

Original Research Article

Burden and resilience in caregivers of patients on maintenance haemodialysis

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ABSTRACT

Background: Chronic renal failure is one among the chronic illness which due to persistence of the disease has various effects on the physiological, psychological and functional ability of the patient and his family. Although haemodialysis has become a highly safe medical procedure that significantly extended life of such patients, it is nevertheless a stressful and lengthy treatment process. The task of personal life care for such patients falls primarily on the family members. The caregiver is expected to aid in patient's daily life activities resulting in increased physical and emotional burden. With the considerable level of burden involved the concept of resilience thus become crucial as they could function as protective factors. The current study aims to assess the level of caregiver burden and resilience in caregivers of haemodialysis patients.

Methods: A cross sectional observational study was done in 120 caregivers of patients diagnosed as having ESRD on maintenance hemodialysis. Zarit Burden Interview was used for assessing caregiver's burden. Brief Resilience Scale was used to assess caregiver's resilience.

Results: 35.8% of caregivers had severe caregiver burden while looking after dialysis patients while 45% of caregivers had moderate burden. Caregivers showed low resilience about 72.5% which displays poor problem solving and emotion-focused coping strategies.

Conclusions: The study shows that more than 80% of caregivers suffered from moderate to severe burden and poor resilience among them would be a contributing factor. The study also shows that female caregivers were most affected. The burden was significantly higher in caregivers as the years spent on caregiving increased and more hours spent per day looking after the patients. Health-care providers need to address these concerns based on both patient- and caregiver-focused approaches, rather than only patient focused.

Keywords: Burden, Caregiver, Chronic renal failure, Haemodialysis, Resilience

INTRODUCTION

Chronic Kidney Disease is a serious illness of chronic nature that progresses through stages of deteriorations from stage 1 to 5 and at Stage 5, it is called the End Stage Renal Disease (ESRD). The patient requires Renal

Replacement Therapy like the Dialysis (Haemodialysis and Peritoneal Dialysis) or Kidney Transplantation in End Stage Renal Disease. Most common form of renal replacement therapy is Dialysis, commonly hemodialysis. In India, the age-adjusted incidence rate of End Stage Renal Disease is 229 per million population, and >100,000 new patients enter renal replacement programs

annually as reported by SEEK (Screening for Early Evaluation of Kidney Disease project).¹

Hemodialysis imposes a variety of physical and psychosocial stressors that challenge not only the patients but also the caregivers. Providing long-term help to severely ill and disabled person on an everyday basis may be a serious physical and psychological burden for the caregiver. The demand of caregiving, especially in managing the dialysis has a profound and pervasive effect on family and friends, exert a toll on the physical, social and emotional well-being of caregivers.²

The caregiver burden increases significantly as functional and cognitive impairments imposed by the chronic disease limit the ability of the patient to care for themselves. Frequent hospitalizations of the patients and factors associated with the disease can lead to reduction of caregiver's quality of life. Additional factors associated with burden include the relationship between caregiver and patient, behavioral and psychological symptoms displayed by the patient, gender and adverse life events.³ These difficulties impose a substantial burden on those directly responsible for giving care, especially for family members. Despite such challenges caregivers often receive little attention and the main focus is on the patient. The concept of 'caregiver burden' has thus been used to capture this impact.

Caregivers can be identified as the individual(s) who during the course of treatment are most closely involved in caring for the patient and helping the patient cope with and manage his chronic illness.³ Family caregivers are those individuals who provide the majority of the patient's physical, emotional, financial, and social care needs throughout the continuum of care, from being hospitalised to providing care at home, without receiving any remuneration.⁴

Caregiver burden is defined as permanent difficulty, stress or negative experiences resulted from providing care by caregiver.⁵ Burden is definable subjectively and objectively. Objective burden is defined as the changes and disruptions appeared in life as a result of care. Subjective burden definition is the reaction or attitude of caregiver against care experience.⁶

Exploring ways of supporting caregivers can have beneficial effects on the outcomes for both the patient and the caregiver. Timely identification of family caregivers and monitoring their caregiver burden plays a decisive role in the promotion of their mental health. With the considerable level of stress and burden involved in providing caregiving, the concept of resilience thus become crucial as they could function as protective factors to guard caregivers from the caregiving burden. Resilience is defined as 'positive adaptation to face adversity, flexibility, psychological well-being, strength, healthy life, social network, and satisfaction with social support.'⁷ Studies show that caregivers who have low

resilience would experience high burden even in the presence of low care demand from a care-recipient. On the contrary, caregivers who have high resilience would experience low burden even when they experience high care demand.⁸ This perceived low burden could be attributed to effective coping strategies where resilience was associated with problem- and emotion-focused coping strategies and sense of self-efficacy.⁹ Therefore, resilience might be a key variable that explains the ability of some caregivers to 'bounce back' and challenges for caring their loved ones.¹⁰

Despite overwhelming evidences of the problems that caregivers face, studies pertaining pertaining to caregiver burden are rather limited. The objective of this study is to assess the level of caregiver burden and resilience in caregivers of patients on maintenance hemodialysis.

METHODS

The study was a cross sectional study which was conducted in the Dialysis unit under Department of Nephrology, Travancore Medical College, Kollam. Caregivers of patients registered in dialysis unit of Nephrology Department in Travancore Medical College; Kollam were recruited into the study. About 120 caregivers satisfying the inclusion and exclusion criteria were recruited for the study. Caregivers were educated about the study and informed consent was taken. Caregivers were screened by a semi-structured questionnaire which includes the caregiver's socio-demographic data, clinical details of patients

Inclusion criteria

- Caregivers of ESRD patients undergoing maintenance hemodialysis.
- Age of caregivers more than 18 years.

Exclusion criteria

- Caregivers of patients undergoing dialysis for disease other than CKD.

Zarit Burden Interview was used for assessing caregiver's perceived burden. It is one of the most commonly used burden measures and has been validated in many culturally or ethnically different populations. The revised version contains 22 items. Each item is scored using a 5-point scale. Response options range from 0 (never) to 4 (nearly always). More the score, greater is the burden perceived.¹¹

Brief Resilience Scale (BRS) was used to assess caregiver's resilience. Adding the value of your responses (1-5) for all six items, creating a range from 6-30 followed by dividing the sum by the total number of questions answered (6) gives the final score. BRS score of 1.00 - 2.99 shows low resilience.¹² Results were noted, tabulated and analysed using SPSS version 16.0 software

RESULTS

Table 1 shows the socio-demographic details of caregivers, 31.7% of caregivers were between age of 40-50 years and 29.2% of caregivers were older than 50 years. Majority of caregivers were female (65%). Spouses were the primary caregivers (59.2%) in the study. Majority of the caregivers (51.7%) spent around 1-5 hours for taking care of the patient in a day, 36.7% of caregivers were giving care for period of 1-3 years while 33.3% of caregivers were giving care for more than three years.

Table 1: Socio-demographic details of caregivers.

| Caregiver age | Frequency(n=120) | Percentage |
|---------------------------------|------------------|------------|
| <20 | 2 | 1.7 |
| 20-30 | 13 | 10.8 |
| 30-40 | 32 | 26.7 |
| 40-50 | 38 | 31.7 |
| >50 | 35 | 29.2 |
| Caregiver sex | | |
| Male | 42 | 35.0 |
| Female | 78 | 65.0 |
| Caregiver relation with patient | | |
| Parents | 24 | 20.0 |
| Spouse | 71 | 59.2 |
| Siblings | 5 | 4.2 |
| Others | 20 | 16.7 |
| Caregiver marital status | | |
| Single | 6 | 5.0 |
| Married | 114 | 95.0 |
| Duration of caregiving | | |
| <1 year | 36 | 30.0 |
| 1-3 years | 44 | 36.7 |
| >3 years | 40 | 33.3 |
| Time spent in caregiving | | |
| 1-5 hrs | 62 | 51.7 |
| 6-10 hrs | 34 | 28.3 |
| >10 hrs | 24 | 20.0 |

Table 2 shows the clinical profile of patients on hemodialysis, 50% of the patients had multiple causes for their end stage kidney disease while 27.5% had hypertension as a cause for kidney disease, 68.3% patients underwent two or less than two dialysis per week, 56.7% of patients had undergone dialysis for more than 12 months, 56.7% of patients had more than one comorbid medical illness while 25.8% patients had hypertension as co-morbid medical illness and 14.2% had Diabetes Mellitus as co-morbid medical illness.

Table 3 shows the distribution of Zarit Burden Score among caregivers, 43(35.8%) of caregivers had severe

caregiver burden while looking after dialysis patients while 54(45%) of caregivers had moderate burden, 16.7% of caregivers experienced mild burden symptoms. This finding provides insight on the difficulties of the caregiver's face while looking after of patients on hemodialysis. Table 4 shows the distribution of brief resilience score among caregivers, 17.5% of caregivers had normal resilience score while 10% of caregivers had high resilience score, 72.5% (87) had low resilience which shows poor problem and emotion-focused coping strategies among the caregivers in the study population.

Table 2: Clinical profile of patients on hemodialysis.

| Native kidney disease | Frequency (n=120) | Percentage |
|-------------------------------|-------------------|------------|
| Diabetic | 22 | 18.3 |
| Glomerular | 5 | 4.2 |
| Hypertensive/Vascular | 33 | 27.5 |
| Multiple diseases | 60 | 50.0 |
| Frequency of dialysis/week | | |
| <2 / week | 82 | 68.3 |
| >2 / week | 38 | 31.7 |
| Duration of dialysis (months) | | |
| <12 months | 52 | 43.3 |
| >12 months | 68 | 56.7 |
| Comorbid medical illness | | |
| DM | 17 | 14.2 |
| HTN | 31 | 25.8 |
| CAD | 4 | 3.3 |
| Multiple co morbidities | 68 | 56.7 |

Table 3: Distribution of Zarit Burden Scale score.

| ZARIT burden scale | Frequency | Percentage (%) |
|--------------------|-----------|----------------|
| No burden | 3 | 2.5 |
| Mild | 20 | 16.7 |
| Moderate | 54 | 45.0 |
| Severe burden | 43 | 35.8 |
| Total | 120 | 100.0 |

Table 4: Distribution of Brief Resilience Scale score.

| Brief resilience scale | Frequency | Percentage |
|------------------------|-----------|------------|
| Low Resilience | 87 | 72.5 |
| Normal Resilience | 21 | 17.5 |
| High Resilience | 12 | 10.0 |
| Total | 120 | 100.0 |

Table 5 shows the associations between ZARIT burden scale with socio-demographic variables and brief resilience scale using chi-square test. There was statistically significant relationship between caregiver burden score and caregiver gender, duration of caregiving, time spent per day for caregiving with p

values <0.001. Significant association was also found between burden score and brief resilience score in the

study population, which means as the caregiver burden increased the resilience among the caregivers were low.

Table 5: Associations between Zarit Burden Scale with socio-demographic and brief resilience scale.

| Caregiver age | ZARIT burden scale | | | | Chi square value | p value |
|---------------------------------|---------------------|-------------|-----------------|---------------|------------------|---------|
| | Little or No burden | Mild burden | Moderate burden | Severe burden | | |
| <20 | 0(0.0%) | 0(0.0%) | 1(50.0%) | 1(50.0%) | 9.826 | 0.631 |
| 20-30 | 0(0.0%) | 3(23.1%) | 7(53.8%) | 3(23.1%) | | |
| 30-40 | 2(6.2%) | 3(9.4%) | 15(46.9%) | 12(37.5%) | | |
| 40-50 | 0(0.0%) | 7(18.4%) | 13(34.2%) | 18(47.4%) | | |
| >50 | 1(2.9%) | 7(20.0%) | 18(51.4%) | 9(25.7%) | | |
| Caregiver sex | | | | | | |
| Male | 3(7.1%) | 20(47.6%) | 10(23.8%) | 9(21.4%) | 52.904 | 0.001* |
| Female | 0(0.0%) | 0(0.0%) | 44(56.4%) | 34(43.6%) | | |
| Duration of caregiving | | | | | | |
| <1 year | 1(2.8%) | 8(22.2%) | 18(50.0%) | 9(25.0%) | 13.254 | 0.039* |
| 1-3 years | 2(4.5%) | 10(22.7%) | 20(45.5%) | 12(27.3%) | | |
| >3 years | 0(0.0%) | 2(5.0%) | 16(40.0%) | 22(55.0%) | | |
| Time spent in caregiving | | | | | | |
| 1-5 hrs | 2(3.2%) | 15(24.2%) | 45(72.6%) | 0(0.0%) | 78.573 | 0.001* |
| 6-10 hrs | 1(2.9%) | 5(14.7%) | 7(20.6%) | 21(61.8%) | | |
| >10 hrs | 0(0.0%) | 0(0.0%) | 2(8.3%) | 22(91.7%) | | |
| Brief resilience scale | | | | | | |
| Low Resilience | 0(0.0%) | 3(3.4%) | 41(47.1%) | 43(49.4%) | 59.316 | 0.001* |
| Normal Resilience | 2(9.5%) | 12(57.1%) | 7(33.3%) | 0(0.0%) | | |
| High Resilience | 1(8.3%) | 5(41.7%) | 6(50.0%) | 0(0.0%) | | |

DISCUSSION

Statistically 31.7% of caregivers were between age of 40-50 years and 29.2% of caregivers were older than 50 years. Majority of caregivers were female (65%). Spouses were the primary caregivers (59.2%) in the study. Majority of the caregivers (51.7%) spent around 1-5 hours for taking care of the patient in a day. Certain clinical profile data of the patients were taken in the study, 50% of the patients had multiple causes for their end stage kidney disease while 27.5% had hypertension as a cause for kidney disease, 68.3% patients underwent two or less than two dialysis per week, 56.7% of patients had undergone dialysis for more than 12 months, 56.7% of patients had more than one co-morbid medical illness.

This study was an attempt to provide insight on the difficulties of the caregivers of patients on maintenance hemodialysis. ZARIT burden interview was used for assessing caregiver’s perceived burden. Data wise 35.8% of caregivers had severe caregiver burden while looking after dialysis patients while 45% of caregivers had moderate burden. The results were similar to the study done by Mashayekhi et al, which showed that 72.5% of caregivers had moderate to severe caregiver burden.¹³ In

another study by Jafari et al, 37.4% of caregivers were experiencing high and very high levels of care burden and 42.7% of them were experiencing a moderate level of care burden.¹⁴ These points to the strain experienced by the caregivers of the patient.

Thus, 72.5% had low resilience which shows poor problem and emotion-focused coping strategies in them. This shows resilience plays an important role in the care of the patients and improving resilience can also improve the quality care service provided to the care recipients. The result of ours indicates that besides financial strain, mental and physical status of the caregivers also plays a significant part in the burden experienced by them.

The study also showed association between burden scale and caregiver gender which was statically significant. Female caregivers were most affected by burden of care. Burden was significantly higher in caregivers as the years spent on caregiving increased. Also the burden was higher in caregivers who spent more hours per day looking after the patient. The study showed that as the caregiver burden increased the resilience among the caregivers were low. The very low number of caregivers with high resilience signified 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.

CONCLUSION

In conclusion, caregivers of hemodialysis patients experienced a significant level of care burden. In the context of holistic health conception, it is important to evaluate hemodialysis patients and their relatives together, to inform caregivers about the problems they may encounter, and to develop strategies in them to cope with these problems.

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