



Assessing burden and its determinants in caregivers of chronic kidney disease patients undergoing haemodialysis

Abstract

Background: Caregivers face a lot of adversities while supporting their near ones undergoing haemodialysis, and their burden is often ignored by health professionals. The paucity of research in the Indian context has kept their needs out of sight. **Aim:** To explore the level of burden in the caregivers of patients with chronic kidney disease (CKD) undergoing haemodialysis and to assess whether patient related variable affects the burden. **Methods:** Fifty-one patients and their caregivers from two dialysis units in Sikkim, India, were assessed cross-sectionally. The Zarit Caregiver Burden Scale (ZCBS) was administered to measure the caregiver burden. The Patient Health Questionnaire-9 (PHQ-9) and the Charlson's Comorbidity Index (CCI) assessed the patient's depression and medical comorbidities, respectively. Descriptive analysis was done for the sociodemographic and clinical variables. Chi-square test was used to find the association between the categorical data. Kruskal-Wallis tested the association between categorical and quantitative variables. **Results:** Mean age of patient was 46.13 (± 13.15) years and that of the caregiver was 44.78 (± 12.14) years. 68.6% of caregivers had mild to severe levels of caregiver burden. Caregivers who were unemployed and educated till secondary school were more likely to report caregiver burden. Female gender, older caregivers, and caregivers attending patients with a longer history of haemodialysis reported a more severe burden. **Conclusion:** The level of burden in caregivers of CKD patients is significant and is affected by various factors, which, in turn, also affects patient's wellbeing. Further research in this area is needed in our country for better management of patients and policymaking.

Keywords: Patient Health Questionnaire. Depression. Comorbidity.

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INTRODUCTION

As a result of the swiftly rising number of patients with chronic kidney disease (CKD) and those with comorbid illnesses receiving haemodialysis, loads on their family members and near and dear ones to deliver support have amplified.[1] Chronic illnesses distress not only the patients, but also their families who support them.[2] Many times, health professionals may overlook families, friends, and personal care attendants, who essentially form a support system for the patient.[3] Caregivers are individuals who have the utmost commitment in patient care during the course of a patient's illness and are fully aware of the patient's needs [4] Caregiver burden is a universal and widely accepted term used to depict the physical, emotional, and financial cost of the care.[5] This burden is expressed as long-lasting toil, stressful states, or undesirable experiences that have stemmed from delivering care by the caregiver.[6] The caregiver burden surges significantly as functional damages inflicted by the chronic disease restrict the patient's faculty to care for himself or herself.[7] Burden may be explained subjectively and

objectively. The objective burden is described as the alterations and disruptions which appear in life of the caregivers as an upshot of caregiving and subjective burden is the response or attitude of caregiver of the caregiving experience.[8] For caregivers of such mostly dependent patients, burden adversely affects the caregiver's physical, emotional, and economic status.[9]

There are various factors related to caregiver burden, such as the relationship between caregiver and patient, education and occupational status, behavioural symptoms presented by the patient, gender, and adversative life events [7] A complex role and inter-dependence of such factors must be assessed to measure the impact of the caregiver burden.[10-12] The concept of 'caregiver burden' has thus been used to capture this impact.[7] The quality of life of caregivers, when compared to their counterparts in terms of age and sex is compromised. This can in turn, raise the risk of depression and poor quality of life in haemodialysis patients because of the weakening of social support. Among the predictors of burden, mental health of the caregiver, especially if the caregiver is female spouse

and that of the patients, is a significant one. Interventions directed at enhancing the caregiver's social support and psychological well-being can improve caregiver's life and patient outcomes [1]

The period amid maintenance in adding new responsibilities of family care leads to burden and intensifies the risk of developing depression.[13] Appropriate identification of these gravities in caregivers would play a critical role in improving their mental health.[14] Unlike in the Western countries, the literature regarding caregiver burden and various factors affecting this burden in India is scarce.[15-17] As caregivers form a crucial part of the patient's support system and treatment system, it is important to assess caregiver burden. This would lead to a better quality of life of both the patient's undergoing haemodialysis as well as their caregivers. The aim of the study was to assess the caregiver burden in caregivers of patients with CKD undergoing dialysis, the impact of sociodemographic and patient related variables on caregiver burden, and to assess the correlation between patient's depression and the caregiver burden.

MATERIALS AND METHODS

This study is a hospital-based cross-sectional study, and the participants were the patients attending the haemodialysis unit of Sikkim Manipal Institute of Medical Sciences (SMIMS) and Sir Thutob Namgyal Memorial (STNM) Hospital, Gangtok, Sikkim, India. The study was done from March 2016 to March 2017. The study was approved by the Institutional Ethics Committee (IEC, Reg. No. 360/15-083) of SMIMS. The participants were selected by convenience sampling. A total of 51 caregivers who attended the dialysis unit of SMIMS and STNM hospitals and who were willing to participate in the study were included after written consent was obtained from them. Consents from the patients who were attended by the caregivers was taken and were explained the specifics of the study. Letter of consent was presented in Nepali and English.

Inclusion and exclusion criteria

Those caregivers who were between 18 and 65 years of age and were attending the patients undergoing haemodialysis for at least the last three months were included in the study. A time lag of three months was taken to avoid taking into account the initial depressive reaction which the patient may respond to the initiation of haemodialysis. Participants were interviewed for any history of psychiatric illness and substance use, and the findings were cross-checked by interviewing the caregivers. The patients who had a past history of psychiatric illness or substance abuse or who had a family history of psychiatric illness were excluded from the study. Also, those patients who were critically ill or were unable to comprehend or reply were excluded from the study. Those patients and/or their caregivers who did not give consent were also excluded.

Tools used

Zarit Caregiver Burden Scale (ZCBS)

The caregivers were given the Zarit Caregiver Burden Scale (ZCBS), which is a self-reported questionnaire consisting of

22 items with five responses for each question varying from "never" to "nearly always"; the total score of which gives the severity of burden.[18] ZCBS has been used to assess the burden in caregivers caring for patients with different chronic illnesses.[13,18-22].

Patient Health Questionnaire-9 (PHQ-9)

The Patient Health Questionnaire-9 (PHQ-9) is a nine-item depression module, a self-administered version of the Primary Care Evaluation of Mental Disorders (PRIME-MD) diagnostic tool screening, diagnosing, and measuring the severity of depression. The sum of scores would give a total score representing the severity of depression. The severity of depression is graded as for PHQ-9 score one to four, and the depression severity is none; PHQ-9 score five to nine, depression severity is mild; for score ten to 14, depression severity is moderate; for score 15-19, depression severity is moderately severe and for score more than 20, the depression severity is severe.[23] The sensitivity and specificity of PHQ-9 were found to be 92% and 92%, respectively.[24]

Charlson's Comorbidity Index (CCI)

The Charlson's Comorbidity Index (CCI) is a method of predicting mortality by classifying or weighing comorbid physical conditions. The index comprises 16 illnesses weighted on the basis of morbidity and mortality (one to six points), which are summated to arrive at the comorbidity score. The final comorbidity index is calculated by adding this to the age scores (zero to four).[25] The caregivers and the patients were interviewed for details about medical illnesses and the medical record files were also checked to find out the comorbid medical conditions.

Statistical analysis

Sociodemographic and clinical variables were described using mean and standard deviation (SD) for continuous variables, while categorical variables were represented using percentages. The normality of the distribution was assessed by Shapiro-Wilk test before choosing the method of data analysis. Non-parametric tests were used for inferential analysis. Chi-square test was used to analyse the categorical data except when at least one box displayed an expected frequency of less than five, in which Fisher's exact correction was applied. Kruskal-Wallis test was used to find the association between categorical and quantitative variables. Spearman's rho test was used to determine the correlation between quantitative variables. Data analysis was performed using the International Business Machines Corporation (IBM) Statistical Package for Social Sciences, version 20.0 (SPSS 20.0).

RESULTS

Caregivers' and patients' characteristics

In this study, 51 caregivers of patients suffering from CKD, undergoing haemodialysis in an Indian population, from the state of Sikkim were assessed. Minimum and maximum ages of the caregivers were 20 years and 64 years respectively with a mean of 44.78 years and SD of 12.14 years. Minimum and maximum ages of the patients undergoing haemodialysis were 21 years and 69 years respectively with a mean of 46.13 years

and SD of 13.15 years. The sociodemographic characteristics of the caregivers and the patients are shown in Table 1.

The mean duration of dialysis of the patients was 19.92 months with SD of 15.4 months. The prevalence of major depressive disorder amongst the patients was 27.4 %. The depression severity among the patients is shown in Table 2.

Caregiver burden

68.6 % (N=35) of caregivers were experiencing the caregiver burden. The caregivers who reported experiencing little or no burden were 31.4% (N=16). More than half of the caregivers, 52% (N=27) reported mild to moderate burden (Figure 1).

Relationship between caregiver burden and characteristic variables

There was a significant relationship between caregiver gender and the caregiver burden [$\chi^2(3)=9.8$, $p=0.02$]. Female caregivers were more likely to experience mild to moderate and severe burden when compared to males. Caregivers who were lesser educated also experienced a greater burden [$\chi^2(12)=44.28$, $p<0.01$]. A Kruskal-Wallis H test showed that with the increasing age of the caregivers, the burden perceived by them is significantly higher [$\chi^2(3)=14.48$, $p=0.002$] (Figure 2).

The occupation of the caregivers also determined the burden they were experiencing; unemployed, semi-skilled, or skilled workers were more likely to experience a more significant burden when compared to businessman, private and government sector salaried individuals [$\chi^2(15)=43.81$, $p<0.01$].

The caregiver burden was significantly affected by the increasing age of the CKD patients [$H(3)=8.15$, $p=0.04$] and also by the score on CCI [$H(3)=12.23$, $p<0.01$], suggesting both older patients and with an increasing number of medical comorbidities, the burden on the caregivers increases. Caregivers who have been attending to their patients who were undergoing dialysis for a longer period of time than those whose dialysis started more recently were likely to experience greater burden [$H(3)=28.12$, $p<0.01$] (Table 3).

Relationship between caregiver burden and patient's depression

A significant relationship was found between caregiver burden and depression in patients [$\chi^2(12)=67.20$, $p<0.01$]. There is also a positive correlation between caregiver burden and severity of depression in patients [$\rho(49)=0.435$, $p<0.01$].

DISCUSSION

In this study, we tried finding out the burden as perceived by the caregivers of patients undergoing haemodialysis. We found that 68.6% of the caregivers were experiencing the caregiver burden and most of them were experiencing mild to moderate level of caregiver burden. We found female caregivers, caregivers who were lesser educated, older in age, unemployed, or having lower employment profile were more likely to report the burden. We also found that caregivers attending to patients who were more depressed, with more

Table 1: Caregivers' and patients' characteristics

Sociodemographic variables		Caregiver N (%)	Patient N (%)
Gender	Male	29 (56.9)	31 (60.8)
	Female	22 (43.1)	20 (39.2)
Marital status	Single	6 (11.8)	6 (11.8)
	Married	44 (86.3)	42 (82.4)
	Widowed	1 (2)	3 (5.9)
Education	Primary school	4 (7.8)	1 (2)
	Secondary school	16 (31.4)	8 (15.7)
	Senior secondary	15 (29.4)	13 (25.5)
	Graduate	15 (29.4)	26 (51)
	Postgraduate	1 (2)	3 (5.9)
Occupation	Unemployed	10 (19.6)	28 (54.9)
	Unskilled labour	1 (2)	1 (2)
	Semi-skilled labour	2 (3.9)	14 (27.5)
	Business	18 (35.3)	3 (5.9)
	Salaried (Pvt.)	3 (5.9)	1 (2)
	Salaried (Govt.)	17 (33.3)	4 (7.8)
Religion	Hindu	31 (60.8)	31 (60.8)
	Christian	1 (2)	1 (2)
	Buddhist	19 (37.3)	19 (37.3)
Socioeconomic status	Lower	23 (45.1)	23 (45.1)
	Lower-middle	18 (35.3)	18 (35.3)
	Middle	4 (7.8)	4 (7.8)
	Upper-middle	5 (9.8)	5 (9/8)
	High	1 (2)	1 (2)

Table 2: Severity of depression among the CKD patients (PHQ-9 score)

Depression severity	Frequency	Percent
No depression	25	49.0
Mild	12	23.5
Moderate	7	13.7
Moderately severe	4	7.8
Severe	3	5.9

CKD: Chronic kidney disease; PHQ-9: The Patient Health Questionnaire-9

Table 3: Caregiver burden with the duration of dialysis and patient's medical comorbidities

Characteristic variables	Caregiver burden		
	H*	df	p-value
Duration of dialysis	28.121	3	<0.001
Medical comorbidities	12.230	3	0.007

*Kruskal-Wallis test; df: degree of freedom

medical comorbidities and longer duration of dialysis are also more likely to report caregiver burden.

The interest has always been on psychological well-being and quality of life of patients with CKD and those who are

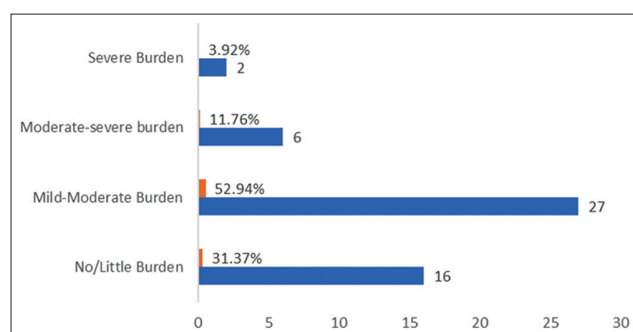


Figure 1: Level of caregiver burden.

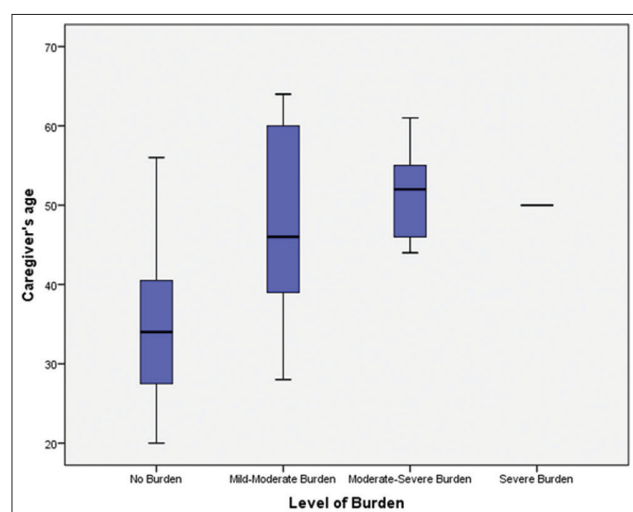


Figure 2: Perceived burden by caregivers of different ages.

undergoing haemodialysis, but the caregivers of such patients who are their support system failed to gain much attention. This is true, particularly when it comes to studies done in our country. The number of caregivers in this study is 51, which, even though is less, comprised of caregivers of all haemodialysis patients, from a state with less population and which has only two dialysis units. The caregiver burden levels in this study are comparable to results from various similar studies done around the world. A study done in China found that 51% of the caregivers had mild to moderate burden and 25.2% had moderate to severe burden.[26] Similarly, a study in Nepal revealed four percent with little or no burden, 30% with mild to moderate burden, 49% with moderate to severe burden, and 17% with severe burden.[27] Rioux *et al.*[28] reported low perceived caregiver burden by the caregivers, possibly because of underestimation by self of the burden experienced caring for their near and dear ones.

The age of the caregiver is an important determinant of the burden perceived by the caregivers. With increasing age of the caregivers, the perceived burden increases.[27] This is similar to the finding in this study, possibly because of the physical difficulties they experience with increasing age. However, some studies have found a higher caregiver burden in younger caregivers.[29,30] This may be explained by the impact of caregiving on their education, work, and other responsibilities in their families.

This study found that higher the education level of the caregivers, lesser was the level of burden perceived. With regard to education, it is commonly known that higher levels of education and awareness about a disease condition may make it more acceptable for patients and their families [31] Educated people have access to information on health resources, appreciate the disease process better, and cope well with adversative situations, which may be the reason for lesser burden in more educated population. Conversely, Mollaoglu *et al.*[29] reported higher caregiver burden in more educated caregivers; this paradox may be because educated caregivers are more aware with the complications of the disease, other responsibilities, and expectations, causing them more stress and more burden.

Occupational status and ranks also have been found to be associated with lesser levels of caregiver burden in this study, as found in the literature. Contrariwise, Mollaoglu *et al* [29] found 80.3% of the caregivers to be housewives and that profession had no impact on caregiver burden.

In this study, no significant relationship between marital status and caregiver burden was found. A study revealed that there is significant difference in burden among caregivers in terms of marriage; the widowed scoring the highest median score in burden, followed by married and then single.[27] Usually, the widows and widowers have nobody to share their sorrows with and often feel more troubled. Also, the married caregivers have not only the patient but also the whole family to look after and hence, have a higher amount of burden scores. In contrast to this finding was the finding of Mollaoglu *et al* [29] in which caregiver burden was found to be statistically significantly higher in single than in married caregivers.

Duration of dialysis and medical comorbidities both were found to have a significant relationship with caregiver burden in this study like in several studies. However, a study found that there is no significant relationship between them [27] This may probably be explained by caregivers developing coping strategies during the course of treatment or by sharing of caregiving responsibilities among different family members. We did not assess for the coping strategies which the caregivers employed, and this is one of the limitations of the study. As the study was cross-sectional, the causal association could not be established between the caregiver burden and chronicity of illness of those whom they are taking care of or because of the financial implications of the treatment.

Though studies have investigated between caregiver burden and caregiver depression,[27] this study probably would be the first of its kind in the Asian countries or may be around the globe assessing caregiver burden with CKD patients' depression. It was found that there is a significant association and correlation between caregiver burden and depression in CKD patients. Depressed patients tend to lose interest in everything including self-care and may poorly adhere to prescribed treatment which may result in complications and which further increase the burden on the caregivers.

Conclusion

India has been facing population explosion and at the same time, increased incidence of chronic medical illnesses like

CKD. Quality of life of not only the patient but also the caregiver is a neglected aspect of CKD management, and the minimal resources are often rerouted to address the general medical needs alone. More research in this realm is needed to improve the quality of healthcare of such patients and their caregivers, and also, to add on to the policy-making in our country with regard to the same.

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