



CARE BURDEN OF CAREGIVERS OF HEMODIALYSIS PATIENTS

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ABSTRACT A descriptive study to assess the care burden of caregivers of hemodialysis patients. The objectives were to assess the care burden of caregivers of hemodialysis patients, to determine the association between care burdens of caregivers of hemodialysis patients with the selected socio-demographic variables. A qualitative research approach and non-experimental descriptive design was adopted for the study. Data was collected by using Zarit Burden Interview (ZBI). The collected data from 60 primary caregivers of hemodialysis patients at KGMU selected by purposive sampling technique and was analyzed using descriptive and inferential statistics. Maximum caregivers had mild to moderate level of care burden (43.3 %), 38.3% had moderate to severe level of care burden, 11.7% has no to minimal level of care burden and 6.7% had severe level of care burden. According to domains of care burden, highest mean care burden score (12.5) was in the domain of burden in the relationship, 10.3 mean care burden score in emotional well-being, 7.6 mean care burden in loss of control over one's life, 5.2 mean care burden score in social & family life, and 2.9 mean care burden score in finances. The association of selected socio-demographic variables with care burdens of caregivers of hemodialysis patients was found to be non-significant at $p < 0.05$. Hence it was concluded that maximum participants had mild to moderate care burden in the domain of burden in the relationship. Effective measures could be planned to meet the needs of these caregivers at different settings.

KEYWORDS : Care Burden, Caregivers, Hemodialysis**I. INTRODUCTION**

Hemodialysis is the most commonly employed renal replacement therapy in patients with chronic kidney disease (CKD). Caring an individual with a CKD may cause an additional stress for the family members, who also make efforts to struggle against difficult situations imposed by the chronic illness.¹ Caregiver burden is a common response to the problems and challenges associated with caregiving. Generally, caregiver burden encompasses physical, psychological and emotional responses.²

Family members are those who provide the most intensive support to the patients and who suffer the most from the burden of this care.³ Chronic illness of one of the family members concerns the whole family due to its economic and psychosocial consequences, and affects their lifestyles.^{4,5} Recent studies has reported moderate care burden with a higher burden of care in female caregivers and in those who were being employed by an income-generating job, having difficulty in meeting their health expenses, reporting that their role in the family and work is negatively affected, and giving care longer than 5 years.⁶ Previous research studies indicate that higher levels of family support are associated with lower psychological distress among caregivers⁷ and suggests that, when possible, family counselling or some other family-focused service is needed to increase a caregivers' emotional support from other family members.⁸

II. MATERIALS AND METHODS

A descriptive study was conducted to assess the care burden of caregivers of hemodialysis patients in the Department of Nephrology, KGMU, Lucknow, Uttar Pradesh. The objectives were to assess the care burden of caregivers of hemodialysis patients, to determine the association between care burdens of caregivers of hemodialysis patients with the selected socio-demographic variables.

Research Design & Approach: A qualitative research approach and non-experimental descriptive design was adopted for the study.

Target Population: Primary Caregivers of Hemodialysis Patients in KGMU

Sampling Technique: Non-probability Purposive sampling technique
Sample Size and sample size calculation: for the present study, 60 participants were taken Sample size was calculated on the basis of variation in caregiver burden scale score and its overall average in the study population (caregivers of patient undergoing hemodialysis) using the formula

$$n = (z\alpha)^2 \sigma^2 / d^2$$

Where $\sigma = 14.2$, the SD of caregiver burden scale score (according to the reference paper by Kilic Hulya Firat, Kaptanogullari Hakan, 2017)⁹

$d = 10\%$ of mean ($=39.3$) caregiver burden scale score with type II error $\beta = 10\%$ for detecting results with 90% power of study

Type I error $\alpha = 5\%$ corresponding to 95% confidence level.

Then the required sample size $n=50$

INCLUSION CRITERIA:

The study will be performed on the people who:

- Are aged 18 years or above.
- are primary caregivers of hemodialysis patients in Department of Nephrology, KGMU, Lucknow

EXCLUSION CRITERIA:

The study will not be performed on the people who:

- Cannot read English or Hindi language.
- Are not willing to participate.

Description of the tool: The tool had 2 sections.

- **Section A:** Sociodemographic variables: age, gender, educational qualification, marital status, number of children, relationship to the patient, income-generating job, monthly family income, duration of the illness.
- **Section B:** Zarit Burden Interview (ZBI) a 5-point scale was used after obtaining proper User Licence Agreement to assess the Care Burden of Caregivers of Hemodialysis Patients. It was composed Likert-type 22 items.
- 0= Never 1= Rarely 2= Sometimes 3= Frequently 4= Nearly always

The validity and reliability of the scale has been evaluated by various researchers and the tool was found to be highly reliable.¹⁰

Data Management and Analysis: Data will be analyzed by descriptive and inferential statistics (frequency distribution, mean, standard deviation, and chi-square). Criterion measure was set to determine the levels of care burden. (Fig 1)

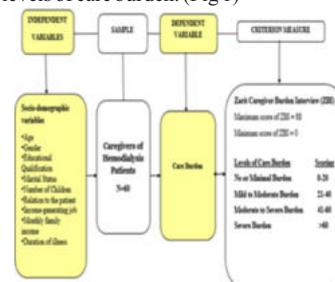


Fig. 1 Research Design

Ethical considerations: Approval from KGMU Research Ethical Committee was taken. Anonymity of the subjects and confidentiality of information was maintained. Informed written consent from subjects was obtained.

III. RESULTS

Finding related to sample characteristics:

Maximum primary caregivers were in the age group of 18-28 years (43.33%), 61.67% were males, 26.67% had primary education, 65% were married, 36.67% had no children, 36.67% were son/daughter of the hemodialysis patients, 53.33% had no income-generating job, 61.67% had monthly family income of <5000 rupees and 45% primary caregiver's patients had >2 years of duration of illness. (Table 1).

Table 1: Frequency, Percentage Distribution, Mean, Standard Deviation & Chi square of Caregivers of Hemodialysis Patients according to Socio-Demographic Variables

Socio-Demographic Variables	Primary Caregivers (N=60)				
	n	Percentage (%)	Mean	SD	p-value
1. Age (in years)					
a) 18-28	26	43.33	34.04	13.42	0.373
b) 29-38	17	28.33	44.18	8.97	
c) 39-48	10	16.67	37.30	18.86	
d) 49-58	5	8.33	36.20	9.34	
e) >58	2	3.33	59.50	16.26	
2. Gender					
a) Male	37	61.67	37.59	14.95	0.588
b) Female	23	38.33	40.04	12.75	
3. Educational qualification					
a) Illiterate	9	15.00	47.22	8.38	0.313
b) Primary	16	26.67	44.00	9.56	
c) Secondary	11	18.33	37.09	13.52	
d) Senior secondary	7	11.67	35.43	9.54	
e) Graduation & above	16	26.67	30.06	18.02	
4. Marital status					
a) Married	39	65.00	41.05	12.29	0.404
b) Unmarried	21	35.00	33.71	15.99	
c) Widow /widower	0	0.00	0.00	0.00	
d) Divorced/ separated	0	0.00	0.00	0.00	
5. Number of children					
a) None	22	36.67	33.32	15.72	0.803
b) 1-2 children	19	31.67	40.05	13.46	
c) 3 & more	19	31.67	42.89	10.90	
6. Relation to the patient					
a) spouse	17	28.33	39.41	9.28	0.558
b) son/daughter	22	36.67	38.77	17.79	
c) parent	3	5.00	28.00	3.00	
d) other	18	30.00	39.56	14.08	
7. Income-generating job					
a) yes	28	46.67	39.64	13.43	0.486
b) no	32	53.33	38.47	14.90	
8. Monthly family income					
a) <5000	37	61.67	35.11	14.13	0.183
b) 5001-10000	18	30.00	44.78	10.58	
c) 10001-20000	3	5.00	49.67	16.26	
d) >20000	2	3.33	27.50	14.85	
9. Duration of illness					
a) <1yr	19	31.67	34.84	9.71	0.790
b) 1-2yrs	14	23.33	41.36	12.26	
c) >2yrs	27	45.00	39.56	17.03	

Finding related to care burden of caregivers of hemodialysis patients

Maximum caregivers had mild to moderate level of care burden (43.3%), 38.3% had moderate to severe level of care burden, 11.7% has no to minimal level of care burden and 6.7% had severe level of care burden. (Fig. 2).

According to domains of care burden, highest mean care burden score (12.5) was in the domain of burden in the relationship, 10.3 mean care burden score in emotional well-being, 7.6 mean care burden in loss of control over one's life, 5.2 mean care burden score in social & family life, and 2.9 mean care burden score in finances. (Fig. 3)

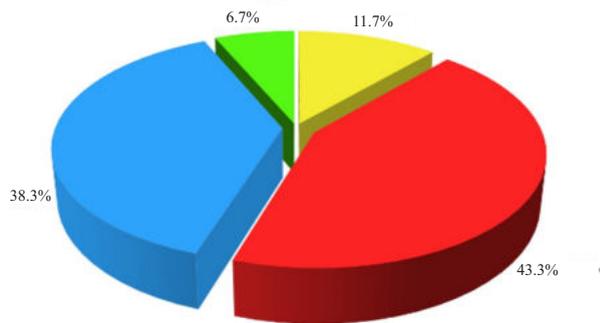


Fig 2: Percentage Distribution of Caregivers of Hemodialysis Patients according to Levels of Care Burden

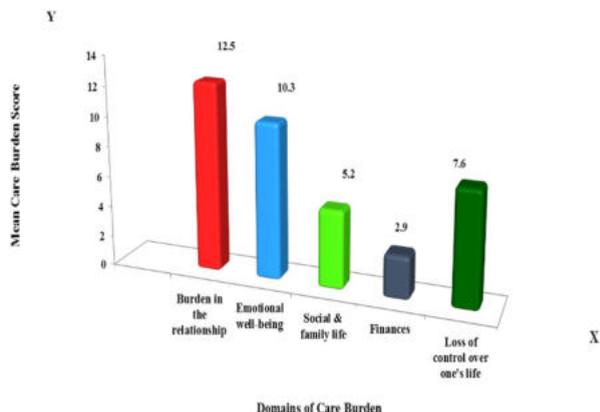


Fig. 3: Percentage Distribution of Caregivers of Hemodialysis Patients according to Domains of Care Burden

Finding related to association of care burden of caregivers of hemodialysis patients with socio-demographic variables

The association of selected sociodemographic variables with care burdens of caregivers of hemodialysis patients was found to be non-significant at p<0.05. (Table 1)

IV. DISCUSION

In the present study, higher care burden score was among caregivers of age >58years, who were females, illiterate, married, with 3 or more children, with an income generating job, and giving care for 1-2 years. However, no significant association was found. These results were similar to the study done by **Cagan O et al.**¹¹ which found a higher burden of care among caregivers of age 50-59 years, in female caregivers and in those who were being employed by an income-generating job and giving care longer than 5 years however without any significant association between the burden of care and related factors. Study done by **Zhang R et al.**¹² also had similar findings, which assessed the burden for caring patients on maintenance hemodialysis by primary family caregivers. Social and demographic factors including age, educational levels, caring hours and relationship with patients were correlated with the severity of burden. Similar to our study, maximum (51%) caregivers had mild to moderate care burden. Age was found to be significantly correlated with care burden. The higher educational levels of caregivers were associated with lesser burden. The study by **Alnazly EK et al.**¹³ revealed that the majority of caregiver subjects reported social isolation, health problems, and little time for self-care. Factors alleviating caregiver burdens included faith in God, participating in religious practices and venting of feelings. The study concluded that identification of caregiver burdens and of coping strategies should help healthcare professionals understand the caregivers' burdens and identify their needs by patients receiving hemodialysis to relieve their psychosocial and physical burdens.

V. CONCLUSION

Chronic diseases affect not only the patients, but also their caregiving relatives. The knowledge of the caregiver burden and influencing

factors is of utmost importance to protect health of the patients and plan treatment and care methods, and nursing services.¹⁴ The caregivers of dialysis patients face various challenges and complex problems due to emotional, economic, cognitive and social limitations due to chronic renal failure. Taking an important place in supporting patients, caregivers must be provided sufficient social and physical support.^{15,16}

It is recommended that this study could further be replicated on a larger sample using different research designs and at different settings for better generalization of the results. Effective interventions could be planned for the caregivers to help them cope and reduce their burden.

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