



ASSESSMENT OF CAREGIVERS' BURDEN AMONG PRIMARY CAREGIVERS OF PATIENTS WITH SELECTED MEDICAL DIAGNOSIS

Pramilaa R

Principal, Chirayu College of Nursing, CMCH Campus, Near Bairagarh, Bhopal, India.

ABSTRACT

The aim of the study was to a) assess the caregiver burden among the primary caregivers; b) categorize the range of four dimension of caregivers' burden tool in three areas; c) compare the four dimensions of caregivers' burden among three areas; and d) associate the level of caregiver burden with selected demographic variables. A descriptive study was carried out with a sample size of 150 selected by purposive sampling method; 50 each in respiratory, cardiac and neurology areas. The results revealed that overall caregivers' burden was 38.54%; majority (87%) reported to have mild burden and dimension wise also majority of them had mild burden. Physical burden was significantly more among caregivers rendering care to patients with neuro problems, social burden was significantly more in cardiac, and emotional and economical was same in all areas. Association showed no significance except for time spent in hospital and admission of patients to hospital.

Key words: Caregivers' Burden, Neurology, Cardiac, Respiratory.

Corresponding Author

Pramilaa R

Email:- pramilaravi@yahoo.com

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INTRODUCTION

Chronic illness affects people of all ages and they are found in all ethnic, cultural and racial groups. Patients affected with chronic conditions are frequently dependent on others for close monitoring or placement in long- term facilities. Once a chronic condition has occurred, the focus shifts to managing symptoms and avoiding complications. Health- promoting behaviors are essential to improve quality of life as they help to maintain functional status of patients. Although co-workers, extended family and health care professionals are affected by chronic illness, the problems of living with chronic conditions are most acutely experienced by patients and their immediate family members [1].

Amidst the high- tech, fast- paced environment of the health care agencies, family members often play an important role in promoting the psychological well- being of the patient through familiar and caring presence, meaningful interaction of the patient, and collaboration with the treating team in planning care. A family's ability

to support the patient may become compromised by their own psychological distress. In order to promote the optimal outcomes for both patient and family, a vital responsibility of the nurse is to address the needs and concerns of family members during hospitalization [2].

Research studies shows that the families need help for the constant adaptation, and their main need is education and support, but recently, modern medical technology has not paid enough attention to this issue of family support, so that families have not received adequate support [3]. As family members play an important role in interaction with their patient as well as cooperating with the treatment team in administration of care, their ability to support patient may be impaired due to imposed tensions [4].

Care givers are people who have greatest involvement in patient care and assistance during course of the disease in order to adapt and manage the patient[5]. Caregivers often receive little attention and the main focus is on the patient. Frequent hospitalization of the patients



and factors associated with the disease can lead to deterioration of depression and reduction in caregiver's quality of life[6]. Thus, caregiver's status and determination of their needs are very important. Caregiver burden is defined as permanent difficulty, stress or negative experiences resulted from providing care by caregiver. Timely identification of pressures in caregivers plays a decisive role in the promotion of their mental health [7].

The term family caregiver refer to an unpaid family member, friend or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding. Recent surveys estimate there are 44 million caregivers over the age of 18 years[8]. Most care givers are women who handle time-consuming and difficult tasks like personal care[9]. But at least 40 percent of caregivers are men, a growing trend by a 50 percent increase in male caregivers. These male care givers are becoming more involved in complex tasks like managing finances and arranging care, as well as direct assistance with more personal care. Nurses are likely to see many of them will not identify themselves as a caregiver[10]. Care giver burden threatens the physical, psychological, emotional and functional health of caregivers. Caregivers frequently suffer from depression, exhibit maladaptive coping strategies and express concern about their poor quality of life[6].

The aforementioned studies state the caregivers' role has been expanded to teaching and assisting family members to provide care. And it has all features of a chronic stress experience to them. It creates physical and psychological strain in the long run. Thus, the present study is taken up to assess the caregivers' burden among primary caregivers of patients with selected medical diagnosis.

Statement of the problem:

A study to assess the caregivers' burden among primary caregivers of patients with selected medical diagnosis at CMCH, Bhopal.

Objectives of the study:

1. Assess the caregiver burden among the primary caregivers
2. Categorize the range of four dimension of caregivers' burden tool in three areas
3. Compare the four dimensions of caregivers' burden among three areas
4. Associate the level of caregiver burden with selected demographic variables

Materials and Methods:

Research approach and design: The research approach adopted for the study was quantitative and research design was descriptive study of non- experimental type.

Setting: The setting of the study was the medical wards of Chirayu Medical College and Hospital (CMCH), Bhopal.

Population: The accessible population of the study was the primary caregivers of patients admitted in medical wards of CMCH.

Sampling criteria:

Inclusion criteria:

- Chronic illness includes neurological conditions and systemic diseases
- Primary caregivers of the patients with chronic illness and hospitalized in CMCH
- Person who is directly caring for the patients
- Primary caregivers available at the time of data collection
- Primary caregivers who are willing to participate in the study
- Primary caregivers who can read and write Hindi

Exclusion criteria:

- Primary caregivers who are health professionals
- Person caring for patients temporarily only in hospital

Sampling technique: The sampling technique adopted for the present study was purposive sampling technique

Sample size: A total of 150 respondents were the sample size; 50 from each area such as respiratory, cardiac and neurology, respectively.

Tools for data collection: It comprises of two sections. Section A with demographic categories and Section B with Caregivers Burden Tool. It is a 20- itemed rating scale with four dimensions.

Data collection procedure: The study was furthered by obtaining ethical clearance from the Research Committee of the Institution. Permission from the respondents was solicited with the persons who met the sampling criteria. The demographic data was gathered using interview method and caregivers' burden tool was administered to them and self reports were gathered. The study was conducted in February 2017.

RESULTS:

The results are organized in accordance to the objectives of the study below:

Characteristics of the respondents: Majority (31.3%) belonged to age group of 31- 40; 59.3% were males; 57.3% were literates; 39.3% were working for daily wages; 27.3% were having spouse and children as relationship with care receiver ; 57.3% had experience for caring before; 77.3% caregiver reported that duration of illness were less than one year; 54% spent 10-12 hours per day in caring the patient; 99.3% had no disability and 85.3% reported that they were not short tempered.



Characteristics of the patient: Majority were males (65.3%); 39.3% were above 50 years; 62% were admitted

unexpectedly to hospital; and 45.3% were hospitalized for the duration of 1-5 days.

Table 1. Overall mean, median, mean% and range of dimensions of caregivers burden scale among three areas

N=150

Care giver burden scale	Mean	Median	SD	Mean %	Range
Physical Burden	6.68	7.0	3.386	33.40	0 - 18
Emotional Burden	5.28	5.0	3.048	26.40	0 - 20
Social Burden	6.02	6.0	2.757	30.10	0 - 15
Economical Burden	12.85	13.5	5.720	64.27	3 - 20
Over all Care-giver Burden	30.83	32.0	11.26	38.54	6 - 73

The above table 1 demonstrates that the overall mean percentage of caregivers' burden was 38.54. Among the dimensions of caregiver burden scale, the mean was highest in the economical burden and lowest in emotional burden.

Table 2. Overall percentage on level of caregivers' burden in relation to dimensions

N=150

Care-giver Burden	Frequency	Percent
Physical Burden		
Little	55	36.7%
Mild	78	52.0%
Moderate	15	10.0%
Severe	2	1.3%
Emotional Burden		
Little	82	54.7%
Mild	63	42.0%
Moderate	4	2.7%
Severe	1	0.7%
Social Burden		
Little	63	42.0%
Mild	80	53.3%
Moderate	7	4.7%
Severe	0	0.0%
Economical Burden		
Little	20	13.3%
Mild	44	29.3%
Moderate	27	18.0%
Severe	59	39.3%
Care-giver Burden		
Little	33	22.0%
Mild	85	56.7%
Moderate	31	20.7%
Severe	1	0.7%

The above table 2 states that majority 56.7 % of the respondents' experienced mild burden; 22% experienced little and 20.7% moderate.

Table 3. Percentage distribution of caregivers' burden in three areas

N=150

Care-giver Burden	Respiratory	Cardiac	Neuro
Physical Burden			
Little	11 (22.0%)	29 (58.0%)	15 (30.0%)
Mild	35 (70.0%)	18 (36.0%)	25 (50.0%)
Moderate	4 (8.0%)	2 (4.0%)	9 (18.0%)
Severe	0 (0.0%)	1 (2.0%)	1 (2.0%)
Emotional Burden			
Little	27 (54.0%)	31 (62.0%)	24 (48.0%)
Mild	21 (42.0%)	17 (34.0%)	25 (50.0%)
Moderate	2 (4.0%)	1 (2.0%)	1 (2.0%)



Severe	0 (0.0%)	1 (2.0%)	0 (0.0%)
Social Burden			
Little	23 (46.0%)	15 (30.0%)	25 (50.0%)
Mild	26 (52.0%)	31 (62.0%)	23 (46.0%)
Moderate	1 (2.0%)	4 (8.0%)	2 (4.0%)
Severe	0 (0.0%)	0 (0.0%)	0 (0.0%)
Economical Burden			
Little	2 (4.0%)	11 (22.0%)	7 (14.0%)
Mild	19 (38.0%)	10 (20.0%)	15 (30.0%)
Moderate	11 (22.0%)	7 (14.0%)	9 (18.0%)
Severe	18 (36.0%)	22 (44.0%)	19 (38.0%)
Care-giver Burden			
Little	12 (24.0%)	10 (20.0%)	11 (22.0%)
Mild	27 (54.0%)	32 (64.0%)	26 (52.0%)
Moderate	11 (22.0%)	7 (14.0%)	13 (26.0%)
Severe	0 (0.0%)	1 (2.0%)	0 (0.0%)

Table 3 projects that majority of respondents in all three areas experienced mild burden.

Table 4. Difference in physical burden between three areas N=150

Areas	Mean	SD	F - value	df	p - value
Respiratory	7.120 ^B	2.847	6.558**	2 & 147	0.002
Cardiac	5.340 ^A	3.491			
Neuro	7.580 ^B	3.423			
Total	6.680	3.386			

** The difference is significant at 0.01 level ; Values with same letters showing no significance

Here the p-value is less than the significance level 0.01; the difference in physical burden between areas is significant. The table shows that the physical burden is significantly higher in neuro (7.580 ± 3.423) and respiratory (7.120±2.847) compared to cardiac (5.340± 3.491).

Table 5. Difference in Emotional Burden between three Areas N=150

Areas	Mean	SD	F - value	df	p - value
Respiratory	4.940 ^A	3.119	0.490 ^{NS}	2 & 147	0.614
Cardiac	5.520 ^A	3.190			
Neuro	5.380 ^A	2.856			
Total	5.280	3.048			

NS → The difference is not significant; Values with same letters showing no significance

Here the p-value is greater than the significance level 0.05; the difference in emotional burden between areas is not significant. The table shows that the emotional burden is almost same in respiratory (4.940±3.119), cardiac (5.520 ±3.190) and neuro (5.380± 2.856).

Table 6. Difference in Social Burden between three Areas N=150

Areas	Mean	SD	F - value	df	p - value
Respiratory	5.500 ^A	2.852	4.200*	2 & 147	0.017
Cardiac	6.920 ^B	2.769			
Neuro	5.640 ^A	2.464			
Total	6.020	2.757			

* The difference is significant at 0.05 level; Values with same letters showing no significance

Here the p-value is less than the significance level 0.05; the difference in social burden between areas is significant. The table shows that the social burden is significantly higher in cardiac (6.920±2.769) compared to respiratory (5.500± 2.852) and neuro (5.640 ±2.464).

Table 7. Difference in Economical Burden between three Areas N=150

Areas	Mean	SD	F - value	df	p - value
Respiratory	13.08 ^A	5.134	0.073 ^{NS}	2 & 147	0.929
Cardiac	12.84 ^A	6.222			



Neuro	12.64 ^A	5.858		
Total	12.85	5.720		

NS → The difference is not significant; Values with same letters showing no significance

Here the p-value is greater than the significance level 0.05; the difference in economical burden between areas is not significant. The table shows that the economical burden is almost same in respiratory (13.08±5.134), cardiac (12.84±6.222) and neuro (12.64±5.858).

Table 8. Difference in overall Care-givers’ Burden between three Areas N=150

Areas	Mean	SD	F - value	df	p - value
Respiratory	30.64 ^A	10.74	0.048 ^{NS}	2 & 147	0.953
Cardiac	30.62 ^A	12.09			
Neuro	31.24 ^A	11.11			
Total	30.83	11.26			

NS → The difference is not significant; Values with same letters showing no significance

Here the p-value is greater than the significance level 0.05; the difference in care-giver burden between areas is not significant. The table shows that the care-giver burden is almost same in respiratory (30.64±10.74), cardiac (30.62±12.09) and neuro (31.24±11.11).

Association between caregivers burden with demographic variables: There is no significant association except for gender of caregiver, time spent in the hospital and admission of hospital of the patient.

DISCUSSION

The present study was aimed to assess the Care Givers burden (CGB) among caregivers of patients with respiratory, cardiac and neurological conditions. The present study findings revealed overall mean burden score as 30.83. Of the dimensions in CGB scale, mean in the economical burden 12.85 was the highest and emotional burden 5.28 was the lowest. This is similar to the finding of a study done among 231 caregivers of patients identified a median score of 25[11]. Another study done among dementia caregivers demonstrated mean burden score to be 47.7, that is, on the higher side which may be due to the condition that demands more hours to be spent with the patients[12]. Yet, one another study showed contrast finding with Zarit burden score as 20 that was done among caregivers of epilepsy[13].

The statistical analysis on the level of CGB depicted majority 56.7% experienced mild burden from the overall scores. This is in line with a study that showed majority 57.6% of respondents had mild to moderate burden [14]. One another study is almost consistent with a study that corroborated 45% of subjects belonged to mild to moderate level of burden[15]. Also, a survey revealed 83.5% of caregivers reported high level of burden[16]. This reflects the burden in the stroke survivors. The present finding is again supported by a descriptive cross-sectional design used to assess home-care burden experienced by primary caregivers of patients operated for intracranial tumors. Seventy patient-caregiver pairs were enrolled. Modified caregiver strain index (MCSI) was used to assess the caregiver burden. It was found that of 70 caregivers, 45(64%) had mild, and 22 (31%) had moderate MCSI burden[17]. Yet, another study conducted to explore burden and coping strategies of stroke survivors revealed the level of caregiver burden reported by caregivers of stroke patient was high [18]. The studies have

demonstrated fluctuations as low burden among epilepsy caregivers and high burden among stroke survivors could be related to the intensity of dependence of care among patients. There may be various influencing factors as well that need to be explored.

Recommendations of the study:

- Similar study including coping strategies can measure the decline in the level of caregivers’ burden
- Conducting the study at larger population can generalize the findings of the study

Implications of the study:

- The study provides basic information on the appropriate priority of caregivers’ burden’s dimensions that can enable to create interventions
- The findings suggest that interventions for primary caregivers can eliminate the unnecessary burden
- The study can assist researchers to conduct in all areas of nursing at a larger scale

CONCLUSION

The results of the study reflect the need for care of the patients who have chronic illness and at the same time level of burden among primary caregivers. Furthermore, when spouse or the children are the primary caregivers the entire family process gets altered. Many studies have pointed out that the level of caregivers burden is directly proportional to the amount of hours they spend in providing the care to the patient. Planning and designing interventions for the caregivers may help to deal with their burden supplemented by preventing other related morbidities.



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Conflict of interest: None

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