

## A Cross Sectional Study Assessing the Psychological Distress and Caregiver Burden among Care Givers of Schizophrenia Patients

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Conflict of interest: Nil

### Abstract

**Aim:** The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

**Methods:** The cross-sectional study conducted in the Department of Psychiatry. A total of 100 subjects were included in the analysis. Primary Caregivers of psychiatric inpatients and outpatients in Jay Prabha Medanta Hospital, Patna, Bihar, India 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.

**Results:** The majority of patients were female (68%). 85% were married. The majority of the patients had low educational level with 12% of them being illiterate and 35% of the patients were unemployed. 90% were in the nuclear family. The odds of psychological distress were 1.075 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 were 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 presence or absence of psychological distress among the study population was determined using Self-reporting questionnaire 20. 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.

**Conclusion:** Caregivers of schizophrenic patients suffered from significant burden. It thus becomes important to plan interventions that would reduce their burden of care and thus improving their psychological well-being.

**Keywords:** Family, Caregivers, Psychological stress, Schizophrenia.

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### 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. [1] Schizophrenia is one such psychiatric illness, which is reported to result in heavy burden and psychological distress in various settings. [2,3] 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]

Caregivers also tend to experience social problems because of the people around them. Magaña et al [4] found that perceived stigma and symptoms of depression among caregivers were significantly

associated. Struening et al [5] reported that society often relates serious mentally ill patients with violence and ~70% of the respondents included in their study believed that such patients were dangerous. This leads to a stereotype and discrimination against caregivers making it even more difficult for them to seek help and support from others. It could also result in symptoms of serious distress such as depression, sadness, anxiety, physical disorder, and demoralization to the stigmatized person. In the face of the psychological distress and societal problems, although some of these strategies help reduce their burden or stress, others are not particularly helpful. Kausar and Powell [6] found that the caregivers of patients with neurological disorders who used emotional coping experienced higher distress than those who used problem coping.

There are very limited numbers of studies available on the subject in the Indian population. Jagannathan, A. et al [7] 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 [8] 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. Caregivers often encounter increased psychological stress due to financial, psychological, and social demands of chronically ill patients [9-11] Psychological stress is conceptually defined as a "unique, discomforting, emotional state experienced by an individual, in response to a specific stressor or demand, that results in harm, either temporary, or permanent, to the person". [12] Depression is more frequently reported by caregivers of patients with chronic mental illness. [13] Caregivers who have a persistent high stress level are more likely to have a lower quality of life and greater physical health risks in comparison with the general population. [14,15]

The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

### Materials and Methods

The cross-sectional study conducted in the Department of Psychiatry, Jay Prabha Medanta Hospital, Patna, Bihar, India for six months A total of 100 subjects were included in the analysis. Primary Caregivers of psychiatric inpatients and outpatients in Jay Prabha Medanta Hospital, Patna, Bihar, India 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. 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. [16]
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. [17]
3. PANSS (Positive and Negative symptom scale). [18] This consist of 3 dimensions-Positive symptoms, Negative Symptoms and General symptoms to assess the severity of symptoms in patients with schizophrenia.

### 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

**Table 1: Socio-demographic parameters of study population**

Demographic parameter	Mean/Frequency	SD/Percentage
Age (Mean $\pm$ STD)	46.04	$\pm$ 14.16
<b>Gender</b>		
Male	32	32
Female	68	68
<b>Marital status</b>		
Married	85	85
Unmarried	15	15
<b>Education</b>		
Middle School	36	36
Primary School	32	32
High School	20	20
Illiterate	12	12
<b>Occupation</b>		
Unemployed	35	35
Unskilled Worker	33	33
Employed	32	32

Family type		
Joint	10	10
Nuclear	90	90

The majority of patients were female (68%). 85% were married. The majority of the patients had low educational level with 12% of them being illiterate and 35% of the patients were unemployed. 90% were in the nuclear family.

**Table 2: Univariate logistic regression analysis factors associated with psychological distress in the study population**

Parameter	Odds ratio	95% CI		P value
		Lower	Upper	
Age	1.075	1.002	1.149	0.044
<b>Gender (baseline= Male)</b>				
Female	2.250	0.499	10.143	0.291
<b>Marital status (baseline = Married)</b>				
Unmarried	1.128	0.166	7.665	0.902
<b>Education (base line= Illiterate)</b>				
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
<b>Occupation (baseline= Unemployed)</b>				
Unskilled Worker	1.125	0.236	5.371	0.883
Employed	1.125	0.236	5.371	0.883
<b>Patient primary earning member of the family (Baseline=No)</b>				
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
<b>Type of symptoms</b>				
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 odds of psychological distress were 1.075 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 were 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)**

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

The presence or absence of Psychological distress among the study population was determined using

Self-reporting questionnaire 20. 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 were 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

Psychological distress is defined as the discomfort of a patient while experiencing symptoms of disorders or anxiety before and after treatment.<sup>19</sup> It refers to the context of strain, stress, and distress. Past research often described it as an emotional suffering condition with symptoms of depression and anxiety. [20,21] These symptoms can range from a person showing disinterest, feeling sad, or losing hope to depression, anxiety, nervousness followed by some somatic symptoms such as headache, fatigue, and insomnia. [22] Psychological distress is not merely associated with the inability to conduct daily chores, but it is also a measure of the other psychiatric disorder symptoms, such as major depression and generalized anxiety disorder. [23] Caregivers also tend to experience social problems because of the people around them.

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. The majority of patients were female (68%). 85% were married. The majority of the patients had low educational level with 12% of them being illiterate and 35% of the patients were unemployed. 90% were in the nuclear family. In a similar study done by Shah, S. T., et al. [24], the mean age of the caregivers was  $45.44 \pm 14.25$  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.

Among the study population, the mean duration of the schizophrenia was  $8.8 \pm 8.52$  with the range of 2 to 40 years. The mean duration of caregiving was  $7 \pm 5.87$  years and mean time of care giving per day was  $7.63 \pm 2.37$  hours per day. The mean PANSS total of the study population was  $57.30 \pm 12.74$ , and the mean caregiver burden schedule of the study population was  $44.60 \pm 18.44$ . In the study by Kumar, C. N., et al. [25] 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 [28] 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. The odds of psychological distress were 1.075 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 were 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).

Jagannathan, A., et al. [26] 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. The presence or absence of Psychological distress among the study population was determined using Self-reporting questionnaire 20. 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 were increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in caregiver burden schedule score.

Kumar C. N., et al. [25] 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;  $t = 4.37$ ;  $p < .01$ ), 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.

### Conclusion

Caregivers of schizophrenic patients suffered from significant burden. It thus becomes important to plan interventions that would reduce their burden of care and thus improving their psychological well-being. 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 further longitudinal study may provide a better insight on burden and distress among caregivers of schizophrenia.

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