

Burden and Resilience among Care Givers of Patients with Chronic Kidney Disease - A Cross-Sectional Study at Government Medical College, Kottayam

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ABSTRACT

BACKGROUND

Chronic kidney disease (CKD) is a major health issue around the globe. The illness and its treatment affect both the patients and care givers life. Care giving can have varying effects on the caregiver's life. It can disrupt the family routines, can contribute to occupational and financial problems and can affect the physical and psychological health of the carer. The purpose of this study was to assess the caregiver burden and resilience of the caregivers of patients undergoing maintenance haemodialysis.

METHODS

This is a cross-sectional study. The sample of the study consisted of caregivers of 180 patients with chronic kidney disease undergoing maintenance haemodialysis. Specially designed pro-forma, Burden Scale for Family Caregivers (BSFC), Brief Resilience Scale (BRS) are the tools used for the study.

RESULTS

The mean age of patients in bystanders with significant caregiver burden was 47.36 years and those with low burden was 48.12 years respectively. Among the 180 care givers, 8.9 % had low burden and 91.1 % had significant burden. Resilience was low in 27.2 % of caregivers, medium in 72.2 % and high in 0.6 % of caregivers. The mean BRS score was 3.81 + 0.473 in low burden group against a BRS score of 3.15 + 0.543 in significant burden group. There was a significant association between caregiver resilience and caregiver burden.

CONCLUSIONS

Chronic kidney disease, due to its long course and prolonged treatment, affects the physical, psychological and social spheres of patient and family. This may result in the feeling of burden among caregivers and affects the various aspects of carer's life. Burden was high and resilience was low among the caregivers of patients with CKD. Attention should be given to the strategies to support the caregivers.

KEYWORDS

Care Giver Burden, Resilience, Chronic Kidney Disease

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BACKGROUND

Chronic kidney disease is a major health issue around the globe due to its increasing prevalence. As per the report of the chronic kidney disease registry of India, 63538 cases of chronic kidney disease were registered in India in the year 2011. The disease was more in men and mean age of the patients was 50.7 in males and 48.1 in females. 17.38 % of patients were undergoing haemodialysis and 2.19 % of patients were on peritoneal dialysis.¹ World health organisation bulletin in 2018 pointed out the that low and middle income countries suffer very high burden due to chronic kidney disease.² A review on the adaptation to dialysis pointed out that, during the initial stages, patients accept dialysis, but later increase anxiety, depression and confusion occurs. The long-term effects of dialysis include regression, depression and denial.³ An Indian study reported 44.1 % prevalence of depression in patients with chronic kidney disease. The study reported an association of depression with the financial situation of the patient, duration of the chronic kidney disease, haemodialysis and presence of comorbidities.⁴

The illness and its treatment affect both the patients and care givers life. Long-term dialysis therapy itself often results in loss of freedom, dependence on caregivers, disruption of marital, family, and social life, and reduced financial income. Due to these reasons, the physical, psychological, socioeconomic, and environmental aspects of life are negatively affected, leading to compromised quality of life.⁵ The burden felt by the care giver depends not only on the patient's disability. It depends on factors such as the behaviour of the patient, patient's cognitive function, and the intensity of caregiving. Gender, personality traits and coping strategies used by the caregiver, the quality of the relationship between caregiver and the patient, financial and social support available also affects the caregiver burden. Care giving can have varying effects on the caregiver's life. It can disrupt the family routines, can contribute to occupational and financial problems and can affect the physical and psychological health of the carer. Increased vulnerability to physical illness and psychiatric morbidities like depression and anxiety were reported among care givers. Care giving can also have positive effects such as increased self-esteem, satisfaction and improved mental health.⁶

A study among caregivers of patients on haemodialysis reported high levels of burden among care givers. 37.4 % of caregivers experienced high or extremely high care burden and 42.7 % of them experienced moderate care burden. The care givers burden was more in caregivers of patients with reduced capacity for self-care activities, patients with comorbid chronic illness and with increased age of the care giver.⁷

A study among patient's perception of care giver burden reported that more than half of the haemodialysis patient felt that their caregivers were strained. The burden was found to have relationship with poor health related quality of life and depression in patients themselves. Age, gender, duration of illness, presence of other comorbidities was found to have no association with the patient's perceived

care giver burden. 60 % of patients expressed that their caregivers could handle the care.⁸

A review regarding the burden of patient and care giver reported that patient's experience sleep problems, anxiety, social withdrawal and financial problems which adversely affect their quality of life. The caregiver experiences a lot of psychosocial distress which may lead to burnout in the caregiver and the patients worry about their stressful home environment.⁹

A study on the frequency of haemodialysis and care giver burden demonstrated no significant difference in caregiver burden among patients undergoing conventional haemodialysis and in-centre daily haemodialysis. The patients who were undergoing nocturnal home dialysis perceived a higher burden of their caregivers and this was found to have correlation with treatment adherence.¹⁰

A study among spouses of kidney transplant patient reported both care giving burden and care giving benefits before and after transplantation. Compared to care givers of patients with other organ transplants, caregivers of kidney transplant patients had better quality of life, life satisfaction, psychological, and social outcomes.¹¹

In another study among family care givers, an inverse relationship with care givers burden and care givers quality of life was reported. The age of the patient, the time that needed for caring and the financial cost of medicines were found to have relationship with care givers quality of life.¹²

Another study demonstrated that care givers of male haemodialysis patients have more burden. Income of the patient was also found to have relationship with care giver burden. Caregivers of patients with low income reported higher care giving burden. In that study 72.5 % of caregivers reported moderate to severe caregiver burden.¹³

A study among 57 caregivers of patients with chronic kidney disease reported high levels of anxiety and depression among the care givers. 49.1 % of the caregivers reported mild to moderate burden and 33.3 % of caregivers reported high burden. The depression score and caregiver's burden was more in female caregivers. The care giver burden was found to have positive correlation with anxiety and depression. Females constituted 57.9 % of the care givers. More than half of the carers were below the age of 40 years. The median duration of the kidney disease was 9 months and the median duration of maintenance haemodialysis was 7 months.¹⁴

A study on burden of caring renal patients, from the perspective of health care staff (nurses) reported that 48.3 % of nurses experienced mild-to-moderate burden, 10.4 % experienced severe burden and 1.3 % experienced very severe burden. The greatest burden was associated with dialysis procedure. There was no association between caregiving burden with age, gender, or years of experience.¹⁵

Resilience is a construct that concerns the human being's capacity to respond positively to the adverse situations an individual faces, even when these pose a potential risk to his/her health or development.¹⁶

Resilience can be defined as a "complex repertoire of behavioural tendencies that may be evoked or activated by environmental demands."¹⁷ Demographic factors such as

male gender, older age, greater education; social factors such as supportive relations, community resources; and individual factors such as personality, coping strategies were found to promote resilience.¹⁸ Optimal coping and adaptation were found in person with high resilience.¹⁷

On reviewing the literature, the researchers could not find studies related to resilience in caregivers of patients on haemodialysis. Studies among individuals taking care of elderly people demonstrated association between resilience and care giver burden. The carer who perceived social support was found to have a mediating effect in the association between caregiver burden and resilience.¹⁹

A Spanish study on resilience among caregivers of patients with Alzheimer’s disease demonstrated average resilience among half of the care givers. Severe caregiver burden was found in 61.6 % of participants. 63.3 % of caregivers were having anxiety symptoms and 62.5 % were having depressive symptoms. 64.6 % of caregivers were females. 73.7 % of caregivers were in the age group 40 - 65 years. Having control over own life, competence, secure relationships, accepting the changes positively, tolerance and spirituality were the factors that affected the resilience. Resilience was found more in caregivers who were employed, living with the patient, having direct relationship with the patient, and who were getting economic support and extra help. Resilience was high in caregivers of patients who are less dependent and having good cognitive function. Negative correlation was found between resilience and both subjective and objective burden. Depression and anxiety in care giver was having inverse relationship with resilience. Care giver’s quality of life was affected and the most affected quality of life domain was physical functioning, followed by mental health. Participants with high resilience were having high scores in the quality of life. High level of resilience was also found to have association with high self-esteem, good social support and use of problem based coping strategies in care givers.²⁰

Objectives

1. To determine the caregiver burden of the caregivers of patients undergoing maintenance haemodialysis.
2. To determine the resilience of the caregivers of patients undergoing maintenance haemodialysis

METHODS

A cross-sectional study regarding burden among caregivers of patients on haemodialysis was conducted from June 1st 2017 to May 31 2018. It was reported that 80 % of care givers experience moderate to extremely high care giver burden. [7]. Hence the sample size for the study is estimated using the formula, $4PQ / d^2$, where $P = 80$, $Q = 20$ & at 10 % allowable error i.e., $d = 8$. Hence, sample size = $4 \times 80 \times 20 / 64 = 6400 / 64 = 100$. The study consisted of caregivers of 180 patients with chronic kidney disease (CKD) undergoing maintenance haemodialysis in a tertiary care institute. Caregivers of patients of age above 18 years with chronic kidney disease undergoing maintenance

haemodialysis are included. Caregiver is operationally defined as a first degree relative of the patient who spent a minimum of two hours per day for caregiving for at least one month. Specially designed pro-forma, Burden Scale for Family Caregivers, Brief Resilience Scale are the tools used for the study. Details regarding the study was explained to the caregivers. A written informed consent was obtained. The specially designed pro-forma was completed to collect the relevant socio demographic profile and clinical details of the patients and the caregivers. The subjects were given the Malayalam version of Burden Scale for Family Caregivers and Brief Resilience Scale (BRS) with appropriate instructions after the haemodialysis session in the dialysis unit. Patient caregiver burden was assessed by Burden Scale for Family Caregivers. The responses to the 10 statements of the BSFC-s are rated according to a scoring system. This score is statistically analysed as percentiles. Brief Resilience Scale was used to assess resilience of care givers. The score was classified as low, medium and high. Data was coded and entered in R software. Association between various factors was assessed using t test and Mann-Whitney U test. The level of statistical significance was P value less than 0.05.

Statistical Analysis

The collected data was coded and entered in R software. Association between various factors was assessed using t test and Mann-Whitney U test. The level of statistical significance was P value less than 0.05.

RESULTS

The mean age of the study population was 47.43 with a standard deviation of 13.87. Median age was 49. Minimum age was 19 and maximum age was 86. Among the total 180 patients, 46 (25.6 %) were females and 134 (74.4 %) were males. 82 (45.6 %) had plan for renal transplant and 98 (54.4 %) had no plan for transplant. Among the patients, 2 (1.1 %) were on once weekly maintenance haemodialysis, 112 (62.25 %) on twice weekly maintenance haemodialysis and 66 (36.7 %) on thrice weekly dialysis schedule. Comorbid psychiatric illness was present in 44 (24.4 %) patients.

Variable	Frequency	Percentage	
Gender	Female	46	25.6
	Male	134	74.4
Plan for transplant	No	98	54.4
	Yes	82	45.6
Schedule for haemodialysis	Once weekly	2	1.1
	Twice weekly	112	62.2
	Thrice weekly	66	36.7
Co morbid psychiatric illness	Present	44	24.4
	Absent	136	75.6

Table 1. Gender and Disease Characteristics of Patients

Care Givers Burden and Resilience

Mean score for Burden Scale for Caregivers was 14.51 with a standard deviation of 5.922. Median score was 15.00 and mode score was 14. Minimum score observed was 2 and maximum score was 30. Percentiles scores were 11.00,

15.00 and 18.00 for 25th, 50th and 75th centiles, respectively. The caregiver burden was classified into low burden and significant burden group based on the score obtained. A score of more than 6 was considered significant burden. 16 (8.9 %) had low burden and 164 (91.1 %) had significant burden. Mean score for brief resilience score of care givers was 3.21 with a standard deviation of 0.568. Median score was 3.00 and mode score was 3.00. Minimum score was 2 and maximum score was 5. Percentiles scores were 2.80, 3.00 and 3.60 for 25th, 50th and 75th centiles.

Out of 180, 49 (27.2 %) caregivers had low resilience. 130 (72.2 %) caregivers had medium resilience and 1 (0.6 %) had high resilience. The mean age of patients in bystanders with significant caregiver burden was 47.36 years and those with low burden was 48.12 years respectively. T test was carried out and no statistically significant difference was found between the mean age of patients whose care givers reported low and significant burden. Of the 46 female patients (25.6 % of total) in the study group, 41 caregivers (22.8 % of total) had significant burden and 5 (2.8 % of total) had low burden. Care givers of 123 male patients (68.3 % of total) had significant burden and 11 caregivers (6.1 % of total) of male patients had low burden. The mean duration of the disease was 11.62 ± 5.07 in low burden group and 8.75 ± 5.62 in the significant burden group. t test was carried out and the difference was found to be statistically significant. Mean duration of haemodialysis was 2.25 ± 2.324 for low burden group and 2.25 ± 1.719 for significant burden group. Mann-Whitney U was carried out and there was no difference in the mean duration of dialysis between the groups. Of the 49 care givers with low resilience, 1 had low burden (0.6 % of total) and 48 (26.7 % of total) had significant burden. Caregivers with medium resilience carried low burden in 14 (7.8 % of total) and significant burden in 116 (64.4 % of total). The only caregiver noted to have high resilience had low burden. The mean BRS score was $3.81 + 0.473$ in low burden group against a BRS score of $3.15 + 0.543$ in significant burden group. Mann-Whitney U was carried out and the difference between the two groups in relation with brief resilience score was significant. (P value - 0.02)

Variable	Burden	N	Mean	Standard Deviation	Standard Error Mean	P Value
Age	Low burden	16	48.12	10.972	2.743	0.834
	Significant burden	164	47.36	14.149	1.105	
Duration of disease	Low burden	16	11.6250	5.07116	1.26779	0.05
	Significant burden	164	8.7561	5.62872	.43953	
Duration on haemodialysis	Low burden	16	2.25	2.324	.581	0.789
	Significant burden	164	2.25	1.719	.134	
Brief resilience scale score	Low burden	16	3.81	.473	.118	0.02
	Significant burden	164	3.15	.543	.042	

Table 2. Caregiver Burden and Associated Variables

DISCUSSION

Chronic kidney disease is a major health issue to be discussed in this current era due to its increasing prevalence. The patient characteristics in the present study is consistent

with 2011 report of chronic kidney disease registry of India.¹ Majority of the patients were males and the median age of the patients was 49 years. Significant burden was found in majority of the care givers. Among 73 caregivers, 56 (76.7 %) of them had significant burden which was consistent with other studies.⁷⁻⁸ The caregiver burden was irrespective of patient age and gender, caregiver age and gender, schedule of dialysis, transplant plan and co morbidities. This result indicates that besides financial strain, mental and physical status of the caregiver also plays a significant part in the burden experienced. The burden of the caregivers of these patients should be focused as they have to face challenges regarding the patient care mentally physically and financially.

Resilience which is the capacity of an individual to bounce back from a stressful situation should also be improved in the caregivers to cope up with the situation. Care of carers is an important aspect to be discussed. The challenges faced by the caregivers as mental, physical, social and financial strains are less addressed and these problems are often denied. Resilience in the caregivers was also assessed in this study as these play an important role in the care of the patients. When resilience in the caregivers increases the burden, their experiences become lenient, thereby improving the care of the patient and the mental status of the caregivers.

On literature search, we could not retrieve any data regarding resilience in caregivers of patients on haemodialysis. The study has proven inverse correlation between caregiver burden and resilience. This is consistent with the studies among caregivers of elderly patients.¹⁹⁻²⁰ The exceptionally low number of caregivers with high resilience noted in this study indicates the need for strategies to improve the resilience level of the caregivers, which will have a positive impact on the caregiver burden.

CONCLUSIONS

This study also showed that 76.5 % of caregivers reported significant levels of caregiver burden. Majority of patients had medium resilience (75.3 %). Only 2.8 % of caregivers had high resilience. This was irrespective of caregiver age and gender, transplant plan, schedule of dialysis, and co morbidities. Chronic kidney disease, due to its long course and prolonged treatment, affects the physical, psychological and social spheres of patient and family. This may result in the feeling of burden among caregivers and affects the various aspects of carer's life. Hence it is recommended to give attention to the caregiver of patients undergoing haemodialysis and educate them the adaptive coping strategies.

Limitations

The major limitation of this study was regarding the sample size, which was less in number, and the study was confined only to the caregivers of the haemodialysis patients. Other chronic illness was not considered.

Data sharing statement provided by the authors is available with the full text of this article at jebmh.com.

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