

Assessment of caregiver burden of patients receiving dialysis treatment in Rawalpindi

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Abstract

Objective: To determine the burden on the caregivers of patients receiving dialysis treatment.

Methods: This cross-sectional study was carried out in four different dialysis centres of Rawalpindi, Pakistan, from June 1 to December 1, 2015, and comprised attendants of patients receiving dialysis. The data was collected from the attendants of patients receiving dialysis, and caregiver burden was measured using the Zarit Burden Interview questionnaire. SPSS 22 was used for data analysis.

Results: Of the 164 subjects, 97(59%) were females. The majority of caregivers reported stress for caring (2.28 ± 1.31), patients asking for more help than needed (2.14 ± 1.13), health problems (1.03 ± 1.11), financial constraints (1.70 ± 1.15) and little time for self-care (2.15 ± 1.21). Besides, 107(65%) caregivers perceived the burden of their patients as mild to moderate. A positive correlation was found between the duration of a person on dialysis, daily hours of care-giving and the total burden score of his/her caregiver ($p < 0.05$ each).

Conclusion: Care-giving can create enormous burdens on caregivers, affecting their physical and psychological health.

Keywords: Caregiver burden, Patients, Dialysis, Zarit burden interview. (JPMA 67: 1498; 2017)

Introduction

The patients with end-stage renal disease (ESRD) require dialysis, which has become an established mainstay for its treatment since 1960s.¹ This procedure is repeated lifelong, twice or thrice a week depending upon condition of the patient and, hence, this is a tiresome activity for patient as well as for the family requiring endless contribution by caregivers.^{1,2}

The patients with ESRD often rely on informal caregivers to help them with their everyday living and medical needs, including administration of medicines, driving the patient to hospital for dialysis and routine/emergency check-ups, maintenance of personal hygiene and appropriate renal diet.³⁻⁵ These unpaid caregivers are usually family members or friends, especially in Pakistan who also provide regular emotional and psychosocial support owing to cultural and traditional values for caring of the sick.⁶⁻¹⁰

These informal caregivers can experience stress, depression, restlessness and poor quality of life.^{5-7,11} The burden is multidimensional bio-psychosocial reaction,

determined by financial status of the family, time available to look after the patient, compromising personal time, physical health, social life and emotional strain.^{4,6,8,11} The caregiver burden is relatively less in developed countries such as the United States, United Kingdom and Australia because of the availability of formal or paid caregiver.¹²⁻¹⁵ In Pakistan, it has been estimated that only 40% of patients with ESRD have access to dialysis, and out of these, 67% are under dialysed becoming lifelong burden and constant source of stress for the caregivers.^{13,14,16}

The present study was conducted to assess the care giver burden of dialysis patients and its consequences on the quality of life.

Subjects and Methods

This cross-sectional study was carried out in different dialysis centres of public and private hospitals and healthcare centres of Rawalpindi, Pakistan, from June 1 to December 1, 2015, and comprised attendants of patients receiving dialysis. The hospitals and centres in the survey were the Kidney Centre, Benazir Bhutto Hospital, District Headquarters (DHQ) Hospital and Rawalpindi Eye Donors Organisation (REDO). There were more than 10 dialysis centres in Rawalpindi. We selected randomly only those having more than 5 dialysis machines and where dialysis was done in two or more shifts. Some hospitals fulfilling the criteria did not give permission for data collection

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(two armed forces institutes and two private set-ups). The data was collected from 164 attendants (immediate family members like spouse, children and parents) of dialysis patients selected through non-probability consecutive sampling technique. The sample size was calculated using 14%^{3,8} expected family burden at 6% margin of error and 95% confidence level using World Health Organisation's (WHO) sample size calculator. Researchers approached 186 attendants at the time when their patients were undergoing dialysis. Some of them refused to give data, while the rest were not the immediate family members. The informal caregivers of patients receiving dialysis therapy for more than 5 months, (studies show that mostly it takes more than 2-3 months for the caregiver to feel the burden^{2,3,7}) irrespective of age and gender were included in the study. Pushto speaking patients/attendants from KPK, who did not understand Urdu were excluded from the study.

Information was obtained through direct interview using local language from the attendants and standardised questionnaires were filled in by the researchers using the Zarit Burden Interview (ZBI).¹⁷ The ZBI scale was used to measure burden among caregivers because of high reliability and validity.^{15,16} The burden interview is scored by summing the responses of the individual items. The score range is from 0 to 88 and higher scores indicate greater caregiver distress. Data analysis was done using SPSS 22. Total scores with mean and standard deviation were calculated. Chi-square was used to establish relationship between socio-economic class, type of dialysis facility, patient functional dependency and total burden. Correlation test was applied to ascertain association between years on dialysis, daily hours of care giving and total burden on caregivers.

The level of subjective burden was determined according to the following scoring:

(0-20) no burden to little burden,

(21-40) mild to moderate,

(41 to 60) moderate to severe burden and

(61 to 88) severe burden

Informed consent was taken from all participants. No financial incentives were offered to the study participants. Permission was also taken from respective hospital's administration and ethics review board of Yusra Medical and Dental College.

Results

Of the 186 attendants approached, 164(88.2%) were included. The overall mean age was 45 ± 11.23 years.

Table: ZB interview scores of individual questions.

Q no.	ZBI items	Mean \pm SD
1	Asking for more help than needed	2.14 \pm 1.13
2	Not enough time for my self	2.15 \pm 1.21
3	Stressed for caring and other responsibilities	2.28 \pm 1.31
4	Embarrassment over relative's behaviour	1.67 \pm 1.30
5	Angry	0.98 \pm 1.17
6	Negative relationship	2.13 \pm 1.16
7	Afraid about the future	1.31 \pm 1.32
8	Relative's dependence on you?	2.33 \pm 0.73
9	Strained by relative?	1.43 \pm 1.13
10	Health decrease?	1.03 \pm 1.11
11	Lack of privacy	0.99 \pm 1.19
12	Lack of social life?	1.35 \pm 1.10
13	Feel uncomfortable having friends over	0.56 \pm 0.94
14	Expecting to be cared by you?	1.70 \pm 1.17
15	Lack of enough money to pay for the expenses	1.70 \pm 1.15
16	Unable to care much longer?	1.60 \pm 1.19
17	Lost control of life?	0.75 \pm 1.09
18	Leave the care to someone else?	0.48 \pm 0.96
19	Uncertain about what to do?	1.16 \pm 1.11
20	Should do more for my relative	1.73 \pm 1.17
21	Could do a better caring job	1.88 \pm 1.12
22	Overall feeling of burden	1.83 \pm 1.26
	Total Burden score	31.39 \pm 12.31

ZBI: Zarit Burden Interview.

Moreover, 97(59%) participants were female. The mean duration of patients on dialysis was 2.2 ± 0.96 years. The overall burden score was 31.39 ± 12.31 (Table).

Besides, 107(65%) caregivers were having mild to moderate burden, whereas 21(13%) had moderate to severe burden while providing care to their family members (Figure).

The use of government health facility for dialysis patients was usually seen in the lower and middle social class (which was divided in low socio-economic status keeping in view the government's new laid-down minimum pay scale of Rs15,000/month or below), while patients of high social class preferred private set-ups ($p < 0.001$).

The association was also determined between total burden score and socio-economic class, dialysis done in government or private facility and patient functional dependency. It was established that caregivers belonging to low socio class had moderate to severe burden ($p < 0.001$). Caregivers of the patients coming to government hospitals for dialysis showed more burden ($p = 0.031$), main reason being low socio-economic class. Patients who needed less assistance in their daily life, their attendants had lower burden as compared to patients who needed more assistance ($p < 0.001$).

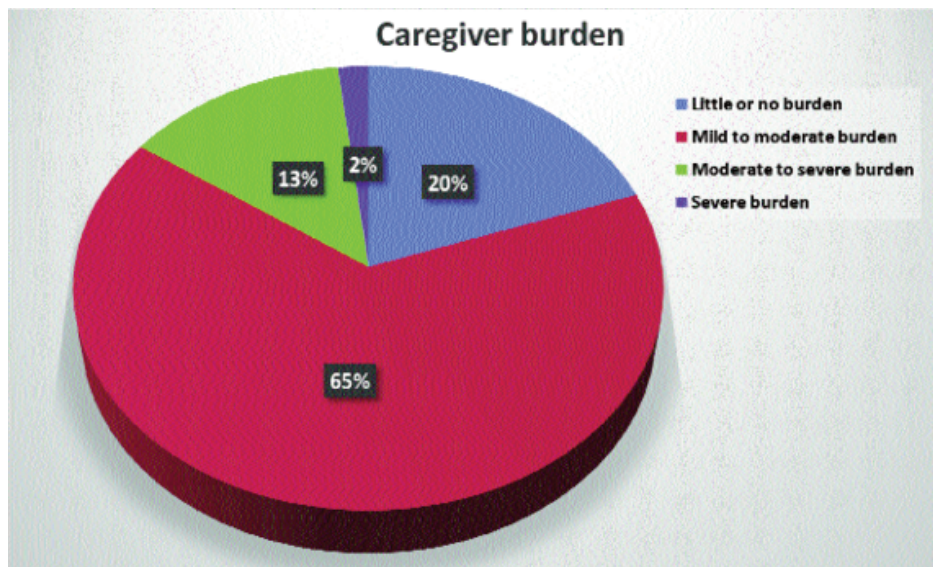


Figure: Overall burden on caregivers.

The informal caregivers mainly included spouses 112(68%), children 43(26%) and relatives 10(6%) looking after their patients on dialysis. It was seen that all of them had mild to moderate burden of taking care of their patients. A strong positive correlation of 0.82 ($p < 0.001$) was found between the number of years a person is on dialysis and the total burden score of his/her caregiver. Similarly, a weak but positive correlation of 0.30 was found between daily hours of care giving and the total burden score ($p < 0.001$).

Discussion

The findings of this study gave an insight into the difficulties of caregivers for patients on haemodialysis. The patients with ESRD have to undergo regular lifelong dialysis. Both the disease and its treatment (i.e. dialysis) had serious effects on the patient and his/her caregivers.¹⁸ The task of providing long-term help to a severely ill person on an everyday basis had an impact on caregiver's social, financial and psychological well-being.^{18,19} Initially, these unpaid caregivers are very enthusiastic, but with the passage of time frustration, fatigue and exhaustion may progress causing serious social and psychological problems.²⁰

According to our results, most of the caregivers perceived the burden as mild to moderate. They were found to be overwhelmed with responsibilities, deteriorating health, and having little time for self-care. Most of the caregivers were not in a state of good health and were elderly, as a result they felt considerable burden. Studies done in other parts of the world also show similar findings.^{15,16,20}

Even with all this burden and financial constraints, our study participants added that they would love to do their duty towards their patients in the future as well.

Our results complimented that unlike caregivers in developed countries, our study participants did not report feeling that their social life had suffered due to their caregiving.²¹ The study participants did not voice the burden of social isolation from family and friends, similar findings were seen in a study conducted in Japan.²² This may be because of the different cultural and religious norms which define 'social life'. Strong religious beliefs and bonding

helped caregivers to cope up with the menace of social isolation.

Most of the caregivers reported worsening of their own emotional and personal health, despite maintaining good social life. This can be understood that the fatigue, constant stress, agony, worry, workload, anxiety and old age of the caregivers were the most common factors driving caregivers to their declining health and burden. These findings were consistent with findings of other studies conducted on the caregivers of stroke and dialysis patients.^{16,20-22}

The results show that the caregivers who provided more hours of care per day and their patients are on dialysis for years did have a greater burden. These findings were consistent with the findings of studies done by Morimoto et al.²² and Yates et al.²³ Similarly, our study showed that caregivers of patients with functional dependency had more burden as compared to those who were independent; these findings were different from the findings of some studies conducted on the stroke patients where burden among caregivers was independent of functional dependency.^{21,22}

The findings of our study also revealed that total burden score was largely driven by caregiver's feeling of being stressed for caring and other responsibilities, patients asking for more help than needed and more than anything, lack of personal time. Similar findings were seen in a study of Japan²² and Jordan.¹⁰ Some other studies referred irritability and dependency to be major

contributors.^{21,24} As a result of strong religious beliefs and trust enabled caregivers to control their anger, they did not feel that they have lost control over their life. These informal caregivers feel greater strength to cope up with the situation and had less worries about their future. Because of the strong family ties even though they feel the burden but they were not willing to leave the care of their patient to someone else (mean 0.48± 0.96). These findings were not seen in the studies conducted in other developed countries.^{12,13,16,25}

The main limitations of our study were language barrier (Push-to-speaking attendants) and permission was not given by some busy tertiary care hospitals leading to difficulty to collect a big sample size.

Conclusion

There is a need to recognise and address the inevitable stress and subjective burden on informal caregivers of dialysis patients. Caregiving can create enormous burdens on caregivers, declining their physical and psychological health. The various strategies needed to be considered to reduce this burden include improving patients' quality of life, caregivers' appraisal, coping strategies, addressing interpersonal relationship issues and psychosocial support.

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Conflict of Interest: None.

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