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RESEARCH ARTICLE

ASSESSMENT OF CARE GIVER BURDEN AMONG PATIENTS WITH HEART FAILURE IN A TERTIARY CARE HOSPITAL

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ABSTRACT

Objective: Identify the care giver burden among primary care givers of patients with Heart Failure and to find out the relationship between care giver burden and selected demographic and clinical variables of patients with heart failure.

Materials and methods: The quantitative research approach and descriptive design was used to accomplish the aim of the study. The setting was cardiology Inpatient and out patient units of AIMS, Kochi. Study included 40 caregivers of patients with heart failure. Data was collected using caregiver burden questionnaire for heart failure (CBQ-HF). The data was transferred to SPSS -21. Analysis were done using descriptive and inferential statistics.

Results: The results of the study show that majority of 24 subjects (60%) have mild burden, 12 subjects (30%) have moderate burden and 4 (10.0%) have severe burden. There is significant association between care giver burden and age of the client, occupation, presence of comorbidities, and exacerbation of heart failure symptoms.

Conclusion: Study throws light into the necessity for care giver education and social support which positively influence the quality of life of patients with heart failure.

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INTRODUCTION

Heart failure (HF) is one of the most common progressively debilitating disorders. Hospital readmission rates for patients with HF are 20% at 30 days and 50% at 6-12 months.¹ Based on disease-specific estimates of prevalence and incidence rates of heart failure, researchers conservatively estimate the prevalence of heart failure in India due to coronary heart disease, hypertension, obesity, diabetes and rheumatic heart disease to range from 1.3 to 4.6 million, with an annual incidence of 491 600–1.8 million.²

The Rotterdam Study, prospective population-based cohort study in 7983 participants aged > or =55 reported that prevalence was higher in men and increased with age from 0.9% in subjects aged 55–64 to 17.4% in those aged 85. Incidence rate of heart failure was 14.4/1000 person-years (95% CI 13.4–15.5) and was higher in men (17.6/1000 man-years, 95% CI 15.8–19.5) than in women (12.5/1000 woman-years, 95% CI 11.3–13.8). Lifetime risk was 33% for men and 29% for women at the age of 55. Survival after incident heart failure was 86% at 30 days, 63% at 1 year, 51% at 2 years and 35% at 5 years of follow-up. The study concluded that prevalence and incidence rates of heart failure are high. In individuals aged 55, almost 1 in 3 will develop heart failure during their remaining lifespan. Heart failure continues to be a

fatal disease, with only 35% surviving 5 years after the first diagnosis.³

As the disease progresses, it is common for the patient to experience diminished physical, psychological, cognitive and social functioning. As heart failure worsens home management of HF requires a complex and ever-changing programme of balancing, medication, diet and implanted devices with activity and symptoms. The goal of reduction of mortality, prevention and control of symptoms of dyspnoea, fatigue, edema, and anxiety and maintenance of physical and psychological well being can be daily challenge for the aging patient.¹

Consequently, the number of patient's family members who provide care at home to these patients is increasing. Moreover greater emphasis on self management for patients with heart failure requires more time and energy from the patient's family care givers to ensure adherence to complex therapeutic regimens. Although family care givers are pivotal in the care of any patient with heart failure, care giving, unfortunately, can have adverse effects, including physical, emotional, social and financial problems that often result in stress, health problems and depression.¹ Boyoung H, Kirsten E. F, Nancy A S, Kathleen D, Jill H. conducted a cross-sectional study on caregiving for patients with heart failure and impact on patients' families in the year 2011 among 76 patients in

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California. The family caregivers' perceived physical and mental health status were not significantly different from those of the general population norms ($t=-0.77$; $P=.45$; $t=1.08$; $P=.28$). The mean score for the PHQ-8 for the caregiver sample was 3.5 (SD, 4.6). Study revealed that compared with other caregivers, caregivers of patients with severe heart failure, nonspousal care givers, and care givers with low socioeconomic status and no assistance from others in care giving are more likely to feel burdened in the care giving role. Interventions for family care giving should be aimed at increasing the care giver's sense of control and social support.⁴

Issues associated with caregiving by family members of patients with heart failure have not been adequately addressed and the inconsistent findings warrant further investigation.

MATERIALS AND METHODS

The quantitative research approach and descriptive design was used for the study. The setting was cardiology Inpatient and outpatient units of AIMS, Kochi. Study included 40 caregivers of patients with heart failure.

Section I Demographic data of care giver n=40

Variables	Frequency	Percent
Age		
18 - 32 Years	0	0.0
33 - 46 Years	10	25.0
47 - 60 Years	28	70.0
Above 60 Years	2	5.0
Sex		
Male	4	10.0
Female	36	90.0
Religion		
Hindu	26	65.0
Christian	10	25.0
Muslim	4	10.0
Educational Qualification		
Illiterate	0	0.0
Primary	2	5.0
Secondary	16	40.0
Higher Secondary	12	30.0
Dilpoma	3	7.5
Graduate	4	10.0
Post Graduate	3	7.5
Occupation		
Homemaker	18	45.0
Skilled	11	27.5
Unskilled	6	15.0
Professional	1	2.5
Retired	4	10.0
Unemployed	0	0.0
Distribution of Socio-economic Status		
Below Rs. 5000	6	15.0
Rs. 5001 - 15000	10	25.0
Rs. 15001 - 25000	18	45.0
Rs. 25001 - 50000	4	10.0
Above Rs. 50000	2	5.0
Below Rs. 5000		
Distribution of Types of Family		
Nuclear	30	75.0
Joint	10	25.0
Extended	0	0.0
Relation with the Patient		
Parent	4	10.0
Spouse	25	62.5
Son / Daughter	8	20.0
Others	3	7.5

The sample was selected from the accessible population based on the sampling criteria. The sampling technique used for the

study is non – probability purposive sampling. The sample size estimated was 40. Data was collected using caregiver burden questionnaire for heart failure (CBQ-HF). Patient and care giver's sociodemographic included variables such as age, sex, marital status, education and income. In addition data on relationship with the patient, comorbid conditions, NYHA classification, duration of illness and exacerbation of heart failue were collected. The data was transferred to SPSS -21. Analysis was done using descriptive and inferential statistics.

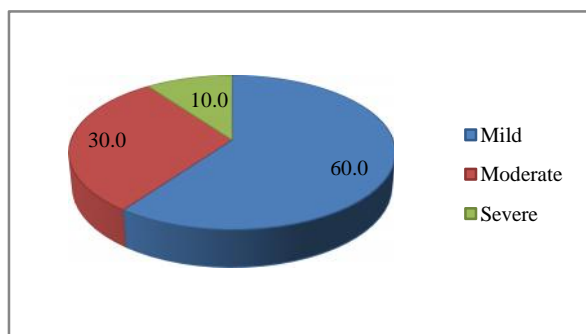
RESULTS

Around 70 per cent of the caregivers were between the age group 47 to 60 years and majority 90 percent were females. Most of the subjects were educated above higher secondary level. Majority of the care givers (45%) were home makers. Only 5% of subjects belong to low socioeconomic status. Majority (75%) were from nuclear family. Most of the care givers are 25 (62.5%) spouse of the patient.

Section II Demographic data of patient with heart failure n=40

Variables	Frequency	Percentage
Age of the Client		
40 - 50 Years	1	2.5
51 - 60 Years	10	25.0
61 - 70 Years	23	57.5
71 - 80 Years	6	15.0
Sex		
Male	29	72.5
Female	11	27.5
Educational Qualification		
Illiterate	2	5.0
Primary	8	20.0
Secondary	7	17.5
Higher Secondary	13	32.5
Graduate	8	20.0
PG and Above	2	5.0
Dropout	0	0.0
Occupation		
Employed	9	22.5
Private Employee	9	22.5
Govt. Employee	6	15.0
Retired	16	40.0
Co-morbidities		
Diabetes Mellitus	6	15.0
Dyslipedemia	19	47.5
Coronary Artery Disease	8	20.0
Hyper/Hypothyroidism	6	15.0
COPD / Aathma	1	2.5
Peripheral Arterial Disease	0	0.0
Cerebro Vascular Disease	0	0.0
Hypertension	10	25.0
Renal Failure	0	0.0
Duration of Illness		
6 - 12 Months	11	27.5
1 - 2 Years	15	37.5
2 - 4 Years	4	10.0
Above 4 Years	10	25.0
Exacerbation of Heart Failure		
Once	8	20.0
Twice	10	25.0
Trice or More	9	22.5
Nil	13	32.5

Majority of patients 23(57.5%) belong to the age group 61 - 70 Years. Duration of illness for half of the subjects is between 6 months to 2years .Number of hospitalization was once for 20%, twice for 25%, more than thrice for 22.5%.



Section III a Distribution of Care-giver Burden
Figure1. Distribution of Care-giver Burden

The pie diagram clearly shows that majority of the subjects (60%) had mild burden, whereas 30% presented with moderate burden and 10% showed severe burden. As more than half of the patient's had recently diagnosed illness (less than two years) the probability of mild burden to proceed to moderate to severe category is high.

Section III Area wise analysis of Caregiver burden

Table 1 Item wise analysis of care giver burden with respect to components of caregiver burden questionnaire.

Domains / Areas	Mean	Median	SD	Mean %	Minimum	Maximum
Physical Well-being	11.0	10.5	4.85	43.9	5	24
Emotional Well-being	35.0	30.0	12.66	58.3	17	66
Social Life and Relationships	4.3	4.0	1.88	43.0	2	10
Life Style	9.1	8.0	4.40	45.3	4	19

The subjects mean scores and mean percentages of scores in relation to various components of the caregiver burden questionnaire. It is evident from the table that emotional well being is the area which is mostly affected 35.0(58.3%). The second affected area is physical well being. The least involved area is social life and relationships.

Section IV Association between Caregiver burden and clinical and demographic variables. n= 40

Variables	Fischer's value	P - value
Age of the client	11.707	0.030
Occupation	11.508	0.033
Co morbidities	14.871	0.019
Exacerbation of heart failure symptoms	11.287	0.038
NYHA Classification	13.435	0.011

The calculated fishers exact test value in case of age of client, Occupation, comorbidities, exacerbation of heart failure symptoms and NYHA classification were less than p value 0.05. So, there is significant association between these socio demographic variables and caregiver burden. Study revealed that there is progressive burden in care giving as the age increases and male partners experience more burden as when compared to female partners. Another significant finding is caregiver burden increases with duration of illness, exacerbation of heart failure symptoms and with higher NYHA classification. No statistical association was found between other socio demographic variables with caregiver burden.

DISCUSSION

The results of the present study show that majority of 24 subjects (60%) have mild burden, 12 subjects (30%) have

moderate burden and 4 (10.0%) have severe burden. A descriptive study on Caregiver burden among partners of patients with chronic heart failure perceived caregiver burden as medium in 30% of the partners. The patients' Physical Component Score of SF-36 ($p < 0.001$), partners' Mental Component Score of SF-36 ($p < 0.001$) and perceived control ($p < 0.01$) accounted for 39% of the variance in caregiver burden. These results are consistent with the present study findings. Another study by Agren S with the same title reported moderately poor physical and emotional health-related quality of life among care givers ($p < 0.001$)⁶

A survey of caregivers of breathless patients with lung cancer or heart failure revealed that higher burden is associated with poorer 'quality of patient care' and worse carer psychological health ($R(2) = 0.37$, $F = 12.2$, $p = 0.01$). Caregiver depression and looking after more breathless patients were associated with fewer positive caring experiences ($R(2) = 0.15$, $F = 4.4$, $p = 0.04$) that is as same as in the present study where psychological well being was mostly affected (58.3%)⁷.

Investigator found that there is significant association between care giver burden and age of the client, occupation, presence of comorbidities, and exacerbation of heart failure symptoms ($p < 0.05$). A descriptive study on 357 partners of patients with heart failure revealed significant association between care giver burden and disruption of daily schedule and loss of physical strength. No associations were found with age, co-morbidity and LV ejection fraction.⁸

A descriptive study on Family caregiving in heart failure describes the similar findings as performing household tasks and managing patient behaviors were most difficult, and the caregiver's emotional and financial well-being, time for social activities, and general health had deteriorated.⁹

Whereas one of the contradictory studies on caregiver burden in partners of Heart Failure patients; limited influence of disease severity gives finding that there are no prospective effects of the patient's distress on the spouse's health, however, suggesting that partner distress had asymmetric health consequences for patients and spouses.¹⁰

All the previous study findings show that there is significant caregiver burden among patients with heart failure with varying involvement in different domains such as physical and emotional wellbeing, lifestyle social life and relationships.

CONCLUSION

Study findings reinforce the importance of assessing the needs of family members who provide care for patients with heart failure. The assessment should be initiated during the patient's hospitalization to minimize the negative impact of caregiving on caregivers' health. In addition, clinicians should provide extra support for family caregivers during the period immediately after hospitalization. Care and support from a partner are important for the well-being of patients with heart failure and may potentially delay disease progression. In congruent with the present study, many studies draw the same inference that care giving is associated with burden and stress.

Studies are needed in larger samples to identify needs of vulnerable populations of caregivers of patients with heart failure and to develop and test interventions for improving caregivers' outcomes.

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