



FAMILY BURDEN IN CARE GIVERS OF PATIENTS WITH CHRONIC PSYCHIATRY AND CHRONIC MEDICAL PATIENTS: A COMPARATIVE STUDY IN TERTIARY CARE HOSPITAL OF RAJASTHAN

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ABSTRACT

BACKGROUND: Chronically ill patients need assistance or supervision in their daily activities often placing a major burden on caregivers who take care of patients, placing them at a great risk of mental and physical problems. The burden perceived by the caregivers is an important prognostic aspect which refers to daily difficulties and negative life events resulting from caring for or living with the ill member and can be said as physical, emotional and financial toll of providing care.

OBJECTIVES: This study aims to compare the family burden of caregivers of patients with chronic psychiatric disorders (schizophrenia and OCD) with that of chronic medical illnesses (Chronic Renal Failure CRF and Chronic Obstructive Pulmonary Disease COPD).

METHODS: This is a hospital based observational analytical study conducted on 120 care givers of 120 chronic patients consisting 60 from Psychiatry and 60 from Medicine OPD of SMS medical college and attached hospitals, Jaipur. For study, healthy caregivers in blood relation and spouse, residing for at least 2 years with patients of chronic psychiatric disorders and chronic medical illnesses were included. Modified Mini Scale was used to identify Psychiatric illnesses and Family Burden Interview Schedule (FBIS) was used to assess family burden. For comparison, either chi square test or unpaired 't' test was used as test of significance.

RESULTS: Family burden was significantly higher in caregivers of chronic psychiatric illnesses in all the domains i.e. financial burden ($t=2.17$, $p=0.032$), family routine ($t=6.75$, $p=0.00$), family leisure's activity ($t=4.52$, $P=0.00$), family interactions ($t=5.07$, $p=0.00$), physical health ($t=2.45$, $p=0.02$), mental health ($t=2.98$, $p=0.00$) and subjective burden ($t=2.82$, $p=0.01$).

CONCLUSION: Caregiver burden was significantly higher in psychiatric illnesses compared to medical illnesses. Interventions to reduce caregiver burden better patient care facilities should be encouraged.

KEYWORDS : Family Burden, Caregivers, Family Burden Interview Schedule (FBIS), Modified Mini Scale.

INTRODUCTION-

The family constitutes a major support system in the continuing care of the mentally and psychically ill in the community. [2] Although many families show a strong resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored.[2] Further, the families of persons with chronic mental as well as physical disorders undergo considerable care giving stress on a regular basis.[1]

A caregiver has been defined as a family member who has been living with the patient and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.[2] Moreover, Chronic diseases place a considerable burden on family caregivers who take the sole responsibility for caring for chronically ill patients. [1,2]

Caregiving has been identified as a basic component of human nature and a primary element of close relationship.[6] Furthermore, in an effort to provide the best possible care for a family member, caregivers often sacrifice their own physical

and emotional needs. [2,6] Caregiver burden is a multi-dimensional response to the perceived stress and negative appraisal resulting from taking care of an ill individual.[8] The World Health Organization (WHO) states caregiver burden as the "the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system. [2]

The costs that families incur in terms of economic hardships, social isolation and psychological strain, are referred to as family burden. [4] Additionally, family burden in care giving of chronic mental illness includes financial stress, domestic routine disturbance, disruption of social and leisure activities of the family and less caring for other family members. [2,5]

There is a dearth of information on burden among caregivers of patients with chronic mental and physical illness in developing countries.[2] Moreover, it is crucial for mental health professionals to be sensitive to the stress and burden experienced by families, in order to plan and implement a comprehensive treatment programme. This would also

facilitate enhancing the quality of life of both- the ill, and their families. [2,9] In the Indian scenario, the burden and coping strategies of caregivers have not been adequately studied, and there is a paucity of research directed toward comparison of caregivers of medical and psychiatric illnesses. [9] The objective of this study was to compare family burden in caregivers of patients with chronic psychiatric disorders and chronic medical illness.

MATERIAL AND METHODS-

This hospital based analytic type of observational study was conducted on 120 care givers of chronic patients of department of Psychiatry and Medicine of SMS Hospital Jaipur, Rajasthan, India.

Selection of patients-

For chronic psychiatric patients: Patients of chronic psychiatric illness including Schizophrenia and Obsessive-Compulsive Disorder (OCD) patients of at least 2 years duration and aged 18-60 years attended at Psychiatric OPD of SMS MC Jaipur were included in this study. The diagnosis of schizophrenia and OCD was made according to ICD-10 on independent interview by two psychiatrists after applying Modified MINI scale. After excluding those who had co-existing other significant physical or mental condition, 30 Schizophrenia Patients and 30 Obsessive- Compulsive Disorder OCD Patients were included in this study.

For chronic Medical patient: Patients of chronic medical illness including confirmed cases of Chronic Renal Failure and Chronic Obstructive Pulmonary Disease patients of at least 2 years duration and aged 18-60 years undergoing treatment at medical OPD of SMS MC Jaipur were included in this study. The diagnosis of Chronic Renal Failure and Chronic Obstructive Pulmonary Disease was made according to ICD-10 on independent interview by two psychiatrists after applying Modified MINI scale. After excluding those who had co-existing other significant physical or mental condition, Chronic Renal Failure and Chronic Obstructive Pulmonary Disease patients were included in this study.

Selection of caregivers-

Healthy caregivers of age 18 to 60 years of either sex in blood relation or spouse, residing for at least 2 years with selected patients were included in the study. Caregivers with a significant physical or mental condition/disability were excluded from the study.

Study tools-

- 1. Socio-demographic sheet:** This is used to collect various socio-demographic details of caregivers.
- 2. Modified Mini Scale [17]:** The Modified Mini Screen is a 22-item questionnaire that is administered by a clinician in about 15 minutes. The tool uses a set of "gateway" questions that relate to signs of distress that may be attributed to a diagnosable psychiatric disorder; however, no specific diagnosis should be inferred.
- 3. Family burden scale [18]:** This is developed by Pai and Kapur in 1981. This scale is widely used to measure caregiver stress of those who are performing care giving activities to any chronic illness patients. This is a semi-structured interview schedule comprising of 24 items grouped under 6 areas: 1) financial burden, 2) disruption of routine family activities, 3) disruption of family leisure, 4) disruption of family interaction, 5) effect on physical health of others and 6) effect on mental health of others. The burden was rated on a 3-point scale for each item, and a standard question to assess the "subjective" burden was also included in the schedule. This scale has been developed for the Indian setup. The interrelated reliability for each item was reported to be more than 0.78 by the authors, which indicates that the present schedule is a reliable tool.

Ethical approval-

This study was approved form institutional research review board and ethics committee (IEC) of SMS medical college, Jaipur. Furthermore, written informed consent was taken from the subjects participants before administering the tools and their identities were kept confidential as anonymous data was collected.

RESULTS –

Both groups of care givers i.e. care givers of chronic psychiatric patient and care givers of chronic medical patients, were comparable as per all the characteristics except type of family where significantly higher proportion of care givers were from nuclear family otherwise other variable were not having significant (P>0.05) variation in both the groups. (Table 1)

Table No. 1: Comparisons of characteristics of Caregivers of both type of patients

S. No.	Characteristic of Caregiver	Care Givers of Chronic Psychiatric (N=60)	Care Givers of Chronic Medical patients (N=60)	*P value LS	
1	Age in years (Mean ± SD)	36.83 ±11.46	0.171 NS	0.171 NS	
2	Male: Female	50:10:00	54:06:00	0.420 NS	
3	Marrietal Status	Married	44	44	0.340 NS
		Un Married	14	16	
		Widow/ Divorce	2	0	
4	Religion	1.Hindu	50	54	0.422 NS
		2.Muslim	10	6	
5	Locality	1.Urban	46	40	0.311 NS
		2.Rural	14	20	
6	Type of family	1.Nuclear	30	16	0.028 S
		2. Three generation	22	30	
		3.Joint	8	14	
7	Education	1.Upto Middle	16	22	0.101 NS
		2.Middle to Sr. Sec.	20	10	
		3.More than Sr. Secondary	24	28	
8	Occupation	1.Unemployed	22	16	0.383 NS
		2.Retired	2	0	
		3.Professional	10	10	
		4.Bussiness men	0	2	
		5.Farmer/S killed/Semi skilled /Unskilled	22	26	
		6.Other	4	6	
9	Income monthly (in Rupees)	1.Upto 6000	20	26	0.529 NS
		2.6001-15000	12	10	
		3. >15000	28	24	
10	Relation to patient	Spouse	22	12	0.095 NS
		First degree relatives	30	41	

		Others	8	7	
11	Duration of care giving (in Years)	21.33±8.8	25.03±8.07	0.024	S

*In quantitative data i.e. '1' and '11' p value is inferred by Unpaired 't' test and in qualitative data i.e. '2' to '10' it inferred by Chi-square test

Comparison of family burden:

Family burden was significantly higher in caregivers of chronic psychiatric patients in all the domains i.e financial burden (p= 0.032), family routine(p<0.001), family leisure's activity (p<0.001) and family interactions (p<0.001) than in care givers of chronic medical patients. Likewise physical health burden (p=0.02) and mental health burden (p<0.001) were also significantly higher in caregivers of chronic psychiatric patients than in care givers of chronic medical patients. Total Objective Family Burden (TOFB) and Total Subjective Family Burden (TSFB) both were also significantly higher in caregivers of chronic psychiatric patients than in care givers of chronic medical patients ((p<0.05). (Table 2)

Table No. 2: Family Burden wise Comparison of Caregiver of Patients of both the Groups

S. No.	Type of Burden	Care Givers of Chronic Psychiatric (N=60)	Care Givers of Chronic Medical patients (N=60)	P value	LS
1	Financial Burden	6.07±2.24	5.20 ±2.12	0.032	S
2	Family Routine Burden	6.30±2.62	3.7±1.43	<0.001	S
3	Family Leisure Burden	4.03 ±2.93	1.62 ±0.97	<0.001	S
4	Family Interaction Burden	3.36±1.63	2.13±0.93	<0.001	S
5	Physical Health Burden	1.03±0.84	0.67±0.79	0.024	S
6	Mental Health Burden	1.10±0.84	0.66±0.75	0.003	S
7	Total Objective Family Burden	21.90±6.39	15.30±4.32	<0.001	S
8	Total Subjective Family Burden	1.77 ±0.43	1.53±0.50	0.012	S

DISCUSSION-

In this present study, both groups of care givers i.e. care givers of chronic psychiatric patient and care givers of chronic medical patients, were comparable as per all the characteristics except type of family where significantly higher proportion of care givers were from nuclear family otherwise other variable were not having significant (P>0.05) variation in both the groups. Similar observations were made by observed by Dr. Surjeet sahou et al., 2010 [19], who observed that the caregivers of mentally ill clients belonged to nuclear family (66.68%) rather than joint family.

In present study, family burden was significantly higher in all the domains i.e financial burden, family routine, family leisure's activity and family interactions in caregivers of chronic psychiatric patients than in care givers of chronic medical patients. Present study also observed that physical health burden (p=0.02) and mental health burden (p<0.001) were also significantly higher in caregivers of chronic psychiatric patients than in care givers of chronic medical patients. Total Objective Family Burden (TOFB) and Total Subjective Family Burden (TSFB) both were also significantly higher in caregivers of chronic psychiatric patients than in care givers of chronic medical patients. ((p<0.05).

Shiv Gautam etall (20) also conducted a study in department of psychiatry of SMS medical college, Jaipur and reported the

similar observations i.e. increased family burden in care givers of of chronic psychiatric patients. In abroad also similar observations were made as in present study e.g Magliano Let all (21) conducted a study by department of Psychiatry, University of Naples, in Italy on 709 key relatives of patients with a DSM-IV diagnosis of schizophrenia and 646 key relatives of patients with physical diseases, also reported that family burden with all the domains was significantly higher in caregivers of chronic psychiatric patients than in care givers of chronic medical patients. Other authors (22-25) from various other regions of India also made almost similar observation like Harsh Oza (22) from Ahmadabad, Gururaj GP et all (23) from Bangalore, Vikas A et all (24) from Chandigarh and Ampalam P et all (25) from Andhra Pradesh.

REFERENCES

- Purkayastha M, Chavan BS, Kumar S. Quality of life in caregivers of persons with mental retardation and chronic schizophrenia: A comparative study. J Ment Health Hum Behav. 2012;17:53-9.
- Ravi S, Goud BR, Archana M, Pius TM, Pal A, John V. Burden among caregivers of mentally-ill patients: a rural community-based study community medicine. Int J Res Dev Health. 2013;1:29-34.
- Karim N, Ali A, Deuri SP. A comparative study of care burden and social support among caregivers of persons with schizophrenia and epilepsy. Open Journal of Psychiatry & Allied Sciences. 2015 Mar 1;6(2).
- Bora DK, Das A. Family burden in caregivers of chronic schizophrenia and bipolar affective disorder-A comparative study. Journal of Medical Science and Clinical Research. 2017;5(11):30237-47.
- Koujalgi SR, Patil SR. Family burden in patient with schizophrenia and depressive disorder: a comparative study. Indian journal of psychological medicine. 2013 Jul;35(3):251-5.
- Vasudeva S, Sekhar CK, Rao PG. Caregivers burden of patients with schizophrenia and bipolar disorder: A sectional study. Indian journal of psychological medicine. 2013 Oct;35(4):352-7.
- Sharma R, Sharma SC, Pradhan SN. Assessing caregiver burden in caregivers of patients with schizophrenia and bipolar affective disorder in Kathmandu medical college. Journal of Nepal Health Research Council. 2017;15(3):258-63.
- Swain SP, Behura SS, Dash MK. A comparative study of family burden and quality of life between caregivers of schizophrenia and dementia patients. Int J Community Med Public Health. 2017 Jun;4(6):2021-6.
- Mathur S, Chandran S, Kishor M, Prakrithi SN, Rao TS. A comparative study of caregiver burden and self-efficacy in chronic psychiatric illness and chronic medical illness: A pilot study. Archives of Mental Health. 2018 Jul 1;19(2):115.
- Behere PB, Bansal A, Nagdive AB, Behere AP, Chowdhury D, Yadav R, Fernandes R. Comparative study of burden in caregivers of patients with schizophrenia and depression. European Journal of Molecular and Clinical Medicine. 2020;7:1916-30.
- Shamsaei F, Cheraghi F, Bashirian S. Burden on family caregivers caring for patients with schizophrenia. Iranian journal of psychiatry. 2015 Sep;10(4):239.
- Parija S, Yadav AK, Sreeraj VS, Patel AK, Yadav J. Burden and expressed emotion in caregivers of schizophrenia and bipolar affective disorder patients: A comparative study. MAMC journal of medical sciences. 2018 May 1;4(2):68.
- Siddiqui S, Khalid J. Determining the caregivers' burden in caregivers of patients with mental illness. Pakistan journal of medical sciences. 2019 Sep;35(5):1329.
- Süccüllüoğlu Dikici D, Eser E, Çökmiş F, Demet MM. Quality of Life and associated risk factors in caregivers of patients with obsessive compulsive disorder. Psychiatry and Clinical Psychopharmacology. 2019 Oct 2;29(4):579-86.
- Zhou Y, Rosenheck R, Mohamed S, Ou Y, Ning Y, He H. Comparison of burden among family members of patients diagnosed with schizophrenia and bipolar disorder in a large acute psychiatric hospital in China. BMC psychiatry. 2016 Dec;16(1):1-0.
- Shah R, Ali FM, Finlay AY, Salek MS. Family reported outcomes, an unmet need in the management of a patient's disease: appraisal of the literature. Health and quality of life outcomes. 2021 Dec;19(1):1-35.
- Modified Mini Screen (MMS) CO-OCCURRING DISORDERS PROGRAM: SCREENING AND ASSESSMENT Document is in the public domain. Duplicating this material for personal or group use is permissible https://www.ncdhhs.gov/media/1445/open
- Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an assessment scale. Br. J. Psychiatry 1981;138: 332-335.
- Surjeet Sahoo, Prasanta Kumar Brahma burden of caregiver's among the mentally ill and diabetic patients - a comparative study, Orissa Journal of Psychiatry.
- Shiv gautam, madhu nihawan et all' burden on families of schizophrenic and chronic lung disease patients. Indian j. Psychiat. (1984; 26(2), 156-159
- Magliano L, Fiorillo A, De Rosa C, Malangone C, Maj M, National Mental Health Project Working Group. Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. Soc Sci Med. 2005 Jul;61(2):313-22
- Harsh Oza, Minakshi N. Parikh, Ganpat K. Vankar. Comparison of caregiver burden in schizophrenia and obsessive-compulsive disorder. Archives of Psychiatry and Psychotherapy. 2017; 2: 32-41.
- Gururaj GP, Math SB, Reddy JY, Chandrashekar CR. Family burden, quality of life and disability in obsessive compulsive disorder: an Indian perspective. J Postgrad Med. 2008 Apr-Jun;54(2):91-7. doi: 10.4103/0022-3859.40773. PMID: 18480523
- Vikas A, Avasthi A, Sharan P. Psychosocial impact of obsessive-compulsive disorder on patients and their caregivers: a comparative study with depressive disorder. Int J Soc Psychiatry. 2011 Jan;57(1):45-56. doi: 10.1177/0020764009347333. PMID: 21252355
- Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. Indian J Psychiatry. 2012 Jul;54(3):239-43. doi: 10.4103/0019-5545.102423. PMID: 23226847; PMCID: PMC3512360