

Burden and its Associated Factors among the Caregivers of the Older Adults

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Abstract: *The elderly population in South Asia is growing. In India trained caregivers are scarce and culturally not accepted and also cannot be afforded by the majority of the population. The burden faced by caregivers undertaking caregiving responsibilities may affect their health. This study aims to determine the burden and its associated factors among primary caregivers of older adults based on caregiver's socio demography, experience and older adults dependence level. A cross-sectional study involving 100 caregivers of older adults was conducted at a tertiary care teaching hospital in south India. The Barthel's Index (BI) of Activity of Daily Living (ADL) scale was used to assess the degree of physical care required by the elderly. Caregiver Burden Inventory (CBI) Scale was to assess the level of burden of caregivers and the associated factors of burden were assessed by a questionnaire developed by investigator. Descriptive statistics was used to determine the socio demographic characteristics of caregiver and the level of elderly dependency. Of the elderly, 45% suffered medium to high range of functional disabilities, 23.0% were partially dependent and 28% were independent. Among caregivers 89% experienced low level of burden and most were in the domain of time-dependence followed by physical and emotional burden. Caring for elderly with greater functionally dependence care was significant for care givers burden. It showed that caregivers had physical strain especially in relation to lifting, ambulating and meeting toilet needs of older adults. There was a significant relationship between the age of older adults with Physical, emotional, financial and social domains ($p=0.042$, 0.030 , 0.015 & 0.005 respectively). Most of them faced financial crisis to meet the health needs of the older adults. They were disturbed emotionally in relation to poor prognosis and fear of losing the loved one. It also lead to sleep disturbances among the caregivers and was significant with high burden ($p=0.038$). Results highlighted that the health care provider should consider these factors when planning interventions to alleviate the burden of caregivers of older adults.*

1. Introduction

The older adult's population of South Asia is seeing an unprecedented rise. According to WHO, 2013 data 6.5% of the population is elderly and the total population was expected to be 7.2 billion in mid-2013. It is expected to increase by almost 1 billion in next 12 years and will reach 8.1 billion in 2025, 9.6 in 2050 and 10.9 by 2100. The number of older adults in the developing countries has been growing at a phenomenal rate. By 2050, 80% of world's older adult's population will live in developing countries with China and India contributing to over a third of that number. Caregiving of the older adults has long been identified as a source of stress and burnout. The emotional and physical strain, besides perceived negative impacts due to caregiving can take many forms such as frustration, anger, guilt, loneliness and exhaustion. It can predispose caregivers to deteriorating health, helplessness and social isolation. It also states that caregiving becomes a burden when the elders have multiple chronic illnesses with functional disability leading to total or partial dependence on the caregivers.

The researcher with hers experience in the Geriatric ward has observed many caregivers of the older adults and witnessed the problems they face. Caregivers are hidden patients who need support from the health personnel for their physical, social and emotional needs and problems. This has triggered the need to study the burden of caregivers in detail so as to help them and sensitize health care personnel towards their unique needs. Therefore this study was done with the following objectives:

- To assess the burden of primary care givers of older adults

- To determine relationship between patient's functional ability, clinical profile and caregiver burden
- To find association between selected demographic variables, associated factors and caregiver burden

2. Methods

Design and Sampling

A cross sectional descriptive study was adopted for the study. The study was conducted among the primary caregivers who were the relatives of older adults and had been providing care continuously for minimum period of 2 months. Simple random sampling technique was used to include the 100 primary caregivers from medical wards and geriatric outpatient department.

Data collection instrument

Part A- Socio demographic data of caregivers

Part B-

- a) Sociodemographic and clinical profile of the older adult
- b) Barthel index scale. Reliability with Cronbach alpha of 0.92 (Mahoney F. Barthel D (1965).

Part C-Caregiver burden inventory

A multi-dimensional questionnaire consists of 5 subscales with 24 items. Internal consistency & reliability of each domain is .85, .85, .86, .73 and .77 respectively (Novak M, Guest C, 1989).

Part D: Investigator developed questionnaire on associated factors. It has 4 domains with 42 items.

Data was collected over a period of two months after obtaining written informed consent from the caregivers in the medical wards and geriatric outpatient department.

3. Results and Discussion

A p value of <0.05 was considered statistically significant. The study included 100 caregivers aged 18-78 years with mean age of 47 years while 68% were female caregivers. Sisters (32%), daughters (21%), sons (21%) and spouses (21%) were the primary caregivers. Three fourth of them were from Hindu background. Majority (67%) of them was married and 44% had completed secondary school level of education. About 51% of the care givers were employed and 32% were reported having family income of Rs.1000 or less per month. About half (52%) of them had others to help in their caregiving. Half of the caregivers had spent 3-5 hours per day of caregiving along with caring for their own children. Twenty eight percent perceived their general health to be excellent and majority (65%) of them perceived it to be good.

In relation to patients, the mean age group was 71 years and 58% of them were males. The current admission was for medical conditions viz. Heat related illness (27%), Stroke

(20%), Respiratory illnesses (16%), Diabetes mellitus (13%) & Hypertension (13%). They also had comorbidities such as diabetes, hypertension while 34% of them had both, 33% had single and 27% had more than three co-morbidities.

The functional dependence using Barthel index showed that 40% were below score of 10 which indicated that they were functionally dependent on caregivers for most of their day to day activities viz. climbing stairs (83%), walking (60%) and also transferring (65%).

Table 1: Severity of Caregiver Burden

S. No	Burden Severity	CBI-Score	n	%
1	Low Burden	0-24	89	89
2	High Burden	>24-36	9	9
3	Severe Burden	>36	2	2

It was found that 89% of them had low burden, while 11% had high to severe burden. It also showed that the burden was high in relation to time dependence and physical demands.

There was no correlation between burden of the caregiver and functional ability and clinical profile of the older adult.

Table 2: Association between Selected Socio Demographic Variables and Caregiver Burden

Variables	Caregiver Burden			Chi-Square Value	P Value
	Low Burden n=89	High Burden n=9	Severe Burden n=2		
Age (yrs.)				6.675	0.572
60-70	47	6	1		
71-80	35	2	1		
>81	7	1	0		
Hrs of Care Received /Day				3.798	0.434
3-5 hrs./day	47	2	1		
6-10hrs/day	24	4	1		
>11 hours	18	3	0		
Barthel Index				3.742	0.442
0-10	40	4	1		
11-15	11	3	0		
16-20	38	2	1		

No association was found between socio demographic variables and the care giver burden.

Table 3: Association between Caregiver Burden and Associated Factors

Associated Factors	Sum of square	df	Mean square	f	p Value
Physical	2750.04	2	589.414	36.388	0.000*
Emotional	549.96	2	46.889	9.970	0.000*
Financial	24.99	2	0.639	2.614	0.078
Social	110.16	2	5.642	5.535	0.005*
Overall	4615.79	2	880.470	29.916	0.000*

There was significant association between care giver burden and associated factors viz. physical (p=.000), emotional (p=.000) & social (p=.000) factors.

4. Discussion

The study showed revealed that 40% of the older adults were dependent for their functional activities. These findings were supported by Ziauddin et al., (2001) who reported 69% of older adults had problems in one or more ADL. The overall burden in this current study was found to be low burden

89%, 9% high burden and 2% has severe burden among the older adults lower than finding is supported by S. Luckhmana et al., (2015) in their study on family caregiver burden in North India showed caregiver burden was 57% minimal burden and 38% had mild to moderate burden. One reason that can account for the low levels of burden in the

current study was that 28% had excellent 65% enjoyed good health which made them fit to take care of older adults.

5. Conclusion

In India it is still common to find family members who accompany and stay with their patient who is admitted in the hospital. They have their own family commitments, and multiple other responsibilities which are an added source of high stress and burden. The study findings draw the attention of health care providers to the caregivers who experience burden in caring for older adults at home and in the hospital setting. Interventions that could be considered to assist them include effective coping strategies, adjustment in caregivers daily tasks, specific training and educational support, counseling, referral to local support networks, delegating caregiving responsibilities among family members and respite care to alleviate their burden.

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