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Original Article

Burden and its Determinants among Caregivers of Patients undergoing Hemodialysis

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Abstract

Background
Chronic kidney disease affects more than ten percent of general population worldwide. Patients with end-stage renal disease require lifelong renal replacement which affects patient's functioning leading to disruption of conventional lives of both patients and caregivers.The objective of this study was to identify the level of caregiver burden and to identify its determinants.

Materials and Methods
A cross-sectional study was conducted in the dialysis unit of Nobel Medical College Teaching Hospital, Biratnagar from November 2024 to January 2025 following ethical approval. A total of 170 respondents were selected through convenience sampling. Data were collected via face-to-face interviews using a structured questionnaire, including sociodemographic details and Zarit Burden Scale. Statistical analysis was performed using SPSS, with ordinal logistic regression used to identify determinants of caregiver burden.

Results
Present study showed that majority of the respondents (72.4%) experienced mild to moderate burden, less than two-fifths (15.3%) experienced moderate to severe burden, few of the respondents(9.4%) experienced little or no burden,and only2.9%experienced severe burden. Marital status, habit of alcoholism, smoking or substance use, patient's sex, duration of dialysis, availability of caregiving support and difficulty in meeting health expenses were identified as key determinants of caregiver burden. (p<0.05)

Conclusion
This study showed that majority of the caregivers experienced mild to moderate burden. Marital status, habit of alcoholism, smoking or substance use, patient's sex, duration of dialysis, availability of caregiving support, and difficulty in meeting health expenses were identified as key determinants of caregiver burden.

Keywords: *Caregiver Burden, Kidney Failure, Renal Dialysis*

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Introduction

Chronic kidney disease (CKD) impactsover ten percent of the global population [1]. Since 1990, the number of individuals receiving dialysis for End-Stage Renal Disease (ESRD) has risen significantly, with a 43.1% increase [2]. In 2018, the median prevalence of renal replacement therapy globally was 759 per million population [3]. Prevalence of new ESRD was 11.36% according to a hospital-based study in Chitwan, Nepal from 2016 to 2018 [4].

Patients with ESRD require lifelong renal replacement which affects patient's functioning leading to disruption of conventional lives of both patients and caregivers [5]. Caregivers of hemodialysis patients experience a great deal of burden owing to constant requirement of assistance and care [6]. Physical work, emotional pressure, social restrictions, and economic demands significantly increase the burden leading to impaired quality of life compared to the individuals of same age and sex groups in society [6, 7].

Materials and Methods

A cross-sectional study was conducted in the dialysis unit of Nobel Medical College Teaching Hospital (NMCTH), Biratnagar from November 2024 to January 2025 following ethical approval from the institutional review committee (IRC) of NMCTH. Verbal and written informed consent were obtained from all the respondents before data collection. The study included adult caregivers aged 18 and above who had been caring for patients for at least one month and caregivers unwilling to participate were excluded. The sample size was calculated using Cochran's formula, $n=Z^2pq/d^2$ where, Z= 1.96 at 95% confidence level, p= 11.36%= 0.1136,[4] q= 1-p, i.e., 0.886, d= 0.05 and adding a 10% non-response rate, the required sample size was determined to be170. Respondents were selected using convenience sampling method. Data were collected through face-to-face interviews using Zarit Burden Scale to measure caregiver burden which was obtained from e-provide. Data were analyzed using SPSS version 20, for descriptive statistics, mean, standard deviation, frequency and percentage were calculated and for inferential statistics, ordinal logistic regression was used to identify the determinants of caregiver burden.

Results

Table 1. Sociodemographic Characteristics of the Respondents n=170

Variables	N	%
Age		
Mean± SD 40.57± 12.32		
Sex		
Male	67	39.4
Female	103	60.6
Education		
Less than secondary	90	52.9
Secondary and above	80	47.1
Employment		
Unemployed	23	13.5
Employed	147	86.5
Income		
More than or equal to expenses	42	24.7
Less than expenses	128	75.3
Marital status		
Married	142	83.5
Unmarried	28	16.5
Alcoholism, smoking or substance use		
Yes	31	18.2
No	139	81.8
Relationship with patients		
Spouse	95	55.9
Parent	14	8.2
Offspring	38	22.4
Other	23	13.1

Table 1 shows that the majority of respondents (60.6%) were female, with an average age of the respondents being 40.57±12.32 years. Nearly half (47.1%) of respondents had completed secondary education and above, and most of the respondents (86.5%) were employed, with the clear majority (75.3%) saying that their income was insufficient to cover expenses. A significant proportion (80%) of respondents were married.

A vast majority (81.8%) reported no habits of alcoholism, smoking or substance use. More than half (55.9%) of the caregivers were the patient's spouse.

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Table 2: Patient Information and Caregiving Details n=170

Variables	N	%
Patient's age		
Mean± SD 48.05± 14.33		
Patient's sex		
Male	117	68.8
Female	53	31.2
Comorbidity		
No	43	25.3
Yes	127	74.7
Duration of dialysis		
Less than 1 year	48	28.2
1-3 year	95	55.9
More than 3 years	27	15.9
No. of dialysis in a week		
Once	6	3.5
Twice	107	62.9
Thrice	57	33.5
Average hour of caregiving in a day		
Mean± SD 12.94± 6.73		
Support in caregiving		
Yes	103	60.6
No	67	39.4
Difficulty in meeting health expenses		
Yes	152	89.4
No	18	10.6

Table 2 depicts that the majority of the patients (68.8%) were male with a mean age of 48.05±14.33 years. A substantial proportion (74.7%) had comorbid conditions. More than half (55.9%) had been undergoing dialysis for 1-3 years, with the majority (62.9%) attending dialysis sessions twice per week

The respondents reported that they spent an average of 12.94±6.73 hours per day on caregiving. The majority (60.6%) of the respondents had some form of caregiving support and a significant proportion (89.4%) faced difficulty in covering health expenses.

Table 3: Level of caregiver burden n=170

Level	N	%
Little or no burden	16	9.4
Mild to moderate burden	123	72.4
Moderate to severe burden	26	15.3
Severe burden	5	2.9

Table 3 illustrates that a significant majority of the respondents (72.4%) experienced mild to moderate burden and a very few (2.9%) experienced severe burden

Table 4: Model fit and assumption

Model fit and assumption test	p-value
Model fitting information	0.00
Goodness of fit	1.00
Pseudo R-square	0.25
Test of parallel lines	1.00

Table 3 shows that model fitting information was significant (p=0.00) which indicated significant improvement in predicting the outcome in the model. The goodness of fit of ordinal logistic regression model was assessed using the deviance goodness of fit test p=1.00 which indicated acceptable fit. The proportional odds assumption was tested using the test for parallel lines which was not significant (p=0.21) confirming that the assumption was met validating the use of ordinal regression. The model explained a 25% variation in the outcome showing moderate predictive power (McFadden's R-square =0.25)

Table 5: Determinants associated with respondent's characteristics n= 170

Variables	Estimates (â)	Odds ratio (95%CI)	p-value
Age	0.30	1.03 (-0.02, 0.08)	0.31
Sex			
Male	0.03	1.03 (-0.99, 1.05)	0.95
Female	0	-	-
Education			
Less than secondary	1.07	2.94 (0.35, 1.80)	0.05
Secondary and above	0	-	-
Employment			
Unemployed	-0.23	0.79 (-1.25, 0.79)	0.65
Employed	0	-	-
Income			
More than or equal to expenses	0.54	1.11 (-0.69, 0.90)	0.79
Less than expenses	0	-	-
Marital status			
Married	2.82	16.85 (0.43, 5.21)	**0.02**
Unmarried	0	-	-
Alcoholism, smoking or substance use			
Yes	1.71	5.55 (0.59, 2.83)	**0.00**
No	0	-	-
Relationship with patients			
Spouse	0.58	1.79 (-0.48, 1.65)	0.28
Parent	-0.12	2.28 (-1.71, 1.46)	0.87
Offspring	-1.54	0.21 (-2.81, -0.28)	0.05
Other	0	-	-

Table 4 shows that there was a significant association between caregiver burden and respondent's characteristics like marital status, habit of alcoholism, smoking or substance use(p<0.05). Study findings showed married caregivers had 16.85 times higher odds of experiencing a higher level of burden compared to unmarried caregivers (OR=16.85, 95% CI=

0.43-5.21, p value=0.02). Similarly, respondents with a habit of alcoholism, smoking, or substance use were 5.55 times more likely to experience higher level of burden compared to respondents with no such habits (OR=5.55, 95% CI= 0.59-2.83, p value=0.00).

Table 6: Determinants associated with patient charac-teristics and caregiving aspect n=170

Variables	Estimates (â)	Odds ratio (95%CI)	p-value
Patient's age	-0.01	0.98 (-0.05, 0.02)	0.56
Patient's sex			
Male	1.10	3.00 (0.14, 2.05)	**0.02**
Female	0	-	-
Comorbidity in patients			
Yes	0.57	0.51 (-0.43, 1.57)	0.26
No	0	-	
Duration of dialysis			
Less than 1 year	-19.44	0.00 (-20.87, -18.01)	**0.00**
1-3 year	0.84	2.31 (-0.38, 2.06)	0.17
More than 3 years	0	-	-
No. of dialysis in a week			
Once	0.49	1.63 (-1.72, 2.70)	0.66
Twice	-0.54	0.58 (-1.46, 0.37)	0.24
Three and above	0	-	-
Average hour of caregiving in a day Mean± SD 12.94± 6.73	-0.01	0.98 (-0.05,0.02)	0.71
Support in caregiving			
Yes	-1.03	0.35 (-1.97, -0.10)	**0.02**
No	0	-	-
Difficulty in meeting health expenses			
Yes	1.46	4.31 (0.02, 2.90)	0.04
No	0	-	-

Table 6 illustrates that the caregivers of male patients experienced a 3-fold increase in burden compared to those caring for female patients (OR=3.00, 95% CI= 0.14-2.05, p value=0.02). Additionally, caregivers of patients undergoing dialysis for over three years reported significantly higher level of burden, while those caring for patients on dialysis for less than one year had lower odds of experiencing burden (OR=0.00, 95% CI= -20.87- -18.01, p value=0.00). The presence of caregiving support was associated with reduced burden (OR=0.35, 95% CI= -1.97- -0.10, p value=0.02), whereas caregiver who faced difficulty meeting health expenses had 4.31 times higher odds of experiencing increased burden compared to those without financial challenges (OR=4.31, 95% CI= 0.02-2.90, p value=0.04).

Discussion

Present study showed that a significant majority of the respondents experienced mild to moderate burden which is similar to the study conducted in Chitwan, Nepal [6]. Similarly, a study conducted in Andra Pradesh, India also reported that the majority of the respondents experienced mild to moderate burden [8]. Likewise, in Iran, most of the caregivers also experienced mild to moderate burden [9]. Similarly, caregivers in Rawal-pindi, Pakistan also reported mild to moderate burden [10].

However, in contrast to current study findings, a study conducted in Saudi Arabia showed that less than two-fifths of the respondents experienced mild to moderate burden [11]. The present study finding is also contradicted by findings of the study conducted in Indonesia, which showed that less than two-fifths of the respondents experienced mild to moderate burden [12]. A study conducted in Netherlands across multiple medical centers showed that a third of the respondents experienced moderate to high caregiver burden. In contrast, the present study found that fewer than one-fifth of the respondents experienced moderate to severe burden. However, it is important to note that a different assessment tool was used in this study to measure caregiver burden, which may account for the variation in findings [13]. Likewise, contradicting result was noted in a study conducted in Sikkim India which reported that more than half of the caregivers experienced mild to moderate burden whereas in the present study, majority of the caregivers of hemodialysis patients experienced mild to moderate burden [14].

The present study found an association between marital status and caregiver burden, with married caregivers having higher odds of experiencing a greater level of burden. Similarly, a study conducted in Bhaktapur, Nepal, also identified a link between marital status and caregiver burden; however, its findings indicated that widowed caregivers experienced a higher burden followed by married and singles, whereas present study showed married individuals experienced higher burden compared to caregivers who were unmarried. This difference could be attributed to the absence of widowed participants in the present study [15]. Similarly, a systematic review also identified that marital status was associated with the level of burden [6]. A study conducted in Indonesia identified age and salary as determi-nants of caregiver burden. However, this con-trasts with the findings of the present study, which found no association between caregiver's age or

income and level of burden [16]. Just as reported in the present study, a systematic review also reported association between duration of dialysis, patient's age, smoking and alcohol consumption and level of caregiver burden. However, in the systematic review, significant association was also reported between caregiver's age, education, income, frequency of dialysis, relationship with patient, number of children whereas the present study showed no such associations [6].

A study conducted in Isfahan found no significant association between caregiver burden and variables such as age of the caregivers, average caregiving hours, income level, number of dialysis session, relationship with the patient, and marital status. These findings are largely consistent with the present study, except for marital status, which in the current study showed a statistically significant association with caregiver burden [17].

This study has several limitations. First, the use of convenience sampling technique may limit the generalizability of the findings, as the sample may not be fully representative of the broader caregiver population. Second, findings rely on self-reported data and may be subject to response bias. Additionally, the study did not account for potential confounding factors that could influence caregiver burden, such as coping mechanism, functional status of patient or cultural differences.

Conclusion

This study showed that a significant majority of the respondents experienced mild to moderate caregiver burden. Factors such as marital status, habit of alcoholism, smoking or substance use, patient's sex, duration of dialysis, availability of caregiving support, and difficulty in meeting health expenses were identified as key determinants of caregiver burden.

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