keep the illness secret and remain reluctant to seek and pursue professional mental health services. Family stigma comprises the stereotypes of shame, blame, and contamination; public outlooks which hold responsible the family members for incompetence can invoke relapse or trigger the onset of family member's psychiatric illness. Stigma associated to mental illnesses among people has detrimental effects on people having mental health problems. People have very limited information and knowledge about psychiatric illnesses. Due to this reason, intensity of the stigma which the caregivers and patients have to suffer is high.

The experiences of the stigma among patients with schizophrenia are found to be influenced by the causal beliefs, severity and type of psychopathology, depression, social support, self-efficacy, self-esteem, coping, insight, and self-directness. Stigmas are known to influence quality of life, social functioning and medication compliance. Research studies are scanty as compared to level of stigma perceived by caregivers of patients suffering from schizophrenia. In addition to the caregiver variables, different patient variables of schizophrenia distinctively modify the stigma experienced by the patient's caregivers. Different interventions can decrease the stigma experiences of patients and their caregivers. It has been put forward by various studies which evaluated the stigma experienced by patients of schizophrenia and their caregivers that stigma remains highly prevalent amongst patients and their families.

Hence the present cross sectional study was done at our tertiary care center on stigma associated with schizophrenia among people and their caregivers and evaluate the relationship of stigma experienced by caregivers of schizophrenic patients with their socio-demographic variables.

AIM AND OBJECTIVES
Aim
To study the stigma perceived by patients with schizophrenia and their caregivers.

Objectives
1. To measure the stigma perceived by patients with schizophrenia.
2. To measure stigma perceived by caregivers of patients with schizophrenia.

3. To assess the relationship of stigma experienced by patients with socio-demographic and clinical variables.
4. To evaluate the relationship of stigma experienced by caregivers of schizophrenic patients with their socio-demographic variables.

MATERIALS AND THE METHODS
Hospital basis cross-sectional analysis experimentation was undertaken which comprised 100 patients and 100 caregivers to analyze the stigma faced by the patients of schizophrenia with their caregivers.

Study design: The study proposal was cross-sectional analysis study.

Study background: Study was carried out on out-patients and in-patients department admitted in psychiatry ward in Acharya Vinoba Bhave Hospital which is a rural based hospital located at Sawangi (Meghe), Wardha. The caregivers of the patient were also interviewed.

Study duration: 2 years.

Study population: All patients admitted in psychiatry ward in Acharya Vinoba Bhave Hospital, Sawangi (Meghe), Wardha to analyze the stigma faced by the patients of schizophrenia with their caregivers.

Sample size: 200
100 patients and 100 caregivers were taken up for the study.

Considering 95% confidence level and confidence interval of 7, the number of patients in our study to achieve statistical significance is 196. This was calculated by the survey methodology (http://www.surveysystem.com/sscalc.htm#one).

Survey system disregards the populace size if it is found to be "large" or unidentified. Population size remains single expected factor while one works with a comparatively smaller and known group of persons (for example, the participants of an association). Hence a sample size of 200 was considered adequate for our study.

Inclusion criteria which was used for patients is as follows:
▪ ICD -10 diagnosis system for the patients of schizophrenia.
▪ Patients who were between ages of 18 years to 60 years.
▪ Patients who had willingly given on paper educated permission.
▪ Patients who were able to understand Hindi, Marathi or English.

Exclusion criteria which was used for patients is as follows:

- Patients who were found to have mental retardation or cognitive impairment.
- Patients who were found to have acute psychotic state.
- Patients who were found requiring serious attention for medical complications.

Inclusion criteria for caregivers:
1. Age more than 18 years.
2. Presence of participation in providing constant care to the patient for not less than one year.
3. Currently, not having any psychiatric or physical morbidity (except tobacco dependence).
4. Able to read Hindi/Marathi/English.

Exclusion criteria for caregivers:
1. Age less than 18 years.
2. Caregivers who are not ready to give consent.

METHODOLOGY
Definition of caregiver: Caregiver was described as an individual who inhabited with the mentally ill person and intimately cared to that patient for not less than one year period of time for example, attending to the daily necessities, administering the medications, accompanying the patient to the clinic, hanging on with patient in the hospital if he/she has to get admitted to the hospital and keeping harmonious relations with the doctors and hospital workforce. Such a person was also spending a substantial amount of time (a minimum of one hour per day) by remaining physically present with the patient.

Tools used
1) Semi structured proforma for socio demographic and clinical variables.
2) "The internalized stigma for mental illness inventory scale (ISMII; Ritsher et al., 2003)" ISMIS is an interview-centered tool, which evaluates self-stigma or internalized stigma, according to the viewpoint of stigmatized persons. This tool consisted 29 interview-centered questions which were distributed into five constituents. These five components were alienation, social withdrawal, stigma resistance, stereotype endorsement and perceived discrimination. The Alienation subscale, which contains six constituents, measured the subjective feelings and experiences which were having less potential as compared to a full member of society. The Stereotype Endorsement subscale comprises seven constituents, which tried to measure the extent up to which the patients agreed to common stereotypes regarding persons of mental disorders. The understanding of the discrimination experience component of the subscale contains five elements which measure the patient's awareness of the manner through which they get treated by other people. Social withdrawal component of the

subscale, which contains six elements, tries to measure the features of social withdrawal. The stigma resistance component of the subscale comprises five elements which measure one's competence to withstand the internalized stigma. Entire items were assessed on four point likert category arrangement scale. If the score comes out higher, higher will be level of the experience of self-stigma. Because it is a generic scale, one can make use of it in diverse health situations. Although various researchers have used different cut offs, the inventor of this scale employed a cut off limit value of 2.5 for the aggregate score and the subscales scores of ISMIS to label the existence or non-existence of the stigma. In this study, the present scale was used for the patients, and the original cut-offs were used. Hindi language translation of "the internalized stigma of mental illness scale (ISMIS)" has been authenticated. Cronbach's alpha value for the assessment of internal reliability of the Hindi language version was 0.863. In general, cronbach's alpha value up to 0.7 is believed as a desired characteristic of the scales which are used in clinical practice. Therefore, version of the scale, if used in Hindi language will have decent internal reliability and the characteristics assessed will have no difference as compared to English language version. The version of ISMI scale which was released previously had cronbach alpha value of 0.92, value of 29 item version was 0.90 and the finding of the hindi version is comparable with the same. Guttmann's split-half coefficient and Spearman–Brown constant for this scale were 0.645 and 0.661 indicating high split-half consistency. The test–retest consistency for each item and that for various domains of ISMI scale was also high.[30,31]

3) Stigma scale which is used for the caregiver of person of mental Illness, abbreviated as CPMI (Cheung and Mak, 2008): CPMI is a scale which consists of 22 elements utilized to assess caregivers' interiorization of stigma or affiliate stigma. This scale elements measure the behavioral, cognitive, and affective parts of the affiliate stigma. For illustration, some items are as follows:
1. "As one of my family members is a person with mental illness, I feel that I am inferior to others (cognitive)"; "I feel sad to have a family member with mental illness at home (affective)" and "I dare not tell others that there is a person with mental illness in my family (behavioral)". Participant subjects rate the degree for which they endorse each element upon a four point Likert scale which ranges from [1] to [4] i.e. from [1] strongly agree to [4] strongly disagree. The average score of the 22 elements is taken, if the result of the scores is high, then the interpretation would be indicative of greater amount of affiliate stigma. The aggregate sum of this tool's internal reliability is considered excellent

with cronbach's alpha value of 0.95. This scale was used for caregivers only.[32]

Statistical analysis

Quantitative data is represented by taking assistance of values assessed of the mean and standard deviation. Differentiation between the study groups is done using the assistance of unpaired t test in accordance with the outcomes of the normality test. Qualitative data is represented using the assistance of frequency and percentage table. Relationship between the study groups is evaluated using the assistance of Student's t-test, χ^2 test (Chi-Square), and Fisher test. P-value (probability value) lower than 0.05 is considered as significant.

Pearson's chi-squared test

$$X^2 = \sum_{i=1}^{n} \frac{(O_i - E_i)^2}{E_i}$$

Where, X^2 = Pearson's cumulative test statistic.
O_i = observed value;
E_i = expected value, asserted through null hypothesis;
n = the sum number of cells of table.

Results were graphically represented where deemed necessary.

Suitable statistical software utilities, which comprised Microsoft Excel, SPSS ver. 20 were used for the statistical analysis. Graphical representation was done in Microsoft Excel version 2010.

OBSERVATIONS AND RESULTS

A hospital centered cross-sectional analysis study was done which comprised 100 patients and 100 caregivers to evaluate the stigma faced by the patients of schizophrenia as well as their caregivers.

Table 1: Distribution of patients according to demographic characteristics.

Demographic characteristics	No of patients	Percentage
Age in years		
18-30 yrs	29	29
31-45 yrs	47	47
46-60 yrs	24	24
Gender		
Male	50	50
Female	50	50
Marital Status		
Single	35	35
Married	56	56
Remarried	0	0
Widowed	5	5
Divorced	4	4
Separated	0	0
Education		
Illiterate	3	3
1-5 class	19	19
6-10 class	41	41
11-12 class	21	21
>12 class	16	16

Table 1.1: Distribution of patients according to demographic characteristics.

Demographic characteristics	No of patients	Percentage
Occupation		
Unemployed	48	48
Unskilled	4	4
Semiskilled	2	2
Skilled	8	8
Clerical/shop-owner/farmer	36	36
Semi Professional	2	2
Professional	0	0
Income		
≤ Rs 1600	50	50
Rs. 1601-4809	5	5
Rs 4810-8009	1	1
Rs 8010-12019	0	0
Rs 12020-16019	0	0
Rs 16020-32049	44	44
>Rs 32050	0	0
Family Type		
Nuclear	78	78
Extended/Joint	22	22
Locality		
Urban	0	0
Rural	100	100
Duration of illness		
Between 1-5 yrs	35	35
Between 6-10 yrs	40	40
>10 yrs	25	25
Current status of illness		
In remission	68	68
Not in remission	32	32

Distribution of patients of schizophrenia according to demographic characteristics is as follows:

29% patients were found to be in the age range of 18-30 years while 47% and 24% were in the age range of 31-45 years and 46-60 years respectively. 50% patients each were male and female. 35% patients were single, 56% were married while 5% and 4% patients were widowed and divorced respectively.

3% patients were illiterate while 19% patients and 41% patients were educated up to 1-5th class and up to 6-10th class respectively. 21% patients and 16% patients were educated up to 11-12th class and more than 12th class respectively.

48% patients were unemployed while 4%, 2% and 8% patients were unskilled laborer, semiskilled and skilled worker respectively. 36% and 2% patients were clerical/shop-owner/farmer and semi-professional respectively.

50% patients had income ≤Rs 1600 while 5%, 1% and 44% patients had income between Rs. 1601-4809, Rs. 4810-8009 and Rs. 16020-32049 respectively. 78% patients belonged to nuclear families and 22% lived in extended/joint families. All patients (100%) were from rural areas.

35% patients were having period of illness among the range of 1-5 years while 40% patients and 25% patients were having period of illness among the range of 6-10 years and more than 10 years respectively. 68% patients were in remission and 32% were not in remission.

Table 2: Distribution of caregivers according to demographic characteristics.

Demographic characteristics	No of caregivers	Percentage
Age in years		
18-30 yrs	14	14
31-45 yrs	24	24
46-60 yrs	62	62
Gender		
Male	58	58
Female	42	42
Marital Status		
Single	13	13
Married	78	78
Remarried	0	0
Widowed	9	9
Divorced	0	0
Separated	0	0
Education		
Illiterate	4	4
1-5 class	35	35
6-10 class	34	34
11-12 class	18	18
>12 class	9	9
Occupation		
Unemployed	26	26
Unskilled	2	2
Semiskilled	3	3
Skilled	8	8
Clerical/shop-owner/farmer	60	60
Semi Professional	1	1
Professional	0	0
Income		
≤ Rs 1600	28	28
Rs. 1601-4809	1	1
Rs 4810-8009	2	2
Rs 8010-12019	1	1
Rs 12020-16019	2	2
Rs 16020-32049	66	66
>Rs 32050	0	0

Table 2.1: Distribution of caregivers according to demographic characteristics.

Demographic characteristics	No of caregivers	Percentage
Relationship with patient		
Mother	24	24
Father	19	19
Brother	5	5
Sister	5	5
Husband	21	21
Wife	14	14
Other	12	12
Is the caregiver only earning member of family		
Yes	27	27
No	73	73
Is the caregiver head of the family		
Yes	58	58
No	42	42
Duration of being in caregiver role		
1-5 yrs	37	37
6-10 yrs	40	40
11-15 yrs	15	15
>15 yrs	8	8
Does the caregiver supervise the medication		
Yes	96	96
No	4	4
Previous involvement of caregivers in providing care to some other relatives with prolonged, physical or psychiatric illnesses.		
Yes	39	39
No	61	61

Distribution of caregivers according to demographic characteristics.

14% caregivers were found to be in the age range of 18-30 years whereas 24% and 62% caregivers were found to be in the age range of 31-45 years and 46-60 years respectively. 58% caregivers were males while 42% caregivers were females.

13% caregivers were single while 78% and 9% caregivers were married and widowed respectively. 4% caregivers were illiterate while 35% and 34% caregivers were educated from 1-5th class and 6-10th class respectively. 18% and 9% caregivers were educated between 11-12th class and more than 12th class respectively.

26% caregivers were unemployed while 2%, 3% and 8% caregivers were unskilled workers, semiskilled and skilled workers respectively. 60% and only 1% caregivers were clerical/shop-owner/farmer and semi-professional respectively.

28% caregivers had income of ≤Rs 1600 while 1% caregivers each had income between Rs. 1601-4809 and

Rs 8010-12019. 2% caregivers each had income between Rs. 4810-8009 and Rs. 12020-16019 while 66% caregivers had income between Rs 16020-32049.

24% caregivers were mothers, 19% caregivers were fathers, and 5% caregivers each were brother and sister. 21% caregivers were husband while 14% and 12% caregivers were wife or having other relationship with the patients respectively.

27% caregivers were only earning members of the family and 73% caregivers were not earning members of the family. 58% care givers were head of the family and 42% caregivers were not the head of the family. 37% caregivers were in the caregiver role from 1-5 years while 40%, 15% and 8% were in the caregiver role from between 6-10 years, between 11-15 years and more than 15 years respectively.

96% caregivers supervised the medication and 39% caregivers were involved previously in providing care to some other relatives with prolonged, physical or psychiatric illnesses.

Table 3: Assessment of stigma perceived by patients with schizophrenia.

	No of items	Did not report high internalized stigma (1-2.5)	Reported high internalized stigma (2.51-4.00)	Total
Alienation	6	42(42%)	58(58%)	100
Stereotype Endorsement	7	56(56%)	44(44%)	100
Discrimination Experience	5	44(44%)	56(56%)	100
Social Withdrawal	6	72(72%)	28(28%)	100
Stigma Resistance	5	78(78%)	22(22%)	100
Overall	29	58(58%)	42(42%)	100

Assessment of the stigma perceived by the patients of schizophrenia.

42% patients with alienation did not report high internalized stigma while 58% patients reported high internalized stigma.

56% patients with stereotype endorsement did not report high internalized stigma while 44% patients reported high internalized stigma.

44% patients with discrimination experience did not report high internalized stigma while 56% patients reported high internalized stigma.

72% patients with Social withdrawal did not report high internalized stigma while 28% patients reported high internalized stigma.

78% patients with stigma resistance did not report high internalized stigma while 22% patients reported high internalized stigma.

Overall 58% patients did not report high internalized stigma while 42% patients reported high internalized stigma.

Table 4: Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100] Affective.

Items	Mean±SD	Strongly Disagree	Disagree	Agree	Strongly Agree	Total
"I feel inferior because one of my family members is having mental illness".	2.54±1.02	16(16%)	38(38%)	22(22%)	24(24%)	100
"I feel emotionally disturbed because I have a family member with mental illness".	2.60±0.58	0(0%)	44(44%)	52(52%)	4(4%)	100
"The behavior of my family member with mental illness makes me feel embarrassed".	2.40±0.66	2(2%)	64(64%)	26(26%)	8(8%)	100
"I feel helpless for having a family member with mental illness".	2.42±0.72	4(4%)	48(48%)	38(38%)	6(6%)	100
"I feel sad because I have a family member with mental illness".	2.76±1.12	20(20%)	18(18%)	28(28%)	34(34%)	100
"I worry if other people would know I have a family member with mental illness".	2.30±0.94	22(22%)	38(38%)	28(28%)	12(12%)	100
"I am under great pressure as I have a family member with mental illness".	2.34±0.84	14(14%)	48(48%)	28(28%)	10(10%)	100

Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100].

24% caregivers strongly agreed for "I feel inferior because one of my family members is having mental illness" while 52% caregivers agreed for "I feel emotionally disturbed because I have a family member with mental illness". 26% caregivers agreed for "The behavior of my family member with mental illness makes me feel embarrassed" and 38% caregivers agreed for "I feel helpless for having a family member with mental illness". 34% caregivers agreed for "I feel sad because I have a family member with mental illness", 28% caregivers agreed for "I worry if other people would know I have a family member with mental illness" and 28% caregivers agreed for "I am under great pressure as I have a family member with mental illness".

Table 5: Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100] Cognitive.

Items	Mean±SD	Strongly Disagree	Disagree	Agree	Strongly Agree	Total
"Other people would discriminate against me if I am with my family member with mental illness".	2.26±0.79	12(12%)	60(60%)	18(18%)	10(10%)	100
"My reputation is damaged because I have a family member with mental illness at home".	2.08±0.87	26(26%)	48(48%)	18(18%)	8(8%)	100
"People's attitude towards me turns sour when I am with family member with mental illness".	2.20±0.72	14(14%)	56(56%)	26(26%)	4(4%)	100
"Having a family member mental illness with imposes a negative impact on me".	1.94±0.76	30(30%)	48(48%)	20(20%)	2(2%)	100
"Having a family member with mental illness makes me think that I am incompetent compared to other people".	2.08±0.84	24(24%)	52(52%)	16(16%)	8(8%)	100
"Having a family member with mental illness makes me think that I am lesser to others".	1.80±0.80	40(40%)	44(44%)	12(12%)	4(4%)	100
"Having a family member with mental illness makes me lose face".	2.14±0.89	28(28%)	36(36%)	30(30%)	6(6%)	100

Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100]

26% caregivers agreed for "People's attitude towards me turns sour when I am with family member with mental illness", 20% caregivers agreed for "Having a family member mental illness with imposes a negative impact on me", 16% caregivers agreed for "Having a family member with mental illness makes me think that I am incompetent compared to other people" and 30% caregivers agreed for "Having a family member with mental illness makes me lose face"

Table 6: Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100] Behavioral.

Items	Mean±SD	Strongly Disagree	Disagree	Agree	Strongly Agree	Total
"I avoid communicating with my family member with mental illness".	2.16±0.88	26(26%)	38(38%)	30(30%)	6(6%)	100
"I dare not to tell others that I have a family member with mental illness".	2.14±1.02	34(34%)	30(30%)	24(24%)	12(12%)	100
"I reduce going out with my family member with mental illness".	2.14±1.02	32(32%)	36(36%)	18(18%)	14(14%)	100
"Given that I have a family member with mental illness, I have cut down the contacts with my friends and relatives".	2.10±0.96	32(32%)	36(36%)	22(22%)	10(10%)	100
"When I am with my family member with mental illness, I would keep an especially low profile".	2.08±1.06	36(36%)	36(36%)	12(12%)	16(16%)	100
"I have cut down the contacts with my family members with mental illness".	1.68±0.81	50(50%)	36(36%)	10(10%)	4(4%)	100
"I dare not to participate in activities related to mental illness that other people would suspect that I have a family member with mental illness".	2.06±0.95	34(34%)	34(34%)	24(24%)	8(8%)	100
"Given that I have a family member with mental illness I have cut down the contacts with my neighbors".	2.14±1.18	44(44%)	18(18%)	18(18%)	20(20%)	100

Caregivers' stigma according to scale devised for the caregivers of mentally ill persons (CPMI) [N=100]

30% caregivers agreed for "I avoid communicating with my family member with mental illness", 24% caregivers agreed for "I dare not to tell others that I have a family member with mental illness", 22% caregivers agreed for "Given that I have a family member with mental illness, I have cut down the contacts with my friends and relatives" and 20% caregivers strongly agreed for "Given that I have a family member with mental illness I have cut down the contacts with my neighbors".

Table 7: Association of ISMI score and socio-demographic variables of patients.

Demographic characteristics		Alienation Mean(sd)	Stereotype Endorsement Mean(sd)	Discrimination Experience Mean(sd)	Social Withdrawal Mean(sd)	Stigma Resistance Mean(sd)	Overall Mean(sd)
Age in years	18-30 years	14.96±3.74	16.82±3.08	12.62±2.61	13.96±1.93	11.27±2.51	128.03±17.47
	31 -45	15.29±3.35	16.74±3.24	12.48±2.73	14.53±1.67	11.29±2.44	129.42±18.96
	45+	15.20±3.42	17.20±3.21	12.95±2.57	14.66±2.21	11±2.34	131.08±18.56
	p-value	0.92,NS	0.84,NS	0.78,NS	0.33,NS	0.87,NS	0.83,NS
Gender	Male	14.68±3.40	16.40±3.01	12.16±2.55	14.24±1.69	11.12±2.42	126.08±17.20
	Female	15.68±3.46	17.36±.26	13.12±2.66	14.56±2.08	11.32±2.44	132.76±18.90
	p-value	0.14,NS	0.13,NS	0.06,NS	0.40,NS	0.68,NS	0.06,NS
Marital Status	Married	14.88±3.81	16.65±2.66	12.77±2.89	14.42±2.03	11.17±2.83	128.65±19.55
	Others	15.33±3.26	17±0	12.56±2.51	14.38±1.83	11.24±2.19	129.83±17.72
	p-value	0.53,NS	0.60,NS	0.71,NS	0.91,NS	0.88,NS	0.76,NS
Education	Illiterate	15.66±1.52	20.66±4.04	12±1	12.66±2.51	11.33±1.52	133.33±4.04
	Upto10	15.52±2.95	16.94±3.37	12.73±2.82	14.52±1.50	10.63±1.86	130.10±18.03
	10+	15.07±3.63	16.71±3.03	12.64±3.65	14.43±1.95	11.35±2.56	129.10±18.78
	p-value	0.85,NS	0.10,NS	0.90,NS	0.27,NS	0.50,NS	0.91,NS
Occupation	Unemployed	15.18±3.45	17.37±2.65	12.72±2.51	14.47±1.78	1.47±2.75	131.02±18.20
	Employed	15.20±3.54	16.42±3.60	12.64±2.79	14.32±2.04	11±2.10	128.16±18.72
	p-value	0.74,NS	0.25,NS	0.54,NS	0.55,NS	0.11,NS	0.20,NS
Income	<1600	15.18±3.77	17.38±2.69	12.96±2.62	14.62±2.06	11.46±2.79	131.74±19.67
	>1600	15.18±3.14	16.38±3.52	12.32±2.64	14.18±1.69	10.98±1.98	127.10±16.67
	p-value	1.00,NS	0.11,NS	0.22,NS	0.24,NS	0.32,NS	0.20,NS
Family Type	Joint	15.05±3.59	16.91±3.21	12.75±2.63	14.44±1.86	11.08±2.37	124.42±18.56
	Nuclear	15.63±2.92	16.77±3.03	12.22±2.68	14.22±2.04	11.68±2.58	129.40±17.74
	p-value	0.48,NS	0.85,NS	0.40,NS	0.63,NS	0.32,NS	0.99,NS

Table 8: Association of ISMI score and socio-demographic variables of patients.

Demographic characteristics		Alienation Mean(sd)	Stereotype Endorsement Mean(sd)	Discrimination Experience Mean(sd)	Social Withdrawal Mean(sd)	Stigma Resistance Mean(sd)	Overall Mean(sd)
Duration of illness	1-5 years	14.82±4	16.22±3.33	16.22±3.33	12.20±3.03	14.25±2.36	126.45±21.31
	5-10	15.42±3.20	17.07±3.39	17.07±3.39	12.87±3.65	14.40±1.54	130.57±17.38
	10+	15.28±3.10	17.48±2.38	17.48±2.38	12.88±1.96	14.60±1.70	131.72±15
	p-value	0.75,NS	0.28,NS	0.47,NS	0.79,NS	0.77,NS	0.48,NS
Current status of illness	Remission	15.10±3.30	16.63±3.10	12.52±2.67	14.32±1.76	10.95±2.25	128.13±17.83
	Not in remission	15.34±3.81	17.40±3.26	12.87±2.59	14.56±2.16	11.78±2.69	132.15±19.24
	p-value	0.74,NS	0.25,NS	0.54,NS	0.55,NS	0.11,NS	0.20,NS

None of the demographic characteristics of patients were associated with ISMI or its subscale scores i.e. internalized self-stigma was present equally among all the patients, overall as well as on all the five subscales.

Table 9: Association of CPMI score and socio-demographic variables of caregivers.

	Demographic characteristics	Affective Mean(sd)	Cognitive Mean(sd)	Behavioral Mean(sd)	Overall Mean(sd)
Age in years	18-30 yrs	17.92±3.38	15.92±4.46	17.50±5.81	51.35±12.07
	31-45 yrs	16.33±2.77	13.58±4.28	15.16±5.31	45.08±10.34
	46-60 yrs	17.62±3.63	14.53±4.22	16.79±6.28	18.95±11.72
	p-value	0.21,NS	0.36,NS	0.45,NS	0.56,NS
Gender	Male	16.93±3.17	13.84±3.75	15.39±5.81	46.17±10.02
	Female	17.95±3.46	15.40±4.83	18.02±6.45	51.38±12.83
	p-value	0.13,NS	0.07,NS	0.03,S	0.02,S
Marital Status	Married	17.07±2.62	14.84±3.62	15.46±5.18	47.38±9.69
	others	17.40±3.42	14.44±4.39	16.65±6.34	48.50±11.81
	p-value	0.74,NS	0.75,NS	0.52,NS	0.74,NS
Education	Illiterate	20±3.55	14.50±6.13	19±7.87	53.50±16.44
	1-10	17.60±3.22	15.68±4.94	17.28±6.36	50.57±13.01
	10+	17.04±3.32	13.81±3.64	15.88±3.01	46.75±10.11
	p-value	0.19,NS	0.12,NS	0.40,NS	0.19,NS
Occupation	Unemployed	17.50±3.47	14.30±4.42	17.38±6.94	49.19±12.89
	Clerical	18.50±6.36	18.±5.65	24±7.07	60.50±19.09
	Others	17.25±3.25	14.46±4.26	15.95±5.84	47.67±10.86
	p-value	0.90,NS	0.71,NS	0.26,NS	0.45,NS
Income	<1600	17.57±3.57	14.57±4.50	17.85±7.03	50±13.27
	1600-16019	17.12±3.10	14.37±4.02	15.74±5.56	47.24±10.02
	16019+	22.50±4.94	18±11.33	24±11.31	64.50±27.57
	p-value	0.07,NS	0.50,NS	0.06,NS	0.07,NS

Table 10: Association of CPMI score with clinical variables of caregivers.

Relationship with patient	Parent	18.62±3.85	15.91±5.42	18.94±6.97	53.45±14.12
	Sib	17.31±3.60	14.52±3.73	15.84±6.20	47.68±10.92
	Spouse	18.60±3.36	13.20±5.54	14.20±6.72	46±14.23
	Other	16.67±2.79	13.96±3.69	15.84±5.63	46.48±9.65
	p-value	0.09,NS	0.27,NS	0.16,NS	0.09,NS
Is the caregiver only earning member of family	Yes	17.48±3.96	14.74±4.65	16.55±7.01	48.77±12.91
	No	17.31±3.07	14.41±4.17	16.47±5.92	48.20±11.05
	p-value	0.82,NS	0.73,NS	0.95,NS	0.8±2,NS
Is the caregiver head of the family	Yes	16.96±3.03	13.96±3.72	15.63±5.67	46.56±9.54
	No	17.90±3.64	15.23±4.91	17.69±6.74	50.83±13.53
	p-value	0.16,NS	0.14,NS	0.10,NS	0.06,NS
Duration of being in caregiver role	1-5 yrs	18.05±4.02	13.86±5.12	17.54±7.01	49.45±14.06
	6-10 yrs	17.07±2.97	15.37±3.88	16.37±6.29	48.82±11.07
	11-15 yrs	16.93±2.86	13.73±3.03	15.13±4.20	45.80±6.63
	>15 yrs	16.37±1.50	14.50±3.81	14.87±4.67	45.75±7.74
	p-value	0.41,NS	0.40,NS	0.51,NS	0.67,NS
Does the caregiver supervise the medication	Yes	17.39±3.31	14.53±4.31	16.42±6.26	48.35±11.59
	No	16.50±3.78	13.75±4.19	18.25±4.57	48.50±11.03
	p-value	0.59,NS	0.72,NS	0.56,NS	0.98,NS
Prior involvement in taking care of some other relative with chronic, physical or psychiatric illness	Yes	16.69±3.49	13.35±3.45	16.23±5.44	46.28±9.08
	No	17.78±3.15	15.22±4.62	16.67±6.67	49.68±12.73
	p-value	0.10,NS	0.03,S	0.73,NS	0.15,NS

Among socio-demographic variables of the caregivers, genders of the caregivers were associated with behavioral component of the CPMI scale. Women caregivers had higher scores on CPMI scores as well as on behavioral component subscale.

DISCUSSION
Hospital centered cross-sectional analysis study was undertaken, which included 100 patients and 100 caregivers to analyze the stigma faced by the patients of schizophrenia along with their caregivers.

People who are mentally ill suffer for long periods by continually having to fight multiple difficulties and problems. In addition to struggling with the symptoms and disability due to their disorder, they have to deal with the societal stereotypes about the illness. Such stereotypes have deep impact on the behaviour of the person with mental illness. These stereotypes are interpreted as stigma. Stigmas are known to create substantial hurdles in the process of treatment of different mental disorders.

In our country, utilization of mental health services to the optimum level is not made because of the discrimination and ill consequences of the stigma faced by the patients of mental illnesses. The harmful effects of stigma leads to the ill consequences for example; delay in the pathway to seek care, delay of the diagnosis on right time, unnecessary delay of the initiation of treatment, delay in the process of rehabilitation plus recovery, and finally decreased chances of the patient to take full contribution in his life. In our country, it is very essential to build proof base for stigma specific interventions which can help have a change in people's detrimental attitude into a positive one towards mentally ill persons. For good and better treatment of mentally ill people, these interventions have a need to get executed from grass root level to the top level; for example starting from social-workers, staff working at mental hospitals, nursing staff to the doctors and psychiatrists also.[33]

The discrimination component of the scale covers parts that denote to negative responses from other people, comprising deeds of discrimination via police, health professionals and employers. Discrimination of mentally ill patients at job places is found to occur through two patterns i.e. subtle and overt pattern. Overt pattern comprises discrimination regarding matters of postings, promotions at job places, and labelling entire acts of mentally ill person due to the result of their mental illness. A distinction has been drawn amongst 'felt' and 'enacted' stigma.[34] Both stigmas are observed to happen at one place and are not related to the patient's personal feelings of embarrassment and lowliness. In the enacted stigma, the discrimination is known to occur in episodes. It comprises lack of job chances, hostile reactions of friends, family and crafty, condescending behaviours and attitudes towards mentally ill persons. It is a fact that large proportion of people with mental illness have reported that they had to face discrimination and hence the matter needs to be taken care of at the earliest.

Anxiety and depression in the caregivers and declined QoL of caregivers has been well-known.[35,44] Interventions must be designed for them which can address their psychiatric needs. These interventions can bring about reduction in health care costs and improvement in both the patient and caregiver outcomes.[36]

In the present study, 29% patients were found in the age range of 18-30 years while 47% and 24% were found in the age range of 31-45 years and 46-60 years respectively. 50% patients each were male and female. 35% patients were single, 56% were married while 5% and 4% patients were widowed and divorced respectively. 3% patients were illiterate while 19% patients and 41% patients were educated up to 1-5th class and up to 6-10th class respectively. 21% patients and 16% patients were educated up to 11-12th class and more than 12th class respectively.

48% patients were unemployed while 4%, 2% and 8% patients were unskilled laborer, semiskilled and skilled worker respectively. 36% and 2% patients were clerical/shop-owner/farmer and semi-professional respectively. 50% patients had income ≤Rs 1600 while 5%, 1% and 44% patients had income between Rs. 1601-4809, Rs. 4810-8009 and Rs. 16020-32049 respectively. 78% patients belonged to nuclear families and 22% lived in extended/joint families. All patients (100%) were from rural areas.

35% patients in our study were having period of illness among the range of 1-5 years while 40% patients and 25% patients were having period of illness among the range of 6-10 years and more than 10 years respectively. 68% patients were in remission and 32% were not in remission. This is similar to the Singh A et al[37] and Mukherjee S et al.[38]

Singh A et al[37] cross-sectional study assessed the stigma in the persons of schizophrenia. In that study, they assessed social-participation-restriction stigma, internalized stigma, and perceived stigma. The stated average age in that study sample was found to be 36.8, [SD] standard deviation was 12.1; and range was 18–65 years. Males (n = 54) were more in number than females (n = 46) in this study group. More than half of the patients were found to be presently married (n = 61), did not have a job with payment (n = 58), belonged to Hindu religion (n = 69), belonged to urban locality (n = 58), nuclear families (n = 56), and middle socioeconomic strata (n = 59). It was observed that the mean amount of years which were spent on education by the patients was found to be 10.5 [SD was 4.4]; range was between 0–17. Majority of diagnostic subtypes were found to be paranoid i.e. 63%, while the percentage of undifferentiated schizophrenia was 34%. The average

age of the onset of the illness noted in the study was 26.5 [SD was 8.9], range was between 12 to 53 years. The average years of duration of the illness observed was found to be 10.2 years, [SD was 8.1] and range was between 2 to 40 years. The average number of times hospital visits undertaken during 3 months prior to this study intake was found to be 1.2 [SD was 0.8]. The average aggregate PANSS score observed was 34.4 [SD was 2.1] and range was 31 to 41. The average GAF score (global assessment of the functioning) in this study was found to be 92.9 [SD was 4.3] and range was 80 to 98.

Mukherjee S et al[38] cross-sectional, descriptive study to determine the degree of self-perceived stigma towards mental illnesses reported that out of 198, approximately two-thirds were female (65.7%), resident of urban/semi-urban areas (67.7%), and were currently married (63.1%). Majority of the participants were either manual workers or homemakers (71.7%) having PCMI ≤ INR 1600 (64.6%). Mean (± SD) age of the respondents was 39.7 (±12.2) years. On an average, the duration of formal education of the participants was 6.5 (±5.0) years; 13.1% were illiterate and 15.7% were graduate. The average PCMI of the family of the participants was INR 1533.3 (±518.0).

In our study, 14% caregivers were found to be in the age range of 18-30 years whereas 24% and 62% caregivers were found in the age range of 31-45 years and 46-60 years respectively. 58% caregivers were males while 42% caregivers were females. 13% caregivers were single while 78% and 9% caregivers were married and widowed respectively. 4% caregivers were illiterate while 35% and 34% caregivers were educated from 1-5th class and 6-10th class respectively. 18% and 9% caregivers were educated between 11-12th class and more than 12th class respectively.

26% caregivers were unemployed while 2%, 3% and 8% caregivers were unskilled workers, semiskilled and skilled workers respectively. 60% and only 1% caregivers were clerical/shop-owner/farmer and semi-professional respectively. 28% caregivers had income of ≤Rs 1600 while 1% caregivers each had income between Rs. 1601-4809 and Rs 8010-12019. 2% caregivers each had income between Rs. 4810-8009 and Rs. 12020-16019 and 66% caregivers had income between Rs 16020-32049.

24% caregivers in our study were mothers, 19% caregivers were fathers, and 5% caregivers each were brother and sister. 21% caregivers were husband while 14% and 12% caregivers were wife or having other relationship with the patients respectively. 27% caregivers were only earning members of the family and 73% caregivers were not earning members of the family. 58% caregivers were head of the family and 42% caregivers were not the head of the family. 37% caregivers were in the caregiver role from 1-5 years while 40%, 15% and 8% were in the caregiver role from

between 6 to 10 years, between 11 to 15 years and beyond 15 years respectively. 96% caregivers supervised the medication and 39% care givers were previously involved in providing care to some other relatives with prolonged, physical and psychiatric illnesses.

It was detected in our study that 42% patients with alienation did not report high internalized stigma while 58% patients reported high internalized stigma. 56% patients with stereotype endorsement did not report high internalized stigma while 44% patients reported high internalized stigma. 44% patients with discrimination experience did not report high internalized stigma while 56% patients reported high internalized stigma.

72% patients with social withdrawal did not report high internalized stigma while 28% patients reported high internalized stigma. 78% patients with stigma resistance did not report high internalized stigma while 22% patients reported high internalized stigma. Overall 58% patients did not report high internalized stigma while 42% patients reported high internalized stigma. This is comparable to the studies of Loganathan S et al[39] and Singh A et al.[37]

Loganathan S et al[39] study which evaluated the stigma experiences and the method used was conduction of semi structured interviews of 200 patients. This study reported majority of male patients of schizophrenia unmarried, did hide their illness at job interviews and from other people. They also reported experiencing shame and ridicule. They stated that their experiences of stigma were more acutely felt at their work places. Females stated experiences associated to stigma with regard to childbirth, marriage and pregnancy.

Singh A et al[37] cross-sectional study evaluated for the components of ISMIS, the highest mean score was for alienation component, after that second highest was noted for discrimination experience, stereotype endorsement and stigma resistance, while lowest score was of social withdrawal component. When cut-off limit of 2.5 was employed for evaluating the existence or non-existence of the stigma, 81% patients reported presence of stigma with alienation component while 45% patients submitted to the component of stigma resistance. The total average score, when scale of EMIC stigma was used was found to be 22.0 [SD was 7.4] and when P-scale (participation scale) was used, the mean score was found to be 18.3 [SD was 9.1]. When the cut off limit value of 12 was employed to determine the amount of restriction attributable to the stigma, 67% patients were found to have reported the experiencing of substantial restriction, while most conveyed mild to moderate restriction. The mean aggregate score reported from the scale which assessed the knowledge of illness was 4.5 (SD: 1.5). No significant correlation was found between age and education with total ISMIS score, EMIC score and P-scale score. Nonetheless, age of the patients correlated positively with the stigma resistance

component. No significant difference was found in the mean total score on ISMIS, EMIC and P-scales among patients from different socioeconomic classes, type of family (whether it was nuclear or nonnuclear), localities and religions. Also no major difference came out in the total average ISMIS and EMIC scores across the two genders. However, as compared to males, females had significantly higher scores in the components of stereotype endorsement and total P-scale score. To the contrary, males had significantly higher scores in the component of stigma resistance. Significantly lower scores in the components of total P-scale score and social withdrawal were noted in those who were not wage earners. Similarly, those who were employed were found to have noteworthy high scores during the assessment of component of stigma resistance. No significant correlations were reported between different stigma scores and age of beginning of illness, period of illness, period of current treatment and PANSS score. No difference was observed in the stigma experienced by those with paranoid and other types of schizophrenia. No significant correlation was found between the current level of insight and stigma. Significantly lesser number of visits, higher level of general psychopathology as per PANSS, lower scores for knowledge about diagnosis and causes and total knowledge score were reported in those who experienced alienation component.

In the present study, 24% caregivers strongly agreed for "I feel inferior because one of my family members is having mental illness" while 52% caregivers agreed for "I feel emotionally disturbed because I have a family member with mental illness". 26% caregivers agreed for "The behavior of my family member with mental illness makes me feel embarrassed" and 38% caregivers agreed for "I feel helpless for having a family member with mental illness". 34% caregivers agreed for "I feel sad because I have a family member with mental illness", 28% caregivers agreed for "I worry if other people would know I have a family member with mental illness" and 28% caregivers agreed for "I am under great pressure as I have a family member with mental illness".

26% caregivers agreed for "People's attitude towards me turns sour when I am with family member having mental illness", 20% caregivers agreed for "Having a family member with mental illness imposes a negative impact on me", 16% caregivers agreed for "Having a family member with mental illness makes me think that I am incompetent compared to other people" and 30% caregivers agreed for "Having a family member with mental illness makes me lose face".

30% caregivers agreed for "I avoid communicating with my family member with mental illness", 24% caregivers agreed for "I dare not to tell others that I have a family member with mental illness", 22% caregivers agreed for "Given that I have a family member with mental illness, I have cut down the contacts with my friends and relatives" and 20% caregivers strongly agreed for "Given

that I have a family member with mental illness, I have cut down the contacts with my neighbors". This is concordant to the studies of Koschorke M et al[40] and Surg Pawar AA et al.[41]

Koschorke M et al[40] randomized control study of combined community care for the PLS in Indian territory (COPSI trial) illustrating the determining factors and experiences of stigma stated that 'high caregiving stigma' was revealed by a prominent smaller percentage of caregivers (21%) and that a lot felt embarrassed to reveal their patient's condition (45%). Caregiver stigma was found to be independently related with greater levels of impairment, greater levels of manifestation of positive symptoms associated with schizophrenia, household schooling at high school grade and younger PLS age group. Awareness and understanding of schizophrenia was not related with the caregiver stigma. Qualitative data explained several ways by which the stigma impacted the life of the caregiver and disclosed appropriate links among caregiver-stigma associated themes ('negative outlooks', 'other people finding out', 'negative responses' and 'opinions regarding the self') and the other themes. Findings of the data stressed the necessity for actions that tackle both the requirements of PLS as well as their caregivers. Besides qualitative data demonstrated the complexities about the relationship amongst stigma and knowledge, it also suggested that imparting 'awareness and understanding of schizophrenia' can influence the procedure of stigmatization in both negative as well as positive manner. Educational interventions stress the necessity to think through context-specific aspects when selecting anti-stigma tweets to be delivered. The findings advocate that the tweets for example 'nobody is to be blamed' and 'recovery is attainable' can be further helpful than just concentrating only on bio-medical science.

Surg Pawar AA et al[41] cross sectional study of patients measuring stigma perceived by patients of mental illness and their caregivers using disclosure subscale. Unpredictably all patients were found to score exceeding the cut-off limit. This study also showed that mentally ill people were well aware that it was not always possible to hide their illness from people for a long time especially at job places; perhaps they did not care about the disclosure of their illness to others in spite of suffering from discrimination. It was also found in this study that all the subjects scored above the cut off when positive elements of the scale were used. It was noted that mentally ill people had become positive towards the illness and embraced it with good attitude and acceptance. They also reported that mental illness has made them a stronger and understanding person. The study also confirmed that mentally ill persons did not expect any leniency as regards to their illness nor did they experience advantage from the illness.

In the present study, none of the demographic characteristics of patients were associated with ISMI or

its subscale scores i.e. internalized self-stigma was present equally among all the patients, overall as well as on all the five subscales.

Surg Pawar AA et al[41] cross sectional study of patients measured stigma experienced by the mentally ill patients plus their caregivers. This study reported that caregivers of the people with mental illness believed that majority of people in the society were not interested in befriending them. They also believed that due to association of mental illness with their family, their old friends and relatives used to avoid them. They claimed that people blamed them for not taking responsibility, loving and caring their mentally ill kin. Majority of caregivers stated that people in the society held them responsible for the suffering of their mentally ill offspring (92% vs. 80%). The findings in this study correlated with statistical significance. This study emphasizes that caregivers must be given knowledge, procedures, information and counselling about how to deal with mentally ill persons.

In the present study, among socio-demographic variables of the caregivers, genders of the caregivers were associated with behavioral component of the CPMI scale. Women caregivers had higher scores on CPMI scores as well as on behavioral component subscale.

Similar observations were noted in the results of Sharma H et al[127], Mukherjee S et al[38], Raguram R et al[42] and Singh A et al.[37]

Sharma H et al[43] cross-sectional hospital based study assessed the objective and subjective impact of distress in caregivers of schizophrenia and bipolar affective disorder patients, measured the perceived stigma in primary caregivers, identified the coping mechanisms used by the caregivers and reported that the level of burden for schizophrenic caregivers is more as compared to the caregivers of BD. The caregivers who were involved in the care of people of schizophrenia were found to be more stigmatized as compared to caregivers of BD patients. Females were more stigmatized than males in both the groups. The caregivers of both BD and schizophrenic patients used active emotional coping to combat the situation.

Mukherjee S et al[38] cross-sectional, descriptive study to determine the magnitude of self-perceived stigma toward mental illnesses reported mean (± SD) and median (± IQR) of the stigma score as perceived by the caregivers towards mental illness were 53.3 (±13.2) and 51.7 (±18.3) respectively. Similarly, the corresponding figures for perception score were 59.3 (±11.4) and 60.0 (±15.0) respectively. Stigma was higher among participants aged >40 years, of female gender, single/widowed, having less income, with higher education, manual workers and those residing in rural areas than their counterparts as evident from mean stigma score. There was almost no difference in mean perception score based on socio-demographic characteristics. Normality of the distribution of both scores were tested with Shapiro–Wilk test and found it to be non-significant. Participants with male gender were less likely to have stigma than females ($\beta = -0.177$, $t = -2.717$, and $P = 0.007$), while those of rural residence ($\beta = 0.170$, $t = 2.604$, and $P = 0.010$) were at higher risk of having stigma than those of urban/semi-urban areas. Normality of distribution, no multicollinearity (variance inflation factor = 1.035–1.226 and tolerance = 0.816–0.963), significant ANOVA, independence of errors (Durbin–Watson = 2.1) were tested and the results substantiated the use of linear model.

Raguram R et al[42] study evaluated thirty patients with schizophrenia by using Link's perceived stigma questionnaire and a short explanatory model interview for beliefs about the illness. This study reported that patients were found likely to hide their history of schizophrenia. Caregivers of patients reported that similar impact of the illness was observed on their work, finances and social interactions.

Singh A et al[37] cross-sectional study stated that among those who had an experience of significant restriction were females, who were younger in age and unemployed. Alienation component was elucidated with the help of KMI diagnosis, number of visits during past 3 months and GAF score. 19.1 was the percentage of variance sought by all the variables together. Patient's gender alone contributed to 11.5% of variance of the component of stereotype endorsement. The variance was observed to attain the level of 16.2% when both the gender of the patient and level of functioning by GAF score were taken into account. Other variables were not found to have any substantial influence on the variance of stereotype endorsement. GAF score revealed 19.7% of the variance in the component of discrimination experience and 10.6% of the variance in the component of social withdrawal. 17.9% was the variance assessed in the stigma resistance component computed by combining together the gender and total duration of treatment in years. It was noted that only 13.9% of the variance of ISMIS total could be explained by GAF score. Likewise, 19.9% of variance of EMIC total score could be explained by GAF score. Occupation was the only one variable that could explain maximum variance of stigma by P-scale (69.5%). For alienation, odds ratio was found to be significant and more than one for general psychopathology score. GAF score was the only noteworthy predictor found for the components like social withdrawal, social discrimination, and stereotype endorsement. The odds ratio assessed came out to be 4 for gender in the component like stigma resistance and ISMIS aggregate score minus stigma resistance. GAF score was important predictor of ISMIS score on stigma resistance component. For the participation restriction as gauged by P-scale, the odds ratio for occupation was 395.65.

Strengths and limitations

The strength of the study was that it is one of the few studies from India where stigma of schizophrenia is assessed using well validated and standardized scales.

The limitations of the study were small sample size and the study being a cross sectional hospital-based study the results may not be generalizable for the rest of general population.

SUMMARY

A hospital centered cross-sectional analysis study was carried out with 100 patients and 100 caregivers to analyze the stigma faced by the patients of schizophrenia along with their caregivers. The following observations were noted:

1. 29% patients were found to be in the age range of 18-30 years while 47% and 24% were found in the age range of 31-45 years and 46-60 years respectively. 50% patients each were male and female. 35% patients were single, 56% were married while 5% and 4% patients were widowed and divorced respectively.

2. 3% patients were illiterate while 19% patients and 41% patients were educated upto 1-5th class and upto 6-10th class respectively. 21% patients and 16% patients were educated upto 11-12th class and more than 12th class respectively.

3. 48% patients were unemployed while 4%, 2% and 8% patients were unskilled laborer, semiskilled and skilled worker respectively. 36% and 2% patients were clerical/shop-owner/farmer and semi-professional respectively.

4. 50% patients had income ≤Rs 1600 while 5%, 1% and 44% patients had income between Rs. 1601-4809, Rs. 4810-8009 and Rs. 16020-32049 respectively. 78% patients belonged to nuclear families and 22% lived in extended/joint families. All patients (100%) were from rural areas.

5. 35% patients were having period of illness among the range of 1-5 years while 40% patients and 25% patients were having period of illness among the range of 6-10 years and more than 10 years respectively. 68% patients were in remission and 32% were not in remission.

6. 14% caregivers were found in the age range of 18-30 years whereas 24% and 62% caregivers were in the age group of 31-45 years and 46-60 years respectively. 58% caregivers were males while 42% caregivers were females.

7. 13% caregivers were single while 78% and 9% caregivers were married and widowed respectively. 4% caregivers were illiterate while 35% and 34% caregivers were educated from 1-5th class and 6-10th class respectively. 18% and 9% caregivers were educated between 11-12th class and more than 12th class respectively.

8. 26% caregivers were unemployed while 2%, 3% and 8% caregivers were unskilled workers, semiskilled and skilled workers respectively. 60% and only 1% caregivers were clerical/shop-owner/farmer and semi-professional respectively.

9. 28% caregivers had income of ≤Rs 1600 while 1% caregivers each had income between Rs. 1601-4809 and Rs 8010-12019. 2% caregivers each had income between Rs. 4810-8009 and Rs. 12020-16019 and 66% caregivers had income between Rs 16020-32049.

10. 24% caregivers were mothers, 19% caregivers were fathers, 5% caregivers each were brother and sister. 21% caregivers were husband while 14% and 12% caregivers were wife or having other relationship with the patients respectively.

11. 27% care givers were only earning members of the family and 73% caregivers were not earning members of the family. 58% care givers were head of the family and 42% caregivers were not the head of the family. 37% caregivers were in the caregiver role from 1-5 years while 40%, 15% and 8% were in the caregiver role from between 6-10 years, between 11-15 years and more than 15 years respectively.

12. 96% caregivers supervised the medication and 39% care givers were previously involved in providing care to some other relatives with prolonged, physical and psychiatric illnesses.

13. 42% patients with alienation did not report high internalized stigma while 58% patients reported high internalized stigma.

14. 56% patients with stereotype endorsement did not report high internalized stigma while 44% patients reported high internalized stigma.

15. 44% patients with discrimination experience did not report high internalized stigma while 56% patients reported high internalized stigma.

16. 72% patients with social withdrawal did not report high internalized stigma while 28% patients reported high internalized stigma.

17. 78% patients with stigma resistance did not report high internalized stigma while 22% patients reported high internalized stigma.

18. Overall 58% patients did not report high internalized stigma while 42% patients reported high internalized stigma.

19. 24% caregivers strongly agreed for "I feel inferior because one of my family members is having mental illness" while 52% caregivers agreed for "I feel emotionally disturbed because I have a family member with mental illness". 26% caregivers agreed for "The behaviour of my family member with mental illness makes me feel embarrassed" and 38% caregivers agreed for "I feel helpless for having a family member with mental illness". 34% caregivers agreed for "I feel sad because I have a family member with mental illness", 28% caregivers agreed for "I worry if other people would know I have a family member with mental illness" and 28% caregivers agreed for "I am under great pressure as I have a family member with mental illness".

20. 26% caregivers agreed for "People's attitude towards me turns sour when I am with family

member having mental illness", 20% caregivers agreed for "Having a family member with mental illness imposes a negative impact on me", 16% caregivers agreed for "Having a family member with mental illness makes me think that I am incompetent compared to other people" and 30% caregivers agreed for "Having a family member with mental illness makes me lose face"

21. 30% caregivers agreed for "I avoid communicating with my family member having mental illness", 24% caregivers agreed for "I dare not to tell others that I have a family member with mental illness", 22% caregivers agreed for "Given that I have a family member with mental illness, I have cut down the contacts with my friends and relatives" and 20% caregivers strongly agreed for "Given that I have a family member with mental illness, I have cut down the contacts with my neighbors".

22. None of the demographic characteristics of patients were associated with ISMI or its subscale scores i.e. internalized self-stigma was present equally among all the patients, overall as well as on all the five subscales.

23. Among socio-demographic variables of the caregivers, genders of the caregivers were associated with behavioral component of the CPMI scale. Women caregivers had higher scores on CPMI scores as well as on behavioral component subscale.

CONCLUSION
From the observation of various studies, it is known that the intensity of stigma experienced as a consequence of having mental illness is quite high. Stigma experienced is found to be not associated with the diagnosis, age of the patient, sex of the patient, marital status, duration of the illness, status and presence of the family history of psychiatric illness. Caregivers living with the patients of mental illness reported having the experience of stigma, plus they had awareness of the outlooks of the people. Caregivers believed that people in the society often held them responsible as the reason for the suffering of their offspring's mental illness. They believed their own personal failure as a reason for the on-going treatment of their kin for mental illness. The presence of the practice of stigma regarding mental illness by the people in the society addresses the need that the issue must be dealt with high priority because it is often observed that stigma discourages a mentally ill person from seeking treatment which may have bad impact on the family as well as the society.

Patients of schizophrenia experience high level of stigma. Due to this, many facets of their lives get restricted. Level of functioning achieved by the patients with treatment is agreed upon to influence the stigma. It is observed that those patients who achieve higher level of functioning have lower experience of self-stigma, anticipated stigma and lower participatory restriction. It is crucial that clinicians know the implication of vicious cycle which involves lower level of improvement, lower

level achievement of good functioning with higher perception of stigma. Lack of knowledge to the patients about their diagnosis and treatment influence the alienation component of stigma. It is essential to provide psycho-education which helps reducing the feelings of alienation. It is generally agreed upon that there is inverse relationship of being getting paid for the job they do to the experiencing of stigma. It is difficult to establish the cause-effect relationship to this observation; nonetheless this finding suggests that if suitable job opportunities are provided to patients of schizophrenia, it can help boost their self-esteem. Likewise, the need to improve politico-administrative policies to provide suitable job opportunities for patients with schizophrenia seems to be crucial. Considerable level of self-perceived stigma among caregivers of people with mental illness was observed. Three factors of the caregivers namely; gender, place of residence and perception towards mental illness were found to be significantly associated with stigma. The present study pointed toward the opportunity of addressing and shaping the perceptions of caregivers to mitigate stigma among them, with a focus to the vulnerable groups such as females and rural residents. In the Indian context, policies and programs for effective health communications with the caregivers may be designed to include them in standard care protocols. The study emphasized the need of greater collaboration between health-care providers and caregivers in order to make them mental health literate and address their prejudices which in turn would reduce their stigma.

Recommendations
The following recommendations are made:
1. Psycho-education should be provided to patients and their caregivers to empower them to understand and accept the illness and cope with it in a successful manner. Also programs such as individual behavioral therapy, self-assertiveness training, problem-solving training, communication training and further family therapy interventions can be added in it.

2. Appropriate employment opportunities should be created by government in partnership with private sector for patients of schizophrenia to boost their self-esteem.

3. Government policies with focus on the vulnerable groups such as females and rural residents and programs for effective health communications with caregivers should be designed. Emphasis should be on greater collaboration between health-care providers and caregivers in order to make them mental health literate and address their prejudices which in turn would reduce their stigma.

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