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ORIGINAL RESEARCH PAPER

General Medicine

CAREGIVER BURDEN AMONG THE CAREGIVERS OF OLDER ADULTS WITH PALLIATIVE CARE NEEDS

KEY WORDS: Caregiver ,geriatric, Palliative Care

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ABSTRACT

AIM: To examine caregiver burden among caregivers of hospitalised geriatric patients with palliative care design.
METHODOLOGY: Caregivers of 330 geriatric patients with various chronic end stage diseases. They were assessed using BSFC-s questionnaire.
RESULTS: Majority of caregivers were spouses (26%). Mean age group being 68.2 years. The caregiver burden across the categories was more than 60% across all the questions asked in the BSFC-s questionnaire. Maximum in the caregiver with end stage renal disease (60.3%) and minimum in the caregivers of frail elderly (50.2%).
CONCLUSION: Caregiver burden was common in caregivers of geriatric patients with end stage chronic diseases. Burden was associated with the caregiver's report of need for greater help with daily tasks but not with objective measures of the patient's need for assistance, such as symptoms or functional status, suggesting that burden may be a measure of the caregiver's ability to adapt to the care giving role.

INTRODUCTION

Physical and mental disability is prevalent among the elderly which increases with age. Consequently, older people usually need more assistance with daily activities when they are older. To accomplish good clinical care, the caregiver is one of the essential keys[1].

In particular, health of the caregiver can influence the overall health of chronically-ill elderly. Caregiver burden refers to the physical, financial, and psychosocial hardships of caring for a loved one, usually a family member who struggles with a medical condition. The impact of chronic illness does not only affect on patient's life but also the family and in particular the partner's life. Caregiver burden is associated with a decline of physical and psychological health of caregivers in addition to the deteriorating health-related quality of life. Caregivers who live with chronically ill persons can experience consequences in 4 areas which are their personal life strain, social isolation, financial burden, and intrinsic reward[2.]

Physical impairments are associated with greater personal life strain and financial burden while social impairment has a high impact on all 4 factors. There are several factors associated with caregiver burden which can be classified as caregiver characteristics and patient characteristics. The first one is stronger when related to caregiver burden than the other. High burden is associated with caring for a person who requires more assistance with daily tasks, similar to the relationship to patient-to child and the need for more communication with the patient's doctor.

Most studies about caregiver burden have been in Western countries and were focused on single end stage chronic illness of elderly. There was no study which encompassed all the chronic illness mong elderly such as end stage renal, cardiac, pulmonary disease, stroke, multiple morbidities , dementia and frailty. As Indian people have diverse cultures, focusing on this issue in the area of the psychosocial aspect should perform optimally. The differences in cultures can make the results different between regions. Identifying problems can be a great help in recognizing the basal state of the caregivers, providing recommendations and possible services for them to alleviate their burdens. Therefore, the objective was to identify severity of caregiver burden and later plan to develop the strategies or interventions that could support them.

METHODOLOGY

Participants were family caregivers of the elderly patient. Study participants were recruited over a two-year period (2017-2019). 330 Participants were recruited while assessing the palliative care needs of the elderly individual admitted in tertiary health care centre for chronic terminal illness. Inclusion criteria for study participants were that the patient was 60 years or older, the family caregiver would provide informed consent. Caregivers were excluded from the study if the patient had survival <less than 1week or comatose patient. Caregivers were defined as relatives of the patient who provided care to that individual on a regular basis, and did not receive remuneration for such services.

The burden scale for family caregivers -short (BSFC-S) tool was used to determine the experience of care giving. The BSFC-s is a 10-item scale measuring the reaction of family caregivers, caring for older adults with physical and mental impairments participants were asked to respond to 10 items on a four-point scale ranging from 'strongly disagree-0' to 'strongly agree-3'. The scoring of positively worded questions was reversed such that higher scores indicated more negative impacts of care giving. The total possible score was calculated. The instrument has been shown to be multidimensional and invariant across different patient disease groups. the study also found that the subscales represented conceptually different dimensions within the care giving situation .The BSFC-s was preferred above other caregiver burden instruments for this study because other instruments were developed for caregivers of persons with mental impairment only or addressed only the negative consequences of care giving.

RESULTS

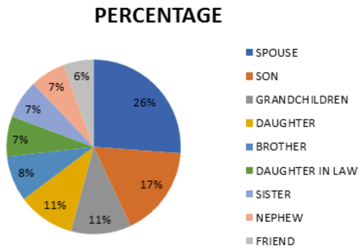
In this study of 330 participants i.e. caregivers of geriatric patients with palliative care needs having end stage illness were taken and questionnaire was answered following are the results based on the questionnaire.

As depicted in table-1, Spouses were the primary caregivers of this patients(26%), followed by son (17%) and grand children (11%).

TABLE -1 RELATION WITH CAREGIVER OF 330 GP

RELATION OF CAREGIVER WITH THE PATIENTS	FREQUENCY	PERCENTAGE
SPOUSE	84	25.5
SON	54	16.4
GRANDCHILDREN	36	10.9
DAUGHTER	34	10.3
BROTHER	27	8.2
DAUGHTER IN LAW	24	7.3
SISTER	23	7.0
NEPHEW	21	6.4
FRIEND	18	5.5
SON IN LAW	9	2.7
Total	330	100

CHART 1 DEPICTS RELATION OF CAREGIVERS TO GERIATRIC PATIENT WITH PALLIATIVE CARE NEEDS.



The distribution among the gender of caregivers was almost equal .The mean age of the geriatric patients with palliative care needs was 68.2 years .Majority of the patients belong to age of 60 to 65 years(44.9%).

TABLE 2 DEPICTS DEMOGRAPHY DETAILS OF THE GERIATRIC PATIENTS WITH PALLIATIVE CARE NEEDS.

DEMOGRAPHY		
Female	48%	
Male	52%	
AGE IN YEARS	**AGE DISTRIBUTION**	%
60 – 65	148	44.90%
66 – 75	136	41.40%
Above 75	46	13.70%
TOTAL	330	100%
MEAN AGE OF THE GERIATRIC PATIENTS	68.2 years	

TABLE 3 DEPICTS THE CAREGIVER ISSUES DEALING WITH GERIATRIC PATIENT WITH PALLIATIVE CARE NEEDS.

	QUESTIONS	0		1		2		3	
		N	%	N	%	N	%	N	%
1	My life satisfaction has suffered because of the care.	55	16.7	77	23.3	141	42.7	57	17.3
2	I often feel physically exhausted.	42	12.7	67	20.3	150	45.5	71	21.5
3	From time to time I wish I could “run away” from the situation I am in.	55	16.7	71	21.5	151	45.8	53	16.1
4	Sometimes I don't really feel like “myself” as before	35	10.6	93	28.2	142	43	60	18.2
5	Since I have been a caregiver my financial situation has decreased	36	10.9	86	26.1	155	47	53	16.1
6	My health is affected by the care situation.	56	17	79	23.9	141	42.7	54	16.4
7	The care takes a lot of my own strength.	43	13	65	19.7	150	45.5	72	21.8
8	I feel torn between the demands of my environment (such as family) and the demands of the care.	54	16.4	76	23	147	44.5	53	16.1
9	I am worried about my future because of the care I give.	42	12.7	92	27.9	139	42.1	57	17.3
10	My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.	36	10.9	84	25.5	156	47.3	54	16.4

The questionnaire depicted the areas where caregiver faces burden while taking care of the elderly with palliative care needs among various palliative care categories. 60% of the caregivers reported that their satisfaction of life has suffered because of the care they offer. 61.9% felt that they were exhausted after care giving. 67% felt that they wish they could run away from the situation.61.2% felt that sometimes they don't feel like themselves. 59.1% felt that their health was affected due to care giving. 66.6% felt that they were torn between the demands of the family and care giving. 59.4% were worried about their future beyond caregiving.63.7% felt that their relationship with the families, friends is affected due to care giving. Overall, More than 60% had “agreed (2)” and “strongly agreed (3)” to the questions asked to them. These are the areas where interventions will help reduce the care giver burden.

TABLE 4 :DEPICTS THE MEAN SCORE AMONG CARE GIVER OF GERIATRIC PATIENTS WITH PALLIATIVE CARE NEEDS.

SR NO.	PRIMARY PALLIATIVE CONDITION	MEAN SCORE	%
1	PULMONARY	15.9	53.0
2	CARDIAC	17.5	58.3
3	RENAL	18.1	60.3
4	NEUROLOGICAL	17.5	58.3
5	DEMENTIA	16	53.3
6	CANCER	16.3	54.3
7	IMMOBILIZATION	16.6	55.3
8	MULTIPLE MORBIDITIES	16.1	53.7
9	ICU	16.9	56.3
10	FRAILITY	15.1	50.7
11	CHRONIC LIVER DISEASE	15.8	52.7

Table -4 shows that the mean scores assessed by question across the palliative care categories were similar. However, caregivers of the geriatric patients with end stage renal disease faced maximum burden (60.3%) and with caregivers of frail elderly had least burden (50.7%).

DISCUSSION

Majority of the caregivers in this study were the spouses of the patient. They lived with the patient and were not employed outside the home while care giving. As most of them were spouses ,they also belong to geriatric age group. Hence, caregivers of today may become care recipients of tomorrow.

The BSFC-S tool used in this study showed that the reaction to care giving varied across several care giving domains. In particular, a considerable proportion of caregiver burden was attributable to the impact that care giving has on the personal health of the caregiver and on the extent to which care giving interrupts the usual activities of the caregiver.

In this study we developed score system that considered the quality of the assistance had been provided. Composite score captured the cumulative effect of care giving on the care giver over time. Nearly 60% of the response was suggestive of increased burden such as The feeling of exhaustion, feeling to run away from situation, health being affected due to care taking, feeling of being torn between demands of family and care giving, being worried of future , relationships with family and friends being affected because of care giving and not being satisfied and feels that life has suffered because of care giving. results of analysis of predictors of caregiver burden revealed that caregivers providing greater assistance were at greater risk of high caregiver burden. Psychosocial support is being given now to the geriatric patient admitted to tertiary care hospital. Exclusive psychosocial support is recommended t in reducing care giver burden. There was no difference in care giving among the elderly with terminal illnesses. Caregivers of elderly with end stage renal disease faced a little more caregiver burden as they had an option of long term dialysis and inability to meet the financial requirement and this also added to the emotional burden.

Wolff et al[7] study revealed the caregiver burden in aging elderly and addressed it by including different measures like focused group interviews, and requirement of help while taking care of elderly.

George et al[4] dealt with study comprising on 42 caregivers coming to ER department suggested the caregiver faces burden due to finance and the exhausation they felt while handling the elderly.

Our study is encompassing caregiver burden among the caregiver of elderly with terminal illness such as end stage pulmonary, cardiac, liver, renal disease, multiple morbidities, stroke, dementia, intensive care units and frailty.

The results of this study reveal that the demands of care giving and their cumulative effect are associated with caregiver burden. Caregivers have unique and vastly different needs. Our findings suggest that caregiver interventions should have strong emphasis improving the quality provided by family caregivers by appropriate counselling.

Our hospital being NABH accredited has caregiver counselling and education regarding the diet and appropriate measures taken to handle the patient as one of the parameters .the social workers are helping of the same. The network of social workers is strong and has improved the burden of caregivers irrespective of age and disease to a great deal. However, there is still scope to improve further.

Examples of such interventions include respite care provided in the home where family caregivers receive supporting activities in daily living, or skilled nursing care designed to give the caregiver time off. Other interventions could include education, where caregivers are provided information about the patient's disease process and about resources and services that enable caregivers to anticipate and respond effectively to disease related problems.

The role of informal caregivers[1] and the impact of care giving must be recognized and incorporated into the care planning of the terminally ill elderly. Health care providers need to be aware of the potential threat to caregiver health associated with the care giving role. Exhausted caregivers of the geriatric patients today could become future care recipients, an outcome that may be preventable when the appropriate supports are provided.

CONCLUSION

Caregiver burden was common in caregivers of geriatric patients with end stage chronic diseases. There is a need to develop psycho-social worker exclusively for caregivers. to provide time to time counselling on care giving. Measures should be taken to address the caregiver burden. As the quality of care giving will improve if burden is reduced.also, we recommend that primary care giver should be given a break for few hours a day or few days a month and responsibility can v=be shared by other family members.

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