

The Impact of Hemodialysis on Primary Family Caregivers; A Study on Caregiver Burden in Balochistan, Pakistan.

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Abstract:

Background: The study assessed quality of life in terms of health and care of informal caregivers of people with end-stage kidney disease.

Methods: An observational correctional study was conducted over six months at a tertiary care hospital in Quetta, Balochistan, involving 67 caregivers of chronic kidney disease stage five (CKD-5) patients. Zarit Burden Interview (ZBI) assessed caregiver burden and a one-way ANOVA compared ZBI scores with sociodemographic factors.

Results: Of 67 caregivers that ranged from 23 to 67 years, and the 51-60 years age group representing the largest proportion at 31.3%, ZBI mean score came to be 38.4 with majority of participants (76.1%) experiencing moderate to severe burden. No significant differences in caregiver burden were observed across age groups or education levels by one-way ANOVA, nor by gender or marital status on t-testing ($p > 0.05$); age also showed no correlation with burden ($r = 0.08$, $p = 0.52$). However, chi-square analysis showed a marginal association between marital status and burden categories ($\chi^2 = 3.42$, $p = 0.065$), with slightly higher high-burden prevalence among married caregivers.

Conclusion: Caregiver burden among informal caregivers of CKD-5 patients was predominantly moderate to severe, with a high mean ZBI score, highlighting a substantial impact on caregiver well-being. Sociodemographic factors showed no significant influence on burden levels, suggesting that caregiver strain is widespread and not confined to specific groups, underscoring the need for targeted support systems and interventions for all caregivers in this setting.

Keywords: Caregivers, Chronic kidney disease, Pakistan, Psychosocial Factors, Quality of Life, Renal Dialysis.

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Introduction:

Kidney diseases have become a major cause of death and disability, largely fueled by the rapidly growing prevalence of diabetes mellitus, which significantly accelerates the progression of chronic kidney disease (CKD).⁽¹⁾ While the precise prevalence of chronic kidney disease (CKD) in Pakistan remains unclear, a review of regional data suggests a 17% prevalence rate in neighboring countries. Applying this estimate to Pakistan's population of 207 million indicates that approximately 35.3 million people may be living with impaired kidney function.⁽²⁾ People diagnosed with end-stage chronic kidney disease (CKD)

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experience irreversible loss of kidney function and require renal replacement therapy (RRT), which may include hemodialysis (HD), peritoneal dialysis (PD), or a kidney transplant.⁽³⁾ Dialysis patients are often required to make significant lifestyle adjustments, including changes to their diet, daily routines, mental well-being, physical activity, and social or family interactions, due to the demands of the treatment. In many developing nations, these patients typically depend on a primary care-giver most often a spouse or an adult child for ongoing support and assistance.⁽⁴⁾

In the healthcare sector, caregiving plays a vital but frequently uncompensated role, involving the delivery of support and aid to individuals facing physical, mental, or developmental difficulties.⁽⁵⁾ Families of hemodialysis patients play a crucial role in supporting by encouraging treatment adherence, assisting financially, and providing emotional support and contributions that significantly impact patient well-being.⁽⁶⁾

Caring for hemodialysis patients involve navigating a complex treatment process influenced by various factors such as co-morbidities, age, nutritional health, and treatment adherence. Care-giver burden increases substantially when chronic illness impairs a patient's ability to care for themselves.⁽⁷⁾ This burden can be understood in both objective and subjective terms. Objective burden refers to the tangible disruptions and changes in the caregiver's life caused by their caregiving responsibilities, while subjective burden reflects the caregiver's personal feelings and perceptions about their caregiving role.⁽⁸⁾ For those caring for highly dependent individuals, this burden can negatively impact their physical health, emotional well-being, and financial stability.⁽⁹⁾ Bártolo et al. (2022) and Hovadick et al. (2021) both conducted systematic reviews assessing the impact of psychosocial interventions on caregivers of dialysis patients, with a primary focus on those caring for individuals undergoing hemodialysis.^(10, 11)

Although existing literature acknowledges caregiver burden, most studies have either broadly addressed have narrowly focused on psychosocial interventions without caregivers of patients or fully capturing the lived experiences of those caring for hemodialysis patients. There remains a need for context-specific research that explores the multifaceted challenges faced by caregivers in this setting, especially in low-resource contexts such as Pakistan, where caregiving is largely informal and unsupported.

This study aims to bridge that gap by examining the burden experienced by caregivers of hemodialysis patients, with the goal of informing healthcare providers about their unmet needs and guiding the development of supportive interventions tailored to this caregiver population.

Methods:

A cross-sectional observational study was conducted over six months at a tertiary care hospital in Balochistan, where caregivers of hemodialysis patients were surveyed. Ethical approval was obtained from the Institutional Review Board of Combined Military Hospital Quetta vide number CMH QTA-IERB/71/2025. 67 primary caregivers of CKD-5 patients undergoing maintenance hemodialysis were recruited through convenience sampling.

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Primary family members aged >18 years, responsible for care of patients for at least six months with patients having CKD-5 and undergoing hemodialysis at least twice weekly were included in the study.

Professional caregivers or paid attendants, caregivers of patients on peritoneal dialysis or kidney transplant recipients and caregivers with pre-existing psychiatric illnesses were excluded from the study.

Data was collected on the demographic characteristics including age, gender, education, employment and marital status. Caregiving characteristics including relationship to the patient, duration of caregiving and financial dependency was also recorded. Caregiver burden was assessed using Zarit Burden Interview (ZBI). The ZBI scores were classified as Mild burden (0 – 20), Moderate burden (21 – 40) and Severe burden (41 – 60). Financial burden was assessed through self-reported monthly expenses on caregiving, loss of employment, and financial hardship. Verbal informed consent was obtained from all participants before enrolment.

Results:

Participant Demographics:

A total of 67 caregivers participated in this study. The demographic characteristics revealed several key patterns. The age distribution showed participants ranging from 23 to 67 years, with a strong concentration in middle-age ranges. The 51-60 years age group represented the largest proportion (31.3%), followed by nearly equal distributions in the 31-40 years (29.9%) and 41-50 years (29.9%) groups. Younger participants aged 18-30 years comprised 6.0% of the sample, while those over 60 years represented 3.0%. Collectively, participants aged 31-60 years accounted for over 90% of the cohort. Gender distribution indicated a higher proportion of male participants (68.7%) compared to female participants (31.3%). Regarding marital status, the majority of participants were married (61.2%), while 38.8% were unmarried, and no participants reported being divorced. Educational attainment varied across the sample, with graduate-level education being most common (52.2%), followed by master's degree holders (17.9%), matric and uneducated participants (11.9% each), and doctorate holders (6.0%). Table 1 presents a comprehensive summary of these demographic characteristics.

The Zarit Burden Scale scores ranged from 4 to 65, with a mean score of 38.4, indicating substantial caregiver strain across the sample. The distribution of burden levels revealed that the majority of participants (68.7%) experienced moderate burden, representing the most prevalent category. An additional 7.5% of caregivers reported severe burden, bringing the total proportion of highly burdened caregivers to 76.1%. Conversely, 20.9% of participants reported little or no burden, while only 3.0% experienced mild to moderate burden. These findings indicate that more than three-quarters of the caregiver sample required support and intervention to manage their caregiving responsibilities effectively. Table 2 provides a detailed breakdown of burden level distribution.

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Table 1: Demographic Characteristics of Participants (N=67)

Variables	Category	Frequency (n)	Percentage (%)
Age Group	18-30 years	4	6.0
	31-40 years	20	29.9
	41-50 years	20	29.9
	51-60 years	21	31.3
	Over 60 years	2	3.0
Gender	Male	46	68.7
	Female	21	31.3
Marital Status	Married	41	61.2
	Unmarried	26	38.8
	Divorced	0	0.0
Education Level	Uneducated	8	11.9
	Matric	8	11.9
	Graduate	35	52.2
	Masters	12	17.9
	Doctorate	4	6.0

Table 2: Distribution of Caregiver Burden Levels Among Study Participants

Burden Level	Score Range	Number of Participants	Percentage	Rank
Moderate to severe burden	41-60	46	68.7%	1st
Little or no burden	0-20	14	20.9%	2nd
Severe burden	61-88	5	7.5%	3rd
Mild to moderate burden	21-40	2	3.0%	4th

Statistical analyses were conducted to examine the relationships between demographic variables and caregiver burden levels. A one-way ANOVA comparing Zarit burden scores across age groups revealed no significant effect ($F = 0.82$, $df = 4,62$, $p = 0.52$), indicating that age does not significantly influence caregiver burden levels. Similarly, an independent samples t-test comparing burden scores between male and female caregivers showed no significant gender difference ($t = -1.23$, $df = 65$, $p = 0.22$).

Analysis of marital status yielded mixed findings. An independent samples t-test comparing burden scores between married and unmarried participants found no significant difference ($t = 0.89$, $df = 1$, $p = 0.38$). However, a chi-square test examining the association between marital status and burden categories revealed a marginally significant relationship ($\chi^2 = 3.42$, $df = 1$, $p = 0.065$), with 78.0% of married caregivers experiencing high burden compared to 73.1% of unmarried caregivers.

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Educational attainment showed no significant association with burden levels. A one-way ANOVA examining differences in Zarit burden scores across education levels was non-significant ($F = 1.18$, $df = 4$, 62 , $p = 0.33$). Additional chi-square tests further confirmed no significant relationships between education level and burden categories ($\chi^2 = 2.15$, $df = 2$, $p = 0.34$; $\chi^2 = 4.67$, $df = 8$, $p = 0.79$). Finally, Pearson correlation analysis between age and Zarit burden scores demonstrated no linear relationship ($r = 0.08$, $p = 0.52$).

Collectively, these findings indicate that demographic characteristics do not significantly predict caregiver burden levels, with all statistical tests except one yielding p-values exceeding the 0.05 significance threshold. The universal nature of high burden across demographic subgroups suggests that caregiving demands transcend individual demographic characteristics and necessitate comprehensive support systems for all caregivers.

Discussion:

Chronic kidney disease is defined as the drop in the rate of glomerular filtration rate less than 60 ml /min/1.73 meter square. Irreversible sclerosis leads to progressive loss of nephron which eventually results in end stage renal failure in which the rate of glomerular filtration drops to less than 15 ml /min /1.73 meter square.^(12, 13) ESRD can be treated with either hemodialysis or kidney transplantation. Consequently, the choice of the treatment for patients is hemodialysis due to unavailability of kidney transplant⁽¹⁴⁾. The initiation of hemodialysis should be shared decision between the physician, patient and family members of patient.⁽¹⁵⁾ Chronic hemodialysis is associated with generation of dependency which eventually involves one of the family members to assist in particular responsibilities regarding dietary needs, clinical consultations, psycho-social issues and trips to the hemodialysis clinic. Consequently, over the time the burden on the primary care giver would lead to symptoms of depression, anxiety, exhaustion, feelings of social isolation, tensions in relationships, financial struggles, and stress, contributing to their mental and physical health issues.^(16, 17)

In a province with limited resources like Baluchistan, support for caregivers is minimal, despite the increasing global awareness. Understanding the difficulties faced by primary caregivers in rural and underdeveloped regions creates a gap that complicates efforts to advocate for caregiver health and develop effective interventions. Thus, this study seeks to address this gap by evaluating the prevalence and factors related to caregiver burden among families of hemodialysis patients in Baluchistan, offering important insights for future support initiatives.

Global studies have shown that caregivers of hemodialysis patients frequently experience moderate to severe levels of burden. The Zarit Burden Interview (ZBI) is one of the most widely used tools to measure this burden, with higher scores indicating greater stress and impact on well-being. A study in Sikkim India revealed that 68.6 % of caregivers were experiencing the caregiver burden in which 3.92% severe burden, 11.97 % with moderate and 52.94 % with mild burden had experienced by care givers.⁽⁹⁾ Likewise, another study in Nepal revealed that about 44.65% in which 60 (48.78%) had mild to moderate, 53 (43.08%)

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had moderate to severe and 3.25 % had experienced severe disease burden.⁽¹⁸⁾ Alshammari et al reported in a study in Saudi Arabia that 29.5% caregivers experienced mild burden, 11.5% reported moderate burden and none of the primary care givers had severe burden.⁽¹⁹⁾ Similarly, the trends of burden were also reported in another cross sectional study in Saudi Arabia in which No to mild burden was reported to be 46% Mild to moderate burden of 38% and High burden severity of 16%.⁽²⁰⁾

A key factor influencing caregiver burden is the socio-demographic profile of the caregiver. As in our study revealed that the females especially the wife and daughters are affected more in the role of primary care giver. Additionally, the rate of literacy among the primary care giver are proportional to the stress load in the role. Joseph et AL' s finding also aligns with our study in which the gender (female) and education (less education) are related to high burden of suffering.^{(18),(21)} A similar study conducted in Nepal revealed that most primary care givers were female, together with this the duration of disease more than 3 years leading to high disease burden also align with our study.⁽¹⁸⁾ Similarly, Alshammari et al support the care giver burden on females and the increasing age. Conversely, the study was unable to find significant association between caregiver burden and the education.⁽¹⁹⁾ However, Alaryni ET AL reported no significant association between care giver burden and age, gender and the employment. However, the education level had significant association.⁽²⁰⁾

Another significant factor in caregiver burden, particularly in environments with limited resources, is financial hardship. Even when hemodialysis is subsided, the cost is increased by indirect expenses such as missed workdays, nutritional needs, and transportation. Darwish et al reported that the majority of carer' s had varying degrees of financial difficulties and were either fully or partially responsible for paying for their children's medical care. The responding carer, level of financial hardship, treatment mode, and socioeconomic status were all significant predictors of the Total FIM.⁽¹³⁾ Reddy et al reported that Carer' s of children with renal failure, recent hospitalization, non-earning carer' s, caring for more than two dependents, and significant medical expenses had higher Pediatric Renal Caregiver Burden Scale PRCBS scores. Of the 43 (96%) carer' s who had CHE, 37 (82%) paid for it out of pocket.⁽²³⁾ Furthermore, in Pakistan similar trends were observed. The majority of carer' s considered the burden to be modest to moderate, based on study findings. Their health deteriorated, they had little time for self-care, and they were overburdened with obligations.⁽²⁴⁾

The psychological effects of providing care are significant. Anxiety, depression, sleep issues, and social isolation are symptoms that many carer' s report experiencing. Numerous studies have employed the Hospital Anxiety and Depression Scale (HADS) to assess mental health, with concerning results. Our study findings align with Adejumo et al which reported the significant association of depression and anxiety among the female care givers.⁽²⁵⁾ Similarly, association of depression with CB was reported by Joseph et al.⁽⁹⁾ In another systematic review Alshammari et al also reported the highest trends of psychological effects like depression in primary care giver as in most of the previous studies.⁽²⁶⁾ Mahmoud et al revealed that of those who cared for children with chronic renal illness, over half reported moderate

depression, compared to mild depression and severe depression.⁽²⁷⁾ It was discovered that 90.4% of carer's suffered from severe anxiety and depression in southern Punjab Pakistan.⁽²²⁾ likewise, in another study in Pakistan None of the patients in experienced severe depression, while 99 (53.5%) had mild depression.⁽²⁴⁾

Conclusion: Caregiver burden is a serious issue resulting from various, socioeconomic and cultural factors that might result in adverse outcomes for the patients. Nephrologists and dialysis paramedical staff should be educated and trained to handle caregiver burden.

Conflict of interest: None

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