

Original Paper

The Burden of Caregivers of Patients Undergoing Hemodialysis



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ABSTRACT

Introduction: There is a scarcity of literature about the burden of hemodialysis patients' caregivers. Caregivers often receive little attention, and the primary focus is always on the patients. Frequent hospitalizations and factors associated with the disease can lead to depression and reduce the caregiver's quality of life.

Objective: The study aimed to determine the burden of caregivers of patients undergoing hemodialysis at a tertiary care hospital.

Materials and Methods: This cross-sectional analytical study was conducted in a tertiary care hospital in northern India. A total of 110 caregivers who were providing care to their patients for more than 3 months were selected by purposive sampling method. The study data were collected by self-prepared demographic questionnaire to collect basic information regarding patients and caregivers, and the level of burden was assessed by a revised Zarit Burden Interview (ZBI) standardized on a 5-point scale. Descriptive and inferential (the Chi-square and Fisher exact test, 1-way ANOVA test) statistics were used for data analysis.

Results: The Mean±SD age of caregivers was 37±13 years. Nearly half of caregivers, 50 (45.46%), reported mild to moderately burdened, while 15 (13.63%) caregivers had moderate to severely burdened. The caregivers were mild to moderately burdened as the mean burden score was 25±12. There was no significant association between the levels of burden scores and selected sociodemographic variables of the participants.

Conclusion: It was found that caregivers of hemodialysis patients experienced moderate burden while caring and being with the patient, which may alter their health and quality of life.

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Highlights

- Patients with lifelong chronic kidney disease are dependent on family members for their routine activities.
- Caregivers spent most of the time caring for hemodialysis patients, which results in a burden.
- It is essential for health care professionals to identify the burden of caregivers of hemodialysis patients and develop appropriate interventions.

Plain Language Summary

This study aimed to determine the perceived burden of caregivers of patients undergoing hemodialysis at a tertiary care hospital. In India, caregivers do not receive much attention. They spent most of the time assisting personal hygiene, administering medicines, feeding, and taking the patient to health care centers for dialysis and routine health care. This condition results in physical, psychological stress, and gradually caring for family members becomes a burden that cannot be expressed with everyone. This study reported that nearly half of the caregivers were mild to moderately burdened, and few had a severe level of burden. At this point, it is essential for the nurse or other health care personal to explore these burden and plan for appropriate interventions which can help caregivers to maintain their health at an optimum level.

Introduction

Chronic Kidney Diseases (CKDs) are among major health problems, and most of the patients need to undergo dialysis or a kidney transplant [1]. The patients with End-Stage Renal Diseases (ESRD)/CKDs often rely on informal caregivers to help them with their everyday living [2] and medical needs, including administration of medicines, driving the patient to the hospital for dialysis and routine/emergency check-ups, maintenance of personal hygiene and appropriate renal diet. These unpaid caregivers are usually family members, friends, or relatives [3]. The number of dialysis patients in India is estimated to be 174478 in 2018, and each year approximately 210000 new patients develop kidney failure. So the need for dialysis will increase over time. However, there is a lack of information about the number of dialysis patients in Uttarakhand state [4]. Caregivers often receive little attention, and the main focus has remained on the patients. Most of the time, family members are busy caring for the patient resulting in social isolation, the decline in physical and psychological health, low coping capacity, poor sleep quality, and loss of working hours [2]. Frequent hospitalizations and factors associated with the disease can lead to depression and reduce the caregiver's quality of life. Therefore, the evaluation of caregivers' status and determination of their needs is critical [5, 6].

A study conducted by Nagarathnam et al. [7] on the burden and quality of life of caregivers of hemodialysis patients in the southern part of India concluded that caregivers experienced moderate to severe burden, which affected their quality of life. In contrast, another study conducted in Nepal by Shakya et al. [8] stated that caregivers experienced severe burden while caring for their patients undergoing hemodialysis. The number of dialysis patients is significantly increasing in one of the tertiary care institutes in the region. It is becoming of utmost importance to explore the burden experienced by caregivers as there is a lack of data about burden among caregivers in this northern part of India. Therefore, we planned to determine the burden of caregivers of hemodialysis patients at a tertiary care hospital in Uttarakhand.

Materials and Methods

This cross-sectional study was conducted at a tertiary care hospital in the northern part of Uttarakhand, India, to determine the perceived burden of hemodialysis patients' caregivers. At the center, 56 hemodialysis patients were regular patients, and 97 were referred patients during the study period. Of 153 patients, 110 patients' caregivers of hemodialysis during 6 months from March to August 2019 were recruited as study participants. Caregivers who provided care to the patient for more than three months, aged between 18-75 years, and can read and understand Hindi or English were included in the study. Simultaneously, caregivers of hemo-

dialysis patients other than chronic kidney disease and those who were not willing to participate in the study were excluded from the study.

The sample size was estimated using online Raosoft [9], where the study population size, which was 153 based on the 5% margin of error and 95% confidence level. The estimated sample size was 110 participants. A sample of 110 eligible participants who met the inclusion and exclusion criteria were selected using the purposive sampling technique.

The questionnaire consisted of two sections: 1. Questionnaire of sociodemographic characteristics; and 2. Zarit Burden Interview (ZBI) scale to determine the burden of caregivers. The revised version of ZBI in Hindi language (Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit) [10] contains 22 items. It is a standardized, pretested and reliable tool ($r=0.93$) [11, 12]. The ZBI has been used in India to determine the burden of caregivers of patients suffering from other non-communicable diseases in India [13, 14]. Each item is scored using a 5-point scale. Response options range from 0 (never) to 4 (nearly always). The burden interview is scored by summing the responses of the individual items. The score range is from 0 to 88, and higher scores indicate greater caregiver distress. The level of subjective burden was determined according to the following scoring: (0-20) no burden to little burden, (21-40) mild to moderate, (41 to 60) moderate to severe burden, and (61 to 88) severe burden.

Caregivers who were accompanying their patients in the hemodialysis center were included as study partici-

pants. Written consent was taken after explaining the purpose of the study and developed rapport with the caregivers. Demographic information from participants was obtained through self-reported interviews, and standardized questionnaires were filled by the researchers using the ZBI.

The obtained data were coded and then entered into Excel sheets, and SPSS V. 21 was used for statistical analysis. Descriptive and inferential statistics were used for data analysis. Sociodemographic characteristics and ZBI scores were presented using frequency and percentage. One-way Anova test for continuous variables and categorical Chi-square and Fisher exact test were used to determine the association of ZBI scores with selected demographic variables of participants at 0.05 level of significance.

Results

The Mean \pm SD age of the patients and caregivers were 47 \pm 17.94 and 37 \pm 13 years, where the majority of caregivers were male 63 (57%), married 80 (73%), and were from joint family 58 (53%), and one-third of participants were spouse 41 (37%), graduated 39 (35%) and working in a private job 42 (38%). The majority of caregivers, 60 (55%) were spending 5-10 hours per day caring for their patients, and 67 (61%) were caring for their patients from 3-6 months duration (Table 1).

The Mean \pm SD total score of Zarit burden was 25 \pm 12 (range 0-88). The majority of caregivers (45.46%) reported mild to moderate burden, while 39.10% of caregivers had no burden, 13.63% caregivers had moderate

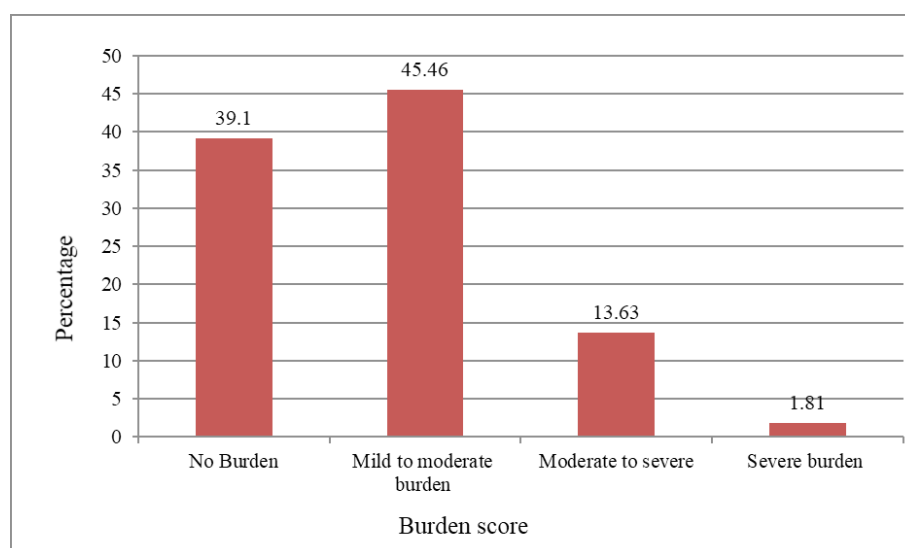


Figure 1. Distribution of Zarit burden inventory score

Table 1. The sociodemographic characteristics of caregivers (N=110)

Variables		No. (%)
Gender	Female	63 (57)
	Male	47 (43)
Marital status	Married	80 (73)
	Unmarried	29 (26.1)
	Divorced	1 (0.9)
Type of family	Nuclear	52 (47)
	Joint	58 (53)
Relation with the patient	Son	31 (28)
	Daughter	13 (12)
	Spouse	41 (37)
	Other	25 (23)
Educational qualification of the caregivers	Illiterate	23 (21)
	Primary	13 (12)
	Senior secondary education	35 (32)
	Graduation Post graduation	39 (35)
Occupation of the caregivers	Government service	29 (27)
	Private Job	42 (38)
	Own business	28 (25)
	Other	11 (10)
Number of hours per day for caring (h)	<5	41 (37)
	5-10	60 (55)
	>10	9 (8)
Duration of care (m)	3-6	67 (61)
	6-9	28 (25)
	9-12	13 (12)
	12	2 (2)

to severe burden, while only 2 (1.81%) experienced severe burden (Figure 1).

The Chi-square and Fisher exact test was used to determine the association of burden score with selected demographic variables. There was no statistically significant association between caregiver burden score and selected sociodemographic characteristics (Table 2).

Discussion

In this study, the perceived level of burden was explored among 110 caregivers of hemodialysis patients. Although in health care facilities, hemodialysis patient receives the quality of care, but there is no evidence regarding kind of measures taken for caregivers of hemodialysis patients as they also go through the crisis at

Table 2. Association of Zarit burden inventory score with sociodemographic variables (N= 110)

Variables		Zarit Burden Inventory Score (0-88)				Sig.
		No Burden (n=43)	Mild to Moderate (n=50)	Moderate to Severe (n=15)	Severe (n=2)	
Age of patient (y)		48.6±16.75	43.9±18.32	51.4±20.26	57.0±2.28	0.34**
Age of caregivers (y)		37.88±13.06	34.96±13.57	35.53±14.67	38.5±10.6	0.08**
Gender	Male	20	22	4	1	0.565*
	Female	26	25	11	1	
Marital Status	Married	34	36	9	1	0.481*
	Unmarried	11	11	6	1	
	Divorced	1	0	0	0	
Type of family	Nuclear	23	20	7	02	0.313*
	Joint	23	27	8	0	
Relation with patient	Son	10	7	3	1	0.853*
	Daughter	3	7	2	1	
	Spouse	16	14	4	1	
	Other	17	19	6	0	
Education of caregiver	Illiterate	08	11	3	1	0.880*
	Primary	12	15	3	0	
	Senior secondary	13	10	5	0	
	Graduation/Post Graduation	13	11	4	1	
Number of hours spent per day	<5	19	15	4	1	0.869*
	5-10	24	27	15	1	
	>10	1	1	1	1	
Occupation of caregiver	Government Job	7	3	2	0	0.800*
	Private Job	20	20	6	2	
	Own business	2	5	1	0	
	Others	17	19	6	0	

*Fisher exact test; ** One-way ANOVA test.

personal and professional front. Therefore, the present study was carried out to determine the caregiver's burden of hemodialysis patients so that remedial measures can be taken to address the issues and challenges faced by them and enhance the ability of caregivers to take care of their loved ones.

In the present study, the majority of the subjects were middle-aged, and their average age was more than 40 years, where Kilic et al. [15] reported lower mean age. In the present study, more than half of caregivers were male and married, consistent with a study conducted by Mashayekhi et al. [16]. The present study demonstrates that more than one-third of caregivers were spouses followed by sons, which is consistent with the study

conducted by Kilic et al. [15], where most caregivers were spouses followed by their children. This finding, however different from a study done by Sotoudeh et al. [17], where the majority of caregivers were relatives.

Concerning the education qualification of caregivers, the present study showed that one-third of caregivers were graduate and postgraduate, which is inconsistent with investigations conducted by Jafari et al. [18] and Joy et al. [19], where half of the caregivers' qualification was under diploma and illiterate.

This study was an effort to provide an understanding of the burden faced by caregivers of hemodialysis patients. In the present study, caregivers' burden score was mild to moderate, consistent with the studies conducted by Joy et al. [19] and Usman Shah et al. [5], where the majority of caregivers experienced mild to moderate burden, i.e. 52% and 45%, respectively. Whereas the study was done by Sajadi et al. [20], caregivers experienced moderate to severe burden, which is not in line with the present study burden score. We found that the caregivers experienced mild to moderate burden though most caregivers spent 5-10 hours caring for their loved ones. This result may be because strong family ties are embedded in the Indian culture and tradition where people consider caring for their sick family members or relatives as a responsibility rather than as a burden.

The Mean \pm SD total ZBI score of caregivers in the present study was 25 \pm 12, which is inconsistent with studies were done by Adejumo et al. with lower [21] and higher ZBI scores Senmar et al. [22]. These differences could be due to different socio-cultural, economic, and availability of health care services, which can influence the patient and family care. Also, Adejumo et al. [21] used a modified ZBI questionnaire with 12 questions was used in our study. In contrast, Senmar et al. [22] used Novak and Guest caregiver burden inventory to assess the burden of caregivers.

The current study did not show any significant association of burden score with selected demographic variables like gender, marital status, type of family, relation with patient, and education qualification of caregivers, which is inconsistent with the study conducted by Mashayekhi et al. [16], where there was a significant association with gender, relation with patient and educational qualification. In contrast, Joy et al. [19] showed a substantial relationship with caregiver gender, duration of caregiving, time spent per day for caregiving.

It was found that caregivers of hemodialysis patients experienced mild to the moderate burden while caring

and being with the patient most of the time, which may alter their health and quality of life. In the context of holistic health conception, it is essential to evaluate and care for hemodialysis patients and their caregivers together. There is a great need to recognize and address the inevitable stress and subjective burden caregivers encountered. Along with patients, it is also essential to identify the condition of caregivers and timely intervene in terms of counseling, teaching about patient care, and coping mechanisms. A large scale multistate study is recommended due to the lack of literature on caregivers' burden. Although we had calculated the sample size based on the population in 2019 from one center only, we did not include other hemodialysis centers, which could be one of the limitations of the present study. Thereby it is difficult to generalize the findings of the present study. The other variables such as quality of life, perceived social support, depression, and anxiety also could have been studied.

Ethical Considerations

Compliance with ethical guidelines

Ethical permission was obtained from the Institutional Ethics Committee (IEC) with letter No. AIIMS/IEC/19/53. The participants were informed about the research's purpose and ensured anonymity and confidentiality of the information. A written informed, voluntary participation consent was obtained from each participant.

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Authors contributions

Study concept: Maneesh Sharma and Pooja Lakhara; Writing the original draft: Maneesh Sharma, Pooja Lakhara, and Prasuna Jelly; Data collection: Pooja Lakhara; Data analysis: Maneesh Sharma, Suresh K Sharma, and Rakesh Sharma; Reviewing the final edition: All authors.

Conflict of interest

The authors declared no conflict of interest.

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