IJRAR.ORG E-ISSN: 2348-1269, P-ISSN: 2349-5138

INTERNATIONAL JOURNAL OF RESEARCH AND ANALYTICAL REVIEWS (IJRAR) | IJRAR.ORG

An International Open Access, Peer-reviewed, Refereed Journal

A STUDY TO ASSESS THE BURDEN AND RESELIENCE AMONG CAREGIVERS OF PATIENTS WITH CHRONIC KIDNEY DISEASE UNDERGOING HEMODIALYSIS IN ASTER MIMS CALICUT

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ABSTRACT

Background: Chronic kidney disease is a major health issue around the globe due to its increasing prevalence. Caregivers of patients with CKD are often required to take on multiple responsibilities and tasks while caring for patients. Caregiver burden typically manifests as high rates of psychological distress, mental health diagnoses, fatigue, sleep disturbances and suicide attempts. Resilience is a construct that concerns the human being's capacity to respond positively to the adverse situations an individual faces, even when these pose a potential risk to his/her health or development.

Research Question: 1. What is the level of caregiver burden on primary caregivers of chronic kidney disease patients? 2. How resilient are primary caregivers of patient with chronic kidney disease?

Objectives: 1**.** Assess the burden of caregivers of patients with CKD. 2. Assess the resilience among caregivers of patients with CKD. 3. Find the correlation between burden and resilience of caregivers of patients with CKD. 4. Find the association between burden of care givers with demographic variables. 5.Find the association between resilience of caregivers with demographic variables.

Methodology: The research design used for this study was descriptive correlational study. The research approach used in this study was Quantitative research approach. In this study, population refers to the caregivers of patients with chronic kidney disease undergoing hemodialysis at ASTER MIMS Hospital, Calicut. The sample size is 100.

Result: The study findings showed that caregivers of CKD patients undergoing hemodialysis experienced varying levels of burden. Among the participants, 43% reported no to mild burden, 45% had mild to moderate burden, 10% experienced moderate to severe burden, and 2% had severe burden, with a mean ZBI score of 1.71. In terms of resilience, the majority (67%) of caregivers exhibited normal resilience, while 32% demonstrated low resilience and only 1% reported high resilience, with a mean BRS score of 1.69. A Pearson correlation analysis revealed a moderate, negative, and statistically significant relationship between burden and resilience ($r = –0.396$, $p < 0.01$), suggesting that higher caregiver burden was associated with lower resilience. Analysis of associations showed that burden was not significantly related to most demographic and clinical variables. Also resilience was significantly associated with place of residence ($p = 0.023$) and current treatment ($p = 0.042$), while other variables showed no significant association.

Discussion: The findings indicate that nearly half of the caregivers experienced mild to moderate burden, reflecting the physical, emotional, and social demands of caring for CKD patients on hemodialysis. This aligns with previous studies where caregivers often reported moderate burden, influenced by the chronic and demanding nature of dialysis treatment. Despite the burden, most caregivers in this study maintained normal resilience, though a considerable proportion still demonstrated low resilience, pointing to a need for interventions that strengthen coping mechanisms. The negative correlation between burden and resilience suggests that as stress and caregiving responsibilities intensify, caregivers' ability to adapt and cope diminishes. Interestingly, caregiver burden showed no significant association with socio-demographic and clinical characteristics. However, resilience was influenced by contextual and treatment-related factors such as place of residence and current treatment modality, highlighting that environmental support and medical management may play a role in enhancing caregivers' coping abilities. Overall, the findings emphasize the importance of targeted support strategies, such as counselling, educational programs, and community-based resources, to reduce caregiver burden while fostering resilience.

CHAPTER 1
INTRODUCTION

Background of the study

"It is not how much you do, but how much love you put in the doing "

~ Mother Theresa.

Hemodialysis imposes a variety of physical and psychosocial stressors that challenge not only the patients but also the caregivers. Long-term caregiving for any chronic and incurable illness, especially CKD, on a day-to-day basis ultimately results in step-by-step progression of frustration and exhaustion which gives rise to physical and psychological illness. Failure to recognize, identify, and address the issues of caregivers will ultimately decrease the quality of living of the patients and also the health of the caregivers. Hence, it is of utmost importance to provide support and service to caregivers.[1]

Frequent hospitalizations of the patients and factors associated with the disease can lead to reduction of caregiver's quality of life. Additional factors associated with burden include the relationship between caregiver and patient, behavioral, psychological symptoms displayed by the patient, gender and adverse life events. These difficulties impose a substantial burden on those directly responsible for giving care, especially for family members. Despite such challenges caregivers often receive little attention and the main focus is on the patient. The concept of 'caregiver burden' has thus been used to capture the physical and psychological impact faced by the caregivers.[2]

Resilience among caregivers of patients with chronic kidney disease plays a crucial role in maintaining both their emotional well-being and caregiving effectiveness. These caregivers often face long-term physical, emotional, and financial challenges due to the demanding nature of the disease and its treatments, such as dialysis. Despite these stressors, many caregivers demonstrate remarkable resilience, drawing on personal strengths, social support systems, and coping strategies to adapt and continue providing care. Building resilience not only helps them manage daily caregiving tasks but also reduces the risk of burnout and improves their overall quality of life. Strengthening resilience through counseling, support groups, and education is essential for sustaining caregiving over the long term.[3]

Chronic kidney disease is characterized by the presence of kidney damage or an estimated glomerular filtration rate (eGFR) of less than 60 mL/min/1.73 m^2, persisting for 3 months or more. CKD involves a progressive loss of kidney function, often leading to the need for renal replacement therapy, such as dialysis or transplantation. The 2012 Kidney Disease: Improving Global Outcomes CKD classification considers the underlying cause and categorizes CKD into 6 stages of progression and 3 stages of proteinuria based on glomerular filtration rate and levels of albuminuria. Although the causes of CKD vary, certain disease processes exhibit similar patterns.[4]

Hemodialysis (HD) is a technique that is used to accomplish the extracorporeal removal of waste substances such as urea, creatinine and free water from the blood when kidneys are in a state of failure. Patients undergoing hemodialysis have multiple problems, such as retention of water and sodium, anemia, hypertension, and heart disease. These patients are not only treated for problems associated with hemodialysis, such as atherosclerosis, left ventricular hypertrophy and secondary hyperparathyroidism, but also for changes in self-perception, self-care, confidence and sometimes for reversal of roles in the family. They also faces psychological issues such as anxiety, stress, social isolation, sleep disturbances, fear of death and so on. When a patient starts dialysis treatment, his life will be thoroughly changed, he should attend the dialysis session regularly, modify anything he eats or drinks, and use prescribed drugs. Dialysis is required for treatment when patient sustain enough kidney damage and moves into the 5th or final stage of Chronic Kidney Disease (also referred as Chronic Renal Failure or End Stage Renal Disease). In 1861 Thomas Graham coined the word dialysis and laid the foundation ground work also he developed the foundational principles and apparatus for dialysis. The first successful dialysis was done by Dr. William Johan Koff in 1945.[5]

In March 2025 qualitative study in Palestine underscores the multidimensional burden experienced by caregivers of end stage renal disease patients, shaped by emotional strain, systemic healthcare barriers, and logistical challenges including travel and rigid dialysis schedules. Complementary randomized trials in Iran (late 2024) demonstrate that targeted psychoeducational interventions like stress management training and peer-support groups can meaningfully reduce perceived stress and overall caregiving burden. However, persistent financial and economic pressures often remain unaddressed by these programs, confirming that comprehensive support spanning emotional, educational, and fiscal domains is essential for mitigating the burden on caregivers of chronic kidney disease patients.[6]

Caregivers of patients undergoing hemodialysis play a crucial and often demanding role in supporting the patient's physical, emotional, and practical needs. They assist with transportation to dialysis sessions, medication management, diet restrictions, and monitoring the patient's symptoms, while also providing continuous emotional reassurance. The long-term nature of dialysis can place a significant burden on caregivers, leading to fatigue, stress, and emotional strain as they balance their own responsibilities with the patient's needs. Despite these challenges, caregivers remain an essential part of the patient's support system, helping them cope with the limitations of chronic kidney disease and improving their overall quality of life.[7]

Need and significance of the study.

One of the global public health problems affecting 5-10% of world population in general is Chronic Kidney Disease. Chronic Kidney Diseases are evolving as a most important health threat. The people suffering from kidney diseases finally require an expensive and lifelong Renal Replacement Therapies. Patients who suffer with CKD have to be taken care at home for a longer time before Kidney Transplantation and they depend on intermittent dialysis and drugs to maintain optimum health. Also the caregivers

commonly face a variety of challenges while caring for the patients, including issues related to day-to-day responsibilities, psychological stress, financial strain, social difficulties, physical demands, spiritual concerns, and travel-related burdens.

Caregiver burden is a significant issue in the care of patients with advanced kidney disease. Its assessment is crucial for evaluating the needs of caregivers and for the development of interventions to support them. Several instruments have been developed to measure caregiver burden in these patients.[8]

1. Increasing Burden of Chronic Kidney Disease and the Role of Caregivers

CKD is a global health crisis with an increasing prevalence, particularly due to the rise in lifestyle diseases such as diabetes and hypertension. According to the Global Burden of Disease Study (2019), CKD affects over 700 million people worldwide, and its incidence continues to increase as the population ages. As CKD progresses, patients often require intensive management, including dialysis, transplantation, and long-term medication. This increases the caregiving burden on families and loved ones who provide hands-on care, emotional support, and assist with medical management.[9]

2. Caregiver Burden and Health Consequences

Caregivers of patients with CKD are at risk for emotional, physical, and financial burdens. Research indicates that caregiver burden in chronic diseases like CKD is associated with higher levels of psychological distress. Caregivers experience higher levels of anxiety, depression, and fatigue compared to non-caregivers. This can lead to chronic stress, which is linked to adverse physical health outcomes, such as hypertension, weakened immune function, and increased susceptibility to chronic diseases. Caregiver burden can also result in reduced quality of life for caregivers. In CKD, this burden is compounded by the complexity of managing medical treatments such as dialysis, which demands significant time and efforts. As the disease progresses, caregivers may experience even higher levels of burden.[10]

3. Psychological Impact on Caregivers

The psychological distress faced by caregivers is substantial, with many reporting feelings of guilt, stress, and emotional exhaustion. This emotional burden is heightened by the perceived lack of control over the patient’s health, which can exacerbate feelings of helplessness. Additionally, the need for constant monitoring, assistance with personal care, and frequent hospital visits can result in caregiver burnout. Studies highlight that caregivers’ mental health is significantly affected, leading to increased levels of depression and anxiety. These mental health issues, if left unaddressed, can negatively influence the quality of care provided to CKD patients.[11]

4. Resilience as a Coping Mechanism for Caregivers

While the burden of caregiving is significant, many caregivers show resilience, adapting to their situation and finding ways to manage the challenges they face. Resilience refers to a caregiver's ability to adapt to adversity and maintain their well-being despite the stresses associated with caregiving. Research has shown that coping strategies, such as emotional regulation, social support, and problem-solving skills, can enhance caregivers' resilience and reduce the negative impact of caregiving. [12]

5. Financial Strain on Caregivers

The financial burden on caregivers of CKD patients is significant. Caregivers often have to reduce their working hours or even quit their jobs to care for a loved one, leading to lost income and increased financial stress. In addition to the direct costs of caregiving (e.g., transportation, medical expenses), the indirect costs, such as the caregiver's lost productivity, can be substantial. Financial stress is a major factor contributing to the overall burden caregivers face and can further exacerbate their psychological distress. [13]

6.Importance of Support Systems and Interventions

Support systems, such as caregiver support groups, psychoeducation and respite care, are essential in mitigating caregiver burden and fostering resilience. Social support from family, friends, and the community has been shown to buffer the negative effects of caregiving on mental and physical health. Interventions aimed at improving caregivers' coping skills, reducing stress, and enhancing resilience can lead to better health outcomes for both the caregiver and the patient. Healthcare providers need to recognize the impact of caregiving and offer multidimensional support to caregivers, including access to mental health services, financial resources and respite care. [14]

Considering the above factors, the investigator felt that there is a need to assess the burden and resilience of caregivers of patients with chronic kidney disease undergoing dialysis in Aster Mims Hospital, Calicut.

Statement of the problem

A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis in ASTER MIMS hospital, calicut.

Research Question

What is the level of caregiver burden of primary caregivers of chronic kidney disease patients?

How resilient are the primary caregivers of patients with chronic kidney disease?

Aims

The study aims to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis.

Objectives

1. Assess the burden of caregivers of patients with CKD.
2. Assess the resilience among caregivers of patients with CKD.
3. Find the correlation between burden and resilience of caregivers of patients with CKD.
4. Find the association between burden of care givers with demographic variables.
5. Find the association between resilience of caregivers with demographic variables.

Operational definitions

Burden

Burden refers to the measurable level of physical, emotional, social, and financial stress experienced by a caregiver, as assessed through their responses to a structured questionnaire. It is quantified by the total score on the ZBI, where higher scores indicate greater perceived caregiver strain.

Resilience

It refers to the care giver's ability to adapt and persist through challenging circumstances or situations while caring for a family member with CKD undergoing hemodialysis which will be measured using Brief resilience Scale [BRS].

Care Giver

Those who are related to the patients with chronic kidney disease by birth, marriage or adoption who stayed 7 or more days with patient during all aspect of care to a person with CKD.

CKD Patients

It refers to the patients who have been diagnosed as CKD and undergoing dialysis.

Assumptions

1.Caregivers of patients with chronic kidney disease undergoing hemodialysis will have various physical, emotional and social burden.

2.Caregivers of patients with chronic kidney disease undergoing hemodialysis will have decreased resilience.

Hypothesis

H0 – There will be no significant relationship between caregiver burden and resilience with selected demographic variables.

H1 - There will be significant correlation between caregiver burden and Resilience among caregivers of patients with CKD undergoing Hemodialysis

H2 - There will be significant association between burden of care givers and demographic variables.

H3- There will be significant association between Resilience of care givers and demographic variables.

Conceptual framework

The theoretical framework used in the study is Roy's adaptation model. Roy considers the recipient of care to be an open, adaptive system. It reacts to and interact with each other systems in the environment. In Roy's system, input is identified as stimuli which can come from the environment or from within a person. Coping mechanisms are the behaviour patterns that a person uses for self-control. These are the subsystems of the person's adaptive system. These subsystems have four adaptive modes such as physiological, self-concept, interdependence and role function. They are interrelated to form a complex for the purpose of adaptation. Relationships among the four adaptive modes occur when internal and external stimuli affect more than one mode or when disruptive behaviour occurs in more than one mode. In Roy's system, output is categorized as adaptive and inefficient responses. These responses provide feedback for the system.

1.STIMULUS

Stimulus is any factor, event, or demand that triggers stress or strain on the caregiver. These are the starting points that challenge their resilience**.** Examples include taking care of a patient with CKD undergoing hemodialysis, high treatment and hospital expenses, fear of patient's health worsening, regular checkups and dialysis schedules disrupting caregiver's routine, dependence on caregiver for daily activities, diet, and medication.

2.FEEDBACK

Feedback refers to the continuous loop of interaction between the caregiver and the caregiving situation. The caregiver's responses (adaptive or maladaptive) influence how they perceive and manage future challenges. If a caregiver learns coping skills and gets social support, they may adapt better (positive feedback). On the other hand, constant stress without support may worsen their burden, creating negative feedback.

3.ADAPTIVE MODES

i. Physiological

Refers to the physical effects of stress and caregiving on the caregiver's body and health. Examples include, Continuous caregiving with little rest, long-term stress leading to physical and emotional depletion, constant tiredness from juggling multiple responsibilities, sleep disturbance: Caregiver may stay awake due to worry or patient's needs.

ii. Self-concept

Self-concept refers to the caregiver's perception of themselves and their emotional state while providing care. It reflects their inner world. Examples include feeling overwhelmed by constant responsibility, worry about patient's health outcomes, and future, concern about patient's death, complications, or financial instability, caregiver ignores own health, diet, or rest due to prioritizing the patient.

iii. Interdependence

This describes how caregiving affects the caregiver's social connections and relationships. It highlights dependency and support systems. Examples include limited time for friends/social life due to caregiving duties, fear of losing financial stability or support, caregivers may avoid gatherings due to lack of time or emotional strain.

iv. Role function

This refers to how caregiving alters the caregiver's roles and responsibilities in family, social, and professional life. Examples include neglecting spouse/children due to patient care, missing social functions or community activities,

reduced productivity, absenteeism, or even job loss because of caregiving duties.

4.RESPONSE

Response refers to how the caregiver reacts to the stimuli and challenges, which may be adaptive or maladaptive. The types are adaptive (high resilience), maladaptive (low resilience).

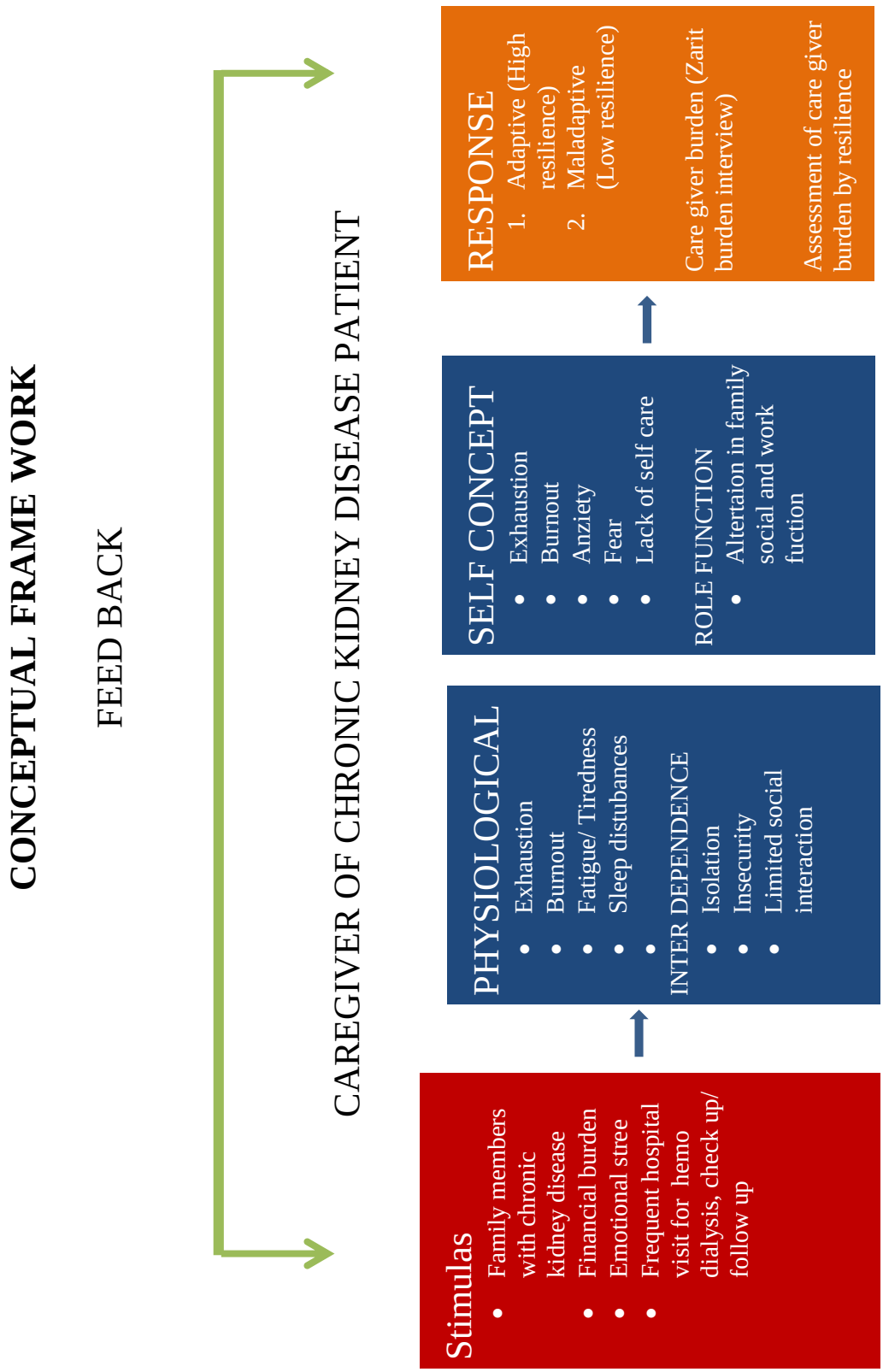

Figure 1; Conceptual frame work of the study

REVIEW OF LITERATURE

Review of literature related to burden of caregivers

1.The relationship between care burden and quality of life in caregivers of hemodialysis patients. Haleh Jafari, Azita Ebrahimi, Abbas Aghaei and Alireza Khatony.

A descriptive analytical study was conducted in hemodialysis centers in Imam Reza and Imam Khomeini hospitals of Kermanshah-West of Iran. 246 samples were selected in the study using census method. The study tool was a three-part questionnaire, which included personal information, Novak & Guest Care burden Questionnaire, and WHOQOL-BREF Quality of Life Questionnaire. In total, 37.4% of caregivers were experiencing high and very high levels of care burden and 42.7% of them were experiencing a moderate level of care burden. The mean and standard deviation of the quality of life of caregivers was 76.27 ± 13.67 out of 130. There was a significant and negative correlation between the total scores of care burden and quality of life

($r = -0.436$, $P < 0.001$).[15]

2.The Burden of Caregivers of Patients Undergoing Hemodialysis Maneesh Sharma, Pooja Lakhara, Suresh Kumar Sharma, Prasuna Jelly, Rakesh Sharma.

A cross-sectional study was conducted at a tertiary care hospital in the northern part of Uttarakhand, India, to determine the perceived burden of hemodialysis patients' caregivers. A sample of 110 were selected using the purposive sampling technique. The Mean±SD age of caregivers was 37±13 years. Nearly half of caregivers, 50 (45.46%), reported mild to moderately burdened, while 15 (13.63%) caregivers had moderate to severely burdened. There was no significant association between the levels of burden scores and selected sociodemographic variables of the participants.[16]

3.Peer support groups and care burden in hemodialysis caregivers: a RCT in an Iranian healthcare setting. Nader Ghenaati, Hamid Reza Zendehtalab, Masoud Zare.

A parallel-controlled clinical trial was conducted involving 60 caregivers, divided into intervention and control groups. The intervention group participated in an 8-session peer support program tailored to their identified needs, including coping with stress, social isolation, and financial challenges. The Zarit Care Burden Interview Scale was used to measure care burden before and after the intervention. The study revealed statistically significant reductions in care burden, particularly in physical, social, and emotional dimensions, among caregivers in the intervention group compared to the control group. The total care burden score showed a marked decrease, indicating the effectiveness of the peer support intervention. While economic challenges remained a concern, the intervention had a limited impact in this domain.[17]

4.Caregiver Burden Among Families of Hemodialysis Patient: a Cross-Sectional Study. Novita Nirmalasari, Faculty of Health, Universitas Jenderal Achmad Yani Yogyakarta and Ike Wuri Winahyu Sari, Faculty of Health, Universitas Jenderal Achmad Yani Yogyakarta.

This study was a cross-sectional study conducted in May 2021 on 60 family caregivers of hemodialysis patients selected using a purposive sampling technique. Semi structured questionnaires were used to measure socio-demographic. The Caregiver Reaction Assessment-Indonesian Version (CRA-ID) was used to measure their burden. Data were analyzed using descriptive analyzes and bivariate analyzes. The analysis showed that the mean overall burden score with CRA-ID was 2.88Â±0.69 (ranging 1.00 to 5.00). The highest burden was the lack of family support dimension of 3.47Â±0.42. Caregiver burden among caregivers of patients on hemodialysis showed that the variables related to family burden were age, an education level, and family income (p-value<0,05).[18]

5.An analysis of caregiver burden of patients with hemodialysis and peritoneal dialysis. Işın Cantekin, Mehtap Kavurmacı, Mehtap Tan.

A descriptive study was conducted with the family caregivers of 114 patients from Erzurum Ataturk University's Medical Faculty Nephrology Department to determine the burden to primary caregivers of patients undergoing dialysis: 54 were relatives of patients receiving hemodialysis and 60 were relatives of patients receiving peritoneal dialysis during August to December. The percentage of the patients with low levels of caregiver burden is 13% in the hemodialysis group, while it is 35% in the peritoneal dialysis group. These findings are statistically significant. To conclude, chronic diseases affect not only patients, but also their relatives who care for them. Nursing care needs to include both patients and their relatives and support them.[19]

6.Care burden of caregivers of hemodialysis patients and related factors. Ozlem Cagan, Alaettin Unsal, Nese Celik, Aysun Ture Yilmaz, Ilkay Culha, Hulya Kok Eren

A cross-sectional study conducted on primary caregivers of patients receiving treatment at three private hemodialysis centers in Eskisehir city center between January 15 and May 1. This study included 163 caregivers. This study was conducted to examine the burden of caregivers of hemodialysis patients and some related variables. 109 (66.9%) were female and 54 (33.1%) were male. Their ages ranged from 23 to 87 years, with a mean of 52.2±12.8 years. The scores obtained with the Zarit Caregivers Burden Scale varied from 0 to 82, with a median score of 46.9. In the study group, we found a higher burden of care in female caregivers and in those who were being employed by an income-generating job, 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 ($p < 0.05$ for each).[20]

7.Caregiver burden among family caregivers of older patients receiving hemodialysis and its relevant factors. Mojtaba Senmar, Hossein Rafiei, Fateme Yousefi, Ali Razaghpoor, Mohammad Bokharaei.

A descriptive analytical study was done using 52 caregivers of elderly patients receiving hemodialysis. Data collection was carried out using a researcher made demographic variables checklist and Novak and Guest Caregiver Burden Inventory (CBI). The mean age of caregivers' patients was 72.4 years. The mean total score of care burden was 57.9±20.1. Totally, 23.1%, 51.9% and 25% of the subjects had mild, moderate and severe level of burden respectively. Caregiver of ages, age of the elderlies and relationship status were effective factors on caregiver's burden ($P<0.05$).[21]

8.Burden among caregivers of patients on hemodialysis in a tertiary care hospital. Bonthu Srinitha, Dr. Manjusha Yadla, Dr. B. Vikram kumar, Dr. Sreekanth Burri, Dr. P. Srinivas.

A descriptive cross-sectional study among 100 caregivers of haemodialysis patients was done. Care givers of patients undergoing hemodialysis for atleast 3 months were included in the study after taking consent and following variables were assessed. Socio-demographic variables like age, gender, relationship to the patient, income and duration of illness were noted. Level of burden was evaluated using Zarit burden questionnaire. In this study moderate to severe burden is observed in female caregivers. Longer the duration of illness, more is the caregiver burden. Study concluded that attention should be paid to needs of caregivers to provide adequate social, economic, physical and psychological support.[22]

9.The assessment of caregiver burden in caregivers of hemodialysis patients. Fatemeh Mashayekhi, Motahareh Pilevarzadeh, Foozieh Rafati

A is a cross-sectional analytical descriptive study that was conducted on 65 caregivers of hemodialysis patients. Research instruments were consisted of two parts: demographic data check list and caregiver burden questionnaire. Data were analyzed by SPSS statistical software and Pearson correlation coefficient tests. A p value of less than 0.05 was considered statistically significant. In this study, 72.5% of caregivers reported moderate to severe levels of caregiver burden. A significant relationship was observed between gender of the patient with caregiver burden score of ($p=0.031$) and type of the income with caregiver burden score of ($p=0.000$). Caregivers of male patients and patients with inadequate income had a higher caregiver burden score.[23]

10.Study of Caregiver Burden in Continuous Ambulatory Peritoneal Dialysis. Shashank Sudarshan Dhareshwar, R. Nithin, Jairam Anantharam, Prashant Kedlaya, Renuka Satish, Kumar Jha, Ramanjit Singh Akal.

A cross-sectional study was conducted among 51 caregivers of Continuous Ambulatory Peritoneal Dialysis patients visiting the dialysis centers from July to August. Caregiver burden score was determined using ZBI method. The mean age of caregivers was 42.8 ± 10.83 years with 52.9% females. The mean Zarit burden score of the caregivers was 29.18 ± 11.81. Younger caregivers experienced significantly higher burden ($r = -0.34$, $P = 0.013$). Lesser educated caregivers were perceiving a higher burden. Lower socioeconomic strata people had significantly higher burden ($P < 0.001$) and especially so when there was a loss in income

attributed to caregiving.[24]

Review of literature related to burden and resilience of caregivers:

1.The mediating effect of family resilience between coping styles and caregiver burden in maintenance hemodialysis patients: a cross-sectional study. Qianjun Zhang, Qiaoling Liu, Li Zhang, Yabin Jin, Xia Xiang, Xuefang Huang, Jiezhen Mai, Tingfen Zhao and Wen Cui.

The study was a cross-sectional and descriptive-analytical study that interviewed 173 pairs of hemodialysis patients and their caregivers at a blood purification center in a public hospital in China. A convenience sample of Maintenance Hemodialysis patients and their primary caregivers was conducted from September to October at the Hemodialysis Center of Foshan First People's Hospital in China. Coping styles showed a significant positive correlation with family resilience ($r=0.347$, $P<0.01$) and a negative correlation with caregiver burden ($r = -0.379$, $P<0.01$).[25]

2.Burden and resilience in caregivers of patients on maintenance hemodialysis, Jomon Joy, Hussain Khan T. J, Pretty M. Abraham, Sreedas Gopalakrishnan.

Study was conducted in the Dialysis unit under Department of Nephrology, Travancore Medical College, Kollam. A cross sectional observational study was done in dialysis unit of medical college Kollam, 120 caregivers of patients diagnosed as having End Stage Renal Disease on maintenance hemodialysis was selected for the study. Zarit Burden Interview was used for assessing caregiver's burden. Brief Resilience Scale was used to assess caregiver's resilience.35.8% of caregivers had severe caregiver burden while looking after dialysis patients while 45% of caregivers had moderate burden. Caregivers showed low resilience about 72.5% which displays poor problem solving and emotion-focused coping strategies.[26]

3.Burden and Resilience among Care Givers of Patients with Chronic Kidney Disease - A Cross-Sectional Study at Government Medical College, Kottayam Shameena Abdullah, P.G. Saji, Ganga Gangadhara Kaimal, K.P. Jayakumar.

A cross sectional study regarding burden among caregivers of patients on hemodialysis was conducted at government medical college Kottayam. The sample of the study consisted of caregivers of 180 patients with chronic kidney disease undergoing maintenance hemodialysis. Specially designed sociodemographic pro-forma, Burden Scale for Family Caregivers (BSFC), Brief Resilience Scale (BRS) were the tools used for the study. The mean age of patients in bystanders with significant caregiver burden was 47.36 years and those with low burden was 48.12 years respectively. Among the 180 care givers, 8.9 % had low burden and 91.1 % had significant burden. Resilience was low in 27.2 % of caregivers, medium in 72.2 % and high in 0.6 % of caregivers. The mean BRS score was 3.81 + 0.473 in low burden group against a BRS score of 3.15 + 0.543 in significant burden group. There was a significant association between caregiver resilience and caregiver burden.[27]

4.The role of peer social support on family psychological resilience in caring for chronic kidney disease patients receiving hemodialysis. Lilik Supriati, Muhammad Sunarto, Ikhda Ulya, Muhammad Rodli, Rendi Yoga Saputra, Renny Nova, Nur Hidaayah.

A cross sectional study was conducted in, engaging 134 families caring for CKD patients receiving hemodialysis Therapy using purposive sampling technique at Lavallette Hospital in Malang City, East Java Province. Patients receiving HD faced mental and health challenges which also affected their families. In Malang city, families played a crucial role as primary caregivers, with the majority of participants having a relationship with CKD patients as spouses (58,2%). Families served as the primary caretaker and provided support for self-management and other necessities. Caring for a chronic disease, particularly CKD comprised managing the demands of the disease and coping with the associated stress. The results showed the majority of families had high resilience (82.83%), attributed to the fact that most of them (63.8%) had been caring for CKD patients for 1-2 years.[28]

Review of literature related to caregiver burden and other associated factors:

1.Stress management training program to address caregiver burden and perceived stress among family caregivers of patients undergoing hemodialysis: a randomized controlled trial study. Ramisa Khouban-Shargh, Seyed mohammad Mirhosseini, Saeed Ghasempour, Mohammad Hasan Basirinezhad & Ali Abbasi

This two-group clinical trial study was conducted in parallel design among 60 family caregivers of patients on hemodialysis. The participants were divided into two groups of training and control using a random quadruple block allocation method. The intervention took place over two months, in six online group sessions of 35–45 min. ZBI and Cohen's Perceived Stress Scale (PSS-14) were used to collect information before and two weeks after the intervention. The study data were analyzed using and analysis of covariance (ANCOVA), pair, and independent t-tests at a significance level of 0.05. Nevertheless, following the intervention, there was a significant decrease in caregiving burden (Training group = 45.9 ± 4.1; Control group = 49.0 ± 5.8; P = 0.017) and perceived stress (Training group = 28.0 ± 4.4; Control group = 30.7 ± 3.5; P = 0.01) scores within the training group compared to the control group.[29]

2.Functional status and caregiver burden of patients on maintenance hemodialysis in Cameroon: a two-Centre cross-sectional study. Alex Tatang Mambap, Innocent Abong Che, Maimouna Mahamat & Gloria Enow Ashuntantang

A Cross sectional study was conducted and consecutively enrolled patients on maintenance hemodialysis at the Bamenda Regional, and Yaounde General Hospitals over a period of 3 months. This study includes patients on Maintenance Hemodialysis for ≥ 3 months and their caregivers. Through a face-to-face interview, Functional status was assessed by combining self-reports of 8 instrumental, and 5 basic activities of daily living using the Lawton-Brody and the Katz (LBKQ) scales, and caregiver burden was assessed using the Zarit Caregiver Burden Scale (ZCGBS). A total of 115 patients and 51 caregivers (CGs) were enrolled. The

mean age of the patients was 46.9 ± 15.0 years, and 54.8% (n = 63) were males, whereas the mean age of the CGs was 38.30 ± 13.10 years with 72.5% (n = 39) being females. A total of 90 (78.3%) patients had functional status impairment (FSI), while 78.4% (n = 40) of caregivers experienced a burden (41.2% classified as moderate, and 37.2% as high. There was a strong positive correlation between functional status and caregiver burden.[30]

3.Experiences of family caregivers of individuals undergoing hemodialysis in Iran about caring during the COVID-19 pandemic: a qualitative study Sima Hejazi, Rezvaneh Manzour, Arezoo Shahsavari, Saeed Ghasemi & Mahdieh Roshan Nejad

This qualitative study was conducted with 17 family caregivers of individuals undergoing hemodialysis in Bojnurd, Iran using inductive qualitative content analysis. The participants were selected using convenience and purposive sampling method with maximum variation. Semi-structured interviews were used in data collection based on the interview guide. The data were analyzed with MAXQDA10. The results culminated in the identification of a main category of the COVID-19 care burden on caregivers and two generic categories including the COVID-19 Overt (financial/constraining) care burden (subcategories: Non-adherence to Health Protocols, COVID-19 Financial Costs, COVID-19 Restrictions and Hemodialysis Appointments, and Decreased Caregiver Support during the COVID-19 Era), and the COVID-19 Covert (emotional/psychological) Care Burden (subcategories: Caregiver's Loneliness in the Care, Stress of Contracting COVID-19, Psychological Consequences of individuals undergoing hemodialysis Staying at Home, The burden of other Individuals' Expectations of the Caregiver, and Physical and emotional pressure on the Caregiver).[31]

4.Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. Oluseyi A Adejumo et al. Ghana Med J. 2019 Sep.

A cross sectional study on burden of caregiving, quality of life, depression, and anxiety were assessed using standardized instruments; modified Zarit questionnaire, modified SF-12 questionnaire and Hospital Anxiety and Depression Scale (HADS) respectively among 57 caregivers of CKD patients on maintenance hemodialysis and controls. Anxiety was significantly higher in caregivers compared to control (31.6% vs 5.3%, p = 0.004). Also, depression was significantly higher in caregivers (31.6% vs 3.5%, p= <0.001). Twenty-eight (49.1%) of the caregivers had mild to moderate burden and 19 (33.3%) had a high burden. The mean Zarit burden score was higher in female caregivers compared to male caregivers (18.30±8.11 vs 14.83±6.70, p = 0.09). The mean depression score was higher in female caregivers compared to male caregivers (8.58±3.83 vs 6.75±3.80, p= 0.08). There was significant positive correlation between Zarit burden and hospital anxiety score (r = 0.539, p=< 0.001) and depression score (r = 0.472, p = 0.005).[32]

5.The relationship between care burden and quality of life in caregivers of hemodialysis patients. Haleh Jafari, Azita Ebrahimi, Abbas Aghaei, Alireza Khatony.

A descriptive-analytical study was conducted. 246 caregivers of hemodialysis patients were enrolled by census method. The study tool was a three-part questionnaire, which included personal information, Novak & Guest Care burden Questionnaire, and WHOQOL-BREF Quality of Life Questionnaire. Data were analyzed by descriptive, statistical and inferential tests. In total, 37.4% of caregivers were experiencing high and very high levels of care burden and 42.7% of them were experiencing a moderate level of care burden. The mean and standard deviation of the quality of life of caregivers was 76.27 ± 13.67 out of 130. There was a significant and negative correlation between the total scores of care burden and quality of life ($r = -0.436$, $P < 0.001$).[33]

6. Caregiver burden and quality of life among family caregivers of hemodialysis patients from South India Azeez, Afina; Ambatipudi, Srikant.

A cross-sectional study was conducted among conveniently sampled, consenting family caregivers (N = 200) of hemodialysis patients in tertiary care dialysis centers in Thiruvananthapuram, Kerala, India, from March 2022 to May 2022. A structured interview schedule was used to collect sociodemographic data from participants. The caregiver burden and quality of life were assessed using the Zarit Burden Interview and the World Health Organization (WHO) Quality of Life (QoL) BREF scale. Univariate and multivariate analyses were performed to determine the association between the variables.

Fifty-eight percent of the caregivers reported caregiver burden. Caregivers with no leisure time (ORadj = 3.29 [95% CI: 1.73–6.41]), perceived financial stress (ORadj = 2.27 [95% CI: 1.16–4.49]), and having comorbidities (ORadj = 2.92 [95% CI: 1.43–6.12]) had an increased odds of experiencing caregiver burden. The CB score was inversely correlated with all domains of QoL. Moreover, the QoL score was lower among family caregivers with caregiver burden than those without caregiver burden.[34]

CHAPTER 2

METHODOLOGY, RESULTS, DISCUSSION

This chapter deals with the research methodology adopted in the study, results of the study and discussions. It includes research approach, research design, variables, schematic representation of the study, setting of the study, population, inclusion and exclusion criteria, sample and sampling techniques, tools used, development or selection of the tool, description of the tool, content validity, reliability of the tool, pilot study, data collection process, plan for data analysis, section wise presentation of data, results and discussions.

Objectives

1. Assess the burden of caregivers of patients with CKD.
2. Assess the resilience among caregivers of patients with CKD.
3. Find the correlation between burden and resilience of caregivers of patients with CKD.
4. Find the association between burden of care givers with demographic variables.
5. Find the association between resilience of caregivers with demographic variables.

Research approach:

The present study is aimed to evaluate the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis.

The research approach used in this study was Quantitative research approach.

Research design:

The research design used for this study was descriptive correlational study.

Variables:

Research variables: Burden and Resilience of caregivers of patients with chronic kidney disease undergoing hemodialysis.

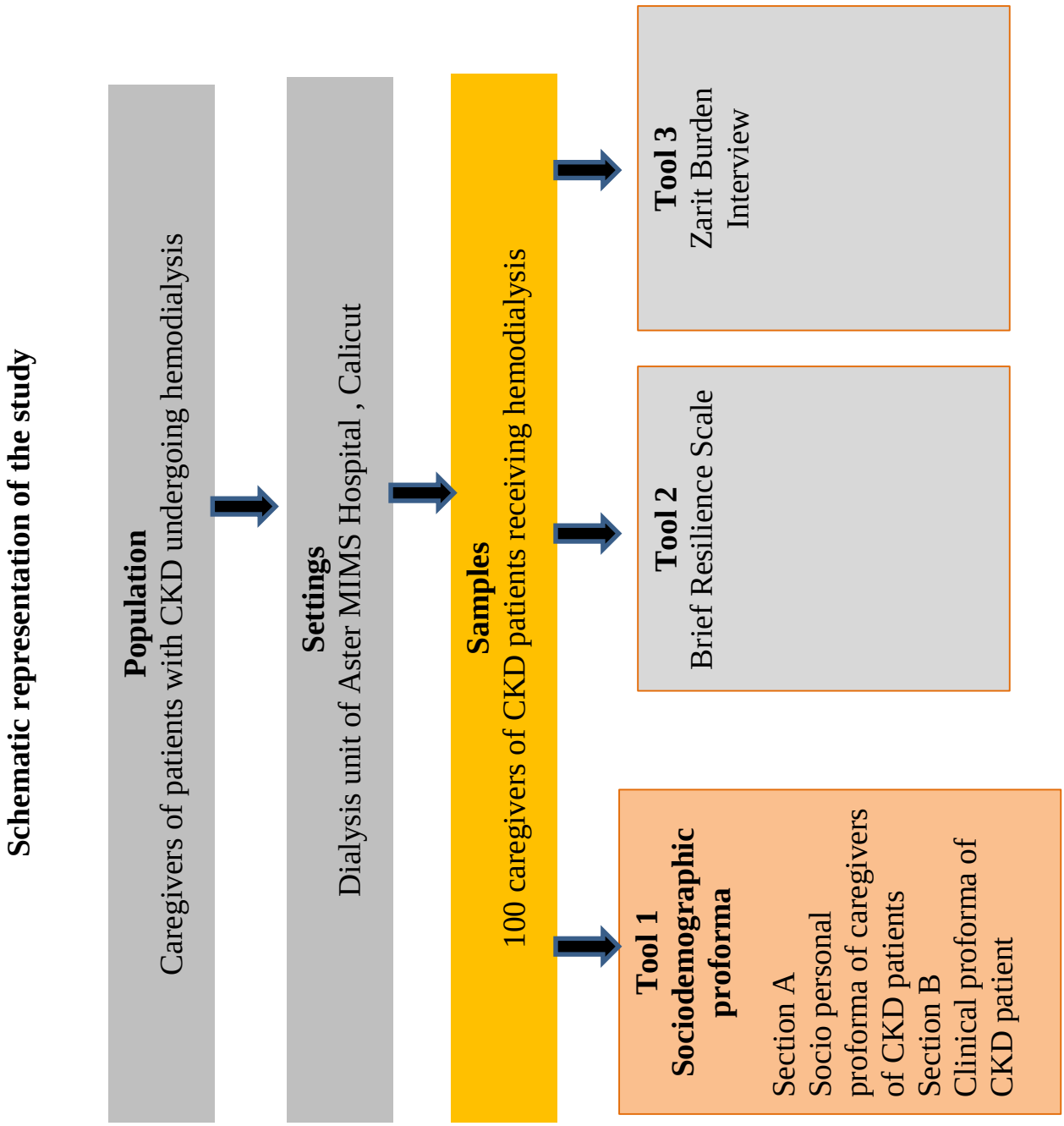

Figure 2; schematic representation of the study

Setting of the study:

The setting of the study is hemodialysis unit of ASTER MIMS Hospital, Calicut.

Population of the study:

In this study, population refers to the caregivers of patients with chronic kidney disease undergoing hemodialysis at ASTER MIMS Hospital, Calicut.

Inclusion criteria:

- Caregivers of age between 18 and 65 years.
- Caregivers of CKD patients undergoing hemodialysis for more than 3 months.
- First degree relative of the patient.
- Caregivers who spent a minimum of 2 hours per day for caregiving for at least 1 month.
- Caregivers of CKD patients in dialysis unit and other wards

Exclusion criteria:

- Caregivers unable to comprehend or replay to the questions.
- Caregivers who are critically ill.
- Caregivers who are not willing to participate.

Sample and Sampling technique Sample

In this study, samples were caregivers of patients with chronic kidney disease undergoing hemodialysis in the dialysis unit of ASTER MIMS Hospital, Calicut.

Sample size calculation

The overall mean burden score was $\pm$ 11.68 (chhetri et al. 2020)

The following formula is used to compute the size

$$n = \frac{z^2 \times \sigma^2}{d^2}$$

n=94.26, the obtained sample size is rounded as 100

n= required sample size

z= z score (1.96 for 95% confidence interest)

σ= standard deviation (estimated from previous studies)

d= 2.358 with margin of error 6% (6% of 39.30)

$$n = \frac{1.96^2 \times 11.68^2}{2.358^2} = 94.26$$

In order to determine the expected prevalence with a 95% level of confidence and a 6% margin of error, the study included 100 subjects.

Sampling technique

Non-probability purposive sampling technique.

Tool or instruments

Tool for study includes:

Tool-1: Questionnaire for assessing socio demographic information of caregivers and patients.

Tool-2: Brief Resilience Scale [BRS].

Tool-3: Zarit Burden Interview [ZBI].

Development / selection of tool

The following steps were taken for the selection of items and preparation of the research tool.

- Review of research and non- research literature was made in related areas.
- Formal discussion held with teaching experts and their valuable suggestions were utilized for developing the tool.
- Clinical experience of the investigators helped in determining the important areas to be included in the tool.

Description of tool:

Tool-1 sociodemographic proforma

Socio demographic proforma is divided in to section A and B.

Section A: Includes socio personal proforma of caregivers of chronic kidney disease, which consisted of age, gender, education, religion, occupation, marital status, relationship with patient, type of family, place of residence, monthly income in rupees, health insurance.

Section B: Includes clinical Performa of chronic kidney disease patients which consisted of stage of CKD, duration of illness, current treatment, duration of dialysis and details about comorbidities.

Content validity of the tool:

In order to establish content validity, the tool was submitted to 5 experts. After the discussion with the guide, suggestions from the experts were incorporated into the tool and it was finalized.

Tool-2 Brief Resilience Scale [BRS]:

Brief resilience scale is a standardized psychological tool designed to measure a person's ability to bounce back or recover from stress. It was developed by Smith et al. in 2008. It has 6 items. Respondents rate each item on a 5-point scale from 1-strongly disagree to 5-strongly agree. Some items are positively worded and some items are negatively worded. In this higher score indicates higher resilience.

Interpretation:

Average the scores of all six items. Higher scores indicate higher resilience.

1.99-2.99: low resilience
3.00-4.30: normal resilience

4.31-5.00: high resilience

Content validity of the tool:

In order to establish content validity, the tool was submitted to 5 experts. After the discussion with the guide, suggestions from the experts were incorporated into the tool and it was finalized. The content validity index is S-CVI $\geq$ 0.90, I-CVI $\geq$ 0.80(Scale content validity index, item content validity index)

Reliability of the tool

The Brief Resilience Scale has good reliability, with Cronbach's alpha values ranging from 0.80 to 0.91 across studies, and test–retest reliability between 0.62 and 0.80, indicating that it is a consistent and stable measure of resilience.

Tool-3 Zarit Burden Interview [ZBI]:

The Zarit Burden Interview [ZBI] is a standardized tool to assess the caregiver burden meaning the level of stress and strain experienced by the people who care for someone who is chronically ill, disabled or elderly. It is used to measure the emotional, physical, social and financial burden felt by caregivers. Its original version has 22 items. Caregivers responds to each item based on how often they feel a certain way, usually on a 5-point scale. Then the total scores will be added across all items.

Interpretation:

Add all scores across all the items.
0-20: little or no burden
21-40: mild to moderate burden.

41-60: moderate to severe burden

61-88: severe burden.

Content validity of the tool:

In order to establish content validity, the tool was submitted to 5 experts. After the discussion with the guide, suggestions from the experts were incorporated into the tool and it was finalized. The content validity index is Item CVI (I-CVI): 0.80 – 1.00, Scale CVI (S-CVI): 0.90 – 0.96

Reliability of the tool:

Internal consistency reliability has been reported with Cronbach's alpha ranging from 0.79 to 0.91, while test–retest reliability coefficients range from 0.71 to 0.85.

Pilot Study:

After obtaining permission a pilot study was conducted among 10 caregivers of patient with chronic kidney disease undergoing hemodialysis from Aster Mims Hospital, Calicut on 25/7/25.

Data were collected by using tools like socio-demographic proforma, Brief Resilience Scale, Zarit Burden Interview. The main objectives was to assess the feasibility of this study. Pilot study revealed that the tools used in the study were simple, clear and unambiguous. The data collected were amenable for descriptive statistical analysis.

Data collection process

The study began after getting approval from the Institutional Ethics Committee. Also took permission from the Principal of MIMS College of Nursing and from the HOD of the dialysis unit of Aster MIMS Hospital Calicut. The study was conducted among 100 samples. The data were collected from caregivers of CKD patients undergoing hemodialysis by administering the tools consisting of a questionnaire on demographic profile, Zarit Burden Interview [ZBI] to assess the burden of caregivers and Brief Resilience Scale [BRS] to assess the resilience of the patients. Written consent was taken from subjects and assured the confidentiality of the information and anonymity by the researchers.

Plan for data analysis:

- The collected Information will be summarized by using the descriptive Statistics such as Frequency, Percentage, Mean and Standard Deviation.
- Pearson correlation will be used to find the correlation between Burden and Resilience Score
- Chi-square test will be used to find the association of Burden and Resilience Score with demographic variables.

Organization of study findings

Section wise presentation

Section 1-A: socio personal proforma of caregivers of CKD patients.

The data was collected from 100 caregivers of CKD patients undergoing hemodialysis in selected hospital at Calicut using Nonprobability purposive sampling technique. Sample characteristics are explained as frequency and percentage.

Socio personal proforma of caregivers of CKD patients include age, gender, education, religion, occupation, marital status, relationship with patient, type of family, place of residence, monthly income and health insurance.

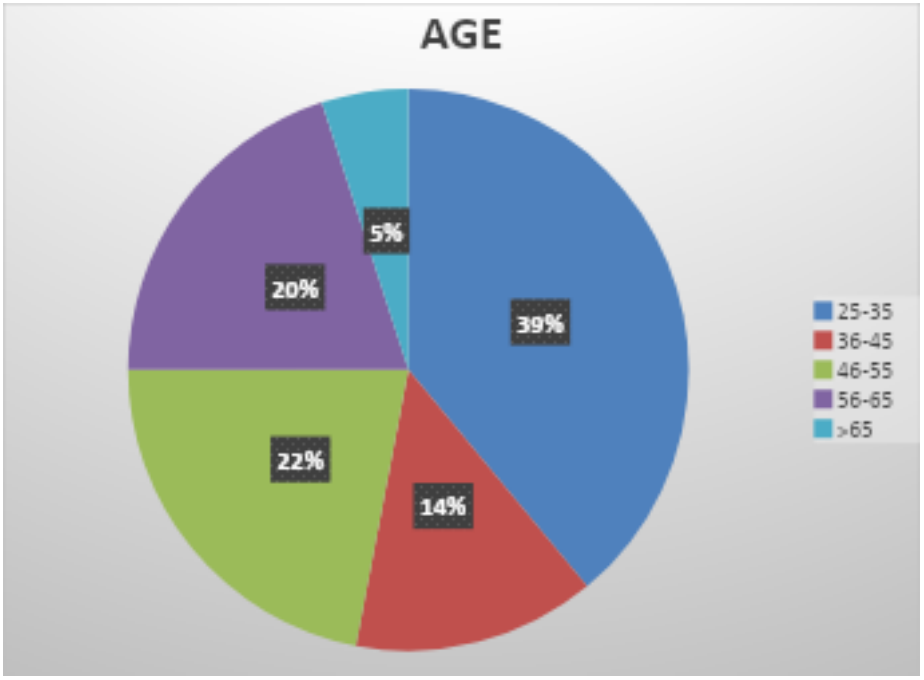

Figure 3: Distribution of sample based on age

Figure 1 shows that, 39% of samples were aged between 25-35, 14% were between 36-45, 22% were between 46-55, 20% were between 56-65 and 5% were aged above 65 years.

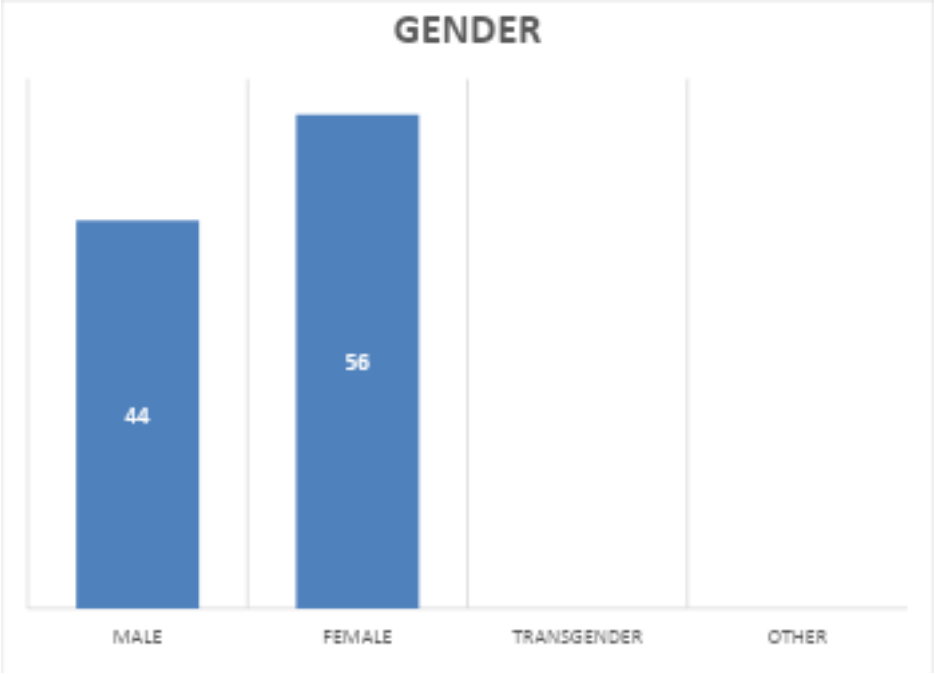

Figure 4: Bar diagram showing the distribution of samples according to gender.

The data presented in the figure shows that 44% of participants in the study were male and 56% were female

Table 1: Distribution of subjects based on education

(N=100)

Sample characteristics	**Frequency (f)**	**Percentage (%)**
Education		
No formal education	2	2%
Primary	32	32%
Secondary	11	11%
Higher secondary	15	15%
Graduate/ diploma	37	37%
Post graduate	3	3%

Table 1 shows that, 2% of total participants have no formal education, 32% have primary education, 11% have secondary education, 15% have higher secondary education, 37% were graduate/ diploma, and 3% have post graduate.

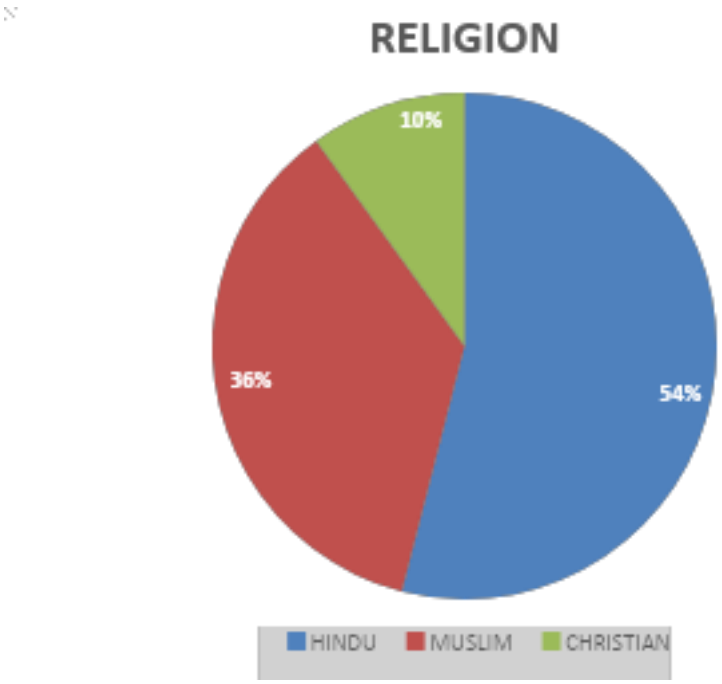

Figure 5: Pie diagram showing the distribution of subjects based on religion

Figure 3 shows that out of 100, 54% of total participants were Hindu, 36% were Muslim and 10% were Christian.

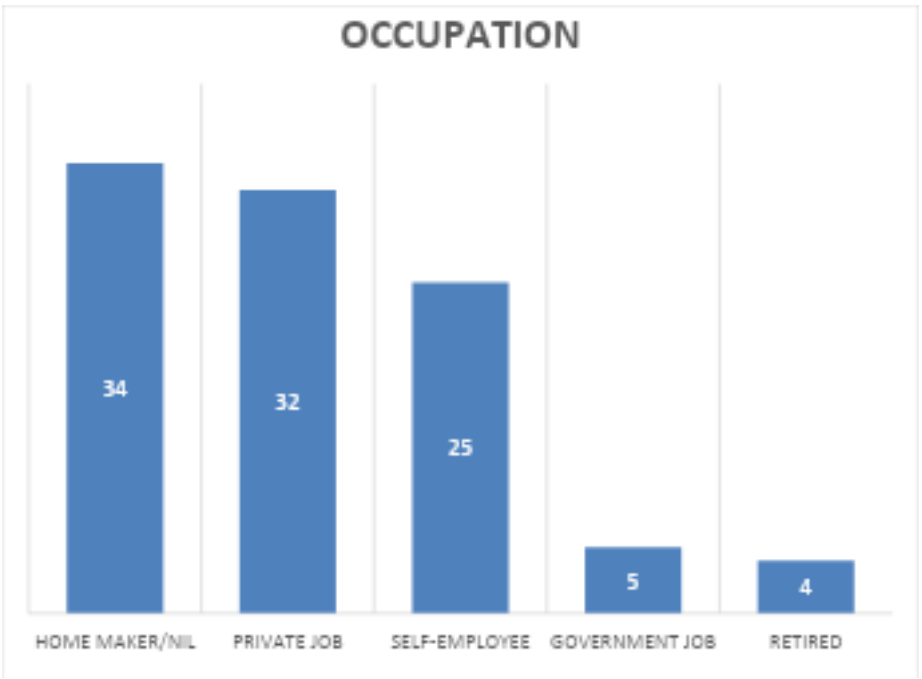

Figure 6: Distribution of subjects based on occupation

Figure 4 shows that, 34% of total samples were home-makers, 32% have private job, 25% were self-employed, 5% have government job and 4% were retired.

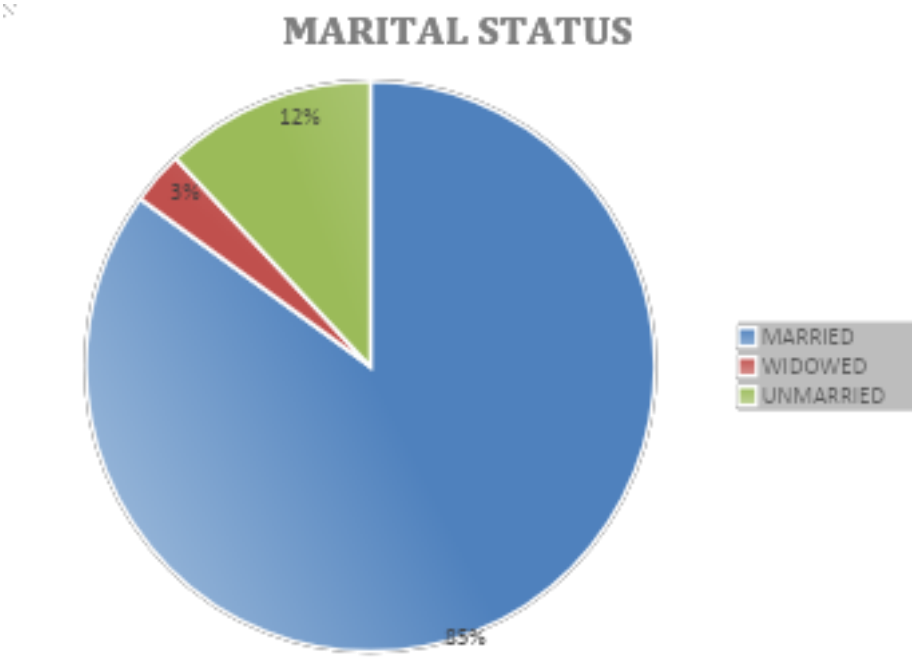

Figure 7: Distribution of sample based on marital status.

Figure 5 shows, 85% of total participants were married, 3% were widowed and 12% were unmarried.

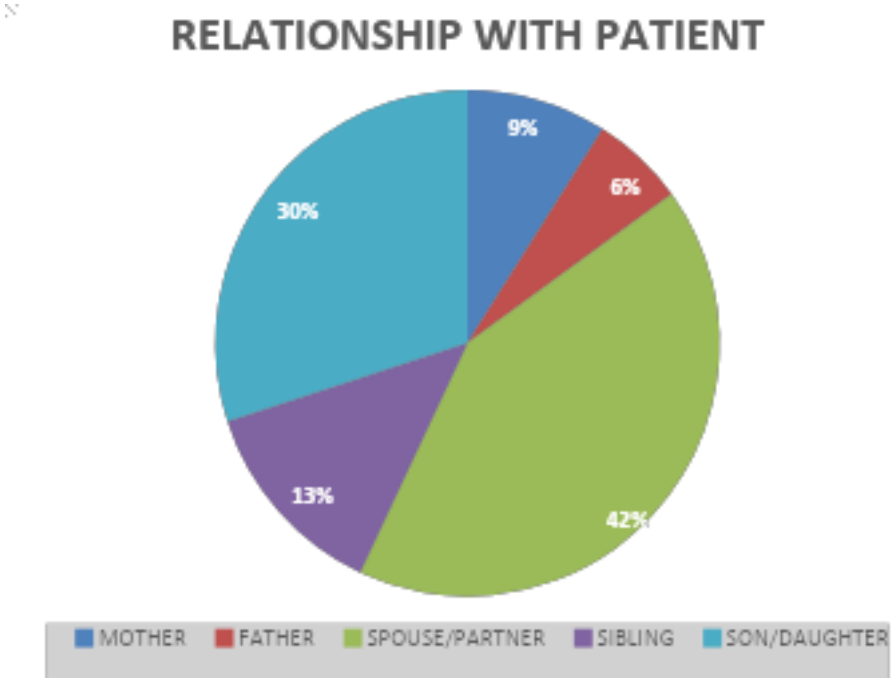

Figure 8: Distribution of samples showing care giver's Relationship with patient

Figure 6 shows that, 9% of total participants were the mothers of patients, 6% were fathers, 42% were spouse/ partner, 13% were siblings and 30% were son or daughter of the patients.

Table 2: Distribution of subjects based on type of family, place of residence and monthly income in rupees.

(N=100)

Sl no.	Sociodemographic characteristics	Frequency(f)	Percentage (%)
1	**Type of family**		
	Nuclear family	87	87%
	Joint family	12	12%
	Extended family	1	1%
2	**Place of residence**		
	Rural	51	51%
	Urban	39	39%
	Semi urban	10	10%
3	**Monthly income in rupees**		
	<5000	7	7%
	5001-10000	7	7%
	10001-15000	18	18%
	15001-20000	21	21%
	>20001	47	47%

Table 2 shows that majority of the samples were from a nuclear family 87%, 12% were from joint family, and 1% were from extended family. Majority of participants resides in rural area 51%, 39% at urban area and 10% at semi urban area and majority of samples have a monthly income of >20001 rupees per month 47%, 7% of subjects have a monthly income of rupees less than 5000, another 7% of participants have a monthly income of rupees within 5001-10000, 18% of samples have a monthly income of rupees within 10001-15000, and 21% of participants have a monthly income of rupees between 15001-20000.

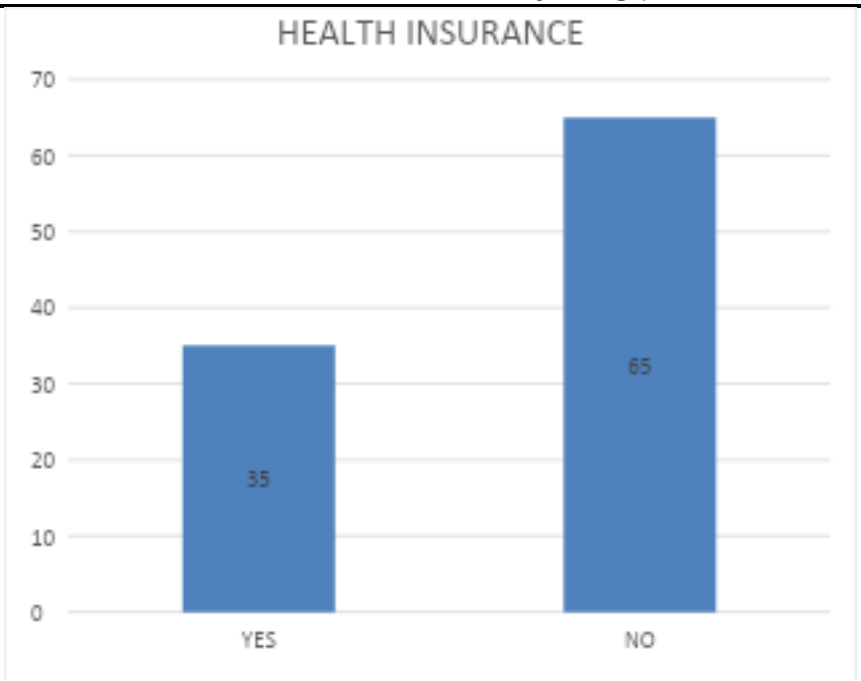

Figure 9: Bar diagram showing the distribution of participants having health insurance

Figure 7 shows that, 35% of samples have health insurance and 65% doesn't have a health insurance.

Section 1-B: Clinical proforma of CKD patients:

This section includes 9 items- stage of the kidney disease, duration of illness, current treatment, duration of dialysis, comorbidities, frequency of dialysis, presence of diabetes and hypertension, transplantation, and complications of dialysis.

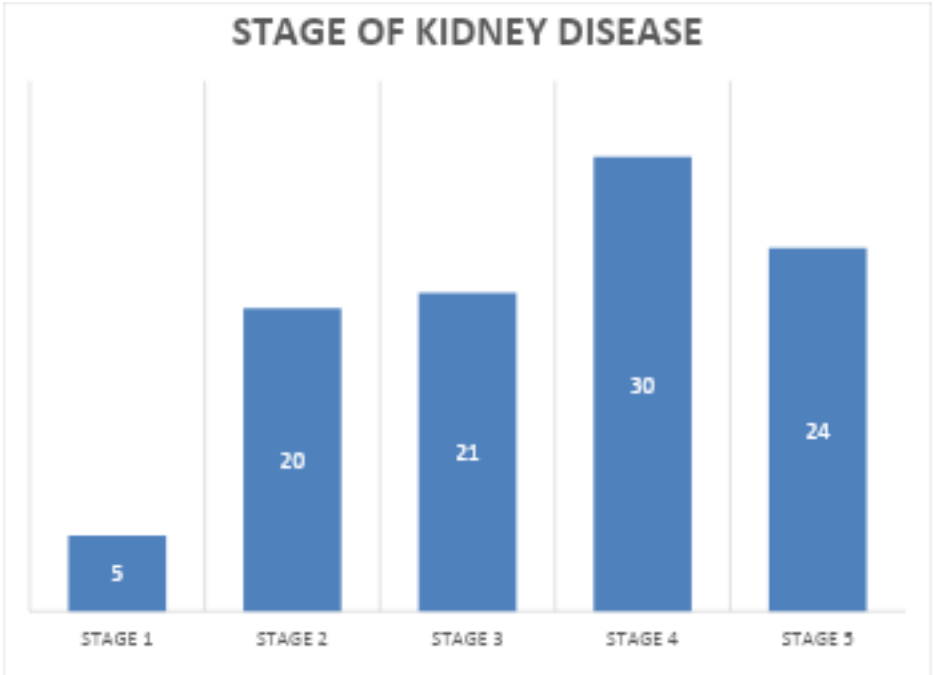

Figure 10: Bar diagram showing distribution of subjects based on stag24e of the kidney disease

Diagram shows 5% of total patients have stage 1 of kidney disease, 20% have stage 2, 21% have stage 3, 30% have stage 4 and 24% have stage 5 of kidney di

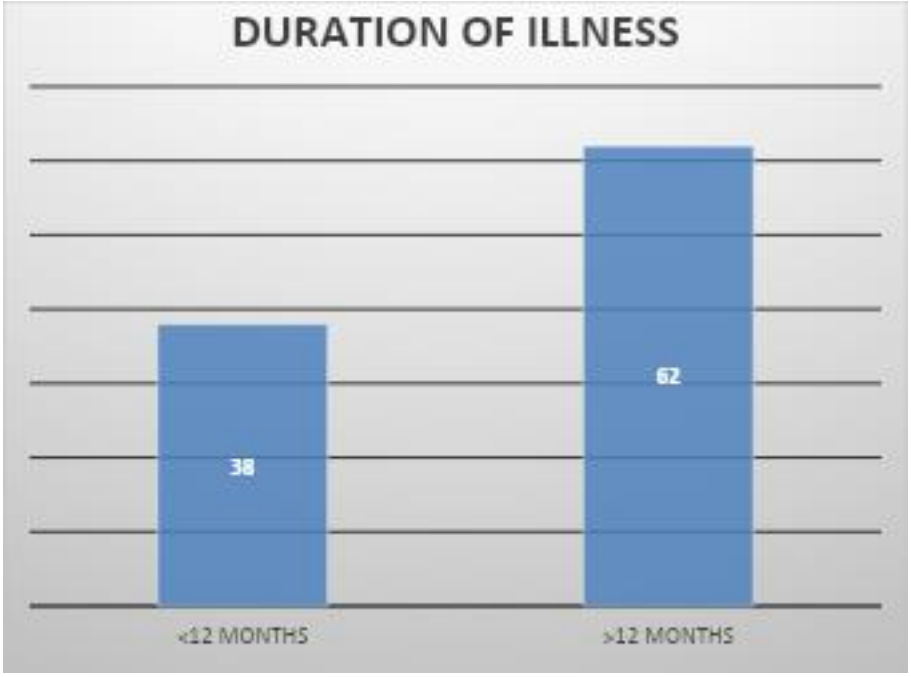

Figure 11: Distribution of patients based on Duration of illness

Figure 2 shows that, 38% of total patients have CKD with a duration of less than 12 months and 62% of patients have CKD since more than 12 months.

Table 3: Distribution of patients based on current treatment, duration of dialysis and presence of comorbidities.

(N=100)

Sl. no	Sociodemographic variables	Frequency (f)	Percentage (%)
1	**Current treatment**		
	Dialysis only	59	59%
	Dialysis and medications	41	41%
2	**Duration of dialysis**		
	<12 months	43	43%
	>12 months	57	57%
3	**Comorbidities**		
	Yes	53	53%
	No	47	47%

Table 3 shows that, major portion of the patients were on dialysis only (59%), majority of patients were on dialysis since more than 12 months (57%) and they have comorbidities present (53%).

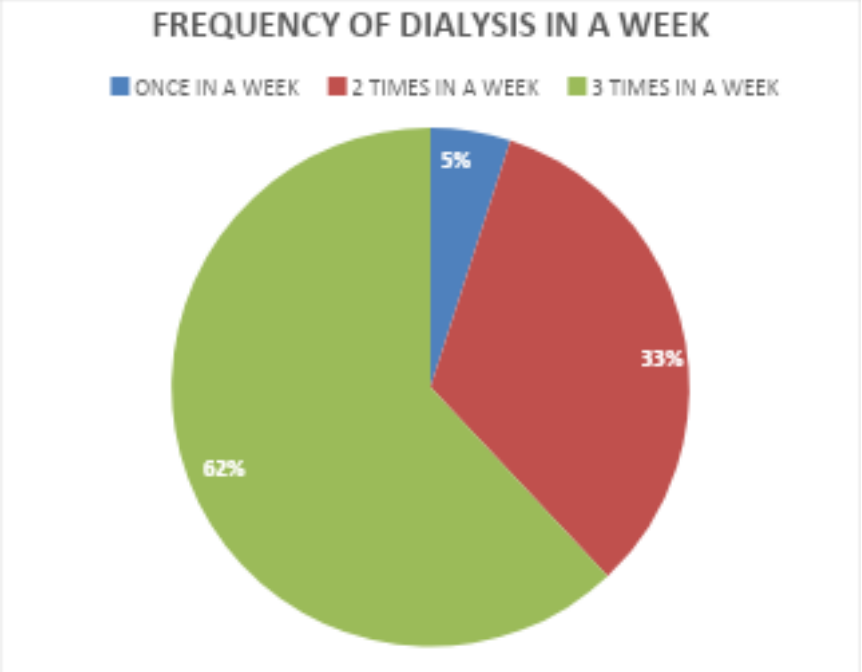

Figure 12: Pie diagram showing distribution of patients based on frequency of dialysis in a week.

Figure 3 shows that, 5% of patients undergoes hemodialysis once in a week, 33% undergoes 2 times in a week and 62% undergoes hemodialysis 3 times in a week.

Table 4: distribution of patients on the basis of presence of diabetes and hypertension and transplantation status of patients

(N=100)

Sl no.	Sociodemographic variable	Frequency (f)	Percentage (%)
1	**Diabetes and hypertension**		
	Diabetes only	31	31%
	Hypertension only	23	23%
	Both present	31	31%
	Both absent	15	15%
2	**Transplantation**		
	Not done	100	100%

Table 4 shows that, 31% of patients have only diabetes, 23% have only hypertension, 31% have both of them, and 15% of them doesn't have both of them. Also 100% of patients have not done transplantation.

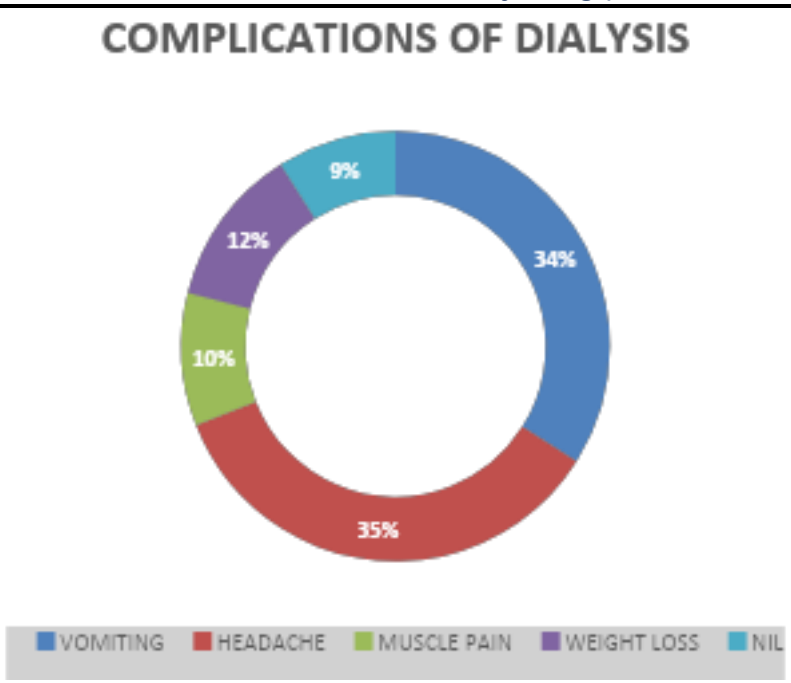

Figure 13: distribution of samples based on complications of dialysis.

Figure 13 shows that, 34% of total patients have vomiting as a complication of dialysis, 35% have headache, 10% have muscle pain, 12% have weight loss and 9% of patients doesn't have any complications.

Section 2: Assessment of the burden of caregivers of patients with CKD.

Table 5: distribution of burden of participants represented in frequency, percentage, mean, median and standard deviation

N=100

Zarit criteria	Frequency (f)	Percentage (%)	Mean	Median	Standard deviation
No to mild burden	43	43.0%			
Mild to moderate burden	45	45.0%	1.7100	2.0000	.72884
Moderate to severe burden	10	10.0%			
Severe burden	2	2.0%			

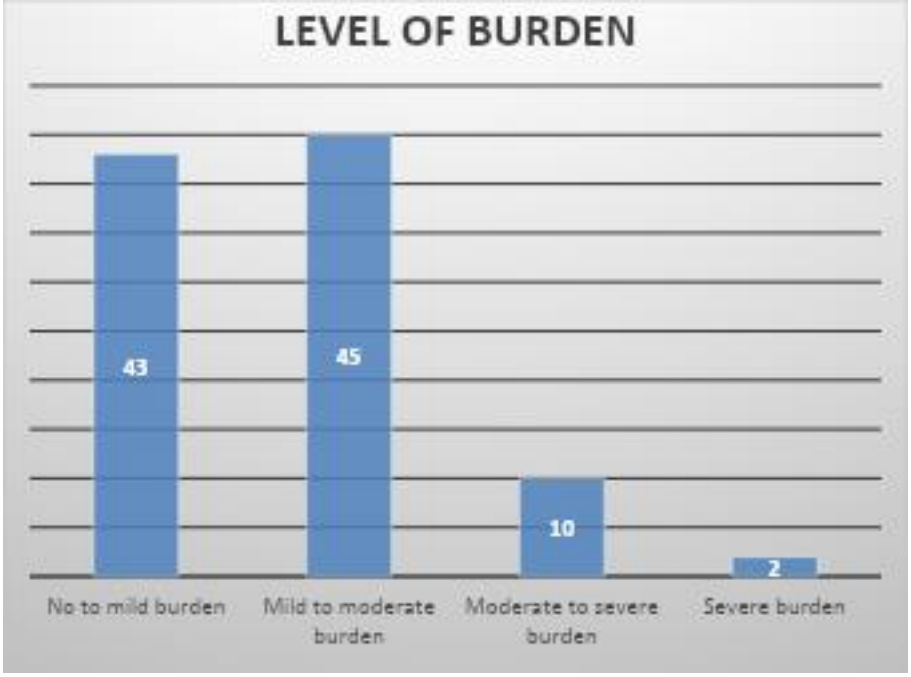

Figure 14: distribution of samples based on the level of burden

Mean total score of ZBI assessment scale was 1.7100 with median of 2.0000 and standard deviation of .72884. 45% of total participants have mild to moderate burden.

Section 3: assessment of the resilience among caregivers of patients with CKD.

Table 6: distribution of resilience of participants based on frequency, percentage, mean, median, and standard deviation.

N=100

BRS Criteria	Frequency (f)	Percentage (%)	Mean	Median	Standard deviation
Low resilience	32	32.0%			
Normal resilience	67	67.0%	1.6900	2.0000	.48607
High resilience	1	1.0%			

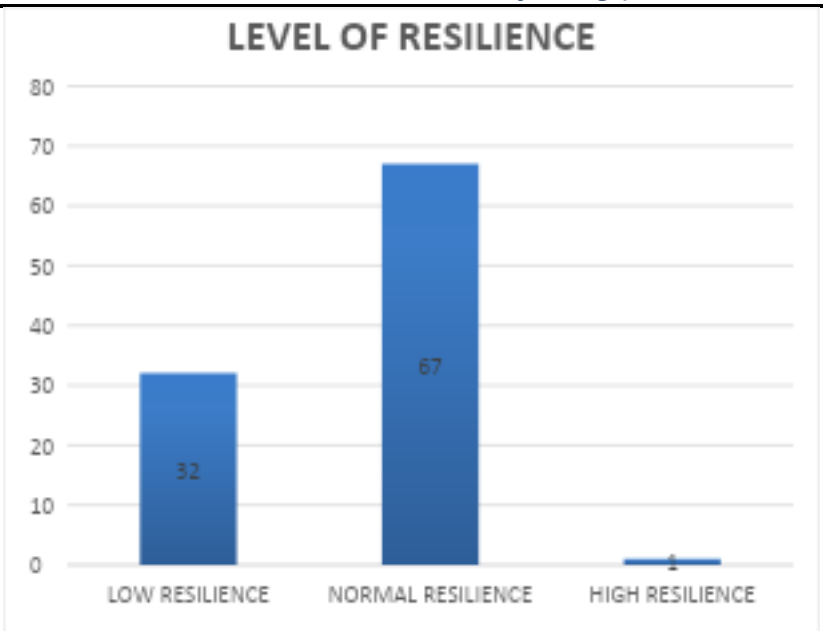

Figure 15: Distribution of samples based on level of resilience of caregivers of patients with CKD.

Mean total score of Brief Resilience Scale was 1.6900 with median of 2.0000 and standard deviation of 0.48607. 67.0% of total participants have normal resilience.

Section 4: correlation between burden and resilience of caregivers of patients with CKD

To test the statistical significance the following null hypothesis was stated

H_{01}: There is no significant correlation between burden and resilience of caregivers of patients with CKD.

Table 7: correlation between burden and resilience of caregivers of patients with CKD

N=100

		ZBI total score	BRS total score
ZBI TOTAL SCORE	Pearson correlation	1	-.396**
	Sig. (2-tailed)		.000
	N	100	100
Resilience total	Pearson correlation	-.396**	1
	Sig. (2-tailed)	.000	
	N	100	100

**. Correlation is significant at the 0.01 level (2-tailed).

A Pearson correlation was computed to assess the relationship between caregiver burden and resilience. There was a moderate, negative correlation between Zarit Burden Interview scores and Brief Resilience Scale scores, r (100) = –.396, p < .01. This indicates that higher caregiver burden is significantly associated with lower resilience among the caregivers studied.

H0: There will be no significant correlation between burden and resilience of caregivers of patients with CKD.

H1: there will be a significant correlation between caregiver burden and resilience among caregivers of patients with CKD undergoing hemodialysis.

Section 5: association between burden of caregivers with demographic variables.

To test the statistical significance the following null hypothesis was stated

H_{02}: There is no significant association between burden of caregivers and demographic variables.

Table 8: association between burden of caregivers and demographic variables

N=100

Variable	Chi-square value(x^2)	df	p-value
Age	17.299	12	0.139
Gender	0.098	3	0.992
Education	23.033	15	0.083
Religion	7.950	9	0.539
Occupation	16.741	12	0.16
Marital status	2.032	6	0.917
Relation with patient	13.692	12	0.321
Type of family	3.256	6	0.776
Place of residence	5.359	6	0.499

Income	17.991	12	0.116
Health insurance	3.074	6	0.8
Stage of CKD	8.863	12	0.715
Duration of illness	1.728	3	0.631
Current treatment	1.833	3	0.608
Duration of dialysis	1.075	3	0.783
Comorbidities	2.921	3	0.404
Frequency of dialysis	6.428	6	0.377
DM/HTN	11.397	9	0.249
Transplantation	—	—	—
Complications	13.709	12	0.32

Significant association ($p < 0.05$)

For ordinal variables like frequency of dialysis and complications, mention the Linear by-Linear Association test separately as showed significance. Frequency of dialysis × ZBI. Here Pearson Chi-Square: 6.428, df = 6, $p = 0.377$ → not significant. But Linear-by-Linear Association: $p = 0.046$. This test checks for a trend across ordered categories (e.g., 1/week → 2/week → 3/week). Since $p < 0.05$ that mean significant association present. Also in Complications × ZBI

Pearson Chi-Square is 13.709, df = 12, $p = 0.320$ that is not significant. But Linear-by-Linear Association: $p = 0.024$ → significant trend.

Most variables had Pearson Chi-Square $p > 0.05$, meaning no significant association. Only Frequency of Dialysis and Complications showed $p < 0.05$ in Linear-by-Linear Association, so It can be mentioned as significant.

Hence null hypothesis is rejected and research hypothesis is partially accepted.

H0: There will be no significant association between burden of caregivers and demographic variables.

H2: There will be a significant association between burden of caregivers and demographic variables

Section 6: Association between resilience of caregivers with demographic variables.

To test the statistical significance the following null hypothesis was stated

H_{03}: There is no significant association between resilience of caregivers and demographic variables.

Table 9: association between resilience of caregivers with sociodemographic variables.

N=100

Variable	Chi-Square Value (χ^2)	df	p-value
Age	3.158	8	0.924
Gender	2.861	2	0.239
Education	12.92	10	0.228
Religion	3.114	6	0.794
Occupation	5.964	8	0.651
Marital status	0.516	4	0.972
Relation with patient	15.127	8	0.057
Type of family	1.007	4	0.909
Place of residence	11.39	4	0.023
Income	10.511	8	0.231
Health insurance	5.556	4	0.235
Stage of CKD	6.488	8	0.593
Duration of illness	0.942	2	0.624
Current treatment	6.362	2	0.042*
Duration of dialysis	0.99	2	0.609
Comorbidities	2.784	2	0.249
Frequency of dialysis	6.873	4	0.143
DM/HTN	10.463	6	0.106
Transplantation	—	—	—
Complications	13.452	8	0.097

Significant association ($p < 0.05$)

Data in table reveals that, among the sociodemographic variables, place of residence was found to be

significantly associated with CKD-related factors ($\chi^2 = 11.39$, df = 4, p = 0.023). Other sociodemographic variables including age, gender, education, religion, occupation, marital status, relation with patient, type of family, income, and health insurance showed no statistically significant associations (p > 0.05).

Regarding clinical variables, current treatment showed a significant association ($\chi^2 = 6.362$, df = 2, p = 0.042). Variables such as stage of CKD, duration of illness, duration of dialysis, comorbidities, frequency of dialysis, DM/HTN, and complications were not significantly associated with CKD-related factors (p > 0.05).

So it can be mentioned as significant. Hence null hypothesis is rejected and research hypothesis is accepted.

H0: There will be no significant association between resilience of caregivers and demographic variables.
H_3: There will be a significant association between resilience of caregivers and demographic variables.

RESULTS

This section deals with the results in accordance with the objectives and hypothesis. The purpose of the study was to assess the burden and resilience among caregivers of chronic kidney disease patients undergoing hemodialysis. The data was collected from 100 primary caregivers of CKD patients. The tools used were sociodemographic proforma, brief resilience scale and Zarit burden interview.

OBECTIVES

- Assess the burden of caregivers of patients with CKD.
- Assess the resilience among caregivers of patients with CKD.
- Find the correlation between burden and resilience of caregivers of patients with CKD.
- Find the association between burden of care givers with demographic variables.
- Find the association between resilience of caregivers with demographic variables.

HYPOTHESIS

H0 – There will be no significant relationship between caregiver burden and resilience with selected demographic variables.

H1 - There will be significant correlation between caregiver burden and Resilience among caregivers of patients with CKD undergoing Hemodialysis

H2 - There will be significant association between burden of care givers and demographic variables

H3- There will be significant association between Resilience of care givers and demographic variables

MAJOR FINDINGS OF THE STUDY

SECTION A: Sociodemographic characteristics.

- Among 100 subjects 39% of samples were aged between 25-35, 14% were between 36-45, 22% were between 46-55, 20% were between 56-65 and 5% were aged above 65 years.
- In those100 participants 44% were male and 56% were female
- 2% of total participants had no formal education, 32% had primary education, 11% had secondary education, 15% had higher secondary education, 37% were graduate/ diploma, and 3% were post graduates.
- Most of the subjects, 54% of total participants were Hindu, 36% were Muslim and 10% were Christian.
- Majority of samples, 34% of total samples were homemakers, 32% had private job, 25% were self-employed, 5% had government job and 4% were retired.
- Most of the samples, 85% were married, 3% were widowed and 12% were unmarried.
- Among that 100 samples, 9% were the mothers of patients, 6% were fathers, 42% were spouse/ partner, 13% were siblings and 30% were sons or daughters of the patients.
- Majority of participants, 87% belongs to nuclear family, 12 % belongs to joint family and 1% belongs to extended family.
- Most of the samples, 51% were residing at rural area, 39% were at urban area and 10% were at semi urban area.
- In that 7% of participants had a monthly income of <5000 rupees, 7% had 500110000 rupees, 18% had 10001-15000, 21% had 15001-20000 and 47% had a monthly income of >20001 rupees.
- Majority of total participants, 65% had no health insurance and 35% had health insurance.

SECTION B: Clinical variables

- 5% of total patients were having stage 1 of kidney disease, 20% had stage 2, 21% had stage 3, 30% had stage 4 and 24% had stage 5 of kidney disease.
- Among the 100 patients 62% were having kidney disease since more than 12 months and 38% were having kidney disease since less than 12 months.
- Majority of patients 59% were on dialysis only and 41% of patients were on both dialysis and medications.
- 57% of total patients were on hemodialysis since more than 12 months and 43% of total patients were on hemodialysis since less than 12 months.
- Most of the patients, 53% of them had comorbidities and 47% had no comorbidities.
- 5% of total patients were undergoing hemodialysis once in a week, 33% were undergoing 2 times in a week and 62% were undergoing dialysis 3 times in a week.
- 31% of them had diabetes only, 23% had hypertension only, 31% had both diabetes and hypertension and 15% had no diabetes or hypertension.

- 100% of them didn't undergo transplantation.
- 34% of them had vomiting as a complication of dialysis, 35% had headache, 10% had muscle pain, 12% had weight loss and 9% had no complications related to dialysis.

SECTION C: Assess the burden of caregivers of patients with CKD

The study assessed the burden of caregivers of patients with CKD using the Zarit criteria. The distribution of burden among participants was as follows: 43% experienced no to mild burden, 45% had mild to moderate burden, 10% reported moderate to severe burden, and 2% experienced severe burden. The mean total score of the Zarit Burden Interview (ZBI) assessment scale was 1.7100, with a median of 2.0000 and a standard deviation of 0.72884. Notably, 45% of the total participants reported a mild to moderate burden, indicating a significant proportion of caregivers experiencing a considerable level of caregiving burden.

SECTION D: Assess the resilience of caregivers of patients with CKD

The findings of the study revealed that out of the total participants, 32 (32.0%) caregivers of patients with chronic kidney disease demonstrated low resilience, while the majority, 67 (67.0%), were found to have normal resilience. Only 1 caregiver (1.0%) showed high resilience. The mean total score of the Brief Resilience Scale was 1.69, with a median score of 2.00 and a standard deviation of 0.48607. These results indicate that most caregivers of chronic kidney disease patients in the study population tend to have normal resilience, while a considerable proportion still experiences low resilience, highlighting the need for supportive interventions to enhance their coping ability.

SECTION E: Correlation between burden and resilience of caregivers of patients with CKD

A Pearson correlation analysis was conducted to examine the relationship between caregiver burden and resilience. The results showed a moderate, statistically significant
negative correlation between Zarit Burden Interview (ZBI) scores and Resilience scores ($r = –0.396$, $p < 0.01$). This finding indicates that as caregiver burden increases, resilience tends to decrease among the caregivers studied, suggesting that higher levels of burden are associated with lower resilience.

SECTION F: Association between burden of caregivers with demographic variables

The association between demographic and clinical variables with Zarit Burden Interview (ZBI) scores was analyzed using the Chi-square test. The findings revealed that none of the demographic or clinical variables showed a statistically significant association with caregiver burden ($p > 0.05$). Among the demographic factors, education ($\chi^2 = 23.033$, df = 15, $p = 0.083$), income ($\chi^2 = 17.991$, df = 12, $p = 0.116$), and age ($\chi^2 = 17.299$, df = 12, $p = 0.139$) demonstrated relatively lower p-values compared to other variables, though they did not reach statistical significance. Clinical factors such as stage of CKD ($\chi^2 = 8.863$, df = 12, $p = 0.715$),

duration and frequency of dialysis, comorbidities, and complications also showed no significant relationship with caregiver burden. These results suggest that caregiver burden, as measured by ZBI, is not significantly influenced by the assessed demographic or clinical characteristics in this study population.

SECTION G: Association between resilience of caregivers with demographic variables

The association of demographic and clinical variables with Brief Resilience Scale (BRS) was examined using the Chi-square test. The analysis revealed that most demographic and clinical factors, including age, gender, education, religion, occupation, marital status, type of family, income, health insurance, stage of CKD, duration of illness, duration and frequency of dialysis, comorbidities, DM/HTN, and complications, did not show a statistically significant association with resilience ($p > 0.05$). However, significant associations were observed for place of residence ($\chi^2 = 11.390$, $df = 4$, $p = 0.023$) and current treatment ($\chi^2 = 6.362$, $df = 2$, $p = 0.042$), indicating that these factors had a meaningful impact on resilience levels among the participants.

DISCUSSION

This section presents a discussion on study findings. the

Objectives

- Assess the burden of caregivers of patients with CKD.
- Assess the resilience among caregivers of patients with CKD.
- Find the correlation between burden and resilience of caregivers of patients with CKD.
- Find the association between burden of care givers with demographic variables.
- Find the association between resilience of caregivers with demographic variables.

Discussion on findings of the study:

The findings of the study are discussed in relation to findings of the similar studies reviewed by investigators.

Assess the burden of caregivers of patients with CKD.

The findings of the current study shows that majority of the samples 54% had mild to moderate burden, 43% had no to mild burden, 10% had moderate to severe burden, and 2% had severe burden.

A one-group pre-test post-test study was conducted to assess the effect of an educational intervention on the caregiver burden of family caregivers of hemodialysis patients. A total of 169 caregivers were recruited using convenience sampling. A socio- demographic questionnaire, the Oberst Caregiving Burden Scale (OCBS), and the Bakas Caregiving Outcomes Scale (BCOS) were administered at baseline

(pre-test) and again two weeks after the educational intervention. Before intervention the caregivers were found to have moderate burden (M = 2.73, SD = 0.23), and their lives had changed for the worse as result of caregiving (M = 3.17, SD = 5.89). After the intervention there was a statistically significant reduction in their burden scores (time point post-test) compared to the pre-test.[35]

Assess the resilience of caregivers of patients with CKD.

The findings of this study shows that 67% of total participants had normal resilience, 32% had low resilience and 1% had high resilience.

A cross-sectional observational study was conducted to assess psychological resilience among 247 caregivers of children with chronic kidney disease (CKD) across 13 provinces in China. Data were collected in March 2020 using structured questionnaires measuring socioeconomic status, medical accessibility (including online consultation duration, medical delay duration, traffic pressure), hope (positive attitude, positive action, intimate relationship), and psychological resilience (optimism, tenacity, strength). Exploratory factor analysis identified four common factors with a cumulative contribution rate of ~ 65.34 %. The study concluded that improving socioeconomic conditions, enhancing access to medical services, and fostering hope could help strengthen resilience in caregivers of children with CKD.[36]

Find the correlation between burden and resilience of caregivers of patients with CKD.

The results showed a moderate, statistically significant negative correlation between Zarit Burden Interview (ZBI) scores and Resilience scores ($r = –0.396$, $p < 0.01$). This finding indicates that as caregiver burden increases, resilience tends to decrease among the caregivers studied, suggesting that higher levels of burden are associated with lower resilience.

A cross-sectional observational study was conducted among 120 caregivers of end-stage renal disease (ESRD) patients on maintenance hemodialysis to assess both caregiver burden and resilience. Caregiver burden was measured using the Zarit Burden Interview and resilience was assessed using the Brief Resilience Scale. The results showed that 35.8% of caregivers had severe burden, 45% had moderate burden, and about 72.5% of caregivers exhibited low resilience, indicating poor problem-solving and emotion-focused coping strategies. Although the study doesn't report a numeric correlation coefficient between burden and resilience in that paper, its findings suggest that high burden is associated with low resilience in caregivers of hemodialysis patients.[37]

Find the association between burden of care givers with demographic variables.

The association between demographic and clinical variables with Zarit Burden Interview (ZBI) scores was analyzed using the Chi-square test. The findings revealed that none of the demographic or clinical variables showed a statistically significant association with caregiver burden ($p > 0.05$). Among the demographic factors, education ($\chi^2 = 23.033$, $df = 15$, $p = 0.083$), income ($\chi^2 = 17.991$, $df = 12$, $p = 0.116$), and age ($\chi^2 = 17.299$, $df = 12$, $p = 0.139$) demonstrated relatively lower p-values compared to other variables, though they did not reach statistical significance. Clinical factors such as stage of CKD ($\chi^2 = 8.863$, $df = 12$, $p = 0.715$),

duration and frequency of dialysis, comorbidities, and complications also showed no significant relationship with caregiver burden. These results suggest that caregiver burden, as measured by ZBI, is not significantly influenced by the assessed demographic or clinical characteristics in this study population

A descriptive cross-sectional study examined the association between caregiver burden and selected sociodemographic characteristics among family caregivers of patients with chronic kidney disease undergoing dialysis. Using convenience or simple random sampling, 120–228 caregivers were recruited, and data were collected with a socio-demographic proforma and the Zarit Burden Interview. Findings showed a high prevalence of moderate-to-severe burden. Female gender, lower education, unemployment, and increasing caregiver age were significantly associated with higher burden ($p < 0.05$). No consistent association was found with marital status or caregiving duration. The authors concluded that caregiver sex, education, and employment status are important determinants of burden and recommended targeted interventions, including education, financial support, and respite services for high-risk caregivers.[38]

Find the association between resilience of caregivers with demographic variables.

The association of demographic and clinical variables with Brief Resilience Scale (BRS) was examined using the Chi-square test. The analysis revealed that most demographic and clinical factors, including age, gender, education, religion, occupation, marital status, type of family, income, health insurance, stage of CKD, duration of illness, duration and frequency of dialysis, comorbidities, DM/HTN, and complications, did not show a statistically significant association with resilience ($p > 0.05$). However, significant associations were observed for place of residence ($\chi^2 = 11.390$, df = 4, $p = 0.023$) and current treatment ($\chi^2 = 6.362$, df = 2, $p = 0.042$), indicating that these factors had a meaningful impact on resilience levels among the participants.

A study was conducted to assess the resilience levels of caregivers of patients undergoing hemodialysis using the Brief Resilience Scale (BRS). The researchers evaluated caregivers' ability to recover from stress and adversity associated with long-term care responsibilities. Findings indicated that many caregivers demonstrated low-to-moderate resilience, with factors such as caregiver age, duration of caregiving, gender, and socioeconomic status influencing resilience scores. The study highlighted the need for interventions that strengthen coping skills, enhance emotional well-being, and provide social support to improve resilience among caregivers of hemodialysis patients.[39]

CHAPTER 3

LIMITATIONS AND SCOPE OF STUDY

Limitations

This descriptive study aimed to evaluate the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis. The limitations of the study include:

- Limited generalizability and small sample size may reduce statistical significance and limit broader applicability.
- Caregivers self-reported burden and resilience levels might not fully reflect their actual experiences and coping strategies.
- Findings may not apply to caregivers in other settings or regions.
- Differences in socioeconomic status, family structure, and availability of social support among participants could affect burden and resilience levels.
- Assessing burden and resilience does not ensure understanding of long-term psychological adaptation or coping outcomes.

Scope for future studies

- Compare burden and resilience levels between male and female caregivers.
- Explore the relationship between duration of caregiving and caregiver resilience.
- Study how socioeconomic and cultural factors influence caregiver burden and coping strategies.
- Compare burden and resilience among caregivers of patients undergoing hemodialysis, peritoneal dialysis, and renal transplantation.
- Assess the impact of caregiver support groups and counseling programs on burden and resilience.
- Evaluate the effectiveness of hospital-based psychosocial interventions for caregivers.
- Investigate the role of family and community support systems in reducing caregiver burden.
- Examine the long-term psychological outcomes of caregivers providing dialysis care.
- Identify strategies used by highly resilient caregivers that can be adapted in caregiver training programs.
- Explore the effectiveness of mobile apps or online support systems in promoting caregiver resilience.

CHAPTER 4

CONCLUSION

The study aimed to assess the burden and resilience among caregivers of patients with CKD undergoing hemodialysis at Aster MIMS Hospital, Calicut. 100 subjects were selected through non-probability purposive sampling technique. Utilizing sociodemographic and clinical proforma along with validated questionnaires like the Zarit Burden Interview and Brief Resilience Scale. The study was conducted in the dialysis unit of Aster MIMS Hospital, Calicut. Anonymity was ensured throughout the process. The result of the study indicates that most of the caregivers of the patients undergoing hemodialysis had normal resilience (67%) and mild to moderate burden (45%).

NURSING IMPLICATIONS

The findings of the study have several implications in nursing practice, nursing education, nursing research and nursing administration.

Nursing practice

During the course of treatment for chronic kidney disease patients, nurses can play a crucial role. Nurses can influence the primary caregivers of chronic kidney disease patients by providing psychological support, clearing their doubts, and explaining the treatment procedures and their outcomes. Specialized nursing care is essential before, during, and after therapies of dialysis to the chronic kidney disease patients and their primary caregivers. Proper health education should be provided to the primary caregivers of chronic kidney disease patients regarding the burden and resilience during care**.**

Nursing education

Nursing is a caring profession. Core values of nursing include maintaining integrity and human dignity. The findings of the study will help the nurses identify the caregiver burden and resilience of primary caregivers of chronic kidney disease patients, and it will help them use this in their daily life for providing special attention and support to the primary caregivers of CKD patients. Then only the nursing students can be able to provide adequate psychological support and attention to the primary caregivers of CKD patients. Nursing students can utilize the study findings.

Nursing administration

The primary caregivers of chronic kidney disease are impacted psychologically and may be physically by taking care of patients with CKD. During the course of care, the primary caregivers of CKD patients may have to cope with various problems, it may be psychological, physical, or financial. Poor coping with stress may lead to inadequate psychological problems.

The nurses working in the nephrology departments should be proficient in identifying the problems of the patients along with the primary caregivers of CKD patients. Training programs should be initiated not only for nurses but also for auxiliary nurses, village nurses, and community health nurses regarding caregiver burden and quality of life.

The nurse administrator can plan staff development programs, in-service educational programs, etc., for nurses who are working in the nephrology department to provide efficient psychological support for caregivers, and also improve the resilience and decrease the burden of primary caregivers of CKD patients.

Nursing research

Nursing studies are required to evaluate the caregiver burden and resilience of primary caregivers of chronic kidney disease patients. Development of evidence-based guidelines and novel models of nursing care are needed, which are well fitting for the organizational and societal context are required for further decreasing the caregiver burden and improving the resilience of primary caregivers of CKD patients.

CHAPTER 5

SUMMARY

A descriptive study to "Assess the Burden and Resilience among Caregivers of Patients Undergoing Hemodialysis in Aster MIMS Hospital, Calicut" is aimed to assess the level of burden experienced by caregivers and their resilience in coping with the challenges of caregiving. The key findings of the study explore the degree of burden experienced by caregivers and their level of resilience in managing stress associated with the long-term care of patients on hemodialysis. The findings of the study can inform healthcare providers about the necessity of structured support systems and resilience-building interventions for caregivers. It also emphasizes the importance of psychological and social support in reducing caregiver burden and promoting well-being. The study suggests avenues for future research, such as intervention-based studies to strengthen caregiver resilience, longitudinal studies to track changes in burden and resilience over time, and comparative studies across different healthcare settings. The study findings showed that caregivers of CKD patients undergoing hemodialysis experienced varying levels of burden. Among the participants, 43% reported no to mild burden, 45% had mild to moderate burden, 10% experienced moderate to severe burden, and 2% had severe burden, with a mean ZBI score of 1.71. In terms of resilience, the majority (67%) of caregivers exhibited normal resilience, while 32% demonstrated low resilience and only 1% reported high resilience, with a mean BRS score of 1.69. A Pearson correlation analysis revealed a moderate, negative, and statistically significant relationship between burden and resilience ($r = –0.396$, $p < 0.01$), suggesting that higher caregiver burden was associated with lower resilience. Analysis of associations showed that burden was not significantly related to most demographic and clinical variables, though a trend was noted for frequency of dialysis and complications. In contrast, resilience was significantly associated with place of residence ($p = 0.023$) and current treatment ($p = 0.042$), while other variables showed no significant association.

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APPENDIX A

07/1NT/MIMSCON/04/2025 05-04-2025

To

Dr. Sajith Narayanan
Senior Consultant Nephrologist
Aster MIMS Hospital Kozhikode
Sir/Madam,

Sub: - Permission to Conduct Research in the Department

I would like to invite your kind attention that below mentioned 4th year B.Sc. Nursing students (7th semester) are planning to conduct a research study in your department on the topic:

Title of study: A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing Hemodialysis at Aster MIMS Hospital, Calicut.

Student Name:

1) Ms. Navya Pavithran
2) Mr. M Z Rizal Moopan
3) Ms. Fathimath Safa K M
4) Ms. Krishnendu P

I humbly request you to give permission for conducting the research study on the specified topic. We assure that utmost decorum will be maintained during the course of the study,

Thanking you.

Yours faithfully

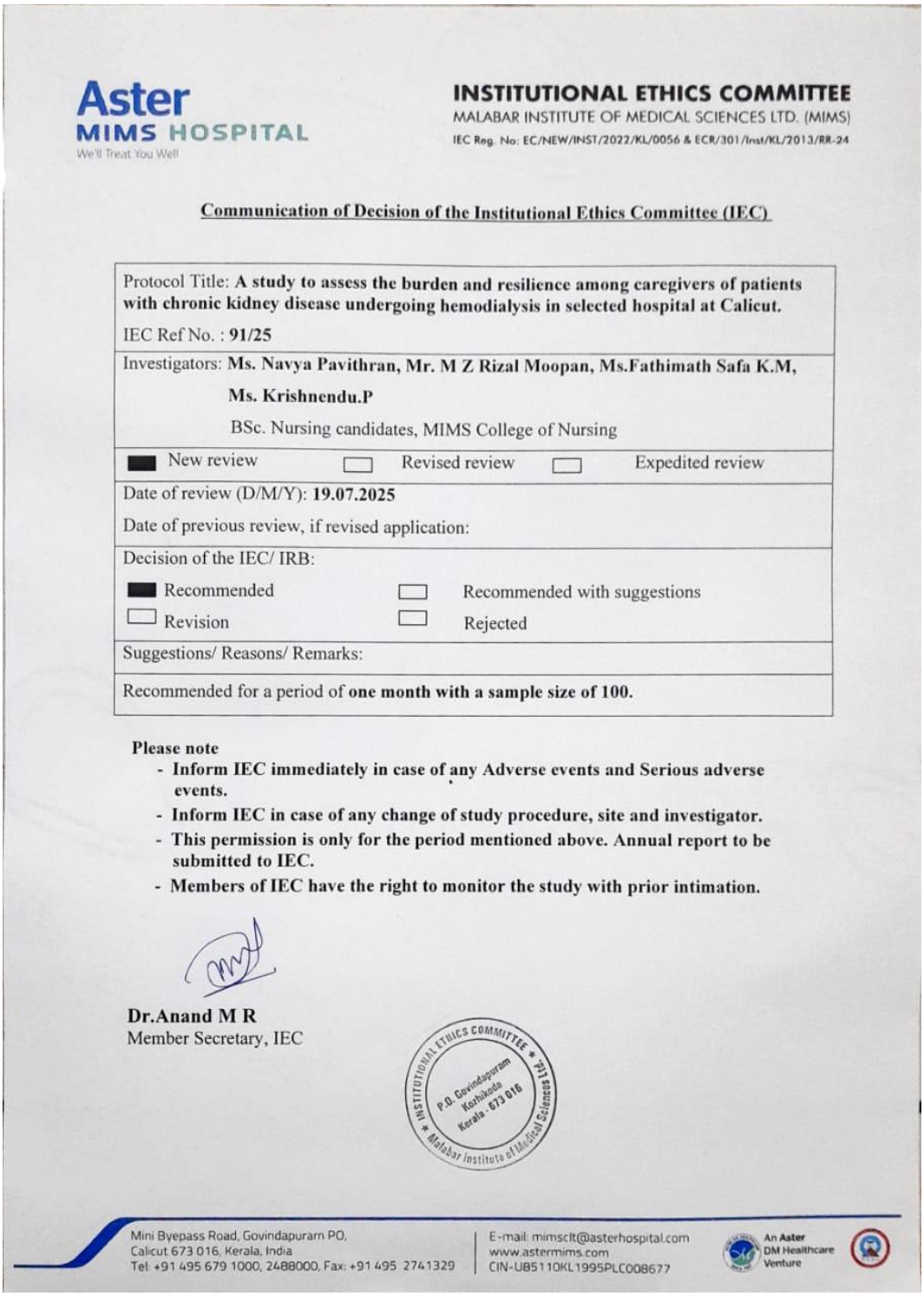
PRINCIPAL
MIMS COLLEGE OF NURSING
PUTHUKODE
673 633
MALAPPURAM

MIMS College of Nursing Pin 673 633 Puthukode

Accepted for Research & IEC clearance

Sajith Narayanan (Nephrology) Nephrologist ASTER MIMS, Calicut. Reg. No : 34399

APPENDIX B



Aster MIMS HOSPITAL
We'll Treat You Well

INSTITUTIONAL ETHICS COMMITTEE
MALABAR INSTITUTE OF MEDICAL SCIENCES LTD. (MIMS)
IEC Reg. No: EC/NEW/INST/2022/KL/0056 & ECR/301/Inst/KL/2013/RR-24

Communication of Decision of the Institutional Ethics Committee (IEC)

Protocol Title: **A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis in selected hospital at Calicut.**

IEC Ref No. : **91/25**

Investigators: **Ms. Navya Pavithran, Mr. M Z Rizal Moopan, Ms.Fathimath Safa K.M, Ms. Krishnendu.P**

BSc. Nursing candidates, MIMS College of Nursing

■ New review ☐ Revised review ☐ Expedited review

Date of review (D/M/Y): **19.07.2025**

Date of previous review, if revised application:

Decision of the IEC/ IRB:

■ Recommended ☐ Recommended with suggestions

☐ Revision ☐ Rejected

Suggestions/ Reasons/ Remarks:

Recommended for a period of **one month with a sample size of 100.**

Please note

- **Inform IEC immediately in case of any Adverse events and Serious adverse events.**
- **Inform IEC in case of any change of study procedure, site and investigator.**
- **This permission is only for the period mentioned above. Annual report to be submitted to IEC.**
- **Members of IEC have the right to monitor the study with prior intimation.**

Dr.Anand M R
Member Secretary, IEC

INSTITUTIONAL ETHICS COMMITTEE * P.O. Govindapuram Kozhikode Kerala : 673 016 * Malabar Institute of Medical Sciences *

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www.astermims.com
CIN-U85110KL1995PLC008677

An Aster DM Healthcare Venture

APPENDIX C

REQUEST FOR VALIDATION OF RESEARCH TOOL

From,

Ms. Navya Pavithran
Mr. M Z Rizal Moopan
Ms. Fathimath Safa K M
Ms. Krishnendu P
7th semester BSc Nursing
MIMS College of Nursing, Puthukode

Subject: Request for opinion and suggestion for establishing content validity of tool.

Respected madam,

We are 7th semester B.Sc. nursing students of MIMS College of Nursing, Puthukode, for the practical fulfillment of course, we need to undertake a research project and the problem statement of the selected research topic "A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis in Aster Mims Hospital Calicut." We kindly request you to go through the content of tool and validate in terms of the relevance, appropriateness and accuracy. I also request you to give your valuable suggestion which will enable us to establish the content validity of tool.

Thanking you.

Enclosed:

1.Proposal of the study

2.Tool

Yours sincerely,

Ms. Navya Pavithran

Mr. M Z Rizal Moopan

Ms. Fathimath Safa K M

Ms. Krishnendu P

Place: Puthukode.

Date:

APPENDIX D

CERTIFICATE OF CONTENT VALIDITY

Certificate of content validity of the data collection tool from experts

Certificate of content validity of data collection tool, "A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis in Aster Mims, Calicut". This is to certify that the tool for assessing the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis, prepared by Ms. Navya Pavithran, Mr. M Z Rizal Moopan, Ms. Fathimath Safa K M, Ms. Krishnendu P, seventh semester BSc Nursing students, Mims college of nursing to be used in the study has been validated by meant can be used for data collection.

Suggestion:

Adequacy of tool:

Organization of tool:

Feasibility of tool:

Validation Details

Signature:

Name:

Designation:

APPENDIX E

LIST OF EXPERTS FOR CONTENT VALIDITY

1. Dr. Sheeja C V
   Principal
   Ph. D (N)
   Mims College of nursing, Puthukode

2. Prof. Isha S
   Professor and Vice Principal
   Department of Obstetrics and Gynecology nursing
   Mims College of nursing, Puthukode

3. Ms. Mary Elizabeth
   Associate Professor
   Department of medical surgical nursing
   Mims College of nursing, Puthukode

4. Ms. Rakhi Seban
   Professor
   Department of Obstetrics and Gynecology nursing
   MIMS College of Nursing

5. Ms. Jipsa K
   Associate Professor
   Department of community health nursing
   MIMS College of Nursing

APPENDIX F

PARTICIPANT INFORMATION SHEET- ENGLISH

Protocol title: A study to assess the burden and resilience among caregivers of patients with chronic kidney disease undergoing hemodialysis in a selected hospital, Calicut.

Principal Investigator: Ms. Navya Pavithran
Mr. M Z Rizal Moopan
Ms. Fathimath Safa K M
Ms. Krishnendu P

Designation: BSc Nursing Student

College: MIMS College of Nursing, Malappuram

Contact number: 8590635714
8129921819
7025721861
8848632087

Please read this form carefully. If you don't understand the language or any information in this document, please discuss with principal investigator. If you decide to volunteer to take part in this study you must sign the end of this form.

1. **Introduction to the research study:** This study aims to assess the level of burden and resilience among caregivers of chronic kidney patients undergoing hemodialysis.

2. **Purpose of the study:** The purpose of the study is to identify the care giver burden and resilience among caregivers of chronic kidney patients undergoing hemodialysis**.**

3. **Who can take part:** Primary caregivers of chronic kidney disease patients can take part in the study.

4. **Information about the study:** Total number of patients expected to participate is 110, you have to fill up a questionnaire related to the study.

5. **Your role/responsibility in the study**:

✓ Provide accurate information whenever asked.

✓ Follow the investigators instruction.

✓ Inform the study investigator about any problem experienced during the study.

✓ If you want to discontinue from the study, principal investigator should be informed.

5. **What are the risks:** There are no risks involved in participating in the study.

6. What are the potential benefits of participating in the study: You may or may not get benefit from participating in this study. It is possible that you will get better or stay the same.

7. What are the alternative treatments available: There are no specific alternative treatments available.

8. Cost of participating in the study: There is no cost involved in participating in this study.

9. Compensation for injury: There are no risks involved in participating in the study. If a medical problem arises during this research study as a direct result of the study the investigator will be responsible for making sure that proper medical care is provided to you.

10. Confidentiality of information: Information from the study including your name, address, medical records will be reviewed only by authorized personnel. Information and results from this study may be presented at meetings or published in journals without including your name and personal identifications and anonymity of the information will be maintained.

11. Voluntary participation: Entering the research study is voluntary. If you volunteer for the research study, you have the right to stop at any time and you need not give any reason for the same.

12. Whom to contact in case of any questions: If you have any questions about this form or any study related issue, you may contact the following person.

Name: Mr. Kiran V Nair

Address: Senior Lecturer, Department of medical and surgical nursing, MIMS College of Nursing.

Mobile no: 8086248010

APPENDIX G

Informed Consent Form

I confirm I have read the Participant Information Sheet for the above study and its content were explained and I have had the opportunity to ask questions and received satisfactory answers

I understand that my participation in the study is voluntary and that I have the right to withdraw at any time without giving any reason, I agree to take part in the above study. I agree to record my verbatim also.

I confirm that I have received a copy of the subject information sheet along with this signed and dated informed consent form.

Name of the participant :…….……

Signature of the participant :…….

Date:…….

Name of the witness:…….……....

Signature of the witness:…….……..

Date:……

APPENDIX H

TOOL 1: SOCIO – DEMOGRAPHIC PROFORMA

Section A: Socio personal Proforma of caregivers of chronic kidney disease patients

1. Age:
   a. 25-35
   b. 35-45
   c. 45-55
   d. 55-65
   e. Above 65

2. Gender
   a. Male
   b. Female
   c. Transgender

3. Education
   a. No formal education
   b. Primary
   c. Secondary
   d. Higher secondary
   e. Graduate /Diploma
   f. Post graduate

4. Religion
   a. Hindu
   b. Muslim
   c. Christian
   d. Others

5. Occupation
    a. Home maker / Nil
    b. Private job
    c. Self-employee
    d. Government
    e. Retired
6. Marital status
    a. Married
    b. Widowed
    c. Separated
    d. Divorced
    e. Unmarried

7. Relationship with patient
    a. Mother
    b. Father
    c. Spouse/partner
    d. Sibling
    e. Son / daughter
    f. Cousin

8. Types of family
    a. Nuclear family
    b. Joint family
    c. Extended

9. Place of residence
    a. Rural
    b. Urban
    c. Semi-urban

10. Monthly income in rupees
    a. <5000
    b. 5001-10000
    c. 10001-15000
    d. 15001-20000
    e. >20001

11. Health insurance
    a. Yes
    b. No

Section B: Clinical Proforma of chronic kidney disease patients

1. Stage of chronic kidney disease
   a. Stage 1
   b. Stage 2
   c. Stage 3
   d. Stage 4
   e. Stage 5

2. Duration of illness
   a. <12 months
   b. >12 months

3. Current treatment
   a. Dialysis only
   b. Surgery
   c. Medication only
   d. Dialysis and medication

4. Duration of dialysis
   a. <12 months
   b. > 12 months

5. Co morbidities
   a. Yes
   b. No

   If yes: …….

6.Frequency of dialysis

   a. Once in a week
   b. Two times in a week
   c. Three times in a week
   d. Four times in a week

7. Presence of diabetes and hypertension

   a. Diabetes only
   b. Hypertension only
   c. Both present
   d. Both absent

8. Transplantation

   a. Done
   b. Not done

9. Complications

a. Vomiting

b. Headache

c. Muscle pain

d. Weight loss

e. Nil

SECTION B: BRIEF RESILIENCE SCALE (BRS)

Table 10; brief resilience scale questions

Sl. no.	Question	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
BRS 1	I tend to bounce back quickly after hard times.	1	2	3	4	5
BRS 2	I have a hard time making it through stressful events.	5	4	3	2	1
BRS 3	It does not take me long to recover from a stressful event.	1	2	3	4	5
BRS 4	It is hard for me to snap back when something bad happens.	5	4	3	2	1
BRS 5	I usually come through difficult times with little trouble.	1	2	3	4	5
BRS 6	I tend to take a long time to get over set-backs in my life.	5	4	3	2	1

Table 11; interpretation of brief resilience scale

BRS SCORE	INTERPRETATION
1.00-2.99	LOW RESILIENCE
3.00-4.30	NORMAL RESILIENCE
4.31-5.00	HIGH RESILIENCE

Scoring: Add the responses varying from 1-5 for all six items giving a range from 6-30. Divide the total sum by the total number of questions answered

TOOL 2: ZARIT BURDEN INTERVIEW (ZBI)

Table 12; zarit burden interview questions

		Never (0)	Rarely (1)	Sometimes (2)	Frequently (3)	Nearly Always (4)
1.	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2.	Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3.	Do you feel angry when you are around your relative?	0	1	2	3	4
4.	Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5.	Are you afraid what the future holds for your relative?	0	1	2	3	4
6.	Do you feel strained when you are around your relative?	0	1	2	3	4
7.	Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8.	Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9.	Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10.	Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11.	Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4

12.	Do you feel uncertain about what to do about your relative?	0	1	2	3	4
13.	Do you feel that you should be doing more for your relative?	0	1	2	3	4
14.	Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15.	Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16.	Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17.	Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18.	Do you feel your relative is dependent upon you?	0	1	2	3	4
19.	Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20.	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	0	1	2	3	4
21.	Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22.	Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

Scoring Instructions:

Add Items 1-12 - Total 1-12 (maximum score = 48)

Add Items 13-21 - Total 13-21 (maximum score = 36)

Score # 22 (maximum score = 4)

Total Score (88)

Interpretation:

Total score range: 0 to 88

0-21: no to mild burden

21-40: mild to moderate burden

41-60: moderate to severe burden

≥ 61: severe burden

APPENDIX I

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Cu t^mw {i²m]qÀÆw hmbn¡pI. Cu tUmIypsaânse `mjtbm hnhc§tfm \n§Ä¡v a\ÊnemIp¶nsÃ¦nÂ. Zbhmbn {][m\ At\zjI \pambn NÀ¨ sN¿pI. Cu]T\¯nÂ]s¦Sp¡m³ \n§Ä k¶²cmIm³ Xocpam\n¡pIbmsW¦nÂ, Cu t^man³sä Ahkm\w \n§Ä H¸nSWw.

1) **KthjW]T\¯nsâ BapJw**: lotamUbmenknkn\v hnt[bcmb hn«pamdm¯ hr¡tcmKnIsf]cnNcn¡p¶hÀ¡nSbnse `mchpw {]Xntcm[tijnbpw hnebncp¯m³ Cu]T\w e£yanSp¶p.
2) **]T\¯n³sä Dt±iw**: lotamUbmenknkn\v hnt[bcmb hn«pamdm¯ hr¡tcmKnIsf]cnNcn¡p¶hÀ¡nSbnse]cnNcWw \ÂIp¶ bmfpsS `mchpw {]Xntcm[tijnbpw Xncn¨dnbpI F¶XmWv]T\¯n³sd e£yw.

3) **BÀs¡ms¡]s¦Sp¡mw** : hn«pamdm¯ hr¡tcmKapÅ tcmKnIfpsS {]mYanI ip{iqjIÀ¡v]T\¯nÂ]s¦Sp¡mw

4) **]T\s¯¡pdn¨pÅ hnhc§Ä** :]s¦Sp¡m³ {]Xo£n¡p¶ sam¯w tcmKnIfpsS F®w 100 BWv,]T\hpambn _Ôs¸« Hcp tNmZymhen \n§Ä]qcn¸n¡Ww.

5)]T\¯nÂ \n§fpsS]¦v/D¯chmZn¯w:

- tNmZn¡pt¼msgÃmw IrXyamb hnhc§Ä \ÂIpI.
- At\zjIcpsS \nÀt±i§Ä]men¡pI.
-]T\kab¯v A\p`hs¸Sp¶ GsX¦nepw {]iv--\s¯¡pdn¨v]T\ At\zjIs\ Adnbn¡pI.
- \n§Ä¡v]T\w \nÀ¯Wsa¦nÂ, {][m\ At\zjIs\ Adnbn ¡Ww.

6) F´mWv A]ISkm[yXIÄ :]T\¯nÂ]s¦Sp¡p¶XnÂ A]IS km[yXIsfm¶panÃ.

7)]T\¯nÂ]s¦Sp¡p¶Xn³sd km[yXbpÅ t\«§Ä Fs´m s¡bmWv:

Cu]T\¯nÂ]s¦Sp¡p¶XneqsS \n§Ä¡v {]tbmP\w e`n¡pItbm e`n¡mXncn¡pItbm sN¿mw. \n§Ä sa¨s¸Smt\m AsÃ¦nÂ AtX]Sn XpScmt\m km[yXbp-v.

**8) e`yamb CXc NnInÕIÄ Fs´ms¡bmWv:** {]tXyI _ZÂ NnInÕIÄ e`yaÃ.

9)]T\¯nÂ]s¦Sp¡p¶Xn\pÅ sNehv: Cu]T\¯nÂ]s¦Sp¡p¶Xn\v bmsXmcp sNehpw DÄs¸Sp¶nÃ.

10)]cn¡n\pÅ \ã]cnlmcw:]T\¯nÂ]s¦Sp¡p¶XnÂ A]ISkm[yXIsfm¶panÃ.]T\¯n³sd t\cn«pÅ ^eambn Cu KthjW]T\¯n\nSbnÂ Hcp saUn¡Â {]iv\w DbÀ¶ph¶mÂ, \n§Ä¡v icnbmb sshZyklmbw \ÂInbn«ps-¶v Dd¸m¡m³ At\zjI³sd D¯chmZn¯w D-mbncn¡pw.

11. hnhc§fpsS clkymßIX: \n§fpsS t]cv, hnemkw, saUn¡Â tcJIÄ F¶nh DÄs¸sSbpÅ]T\¯nÂ \n¶pÅ hnhc§Ä AwKoIrX DtZymKØÀ am{Xta AhtemI\w sN¿pIbpÅq. Cu]T\¯nÂ \n¶pÅ hnhc§fpw ^e§fpw \n§fpsS t]cpw hyànKX sFUân^nt¡j\pIfpw DÄs¸Sp¯msX aoänwKpIfnÂ AhXcn¸n¡pItbm tPWepIfnÂ {]kn²oIcn¡pItbm sN¿mw.

12. k¶²]¦mfn¯w: KthjW]T\¯nÂ {]thin¡p¶Xv kzta[bm DÅXmWv. \n§Ä KthjW]T\¯n\v k¶²Xbps-¦nÂ, Ft¸mÄ thWsa¦nepw \nÀ¯m\pÅ AhImiw \n§Ä¡p-v, AXn\v \n§Ä Hcp ImcWhpw]dtb-XnÃ.

13. Fs´¦nepw tNmZy§fps-¦nÂ Bsc _Ôs¸SWw: Cu t^mans\¡pdnt¨m]T\hpambn _Ôs¸« GsX¦nepw {]iv--\s¯¡pdnt¨m \n§Ä¡v Fs´¦nepw tNmZy§fps-¦nÂ, \n§Ä¡v C\n¸dbp¶ hyànbpambn _Ôs¸Smw.

t]cv: Inc¬ hn \mbÀ

hnemkw: ko\nbÀ eIv--NdÀ, anwkv tImtfPv Hm^v \gvk--nwKv

sSent^m¬ \¼À: 8086248010

APPENDIX J

k½X]{Xw

F\n¡v apIfnepÅ]T\¯n\mbpÅ]¦mfn¯ hnhc]{Xw hmbn¨n«p s-¶pw AXnsâ DÅS¡w Rm³ DÄs¡m-psh¶pw ØncoIcn¡p¶p. F\n¡v kwib§Ä tNmZn¡m\pw Ah¡v Xr]vXnIcamb adp]Sn e`n¡m\pw Ahkcw e`n¨n«p-v. Cu]T\¯nÂ]s¦Sp¡p¶Xv k½Xt¯msSbmsW¶pw, F\n¡v GXv kab¯pw ImcWw]dbmsX Xs¶]T\¯nÂ \n¶v]n³hm§mw. AXn\mÂ Fsâ BtcmKy]camb \nba]camb AhImi§fnepw _m[IXbp-mInsÃ¶pw F\n¡v a\Ênem¡mw.

Rm³ apIfnepÅ]T\¯nÂ]s¦Sp¡m³ k½Xn¡p¶p. Cu H¸n«Xpw XobXn tNÀ¯Xpamb k½X]{Xt¯msSm¸w]¦mfn¯ hnhc]{Xw Hcp]IÀ¸v e`n¨n«ps-¶v Rm³ ØncoIcn¡p¶p.

]s¦Sp¡p¶ hyànbpsS t]cv:

]s¦Sp¡p¶ hyànbpsS {]mbw:

]s¦Sp¡p¶ hyànbpsS hnemkw:

H¸v :

XobXn:

k½Xw hniZoIcn¨ hyànbpsS t]cpw H¸pw:

XobXn:

APPENDIX K

hn`mKw F

hy¡ tcmKnIfpsS]cnNmcIcpsS kmaqlnI hyànIX {]IS\w

1.{]mbw (hÀj¯nÂ):

2.enwKw:

F)]pcpj³ ( )

(_n) kv{Xn ( )

kn) .{Sm³kvsP³UÀ ( )

3.hnZym`ymkw:

F) .\nc£c³ ()

_n) .{]mYanI hnZym`ymkw ()

kn).sk¡³Udn ()

Un) .lbÀsk¡³Udn ()

C). _ncpZw /Unt¹ma ()

F^v) ._ncpZm\µc _ncpZw ()

4. aXw

F) lnµp ()

_n) .apÉnw ()

kn) .{InkvXy³ ()

Un) .aäpÅh ()

5.sXmgnÂ

F) .Krl]cn]me\w/ CÃ ()

_n) . kzImcy Poh\¡mc³ ( )

kn) .kzbwsXmgnÂ ()

Un) .kÀ¡mÀ DtZymKØ³ ()

C) hncan¨hÀ ()

6. hnhmlnX ØnXn:

F) hnhmlnX³ ()

_n) . hn[h ()

kn). thÀ]ncnªh³ ()

Un). hnhmltamNnX³ ()

C) AhnhmlnX³. ()

7.tcmKnbpambpÅ _Ôw:

F) A½ ()

_n).AÑ³ ()

kn) .`À¯mhv/`mcy /]¦mfn()

Un) .ktlmZc³ / ktlmZcn ()

C) aI³ ()

F^v) . A\´ch³ ()

8.IpSpw_¯nsâ Xcw:

F) .AWp IpSpw_w ()

_n) .Iq«pIqSpw_w ()

kn) .hn]peoIcn¨ IpSpw_w ()

9.Xmakn¡p¶ Øew:

F) .{Kmaw ()

_n) .\Kcw ()

kn). D]\Kcw ()

10.amk hcpam\w (cq]bnÂ):

F). 5000 ¯nÂ Xmsg ( )

_n). 5001-10000()

kn). 100001-15000 ()

Un). 15001-20000 ()

C). 20000 \v apIfnÂ ()

11. BtcmKy C³jpd³kv:

F) D-v ()

_n) .CÃ ()

hn`mKw _nþhy¡ tcmKnIfpsS tcmKhnhc§Ä

1.hy¡ tcmK¯nsâ L«§Ä:

F) L«w 1 ()

_n). L«w 2()

kn). L«w 3 ()

Un). L«w 4 ()

C) L«w 5 ()

2.tcmK¯nsâ Imebfhv:

F). 12 amk¯nÂ Xmsg ()

_n). 12 amk¯nÂ IqSpXÂ ()

3.\nehnse NnInÕ:

F). Ubmenknkv am{Xw ()

_n). ikv{X{Inb ()

kn). acp¶pIÄ ()

4. Ubmenknknsâ Imebfhv:

F). 12 amk¯nÂ Xmsg ()

_n). 12 amk¯nÂ IqSpXÂ ()

5.kltcmK§Ä:

F). D-v ()

_n) CÃ. ()

6. F{X XhW Ubmenknkv sN¿pw

F) Bgv--NbnÂ Hcp XhW ()

_n). BgvNbnÂ c-v XhW ()

kn). Bgv--NbnÂ aq¶p XhW ()

Un) . BgvNbnÂ \mev XhW ()

7. {]jdpw {]talhpw Dt-m

F). {]jÀ D-v ()

_n) .{]talw D-v ()

kn) .c-pw D-v ()

8. {Sm³kv¹tâj³ sNbvXn«pt-m

F) D-v ()

_n) CÃ ( )

9. Ubmenknknsâ k¦oÀWXIÄ

F) NÀ±n ( )

_n) XethZ\ ( )

kn) t]in thZ\ ( )

Un) icoc`mcw Ipdbp¶p ( )

SECTION B : BRIEF RESILIENCE SCALE (BRS)

{Ia \¼À	{]kvXmh\	Xo{hamb n hntbmPn¡p¶p	hntbmPn¡p¶p	\njv]£w	AwKoIcn¡p¶p	Xo{hamb n AwKoIcn¡p¶p
BRS 1	hnjaIcamb kmlNcy§fnÂ \n¶v Rm³ thK¯nÂ Xncn¨p hcm³ {ian¡mdp-v	1	2	3	4	5
BRS 2	k½À±Icamb kw`h§sf XcWw sN¿m³ F\n¡v _p²nap«p-v	5	4	3	2	1
BRS3	k½À±Icamb Hcp kmlNcy¯nÂ \n¶v Ic Ibdm³ F\n¡v A[nI kabw BhiyanÃ	1	2	3	4	5
BRS 4	tamiw Imcy§Ä kw`hn¡pt¼mÄ AXnÂ \n¶v]pd¯p hcm³ F\n¡v _p²nap«p-v	5	4	3	2	1
BRS 5	km[mcWbmbn hnjaIcamb kab§enÂ Rm³ sNdnb {]iv\§tfm sS IS¶p t]mImdp-v	1	2	3	4	5
BRS 6	Fsâ PohnX¯nse Xncn¨SnIfnÂ \n¶v Ic Ibdm³ F\n¡v IqSpXÂ kabw thWw	5	4	3	2	1

Tool 2 Zarit caregiver burden interview

		Hcn¡e panÃ (0)	A]qÀ Æamb n (1)	Nnet¸ mÄ (2)	CSbv ¡nsS (3)	Ft¸mg pw (4)
1	\n§fpsS _Ôp Bhiy¯ns\ ¡mÄ A[nIw klmbw Bhiys¸Sp¶Xmbn \n§Ä¡v tXm¶p¶pt-m?					
2	\n§fpsS _Ôphn\v th-n Nnehgn¡p¶ kabw ImcWw \n§Ä¡v kz´w Imcy§Ä t\m¡m³ kabansÃ¶v tXm¶p¶pt-m?					
3	\n§fpsS _Ôphns\ ]cnNcn¡p¶Xnt\msSm¸w \n§fpsS IpSpw_¯nse AsÃ¦nÂ tPmen Øes¯ aäp NpaXeIÄ \ndthäm³ {ian¡pIbpw sN¿p¶XnÂ \n§Ä¡v Bbmkw A\p`hs¸Sp¶pt-m?					
4	\n§fpsS _Ôphnsâ s]cpamäw ImcWw \n§Ä¡v \mWt¡Sv A\p`hs¸Smdpt-m?					
5	\n§Ä¡v _Ôphnsâ kao]ambncn¡pt¼mÄ tIm]w A\p`hs¸Smdpt-m?					
6	\n§fpsS kplr¯p¡fpw aäv IpSpw_mwK§fpambpÅ _Ôs¯ \n§fpsS _Ôp Ct¸mÄ {]XnIqeamb hn[w kzm[o\n¡p¶Xmbn \n§Ä¡v tXm¶p¶pt-m?					
7	\n§fpsS _Ôphnsâ `mhn F´mIpsa¶v \n§Ä `bs¸Sp¶pt-m?					
8	\n§fpsS _Ôp \n§sf B{ibn¡p¶p F¶v \n§Ä IcpXp¶pt-m?					
9	\n§fpsS _Ôphnsâ kao]¯mIpt¼mÄ \n§Ä¡v]ncnapdp¡w A\p`hs¸Smdpt-m?					
10	\n§fpsS _Ôphnsâ Imcy§fnÂ CSs]«XpsIm-v \n§fpsS BtcmKy¯n\v {]iv\ap-msb¶v \n§Ä¡v tXm¶p¶pt-m?					
11	\n§fpsS _Ôp ImcWw \n§Ä¡v Bhiyamb{X kzImcyX e`n¡p¶nÃ F¶v \n§Ä¡v tXm¶p¶pt-m?					
12	\n§fpsS _Ôphns\ ]cnNcn¡p¶Xv sIm-v \n§fpsS kmaqlnI PohnXw XIcmdnembXmbn \n§Ä¡v tXm¶p¶pt-m?					
13	\n§fpsS _Ôp ImcWw \n§fpsS kplr¯p¡Ä kµÀin¡p¶Xv AkuIcyambn tXm¶p¶pt-m?					
14	\n§fpsS _Ôp \n§sf am{Xta hnizkn¡m³ km[n¡q F¶v IcpXp¶Xv sIm-v \n§Ä _Ôphns\ ]cnNcn¡psa¶v {]Xo£n¡p¶p F¶v \n§Ä¡v tXm¶p¶pt-m?					
15	\n§fpsS NnehpIÄ¡v tijw \n§fpsS _Ôphns\ ]cnNcn¡p¶Xn\v am{Xw]Ww \n§fpsS]¡Â D-mhnÃ F¶v \n§Ä¡v tXm¶p¶pt-m?					

16	\n§Ä¡v A[nI Imew \n§fpsS _Ôphns\ ]cnNcn¡m³ km[n¡nsÃ¶v \n§Ä¡v tXm¶p¶pt-m?					
17	\n§fpsS _Ôphnsâ AkpJ¯n\v tijw \n§Ä¡v \n§fpsS PohnX¯nse \nb{´Ww \jvSs¸«Xmbn tXm¶p¶pt-m?					
18	_Ôphns\ ]cnNcn¡p¶Xv aämscsb¦nepw GÂ¸n¡m³ km[n¨ncps¶¦nÂ F¶v \n§Ä B{Kln¨n«pt-m?					
19	\n§fpsS _Ôphn\v F´msW sNt¿-Xv F¶Xns\Ipdn¨v \n§Ä¡v A\ninNnXXzw A\p`hs¸Smdpt-m?					
20	\n§fpsS _Ôphn\v th-n IqSpXÂ Imcy§Ä sNt¿-Xp-v F¶v \n§Ä¡v tXm¶mdpt-m?					
21	\n§fpsS _Ôphns\ ]cnNcn¡p¶Xv Ipd¨v IqSn sa¨s¸Sp¯m³ km[n¡psa¶v \n§Ä¡v tXm¶p¶pt-m?					
22	sam¯¯nÂ \n§fpsS _Ôphns\ ]cnNcn¡p¶Xv F{Xt¯mfw ZpcnXambncp¶p?					