

Original Article

CAREGIVER BURDEN IN PATIENTS WITH SCHIZOPHRENIA

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Abstract

Background: Schizophrenia is a chronic psychiatric disorder. It imposes high level of burden on the caregivers who look after those patients. Previous studies tried to point out various factors which effected caregiver's burden. Burden Assessment Schedule (BAS) is an Indian tool to assess severity of burden in chronic mentally ill patients. **Aims & objectives:** to measure caregiver burden of patients with schizophrenia and to find out its various determinants in Bengali culture. **Methodology:** Consecutive 30 OPD patients fulfilling ICD-10 DCR criteria for schizophrenia and their caregivers, fulfilling inclusion and exclusion criterion were interviewed for socio-demographic data. Caregiver burden was measured on Burden Assessment Schedule. Collected data was assessed for statistically significant relation between socio-demographic variables and severity of burden. **Results:** Adjusted total score of burden was 64.26(\pm 7.68). Statistically significant ($p < 0.05$) relation was found between caregivers' burden and their distribution of sex ($p = 0.013$), educational status ($p = 0.006$), family type ($p = 0.002$) and residence ($p = 0.002$). There was no significant relationship found between severity of burden and caregiver's socio-economic status, marital status, religion, occupation and with their relationship with patient ($p > 0.05$) **Conclusion:** Caregivers of patients with schizophrenia suffer from high level of burden. Sex, education, family type, residence and duration of illness are statistically related to severity of burden.

Key word: schizophrenia, caregiver, burden assessment schedule, burden

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Introduction

Schizophrenia is a chronic psychiatric disorder that affects around 0.3–0.7% of people at some point in their life time.¹ Due to deinstitutionalization of psychiatric disorders and lack of trained human resources and infrastructure, psychiatric disorders, also schizophrenia, are now mostly taken care of by family members and by close relatives.² Caregiver burden, the subjective stress, which is perceived by those family members and close relatives due to the home care situation, is one of the most important predictors for negative outcomes of the care situation, both for themselves as well as for their patients. Researcher³ tried to divide caregiver burden into two dimensions, objective, and subjective burden and tried to find out predominant determinants of them. Where objective burden refers to effects on the household including financial loss, effects on family routine and the abnormal behaviors of the patient, subjective burden refers to impact on health, risk of mortality and caring style of the caregiver.^{4,5} Caregiver, who must look after patient with schizophrenia, poses significant burden in their financial, physical and on mental health and in other areas of functioning.⁶ Various factors, supported by previous studies⁷⁻¹⁰, were showed to play significant role behind caregivers' burden of patients with schizophrenia, include gender, relationship with patient, personality characteristics, social support, degree of social labeling, socioeconomic and cultural characteristics, and quality, accessibility of psychological health services, etc. Cultural factors, social support system and availability of adequate health infrastructure have shown to influence caregiver burden. As those factors are different for different countries, determinants of caregiver burden can't be generalized.^{11,12} Our study was aimed to measure caregiver burden of patients with schizophrenia and to find out its various determinants in Bengali culture.

Materials and Methods

This hospital based cross-sectional study was conducted in the psychiatry department of a medical college and hospital in Kolkata, India on outpatient basis in the year 2018. The study was conducted after getting approval from the ethical committee of the hospital. Consecutive thirty (n=30) schizophrenia patients of either sex according to ICD-10-DCR diagnostic criterion were selected and their caregivers were interviewed after fulfilling prefixed inclusion and exclusion criterion.

Inclusion criterion for patients were -1) age ≥ 18 years, 2) duration of illness 1 year or more, 3) on maintenance treatment and regular follow up for last 3 months and exclusion criterion for patients were presence of comorbid major psychiatric disorder, intellectual disability, or major neurological illness.

The primary caregiver^{13,14} is an adult relative living with the patient, in the same environment, for at least 1 year and is directly involved in giving care to the patient without any financial gain, meaning unpaid and is most supportive either emotionally or financially, felt most responsible for the patient.

Inclusion criterion for caregivers were- 1) age ≥ 18 years, 2) fulfilling the role of primary care giver (non-professional) for at least last 6 months, 3) willing to give written informed consent and exclusion criterion was presence of any psychiatric disorder. Socio-demographic data were collected on standard proforma and caregiver burden was measured on Burden Assessment Schedule (BAS).

BAS was developed by Thara and her colleagues¹⁵ at the Schizophrenia Research Foundation (SCARF), India to measure burden of caregiver of chronic mentally ill patients using the process of stepwise ethnographic exploration. It is a 40-item semi-quantitative scale measuring 9 different areas of objective and subjective caregiver burden, covering various domains including finance, health, occupation, marital and sexual relation, emotional and psychosocial support, external support, caregiver's routine, and strategies. Each item is rated on a 3-point scale, meaning responses are- "not at all", "to some extent", and "very much". Some of the items are reverse coded. Scores range from 40 to 120 with higher scores indicating greater burden. It has 4 items (Item no. 17, 18, 19, 20) which are to be answered only by that caregiver who is spouse also. So there remains a discrepancy between total scores of spouses (maximum score=120) and other caregivers (maximum score=108). To overcome this discrepancy, an adjusted burden score was calculated for each patient in previous study¹⁴ by using the formula: score obtained/maximum score x 100. With this modification, an adjusted score of 33.33 or less means mild or no burden, score of 33.33-66.66 will mean moderate burden and adjusted score above 66.66 will indicate severe burden. Its validity has been statistically established by comparing with Family Burden Schedule with inter-rater reliability for the scale is 0.80 (kappa, $p < 0.01$),

test-retest reliability is 0.91 (computed for a period of 3 months) and the alpha co-efficient is 0.92.¹⁶

Statistical Analysis

Statistical analysis of results was done according to standard statistical methods and by using SPSS-version 10.0 for Windows® (SPSS Inc., Chicago, IL, U.S.A.). Statistical distribution of socio-demographic data, like-age, sex, religion, residence, family type, BAS total score, adjusted total score etc, were calculated using descriptive and frequency statistics. Total caregiver population was further grouped into two subgroup, moderate burden group and severe burden group, with adjusted total burden score. Later statistical significance ($p < 0.05$) of distribution of socio-demographic variables of caregivers along those subgroups and their relationship were calculated using cross table method and Pearson chi-square test.

Results

Median age of patients was 35.56 (12.08) years and that of caregivers were 45.60 (12.67). Frequency distribution of Sex, Educational status, Socio-economic status (SES), Marital status, Family type, Residence, Religion, Occupation, both for patients and their caregivers, were given in Table-1. Duration of illness of patients was divided into three subgroup, 1-3 years, 3-5 years and more than 5 years and their frequency distribution were given in Table-1. Factorial distribution of BAS score for various factors of the schedule and adjusted total BAS score were given in Table-2. Distribution of relationship of caregiver with patient was also shown in Table 1. Statistically significant ($p < 0.05$) relation was found between caregivers' burden and their distribution of sex ($p = 0.013$), educational status ($p = 0.006$), family type ($p = 0.002$) and residence ($p = 0.002$) (Table-3). There was no significant relationship found between severity of burden and caregiver's SES, Marital status, Religion, Occupation and with their Relationship with patient ($p > 0.05$) (Table-3).

Table-1: Socio-demographic variables of both Patients and Caregivers

Socio-demographic variables		Patient		Care Giver	
Age (Years)		35.56(12.08)		45.60(12.67)	
Sex	Male	13	43.3	15	50
	Female	17	56.7	15	50
Education	Primary	1	3.3	3	10
	Secondary	19	63.3	9	30
	Higher Secondary	8	26.7	12	40
	Graduate	2	6.7	6	20
SES	Lower	8	26.7	8	26.7
	Middle	17	56.7	16	53.3
	Upper	5	16.7	6	20
Marital	Married	13	43.3	26	86.7
status	Unmarried	13	43.3	1	3.3
	Divorced/Widowed	4	13.3	3	10
Family Type	Nuclear	14	46.7	13	43.3
	Joint	16	53.3	17	56.7
Residence	Rural	17	56.7	17	56.7
	Urban	13	43.3	13	43.3
Religion	Hindu	24	80	24	80
	Muslim	6	20	6	20
Occupation	Employed	6	20	11	36.7
	Unemployed	13	43.3	4	13.3
	Housewife	10	33.3	10	33.3
	Retired	1	3.3	5	16.7
Duration of illness	1-3 Years	4	13.3		
	3-5 Years	16	53.2		
	>5 Years	10	33.5		
Caregiver	Spouse			9	30
relation	Parents			14	46.7
	Siblings			4	13.3
	Offspring			2	6.7
	Others			1	3.3

Table-2: Factorial distribution of BAS score and adjusted total score of burden for Caregivers

Factorial distribution of BAS	Mean	Std. deviation
Score		
Spouse related	3.7667	3.75714
Physical and mental health	11.7333	2.06670
External support	9.2333	1.73570
Caregivers' routine	8.0667	1.46059
Support of patient	6.0000	1.41421
Taking responsibility	8.3667	1.71169
Other relations	5.2000	1.44795
Patients' behavior	7.6333	1.54213
Caregivers' strategy	11.7333	1.94641
Total adjusted score	64.2623	7.68880

Table-3: Distribution of socio-demographic variables of caregivers along severity of burden and their statistical relation

Care Giver		Moderate Burden	Severe Burden	P Value
Sex	Male	12	3	0.013
	Female	5	10	
Education	Primary	0	3	0.006
	Secondary	9	0	
	Higher Secondary	6	6	
	Graduate	2	4	
SES	Lower	3	5	0.324
	Middle	11	5	
	Upper	3	3	
Marital Status	Married	14	12	0.615
	Unmarried	1	0	
	Divorced	2	1	
Family Type	Nuclear	3	10	0.002
	Joint	14	3	
Residence	Rural	14	3	0.002
	Urban	3	10	
Religion	Hindu	13	11	0.469
	Muslim	4	2	
Occupation	Employed	9	2	0.203
	Unemployed	2	2	
	Housewife	4	4	
	Retired	2	3	
Care Giver Relation	Spouse	6	3	0.591
	Parents	6	8	
	Siblings	3	1	
	Offspring	1	1	
	Others	1	0	
Duration of Illness	1-3 Years	4	0	0.009
	3-5 Years	11	5	
	>5 Years	2	8	

SES-socio-economic status, $p < 0.05$ - statistically significant relation

Discussion

The present study was aimed to assess caregiver burden in patient with schizophrenia and its relation to various socio-demographic variables. In our study all the caregiver suffered from moderate to severe burden on adjusted BAS score (adjusted BAS > 33.33), signifying high burden in the caregiver of patient with schizophrenia of our demographic area. Mean adjusted total BAS score was 64.26, which was similarly higher as found in other study^{14,17} from India. They scored higher burden in the areas of burden related to Physical and mental health (mean=11.7333), external support (mean=9.2333) and in caregivers' strategy (mean=11.7333). We also found that, in our population female caregivers had more burden than male caregivers of Schizophrenia, in similarity with previous study by Prashant *et al.*¹⁴

In previous study, caregiver's education was one of the most important factors that were reported to have relation with their burden, though consistent unidirectional relation was lacking. Where few studies^{18,19} reported higher burden in low education group, others reported more burden in high level of education²⁰. We found statistically significant higher burden in both primary education group and in higher education (graduate) group than those of secondary and higher secondary level. It was possible that higher level of education was responsible for greater perception of complexity of the situation, leading to more frustration and higher burden. On the other side lower education, mostly within female spouse, may be related to cut down of income within family, leading to suffer from higher burden.

Whereas joint family system is more supportive and helpful in reducing caregiver's burden, nuclear family lacks that support and is more vulnerable to stress. With modernization of our society, family tends to be more towards nuclear type, more for urban population, causing lack of family support for patients with schizophrenia.²¹ We had similar type results when tried to find out relationship between family type and severity of burden. We found that caregiver from a nuclear family had more burden than from a joint family.

Due to the high-expressed emotion and maladaptive way of functioning within one's family, burden seemed to be higher within their family.²² Family members, living with the patient with

schizophrenia, suffered from higher burden for patient's unwanted behavior and misunderstanding within family members, than those not.²³ In our study we also found higher burden in family members than non-family member though their distribution was not statistically significant ($p>0.05$).

In our study we also found lower burden in spouse than other family member of the patient with schizophrenia. Victor and Olatunde,²⁰ reported that spouses were found to have lowest mean burden score in their study in the areas of “effect of illness on physical health of others” and “effect of illness on the mental health of others”, in contrary to studies^{19,24} those reported high level of burden among the spouses. In our study we also found lower burden in spouse than other family member of the patient with schizophrenia.

Previous studies^{25,26} showed a positive and direct relationship between duration of illness and severity of burden. The longer duration of schizophrenia was likely to increase the objective burden of caregivers. Giel *et al.*,²⁷ in their study, reported that families of patients with schizophrenia with chronic illness experienced higher burden due to loss of insight. Our study also supported previous findings and showed that duration of illness had a direct relation with severity of burden ($p<0.05$).

Our study failed to establish statically significant relation between severity of burden and marital status, socio-economic status, relationship of caregiver to patient, religion and occupation. Future study with larger sample size may enlighten those areas to establish significant relation with caregiver's burden for schizophrenia.

Conclusion

Caregivers of patients with schizophrenia suffer from high level of burden, mostly in the areas of Physical and mental health, external support and in caregivers' strategy. Sex, education, family type, residence and duration of illness are statistically related to severity of burden.

Limitations

The main limitation of our study was its sample size. Study with larger sample size may overcome those hurdles we are facing now. Second one was that it was an OPD based study, for

that reason actual community representation at large may be inadequate. Future community-based study with larger sample size is advised.

Conflict of interest: none

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