

# A Prospective Assessment of the Psychological Distress and Caregiver Burden Among Care Givers of Schizophrenia Patients

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## Abstract

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

**Material & Methods:** The study sample consisted of 60 patients with schizophrenia and their caregivers who were randomly selected from the Darbhanga Medical College & Hospital's OPD, Laheriasarai, Darbhanga, Bihar, India. The study relied on the Burden Assessment Schedule and the General Health Questionnaire-12.

**Results:** Our research also found that 45.76 percent of caregivers were under a lot of stress. Caregivers of patients with low education levels reported a higher level of stress. Parents and spouses had a moderately greater amount of stress, whereas siblings had the highest level of stress. Parents had more psychological distress than spouses and siblings. Caregivers with a higher level of psychological stress were found to have a greater burden of caregiving.

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

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

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## Introduction

Schizophrenia is a disabling, chronic mental disorder that gives rise to numerous challenges in its management and consequences. [1] It has a significant cost to the patient in terms of personal suffering, to the caregiver as a result of the shift of care burden from the hospital to the family, and to society as a whole in terms of significant direct and indirect costs, such as frequent hospitalizations and the need for long-term psychosocial and economic support, as well as lost productivity throughout one's life. [2]

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. [3]

Schizophrenia is one such psychiatric illness, which is reported to result in heavy burden and psychological distress in various settings. [4, 5, 6] The addition of the caregiving duty to other responsibilities causes physical, psychological, and financial stress. [7]

Relatives of the patient experience a wide range of emotions, ranging from loss and grief to guilt and anger. They also perceive themselves to be isolated and stigmatized. [8]

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. [9]

However, drawing comparisons between studies conducted in different settings is difficult due to wide variations in the tools and methods used to assess the psychological impact and caregiver burden. Furthermore, because of the vast variances in stigma, cultural characteristics, and sociodemographic profile of persons across different locations, it is critical to gather research on local communities in order to build culture-specific therapies. As a result, the current study was conducted with the goal of determining the correlates of caregiver burden among caregivers of schizophrenia patients & to assess the psychological well-being of caregivers of patients with schizophrenia in a hospital in Bihar.

#### **Material and Methods:**

After receiving ethical approval from the institution, this cross-sectional investigation was conducted in the Department of Psychiatry, Darbhanga Medical College & Hospital, Laheriasarai, Darbhanga, Bihar, India for 1 year. The study looked at 60 main caregivers who routinely accompanied patients who had been diagnosed with schizophrenia using the ICD-10 DCR criteria. [10]

#### **Inclusion criteria:**

A random selection was made, if the following inclusion criteria were satisfied.

#### **For patients:**

- Age range 18-65 years.
- Diagnosis of schizophrenia as per the ICD-10 DCR criteria. [10]
- At least 1 year duration of illness.
- Clinical stability for a minimum period of 3 months before study. (It was defined as no major changes in medication and no hospitalization in the 3 months preceding the intake of the patients in the study.)

#### **For caregivers:**

- Age >18 years
- Any family member (first degree relative like 'parents, siblings, off springs', or spouse or others) who assist the patient in their daily functions, performing their medical monitoring and treatment, and meeting their needs and who look after the patient as priority work but who do not perform this work as a professional job.
- Duration of care should be at least 1 year.

#### **Exclusion criteria**

- Patients with any chronic physical illness or any co-morbid substance use disorder were excluded.
- Caregivers with any intellectual disability or any disease that could affect their cognitive or mental functions.

#### **Data Collection:**

Patients and caregivers who met the criteria were questioned over the course of a year after giving their written informed consent. Socio demographic and clinical data was recorded using the data sheet which was prepared for noting down the socio-demographic details of the patients and caregivers. The Burden Assessment Schedule (BAS) was used to assess caregiver burden. [12] The mental problem was assessed using General health questionnaire 12 (GHQ12 Scale). [13]

**Statistical Analysis:**

The collected data was entered in Microsoft-Excel 2016 and converted into SPSS 22.0 for statistical analysis. Descriptive statistics were analyzed using mean, standard deviation, number and percentage while for inferential statistics One-way Anova, Independent t-test and Pearson correlation was used.  $P < 0.05$  was considered statistically significant.

**Results:**

The sociodemographic characteristics of the patients and care givers are shown in Table 1. 55.0 percent of the patients were between the ages of 20 and 29. Males made up the majority of the patients (58.3 percent). The majority of the patients were uneducated, with 28.3% of them being illiterate; 71.6 percent of the patients came from a rural background, while 28.3 percent came from an urban background; and 75.0 percent of the patients were unemployed. 45.0 percent of care givers were above the age of 50, while 33.3 percent were between the ages of 40 and 49. Male care givers made up 55.0 percent of the total, with female caregivers accounting for 43.3 percent of the total; 66.6 percent of caregivers were employed.

The duration of caregiving is shown in Table 2. The majority of the patients had been receiving care for less than ten years, with 60.0 percent receiving care for less than five years.

Table 3 illustrates the relationship between sociodemographic factors and caregiver load. There was a statistically significant difference in caregiver burden and educational status ( $P = 0.001$ ), indicating that caregivers who were illiterate had a higher level of burden than caregivers with a primary level of education or higher. There was no statistically significant relationship between caregivers' age and their level of burden. The level of burden experienced by male and female caregivers

did not differ statistically significantly. The level of burden experienced by urban and rural caregivers did not differ statistically significantly.

Table 4 depicts the relationship between sociodemographic characteristics and caregiver's psychological well-being. Caregivers with a higher educational status have a better quality of life, with a mean GHQ score of 14.21 2.78 for illiterate caregivers and 12.65 2.70 for graduate and above. There was no statistically significant relationship between caregiver's psychological well-being and their age. In terms of psychological well-being, there was no statistically significant difference between urban and rural caregivers. There was no statistically significant relationship between caregiver's psychological well-being and their age.

Table 5 depicts the burden distribution based on the caregiver's relationship with the patient and the average length of caregiving. Siblings were burdened more than parents, spouses, and others, and this difference was statistically significant. There was no link between caregiver burden and the length of time they were providing care.

Table 6 shows the distribution of psychological well-being based on caregivers' relationship with the patient and the average length of time spent caring for them. Parents had more psychological stress than spouses and siblings, and the difference was statistically significant. There was no link between caregiver's psychological well-being and the length of time they spent caring for them.

Table 7 indicates the relationship between caregiver's psychological well-being and their burden. Caregiver load has a statistically significant positive relationship with psychological stress.

**Table 1: Sociodemographic data of patients and caregivers.**

Variables	No of Patients(n=60)	Percentage (%)	No of caregivers (n=60)	Percentage (%)
Age(years)				
20-29	33	55.0%	7	11.6%
30-39	12	20.0%	6	10.0%
40-49	10	16.6%	20	33.3%
≥ 50	5	8.3%	27	45.0%
Gender				
Male	35	58.3%	34	56.6%
Female	25	41.6%	26	43.3%
Education				
Illiterate	17	28.3%	25	41.6%
Primary	10	16.6%	10	16.6%
middle	8	13.3%	8	13.3%
Inter	15	25.0%	5	8.3%
Graduate and above	4	6.6%	9	15.0%
Residence				
Urban	17	28.3%	12	20.0%
Rural	43	71.6%	48	80.0%
Occupation				
Employed	15	25.0 %	40	66.6%
Un employed	45	75.0%	20	33.3%

**Table 2: Duration of caregiving.**

Duration of caregiving (years)	No of caregivers (n=60)	Percentage (%)
0-5	36	60.0%
6-10	17	28.3%
>10	7	11.6%

**Table 3: Correlations between caregiver sociodemographic variable and burden.**

Variables	Mean BAS ± SD	statistical significance
Age(years)		
20-29	87.00 ± 12.87	f=0.956, P = 0.542
30-39	89.12 ± 17.32	
40-49	85.65 ± 8.27	
>50	80.10 ± 19.21	
Gender		
Male	83.87 ± 9.76	t=0.976, P = 0.429
Female	80.20 ± 19.55	
Education		
Illiterate	82.87 ± 11.54	f=8.769, P < 0.001*
Primary	89.2 ± 8.78	
Secondary	92.65 ± 10.65	
Sr. Secondary	90.43 ± 10.87	
Graduate and above	69.34 ± 14.34	

Residence		
Urban	85.29 ± 10.67	t=1.809, P = 0.156
Rural	73.76 ± 16.80	

\*p < 0.05 considered statistically significant

**Table 4: Relationship between sociodemographic characteristics and caregiver's psychological well-being**

Variables	Mean GHQ ± SD	Percentage (%)
Age(years)		
20-29	15.98 ± 4.5	f=1.657, P = 0.337
30-39	14.78 ± 1.43	
40-49	15.09 ± 2.78	
>50	19.45 ± 5.87	
Gender		
Male	13.46 ± 2.67	t=0.340, P = 0.871
Female	13.27 ± 2.14	
Education		
Illiterate	14.21 ± 2.78	f=4.519, P = 0.004*
Primary	17.66 ± 5.76	
Secondary	17.67 ± 3.01	
Sr. secondary	18.00 ± 2.90	
Graduate and Above	12.65 ± 2.70	
Residence		
Urban	14.78 ± 3.00	t = 1.546, P = 0.189
Rural	16.89 ± 3.54	

\*p < 0.05 considered statistically significant.

**Table 5: Correlation of burden on basis of caregiver's relationship with the patient and duration of care.**

Variables	Mean BAS ± SD	Percentage (%)
Parents	79.21 ± 16.89	f = 4.129, P = 0.007*
Spouse	75.43 ± 8.2	
Sibling	97.44 ± 7.90	
Others(son/daughter)	80.87 ± 2.5	
Mean duration of caregiving 6.46 ± 5.64	83.56 ± 18.76	r = 0.011, p = 0.876

\*p < 0.05 considered statistically significant.

**Table 6: Correlation of GHQ on basis of caregiver's relationship with the patient and duration of care.**

Variables	Mean GHQ ± SD	Percentage (%)
Parents	17.32 ± 5.76	
Spouse	15.98 ± 5.67	f=4.671, P = 0.013*
Sibling	17.34 ± 1.89	
Others(son/daughter)	13.78 ± 1.56	
Mean duration of caregiving 6.46 ± 5.64	13.0 ± 23.44	r=0.05, p=0.332

\*p < 0.05 considered statistically significant.

**Table 7: Correlation of GHQ on basis of caregiver's burden.**

Variables	Mean GHQ $\pm$ SD	Percentage (%)
Mean BAS of caregiving 80.65 $\pm$ 12.65	16.78 $\pm$ 3.45	r=0.432, p=0.00*
*p < 0.05 considered statistically significant.		

**Discussion:**

The increasing involvement in caring for the patient had a negative influence on the caregiver's own health, and caregivers said that they spent less time on taking care of themselves as a result of their greater involvement in caring for the patient. In both Indian [13, 14] and Western contexts [15], the same findings have been found in research literature on careers.

The majority of the patients in the study were male and had a low level of education. The majority came from a rural background, and the majority were unemployed, indicating the occupational and functional damage caused by such a long-term mental illness. The majority of the caretakers were working men.

Jagannathan, A., et al 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. [16]

The fact that caregivers of patients with schizophrenia experience substantial burden has been shown in several previous studies. [17, 18, 19]

The mean burden score in the caregivers was  $83.56 \pm 18.76$  years. Of the caregivers, 59.60% experienced moderate

levels of burden whereas 46.81% experienced severe burden the mean score of  $83.56 \pm 18.76$  indicating severe burden is similar to the findings of Mishra et al. and Ram Mohan et al. [20, 21]

Caregivers of patients with low education levels reported a higher level of stress.

Parents and spouses reported a moderately greater level of hardship, similar to Ram Mohan et al findings by Ram Mohan et al whereas siblings reported the highest amount of burden. This could be because all of the siblings were brothers with their own families to care for. This could explain why they are feeling more burdened than usual.[21]

Caregivers of persons with schizophrenia experience more stress due to the nature of the symptoms as well as the prolonged duration of illness. Caregivers with higher educational level experienced better psychological well-being than caregivers who were illiterate, a finding similar to similar to a study by Ukpong et al. [22] Parents had greater psychological stress as compared to spouses and siblings and it was statistically significant which is in contrast to the studies done by It may be explained by the possibility that parent caregivers face issues such as uncertainty regarding patient's future, and have concerns as to who will take over caregiving responsibilities. Caregivers with higher psychological stress found to have a heavier caregiving burden which is in accordance with the previous studies. [24] Duration of illness which coincided with duration of care was not associated with psychological well-being. This finding was also reflected in a previous study done by McClure et al. [23]

Because the research was cross-sectional, the findings could not be regarded as causal inferences. The research was conducted in a single center with a modest sample size. As a result, the findings of the study could not be applied to the remainder of the population. The study used a purposeful sampling technique, which is not a realistic reflection of the general population.

### Conclusion:

Our study found high levels of burden and severe psychological stress among caregivers of patients with schizophrenia, which is consistent with earlier research. The majority of caregivers experienced moderate to severe levels of strain, according to the survey. Burden was much higher among caregivers with lower levels of education, despite the fact that age and gender had no effect on burden.

Siblings had the highest amount of load, followed by parents and spouses, and the level of burden was unrelated to the length of care. Psychological well-being was also shown to be lowest in older caregivers and those with a lower educational level. There was a strong positive relationship between caregiver load and psychological stress, indicating that a higher level of caregiver burden may have resulted in poor psychological well-being.

The level of caregiving load was the most important predictor of psychological discomfort among carers. However, a longer-term study could shed more light on the difficulty and distress experienced by caretakers of people with schizophrenia.

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