

A Study of Psychological Stress and Burden on Caregivers of Schizophrenic Patients

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ABSTRACT

Introduction: Schizophrenia is a chronic severe mental illness which not only affects patients but also causes significant burden and stress to the caregivers. There is definite lack of studies in India exploring caregiver burden and psychological stress. Study objective was to assess psychological stress and burden on caregivers of schizophrenic patients.

Material and methods: The study sample included 52 patients with a diagnosis of schizophrenia and their caregivers, randomly selected from the patients coming to the OPD of two tertiary care centres in Bareilly, as per inclusion and exclusion criteria. Burden Assessment Schedule and General health questionnaire-12 were used for the study.

Results: Our study also shows that 42.31% caregivers experienced severe burden. Caregivers of patients with low levels of education reported greater burden. Parents and spouses reported moderately higher level of burden, but siblings reported highest level of burden. Parents had greater psychological stress as compared to spouses and siblings. Caregivers with higher psychological stress found to have heavier caregiving burden.

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: Caregiver, Burden, Schizophrenia, Stress

no choice.⁷

The key carer is seen as the person who provides the most support of patient, often devoting substantial numbers of hours each day towards taking care of the patient.⁸ Caregiver burden has thus been defined as “a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arises of taking care of the patients.”⁹ Burden has mainly two elements – objective and subjective. Objective burden refers to the quantifiable challenges faced by the family members in everyday life such as financial costs, loss of free time and altered social relationships. Subjective burden refers to the abstract or emotional cost faced by the family as a result of the patient’s illness.¹⁰

Caregivers often encounter increased psychological stress due to financial, psychological, and social demands of chronically ill patients.¹¹⁻¹³ Psychological stress is conceptually defined as a “unique, discomfiting, 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”.¹⁴ Depression is more frequently reported by caregivers of patients with chronic mental illness.¹⁵ 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.^{16,17}

Caregiver burden and psychological well-being need to be

INTRODUCTION

Schizophrenia is a disabling, chronic mental disorder that gives rise to numerous challenges in its management and consequences. It exerts a significant cost to the patient in terms of personal suffering, on the caregiver as a result of the shift of burden of care from hospital to families, and on society at large in terms of significant direct and indirect cost that include frequent hospitalizations and need for long-term psychosocial and economic support, as well as life-time lost productivity.¹ Patient’s relatives feel wide range of emotions, from loss and grief to guilt and anger. They also feel secluded and stigmatized.² The addition of the caregiving role to already existing roles becomes stressful physically, psychologically and financially.³

Caregivers are often bound by kinship commitments to take up certain duties and responsibilities that are far in excess of those normally associated with a family role at a particular stage.⁴⁻⁶ If caregiving is prolonged (and in many health conditions, it can last until one of the pair dies), problems can be aggravated, situation may not get better with time. A further difficulty is that caregivers find that they are left with

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assessed to develop strategies to aid in caregiving. This study aims to evaluate the psychological well-being and burden in caregivers of the patients with schizophrenia.

The present study was conducted on primary caregivers of patients with schizophrenia. The study aimed to assess:

- To assess the burden of care in caregivers of patients with schizophrenia.
- To assess the psychological well-being of caregivers of patients with schizophrenia.

MATERIAL AND METHODS

This cross-sectional, multi-centric study was done in the Psychiatry OPD of two Tertiary Care Hospitals in Bareilly after the ethical approval from the institution. Study was done on 52 primary caregivers regularly accompanying patients diagnosed as having schizophrenia as per the ICD-10 DCR criteria.¹⁸

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 criteria¹⁸
- 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 comorbid substance use disorder were excluded
- Caregivers with any intellectual disability or any disease that could affect their cognitive or mental functions.

Data collection: Over a period of 1 year, patients and corresponding caregivers who satisfied the criteria were interviewed after obtaining their written informed consent. The data were recorded and further aspects were studied as described below.

Tools

1. **Socio demographic and clinical data sheet (self-prepared):** The data sheet was prepared for noting down the socio-demographic details of the patients and caregivers like- name, age, sex, marital status, religion, education level, occupation, background, state, socio-economic status, income, type of family as well as clinical details like- duration of illness, age of onset of

illness, mode of onset of illness, precipitating factors, current diagnosis, past history of medical and psychiatric illness, family history of medical and psychiatric illness, duration of care, etc.

2. **Burden Assessment Schedule¹⁹:** The Burden Assessment Schedule (BAS) was developed at the schizophrenia Research Foundation, Chennai, India, to assess caregiver burden. The scale was developed using the stepwise ethnographic exploration method, to develop items that are contextual and reflected opinions of the caregivers themselves rather than those of the researchers. There are 40 items that are rated on a three-point scale, marked 1–3. Some of the items are reverse-coded. The score ranges from 40 to 120, with higher scores indicating higher burden. The BAS had been validated against the family burden schedule of Pai and Kapur²⁰ and the correlations ranged from 0.71 to 0.82 for most items.
3. **General health questionnaire 12(GHQ12 Scale)²¹:** The 12-Item General Health Questionnaire (GHQ-12) consists of 12 items, each one assessing the severity of a mental problem over the past few weeks using a 4-point Likert-type scale (from 0 to 3). The score was used to make a total score ranging from 0 to 36. The positive items are corrected from 0 (always) to 3 (never) and the negative ones from 3 (always) to 0 (never). High scores indicate worse health.

STATISTICAL ANALYSIS

The collected data was entered in Microsoft-Excel 2016 and converted into SPSS 22.0 for statistical analysis. Descriptive statistics were analysed 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.

RESULT

Table 1 shows the sociodemographic characteristics of the patients and caregivers. Among patients, 57.69% were aged between 20 and 29 years. The majority of patients were male (61.54%). The majority of the patients had low educational level with 26.92% of them being illiterate; 80.77% patients were from rural background, 19.23% were from urban background; 76.92% of the patients were unemployed. Among caregivers, 46.15% were aged 50 years or above whereas 34.62% were aged between 40-49 years. The majority of caregivers were male (57.69%) with 42.31% of the caregivers being female; 73.08% of the caregivers were employed.

Table 2 shows the duration of caregiving. Majority of the entire patients had been provided care for less than 10 years with 53.85% of them having provided cared for less than 5 years.

Table 3 shows the correlation between sociodemographic variables and level of burden in caregivers. Statistically significant difference was found in the level of burden and educational status of the caregivers (P < 0.001) i.e.

Variables	No of Patients(n=52)	Percentage (%)	No of caregivers (n=52)	Percentage (%)
Age(years)				
20-29	30	57.69%	6	11.54%
30-39	10	19.23%	4	7.69%
40-49	8	15.38%	18	34.62%
≥ 50	4	7.69%	24	46.15%
Gender				
Male	32	61.54%	30	57.69%
Female	20	38.46%	22	42.31%
Education				
Illiterate	14	26.92%	20	38.46%
Primary	8	15.38%	8	15.38%
middle	8	15.38%	8	15.38%
Inter	16	30.77%	6	11.54%
Graduate and above	6	11.54%	10	19.23%
Residence				
Urban	10	19.23%	10	19.23%
Rural	42	80.77%	42	80.77%
Occupation				
Employed	12	23.08%	38	73.08%
Un employed	40	76.92%	14	26.92%

Table-1: Sociodemographic data of patients and caregivers.

Duration of caregiving (years)	No of caregivers (n=52)	Percentage (%)
0-5	28	53.85%
6-10	16	30.77%
>10	8	15.38%

Table-2: Duration of caregiving.

Variables	Mean BAS ± SD	statistical significance
Age(years)		
20-29	83.00 ± 10.16	f=0.924, P = 0.436
30-39	84.0 ± 16.17	
40-49	83.33 ± 7.56	
>50	77.5 ± 15.39	
Gender		
Male	82.06 ± 8.51	t=0.939, P = 0.352
Female	78.72 ± 16.79	
Education		
Illiterate	79.80 ± 9.54	f=8.947, P < 0.001*
Primary	86.0 ± 7.17	
Secondary	90.25 ± 9.26	
Sr. Secondary	88.33 ± 9.64	
Graduate and Above	65.80 ± 12.76	
Residence		
Urban	83.33 ± 10.42	t=1.609, P = 0.127
Rural	69.40 ± 15.42	

*p < 0.05 considered statistically significant.

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

caregivers who were illiterate had higher level of burden than caregivers who had primary level of education and above. No statistically significant difference was found between the age of the caregivers and the level of burden. No statistically significant difference was found in the level of

Variables	Mean GHQ ± SD	Percentage(%)
Age(years)		
20-29	12.33 ± 3.14	f=1.462, P = 0.237
30-39	11.50 ± 0.58	
40-49	13.67 ± 2.11	
>50	13.75 ± 2.57	
Gender		
Male	13.46 ± 2.67	t=0.280, P = 0.780
Female	13.27 ± 2.14	
Education		
Illiterate	13.90 ± 1.97	f=4.456, P = 0.004*
Primary	14.75 ± 3.57	
Secondary	13.00 ± 1.85	
Sr. secondary	14.33 ± 1.86	
Graduate and Above	11.00 ± 1.33	
Residence		
Urban	12.40 ± 2.06	t=1.433, P = 0.158
Rural	13.61 ± 2.48	

*p < 0.05 considered statistically significant.

Table-4: Correlations between caregiver sociodemographic variable and GHQ.

burden between male and female caregivers. No statistically significant difference was found in the level of burden between urban and rural caregivers.

Table 4 shows the correlation between sociodemographic variables and their psychological well-being in caregivers. Caregivers with higher educational status experience better well-being with mean GHQ score for illiterate caregivers being 13.90 ± 1.97 whereas that for graduate and above was 11.00 ± 1.33 . No statistically significant difference was found between psychological well-being and age of the caregivers. No statistically significant difference was found in the psychological well-being between urban and

Variables	Mean BAS ± SD	Percentage (%)
Parents	77.80 ± 14.03	f=4.429, P = 0.008*
Spouse	77.33 ± 7.81	
Sibling	92.60 ± 6.38	
Others(son/daughter)	78.33 ± 1.36	
Mean duration of caregiving 6.46 ± 5.64	80.65 ± 12.65	r=0.010,p=0.946
*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 GHQ ± SD	Percentage(%)
Parents	14.26 ± 2.30	
Spouse	12.0 ± 3.22	f=3.825, P = 0.016*
Sibling	12.60 ± 1.83	
Others(son/daughter)	11.66 ± 1.36	
Mean duration of caregiving 6.46 ± 5.64	13.38 ± 2.44	r=0.07,p=0.493
*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(%)
Mean BAS of caregiving 80.65 ± 12.65	13.38 ± 2.44	r=0.473,p=0.00*
*p < 0.05 considered statistically significant.		
Table-7: Correlation of GHQ on basis of caregiver's burden.		

rural caregivers. No statistically significant difference was found between the psychological well-being and age of the caregivers.

Table 5 shows the distribution of burden on the basis of caregiver's relationship with the patient and mean duration of caregiving. The level of burden was higher among siblings than among parents, spouse and others and it was statistically significant. There was no significant correlation between duration of caregiving and burden among caregivers.

Table 6 shows the distribution of psychological well-being on the basis of caregivers' relationship with the patient and mean duration of caregiving. Parents had greater psychological stress as compared to spouses and siblings and it was statistically significant. There was no significant correlation between duration of caregiving and psychological well-being among caregivers.

Table 7 shows the correlation between psychological well-being and burden among caregivers. Caregiver burden is positively correlated with psychological stress and it is statistically significant.

DISCUSSION

The majority of patients in the study were male with lower educational status. Majority of them were from rural background and most of them were unemployed, which

indicates the occupational and functional impairment caused by such a long standing mental illness. Most of the caregivers were male and employed. Among 52 caregivers, 30 (57.69%) were parents, 10 (19.23%) were spouses, 6(11.54%) were siblings and 6(11.54%) were others(son/daughter). The average duration of caregiving corresponded with the duration of illness in the patient, indicating that these caregivers were the stable and long-term providers of care.

Providing care to the patient had a deleterious impact on the caregiver's own health, and caregivers stated that they spent lesser time on taking care of their own health due to increased involvement in caring for the patient. The same findings have been reported in research literature on caregivers in both Indian context^{22,23} and Western settings.²⁴

The fact that caregivers of patients with schizophrenia experience substantial burden has been shown in several previous studies.^{16,25,26} The mean burden score in the caregivers was 80.65 ± 12.65 years. Of the caregivers, 57.69% experienced moderate levels of burden whereas 42.31% experienced severe burden. The mean score of 80.65 ± 12.65 indicating severe burden is similar to the findings of Mishra et al. and Rammohan et al.^{26,27} Caregivers of patients with low levels of education reported greater burden.²⁷ Parents and spouses reported moderately higher level of burden, a finding similar to that reported by Rammohan et al.²⁷ but siblings reported highest level of burden. This may be due to the fact that all the siblings were brothers and had their own family to look after. This may be the reason for the additional level of burden perceived by them.

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.²⁸ 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 studies²⁹ 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 McCleery et al.³⁰

CONCLUSION

Consistent with the previous research literature, our study shows high levels of burden and significant psychological stress among caregivers of patients with schizophrenia. The study concluded that majority of the caregivers had moderate to severe levels of burden. Burden was significantly higher among caregivers with lower levels of education whereas age and gender exerted no significant effect on burden. The

burden was significantly higher among siblings followed by parents and spouses, and the level of burden was not correlated with the duration of care. It was also found that psychological well-being was lowest in older caregivers and those with lower educational level. There was significant positive correlation between burden and psychological stress, thus showing that a higher level of burden in caregivers could have resulted in poor psychological well-being.

One limitation of the present study was that it was carried out in tertiary care hospitals and that are mainly catering rural population hence the results cannot be generalized to the population at large. The size of the sample was small and a larger sample size is required to get more generalized findings.

The evidence relating to dealing with caregiving issues convincingly demonstrates the usefulness of family-based interventions in lessening negative outcomes for caregivers. While the focus of clinical intervention has been on the patient, this tends to disregard the needs of caregivers with no supportive intervention strategies put in place to enable them deal effectively with the demands and challenges encountered in caregiving. There is also evidence that social support is a major issue that influences the burden perceived by caregivers. We are of the view that clinical settings such as the one where this study was done need to have an active caregivers management plan that begins once a patient is registered for treatment. At the least, this could incorporate a family psychoeducation approach combined with facilitating participation in a peer support group. These measures would provide the necessary care and support that caregivers of patients with schizophrenia currently lack in the Indian context.

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