

**THE BURDEN OF CARE AMONGST CAREGIVERS OF CHILDREN WITH CHRONIC  
KIDNEY DISEASE ON DIALYSIS AT THE KENYATTA NATIONAL HOSPITAL**

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**H56/37557/2020**

**A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF DEGREE IN MASTERS OF SCIENCE IN  
RENAL NURSING OF THE UNIVERSITY OF NAIROBI**

**NOVEMBER, 2022.**

## DECLARATION

I FAITH WANGUI WARIGUAH, MSc. Renal Nursing student (UON) do hereby declare that this research thesis is my original work and has not been submitted for examination purposes or award of credit in any other institution of higher learning.

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## **DEDICATION**

I dedicate this research work to my beloved husband who is my biggest support system. Thank you for all your encouragement and cheering me on throughout this course.

## **ACKNOWLEDGEMENTS**

I wish to thank everyone who encouraged and supported me throughout the process of research and thesis writing.

I am grateful to my supervisors, Ms. H. Inyama and Dr. J. Mwaura, for their time and dedication in guiding me through this process.

Special thanks to my family- My parents, my brothers and sisters, for your spiritual and emotional support. God bless you.

To my dear husband, words cannot express my deepest gratitude for your moral, financial, emotional and technical support. Your advice has been and will always be cherished.

Last but not least- The Lord has been my pillar of strength and it's by His grace that I have made it this far.

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## **LIST OF ABBREVIATIONS**

CKD	Chronic Kidney Disease
ERC	Ethics and Research Committee
ESRD	End Stage Renal Disease
KDOQI	Kidney Disease Outcomes Quality Initiative
KDIGO	Kidney Disease Improving Global Outcomes
KNH	Kenyatta National Hospital
PI	Principal Investigator
RRT	Renal Replacement Therapy
SSA	Sub Saharan Africa
UoN	University of Nairobi
WHO	World Health Organization
ZBI	Zarit Burden Interview

## OPERATIONAL DEFINITIONS

**Chronic Kidney Disease:** According to KDIGO, CKD is defined as kidney damage or glomerular filtration rate (GFR)  $<60 \text{ mL/min/1.73 m}^2$  for 3 months or more, irrespective of cause. It is the progressive and irreversible loss of kidney function that requires renal replacement therapy to sustain life and increase longevity and quality of life. It is classified in 5 stages, that is, stage 1 which refers to mild CKD to stage 5 which refers to ESKD.

**Caregiver:** A caregiver is a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability.

**Caregiver burden:** It is the physical, psychological, and social reaction of caregivers to the act of caring that occurs as a result of a conflict between caring demands and other responsibilities such as personal/social responsibilities, employment, and family roles. (Alshammari et al., 2021; Oyegbile&Brysiewicz, 2017)

**Child:** A child is any person under the age of 18.

## ABSTRACT

**Background:** In children, chronic kidney disease (CKD) differs from that of adult people, with the most prevalent basis/roots of CKD in children are congenital malformations and genetic disorders. While adolescents and children make up a tiny percentage of patients having CKD, the consequences are far-reaching, not just for the child but also for the child's primary caregiver. Family caregivers take on a variety of responsibilities on management of the child's condition while dealing with the psychological stress of caring for a chronically ill child. The burden associated with the caregiver position arises from a caregiver's negative emotional and physical reactions to the changes and pressures encountered while giving care. Healthcare professionals should therefore focus not just on the health of their patients, but also on the health of their caregivers, who are an important component of the patient's care because, overburdened carers are unlikely to adequately meet the needs of those that they care for.

**Objective:** To undertake an evaluation of the care burden amongst persons who cared for children having CKD being offered dialysis at the Kenyatta National Hospital

**Methods:** This was a descriptive cross-sectional study that was performed amongst caregivers of children with CKD on dialysis at Kenyatta National Hospital. Both qualitative and quantitative methods were used. A census was done for all eligible caregivers within the study period where a total of 18 children with CKD were identified. The study tools included a self-created questionnaire on the socio-demographic data of the respondents and the Zarit Burden Interview (ZBI) tool for evaluating carer's level of difficulty, all of which were interviewer-administered. Pretesting of the tools was done during the pilot study. The study data was analyzed descriptively utilizing SPSS version 28.0 with findings shown as frequencies and percentages. Associations were measured using Fisher's exact test. All statistical tests were assessed at 95% CI ( $P < 0.05$ ).

**Results:** The median age among caregivers was 42 (IQR: 31 – 50) years, 12 (66.7%) were female, 13 (72.2%) had secondary education as their highest level of education, 14 (77.8%) were married. Most of the caregivers, 12 (66.7%) of the caregivers were self-employed, 8 (44.4%) had monthly income which was barely adequate for basic family needs, 17 (94.4%) of caregivers were parents to the patients. The characteristics of the patients revealed that the median age was 16 (IQR: 11 – 18) years, 11 (61.1%) were male, 15 (83.3%) had acquired CKD. The median duration of illness was 27 (20 – 60) months, 10 (55.6%) had pre-existing comorbidity. The average burden of care score was 46.27 ( $SD \pm 14.5$ ), 8 (44.4%) of the caregivers had mild to moderate burden, 6 (33.3%) had moderate to severe burden while 4 (22.2%) had severe burden. Monthly income and duration of illness were key factors significantly associated with burden of care.

**Conclusion and recommendations:** The findings have established that all of the caregivers have at least mild care burden with majority having moderate to severe burden of care. Duration of illness and monthly income have been identified as key factors associated with burden of care. Therefore, healthcare providers ought to communicate clearly about the condition of the child and the level of care needed to achieve improved health outcomes as well as ensuring that insurance covers most common and costly tests and investigations done.

## CHAPTER 1 : BACKGROUND

### 1.1.Introduction

Chronic kidney disease (CKD) is an issue of significant concern health-wise around the world, affecting 10% of the population and making it one of the most common chronic diseases. Though there's a lot of research involving adult population, but little is known about the epidemiology of CKD in children. Based on guidelines issued by KDIGO, CKD's defined as evidence of existence of renal impairment, either structurally or functionally or alternatively as a drop in glomerular filtration rate (GFR) below 60 mL/min/1.73 m<sup>2</sup> of body surface area that lasts longer than three months (Alshammari et al., 2019).

Chronic kidney disease (CKD) in children differs from that of adults, and the highly prevalent basis/roots leading to CKD in children being kidney's anomalies at birth and those affecting the urinary tract (CAKUT), followed by nephropathies and glomerulonephritis that are genetic (Harambat et al., 2012, )(Francesca B, at al., 2016). Defects at birth and hereditary ailments constitute the leading contributors of kidney failures starting at birth to 4 years. Between ages 5 and 14, nephrotic syndrome, genetic illnesses and systemic ailments constitute the most prevalent reasons behind kidney failure. Glomerular diseases take precedence in leading to failure in kidney for between ages 15 and 19 years. (USRDS Annual Data Report, 2021).

Since early-stage CKD is typically symptomless hence rarely medically detected and is ill reported, there is little data on the epidemiology of the disease in children.

While adolescents and children make up a tiny percentage of patients suffering from CKD (UK Renal Registry, 2009), the consequences are far-reaching, not just for the child but also for the child's primary caregiver. Hemodialysis is the most frequent type of renal replacement therapy (RRT) worldwide, and it prolongs life in end-stage renal disease-patients. The advances in the treatment of pediatric chronic illnesses such as CKD have led to patient care delivered at home, primarily offered by family caregivers, and is progressively replacing hospital-based care. In the case of pediatric CKD, carers at family level may take on a variety of responsibilities, such as giving of medicines, helping patients adhere to prescribed diet and fluid intakes, transportation to

the hospital, and dialyzing when necessary; all while dealing with the psychological stress of caring for a child who is severely sick. (Parham et al., 2016)

This long-term care is on the other hand very demanding because it necessitates significant lifestyle adjustments. The associated demands have a great impact on a person's social life, especially for family members who offer most of the support.

Studies done to assess the caregiver burden have shown a variety of factors that contribute to high caregiver burden. These include the care giver's financial situation, occupation, supportive resources, and culture. These factors may greatly influence how caregivers approach caring for a chronically ill patient.(Adib-Hajbaghery&Ahmadi, 2019; Mwenda et al., 2019)

A number of empirical investigations focusing on difficulties of care among persons who care for adult patients undergoing dialysis have been done in Kenya (Gatua, 2016; Stanley, 2019). There are however no studies done on care related difficulties for those caring for children suffering from CKD in the country. This study therefore was an evaluation of the care burden and associated determinants in carers of pediatrics on maintenance dialysis.

## **1.2.Problem statement**

Across the world, chronic kidney disease (CKD) is an issue of significant people's health concern. It is estimated that, in 2019, approximately 1.4 million people died of CKD in the globe, a rise of about 20 percent compared to 2010, hence CKD had one of the most significant increases among leading mortality causes globally. Low and middle income countries are affected by CKD in a much bigger way as they have significantly higher CKD prevalence and mortality.(GBD, 2019) 13.4% with ranges of 11.7 to 15.1% is the CKD prevalence at the global level, and patients diagnosed with end-stage kidney disease (ESKD) requiring renal replacement therapy are estimated as ranging 4.902 to 7.083 million. (Lv JC, 2019)

In Sub-Saharan Africa (SSA) and most developing countries, the rates of CKD among children are not known and estimates are difficult to generate due to paucity of data regarding children's kidney disease largely due to the general lack of national renal registries. Following this, deaths and morbidity are particularly elevated in SSA especially due to very limited availability of



dialysis services. Care outcomes are thus often quite poor with death rates as high as 34% compared to global rates of 13.8%.(Halle, M.P., Lapsap, C.T., Barla, 2017)

Over 4 million Kenyans are estimated to have chronic kidney disease, with a significant portion of this population eventually developing kidney failure, according to estimates from the Ministry of Health. Only 10% of those who require dialysis can access the services; of those, about 10,000 have end-stage renal disease and need it (MOH Kenya, 2017)

The burden associated with the caregiver position arises from a carer's negative emotional and physical reactions to the changes and pressures encountered while assisting persons with a mental or physical condition. It's a multifaceted notion that incorporates the mental, physiological, social and financial care aspect (Gatua, 2016; Lima et al., 2019; Tsai et al., 2006)

Parents in many times constitute the main carers for chronically ill adolescents and children. A child's diagnosis with a long term condition or handicap has a detrimental impact on not just the patient's physical, psychological, and social health, but also on the caregivers'. Depressive symptoms are found to be more common in persons who care for severe long term conditions patients than in the general population. (Mahmoud et al., 2021) The combination of physical exertion, emotional pressure, social restrictions, and economic pressures that caregivers face while providing care to their patients causes family strain, leading to a considerable drop in caregivers' life standards and status of health. (Adib-Hajbaghery&Ahmadi, 2019; Toledano-Toledano et al., 2020).

Furthermore, children and their caregivers face the task of navigating different social and health care settings, seeking treatments and expenses, financing their healthcare, and gaining access to educational programs. Difficulties are much more in developing countries for patients with ESRD, as many areas lack pediatric care centers; at the same time, this places a burden on the patient and their caregivers, who are often unprepared to take on this emerging role, causing them to suffer from adverse effects such as stress, anxiety and depression, which can negatively impact their own health.

Healthcare professionals should focus not just on the health of their patients, but also on the health of their caregivers, who are an important component of care at home, because patients' need are greatly unlikely to be adequately met by an overburdened caregiver.

### **1.3.Study justification**

In paediatric CKD care, the focus is mainly on the child's medical treatment and overall well-being. Less focus is given to the caregivers. In view of data demonstrating a link established between elevated stress level in carers and poorer medical and developmental results in children being treated for CKD (El Shafei et al., 2018;(Sou'ub R, Masa'Deh R et. al, 2018), it has been suggested that family caregiver performance needs monitoring for them to be offered appropriate assistance when necessary. (Tong et al., 2008; Watson, 2014)

It's critical that persons who care for pediatric CKD patients are offered necessary support and information to better their life's quality and to help them better cope with the caregiving role. They also need to be equipped with appropriate know-how, insights, education and competencies so they can effectively support their patients to better adhere to the HD therapy. (Eirini, G., & Georgia, 2017).

Therefore, considering that most existing research focuses on CKD's burden to patients and only few studies have focused on their caregivers, it's evident that there's scarcity of knowledge regarding the burden experienced by the CKD children's carers and regarding their general psychosocial well-being in Africa.

Some research on the burden of adult patient caregivers have been conducted in Kenya (Gatua, 2016; Stanley, 2019). There are no studies done on the burden of care in children having CKD in Kenya.

The current study therefore, sought to evaluate the care difficulties experienced by carers of adolescents and children with long-standing kidney disease who undergo renal replacement therapy at the KNH Renal Unit and additionally, to identify the possible factors associated with the outcome variables.

This study's results are essential for healthcare providers to become aware of the burden of care among caregivers of children and adolescents undergoing renal replacement therapies. This may also offer evidence and inform the importance of including an assessment of the carers in guidelines regarding treatment of CKD patients and to develop support programs critical for helping them to effectively cope with the caregiving role as well as reducing associated burden. At the national level, these results inform development of policies and guidelines on management of chronic kidney diseases in Kenya.

#### **1.4. Research topic**

The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital, Kenya

#### **1.5. Research questions**

1. What is the level of burden amongst caregivers of children with CKD on dialysis?
2. What are the factors associated with caregiver burden amongst caregivers of children with CKD on dialysis?

#### **1.6. Research objectives**

##### **1.6.1. Broad objective**

To evaluate the burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital

##### **1.6.2. Specific objectives**

1. To quantify the care burden amongst caregivers of children with CKD on dialysis at KNH
2. To assess the patient-related factors associated with high caregiver burden amongst caregivers of children with CKD on maintenance dialysis at KNH

3. To find out the caregiver-related factors associated with high caregiver burden amongst caregivers of children with CKD on maintenance dialysis at KNH

### **1.7. Research hypothesis**

The level of care difficulties experienced by persons that cared for children with long standing disease of the kidneys on maintenance dialysis is severe based on Zarit burden interview.

### **1.8. Significance of the study**

Because of the rising number of persons requiring dialysis treatment and the increased focus on home therapies, informal caregiver burden is becoming a serious concern in renal care. The renal team may be able to identify specific caregivers who require support by assessing the caregiver burden of people whose family members are on dialysis therapy. Furthermore, determining which caregiving activities are strongly linked to the burden experienced by informal caregivers could help renal nurses and social workers provide more suitable support for these caregivers. (Hoang et al., 2019)

There are several determinants found to be connected to distinct feelings of carer difficulties such as living with the patient, age, gender, education, socioeconomic level, how they related to the one being cared for and comorbidities. The strain on caretakers of chronically ill patients has received minimal attention, with most studies focusing on psychiatric illnesses like dementia and breast cancer, with less attention paid to caregiver burden in CKD and especially in the pediatric population. (Alshammari et al., 2019, 2021; Oyegbile & Brysiewicz, 2017; Zhang et al., 2016)

Given the high level of care burden experienced by hemodialysis patients' caregivers and the negative consequences, it's suggested that health care team members pay more attention to caregivers' health as hidden patients when planning, and that necessary interventions such as patient and caregiver education, counseling, support resources, and referral services be considered for reducing caregiver care burden and improving their life's quality. It is also recommended that studies be undertaken to explore effective strategies for reducing the care burden in dialysis patients, so that the quality of care delivered to patients and their quality of life can be improved by enhancing caregivers' health. In addition, conducting systematic reviews and meta-analysis

studies to accurately and timely estimate the level of care burden and avoid the negative consequences can be beneficial in a number of other conditions. (Jafari-Koulaee, A., Goudarzian, A. H. ., Beik, S. ., Heidari, T. ., &Hesamzadeh, 2020)

As a result, coping methods, social support, and support interventions should be established to help caregivers fulfill their responsibilities in caring for patients while also strengthening their ability to withstand effectively with the patient's condition. (Bayoumi, 2014; Darwish et al., 2020) Diverse teams helping children with CKD and their core carers could formulate a caregiver burden measure that is unique to those who cared for CKD pediatric patients that may assist in identifying those who are in need and planning targeted assistance and personalized intervention where possible. (Gilbertson et al., 2019) This would help them tailor treatments in ways that best serves the CKD patients and their primary caregiver and entire family as well.

## **2. CHAPTER: LITERATURE REVIEW**

### **2.1.Introduction**

This chapter highlighted studies done on the research subject following the guidance of the study objectives. It began with an overview of prevalence of CKD in children and adolescents and renal replacement therapies. It also contained a review of empirical literature on the caregiver burden in children with CKD, the factors associated with high levels of burden and the assessment of the caregiver burden. The chapter also presented the study's theoretical and conceptual frameworks.

### **2.2.Prevalence of CKD in children and adolescents**

Despite the fact that several pediatric CKD registries employing categorization by the Kidney disease outcomes Quality initiative (K/DOQI) are emerging, information regarding the epidemiology of the various stages of CKD in children is largely lacking with the situation in low-income countries remaining greatly unexplored. Most of the data for these countries comes from reports from major tertiary care referral centers, and the credibility of the information can vary. A lot of the epidemiological data comes from ESRD registries and therefore information on the early phases of pediatrics' CKD is still scarce.(Harambat et al., 2012). Furthermore, most childhood CKD registries are constrained to small reference groups, which limit their use. These restrictions notwithstanding, the childhood rates of CKD are estimated at about 11–12 per million of age-related population (pmarp) in Europe for stages 3–5, with a prevalence of 55–60 pmarp. (Halle, M.P., Lapsap, C.T., Barla, 2017; Harambat et al., 2012)

Patients requiring renal replacement therapy (RRT) due to having ESRD have been the focus of specific reporting in children's CKD epidemiology. RRT in children has a global median incidence of 9 pmarp in children under the age of 20, with a prevalence of 65 pmarp. Furthermore, higher incidence and prevalence rates have been recorded in the United States, owing to the fact that RRT is started sooner at higher GFR levels in the United States than in other developed countries. The bulk of RRTs in children are undertaken in the developed countries; particularly North America, Europe and Japan where these exceptionally expensive therapies may be

afforded. As a result, the true effect of CKD on children in underdeveloped nations is still unknown, particularly among nations where resources allocated to RRT are insufficient or nonexistent, and children with CKD commonly die.(Lesley Rees, Franz Schaefer, Claus Peter Schmitt, RukshanaShroff, 2017)

Because of higher rates of kidney congenital abnormalities and urinary tract (CAKUT) in males, the incidence and prevalence of CKD is higher in them than in females.(Harambat et al., 2012)

In empirical studies carried out in single facilities in SSA, CKD incidence was approximated to be 3 pmarp in Nigeria, which offered not pediatric RRT, and 1 to 2 pmarp in South Africa (Bhimman, R., Adhikari, M., Asharam, 2008). The actual frequency and burden of CKD in children in Kenya is unknown due to the lack of a national registry. End-stage renal disease (ESRD) is likely a "tip of the iceberg" in a developing nation like Kenya with insufficient diagnostic resources, and many patients are likely to have late diagnosis with renal disease after they have already developed end-stage renal failure.

### **2.3.Renal replacement therapy (RRT)**

Renal replacement therapy (RRT), entailing dialyzing or organ transplantation, is not common in adolescents and children suffering from severe chronic kidney disease. End-stage renal disease and the requirement for RRT in children are reported to vary around the world, with disparities related to genetic and environmental variables, as well as the financial ability to treat affected children.(Bertram, J. F., et.al. 2016)

The leading causes of end-stage kidney disease in children are congenital kidney and urinary tract anomalies; the prevalence of these anomalies reduces proportionately with age, but the prevalence of glomerular disease increases. Receiving organ transplant is the first choice of RRT in children due to its improved survival and quality of life. If pre-emptive transplantation is not possible, peritoneal dialysis and haemodialysis are two dialysis choices.(Lesley Rees, Franz Schaefer, et. al, 2017)

Peritoneal dialysis is more typically utilized in newborns with limited vascular access. Following that, preferences differ all throughout the world. Dialysis access sites must be retained for peritoneal dialysis and haemodialysis because children will be on renal replacement treatment for the rest of their lives. Because peritoneal dialysis is done at home, it's the most convenient for children's schooling and social lives. The willingness and capacity of families to assume responsibility for ambulatory medical care, however, this is critical to the strategy's effectiveness.

When compared to peritoneal dialysis, the proportion of patients on hemodialysis rises with age. Hemodialysis is normally done three times a week in a clinic for three to five hours each time. High-quality vascular access is required to achieve elevated plasma flow rates of 140–200 mL/min per m<sup>2</sup> body surface area, which are required for adequate elimination during a dialysis session of appropriate time interval. Fistula creation in children less than 6–8 years is a technically hard surgical technique that requires psychological preparation for the painful needling. Most child haemodialysis units still employ central venous catheters. Catheters, however, have a significantly elevated risk of infections and operation failure than fistulas, though they allow for higher rates of blood flow.

In children and adolescents, no differences in mortality and morbidity are observed between peritoneal dialysis and haemodialysis. Peritoneal dialysis is often favored in newborns since vascular access for haemodialysis is difficult to obtain and maintain, especially in infants, though even neonates can be effectively haemodialyzed with competent professionals. Peritoneal dialysis can be started at birth and continued until the patient reaches a bodyweight of 8–10 kg (around 15–2 years).

About 80 percent of all paediatric RRT patients reside in North America, Europe or Japan, where RRT is available to almost all children with end-stage kidney disease. RRT, on the other hand, is sparse or non-existent in low- and middle-income nations, where fiscal resources are limited and skilled staff are scarce. Dialysis is excessively expensive in many low- and middle-income nations due to budget constraints imposed by resident health authorities and the fact that dialysis costs annually may be more than the gross domestic income per capita of most developing countries. (Bertram, J. F., Goldstein, S. L., et al, 2016; Schaefer, F., Borzych–Duzalka, et. al, 2012)



According to a study that focused on publications evaluating the access to, quality and outcomes of dialysis treatment for patients diagnosed with end-stage kidney disease in Sub-Saharan Africa, only 61 percent of children with end-stage kidney disease in Sub-Saharan Africa get one or more dialysis sessions, and only 35 percent of children stayed on dialysis for at least three months. This brief treatment was most likely due to the children's families not being able to foot the costs for the treatment. (Ashuntantang G, Osafo C, Olowu WA, 2017)

#### **2.4. Caregiver burden in children with CKD**

A major consequence of caring for a chronically ill patient is caregiver burden. Physical exhaustion, long-standing and severe illnesses physically, being depressed, feeling socially isolated, and experiencing financial difficulties have all been linked to caregiver stress in prior studies. It's also acknowledged that carers of pediatrics with long term ailments suffered average to serious burden (Gatua, 2016; Lima et al., 2019)

An individual's subjective perception of overload in one or more of the four dimensions of caregiving - social, physical, financial and psychological - is referred to as caregiver burden, according to Chou (2000). In fact, research into the experiences of caregivers of children with CKD has found a number of stressors connected to revealed challenges, such as poor health physically, being restless, powerlessness, lack of certainty, constant obsession with the coming years, worry about their child's development and growth diminished household income, malfunctions to family relationships and activities loss of social interactions, and problems related to the complexity of CKD treatment. (Adib-Hajbaghery & Ahmadi, 2019; Alshammari et al., 2021; Chhetri & Baral, 2020; Zhang et al., 2016)

While particular interventions for caregivers of individuals with kidney disease are emerging, they tend to operationalize the non-personal component of burden faced by a caregiver, or both the subjective and objective elements at the same time, and are designed for caregivers of persons with renal disease. According to Gerritsen and Van der Ende (1994), "only the personal component should be operationally defined to enhance the precision of the construct, since anguish is considered as the fundamental of consensus on what represents burden, i.e. "fears, nervousness, despair, feelings of hopelessness, tiredness, poor health, remorse and animosity"" (p. 483); several

researchers who have studied caregiver burden agree (e.g. Chou, 2000; Poulshock and Deimling, 1984; Stommel et al., 1990).

Interdisciplinary team teams working with these caregivers may find it easier to identify those in need and plan targeted assistance and personalized intervention when a caregiver burden measure specific to caregivers of children with CKD is developed. 2019 (Gilbertson et al.)

It's also been proven that persons who care for children suffering from long term health conditions have sleeping related problems, have problems communicating with their families and friends, and have a poorer life standard. They also have more quarrels compared to other households (Tsai et al., 2006). Furthermore, parents' psychosocial problems and coping techniques may have an impact on parent-child interactions, as well as the quality of care they provide. (Cagan et al., 2018; Chhetri&Baral, 2020; Lima et al., 2019)

Because of the rising numbers of individuals in need of dialysis treatment and the increased focus on home therapies, informal caregiver burden is becoming a serious concern in renal care. The renal team may be able to identify specific caregivers who require support by assessing the caregiver burden of people whose family members are on dialysis therapy. Furthermore, determining which caregiving activities are strongly linked to the burden experienced by informal caregivers could help renal nurses and social workers provide more suitable support for these caregivers. (Hoang et al., 2019)

Chronic dialysis care for children is linked to a variety of psychosocial concerns that influence not only individual patients but also their families, emphasizing the significance of including play therapists, mental health experts and social workers on the team involved in dialysis of the pediatric patients. Except for cancer, children who get long-term dialysis had poorer overall health-based life standard values than those who do not get dialysis. (Tong et al., 2008) Depression is very common, and it is likely linked to a person's reliance on dialyzing machines for living, as well as regular school absences due to need for dialyzing or hospitalization. Caregivers frequently struggle to fulfill their responsibilities as carer or care-givers.

Spousal conflict and sibling neglect can result from parental stress, worries about their possible contribution to their child's complications, and the agony of watching their child undergo invasive procedures. It has been demonstrated that parents of children receiving home-based peritoneal dialysis are depressed, so regular assessment of their physical and mental health is necessary to ensure prompt intervention when necessary. T. C. Tsai and others (2006)

## **2.5.Factors associated with high burden of care**

In contemporary periods, increasing number of empirical investigations have been undertaken all around the world to assess caregiver burden. This research revealed that a variety of factors, including carers' financial situation, occupation, supportive resources, and culture, may influence how they approach caring for a chronically ill patient(Adib-Hajbaghery&Ahmadi, 2019; Mwenda et al., 2019)

There are several elements found to be connected to distinct feelings of difficulties on caregivers such as living with the patient, age, gender, education, socioeconomic level, how they relate with the patient as well as comorbidities. The strain on caretakers of chronically ill patients has received minimal attention, with most studies focusing on psychiatric illnesses like dementia and breast cancer, with less attention paid to caregiver burden in CKD and especially in the pediatric population(Alshammari et al., 2019, 2021; Oyegbile&Brysiewicz, 2017; Zhang et al., 2016)

Previous research has found that stronger family support is linked to better patient survival, treatment adherence, and health-based life standard among hemodialysis patients.(Hoang et al., 2019). Only one study focusing on strain on the part of carers of children suffering from long standing illnesses is known. It was done south of the country, focusing solely on carers of pediatrics aged below 12 years olds receiving in-hospital care or those referred to outpatient care centres. (Piran et al., 2017)

According to the findings of a Chinese study, family carers of Chinese patients on maintenance hemodialysis face a comparatively high physical and mental burden. Caregivers' level of education, age, working or not working, hours of caring, carer and patient connection, wellbeing physically and emotionally have all been identified as factors that contribute to caregiver burden.

The underlying condition of the patient, the number of co-morbidities, as well as the patient's income and medical expenses, all had an impact.(Zhang et al., 2016) physical exhaustion, long-standing and severe illnesses, feeling depressed, feeling socially isolated, and having financial difficulties have all been linked to caregiver burden in a prior study. It's also been discovered that persons who care for children suffering from long term diseases are under a lot of stress. In periods past, increasing number of empirical studies have been undertaken all around the world to assess difficulties on caregivers. These research revealed that a variety of factors, including carers' financial situation, occupation, supportive resources, and culture, may influence how they approach caring for a chronically ill patient.(Adib-Hajbaghery&Ahmadi, 2019)

Furthermore, according to the findings of a systematic review study on the attributes connected to carers' difficulties for ESKD patients, increased reported difficulties on the part of the carers was linked to being female; caregiver uneasiness, depression, and being sick while taking care of patients on HD treatment; utilizing more durations in care provision; being socio-economically poor; and living far away from dialyzing centers. Protective effects may be offered by a longer caregiver-patient relationship, higher marriage contentment, and being adequately supported socially by fellow household members. To decide how HCPs may offer efficient and desirable help to increase the caregiving productivity and lower caregiver strain, all of the components must be understood.(Alshammari et al., 2021)

## **2.6.Caregiver burden assessment**

Because of the correlation between the quality of care and parents' multifaceted health concerns, as well as the effects of caregivers' culture on how they experience caring, more multicenter studies need to be done to assess the burden of care and understand about the associated factors in first-degree caregivers of children with chronic disorders. (Adib-Hajbaghery&Ahmadi, 2019) (Zhang et al., 2016).

Caregivers of ESRD patients should be evaluated for their burden. Throughout this chronic illness journey, supportive psychosocial interventions should be accessible to improve the well-being and quality of life of caregivers as well as their ESRD patients. As a result, both medical and

psychosocial components of care for juvenile patients with CKD and their carers must be given. (Mahmoud et al., 2021)

According to some studies, different levels of appraisal among parents of ill children regarding the source of income, the role of the CKD child, the need for social relations adaptation, and the need to maintain relationships with medical staff, all of these things, without receiving proper support from social workers, can lead to a conflict, resulting in the patient's clinical response being suboptimal. (Mahmoud et al., 2021; Oyegbile&Brysiewicz, 2017; Parham et al., 2016)

Given the high level of care burden experienced by caregivers of hemodialysis patients and the negative consequences, it is recommended that health care team members pay more attention to caregivers' health as hidden patients when planning, and that appropriate strategies such as patient and caregiver education, counseling, support resources, and referral services be considered to reduce caregiver care burden and improve quality of life (Jafari-Koulaee, A., Goudarzian, et. al, 2020)

A study of caregiver burden, psychological well-being, and quality of life of patients with end-stage renal disease conducted in Ghana found that depression, anxiety, and distress were common among caregivers of patients with CKD, especially among caregivers. It was concluded that Woman. It was recommended that these supportive interventions for nurses be included in treatment guidelines to improve overall patient outcomes. A formal caregiver network should also be established, including social workers and clinical psychologists. (Adejumo et al., 2019)

Caregivers may experience emotional and psychological stress, as well as a decreased quality of life, financial difficulties, greater workload, anger, depression, a sense of powerlessness, and an increased burden. As a result, coping methods, social support, and support interventions should be established to help caregivers fulfill their responsibilities in caring for patients while also strengthening their ability to deal effectively with the patient's condition. (Bayoumi, 2014; Darwish et al., 2020) different care teams involved in care of children suffering from CKD and their core carers could use a measure established particularly for this purpose to help them tailor a treatment plan which optimally serves the needs of both the pediatric CKD patients, those of their immediate carers and of the entire household.

## 2.7.Theoretical framework

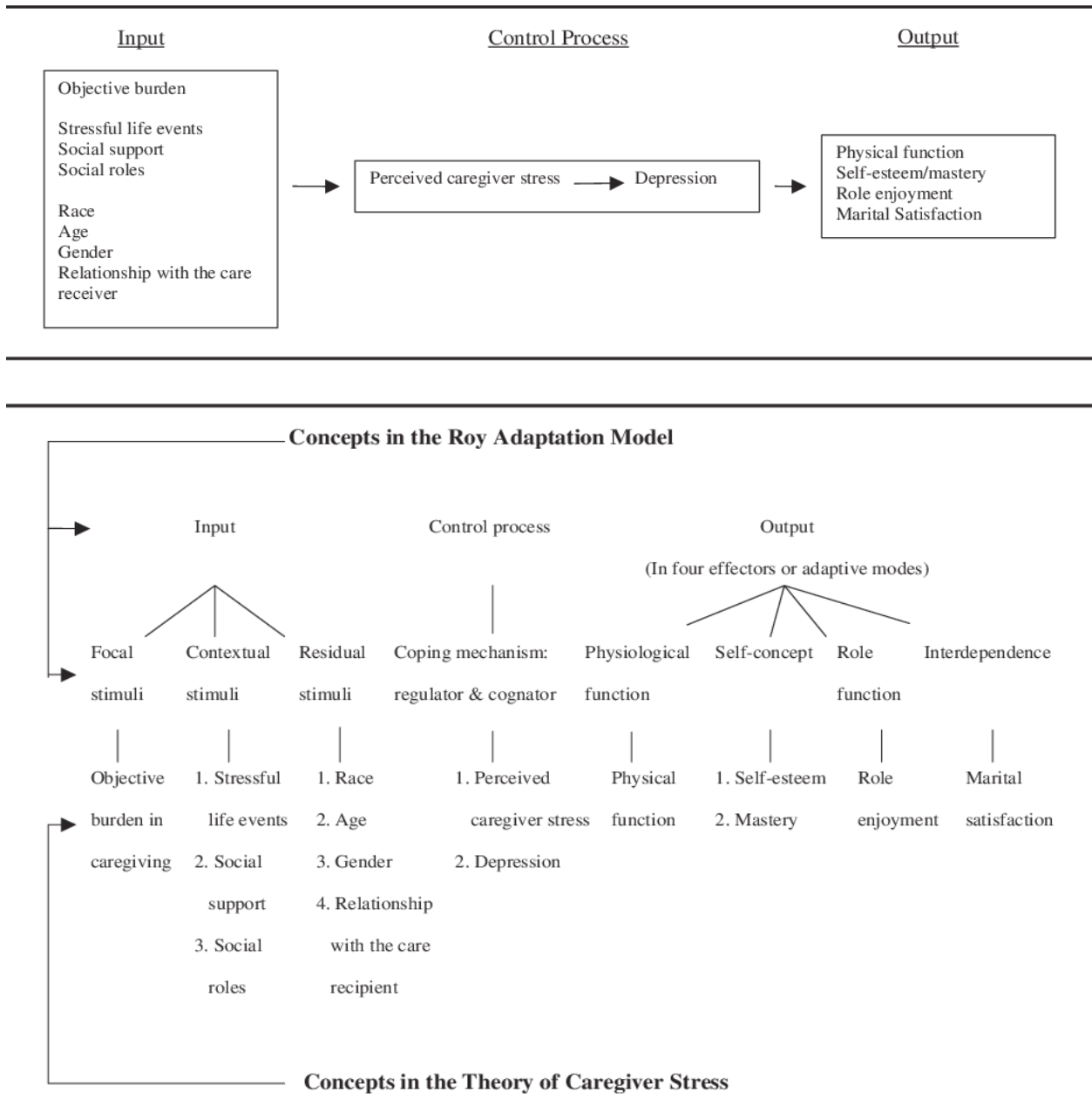


Figure 2.1: Theoretical-framework

Source: (P. Tsai, 2003)

Roy Adaptation Model (RAM) has the five main concepts of nursing theory: the health, the person, the nurse, the adaptation and the environment. Roy views the person in a holistic way. The core concept in her model is adaptation. The concept of adaptation assumes that a person is an open system who responds to stimuli from both internal and external aspects of the person. This study will be guided by Roy Adaptation Model as a conceptual framework in order to (1) to investigate the relationship between environmental stimuli (focal, contextual, and Residual stimuli) and four adaptive modes of RAM which causes caregiver burden (2) and to determine the effect of environmental stimuli on the level of caregiver burden (3) to correlate research variable with theory concept, and to assist the researcher to predict the results and recommendations by answering the research questions.

**2.8 Conceptual framework**

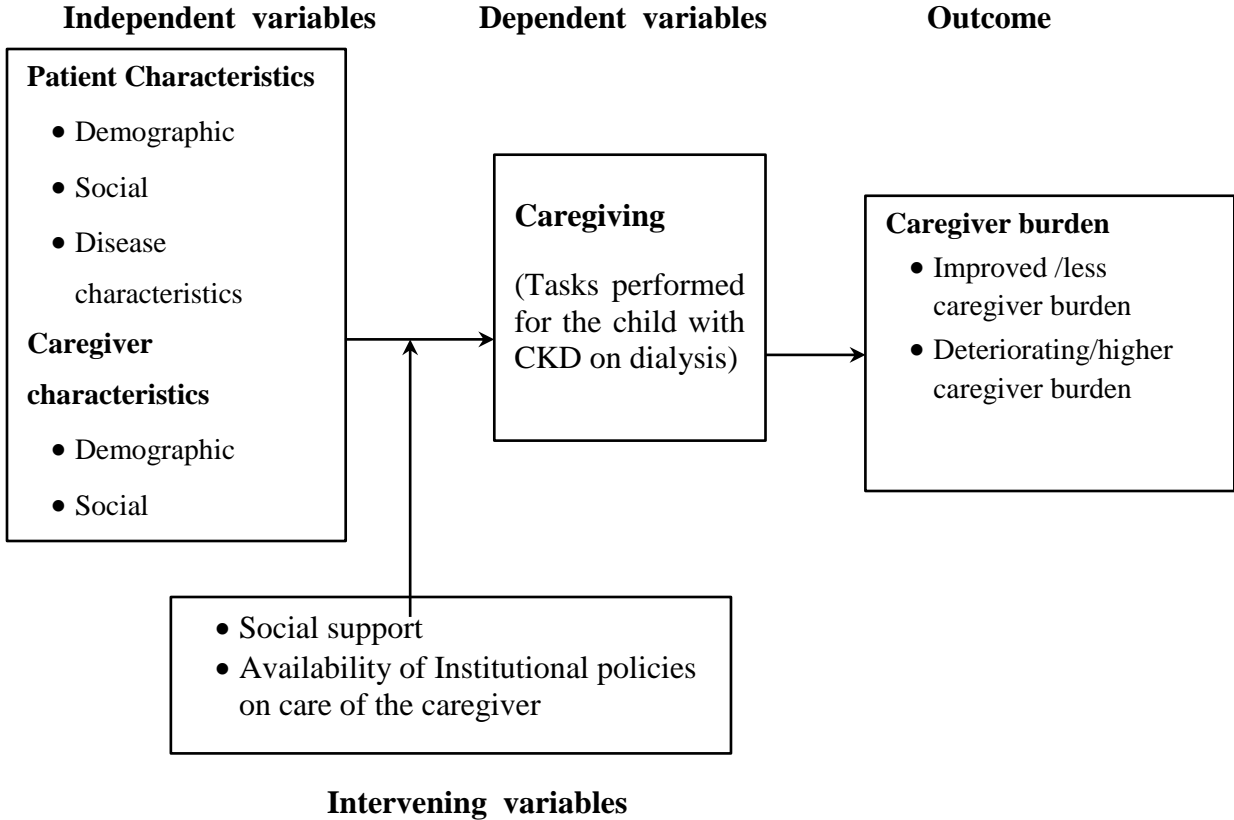


Figure 2.2: Conceptual framework

Source: Researcher, 2022

### **3. CHAPTER: RESEARCH METHODOLOGY**

#### **3.1.Introduction**

The chapter contained explanations on research materials and methods that were used to conduct the research study for the purpose of attaining its objectives. This chapter described in detail the study design, study location, study population, how the participants were selected, sample size and sampling technique, tools for collecting the data, ways in which the data were organized and analyzed, how findings were shared, study's ethical principles and study limitations.

#### **3.2.Study design**

The study applied a cross-sectional descriptive research design. The design best suited the current research as it allowed the PI to accurately describe variables being investigated in the study with minimum bias in data collection and to present facts concerning the variables under investigation as they were when the study was being performed and any trends emerging.

#### **3.3.Study location**

The Main Renal Unit and the Pediatric Renal Unit of the Kenyatta National Hospital constituted the study site. It's the country's oldest national teaching and referral facility. The Renal Unit and the Pediatric Renal Unit are the largest hemodialysis units in the country.

KNH was founded in 1901 with 40 patients with the hospital having grown over the years to its current bed capacity of about 2,000. It is situated on Hospital Road, off Ngong' road in a distance of 4km from Kenya's capital. The facility offers a wide range of specialized in-patient and out-patient health care services. It's also a centre for research and training in medical studies and also supports planning on health care matters nationally.

The Renal Unit has 22 hemodialysis machines serving an average of 45 patients daily and about 135 patients are dialyzed monthly. Most of the patients undergoing hemodialysis attended at the unit have 2 dialysis sessions per week. The Pediatric Renal Unit has a bed capacity of 6. It is the only public pediatric renal unit in Kenya and it serves an average of 29 patients per month.



Both units are working throughout day and night, 7 days a week. The services offered in the renal unit include hemodialysis, peritoneal dialysis, management of ESKD patients' pre- and post-kidney transplant care, patient counseling and patient investigations such as kidney biopsy.

Kenyatta National Hospital is an appropriate area of study for this research as it has a wide catchment area from which it draws its clients. The hospital is also a leading centre of care for children undergoing hemodialysis in the country and beyond. Hence, KNH's renal units offer an appropriate setting for exploring the study subject.

### **3.4. Study population**

The population under review were caregivers of children with CKD on maintenance dialysis. The pilot study conducted in the first 2 weeks of April showed that the Pediatric Renal Unit has 8 patients with CKD on scheduled maintenance dialysis. The main Renal Unit had 7 patients aged 18 and below on maintenance dialysis (KNH Renal Unit and PRU Records, 2022). The total population of care givers is estimated at 15 since no patient shared a caregiver.

### **3.5. Case definition**

A caregiver referred to the individual involved in taking care of the dialyzing patient on a consistent basis and closely with no payment and having got involved in the caring role to the patient for not less than 3 months.

### **3.6. Inclusion criteria**

- 1) Identified as the caregiver using the case definition criteria
- 2) Willingness to participate in the study
- 3) Informed and signed consent from the caregiver
- 4) Caregiver is  $\geq 18$  years of age

### **3.7.Exclusion criteria**

Those who declined to participate in the study

### **3.8. Sample size calculation**

Since the study population is a small number, a census was done to target every eligible caregiver in both dialysis units during the study period.

### **3.9. Sampling method**

The first participant was selected randomly followed by subsequent recruitment of all other eligible participants within the study period.

### **3.10. Research tool**

The study tools included a self-created questionnaire on the socio-demographic data of the respondents and the Zarit Burden Interview (ZBI) tool to assess the caregiver's level of burden, all of which were interviewer-administered. Mapi Research Trust granted permission for its use in this study.

The ZBI questionnaire consists of 22 questions with answers varying from 0=Never, 1=Rarely, 2= Sometimes, 3=Quite frequently and 4=Nearly always. The scores are added up to give a total score ranging from 0(no burden) to 88(maximum burden). The questions focus on major domains such as caregiver's:burden in the relationship, emotional wellbeing, social and family life, finances and loss of control over one's life.

The score value estimates the degree of burden as tabled below.

Table 3.1: Zarit Burden Score Values

0-20	Little or no burden
21-40	Mild to moderate burden
41-60	Moderate to severe burden
61-88	Severe burden

### **3.10.1. Validity and reliability of the study tool**

Zarit Burden Interview (ZBI) is a widely applied evaluation of caregivers' own reporting formulated in 1980s by Zarit and others, originally with 29-items, though later modified to 22 items while the short version 12 items. It was intended at assessing burden level that principle carers of patients with chronic conditions do experience. The tool offered a mechanism of evaluating carers' own view of the burden they carry attributable to their caregiving role. The tool has been evaluated as valid and reliable as measured in earlier empirical studies. (Seng BK, Luo N, et al, 2010) (Ojifinni OO, 2018)(Kühnel, M. B., et al, 2020)

### **3.10.2. Pretesting of the study tool**

Pretesting of the study tool was carried out among those who care for children undergoing dialysis at Kenyatta National Hospital. Three (3) questionnaires were used and upon completion of the pretesting, the study tool was modified where applicable and a final study tool was formulated.

### **3.11. Data collection**

Data was collected through interviewer-administered questionnaires containing the study tools. This included the Zarit Burden Interview tool and a socio-demographic data entry form. These were tested during the pilot study for applicability.

Following permission from the Head of the Renal Unit, the principal researcher approached the caregivers of the children at the waiting bay of the Renal dialysis Unit as they waited for their turn to be served. During this brief encounter; that did not last more than 5 minutes, the PI introduced herself, inform the caregivers about the current study, its purpose, emphasize on the selection criteria and indicate to them where within the Renal Unit the study was conducted to ensure privacy and confidentiality.

Those caregivers that met the inclusion criteria and were willing to participate were directed by the PI to the Patient's Confidential Room of the Renal Unit to participate in the study after their patient has been commenced on dialysis and are comfortable. The respondents were required to

offer their informed consent before responding to the questionnaires by signing the consent document.

For those in the Renal wards, the same recruitment procedure was followed and was done at the bed side. Those that met the inclusion criteria and were willing to participate were directed to the Patient's Counselling Room of the ward by the PI to participate in the study. The respondents offered their informed consent before responding to the questionnaire.

Data collection process from the recruited participants entailed the respondents providing their responses to the questions in the questionnaire as the PI reads through the questions to them and documents their answers. At the end of each day, data from the completed questionnaires was cleaned and entered into Ms Excel for storage awaiting analysis using SPSS version 28.0.

COVID-19-prevention guidelines were adhered to during the data collection process. The data collection exercise took 4 weeks.

### **3.11.1. Quality Assurance**

For quality control, the questionnaire was pretested during a pilot study for applicability and at the end of each day; data on the completed questionnaires were carefully cleaned before entering into SPSS. All study material was kept under lock and key and access limited to the PI only.

### **3.12. Data management and analysis**

Data cleaning and entry was done before analysis of the study data obtained. Data for the study was analyzed using the SPSS version 28.0. Demographic data and other patient and caregiver variables were analyzed descriptively as percentages, proportions, frequencies, means, modes and median as applicable. Associations were measured using fishers exact test to ascertain the association between the level of caregiver burden and the patient's and caregiver's factors. Results of the study were presented in tables, graphs and charts. All tests were statistically evaluated at 5% significance level ( $P < 0.05$ ).

### **3.13. Data storage**

Immediately after data collection, the responded to questionnaires and the signed informed consents was safely locked in a cupboard accessed only by the principal researcher. This data will be available for 5 years after which it may be destroyed. At the end of each day, data in the filled-in questionnaires was entered into Ms Excel for storage awaiting analysis in a password protected computer only used by the principal researcher. Further, a copy of the data was also saved in a password protected flash disk kept by the PI as back-up. All these was done to ensure safety of the study data.

### **3.14. Ethical considerations**

The study was ethically approved by the KNH-UoN ERC upon submission by the researcher. The researcher also sought permission to collect data among the targeted respondents from the Head of Department of the Renal Unit of KNH. All participants were required to give written consent before they participate in the study. Information issued by the respondents was dealt with in utmost confidence. Questionnaires were coded hence participants remained anonymous. Participants did not indicate their own personal identity details on the tools. There was no harm to participants anticipated in the study. In the event where psychological distress was evoked at the completion of the questionnaire, the participant was referred to the Renal Counselor for professional psychological support. Dissemination of the study's findings was only done as per the University's guidelines and anonymity and confidentiality of the participants was ensured during the finding's dissemination. Questionnaires answered were stored in a safe manner before analyzing of their content and reporting. COVID-19 prevention guidelines given by the Ministry of Health were followed during data collection.

### **3.15 Study limitations**

The study included a small population and was undertaken in a single health facility.

### **3.16 Study delimitation:**

Since the study population was small, all efforts were put to target and recruit all eligible participants considering the study area is a national referral, research and training facility where most of the cases under study are managed.

### **3.17 Study findings disseminating plan**

Results of the study was shared through forwarding the final dissertation project report to the University of Nairobi's Department of Nursing Sciences, to UoN Library and to the Renal Unit of Kenyatta National Hospital. The final research project report was also uploaded to UoN's repository. The researcher also endeavored to present the findings in appropriate academic and scientific workshops and conferences as well as publishing the work in a relevant peer-reviewed journal.

## **4. CHAPTER: RESULTS**

The study evaluated the burden of care among caregivers of children with chronic kidney disease at Kenyatta National hospital. A total of 18 patients and their caregivers were enrolled into the present study.

### **4.1.Characteristics of caregivers of children with chronic kidney disease**

The findings established that the median age among caregivers was 42 ranging between 36 and 46 years, 14(77.8%) were aged between 31 to 50 years. Majority of the caregivers, 12(66.7%) were female, 13(72.2%) had secondary education as their highest level of education. Marital status analysis revealed that 14(77.8%) were married. Most of the caregivers, 12(66.7%) of the caregivers were self-employed, 8(44.4%) had monthly income which was barely adequate for basic family needs, 17(94.4%) of caregivers were parents to the patients. The findings also showed that 15(83.3%) of the caregivers were financing their health through both NHIF and Out of pocket as shown in Table 4.1.

Table 4.1: Characteristics of caregivers of children with chronic kidney disease

<b>Caregiver factors</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Age(Median(IQR))</b>	42(IQR:36 – 46)	
Less than 30 years	2	11.1
31 - 50 years	14	77.8
>50 years	2	11.1
<b>Gender</b>		
Male	6	33.3
Female	12	66.7
<b>Education level</b>		
Primary	2	11.1
Secondary	13	72.2
Tertiary	3	16.7
<b>Marital status</b>		
Single	4	22.2
Married	14	77.8
<b>Occupation</b>		
Formal employment	2	11.1
Self-employment	12	66.7
Unemployed	4	22.2
<b>Monthly income</b>		
Adequate for basic family needs	5	27.8
Barely adequate for basic family needs	8	44.4
Inadequate for basic family needs	5	27.8
<b>Relationship with patient</b>		
Parent	17	94.4
Sibling	1	5.6
<b>Health financing</b>		
Out of pocket	3	16.7
Both NHIF and out of pocket	15	83.3

#### 4.2.Characteristics of patients with chronic kidney disease

The median age was 16 years ranging between 11 years to 18 years, 11(61.1%) of the patients were aged between 15 and 18 years. Majority of the respondents 11(61.1%) were male. The median number of siblings was 2 with a range of 1 to 3. The results revealed that 9(50.0%) had secondary level education, 15(83.3%) had acquired CKD. Further, 17(94.4%) were undergoing hemodialysis. The median number of dialysis sessions was 8 ranging between 8 and 12 in a month. The median number of doctor’s appointments was 1 ranging between 1 and 2 in a month. The findings also



showed that 10(55.6%) had pre-existing comorbidity with 9(90%) having hypertension and 1(10%) having cardiomegaly as shown in Table 4.2.

Table 4.2: Characteristics of patients with chronic kidney disease

<b>Patient</b>	<b>Frequency</b>	<b>Percent</b>
<b>Age (Median(IQR))</b>	16(IQR:11 - 18)	
<9 years	4	22.2
9 - 14 years	3	16.7
15 - 18 years	11	61.1
<b>Gender</b>		
Male	11	61.1
Female	7	38.9
<b>Number of siblings (Median(IQR))</b>	2(IQR:1 - 3)	
<b>Education level</b>		
Not schooling	2	11.1
Primary	7	38.9
Secondary	9	50.0
<b>Etiology of the CKD</b>		
Congenital	3	16.7
Acquired	15	83.3
<b>Mode of dialysis</b>		
Peritoneal dialysis	1	5.6
Hemodialysis	17	94.4
<b>Duration of illness (Median(IQR))</b>	27(IQR:20 - 60)	
<b>Number of sessions (Median(IQR))</b>	8(IQR:8 - 12)	
<b>Number of appointments (Median(IQR))</b>	1(IQR:1 - 1.25)	
<b>Presence of comorbid</b>		
Yes	10	55.6
No	8	44.4
<b>Comorbid conditions (n =10)</b>		
Hypertension	9	90
Cardiomegaly	1	10

#### **4.3. Quantification of the care burden amongst caregivers-of-children with CKD on dialysis at KNH**

The Zarit burden interview was utilized in evaluation of the difficulty of care among persons who cared for children with chronic kidney disease. The tool assesses five major components which include difficulties in how one related with others, family life, wellbeing socially and emotionally, household incomes and inability to effectively manage personal life.

### 4.3.1. Burden in the relationship among caregivers of children with chronic kidney disease

The findings showed that 3(16.7%) nearly always feel that their relatives ask for more help than they need, 17(94.4%) of the caregivers rarely feel that their relatives are dependent on them, 3(16.7%) stated that they quite frequently feel they lack privacy as they may desire due to their relatives. The findings further showed that 11(61.1%) of the caregivers quite frequently feel that their relatives seem to expect to be cared for as if they were only one they could depend on, 12(66.7%) never wished to leave the care of their relatives to someone else. The findings also revealed that 7(38.9%) of the caregivers felt that should be doing more for their relative as shown in Table 4.3.

**Table 4.3: Burden in the relationship among caregivers of children with chronic kidney disease**

Components	Never n(%)	Rarely n(%)	Sometimes n(%)	Quite frequently n(%)	Nearly always n(%)
Do you feel that your relative asks for more help than he/she needs	7(38.9)	3(16.7)	3(16.7)	2(11.1)	3(16.7)
Do you feel your relative is dependent upon you?	1(5.6)	0	0	0	17(94.4)
Do you feel that you don't have as much privacy as you would like, because of your relative?	5(27.8)	4(22.2)	5(27.8)	3(16.7)	1(5.6)
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?	2(11.1)	1(5.6)	4(22.2)	11(61.1)	0
Do you wish you could just leave the care of your relative to someone else?	12(66.7)	1(5.6)	2(11.1)	3(16.6)	0
Do you feel you should be doing more for your relative?	2(11.1)	1(5.6)	4(22.2)	4(22.2)	7(38.9)

### 4.3.2. Emotional wellbeing among caregivers of children with chronic kidney disease

The findings established that 5(27.8%) nearly always felt that due to time spent with their relatives they lacked sufficient personal time, 10(55.6%) of the caregivers never felt embarrassed in relation to their behaviours of their relative, 14(77.8%) never feel angry when around their relatives. The findings also showed that 8(44.4%) of the caregivers sometimes feel strained when they are around their relatives, 7(38.9%) of the caregivers nearly always feel they may perform a better in relation to caring for the sick relative and 10(55.6%) of the caregivers stated that overall, they have been burdened in caring for their relatives as shown in Table 4.4.

Table 4.4: Emotional wellbeing among caregivers of children with chronic kidney disease

<b>Components</b>	<b>Never n(%)</b>	<b>Rarely n(%)</b>	<b>Sometimes n(%)</b>	<b>Quite frequently n(%)</b>	<b>Nearly always n(%)</b>
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	3(16.7)	2(11.1)	3(16.7)	5(27.8)	5(27.8)
Do you feel embarrassed over your relative's behavior?	10(55.6)	1(5.6)	5(27.8)	2(11.1)	0
Do you feel angry when you are around your relative?	14(77.8)	2(11.1)	1(5.6)	1(5.6)	0
Do you feel strained when you are around your relative?	5(27.8)	0	8(44.4)	3(16.7)	2(11.1)
Do you feel your health has suffered because of your involvement with your relative?	8(44.4)	1(5.6)	5(27.8)	2(11.1)	2(11.1)
Do you feel you could do a better job in caring for your relative?	3(16.7)	0	5(27.8)	3(16.7)	7(38.9)
Overall, how burdened do you feel in caring for your relative?	2(11.1)	1(5.6)	2(11.1)	3(16.7)	10(55.6)

**4.3.3. Social and family life among caregivers of children with chronic kidney disease**

The findings showed that 7(38.9%) nearly always feel stressed between caring for their relatives and trying to meet other responsibilities, 9(50%) of the caregivers never feel that their relatively affect their relationship with other family members or friends in a negative way, 8(44.4%) of the caregivers sometimes feel that their social life has suffered because of caring for their relatives, 12(66.7%) of the caregivers never feel uncomfortable about having friend of over because of their relatives as shown in Table 4.5.

Table 4.5: Social and family life among caregivers of children with chronic kidney disease

	Never	Rarely	Sometimes	Quite frequently	Nearly always
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	3(16.7)	1(5.6)	4(22.2)	3(16.7)	7(38.9)
Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	9(50)	0	5(27.8)	2(11.1)	2(11.1)
Do you feel that your social life has suffered because you are caring for your relative?	1(5.6)	3(16.7)	8(44.4)	3(16.7)	3(16.7)
Do you feel uncomfortable about having friends over, because of your relative?	12(66.7)	2(11.1)	3(16.7)	1(5.6)	0

**4.3.4. Financial and loss of control over one’s life among caregivers of children with chronic kidney disease**

In assessing finances, 9(50%) of the caregivers sometimes feel that they do not have enough money to care for their relatives in addition to the rest of their expenses. Loss of control over one’s life component was also investigated as shown in Table 6. The findings established that 5(27.8%) of the caregivers nearly always are afraid of what the future holds for their relative, 5(27.8%) of the caregivers sometimes feel that they will be unable to take care of their relatives much longer with similar percentage of caregivers asserting that they feel they have lost control of their life since their relatives’ illness while 4(22.2%) of caregivers sometimes feel uncertain about what to do about their relatives.

Table 4.6: Financial and loss of control over one’s life among caregivers of children with chronic kidney disease

<b>Components</b>	<b>Never n(%)</b>	<b>Rarely n(%)</b>	<b>Sometimes n(%)</b>	<b>Quite frequently n(%)</b>	<b>Nearly always n(%)</b>
<b>Financial</b>					
Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?	0	1(5.6)	9(50)	2(11.1)	6(33.3)
<b>Loss of control over one's life</b>					
Are you afraid what the future holds for your relative?	5(27.8)	0	4(22.2)	4(22.2)	5(27.8)
Do you feel that you will be unable to take care of your relative much longer?	4(22.2)	1(5.6)	5(27.8)	4(22.2)	4(22.2)
Do you feel you have lost control of your life since your relative’s illness?	4(22.2)	5(27.8)	4(22.2)	5(27.8)	0
Do you feel uncertain about what to do about your relative?	6(33.3)	3(16.7)	4(22.2)	3(16.7)	2(11.1)

#### 4.3.5. Care burden amongst caregivers of children with CKD

The findings revealed that social and family life had the lowest burden score with an average of 36.97(SD±20.4) while finances was biggest burden to caregivers of children with chronic kidney disease with an average of 59.89(SD±22.4). The overall of the burden score among caregivers was 46.27(SD±14.5) which shows moderate burden of care as shown in Table 4.7.

**Table 4.7: Care burden amongst caregivers-of-children with CKD**

Care burden	Minimum	Maximum	Mean $\pm$ SD	Level of burden
Burden in the relationship	25.67	69.67	49.50 $\pm$ 11.5	Moderate to severe
Emotional wellbeing	9.43	72.29	39.46 $\pm$ 19.4	Mild to moderate
Social and family life	0.00	82.50	36.97 $\pm$ 20.4	Mild to moderate
Finances	22.00	88.00	59.89 $\pm$ 22.4	Moderate to severe
Loss of control over one's life	0.00	82.50	45.53 $\pm$ 20.8	Moderate to severe
Overall Burden	23.52	70.92	46.27 $\pm$ 14.5	Moderate to severe

#### 4.3.6. The level of care burden among caregivers of children with CKD

The findings established that 8(44.4%) of the caregivers had Mild to moderate burden, 6(33.3%) had Moderate to severe burden while 4(22.2%) had severe burden as shown in Figure 4.1.

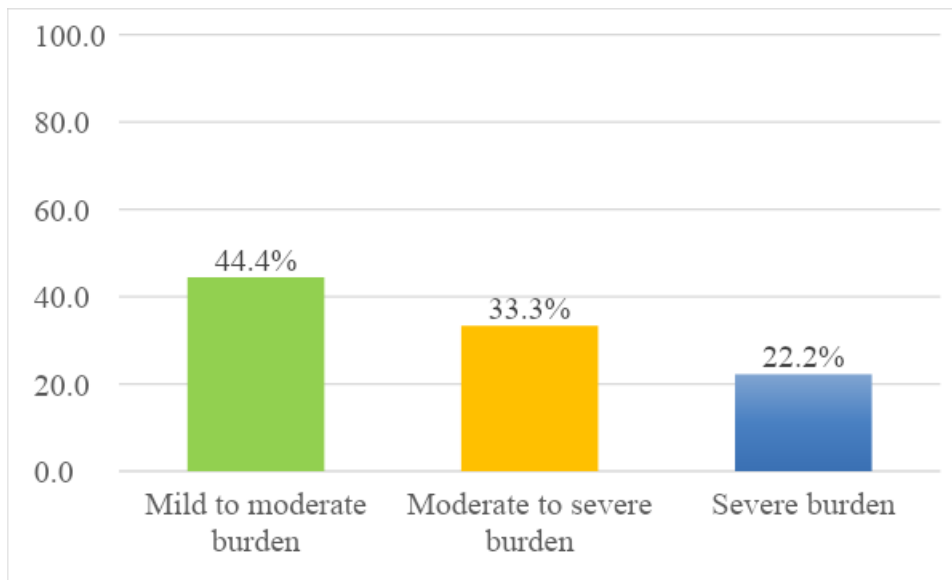


Figure 4.1: The level of care burden among caregivers-of-children with CKD

#### 4.3.7. Hypothesis evaluation

Based on the results, we reject the hypothesis and conclude that the level of burden among caregivers of children with chronic kidney disease on maintenance dialysis is moderate to severe.

#### 4.4. Caregiver-related factors associated with high caregiver burden amongst caregivers-of-children with CKD on maintenance dialysis at KNH

The findings from Fischer's exact test revealed that monthly income was significantly associated with care burden. Those whose monthly income was inadequate for basic family needs were 2.3 times more likely to have high burden compared to those who had adequate for basic family needs (OR =2.31, 95%CI:1.13 – 4.42, p =0.043) as shown in Table 4.8.

Table 4.8: Caregiver-related factors associated with high caregiver burden amongst caregivers-of-children with CKD

	Low burden n(%)	High burden n(%)	OR(95%)	P-value
<b>Age group</b>				
Less than 30 years	1(12.5)	1(10)	1.41(0.22 – 5.23)	0.443
31 - 50 years	6(75)	8(80)	1.32(0.11 – 2.31)	
>50 years	1(12.5)	1(10)	Ref	
<b>Gender</b>				
Male	2(25)	4(40)	0.45(0.23 – 4.55)	0.572
Female	6(75)	6(60)	Ref	
<b>Education level</b>				
Primary	0	2(20)		0.487
Secondary	7(87.5)	6(60)		
Tertiary	1(12.5)	2(20)		
<b>Marital status</b>				
Single	1(12.5)	3(30)	0.22(0.11 – 2.31)	0.137
Married	7(87.5)	7(70)	Ref	
<b>Occupation</b>				
Formal employment	2(25)	0		0.118
Self-employment	5(62.5)	7(70)		
Unemployed	1(12.5)	3(30)		
<b>Monthly income</b>				
Adequate for basic family needs	2(25)	3(30)	Ref	0.123
Barely adequate for basic family needs	5(62.5)	3(30)	0.43(0.22 – 2.45)	
Inadequate for basic family needs	1(12.5)	4(40)	<b>2.31(1.13 – 4.42)</b>	
<b>Relationship with patient</b>				
Parent	8(100)	9(90)		0.611
Sibling	0	1(10)		
<b>Health financing options</b>				
Out of pocket	0	3(30)		0.147
Both	8(100)	7(70)		

#### 4.5. Patient-related factors associated with high caregiver burden amongst caregivers of children with CKD on maintenance dialysis at KNH

The results from independent sample t-test established that there was significant difference in duration of disease. Those who had low burden had longer duration of disease with an average of 62.49 (SD±49.6) months compared to those who had higher burden with an average of 13.86(SD±10.1) months. Those who had shorter duration of disease were 2.42 times more likely to have high burden compared to those with longer duration of disease, (OR =2.42 – 3.22,95%CI:1.01 – 3.22, p =0.027 as shown in Table 4.9.

Table 4.9: Patient-related factors associated with high caregiver burden amongst caregivers of children with CKD on maintenance dialysis at KNH

	Low burden n(%)	High burden n(%)	OR(95%)	P-value
<b>Age</b>				
<9 years	2(25)	3(30)		
9 - 14 years	2(25)	0		0.243
15 - 18 years	4(50)	7(70)		
<b>Gender</b>				
Male	3(37.5)	8(80)	Ref	
Female	5(62.5)	2(20)	0.23(0.11 – 2.12)	0.417
<b>Siblings (Mean)</b>	2.45(1.6)	2.0(1.2)		0.070
<b>Education</b>				
Not schooling	0	2(20)		
Primary	3(37.5)	4(40)		0.106
Secondary	4(50)	3(30)		
Tertiary	1(12.5)	1(10)		
<b>Etiology of the CKD</b>				
Congenital	2(25)	1(10)	0.87(0.67 – 2.33)	0.245
Acquired	6(75)	9(90)	Ref	
<b>Mode of dialysis</b>				
Peritoneal dialysis	0	1(10)		0.389
Hemodialysis	8(100)	9(90)		
<b>Duration of disease (Mean)</b>	62.8(49.6)	13.86(10.1)	<b>2.42(1.01 – 3.22)</b>	<b>0.027</b>
<b>Number of appointments</b>	1.18(0.4)	1.29(0.49)	0.61(0.33 – 1.45)	0.075
<b>Number of sessions</b>	7.27(1.6)	10.29(2.1)	0.34(0.11 – 2.33)	0.906

Key: (OR=Odds Ratio)



## CHAPTER 5: DISCUSSION

The present study investigated the burden of care amongst caregivers of children with chronic kidney disease. The findings showed that the average age of 42 years with majority of caregivers aged between 31 to 50 years. These findings are comparable to a study conducted in Iran by Adib-Hajbaghery and Ahmadi (2019) who found that more than half of the caregivers, 51.5% were aged between 30 to 40 years. Similarly, Adejumo et al. (2019) in a study conducted in Nigeria also revealed that the average age of caregivers was 43 years. The findings from present study also found that 66.7% of the caregivers were female. Comparable findings were also obtained by Bayoumi et al. (2014) in a study conducted in Saudi Arabia which found that 70% of the caregivers were female. However, in a study conducted in Iran by Adib-Hajbaghery and Ahmadi (2019) found contrasting findings where 50.1% of the caregivers were male. The difference could be attributed to increasing role of men in the wellbeing of their children. Majority of the caregivers, 72.2% had secondary level of education. According to Kenya Census Data in 2019, most of Kenyans had at least secondary level education which explains higher proportion of caregivers in present study having secondary education as the highest level of education attainment. These findings are comparable to past studies among caregivers which found that secondary level was the highest level of education (Cagan et al., 2018; Adejumo et al., 2019; Adib-Hajbaghery&Ahmadi, 2019).

Among the children with chronic kidney disease on maintenance dialysis, the average age 16 years ranging between 11 to 18 years. These findings however, differ from those from a study in Iran which established that almost half of the patients (39%) were aged from 6 to 12 years Adib-Hajbaghery&Ahmadi, 2019). This could be due to the distribution of children with chronic kidney disease in their study. In their study, most of the patients were aged less than 12 years while in our study majority were aged above 14 years. The current results also identified that 61.1% of patients were male. This is comparable to Adib-Hajbaghery and Ahmadi (2019) who found that 60.3% of CKD patients were male. Darwish et al. (2020) in a study conducted in Egypt also revealed that 67.2% of the CKD patients were male. The findings from present study also revealed that majority of patients, 77.8% had at least secondary level education. These findings however differ from Darwish et al. (2020) who found that 57.6% of the CKD patients had primary level education. This

could be explained by the distribution of CKD patients in their study where average age was 11 years compared to 16 years in our present study.

The findings from the present study established that the average burden score was 46 representing moderate burden. Additional analysis in present study established that 44.4% of the caregivers had mild to moderate burden, 33.3% had moderate to severe burden while 22.2% had severe burden. Comparable findings were obtained in a study in Nepal which found that the average burden score was 46.99 (Shakya, 2017). These findings are comparable to a study conducted in Nigeria by (Oyegbile&Brysiewicz, 2017) indicating average burden score of 50.2 indicating that majority of caregivers experienced moderate to severe burden of care. Similarly, these findings are comparable to a study conducted in Iran which found that most of the caregivers had mild to moderate burden (47%), followed by moderate to severe (35.1%) and severe burden (8.5%). Adejumo et al. (2019) in a study conducted in Southern Nigeria revealed comparable results with most of caregivers having mild to moderate burden (47%) although in their study, 8.5% of caregivers had severe burden compared to 22.2% in our present study. In our present study, all of the caregivers had at least mild burden. In the study by Adejumo et al. (2019) 9.7% of the caregivers did not have any burden. This could be attributed to smaller sample size in our present study which shows that there was slight variation in the burden scores.

These findings from present study are inconsistent with those from a study conducted in Indonesia by (Pio et al., 2022) established that majority of the caregivers (52%) had little or no burden, 35.6% had mild to moderate burden 10.6% had moderate to severe burden while 1% had severe burden. This is similar to a study conducted in Turkey, which found a low burden (45.6%) (Avşar et al., 2015), and unexpectedly, so indicated the results from Nepal (49.4%) (Shakya, 2017) and Vietnam (80.9%) (Hoang et al., 2019). An interesting assertion has been the fact developed countries such as Japan, United Kingdom, Sweden and the United States who have advanced healthcare systems have reported high burden among caregivers of patients with chronic illness reporting between 30 to 47 percent (Washio et al., 2012). The extent of difficulties that caregivers experienced may be attributable to numerous factors, including the societal culture and support accorded to them by public and non-public actors. In accordance with reported empirical evidence (Mashayekhi et al., 2015)(Jadhav et al., 2014), experienced caregiving difficulties also

seem to be higher in emerging economies as established in our current study where among caregivers investigated, none had little or no burden of care.

The current study established that a notable connection existed between monthly income and reported care burden. almost half of the caregivers (40%) who asserted that their family income was inadequate for basic family needs had high burden of care. inability to meet family needs is a major challenge for many caregivers considering the high cost of care for CKD patients. A study conducted in Iran identified comparable findings where financial status was associated with burden of care. The findings from their study established that caregivers who asserted that their income was insufficient for expenses had moderate burden compared to those whose income was sufficient for their expenses had mild burden of care (Adib-Hajbaghery&Ahmadi, 2019). Darwish (2020) also affirmed that a financial challenge is a major factor contributing to high burden among caregivers. The nature of care needed for children with CKD limit caregivers from being employed because majority of these patients are fully dependent on their caregivers. Regular dialysis sessions mean that there is need caregivers to avail themselves every dialysis session with each patient having at least eight dialysis sessions.

The findings from this empirical investigation established that a prominent connection existed between duration of disease and burden of care. Caring difficulty was higher among those who cared for patients with short duration of ailment. For the current empirical investigation, the average burden on the caregivers as perceived had no any notable association with various variables including duration of the ailment, the child's age group and gender as well as the carers' age,. Some studies though had identified notable connection between the carer's experienced difficulty and duration of the ailment (Hu et al., 2016)(Udoh et al., 2021).

Caregivers gradually develop new coping mechanisms for dealing with caregiving-related difficulties, which lessens their sense of responsibility. However, it appears that despite the coping mechanisms learnt, the worries about the illness and the child's future may endure. Studies on the relationship between the carers' perceived burden and age are contradictory (Mashayekhi et al., 2015). While other investigations were unable to support this link, some studies claimed a direct correlation existed between these two characteristics.

## 6. CHAPTER: CONCLUSION AND RECOMMENDATIONS

### 6.1. Conclusion

The average burden of care score was 46.27 (SD±14.5) illustrating moderate burden of care. The findings also revealed that none of the surveyed carers lacked any difficulties of care, 44.4% of the caregivers had mild to moderate burden, 33.3% had moderate to severe burden while 22.2% had burden that was severe. Social and family life had the lowest burden score with an average of 36.97(SD±20.4) while finances were the biggest burden to carers of pediatrics being treated for CKD with an average of 59.89(SD±22.4).

In investigating caregiver factors, monthly income had a notable association with the care burden. The burden of care was higher among those whose monthly income was barely adequate for basic family needs (40%).

The patient factors linked with care burden established that illness duration had a notable connection with the care burden. Those who had high burden of care reported lower duration of illness with an average of 13.86(SD±10.1) months compared to 62.8(SD±49.6) months.

### 6.2. Recommendations

- 1) Healthcare providers to communicate clearly about the condition of the child and the level of care needed to achieve improved health outcomes.
- 2) The ministry of health should incorporate regular tests and investigations into the NHIF dialysis package to reduce cost of care among caregivers.
- 3) Both individualised counselling and group therapy sessions should be organized to help caregivers understand the different approaches to deal with their wellbeing emotionally and, socially as well as with funds, household matters and inability to manage their life.
- 4) The hospital should institute a close follow up plan to ensure that all children receive care within the required time schedule.

#### **Suggested areas for further studies**

- 1) A qualitative study to explore the caregiver experience, barriers and facilitators in caregiving.
- 2) A similar multi-centred study for broader comparison and generalization of findings.

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## APPENDICES

### Appendix 1: Research work plan

Activity	2022								
	March	April	May	June	July	August	September	October	November
Development of the concept									
Proposal writing and presentation									
Pretesting the study tool									
Submission and approval by ERC									
Collection of data									
Data analysis and report writing									
Project defense									

## **Appendix 2: Consent explanation document**

**Title of Study:** The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital, Renal Unit.

**Principal Investigator and Institution:** Faith Wangui Wariguah - University of Nairobi

**Supervisors:** Ms. Hannah Inyama & Dr. James Mwaura, University of Nairobi, Faculty of Health Sciences, Department of Nursing Sciences.

### **Introduction**

My name is Faith W. Wariguah a student at the University of Nairobi pursuing a Master of Science Degree in Renal Nursing. I am carrying out a research study on: The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital, Renal Unit.

### **Purpose of the study**

The purpose of this study is to determine the burden of care and the factors associated with it amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital, Renal Unit.

### **Description of the study process**

I'm requesting your participation in this study by giving your views and opinions about the research subject through the research tool provided. If you consent to participate, the researcher will request you to respond to a series of questions based on the research objectives. This will be conducted in a private area where you will feel comfortable answering the questions. Completing the questionnaire will take approximately 10 minutes. After the interview is over and you feel you need psychological support, you'll be referred to the Renal Counselor for further professional psychological care and support.

## **Confidentiality**

All information provided will be handled and processed with utmost confidentiality. All information given herein will only be used for purposes of the research study. Your data will be labeled with a unique identifier and your name concealed maintaining confidentiality when taking part in the study. The same confidentiality will be maintained in any reports or publications of the research thereafter.

## **Voluntary participation**

Your participation in this study is voluntary. That is, on your own free will and without any coercion.

## **Right of withdrawal**

Should you feel/wish to terminate your participation in this study, you have the right to do so at any time without facing any consequences/penalties.

## **Benefit**

This study is for academic purpose only and your participation and information that you will provide will be of great importance in informing the need to develop strategies and necessary interventions to help ease the burden of care of caregivers of children with chronic kidney diseases undergoing dialysis at the Kenyatta National Hospital.

## **Cost**

There will be no direct cost incurred by you neither will you receive any money for participating in this study

## **Risks**

There is no health risk or any harm for participating in this study. In the event psychological distress is evoked during questionnaire completion, you will be referred to the Renal Counselor for professional psychological care and support.

## Sharing of results

The results of this study may be presented during scientific and academic forums and may be published in scientific medical journals and academic papers.

## Contacts

For any queries regarding this research study, kindly contact;

<b>Principal Investigator</b>		<b>Lead supervisor</b>		<b>Secretary</b>
Faith Wangui Wariguah	O R	Ms. Hannah Inyama	O R	KNH-UoN ERC
Tel: 0726850851		Tel: 0723065246		Telephone: 020-2726300
Email: <a href="mailto:faithwariguah@students.uonbi.ac.ke">faithwariguah@students.uonbi.ac.ke</a>		Email: hinyama@uonbi.ac.ke		Email: uonknh_erc@uonbi.ac.ke
				P.O. Box 19676 – 00202 Nairobi

**Appendix 3: Consent Form (Statement of Consent)**

**Participant’s statement**

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with the researcher. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential.

By signing this consent form, I agree to participate in this research study.

Participant printed name: \_\_\_\_\_

Participant signature / Thumb stamp \_\_\_\_\_ Date \_\_\_\_\_

**Researcher’s statement**

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher’s Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix 4: Study Questionnaire**

**Study title:** The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital.

**Date:** ..... **Participant’s code:** .....

Instructions;

- Do not write your name or any personal identification on the questionnaire.
- Answer all the questions by putting a tick (✓) in the preferred box.
- Information obtained will be handled and processed in strict confidence.

**SECTION 1: CAREGIVER’S CHARACTERISTICS (Tick the most appropriate answer)**

1. Age in years .....

2. Gender

Male [ ] Female [ ]

3. Highest level of education

No formal education [ ]

Primary [ ]

Secondary [ ]

Tertiary [ ]

4. Marital status

Single [ ]

Married [ ]

Separated [ ]

5. Occupation

Formal employment [ ]

Self-employment [ ]

Unemployed [ ]

6. Monthly income

Adequate for basic family needs [ ]

Barely adequate for basic family needs [ ]

Inadequate for basic family needs [ ]

Not Applicable [ ]

7. Relationship with the patient

Parent [ ]

Sibling [ ]

Grand-parent [ ]

Relative [ ]

Not related [ ]

8. Health financing option for the patient

Out-of-pocket [ ]

NHIF [ ]

Both [ ]

Do not know [ ]



## SECTION 2: PATIENT'S CHARACTERISTICS

1. Age in years .....

2. Gender            Male [ ]            Female [ ]

3. Number of siblings .....

4. Education level

    Not schooling [ ]

    Primary [ ]

    Secondary [ ]

    Tertiary [ ]

5. Duration of illness in months .....

6. Etiology of the Chronic Kidney Disease

    Congenital [ ]

    Acquired [ ]

7. Mode of dialysis

    Peritoneal dialysis [ ]

    Hemodialysis [ ]

8. Number of hospital visits per month .....

9. Current comorbid illness

    Yes [ ] No [ ]

    If yes, specify .....

### **SECTION 3: THE ZARIT BURDEN INTERVIEW (ZBI) QUESTIONNAIRE**

**INSTRUCTIONS:** The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers. (Tick or circle your answer)

1. Do you feel that your relative asks for more help than he/she needs?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

4. Do you feel embarrassed over your relative's behavior?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

5. Do you feel angry when you are around your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

7. Are you afraid what the future holds for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

8. Do you feel your relative is dependent upon you?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

9. Do you feel strained when you are around your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

14. 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. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

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What would you recommend to Kenyatta National Hospital and the Renal Unit healthcare providers to do, that would help ease your burden?

.....  
.....  
.....  
.....  
.....  
.....  
.....

## Appendix 5: Approval by UoN-KNH Ethics and Research Committee



UNIVERSITY OF NAIROBI  
FACULTY OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
Tel:(254-020) 2726300 Ext 44355

Ref: KNH-ERC/A/373

Faith Wangui Wariguah  
Reg. No. H56/37557/2020  
Dept. of Nursing Sciences  
Faculty of Health Sciences  
University of Nairobi

Dear Faith,

**RESEARCH PROPOSAL: THE BURDEN OF CARE AMONGST CAREGIVERS OF CHILDREN WITH CHRONIC KIDNEY DISEASE ON DIALYSIS AT THE KENYATTA NATIONAL HOSPITAL (P409/05/2022)**

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P409/05/2022**. The approval period is 27<sup>th</sup> September 2022 – 26<sup>th</sup> September 2023.

This approval is subject to compliance with the following requirements;

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

**KNH-UON ERC**  
Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)  
Website: <http://www.erc.uonbi.ac.ke>  
Facebook: <https://www.facebook.com/uonknh.erc>  
Twitter: @UONKNH\_ERC [https://twitter.com/UONKNH\\_ERC](https://twitter.com/UONKNH_ERC)



**KENYATTA NATIONAL HOSPITAL**  
P O BOX 20723 Code 00202  
Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

27<sup>th</sup> September, 2022

Protect to discover

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <https://research-portal.nacosti.go.ke> and also obtain other clearances needed.

Yours sincerely,



**DR. BEATRICE K.M. AMUGUNE**  
**SECRETARY, KNH-UoN ERC**

- c.c. The Dean, Faculty of Health Sciences, UoN  
The Senior Director, CS, KNH  
The Assistant Director, Health Information Dept., KNH  
The Chairperson, KNH- UoN ERC  
The Chair, Dept. of Nursing Sciences, UoN  
Supervisors: Ms. Hannah Inyama, Dept. of Nursing Sciences, UoN  
Dr. James Mwaura, Dept. of Nursing Sciences, UoN

Appendix 6: Approval by KNH Research Department



KENYATTA NATIONAL HOSPITAL  
P.O. Box 20723-00202 Nairobi

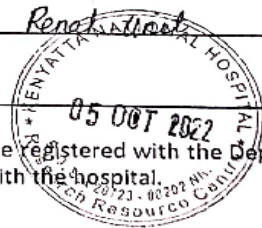
Tel.: 2726300/2726450/2726565  
Research & Programs: Ext. 44705  
Fax: 2725272  
Email: [knhresearch@gmail.com](mailto:knhresearch@gmail.com)

KNH/R&P/FORM/01

**Study Registration Certificate**

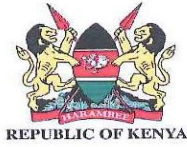
1. Name of the Principal Investigator/Researcher  
FAITH WANJAU WARIQUAH
2. Email address: faithwanjau@students.uonbi.ac.ke Tel No. 0726 850851
3. Contact person (if different from PI).....
4. Email address: ..... Tel No. ....
5. Study Title  
The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital.
6. Department where the study will be conducted Paediatric Renal Unit Department  
(Please attach copy of Abstract)
7. Endorsed-by KNH Head of Department where study will be conducted.  
Name: Dr. Wambui B.M. Signature [Signature] Date 5/10/2022
8. KNH UoN Ethics Research Committee approved study number P 409/05/2022  
(Please attach copy of ERC approval)
9. I Faith Wanjau Wariquah commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.  
Signature [Signature] Date 04/10/2022
10. Study Registration number (Dept/Number/Year) Renal Unit 1191/2022  
(To be completed by Medical Research Department)
11. Research and Program Stamp

All studies conducted at Kenyatta National Hospital must be registered with the Department of Medical Research and investigators must commit to share results with the hospital.





**Appendix 7: NACOSTI Approval**



REPUBLIC OF KENYA



NATIONAL COMMISSION FOR  
SCIENCE, TECHNOLOGY & INNOVATION

RefNo: 674991

Date of Issue: 28/October/2022

**RESEARCH LICENSE**



This is to Certify that Ms.. Faith Wariguah of University of Nairobi, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Nairobi on the topic: The burden of care amongst caregivers of children with chronic kidney disease on dialysis at the Kenyatta National Hospital. for the period ending : 28/October/2023.

License No: NACOSTI/P/22/21266

674991

Applicant Identification Number

Director General  
NATIONAL COMMISSION FOR  
SCIENCE, TECHNOLOGY &  
INNOVATION

Verification QR Code



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