

The assessment of caregiver burden in caregivers of insured haemodialysis patients at a tertiary hospital in Bangalore

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Abstract: Introduction: Caregivers of Chronic Kidney Disease play a major role in patient care in performing supportive and care functions at home or in outpatient centers, such as dialysis units of hospitals. The caregivers experience stress from added responsibilities of managing the patient's care and often receive little or no attention. Objectives of the study were to assess the caregiver burden and factors associated among caregivers of patients undergoing haemodialysis.

Methods: Cross sectional study among 86 care givers of haemodialysis patients at a Insurance corporation hospital. Study tool consisting of a questionnaire comprising of detailed socio-demographic profile of caregivers and patients, morbidity profile of patients and Zarit burden score to assess caregiver burden was administered.

Results: The mean age of Haemodialysis caregivers was found to be 46.3 ± 12.5 years and 68.6% of them were females. Wife was caregiver in 51.2% patients and 89.5% caregivers were married. Most (71%) of the cases had more than 2 co-morbidities and 61.6% patients were independent on activities of daily living measurement. Mean Zarit score was found to be 24.36 ± 14.9 with 53.6% of the caregivers having some burden in caregiving. Zarit scores were significantly higher when number of co-morbidities among patients was more than two than compared to the counter group.

Conclusion: Care giver burden is high among caregivers of haemodialysis patients. This burden is more among patients suffering with more than two co-morbidities. Understanding and managing the care burdens of caregivers of the patients has a great importance in maintaining the health of patient's, treatment planning and care process.

Keywords: Haemodialysis, caregiver burden, chronic kidney disease, caregivers

I. INTRODUCTION

Chronic kidney disease (CKD) leads to progressive decline in glomerular filtration rate leading to electrolyte and metabolic imbalance¹. Prevalence of stage 3 and above CKD in Indians is found to be 0.16% and 0.79% in two community based studies.² It has been observed that lifestyle changes which lead to diabetes and hypertension account for over 2/3rd of the cases of chronic renal disease.³ CKD and the diseases leading to it are high and increasing in India.

Though permanent and cost effective cure for this is renal transplantation, most can't afford it because of difficulty in finding right donor. Studies have shown only 2.5% of patients with end stage renal diseases undergo transplantation as initial Renal Replacement Therapy.⁴ Therefore, for the rest, dialysis is the mainstay of treatment. The frequency of haemodialysis is twice in a week to everyday depending on the condition of the patient and each session lasts for about four hours. The cost of dialysis in India, is estimated to be around Rs.20,000/month. There are hardly any state-funded medical treatment and medical insurance facilities for CKD patients in India ².

Caregivers of CKD play a major role in patient care in performing supportive and care functions at home or in outpatient centers, such as dialysis units of hospitals. Caregivers often receive little attention as the main focus is on the patient.⁵ The caregivers experience stress from added responsibilities of managing the patient's medical treatments, dietary requirements, clinic appointments and psychosocial issues like depression, anxiety, social isolation, relationship strains and financial strains.^{6,7} Studies have also shown that caregivers of haemodialysis patients have experienced a significant burden and an adverse effect on their quality of life as compared to general population. 8,9,10 Meanwhile, despite such challenges, caregivers disappointment, isolation and failure due to the lack of support, training and experience.¹¹

Timely identification of these pressures and taking corrective measures in caregivers plays a decisive role in the promotion of their and patient's health. Assessment of caregiver burden will help us in better understanding and designing strategies to reduce the burden and improve patient care. Therefore, the evaluation of caregiver's burden and determination of their needs are very important. Hence we undertook this study with the objectives to assess the caregiver burden among caregivers of patients undergoing haemodialysis and to study the association between care giver burden of patients undergoing haemodialysis with their socio demographic variables and co-morbidities.

II. MATERIALS AND METHODS:

It was a cross sectional study done among Caregivers of haemodialysis patients at ESIC-MC & PGIMSR hospital. This is a tertiary hospital which caters health needs of insured persons. There is a dialysis unit with 24 haemodialysis machines, where patients get dialysis in three shifts.

Study population includes caregivers, any lay person, who is unpaid and willing to participate, whom the patient himself/herself identified as being in a close supportive role, and having a good share in his/her illness experience. We requested patient to identify their primary caregiver if more than one caregiver was present.

Sample size was calculated based on prevalence of burden on caregivers of haemodialysis patients as mentioned by Subhashini et al⁸, to be 86% with 99% confidence level and a relative precision of 10%, using Epi info software, a sample size of 86 was calculated.

Selection criteria: Caregivers of patients admitted to nephrology ward of ESIC-MC& PGIMSR for haemodialysis are eligible to participate in the study. All the patients undergoing dialysis at the nephrology ward will be listed and study sample of 86 will be selected using simple random sampling method. Study period was six months from January 2018 to June 2018.

Study tool consisted of a questionnaire comprising of detailed socio-demographic profile of caregivers and patients like age, gender, marital status, educational status, occupation, income, relativity to patient and disease profile of the patients will be designed. Zarit Burden Interview will be used to assess caregivers burden.

Zarit Burden Interview^{12,13} which is a standard, validated tool was used to assess the burden on family caregivers (Cronbach's alpha = 0.92). It is a 5-point (0-4; a higher score denotes higher burden), 22-item Likert scale with a Questionnaire. The final scores range from 0 to 88. It is further stratified into four categories, that is, a score of 0-20 indicates no or minimal burden, 21-40 mild to moderate burden, 41-60 moderate to severe burden and 61-88 indicates severe burden. This scale has been previously used in studies to assess burden on caregivers of patients with chronic kidney disease undergoing hemodialysis in both developed and developing countries. This tool is validated and translated into local language (kannada).

Quality control: Study tool was translated to local language and back translated to check for consistency. Study tool was validated on 5% sample and suitable changes were made in the final proforma. Proposal was submitted to Institutional ethical committee for approval and ethical approval was obtained. The aim of the study was explained to all study subjects and a written informed consent was obtained from caregivers and their patients before the interview. Informed consent and left thumb impression was taken from the caregivers who cannot read or write. Caregivers were interviewed in privacy in a separate room in the hospital. Subjects were assured of complete and strict confidentiality of the information collected.

Statistical analysis: The information so collected was fed into a computer based spreadsheet using Microsoft Excel software. Statistical analysis will be done using epi info 06 package. Sociodemographic details of patients and caregivers, comorbidities among patients will be calculated

and expressed as proportions. Percentage of care giver burden will be analysed according to Zarit Burden Interview guidelines. Mean Zarit scores was analyzed between socio-demographic characteristics and co-morbidities and difference.

III. RESULTS:

Table 1 shows the socio-demographic characteristics of cases and caregivers. Fifty percent of the haemodialysis patients were between 51-60 years where as 50% of the caregivers were between 31-50 years of age. The mean age of Haemodialysis patients was found to be 53.8 ± 8.8 years whereas that of caregivers was found to be 46.3 ± 12.5 years. When the amount of income earned was enquired 30.2% of haemodialysis patients had no income and 51.2% of caregivers had no income. The average income of Haemodialysis patients was found to be 8081.4 ± 6612.3 rupees whereas that of caregivers was found to be 6482.6 \pm 8085.7 rupees. About 66.3% of haemodialysis patients were males where as 68.6% of caregivers were females. Around 70% of the haemodialysis patients were still employed. Seven percent of the patients were widowed where as 10.5% of the caregivers were unmarried. Wife was caregiver in 51.2% of cases, father in 16.2%, son in 12.8% of the cases, daughter in law in 8.1%, daughter in 5.8%, mother in 3.5% and husband in 2.3%.

Table 2 shows the characteristics of disease among haemodialysis patient. When characteristics of disease among patients were studied disease duration and dialysis duration both was on an average of 2.8 years with 2-3 dialysis per week. Hypertension was the most common co-morbidity followed by diabetes and insomnia. Seventy one percent of the cases had more than 2 co-morbidities. When activities of daily living were measured 61.6% patients were independent.

Table 3 shows Zarit care giver burden score among haemodialysis patients. Zarit scores ranged from 0-58 among the participants of the study. Mean Zarit score was found to be 24.36 ± 14.9 indicating mild to moderate burden among caregivers of haemodialysis patients. 53.6% of the caregivers had some burden in care-giving and 15.1% of them had severe burden according to scores.

Table 4 shows the social-demographic and medical factors associated with caregiver burden. Mean Zarit scores were higher among caregivers when patient was male, patients education status was high school and above or when the patient was widowed or when patients were dependent for activities of daily living as compared to their counterparts. Caregiver burden was higher among female caregivers, caregivers with education level of high school and above and among married caregivers as compared to their counter parts. Zarit caregiver burden scores were significantly higher when number of co-morbidities among patients was more than two compared to those caregivers of patients whose co-morbidities were two or less than that.

IV. DISCUSSION:

In our study mean age of Haemodialysis patients was found to be 53.8 ± 8.8 years whereas that of caregivers was found to be 46.3 ± 12.5 years. Majority of the patients (66.3%) were males and majority (68.6%) of caregivers were



females. Wife was the common caregiver in 51.2% of cases followed by father, son, daughter in law, daughter and husband. Most caregivers were married and unemployed or homemakers.

Angelica et al in their study has reported similar results to our study with mean age of caregivers to 46.4+/-1.6years, most were women (84%), married, and unemployed or homemakers. The majority were wives, followed by sons or daughters, husbands, and mothers. ¹⁴ Many other studies also reported similar reports in their study. ¹⁵⁻¹⁹In a systematic analysis done by Gilbertson et al on 61 studies mean age of caregivers ranged from 31.5 to 67.9 years the majority of caregivers were female and 34.5% being employed in an occupation. ²⁰ Unlike few countries concept of paid caregiver is not prevalent in India.

The average income of Haemodialysis patients was found to be around 8081 rupees whereas that of caregivers was found to be 6482 rupees. Expenses for a patient ranged from 800-20,000 rupees per month with an average of 5727 rupees per month. This is still high considering patients availing health services are covered by social security scheme and most treatment cost is taken care free of cost. The expenses incurred were for transport, drugs, food and other miscellaneous expenses.

Average disease duration and dialysis duration was around 2.8 years with 2-3 dialysis per week. Senmar et al have reported mean years of hemodialysis to 2.7± 1.1 years with 2-3 dialysis per week. ¹⁸ Hypertension was the most common co-morbidity followed by diabetes and insomnia in our study. Seventy one percent of the cases had more than 2 co-morbidities. When activities of daily living were measured 61.6% patients were independent. Jafari et al in their study reported patients having co-morbidities like cardiovascular disease and diabetes. ¹⁵ Zhang et al reported that 48% of the patients were having more than two co-morbidities. ¹⁹

Zarit caregiver burden scores ranged from 0 - 58 among the participants of the study. Mean Zarit score was found to be 24.36 ± 14.9 indicating mild to moderate burden among caregivers of haemodialysis patients. 53.6% of the caregivers had some burden of which 38.4% had mild to moderate burden and 15.1 % had moderate to severe burden in care giving. In our study, most caregivers experienced moderate to high levels of care burden, which is consistent with many studies that have been investigating the care burden in caregivers of hemodialysis patients.²¹⁻²⁴In a study done in Iran and Gogan have reported slightly higher levels and 74.2% respectively of caregivers had like 72.5% moderate to severe caregiver burden.^{25,26} Studies conducted by Cagan et al and Jafari et al have reported relatively lesser levels like 37.4% and 42.7% respectively experiencing a moderate to severe level of care burden compared to our study. 15,16 Senmar et al in their study reported a mean total score of care burden was 57.9±20.1, with 23.1%, 51.9% and 25% of the subjects had mild, moderate and severe level of burden respectively. ¹⁸

Mean Zarit scores were higher among caregivers when patient was male, patients education status was high school and above, when the patient was widowed or when patients were dependent for activities of daily living as compared to their counterparts in this study. However the difference was not statistically significant. In a study done in Iran , caregivers of male patients and patients with inadequate income had a significantly higher caregiver burden score than their counterparts. Unlike the present study, Mashayekhi et al. found a statistically significant relationship between the sex of the patients, their income and the level of care burden in their caregiver. Thus, the male caregivers and caregivers of low-income patients were experiencing higher levels of care burden. ²⁵ Patient's income levels and medical expense had significant impact on caregiver burden in a study conducted by Zang et al. ¹⁹Income has shown to have a negative correlation with increased caregiver burden scores.

In our study caregiver burden was higher among female caregivers, caregivers with education level of high school and above and among married caregivers as compared to their counter parts. However the difference was not statistically significant. Angelica et al stated that caregivers of patients with a low education level had a higher mean score than those with higher degrees which is contrary to our findings, however female spouses experienced a greater burden than others. ¹⁴ Cagan et al reported higher burden of care in female caregivers and in those who were being employed, having difficulty in meeting their health expenses, reporting that their role in the family and work is negatively affected, and giving care longer than 5 years. ¹⁶

Senmar et al reported similar Zarit scores between males and female caregivers or patient and a direct and significant correlation between the patients, caregivers age and the total score of burden. There was no significant difference in the scores observed for marital status of the patient/ caregiver, educational status or financial status. ¹⁸ Zang et al demonstrated in their study that higher educational levels of caregivers as associated with lesser burden compared to that of in caregivers with lower education levels. In their study spouses, parents and adult children felt more stressful and burdened than other caregivers. ¹⁹

In this study Zarit caregiver burden scores were significantly higher when number of co-morbidities among patients was more than two compared to those caregivers of patients whose co-morbidities were two or less than that. Similar results were observed in a study done by Suri et al and Zang et al. ^{19, 27}

Caregiver burden is one of the challenging and neglected concern that should be examined. Patients and caregivers require enormous support to undergo these haemodialysis. Giving care to dialysis patients cuts into time for work, relaxation and social relations and requires careful time management.²⁸ Caregivers participate less in social activities, and their family and work lives are disrupted.

Based on the findings of the study Chronic Kidney Diseases affect not only patients, but also at different levels cause moderate to severe burden in the caregivers of haemodialysis patients. Understanding and managing the care burdens of caregivers of the patients has a great importance in maintaining the health of patient's, treatment planning and care process. Staff working at haemodialysis should support caregivers in handling the burden which increase the quality of the patients. Thus, social support and psychological interventions should be executed in order to

improve the lives of the caregivers and subsequently the patients.

Chronic kidney disease treatment is expensive and lifelong; caregiver burden can end up in adverse consequences on self, patients and health care. But caregivers and their problems are often neglected and underprioritized. Instead of looking at the patient as a patient per say we have to look at them as a part of a family. Timely identification and management will have a positive impact on patient's health. This study has provided us baseline information to conduct further research in evaluating implementation of intervention strategies in reducing caregiver burden.

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Tables:

Table 1: Sociodemographic characteristics of Haemodialysis patients and their caregivers

| | Haemodialysis patient N(%) | Care giver N(%) | | | |
|------------------|----------------------------|-----------------|--|--|--|
| Age in years | | | | | |
| < 30 | 1 (1.2) | 1 (1.2) | | | |
| 31 – 40 | 8 (9.3) | 20 (23.3) | | | |
| 41 -50 | 18 (20.9) | 22 (25.3) | | | |
| 51 – 60 | 43 (50.0) | 26 (30.2) | | | |
| >60 | 16 (18.6) | 9 (10.5) | | | |
| Income in rupees | | | | | |
| 0 | 26 (30.2) | 44 (51.2) | | | |
| 1-10000 | 41 (47.7) | 20 (23.3) | | | |



| 10001-20000 | 17 (19.8) | 20 (23.3) | | |
|--------------------|-----------|-----------|--|--|
| >20000 | 2 (2.3) | 2 (2.3) | | |
| Gender | | | | |
| Male | 57 (66.3) | 27 (31.4) | | |
| Female | 29 (33.7) | 59 (68.6) | | |
| Employment status | | | | |
| Unemployed | 26 (30.2) | 42 (48.8) | | |
| Employed | 60 (69.8) | 44 (51.2) | | |
| Marital status | | | | |
| Married | 80 (93) | 77 (89.5) | | |
| Unmarried | 0 (0) | 9 (10.5) | | |
| Widowed | 6 (7) | 0 (0) | | |
| Educational status | | | | |
| Illiterate | 14 (16.3) | 12 (14.0) | | |
| upto 5th std | 13(15.1) | 10 (11.6) | | |
| upto 10th std | 47 (54.6) | 36 (41.9) | | |
| More than 10th std | 12(14.0) | 28 (32.5) | | |

Table 2 : Characteristics of disease among haemodialysis patient

| Table 2: Characteristics of disease among haemodialysis patient | | | | | |
|---|-----------------|------------------|--|--|--|
| Characteristic | $Mean \pm S.D.$ | Minimum- Maximum | | | |
| Duration of disease in years | 2.84 ± 2.46 | 0.5-10 | | | |
| Duration of dialysis in years | 2.85 ± 2.46 | 0.1 - 10 | | | |
| Weekly dialysis frequency | 2.83 ± 0.43 | 1 – 4 | | | |
| Expenses in rupees | 5727.2 ±2866 | 800-20000 | | | |
| Co-morbidities | Frequency | Percentage | | | |
| Hypertension | 79 | 91.9 | | | |
| Diabetes | 52 | 60.5 | | | |
| Insomnia | 26 | 30.2 | | | |
| Osteoarthritis | 8 | 9.3 | | | |
| Ischemic Heart Disease | 4 | 4.65 | | | |
| Depression | 2 | 2.3 | | | |
| No co-morbidity | 2 | 2.3 | | | |
| Number of co-morbidities | Frequency | Percentage | | | |
| ≤ 2 | 25 | 29.0 | | | |
| > 2 | 61 | 71.0 | | | |
| Activities of daily living | Frequency | Percentage | | | |
| Independent | 53 | 61.6 | | | |
| Partially dependent | 26 | 30.2 | | | |
| completely dependent | 7 | 8.1 | | | |

Table 3: Zarit care giver burden score among haemodialysis patients

| Zarit burden score | Frequency | Percent | |
|--------------------|-----------|---------|--|
| <20 | 40 | 46.5 | |
| 21-40 | 33 | 38.4 | |
| 41-60 | 13 | 15.1 | |
| Total | 86 | 100 | |

Table 4: Social-demographic and medical factors associated with caregiver burden

Characteristics N Mean SD p value

| Gender of patient | | | | | | |
|-----------------------------|----|------|------|--------------|--|--|
| Male | 57 | 25.1 | 16.2 | 0.548 | | |
| Female | 29 | 23.0 | 11.9 | 0.348 | | |
| Education status of patient | | | | | | |
| upto high school | 34 | 22.1 | 12.6 | 0.254 | | |
| High school and above | 52 | 25.8 | 16.1 | 0.234 | | |
| Marital status of patient | | | | | | |
| Widowed | 6 | 24.8 | 15.1 | 0.28 | | |
| Married | 80 | 18.0 | 9.1 | 0.20 | | |
| Activities of Daily Living | | | | | | |
| Dependent | 33 | 27.2 | 15.5 | 0.16 | | |
| Independent | 53 | 22.6 | 14.3 | 0.10 | | |
| Caregiver Gender | | | | | | |
| Male | 27 | 20.1 | 14.3 | 0.07 | | |
| Female | 59 | 26.3 | 14.8 |] 0.07 | | |
| Care giver Education status | _ | | | - | | |
| upto high school | 30 | 22.7 | 12.9 | 0.45 | | |
| High school and above | 56 | 25.2 | 15.8 | 0.15 | | |
| Caregiver marital status | | | | | | |
| Widowed/unmarried | 9 | 23.2 | 10.6 | 0.81 | | |
| Married | 77 | 24.5 | 15.3 | 0.01 | | |
| Number of co-morbidities | | | | | | |
| ≤2 | 25 | 20.0 | 11.1 | 0.04 | | |
| >2 | 61 | 26.1 | 15.9 | | | |