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Assessing Caregiver Burden in Relatives of Patients Undergoing Dialysis in Civil Hospital Hyderabad

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ABSTRACT

Chronic kidney disease (CKD) and end-stage renal disease (ESRD) present a growing global health burden, with dialysis being a critical yet demanding treatment. In resource-constrained settings like Pakistan, caregiving responsibilities often fall on family members who face emotional, social, physical, and financial stressors. Despite their vital role, limited research exists on the extent of caregiver burden in such settings. This study aimed to assess the level and types of burden experienced by caregivers of dialysis patients at Civil Hospital, Hyderabad.A descriptive cross-sectional study was conducted on 35 primary caregivers selected through non-probability convenience sampling. Data were collected through face-to-face interviews using a demographic questionnaire and the ZBI-12 tool, which assesses emotional, social, and time-dependency burdens.Most caregivers (62.9%) experienced a moderate burden, while 20.0% reported mild and 17.1% severe burden. Emotional burden had the highest correlation with overall burden ($r = 0.924$, $p < 0.01$), followed by time-dependency ($r = 0.724$) and social burden ($r = 0.732$). The study revealed a significant caregiving burden, particularly related to emotional and time-dependent stress, among relatives of dialysis patients. Findings highlight the urgent need for caregiver-centered interventions, such as psychosocial support, educational programs, and institutional policies that address financial and emotional challenges in dialysis care settings.

Keywords: *Chronic Kidney disease, Renal disease, Emotional burden*

INTRODUCTION

The population affected by chronic kidney disease (CKD) is increasing worldwide, largely due to the growing prevalence of hypertension, diabetes, and obesity. Globally, CKD affects approximately 11 to 13.4% of the general population, making it one of the most common chronic diseases worldwide.[1] Chronic kidney disease (CKD) and end-stage renal disease (ESRD) are critical health issues that affect populations worldwide at an increasing rate.2 Chronic kidney disease (CKD) has become a growing health problem in the world over the recent decades. The Global Burden of Disease Study 2021 estimates an estimate of 673.7 million individuals living with CKD in the year 2021, or about8.5% of the world population, which is a nearly 92 percent increase in CKD patients compared to the 1990 facility.3 Dialysis plays a vital role in helping patients survive, but it also causes a lot of emotional, physical, and financial burden not only to the patient but also to their caregivers. Some of these multidimensional challenges can occur to caregivers, who in most times are family members, in support of the treatment and daily needs of dialysis patients. The burden on the caregiver is a perceived stressor caused by the obligation to care about a chronically ill person. Common effects of high care giver burden include depression, anxiety, and worsening physical conditions that eventually affect the quality of care given to the patient. Cognitive impairments and behavioral issues along with physical and mental dependency of the care recipient has been cited as a big predictor of caregiver burden.[5]

Additionally, the research reported that the quality of life of caregivers to dialysis patients is considerably low compared to that of the general population, and the level of caregiver burden is also negatively associated with the overall well-being of caregivers.6 The quality of life of caregivers was found to be lower as compared to that of general population. This loss has the potential to augment the risk of depression and poor life quality among hemodialysis patients because of the deteriorated social support systems in developing countries. The cost of hemodialysis is quite high and most families cannot afford it. As an example, a survey carried out in Bangladesh found that a large number of patients had to resort to loans or selling of family assets to pay their treatment bills, with some families suffering a full loss in income.7 These results indicate that caregivers in low-resource settings are under a very serious economic burden, and this situation is probably the situation in Pakistan, even in places like Hyderabad, where families usually incur similar economic costs when taking care of dialysis patients. These findings highlight that in low- and middle-income countries, including Pakistan, caregivers of dialysis patients face not only financial hardship but also emotional and social pressures, which can negatively impact both their well-being and the quality of care they provide. Despite its importance, caregiver burden remains under-researched in Pakistan, particularly in the context of dialysis care. This study aims to assess the level of caregiver burden among relatives of dialysis patients using the validated 12-item Zarit Burden Interview (ZBI) short version. The findings will help identify contributing factors and support systems needed to alleviate caregiver burden.

Objectives

- To assess the level of caregiver burden among relatives of patients undergoing dialysis using the ZBI-12 scale.
- To determine the relationship between caregiver burden and key influencing factors (demographics, emotional, physical, social, and financial challenges).

METHODOLOGY

Study Design

This research adopted a descriptive, cross-sectional design to assess the caregiving burden experienced by relatives who were directly responsible for providing care to patients undergoing dialysis. These caregivers included siblings, spouses, children, cousins, or other close family members.

Study Setting

Nephrology and Dialysis Unit at Liaquat University Hospital, Hyderabad.

Study Population

Primary caregivers of patients undergoing dialysis at Liaquat University Hospital include as Brother, Son, Husband, if the female is married, Wife, if the patient is married male, Mother, or Sister.

Sample Size and Sampling Technique

Non-probability convenience sampling. Data were collected from 35 individuals who were primarily involved in the care of dialysis patients.

Inclusion Criteria

- Caregivers aged 18 years and above.
- Primary caregivers of patients who have been receiving dialysis for at least 3 months.
- Willing to participate and respond positively to informed consent.

Exclusion Criteria

- Caregivers diagnosed with any psychiatric illness or cognitive impairment.
- Paid or professional caregivers.

Data Collection Tool

A structured demographic questionnaire was used to collect background information from participants. The caregiver-related variables included age, gender, educational status, relationship to the patient, employment status, monthly income, and duration of caregiving. Patient-related information was also recorded, including age, gender, duration on dialysis, and presence of comorbidities.

12-item Zarit Burden Interview (ZBI-12)

Caregiver burden was assessed using the Zarit Burden Interview Short Form (ZBI-12). This tool consists of 12 items rated on a 0–4 Likert scale, yielding a total score range of 0–48, where higher scores indicate greater perceived burden. The ZBI-12 has been widely validated across diverse care settings and demonstrates strong internal consistency (Cronbach's $\alpha \approx 0.88$–0.93).

The instrument measures three major dimensions of burden:

- **Emotional Burden**: feelings of stress, anxiety, uncertainty, and depression associated with caregiving responsibilities.
- **Time-Dependency/Physical Burden**: strain related to the extensive time demands of caregiving, including fatigue, sleep disturbances, and reduced personal time.
- **Social Burden**: negative effects on interpersonal relationships, social activities, and overall social isolation.

Data Collection Procedure

Ethical approval for the study was obtained from the Institutional Review Board (IRB) of Liaquat University of Medical and Health Sciences (LUMHS). Written informed consent was obtained from all participants before their inclusion in the study. Data were collected through face-to-face interviews conducted by trained research assistants using a structured demographic questionnaire and the 12-item Zarit Burden Interview (ZBI-12). This approach ensured completeness of responses and minimized potential misunderstandings, thereby enhancing the reliability of the data.

ETHICAL CONSIDERATIONS

Caregivers provided written informed consent before they participated in the study. All data collected were handled with strict confidentiality and used solely for research purposes. The identities of caregivers were protected, and no personally identifiable information was disclosed at any stage of the research.

RESULTS

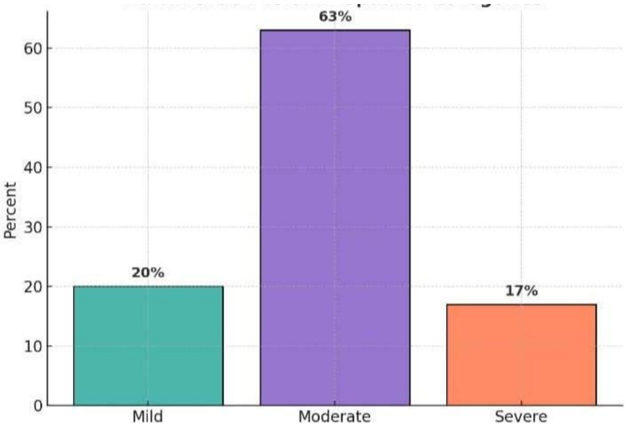
Table 1 Demographic Distribution of Participants

Variable	Frequency	Percentage (%)
Gender Distribution		
Male	20	57.1
Female	15	42.9
Age distribution		
<20	1	2.9
21–30	13	37.1
31–40	8	22.9
41–50	7	20.0
51–60	6	17.1
Literacy Distribution		
Illiterate	15	42.9
Primary	2	5.7
Secondary	7	20.0
Intermediate	4	11.4
Graduate	3	8.6
Postgraduate	4	11.4
Monthly Income Distribution		
<20,000	13	37.1
20,000–40,000	13	37.1
41,000–60,000	5	14.3

61,000–80,000	2	5.7
>80,000	2	5.7
Relationship Distribution		
Spouse	9	25.7
Son/Daughter	8	22.9
Parent	5	14.3
Sibling	11	31.4
Other	2	5.7

The above table presents the demographic distribution of participants; most caregivers were male (57.1%) and belonged to the young to middle-aged group, with the largest proportion between 21–30 years (37.1%). Nearly half were illiterate (42.9%), while only a small proportion had higher education. The majority reported low monthly household incomes (74.2% earning ≤40,000 PKR), reflecting financial strain. In terms of relationships, siblings (31.4%), spouses (25.7%), and sons/daughters (22.9%) were the main caregivers, showing that caregiving responsibilities were primarily shared within close family members.

Graph.1 Caregiver Burden Distribution



Among the 35 caregivers, the majority (62.9%) experienced a moderate level of burden, followed by 20% with mild burden, and 17.1% with a severe burden. This indicates that most caregivers face a significant caregiving load, highlighting the need for supportive interventions to reduce stress and improve their well-being.

Table 2: Burden on caregivers according to different classifications

Burden Type	Mean Score	Interpretation
Social Burden	1.97	Lowest average burden among the three
Time Dependency Burden	9.29	Highest average burden

Emotional Burden	5.54	Moderate average burden

Caregivers reported the highest burden in time-dependency (M = 9.29), followed by a moderate emotional burden (M = 5.54), while the lowest burden was social (M = 1.97). This indicates that caregiving demands were most strongly linked to time constraints, with moderate psychological strain and relatively less social disruption.

Table.3 Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total Score of the whole 12 items	Equal variances assumed	.242	.626	.051	33	.960	.11667	2.28857	-4.53947	4.77280
	Equal variances not assumed			.052	32.276	.959	.11667	2.23985	-4.44422	4.67756

Table 10

The t-test results showed no significant difference in caregiver burden scores between caregivers of male (M = 16.85, SD = 7.10) and female patients (M = 16.73, SD = 6.12), t (33) = 0.051, p = 0.960. This indicates that patient gender does not significantly affect caregiver burden in this sample.

DISCUSSION

The study shows that 82.4% of caregivers experience mild to moderate burden, while severe burden is 17.6 %. This may reflect strong cultural and familial values in Pakistan, particularly in Hyderabad and Jamshoro, where caregiving is often seen as a shared duty rather than a stressor. Emotional burden was the most significant component ($r = 0.924$, $p < 0.01$), consistent with prior findings that link caregiver burden to psychological distress like anxiety and depression.[8]

Strong associations were found between total burden and time-dependence ($r = 0.724$, $p < 0.01$) and social burden ($r = 0.732$, $p < 0.01$), suggesting that caregiving disrupts personal schedules and social life, echoing global and regional studies.[9] No significant link was found between patient gender and caregiver burden ($p = 0.532$), indicating caregiving stressors are consistent across genders. Most caregivers were young adults (21–30 years), suggesting caregiving spans across age groups, possibly influencing burden through differing coping capacities. The lack of severe burden may point to protective cultural or familial support mechanisms. Caregivers are frequently young adults, but burden levels do not always increase with age. Some studies show older caregivers report higher fatigue, but age alone is not a reliable predictor of burden; rather, coping strategies and support systems play a larger role.[10]

These results underline the need for supportive strategies like counseling, education, and respite care to reduce emotional and time-related strain.[11] Financial strain, although not detailed, likely exists in public hospitals and should be addressed through policy and institutional support. Caregivers in public hospitals frequently report both acute and chronic financial stress, including out-of-pocket costs, lost income, and challenges accessing financial support.[12]

Comparisons with high-income countries emphasize the need for culturally appropriate interventions in Pakistan. Interventions that engage family members, community leaders, and religious organizations are more acceptable and effective, as they align with local values and care-giving traditions.[13]

CONCLUSION

The results indicate That most caregivers faced a moderate burden, with emotional, time-dependent, and social factors being the strongest contributors. No gender differences were observed, highlighting the need for interventions that address psycho-social and time-related challenges in care-giving.

LIMITATIONS

The study's limitations include a small sample size, single-center design, reliance on self-reported measures, and lack of economic assessment, which together restrict the generalizability and depth of the findings

REFERENCES

Alshammari B, Noble H, McAneney H, Alshammari F, O'halloran P. Factors associated with burden in caregivers of patients with end-stage kidney disease (A systematic review). Healthc. 2021;9(9).

Deng L, Guo S, Liu Y, Zhou Y, Liu Y, Zheng X, et al. Global, regional, and national burden of chronic kidney disease and its underlying etiologies from 1990 to 2021: a systematic analysis for the Global Burden of Disease Study 2021. BMC Public Health. 2025;25(1).

Wetmore JB, Collins AJ. Global challenges posed by the growth of end-stage renal disease. Ren Replace Ther. 2016;2(1).

Lindt N, Van Berkel J, Mulder BC. Determinants of overburdening among informal carers: A systematic review. BMC Geriatr. 2020;20(1).

Joseph SJ, Bhandari SS, Dutta S, Khatri D, Upadhyay A. Assessing burden and its determinants in caregivers of chronic kidney disease patients undergoing haemodialysis. Open J Psychiatry Allied Sci. 2021;12(2):96–100.

Ahmed A, Alhamdan F, Ashraf A, Mangrio FA, Shaikh S, Ali A. Socio-Economic Burden of Hemodialysis on Patients' Families. Pakistan J Med Heal Sci. 2023;17(4):648–51.

Malki ST, Johansson P, Andersson G, Andréasson F, Mourad G. Caregiver burden, psychological well-being, and support needs among Swedish informal caregivers. BMC Public Health. 2025;25(1).

Oluseyi A Adejumo, Ikponmwosa O Iyawe, Ayodeji A Akinbodewa, Olatunji S Abolarin, Emmanuel O Alli. Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. Ghana Med J. 2019;53(3):190–6.

Hovadick AC, Jardim VR, Paúl C, Pagano A, Reis I, Torres H. Interventions to improve the well-being of family caregivers of patients on hemodialysis and peritoneal dialysis: A systematic review. PeerJ. 2021;9.

Bongelli R, Busilacchi G, Pacifico A, Fabiani M, Guarascio C, Sofritti F, et al. Caregiving burden, social support, and psychological well-being among family caregivers of older Italians: a cross-sectional study. Front Public Heal. 2024;12.

Molassiotis A, Wang M. Understanding and Supporting Informal Cancer Caregivers. Curr Treat Options Oncol. 2022;23(4):494–513.

Nadarajah A, Lazor T, Meserve A, Buchanan F, Birken C, van den Heuvel M. Experiences of Financial Stress and Supports in Caregivers During Pediatric Hospital Admission. Hosp Pediatr. 2024;14(4):233–41.

Yaqoob E, Khan S, Sahitia N, Barkatullah Z, Abbas Zaidi D, Ali Khan S, et al. Caregiver burden in stroke care. Ann Med Surg. 2025;87(6):3458–63.