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# Mental health status of Care givers of Chronic Kidney Disease (CKD) patients on haemodialysis visiting a secondary care teaching hospital in semi-rural India: A survey

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**Abstract**

**Background:** Chronic Kidney Disease (CKD), with its high prevalence, morbidity, and mortality, is a major public health problem. The team that takes care of primary patients often overlooks the need of care givers especially psychological or mental health related issues. The caregivers experience huge socio-economic, physical, and psychological burden in the journey of caring for their patients. They tend to experience psychological distress and may develop problems like depression, anxiety, and burden.

**Objectives:** To assess the mental health status of Care givers of Chronic Kidney Disease (CKD) patients on haemodialysis in semi-rural India through a survey.

Materials and methods: Cross sectional survey conducted over 48 participants through a self-designed screening proforma and applying psychometric scales-General Health Questionnaire-28 (GHQ-28), Personal Health Questionnaire-9 (PHQ-9); Hamilton Anxiety Rating Scale (HARS) and Zarit's Burden Interview.

**Results:** 40% of the care-givers showed depression on PHQ-9, 21% showed anxiety on the HAM-A, 33% showed Mild-Moderate burden and 11% showed Moderate-Severe burden on Zarit's Burden Interview. 29.1% of the care givers scored 24 and above which indicates the presence of psychological or psychiatric entities in 14 care givers.

**Conclusion:** Caregivers of CKD patients on dialysis show presence of significant depression, anxiety, and burden. Psychological problems are seen in care givers in their initial one year of accompanying the care-giver for dialysis and those accompanying for a long period.

**Keywords:** Anxiety, depression, burden, hamilton anxiety rating scale, general health questionnaire-28

## Introduction

Chronic Kidney Disease (CKD) is ranked among the 20 top causes of death according to the Global Burden of Disease and has become a disease of public health importance. Patients with advanced stage of CKD often require assistance from other people i.e. care-givers; for their activities of daily living. Caregivers are majorly involved in caring and assisting patients during the period of disease. It is associated with a huge socio-economic, physical, and psychological burden on its sufferers and their caregivers [1]. In many patients, immediate family members take the role of "informal care-givers" and are referred as "secondary patients. They often experience all sorts of mental health related issues and have an increased risk of stress, depression, anxiety, and poor quality of life in the process of providing care and support to the primary patient i.e., for their close and loved ones [2]. The caregiver burden increases significantly as functional and cognitive impairments imposed by the chronicillnesslimits the ability of the patient to care for him. Additional factors associated with caregiver burden include the relationship between caregiver (and their career) and patient, behavioural and psychological symptoms displayed by the patient, gender, and adverse life events. A multi-factorial role and inter-dependence of these factors must be assessed to measure the impact of the caregiver burden. The association of CKD with a variety of co-morbid conditions presents special challenges. To the extent that these co morbidities compromise the patients' overall functional and cognitive capacity, there is an increase in caregiver burden [3].

It is important to note that caregivers tend to go through greater psychological and emotional distress as the care-receiver's functionality deteriorates [4]. As per the study conducted by Bindu Jadhav, *et al*. in 2014 on 50 care givers of patients receiving dialysis in whom perceived burden of care in care giver is high i.e., 26 (52%) of the caregivers [5]. A study conducted in Southern Nigeria measured the psychological wellbeing of caregivers in Southern Nigeria. It found significantly higher anxiety and depression in the caregivers as compared to the controls. 49.1% of the caregivers had mild to moderate burden while 33.3% had high burden [1]. A Japanese study says that caregivers carry out long term caregiving which is accompanied with a lot of struggles [6]. Hence this survey aims at assessing the mental health status of caregivers of the CKD patients.

## Materials and Methodology

1. **Study design:** Cross-sectional Survey.
2. **Study setting:** Dialysis unit of a secondary care teaching hospital.
3. **Study duration:** Survey conducted from September 2021 to December 2021.
4. **Study populations:** Caregivers accompanying their CKD patients for Hemodialysis Inclusion criteria:

- Care givers willing to participate in the study.

5. **Exclusion criteria:** Care givers diagnosed with psychiatric conditions and on regular medication for the same.
6. **Data collection:** Almost 60 care givers were contacted. In the common orientation session objectives and purpose of the study was explained. A good rapport was formed by mounting focused group discussion after the orientation session. All the queries and doubts were explained to the caregivers. Participation was on voluntary. Those willing to participate were subjected for participant information sheet and consent form. Out of 60 care givers 48 were willing to participate.

Screening was done with the help of a self-designed screening proforma covering all the preliminary information and socio-demographic features.

Standard questionnaires were applied-General Health Questionnaire-28 (GHQ-28), Personal Health Questionnaire-9 (PHQ-9), Hamilton Anxiety Rating Scale (HARS) and Zarit's Burden Interview. All the participant information sheets, consent forms and all the scales were translated in the languages known to the participants.

## Results

### A. Demographic data

#### 1. Gender

Out if the 48 care-givers, 26 were males (54%) while 22 females (46%)

#### 2. Age group

The care-givers fell into a varied range of ages which is as follows: 3 in the age group of 16-20 years, 6 in 21-25 years, 5 in 26-30 years, 6 in 31-35 years, 4 in 36-40 years, 6 in 41-45 years and 45-50 years each, 3 in 51-55 years, 4 in 56-60 years and 61-65 years each and one in the range of 66-70 years.

### B. Results as per the psychometric scales administered

1. **GHQ 28:** 29.1% of the care givers scored 24 and above which indicates the presence of psychological or psychiatric entities in 14 care givers.
2. **Depression:** PHQ-9 (which signifies the disturbed mood since last 2 weeks of application of scale) showed presence of depression in 40% (19 care-givers).
3. **Anxiety:** Anxiety was found in 21% (10 care-givers) of care-givers which is in accordance with some studies.
4. **Burden:** There was little to no burden found in 56%, mild to moderate in 33% i.e. 16 care-givers (which is a large number compared to the previous study) and moderate to severe burden in 11% i.e. 5care-givers.

### C. Relation of depression, anxiety and burden to time spent with patient

#### 1. Duration of accompanying patients on dialysis

The majority i.e. 17 care-givers were the ones accompanying patients since up to 1 years. 7 had been accompanying for the duration of 1-2 years and 2-3 years each. 3 had been accompanying for 3-4 years, 8 for 4-5 years, 2 for 5-6 years and 4 for 6-7 years.

Care-givers who had been accompanying dialysis patient since one year showed prevalence of 58% of burden, 47% of depression and 28% of anxiety. Of the 4 care-givers accompanying since more than 6 years, all had presence of depression and 75% showed anxiety and burden each. Among these 4 care-givers, 3 of their patients required assistance for everything and had to be looked up for 24 hours daily.

#### 2. Time spent in care of patient

2 care-givers spent time with their patients twice a week, 6 spent up to 3 hours daily, 10 up to 3-6 hours daily while 10 spent 6-12 hours daily. 14 caregivers spend 12-24 hours daily.

The 2 care-givers who spent twice a week in care of the patient, both had positive scores of depression and burden. Care-givers spending 3-6 hours daily showed 50% prevalence of both depression and burden. Significant findings were seen in care-givers spending more than 12 hours daily in patient's care i.e. depression in 50% and burden in 64%.

Care-givers accompanying the patients for a period of less than one year and beyond 6 years showed major presence of psychological distress. Care-givers who had been accompanying the dialysis patient since one year showed prevalence of 58% of burden, 47% of depression and 28% of anxiety. Of the 4 care-givers accompanying since more than 6 years, all have presence of depression and 75% show anxiety and burden each. Findings were positive in a majority of care-givers spending more than 3 hours daily in the care of patient. The care-givers spending more than 12 hours daily in patient's care show depression in 50% and burden in 64%.

## Discussion

The study aimed at conducting a survey to assess the mental health status of the caregivers of CKD patients. Family Caregiver Alliance of USA estimated that 25% to 50% of caregivers meet the diagnostic criteria of major depression, and 40% to 70% show significant depressive symptoms [7]. This study showed 40% of the care-givers having depression on PHQ-9 while 21% showed anxiety on the HAM-A. This is more as compared to the study conducted at Nigeria that showed anxiety and depression in 31.6% caregivers, measured on Hospital Anxiety and Depression scale. 33% of the caregivers had Mild-Moderate burden and 11% had Moderate-Severe burden on Zarit's Burden Interview while an Indian study showed presence of high burden in 52% of the caregivers [5]. A study published in Indian Journal of Psychiatry in 2019 assessed the burden on caregivers of patients undergoing haemo-dialysis in a sample size of 30, showing little to no burden in 33%, mild to moderate in 16%, moderate to severe in 40% (which is quite high than the findings of this study) and severe in 10% [8].

The care-givers show markedly disturbed mental health state in the initial period and the long run. Those accompanying their patient for more than one year upto 6 years had markedly less prevalence. A prevalence of 40% of anxiety, depression or burden was seen irrespective of education status. Depression and burden was seen more in those who spent more than 12 hours daily in the care of the patient.

## Conclusions

The caregiver of CKD patients on haemodialysis tend to experience psychological distress and may experience depression, anxiety and burden. Significant psychological issues are seen in the initial year of caregiving and in those spending more time with their patient.

## Limitations

Evaluation of the psychiatric diagnosis of those showing presence of anxiety and depressed on the scales could add more value to the survey.

**Conflict of Interest:** None

**Financial support:** Since it is a survey, no financial aid was required.

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## Conflict of Interest

Not available

## Financial Support

Not available

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