

## **Causal Beliefs, Stigma and Social Support in Persons with Schizophrenia and their Caregivers**

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## Abstract

**Purpose:** To understand causal beliefs, stigma and social supports among persons with schizophrenia and their caregivers

**Methods:** A cross sectional study design on a purposive sample of persons with schizophrenia (ICD-10) and their caregivers attending National Institute of Mental Health and Neurosciences (NIMHANS) at Bangalore, India. Socio demographic and clinical data were collected using a structured questionnaire. Link's Perceived Stigma questionnaire was administered to each subject and caregivers and a Short Explanatory Model Interview was used to study the beliefs of patients. A semi structured interview schedule for social supports was used to assess the available social supports for subjects in the study.

**Results:** Thirty subjects and caretakers, with a mean age of  $27.90 \pm 5.28$  years and  $46.03 \pm 12.52$  years for patients and caregivers respectively, were enrolled in the study. The mean duration of caregivers living with the subject was  $17.62 \pm 6.18$  years. There was a significant difference (t test p value=0.04) between patients and caregivers in the devaluation and discrimination scale of the perceived stigma scales. Caregivers believed that employability was lower for persons with previous history of schizophrenia. Both patients and caregivers were likely to hide the history of schizophrenia among patients. Major perceived causes for the illness did not differ significantly between persons with schizophrenia and caregivers. Both caregivers and persons with schizophrenia reported similar impact of the illness on their work, finances and social interactions. Strains in marital relationship were reported by persons with schizophrenia.

**Conclusion:** The results of this study indicate that causal beliefs, perceptions of stigma and the impact of the illness are primarily driving the need for secrecy and confidentiality and possibly restricting the utilization of support to the immediate family of persons with schizophrenia. The impact of support systems and psychoeducation on persons with schizophrenia and their caregivers has to be studied further.

## Introduction

The prevalence of schizophrenia in India ranges from 1.49 to 2.5 per 1000 for schizophrenia.<sup>1-5</sup> It is estimated that the global burden of disease for neuropsychiatric disorders as measured by the loss of disability adjusted life years (DALYs) will increase from 6.8% in 1990 to 15% by the year 2020.<sup>6,7</sup> There is a stigma associated with psychiatric disorders despite increased awareness of these conditions. The stigmatization may delay appropriate care at the appropriate time with consequences on the morbidity and course of the illness and pose a significant barrier to the process of recovery and integration into the peer community. Stigmatization also increases risk for a systematic exclusion from social interactions and reduced social support. The role of causal beliefs is important in the process of stigmatization. Several studies from India have reported that supernatural causes are perceived as a major cause of schizophrenia.<sup>8,9</sup> Such misguided beliefs regarding the causation of the disease may influence the stigma attached to the disease.

The causal beliefs, stigma and social supports among persons with schizophrenia and their caregivers were explored using a cross sectional study design. Information from this study is expected to provide a better understanding of the perceptions surrounding these factors and may lead to development of improved psycho education material for persons with schizophrenia and their caregivers.

## Method:

This study was conducted on persons with schizophrenia and their caregivers at the National Institute for Mental Health and Neurosciences (NIMHANS), Bangalore, India. The study was conducted during the years 2002 to 2003 after obtaining approval from the scientific committee of the Department of Clinical Psychology at NIMHANS.

Causal beliefs or attributions were defined as the knowledge of beliefs that a person holds about the causes of events. Stigma was defined as an undesirable deeply discrediting attitude that disqualifies one from full social acceptance and motivates efforts of the stigmatized individual to hide the mark when possible.<sup>10</sup> Social supports were defined as the existence or quantity of social relations measured in terms of the functional content of the support such as emotional, instrumental and informational support. A caregiver was defined as a person living the same household as the patient at least for the past 6 months and involved with the daily care of the patient.

A purposive sampling technique was used to identify 30 patients, who were diagnosed with schizophrenia (based on the ICD-10 criteria) after a comprehensive psychiatric evaluation, from the outpatient and inpatient departments of NIMHANS. Patients who were aged 18 to 40 years, had a minimum education of 7<sup>th</sup> grade, were able to converse in English and/or Telugu, were currently living in the family context, whose duration of illness was less than 5 years and had a score  $\leq 9$  on the Brief Psychiatry Rating Scale (BPRS) were included in the study. Patients who were determined to have co-existing major physical morbidities, substance abuse or mental retardation were excluded from the study. Thirty caregivers accompanying the patients and conversant in English and/or Telugu were selected for the study on caregivers. Written informed consent was obtained from all included patients prior to the administration of the study tools. The tools for the study were translated from English to

Telugu language. The translated versions and the original versions in English were provided to three independent mental health professionals with at least 5 years experience in the profession to check if the translated versions maintained the conceptual clarity and comprehensiveness of the original tools. The translated tools were further revised based on these inputs and were then administered to three patients who fulfilled the inclusion and exclusion criteria for the study and caregivers prior to finalization.

A socio-demographic data sheet was used to collect information on age, gender, education, occupation, income, type of family and family size from the included patients and caregivers. Information relating to the relationship of the caregiver with the subject and the duration of living with the subject, and prior psychiatric consultation for the subject was collected. Information on the age of subject at onset of disease, duration of illness, course, number and duration of episodes, major complaints, and details of treatment, compliance to treatment and current status of the subject was also collected.

Link's Perceived Stigma questionnaire was administered to each subject and caregivers to measure the perception of and coping with stigma.<sup>11</sup> The questionnaire has four scales: devaluation and discrimination, secrecy, withdrawal and education. Individual items are scored using a 6 point likert scale. Scores for the scales are obtained by summing the scores for each item in the scale divided by the number of items in the scale.

The Short Explanatory Model Interview<sup>12</sup> was used to study the beliefs of patients in relation to the name and nature of the problem, reasons for consulting, perceived causes, consequences, the severity of the problem and its effects on the body, emotions, social network, home life, and on work. A semi structured interview schedule for social supports was used to assess the social supports available to the subject, utilization of available supports and satisfaction with utilized supports, available supports that were not utilized and reasons for non utilization of such support systems, and support that was voluntarily provided to patients.<sup>13</sup> The dimensions of support measured include emotional (showing concern and listening), informational (giving advice, suggestions, information) and instrumental (physical and/or financial aid). Satisfaction is measured using a 3 point scale that ranges from totally satisfied (1) to not at all satisfied (3). All questionnaires were administered by a single investigator (CK) who spent approximately 2 to 2.5 hours were spent with each subject and caregiver for the administration of the questionnaires.

Data were entered into an excel worksheet and analyzed using SPSS statistical software. The students t-test was used to compare scores on the stigma scale between patients and caregivers, and the independent two sample test for proportions to compare responses provided by the subject and caregiver. A P value less than 0.05 was considered as statistically significant.

## Results

Seventeen (56.67%) of the 30 patients and 17 (56.67%) of 30 caregivers were males. The mean age was  $27.90 \pm 5.28$  years and  $46.03 \pm 12.52$  years for patients and caregivers respectively. The mean number of years of education was  $12.53 \pm 3.04$  and  $10.93 \pm 3.14$  for patients and caregivers respectively. Fourteen (46.67%) of 30 patients and 18 (60.00%) of 30 caregivers were employed. Five (35.71%) of the 14

patients who were employed had a monthly income less than 1000 Indian rupees. Thirteen (43.33%) patients were married. Twenty six (86.67%) of patients were living in a nuclear family setting. The mean family size was  $5.26 \pm 3.38$  members. The mean duration of caregivers living with the subject was  $17.62 \pm 6.18$  years. Sixteen (53.33%) of caregivers were parents of the subject, 8 (26.67%) were a sibling. Only 2(15.38%) of the 13 married patients had their spouse as the caregiver.

Twenty three (73.67%) of patients were treated as outpatients. Twenty eight (93.33%) patients were diagnosed with paranoid schizophrenia. The mean age at onset of illness was  $24.38 \pm 4.71$  years and the mean duration of illness was  $3.35 \pm 1.04$  years. Thirteen (43.33%) patients gave a prior history of psychiatric consultations. The course of illness was continuous in 24 (80.00%) patients.

The mean BPRS score of the 30 patients was  $4.43 \pm 1.77$ . There was a significant difference (t test p value=0.04) between patients and caregivers in the devaluation and discrimination scale of the perceived stigma scales (Table 1).

Table 1: Scores of stigma of patients and caregivers

Scales	Patients		Patients		P- value (t-test)
	Mean	SD	Mean	SD	
Devaluation and Discrimination	3.03	0.61	3.33	0.51	0.04
Secrecy	3.17	1.16	2.87	1.10	0.31
Withdrawal	2.37	0.91	2.20	0.74	0.43
Education	1.79	0.74	1.78	0.66	0.96

The major reasons for availing consultation -medication related issues for 15 (50.00%) patients and 13 (43.33%) caregivers respectively ( $p=0.59$ ) and routine follow up 10 (33.33%) patients and 12 (40.00%) caregivers ( $p=0.57$ ) - did not differ significantly between patients and caregivers. Eight (26.67%) caregivers cited concerns about the future of the subject as a reason for seeking consultation while none of the patients cited this reason.

Majority of the patients ( $n=24$ , 80.00%) and caregivers ( $n=22$ , 73.00%) perceive the illness to be a serious problem with the severity being rated as  $> 75\%$ . Work and study related issues (11 (36.67%) patients and 13 (43.33%) caregivers respectively) and psychosocial causes (13 (43.33%) patients and 12 (40.00%) caregivers respectively) were cited as the major reason for the disease (Table 2). Seven (23.33%) patients and 6 (20.00%) caregivers perceived supernatural causes as the reason for the disease. A significant higher proportion of caregivers ( $n=10$ , 33.33%) perceived personality factors as the cause for the illness ( $p=0.02$  using the independent two sample test of proportions).

Table 2: Causes for the problem as perceived by patients and caregivers

Categories	Patients (n, %)	Caregivers (n,%)	P value
Work/study related	11 (36.67%)	13 (43.33%)	0.60
Psychosocial causes	13 (43.33%)	12 (40.00%)	0.79
Medical/Physical causes	6 (20.00%)	10 (33.33%)	0.05
Personality factors	5 (16.67%)	10 (33.33%)	0.02
Problems in heterosexual relations	4 (13.33%)	7 (23.33%)	0.31
Supernatural causes	7 (23.33%)	6 (20.00%)	0.77
Property/financial	3 (10.00%)	2 (6.67%)	0.68
Masturbation	2 (6.67%)	2 (6.67%)	1.00
Don't know	4 (13.33%)	2 (6.67%)	0.44

Fourteen (46.67%) patients and 18 (60.00%) caregivers felt the illness impacted upon their financial resources (Table 3). There was a significant difference on the perceived impact of the illness on work between patients and caregivers (p value=0.03 using the independent two sample test of proportions)

Table 3: Impact of the illness as perceived by patients and caregivers

Categories	Patients (n, %)	Caregivers (n,%)	P value
Financial	14 (46.67%)	18 (60.00%)	0.28
Work	14 (46.67%)	6 (20.00%)	0.03
Social interaction	9 (30.00%)	5 (16.67%)	0.19
Marital problems on self	10 (33.33%)	4 (13.33%)	0.07
Study	5 (16.67%)	4 (13.33%)	0.74
Burden on family	4 (13.33%)	4 (13.33%)	1.00
Future of family	4 (13.33%)	4 (13.33%)	1.00
Marital impact on other family members	0 (0.00%)	3 (10.00%)	0.08
Neglect of other family members	0 (0.00%)	3 (10.00%)	0.08
Physical	3 (10.00%)	2 (6.67%)	0.57
No difficulties	1 (3.33%)	2 (6.67%)	0.57

There was a significant difference pertaining to the effects on the body between patients and caregivers with patients more likely to suggest an effect of the illness on the brain/head (p=0.03) and caregivers more likely to suggest increased tension/worry (p=0.005). More patients (n=11, 36.67%) reported sadness as the predominant emotion while more caregivers (n=10, 33.33%) reported tension/worry as the predominant emotion. Only one patient (3.33%) reported no effects on emotions because of the illness compared to 8 (26.67%) of caregivers (p value=0.009 using the independent two sample proportion test).

There were no statistically significant differences for perceived effects on social life between patients and caregivers. Nine (30.00%) patients and 15 (50.00%) caregivers did not perceive any effect on their social life because of the illness. Decreased participation in social functions was cited by 13 (43.33%) patients and 8 (26.67%) caregivers respectively, secrecy by 9 (30.00%) patients and 8 (26.67%) caregivers and decreased contact with friends by 6 (20.00%) patients and 4 (13.33%) caregivers.

Nine (30.00%) patients stated discontinuation of job/studies and physical problems, and 8 (26.67%) patients stated difficulty in concentrating on work. Most caregivers (n=8, 26.67%) did not perceive any effect on their work compared to 1 (3.33%) patients (p value=0.009 using the independent two sample proportion test).

The perceived effects of the illness on the life at home were significantly different between patients and caregivers for strained family relations and positive effects (Table 4).

Table 4: Perceived effects on the life at home by patients and caregivers

Categories	Patients (n, %)	Caregivers (n, %)	P value
Strained family relations/separation	2 (6.67%)	11 (36.67%)	0.005
No effect	2 (6.67%)	8 (26.67%)	0.04
Sad/upset/worry	3 (10.00%)	4 (13.33%)	0.71
Less time for other family members	0 (0.00%)	3 (10.00%)	0.07
Positive effect	11 (36.67%)	3 (10.00%)	0.01
Decreased respect/status	1 (3.33%)	2 (6.67%)	0.48
More care/attention	1 (3.33%)	1 (3.33%)	1.00
Financial effect	4 (13.33%)	1 (3.33%)	0.15
Marital problems	1 (3.33%)	0 (0.00%)	0.34
Fear	3 (10.00%)	0 (0.00%)	0.07
Physical problems/tiredness	1 (3.33%)	0 (0.00%)	0.34

Majority of patients (n=26, 86.67%) and caregivers (n=19, 63.33%) sought help initially from their parents. Siblings were the other major social support utilized by patients (n=16, 53.33%) and caregivers (n=9, 30.00%). Over 80% of patients (83.00 to 87.00%) and 43.00% to 47.00% of caregivers reported receiving support in the form of concern, listening, receiving advice, and financial and physical aid. Professional were perceived as available for support by 29 (96.67%) of patients and caregivers. Twenty seven (90.00%) of patients and caregivers were completely satisfied with the support they received. Majority of patients (n=21, 70.00%) and caregivers (n=22, 73.33%) found it difficult to approach neighbors for help. Difficulty in approaching relatives for help was expressed by 16 (53.33%) patients and 18 (60.00%) caregivers. Twenty seven (90.00%) of caregivers were not willing to seek help because they felt family secrets have to be kept within the family itself (Table 5).

Table 5: Reasons for not seeking help by patients and caregivers

Reason	Subject (n, %)	Caregiver (n, %)
Family secrets to be kept within family	15 (50.00%)	27 (90.00%)
Confidentiality	15 (50.00%)	19 (63.33%)
Not intimate to ask help	17 (56.67%)	16 (53.33%)
Don't like to ask for help	15 (50.00%)	16 (53.33%)
Feel embarrassed	14 (46.67%)	15 (50.00%)
Would not help	3 (10.00%)	7 (23.33%)
Previous bad experience	5 (16.67%)	4 (13.33%)
Friends live far away	4 (13.33%)	3 (10.00%)
No one to help	2 (6.67%)	1 (3.33%)

## Discussion

Significantly higher scores for caregivers on the devaluation and discrimination scale of the Link's Perceived Stigma Questionnaire indicate that caregivers believe people may be reluctant to accept a person with previous history of schizophrenia in different social roles, that people may think less of a person who has had schizophrenia and that persons who have had schizophrenia may receive differential treatment. Caregivers also believed that employability was lower for persons with previous history of schizophrenia. Both patients and caregivers were likely to hide the history of schizophrenia among patients, and were likely to use withdrawal and educating others about the illness as coping strategies. These results indicative of the stigma attached to schizophrenia in this population are consistent with several other studies.<sup>14-16</sup>

Psychosocial and supernatural causes have previously been reported as perceived causes for the illness.<sup>9, 17,18</sup> The major perceived causes in this study were psychosocial causes (strained family relations, death of a loved one, and mental pressures), work or study related issues (failure in exams or loss of job). Supernatural causes were reported by persons with schizophrenia and caregivers but was lower down in the hierarchy of reported causes. Caregivers were significantly more likely to cite personality related factors (such as sensitiveness to criticism, introvert nature, and negative personality) as a cause for the illness. It is interesting that major perceived causes for the illness did not differ significantly between persons with schizophrenia and caregivers. This probably suggests the deep rooted belief systems regarding causes for schizophrenia in the family especially when one considers that both persons with schizophrenia and caregivers in this study had a mean education of more than 10 years.

Both caregivers and persons with schizophrenia reported similar impact of the illness on their work, finances and social interactions. Strains in the marital relationship were also reported by persons with schizophrenia. Consistent with other reports, the study found that the illness increased tension and worry significantly among caregivers compared to persons with schizophrenia and that most families of persons with schizophrenia cope well with the illness.<sup>19,20</sup> A definite impact on the social life of persons



with schizophrenia and caregivers with both groups reporting decreased social interactions, decreased contact with friends, and secrecy regarding the illness was also found. The illness seemed to produce different effects on the life at home. A significant proportion of persons with schizophrenia reported positive effects of the illness such as improved care, better understanding and a feeling of closeness with the other family members. The positive effects may also possibly be related to a potential shift of family responsibilities from the person with schizophrenia to the caregiver. This perception of positive effects was in contrast to a significant proportion of caregivers who reported strained relationships between family members.

The causal beliefs, perceptions of stigma and the impact of the illness among persons with schizophrenia and their caregivers appear to influence the utilization of social supports. The results of this study indicate that these factors are primarily driving the need for secrecy and confidentiality and possibly restricting the utilization of support to the immediate family- parents and siblings. This may have several implications including a greater sense of social isolation leading to a vicious cycle of withdrawal from social interactions, greater stigmatization and reduced integration into the community. These factors may also affect appropriate care being sought at the appropriate time for persons with schizophrenia since families may be more concerned with maintaining secrecy regarding the illness.

The purposive sampling and the small sample size are limitations of the study that prevent generalization of the results to a larger population. However, the results suggest that causal beliefs, stigma, social supports and the impact of the illness are closely interlinked. These results suggest the need to develop more support systems to supplement the therapeutic interventions for the management of schizophrenia. These may include psycho education modules for both persons with schizophrenia and their immediate families and caregivers focused on improving understanding of the illness and the potential short and long term effects of the illness. Support systems have to be developed to help persons with schizophrenia improve their social interaction skills and integrate with the community. These systems have to be developed with the family as an integral part of the therapy such that perceptions of stigma among caregivers may reduce. It is important that the support systems also explore options of gainful employment for persons with schizophrenia since reduced employment potential is viewed as a major effect of the illness. Further research is necessary to study the impact of such support systems including psycho education on the perceptions of persons with schizophrenia and their caregivers.

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