

**BURDEN OF CARE AND HEALTH-RELATED QUALITY OF  
LIFE AMONG CAREGIVERS OF PATIENTS UNDERGOING  
MAINTENANCE HEMODIALYSIS AT THE RENAL UNIT OF  
KENYATTA NATIONAL HOSPITAL**

**A Dissertation submitted in part fulfillment for the degree of Masters of  
Medicine in Internal Medicine University of Nairobi**

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## **DECLARATION**

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## **DEDICATION**

To my wonderful sons K'nan and Zack- No words can express my love for you.  
The joy in your faces is what keeps me going-God bless you.

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## **LIST OF ABBREVIATIONS**

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AKI-</b>	Acute Kidney Injury
<b>ART-</b>	Antiretroviral therapy
<b>CKD-</b>	Chronic Kidney Disease
<b>eGFR-</b>	Estimated Glomerular Filtration Rate
<b>ESKD-</b>	End-Stage Kidney Disease
<b>FHN-</b>	Frequent Hemodialysis Networks
<b>GDP-</b>	Gross Domestic Product
<b>HD-</b>	Hemodialysis
<b>HIV-</b>	Human Immunodeficiency Virus
<b>HRQoL-</b>	Health-Related Quality Of Life
<b>IGA-</b>	Income Generating Activity
<b>KDIGO-</b>	Kidney Disease Improving Global Outcome
<b>KNH-</b>	Kenyatta National Hospital
<b>LSEC-</b>	Low Social Economic Country
<b>LSES-</b>	Low Social Economic State
<b>NAC-</b>	National Alliance for Caregiving
<b>NHANES-</b>	National Health and Nutrition Examination Survey
<b>PMP-</b>	Per Million Populations
<b>QoL-</b>	Quality of Life
<b>RRT-</b>	Renal Replacement Therapy
<b>SSA-</b>	Sub Saharan Africa
<b>UoN-</b>	University of Nairobi
<b>USRDS-</b>	United States Renal Data System
<b>WHO-</b>	World Health Organization
<b>ZBI-</b>	Zarit Burden Interview

## **ABSTRACT**

**Background-** Commencement of maintenance hemodialysis to sustain life is a chronic stress experience. It has significant consequences for both the patients and their caregivers. Although studies outside Africa recommend that hemodialysis units incorporate tools to determine caregiver burden and quality of life, as well as offer support interventions to those in need, the burden, and health-related quality of life (HRQoL) amongst caregivers in Kenya, remains largely unknown.

**Objective-** To determine the burden of care and health related quality of life (HRQoL) among caregivers of patients on maintenance hemodialysis at the renal unit of Kenyatta National Hospital.

**Design:** A cross-sectional descriptive study.

**Setting:** Hemodialysis unit of Kenyatta National Hospital.

**Subjects:** Caregivers accompanying their care recipients undergoing maintenance hemodialysis at Kenyatta National Hospital.

**Sampling:** Convenient sampling.

**Methodology-** The study participants that met the inclusion criteria and consented to participate were enrolled until the desired sample size of 113 caregivers was reached. Caregiver burden and HRQoL were determined using the Zarit Burden Interview and the WHOQOL-BREF questionnaires respectively. A self-designed structured proforma was used to record caregiver's social demographic characteristics while the Karnofsky performance scale was used to determine the global functioning state of the patient.

**Study period-** The study was done over a period of 3 months beginning June-September 2016.

**Study Analysis-** Statistical analysis was done using SPSS version 21.0. Social-demographic characteristics were summarized into means/medians and percentages. Burden was categorized and presented as proportions while HRQoL was analyzed and presented as mean scores with standard deviation for each domain. Global functioning state was presented as a percentage. The severity of burden was associated with HRQoL using ANOVA test. The severity of burden was associated with the socio-demographic characteristics of the caregivers using chi-square. The severity of burden was also associated with the global functioning state of the hemodialysis patient using chi-square test. Ordinal regression was used to determine the predictors of severity of caregiver burden. All statistical tests were conducted at 5% level of significance (p-value less or equal to 0.05).

**Results-** Majority of the caregivers at 48.7% experienced mild-moderate burden in their caregiving role. In HRQoL scores, highest scores were in the domains psychological (mean 57.1, SD=17.5) and physical (mean 56.2, SD=17.5) with the lowest scores observed in domains social (mean 48.3, SD=23.9) and environment (mean 45.5, SD=19.5).The HRQoL scores decreased significantly with a rise in the severity of burden (p-value of < 0.05 in all domains). The caregiver's age was the only predictor of burden (p-value= 0.024).

**Conclusion-** Findings from this study showed that caregivers of patients on maintenance hemodialysis do experience burden in their caregiving role and their quality of life is compromised. There was a significant negative association between burden levels and quality of life. Age was a predictor of burden with those above 60 years experiencing a higher level of burden.

## 1.0 INTRODUCTION

Chronic kidney disease (CKD) affects all nations regardless of economic status or ethnicity<sup>(1)</sup>. It leads to several complications including but not limited to- an increase in cardiovascular mortality and infections, cognitive impairment, metabolic disorders and drug toxicities due to reduced renal clearance<sup>(2,3)</sup>. It is a major contributor towards the poor health outcomes of non-communicable diseases<sup>(4)</sup>. The costly end result is the need for renal replacement therapy (RRT) to maintain long-term survival<sup>(3)</sup>. The asymptomatic nature of the disease results in a lost opportunity for preventing progression to kidney failure and development of the adverse outcomes associated with it<sup>(4)</sup>. Kai-Uwe Eckardt and colleagues estimate that greater than 10% of the world's population have CKD,<sup>(5)</sup> although this could be an underestimate. Similarly, the annual death rate from CKD is rising <sup>(6)</sup> with an overall increase in lives lost prematurely<sup>(7)</sup>. The rise in the incidence and prevalence of CKD is brought on by the increased prevalence of non-communicable diseases, aging population, as well as improved diagnostic capabilities<sup>(8)</sup>. It reduces lifespan significantly and is costly to manage despite the fact that only 1% of those with CKD will need renal replacement therapy<sup>(2,3)</sup>. In countries where access to RRT is restricted, the end result is death<sup>(2,3)</sup>.

Renal replacement therapy causes physical, financial and psychosocial challenges that affect both the patients and their caregivers<sup>(9)</sup>. Those undergoing maintenance hemodialysis rely on their unpaid family caregivers not only to assist with activities of daily living but to cater to their medical needs as well<sup>(10)</sup>. The role of caregiving adversely affects several facets of the caregiver's life. It places substantial demands on their financial resources and negatively impacts on their social life, physical and emotional state. Caregiving can lead to disorders of affect such as depression and anxiety related symptoms leading to chronic medication use<sup>(11)</sup>. Caregivers who are strained have a higher mortality rate than non-caregiving controls<sup>(12)</sup>. In a qualitative study by Alnazky et al in a Jordan hemodialysis unit, caregivers were found to be socially isolated and had multiple health-related problems that limited their own physical function<sup>(13)</sup>. Many other studies undertaken have shown that caregivers of hemodialysis patients experience significant caregiver burden and a lower quality of life <sup>(14-18)</sup>.

The concept of burden of care was defined by SH Zarit in 1980 and overtime interest has increased in the study of the burden of care in various fields<sup>(19)</sup>. According to (Given et al... 1992) caregiver burden is a multidimensional psychosocial reaction that arises from an imbalance of care demands relative to the caregiver's ability to meet them<sup>(20)</sup>. A caregiver can

be identified as the unpaid individual(s) who is/are mostly involved in the care of the recipient and help the recipient cope with and manage the chronic illness they are experiencing<sup>(11)</sup>.

Due to the growing awareness of the influence of hemodialysis on family caregivers, this study was designed to determine the burden of care and health-related quality of life among the said caregivers. It provides integral information that would aide health workers to design interventional tools that help to attenuate the negative aspects of caregiving and subsequently enhance both the caregiver and care recipients overall wellbeing.

## **2.0 LITERATURE REVIEW**

### **2.1 Definitions**

#### **2.1.1 Caregiver**

A caregiver is an unpaid individual involved in assisting others with activities of daily living and or medical tasks<sup>(21)</sup>.

#### **2.1.2 Caregiver Burden**

Caregiver burden is an all-encompassing term used to describe the physical, emotional, social and financial toll of providing care<sup>(21,22)</sup>.

#### **2.1.3 Caregiver Strain**

Caregivers perceived difficulty in performing their roles or feeling overwhelmed by their tasks<sup>(20)</sup>.

#### **2.1.4 Quality of Life**

Defined as an individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns<sup>(23)</sup>.

### **2.2 Chronic Kidney Disease**

It is estimated that 500 million people have chronic kidney disease (CKD)<sup>(1)</sup>. A systematic review looking at 26 population-based studies showed that 7.2% of those above 30 years had CKD with higher prevalence rates recorded for those above 65years of age<sup>(24)</sup>. According to the (2007-2012) NHANES database, 13.6% of non-institutionalized US adults aged 20 years and above have CKD<sup>(25)</sup>. Population prevalence of CKD in UK adults aged 16 years and above is 14% in males and 13% in females while in Australia 12.1% of adults above 25 years have CKD.

The prevalence of CKD in low-income countries is becoming comparable to that of established economies<sup>(26)</sup>. In Sub-Saharan Africa (SSA), it is a prevalent and potentially escalating disease burden with an overlap of risk factors<sup>(4,27)</sup>. It mainly affects young adults, who are in their economically productive years. It has been primarily shown to be due to glomerular disease unlike in established economies where it is more prevalent in those above 65 years of age and is largely due to type 2 diabetes mellitus and hypertension<sup>(4,28)</sup>. However rapid urbanization with resultant lifestyle changes is fuelling the rising global epidemic of

non-communicable diseases that are disproportionately causing a rise in the prevalence of CKD in SSA<sup>(8)</sup>. The global prevalence of diabetes was estimated at 2.8% in 2000 with an estimated increment to 6.5% by 2030 with the largest rise being in developing countries<sup>(29)</sup>. The resultant increase in the number of patients requiring maintenance RRT for ESKD will put an enormous economic burden not only at the national level but at an individual level as well. In a systematic review looking at the epidemiology of CKD in SSA, the overall prevalence was 13.9% similar to established economies. Data for 64,307 people were analyzed and in this population 72% had diabetes, 58% were HIV positive and 12% had hypertension<sup>(27)</sup>. The HIV epidemic is escalating the burden of CKD with a potential for an overwhelming CKD burden. In addition increasing age and presence of traditional co-morbidities in HIV patients makes CKD a leading cause of morbidity and mortality in this group<sup>(30,31)</sup>. Genetic factors like the variation of the MYH9 and APOL1 increase the risk of non-diabetic CKD in individuals of African origin<sup>(8)</sup>.

### **2.3 Renal Replacement Therapy**

The treatment options for ESKD include hemodialysis, peritoneal dialysis, kidney transplantation and conservative management (KDIGO 2012)<sup>(2)</sup>. Globally 3,010,000 patients were undergoing treatment for ESKD in 2012 with 78% undergoing dialysis and 21% living with a kidney transplant<sup>(32)</sup>. This represents an increase in the incidence of patients on RRT estimated at 7% annually<sup>(4)</sup>. In developed countries, national registries gather data on the various aspects of ESKD demographics, dialysis, transplants and patient outcomes<sup>(4)</sup>. In addition to the current data provision, patients access RRT through the safety net of a central registry. In Africa and other LSEC, renal registries are none existent and therefore data is mainly hospital derived. In 2007 only 4.5% of Africans constituted the world's dialysis population with a prevalence of 74 pmp compared to the global average of 430 pmp. A comparison of national GDP with the prevalence of RRT reveals that economic factors are majorly responsible for the restrictions on treatment<sup>(32)</sup>. In developed countries, treatment for ESKD accounts for more than 2-3% of their annual health-care budget for 0.02-0.03% of their ESKD patients<sup>(3)</sup>. This is not the case in LSEC where RRT is unaffordable or unavailable and approximately 1 million people with ESKD die each year. Constraints on capital and human resources combined with a rapidly escalating burden of CKD have forced many countries to ration dialysis therapy with a large proportion of those deserving RRT being denied treatment.



Lack of healthcare insurance makes ESKD treatment unaffordable for those living in LSEC<sup>(4)</sup>. In most African countries the cost of RRT is largely dependent on the patient's resources and in countries that offer dialysis treatment at low or no cost, treatment is of a conditional nature<sup>(33)</sup>. In South Africa, a criterion process based on the national guidelines is applied to those seeking care through public hospitals<sup>(34)</sup>. In a study by Moosa and Kidd et al more than half of the newly diagnosed ESKD were not offered RRT due to poverty-related contraindications<sup>(35)</sup>. Similarly, in India, only 5-10% of the ESKD patients are accepted for RRT<sup>(36)</sup>. Equally many patients are under dialyzed; in a Nigerian center only 20 % of the patients could afford dialysis three times weekly and 70% could afford once weekly while only a few were able to sustain chronic hemodialysis beyond 6 months and had to stop when funds got depleted<sup>(37,38)</sup>.

Hemodialysis is the primary modality used worldwide and accounts for 89% of the total number of patients undergoing dialysis<sup>(32)</sup>.

## **2.4 Burden of Care and Quality of Life**

Unpaid family caregivers who provide care to sick dependent relatives are a great asset to society even though their role is often neglected with no support intervention availed to them<sup>(39)</sup>. While both men and women of all ages serve as caregivers majority of the caregivers are women, with low to moderate income and of low educational status<sup>(15,16,40,41)</sup>. In many settings, caregivers are either middle-aged daughters or wives of the care recipient<sup>(42)</sup>. Caregiving can be beneficial, providing personal fulfillment and satisfaction from helping another. Those who appraise their caregiving role as being a positive one have lower burden scores and better self-assessed health. However, evidence shows that in the long run, it results in caregiver strain, burden and a lowered quality of life<sup>(42,43)</sup>. Caregiving demands have a pervasive effect on the caregiver exacting a toll on the physical, social, financial and emotional well-being of the caregiver. Nevertheless, family support is vital to the HD patient. It leads to successful adaptation to hemodialysis and compliance to medical therapy leading to lower risk of hospitalization as well as greater satisfaction with their care and their QoL<sup>(44,45)</sup>. Dialysis withdrawal has become a major cause of death in ESKD patients. Those who perceive themselves as a burden to caregivers are more likely to discontinue dialysis<sup>(46,47)</sup>. They are also more likely to be depressed and have a poorer self-reported HRQoL<sup>(10)</sup>. The mortality rate in patients having poor family support is 3 times higher compared to high support patients and they have a higher likelihood of non-adherence with medical care<sup>(44,48)</sup>.

High caregiver burden can cause premature institutionalization, abandonment as well as mistreatment of the care recipient<sup>(21)</sup>.

End-stage kidney disease and commencement of HD results in the patient and caregiver undergoing lifelong lifestyle modifications<sup>(49)</sup>. Renal care is extensive as it requires continuous repeated long distance visits to a hemodialysis unit with the caregiver assuming the role of a “chauffeur/escort”. In addition, there is constant need to cater to their daily dietary and fluid restrictions as well as the number of medications needed. Hemodialysis, in particular, is time-consuming and results in loss of personal freedom of the patient as well as the caregiver leading to reduced working capacity and thereby lower income<sup>(50)</sup>. It places both of them in a position of dependence not only on the dialysis machine but to the healthcare personnel managing these dialysis units<sup>(51)</sup>. CKD is associated with a number of co-morbid disorders especially in those above 65 years of age which compromises the overall functional and cognitive capacity of the patient<sup>(11)</sup>. The USRDS database notes that of those above 65 years nearly 40% have 5 or more associated co-morbidities<sup>(25)</sup>. Other burdensome conditions which afflict ESKD patients include dementia, sleep disturbances and physical pain<sup>(52)</sup>. Physical dysfunction has also been reported in studies to occur and has been regarded as the most pervasive and debilitating<sup>(52)</sup>. It results from the hematological disorders, peripheral neuropathy, and renal osteodystrophy that they develop affecting ambulation, therefore, increasing dependency<sup>(50)</sup>. Psychiatric disorders especially depression and a sense of hopelessness despite a good relationship with the caregiver are common<sup>(50,51,53)</sup>. Nutritional disorders due to nausea and vomiting, fluid retention and weight gain in between HD sessions, refractory ascites, pericarditis, poorly controlled hypertension are a hallmark of inadequate HD and promote dependency on the caregiver in activities of daily living<sup>(50)</sup>. It's also been shown that due to exhaustion after HD, patients take longer to think and carry out tasks. Therefore caregivers of patients on HD are expected to function broadly and assume multiple roles and this is associated with increased strain and burden. Burden increases as the ability of the patient to care for themselves diminish.

#### **2.4.1 Physical, Social and Mental Health Effects of Caregiving**

Caregiving is a chronic stress experience and is accompanied by high levels of uncertainty over the future, loss of control over their life and the possibility of their care recipient dying. It also has the capability of straining work and family relationships<sup>(54)</sup>. Due to the multiple roles

they play, the caregiver has to juggle between their caregiving role as well as attend to their work obligation and cater for other family responsibilities<sup>(55)</sup>. Objective stressors to the caregivers looking after a HD patient include the physical, psychiatric and cognitive impairments that the HD patient exhibits<sup>(11,50-52)</sup>. This leads to caregivers psychosocial stress and impaired health-seeking behaviors which trigger physiological responses that put them at risk of developing secondary health problems that would undermine their caregiving capacity<sup>(54)</sup>. Studies have shown that caregivers who report strain exhibit greater cardiovascular reactivity, have lowered immunity, greater concentrations of stress hormones as well as a higher estimated stroke risk<sup>(54,56,57)</sup>. Due to their frailty older spousal caregivers who report caregiver strain have a 63% higher mortality rate in 4 years than non-caregivers of the same age as shown in the Caregiver Health Effects Study<sup>(12)</sup>. Caregiver strain is also associated with sleep disturbances, fatigue, and neglect of one's health<sup>(50,58)</sup>. In a survey conducted by NAC in the USA, 17% of caregivers reported fair or poor health compared to 9% respondents in the general population<sup>(43)</sup>. The highest level of stress was reported in those who were in poorer health and performing a more intense level of caregiving.

Emotional stress leading to depression and anxiety related symptoms are frequent with a prevalence ranging from 18-47%. Those who exhibit emotional stress report higher degrees of caregiver burden<sup>(58,59)</sup>. Caregiver emotional disorders are driven not only by the work of caregiving but from the daily contact with a suffering loved one<sup>(43)</sup>. These disorders are more frequent in women than in men<sup>(60)</sup>. Any emotional disorder results in substantial consequences through reduced quality of life among the caregivers as well as reduced quality of care to the care recipient. In a study comparing caregivers of HD patients and those with a renal transplant, caregivers of HD patients had higher rates of emotional disturbances as well as poor sleep quality compared to the transplant arm<sup>(9)</sup>. As caregiving is time-consuming, it can lead to social isolation as it leads to loss of personal time<sup>(50,58)</sup>. A literature review looking at the impact of ESKD on close persons revealed that caregivers had a lower quality of life compared to age-matched controls<sup>(49)</sup>.

**Table 1: Negative effects of caregiving on the caregiver**

<b>Physical effects</b>	<b>Mental effects</b>	<b>Social Effects</b>
Increased cardiovascular disorders	Depression	Reduced free time
Lowered Immunity	Anxiety	Reduced leisure activities
Excessive fatigue	Excessive psychotropic drug use	Social isolation
Neglect of their own health	Poor sleep quality	Family and marital conflicts
Lower probability to seek medical care	Negative evaluation of their health	
Increased risk of premature mortality		

Mental health and social functioning were the most affected with higher perceived burdens significantly related to a lower HRQoL. Caregiver's also reported feeling confined and socially isolated as they lacked time for social interactions<sup>(49)</sup>. See Table 1 above.

#### **2.4.2 Financial burdens**

Families do incur financial costs either through direct caregiving expenses or indirectly through missed monetary/job opportunities secondary to their caregiver role. Care of patients with ESKD especially those presenting late causes deleterious financial burden in those with no health insurance<sup>(37,38)</sup>. The financial commitment that accompanies any RRT can be a source of burden to the caregiver<sup>(21,39,42,43)</sup>. Due to chronicity of the disease, resources get depleted and several studies have shown that most patients cannot afford dialysis beyond 3 months<sup>(37,38)</sup>. In addition, they tend to require multiple admissions in the hospitals due to complications from the HD or the disease itself. They also have associated psychiatric and medical co morbidities that do not allow them to engage in any meaningful IGA or to be employed<sup>(52)</sup>. Other factors leading to economic catastrophe include quitting their job, inability to access the job market, negative effects on promotion or job advancement among others<sup>(21,55)</sup>. Lai et al showed that financial costs were a significant contributor to the level of burden perceived by both male and female caregivers<sup>(61)</sup>.

### **2.4.3 Factors contributing to caregiver burden and reduced HRQoL**

The degree of burden experienced by the caregiver is dependent on multiple variables. Social demographic variables of the caregiver that predict higher levels of burden and poorer HRQoL include older age, being female, being a spouse, low educational status, emotive coping strategy, residing with the care recipient, longer duration of caregiving, social isolation and absence of an alternative caregiver<sup>(15,17,41,62,63)</sup>. On the other hand, emotionally stable patients and those who use problem-oriented coping strategy are more likely to report lower levels of burden as they are able to adapt accordingly<sup>(64,65)</sup>. Caregiver burden is higher in those of lower social economic state as they are prone to live in an environment where they lack social and psychological support. They will have difficulties in acquiring medication and have worse transportations to dialysis units<sup>(41)</sup>. Younger caregivers report better physical health but more caregiving burden and depression whereas older ones have more impairments in the physical health<sup>(63)</sup>. This could be explained by the competing demands of caregiver role and other social roles in the former. Female spousal caregivers exhibit more mental health impairment than physical health disorders due to the greater emotional investment and physical closeness of the spouses. Another compelling predictor of caregiver burden is the functional, cognitive and psychiatric impairments imposed by the disease on the care recipient leading to a higher level of dependency on the caregiver in activities of daily living<sup>(51)</sup>. Kidney transplant which is the gold standard of treatment in ESKD is associated with excellent HRQoL and a reduced level of burden of care<sup>(9)</sup>. See Table 2 below

**Table 2: Factors contributing to caregiver burden**

<b>Caregiver factors</b>	<b>Care Recipient factors</b>
Older age	Functional impairment
Female gender	Cognitive Impairment
Being a spouse	Psychiatric co-morbidity
Low educational level	Hemodialysis
Emotive coping strategy	
Low social economic state	
Living with the care recipient	
Longer duration spent caregiving	
Poor access to social support	

## **2.5 Caregiver Assessment**

It is an undertaking of collecting facts about a caregiving situation to identify wants, capabilities, and finances available to the informal caregiver and can be done by any health care team member<sup>(42)</sup>. Determining a caregiver's burden and quality of life is a concept that should be incorporated into any health care model<sup>(20,43)</sup>. By determining the perception they have of their own well-being and their quality of life, the healthcare team can gather integral information that can be used to develop a management strategy for the caregiver and determine needed support services.

Burden appraisal can be done either subjectively or objectively. The objective assessment looks at the variables associated with caregiving i.e. number of hours spent caregiving. It is geared to establish the degree of disruption in the caregiver's life due to their caregiving role<sup>(20,66)</sup>. An advantage of using objective assessment is that it's less prone to bias and clearly highlights areas of intervention. However, it does not accurately capture the complexity of the caregiver's distress and may overlook areas they perceive as causing greatest distress. On the other hand, subjective assessment is a more representative measure of the caregiver's emotional reaction to their caregiving role. Studies have indicated that caregiving tasks do not lead to negative caregiver outcomes but it's the emotive response of the caregiver to their role that leads to burden and its negative outcomes<sup>(67)</sup>.

WHO defines quality of life as "an individual's perception of their position in life in the cultural context and in the value systems in which they live and in relation to their goals, expectations, standards, and concerns"<sup>(68)</sup>. Several studies have demonstrated that caregiving

has a negative influence on the overall HRQoL<sup>(14,17,41)</sup>. Assessment of HRQoL is mainly subjective and is influenced by both the caregiver's and care recipient's variables. One of the variables that are consistently associated with low levels in QoL measures, is the level of burden that the caregiver perceives<sup>(15,41,69)</sup>. Determining caregivers QoL has numerous benefits. It enables the healthcare provider to gain new perspectives on the areas that have been impacted greatly by caregiving. Through understanding what the caregiver is experiencing, the relationship between the health care provider and the caregiver improves. It can also be used to assess the effectiveness of different interventional tools as well as be used as an invaluable tool for appraising health care service delivery<sup>(23)</sup>.

Perceived HRQoL among caregivers of hemodialysis patients has been assessed through the medical outcomes study short form-36(SF-36) or the WHOQOL-BREF score while the burden of care has been assessed through a number of tools<sup>(49)</sup>. The Zarit Burden Interview (ZBI) is one of the most commonly referenced burden measures and has been validated in many culturally or ethnically different population<sup>(49,60,67,70,71)</sup>. Ajitpal et al in India randomized caregivers according to those whose patients were on maintenance HD vs. not on HD. Majority of the caregivers were middle-aged spouses. Caregivers of those on HD experienced significantly more burden and worse QoL compared to caregivers of those not on HD<sup>(14)</sup>. Nagarathnam et al, also assessed caregiver burden at a tertiary care hospital in India using the ZBI tool<sup>(72)</sup>. In this study, it was surprising to note that higher mean burden score was observed in male caregivers compared to female caregivers. Mashayekhi et al while using the caregiver burden questionnaire noted that 49% of the 51 subjects in two government hospitals experienced caregiver burden. Higher burden scores were recorded among those caring for male patients and patients with lower income<sup>(66)</sup>. Alvarez ude et al showed that majority of the caregiver's perceived moderate-severe burden and the physical and mental component of HRQoL were affected. Mental component was affected more in those who perceived lower social support, perceived higher burden and took care of a patient with psychiatric co morbidity whereas physical component was affected more in the younger caregivers. Subjective burden was higher in those with less social support and worse physical and mental health status<sup>(15)</sup>. A Significant correlation was observed between lower scores in quality of life dimensions in patients as well as caregivers and higher perceived caregiver burden (Belasco et al)<sup>(41)</sup>. Bayoumi et al investigated perceived burden among fifty caregivers in a Saudi Arabia hospital using the caregiver burden interview questionnaire. Majority experienced moderate to

severe burden. The burden scores correlated positively with the care recipient's age and negatively with their education level<sup>(16)</sup>.

In a South African study, 46.6% of the caregivers experienced burden with majority experiencing no burden. The limitation of this study was that it was carried out in the private sector where patients were of a higher social economic group and might not reflect on patients cared for in government hospitals<sup>(1)</sup>. There were no studies in Kenya and the rest of Africa regarding caregiver burden and HRQoL among family caregivers of patients undergoing maintenance hemodialysis.

## **2.6 Impact of Interventions**

The healthcare personnel should be cognizant of the important role caregivers do play and the impact they have on the outcome of their ESKD patients. They should also be aware of the tremendous impact that ESKD and its treatment can have on families in an era where it is possible to sustain life for years with the use of advanced technology<sup>(49,71)</sup>. In initiating HD, establishing who the primary caregiver will be, is important as discussing coping skills can reduce their burden and improve their HRQoL. There is a need to develop interventional tools for caregivers of HD patients that educate and provide psychosocial and practical support with the outcomes of improving caregivers knowledge and skills, physical, psychological, emotional and social status, therefore, reducing burden and improving their quality of life<sup>(21)</sup>. When both the patient and the caregiver are treated as a team, outcomes for both improve.

The model of the intervention to be applied should be specific for each HD unit. Studies looking at interventional outcomes of HD patients caregivers are few. Two of these studies used a pre-test and post-test design and were short term while the third was a participatory action research method. Ghane et al conducted a randomized controlled clinical trial and showed the effectiveness of problem-focused coping strategies on reducing the burden among caregivers of hemodialysis caregivers<sup>(73)</sup>. Mukadder echoed the same by showing that educating the caregivers on coping strategies as well as providing needed information on renal care reduced perceived burden<sup>(74)</sup>. Despite a paucity of studies in CKD, research has clearly shown the benefit of support interventions when provided to caregivers of other chronic illness with reduced caregiver burden and improved HRQoL of both the caregiver and the recipient<sup>(56,75)</sup>.



## **2.7 Kenyan Situation Analysis**

Kenya just like other African countries does not have a renal registry data collecting system. Therefore, the true burden of CKD is unknown. Being a LSEC, caregiving is shouldered mainly by family members or other relatives. However this rich social and cultural resources provided by the extended family is on the decline as we adopt the nuclear-based westernized families<sup>(76,77)</sup>.

The Ministry of Health estimates that 1 million Kenyans suffer from kidney related diseases which is consistent with the global CKD prevalence<sup>(78)</sup>. Kidney disease deaths account for 0.92% of total deaths with an age-adjusted death rate of 14.24/100,000<sup>(79)</sup>. There are an estimated 6000 patients suffering from kidney failure annually in Kenya according to the Kenya Renal Association<sup>(80)</sup> with a majority not accessing the few available dialysis units. In-center hemodialysis is the commonest mode of RRT<sup>(81)</sup>. Kwalimwa et al in his study showed that economic factors were major barriers to good quality care at the KNH renal unit<sup>(81)</sup>. Resource limitations like an inadequate number of dialysis machines and nephrology staff at the unit may serve to act as a source of burden not only to the patients accessing the HD unit but to their caregivers as well. Due to the frailty of the HD patients as majority present late for HD<sup>(82)</sup>, it is their caregivers who manage the dialysis appointments which may take a number of hours due to a dearth of hemodialysis machines. Many of the patients presenting at the KNH HD unit are of low social economic status and 83% rely on family contributions resulting in an increase in the number of missed HD sessions<sup>(81)</sup>. Inadequate HD results in more functional, cognitive and psychiatric impairments on the patients resulting in more caregiver burden<sup>(51)</sup>. As previous studies have shown, LSES is associated with poor formal and informal social support as well as a high risk for increased caregiver burden and reduced quality of life<sup>(41)</sup>. There is a dearth of quality of life and burden of care studies among caregivers in Kenya. In one of the studies, Kimemia et al noted that the mean age of the caregiver was 35 years and the mean ZBI score was 37.18 (SD=17.5) indicative of mild to moderate burden. An increase in age correlated with a decrease in burden while an increase in education level correlated with a decrease in burden<sup>(77)</sup>. Other studies examining caregivers in Kenya noted that they were at a higher risk of clinical depression than the general population<sup>(83-85)</sup>.

## **2.8 Study Justification**

There is a growing global awareness of the influence of ESKD on the Burden and HRQoL of patients and their family caregivers and several studies addressing the same have been carried

out<sup>(14-17,41)</sup>. Therefore there is need to develop support interventions that incorporate the family caregiver. In Kenya where majority pay for dialysis out of pocket, economic factors and resource limitations serve to act as a source of significant burden not only to the patients but to their caregivers as well<sup>(81)</sup>. Currently, there is no study in Kenya describing the Burden of Care and HRQoL among caregivers of patients on maintenance hemodialysis.

Data obtained from this study will enable us to characterize the caregivers of the HD patients accessing the KNH hemodialysis unit. It will inform us of the burden that caregivers experience and the influence it has on their QoL. This information may impress on the HD unit and other stakeholders to develop tools for caregiver burden assessment as well as interventional tools aimed at minimizing caregiver burden for those at risk.

## **3.0 METHODOLOGY**

### **3.1 Research Question and Hypothesis**

What is the burden of care and health-related quality of life (HRQoL) among caregivers of patients on maintenance hemodialysis at the renal unit of Kenyatta National Hospital?

#### **Hypothesis**

Caregivers of patients on maintenance hemodialysis will report moderate to severe burden and a reduced health-related quality of life (HRQoL).

### **3.2 Objectives**

To determine the burden of care and health related quality of life (HRQoL) among caregivers of patients on maintenance hemodialysis at the renal unit of Kenyatta National Hospital.

#### **3.2.1 Specific Objective**

1. To determine the burden of care among caregivers of patients on maintenance hemodialysis using the Zarit Burden Interview Questionnaire.
2. To determine the Health-Related Quality of Life (HRQoL) among caregivers of patients on maintenance hemodialysis using the WHOQOL-BREF Questionnaire.

#### **3.2.2 Secondary Objective**

1. To determine the association between burden of care and health-related quality of life (HRQoL).
2. To determine the association between burden of care and social demographic characteristics of the caregivers.
3. To determine the association between burden of care and global functioning state of the patient scored as per the Karnofsky performance scale.

### **3.3 Study Location**

The study was conducted at the hemodialysis unit of Kenyatta National Hospital. KNH is a national referral facility in Nairobi Kenya and is the teaching hospital for the University of Nairobi Medical School.

The hemodialysis unit is the largest in the country. A total of 160 patients are on regular hemodialysis and on average 50 patients are dialyzed daily. The unit has 18 hemodialysis machines and is operational all day and night, 7 days of the week.

### 3.4 Study Design

Cross-sectional descriptive study.

### 3.5 Study Population

Caregivers of patients undergoing maintenance hemodialysis at the renal unit of Kenyatta National Hospital

#### 3.5.1 Case Definition

A caregiver was identified by the patient based on the following criterion “The person most closely and consistently involved in caring for the patient after starting hemodialysis without being paid and had been caring for the patient for at least 3 months”.

#### 3.5.2 Inclusion Criteria

1. Identified as the caregiver using the case definition criterion.
2. Informed written consent from the caregiver.
3. Caregivers of patients undergoing maintenance hemodialysis for a minimum of 3 months.
4. Caregivers  $\geq$  18years of age.

#### 3.5.3 Exclusion Criteria

1. Caregivers of patients returning to hemodialysis therapy after failure of renal transplant.

### 3.6 Sample Size Calculation

According to KNH data from hospital records, a total of 160 patients are on follow up for hemodialysis. Therefore, out of this population, a representative sample was drawn and the sample size calculation obtained using the formula for finite population (Daniel, 1999)<sup>(86)</sup>. The calculation was as follows:

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

Where

$n'$  = 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 caregivers with burden of care (Caregiver burden scale score between 21 and 88) = 47% <sup>(1)</sup>

$d =$  margin of error

$$= \frac{160 \times 1.96^2 \times 0.47 \times 0.53}{0.05^2 (160-1) + 1.96^2 \times 0.47 \times 0.53}$$

$=$  **113** caregivers for **113** hemodialysis patients will be sampled.

### 3.7 Sampling Method

Convenient sampling was done to recruit caregivers who satisfied the inclusion criteria during the study period. The principal investigator perused through the records at the dialysis unit to identify patients attending hemodialysis on that particular day. Patients were approached to assent to their caregivers being included in the study. Those who assented were requested to identify their caregiver based on the case definition criterion. Caregivers that met the inclusion criteria were provided with the study information and subsequently, those who consented to participate were administered an informed consent. In the absence of the caregiver, the principal investigator called the caregiver and kindly requested them to avail themselves in the next HD appointment. They were enrolled until the desired sample size of 113 caregivers was reached.

### 3.8 Research Instruments

#### 3.8.1 Zarit Burden Interview Questionnaire (ZBI)

Caregiver's burden was measured using Zarit Burden Interview questionnaire. ZBI questionnaire consists of 22 questions with answers varying from 0 = 'never' 1='rarely' 2='sometimes' 3='quite frequently' and 4 = 'nearly always'. The scores are added up to give a total score ranging from 0 (no burden) to 88 (maximum burden).The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient<sup>(60,70)</sup>.

The score value estimates the degree of burden (see table 3 below)<sup>(70,87,88)</sup>.

**Table 3 : Zarit Burden Score Values**

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

This instrument is the most widely referenced tool in the study of caregivers<sup>(49,60,67,70,71)</sup>. It was initially developed by Steven H Zarit in 1980 to measure subjective burden among caregivers of adults with dementia. The items possess content validity as they were derived from clinical and research experience with caregivers of individuals with dementia and reflect common areas of concern, namely, health, finances, social life, and interpersonal relations. It has excellent internal consistency; Cronbach's alpha = 0.83 and 0.89. It has a test-retest reliability of 0.71<sup>(60,70)</sup>. It has been validated in Nigeria among caregivers of patients with epilepsy<sup>(89)</sup>. In Kenya, it has been used in the assessment of caregiver burden and coping responses for females who are the primary caregivers for a family member living with HIV/AIDS<sup>(77)</sup>. Mapi Research Trust granted permission for its use in this study.

### **3.8.2 WHOQOL-BREF Questionnaire**

The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100, a cross culturally comparable quality of life measure that was developed collaboratively and field tested across a number of cultural contexts. It is recommended for use when the time is restricted or the burden on the respondent needs to be minimized. It produces a profile with four domain scores (see table 4 below). The four domain scores denote an individual's perception of quality of life in each particular domain. The domain scores are scaled in a positive direction with higher scores indicating a higher quality of life.

It also has two individually scored items assessing individual's overall perception of quality of life and health.

**Table 4: WHOQOL-BREF domains**

<b>Domain</b>	<b>Facets incorporated within domains</b>
1. Physical health  (Raw score range:7-35)	<ul style="list-style-type: none"> <li>• Activities of daily living</li> <li>• Dependence on medicinal substances and medical aids</li> <li>• Energy and fatigue</li> <li>• Mobility</li> <li>• Pain and discomfort</li> <li>• Sleep and rest</li> <li>• Work Capacity</li> </ul>
2. Psychological health  (Raw score range:6-30)	<ul style="list-style-type: none"> <li>• Bodily image and appearance</li> <li>• Negative feelings</li> <li>• Positive feelings</li> <li>• Self-esteem</li> <li>• Spirituality / Religion / Personal beliefs</li> <li>• Thinking, learning, memory and concentration</li> </ul>
3. Social relationships  (Raw score range:3-15)	<ul style="list-style-type: none"> <li>• Personal relationships</li> <li>• Social support</li> <li>• Sexual activity</li> </ul>
4. Environment  (Raw score range:8-40)	<ul style="list-style-type: none"> <li>• Financial resources</li> <li>• Freedom, physical safety, and security</li> <li>• Health and social care: accessibility and quality</li> <li>• Home environment</li> <li>• Opportunities for acquiring new information and skills</li> <li>• Participation in and opportunities for recreation / leisure activities</li> <li>• Physical environment (pollution /noise /traffic / climate)</li> <li>• Transport</li> </ul>

Respondents rate the intensity, frequency or evaluation of the selected attributes of QoL during the previous 2 weeks on a 5-point Likert scale (low score of 1 to high score of 5) to determine each item score.

The mean score of items within each domain is used to calculate the domain score. The mean score for each domain is multiplied by 4 in order to make the domain scores comparable with the scores used in the WHOQOL-100. The domain scores are subsequently transformed to a 0-100 scale, to enable comparisons to be made between domains composed of an unequal number of items using the formula below.

$$\text{FINAL TRANSFORMED SCORE} = (\text{SCORE} - 4) \times (100/16).$$

Instructions for checking and cleaning data, and for computing domain scores, are given in Appendix VII<sup>(23)</sup>.

WHOQOL-BREF satisfies the key properties of a QoL questionnaire<sup>(90,91)</sup>.

This tool has been validated in our setting among patients with epilepsy attending the neurology clinic at Kenyatta National Hospital, Nairobi, Kenya<sup>(92)</sup>. WHO granted permission for its use in this study.

### **3.8.3 Karnofsky Performance Scale Status**

It is a physician rating scale that was originally developed to assess quality of life of the cancer patients receiving chemotherapy. It has been adopted for use in objectively assessing a patient's clinical state in other disease states. The scale ranges from scores of 0 to 100%. 100% implies full functional capability to carry out normal daily activities without clinical evidence of disease. A score below 70 indicates that the patient has the functional capacity to care for self but requires some assistance. A score of less than 50 represents the inability to care for self and patient is fully dependent. It has been shown to have good reliability (Pearson correlation of 0.89) and construct validity<sup>(93,94)</sup>.

## **3.9 Data Management and Analysis**

### **3.9.1 Data Collection**

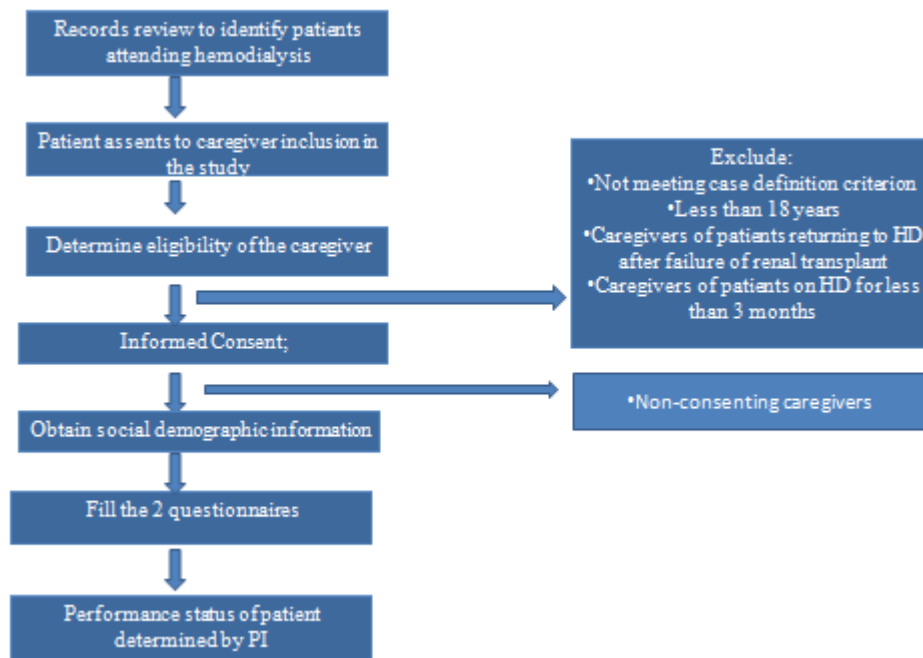
Caregivers were recruited over a three month period between June and September 2016.

Data was collected using four different tools with a corresponding unique identifier for each patient: Study Proforma, ZBI and WHOQOL-BREF questionnaires and Karnofsky Performance Status Scale. The 2 questionnaires were translated to Kiswahili which is the national language of Kenya.

After obtaining consent a self-designed structured study proforma was administered to the caregiver to obtain information on their socio-demographics. Zarit Burden Interview and WHOQOL-BREF questionnaires were administered using caregiver's preferred language. Both questionnaires were self-administered. The principal investigator assisted the caregivers without the capacities to self-administer the questionnaires. The functional status of the patient was assessed by the primary investigator using the Karnofsky performance status scale. Data collection was done by the principal investigator to ensure confidentiality and privacy.



### 3.9.2 Screening and Recruitment Flow Chart



### 3.9.3 Study Variables

#### Independent Variables

- Age
- Gender
- Education level
- Marital status
- Employment status
- Relationship to the patient
- Living with patient
- Duration of hemodialysis
- Presence of chronic medical condition

#### Dependent Variables

- Burden of disease (Zarit scores)
- Health-related quality of life (WHOQOL-BREF scores)
- Karnofsky performance status scale of the care recipient

### **3.9.4 Data Analysis and Presentation**

Data was entered and managed in Microsoft Access 2013 database and statistical analysis done in SPSS version 21.0 software. The characteristics of the caregivers were summarized into means/medians and percentages for continuous and categorical variables respectively. The burden of the caregivers was scored with a possible score range between 0 and 88. Level of burden was categorized as no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60) and severe burden (61-88); and presented as proportions. Health-related quality of life was analyzed and domains scores computed with standard deviations for each domain. The level of burden and HRQoL was analyzed and presented with 95% confidence intervals. The severity of burden was associated with the HRQoL domain scores using ANOVA test. The severity of burden was associated with the socio-demographic characteristics of the caregivers using chi-square test. The severity of burden was also associated with the global functioning state of the patient using chi-square test. Fisher exact test was used interchangeably for cells with small numbers. Ordinal regression was used to determine the predictors of severity of caregiver burden. All statistical tests were conducted at 5% level of significance ( $p \leq 0.05$ ).

### **3.9.5 Data protection and study dissemination plan**

All the raw data collected during the study has been kept safe and will only be accessible to the primary investigator. Data bears a unique code for each participant.

The final results of the study were presented at the Department of Clinical Medicine and Therapeutics. A hard and soft copy of the results is available at the University of Nairobi Library.

### **3.10 Ethical Considerations**

Institutional consent was sought from the Department of Clinical Medicine and Therapeutics, University of Nairobi (UON) and Ethics and Research Committee of KNH. Informed consent was sought from caregivers of patients and enrollment was voluntary. Failure to give consent did not jeopardize patient care. It was a non-invasive study. Confidentiality and privacy were observed throughout the study.

### **3.11 Quality Control**

The primary investigator informed the participants about the study. Those willing to participate were recruited in the study after an informed consent had been obtained. The primary investigator was under the guidance of the designated supervisors and a qualified statistician throughout the study. Validated questionnaires were used for the study.

Translation of the questionnaires to Kiswahili as well as assisting the caregivers without capabilities did not alter the validity of the questionnaires.

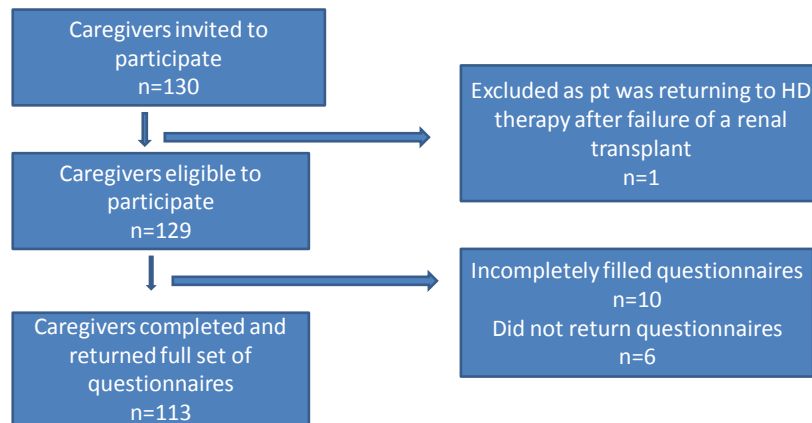
### **3.12 Study Feasibility**

Visits to the hemodialysis unit revealed that majority of the caregivers were accompanied by their primary caregivers who then proceed to wait for their care recipient's four-hour hemodialysis session to end. A pilot study done previously had shown that average interview time with the caregiver was between 30-45 minutes. All caregivers approached were able to answer the questionnaire without difficulty.

## 4.0 RESULTS

One hundred and thirty caregivers of patients on maintenance hemodialysis were enrolled into the study. One caregiver was excluded as his care recipient was returning to hemodialysis after failure of a renal transplant. Ten caregivers were excluded as they incompletely filled the questionnaires while six did not return the questionnaires. One hundred and thirteen caregivers participated in the study which was carried out between the months of June to September 2016.

**Figure 1: Flowchart of caregiver enrolment**



### 4.1 Socio-demographic Characteristics of the Caregivers

Characteristics of the caregivers are shown in table 5.

The study population consisted of caregivers with a mean age of 38.6 years (SD=11.5). Majority of the caregivers, 61.1% (n=69) were between 26 and 45 years of age. With regard to gender, female caregivers formed the largest group of caregivers at 58.4% (n=66). However, the males were well represented at 41.6% (n=47). Most of the caregivers were married 74.3% (n=84), living with their care recipients 86.7% (n=98) and literate with a secondary education and higher at 80.7% (n=90). Of the caregiver relationship, 35.4% were children, 34.5% were spouses, 13.3% parents, and 16.8% other relations. 61.9% were unemployed while 85%

reported the absence of a chronic medical condition. Majority at 64.6% were caregivers for a duration longer than 1 year.

**Table 5: Characteristics of caregivers (n=113)**

<b>Variable</b>	<b>n</b>	<b>Frequency (%) / Mean (SD)</b>
<b>Age in Years</b>		
Mean(SD)		38.6(11.5)
Range		19-66
18-25	12	10.6
26-45	69	61.1
46-60	28	24.8
>60	4	3.5
<b>Gender</b>		
Female	66	58.4
Male	47	41.6
<b>Level of education</b>		
None	2	1.8
Primary	21	18.6
Secondary	46	40.7
Tertiary	44	38.9
<b>Marital status</b>		
Married	84	74.3
Not married	29	25.7
<b>Job status</b>		
Unemployed	70	61.9
Employed	43	38.1
<b>Relation to care recipient</b>		
Child	40	35.4
Spouse	39	34.5
Parent	15	13.3
Others	19	16.8
<b>Duration of caregiving</b>		
>1	73	64.6
<1	40	35.4
<b>Living with care recipient</b>		
Yes	98	86.7
No	15	13.3
<b>Presence of chronic medical condition</b>		
Yes	17	15.0
No	96	85.0

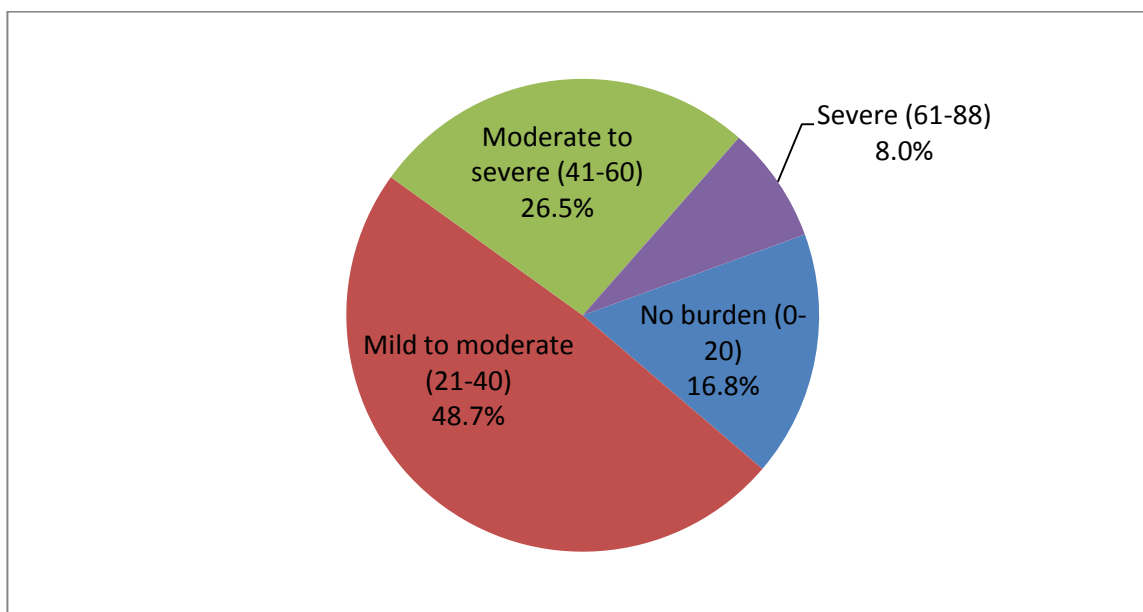
## 4.2 Burden among Caregivers

This is shown in table 6 and figure 2. According to the cutoffs proposed by Steven H Zarit (1980), 19 participants (16.8%) were experiencing no burden, 55(48.7%) had mild to moderate burden, 30(26.5%) reported moderate to severe burden and 9(8.0%) were experiencing severe burden. Cronbach's alpha coefficient for the ZBI items was 0.879, which indicated a high level of internal consistency for the ZBI questionnaire among the caregivers.

**Table 6: Burden of care**

Variable	Frequency (%)
<b>Burden of disease (n=113)</b>	
Range	8-74
<b>Category, n (%)</b>	
No burden (0-20)	19 (16.8)
Mild to moderate (21-40)	55 (48.7)
Moderate to severe (41-60)	30 (26.5)
Severe (61-88)	9 (8.0)

**Figure 2: Burden of care**



## 4.3 Health-Related Quality of Life

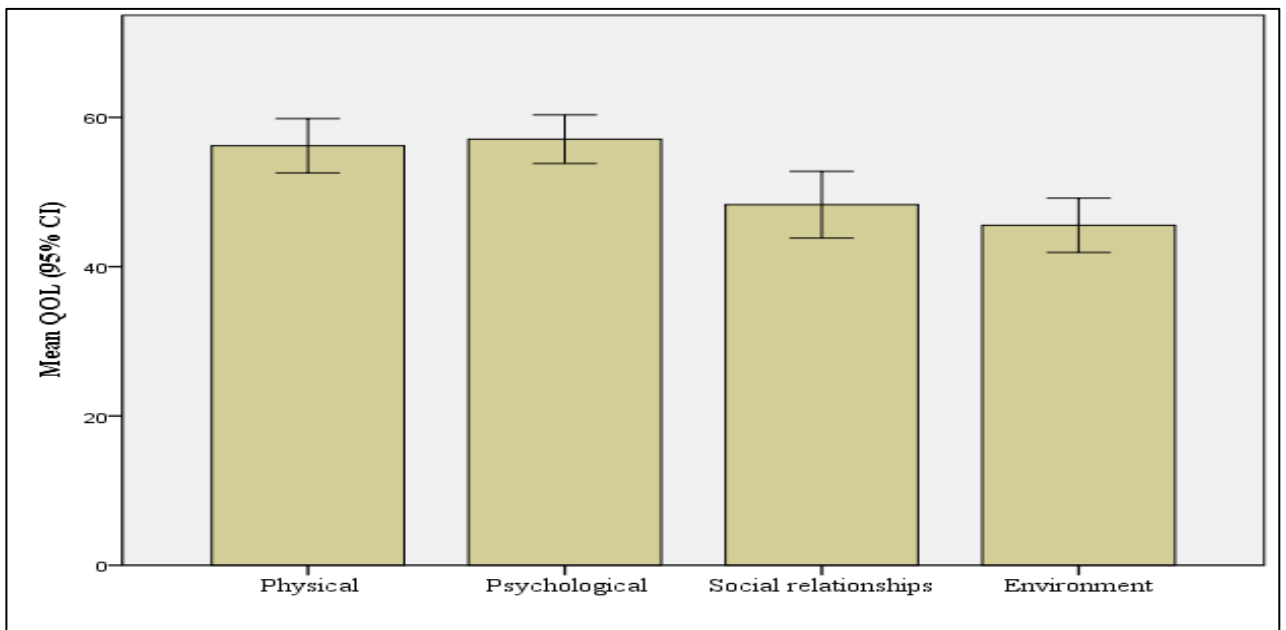
According to the average standardized scores, the highest scores were in the domains psychological (mean 57.1, SD=17.5) and physical (mean 56.2, SD=17.5) with the lowest scores observed in domains social (mean 48.3, SD=23.9) and environment (mean 45.5,

SD=19.5). Cronbach’s alpha coefficient was 0.931 for the WHOQOL-BREF (26 items) and it ranged from 0.709-0.854 for the 4 domains. Table 7 and figure 3 summarize the domain scores and Cronbach’s coefficients for each domain.

**Table 7: Descriptive Statistics: WHOQOL-BREF**

Variable	N	Min	Max	Mean	Standard Deviation	Cronbach’s Alpha
Overall QoL/Health		12.5	100	58.2	17.9	
Physical health	<b>113</b>	10.7	100	56.2	19.5	0.789
Psychological	<b>113</b>	12.5	95.8	57.1	17.5	0.762
Social relationships	<b>113</b>	0	100	48.3	23.9	0.709
Environment	<b>113</b>	0	100	45.5	19.5	0.854

**Figure 3: HRQOL scores**



#### 4.4 Performance Status of the Care Recipient

Majority of the care recipients, 54% (n=61) had a score of 50-70%, 5.3% (n=6) had a score of 80-100%, and 40.7% (n=46) had a score <50%. Table 8 summarizes the findings.

**Table 8: Karnofsky performance status**

<b>Karnofsky performance status</b>	
Range	10-90
<b>Category, n (%)</b>	
80-100%	6 (5.3)
50-70%	61 (54.0)
<50%	46 (40.7)

#### 4.5 Association between Burden of Care and HRQoL (ANOVA TEST)

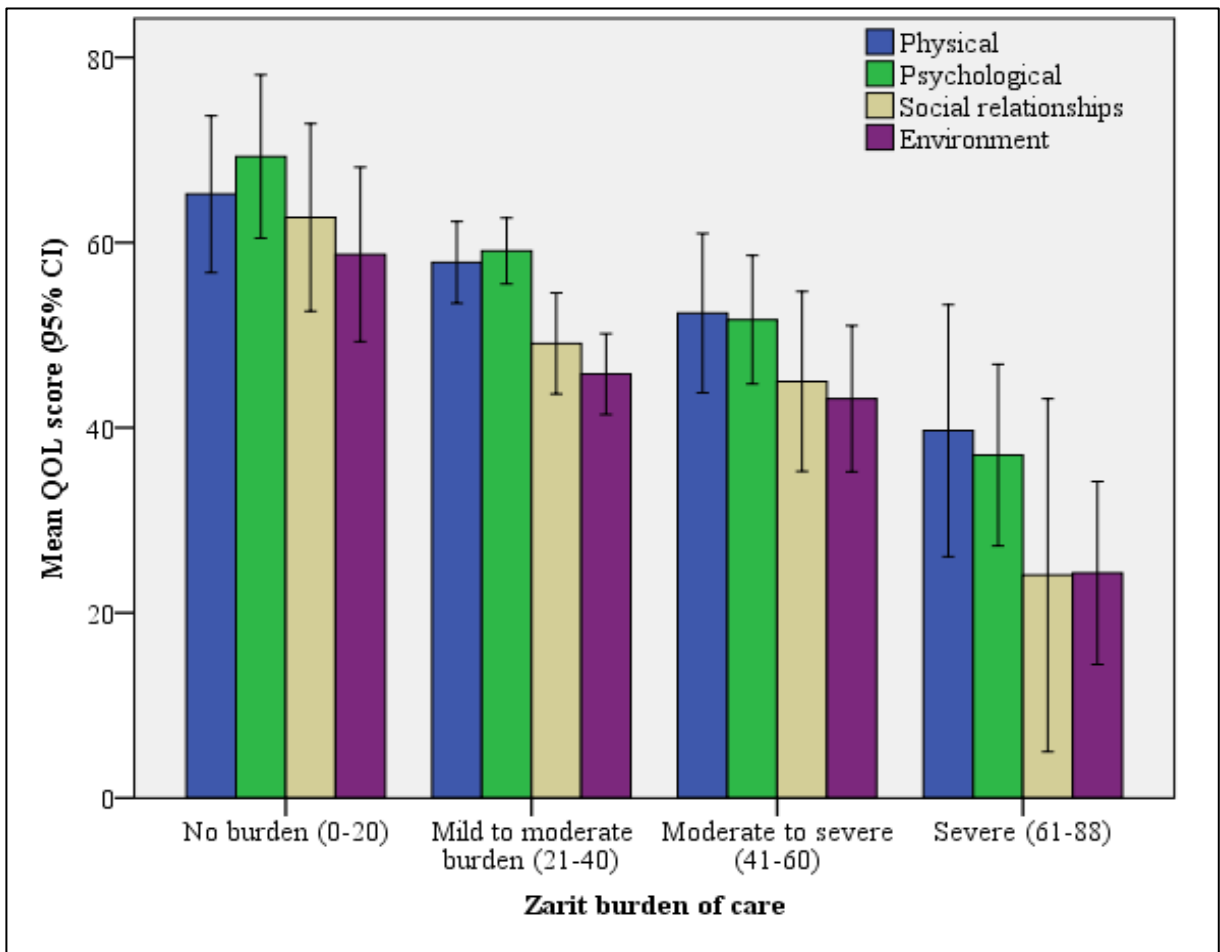
HRQoL scores in the four domains were significantly different in relation to severity of burden of care ( $p < 0.05$ ). As shown in Table 9 and figure 4, caregivers with no burden had the highest mean HRQoL scores in all the domains which reduced significantly as the severity of burden increased.

**Table 9: Association between burden of care and health-related quality of life**

	<b>Zarit Burden score</b>				<b>P value</b>
	<b>No burden (0-20)</b>	<b>Mild to moderate (21-40)</b>	<b>Moderate to severe (41-60)</b>	<b>Severe (61-88)</b>	
<b>Domain</b>					
Physical	65.2 (17.6)	57.9 (16.3)	52.4 (23.0)	39.7 (17.7)	0.006
Psychological	69.3 (18.3)	59.1 (13.2)	51.7 (18.6)	37.0 (12.8)	<0.001
Social relationships	62.7 (21.0)	49.1 (20.2)	45.0 (26.0)	24.1 (24.8)	0.001
Environment	58.7 (19.6)	45.8 (16.1)	43.1 (21.2)	24.3 (12.9)	<0.001



**Figure 4: Health-related quality of life in different categories of Zarit burden of care**



## 4.6 Factors associated with Burden of Disease

### 4.6.1 Association between burden of care and social demographic characteristics of the caregiver (Chi-square test)

Burden scores were significantly different in relation to age ( $p < 0.004$ ) and marital status ( $p < 0.012$ ). As shown in table 10, caregiver burden scores increased significantly with increasing age. Being married was significantly associated with higher burden scores. There was no significant difference in burden scores according to the caregiver's gender, education, employment status, health status, relations, duration of care, or living arrangements.

**Table 10: Social-Demographic variables associated with burden of disease**

Variable	Burden of disease				P value
	No burden (0-20)	Mild to moderate(21-40)	Moderate to severe (41-60)	Severe (61-88)	
Mean age (SD)	33.1 (10.6)	37.2 (10.8)	42.4 (10.5)	46.6 (13.9)	0.004
<b>Gender</b>					
Male	6 (12.8)	25 (53.2)	14 (29.8)	2 (4.3)	0.457
Female	13 (19.7)	30 (45.5)	16 (24.2)	7 (10.6)	
<b>Educational level</b>					
None	0	0	1 (50.0)	1 (50.0)	0.172
Primary	2 (9.5)	8 (38.1)	7 (33.3)	4 (19.0)	
Secondary	8 (17.4)	23 (50.0)	13 (28.3)	2 (4.3)	
Tertiary	9 (20.5)	24 (54.5)	9 (20.5)	2 (4.5)	
<b>Marital status</b>					
Married	9 (10.7)	41 (48.8)	27 (32.1)	7 (8.3)	0.012
Not married	10 (34.5)	14 (48.3)	3 (10.3)	2 (6.9)	
<b>Employment status</b>					
Employed	6 (14.0)	24 (55.8)	13 (30.2)	0	0.056
Not employed	13 (18.6)	31 (44.3)	17 (24.3)	9 (12.9)	
<b>Relationship to patient</b>					
Spouse	5 (12.8)	18 (46.2)	10 (25.6)	6 (15.4)	0.613
Parent	2 (13.3)	6 (40.0)	6 (40.0)	1 (6.7)	
Child	7 (17.5)	22 (55.0)	9 (22.5)	2 (5.0)	
Other	5 (26.3)	9 (47.7)	5 (26.3)	0	
<b>Living with patient</b>					
Yes	16 (16.3)	47 (48.0)	26 (26.5)	9 (9.2)	0.836
No	3 (20.0)	8 (53.3)	4 (26.7)	0	
<b>Duration of caregiving</b>					
<1	10 (25.0)	19 (47.5)	9 (22.5)	2 (5.0)	0.347
>1	9 (12.3)	36 (49.3)	21 (28.8)	7 (9.6)	
<b>Presence of chronic medical condition</b>					
Yes	2 (11.8)	8 (47.1)	4 (23.5)	3 (17.6)	0.461
No	17 (17.7)	47 (49.0)	26 (27.1)	6 (6.3)	

#### 4.6.2 Predictors of Burden

On multivariate analysis using an ordinal regression model, higher age group (over 60 years) was associated with a higher burden scores( $p=0.024$ ). Marital status was not a significant predictor of severity of burden. This is shown in table 11.

**Table 11: Multivariate analysis of factors associated with burden (ordinal regression model)**

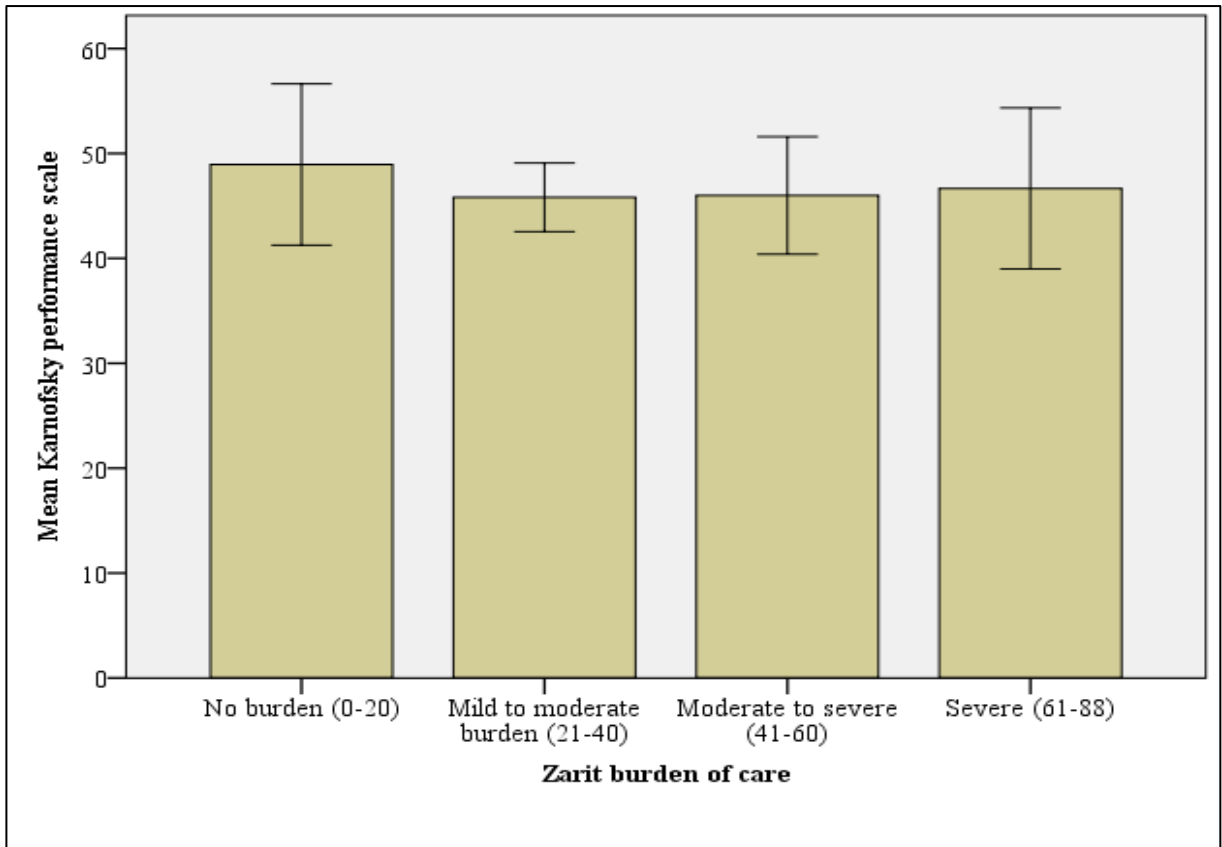
<b>Variable</b>	<b>Cumulative logit (95% CI)</b>	<b>P value</b>
<b>Marital status</b>		
Married	0.88 (-0.18-1.95)	0.105
Not married	Ref	
<b>Age in years</b>		
>60	2.82 (0.38-5.26)	0.024
46-60	1.01 (-0.65-2.68)	0.234
26-45	0.41 (-1.00-1.83)	0.567
18-25	Ref	

#### **4.6.3 Association between Burden of care and the Global Functioning State of the Patient**

There was no significant association between burden of care and the care recipient's performance status as shown in table 12 and figure 5.

**Table 12: Association between burden of care and performance status**

	<b>Zarit Burden score</b>				<b>P value</b>
	<b>No burden (0-20)</b>	<b>Mild to moderate (21-40)</b>	<b>Moderate to severe (41-60)</b>	<b>Severe (61-88)</b>	
Karnofsky score	48.9 (15.9)	45.8 (12.1)	46.0 (15.0)	46.7 (10.0)	0.848
Category, n (%)					0.619
80-100%	2 (33.3)	2 (33.3)	2 (33.3)	0	
50-70%	11 (18.0)	28 (45.9)	15 (24.6)	7 (11.5)	
<50%	6 (13.0)	25 (54.3)	13 (28.3)	2 (4.3)	



**Figure 5: Karnofsky performance scale score versus burden of care**

## 5.0 DISCUSSION

This study was undertaken to determine caregiver burden and HRQoL among caregivers of patients on maintenance hemodialysis at Kenyatta National Hospital in Kenya. It also sought to determine the relationship that existed between burden of care and HRQoL, burden and social-demographic characteristics of the caregivers as well as burden and the functional status of the patient on maintenance hemodialysis.

### 5.1 Caregiver Characteristics

The caregivers had a mean age of 38.6 years (SD=11.6). This is akin to two caregiver studies done in Kenya<sup>(77,84)</sup>. However, in western literature, caregivers of hemodialysis patients are typically older<sup>(15,74,95)</sup>. Therefore this group of caregivers represents a young generation of caregivers. The Kenyan population is still very youthful and this could explain the age difference with other studies done in western countries<sup>(96)</sup>. Being younger in age leads to a negative care-work association<sup>(97)</sup>. Young caregivers although educated like in our study are less likely to participate in the national workforce and are more likely to miss out on job opportunities<sup>(61)</sup>. However, the seemingly high rates of unemployment in caregivers have also been attributed to the fact that those who are unemployed are more likely to be the family's choice to take up the caregiving role. As caregiving is still viewed as a "woman's work" this effect is more likely to be felt by the female caregiver. In addition, young caregivers are more likely to be married and have other obligations in their own households. Most of the caregivers were either children or spouses of the care recipient. Informal caregivers have been described to be close family members, with spouses and children representing equal numbers<sup>(42,95)</sup>. Similarly, in the African culture, children are expected to provide care directly to chronically sick parents<sup>(98)</sup>. Other characteristics like a majority of the caregivers being women, married, living with their care recipient, unemployed and providing care for more than 1 year were consistent with other studies done on caregivers of hemodialysis patients<sup>(14-16,41,53,66,72-74)</sup>. Majority of the caregivers had good health which is contrary to the reported negative association between caregiving and physical health<sup>(97)</sup>. This could be attributed to their young age and was replicated in other studies where most caregivers were in good health<sup>(15,73,74)</sup>. Our study confirmed that women were more likely to be the caregivers. However, the number of men who are actively participating in the caregiving process has been steadily rising<sup>(99)</sup>. In our findings, 41.6% of the caregivers were men. With the entry of

women into the labor market, there is a softening on the traditional male roles inclining more men to be caregivers. 86.7% of our study subjects were living with their care recipients similar to other studies<sup>(13)</sup>. Literature has shown that those who live with their care recipients provide more intensive caregiving tasks which can lead to increased burden<sup>(42)</sup>.

## **5.2 Burden of Care**

Majority of our caregivers at 48.7% (n=55) experienced mild-moderate burden in their caregiving role. This degree of burden is similar to that reported in two studies done in India<sup>(14,72)</sup>. In these studies, it was reported that financial assistance and strong social ties could be attributed to the mild-moderate burden experienced by a majority of the caregivers respectively. The caregivers appeared to have a higher degree of burden in comparison to a USA study where majority reported little to no burden<sup>(69)</sup>, as well as one done in Johannesburg where 53.4% experienced no burden in caring for their hemodialysis patients<sup>(1)</sup>. Possible explanations for these differences could be the financial and social security that is associated with a high-income country whereas in Johannesburg the study was conducted in the private sector. However, our caregivers appeared to have less burden when compared to other studies where majority experienced moderate-severe burden<sup>(15,16,74)</sup>. Main factors associated with higher perceived burden in this studies were, perceived low social support, an older caregiver, low education levels and poor health of the caregiver and care recipient. In one of the studies, it was noted that higher education, younger age and being single was associated with higher levels of burden<sup>(74)</sup>. Studies evaluating caregivers of other chronic conditions in Africa presented varying levels of burden<sup>(89,98,100-103)</sup>. In these African studies, it was noted that living in a multigenerational setting was protective by providing respite caregivers that could assist in the caregiving task.

We had hypothesized that majority of the caregivers would report moderate to severe burden which was not the case in our findings. It has been shown that not all caregiving experience is negative and some derive personal gains and satisfaction from caring for a close family member<sup>(104)</sup>. In looking at the parent-child dyad, the presence of a positive attachment between the two prior to the onset of the health care demand results in the caregiver being motivated more by love and a sense of reciprocity for care provided during childhood and a lower reported burden<sup>(105)</sup>. Although we did not determine their coping strategies, studies have shown that some of the coping mechanisms the caregivers employ may mitigate their caregiver burden<sup>(77,106)</sup>. Finally, we did not determine the presence or absence of a respite

caregiver. The presence of multiple siblings in a family may mean the primary caregiver may have someone to relieve them of their caregiving duties when needed<sup>(105)</sup>.

### **5.3 Health-Related Quality of Life (HRQoL)**

In HRQoL scores, maximum scores of 57.1 (SD= 17.5) were recorded in the psychological domain with the least scores of 45.5 (SD=19.5) noted in the environmental domain. The HRQoL scores decreased significantly with a rise in the level of burden. The domain scores are scaled in a positive direction where higher scores indicate better quality of life. The overall HRQoL score for this population was 58.2 (SD=17.9). When compared to a hypothesized mean of 75 ( $\pm 2.5$ )<sup>(107)</sup>, this value indicates that the caregivers had a reduced QoL. The discussion on QoL scores is limited due to lack of studies applying WHOQOL-BREF among caregivers of hemodialysis patients, especially in Africa. In addition, cut-points and norms have not been established for this group of caregivers that we could use for purposes of comparison. Ajitpal et al evaluated the quality of life among caregivers of CKD patients in India. The mean scores were similar to our study in domains physical (54) and psychological (54). However their mean scores in domains Social (62) and Environmental (59.3) were higher compared to our study population<sup>(14)</sup>. The environment domain relates to financial resources, physical environment, transport among others. The low scores in this domain can be explained by the fact that Kenya is a low-medium income country with a GDP per capita of 1,133.46 \$<sup>(108)</sup>. Majority of the population will have poor finances, poor transportation, and housing as well as inadequate entertainment facilities. This was reflected in our study findings of a high unemployment rate of 61.9%. Chuma et al reported that Kenyans were becoming poorer due to health care payments<sup>(109)</sup>. In countries like Kenya, the economic situation dictates that majority of the people work in the informal sector characterized by long working hours and poor pay and therefore any catastrophic health expenditure can lead them to move further into indigence. Financial costs to this families can be directly related to those incurred from direct care i.e. transport, medication, user fees for assessing health care services among others. Indirect costs result from the inability to take part in their usual economic activities resulting in loss of financial security. The coping responses like borrowing from friends and relatives or selling household assets to raise funds for their rising healthcare costs serve to push them further below the poverty line<sup>(110,111)</sup>. The economic implications of diseases to families in developing countries has been addressed by several authors with several recommendations being suggested<sup>(111)</sup>. High levels of poverty and

unemployment translate to the high probability that caregivers live in informal settlements, areas burdened by poor infrastructure and lack of social amenities leading to lower scores in the environmental domain<sup>(112)</sup>. This was replicated by a study done in Africa where caregivers had fairly high scores in other domains except in the environmental domain<sup>(113)</sup>. The social domain relates to social support, personal relationships and sexual activity. The low scores in social domain can be explained by the loss of the social ties that have come about due to the adoption of nuclear-based families, smaller family units and restructuring of the extended families<sup>(77)</sup>. African culture protects the caregiver due to strong social ties and multigenerational living arrangements<sup>(84)</sup>. Alvarez et al showed that perceived poor social support was significantly associated with higher burden levels and worse scores in the mental functioning of the caregiver<sup>(15)</sup>. A great and extensive social support system acts to serve as a resource for the caregiver by ameliorating the impact of caregiving<sup>(114)</sup>. Due to the demands of caregiving, the marital dyad may undergo poor marital adjustments that can considerably impact negatively on their social well-being<sup>(115)</sup>. Other studies evaluating quality of life in this specific population of caregivers utilized the medical outcomes study short form 36(SF 36) and noted that the caregivers quality of life was significantly poorer compared to the general population<sup>(17,41)</sup>. This is in contrast to a study done by Wick et al, who noted that 96% of the caregivers rated their QoL as good/adequate or excellent<sup>(69)</sup>. Our study subject's domain scores were lower compared to other African studies examining caregivers QoL using the same tool<sup>(113,116)</sup>.

#### **5.4 Burden of Care and HRQoL**

In this study, consistent with findings from other studies<sup>(10,15,41,69)</sup>, there is an inverse relationship between the degree of burden experienced and the HRQoL scores regardless of the assessing tool. Increasing levels of caregiving burden were associated with decreasing mean scores in all domains of life. Suri et al noted that self-perceived burden was associated with worse depression and quality of life<sup>(10)</sup>. Therefore we can conclude and say that burden impacts negatively on all aspects of a caregiver's life. Literature has shown that high perceptions of burden on the caregiver impact negatively on the HD patients. This not only reduces their quality of life but also puts them at risk of dialysis withdrawal<sup>(46)</sup>. Although causality cannot be established from our study, these findings might indicate that interventions geared to lowering perceived burden on the caregiver can lead to an improved quality of life for both the caregiver and the hemodialysis patient.



## 5.5 Predictors of Burden

The degree of burden was significantly more in caregivers who were above 60 years of age. Certain caregiver's social-demographic variables and patient-related determinants have been shown to cause burden<sup>(72,117)</sup> while other studies show no association<sup>(73)</sup>. Our study findings showed that the degree of burden was significantly related to the caregiver's age. 60 years and above was a significant predictor of severe burden. Bayoumi et al noted a statistically significant negative association between the degree of caregiver's burden and age<sup>(16)</sup>. This finding was not replicated in a study done by Harris et al, where there was no significant difference in the degree of burden reported by young or older caregivers<sup>(118)</sup>. Mukadder et al on the other hand, noted that as the age of the caregiver increased, their burden levels decreased<sup>(74)</sup>. There is no consensus in studies, regarding the significant social demographic variables that can predict burden. The differences in burden levels occurring at different age groups can be due to the different aspects of their lives that are interrupted by their caregiving role. For younger and middle-aged caregivers, the time committed to caregiving usually competes with work obligations, family, and marital responsibilities as well as social interactions<sup>(50)</sup>. In contrast, it would be expected that older caregivers have less competing demands, have better problem-solving skills and should view it as an expectation of growing older. However, older caregivers tend to be spouses of the care recipients and this in itself has been associated with a higher degree of burden due to the physical and emotional closeness of the two<sup>(21)</sup>. Similarly, there is evidence to show, that the well-being of a spouse with chronic illness is linked to the spousal caregiver due to the emotions invested in a long-term marriage<sup>(119)</sup>. Older caregivers who report strain are particularly at a higher risk of dying within 4 years<sup>(12)</sup>. Therefore our study provides evidence that older spousal caregivers should be evaluated more frequently as they represent a group that is at risk of experiencing severe burden. Their health status should also be evaluated frequently to determine if they are fit to continue caregiving. Interventions directed at them should include finding an alternative caregiver especially when their own health has been compromised severely by their caregiving role. It is worth to note that although literature provides evidence that women are more burdened our study did not provide evidence for that. This is quite similar to the study done in Kenya. Since women are socialized to provide care in Kenya, it is possible that women caregivers underreport their burden<sup>(77)</sup>. Some studies have observed that male caregivers experienced a significantly higher burden compared to the females. This highlights

the fact that male caregivers should not be ignored in caregiver burden assessments<sup>(72,98)</sup>. It was also surprising to note that there was no association between the functional status of the hemodialysis patient and the degree of burden as indicated in other studies. Harris et al showed that caregivers of patients who independently performed activities of daily living had lesser burden<sup>(118)</sup>. Abbasi et al reported a significant positive correlation between burden and disease severity<sup>(117)</sup>. Kim et al reported that 16% of caregiver burden could be explained by a reducing functional state of the dementia patient<sup>(120)</sup>. However, researchers have suggested that negative outcomes of caregiving are not related to the number or intensity of caregiving tasks that the caregiver performs in everyday life<sup>(20,67)</sup>.

## **6.0 CONCLUSION, RECOMMENDATIONS, AND LIMITATIONS**

### **Conclusion**

This study looked at caregiver burden and quality of life among caregivers of patients on maintenance hemodialysis at the renal unit of Kenyatta National Hospital Kenya. Findings from this study showed that caregivers of hemodialysis patients do experience burden in their caregiving role and their quality of life is compromised. Age was a predictor of burden with those above 60 years experiencing a higher level of burden. There was a significant negative association between burden levels and quality of life.

### **Recommendations**

1. In our hemodialysis unit, caregiver's burden and quality of life assessment should be undertaken.
2. Those above 60 years should be singled out and assessed frequently for burden.
3. A qualitative study to explore the coping mechanisms of the caregivers should be undertaken.

### **Limitations**

1. KNH is a public referral hospital with the highest number of hemodialysis patients. The results of this study may not be generalized to other hemodialysis units in the country.
2. The use of a self-reported questionnaire may have led to response bias. The study participants may have over or underreported their burden as well as their quality of life.
3. It is a cross-sectional descriptive analysis and therefore the causality between the level of burden and HRQoL scores could not be established.

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## APPENDICES

### APPENDIX I: CONSENT EXPLANATION

#### 1. STUDY PARTICIPANT CONSENT FORM

“Burden of care and health related quality of life in caregivers of patients undergoing hemodialysis at the renal unit of Kenyatta National Hospital”.

Name	Qualification	Institution	Department	Position
Dr. Mercy Gatua	MChB Masters student	UON/KNH	Clinical medicine and Therapeutics	Resident Doctor

#### **Purpose of the study**

I, **Dr. Mercy Gatua** am undertaking this study on “Burden of care and health-related quality of life in caregivers of patients undergoing hemodialysis at the renal unit of Kenyatta National Hospital”.

#### **Procedures**

You are being asked to participate in this survey that will take about 45 minutes. If you agree to participate I will ask you to sign a consent form. There will be a series of questions that I will ask you in confidence and all your responses will be noted down. These questions will be in the form of questionnaires and will require you to remember some things in the past.

#### **Risks to you as a participant**

There is no risk that you will be exposed to.

#### **Benefits**

This study will provide an opportunity to estimate the burden of care and health-related quality of life in caregivers of patients undergoing hemodialysis in this hemodialysis unit. This will inform health policy in our country with an aim to improve the services offered at the KNH hemodialysis unit as well as inform the hemodialysis unit staff on the need to develop tools for caregiver burden assessment and interventional tools for minimizing caregiver burden for those at risk.

**Right to refuse.**

Your participation in this research is voluntary. You are free to withdraw from the interview at any time and you shall not be discriminated upon. You are free to ask any questions and have a right to satisfactory answers before you sign the consent form.

If you agree to participate in this survey you may kindly sign the consent form.

Thank you

## APPENDIX 11: FOMU YA MAELEZO

### 1. FOMU YA IDHINI YA MSHIRIKI WA UTAFITI

“Burden of care and health related quality of life in caregivers of patients undergoing hemodialysis at the renal unit of Kenyatta National Hospital”.

Jina	Kiwango cha elimu	Chuo	Kitengo	Kiwango cha kikazi
<b>Dr. Mercy Gatua</b>	MBChB Masters student	UON/KNH	Clinical medicine and Therapeutics	Mwanafunzi

#### **Madhumuni ya utafiti:**

Mimi daktari Mercy Gatua nafanya utafiti wa “kutambua gharama na ubora wa maisha kwa wanaochunga wagonjwa wanao hitaji kuoshwa damu katika kitengo figo ya hospitali taifa ya Kenyatta”.

#### **Taratibu:**

Naomba idhini yako ya kushiriki katika utafiti huu ambao utachukua muda wa dakika arobaini na tano. Ukikubali kujiunga na utafiti huu, nitakupa fomu ya makubaliano, utie sahihi. Baada ya hapo nitakuuliza maswali ambayo utajibu na majibu yako yatanakiliwa kwa usiri. Maswali haya yatakuhitaji ukumbuke mambo umeyapitia hapo awali.

#### **Athari kwa mshiriki:**

Hakuna athari utakayopitia ukijiunga na utafiti huu.

#### **Manufaa ya utafiti huu:**

Utafiti huu utasaidia kutambua gharama na ubora wa maisha kwa wanaochunga wagonjwa wanaohitaji kuoshwa damu katika kitengo figo. Hii itasaidia kuboresha ujuzi wa matibabu haya ya kuoshwa damu. Pia, itasaidia Hospitali taifa ya Kenyatta kuimarisha matibabu ya wagonjwa hawa, nakupunguza mzigo kwa wanaochunga wagonjwa hawa. Tutaweza kuunda mbinu za kutambua watu wenye mzigo mkubwa sana wa kuchunga wagonjwa wao na kuwasaidia kupunguza mzigo huo.

#### **Haki ya kukataa:**

Kujiunga na utafiti huu ni kwa hiari yako. Uko huru kujiondoa ukihojiwa bila kubaguliwa. Uko huru kuuliza maswali yeyote kuhusu utafiti huu, na ujibiwe kikamilifu, kabla ya kutia sahihi fomu ya makubaliano.

Ukikubali kujiunga na utafiti huu, tafadhali tia sahihi fomu hii.

**Asante**

### **APPENDIX III: CONSENT CERTIFICATE BY CAREGIVER**

I.....consent to participate in the study on “Burden of care and health-related quality of life in caregivers of patients undergoing hemodialysis at the renal unit of Kenyatta National Hospital”. I do this with the knowledge of the purposes of the study and the procedures thereof. The purpose of the study and procedure has been explained to me clearly by DR.MERCY GATUA. I am also aware that I can withdraw from this study without losing any benefits and quality of care of my medical condition.

Signature of Caregiver.....Date.....

Signature of witness.....Date.....

If you have any questions during the course of the study, you may contact the following.

**Dr. Mercy Gatua**

**Mobile number 0722-276700**

In case of any ethical concerns please contact

**The Chairman, KNH/UON-Ethics and Research Committee**

**Hospital road along Ngong Road**

**P.O BOX 20723, Nairobi (CODE 00202)**

**Telephone Number (+254-020)2726300 ext 44355**

**Chairperson: Professor A.N Guantai**

**Contact person: Esther Wanjiru Mbuba**

**Email: uonknh\_erc@uonbi.ac.ke**

## **APPENDIX IV: FOMU YA RIDHAA YA MCHUNGA MGONJWA**

Mimi .....nimekubali kushiriki katika utafiti “Burden of care and health-related quality of life in caregivers of patients undergoing hemodialysis at the renal unit of Kenyatta National Hospital”. Ninafanya hivi nikiwa na maarifa ya madhumuni na taratibu za utafiti huu. Zimeelezwa wazi na Dkt. Mercy Gatua. Pia ninafahamu kwamba naweza kujitoa katika utafiti huu bila kupoteza faida yoyote na ubora wahuduma ya kiafya.

Sahihi ya Mchungu mgonjwa.....Tarehe.....

Sahihi yashahidi.....Tarehe.....

Ukiwa na maswali wakati wowote wa utafiti huu unaweza wasiliana na anwani uliopewa.

**Dkt. Mercy Gatua**

**Simu ya rununu 0722-276700**

Ama

**Mwenyekiti, KNH/UON-Kitengo cha utafiti**

**Hospital Road, Ngong Road**

**S.L.P 20723, Nairobi (CODE 00202)**

**Simu nambari: (+254-020)2726300 ext 44355**

**Mwenyekiti: Profesa A.N Guantai**

**Mhusika wa mawasiliano: Esther Wanjiru Mbuba**

**Barua pepe: uonknh\_uonbi.ac.ke**



## APPENDIX V: STUDY PROFORMA

(TO BE FILLED BY INVESTIGATOR)

Participant's number.....

### SOCIAL DEMOGRAPHICS

- Age

18-25 years.....26-45years.....46-60 years.....>61years.....

- Gender

Male..... Female.....

- Level of Education

None.....Primary..... Secondary.....Tertiary.....

- Marital Status

Married.....Not Married.....

- Job Status

Employed..... Unemployed.....

- Relation to care recipient

Spouse.....Parent.....Child.....Other.....

- Duration of caregiving

<1 year..... >1 year.....

- Living with the care recipient

Yes..... No.....

- Presence of chronic medical condition

Yes..... No.....

## **APPENDIX VI: ZARIT BURDEN INTERVIEW QUESTIONNAIRE**

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

1. Do you feel that your relative asks for more help than he/she needs?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
  
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
  
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
  
4. Do you feel embarrassed over your relative's behavior?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
  
5. Do you feel angry when you are around your relative?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
  
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?  
  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

7. Are you afraid what the future holds for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent upon you?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
10. Do you feel your health has suffered because of your involvement with your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like, because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
20. Do you feel you should be doing more for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
21. Do you feel you could do a better job in caring for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
22. Overall, how burdened do you feel in caring for your relative?
0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely



## Instructions

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

*For office use*

Do you get the kind of support from others that you need?

<i>(Please circle the number)</i>				
Not at all	A little	Moderately	Mostly	Completely
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others.

*For office use*

Do you get the kind of support from others that you need?

<i>(Please circle the number)</i>				
Not at all	A little	Moderately	Mostly	Completely
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

*For office use*

Do you get the kind of support from others that you need?

<i>(Please circle the number)</i>				
Not at all	A little	Moderately	Mostly	Completely
<b>①</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

For office use

G1 /G1.1

1. How would you rate your quality of life?

<i>(Please circle the number)</i>				
Very poor	Poor	Neither poor nor good	Good	Very Good
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

For office use

G4 /G2.3

2. How satisfied are you With your health?

<i>(Please circle the number)</i>				
Very dissatisfied	Dissatisfied	Neither Satisfied nor dissatisfied	Satisfied	Very satisfied
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The following questions ask about **how much** you have experienced certain things in the last two weeks.

For office use

F1.4/  
F1.2.5

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

<i>(Please circle the number)</i>				
Not at all	A little	A moderate amount	Very much	An extreme amount
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

F11.3/  
F13.1.4

4. How much do you need any medical treatment to function in your daily life?

**1                      2                      3                      4                      5**

F4.1/  
F6.1.2

5. How much do you enjoy life?

**1                      2                      3                      4                      5**

For office use

F24.2/  
F29.1.3

6. To what extent do you feel your life to be meaningful?

<i>(Please circle the number)</i>				
Not at all	A little	A moderate amount	Very much	An extreme amount

1                      2                      3                      4                      5

For office use

F5.2/  
F7.1.6

7. How well are you able to concentrate?

<i>(Please circle the number)</i>				
Not at all	Slightly	A Moderate amount	Very much	Extremely

1                      2                      3                      4                      5

F16.1/  
F20.1.2

8. How safe do you feel in your daily life?

1                      2                      3                      4                      5

F22.1/  
F27.1.2

9. How healthy is your physical environment?

1                      2                      3                      4                      5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

For office use

F2.1/  
F2.1.1

10. Do you have enough energy for everyday life?

<i>(Please circle the number)</i>				
Not at all	A little	Moderately	Mostly	Completely

1                      2                      3                      4                      5

F7.1/  
F9.1.2

11. Are you able to accept your bodily appearance?

1                      2                      3                      4                      5

F18.1/  
F23.1.1

12. Have you enough money to meet your needs?

1                      2                      3                      4                      5



		<i>(Please circle the number)</i>				
		Not at all	A little	Moderately	Mostly	Completely
<i>For office use</i> F20.1/ F25.1. 1	13. How available to you is the information that you need in your day-to-day life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F21.1/ F26.1. 2	14. To what extent do you have the opportunity for leisure activities?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
		<i>(Please circle the number)</i>				
		Very poor	Poor	Neither poor nor well	Well	Very well
<i>For office use</i> F9.1/ F11.1.1	15. How well are you able to get around?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither Satisfied nor dissatisfied	Satisfied	Very satisfied
<i>For office use</i> F3.3/ F4.2.2	16. How satisfied are you with your sleep?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F10.3/ F12.2. 3	17. How satisfied are you with your ability to perform your daily living activities?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F12.4/ F16.2. 1	18. How satisfied are you with your capacity for work?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither Satisfied nor dissatisfied</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<i>For office use</i>						
F6.4/ F8.2.2	19. How satisfied are you with yourself?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F13.3 F17.2 3	20. How satisfied are you with your personal relationships?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F15.3/ F3.2.1	21. How satisfied are you with your sex life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F14.4/ F18.2.5	22. How satisfied are you with the support you get from your friends?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F17.3/ F21.2. 2	23. How satisfied are you with the conditions of your living place?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F19.3/ F24.2. 1	24. How satisfied are you with your access to health services?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F.23.3/ F28.2. 2	25. How satisfied are you with your mode of transportation?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>



How long did it take to fill out this form?

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**THANK YOU FOR YOUR HELP**

## APPENDIX VIII: STEPS FOR CHECKING AND CLEANING DATA AND COMPUTING DOMAIN SCORES FOR THE WHOQOL-BREF

Steps	SPSS syntax for carrying out data checking, cleaning and computing total scores
Check all 26 items from assessment have a range of 1-5	<p>RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS). (This recodes all data outside the range 1-5 to system missing.)</p>
Reverse 3 negatively phrased items	<p>RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1). (This transforms negatively framed questions to positively framed questions.)</p>
Compute domain scores	<p>COMPUTE PHYS=MEAN.6 (Q3, Q4, Q10, Q15, Q16, Q17, Q18)*4. COMPUTE PSYCH=MEAN.5 (Q5, Q6, Q7, Q11, Q19, Q26)*4. COMPUTE SOCIAL=MEAN.2 (Q20, Q21, Q22)*4. COMPUTE ENVIR=MEAN.6(Q8,Q9,Q12, Q13, Q14 Q23, Q24, Q25)*4. (These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated.)</p>
Transform scores to a 0-100 scale	<p>COMPUTE PHYS= (PHYS-4)*(100/16). COMPUTE PSYCH= (PSYCH-4)*(100/16). COMPUTE SOCIAL= (SOCIAL-4)*(100/16). COMPUTE ENVIR= (ENVIR-4)*(100/16)</p>
Delete cases with >20% missing data	<p>COUNT TOTAL=Q1 TO Q26 (1 THRU 5). (This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-BREF items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment.) SELECT IF (TOTAL&gt;=21). EXECUTE. (This second command selects only those cases where 'total', the total number of items completed, is greater than or equal to 80%. It deletes the remaining cases from the dataset.)</p>

**APPENDIX IX: KARNOFSKY PERFORMANCE SCALE STATUSKARNOFSKY  
PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA**

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead