

Cross-Sectional Study on Stigma among Care Givers of Patients with Mental Illness in Kanchipuram District, Tamil Nadu

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ABSTRACT

BACKGROUND

Stigma experienced by caregivers of patients with mental illnesses remains unnoticed. This study was conducted to evaluate the stigma perceived by the care givers of patients with various mental illnesses and the factors associated with stigma.

METHODS

This cross-sectional study was conducted among the care givers of patients with mental illnesses who accompanied the patients to the outpatient department (OPD) of Psychiatry in Meenakshi Medical College Hospital and Research Institute, from January 2017 to March 2017. A total of hundred care givers were included in the study. All care givers aged between 18 - 50 years of age in both sexes were included in the study. Care givers of substance abuse cases were excluded from the study. A total of hundred care givers with fifty care givers of neurosis patients and another fifty care givers of psychosis were included in the study. Family interview schedule (FIS) stigma scale was used to assess the stigma perceived by care givers. Data was entered in Microsoft excel and data analysis was done using statistical package for social sciences (SPSS) version 17.

RESULTS

Mean perceived stigma score was 12.27 ± 9.43 . High, low and zero stigma was noted among 44 %, 36 % and 20 % of care givers, respectively. Also, it was found that care givers of psychosis patients had more stigma than the care givers of neurosis patients ($P = 0.0008$). Statistically significant association was found between patient's duration of illness ($P = 0.003$), patient's diagnosis ($P = 0.000$) and care givers burden ($P = 0.000$) with severity of stigma perceived by the care givers.

CONCLUSIONS

Proportion of stigma prevailing among the care givers is high and it depicts only the cases which were reported to the health care center, whereas a larger proportion of cases remains not seeking the health care. An early intervention by conducting routine assessments of the mental status of caregivers is necessary.

KEYWORDS

Stigma, Care Givers, Mental Illnesses, Family Interview Schedule

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BACKGROUND

Stigma remains a challenging issue in several diseases. Mainly stigma in mental illness is of greater concern not only to the patients but also to their families. It remains as a major obstacle to recovery and also it restricts the job opportunities and social functioning of patients and family members in almost all the parts of the world.^{1,2} Stigma affects all including the patients, their relatives, friends and all those who come into close contact with the mentally ill, including mental health care professionals.³ Stigma was unaffected by patient background characteristics⁴ and stigmatized persons are more prone to suffer from depressive symptoms.⁵ Stigma towards relatives and the care givers of the particular mentally ill patients must be taken into account when planning for intervention by mental health professionals.² Stigma experienced by caregivers of patients with mental illnesses is called as courtesy or associative stigma and affiliate stigma. Associative or courtesy stigma refers to stigmatized by virtue of their association with another stigmatized individual.^{6,7}

Whereas affiliate stigma occurs when the people affiliated to a stigmatized individual such as caregivers, family members, and friends are personally affected by the public stigma that prevails in the society. Studies conducted in various countries have reported stigmatization and its negative consequences for people with mental illnesses and for their family members.^{8,9} Torrey et al.¹⁰ reported that schizophrenia is the modern-day equivalent of leprosy. There is no other disease in the western world that confers such social ostracism on the people afflicted and on their families. Due to the stigma, patients and their caregivers are hesitant to visit mental health care facilities for treatment of their illness.¹¹ Also, stigma leads to numerous detrimental consequences from economic and social perspective, and has tremendous impact on family relations and employment affecting the quality of life of people with mental illnesses and their caregivers.^{12,13} The literature about the exact prevailing stigma among care givers of mentally ill people is limited and these proportion changes with respect to place and time. Hence this study was planned to explore the stigma perceived by the care givers of patients suffering from various mental illnesses.

Objectives

1. To assess the stigma perceived by the care givers of patients with various mental illnesses.
2. To compare the stigma perceived by the care givers among those with neurosis and psychosis.
3. To find out the factors associated with stigma.

METHODS

This cross-sectional study was conducted from January 2017 to March 2017 among the care givers of patients with mental illnesses who accompanied the patients to the outpatient department of Psychiatry in Meenakshi Medical College

Hospital and Research Institute. All care givers aged between 18 - 50 years of age from both sexes were included in the study. Care givers of substance abuse cases were excluded from the study.

Sample Size

Assuming fifty percentages of the care givers have high stigma, with 95 % confidence and twenty percentage relative precision, the sample size was calculated as 97. Hence a total of hundred consequent care givers with fifty care givers of neurosis patients and another fifty care givers of psychosis were included in the study. Neurosis and psychosis cases were diagnosed based on international classification of diseases (ICD 10).

Data Collection Tools

The individual participants (care givers) were explained about the study and they were also assured that, their identity and their patient's identity would be kept strictly confidential and they have the option to refuse participation in the study. Written informed consent was obtained from the study participant's parents prior to the interview. Every effort was made, to be sure that all information collected from the participants, remain confidential. The study was conducted using a proforma with the clinical details of the patients and the demographic details of the care givers. Socio economic status of the care givers were calculated using Modified Prasad's socio-economic classification.¹⁴

Family interview schedule (FIS) stigma scale,¹⁵ which was developed by world health organization (WHO) was used to assess the stigma among the care givers. FIS stigma scale consists of 14 questions with four-point scale ranging from 0 - 3 which depicts the severity of stigma about each question, where 0 refers to not at all, 1 refers to sometimes, 2 refers to often and 3 refers to a lot. The scores were added and categorised as participants with 0 score as zero stigma, scores between 1 - 14 as low stigma and scores between 15 - 42 as high stigma.

Burdern assessment scale (BAS) was used to assess the burden among them. BAS is a 20-question scale developed by Sell et al.¹⁶ in association with SCARF (schizophrenia research foundation) and WHO to assess caregiver burden. It includes five domains and it uses a three-point scale for all questions and scores 1 refers to not at all, 2 refers to some extent and 3 refers to very much. Thus, the maximum score is 12 in each domain of burden. The higher score indicating higher degree of burden. Ethical clearance for this study was obtained from institutional ethics committee of Meenakshi Medical College Hospital and Research Institute (IEC NO: 36 / MMCH & RI / 2014).

Statistical Analysis

Data was entered in Microsoft excel and data analysis was done using statistical package for social sciences version 17. Data was presented using descriptive statistics, association between variables was assessed using Z test and comparison of two means was done using independent

sample t test. P value < 0.05 was considered as statistically significant.

RESULTS

Demographic characteristics of the study participants are given in the table 1.

	Characteristics	Percentage
Age in years	18 to 40 years	61
	41 to 55 years	39
Gender	Males	37
	Females	63
Socio-economic status	Class 5	9
	Class 4	10
	Class 3	25
	Class 2	44
Educational status	Class 1	12
	Literate	70
	Illiterate	30
Marital status	Married	94
	Unmarried	6
Employment status	Employed	41
	Unemployed	59

Table 1. Demographic Characteristics of Study Participants

Majority of the study patients (18 %) had schizophrenia followed by anxiety disorder (16 %), obsessive compulsive disorder (15 %), depressive disorder (14 %), psychosis (12 %), acute psychosis (8 %), persistent delusional disorder (6 %), bipolar affective disorder currently depression (5 %), mania with psychosis (5 %) and schizotypal (1 %) of cases. The mental illnesses were grouped as neurosis and psychosis and there were equal number (50 %) of patients in each group. Majority of the patients (61 %) had history of mental illness for more than one-year duration and 39 % gave history of mental illness for less than one-year duration. Mean score of burden assessment schedule was found to be 32.06 ± 7.52.

In this study, 44 % of care givers were found to have high stigma, 36 % of care givers had low stigma and only 20 % of care givers had zero stigma. In the present study, 40 % of participants were worried that neighbours would treat differently, 35 % of participants were worried that people would find out, 52 % of participants reported that they need to hide the fact, 36 % of participants reported that they helped other people to understand what it is like to have a family member with psychiatric illness, 49 % of participants made special effort to keep this fact secret, 29 % and 15 % of participants worried that friends and neighbours would avoid and found themselves explaining to others that isn't like their picture of crazy people, respectively.

Also, 53 % of participants were worried people would blame them for his problem, 47 % of participants were worried that person looking to marry would be reluctant to marry in to their family, 30 % of participants were worried about taking the patient outside, 40 % of participants were felt ashamed, 15 % of participants sought people who also had a family member who has had psychiatric problems, 40 % of participants felt grief or depression and 30 % of participants felt somehow it might be their fault. Over all percentage of positive responses were reported by 80 % of participants and over all percentage of zero responses were

reported by 20 % of participants. Proportion of caregivers with stigma with respect to each question is shown in the table 1.

Stigma Question	Percentage
Worried that neighbours would treat differently	40
Worrying people would find out	35
Need to hide the fact	52
Helped other people to understand what it is like to have a family member with psychiatric illness	36
Made special effort to keep this fact secret	49
Worried that friends and neighbours would avoid	29
Found themselves explaining to others that isn't like their picture of crazy people	15
Worried people would blame them for his problem	53
Worried that person looking to marry would be reluctant to marry in to their family	47
Worried about taking the patient outside	30
Felt ashamed	40
Sought people who also had a family member who has had psychiatric problems	15
Felt grief or depression	40
Felt somehow it might be their fault	30
Over all percentage of positive responses	80
Over all percentage of zero responses	20

Table 2. Proportion of Caregivers with Stigma with Regard to Each Question

In the present study, patient's duration of illness was found to be less than or equal to one year in 39 cases among them 71.8 % and 28.2 % were belongs to zero-low stigma and high stigma, respectively and similarly there were 61 cases with illness for more than one year duration among them 45.9 % and 54.1 % of cases had zero-low stigma and high stigma, respectively. On assessing the association between severity of stigma and patient's duration of illness, there was a statistically significant association found (P = 0.011). Also, patient's diagnosis was found to be psychosis in 50 cases among them 28 % and 72 % were belongs to zero-low stigma and high stigma, respectively and similarly there were 50 cases with neurosis among them 84 % and 16 % of cases had zero-low stigma and high stigma, respectively. On assessing the association between severity of stigma and patient's diagnosis, there was a statistically significant association found (P = < 0.000). In the present study, on assessing the caregiver's relation to patient, spouse was found to be the caregiver in 72 cases among them 51.4 % and 48.6 % were belongs to zero-low stigma and high stigma, respectively and similarly there were 28 cases with first degree relatives as caregivers among them 67.9 % and 32.1 % of cases had zero-low stigma and high stigma, respectively. On assessing the association between severity of stigma and caregiver's relationship with the patient, there was no statistically significant association found in this study (P = 0.1362). On assessing the caregivers burden using burden assessment score there were 64 participants who reported high burden assessment score among them 35.9 % and 64.1 % were belongs to zero-low stigma and high stigma, respectively and similarly there were 36 cases with low burden assessment score among them 91.7 % and 8.3 % of cases had zero-low stigma and high stigma, respectively. On assessing the association between severity of stigma and caregivers burden using burden assessment score, there was a statistically significant association found (P = < 0.000). these findings depict that association between severity of stigma and other clinical variables (Table 2), statistically significant association was found between patient's duration of illness, patient's diagnosis and

care givers burden with severity of stigma perceived by the care givers.

Parameter	Variables	Perceived Caregiver Stigma (FIS)		P Value
		Zero and Low Stigma (N = 56)	High Stigma (N = 44)	
Patient's duration of illness	≤ 1 year	28 (71.8)	11 (28.2)	0.011*
	> 1 year	28 (45.9)	33 (54.1)	
Patient's diagnosis	Psychosis	14 (28)	36 (72)	< 0.000*
	Neurosis	42(84)	08 (16)	
Caregiver relation to patient	Spouse	37 (51.4)	35 (48.6)	0.1362*
	First degree relative	19 (67.9)	9 (32.1)	
Caregiver BAS	High (score7 - 12)	23 (35.9)	41 (64.1)	< 0.000*
	Low (score ≤ 6)	33 (91.7)	03 (8.3)	

Table 3. Association between Severity of Stigma and Other Clinical Variables

*Significant; FIS-Family Interview Schedule; BAS- Burden Assessment Score

Mean perceived stigma score among the care givers of patients with mental illnesses was 12.27 ± 9.43. On comparing the mean perceived stigma score among the care giver of psychosis and neurosis patients, it was found that care givers of psychosis patients had more stigma than the care givers of neurosis patients and the difference between groups was found to be statistically significant (P = 0.0008). (Table 3)

	Diagnosis of the Patients		P Value
	Neurosis Group	Psychosis Group	
Care giver's mean perceived stigma score	10.72 ± 9.12	14.22 ± 9.56	0.0008*

Table 4. Comparison of Mean Perceived Stigma Score among Care Givers of Neurosis and Psychosis Patients

*Significant

DISCUSSION

Care givers play a crucial role in the management of patients with mental illnesses. In developing countries still over 60 % of patients with mental illness live with at least one caregiver.¹⁷ In Indian context caregivers are usually patient's relatives and they do take care of their ill relative at home and they participate in treatment decision making and rehabilitation processes. In both developed and developing countries, caregivers experience high levels of burden and stigma.^{18,19} Care givers feel stigmatized due to negative stereotypes of mental illness and thus either do not seek or delay seeking help.²⁰ Hence, care givers tend to conceal the mental illness of the patients.²¹

In the present study, mean perceived stigma score among the care givers of patients with mental illnesses was 12.27 ± 9.43. Also, 44 % of care givers were found to have high stigma, 36 % of care givers had low stigma and only 20 % of care givers had zero stigma. On assessing the association between severity of stigma and other clinical variables, statistically significant association was found between patient's duration of illness, patient's diagnosis and care givers burden with severity of stigma perceived by the care givers. Whereas in a study from Australia, the caregivers reported the experience of stigma similar to that of patients.²² Studies conducted by El Tantawy et al.²³ and Magana et al.²⁴ reported positive association between

perceived stigma and burden experienced by the caregivers. A study from Sri Lanka reported that reluctance to disclose the illness by the caregivers was a unique predictor of delay in treatment seeking. Overall, this public stigma experienced by caregivers accounted for 20 % of the variance in help seeking delay.²⁵

Yin et al.²⁶ reported mean score of modified consumer experiences of stigma questionnaire was 2.44 ± 0.45 for stigma experiences and 1.97 ± 0.37 for discrimination experiences. They reported that about 65 % of caregivers reported that they tried to conceal their family members' illness, and 71 % lacked the support of friends.

Aakanksha et al.²⁷ reported that while assessing the care givers of people with mental illness (CPMI), the score was higher for affective component than for cognitive and behavioural components. On explanatory model interview catalogue stigma scale (EMIC) the stigma score was 21.7 ± 6.3. Higher level of affiliate and/or associative stigma was associated with shorter duration of illness.

Iris et al.²⁸ reported that care givers attribution of depression to cognitive and attitudinal problems significantly predicted patients' decreased adherence, which results in lack to seeking mental health care.

Freeman et al.²⁹ found that life partners of as of late discharged mental patients communicated more concern about disgrace than did folks. Elective forecasts may be drawn concerning the relationship of gang financial status (SES) to disgrace. Since review information has observed higher SES to be connected with additional tolerant states of mind toward persons with emotional instabilities, one strength expects less worry with disgrace in higher-SES families.

Then again, one may expect more prominent concern with stigma among higher-status families for two reasons: In the first place, they may feel they have more status or notoriety to lose by having dysfunctional behaviour in the family, and second, they may be more mindful of the putative part of families in the aetiology of dysfunctional behaviour and subsequently have bigger trepidation of being faulted by others. Angermeyer et al.³⁰ reported two issues including social class decidedly identified with patients worried about disgrace and relatives worried about stigma in the previous.

CONCLUSIONS

Studies from different parts of the world including the results of this study suggest that stigma is highly prevalent among caregivers of patients with mental illnesses. Proportion of stigma differs according to different patients, caregivers and socioeconomic and cultural variables. The proportion of stigma prevailing among the care givers in this study depicts only the cases which were reported to the health care center, whereas a larger proportion of cases remains not seeking the health care. Hence, the proportion of stigma among the care givers of patients with mental illness could be much more in the community than we predict. Hence, there is a need for further research on stigma to have better

understanding and identification of determinants which might suggest ways to reduce stigma and help to prevent its adverse consequences.

Mental health services should aim to assist key caregivers of people with chronic mental illness to manage their stress and related mental disorders. Early interventions by conducting routine assessments of the mental status of caregivers and their available social support, thereby preventing or minimizing the mental illnesses in these caregivers.

Data sharing statement provided by the authors is available with the full text of this article at jebmh.com.

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