

## 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.*

### **Objective**

*This study aimed to assess the level and types of burden experienced by caregivers of dialysis patients at Civil Hospital, Hyderabad.*

### **Methods**

*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.*

### **Results**

*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 ( $r = 0.732$ ).*

### **Conclusion**

*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:** Caregiver, Dialysis

## **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.<sup>1</sup> Chronic kidney disease (CKD) and end-stage renal disease (ESRD) are major global health concerns, with a rising number of patients requiring dialysis.<sup>2</sup> Chronic kidney disease (CKD) has emerged as a rapidly escalating global health challenge over the past few decades. According to the Global Burden of Disease Study 2021, around 673.7 million people, approximately 8.5% of the world's population, were living with CKD in 2021, marking a nearly 92% increase from 1990.<sup>3</sup> While dialysis is essential for patient survival, it imposes significant emotional, physical, and financial stress not only on the patient but also on their caregivers.<sup>4</sup> Caregivers, often family members, face multidimensional challenges while supporting the treatment and daily needs of dialysis patients. Caregiver burden is defined as the perceived strain resulting from caring for a chronically ill individual. High caregiver burden is associated with increased rates of depression, anxiety, and deteriorating physical health, which can ultimately impact the quality of care provided to the patient. The physical and mental dependency of the care recipient, including cognitive impairments and behavioral problems, has been identified as a significant predictor of caregiver burden.<sup>5</sup> Moreover, studies have shown that the quality of life among caregivers of dialysis patients is significantly lower than that of the general population, with caregiver burden levels being negatively correlated with caregivers' overall well-being.<sup>6</sup> The quality of life of caregivers, when compared to age- and sex-matched counterparts, is significantly compromised. This decline can increase the risk of depression and poor quality of life in hemodialysis patients due to weakened social support networks.<sup>3</sup> In developing countries, the financial burden is particularly severe. Hemodialysis is a costly treatment, with many families struggling to afford it. For instance, a study conducted in Bangladesh revealed that a significant portion of patients relied on loans or sold family assets to cover treatment costs, with some families experiencing a complete loss of income.<sup>7</sup> These findings highlight the serious economic strain faced by caregivers in low-resource settings, a situation likely mirrored in Pakistan, including areas like Hyderabad, where families often bear similar financial pressures while supporting 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.

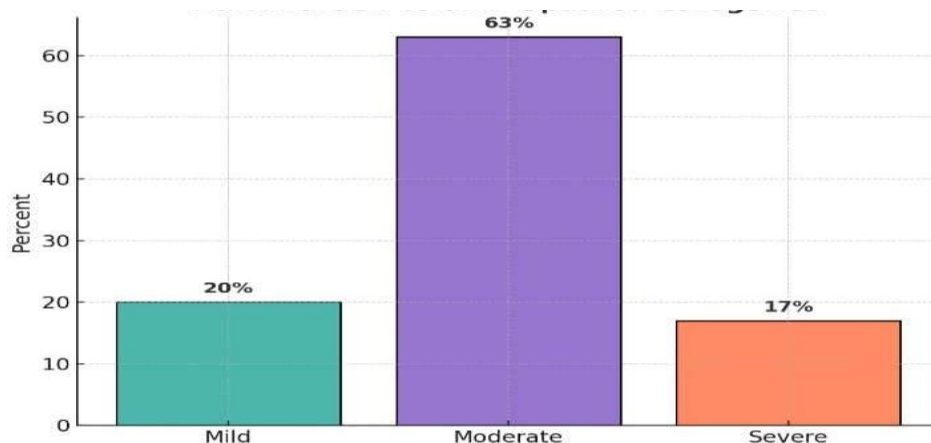
### **RESULTS**

**Table 1: Demographic Distribution of Participants**

<b>Variable</b>	<b>Frequency</b>	<b>Percentage (%)</b>
<b>Gender Distribution</b>		
Male	20	57.1
Female	15	42.9
<b>Age distribution</b>		
<20	1	2.9
21–30	13	37.1
31–40	8	22.9
41–50	7	20.0
51–60	6	17.1
<b>Literacy Distribution</b>		
Illiterate	15	42.9
Primary	2	5.7
Secondary	7	20.0
Intermediate	4	11.4
Graduate	3	8.6
Postgraduate	4	11.4
<b>Monthly Income Distribution</b>		
<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
<b>Relationship Distribution</b>		
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	-4.5394 4.77280
	Equal variances not assumed				.051	32.276	.959	.11667	2.23985	-4.4442 4.67756

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.<sup>8</sup>

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.<sup>9</sup> 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.<sup>10</sup>

These results underline the need for supportive strategies like counseling, education, and respite care to reduce emotional and time-related strain.<sup>11</sup> 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.<sup>12</sup>

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 caregiving traditions.<sup>13</sup>

## 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 psychosocial and time-related challenges in caregiving.

## 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.

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