



## Study of Caregiver Burden in Continuous Ambulatory Peritoneal Dialysis

### Abstract

**Background:** Increased caregiver burden undermines caregivers' mental and physical health and is an under recognized but critical aspect for the success of continuous ambulatory peritoneal dialysis (CAPD). This study was undertaken to quantify and identify the factors determining CAPD caregiver burden. **Materials and Methods:** A cross-sectional study was conducted among 51 caregivers of CAPD patients visiting the centers from July to August 2023. Caregiver burden score was determined using "Zarit Burden Interview" by interview method. **Results:** The mean age of caregivers was  $42.8 \pm 10.83$  years with 52.9% females. The mean Zarit burden score of the caregivers was  $29.18 \pm 11.81$ . Younger caregivers experienced significantly higher burden ( $r = -0.34, P = 0.013$ ). Lesser educated caregivers were perceiving a higher burden. Lower socioeconomic strata people had significantly higher burden ( $P < 0.001$ ) and especially so when there was a loss in income attributed to caregiving. Patients who were covered by state insurance experienced a notably lower caregiver burden ( $19.2 \pm 6.1$ ) when compared to those who were self-financed ( $32.4 \pm 11.08$ ) or had company insurance ( $37.2 \pm 13.6$ ). Gender, religion, marital status, and type of family had no bearing on the caregiver burden. **Conclusion:** Age, loss of income, education, and socioeconomic status are important determinants of caregiver burden. State sponsored program lowers caregiver burden significantly. A CAPD program should address these factors to mitigate caregiver burden.



**Keywords:** Chronic kidney disease, Continuous ambulatory peritoneal dialysis, Caregiver burden, Zarit burden score, End-stage renal disease

### Introduction

Chronic kidney disease (CKD) is a global public health problem. In India, the prevalence of CKD is almost 17%. With the rising incidence of end-stage renal disease (ESRD), the costs related to delivery of renal replacement therapy has also come into the spotlight. In comparison to in-center hemodialysis (HD), continuous ambulatory peritoneal dialysis (CAPD) provides greater freedom, flexibility, and improved quality of life for most patients, while also being linked to reduced healthcare costs.<sup>1-5</sup> CAPD can be performed at home by patients themselves or a caregiver and does not require infrastructure, HD requires specially trained human resource and sophisticated infrastructure. In spite of these obvious advantages, penetration of CAPD is very low as revealed in a recent survey by Jha *et al.* in their study "The state of nephrology in South Asia," where they found that ~1,75,000 and 8,500 people

were receiving HD and CAPD, respectively, in India in 2018.<sup>6</sup>

Caregiver burden is a subjective experience involving multifaceted strains perceived by individuals who provide care for their family or loved ones over an extended period of time. This burden exerts adverse effects on both caregivers themselves and their dependents. CKD is a life-long condition, and its extended treatment places considerable strain on patients and their caregivers. As caregivers play a pivotal role in providing long-term patient care, comprehending and investigating the extent of their burden becomes essential. CAPD, a perpetually administered therapy, demands strict adherence to aseptic protocols during the procedure, financial support for CAPD supplies, advocating for the patient's needs, and mastering technically intricate training. This rigorous routine can take a toll on both patients and caregivers who shoulder the procedural responsibilities. The emotional

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and psychosocial complexities compound the challenges they face. Amplified caregiver burden not only jeopardizes their mental and physical well-being but can also impact the quality of care and patient outcomes.<sup>7,8</sup> Caregivers constitute a vital component of treatment protocols, with their conscientious care playing a preventive role against peritonitis and catheter loss. Yet, the daily regimen and responsibilities can become overwhelming. The accumulation of this prolonged stress has the potential to demotivate continued adherence to CAPD, potentially resulting in its inadequate use or discontinuation.

There are various ways to calculate caregiver burden, and they typically involve a combination of quantitative and qualitative assessments. Several standardized scales and questionnaires have been developed which include the Zarit Burden Interview (ZBI), caregiver strain index, and the caregiver reaction assessment. ZBI is one of the most widely used and well-studied caregiver burden assessment tools. It has been validated in a variety of populations and settings, and it has been shown to be reliable and valid.<sup>9,10</sup>

The assessment of caregiver burden is often overlooked within the realm of healthcare. Given that the efficacy of CAPD is partially reliant on the support of patients' caregivers, we have undertaken a study to delve into the caregiver burden attributed to this treatment method. Our objective is to quantify and discern the factors that contribute to the burden experienced by caregivers of patients undergoing CAPD.

## Materials and Methods

This cross-sectional study was conducted at a Medical College in South India from July to August 2023. In addition, ex-servicemen undergoing CAPD and receiving follow-up care at a Service Hospital were incorporated into the study. The evaluation of caregiver burden encompassed all caregivers of patients undergoing CAPD who were visiting the two centers. Caregivers of CAPD patients who had been admitted with complications associated with CAPD within the past month, as well as those who had commenced CAPD within the past 3 months, were excluded from the study. Using data extracted from the hospital, an average of 12 cases per month indicates an expected total of  $n = 48$  cases. Based on this population size, using YAMANE equation for a known population size, sample size ( $n$ ) =  $n = N/1 + Ne^2$  where  $n$  signifies the sample size,  $N$  is the population size, and  $e$  stands for the margin of error (for a 95% confidence level, the margin of error is typically 0.05). Substituting the given values:  $n = 48/1 + 48 \times 0.05 \times 0.05 = 48/1.12 = 42.85$ . Therefore, after approximating, the sample size was fixed at 50. Approval was obtained by the Institutional Review Board at St Johns Medical College Hospital, number IEC/1/735/2023, dated 15/06/2023 and the Institutional Review Board at IEC Command Hospital (Air Force), number CHAFB/IEC/32/2023, dated 13/07/2023, before commencing the study. Written

informed consent was obtained from all study participants before data collection. Caregiver was defined as the person who stays with the patient, accompanies them during hospital visits, and/or oversees financial matters irrespective of whether the caregiver was physically doing the procedure or not. Information regarding sociodemographic variables and the history of CKD was gathered using a pre-tested, semi-structured questionnaire administered through interviews. The socioeconomic status (SES) was assessed using the modified Kuppaswamy scale. This modified scale encompassed three key parameters: the educational level and occupation of the head of the family, as well as the total family income. Based on the scores attributed to each of these parameters, participants were categorized into five distinct SES classes, as outlined in Table 1.<sup>11</sup> Caregiver burden was assessed using the ZBI. This interview comprises 22 items, each rated on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always), resulting in total scores that fall within the range of 0–88. The scores were interpreted as follows: 0–20 (little or no burden), 21–40 (mild to moderate burden), 41–60 (moderate to severe burden), and 61–88 (severe burden).<sup>12</sup> The data were analyzed using the Statistical Package for the Social Sciences (Version 26.0). Quantitative variables with a parametric distribution were subjected to analysis using Student's *t*-test, and when dealing with more than two groups, analysis of variance was applied. Pearson's correlation coefficient was utilized to verify correlations between continuous variables. For variables with a non-parametric distribution, the Mann–Whitney test was employed. The definitions for the above are shown in Table 1.

## Results

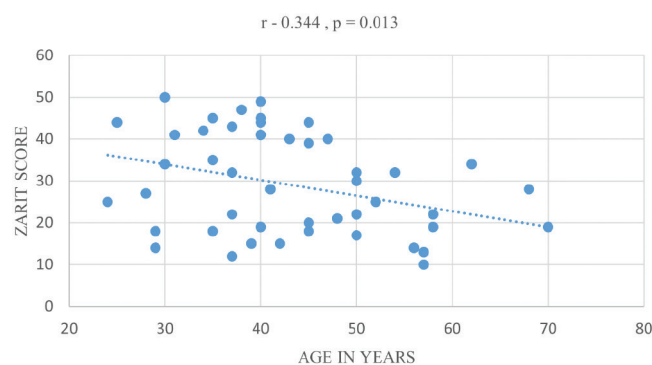
The study population consisted of 51 caregivers [Supplementary Figure 1]. The demographic, social, and clinical characteristics of these caregivers are presented in Table 2. The mean age of the caregivers was  $42.8 \pm 10.8$  years, with a female predominance (52.9%). About 62.7% of the caregivers were from urban areas, with 39.2% belonging to the upper middle class SES. The most common caregivers were wives (35.3%) and parents (33.3%). In terms of religious affiliation, 78.4% identified as Hindu, followed by Christian (11.8%) and Muslim (9.8%). Approximately 52.9% of the caregivers were from nuclear families, and 84.3% were married. About 54.9% of the caregivers were employed. The average CAPD vintage was  $14.1 \pm 3.9$  months. The average monthly household income was Rs.  $92,235.29 \pm 131,250.6$ , while the mean income lost as a result of caregiving was Rs.  $31,725.49 \pm 17,197.76$ .

The mean Zarit burden score of the caregivers was  $29.18 \pm 11.81$ . The burden levels were distributed as follows: 33.3% of caregivers experienced little burden, 39.2% reported mild burden, and 27.4% faced moderate burden.

**Table 1: Definitions: The following terms used in our study are defined as below**

Caregiver	The person who stays with the patient, accompanies to hospital visits and manages the finances.
Caregiver burden	Stress and/or strain that caregivers may experience as a result of engaging in care giving tasks, affecting their mental and physical health and can also affecting care and patient outcomes.
Urban and rural	Caregivers staying in cities, suburbs, and towns were included under urban population. Caregivers staying in villages were included under rural population.
Nuclear and joint family	Nuclear family included parents and their children. Joint family included grand-parents, parents, children, uncle, aunt, and cousins.
Level of education	Secondary schooling and below were considered lesser educated. PU and above were considered better educated.
Employment status	Working and engagement in any economic activity were considered employed. Caregivers not working or looking for a job were considered unemployed.
ZBI	The measure of caregiving burden comprises 22 questions, to which caregivers were asked to respond, assessing the impact of the patient's disabilities on their lives and reflecting the stressors experienced due to caregiving.
Average monthly income	As stated by the caregiver over a 3 month period before starting peritoneal dialysis, was taken as the base line. The mean monthly income over a 3 month period before the ZBI was conducted was considered and the difference between the 2 values was taken as the loss of income

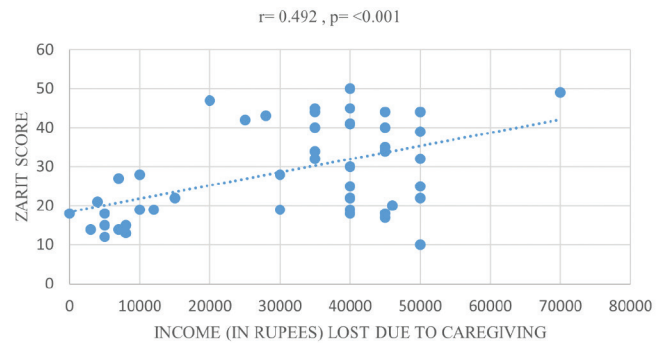
ZBI: Zarit burden interview, PU: Pre-University



**Figure 1:** Correlation of age with Zarit scores.

Among the caregivers, 84.3% were actively engaged in performing CAPD. About 25.4% of the patients had at least one episode of peritonitis in the past.

Several demographic variables were found to influence the Zarit scores. Specifically, females exhibited higher Zarit scores compared to males. Caregivers who identified



**Figure 2:** Correlation of income lost due to care giving with Zarit scores.

as Muslim displayed higher scores than those from other religious backgrounds. Unmarried caregivers also registered higher Zarit scores. Those from joint families reported higher burden compared to those from nuclear families. All caregivers possessed some form of education, with 33.3% having an undergraduate degree and 23.5% holding postgraduate degrees. Interestingly, a negative correlation was observed between the level of education and the severity of caregiver burden ( $P = 0.103$ ).

Furthermore, caregivers who were compelled to change jobs due to their caregiving responsibilities reported higher Zarit scores than those who retained the same employment ( $P = 0.134$ ). Similar patterns were observed with SES, where caregivers from lower strata displayed higher burden scores. The presence or absence of insurance and SES were inversely related to Zarit scores with statistical significance.

Age also demonstrated a significant negative correlation with Zarit scores ( $r = -0.34, P = 0.013$ ) [Figure 1]. Although the monthly household income displayed a weak correlation with caregiver burden ( $r = -0.101, P = 0.48$ ), a noteworthy contribution to the severity of caregiver burden was observed when income was lost due to caregiving ( $r = -0.492, P < 0.001$ ) [Figure 2]. Notably, 64.7% of caregivers did not possess health insurance. Remarkably, lower burden was associated with the government-sponsored CAPD program for service patients ( $P < 0.001$ ) [Figure 3].

### Discussion

In a head-to-head comparison of various dialysis modalities, the results vary from country to country depending on tax breaks and government incentives.<sup>13,14</sup> CAPD, a complex dialysis method, significantly impacts patients and caregivers' lives, affecting their physical and psychosocial well-being.<sup>15,16</sup> Caregivers, crucial to CAPD's success, face increased anxiety, depression, and sleep issues, leading to a lower quality of life.<sup>17</sup> Despite these challenges, their resilience directly influences patient survival and home dialysis support. However, the full impact of CAPD on caregivers is not fully understood.<sup>18</sup> This study used the

**Table 2: Caregiver demographics and characteristics and comparison with burden**

Characteristics	Factor	Value	Zarit score	p value
Age (yrs)		42.8 ± 10.83	-	0.013 <sup>a</sup> (r = -0.34)
Gender, n (%)	Male	24 (47.1%)	28.13 ± 10.4	0.55
	Female	27 (52.9%)	30.1 ± 13.1	
Residence, n (%)	Rural	19 (37.3%)	29.0 ± 11.8	0.89
	Urban	32 (62.7%)	29.5 ± 12.1	
Religion, n (%)	Hindu	40 (78.4%)	28.9 ± 11.2	0.104
	Muslim	5 (9.8%)	39.8 ± 12.0	
	Christian	6 (11.8%)	27.5 ± 12.8	
Marital status, n (%)	Married	43 (84.3%)	27.5 ± 10.2	0.305
	Unmarried	7 (13.7%)	29.0 ± 11.9	
	Separated	1 (2%)	47	
Type of family, n (%)	Nuclear	27 (52.9%)	27.2 ± 12.7	0.238
	Joint	24 (47.1%)	31.9 ± 10.3	
Number of family members, Mean ± SD		5.10 ± 2.03		
Education, n (%)	Primary	1 (2%)	42	0.103
	Secondary	10 (19.6%)	35.1 ± 13.1	
	PU	11 (21.6%)	30.2 ± 10.1	
	UG	17 (33.3%)	23.6 ± 10.5	
	PG	12 (23.5%)	30 ± 11.8	
Employment, n (%)	Employed	28 (54.9%)	28.5 ± 12.2	0.65
	Unemployed	23 (45.1%)	30 ± 11.5	
Change in employment, n (%)	Yes	12 (23.5%)	33.6 ± 12.6	0.134
	No	39 (76.5%)	27.7 ± 11.3	
Insurance n (%)	No insurance	33 (64.7%)	32.4 ± 11.08	<0.001 <sup>a</sup>
	Company	4 (7.8%)	37.2 ± 13.6	
	Govt.	14 (27.5%)	19.2 ± 6.1	
Socioeconomic status, n (%)	Upper	8 (15.7%)	20 ± 9.5	<0.001 <sup>a</sup>
	Upper middle	20 (39.2%)	25.4 ± 10.6	
	Lower middle	13 (25.5%)	32.0 ± 10.1	
	Upper lower	9 (17.6%)	39.6 ± 8.8	
	Lower	1 (2%)	45	
Monthly income of household, Mean ± SD		92235.29 ± 131250.6	-	0.48 (r = -1.01)
Income lost due to caregiving		31725.49 ± 17197.76	-	<0.001 <sup>a</sup> (r = 0.492)
Caregiver health status, n (%)	Nil	40 (78.4%)	30.7 ± 12.3	0.212
	DM	4 (7.8%)	28.5 ± 4.7	
	HTN	5 (9.8%)	22.6 ± 9.0	
	Others	2 (3.9%)	16.5 ± 3.5	
Relation to the patient, n (%)	Husband to wife	7 (13.7%)	27.4 ± 11.8	0.98
	Wife to husband	18 (35.3%)		
	Parent to children	17 (33.3%)		
	Children to parents	4 (7.8%)		
	Siblings	3 (5.9%)		
	Others	2 (3.9%)		
CAPD Vintage(months)		14.1 ± 3.9	-	0.09 (r=0.23)
At least 1 episode of peritonitis previously, n (%)	Yes	13 (25.4 %)	28.8 ± 8.8	0.16
	No	38 (74.6 %)	31.8 ± 5.6	
Zarit score, Mean ± SD		29.18 ± 11.81		
Severity of burden n (%)	Little	17 (33.3%)		
	Mild	20 (39.2%)		
	Moderate	14 (27.4%)		
No. of exchanges done per day by caregiver		3 ± 0.52		
Caregiver doing PD, n (%)	Yes	43 (84.3%)	29.1 ± 11.4	0.934
	No	8 (15.7%)		

SD: Standard deviation, Govt.: Government, CAPD: Continuous ambulatory peritoneal dialysis, r: Correlation coefficient, UG: Undergraduate, PG: Postgraduate, PU: Pre-University, DM: Diabetes mellitus, HTN: Hypertension, <sup>a</sup>: Statistically significant value observed.

ZBI to assess caregiver burden and highlight the challenges they face.<sup>9,10</sup>

Our study primarily involved middle-aged caregivers, with a majority being females. A study by Nagarathnam *et al.* reported a similar age range, but their caregiver cohort was mainly male (mean age  $43.3 \pm 16.4$  years, males 60%).<sup>19</sup> In contrast, Griva *et al.*'s study predominantly included female caregivers (76%).<sup>20</sup> Notably, both studies did not formally analyze caregiver burden based on gender.<sup>19,20</sup> In our study, we noted a marginally higher average Zarit burden score in female caregivers compared to males. This could be due to females often balancing household tasks with providing CAPD assistance. An inverse relationship exists between the caregiver's age and the perceived burden, demonstrated by a negative correlation. This finding is consistent with other studies.<sup>21,22</sup> The observation is expected, as the younger generation, often driven by personal ambitions and career aspirations, is more susceptible to the significant impact of providing CAPD care for a family member.

Our study primarily included participants from the upper-middle-class. Notably, compromised income due to caregiving responsibilities significantly heightened caregiver burden unlike previous studies<sup>23,24</sup> that explored the general association between income and burden, our focus was on the specific impact of income loss once CAPD care commenced. We found a weak correlation between lower income and caregiver burden, suggesting that families with sufficient monthly household income for additional expenditure were not significantly burdened when opting for CAPD. However, the loss of income due to caregiving had a substantial impact, as reflected in high Zarit scores.

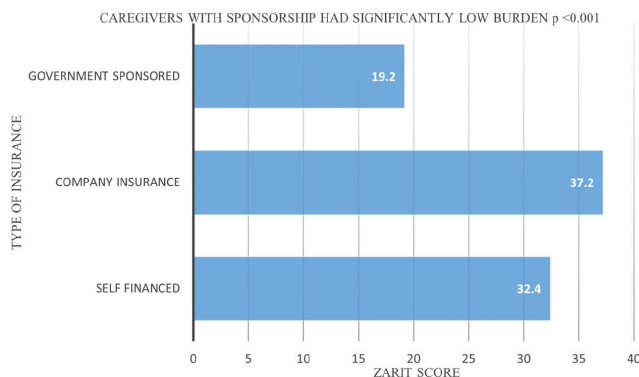
Studies investigating the direct impact of education level on caregiver burden are relatively scarce. In our study, we found a negative correlation between the level of education and the severity of burden. The practice of CAPD is a technically complex procedure with multiple steps requiring stringent aseptic precautions. Among the caregivers in our study, those with lower educational levels faced challenges in comprehending the intricacies

of the procedure. This difficulty could be attributed to the complex nature of CAPD. Interestingly, a study conducted by Nagarathnam *et al.*<sup>19</sup> reported the opposite trend, where higher-educated individuals experienced greater burden. Notably, the study's participant population encompassed caregivers of HD, CAPD, and transplant recipients, with a higher proportion of higher-educated individuals within the CAPD group. On the other hand, Zhang *et al.*<sup>23</sup> did not find any relation between caregiver burden and educational level.

There has been no Indian study comparing mode of finance of CAPD in the context of caregiver burden. In our study, we found that patients who were covered by state insurance experienced a notably lower caregiver burden when compared to those who were self-financed or had company insurance. Specifically, among patients with insurance coverage, those enrolled in the state-sponsored CAPD program reported the least caregiver burden in contrast to other groups, a difference that held statistical significance. Remarkably, caregivers associated with patients under company insurance plans reported the highest burden. This discrepancy might arise due to the diverse reimbursement policies concerning coverage amount and duration, with company policies often being arbitrary, leading to a substantial share of out-of-pocket expenditures for both patients and caregivers. Importantly, the government-sponsored CAPD program for ex-servicemen, which encompassed all CAPD-related expenses, was associated with significantly lower caregiver burden. Zhang *et al.* too<sup>23</sup> found that the financial strain imposed by medical costs related to dialysis results in increased caregiver burden due to disproportionate coverage by different insurances.

The study has its own limitations related to the cross-sectional nature of the study design, as only one assessment of ZBI was done precluding relevant longitudinal comparisons. Furthermore, only two centers were included in our study; hence, extrapolation of findings is uncertain.

Our study's findings highlight that caregivers with higher burden were younger and less educated. In addition, caregivers from lower economic strata tend to experience heightened burdens. The impact of burden is significantly exacerbated when there is a loss of income due to CAPD, coupled with a lack of sponsorship. Considering these outcomes, it is imperative to incorporate an assessment of caregiver burden when evaluating the overall effectiveness of CAPD for patients. Determining the factors that influence burden, evaluating the caregiver's needs, health status, and available financial and support resources, can lead to an improved CAPD experience. Therefore, promoting sponsorship and funding for CAPD implementation is essential. In the future, studies should focus on further elucidating these factors, devising strategies to alleviate



**Figure 3:** Comparing Caregiver Zarit Score (Mean) with Insurance type.

their impact, and ultimately enhancing the quality of life for both patients and caregivers.

### Conflicts of interest

There are no conflicts of interest.

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