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BURDEN AMONG CAREGIVERS OF PATIENTS ON MAINTENANCE HEMODIALYSIS IN A TERTIARY CARE HOSPITAL

Dr. Srinitha Bonthu*, Dr. Manjusha Yadla, Dr. Vikram Kumar B., Dr. Sreekanth B. and Dr. Srinivas P.

India.

***Corresponding Author: Dr. Srinitha Bonthu**

India.

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INTRODUCTION

Burden of Chronic kidney disease (CKD) is on the rise and affects almost all aspects of life of patients and caregivers. Globally, CKD has a prevalence of between 11 to 13.4% in the general population, which makes it one of the most common worldwide diseases.[1] Hemodialysis is the most commonly employed renal replacement therapy in patients with chronic kidney disease. Even though there is an improvement in the quality of life of a CKD patient on hemodialysis, it is a stressful process and involves minor to serious adverse events like vascular access failure, blood pressure abnormalities, dialysis circuit and blood line clotting.[2] Caregivers often receive little attention and the main focus is on the patient. Frequent hospitalizations of the patients and factors associated with the disease can lead to depression and reduction of caregiver's quality of life.[3] Therefore, the evaluation of caregiver's status and determination of their needs are very important. Caregiver burden is a general term used to describe physical, emotional and financial cost of the care.[4] Caregiver burden is defined as permanent difficulty, stress or negative experiences resulted from providing care by caregiver.[5]

The caregiver burden is mainly caused by a combination of physical work, emotional pressure, social restrictions, and economic demands during the provision of care to their patients and this has been found to be associated with a significant reduction in caregivers' quality of life and their health status.[6]

Timely identification of these pressures in caregivers plays a decisive role in the promotion of their mental health. The aim of this study was to assess the scale of caregiver burden in caregivers of hemodialysis patients.

AIM

To study the level of burden among caregivers of patients undergoing haemodialysis.

PATIENTS AND METHODS

STUDY DESIGN: Descriptive cross sectional study among 100 caregivers of haemodialysis patients.

Care givers of patients undergoing hemodialysis for atleast 3 months are included in the study after taking consent and following variables were assessed.

Socio-demographic variables like age, gender, relationship to the patient, income and duration of illness were noted.

Level of burden was evaluated using Zaritt burden questionnaire[7] composed Likert type 22 items.

	Never	**Rarely**	**Sometimes**	**Frequently**	**Nearly Always**
1) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2) Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5) Are you afraid what the future holds for your relative?	0	1	2	3	4
6) Do you feel strained when you are around your relative?	0	1	2	3	4
7) Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative	0	1	2	3	4

9) Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10) Do you feel that you have lost control of your life since your relative’s illness?	0	1	2	3	4
11) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
12) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
13) Do you feel that you should be doing more for your relative?	0	1	2	3	4
14) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15) Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16) Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17) Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18) Do you feel your relative is dependent upon you?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20) Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
21) Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22) Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

STATISTICAL METHODS

Data was analyzed using SPSS v21. Categorical variables were summarized using counts and percentages, presented in tables, and compared using the chi-squared and Fischer’s exact test where appropriate. Continuous variables were summarized using means (with standard deviations), and medians (with inter-quartile ranges) where necessary, and compared using the student’s t-test. A *p*-value < 0.05 was considered statistically significant.

RESULTS

Table 1: Patient Characteristics.

		%
Gender	Male	58
	Female	42
Age group(in years)	<20	1
	21-40	13
	40-60	68
	>60	18
Comorbidities	Diabetes	53
	Hypertension	49
	Cardiovascular disease	26
	Cerebrovascular disease	13
Native Kidney Disease	Diabetic kidney disease	39
	Hypertension	33
	CIN	12
	CGN	9
	Others	5
Hemodialysis Vintage	<1year	9
	1-3 years	45
	>3 years	46

Among 100 caregivers studied, 61% were male and 39% were female.

Majority of caregivers belong to the age group 40-59 yrs (54%). Mean duration of delivery of care was 2.602 yrs, maximum being 6yrs and minimum being 4 months.

Table 2: Caregiver Characteristics.

Gender	Male	61
	Female	39
Age group(years)	20-39	40
	40-59	54
	60-65	6
Relation to patient	Parent	1
	Sibling	10
	Offspring	27
	Spouse	62
INCOME (INR)	<5000	41
	5000-10000	36
	10000-20000	18
	>20000	5
BURDEN SCORE	Little Or No(0-21)	10
	Mild To Moderate (21-40)	36
	Moderate To Severe (41-60)	48
	Severe(61-88)	6

54% of caregivers reported moderate to severe and 36% mild to moderate levels of caregiver burden. Mean burden score for female caregiver is 42.02 as compared to male being 38.73.

Table 3: Comparision of Variables With Burden Score.

		Little or No n(%)	**Mild to moderate**	**Moderate to severe**	**severe**	**p value**
Sex of patient	Male	7(12.1)	15(25.9)	30(51.7)	6(10.3)	0.026
	Female	3(7.1)	21(50)	18(42.9)	0	
Dialysis vintage	<1year	5(55.6)	3(33.33)	1(11.1)	0	0.001
	1-3 years	5(11.1)	23(51.1)	17(37.8)	0	
	>3 years	0	10(21.7)	30(65.2)	6(13)	
Sex of caregiver	Male	4(6.6)	29(47.5)	26(42.6)	2(3.3)	0.015
	Female	6(15.4)	7(17.9)	22(56.4)	4(10.3)	
Age of caregiver	20-39	2(5%)	15 (37.5%)	20 (50.0%)	3(7.5%)	0.881
	40-59	7(13)	19(35.2)	25(46.3)	3(5.6)	
	60-65	1(16.7)	2(33.33)	3(50%)	0	
Relation with patient	Parent	0	0	1(100)	0	0.374
	Sibling	0	2(20)	6(60)	2(20)	
	Offspring	1(3.7)	12(44.44)	13(48.1)	1(3.7)	
	Spouse	9(14.5)	22(35.5)	28(45.2)	3(4.8)	
Income	<5000	2(4.9)	18(43.9)	17(41.5)	4(9.8)	0.391
	5000-10000	5(13.9)	13(36.1)	16(44.44)	2(5.6)	
	10000-20000	2(11.1)	5(27.8)	11(61.1)	0	
	>20000	1(20)	0	4(80)	0	

A significant relationship was observed between gender of the patient with caregiver burden score of (p=0.026), gender of caregiver with burden score (p=0.015) and duration of illness with caregiver burden score of (p=0.001).

There was no relation observed between income and caregiver burden score.

DISCUSSION

This study was done to evaluate the burden among caregivers of maintenance hemodialysis patients. Most of the research has been focused on the hemodialysis patients, while their caregivers who help in their treatment, and experience losses and potential changes were neglected.[8] The level of burden experienced by caregivers can be influenced by many factors such as governmental and non-governmental support of care for patients.

Majority of caregivers belong to the age group 40-59 yrs (54%). Mean duration of delivery of care was 2.602 years, maximum being 6 years and minimum being 4 months. 62% of the caregivers in our study were spouse in the relationship to the patient which is similar to a study done by chhetri SK et al in which 56.09% of the caregivers were spouses.[9]

Maximum 46% of the caregivers belong to more than 3 years of caregiving duration. It can be attributed as, the longer the caregivers took care of their patients, the greater burden they endured as it was observed by severe burden in those with long vintage of dialysis.

In a study done by Habibzadeh H et al, 52% of the care givers of hemodialysis patients had moderate and low levels of quality of life.[10]

Abbasi et al reviewed the caregiver stress and its related factors in caregivers of hemodialysis patients and reported that 74.2% of caregivers suffered from extreme caregiver burden.[11]

Results of this study showed that moderate to severe burden was observed in 54% of the caregivers. Statistical analysis results indicated that female caregiver and long vintage of dialysis were significant predictors of caregiver burden.

CONCLUSION

In our study moderate to severe burden is observed in female caregivers. Longer the duration of illness,more is the caregiver burden. Attention should be paid to needs of caregivers to provide adequate social, economic, physical and psychological support.

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