

A study of psychological distress in caregivers of schizophrenia patients

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Abstract

Introduction: Mental illness in a family member can be a huge burden and problematic on the care givers and family. The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

Materials and Methods: In this cross-sectional study, detailed history, relevant sociodemographic details, clinical and psychological assessment findings were documented in a structured proforma in all the subjects. Burden assessment schedule (BAS) was administered to assess caregiver burden, Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress among the caregivers and Positive and Negative symptom scale (PANSS) for severity of symptoms in schizophrenic patients.

Results: A total of 40 subjects were included in the study. The mean age of the study population was 44.08 ± 12.12 , 12(30%) participants were males and 28(70%) were females. The mean total caregiving time of study population was 7.63 ± 2.37 with the range 3 to 12 hours/days. 15 caregivers (37.50%) had psychological distress, and 25(62.50%) had no psychological distress. On univariate analysis, age, caregiver burden, total caregiving time (hours/day), negative symptoms and total PANSS score were found to be significantly associated with psychological distress among caregivers. After adjusting for the effect of other variables in the equation, it was found that the odds of psychological distress increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in severity of caregiver burden.

Conclusion: The most important predictive factor of psychological distress in caregivers was the severity caregiving burden.

Keywords: Family, Caregivers, Psychological stress, Schizophrenia.

Introduction

Presence of mental illness in a family member can put a huge burden on the caregivers and family members and may lead to not only psychological distress and also physical illness.¹Schizophrenia is one such psychiatric illness, which is reported to result in heavy burden and psychological distress in various settings.^{2,3} Many studies conducted in the community, outpatient and inpatient care settings across the globe have documented high levels of caregiver burden, different types of negative psychological impact.⁴⁻¹⁰ The typology of schizophrenia and the duration of illness were proved to be one of the strong correlates of the high caregiver burden in earlier studies.¹¹⁻¹⁴

It is highly important to understand various disease-related and caregiver-related factors associated with psychological distress to be able to develop appropriate interventions to minimise the burden and associated distress. But a huge variation in the methodology and instruments used precludes effective cross-study comparison.³

There are very limited numbers of studies available on the subject in the Indian population. Jagannathan, A. et al.¹⁵ have reported the duration of illness and perceived social support to be significant predictors of burden in addition to psychopathology and disability. Kumar, C. N., et al.¹⁶ have concluded that burden experienced by family caregivers of schizophrenia patients depends on the level of disability experienced by the patient, age of the family caregivers and gender of the patient. Interventions to reduce disability of the patients may reduce the caregiver burden.

But, because of wide variations in the tools and methods used to assess the psychological impact and caregiver burden, it is very difficult to draw comparisons between studies conducted in different settings. Also due to

huge differences in the stigma, cultural factors and sociodemographic profile of the populations across different settings, it is highly necessary to develop evidence on local populations to be able to develop culture-specific interventions. Hence the current study has been conducted with an objective of assessing the correlates of caregiver burden among caregivers of schizophrenia patients attending a tertiary care teaching hospital in south India.

Objectives

1. To study the prevalence and correlates of psychological distress and caregiver's burden of patients with Schizophrenia.

Materials and Methods

The current study was a cross-sectional study conducted in the Department of Psychiatry, Chettinad Hospital and research institute (CHRI), Kelambakkam. Primary Caregivers of psychiatric inpatients and outpatients in CHRI, Kelambakkam with a diagnosis of Schizophrenia with duration of illness >2yrs classified under F20 according to ICD-10 and aged more than 18 years were included in the study. Exclusion of caregivers of patients with psychiatric illness other than those under F20 and less than 18 years age was done. After obtaining informed written consent, all the subjects were evaluated by detailed history. Relevant sociodemographic details, clinical and psychological assessment findings were documented in a structured proforma. The following scales were administered:

1. Burden assessment schedule (BAS) -A 40 item questionnaire assessing both the objective and

- subjective burden experienced by the caregiver of mentally ill patients. The scores range from 40 to 120.¹⁷
2. Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress. It is a 20-item mental disorder screening instrument developed by World Health Organization.¹⁸
 3. PANSS (Positive and Negative symptom scale).¹⁹ This consist of 3 dimensions-Positive symptoms, Negative Symptoms and General symptoms to assess the severity of symptoms in patients with schizophrenia.

The study was conducted after obtaining ethical clearance Institutional Human Ethics Committee. All patients were given necessary treatment irrespective of their caregiver's participation in the study. In the case of the presence of psychological distress in the caregivers, further evaluation and appropriate management was done.

Sample size

Sample size was calculated assuming the proportion of psychological distress among the caregivers as 31.5% as per the study by Hui Chien Ong et al²¹ The other parameters considered for sample size calculation were 15% absolute

precision and 95% confidence level. The following formula was used for sample size calculation. The required number of subjects as per the above-mentioned calculation was 37. To account for a non-participation rate of about 10 % (3 subjects), it was decided to sample about 40 subjects in to the study.

Statistical methods

Descriptive analysis was carried out by the mean and standard deviation for quantitative variables, frequency and proportion for categorical variables. Univariate binary logistic regression analysis was performed to test the association between the explanatory variables and psychological distress (Self-reporting questionnaire 20). Unadjusted Odds ratio along with 95% CI is presented. Variables with statistical significance in univariate analysis were used to compute multivariate regression analysis. Adjusted odds ratio along with their 95% CI is presented. P value < 0.05 was considered statistically significant. IBM SPSS version 22 was used for statistical analysis.

Results

A total of 40 subjects were included in the analysis.

Table 1: Socio-demographic parameters of study population (N=40)

Demographic parameter	Mean/Frequency	SD/Percentage
Age (Mean \pm STD)	44.08	\pm 12.12
Gender		
Male	12	30.00%
Female	28	70.00%
Marital status		
Married	35	87.50%
Unmarried	5	12.50%
Education		
Middle School	15	37.50%
Primary School	12	30.00%
High School	8	20.00%
Illiterate	5	12.50%
Occupation		
Unemployed	14	35.00%
Unskilled Worker	13	32.50%
Employed	13	32.50%
Family type		
Joint	5	12.50%
Nuclear	35	87.50%
Primary earning member of family		
Caregiver	14	35.00%
Patient	13	32.50%

The mean duration of caregiving of study population was 7 ± 5.87 years with the range of 2 to 30 years. The mean total caregiving time per day of study population was 7.63 ± 2.37 with the range of 3 to 12 hours/days. The mean duration of illness of the patients was 8.8 ± 8.52 with the range 2 to 40 years. Among the schizophrenia patients, 40(100%) had positive symptoms, 22(55%) had negative symptoms and 39(97.50%) had general symptoms. The mean PANSS score of the study population was 57.30 ± 12.74 with the range 36 to 82. The mean caregiver burden schedule score of the study population was 44.60 ± 18.44 with the range of 20 to 80.

Table 2: Univariate logistic regression analysis factors associated with psychological distress in the study population (N=322)

Parameter	Odds ratio	95% CI		P value
		Lower	Upper	
Age	1.073	1.002	1.149	0.044
Gender (baseline= Male)				
Female	2.250	0.499	10.143	0.291
Marital status (baseline = Married)				
Unmarried	1.128	0.166	7.665	0.902
Education (base line= Illiterate)				
Middle School	2.667	0.237	30.066	0.427
Primary School	2.857	0.241	33.902	0.406
High School	2.400	0.175	32.87.9	0.512
Occupation (baseline= Unemployed)				
Unskilled Worker	1.125	0.236	5.371	0.883
Employed	1.125	0.236	5.371	0.883
Patient primary earning member of the family (Baseline=No)				
Yes	0.646	0.158	2.637	0.543
Duration of caregiving(in years)	1.148	0.995	1.324	0.059
Total caregiving time (hours/day)	1.392	0.018	1.904	0.039
Duration of illness(in years)	1.044	0.966	1.129	0.279
Type of symptoms				
Positive symptoms	1.044	0.966	1.129	0.279
Negative Symptoms	1.087	1.002	1.178	0.045
General symptoms	1.086	0.957	1.233	0.200
PANSS total	1.083	0.017	1.154	0.013
Care Giver Burden Schedule	1.117	1.047	1.192	0.001

The presence or absence of Psychological distress among the study population was determined using Self-reporting questionnaire 20. 15(37.50%) were found to have psychological distress and 25(62.5%) did not have distress. The odds of psychological distress were 1.073 times increase with each year increase age which was statistically significant (P value 0.044). The odds of psychological distress were 1.392 times increasing with each one hour increase in total caregiving giving time which was statistically significant (P value 0.039). The odds of psychological distress in caregivers was 1.087 times more in

patients who had negative symptoms compare to those with positive symptoms. The association was statistically significant (P value 0.045). The odds of psychological distress was 1.083 times increased with one unit increase in PANSS total score and was statistically significant (P value 0.013). The odds of psychological distress was 1.117 times increased with one unit increase in Care Giver Burden Schedule score which was statistically significant (P value 0.001). The remaining parameters have not shown any statistically significant association with psychological distress (P value > 0.05).

Table 3: Multivariate logistic regression analysis of factors associated with psychological distress (Self-reporting questionnaire 20) (N=322)

Parameter	Adjusted odds ratio	95% C.I. for the adjusted odds ratio		P value
		Lower	Upper	
Age	1.003	0.924	1.088	0.951
Total caregiving time (hours/day)	1.070	0.625	1.832	0.806
Negative Symptoms	0.988	1.851	1.146	0.870
PANSS total	1.060	0.962	1.168	0.237
Care Giver Burden Schedule	1.099	1.108	1.186	0.015

After adjusting for the effect of other variables in the equation, only one parameter had shown statistically significant association with psychological distress in the study. The odds of psychological distress was increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in caregiver burden schedule score.

Discussion

Caregiver characteristics

The current study which has evaluated the burden of caregivers using Burden assessment schedule (BAS) scale and the presence of psychological distress using Self-reporting questionnaire 20 (SRQ 20) was conducted in a tertiary care teaching hospital in South India. The mean age of the caregivers was 44.08 ± 12.12 years and 70% of caregivers were women. Majority of them were married and studied up to middle school and a major proportion of them were either unemployed or unskilled workers. In more than 50% of the cases, the caregiver was a spouse, and in the remaining cases, it was other family members. More than 80% of the study populations were from nuclear families. In a similar study done by Shah, S. T., et al.²⁰, the mean age of the caregivers was 45.44 ± 14.25 years, which was in accordance with the current study. Forty-two (84%) caregivers were males, and 8 (16%) were females. Twenty-eight (56%) were uneducated, 16 (32%) had Primary education, 4 (8%) were matriculates and 2 (4%), graduates. Thirty-four (68%) of the caregivers were married 8 (16% each unmarried and widows/widowers. Thirty-two (64%) were unemployed, and 18 (36%) were employed. These parameters differed slightly from the current study.

Disease-related characteristics

Among the study population, the mean duration of the schizophrenia was 8.8 ± 8.52 with the range of 2 to 40 years. The mean duration of caregiving was 7 ± 5.87 years and mean time of care giving per day was 7.63 ± 2.37 hours per day. Among the study population, 40(100%) had positive symptoms, 22(55%) had negative symptoms, and 39(97.50%) had general symptoms. The mean PANSS total of the study population was 57.30 ± 12.74 , and the mean caregiver burden schedule of the study population was 44.60 ± 18.44 . In the study by Kumar, C. N., et al.¹⁶ the mean (SD) duration of illness was 154.8 (119.5) months. Symptoms were mild at the time of assessment (Mean (SD) total PANSS score = $50.5(23.6)$), and they had a Mean (SD) total disability of 4.6 (4.2). In the study by Jagannathan, A., et al.¹⁵ the mean (SD) total burden of the caregivers (excluding spouses of the patient) was 80.02 (11.53), and the mean (SD) total burden of caregivers who were spouses of the patients was 74.94(11.27). The average BAS score was 1.94 (0.31). The mean PANSS (total) score was 58.5 (18.9). These studies were in according to ours.

Impact on caregivers

In the current study, 22(55%) had the moderate burden, and 18(45%) had a severe burden. The mean score of self-reporting questionnaire 20 of the study population was 8.78

± 3.98 . Among the study population, 15(37.50%) had psychological distress, and 25(62.50%) had no psychological distress. The stress level was assessed by using the Self Report Questionnaire (SRQ-20) with a cutoff score of 9 being taken as stressed. The study findings were similar to the study by Shah, S. T., et al.²⁰ 36 (72%) had psychological distress, and 14 (28%) had no psychological distress. In our study, 37.50% experienced distress whereas in the study by Shah, S. T., et al.²⁰ where 72% experienced distress. Which was high compared to the current study. Our study was in accordance with the study by Ong, H. C., et al.²¹ where 31.5% of the caregivers experienced psychological distress.

Factors associated with caregiver burden and distress

Jagannathan, A., et al.¹⁵ in their study of caregivers of 137 schizophrenia patients found that duration of illness and levels of psychopathology and disability had a significant direct correlation with total burden score; perceived social support had a significant inverse correlation with total burden score. There was a high correlation between psychopathology and disability ($p < 0.001$). Two separate regression analyses, each including total PANSS score (psychopathology) or total IDEAS score (disability) showed that duration of illness and perceived social support were significant predictors of burden in addition to psychopathology and disability.

Kumar C. N., et al.¹⁶ found in their study that level of burden had a significant direct correlation with disability (Pearson's $r = .35$; $p < .01$) and severity of psychopathology ($r = .21$; $p < .01$). Duration of treatment had an inverse correlation with burden (Pearson's $r = -.16$; $p < .01$). Multivariate analysis revealed that total Indian Disability Evaluation and Assessment Scale (IDEAS) score (Beta = $.28$; $t = 4.37$; $p \leq .01$), duration of treatment (Beta = $-.17$; $t = -2.58$; $p = .01$), age of the family caregiver (Beta = $.15$; $t = 2.4$; $p = .02$) and gender of the patient (Beta = $-.13$; $t = -2.1$; $p = .04$) were significant predictors of burden. The model including total IDEAS score explained 14% of variance (adjusted R (2) = $.139$; $p < .01$). The authors concluded that, Burden experienced by family caregivers of schizophrenia patients depends on the level of disability experienced by the patient, age of the family caregivers and gender of the patient.

This study had a number of strengths. There are barely any Indian studies that have looked at predictors of caregiver burden in first admission acute patients of schizophrenia. This study opens up to wider aspects of mental illnesses where caregivers may also face enormous challenge every day. We need to address the caregivers to help them in the continuum of care. Secondly, even though the study used cross sectional designs, the validated standardized tools were used in this study to establish severity of caregiver's distress and to assess disability and burden.

However, the study was not without limitations. The study was a cross sectional study; thus, the observed association could not be interpreted as causal inferences.

The study was a single centred with small sample size. Hence the study findings could not be generalized to the rest of the population. Purposive sampling technique was employed for the study which is not a true representation of the general population. And self-reported measures often involve response bias or social desirability bias.

Conclusions

Majority of the caregivers in the study were females, with minimal educational qualification and were the spouse of the patients, with parents and siblings involved in care in a minor proportion of the patients. The mean duration of caregiving was 7 ± 5.87 years and mean time of caregiving as 7.63 ± 2.37 hours per day. In the study, the prevalence of psychological distress was 37.50%. 22(55%) reported moderate burden and 18(45%) reported severe burden. High distress and burden were reported in our study. The most important predictive factor of psychological distress in caregivers was the severity caregiving burden. However, a further longitudinal study may provide a better insight on burden and distress among caregivers of schizophrenia.

Conflict of interest

Nil.

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