



Stigma Among Caregivers Of Persons With Psychiatric Disorders

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Abstract

Background: Stigma has long been found to be present among caregivers of persons with psychiatric disorders, but there is a lack of studies examining this issue, especially from India.

Aims: To measure stigma among caregivers of persons with psychiatric disorders, to correlate stigma with various sociodemographic and clinical variables and to compare stigma among caregivers of persons with psychiatric disorders and substance dependence.

Materials & Methods: 202 caregivers of persons with schizophrenia and other psychotic disorders, depression, obsessive compulsive disorder and substance dependence were included. They were assessed on various sociodemographic and clinical variables. Stigma was measured using the stigma scale translated and adapted in Hindi.

Results: Caregivers experience higher stigma if the patient or caregiver were less educated. Parents experienced higher stigma than the siblings and spouses. The stigma experiences were highest among caregivers of persons with substance dependence. In addition, stigma experiences among caregivers were higher if the patient was ill for a longer duration, was not in remission or was ever admitted to psychiatry ward.

Conclusions: In addition to the burden of caring for the patient, family members face stigma and discrimination in various areas. The psychosocial interventions planned for the family members should deal with these experiences.

Keywords: Caregiver's stigma, psychiatric disorders, substance dependence, discrimination, disclosure.

Introduction

In India, majority of the mentally ill persons are cared for by family which stigmatizes the family as well [1]. The process by which a person is stigmatized by virtue of association with another stigmatized individual is called 'courtesy' or 'associative' stigma [2]. Associative stigma in India is scantily researched. In the World Psychiatric Association Project in India, conducted on 463 persons with schizophrenia and 651 family members, two thirds reported discrimination [3]. Other studies found that female sex of the patient and a younger age of both patient and caregiver enhanced associative stigma, [4] and caregivers' stigma increased with male gender, literacy, rural residence [5]. Most stigma research has been carried out

in schizophrenia, ignoring other disorders. No study compared stigma in psychiatric disorders and substance dependence. Studies have mostly used questionnaires which give subjective report only and do not measure stigma. The current study was planned to assess stigma and its correlates among family members of patients with psychiatric disorders using a translated (into Hindi) and adapted version of a structured scale for the first time in India. We also compared stigma among caregivers of patients with psychiatric disorders and substance dependence.

Material and Methods

The study was conducted at a General Hospital Psychiatry Unit in North India from January 1, 2011 to May 31, 2011. Sample consisted of 202 caregivers of consecutive patients with diagnoses of mental and behavioral disorders due to psychoactive substance use, schizophrenia, psychotic disorders other than schizophrenia, depression and obsessive compulsive disorder (OCD). We included caregivers of both sexes, who could read and understand Hindi and gave consent for

participation in the study. The caregivers of patients who had any comorbid stigmatizing medical illnesses like HIV, TB, leprosy, epilepsy, vitiligo etc., were excluded. We also excluded family members who had more than one mentally ill person in the family. The ethics committee of the institution approved the study. It was a cross sectional study where the assessments were carried out by a qualified psychiatrist during a single visit. The diagnosis of the patient was made as per ICD 10 [6]. The participants were administered the following tools for detailed assessment:

1. Socio-demographic Performa: A semi structured performa was used for recording sociodemographic details of the patient and caregiver.
2. Stigma scale developed by King et al. was translated into Hindi [7]. The scale consists of 28 items, divided into 3 domains namely discrimination (13 items), disclosure (10 items) and positive aspects (5 items). Each item was rated as agree, neither agree nor disagree and disagree. Higher scores on total scale and 3 subscales indicated higher stigma. The Hindi version of stigma scale

has been tested on a total of 202 caregivers of patients having different psychiatric illnesses and

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substance dependence [8]. It was found to have good reliability (Cronbach's alpha = 0.812). The domains named discrimination (Cronbach's alpha = 0.778) and disclosure (Cronbach's alpha = 0.805) were also found to be reliable independently. 3. Illness related parameters: A semi structured performa was used for recording diagnosis, total duration of illness, course of illness (episodic or continuous), months of actual illness during the illness period and current status of the patient (in remission or not). 4. Yale Brown obsessive compulsive scale to measure severity of OCD [9]. 5. Hamilton rating scale for depression to measure severity of depression [10]. 6. Brief Psychiatric Rating Scale to measure severity of schizophrenia and other psychotic illnesses [11].

Statistical analysis

The statistical analysis was carried out using Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, version 15.0 for Windows). All quantitative variables were estimated using measures of central location (mean, median) and measures of dispersion (standard deviation and standard error). Normality of data was checked by measures of skewness and Kolmogorov Smirnov tests of normality. For skewed data or scores, Mann-Whitney test was applied for two groups. For more than two groups Kruskal Wallis test was applied. Qualitative or categorical variables were described as frequencies and proportions. Proportions were compared using Chi square or Fisher's exact test whichever was applicable. To see the relationship between two variables Pearson Correlation coefficient or Spearman correlation was calculated. All statistical tests were two-sided and performed at a significance level of $\alpha = .05$.

Results

Socio-demographic data of the caregivers and patients respectively and correlation of stigma with these variables is given in tables 1 and 2 respectively. The caregivers experienced significantly higher discrimination if they were less educated ($p < .001$), if the patients were less educated ($p = .012$) and if their monthly family income was less than Rs 10,000 ($p < 0.037$). No other socio-demographic variable of patient or caregiver significantly affected caregivers' stigma. Tables 3 and 4 relate to correlation

of caregiver's stigma scale scores with the clinical parameters of the patient, and the caregiver's relationship with the patient respectively. On the total score of stigma scale, caregivers of patients with substance dependence (mean = 27.90 ± 8.819) had significantly higher score than caregivers of patients with OCD (mean 16.71 ± 8.807 ; $p = .020$), depression (mean = 18.52 ± 9.932 ; $p = .000$), schizophrenia (mean = 20.40 ± 8.617 ; $p = .002$) and psychotic disorders other than schizophrenia (mean = 22.29 ± 9.696 ; $p = .017$). Caregivers of patients with schizophrenia (mean = 20.40 ± 8.617) had higher score than those of depression (mean = 18.52 ± 9.932 ; $p = .028$). On the discrimination subscale, caregivers of patients with substance dependence (mean = 11.48 ± 5.546) scored significantly higher than caregivers of patients with OCD (mean = 4.29 ± 5.090 ; $p = .006$), depression (mean = 6.89 ± 5.059 ; $p = .001$), schizophrenia (mean = 8.46 ± 4.718 ; $p = .041$) and psychotic disorders other than schizophrenia (mean = 8.08 ± 5.440 ; $p = .012$). On disclosure subscale, caregivers of patients with substance dependence (mean = 11.95 ± 4.727) scored significantly higher than caregivers of patients with depression (mean = 8.00 ± 5.698 ; $p = .008$) and schizophrenia (mean = 8.21 ± 5.282 ; $p = .013$). Also, caregivers of patients with schizophrenia (mean = 8.21 ± 5.282) had a significantly higher score than those of depression (mean = 8.00 ± 5.698 ; $p = .048$). On the positive aspects subscale, caregivers of patients with OCD (mean = 5.29 ± 1.704) showed a higher stigma than caregivers of patients with depression (mean = 3.63 ± 2.268 ; $p = .038$) and schizophrenia (mean = 3.42 ± 1.780 ; $p = .019$). Caregivers of patients with substance dependence (mean = 4.48 ± 1.990) had a higher stigma score than those of schizophrenia (mean = 3.42 ± 1.780 ; $p = .041$). So, overall the stigma of caregivers of patients with substance dependence was much higher than stigma of caregivers of patients with other disorders. Discrimination was also significantly affected by duration of illness. Caregivers of patients who were ill for more than 10 years had significantly higher score on discrimination (mean = 9.26 ± 5.402) than caregivers of patients who were ill for less than 1 year (mean = 5.70 ± 4.850 ; $p = .049$). Caregivers of patients who were admitted had significantly higher score on

discrimination (mean = 10.44 ± 4.984) than caregivers of patients who were never admitted (mean = 7.47 ± 5.275). It was also observed that if the patient was not in remission (mean = 22.28 ± 9.725), the total stigma score of caregiver was much higher than if the patient was in remission (mean = 19.74 ± 9.783 ; $p = .047$). Parents (mean = 10.89 ± 5.206) scored significantly higher on disclosure subscale as compared to siblings (mean = 9.19 ± 6.951), offspring (mean = 8.94 ± 5.879) and spouses (mean = 7.90 ± 5.433). We also correlated stigma with the months of illness and severity of the illness. Stigma was not significantly affected by the months of illness or severity of illness among caregivers of patients with OCD, depression and schizophrenia. However, as the months of illness increased, the score on discrimination increased significantly for caregivers of patients with substance dependence (correlation coefficient = $.452$, $p < .040$). Similarly, score on discrimination was positively correlated with severity of illness for caregivers of patients with psychotic disorders other than schizophrenia (correlation coefficient = $.281$, $p = .018$).

Discussion

The present study attempted to investigate stigma and its correlates among caregivers of patients with psychiatric disorders. To our knowledge, this is the first study to directly compare stigma amongst categories of various psychiatric disorders and substance dependence using an objective scale translated to Hindi. The scale has been found to be reliable in our population. We also overcame the limitations of previous studies by including disorders other than schizophrenia. Stigma experienced by the caregivers was significantly higher when the caregivers or patient were less educated and the monthly family income was less than Rs. 10000. The correlation between lower levels of education and income and higher levels of caregiver stigma is consistent with previous research [12,13]. Low level of education is associated with poverty and lower employment status. Hence, fewer resources are available to caregivers who are faced with challenging behavior and other caregiver-related stressors [14]. Poverty and unemployment further cause stigma. Most of these people are at a higher risk of facing overt stigma and discrimination and are less

Table 1 :Correlation of stigma scale scores with sociodemographic data of the caregivers

Variable	Category (n)	Discrimination total mean (SD)	P	Disclosure total mean (SD)	P	Positive aspects total mean (SD)	P	Total score	P
Age (years)	< 30 (45)	8.09 (4.744)	0.863	9.77 (6.153)	0.108	3.98 (2.107)	0.126	21.84 (10.042)	0.186
	30 – 45 (54)	7.72 (5.282)		7.72 (5.523)		3.43 (1.899)		18.87 (9.343)	
	> 45 (103)	8.09 (5.661)		9.74 (5.605)		4.17 (2.138)		21.903 (9.857)	
Gender	Male (131)	7.82 (5.566)	0.439	9.16 (5.856)	0.997	3.92 (2.027)	0.929	20.90 (10.149)	0.611
	Female (71)	8.30 (4.947)		9.28 (5.589)		3.94 (2.197)		21.52 (9.212)	
Formal education in years	< 12 (112)	9.03 (5.333)	0.001 *	9.30 (5.728)	0.773	3.90 (2.232)	0.606	22.22 (9.657)	0.059
	> 12 (90)	6.71 (5.111)		9.09 (5.805)		3.96 (1.896)		19.76 (9.878)	
Occupation	Housewife (46)	7.31 (5.108)	0.384	8.54 (5.856)	0.380	3.80 (1.847)	0.647	19.64 (9.794)	0.148
	Job (54)	8.35 (5.786)		10.15 (5.564)		3.81 (2.266)		22.31 (10.216)	
	Unemployed (7)	8.85 (5.121)		9.63 (5.519)		4.26 (2.352)		22.73 (9.132)	
	Others (94)	8.71 (6.473)		8.00 (7.095)		4.29 (1.890)		21.00 (10.328)	
Marital status	Single (36)	6.54 (4.871)	0.074	9.80 (6.230)	0.576	3.89 (2.055)	0.731	20.23 (10.732)	0.557
	Married (166)	8.30 (5.407)		9.08 (5.655)		3.93 (2.095)		21.31 (9.629)	
Income	< 10000 (42)	8.83 (5.383)	0.170	8.55 (6.263)	0.446	4.50 (2.200)	0.037 *	21.8810 (9.523)	0.723
	> 10000 (159)	7.77 (5.333)		9.32 (5.645)		3.75 (2.047)		20.9182 (9.904)	
Family type	Nuclear (119)	8.03 (5.533)	0.994	9.29 (5.677)	0.747	3.95 (2.197)	0.898	21.8810 (9.544)	0.761
	Joint (82)	7.93 (5.101)		8.96 (5.933)		3.84 (1.954)		20.9182 (10.239)	
Locality	Rural (35)	8.97 (5.322)	0.196	9.49 (5.638)	0.608	4.29 (2.408)	0.374	22.7429 (9.972)	0.228
	Urban (166)	7.78 (5.346)		9.09 (5.813)		3.83 (2.024)		20.7771 (9.772)	

Table 2: Correlation of caregiver's stigma scores with sociodemographic data of the patients

Variable	Category (n)	Discrimination total mean (sd)	P value	Disclosure total mean (sd)	p value	Positive aspects total mean (sd)	p value	Total score	p value
Age (Years)	< 30 years (77)	7.79 (5.230)	0.254	10.19 (5.817)	0.050	4.25 (2.159)	0.260	22.23 (9.568)	.080
	31 – 45 (61)	8.89 (5.373)		9.27 (5.537)		3.56 (1.870)		21.93 (9.487)	
	> 45 (63)	7.37 (5.437)		7.78 (5.749)		3.83 (2.196)		18.97 (10.209)	
Gender	Males (86)	8.66 (5.474)	0.156	9.92 (5.686)	0.106	3.91 (2.055)	0.919	22.65 (9.877)	.053
	Females (115)	7.49 (5.219)		8.58 (5.793)		3.90 (2.136)		19.97 (9.644)	
Education	< 12 years (123)	8.78 (5.596)	0.012*	8.95 (5.920)	0.557	3.81 (2.086)	0.656	21.54 (10.243)	.474
	> 12 years (78)	6.74 (4.700)		9.48 (5.554)		4.05 (2.118)		20.45 (9.109)	
Occupation	Job (30)	8.37 (5.893)	0.494	9.20 (5.275)	0.125	3.70 (1.878)	0.720	21.27 (10.302)	.182
	Others (35)	8.91 (5.633)		10.29 (5.565)		3.71 (2.191)		22.91 (10.294)	
	Housewife (81)	7.25 (5.068)		8.02 (5.931)		4.09 (2.226)		19.36 (9.434)	
	Unemployed (56)	8.29 (5.269)		10.07 (5.761)		3.88 (1.982)		22.49 (9.601)	
Marital status	Single (75)	7.73 (5.160)	0.548	10.21 (5.866)	0.051	3.93 (2.055)	0.944	22.07 (9.804)	.310
	Married (126)	8.14 (5.471)		8.52 (5.642)		3.89 (2.129)		20.56 (9.809)	

Table 3: Correlation of caretakers stigma scale scores with the clinical parameters

Variable	Category (n = 202)	Discrimination mean (SD)	p value	Disclosure mean (SD)	P value	Positive aspects mean (SD)	P value	Total score mean (SD)	P value
Diagnoses	OCD (7)	4.29 (5.090)	0.005*	7.24 (6.817)	0.028*	5.29 (1.704)	0.053	16.71 (8.807)	.002*
	Substance dependence (21)	11.48 (5.546)		11.95 (4.727)		4.48 (1.990)		27.90 (8.819)	
	Depression (65)	6.89 (5.059)		8.00 (5.698)		3.63 (2.268)		18.52 (9.932)	
	Psychosis (71)	8.08 (5.440)		10.10 (5.955)		4.11 (2.081)		22.29 (9.696)	
	Schizophrenia (37)	8.46 (4.718)		8.21 (5.282)		3.42 (1.780)		20.40 (8.617)	
Duration of illness	< 1 year (27)	5.70 (4.850)	0.049*	7.74 (5.565)	0.211	4.81 (2.113)	0.089	18.26 (9.172)	.440
	1 – 5 years (69)	7.81 (5.042)		10.01 (5.725)		3.48 (1.891)		21.30 (9.958)	
	5 – 10 years (52)	8.10 (5.661)		9.59 (5.463)		3.94 (2.213)		21.63 (10.239)	
	> 10 years (54)	9.26 (5.402)		8.38 (6.118)		3.96 (2.125)		21.83 (9.528)	
Type of illness	Episodic (40)	6.40 (4.372)	0.064	9.25 (6.197)	0.901	3.55 (1.974)	0.246	19.20 (9.646)	.204
	Continuous (161)	8.39 (5.505)		9.14 (5.682)		3.99 (2.122)		21.59 (9.822)	
Current status	In remission (92)	7.35 (5.352)	0.094	8.79 (5.760)	0.390	3.60 (1.899)	0.053	19.74 (9.783)	.047*
	Not in remission (109)	8.53 (5.308)		9.46 (5.789)		4.16 (2.224)		22.28 (9.725)	
Ever admitted or not	Yes (58)	9.27 (5.482)	0.055	9.25 (5.884)	0.920	3.88 (1.936)	0.994	22.64 (10.246)	.229
	No (143)	7.52 (5.248)		9.17 (5.745)		3.93 (2.162)		20.62 (9.608)	

Table 4: Correlation of caregivers stigma scale score with relation to patient

Relation with patient	Discrimination Mean (sd)	P value	Disclosure mean (sd)	P value	Positive aspects Mean (sd)	P value	Total score Mean (sd)	P value
Male caretakers (133)	7.84 (5.593)	0.471	9.17 (5.831)	0.981	3.89 (2.020)	0.925	20.90 (10.211)	.612
Female caretakers (68)	8.28 (4.859)		9.28 (5.627)		3.99 (2.216)		21.54 (9.031)	
Siblings (26)	6.85 (4.576)	0.275	9.19 (6.951)	0.025*	3.96 (2.200)	0.769	20.00 (11.507)	.248
Offspring (33)	6.88 (4.601)		8.94 (5.879)		3.55 (1.697)		19.36 (9.877)	
Parents (65)	8.05 (5.464)		10.89 (5.206)		4.17 (2.020)		23.16 (8.995)	
Spouse (77)	8.81 (5.715)		7.90 (5.433)		3.87 (2.250)		20.57 (9.749)	

likely to protest against discrimination because of their low level in the social hierarchy. In our study, no other socio demographic variable affected stigma. A previous study likewise found no significant correlation between caregiver's stigma and patient's age, gender or caregiver's age [15]. Younger caregivers have been associated with higher levels of caregiver's distress, depressive symptoms and stigma in two studies on caregivers of patients with mental illness [14,16] and one of mental retardation [17]. We found significantly higher stigma among parents than other relatives on disclosure subscale. However, three previous studies found that spouses experienced higher stigma than parents [15,18, 20]. Attempts at secrecy are common among caregivers of patients with mental disorders as they fear that revealing the illness might damage relationships with friends, relatives and community [18,19,20]. The possible reasons for higher stigma in parents in our study could be due to the social structure in India. In western countries, after marriage, the bonds of patients with parents are not strong and spouses are expected to take care of the patient and thus bear the brunt of blame, shame and contamination. However, in India, the patients retain strong bonds with

the parents even after marriage. Even if they do not live in a joint family, it is not uncommon to see aged parents coming for the treatment of their children. If something goes wrong even after marriage, the parents are expected to take responsibility of treatment and social consequences. In case a wife becomes ill, she is generally sent back to her parents and in case husband becomes ill, the wife leaves him to his parents and goes back to her parents. Thus, it seems that the stigma of giving birth to a child who later develops a mental illness is much greater than the stigma of living with the patient and taking care of him. Further, in Asia, a marriage is not just a relation between two individuals but between two families, in contrast to the Western paradigm. In India parents are also worried about the marriage of their other children in case they have a mentally ill child [21]. Mother of a 38 years old male with schizophrenia narrated "My elder son does not agree that the younger one has a mental illness. I avoid meeting my elder son and most of our relatives as they blame me that my patient's behavior is because I pampered him a lot during his early days." Mother of a 19 year old male with psychotic illness explained the stigma of contamination: "A neighbor called my son mad. When I

intervened, he said "You have also become mad with your son. Your whole family is mad." Mother of a 30 years old female with depression said, "My daughter could not take care of her son after delivery. Her husband sent her back to us saying that she is of no use. He has abandoned her but I cannot do the same. I kept her for 9 months in my womb." Father of a 30 year old male with schizophrenia stated, "We did not disclose his illness at the time of marriage. His wife found it within 10 days of marriage and left him. Now we have to get him treated and at the same time, fight the court case on his behalf." We found that stigma was highest among caregivers of patients with substance dependence. Society still believes that addiction is a character flaw or weakness that probably can't be cured and the family is held responsible for the addiction because of their poor parenting. The stigma against people with addictions is so deeply rooted that it continues even in the face of the scientific evidence that addiction is a treatable medical disease. Even people with substance dependence and their families begin to accept the idea that addiction is their own fault and that maybe they are too weak to do anything about it. In many ways, hiding an addiction problem may be the rational thing to do

because seeking help can mean losing a job and social rejection [22]. Largely, in spite of two centuries of claims that addiction is a disease similar to other chronic diseases, the idea that addiction is rooted in repeated bad choices remains widely compelling and in social terms both alcoholism and drug addiction are thoroughly moralized and derogated categories [23]. Daughter of a male with alcohol dependence expressed her feelings “We are so ashamed. Nobody is willing to marry me and my sister because of his alcohol problem. Everybody in the village calls him an addict and keeps making remarks about his drinking.” The father of a 30 years old male with alcohol dependence reports “Most of my relatives and even our daughter in law blame me and my wife for our son’s drinking problem. They say it is due to our faulty upbringing. Gradually, even we have started feeling we are responsible for it. What do you say, Doctor?” Higher stigma among relatives of persons with schizophrenia as compared to patients with depression has been previously reported.[24] It can be attributed to many factors. Labeling a person as having schizophrenia evokes more negative emotions of fear and anger. Their appearance, delusions and hallucinations evoke more social distance and rejection. People generally associate violent behavior with schizophrenia rather than depression. In a survey of a representative sample of 1,444 adults, 61 percent of the respondents indicated that a person described in an accompanying vignette as having symptoms of schizophrenia would be “likely” or “very likely” to do something violent toward other people. For a person described as having symptoms of depression, the percentage was 33 percent [25]. Wife of a 35 years old male with schizophrenia said “My husband keeps

talking to himself. A stranger on the road once told me to keep my husband indoor always as he might hurt anyone without a reason.” Brother and sister in law of a 38 years old male with schizophrenia wept when they told us, “Our neighbors do not talk to us. They repeatedly tell us to get him admitted to a mental hospital because he once became violent. These people do not understand that he is recovered now. They just say he can kill anyone anytime.” We also found that caregivers of patients who had been admitted in the past had more stigma than caregivers of patients who were never admitted. Family members make efforts to conceal the hospitalization of their patients to a mental health facility as it is associated with stigma [18] and stigma increases as the number of hospitalizations increase [21]. In a Nigerian study, 83% respondents never wanted their family member to be ever hospitalized [24]. It has been reported that stigma associated with admission in a state mental hospital is much more than admission in a general hospital [26]. It could be argued that because large and often geographically isolated psychiatric hospitals closely fit the public stereotype of a place where “mentally ill” people are kept for a long duration of time, even lifelong, hospitalization in such institutions may elicit more stigma than hospitalization in General Hospital Psychiatry Units. However, the present study has been conducted in a General Hospital in North India where the situation is quite different from psychiatric hospitals. The finding of higher stigma in our study among caregivers of persons who had been admitted indicates that the fact of psychiatric hospitalization, rather than the type of facility, may be the decisive labeling factor. The parents of a 20 years old male discharged after recovery

from first episode of schizophrenia state: “We tried to hide it but one of the neighbors who works in the hospital told everyone in the locality that our son was admitted to a psychiatry ward. Most of the persons in our community have been avoiding talking to us or visiting us since then.” Stigma increased among caregivers of patients with psychotic disorders other than schizophrenia with increasing severity of illness. Also, it was found that stigma increased significantly with longer duration of illness and if the patients were not in remission. Long-standing chronic illnesses are more likely to cause disability, poor functioning and unemployment, which may affect the self-esteem of the patient as well as the caregiver and lead to high levels of stigma [27]. The severity and number of symptoms would clearly be expected to increase the family members’ fear of stigma as well as the actual stigmatizing responses of others. Further, public concept of mental illness is of psychosis, which is incomprehensible, disturbing and frightening. Hence, psychotic symptoms should be particularly stigmatizing [18]. Stigma and the level of symptoms perpetuate each other. It has been reported in literature that stigma is inversely related to treatment use and thus it is a barrier to remission of symptoms [28]. This further enhances the severity of psychopathology, thus leading to more stigma. In conclusions, stigma, prejudice and discrimination are common negative consequences experienced by caregivers of patients with mental disorders. Mental health professionals should take into consideration the associative stigma while assessing the needs of the family members. Stigma reduction should be an integral part of the psychosocial interventions for family members of persons with mental illnesses.

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