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PSYCHOSOCIAL BURDEN AND RESILIENCE AMONG CAREGIVERS OF PATIENTS UNDERGOING HAEMODIALYSIS: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Chronic kidney disease (CKD), especially end-stage renal disease (ESRD), is a progressive condition that affects patients and their families. Haemodialysis prolongs survival, but imposes significant physical, emotional, and financial strain on caregivers. Assessing caregiver burden and resilience is crucial for planning supportive interventions. **Aims/Objectives:** To evaluate the burden and resilience of caregivers of patients receiving haemodialysis. **Materials and Methods:** The study employed a cross-sectional design and involved 125 caregivers of patients receiving maintenance haemodialysis in the Nephrology unit over a six-month period. Information was collected using pre-validated, semi-structured proforma. Caregiver burden was assessed using the Zarit Burden Interview (ZBI), and resilience was measured using the Brief Resilience Scale (BRS). The data were statistically evaluated using SPSS version 26.0 and were presented as mean values, standard deviations (SD), frequencies, and percentages. **Results:** The mean age of the caregivers was 50.42± 10.68 years. The mean ± SD score for the ZBI scale and BRS was 37.50 ±12.92 and 3.08 ± 1.07, respectively. A moderate burden was experienced by 74 (59.2%) and severe burden by 38 (30.4%). Regarding resilience, 68 (54.4%) had normal resilience and 14 (11.2%) had high resilience. Factors significantly associated with higher burden included age ≥ 50 years (OR 95% CI=32.329 (10.239-102.080) (p <0.001), female caregivers (OR 95% CI = 4.527 (1.463-14.003;) (p < 0.005), duration of care more than 1 year (OR 95% CI=3.487 (0.961-12.656) (p <0.046**)**, frequency of dialysis more than ≥2/week (OR 95% CI=3.635(1.677-7.880) (p <0.001**),** and low resilience (OR 95% CI=30.642(11.165-84.096) (p <0.001). **Conclusion:** A considerable number of caregivers experienced moderate to severe burden. Although overall resilience levels were generally normal, a notable segment demonstrated low resilience, increasing vulnerability to stress. Integrating structured caregiver support, resilience-building interventions, and counselling services into routine renal care may reduce caregiver burden and enhance overall well-being.

INTRODUCTION

Chronic kidney disease (CKD) is a major global public health problem, with an estimated prevalence of 13.5%, affecting approximately 500 million individuals worldwide.[1] In India, CKD prevalence is reported to be 17.2%, and it ranks as the ninth leading cause of death according to the Indian Council of Medical Research (ICMR) “India: Health of the Nation’s States” report (2017).[2,3]

End-stage renal disease (ESRD) represents the irreversible stage of CKD requiring renal replacement therapy for survival.[4] With increasing progression to ESRD, haemodialysis remains the most commonly used treatment modality, particularly in low- and middle-income countries.[5] While haemodialysis improves survival, it places substantial physical, psychological, financial, and social demands on both patients and their caregivers, who are essential for ensuring treatment adherence and continuity of care.[6,7]

Caregivers of haemodialysis patients often undertake extensive responsibilities, including coordinating hospital visits, managing medications and dietary restrictions, and providing emotional and practical support. These prolonged demands frequently result in significant psychosocial burden, such as stress, anxiety, depressive symptoms, social isolation, role strain, and financial hardship.[8-11] Caregiver distress may be further intensified in tertiary care settings, where patients often present with advanced disease and multiple comorbidities, resulting in caregivers being described as “hidden patients”.[12]

Previous studies report moderate to severe caregiver burden in CKD, with emotional distress, fatigue, sleep disturbances, and financial strain being common concerns. Prolonged caregiving, frequent dialysis sessions, higher patient dependency, and multiple comorbidities are key contributors, with female caregivers and those from lower socioeconomic backgrounds being particularly vulnerable.[13,14] Caregivers may experience psychological morbidity comparable to or greater than that of patients, especially in the presence of poor social support and limited coping resources.[15]

Resilience, the capacity to adjust and respond constructively to challenging circumstances has been recognized as a buffering factor that mitigates caregiver burden and psychological distress. Higher resilience is associated with lower perceived burden and better quality of life among caregivers of patients with chronic illnesses, including CKD.[16] However, research that concurrently explores psychosocial burden and resilience among caregivers of patients undergoing haemodialysis—especially within rural tertiary care settings in India—remains scarce. Therefore, the present study seeks to evaluate psychosocial burden and resilience in individuals caring for patients on haemodialysis in a Tertiary Care Centre, addressing an important gap in the existing literature.

MATERIALS AND METHODS

Study design and setting

A cross-sectional study conducted in a clinical setting was carried out among 125 caregivers of patients undergoing haemodialysis at the Dialysis Unit, Department of Nephrology, Sree Mookambika Institute of Medical Sciences, located in Kulasekharam, a rural region of Kanyakumari District, Tamil Nadu. Ethical clearance was obtained from the Institutional Ethics Committee, and informed consent was secured from all participants prior to the commencement of the study.

Study participants

The study was conducted over a six-month period, from February 2025 to July 2025, with participants chosen through purposive sampling. The study participants consisted of caregivers providing care for patients receiving ongoing hemodialysis treatment at the Dialysis Unit. Primary caregivers responsible for individuals diagnosed with CKD and receiving maintenance hemodialysis, aged 18 years or older, who had provided care for at least three months, and who were family members or close relatives, were included in the study. Exclusion criteria included professional or paid caregivers, individuals caring for patients undergoing peritoneal dialysis, post-renal transplant, or experiencing acute kidney injury, caregivers with cognitive impairments that might compromise the accuracy of responses, and those with less than three months of caregiving experience.

Sample size and sampling technique

In a study done by Afina Azeez et al (2022) in Kerala, the prevalence of caregiver burden was found to be 58%.[17] The total sample size was calculated using a 95% confidence interval and a 5% margin of error, applying the formula for proportions (n) $=Z_\alpha^2pq/L^2$ $^($$Z_\alpha$=1.96, p=58, q=42, relative precision of 10% of p); the estimated sample size was 94, but data were ultimately collected from 125 participants.

Data collection tool and technique

Data collection was carried out using a pre-designed, semi-structured questionnaire. The questionnaire consists of four sections: socio-demographic details of the caregivers, clinical profile of the haemodialysis patient, assessment of caregiver burden using the Zarit Burden Interview Scale (ZBI) and the Brief Resilience Scale (BRS) was used to assess the resilience among the caregivers.

Measurements

ZBI

The 22-item Zarit Burden Interview (ZBI) was employed to assess caregiver burden, a validated instrument designed to assess perceived caregiver burden. Each question is scored on a 5-point Likert scale ranging from 0 to 4, yielding a total score between 0 and 88, with higher scores reflecting a greater level of burden. Burden levels were categorised as little or no burden (0–20), mild to moderate (21–40), moderate to severe (41–60), and severe burden (61–88).[18]

BRS

Caregiver resilience was assessed using the 6-item Brief Resilience Scale (BRS), a validated self-report measure developed to evaluate an individual’s capacity to bounce back from stress. The scale includes three positively phrased items and three negatively phrased items, with reverse scoring applied where appropriate. The final score is calculated as the mean of all items**,** which ranges from 1-5 and interpreted as low resilience (1.00-2.99), normal resilience (3.00-4.30) and high resilience (4.31-5.00).[19]

Statistical Analysis

All data were managed in Microsoft Excel 2016 and analyzed using IBM SPSS Statistics, Trial Version 26.0. Frequencies and percentages were used to summarize the data. Associations between caregiver burden and sociodemographic variables were assessed using the Chi-square test for statistical significance. Statistical significance was set at $p < 0.05$. The correlation coefficient (r) was computed to assess the strength and direction of the monotonic association between scores on the Zarit Burden Interview and the Brief Resilience Scale.

Statistical significance was determined at a p-value < 0.05.

RESULTS

A total of 125 caregivers were studied. The mean age of the caregivers was 50.42± 10.678 years. The minimum and the maximum ages were 30 and 69 years, respectively. Among them, the majority, 95 (76%), were females, and 109 (87.2%) were married. The majority of the caregivers, 107 (85.6%), were related to the patient as a spouse. The majority, 68 (54.4%), were giving care for 1-3 years, and more than half of the 65 (52%) caregivers were spending 6-10 hours in caregiving. [Table 1] The clinical characteristics of the haemodialysis patients was presented in Table 2.

The caregiver burden was assessed using the Zarit Burden Interview (ZBI). The mean ZBI score among caregivers was 37.50 ± 12.92, indicating a moderate level of burden. [Figure 1]

Resilience was measured using the Brief Resilience Scale (BRS). The mean BRS score was 3.08 ± 1.07, reflecting a normal level of resilience among the caregivers. Most caregivers demonstrated normal resilience, though over one-third exhibited low resilience, indicating vulnerability to stress. [Figure 2]

The association between caregiver burden and sociodemographic variables was analysed using Chi-square analysis. Bivariate analysis using the Chi-square test showed a significant statistical association between age, gender, duration of care, frequency of dialysis, and resilience. The factors significantly associated with burden were age ≥ 50 years (OR 95% CI=32.329 (10.239-102.080) (p value <0.001), female caregivers (OR 95% CI = 4.527 (1.463-14.003) (p value 0.005), duration of care more than 1 year (OR 95% CI=3.487 (0.961-12.656) (p value 0.046), frequency of dialysis more than ≥2/week (OR 95% CI=3.635(1.677-7.880) (p value <0.001), and low resilience (OR 95% CI=30.642(11.165-84.096) (p value <0.001). [Table: 3]

Correlation between caregiver burden and resilience:

The Shapiro–Wilk test was performed to evaluate the normality of the Zarit Burden Interview (ZBI) and Brief Resilience Scale scores. The Shapiro–Wilk test indicated a significant deviation from normality for ZBI and Brief Resilience Scale scores ($p < 0.05$). Accordingly, Spearman's rank correlation analysis revealed a moderately strong negative association between caregiver burden (Zarit Burden Scale score) and resilience (Brief Resilience Scale score) ($\rho = -0.593$, $p < 0.001$). This suggests that caregivers with greater resilience generally report lower levels of caregiver burden, while those with lower resilience report higher burden. [Figure 3]

Table 1: Socio-demographic characteristics of the caregivers of haemodialysis patients (n=125)

Socio-demographic Characteristics		Frequency (n)	Percentage (%)
Age group	20-29 years	9	7.2
	30-39 years	20	16
	40-49 years	38	30.4
	50-59 years	26	20.8
	60 and above	32	25.6
Gender	Female	95	76
	Male	30	24
Marital Status	Married	109	87.2
	Unmarried	16	12.8
Relationship with the patient	Spouse	107	85.6
	Siblings	9	7.2
	Parents	3	2.4
	Relatives	6	4.8
Duration of Care	< 1 year	20	16
	1-3 years	68	54.4
	> 3 years	37	29.6
Time Spent in Caregiving	1-5 hours	44	35.2
	6-10 hours	65	52
	> 10 hours	16	12.8

Table 2: Clinical profile of patients on haemodialysis (n=125)

Characteristics		Frequency (n)	Percentage (%)
Type of kidney disease	Diabetic	21	16.8
	Glomerular	11	8.8
	Hypertensive	25	20
	Multiple	68	54.4
Frequency of dialysis	> 2/week	53	42.4
	≤ 2/week	72	57.6
Comorbidities	Diabetes Mellitus	18	14.4
	Hypertension	24	19.2
	Coronary Artery Disease	3	2.4
	Multiple	80	64

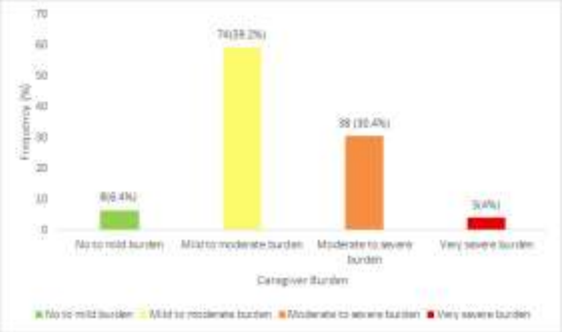

Figure 1: Categorisation of caregiver burden using the ZBI scale (n=125)

ZBI: Zarit Burden Interview scale

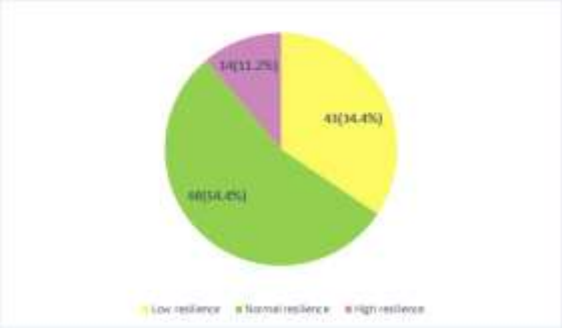

Figure 2: Categorisation of resilience using the BRS scale (n=125)

BRS: Brief Resilience Scale

Table 3: Bivariate analysis of Zarit Burden Interview Scale with socio-demographic variables and Brief Resilience Scale among caregivers of haemodialysis patients (n=125)

Characteristics of participants		Zarit Burden Scale		Chi-Square value	OR (95% CI)	P value
		High burden	Low burden			
Age	≥50 years	39(67.2%)	19(32.8%)	51.718	32.329 (10.239-102.080)	**<0.001***
	<50 years	4(6%)	63(94%)			
Gender	Female	39(41.1%)	56(58.9%)	7.763	4.527 (1.463-14.003)	**0.005**
	Male	4(13.3%)	26(86.7%)			
Marital status	Unmarried	6(31.2%)	10(62.5%)	0.078	1.168 (0.394-3.462)	0.780
	Married	37(33.9%)	72(66.1%)			
Relationship	Spouse	36(37.5%)	71(66.4%)	0.188	0.797 (0.285-2.230)	0.665
	Non-spouse	7(38.9%)	11(61.1%)			
Duration of care	≥1 year	40(38.1%)	65(61.9%)	3.971	3.487 (0.961-12.656)	**0.046***
	<1 year	3(15%)	17(85%)			
Time spent	≤ 5 hours	15(34.1%)	29(65.9%)	0.003	0.979 (0.452-2.122)	0.957
	> 5 hours	28(34.6%)	53(65.4%)			
Frequency of dialysis	> 2/week	27(50.9%)	26(49.1%)	11.159	3.635 (1.677-7.880)	**0.001***
	≤ 2/week	16(22.2%)	56(77.8%)			
Comorbidities	Single	16(35.6%)	29(64.4%)	0.042	1.083 (0.503-2.331)	0.838
	Multiple	27(33.8%)	53(66.2%)			
BRS	Low resilience	34(79.1%)	9(20.9%)	57.960	30.642 (11.165-84.096)	**<0.001***
	Normal/high resilience	9(11%)	73(89%)			

High burden: ZBS score≥40, low burden: ZBS score <40

OR: Odds Ratio; 95% CI: 95% Confidence Interval; * Significant association (* p-value < 0.05)

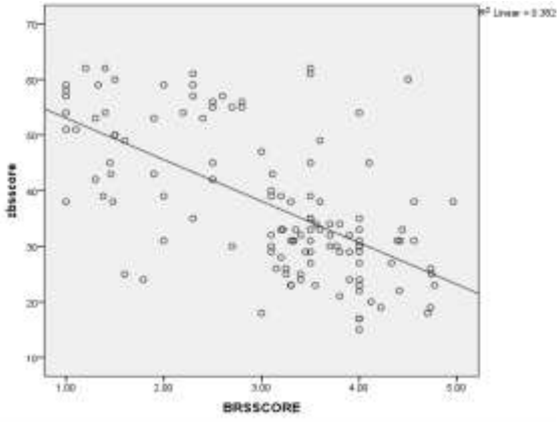

Figure 3: Correlation between the BRS score and the ZBI score in study participants (n = 125)

DISCUSSION

The findings indicate that caregivers experience a substantial burden, with the majority of caregivers experiencing moderate to severe burden, alongside varying levels of resilience. These results highlight the significant psychosocial challenges experienced by caregivers involved in long-term haemodialysis care.

The demographic profile of caregivers in this study showed a predominance of female caregivers, 95 (76%), and in particular, more than 50 years of age, 58 (46.4%), most of whom were married and spouses of the patients, 107 (85.6%). This finding is consistent with traditional caregiving roles observed in many developing countries, including India, where caregiving responsibilities largely fall on female family members. The mean caregiver age of approximately 50 years suggests that many caregivers may themselves be experiencing age-related physical or emotional challenges, potentially compounding the burden of caregiving. This is contrary to the study done by Jomom Joy et al, where only 29.2% of the caregivers were more than 50 years of age, and only 59% were spouses of the patients on haemodialysis.[13] Whereas a study done by Afina

Azeez reported that the caregiver burden may be attributed to the fact that more than 75% of the caregivers were spouses, and among them, 80% were women, which is similar to our study finding.[17] Similar observations were made by studies performed in Nepal,[14] and India,[20] where severe CB was observed in 3.25% and 3.92% of caregivers.

In the current study, 74(59.2%) of the caregivers experienced a mild to moderate level of burden, with nearly one-third of caregivers experiencing severe or very severe burden 43(34.4%). This finding highlights the substantial physical, emotional, and psychosocial demands placed on caregivers of dialysis patients. This is contrary to the study done by Srinithi, where more than half (54%) of the caregivers reported severe or very severe burden, and 36% reported moderate levels of caregiver burden.[21] Our study finding is contrary to the studies done in Iran,[9] where 72.5% of caregivers reported moderate to severe burden, and also in a study done by Mashayekhi et al,[22] which showed that 72.5% of caregivers had moderate to severe caregiver burden and a study in Andhra Pradesh,[23] showed around 85% of caregivers showed mild to moderate caregivers burden. Similar caregiver burden was reported in a study done by Jafari et al and Chhetri et, al where 42.7% and 48.8% experienced a moderate level of care burden, respectively.[10,14] The chronic nature of haemodialysis, frequent hospital visits, prolonged duration of care, and significant time investment—often exceeding six hours per day—may contribute to this elevated burden.

Resilience levels among caregivers were found to be largely within the normal range, 68(54.4%); however, a substantial proportion exhibited low resilience, 43(34.4%), indicating vulnerability to stress and burnout. This variability suggests that while some caregivers can adapt and cope effectively, others find it challenging to handle the ongoing psychological and day-to-day responsibilities in giving care. The presence of low resilience among over one-third of caregivers underscores the need for targeted psychosocial support. A study done in Kollam shows that 72.5% low resilience, which shows poor problem and emotion-focused coping strategies in them.[13]

Notably, resilience emerged as a key protective factor. The strong negative correlation between caregiver burden and resilience indicates that caregivers with higher resilience experience significantly lower levels of burden. The finding highlights resilience as an important factor in buffering the adverse psychosocial effects of caregiving. Enhancing resilience through psychosocial interventions, coping skills training, and support services may therefore be effective in reducing caregiver burden.[13]

The study identified several factors significantly associated with higher caregiver burden, including older age, longer duration of caregiving, higher frequency of dialysis sessions, and low resilience. Caregivers aged over 49 years experienced significantly higher burden, possibly due to declining physical stamina and increased health concerns. Prolonged duration of caregiving and more frequent dialysis sessions likely intensify physical exhaustion, financial strain, and emotional stress, thereby increasing caregiver burden. Similar findings were reported in studies done in Kerala and Nepal.[13,14]

Overall, the findings emphasize the need for routine assessment of caregiver burden and resilience in nephrology care settings. Incorporating caregiver-focused interventions such as counselling, education, peer support groups, and respite care may help mitigate burden and strengthen resilience, ultimately enhancing caregivers' quality of life and contributing to improved patient care.

Limitations

This study has certain limitations that should be noted. The study's cross-sectional design limits conclusions regarding cause and effect between caregiver burden and associated factors. Additionally, the study's dependence on self-reporting may result in biased responses. Differences in socioeconomic status, access to support services, and cultural perceptions of caregiving may further restrict the external validity of the results. Future longitudinal studies are recommended to explore changes in caregiver burden and resilience over time and to determine the effectiveness of interventions aimed at enhancing resilience.

CONCLUSION

In conclusion, caregivers of dialysis patients experience considerable levels of burden, particularly those who are older, have provided care for longer durations, support patients requiring frequent dialysis, and demonstrate low resilience. Strengthening caregiver resilience appears to be a key factor in alleviating burden and enhancing holistic wellness. These findings point to the value of routinely monitoring caregiver burden and resilience in dialysis settings to identify those who may be vulnerable, especially the older and those engaged in long-term caregiving. Implementing timely psychosocial interventions, integrating structured caregiver support programs, promoting resilience-building strategies, and providing accessible counselling services as part of standard renal care can significantly alleviate caregiver burden and foster holistic wellness in both patients and caregivers.

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Declarations

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