

# Burden, Social Support, And Family Well-Being Of Caregivers Of Haemodialysis Patients

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## Abstract:

**Background:** Chronic kidney disease is a loss of kidney function that is progressive and irreversible. Dialysis is a technique in which the constituents of the blood move into dialysate through a semi-permeable membrane, for the removal of metabolic waste products and the correction of fluid and electrolyte imbalances. It is also used to purify the blood in cases of drug overdose. Caregivers of hemodialysis patients may encounter significant burdens and negative effects on their quality of life. The important predictors of the burden are the emotional aspects of the patients and their caregivers. Among the caregivers, the female spouses are particularly more burdened. For the betterment of patient outcomes and for the improvement of the caregiver's life, psychological and social support measures can be considered.

**Materials and Methods:** A total of 162 caregivers were recruited in the study who were taking care of and assisting the hemodialysis patients both when they were at home and when they were undergoing hemodialysis. A correlative survey design was selected to explore the perceived burden, social support, and family well-being of caregivers of hemodialysis patients under treatment. Structured self-administered Caregiver Burden Assessment Scale (CBAS), Social Support Scale (SSS), and Family Well-Being Scale (FWBS) were administered to the caregivers to obtain the necessary data.

**Results:** The present study aimed to assess caregiver burden, social support, and family well-being among caregivers of hemodialysis patients in selected hospitals of Udupi district, Karnataka. The finding of the study has shown that 131 (81%) caregivers were experiencing moderate levels of burden, while 109(67%) had a moderate level of social support and 76(47%) had moderate family well-being.

**Conclusion:** The study has found that the caregivers recruited in the study experience a moderate level of burden. The caregivers have an adequate amount of social support both from the family members and from the society as well.

**Key Word:** caregiver burden; social support; family well- being; haemodialysis

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## I. Introduction

Chronic kidney disease is an irreversible and progressive loss of renal function. It can be defined as the damage of the kidney or GFR of less than 60mL/min for 3 months or more. Kidney damage can be either caused due to pathological disorders or due to abnormal constituents in the blood and urine. Sometimes it may also be caused by drugs and dyes used for imaging studies. Dialysis can be defined as a technique in which the constituents of the blood flow through a semi-permeable membrane into a solution of dialysis called dialysate. Through this movement, the fluid and electrolyte imbalances can be corrected, and waste products will be removed. Peritoneal dialysis and hemodialysis are the two techniques of dialysis.<sup>1</sup> About 4 million people in the world are dependent on dialysis and haemodialysis accounts for about 89% of dialysis.<sup>2</sup>

In India, the incidence of ESRD is estimated to be around 100 per million population and each year, ESRD is diagnosed in 100,000 patients.<sup>3</sup> In India, it is estimated that Renal Replacement Therapy (RRT) is continued only by 10-20 % of ESRD patients on a long-term basis.<sup>4</sup> It is estimated that every year, there are emerging new cases of around 3000 continuous ambulatory peritoneal dialysis (CAPD), 3,500 cases awaiting renal transplant, and 15,000 new patients on Maintenance Haemodialysis (MHD).<sup>5</sup> The quality of life of the hemodialysis patients caregivers is severely affected and they experience a significant amount of burden.<sup>6</sup> The important predictors of the burden are caregivers, especially the female spouse's psychological aspects.<sup>7</sup>

Psychological and social support measures can be considered for the improvement of patient outcomes and the better quality of life of their caregivers.<sup>7</sup>

## **II. Material and Methods**

A purposive non-probability correlative survey design was adopted and carried out on caregivers of hemodialysis patients of Hemodialysis Units at selected tertiary hospitals of Udupi District. A total of 162 adult patients, aged  $\geq 18$  years were included in this study.

**Study Design:** A purposive non-probability correlative survey design.

**Study Location:** This study was done at a tertiary care teaching hospital's Hemodialysis Unit located in Udupi District, Karnataka

**Sample size:** 162 caregivers of hemodialysis patients.

**Sample size calculation:** Sample size was calculated based on a pilot study by using the Cochran (1977) formula,

$n = Z^2_{1-\alpha/2} \times pq / d^2$ , Where,  $z$  = confidence level at 95% (standard value of 1.96),  $p$  = estimated proportion based on the pilot study result,  $q = 1-p$  and  $d$  = allowable error. After substituting the values,  $n = (1.96)^2 \times 0.65 \times 0.35 / (0.075)^2$   $n = 155$ . The sample size calculated for the study is 155. After considering the attrition rate of 4%, researchers have decided to include a sample size of 162.

**Subjects & selection method:** A total of 162 caregivers were recruited in the study who were taking care of and assisting the hemodialysis patients both when they were at home and when they were undergoing hemodialysis.

### **Inclusion criteria:**

1. Caregivers of patients who were diagnosed with CRF and undergoing hemodialysis for more than 6 months
2. Caregivers who were willing to participate in the study
3. Caregivers who were able to speak/read Kannada & English

### **Exclusion criteria:**

1. Caregivers of patients undergoing PD
2. Caregivers of patients who were critically ill
3. Caregivers of patients undergoing hemodialysis for less than 6 months

### **Procedure methodology**

Data was collected from 162 caregivers of hemodialysis patients. Background proforma was developed to collect the demographic data of the subjects. It consisted of 13 items on aspects like their age, gender, marital status, educational status, occupation, monthly family income, the average cost of treatment and the hospitalization, if any, in the last month, source of income of the treatment, relationship with the care receiver, duration of each session of dialysis, number of dialysis sessions per week, duration of illness, time since the patient is undergoing dialysis.

The tool Caregiver Burden Assessment Scale (CBAS) consisted of questions on physical, emotional, personal, economic, and social aspects of the burden that the caregivers may experience in the process of care. The tool had 30 items related to the caregiver's health, loneliness, quality of sleep, helplessness, guilt, lack of privacy, fulfillment of all the roles in life, rest, anger levels, financial problems, and socialization. Each item had a score of 1 to 5. All were positive statements, and the scoring was as follows: Strongly Agree =5; Agree =4; Uncertain =3; Disagree =2; Strongly Disagree =1.

The Social Support Scale (SSS) consisted of items on informational support, emotional support, economic support, and feedback support which the caregivers may or may not get in the process of caregiving. The tool consisted of 23 items on various aspects of social support like the amount of support they got from their doctors and physicians, media, friends, and family, and also monetary help that they had received from the society around them. Each item had a score from 1 to 4. All were positive items, and the scoring was as follows: Yes, always = 4; Yes, sometimes = 3; Yes, but rarely = 2; No, never = 1.

The Family Well-Being Scale (FWBS) tool consisted of items on the caregiver's perception of their health and well-being, the caregiver's perception of the family's health and well-being, and the caregiver's perception of the overall functioning of the family. The tool consisted of 17 items on various aspects of family well-being like how much caregivers care about themselves, the caregivers' perception of their health, ability to mingle with others in the hospital, ability to adjust to the life experiences, hopefulness, and also on family's ability to care, communicating, understanding, working together, taking up responsibilities, trusting each other and also on the atmosphere in the family. Each item had a score from 1 to 4. All were positive items, and the scoring was as follows: Always = 4; Sometimes = 3; Rarely = 2; Never = 1.

Both descriptive and inferential statistics were used to interpret the data. For statistical purposes, the SPSS 20 version was used.

**Statistical analysis**

Data was analyzed using SPSS version 20 (SPSS Inc., Chicago, IL). Descriptive and inferential statistics were used for the analysis of the study. Descriptive statistics including frequency and percentages for describing the sample characteristics, while the Chi-square test was used for determining the correlation between the demographic variables of the caregivers, disease variables of the patient, and the caregiver burden scores. The level  $p < 0.05$  was considered as the cutoff value or significance.

**III. Result**

**Caregiver characteristics:**

Out of 162 caregivers recruited, most of the caregivers 62 (38.3%) were within the age group of 31-45 years and most 82 (50.6%) were females. Almost 96 (59.3%) were married and the majority had secondary school education 31(19.1%). Mostly 70 (43.2%) were unemployed. The majority 46(28.4%) of the caregiver’s monthly income was Rs. 10,000 – 15,000. Most of them, 52(32.1%) reported that the cost of treatment for the last month was Rs. 10,000 – 15,000. The majority 66(40.7%) of the caregivers reported that the source of income for the treatment was the patient’s income. Almost 59(36.4%) were the spouses of the patients. The majority 131 (80.9%) of the caregivers reported that the duration of the hemodialysis was 5 hours. Most of the caregivers 114 (70.4%) reported that their patients were undergoing hemodialysis twice per week. The majority of the patients 116(71.6%) were undergoing hemodialysis for more than one year. The same is depicted in “Table” 1.

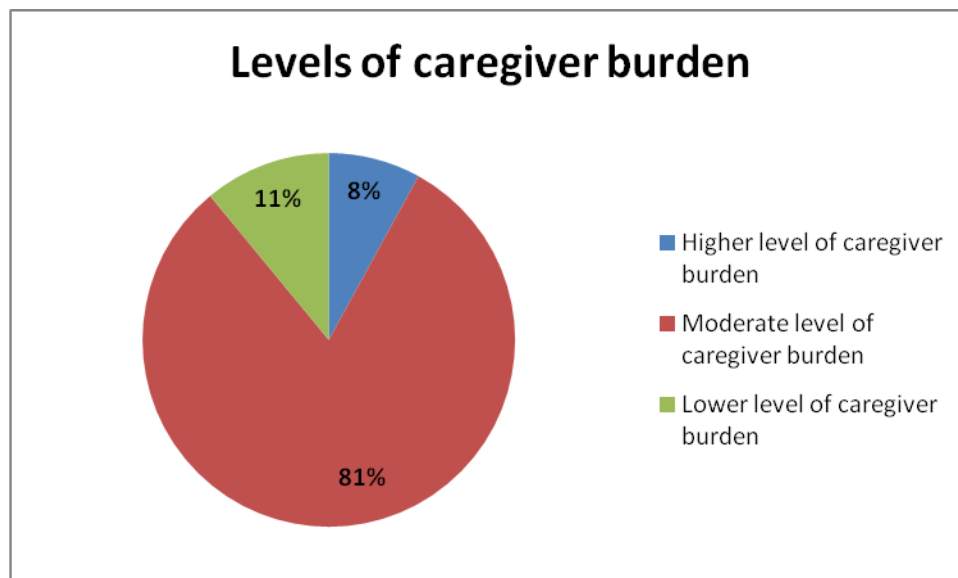
**“Table” 1  
Demographic characteristics of the sample in frequency and percentage**

<b>Variables</b>	<b>Frequency (f)</b>	<b>Percentage (%)</b>
<b>Age (years)</b>		
15 – 30	34	21
31 – 45	62	38.3
46 – 60	52	32.1
61 – 75	14	8.6
<b>Gender</b>		
Male	80	49.4
Female	82	50.6
<b>Marital status</b>		
Married	96	59.3
Single	36	22.2
Widowed	12	7.4
Divorced	8	4.9
Separated but not divorced	10	6.2
<b>Variables</b>	<b>Frequency (f)</b>	<b>Percentage (%)</b>
<b>Educational Status</b>		
Primary education	17	10.5
Higher primary education	24	14.8
Secondary school education	31	19.1
Higher secondary education	26	16.0
Diploma	16	9.90
Graduation	28	17.3
Post-graduation	18	11.1
Any other	02	1.20
<b>Occupation</b>		
Unemployed	70	43.2
Unskilled worker	23	14.2
Office worker	25	15.4

Professional	25	15.4	
Any other	19	11.7	
<b>Monthly family income (in Rs.)</b>			
Less than or equal to 5000	16	9.90	
5001 – 10000	21	13.0	
10001 – 15000	46	28.4	
15001 – 20000	25	15.4	
20001 – 25000	22	13.6	
Above 25000	32	19.8	
<b>Cost of treatment (in Rs.)</b>			
Less than or equal to 5000	10	6.20	
5001 – 10000	32	19.8	
10001 – 15000	52	32.1	
15001 – 20000	26	16.0	
20001 – 25000	18	11.1	
Above 25000	24	14.8	
<b>Source of income for the treatment</b>			
Patient income	66	40.7	
I am paying from my pocket	57	35.2	
The patient has insurance policy			14
The patient doesn't have an insurance policy			04
External agency/trust/ NGO/ any	21	13.0	8.60 2.50
<b>Relationship with the patient</b>			
Mother	13	8.00	
Father	16	9.90	
Son	20	12.3	
Daughter	20	12.3	
Spouse	59	36.4	
Sister/brother	34	21.0	
<b>Duration of dialysis</b>			
5 hours	131	80.9	
6 hours	28	17.3	
8 hours	03	1.90	
Variables	Frequency (f)	Percentage (%)	
<b>Number of dialyses per each week</b>			
One	02	1.20	
Two	114	76.4	
Three	41	25.3	
More than three	05	3.10	
<b>Duration of illness</b>			
Less than one year	29	17.9	
1 – 3 years	49	30.2	
4 – 5 years	43	26.5	
Above 5 years	41	25.3	
<b>Time since the patient is undergoing dialysis</b>			
Less than one year	46	28.4	
1 – 2 years	29	17.9	
2 – 3 years	23	14.2	
3 – 4 years	20	12.3	
4 – 5 years	16	9.9	
More than 5 years	28	17.3	

**Burden characteristics:**

When the question that caregiving is a stressful process was asked, most of them 48 (29.6%) agreed to the statement. About 64 (39.5%) agreed that they have lost themselves in the process of caregiving. The majority 67 (41.4%) agreed that caregiving is a tiring and prolonged process. About 45(27.8%) were uncertain about their adequacy of sleep. Almost 53 (32.7%) disagreed that they felt alone and helpless. The majority 56 (34.6%) disagreed that they get angry with their relative even for the small help asked. Most of the caregivers 52 (32.1%) agreed that they were disheartened when their relatives blamed them that they were not taking care of them properly. About 45 (27.8%) felt that their mistakes in the past have reflected in the form of disease to the relative. Seeing the relative needle punctured is a painful experience for 62 (38.3%) caregivers. About 48 (29.6%) agreed that they feel helpless to see the disease-related changes in the body of the patient. Waiting outside the dialysis unit when the patient is undergoing hemodialysis is a boring process for 73 (45.1%) of the caregivers. Almost 77 (47.5%) agreed that they should have some space and time for them in the process of care. The majority 45 (27.8%) agreed that they are unable to fulfill the other responsibilities as before. About 44 (27.2%) of the caregivers disagreed with the statement that they don't have enough time to take care of their health. Almost 57 (35.2%) have agreed that they were unable to execute their plans. The majority of them 61 (37.7%) agreed that the life they have imagined is completely different from what they are living presently. The majority of them 39 (24.1%) agreed that they felt like running away from the whole situation. Most of them 69 (42.6%) agreed that they should have some break in the process of care. Almost 49(30.2%) disagreed with the statement that they are behaving rudely towards their relative. About 62 (38.3%) agreed that alone they cannot meet the needs of their relative. Almost 68 (42%) have agreed that they were financially going down day by day due to involvement in the process of care. About 66 (40.7%) agreed that they are getting very stressed to adjust the money on time for the treatment. Spending money on only one family member lands the other members in trouble. Almost 75 (46.3%) agreed that they have very little time to meet their friends and relatives. About 51 (31.5%) have agreed that they don't have many visitors these days. Other than taking care of the relative, 74 (45.7%) caregivers said they have other things to be looked upon. Almost 75(46.3%) have said that they feel disappointed when others say that they are providing care that is inefficient. Somebody should take my place in the process of care was disagreed by 50 (30.9%) of the caregivers. The majority 41 (25.3%) said that they agree that there is no good amount of support from others in the process of care. Almost 66 (40.7%) caregivers accepted that they have more responsibility towards the diseased relative when compared to others. The categorization of the caregiver's burden is shown in the Fig. 1



**Figure 1 shows the classification of caregivers into various levels of caregiver burden based on the scores obtained in CBAS**

**Social support characteristics:**

The majority of the caregivers 51 (31.5%) said that sometimes they receive support from other caregivers. Almost 68 (42%) of caregivers said that always treating doctors used to speak regarding the best care to be given to the patients by the caregivers. The majority of the caregivers 62 (38.3%) accepted that social media is used to provide the needed information about the care of diseased relatives. About 63 (38.9%) of the

caregivers reported that nurses used to teach them about the right care to be given to the patient. Always doctors give the needed information about the relative's disease condition, as reported by 81 (50%) of the caregivers.

Almost 65 (40.1%) of the caregivers had accepted that always they used to get the needed care information through the posters, display boards, and other educative materials that are being placed in the ward. Most of the caregivers 52 (32.1%) have reported that sometimes a special person is available for them when they are in emotional outbursts. About 69 (42.6%) of the caregivers said that they can share their pleasant and sad moments of life. There is a person always available to the caregivers who knows and respects the feelings of, as reported by 65 (40.1%). Almost 78 (48.1%) of the caregivers have reported that their family supports them even though there is no support from the others. The majority of the caregivers 69 (42.6%) said that they can openly share their problems.

About 77 (47.5%) of the caregivers reported that the love of their family gives them the biggest strength. The majority, 49 (30.2%) of the caregivers reported that always they were able to get the money for the treatment and 62 (38.3%) said that they were able to do that because of their family. About 46 (28.4%) caregivers had few resources sometimes to help them financially, 47 (29%) of them said that sometimes they get financial help from their relatives and almost 38 (23.5%) said that sometimes they get it from friends. The majority of the caregivers 100 (61.7%) reported that insurance companies never reimbursed money for the treatment. "Always doctors and nurses recognize and appreciate the care I provide", as reported by 62 (38.3%) caregivers. The majority of the caregivers 70 (43.2%) reported that relatives accepted them as efficient caregivers.

Almost 81 (50%) of the caregivers said that their family used to accept them as the caregiver and 80 (49.4%) said that their families always gave some space in the discussions about the care of the patient. Almost 73 (45.1%) of the caregivers reported that their family members care about his/her health.

#### **Family Well-being Characteristics:**

The majority of the caregivers 54 (33.3%) reported that they are caring about themselves as before. As reported by 51 (31.5%) caregivers, they are socializing with others in the hospital. Almost 57 (35.2%) of the caregivers have reported that they are hopeful to adjust to their life experiences. Almost 50 (30.9%) caregivers reported that their family members always kept some time for praying. About 60 (37%) of the caregivers reported that they are hopeful about the cure of a relative's illness. The majority of the caregivers 55 (34%) have reported that their family members are taking care of their health and 62 (38.3%) have said that they are always consulting the doctor if they have any illness. About 58 (35.8%) of the caregivers have reported that their family members are caring for each other, whereas 60 (37%) of the caregivers have reported that their family shows concern towards each other. Even though they have a diseased member in their home, 63 (38.9%) of the caregivers have reported that always their family members were performing the rituals as usual and 52 (32.1%) of them said that family members were always communicating with each other. The majority of the caregivers 52 (32.1%) have said that their family members were willing to take responsibility and 35.8% (58) of the caregivers have reported that their family members were working towards the progress of the family. Regarding the family members, 53 (32.7%) caregivers have said they always understand each other, 67 (41.4%) of them have said that they always have a clear idea about the treatment and care of the ill relative, and 68 (42%) have reported that they always trust each other. Almost 63 (38.9%) caregivers reported that their family atmosphere is always peaceful.

#### **IV. Discussion**

About 162 caregivers of hemodialysis patients were recruited in the study. The finding of the study has shown that the majority 131 (81%) caregivers were experiencing moderate levels of burden, while 109(67%) had a moderate level of social support and 76(47%) had a moderate level of family well-being. These findings were supported by a study conducted to explore the traits of dialysis patients' caregivers and to evaluate their care burden and quality of life. The caregivers of non-elderly HD patients, peritoneal dialysis therapy (PD), and caregivers of elderly HD patients (greater than or equal to 65 years) were included in the study. The results revealed that most elderly patients had women (78%) as their caregivers whose age was 55+/-15 years or wives or husbands (50%) or sons or daughters (41%). The most affected dimensions were the caregiver's mental health, vitality, and emotional aspects. General strain and environment were the dimensions of the most affected Care Giver Burden Scale. Signs of depression were shown in 32% of the caregivers. The authors concluded that elderly HD patients' caregivers experience a significant level of burden and negative effects on quality of life and suggested having social, educational, and psychological support measures to improve the quality of life.<sup>8</sup> Another supporting study which was conducted to explore the burden level of CKD patients revealed that about 68.6% of caregivers had mild to severe levels of burden and it was affected by various factors which has an impact on patient's well-being too.<sup>9</sup> A descriptive-analytical study was conducted among 246 caregivers. Showed that about 37.4% of caregivers were experiencing high and 42.7% were experiencing a moderate level

of care burden. There was a significant and negative correlation between quality of life and care burden ( $p < 0.001$ ) and the authors concluded that caregivers endure a high level of burden and this harms their quality of life.<sup>10</sup> A study investigated the care burden and quality of life among 254 family caregivers and concluded that family caregivers had a low quality of life with more caring burden.<sup>11</sup> A systematic review conducted in a similar study area revealed that the quality of life of hemodialysis patient caregivers is poor compared to the general population.<sup>12</sup>

## V. Conclusion

The present study aimed to assess caregiver burden, social support, and family well-being among caregivers of hemodialysis patients in selected hospitals of Udupi district, Karnataka. The study revealed that caregivers of haemodialysis patients were experiencing moderate levels of care burden. Many caregivers accepted that their family well-being is very poor, with the family members not caring for each other, being hostile to each other, and lack of trust in each other. All these factors will harm the quality of life of the caregiver as well as the patient. More emphasis is to be paid towards the wellbeing of caregivers in terms of providing adequate physical, psychological, social, and financial support to them.

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