

**CAREGIVER BURDEN AS PERCEIVED BY PATIENTS WITH CHRONIC
KIDNEY DISEASE AND UNDERGOING HEMODIALYSIS AT
KENYATTA NATIONAL HOSPITAL.**

NYANGENA.M.STANLEY

H56/7824/2017

**DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE AWARD OF DEGREE OF MASTERS IN
NURSING (RENAL NURSING) OF THE UNIVERSITY OF NAIROBI.**

OCTOBER 2019

DECLARATION

I **Nyangena M Stanley**, declare that this dissertation is my original work and has not been submitted for award of degree in any university.

Signature

Date

CERTIFICATE OF APPROVAL

We the undersigned certify that this research work has been submitted for award of the degree of Masters of Science in Nursing (Renal Nursing) of the University of Nairobi with our approval as internal supervisors.

Dorcas Maina,

PhD, MSc, BScN.

Lecturer, School of Nursing Sciences,

University of Nairobi.

Sign.....Date.....

Professor Anne Karani.

PhD, MSc, BScN.

Lecturer, School of Nursing Sciences,

University of Nairobi.

Sign..... Date.....

LIST OF ABBREVIATIONS

CKD: Chronic kidney disease

ERC: Ethics and Research Committee

ESRD: End stage renal disease.

HRQOL: Health Related Quality of Life

KNH: Kenyatta National Hospital

SPSS: Statistical Package for Social Sciences.

UoN: University of Nairobi

OPERATIONAL DEFINITIONS

Caregiver burden: Stress discerned by those taking care of the patient with chronic illness such as chronic kidney disease.

Health related quality of life: The individual's beliefs, experiences, perceptions and expectations standing for enjoyment in those aspects of life probably influenced by health condition.

Chronic Kidney Disease: Refers to the irreversible and progressive loss of kidney function that requires replacement therapy to sustain life and increase longevity. It occurs in five stages i.e. from stage 1 which refers to mild stage and stage 5 which refers to end stage renal disease..

Perception: Refers to interpretation of a situation in a particular way by an individual.

TABLE OF CONTENTS

DECLARATION	ii
CERTIFICATE OF APPROVAL.....	iii
LIST OF ABBREVIATIONS.....	iv
OPERATIONAL DEFINITIONS.....	v
LIST OF TABLES	xi
ABSTRACT	xii
CHAPTER ONE: INTRODUCTION	1
1.1 Background	1
1.2 Statement of the problem	2
1.3 Justification	3
1.4 Objectives.....	4
1.4.1 Broad objective	4
1.4.2 Specific objectives.....	4
1.5 Research Questions.....	4
1.6 Hypothesis.....	5
1.7 Conceptual framework.....	5
1.8 Theoretical Framework: Sister Calista Roy’s Adaptation Model	6
CHAPTER TWO: LITERATURE REVIEW.....	8

2.1. Introduction	9
2.2 Health related quality of life among caregivers of patients with CKD	9
2.2.1 Physical health	10
2.2.2 Psychological health.....	11
2.2.3 Social relationships among CKD patients.	12
2.3 The level of caregiver perceived burden.....	13
2.3.1 Age	13
2.3.2 Marital status.....	14
2.3.3 Gender	15
2.3.4 Socioeconomic status of the patient	16
2.3.5 Cultural and religious beliefs	17
2.3.6 Patient’s comorbidities	17
2.4 Summary	17
CHAPTER THREE: METHODOLOGY	19
3.1 Introduction	19
3.2 Study design	19
3.3 Study site/location	19
3.4 Study population.....	19
3.5 Inclusion/exclusion criteria	20

3.5.1 Inclusion criteria.....	20
3.5.2 Exclusion criteria.....	20
3.6 Sample size determination	20
3.7 Sampling technique.....	21
3.8 Study participant selection, recruitment and consenting procedure	21
3.9 Study variables	22
3.10 Research tool	22
3.11 Pretest, reliability and validity of the tool.....	23
3.12 Data Collection	23
3.13 Data Cleaning and Entry	24
3.14 Data analysis and presentation	24
3.15 Data Storage	24
3.16 Ethical Consideration.....	25
3.17 Study Limitations and Delimitations	25
3.18 Study findings dissemination plan.....	26
CHAPTER FOUR: RESULTS	27
4.1 Introduction	27
4.2 Socio-demographic factors analysis	27
4.3 The caregiver's level of the burden as perceived by participants.	29

4.3.1. Caregiver’s level of burden as perceived by participants with CKD undergoing hemodialysis at Kenyatta National Hospital.	29
4.3.2. Respondents Cousineau scale average scores.....	30
4.4 The patient factors influencing the caregiver burden as perceived by patients with CKD undergoing hemodialysis	31
4.4.1. The general perception of patients on their quality of health.	31
4.4.2. Rating on how health influence typical day activities.....	31
4.4.3. Problems with work or other regular activities	31
4.4.4. Interference with normal work in the past four weeks	31
4.4.5. Participants perception of things in the past four weeks	32
4.4.6. Participant perception of his/her kidney condition influence on life	32
4.4.7. The rate at which the respondent is bothered by the manifestation of different clinical presentations	33
4.4.8. Participants rating on how much Kidney disease is a bother to their life	33
4.4.9. Predictors of caregiver burden perception among patients.....	34
4.5 The relationship between the health-related quality of life and caregiver burden in patients undergoing hemodialysis at Kenyatta National Hospital	35
4.6 The conclusion of the findings	36
CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS	37

5.1 Discussion of study findings.	37
5.1.1 Patient factors influencing caregiver burden as perceived by CKD patients undergoing hemodialysis	37
5.1.2 Level of caregiver burden as perceived by patients	38
5.1.3 Health related quality life on caregiver burden as perceived by patient	39
5.2 Conclusion.....	42
5.3 Recommendations.....	44
REFERENCES	45
APPENDIX I: CONSENT INFORMATION FORM.....	48
Consent Certificate Form	51
APPENDIX II: QUESTIONNAIRE.....	53
APPENDIX III: KIDNEY DISEASE –QUALITY OF LIFE – SF V.36	55
APPENDIX IV: COUSINEAU BURDEN SCALE	59
APPENDIX V: LETTER REQUESTING FOR ETHICAL APPROVAL	60
APPENDIX VI: AUTHORIZATION LETTER TO KENYATTA.....	61
APPENDIX VII: PROPOSED STUDY WORK PLAN.....	62
APPENDIX VIII: STUDY BUDGET	63
APPENDIX IX: MAP OF STUDY AREA	64

LIST OF TABLES

Table 1: Socio-demographic factors.....	28
Table 2: Level of participant perceived caregiver burden	29
Table 3: Cousineau average scores.....	30
Table 4: Participants perception of how their kidney condition influence their lives.....	34
Table 5: Factors associated with caregiver burden as perceived by patients.....	35
Table 6: Association between the health-related quality of life and caregiver burden in patients undergoing hemodialysis.....	36

ABSTRACT

Background: Caregiver burden refers to the negative feelings and subsequent strain experienced by the relatives or friends of the patients with (CKD) who have to undergo regular hemodialysis. The burden on the caregivers has been extensively studied, however, the perception of the burden on the recipient of the care (patient) has not been well established.

Aim of the study: The aim of the study was to assess caregiver burden as perceived by the patients with CKD undergoing hemodialysis at Kenyatta National Hospital (KNH).

Methods: This a descriptive cross sectional survey where convenience sampling was used to identify 113 study participants. Ethical approval was sought from KNH-UoN Ethics and Research Committee. A demographic questionnaire was used to obtain socio-demographic data. Caregiver burden perception was assessed using Cousineau Scale of Perceived Burden and Health Related Quality of Life by KDQOL-SF.v.36 form.

Results: The findings showed that majority of the respondents perceived themselves as a burden some of the time to their caregivers. There was a significant relationship between perception as a burden to caregivers and health related quality of life at $p=0.00$, $\chi^2=34.18$ ($p<0.05$). Patients who asserted that kidney disease interferes too much with their life were associated with increased perception as burden to their caregiver $p=0.03$, $\chi^2=27.98$ ($p<0.05$). There was a significant association between amount of money spent on hemodialysis treatment and patients' caregiver burden perception $p=0.00$ ($p<0.05$).

Conclusion and recommendations: The burden of (CKD) cuts across the age-groups, gender, social and economic status. The findings show that majority of the participants feel being a burden to their caregivers some of the time in terms of financial dependence, activities of daily living among others. This study recommends making hemodialysis treatment more affordable and accessible, economically empowering dialysis patients and timely treatment of renal failure complications to ease the patients' caregiver burden perception.

CHAPTER ONE: INTRODUCTION

1.1 Background

Chronic kidney disease (CKD) is a chronic and debilitating condition. In CKD, the body loses its ability to maintain electrolyte and metabolic balance leading to increased retention of blood solute wastes and excess fluid (Mashayekhi, Pilevarzadeh & Rafati, 2015). Chronic Kidney Disease (CKD) can result from a number of causes but the main ones remain uncontrolled hypertension and diabetes mellitus, (Sanyaolu, Adekunle, Snouber, Shebab, Alkhatib, Abdallah et al., 2018). It is recognized as a major non-communicable disease of growing epidemic dimension worldwide with prevalence in the general population of between 5% and 13% across countries (De Nicola & Minutolo, 2016). It is associated with impaired quality of life and substantially reduced life expectancy at all ages. In addition, it is associated with a number of signs and symptoms which mostly interfere with the patients independence (Levin, Tonelli, Bonven, Adeera et al., 2017). In majority of the cases, when a patient has CKD, they undergo renal replacement therapies in order to increase their quality of life and its longevity.

Renal replacement therapies (RRT) are stand-in treatments to mitigate lost kidney function. Renal replacement therapies refers to a treatment that replaces the normal function of the kidneys used in renal failure and they include dialysis and kidney transplantation (Khader, 2013). These treatments are life-saving but costly. In Kenya, a CKD patient on hemodialysis requires Kshs.80, 000 monthly (NHIF data). These costs do not include costs for investigations, medications, transport and clinical follow ups, subsequently the costs of treating CKD and its complications are unaffordable for governments and individuals in many parts of the world (Levin et al., 2017). In addition, renal replacement therapies cause physical, financial and psychological challenges to the caregivers and the patients.

Caregiver burden is therefore a major concern among patients with CKD and on hemodialysis. It results in negative consequences to caregivers, CKD patients, family members and health care system (Gatua, 2016).The patients rely on unpaid caregivers to assist them with their activities of daily living and medical needs as well: cleaning, driving, preparing meals, and coordinating medication and other treatment-related activities (Bevans & Sternberg, 2012). The patients require thrice-a-week hemodialysis sessions and a number of clinical follow-ups. Consequently, there are varied burden levels perceived by the patient. This can be related to CKD disease process, lifestyle changes, and loss independence status of the patient.

1.2 Statement of the problem

Chronic Kidney Disease is a progressive and debilitating disease, which presents with a number of complications over time especially at stage 5 (End Stage Renal Disease). Routine investigations, clinical follow ups, dialysis and kidney transplantation replace lost renal function, improve quality of life and its longevity among CKD patients. Most frequently, CKD patients present to the health facility when the disease is at advanced stage and patients are in a frail state necessitating the caregivers to fully take care of these patients until they stabilize (Gatua, 2016).They rely on caregivers to assist them with their activities of daily living and medical needs as well: cleaning, driving, preparing meals, and coordinating medication and other treatment-related activities (Bevans & Sternberg, 2012). Most patients require support due to the debilitating effects of the chronic kidney disease.

Management of a chronic kidney disease is expensive. These patients incur a lot of expenses: hemodialysis procedure, routine investigations, and transport, medical among other costs (Levin et al., 2017). On average a patient with CKD requires 2-3 dialysis sessions per week. Given that

most Kenyans belong to low social economic class earning less than 1 US\$ a day (IMF, 2017) most are reliant on the national insurance cover to sustain hemodialysis. However, this coverage is for hemodialysis sessions only. Most patients especially those without a stable income source rely on regular contributions and fundraising by relatives and friends. The constant need for financial dependence can be a cause of feelings of being a burden for the patient with CKD.

Caregiver burden and its effects among caregivers of CKD has been extensively studied. This study focused on describing the caregiver burden as perceived by the CKD patient and if it plays a role in determining the clinical outcome (quality of life) of the CKD patient undergoing routine hemodialysis.

1.3 Justification

Caregiver burden as perceived by chronic kidney disease patients on routine hemodialysis is poorly understood. This could be related to underreporting, regional disparities and differences in definition and study populations especially in Sub-Saharan Africa. Caregiver burden as perceived by patients undergoing maintenance hemodialysis in Kenyatta National Hospital is not documented and yet it is important to describe it. This study therefore aimed to describe caregiver burden as perceived by patients undergoing routine hemodialysis in Kenyatta National Hospital. This study will improve the multidisciplinary team practice among those involved in the care of CKD patients through development of interventional tools aimed at minimizing strained relationship between CKD patient and their caregivers as a result of CKD patients perceiving themselves as a burden. It will also enable the Kenyatta National Hospital to institute supportive policy measures to avert psychological issue such as depression among CKD patients, therefore, shortening hospital stay time and profitability to the institution as well as improving

the quality of life and its longevity among CKD patients. This study will also serve as a knowledge base to future researchers who will be interested to explore the subject matter.

1.4 Objectives

1.4.1 Broad objective

To assess caregiver's burden as perceived by chronic kidney disease patients undergoing hemodialysis in Kenyatta National Hospital

1.4.2 Specific objectives

- a) To determine the caregiver's level of burden as perceived by patients undergoing hemodialysis at Kenyatta National Hospital.
- b) To investigate the patient factors influencing the caregiver burden as perceived by patients with CKD undergoing hemodialysis at Kenyatta National Hospital.
- c) To assess the relationship between the health-related quality of life and caregiver burden patients undergoing hemodialysis at Kenyatta National Hospital.

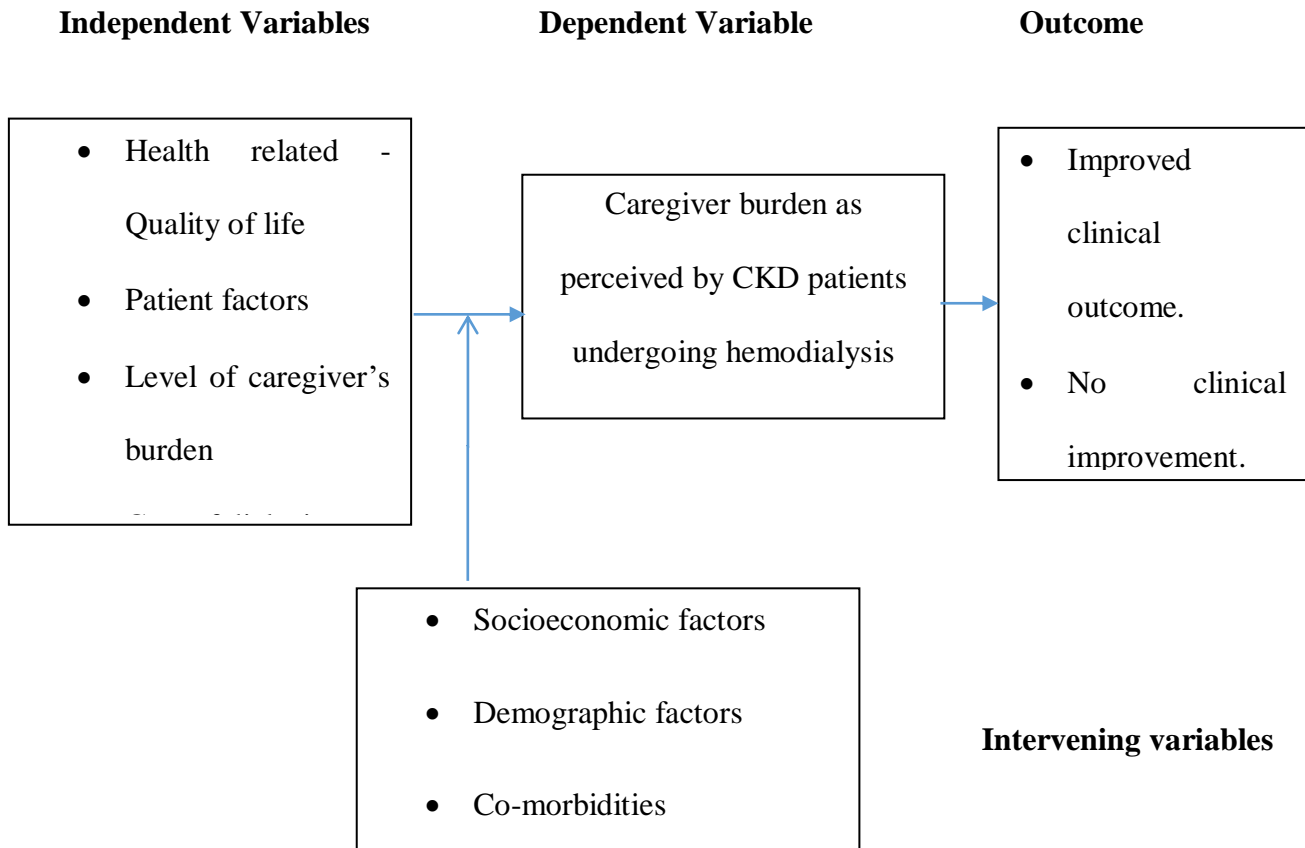
1.5 Research Questions

- a) What is the caregiver's level of burden as perceived by patients with CKD undergoing hemodialysis at Kenyatta National Hospital?
- b) What are the patient factors influencing the caregiver burden as perceived by patients with CKD undergoing hemodialysis at Kenyatta National Hospital?
- c) What is the relationship between the health-related quality of life and caregiver burden among patients undergoing hemodialysis at Kenyatta National Hospital?

1.6 Hypothesis

There is no relationship between the quality of life and the caregiver burden levels as perceived by patients undergoing hemodialysis at Kenyatta National Hospital.

1.7 Conceptual framework



The study was guided by the above variables as shown on the conceptual framework. The independent variables which include health related quality of life, patient factors and level of caregiver's burden, travel and medication expenses as well as care at home. The dependent variable will be the caregiver's burden as perceived by CKD patients undergoing hemodialysis. The resultant outcome variable will be either improved clinical outcome in patients with CKD or no improvement at all.

1.8 Theoretical Framework: Sister Calista Roy's Adaptation Model

Roy's work focuses on human adaptive system responses and environmental stimuli, which are dynamic. Roy's model views the individual as a set of interrelated systems; biological, psychological and social. Adaptation is the process and outcome whereby thinking and feeling persons as individuals or in a group, use conscious awareness and choice to create human and environmental integrations (Roy & Andrew, 1999). Issues with adaptation arise when the human adaptive system is unable to cope with or respond to stimuli from the external or internal environment in a manner that maintains the integrity of the system. The adaptation process that the patients with Chronic Kidney Disease undergoing hemodialysis make Roy's Adaptation Model (RAM) applicable. According to the adaptation theory, human beings are adaptive systems with inputs of stimuli and output as behavior responses that serve as feedback. The systems also have control processes which are known as coping mechanisms.

Roy's Model has three classes of stimuli that confront the human system; focal, contextual and residual stimuli. The focal stimulus is referred to as the stimulus that is immediately confronting the human system. In this study the focal stimuli to the patients is the caregiver burden. Contextual stimuli refers to the other stimuli of the human's internal and external environments they could have a positive or negative effects on the situation. In this study the social needs (care for other siblings, marital duties), the economic needs (medical bills, resigning from job, transport bills) and psychological (aggressive diagnostic procedures), experiences are the contextual stimuli that accompany the issue of the caregiver burden.

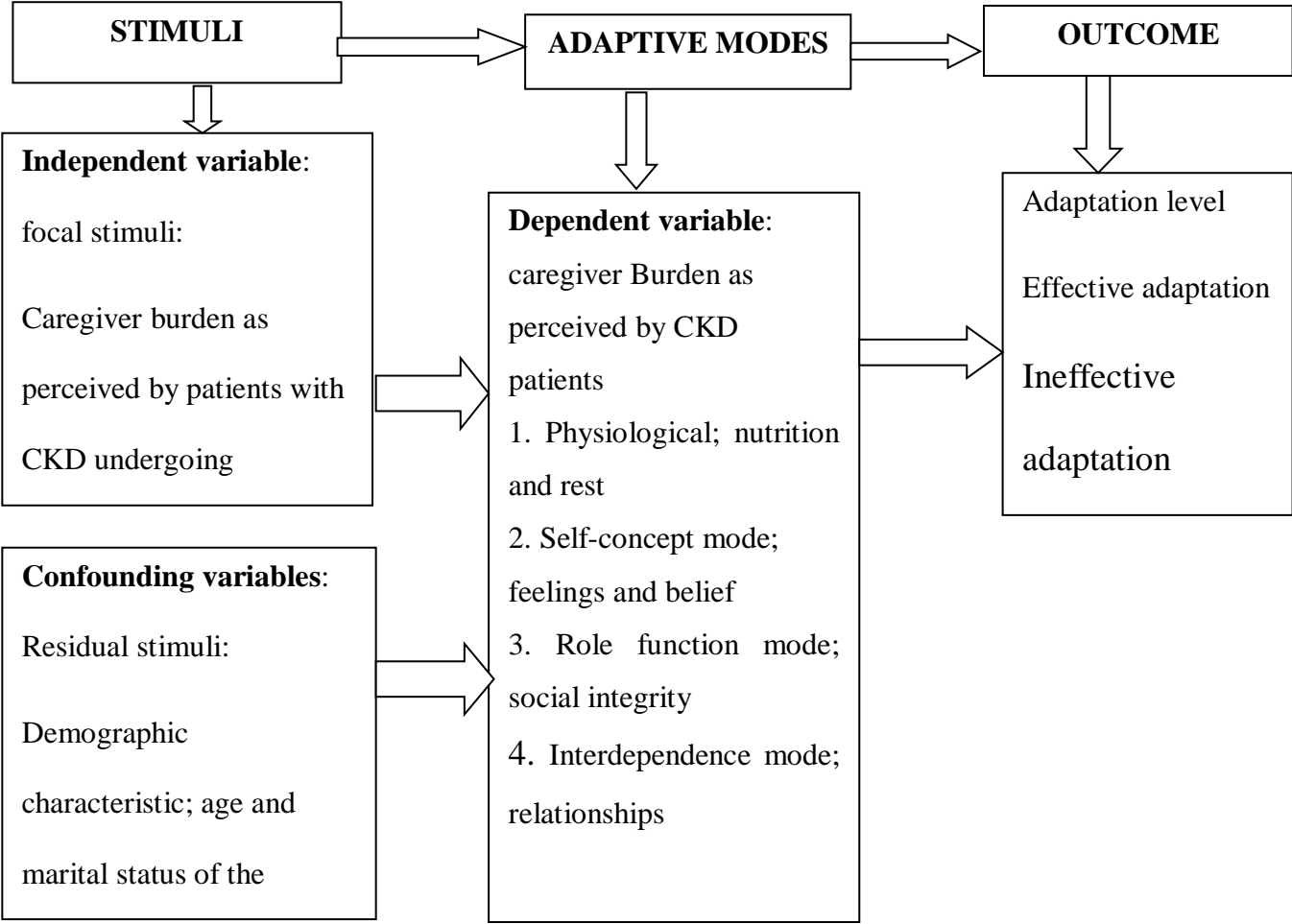
The third stimulus is the residual stimuli and it includes the external factors whose current effect is unclear also known as the confounding. These stimuli are thought to have effect on the

perceived caregiver burden in this study the confounders include: demographic factors of the patients for example age, sex and marital status.

After the stimuli (situation) individuals adapt to these situations differently and in Roy's model she made mention of 4 adaptive modes; physiologic- physical mode where the humans interact as physical beings through activity and resting, nutrition and protection. The role function mode is the underlying need of social integrity. The self-concept mode refers to the self-esteem, hopelessness in an individual. Lastly the interdependence mode which deals with the interaction and emotions related to giving and receiving love and care respect and values from the family and others in the community.

Adaptation finally emerge in to either positive or negative individual behavior and this is the feedback to the system (patients) and to the environment who are the significant others.

ROY ADAPTATION MODEL



CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

Patients with Chronic Kidney Disease (CKD) have varied burden perception levels depending on many factors. This has an impact on the quality of life of the individual patient. The literature search focused on; caregiver burden as perceived by CKD patients, the patients factors that influence their perception as being a burden to their caregivers and the impact of the burden perception on their quality of life. The sources of literature were Google Scholar, Mendeley's Catalogue of academic literature and Pub-med databases. The key words were: "caregivers", "patients", "chronic kidney disease", "hemodialysis", "burden" and "perception on quality of life".

2.2 Health related quality of life among caregivers of patients with CKD

Patients with chronic kidney disease (CKD) and at advanced stage (stage 5) presents with a number of complications on different body systems. Patients often require frequent dialysis which can be very demanding in terms of care both within the hospital and at home (Cousineau, McDowell, Hotz & Hebert, 2003). In addition, the systemic manifestations of CKD can negatively impact various aspects of the patient's health and quality of life where patients feel that they are becoming a burden to their family members and the community (Rioux, Narayana, & Chan, 2012). This is in addition to Belasco and Sesso (2002) established that caregivers of patients undergoing hemodialysis may experience a significant burden that is an adverse effect on their quality of life. These adverse effects may include; emotional stress, socially and economically drain especially for female spouses. These caregivers may require social, psychological and financial support when taking care of patients with chronic kidney disease.

Patients may feel they are a burden to their family members because of the demands of living with a kidney disease. Avsar et al (2015) assessed patients on caregivers' burden, depression and sleep quality differences in caregivers of dialyzing patients. They found out that the patients felt that their caregivers had poor quality sleep, had a lot of anxiety due to their deteriorating condition. This could be related to the increased support needed in chronic kidney disease.

The quality of life of patients with chronic disease is dependent of several factors including adequacy of dialysis. The perceived quality is linked to how best the patient can still perform the activities of daily living independently. According to Boyoumi (2018), health-related quality of life is the individual's beliefs, experiences, perceptions and expectations. These stand for enjoyment in those aspects of life probably influenced by their health condition on their caregivers. In the studies on the Health Related Quality Of Life (HRQOL) lower scores lead to significant risk of hospitalization and mortality. Furthermore, HRQOL has been discovered to be a forecaster of mortality in patients on hemodialysis (Khatib, Hemadneh, Hasan, Khazneh & Saed, 2018). Health related quality of life can be discussed under domains: physical, psychological health and social relationships.

2.2.1 Physical health

Chronic kidney disease (CKD) causes frailty among its patients. Frailty symptoms include weight loss, slowness, exhaustion, weakness, and low physical activity (Ballew, Chen, Daya, Godino, Windham...et al., 2017). Frailty causes suffering among patients and increased health demands on the caregiver (Almazly, 2019) and diminishes the patient's physiological reserves, worsening their quality of life. Further, caring of patients with CKD causes psychological and financial stress among the caregivers. The caregivers may become hopeless when they do not

meet patient's demands and other familial responsibilities (Portilla Franco, Molina &Gregorio, 2016).Most patients with CKD need physical and financial support from their daily.

The prevalence of frailty is high and is a common symptom among patient with CKD at advanced stage. Lee, Son and Shin (2015) investigated the prevalence of frailty among patients with CKD patients and found that majority of the patients were frail. These patients were physically fatigued due to stress, loss of financial power. Brett, et al., (2017) established that majority of the patients feel physically exhausted, have an increased infection risk as well as increased incidence of cardiovascular diseases. Frailty affects not only clinical outcomes but also the patient-centered outcome –HRQOL (McAdams, DeMarco, Ying, Olorundare, King, Desai...et al., 2016.It also incapacitates the patients well-being and makes them to need support to perform activities of daily living.

2.2.2 Psychological health

Due to the chronic nature of chronic kidney disease, patients and caregivers face different psychological difficulties. Cohen, Cukor and Kimmel (2016) found that, anxiety, which is a common manifestation of psychological stress is often overlooked as a psychiatric symptom in caregivers of patients with ESRD undergoing hemodialysis (HD). The increasing demand of such patients to caregivers, the cost of care and delays associated with treatment poses a mental challenge to the caregivers. Most patients with ESRD contribute to development of anxiety among their caregivers.

Psychiatric symptoms are also common among patients with ESRD. Jadhav, Dhavale, Dere & Dadarwala (2014) established that patients with chronic kidney disease feel that their caregiver sometimes develop psychiatric conditions especially when the patient's prognosis worsens and

when the family cannot afford a much lifesaving hemodialysis. Pop-Jordanova & Polenakovic (2016) collaborates this and explains that patients with ESRD expressed increasing dissatisfaction about the time spent for the treatment of their disease, the dependence on the hemodialysis staff, the reduced ability to travel and their inability to work. Still psychological health among hemodialysis patients is understudied. Use of different definitions of psychological conditions and the overlap of depressive symptomatology with symptoms of uremia makes it difficult to conduct relevant studies.

2.2.3 Social relationships among CKD patients.

Social relationship among patients with chronic kidney disease is commonly adversely affected. Many studies have revealed that presence of a chronic illness is a very stressful life event and can create significant social problems for patients and their caregivers (Griva et al., 2016; Jansen et al., 2012). Social support recognizes that caregivers of such patients give and receive aid through various networks as they engage in interactions through social support organization. According to Cohen, Sharma, Acquaviva, Peterson, Patel...et al., (2014), social support can be obtained from family, friends, coworkers, spiritual advisors, health care personnel, or members of one's community or neighborhood with a similar problem and can come in form of moral support as well as financial support. Caregivers of such patients often need to communicate with their support system whenever a social problem arises or whenever they experience any challenge. Xhulia, Gerta, Dajana, Koutelekos & Vasilopoulou (2016) carried out a study among hemodialysis patients and found that difficulties in relationships with family members was associated with the need for support, the need for communication and individualization of care.

Other studies have revealed that lack of social support among the caregivers of patients with CKD can lead to depression or anxiety among the caregivers, which can be transferred to the patient, further worsening the patient's condition (Lilyampaki et al., 2016). Further, caregivers of patients with high level of anxiety and depression felt less support from their significant others, family member and friends. Similarly, Tezel, Karabulutlu and Sahin, (2011) who also found that caregivers of such patients who were dissatisfied with their social support had higher depressions scores. Khalil and Abed (2014) found perceived social support is a partial mediator of the relationship between depressive symptoms and quality of life in patients receiving hemodialysis results.

2.3 The level of caregiver perceived burden

According to Avsar et al., (2015) majority of the patients with CKD have felt that their family members are experiencing a high burden in taking care of their condition and feel that the family is overwhelmed and that they have become a bother to them. Many factors that affect the level of the perceived level of burden of the caregivers include, age, marital status, socio-economic status, cultural factors

2.3.1 Age

Age is an independent predictor of chronic kidney disease and by extension caregiver burden. In a study by Jadhav et al., (2014) majority of patients undergoing hemodialysis were of advanced age, most of their kin are mostly children or young adults. In such situation, the patient who happens to be their relative feels that they are having high level of burden which may affect their future as well as that of their children. Similarly Shdaifat and Manaf, (2012), found that the perceived burden is high if the caregivers are young in age and happens to be the children of the

patients affected. This can be explained by the fact that young adults have their familial responsibilities to take of apart from caring for the sick parent.

According to Manavalan, Majumdar & Kumar (2017) majority of the patients with CKD depends mostly on their spouses and younger children who are just starting their families. Such patients feel that they are causing a lot of financial strain on their spouse and even their children who are relatively young and not well established in life. However, caregivers of patients younger than 47 years old showed better quality of life (QOL) in the functional capacity; however, their QOL was worse in terms of social aspects (Lemos, Rodrigues & Veiga, 2015).

2.3.2 Marital status

Diagnosing a chronic disease in a patient causes emotional and psychological devastation on the spouse (Alnazly et al., 2016). In such cases the spouse that have been diagnosed with the disease feel that he or she has become a serious burden to the remaining spouse who may not have the financial capability to pay for all the medical bills and other demands that are required for the care of the patients. Further, Yoong....et al., (2017) established that the level of perceived burden is extremely high among the married couples if one of them is diagnosed with a chronic disease such as chronic kidney disease.

Marital status and the quality of spousal relationships have been associated with several health outcomes including CKD. Development of CKD may be a source of marital discord or dissatisfaction, as the disease may significantly alter patient-spouse relationship dynamics. CKD may modify patients' ability to work outside the home, inhibit patient contributions inside the home, shift spouses into caregiver roles, or cause sexual dysfunction (Kimmel, Peterson, Weihs Shidler, Simmens,....et al.,2000).This can negatively impact on the patient. The patient with

CKD may perceive himself or herself as a burden because their caregivers are meeting most if not all of their needs.

The marital status can be a determinant of the caregiver burden perception and survival among patients with CKD. In a study among patients receiving hemodialysis, survival was greater among women, but not men, living alone or with a spouse only, compared with those living in households with additional relatives and/or nonrelatives (Turner, Leidner, Simmens, Reiss, Kimmel & Holder, 2010). This can be attributed to marital satisfaction among female patients. The response among male patients may be associated with bruised ego in that they are unable to assert their provider role in the family.

2.3.3 Gender

Different gender perceive burden differently. In study by Jadhav et al, (2014) it established that majority of chronically ill patients felt that their next of kin has a high burden especially if the caregiver is female. In another study, it was shown that caregivers of patients who are younger and are female encounter more difficulty adhering and accepting that their kin has been diagnosed of a chronic illness such as CKD and has to undergo dialysis (Clark-Cutaia, Ren, Hoffman, Burke & Sevic, 2014). The study further established that the perceived burden is high if the patients was a male and was the bread winner to the family. This is because of the loss of family income once the breadwinner is sick. Lost economic support may mean that children will drop out of school and the family may relocate if they are not able to raise the current rental costs.

Sa'ed, Daraghmeh, Mezyed, Khdeir & Sawafta, (2016) established that male patient perceive their female counterparts to be more burdened when left to take care of them plus their children.

However, female patients were found to be strong and were able to encourage the family's members despite their situation. In cohort study, 75 patients undergoing maintenance hemodialysis were involved in the study. Gender plays a role in the perception of the level of burden perceived among patients. Female patients are more resilient compared from their male counterparts.

2.3.4 Socioeconomic status of the patient

The economic status of the patient is a major determinant of their burden perception. Unemployment has been associated with lower HRQOL. African Americans with hypertensive CKD with better social support and coping skills had higher HRQOL (Porter, Fischer, Brooks, Bruce, Charleston... et al., 2012). These patients had better income and they were able to pay for some of the services they need instead of fully depending on unpaid caregivers.

Low socio-economic status (SES) has been associated with depression and poor coping among CKD patients undergoing hemodialysis. Hawamdeh, Almari, Almutairi & Dator, (2017) found that financial strain can seriously impact the compliance to treatment and meeting the family's economic needs. However, studies assessing the relationship between survival and socioeconomic statuses in patients with the CKD have suggested that higher socioeconomic status was associated with improved survival, regardless of race (Robinson, Joffe, Pisoni, Port, Feldman, 2012). Patients in higher socioeconomic status are more likely to feel they do not pose a burden on their caregivers because they can afford to pay some other caregivers to provide a service to them. Consequently patients with a higher social economic status are more likely to comply with treatment compared to those of lower socioeconomic status who may not afford care because of strains in family resources.

2.3.5 Cultural and religious beliefs

The patient's culture, traditions, and religious inclinations are essential in determining their perception about the impact of their health. In a study relating chronic kidney disease patient's spirituality in their care: health benefits and research perspectives. It was indicated that considering, assessing and addressing chronic kidney disease patient's spirituality and spiritual needs is necessary and it can have a positive outcome in health related quality of life, mental health and life expectancy (Fradelos, Tzavella, Koukia, Papathanasiou, Alikari...et al., 2015).

2.3.6 Patient's comorbidities

Patients with CKD can have other comorbidities on top of their primary condition. These comorbidities include: hypertension (88 %), 'painful conditions' (30%) 24 % anemia, 23 %, ischemic heart disease, 17 % diabetes and 12 % thyroid disorders (Fraser, Roderick, May, McIntyre, McIntyre...et al 2014).

In a retrospective cohort study assessing the impact of chronic kidney disease and cardiovascular comorbidity on mortality in a multiethnic population. Risk of death is higher in individuals with CKD and with a higher cumulative cardiovascular comorbidity (Jesky, Lambert, Burden & Cockwell, 2013).

2.4 Summary

According to literature reviewed, the quality of life of patients with chronic kidney is dependent their perception of themselves as a burden to their unpaid caregivers among other factors. Patient's perception about caregiver burden is influenced by gender and age among other demographic factors. Female patients with CKD are more resilient and they support when the disease has really overwhelmed them. On the other side when the CKD patient is a male and the

breadwinner of the family, the level of caregiver burden experienced is heightened. This is because the family members have to adjust in terms of expenditure since family revenue streams are strained.

Caregiver burden perception among patients with CKD also impacts negatively on the psychological status of these patients. Most patients may feel anxious or hopelessness. This is a common finding especially for patients with CKD who have a poor prognosis. The lack of independence both financially and physically drains the energy within the patient to fight the chronic illness.

Socially, patients with CKD are more often isolated. This due to the fact that they undergo regular admissions due to renal replacement therapy complications such as infections or due to their frail status. Their participation in social activities like sports is also curtailed by the fact that they are mostly anemic and weak. This social isolation therefore contributes to their perception of burdensomeness among their caregivers.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter outlines the research methodology used to explain the study phenomenon and includes the research design, sample size determination, sampling, data collection, and data analysis processes. It also highlights the ethical issues considered in the study.

3.2 Study design

This was a descriptive cross-sectional study. This design was the most suited for this study because it allowed the researcher to investigate multiple variables during data collection.

3.3 Study site/location

The study was conducted at the Kenyatta National Hospital (KNH), renal unit. KNH is a national referral facility in Nairobi Kenya and is the teaching hospital for the University of Nairobi, College of Health Sciences. This hospital is located in Upper Hill Area along Hospital Road off Ngong road. It occupies 5 hectares of land. Its total bed capacity is over 1800 inpatients. KNH has 50 inpatient wards and various outpatient and specialized unit and clinics. It is the largest in the country. 160 patients are on regular hemodialysis and on average 50 patients are dialyzed daily. The unit has 22 hemodialysis machines and is operational all day and night, 7 days of the week.

3.4 Study population

The target study population will comprise of patients with Chronic Kidney Disease undergoing maintenance hemodialysis at the renal unit in Kenyatta National Hospital. The participants must have been on hemodialysis for a period of more than six months and are above 18 years of age.

3.5 Inclusion/exclusion criteria

3.5.1 Inclusion criteria

- i. Patients with chronic kidney disease undergoing maintenance hemodialysis for a minimum of 6 months.
- ii. Patients with chronic kidney disease undergoing maintenance hemodialysis who consent to participate in the study.
- iii. Patients with chronic kidney disease undergoing maintenance hemodialysis above 18 years of age.

3.5.2 Exclusion criteria

- i. Patients with chronic kidney disease returning to hemodialysis therapy after failure of renal transplant or peritoneal dialysis.
- ii. Patients with chronic kidney disease below 18 years of age
- iii. Patients who do not consent to participate in the study.
- iv. Patients undergoing maintenance hemodialysis for a less than 6 months.
- v. Patients with Acute Kidney Injury (AKI) undergoing hemodialysis

3.6 Sample size determination

Data obtained from KNH health records office showed that 160 patients above 18 years were on weekly follow up for hemodialysis in the year 2018. Therefore, out of this population, a representative sample was drawn and the sample size calculation obtained using the formula for finite population (Daniel, 1999).

The calculation is as follows:

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1) + Z^2P(1-P)}$$

n' = sample size with finite population correction,

N = size of the target population = 160,

Z = Z statistic for 95% level of confidence = 1.96,

P = Estimated proportion of patients with burden of care (Caregiver burden scale score between 21 and 88) = 47%

d = margin of error

$$\begin{aligned} &= \frac{160 \times 1.96^2 \times 0.47 \times 0.53}{0.05^2(160-1) + 1.96^2 \times 0.47 \times 0.53} \\ &= \mathbf{113} \text{ patients will be sampled.} \end{aligned}$$

3.7 Sampling technique

Simple random sampling was done to recruit patients who satisfy the inclusion criteria during the study period. Convenience sampling was involved to identify the study participants. The Principal Investigator (PI) shall recruit patients while in the waiting bay or while on dialysis on that particular day. The patients were enrolled until the desired sample size of 113 patients was reached

3.8 Study participant selection, recruitment and consenting procedure

All the patients undergoing hemodialysis were identified using the hemodialysis registers available in the renal unit. Convenience sampling was used to enroll CKD patients who have

dialyzed for more than 6 months. Both inpatients and outpatients were eligible for selection. The PI visited the renal unit twice a day: at 9am and at 3pm to recruit study participants.

The PI approached the study participants and established rapport. He then briefed them about the study and asked them whether they will participate in the study. The names and file identification numbers of willing participants were noted by the PI. The PI took the participant through the research expectations: aim, expected co-operation and benefits of the study, levels of caregiver's burden perception. Benefits of the study were explained and included: policy formulation to lessen burden on caregivers. In consultation with the patient, the PI discussed the time and data collection venue.

Before data collection, informed consent was sought from the participant and there after the interview commenced. The information collected from the patient included: age, marital status, level of education, occupation and health-related quality of life.

3.9 Study variables

Independent variables

- Health related quality of life: physical health, psychological health, social relationships

Dependent variable

- Caregiver burden.

3.10 Research tool

Demographic data was collected using a socio-demographic questionnaire. Health related quality of life was assessed using the Kidney Disease-Quality of life –SF V.36 (KDQOL-SF V.36). The reliability of each KDQOL-36™ subscale was very good (Cronbach's alpha >0.8). Construct validity was supported by expected negative correlation between MCS scores and the Beck

Depression Inventory in all three subgroups ($r = -0.56$ to -0.61 , $P < .0001$). Reliability and validity were similar across all racial/ethnic groups analyzed separately (Ricardo, Hacker, Lora, Ackerson, DeSalvo...et al., 2013).

The caregiver burden was measured using the Cousineau Scale of Perceived Burden. This is a 10-item score that assess the degree to which patients perceive themselves as a burden on their caregivers. The patient answered the questions on a 5 point Likert scale and the scores were then summed to get an overall score ranging from 0 (no burden) to 50 (maximum burden). This toll has been applied in patients on HD with the overall reliability of the instrument being 0.93 (Cousineau, McDowell, Hotz & Hebert, 2003).

3.11 Pretest, reliability and validity of the tool

The study questionnaires were pretested in ward 7A in KNH, a ward that also admits CKD patients on hemodialysis but with other comorbidities such as diabetes and hypertension. Ten percent of the study sample size was pre-tested. This helped in verification of the data collection tool before data is actual study is collected. This helped identify some important questions that had been left out, some ambiguous and unnecessary questions as well as to establish how much time the PI required per study respondent. The other tools remained unmodified. Information gained from the pretest was used to refine the research tool.

3.12 Data Collection

The principal investigator (PI) collected data at any given time apart from the morning hours (7a-8 pm every day. The study participants undergoing hemodialysis at KNH renal unit were identified. The PI approached and identified them and introduced himself and informed them the aim of the study to be carried out. They were asked to consent to facilitate their participation in

the study. The study participants were asked to respond to the different questions in the structured questionnaire, KDQOL-SF.V 36 form and Cousineau Scale of Perceived Burden. The PI filled the responses from the study participants in the appropriate questionnaire and forms. The PI remained available for clarification of any questions or for any additional information as needed by the study participants as it regarded the study.

3.13 Data Cleaning and Entry

The data collected using questionnaires and forms were checked daily for completeness by the researcher. Collected data was entered in EpiData 3.1 database then analyzed using SPSS computer package, version 23.

3.14 Data analysis and presentation

The data was analyzed using SPSS computer package, version 23. Categorical data was summarized in percentages. Multiple regression was used to determine the predictors of severity of caregiver burden. Data was presents in tables, charts and graphs. A chi-square test for association was conducted to determine the association between perceive caregiver burden by patients and their quality of life. All statistical tests were conducted at 5% level of significance ($P < 0.05$).

3.15 Data Storage

The consent forms, questionnaires and forms had codes and respondents names. Once they were filled they were locked in a safe cupboard. The laptop that was used in the analysis of the data had password limiting access to PI only. The consent forms and questionnaires will be safely stored for five years after which they will be destroyed.

3.16 Ethical Consideration

The PI obtained an ethical clearance of the study from the Kenyatta National Hospital/University of Nairobi- Ethics and Research Committee (KNH/UoN-ERC). Clearance to conduct the study was obtained from KNH department of research. Permission was sought from KNH administration as well as from the in charge of renal department.

Consent was sought from the study participants to whom the purpose of the research was explained. The participants too gave both a verbal and written consent by signing or providing their thumbprints on the consent forms. Participants were not be coerced and those who declined participation did not suffer negative consequences. It was a non-invasive study. Confidentiality and privacy was observed throughout the study. Data obtained from the patients was used for research purposes only.

3.17 Study Limitations and Delimitations

The research topic was sensitive and emotionally draining and this could have led to emergency of emotional issues during data collection. The principal investigator (PI) provided quality time to the study participants in order to obtain the required information and he also remain focused on the research topic. The PI also involved the renal unit counselor for referral of such cases for continued management.

The ward environment was unfavorable for the patients to give all the required information. Such patients can answered the questionnaires from the side room before or after hemodialysis.

3.18 Study findings dissemination plan

The findings of the study were presented in the renal unit where the study took place during one of the continuous professional development meetings. Presentation of the study findings was made to the panel of the nursing faculty at the University of Nairobi. The study findings has been published in a peer reviewed journal. A copy of the report and recommendations from the study will be submitted to Kenyatta National hospital. A hard and soft copy of the results is available at the University of Nairobi Library.

CHAPTER FOUR: RESULTS

4.1 Introduction

The study was conducted to assess caregiver's burden as perceived by patients with chronic kidney disease and undergoing hemodialysis in Kenyatta National Hospital. 113 questionnaires were issued and returned for analysis, which represented a 100% response.

4.2 Socio-demographic factors analysis

The demographic analysis as presented showed that majority of respondents were male 53.6% (60). The average age among the respondents as obtained in the analysis was 42.63 years. The analysis also showed that 75.7% (81) of the respondents were married. Majority of the respondents had children, 86.6% (97). The analysis also assessed where the respondents lived, and it was determined that 76.8% (86) lived in Nairobi. The average amount spent monthly by respondents was KSh.17, 375.89.

The analysis presented that more than half, 86.4% (95) of the respondents had their relatives as their caregivers. The findings also showed that 56.3% (63) affirmed that their caregiver was the same person who takes them to hemodialysis sessions. The respondents had varied sources of income where 67.3% (76) were engaged in business. Despite having different sources of income, 88.5% (100) of the respondents asserted that their income was unable to meet their treatment costs. These socio-demographic characteristics are presented in Table 1.

Table 1: Socio-demographic factors

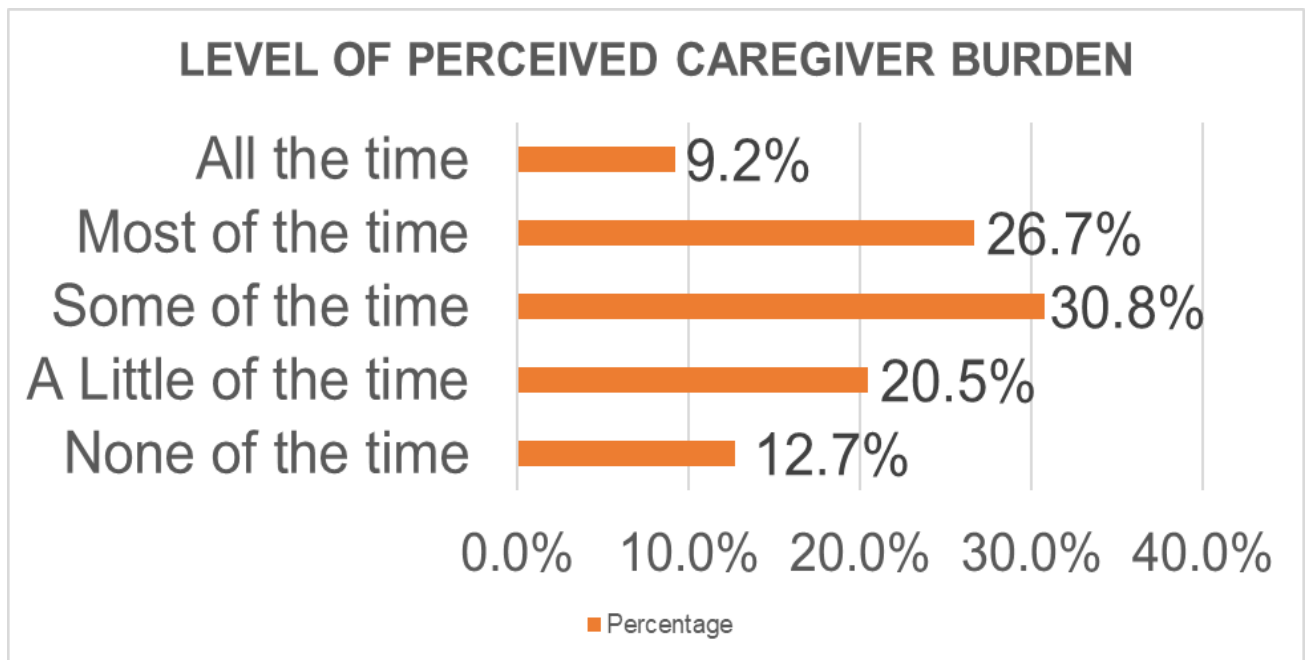
	Frequency (%)
Gender	
Male	60 (53.6%)
Female	53 (46.4%)
Age (Years)	
24 years and below	4 (4%)
25-40	45 (39.8%)
41-55	48 (42.5%)
56-75	17 (15.0%)
76 and above	2 (1.8%)
Marital status	
Single	20 (18.7%)
Married	81 (75.7%)
Divorced	4 (3.7%)
Separated	2 (1.9%)
Number of children	
0	3 (2.6%)
1	12 (3.5%)
2	30 (26.5%)
3 or more	68 (61.9%)
Money spent on treatment/Month (Ksh)	
5000 and below	14 (12.3%)
5001-15000	20 (17.6%)
15001-25000	68 (60.1%)
25001-35000	8 (7%)
Above 35001	3 (2.6%)
Caregiver	
Relative	95 (86.4%)
Friends	3 (2.7%)
Others (Guardians)	9 (8.2%)
Caregiver accompanying to hemodialysis sessions	
Yes	63 (56.3%)
No	49 (43.8%)
Source of income	
None	14 (12.4%)
Employment	13(11.5%)
Business	76(67.3%)
Farming	9(8.0%)
Others	1(0.9%)
Is your income able to meet your treatment costs?	
Yes	13(11.5%)
No	100(88.5%)

4.3 The caregiver's level of the burden as perceived by participants.

4.3.1. Caregiver's level of burden as perceived by participants with CKD undergoing hemodialysis at Kenyatta National Hospital.

The caregiver's level of a burden as perceived by participants was evaluated using Cousineau scale. 113 respondents completed the scale. The average scoring based on the 5-Likert scale was 3.013. The findings show that majority of the respondents rated statements on the Cousineau table as being "**some of the time.**" The statement that I feel that I am a burden to my caregiver averaged a score of 3.11 as shown in Table 2.

Table 2: Level of participant perceived caregiver burden



4.3.2. Respondents Cousineau scale average scores

The average scoring per question on Cousineau scale was evaluated. The overall average score for each question on the scale was 3 representing ‘some of the time’ as shown in Table 3.

Table 3: Cousineau average scores

<i>Statement</i>	<i>Mean</i>
1. I worry that the health of my caregiver could suffer as a result of caring for me	3.45
2. I worry that my caregiver is overdoing her/himself in helping me	3.22
3. I am concerned that it costs a lot of money for my caregiver to care for me	3.16
4. I am concerned that my caregiver is helping me beyond their capacity	2.75
5. I am concerned that I am too much trouble to my caregiver	2.87
6. I am guilty about the demands I make to my caregiver.	2.76
I am concerned that due to my illness, my caregiver is trying to do many things at	
7. once.	2.96
8. I am confident that my caregiver can handle the demands of caring for me.	2.9
9. I think that I make things hard for my caregiver.	2.95
10	
I feel that I am a burden to my caregiver.	3.11
.	
<i>Overall average score</i>	<i>3.013</i>

4.4 The patient factors influencing the caregiver burden as perceived by patients with CKD undergoing hemodialysis

4.4.1. The general perception of patients on their quality of health.

The participants were asked to rate how they perceive their current quality of health. The findings showed that more than half, (65) 57.5% rated their general health as being fair while 31 (27.4%) rated their health as being good.

4.4.2. Rating on how health influence typical day activities

The participants were asked about activities they engage in a typical day and how their health influence these activities. The analysis highlighted that 59 (52.2%) of the respondents agreed that their health limit a little moderate activity such as moving a table, pushing a vacuum cleaner, bowling and or playing golf. The analysis also presented that 46 (40.7%) have a little limitation in climbing several flights of stairs.

4.4.3. Problems with work or other regular activities

The respondents were asked on whether in the past 4 weeks they have had problems associated with their physical health. The analysis highlighted that 63(55.8%) of the respondents accomplished less than they would like while 50 (44.2%) accomplished did not accomplish less task as a result of their physical health. More than half of the respondents 64 (56.6%) worked as careful as usual on work and other activities while 49 (43.4%) did not work or perform other activities as careful as usual as a result of the physical health.

4.4.4. Interference with normal work in the past four weeks

The analysis sought to determine how much pain interfere with the respondents' normal work in the past 4 weeks. The analysis showed that during the past four weeks 46.4 % (52) of the

respondents highlighted that pain interferes with their normal work a little bit, 25.9% (29) asserted that pain influenced their normal work moderately.

4.4.5. Participants perception of things in the past four weeks

Perception of things and participants feeling in the last 4 weeks were evaluated to understand their rating based on the participants scores. The results from the analysis presented that 68 (60.7%) of them felt calm and peaceful, a good bit of time in the last four weeks. 49 (44.1%) felt they had a lot of energy most of the time. The results show that 39 (34.8%) felt downhearted or blue a good bit of time.

4.4.6. Participant perception of his/her kidney condition influence on life

The participants were also asked to determine how they felt their kidney condition influence their lives. Their perception of kidney condition and how it influences their health were analyzed. The results highlighted that 82 (74.5%) of them stated that the kidney disease interferes too much with their life while 15 (13.6%) highlighted that it is definitely true that kidney disease interferes too much with their lives. The findings also emphasized that 68 (61.8%) of the participants stated that it is mostly true that they spend too much of their time dealing with kidney disease. The analysis showed that 54 (49.1%) confirmed that they feel frustrated dealing with kidney disease. More than half, 66 (60%) of them claimed that it is mostly true that they feel like a burden on their families.

4.4.7. The rate at which the respondent is bothered by the manifestation of different clinical presentations

The respondents were asked to rate how clinical presentations related to their kidney conditions bothered them. Different factors were analyzed to determine the extent at which they bother kidney disease patients who are respondents in the study. The findings were evaluated based on a Likert scale analysis. A total of 20 items were evaluated based on a 5-point scale Likert scale. The analysis of the items in the scale shows that the majority of the respondents were moderately or somewhat bothered by the different healthcare presentation. The analysis showed that 40 (36.4%) were moderately bothered with soreness in muscles. Cramps as a factor were evaluated where the majority of respondents, 44 (39.6%) were moderately bothered. The findings show that 42(40.5%) of the respondents were somewhat bothered with dry skin, 36 (32.1%). Majority of the respondents, 60 (54.1%) were somewhat bothered with nausea or upset stomach.

4.4.8. Participants rating on how much Kidney disease is a bother to their life

The effects of kidney disease were assessed in a bid to understand how they influence the daily life of the participants. Different factors were evaluated to understand the burden of the disease on the quality of life. The assessment was based on a 5-point Likert scale. Majority of the respondents were moderately and somewhat bothered by different factors that were being evaluated as shown in table 4.

Table 4: Participants perception of how their kidney condition influence their lives.

	<i>Definitely true</i>	<i>Mostly true</i>	<i>Don't know</i>	<i>Mostly false</i>	<i>Definitely false</i>
<i>My kidney disease interferes too much with my life</i>	15(13.6%)	82(74.5%)	4(3.5%)	8(7.3%)	1(0.9%)
<i>Too much of my time is spent dealing with my kidney disease</i>	36(31.9%)	68(61.8%)	0(0.0%)	5(4.4%)	1(0.9%)
<i>I feel frustrated dealing with my kidney disease</i>	54(49.1%)	44(40%)	1(0.9%)	6(5.3%)	5(4.4%)
<i>I feel like a burden on my family</i>	33(30%)	66(60%)	4(3.5%)	3(2.7%)	4(3.5%)

4.4.9. Predictors of caregiver burden perception among patients

The multiple regression analysis was conducted to determine participant factors that are statistically significant predictors of caregiver burden as perceived. Age, gender, marital status, having children, location, source of income, or whether the caregiver is family or guardian are unrelated to the extent of a burden as perceived by a patient at $P > 0.05$. Amount spent on treatment ($p = 0.00$) was the only significant factor that influences caregiver burden as perceived by patients with CKD at $p < 0.05$ as shown in Table 5.

Table 5: Factors associated with caregiver burden as perceived by patients

Coefficients^a

Model	Unstandardized Coefficients		Standardized Coefficients		p-value	95.0% Confidence Interval for B	
	B	Std. Error	Beta	t		Lower Bound	Upper Bound
(Constant)	28.54	8.03		3.554	0.001	12.584	44.495
Age	0.016	0.056	0.033	0.284	0.777	-0.095	0.126
Gender	0.29	1.035	0.028	0.28	0.78	-1.767	2.347
Marital status	0.455	1.2	0.047	0.379	0.706	-1.931	2.84
Have children?	-1.347	2.056	-0.089	0.655	0.514	-5.432	2.738
Where do you live?	-0.258	1.31	-0.021	0.197	0.844	-2.861	2.346
1 Amount spent on treatment monthly?	1	0	0.382	3.722	0.00	5.345	3.78
Who takes care of you since the diagnosis	-1.152	0.911	-0.135	1.264	0.21	-2.963	0.659
Is your caregiver the same person accompanying to dialysis	0.111	1.161	0.011	0.096	0.924	-2.196	2.419
Source of income	-0.749	0.693	-0.112	1.082	0.282	-2.126	0.627
Is your income able to meet treatment costs	1.66	1.797	0.095	0.924	0.358	-1.91	5.23

a. Dependent Variable: Cousineau score

4.5 The relationship between the health-related quality of life and caregiver burden in patients undergoing hemodialysis at Kenyatta National Hospital

The study sought to understand the relationship between health-related quality of life and caregiver burden. The analysis focused on patient’s response regarding the influence of their kidney condition on their lives as health related quality of life factors. A chi-square test was conducted which sought to determine the relationship between the health-related quality of life and caregiver burden as perceived by patients undergoing hemodialysis. The findings found a significant association between patient perception of their health ($\chi^2 = 34.178$, $P = 0.05$), $P < 0.05$,

and caregiver burden as perceived by patients, $P < 0.05$. Kidney disease interferes too much with my life factor was statistically associated with caregiver burden as perceived by patients, $P < 0.05$ at ($\chi^2 = 27.976$, $P = 0.03$) as shown in Table 6.

Table 6: Association between the health-related quality of life and caregiver burden in patients undergoing hemodialysis

	χ^2 value	P-Value
Patient perception of their health quality	34.178	0.005
Pain interference with normal work	23.418	0.103
Physical or emotional problems interfered with social activities	21.581	0.152
My Kidney disease interferes too much with my life	27.976	0.032
Too much time is spent dealing with my kidney disease	14.799	0.253
I feel frustrated dealing with kidney disease	12.307	0.723
I feel like a burden on my family	56.645	$P < 0.001$

4.6 The conclusion of the findings

The findings showed that majority of the respondents perceived, ‘some of the time’ as burdens to their caregivers. There was a significant relationship between perception as a burden to caregivers and health related quality of life. Patients who asserted that kidney disease interferes too much with their life were associated with increased perception as burden to their caregiver ($P < 0.05$). Patients who felt that they were a burden to their family were associated with increased perception as a burden to their caregiver ($P < 0.05$).

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion of study findings.

5.1.1 Patient factors influencing caregiver burden as perceived by CKD patients undergoing hemodialysis.

The purpose of the study was to assess caregiver burden as perceived by patients with Chronic Kidney Disease (CKD) and undergoing hemodialysis at Kenyatta National hospital. Majority of the patients who were enrolled had their family members as caregivers. Family members play a major role in taking care of their family members suffering from chronic illness. This finding is related to a study conducted by Rioux et al. (2012) which asserted that family members form a primary source of help for chronic ill patients who seek regular healthcare. The results also concurs with another study by Turner et al (1999) on patients receiving hemodialysis which highlighted that majority of them had their caregivers as spouses. The findings from the study also determined that the perceived burden by patients cuts across age groups, gender, social and economic status. According to Shdaifat and Manaf (2012) caregiver burden as perceived by patients is diverse regardless of gender, social and economic status. The study further stresses that any individual is likely to become a burden based on how they perceive their life and changes due to disease process.

The monthly hemodialysis expenditure was extremely high for common citizens where majority of them were engaged in business most of whom are unable to meet their treatment costs. Similar findings were obtained in study by Levin et al (2017) which showed that hemodialysis is

expensive where majority of chronic kidney disease patients are unable to afford thus increasing the level of stress among patients, which means that caregivers need to find ways to ensure patients receive regular care. In another study Robinson et al. (2006), CKD patients with in higher socioeconomic status are more likely to perceive as posing less burden on their caregivers because they can afford to pay caregivers as opposed to fully relying on the unpaid caregivers. The amount of money spent on renal disease treatment and the source of the same are key determinants of caregiver burden perception by the patient.

Couser et al. (2011) also determined that CKD is associated with increased economic burden. The study further stresses that high income countries spend small percentage of their annual healthcare budget on treatment of End Stage Renal Disease (ESRD), even though those receiving such treatment represent very little population. Globally, the total cost of the treatment of the milder forms of Acute Kidney Injury appears to be much greater than the total cost of treating ESRD. In 2015, in the United States of America, for example, Medicare expenditures on ESRD and AKI were more than 64 billion and 34 billion United States dollars, respectively. Much of the expenditure, morbidity and mortality previously attributed to diabetes and hypertension are attributable to kidney disease and its complications.

5.1.2 Level of caregiver burden as perceived by patients

The findings from the study showed that significant number of hemodialysis patients perceive themselves as a burden to their caregivers, some of the time. The perception is influenced by different factors including amount spent on treatment which was a significant predictor to the perceived burden. The cost of hemodialysis has been a major issue among patients especially considering the high rate of poverty in developing countries, Kenya included. The findings

coincide with various researches that have been done previously. In a study conducted by Hawamdeh et al (2017), financial strain can seriously impact the compliance to treatment and meeting the family's economic needs. A report by IMF (2017) also highlighted that on average a CKD patient requires 2-3 dialysis sessions per week. Given that most Kenyans belong to low social economic class earning less than 1 US\$ a day, they are unable to afford all the three sessions of dialysis per week which is detrimental to their quality of life. In a study conducted by Suri et al (2011), the results also determined that age, gender, proximity to a healthcare facility and the number of medications per week were no significant predictors of caregiver burden as perceived by patients. Lilympaki et al. (2016) provided a crucial emphasis on important processes that improve caregiver burden and self-perceived burden can integrate to improve overall burden perception. A study suggest that caregiver burden and self-perceived burden can be decreased through several interventions, such as support programs for informal caregivers, advance care planning for patients, promotion of communication and the organization of "family conferences" to discuss matters important to patients and their relatives (Lemos et al., 2015; Lee et al., 2015).

5.1.3 Health related quality life on caregiver burden as perceived by patient

Majority of the patients (52.2%) agreed that their health has limited their ability to socialize, interact and lead a normal life. They are unable to accomplish regular activities such as moving a table, pushing a vacuum cleaner and bowling. Chronic Kidney Disease patients undergoing hemodialysis experience debilitating health effects related to the disease process and hemodialysis. The health status of the patient determines their activity levels directly. These findings are in line with different studies in the past. Kimmel et al (2000) found that CKD may

modify patients' ability to work outside the home, inhibit patient contributions inside the home, shift spouses into caregiver roles, or cause sexual dysfunction. In addition most CKD patients on hemodialysis have anemia and weak bones due to impaired calcium homeostasis process. Belasso and Sesso (2002) also determined that CKD has a detrimental influence on the ability of a patient to accomplish regular activities as well as complex ones. The authors' further stress that CKD patients have a higher reliance on caregivers which increases their perception as being burden.

The findings also showed that many of the respondents highlighted that kidney disease interferes too much with their life. This means that these individuals are unable to accomplish much as a result of the CKD condition. The results also depict that most of the CKD patients utilize their time dealing with their condition thus having a detrimental influence on their quality of life. These findings coincide with a study conducted by Walker et al. (2016) which asserted that a patient with CKD as it is the case among patients with chronic illness, their normal life is influenced where they spend majority of their time and resources managing their condition. Such measures have a detrimental influence on individual perception on quality of life. These findings are also similar to a study conducted by Misiewicz et al (2010) which showed that 80% of CKD patients gave up travelling in the course of the disease and the attachment that patients had towards a given dialysis unit limited their travelling due to the necessity to receive care in another facility. Patients receiving hemodialysis felt limitations related to longer travelling outside the dialysis unit more frequently than patients receiving peritoneal dialysis (Fructuoso et al., 2011).

The findings also showed that 35% patients CKD condition influences their social, psychological and social lives. Inability to interact and accomplish small activities has been associated with CKD where most of the respondents feel dealing with the condition. The findings are related to a study conducted by Xhulia et al. (2016). The study asserted that CKD patients feel frustrated about their condition because it is a limiting factor in their interactions. Their wellbeing is dictated by their ability to maintain their conditions through regular hemodialysis sessions where it would be possible to interact. A patient is required to remain closer to a health facility due to serious implications associated with missed dialysis sessions. Chronic Kidney Disease is a huge challenge to its patients because of its mostly overt systemic manifestations and its chronicity. Yoong et al. (2017) also stated that CKD is associated with low quality of life among patients who are more likely to perceive themselves as burdens to their caregivers.

Health-related quality of life (QOL) assumes an increasing importance as a marker of treatment quality in many chronic diseases. Its evaluation allows the quantification of the diseases consequences according to the patient's subjective perception and enables adjustment of medical decisions to their physical, emotional and social needs. It also improves the adherence to the therapeutic plan, the quality of the health care provided and the patient survival.

Similar results were obtained by Porter et al. (2012), who highlighted that the QoL of patients suffering from chronic kidney disease is shaped through social and family relationships. Not only family but also good social relationships are of great importance and are the source of positive feelings and self-esteem and improve the QoL. On the other hand, a lack of support and acceptance from family and friends has a negative influence on patients' health through lower

self-esteem, and feelings of hopelessness and helplessness, all of which causes lower mood, depression, feelings of resignation, and a sense of life meaning less.

The results determined that there was a significant association between some healthcare related quality of life factors and caregiver burden as perceived by patients. Patients who asserted that kidney disease interferes too much with their life were associated with increased perception as burden to their caregiver. Patients who felt that they were a burden to their family were associated with increased perception as a burden to their caregiver. Thus, a patient who views himself as a burden to family is likely to perceive themselves as being burden. The findings are linked to a study conducted by Mansur et al. (2014) who asserted that CKD patients are associated poor health related quality of life factors because of high and expensive care needed to manage the condition. In another study Manavalan et al. (2017), quality of life encompasses different factors which are essential in defining a CKD patient development.

5.2 Conclusion

The burden of Chronic Kidney Disease (CKD) cuts across the age-groups, gender social and economic status. Public awareness and education on the disease and its therapy need to be enhanced. Currently, diagnosis and start of therapy are intertwined such that patients with CKD have no adequate time to process rapid lifestyle changes they undergo. The sudden therapy (hemodialysis) onset and the weak clinical condition most dialysis patients present with during diagnosis and treatment necessitates the need for them to have a caregiver in most cases.

The findings show that majority of the respondents feel they are a burden to their caregivers some of the time. This can be attributed to patients being able to perform some activities by themselves but they need help in more labor-intensive ones. Most patients with advanced age

experience more frailty due to both ageing and disease processes hence the more dependency to their caregivers.

From this study, the amount of money spent on renal disease treatment and its source are key determinants of caregiver burden perception by the patient. Patients with good income sources are able to hire a caregiver and pay for their bills. This may lead to patients experiencing less caregiver burden perception. These findings can be attributed to low social economic class of most families in Sub-Saharan Africa and also the fact that governments don't meet the full treatment cost of patients with Chronic Kidney Disease.

Chronic Kidney Disease has major negative impact on the quality of life of most patients. Patient present with systemic manifestations such as: gastritis, nausea, dry scaly skin among others. This negative impact is worsened by dialysis associated complications such as anemia, renal osteodystrophy. From this study, most CKD patients on hemodialysis present with hampered daily activities such as climbing stairs and ability to concentrate. This can be attributed to lack of comprehensive management of Chronic Kidney Disease manifestations and delayed management of dialysis associated complications. Patients with limited activity present more burden to their caregivers.

5.3 Recommendations

1. Development support programs for informal caregivers, advance care planning for patients and social groups to enhance socialization among hemodialysis patients.
2. Education and counselling of unpaid caregivers on what the disease process is and what to focus on in caring for the patient. A standard operating protocol should be developed.
3. Promotion of communication and the organization of family conferences to discuss matters important to patients and their caregivers.

REFERENCES

- Alnazly, E. K. (2016). Burden and coping strategies among Jordanian caregivers of patients undergoing hemodialysis. *Hemodialysis International*, 20(1), 84-93.
- Avşar, U., Avşar, U. Z., Cansever, Z., Yucel, A., Cankaya, E., Certeç, H., & Yucelf, N. (2015, June). Caregiver burden, anxiety, depression, and sleep quality differences in caregivers of hemodialysis patients compared with renal transplant patients. In *Transplantation proceedings* (Vol. 47, No. 5, pp. 1388-1391). Elsevier.
- Ballew, S. H., Chen, Y., Daya, N. R., Godino, J. G., Windham, B. G., McAdams-DeMarco, M., & Grams, M. E. (2017). Frailty, kidney function, and polypharmacy: the atherosclerosis risk in communities (ARIC) study. *American Journal of Kidney Diseases*, 69(2), 228-236.
- Belasco, A. G., & Sesso, R. (2002). Burden and quality of life of caregivers for hemodialysis patients. *American journal of kidney diseases*, 39(4), 805-812.
- Brett, K. E., Bennett, A., Ritchie, L. J., & Knoll, G. A. (2017). Physical frailty and functional status in patients with advanced kidney disease: a protocol for a systematic review. *Systematic reviews*, 6(1), 133.
- Clark-Cutaia, M. N., Ren, D., Hoffman, L. A., Burke, L. E., & Sevcik, M. A. (2014). Adherence to Hemodialysis Dietary Sodium Recommendations: Influence of Patient Characteristics, Self-Efficacy, and Perceived Barriers. *Journal of Renal Nutrition*, 24(2), 92–99. doi:10.1053/j.jrn.2013.11.007
- Cousineau, N., McDowell, I., Hotz, S., & Hébert, P. (2003). Measuring Chronic Patients' Feelings of Being a Burden to their Caregivers. *Medical Care*, 41(1), 110–118. doi:10.1097/00005650-200301000-00013
- Cousineau, N., McDowell, I., Hotz, S., & Hébert, P. (2003). Measuring Chronic Patients' Feelings of Being a Burden to their Caregivers. *Medical Care*, 41(1), 110–118. doi:10.1097/00005650-200301000-00013
- Fradelos, E., Tzavella, F., Koukia, E., Tsaras, K., Papathanasiou, I., Aroni, A., ... Zyga, and. (2016). The Translation, Validation and Cultural Adaptation of Functional Assessment of Chronic Illness Therapy - Spiritual Well-being 12 (facit-sp12) Scale in Greek Language. *Materia Socio Medica*, 28(3), 229. doi:10.5455/msm.2016.28.229-234
- Ghimire, S., Castelino, R. L., Lioufas, N. M., Peterson, G. M., & Zaidi, S. T. R. (2015). Nonadherence to Medication Therapy in Haemodialysis Patients: A Systematic Review. *PLOS ONE*, 10(12), e0144119. doi:10.1371/journal.pone.0144119

- Griva, K., Goh, C. S., Kang, W. C. A., Yu, Z. L., Chan, M. C., Wu, S. Y., ... Foo, M. (2015). Quality of life and emotional distress in patients and burden in caregivers: a comparison between assisted peritoneal dialysis and self-care peritoneal dialysis. *Quality of Life Research*, 25(2), 373–384. doi:10.1007/s11136-015-1074-8
- Alshamsi, I., Khater, E., Al Mutawa, K., Luqman, N., Richards, N., Saleh, A., & Hassan, M. (2019). SP646MAGNESIUM DISORDERS AMONG HEMODIALYSIS PATIENTS IN THE UNITED ARAB EMIRATES. *Nephrology Dialysis Transplantation*, 34(Supplement_1). doi:10.1093/ndt/gfz103.sp646
- Hawamdeh, S., Almari, A., Almutairi, A., & Dator, W. (2017). Determinants and prevalence of depression in patients with chronic renal disease, and their caregivers. *International Journal of Nephrology and Renovascular Disease*, Volume 10, 183–189. doi:10.2147/ijnrd.s139652
- Jadhav, B., Dhavale, H., Dere, S., & Dadarwala, D. (2014). Psychiatric morbidity, quality of life and caregiver burden in patients undergoing hemodialysis. *Medical Journal of Dr. D.Y. Patil University*, 7(6), 722. doi:10.4103/0975-2870.144858
- Jesky, M., Lambert, A., Burden, A. C. F., & Cockwell, P. (2013). The impact of chronic kidney disease and cardiovascular comorbidity on mortality in a multiethnic population: a retrospective cohort study. *BMJ Open*, 3(12), e003458. doi:10.1136/bmjopen-2013-003458
- Kang, S. H., Do, J. Y., Lee, S.-Y., & Kim, J. C. (2017). Effect of dialysis modality on frailty phenotype, disability, and health-related quality of life in maintenance dialysis patients. *PLOS ONE*, 12(5), e0176814. doi:10.1371/journal.pone.0176814
- Khalil, A. A., & Abed, M. A. (2014). Perceived Social Support is a Partial Mediator of the Relationship Between Depressive Symptoms and Quality of Life in Patients Receiving Hemodialysis. *Archives of Psychiatric Nursing*, 28(2), 114–118. doi:10.1016/j.apnu.2013.11.007
- Khatib, S. T., Hemadneh, M. K., Hasan, S. A., Khazneh, E., & Zyoud, S. H. (2018). Quality of life in hemodialysis diabetic patients: a multicenter cross-sectional study from Palestine. *BMC Nephrology*, 19(1). doi:10.1186/s12882-018-0849-x
- Lee, S. J., Son, H., & Shin, S. K. (2015). Influence of frailty on health-related quality of life in pre-dialysis patients with chronic kidney disease in Korea: a cross-sectional study. *Health and Quality of Life Outcomes*, 13(1). doi:10.1186/s12955-015-0270-0
- Lemos, C. F., Rodrigues, M. P., & Veiga, J. R. P. (2015). Family income is associated with quality of life in patients with chronic kidney disease in the pre-dialysis phase: a cross sectional study. *Health and Quality of Life Outcomes*, 13(1). doi:10.1186/s12955-015-0390-6
- Lilympaki, I., Makri, A., Vlantousi, K., Koutelekos, I., Babatsikou, F., & Polikandrioti, and. (2016). Effect of Perceived Social Support on the Levels of Anxiety and Depression of Hemodialysis Patients. *Materia Socio Medica*, 28(5), 361. doi:10.5455/msm.2016.28.361-365

Mansur, H., Colugnati, F. A., Grincenkoy, F. R. dos S., & Bastos, M. (2014). Frailty and quality of life: a cross-sectional study of Brazilian patients with pre-dialysis chronic kidney disease. *Health and Quality of Life Outcomes*, 12(1), 27. doi:10.1186/1477-7525-12-27

McAdams-DeMarco, M. A., Ying, H., Olorundare, I., King, E. A., Haugen, C., Buta, B., ... Segev, D. L. (2017). Individual Frailty Components and Mortality in Kidney Transplant Recipients. *Transplantation*, 101(9), 2126–2132. doi:10.1097/tp.0000000000001546

Porter, A., Fischer, M. J., Brooks, D., Bruce, M., Charleston, J., Cleveland, W. H., ... Lash, J. (2012). Quality of life and psychosocial factors in African Americans with hypertensive chronic kidney disease. *Translational Research*, 159(1), 4–11. doi:10.1016/j.trsl.2011.09.004

Ricardo, A. C., Hacker, E., Lora, C. M., Ackerson, L., DeSalvo, K. B., Go, A., ... Lash, J. P. (2011). 264 Validation of the Kidney Disease Quality of Life 36 (KDQOL-36) U.S. Spanish and English Versions in Hispanics with Chronic Kidney Disease. *American Journal of Kidney Diseases*, 57(4), B82. doi:10.1053/j.ajkd.2011.02.267

Rioux, M. (n.d.). Itinéraire sociologique : Marcel Rioux. La Culture Comme Refus de L'économisme, 562–564. doi:10.4000/books.pum.22101

Odeh, S. et al., A fast weighted median filter architecture for image processing. Proceedings IEEE Southeastcon'98 "Engineering for a New Era." Available at: <http://dx.doi.org/10.1109/secon.1998.673305>.

Turner-Musa, J. et al., 1999. Family structure and patient survival in an African-American end-stage renal disease population: a preliminary investigation. *Social Science & Medicine*, 48(10), pp.1333–1340. Available at: [http://dx.doi.org/10.1016/s0277-9536\(98\)00437-7](http://dx.doi.org/10.1016/s0277-9536(98)00437-7).

Walker, R.C. et al., 2016. The economic considerations of patients and caregivers in choice of dialysis modality. *Hemodialysis International*, 20(4), pp.634–642. Available at: <http://dx.doi.org/10.1111/hdi.12424>.

Yoong, R.K. et al., 2017. Prevalence and determinants of anxiety and depression in end stage renal disease (ESRD). A comparison between ESRD patients with and without coexisting diabetes mellitus. *Journal of Psychosomatic Research*, 94, pp.68–72. Available at: <http://dx.doi.org/10.1016/j.jpsychores.2017.01.009>.

APPENDIX I: CONSENT INFORMATION FORM

Title of the study: Caregivers' Burden as Perceived by Patients with Chronic Kidney Disease and Undergoing Hemodialysis at Kenyatta National Hospital.

Investigator: Stanley Morumbe

Institution of Study: University of Nairobi

I. Introduction to the study

You are invited to fill in the questionnaire as a part of a research study, carried out by **Stanley Morumbe** who is a student pursuing Master of Science in Nursing (Nephrology), at the University of Nairobi. The research will be carried at the renal unit in KNH in the month of May 2019. The purpose of this research study is to assess the **caregiver burden among patients with chronic kidney disease undergoing hemodialysis at Kenyatta National Hospital**. The study will shed light on the psychosocial experiences and help create strategies to alleviate **caregiver burden among patients with chronic kidney disease undergoing Hemodialysis at Kenyatta National Hospital**.

You are being invited to take part because you have been identified as a chronic kidney disease patient who is undergoing Hemodialysis and you may be having experiences that can guide in acquiring the information that is relevant.

This consent form gives you information about the study, the risks and benefits, and the process will be explained to you. Once you understand the study, and if you agree to take part, you will be asked to sign your name or use your thumb finger to put a mark (thumbprint) on the consent form. You will be given a copy of this consent information document to take home.

II. Study

The study objective is to determine caregiver burden as perceived among patients with chronic kidney disease undergoing Hemodialysis at Kenyatta National Hospital. The specific areas of study include: To explore demographic characteristics of the patients with CKD and economic and psychosocial factors that influence care giving burden perception and health related quality of life among this group of patients.

III. Benefits of the study

Regarding benefits, there may not be any direct benefits for you as an individual participant. Indirect benefits: you will have been given an opportunity to express any concerns or suggestions on how to improve the care. The study findings could be used for planning and designing appropriate interventions by the Kenyatta National Hospital and other stakeholders.

IV. Risks

There are minimal risks to you for participating in this study. On potential risk is loss of privacy, please note that all information you provide is strictly confidential. We will use a code number to identify you in a password protected computer database, and all paper records will be kept in a locked file cabinet. There is also a possibility that some of the questions asked may make you feel uncomfortable. If there are any questions you do not want to answer, you skip them. In addition, you have the right to decline giving information. Given the sensitive nature of the topic under study, in case of emotional disturbance you free to discontinue the interview and you will be accorded the necessary counselling and relevant support.

V. Procedures

If you agree to participate in this, study know that there is only one approach:

Filling in the questionnaire which has sections.

i) Questionnaire

You shall be asked to read and understand all the questions before answering them. The questionnaires will be numbered (coded) thus you will not be required to give any personal information like writing your name. The questionnaire will contain both open and close ended questions. You may also be guided by the researcher or the assistant to respond to the questions appropriately. Filling in a questionnaire will take between 30-40 minutes. The questionnaire will be divided into different sections to gather information on demographic data of patients with CKD.

VI. Compensation

There shall be no monetary rewards for the participants in this study.

VII. Voluntary Participation and Withdrawal

Remember, your participation is entirely voluntary. Should you change your mind, Should you change your mind, you have the right to drop out at any time without facing any consequences.

You may skip questions or stop participating at any time.

VIII. Sharing the results

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

IX. Confidentiality

You will not be required to write your name or to give any personal identification in the questionnaire there will be no way to identify individual participants. There shall not be use of any information that would make it possible for anyone to identify you in any presentations or written reports about this.

X. Contacts

Stanley Morumbe, Principal investigator, University of Nairobi, School of Nursing Sciences

Email:snmorumbe@gmail.com, **Cell no: 0725912800**

Miss. Maina Dorcas: 1st Supervisor. Lecturer, School of nursing sciences, University of Nairobi

Email: mainad@uonbi.ac.ke Cell no: **0724 440 843**

Professor Anne Karani: 2nd Supervisor. Lecturer, school of nursing Sciences, University of

Nairobi, Email: kagure@uonbi.ac.ke Cell no: **0721 850 910**

Secretary, KNH –UoN ERC

Email:uonknh_erc@uonbi.ac.ke

Tel: 726300-9 Ext 44355, 44102

Consent Certificate Form

I have read the consent explanation and understood its content. I have been given the opportunity to discuss all my concerns with the researcher. I have had my questions answered in 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 at any time. I understand that all efforts will be made to keep information regarding my personal identity confidential.

I understand that by signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study: Yes No

I agree to fill in the questionnaire Yes No

Participant signature/ Thumb stamp ----- Date-----

Participants' printed name ----- Date -----

Principal Investigator' 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 freely given his/ her consent.

Researchers Name: -----Signature ----- Date -----

Witness Name -----Signature----- Date: -----

Witness contact: Tel Number: ----- P. O Box ----- Email -----

APPENDIX II: QUESTIONNAIRE

Questionnaire Number.....

Instructions

- Before filling in this questionnaire, I am requesting you to read, understand and sign the attached consent.
- Please do not write your name in any of the pages of the questionnaire.
- Please read carefully the instructions at the beginning of each section of the questionnaire before answering the questions in that section
- Please answer all the questions in each section if possible

Demographic data (Choose one response only)

- a. What is your age in complete years.....?
2. What is your gender?
 - a. Male [] Female []
3. Marital Status?
 - a. Single []
 - b. Married []
 - c. Divorced []
 - d. Separated []

4. Do you have children
 - a. Yes []
 - b. No []If **YES**, how many?
5. Where do you live?
 - a. Nairobi []
 - b. Others, please explain.....
6. How much do you spend on treatment per month?
Amount in kShs.....
7. Who takes care of you since the diagnosis was made?
 - a. None
 - b. Relative
 - c. Friends
 - d. Others
8. Is your caregiver the same person who accompanies for hemodialysis sessions?
 - a. Yes
 - b. No
9. What is your main source of income?
 - a. None
 - b. Employment
 - c. Business
 - d. Farming
 - e. Others.....(specify)
10. Is your income able to meet your treatment costs?
 - a. Yes []
 - b. No []

APPENDIX III: KIDNEY DISEASE –QUALITY OF LIFE – SF V.36

This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

1. In general, would you say your health is:

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
2.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
3.	Climbing several flights of stairs			

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

		Yes	No
4.	Accomplished less than you would like		
5.	Didn't work or other activities as carefully as usual		

6. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- a) Not at all
- b) A little bit
- c) Moderately
- d) Quite a bit
- e) Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
7.	Have you felt calm and peaceful						
8.	Did you have a lot of energy						
9.	Have you felt downhearted or blue						

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- a) All of the time
- b) Most of the time
- c) Some of the time
- d) A little of the time
- e) None of the time

How true or false is each of the statements below to you?

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11.	My kidney disease interferes too much with my life					
12.	Too much of my time is spent dealing with my kidney disease					
13.	I feel frustrated dealing with my kidney disease					
14.	I feel like a burden on my family					

15. During the past 4 weeks, to what extent were you bothered by each of the following?

		Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
16.	Soreness in your muscles?					
17.	Chest pain?					
18.	Cramps?					
19.	Itchy skin?					
20.	Dry skin?					
21.	Shortness of breath?					
22.	Faintness or dizziness?					
23.	Lack of appetite?					
24.	Washed out or drained?					
25.	Numbness in hands or feet?					
26.	Nausea or upset stomach?					
27.	(Hemodialysis patient only) problems with your access site?					

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

		Not at all bothered	Somewhat bothered	Moderately	Very much bothered	Extremely bothered
28.	Fluid restriction?					
29.	Dietary restriction?					
30.	Your ability to walk around the house?					
31.	Your ability to travel?					
32.	Being dependent on doctors and other medical staff					
33.	Stress or worries caused by kidney disease?					
34.	Your sex life?					
35.	Your personal appearance?					

APPENDIX IV: COUSINEAU BURDEN SCALE

Please rate each statement in a scale on how often you feel this way, from ‘none of the time’ to ‘all the time’ .Use these codes;1=none of the time 2=a little of the time 3= some of the time 4= most of the time 5= all the time.

	Statement	Code
1.	I worry that the health of my caregiver could suffer as a result of caring for me	
2.	I worry that my caregiver is overdoing her/himself in helping me	
3.	I am concerned that it costs a lot of money for my caregiver to care for me	
4.	I am concerned that my caregiver is helping me beyond their capacity	
5.	I am concerned that I am too much trouble to my caregiver	
6.	I am guilty about the demands I make to my caregiver.	
7.	I am concerned that due to my illness my caregiver is trying to do many things at once.	
8.	I am confident that my caregiver can handle the demands of caring for me.	
9.	I think that I make things hard for my caregiver.	
10.	I feel that I am a burden to my caregiver.	

APPENDIX V: LETTER REQUESTING FOR ETHICAL APPROVAL

Stanley Morumbe,

University of Nairobi.

School of Nursing Sciences,

P.O Box 19676-00202, Nairobi.

Cell no: 0725912800.

The Chairman,

UoN/KNH Ethics and Research Committee,

P.O. Box 20723-00202, Nairobi.

Dear Sir/Madam

RE: ETHICAL REVIEW AND APPROVAL

I am a second year post graduate nursing student, pursuing Master of Science in Nursing (Nephrology).the aim of this letter is to request for permission to carry out research on **caregiver burden among patients with chronic kidney disease undergoing hemodialysis at Kenyatta National Hospital**. The study will be carried out in the renal unit.

Your utmost consideration will facilitate completion of my study. I am looking forward to your comments and suggestions for improvement of the proposed study.

Yours faithfully,

Stanley Morumbe

H56/7824/2017

APPENDIX VI: AUTHORIZATION LETTER TO KENYATTA

Stanley Morumbe

University of Nairobi

School of Nursing Sciences

P.O Box 19676-00202,

Nairobi

Cell no: 0725912800

The Chief Executive Officer

Kenyatta National Hospital

Dear Sir / Madam

RE: PERMISSION TO UNDERTAKE A STUDY

I am a second year post graduate nursing student, pursuing Master of Science in Nursing (Nephrology). I am writing to request permission to carry out research on caregiver burden among patients with chronic kidney disease undergoing hemodialysis at Kenyatta National Hospital.

Your kind consideration to allow me carry out this research in KNH will be highly appreciated. It will go a long way in facilitating completion of my study.

Please find the attached approval letter from KNH/UON ERC

Thanks for your incredible support

Yours sincerely,

Stanley Morumbe

H56/7824/2017

APPENDIX VII: PROPOSED STUDY WORK PLAN

	Dec 2018	Jan 2019	Feb 2019	M ar ch 20 19	March 2019	Apri l 2019	Apr 2019	Ma y 201 9	June 2019	July 2019	Aug 2019	Sep 2019
Proposal development												
Ethical clearance												
Pretesting of the tool												
Data collection												
Data analysis												
Report writing and defense												
Disseminatio n of results												

APPENDIX VIII: STUDY BUDGET

Component	Description	Item	Quantity	Unit of cost(Kshs)	Total cost(ksh)
Literature review	Personal literature search	Browse for literature	8 weeks	@1000	8000
	Stationery	2 reams of papers	1	@800	1600
		Proposal typing	3 drafts	@500	1,500
		Proposal printing	3 drafts	@500	1,500
		Photocopy charges	8 drafts	@400	3200
Approval	KNH/UON Ethics		1	@2000	2,000
Sub total					15900
Research phase	Pretesting	Printing	10 copies	@50	500
	Questionnaires and consent forms	Photocopy	113 copies	@50	5650
Report phase	Draft report	Typing, printing and photocopy	150 pages , 5 copies	@50 @600	7,500 3,000
	Final report	Correction and printing	150 pages	@10	1,500
		Photocopying	5 copies	@600	3,000
		Binding	5 copies	@1000	5,000
Dissemination budget	Dissemination report	Typing and printing	10 pages	@30	3,000
Publishing					30,000
		Contingencies	10% of total		7695
GRAND TOTAL	Kshs.84,645				

APPENDIX IX: MAP OF STUDY AREA

