



RESEARCH ARTICLE

A STUDY TO ASSESS THE BURDEN AMONG THE CAREGIVERS OF CHRONIC KIDNEY DISEASE (CKD) PATIENTS VISITING THE DIALYSIS UNIT OF A SELECTED TERTIARY CARE HOSPITAL, LUDHIANA, PUNJAB

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ABSTRACT

Background: Chronic Kidney Disease (CKD) is a progressive and irreversible condition characterized by the gradual loss of kidney function over time, often leading to end-stage renal disease (ESRD) requiring renal replacement therapy such as dialysis. The increasing global prevalence of CKD has made it a major public health concern, with significant clinical, social, and economic implications. Dialysis, while life-sustaining, imposes a considerable physical, emotional, and financial strain not only on patients but also on their families and caregivers. Therefore, this study aims to assess the burden among the caregivers of Chronic Kidney Disease (CKD) patients. **Aim** To assess the burden among the caregivers of Chronic Kidney Disease (CKD) patients.

Objectives

- To assess the level of burden among the caregivers of Chronic Kidney Disease (CKD) patients.
- To find out the association of burden among the caregivers of Chronic Kidney Disease (CKD) patients with their selected socio-demographic variables.
- To prepare and disseminate IEC material (Pamphlet) on coping strategies for the caregivers of Chronic Kidney Disease (CKD) patients.

Methods: A descriptive study was conducted on 100 caregivers of CKD patients visiting the dialysis unit through a purposive sampling technique at DMC & Hospital, Ludhiana. The Zarit Burden Interview Scale was used to assess the level of burden among the caregivers. The data was analyzed using descriptive and inferential statistics. **Results:** The study revealed that 44.0% of the caregivers belonged to the age group of 39- 59 years, with a mean age of 45.64 ± 15.35 . Furthermore, 60.0% were females, 65.0% belonged to the Hindu religion, 72.0% of the caregivers resided in an urban area. The majority of the caregivers, i.e., 51.0% were graduate and 52.0% belonged to lower middle class family. The study further revealed that 90.0% of the patients suffered from stage 5 of CKD, and 69.0% of the patients underwent dialysis twice a week. The data also showed that 67.0% reported having comorbidity. The study also showed that among 100 caregivers i.e., 45.0% had a mild to moderate level of burden with a mean score of 30.5 ± 5.48 . Lastly, no significance was found between the socio-demographic variables and the level of burden. **Conclusion:** The present study concluded that most of the caregivers of patients visiting the dialysis unit of a tertiary care hospital had a mild to moderate level of burden among them. All the socio-demographic variables in the study showed no association with the level of burden.

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INTRODUCTION

CKD is an aggravated and long-term condition in which the kidneys are not able to maintain electrolyte and metabolic functions, resulting in increased retention of urea and waste in the body. The number of patients with Chronic Kidney Disease (CKD) doubles every 7 years. According to statistics of 1887, 16600 patients are on dialysis. Chronic Kidney Disease (CKD) is among the chronic diseases that is

due to the persistence of disease and the continuing process has various effects on the physiological, psychological, functional ability, lifestyle changes, and independence status of both the patient and the family. However, caregivers are the individuals who show the utmost commitment to patients' care. They accompany them in the whole course of treatment and are fully aware of their needs. Caregiver burden is long lasting toil and stressful, undesirable experiences that depict the physical, emotional, and financial cost of care. The burden

can be explained objectively and subjectively. The objective burden is alterations and disruptions that occur in the caregiver’s life while giving care. Additionally, the response and attitude of caregivers towards the patients is the subjective burden. Family caregivers are forgotten saviors, suffering from neglect of self-care, and often receive inadequate support. The incessant and often lifelong process of providing care can cause mental fatigue in caregivers. They face various problems, including emotional instabilities and reactions, care fatigue, and deterioration of the caregiver’s health. Fatigue is the most important health indicator that is associated with poor work performance, negative emotions, and even increased risk of sudden death. Neglecting the mental health of caregivers may have grave consequences for patients health. Caregivers who were the patient’s spouse and those who had lower incomes had experienced more fatigue. Measuring caregiver burden in patients with Chronic Kidney Disease (CKD)is important to understand the impact of caregiving to identify areas of experiencing difficulty and track changes in caregivers’ burden over time, with the severity of the disease.

MATERIAL AND METHODS

RESEARCH APPROACH: A quantitative research approach was used to assess the burden among the caregivers of Chronic Kidney Disease (CKD)patients visiting the dialysis unit of a tertiary care hospital, Ludhiana, Punjab.

RESEARCH DESIGN: A descriptive research design was used to assess the burden among the caregivers of Chronic Kidney Disease (CKD)patients visiting the dialysis unit of a tertiary care hospital, Ludhiana, Punjab.

RESEARCH SETTING: The study was conducted in the Dialysis unit of DMC & Hospital, Ludhiana, Punjab. The criteria for selecting this setting was availability of subjects, economy of time, easy access, familiarity of the researcher with the setting, expected cooperation, and administrative support for conducting the study.

TARGET POPULATION: The target population of the study was caregivers of CKD patients visiting the dialysis unit.

Inclusion Criteria: The caregivers of CKD patients who were :
≥ 18 years of age.
taking care for ≥ 6 months
able to understand English, Hindi, or Punjabi.

Exclusion Criteria: The caregivers of CKD patients who were :
with a history of any psychiatric illness.
caring for patients in other wards of the hospital
not willing to participate in the study.

SAMPLE : The sample of the study was caregivers of CKD patients taking care ≥ 6 months.

SAMPLING TECHNIQUE: The purposive sampling technique was used in this study.

SAMPLE SIZE: A sample of 100 caregivers was selected.

SELECTION AND DEVELOPMENT OF A RESEARCH TOOL

A comprehensive literature review was done to choose and develop tools for the selection & development of tools. It includes socio demographic profile of the caregiver, the clinical profile of the patient, and the Zarit Burden Interview (Likert scale).

DESCRIPTION OF THE TOOL: The tool consists of the following parts:

PART-A: Socio-demographic profile: It consists of 11 items regarding sociodemographic variables, i.e, age, gender, religion, habitat, type of family, occupation, marital status, education,

relationship with the patient, duration of care, and socio-economic status as per the Kuppuswamy Socioeconomic Status Scale (2024).

PART-B: Clinical Profile: It included components like the stage of the CKD patient, frequency of dialysis visits with the patient, any co-morbidities, intra-dialysis or post-dialysis complications faced by the patient, or any other health department that caregiver visits along with the patient, and if yes, then how frequently.

PART-C: The Zarit Burden Interview: The Zarit Burden Interview (Likert scale) was used to examine the burden among the caregivers of Chronic Kidney Disease (CKD) patients. This tool was developed by Steven H. Zarit, Nancy K. Orr & Judy M. Zarit in 1980. The tool contains 22 items and has responses like never (0), rarely (1), sometimes (2), quite frequently (3), and nearly always (4), rated from 0 to 4. Higher scores indicate a greater burden.

CRITERION MEASURES

The burden score refers to the total score on the items in the questionnaire by the caregivers.

| LEVELS OF BURDEN | SCORE | % |
|---------------------------|-------|--------|
| Little or no burden | 0-20 | 61-88 |
| Mild to Moderate burden | 21-40 | 24-45 |
| Moderate to Severe burden | 41-60 | 46-68 |
| Severe burden | 61-88 | 69-100 |

Total no. of items: 22
Maximum Score: 88
Minimum Score: 0

VALIDITY OF THE TOOL: The tools were valid to use in the research study.

RELIABILITY OF THE TOOL: The obtained value was **0.854**; the tool was found to be reliable.

PILOT STUDY: To assess the feasibility of the study, a pilot study was conducted on 1/10th of the subjects i.e., 10 patients visiting the dialysis unit in DMC & Hospital, Ludhiana, Punjab.

PLAN FOR DATA ANALYSIS: Analysis of data was done in accordance with the objectives of the study by using descriptive and inferential statistics. Calculation has been done using the statistical software SPSS version 25.0, and the significance of the effect or difference was established at a $p \leq 0.05$ level.

PLAN FOR WRITING REFERENCES: The references were written in Vancouver style 1993 as per the recommendations of the research committee of DMC & Hospital, Ludhiana, and Baba Farid University of Health Sciences, Faridkot.

RESULTS

The study revealed that 44% of the caregivers belonged to the age group of 39- 59 years, with the mean age 45.64 ± 15.35 . Furthermore, 60% were females, 65% belonged to the Hindu religion, 72% of the caregivers resided in an urban area. 61% of the caregivers were non-working, and 39% were working. 58% of the caregivers belonged to a nuclear family, and 79% were married. The majority of the caregivers,i.e.. 51% were graduates, and 52% belonged to lower-middle-class families. The study further revealed that 90% of the patients suffered from stage 5 of CKD, and 69% among those were patients undergoing dialysis twice a week. The data also showed that 67% reported comorbidity. Hypertension (65.6%) and diabetes (35.8%) as major ones. The most common complication facedby patients during dialysis was blood pressure fluctuation (27.5%). Post dialysis, generalized weakness (85%) was the most common complication. The study also showed that among 100 caregivers of CKD patients, 45% had a mild to moderate level of burden with a mean score of 30.5 ± 5.48 . Lastly, no statistically significant

association was found between the socio-demographic variables and the level of burden at a $p < 0.05$ level of significance.

Table 1: Frequency and Percentage distribution of primary caregivers as per socio demographic profile

| N = 100 | |
|--------------------------------------|-----------|
| Socio-demographic variable | f(%) |
| Age of caregiver | |
| 18 - 38 | 36 |
| 39 - 59 | 44 |
| 60 - 80 | 20 |
| Gender | |
| Male | 40 |
| Female | 60 |
| Religion | |
| Sikh | 33 |
| Hindu | 65 |
| Muslim | 1 |
| Other | 1 |
| Habitat | |
| Rural | 28 |
| Urban | 72 |
| Type of family | |
| Joint | 41 |
| Nuclear | 58 |
| Extended | 1 |
| Occupation | |
| Non working | 61.0 |
| Working | 39.0 |
| Working, n = 39 | |
| Business | 24 (61.6) |
| Farmer | 3 (7.6) |
| Teacher | 5 (12.8) |
| Shopkeeper | 3 (7.6) |
| Nurse | 1 (2.5) |
| Banker | 2 (5.1) |
| Government employee | 1 (2.5) |
| Marital status | |
| Married | 79 |
| Unmarried/single | 19 |
| Divorced/separated | 2 |
| Educational status | |
| Illiterate | 2 |
| Elementary | 13 |
| Secondary | 34 |
| Graduate or above | 51 |
| Relationship with the patient | |
| Spouse | 47 |
| Children | 26 |
| Grandchildren | 6 |
| Parents | 12 |
| In laws | 9 |
| Duration of care | |
| Less than 1 year | 33 |
| 1 - 3 years | 44 |
| 4 - 7 years | 23 |
| Socio - economic status | |
| Upper class | 2 |
| Upper middle class | 35 |
| Lower middle class | 52 |
| Upper lower class | 10 |
| Lower class | 1 |

Mean of age (in years) = 45.64 ± 15.35

Table no 1 reveals that the majority of caregivers,i.e. 44.0% belonged to the age group of 39- 59 years, 36.0% belonged to the age group of 18- 38 years, and 20.0% belonged to the age group of 60 - 80 years of age.

- Maximum numbers of caregivers,i.e. 60%were female, and 40%were male.
- Majority of the subjects,i.e.65.0%belonged to the Hindu religion followed by 33.0%belonged to the Sikh religion, followed by 1.0% each belonging to the Muslim and other religions.
- Majority of the subjects,i.e.72.0% were living in an urban area, and 28.0% were living in a rural area.
- Majority of the caregivers,i.e. 58.0% belonged to a nuclear family, followed by 41.0%belonged to a joint family, and only 1(1.0%) belonged to an extended family.

- Majority of the caregivers,i.e. 61.0%were non-working,and 39.0% were working.
- Maximum number of caregivers,i.e.79.0%were married, followed by 19.0% were unmarried, followed by 2.0% were divorced.
- Maximum number of caregivers,i.e.51.0% weregraduates, 34.0% were educated up to secondary, 13.0% were educated up to elementary, and 2.0% were illiterate.
- Majority of the caregivers,i.e. 52.0% belonged to lower middle class family, 35.0% belonged to upper middle-class families, 10.0% belonged to upper lower-class families, 2.0% belonged to upper-class families, and 1.0% belonged to lower-class families.

Table 2. Frequency and Percentage distribution as per the clinical profile of the patient

| Clinical profile | f (%) |
|---|-----------|
| Stage of CKD | |
| Stage 4 | 10 |
| Stage 5 | 90 |
| Frequency of dialysis visits (in a week) | |
| a) Once | 17 |
| b) Twice | 69 |
| c) Thrice | 13 |
| d) Five times | 1 |
| Comorbidity * | |
| No | 33 |
| Yes | 67 |
| Comorbidity diagnosis, n = 67 | |
| LVEF | 3 (4.4) |
| Hypertension | 44 (65.6) |
| Hypotension | 2 (2.9) |
| Anemia | 1 (1.4) |
| Diabetes | 24 (35.8) |
| Recurrent UTI | 6 (8.9) |
| Neuropathy | 1 (1.4) |
| Tuberculosis | 1 (1.4) |
| Pitting edema | 1 (1.4) |
| Renal agenesis | 2 (2.9) |
| Paralysis | 1 (1.4) |
| Pott's spine | 1 (1.4) |
| ALD | 1 (1.4) |
| Intra-dialytic complications * | |
| No | 42 |
| Yes | 58 |
| Complications ,n = 58 | |
| Leg cramps | 2 (3.4) |
| Nausea | 10 (17.2) |
| Fainting | 1 (1.7) |
| Dizziness | 6 (10.3) |
| BP fluctuation | 16 (27.5) |
| Acidity | 1 (1.7) |
| Headache | 5 (8.6) |
| Blood clot | 1 (1.7) |
| Hypoglycemia | 3 (5.1) |
| Backache | 8 (13.7) |
| Loose motion | 2 (3.4) |
| Shivering | 2(3.4) |
| Hypoxia | 4 (6.8) |
| Hypotension | 5 (8.6) |
| Vomiting | 3 (5.1) |
| Fever | 2 (3.4) |
| Any complication faced after dialysis * | |
| No | 40 |
| Yes | 60 |
| Complications , n = 60 | |
| Occasional vomiting | 3 (5) |
| Generalized weakness | 51 (85) |
| Fever | 3 (5) |
| Loss of appetite | 2 (3.3) |
| Hypoglycemia | 2 (3.3) |
| Leg cramp | 2 (3.3) |
| Headache | 1 (1.6) |

* - Multiple response table

Table 2 represents that majority of the patients i.e. 90% suffers from stage 5 of CKD and 10% of patients suffer from stage.

- The data shows that the majority of patients 69.0% undergo dialysis twice a week. A significant portion 17.0% visit once a

week, while only 13.0% visit thrice a week. Only a small percentage 1.0% visit five times a week.

- The data shows that the majority of the patients, 67.0%, reported having a comorbidity, whereas 33.0% did not.
- The data shows that the most common comorbidity faced by patients is hypertension by 65.6%, followed by diabetes 35.8%, LVEF by 4.4%, hypertension by 2.9%, recurrent UTI by 8.9 %, anemia, paralysis, pott's spine, heart attack, and ALD by 1.4%, renal agenesis by 2.9%.
- The table presents the percentage of complications experienced by patients during dialysis. Among intra-dialysis complications, blood pressure fluctuation was most commonly reported (27.5%), followed by nausea (17.2%), backache (13.7%), and dizziness (10.3%). Less frequent issues included fainting (1.7%), acidity (1.7%), and blood clot formation (1.7%).
- Post-dialysis, generalized weakness was most common (85.0%), with occasional vomiting (5.0%), fever (5.0%), loss of appetite (3.3%), and hypoglycemia (3.3%) also reported. Additional complaints included leg cramps (3.3%) and headache (1.6%).

Table 3. Level of burden among the caregivers of Chronic Kidney Disease (CKD) patients

| N = 100 | | | | |
|---------------------------|---------|----|----------|-----------|
| Level of Burden | Score | f | Mean (%) | Mean±SD |
| No to mild burden | 0 - 20 | 18 | 18.0% | 10±5.77 |
| Mild to moderate burden | 21 - 40 | 45 | 45.0% | 30.5±5.48 |
| Moderate of severe burden | 41 - 60 | 33 | 33.0% | 50.5±5.48 |
| Severe burden | 61 - 88 | 4 | 4.0% | 77.9±7.79 |

Overall Mean ± SD = 35.17 ± 16.22; Minimum Score = 0
Maximum Score = 88

Table 3 describes that among 100 participants, majority i.e. 45% of the participants had mild to moderate level of burden with a mean score of 30.5±5.48 followed by 33 (33.0%) with moderate to severe level of burden having a mean score of 50.5±5.48 followed by 18 (18.0%) with no to mild level of burden having a mean score of 10±5.77 and 4(4.0%) had severe level of burden with a mean score of 77.9±7.79. Hence, it can be concluded that the majority of the caregivers had a mild to moderate level of burden.

Table 4. Mean , Standard Deviation and Analysis of Variance of Burden Score of Caregivers of CKD patients according to Age (in years).

N=100

| Socio-demographic variables | N | Mean _±SD | df | F/t value | P value |
|-----------------------------|----|------------|----|-----------|---------------------|
| AGE (in years) | | | | | |
| 18 - 38 | 36 | 2.28±0.815 | 2 | F = 0.318 | 0.711 ^{NS} |
| 39 - 59 | 44 | 2.16±0.745 | | | |
| 60 - 80 | 20 | 2.30±0.865 | | | |
| GENDER | | | | | |
| Male | 40 | 2.20±0.791 | 1 | t = 0.095 | 0.758 ^{NS} |
| Female | 60 | 2.25±0.795 | | | |
| RELIGION | | | | | |
| Sikh | 33 | 2.00±0.750 | 4 | F = 2.56 | 0.059 ^{NS} |
| Hindu | 65 | 2.37±0.782 | | | |
| Muslim | 1 | 1.00 | | | |
| Others | 1 | 1.00 | | | |
| HABITAT | | | | | |
| Rural | 28 | 2.07±0.954 | 1 | t = 0.164 | 0.687 ^{NS} |
| Urban | 72 | 2.19±0.741 | | | |
| TYPE OF FAMILY | | | | | |
| Joint | 41 | 2.18±0.772 | 2 | F = 1.361 | 0.261 ^{NS} |
| Nuclear | 58 | 2.25±0.801 | | | |
| Extended | 1 | 1.00 | | | |
| OCCUPATION | | | | | |
| Non working | 61 | 2.31±0.847 | 1 | F = 1.440 | 0.256 ^{NS} |
| Working | 39 | | | | |
| Business | 24 | 2.00±0.659 | | | |
| Farmer | 3 | 1.33±0.577 | | | |
| Teacher | 5 | 2.40±0.548 | | | |
| Shopkeeper | 3 | 2.33±0.577 | | | |
| Nurse | 1 | 3.00±0.000 | | | |
| Banker | 2 | 3.00±0.000 | | | |

| | | | | | |
|-------------------------------------|----|------------|----|-----------|---------------------|
| Government employee | 1 | 2.00±0.000 | | | |
| MARITAL STATUS | | | | | |
| Married | 79 | 2.23±0.767 | 3 | t = 0.967 | 0.384 ^{NS} |
| Unmarried/ single | 19 | 2.32±0.885 | | | |
| Divorced / separated | 2 | 1.50±0.707 | | | |
| EDUCATION | | | | | |
| Illiterate | 2 | 1.50±0.707 | 3 | F = 0.658 | 0.580 ^{NS} |
| Elementary | 13 | 2.15±0.899 | | | |
| Secondary | 34 | 2.24±0.819 | | | |
| Graduate or above | 51 | 2.27±0.750 | | | |
| RELATIONSHIP WITH PATIENT | | | | | |
| Spouse | 47 | 2.21±0.832 | 95 | F = 1.022 | 0.400 ^{NS} |
| Children | 26 | 2.12±0.711 | | | |
| Grandchildren | 6 | 2.83±0.983 | | | |
| Parents | 12 | 2.25±0.866 | | | |
| In laws | 9 | 2.22±0.441 | | | |
| DURATION OF CARE (in months) | | | | | |
| Less than 1 year | 33 | 2.24±0.867 | 97 | F = 0.044 | 0.957 ^{NS} |
| 1 - 3 years | 44 | 2.20±0.823 | | | |
| 4-7 years | 23 | 2.26±0.619 | | | |
| SOCIO-ECONOMIC SCALE | | | | | |
| Upper class (I) | 2 | 2.00±.000 | 95 | F = 0.114 | 0.977 ^{NS} |
| Upper middle class (II) | 35 | 2.29±.825 | | | |
| Lower middle class (III) | 52 | 2.21±.800 | | | |
| Upper lower class (IV) | 10 | 2.20±.789 | | | |
| Lower class (V) | 1 | 2.00 | | | |

NS = Non-significant

Table 4 Association between participant's level of burden and their socio-demographic variables.

- **AGE (IN YEARS):** The association between age and the level of caregiver burden was analyzed among three age groups: 18–38 years, 39–59 years, and 60–80 years. The mean burden scores were found to be 2.28±.815 for the 18–38 age group, 2.16±.745 for the 39–59 age group, and 2.30±.865 for those aged 60–80 years. An ANOVA test was performed to determine the statistical significance of differences among these groups, yielding an F-value of 0.318 with a corresponding p-value of 0.711. Since the p-value is greater than 0.05, the results indicate that there is no statistically significant association between the age of caregivers and their level of burden.
- **GENDER:** The analysis of caregiver burden by gender revealed that the mean burden score for male caregivers (n=40) was 2.20 ± 0.791, while for female caregivers (n=60), it was slightly higher at 2.25 ± 0.795. No transgender participants were reported in the study. An independent samples t-test was conducted to assess the significance of the difference between male and female caregivers, yielding a t-value of 0.095 with a corresponding p-value of 0.758. Since the p-value is greater than 0.05, the result is not statistically significant. This indicates that there is no meaningful difference in the level of burden experienced by male and female caregivers in the study population.
- **RELIGION:** The relationship between caregivers' religion and their level of burden was examined among participants identifying as Sikh, Hindu, Muslim, and others. The mean burden score for Sikh caregivers (n = 33) was 2.00 ± 0.750, while for Hindu caregivers (n = 65), it was slightly higher at 2.237±0.782. Only one caregiver was identified as Muslim and “other” with mean burden scores of 1.00 each, respectively. No participants identified as Christian. A one-way ANOVA test was conducted to determine if there was a statistically significant difference in burden levels across religious groups.

The test yielded an F-value of 2.56 and a p-value of 0.059. Since the p-value is greater than 0.05, the results indicate that there is no statistically significant association between religion and the level of caregiver burden in this study population.

- **HABITAT:** The relationship between the caregivers' place of residence (habitat) and their level of burden was examined by comparing rural and urban populations. Caregivers residing in rural areas ($n = 28$) had a mean burden score of 2.07 ± 0.954 , whereas those from urban areas ($n = 72$) had a slightly higher mean burden score of 2.19 ± 0.741 . An independent samples t-test was conducted to assess the statistical significance of this difference. The test yielded a t-value of .164 with a p-value of .687. As the p-value exceeds the conventional threshold of 0.05, the result indicates no statistically significant association between the habitat of caregivers and the level of burden they experience.
- **TYPE OF FAMILY:** The level of caregiver burden was compared across different types of family structures—joint, nuclear, and extended. Caregivers from joint families ($n = 41$) had a mean burden score of 2.18 ± 0.772 , while those from nuclear families ($n = 58$) had a mean score of 2.25 ± 0.801 . Only one caregiver belonged to an extended family, with a burden score of 1.0, which is not sufficient for meaningful comparison. A one-way ANOVA test was applied to examine the association between family type and burden level, resulting in an F-value of 1.361 and a p-value of 0.261. Since the p-value exceeds 0.05, the result is not statistically significant. This indicates that there is no significant association between the type of family and the level of burden experienced by caregivers in this study.
- **OCCUPATION:** The association between the occupational status of caregivers and their level of burden was assessed by comparing working and non-working individuals. The mean burden score for working caregivers ($n = 39$) was 2.12 ± 0.678 , while that for non-working caregivers ($n = 61$) was 2.31 ± 0.856 . An independent samples t-test was conducted to evaluate the significance of the difference in burden levels between these two groups. The test yielded a t-value of 1.308 and a p-value of 0.256. Since the p-value is greater than the conventional threshold of 0.05, the results indicate that there is no statistically significant association between caregivers' occupational status and their level of burden.
- **MARITAL STATUS:** The association between caregivers' marital status and their level of burden was analyzed among married, unmarried/single, and divorced/separated individuals. The mean burden score for married caregivers ($n = 79$) was 2.23 ± 0.767 , while unmarried/single caregivers ($n = 19$) reported a slightly higher mean burden score of 2.32 ± 0.885 . Only two participants were divorced or separated, with a mean burden score of $1.50 \pm .707$, and there were no participants in the widow/widower category.

A one-way ANOVA test was performed to assess the statistical significance of these differences, resulting in an F-value of .967 and a p-value of 0.384. Although the unmarried group showed a slightly higher burden, the p-value is greater than 0.05, indicating that the difference is not statistically significant. Therefore, it can be concluded that marital status does not have a significant impact on the level of burden experienced by caregivers in this study.
- **EDUCATION:** The association between the caregivers' level of education and their perceived burden was analyzed across four educational categories: illiterate, elementary, secondary, and graduate or above. Caregivers who were illiterate ($n = 2$) reported a mean burden score of $1.50 \pm .707$, followed by those with graduate or higher education ($n = 51$) at 2.27 ± 0.750 . Caregivers with elementary education ($n = 13$) had a mean score

of 2.15 ± 0.899 , and those with secondary education ($n = 34$) reported the mean burden score at 2.24 ± 0.819 . To determine if these differences were statistically significant, a one-way ANOVA test was performed, yielding an F-value of 0.658 and a p-value of 0.580. Since the p-value is greater than 0.05, the results indicate that the differences in burden levels among the various educational groups are not statistically significant.

- **RELATIONSHIP WITH THE PATIENT:** The level of caregiver burden was analyzed in relation to the caregiver's relationship with the patient. The mean burden of spouse is 2.21 ± 0.832 , children is 2.12 ± 0.711 , grandchildren is 2.83 ± 0.983 , parents is 2.25 ± 0.866 , and in-laws is 2.22 ± 0.441 . A one-way ANOVA test was conducted to examine statistical significance, resulting in an F-value of 0.504 and a p-value of 0.400. Since the p-value is much greater than 0.05, the findings indicate that there is no statistically significant association between the caregiver's relationship to the patient and the level of burden experienced.
- **DURATION OF CARE:** The relationship between the duration of caregiving and the level of caregiver burden was evaluated across different time intervals. Caregivers who were giving care for less than 1 year has a mean burden of 2.24 ± 0.867 , 1 - 3 years has mean burden of 2.20 ± 0.823 , and 4 - 7 years has mean burden of 2.26 ± 0.619 .
- A one-way ANOVA was conducted to determine whether these differences were statistically significant, resulting in an F-value of 1.022 and a p-value of 0.957. Since the p-value is greater than 0.05, the difference in caregiver burden across various durations of care is not statistically significant. Therefore, the findings suggest that the length of caregiving does not have a significant impact on the level of burden perceived by caregivers in this study.
- **SOCIO-ECONOMIC SCALE:** The level of caregiver burden was analyzed in relation to the socioeconomic scale. Caregivers belonging to the upper middle class (II) exhibit the highest mean burden score of 2.29 ± 0.825 , indicating a relatively higher level of burden compared to other socioeconomic groups. In contrast, the caregivers belonging to the upper class (I) have the lowest mean burden score of 2.00 ± 0.000 , suggesting a lower level of burden.
- The lower middle class (III) and upper lower class (IV) have mean burden scores of 2.21 ± 0.800 and 2.20 ± 0.789 , respectively, indicating a moderate level of burden. Notably, the lower class (V) has a mean burden score of 2.00, but the small sample size ($n=1$) limits the interpretability of this finding.

A one-way ANOVA was conducted to determine whether these differences were statistically significant, resulting in an F-value of .114 and a p-value of 0.977 suggest that the association between socioeconomic scale and level of burden is not statistically significant.

HENCE: Among all the variables studied, no variable was significantly associated with the level of burden. Therefore, it didn't show a statistically significant relationship.

Figure 3 represents that most of the caregivers, i.e. 61.50% are doing business, 12.80% are teachers, 7.60% are shopkeepers and farmers, 5.10% are bankers and 2.50% are government employees. Hence, it can be concluded that the majority of the caregivers are doing business as an occupation.

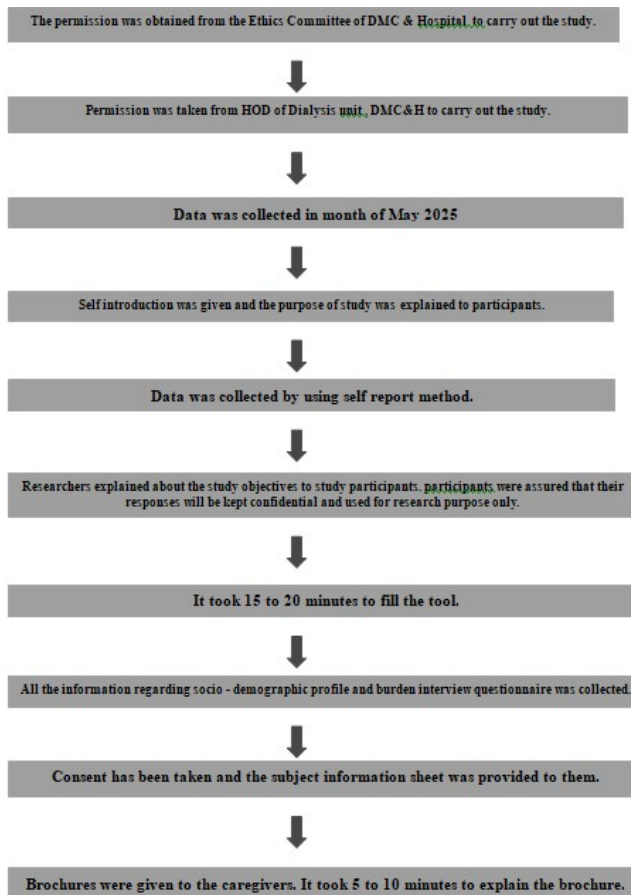


Figure 1. Data Collection Procedure

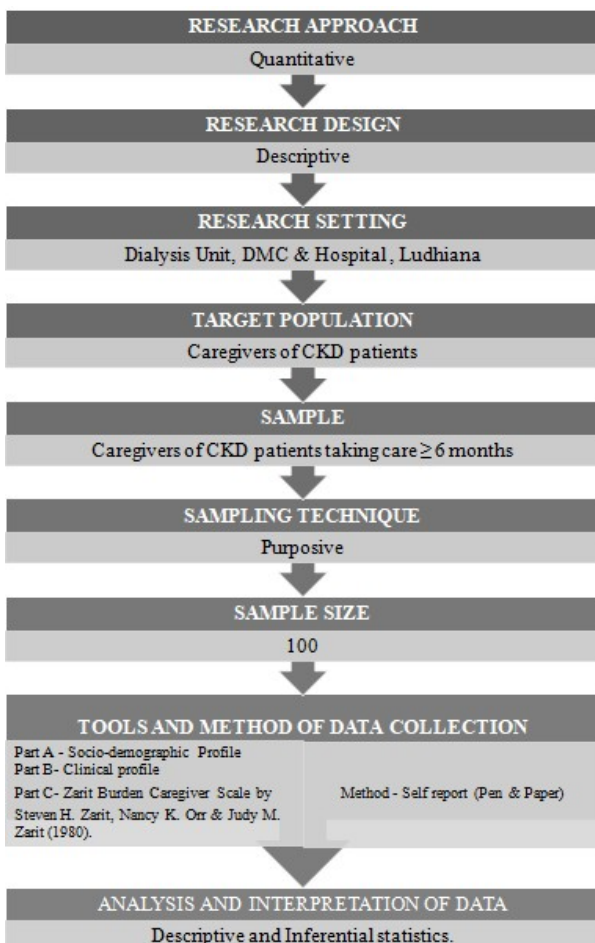


Figure 2. Methodology chart

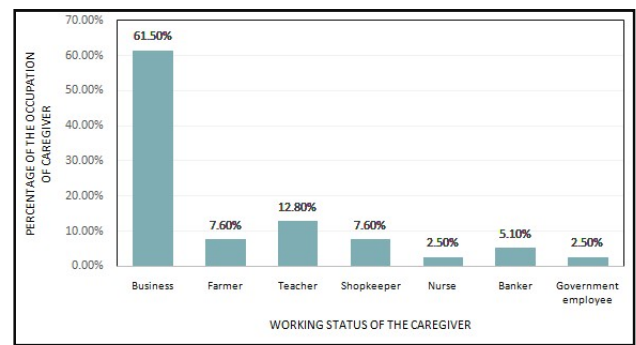


Figure 3. Percentage distribution of occupation of caregivers as per the working status of the caregiver

Objective 2: To find out the association of burden among the caregivers of Chronic Kidney Disease (CKD) patients with their selected socio-demographic variables.

Objective 3: To prepare and disseminate IEC material (Pamphlet) on coping strategies for the caregivers of Chronic Kidney Disease (CKD) patients.

DISCUSSION

Discussion of the findings of this study has been done in accordance with the analysis and interpretations and the major findings of the present study with other studies under the following sections:

PART A: Socio-demographic and clinical profile

PART B

Objective 1: To assess the level of burden among the caregivers of Chronic Kidney Disease (CKD) patients.

PART A

Socio-demographic profile of caregivers: There were a total of 100 caregivers purposively selected from the dialysis ward of DMC and Hospital. Most of the caregivers were in the age group of 39 - 59 years old, with mean age of 45.64 ± 15.35 (years \pm SD) and more than half were female. Moreover, most of the caregivers were residing in urban areas and around half followed the Hindu religion. Also, most of the caregivers were married with graduation and above level of education. Lastly more than half of the sample belonged to lower middle class.

Similarly, Nirmalasari Novita, Sari W Wuri Ike (2022) conducted a study to assess the burden among the caregivers of CKD patients. On 60 family caregivers of hemodialysis patients who were chosen using a purposive technique, a cross-sectional study was carried out in May 2021 in Indonesia. Descriptive and bivariate analysis were used to analyze the data. Of the participants, 65% (n=39) were female, 83.3% (n=50) were married, and 63.3% (n=38) were working. The results showed that hemodialysis patients' caregivers bear a heavy burden. Unlikely Nagarathnam. M Sivakumar Vishnubotla, Latheef A.A.S (2019) conducted a study on caregivers of renal transplant patients from Southern Andhra Pradesh, India, who participated in a prospective study. This study comprised 50 caregivers in all. This study's data were gathered utilizing a two-section questionnaire. The Zarit Burden interview is one of the tools used in the second section to measure burden. Of the participants, the majority of the caregivers, 20(66.66%), were males. With respect to education, the majority of caregivers 10, 33.33% were primary school educated, and 19(63.33%) were unemployed.

Clinical profile of the patient: In the present study, majority of the patients 90% had stage 5 of CKD, and moreover the frequency of dialysis visits (in a week) in majority of patients i.e. 69% was twice a week. With respect to co-morbidities, the majority of patients i.e. 67%

had co-morbidities. The most prevalent co-morbidity present in patients was hypertension i.e. 44(65.6%). Furthermore majority of patients i.e. 58% had intra-dialytic complications. Among them the most common complication i.e. 16(27.5%) was blood pressure fluctuation. Also 60% of had post dialytic complications. About 51(85%) of patients had generalized weakness after dialysis. Similarly Sudhakar Vaishnavi ,R .Deepthi , Vaibhavi (2021) conducted a cross sectional study among caregivers of hemodialysis patients at ESIC - MC & PGIMS hospital. A study sample of 86 was selected using simple random sampling methods. When characteristics of disease among patients were studied duration of dialysis 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.

Unlikely Mashayekhi Fatemeh ,PilevarzadehMotahareh , Rafati Foozieh (2015) conducted a descriptive study in 2014 to assess caregiver burden in the caregivers of patients undergoing hemodialysis in two government hospitals in southern Iran. A total of 69 patients were under hemodialysis. The results showed that most of the patients i.e. 44(86.3%) had a weekly dialysis frequency of 3 times. Also majority of the patients i.e. 25(49%) had diabetes.

PART B

Objective 1 : To assess the level of burden among the caregivers of Chronic Kidney Disease (CKD) patients: Findings of present study revealed that the total mean burden score was 35.17 ± 16.22 in which majority 45% of the caregivers had mild to moderate level of burden ,33% had moderate to severe level of burden , 18% had no to mild level of burden and rest of 4% had severe level of burden.

A similar study was conducted by Chhetri Khatri Srijana , Baral Rojina to assess the level of burden among caregivers of hemodialysis patients . Simple random sampling technique was used. The study revealed that majority 60 (48.78%) had mild to moderate level of burden while 53 (43.08%) had moderate to severe level of burden. The median scores of burden among caregivers was (39.30 ± 11.68) with 44.65%. Unlikely Joseph S.J , Bhandari S.S , Dutta S , khatri D, Upadhyay A (2021) conducted a hospital based cross sectional study at the hemodialysis unit of Sikkim Manipal Institute of Medical Sciences (SMIMS) and Sir Thutob Namgyal memorial hospital, Gangtok ,Sikkim , India. This study was done from March 2016 to march 2017. A total of 51 caregivers between the age of 18 to 65 years of age from two dialysis unit in Sikkim were assessed cross - sectionally. The Zarit caregiver burden scale was administered to measure the caregiver burden. 68.6% of caregivers had mild to severe levels of caregiver burden. Female gender, older caregivers, and caregivers attending patients with a longer history of hemodialysis reported a more severe burden.

Objective 2: To find out the association of burden among the caregivers of Chronic Kidney Disease (CKD) patients with their selected socio-demographic variables.

In the present study ,it is revealed that all socio demographic variables such as age, gender, religion, educational status, habitat, type of family, occupation, relationship with patient, marital status, duration of care and socio –economic status did not show statistical significant associations ($p > 0.05$). A similar study was conducted by Pio T M Theresia ,Prihanto Budi Junaidi , Jahan Yasmin, Hirose Naoki, Kazawa Kana, Moriyama Michiko et al. (2022) conducted a descriptive ,cross sectional study from September to October 2020. A total of 104 caregivers with mean age of 44.4 12.7 years in the hemodialysis department of a hospital in Indonesia were examined. Zarit Burden Interview (ZBI), hospital anxiety and depression scale and WHOQOL - BREF were used. The study revealed that the socio-demographic variables were not associated with the level of burden among the caregivers. Unlikely Sharma Maneesh, Lakhara Pooja, Sharma Rakesh , Jelly Prasuna, Sharma , K Suresh (2020) in their study found a significant association of caregivers burden with various socio-demographic variables. Results had found that female

caregivers, those of middle age , with lower educational level , unemployed or low income families experience higher levels of burden . Longer duration of caregiving increases the frequency of dialysis , hence increases the overall burden .

CONCLUSION

The present study concluded that most of the caregivers of patients visiting the dialysis unit of tertiary care hospital had mild to moderate level of burden among them. All the socio demographic variables in the study showed no association with the level of burden. Given that caregivers experience a mild to moderate level of burden , interventions or support systems could be developed to help alleviate this burden , potentially improving caregiver well being and patient care.

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LIST OF ABBREVIATIONS

| | |
|-------|--|
| * | Multiple Response |
| ANOVA | Analysis Of Variance |
| ALD | Acute Liver Disease |
| ESRD | End-stage renal disease |
| CKD | Chronic Kidney Disease |
| DMC&H | Dayanand Medical College and Hospital |
| df | Degree of Freedom |
| ESRD | End-stage renal disease |
| f | Frequency |
| HOD | Head Of Department |
| IEC | Information Education and Communication |
| LVEF | Left Ventricular Ejection Fraction |
| NS | Non Significant |
| N / n | Sample Size |
| p | Level of Significance |
| SD | Standard Deviation |
| SPSS | Statistical Package ForThe Social Sciences |
| UTI | Urinary Tract Infection |
| ZBI | Zarit Burden Interview |

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