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# Caregiver burden and quality of life among family caregivers of hemodialysis patients from South India

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## Abstract:

**BACKGROUND:** Hemodialysis (HD) patients require assistance from family caregivers in performing daily activities. This additional responsibility may cause caregivers to feel burdened, resulting in a poor quality of life. The current study envisaged assessing the degree of caregiver burden (CB) and quality of life among the primary caregivers of HD patients.

**MATERIALS AND METHODS:** A cross-sectional study was conducted among conveniently sampled, consenting family caregivers ( $N = 200$ ) of HD patients in tertiary care dialysis centers in Thiruvananthapuram, Kerala, India, from March 2022 to May 2022. A structured interview schedule was used to collect sociodemographic data from participants. The caregiver burden and quality of life were assessed using the Zarit Burden Interview and the World Health Organization (WHO) Quality of Life (QoL) BREF scale. Univariate and multivariate analyses were performed to determine the association between the variables.

**RESULTS:** Fifty-eight percent of the caregivers reported CB. Caregivers with no leisure time ( $OR_{adj} = 3.29$  [95% CI: 1.73–6.41]), perceived financial stress ( $OR_{adj} = 2.27$  [95% CI: 1.16–4.49]), and having comorbidities ( $OR_{adj} = 2.92$  [95% CI: 1.43–6.12]) had an increased odds of experiencing caregiver burden. The CB score was inversely correlated with all domains of QoL. Moreover, the QoL score was lower among family caregivers with CB than those without CB.

**CONCLUSION:** The present study highlights a high prevalence of caregiver burden, which negatively impacts the QoL of family caregivers of HD patients. This study opens up new directions for possible policy-making to reduce caregiver burden and improve the QoL of family caregivers.

## Keywords:

Caregiver burden, caregivers, chronic kidney insufficiency, quality of life, renal dialysis

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## Introduction

Chronic kidney disease (CKD) is an emerging public health problem globally, affecting almost 850 million people, and is the third fastest-growing cause of death.<sup>[1]</sup> A recent survey revealed that India has emerged as one of the CKD hotspots contributing to more than a third of the total cases of CKD in Asia.<sup>[2]</sup> Among all Indian states, the population of Kerala is more vulnerable to CKD due to the high prevalence of type 2 diabetes mellitus and hypertension.<sup>[3]</sup> Indeed, a

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recent study revealed that the average age of CKD patients in Kerala was 48.6 years, with 62% of patients in the advanced stage of the disease.<sup>[3]</sup> The advanced stage of CKD rapidly progresses to end-stage renal disease (ESRD), where kidney replacement therapy (KRT) is the only option.<sup>[4]</sup> Among all the modalities available for KRT, hemodialysis (HD) is the most commonly used, accounting for approximately 69% of all KRT and 89% of all dialysis.<sup>[5-7]</sup> Although HD is an undeniable part of ESRD patients' lives and extends individuals' life span, it leads to catastrophic health expenditure, is stressful, and has restraining effects on the patient's life and their family members.<sup>[8,9]</sup>

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ESRD patients primarily rely on their family members for daily activities and medication, transportation during routine check-ups, personal hygiene, appropriate diet preparation, and other household activities.<sup>[10]</sup> These family caregivers divide their time and attention between the patient's needs and their activities, including professional, social, and marital roles. They willingly accept the responsibility of a diseased patient without any monetary support. The long duration of caregiving to ESRD patients puts the family caregivers under a lot of physical, emotional, and financial burden.<sup>[11]</sup> This leads to a perceived deterioration in the caregiver's emotional and/or physical health, social life, and financial status, known as caregiver burden (CB).<sup>[12]</sup> The high CB has been associated with a decrease in caregivers' QoL and the quality of care they provide to HD patients.<sup>[13]</sup>

The caregivers of HD patients experience the highest CB among all modalities of KRT.<sup>[14]</sup> Although a few studies have documented the level of caregiver burden, factors associated with CB and the association of CB with QoL among family caregivers of HD patients.<sup>[15-20]</sup> Moreover, limited programs address the CB and mental health of family caregivers of HD patients, especially from countries with a large burden of ESRD such as India. Previous studies have shown the importance of family-centered support intervention<sup>[21]</sup> and health-promoting behaviors<sup>[22]</sup> in reducing CB and improving the mental health of family caregivers. Although these programs may be effective only when information on the level of CB, factors associated with CB and the association of CB with QoL among family caregivers of HD patients is available. This may help in the proper allocation of resources to improve family caregiver's well-being in general and mental health in particular.

Hence the present study was envisaged to find the CB, its associated factors and QoL assessment among family caregivers of HD patients in South India.

## Materials and Methods

### Study design and setting

A cross-sectional survey was conducted to assess caregiver burden and QoL among the primary caregivers of HD patients from March to May 2022. Twenty-four HD centers were contacted for their willingness to participate in the study. Of these, eight HD centers agreed to participate in the study. sampling.

### Study participants and sampling

After obtaining their consent, 200 family caregivers of the patients undergoing HD at the participating centers, aged 18 years or older, were selected by convenience. The adult caregivers who provided care to the HD patients for at least 3 months were included in the study. The paid

formal caregivers and caregivers of peritoneal dialysis patients were excluded from the study. Similarly, the information of 200 HD patients attended by their family caregivers was also collected.

### Data collection tools and technique

A structured interview schedule was administered to the consenting participants in Malayalam (regional language), divided into three sections. The first section included the family caregivers' and HD patients' socio-demographic and medical details. The second section included the assessment of the degree of CB, which was assessed using the Zarit Burden Interview (ZBI) Scale-22.<sup>[20,23]</sup> The ZBI scale had been previously used in a study from the region.<sup>[20]</sup> The ZBI scale is one of the most frequently used tools for evaluating burden and has been authenticated in many culturally or ethnically diverse populations.<sup>[20]</sup> The revised version of ZBI has 22 items. Each item was scored using a 5-point scale. Response options varied from 0 (never) to 4 (nearly always). A higher ZBI score indicates higher perceived CB. The final score was interpreted as 0–20, little or no burden; 21–40, mild-to-moderate burden; 41–60, moderate-to-severe burden; and 61–88, severe burden.<sup>[24]</sup>

The third section covered the family caregivers' QoL using the WHO QoL BREF scale.<sup>[25]</sup> The WHO QoL-BREF is a shorter version of the WHOQoL-100. It comprises four domains: physical, psychological, social, and environmental. Items on this measure were scored on a 5-point Likert scale. The scores range from 1 (low) to 5 (high), increasing scores from 1 to 5 denoting higher QoL. The raw domain scores acquired from the WHO QoL-BREF were transformed to a 4-20 score and then scaled positively as previously described.<sup>[25]</sup> The mean score within each domain was calculated. A higher score indicates a better QoL. The internal consistency of ZBI and each WHO QoL BREF scale domain was assessed using Cronbach's alpha.<sup>[26]</sup>

### Ethical consideration

The study was conducted after approval from the Institutional Ethics Committee (SCT/IEC/1828/JANUARY/2022) in accordance with the provisions of the Declaration of Helsinki on research involving human participants. Written informed consent was obtained from all study participants, and their confidentiality was maintained throughout the study.

### Statistical analysis

The data entry was performed in Microsoft Excel software, and later, the data were imported into R version 4.3.1 for analysis. Frequencies and proportions were calculated for the categorical variables, and median and standard deviations were calculated for the continuous variables.

Median age and age range were examined, and an independent test was applied to compare the mean and standard deviation in categorical variables. The level of CB was represented as frequencies and percentages in each category. The QoL was reported using mean and standard deviations for each domain. The CB was classified into no burden and burden by categorizing a ZBI score of 0–20 (little/no burden) as no burden and by pooling mild to severe burden levels (ZBI score of 21–88) to the burden category.

Bivariate analysis was performed for the categorical data. Binary logistic regression analysis was conducted to find the association between CB and sociodemographic variables of family caregivers and clinical variables of the HD patients. The associated variables were selected for the multivariate analysis, and the best model was selected based on AIC values using the R package AICcmodavg. The odds ratio was computed for all the associations assessed, and the *P* value obtained was used to determine whether the associations were significant. A *P* value of  $\leq 0.05$  was used as a cut-off for statistical significance.

## Results

### Socio-demographic characteristics of caregivers and HD patients

Socio-demographic characteristics of family caregivers (*N* = 200) and HD patients (*N* = 200) are shown in Table 1 and Supplementary Table 1, respectively. In general, the caregivers were younger than the HD patients. The median and standard deviation of caregivers' and patients' ages were  $55 \pm 12.53$  and  $61 \pm 11.81$  years. Out of 200 family caregivers, more than two-thirds of the family caregivers were women, whereas less than one-fourth of

the HD patients were women. More than three-fourths of the family caregivers were spouses of HD patients. Around three-fourths of the family caregivers had at least one comorbid condition, and more than half had perceived final stress [Table 1].

The treatment duration for half of the HD patients was more than 2 years (50.5%), with two sessions of dialysis (72%) every week. More than half of the HD patients (53.5%) depended on caregivers for their day-to-day activities [Supplementary Table 1].

### Caregiver burden and associated factors in family caregivers

The Cronbach's alpha for ZBI was 0.85, indicating good internal consistency.

The level of CB for family caregivers is shown in Figure 1. About 58% of the caregivers in the study experienced CB. Among them, 46% had mild to moderate caregiver burden, and 11% had moderate to severe caregiver burden. Only 1% of caregivers reported severe caregiver burden.

Univariate analysis revealed that family caregivers in the lower income category ( $\leq ₹ 20000$ ), with the presence of comorbidity, with no leisure time, more than 8 h of caregiving duties, and perceived financial stress had higher odds of experiencing CB as shown in Table 2 and Supplementary Table 2. Upon multivariate analysis, family caregivers with comorbidity, non-availability of leisure time, and perceived financial stress showed increased odds of CB [Table 2]. None of the sociodemographic and clinical variables of HD patients was associated with the CB in family caregivers [Supplementary Table 3].

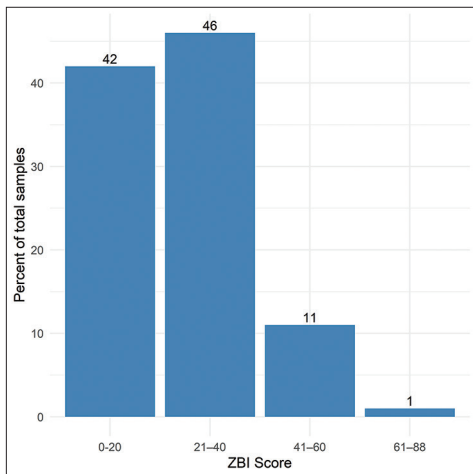
**Table 1: Sociodemographic characteristics of family caregivers of hemodialysis patients**

Variables	n (%)	Variables	n (%)
Age in years median (range)	55 (22-85)	Average caring hours	
Gender		<8 h	188 (94.0)
Male	45 (22.5)	$\geq 8$ h	12 (6.0)
Female	155 (77.5)	Perceived financial stress	
Marital status		No	90 (45.0)
Single	8 (4.0)	Yes	110 (55.0)
Married	187 (93.5)	Distance to the dialysis center	
Divorced/Widowed	5 (2.5)	<1 km	3 (1.5)
Relation of the caregiver to the patient		2-5 km	31 (15.5)
Spouse	155 (77.5)	>5 km	166 (83.0)
Mother	12 (6.0)	Leisure time	
Son	12 (6.0)	No	102 (51.0)
Daughter	13 (7.5)	Yes	98 (49.0)
Siblings	5 (2.5)	Presence of comorbidity	
Other family member	3 (1.5)	No	53 (26.5)
Income range (in ₹ per month)		Yes	147 (73.5)
<20000	140 (70.0)		
$\geq 20000$	60 (30.0)		

### Quality of life and caregiver burden in family caregivers

Cronbach’s alpha for physical, psychological, environmental, and social domains of WHOQoL BREF was found to be 0.87, 0.87, 0.86, and 0.80, respectively. This indicated a good internal consistency of the tool.

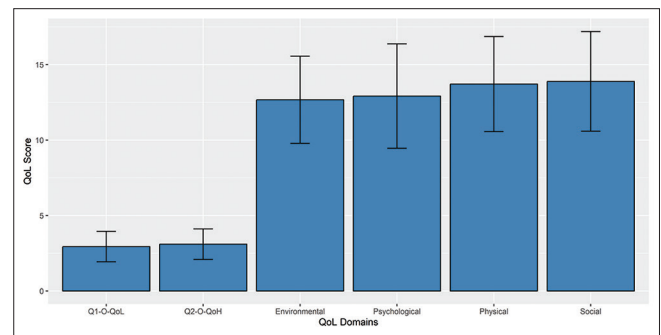
The mean score and standard deviation for each domain of QoL are shown in Figure 2. The mean and standard deviation of overall QoL was  $2.94 \pm 1.01$ , and that of overall quality of health was  $3.10 \pm 1.01$ . The mean score and standard deviation of physical, psychological, social,



**Figure 1:** Barplot showing percentages of study participants (X-axis) categorized by Zarit Burden Score categories (Y-axis) of little or no burden (0-20), mild-to-moderate burden (21-40), moderate-to-severe burden (41-60), and severe burden (61-88)

and environmental domains of QoL were  $13.71 \pm 3.15$ ,  $12.92 \pm 3.46$ ,  $13.89 \pm 3.30$ , and  $12.67 \pm 2.89$ , respectively.

To assess the relationship between CB and QoL of family caregivers, we analyzed the Pearson correlation between the CB score assessed by ZBI and scores for all domains of QoL. We observed a negative correlation between physical ( $r = -0.65, P < 2.2 \times 10^{-16}$ ), psychological ( $r = -0.66, P < 2.2 \times 10^{-16}$ ), environmental ( $r = -0.63, P < 2.2 \times 10^{-16}$ ) and social ( $r = -0.45, P < 2.9 \times 10^{-11}$ ) domains of QoL and CB score indicating that CB increased with decreasing QoL across all domains in family caregivers [Table 3]. Further, we compared the median scores of domains of QoL among caregivers experiencing and not experiencing CB. Our results suggested that caregivers with no caregiving burden had a higher median score of QoL across physical ( $P = 1.06 \times 10^{-16}$ ), psychological ( $P = 2.38 \times 10^{-16}$ ),



**Figure 2:** Barplot representing mean Quality of Life scores for study participants under various domains of WHO-QoL

**Table 2: Association of Caregiver Burden with sociodemographic factors**

Variables	Univariate		Multivariate <sup>a</sup>	
	OR [95%CI]	P	ORadj [95%CI]	P
Income Category				
Income > ₹ 20000	Referent			
Income ≤ ₹ 20000	2.60 [1.40, 4.87]	0.003	1.99 [0.96, 4.18]	0.067
Presence of comorbidity				
No Comorbidity	Referent			
Comorbidity	<b>3.65 [1.91, 7.14]</b>	<b>1.1×10<sup>-4</sup></b>	<b>2.92 [1.43, 6.12]</b>	<b>0.004</b>
Availability of Leisure time				
Yes	Referent			
No	<b>3.86 [2.15, 7.09]</b>	<b>8.70×10<sup>-6</sup></b>	<b>3.29 [1.73, 6.41]</b>	<b>3.54×10<sup>-4</sup></b>
Hours of caregiving				
<8 h	Referent			
≥8 h	<b>8.70 [1.64, 160.55]</b>	<b>0.040</b>	<b>7.38 [1.03, 162.39]</b>	<b>0.096</b>
Perceived financial stress				
No	Referent			
Yes	<b>3.65 [2.04, 6.66]</b>	<b>1.73×10<sup>-5</sup></b>	<b>2.27 [1.16, 4.49]</b>	<b>0.017</b>

<sup>a</sup>Multivariate model. Significant findings are highlighted in Bolds

**Table 3: Correlation between caregiver burden and domains of quality of life in family caregivers of HD patients**

WHO-QoL Domains	Physical		Psychological		Environmental		Social	
	r <sup>#</sup>	95% CI	r <sup>#</sup>	95% CI	r <sup>#</sup>	95% CI	r <sup>#</sup>	95% CI
Zarit Burden Index	-0.65	-0.72/-0.56	-0.66	-0.73/-0.57	-0.63	-0.71/-0.54	-0.45	-0.55/-0.33

<sup>#</sup>Pearson’s correlation coefficient

environmental ( $P = 1.07 \times 10^{-16}$ ) and social ( $P = 4.31 \times 10^{-6}$ ) domains of QoL compared to family caregivers with CB [Table 4] reinstating that CB increased with decreasing QoL across all domains in family caregivers.

### Discussion

In this study, we assessed the caregiver burden and QoL of the family caregivers of HD patients. In doing so, we identified that most family caregivers experienced mild to moderate CB, and the CB was associated with reduced QoL.

We observed that two-thirds of the family caregivers were women. Our findings are in coherence with the previously published work from India, Turkey, and China, where the majority of the caregivers were women. The higher proportion of female caregivers may be the feminization of women tending to emotional work and maintaining identities and relationships.<sup>[27,28]</sup> It may also be because more men (59%) than women (41%) were on HD in our study, as found previously in an independent study.<sup>[29]</sup>

Out of the 200 family caregivers, 58% of the caregivers experienced CB, and 46% of family caregivers experienced mild to moderate caregiver burden. Our results align with recently conducted regional, national,<sup>[30-32]</sup> and international studies Nepal,<sup>[19]</sup> Iran<sup>[33]</sup> and China.<sup>[34]</sup> Further, we observed that severe CB was experienced only by 1% of the family caregivers. The lower proportion of family caregivers experiencing CB may be attributed to the fact that more than 75% of the caregivers were spouses, and among them, 80% were women. Similar observations were made by studies performed in Nepal<sup>[19]</sup> and India,<sup>[31]</sup> where severe CB was observed in 3.25% and 3.92% of caregivers.

We found that experiencing CB was associated with comorbidity, lack of leisure time, and perceived financial stress among family caregivers. A recent systematic review by Alshammari *et al.*<sup>[12]</sup> supports our finding, showing that the majority of the studies have reported caregiver comorbidity as a predictor of CB. Indeed, Mollaoğlu *et al.*<sup>[35]</sup> have demonstrated that the mean score

of CB was higher among caregivers with comorbidity. The increased odds of having CB among family caregivers with co-morbidity may be due to the responsibility of caregiving that may decrease the time available to address their own health needs as revealed by the findings of Zhang *et al.*<sup>[34]</sup> and Jafari *et al.*<sup>[33]</sup> Financial stress has been associated with caregiving burdens for caregivers of patients with various diseases. Similar to our findings, studies performed in Nepal and China also reported that perceiving one's financial status as insufficient increases the CB in caregivers.<sup>[19,36]</sup> Lack of leisure activities encompassing physical activity, hobbies, and social life is known as time poverty.<sup>[37]</sup> Our study revealed that family caregivers lacked leisure time, which was associated with increased CB among them. Studies have shown that family caregivers provide more time to their caregiving activities, thus allocating less time to self-care, which can be detrimental to the health, life satisfaction, and well-being of informal caregivers, leading to CB.<sup>[38]</sup>

Our study revealed that the CB inferred by the ZBI was inversely correlated with all four domains of QoL (physical, psychological, environmental, and social), indicating that increasing CB was correlated with decreasing QoL. Our findings are similar to previously published work from different parts of the world.<sup>[33,34,39-41]</sup> The inverse association of CB with the domains of QoL may be attributed to the long duration of caregiving by the family caregivers.<sup>[33]</sup> Similarly, various factors associated with CB, such as lack of leisure time, presence of comorbidity, and perceived financial stress, may lead to a decrease in QoL in various domains of WHOQoL. A study by Sharma *et al.*<sup>[30]</sup> revealed that caring and being with patients for most of the time resulted in poor health and QoL among family caregivers. Abbasi *et al.*<sup>[15]</sup> showed a negative association with the QoL of the caregivers and the caregiver burden. Also, the study conducted by Jafari *et al.*<sup>[33]</sup> showed a significant and inverse association between QoL and caregiver burden. Belasco and Sesso reported that the QoL of caregivers of HD patients was negatively affected by the higher caregiver burden.<sup>[42]</sup> Caregiving may influence their physical and psychological well-being and result in exhaustion and stress, which in turn affect their QoL.<sup>[42]</sup> According to the study of Alvarez-Ude *et al.*,<sup>[41]</sup> the caregivers of HD showed a considerable decrease in their energy level, and physical and mental health resulting in poor QoL. Our study showed that all domains of QoL decreased with increasing CB among family caregivers. Therefore, reducing the CB among family caregivers may improve their QoL and the level of care they provide to HD patients.

The present study has a few limitations, the first being the nature of the study, which is cross-sectional, so the causal relevance of our findings cannot be established. In addition, the emotional status of the caregivers at the time of the

**Table 4: Difference in scores of quality-of-life domains of caregivers with or without Caregiver Burden in family caregivers of HD patients**

WHO-QoL domains	Caregiver burden		P*
	No burden median±SD	Burden median±SD	
Physical	16.0±2.06	12.6±2.97	1.06×10 <sup>-16</sup>
Psychological	15.3±2.63	11.3±3.07	2.38×10 <sup>-16</sup>
Environmental	15.0±2.35	11.5±2.43	1.07×10 <sup>-16</sup>
Social	16.0±2.60	14.0±3.46	4.31×10 <sup>-6</sup>

\*Mann-Whitney U test

interview may have influenced the response, leading to information bias. Finally, the study was performed using convenience sampling, and therefore, the study participants may not be representative of the general population.

## Conclusions

In conclusion, our study found that caregiver burden was observed among the family caregivers of HD patients. The caregiver burden negatively influences caregivers' QoL, which in turn impacts the quality of care they offer to HD patients. Therefore, healthcare providers and policymakers need to pay attention not only to treatment modalities for HD patients but also to the mental health of caregivers of HD patients while devising comprehensive policies for end-stage renal disease management. In this regard, programs focused on family-centered support intervention and health-promoting behaviors may be introduced for the benefit of family caregivers.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

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**Supplementary Table 1: Sociodemographic and clinical characteristics of hemodialysis patients**

Variables	n (%)
Age in years median (range)	61 (20-86)
Gender	
Male	124 (62.0)
Female	76 (38.0)
Treatment Duration	
3-6 months	39 (19.5)
7-12 months	24 (12.0)
>12 months to 24 months	36 (18.0)
>24 months	101 (50.5)
Weekly Dialysis Sessions	
One	10 (5.0)
Two	144 (72.0)
Three	46 (23.0)
Dependence of HD patients on caregivers for day-to-day activities	
No	93 (46.5)
Yes	107 (53.5)

**Supplementary Table 2: Association of caregiver burden and sociodemographic variables of family caregivers**

Variables	Caregiving Burden		P
	No Burden	Burden	
Age in years, median (SD)	55.0±13.7	55.5±11.7	0.62*
Gender			
Male	18	27	0.89**
Female	66	89	
Religion			
Hindu	63	75	0.25**
Muslim	8	19	
Christian	13	22	
Marital Status			
Single	5	3	0.35***
Married	78	109	
Divorced/Widowed	1	4	
Relationship			
Spouse	64	91	0.17***
Parents	3	9	
Children	11	14	
Others	6	2	
Income category			
≤20,000	49	91	0.004
>20,000	35	25	
Presence of comorbid conditions			
No	35	19	1.37×10 <sup>-4</sup>
Yes	49	97	
Leisure time			
No	27	75	1.10×10 <sup>-5</sup>
Yes	57	41	
Caregiving duties in a day			
<8 hours	83	105	0.015***
≥8 hours	1	11	
Perceived financial stress			
No	53	37	2.30×10 <sup>-5</sup>
Yes	31	79	
Distance to the dialysis center			
<1 km	1	2	0.76***
2-5 km	11	20	
>5 km	72	94	

\*Mann-Whitney U test, \*\*Chi-square test, \*\*\*Fisher exact test



**Supplementary Table 3: Association of caregiver burden of family caregivers, sociodemographic and clinical variables of HD patients**

Variables	Caregiving Burden		P
	No Burden	Burden	
Age in years, median (SD)	61.0±12.3	60.5±11.4	0.37*
Gender			
Male	53	71	0.90**
Female	31	45	
Treatment Duration			
3-6 months	18	21	0.48**
7-12 months	11	13	
>12 months to 24 months	11	25	
>24 months	44	57	
Weekly Dialysis Sessions			
One	4	6	0.08***
Two	67	77	
Three	13	33	
Dependence of HD patients on caregivers for day-to-day activities			
No	44	49	0.20**
Yes	40	67	

\*Mann-Whitney *U* test, \*\*Chi-square test, \*\*\*Fisher exact test