# EVALUATION OF THERAPY ADHERENCE AMONG PATIENTS WITH END STAGE RENAL DISEASE AT KENYATTA NATIONAL HOSPITAL

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# A DISSERTATION PRESENTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF SCIENCE DEGREE IN MEDICAL SURGICAL NURSING OF THE UNIVERSITY OF NAIROBI.

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# DECLARATION

I, **Polly Gichoni**, the undersigned, declare that this is my original work and has not been submitted for any award to any other University or institution of higher learning.

Registration Number: H56/88368/2016

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### **CERTIFICATE OF APPROVAL**

We, the undersigned certify that this dissertation is submitted for partial fulfilment of the award of the degree of Master of Science in Nursing (Medical Surgical Nursing) of the University of Nairobi with our approval as internal supervisors.

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# DEDICATION

I dedicate this work to my family for their love, continued encouragement and support throughout my studies.

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# ABREVIATIONS AND ACRONYMS

AKI: Acute Kidney Injury
ARF: Acute Renal Failure
CKD: Chronic Kidney Disease
<b>CKF:</b> Chronic Kidney Failure
<b>CRRT:</b> Continuous Renal Replacement Therapies
ESRD: End Stage Renal Disease
ESRD-AQ: End Stage Renal Disease Adherence Questionnaire
GFR: Glomerular Filtration Rate
HD: Haemodialysis
<b>KDOQI:</b> Kidney Disease Outcomes Quality Initiatives
KNH: Kenyatta National Hospital
NHIF: National Hospital Insurance Fund
NKF: National Kidney Foundation
PD: Peritoneal Dialysis
PMP: Per Million Populations
<b>RRT:</b> Renal Replacement Therapy
WHO: World Health Organization

#### **OPERATIONAL DEFINITIONS**

**Chronic Kidney Disease (CKD):** Kidney damage or a glomerular filtration rate less than 60 ml/minute/1.73m<sup>2</sup> body surface area present for more than three months (NKF, 2013).

**Diet Recommendation:** Changes made to the diet of persons with Chronic Kidney Disease such as eating a low protein diet, limiting salt, potassium, phosphorous and other electrolytes.

**End Stage Renal Disease:** Also Known as Stage five Chronic Kidney Disease or Kidney failure is defined as the terminal phase of Chronic Kidney Disease. It is characterized by loss of kidneys' ability to filter out toxic compounds which accumulate in body tissues and fluids and eventually cause death unless treatment is initiated. Persons with ESRD require renal replacement therapy to survive.

**Fluid Restriction:** Limit on fluid intake for patients with ESRD to amounts that can be safely removed during dialysis sessions.

Haemodialysis: The process of purifying the blood of a person with Kidney illness using extracorporeal circuit.

**Therapy Adherence:** The ability of persons diagnosed with End Stage Renal Disease to follow treatment modalities: dialysis sessions, medicine prescription and diet and fluid restrictions as recommended by the healthcare providers.

#### ABSTRACT

**Background:** End stage renal disease (ESRD) is a major non-communicable killer disease globally. It is estimated that more than 1.4 million patients worldwide are affected by ESRD. Renal Replacement Therapy (RRT) is important for the survival of patients with ESRD. For RRT to be successful there is need for patients to adhere to therapy regimens that are immensely demanding. Lack of adherence predisposes patients to increased morbidity, mortality, cost and burden on the healthcare system. Globally, it is estimated that 50% of ESRD patients are non-adherent to therapy.

**Main objective:** To determine the level of adherence to therapy among patients with ESRD at Kenyatta National Hospital.

**Methodology:** Cross-sectional descriptive design was used for this study. A total of 103 participants were selected and interviewed. This sample size was calculated using Fisher's formula and the participants were selected using multistage (cluster then simple random) sampling technique. Data was collected through a structured questionnaire and analysed by use of descriptive and inferential statistics.

**Results:** This study revealed that 67% (n=69), 69.9% (n=72), 42.7 % (n=44) and 57.3% (n=59) of the study participants had high levels of adherence to haemodialysis session attendance, prescribed medications, fluid and diet recommendations respectively, with 51.5% (n=53) demonstrating overall adherence to therapy. The study also revealed that 62.1% (n=64), 48.5 % (n=50), 62.1% (n=64) and 65% (n=67) of the study participants were knowledgeable on their dialysis schedule, prescribed medications, fluid and diet recommendations, fluid and diet recommendations respectively. Other findings showed that 60.25% (n=62), 61.2% (n=63), 58.3% (n=60) and 69.9% (n=72) of the study participants had a positive attitude towards their dialysis schedule, prescribed medications, respectively.

**Conclusion:** Adherence levels to haemodialysis session attendance, prescribed medications and diet recommendations among ESRD patients attending haemodialysis at KNH were high whereas that of fluid restriction was sub-optimal. Overall adherence was 51.5%. Generally, the patients were knowledgeable and had a positive attitude on their therapeutic modalities.

**Recommendation:** There is need for embracing a holistic approach in the management of ESRD patients on haemodialysis at KNH so as to have optimal levels of adherence in all the four therapy modalities so as to reduce the associated morbidity and mortality to non-adherence.

#### **CHAPTER ONE: INTRODUCTION**

#### 1.1 Background of the study

The National Kidney Foundation and Kidney Disease Outcomes Quality Initiative (NKF/KDOQI) describes End Stage Renal Disease (ESRD) also referred to as kidney failure as the last stage (stage five) of Chronic Kidney Disease (CKD). CKD refers to abnormalities of kidney function or structure present for more than three months. It is characterized by kidneys failure to filter out toxic compounds which eventually accumulate in the body and death ensues unless treatment is initiated (NKF/KDOQI, 2013).

Renal Replacement Therapy (RRT) is important for the survival of patients with ESRD. Forms of RRT that are available are dialysis and kidney transplantation. Forms of dialysis include: Conventional Haemodialysis (HD), Haemofiltration, Haemodiafiltration, Continuous Renal Replacement Therapy (CRRT) and Peritoneal Dialysis (PD). Kidney transplantation is the RRT of choice for ESRD management (Abecassis, Barlett, Collins, Davis, Delmonico, *et al.*, 2008). However limited availability of organ donors and the cost implications make HD the most popular RRT modality for majority of ESRD patients. Patients on HD require frequent travelling to a dialysis centre for the minimum recommended three sessions per week. In addition they need to routinely take the prescribed medications and alter their diets. For RRT to be successful there is need for patients to adhere to therapy regimens that are immensely demanding (Kugler and Maeding, 2011).

The World Health Organization (WHO) defines adherence as the extent to which a person's behaviour of taking medications, following a recommended diet and/or executing life-style changes, corresponds with the agreed recommendations of a health care provider (WHO, 2003). The NKF/KDOQI describes non-adherence for patients on HD as: a skipped or shortened HD session; excessive intake of fluids and foods high in potassium and phosphorus content and non-adherence to medication (NKF/KDOQI, 2015). According to Reach, (2008) non-adherence is a "disorder" with manifestations of a syndrome referred to as "weakness of will" by philosophers and is likened with gambling, drug addiction or procrastination.

According to the WHO, Kidney disease is a major non-communicable killer disease globally; affecting persons of all ages, races and social-economic groups. It is estimated that more than 1.4 million patients worldwide are affected by ESRD, with incidence increasing by approximately 8% annually (WHO, 2015). The 2010 Global burden of disease study ranked CKD at 27<sup>th</sup> position in the list of causes of total number of global deaths in 1990 and rose to

18<sup>th</sup> position in 2010 with an annual death rate of 16.3 per 100,000 ( Lozano, Mohsen, Foreman, Lim, Shibuya, *et al.*, 2012).

In the USA the prevalence of CKD is 13.2% and it is projected to rise to 14.4% in 2020 and 16.7% in 2030 (Hoerger *et al.*, 2015). In Malaysia, the incidence of patients with ESRD requiring dialysis has been growing from 18 Per Million Populations (PMP) in 1993 to 231 PMP in 2013. 10,208 cases and 19,418 cases are estimated incidences of new dialysis in this country in 2020 and 2040 respectively (Bujang, Adnan, Hashim, Mohan, Ahmad, *et al.*, 2017).

Naicker (2010) observed that CKD has a 3-4 times prevalence in Africa than in the developed world. The prevalence is on the rise and it is largely associated with the rising incidence of CKD risk factors that include diabetes mellitus, hypertension, HIV infection and chronic glomerulonephritis among others. Stanifer, Jing, Tolan, Helmke, Mukerjee, *et al.*(2014) identified a 13.9% prevalence of CKD in Sub Saharan Africa. A study in Nigeria identified a prevalence of 7.8% of CKD (Egbi, 2014). This estimate is similar to another one of 7% in Tanzania (Stanifer, Maro, Egger, Karia, Thielman, *et al.*, 2015). In Kenya, an increase in the number of patients suffering from CKD has been observed with more than one million persons suffering from the disease (Singh, 2012). There is therefore need to evaluate the adherence of ESRD patients to therapy.

#### **1.2 Statement of the problem**

ESRD patients on HD are expected to adhere to a complex comprehensive therapeutic regimen that is difficult to understand and cope with. Comprehensive management of ESRD patients entails four components: Dialysis, medication, fluid and dietary restriction. The delivery of this comprehensive management is imperative in prevention of complications associated with ESRD (Short, 2012).

Patients on HD are considered largely responsible for their therapy success by adherence to medication prescription, diet and fluid restriction and HD sessions (Kugler and Maending, 2011). Lack of adherence predisposes HD patients to increased morbidity, mortality, cost and burden on the healthcare system (Clark, 2014). Evidence has shown that a global estimate of 50% of ESRD patients do not adhere to their prescribed dietary, fluid, medication and dialysis recommendations, hence precipitating challenges in the health care system (Griva, Lai, Lim, Yu, Foo *et al.*, 2014). A global systematic review of literature by Chironda and Bhengu (2016a) on non-adherence to therapy among CKD patients showed non-adherence

rates to HD of 2% to 98% and to medication of 3% to 80%. Non-adherence to dietary and fluid restriction was documented to range from 2% to 81% and from 9.7% to 72% respectively.

A study done on adherence to fluid and dietary restriction among CKD patients in South Africa found out that only 16% had high level of adherence to diet with 42.2 % demonstrating moderate and low levels respectively. The study also found that 11% and 88.9% had moderate and low levels of adherence respectively to fluid restriction. None of the participants had high level of adherence (Chironda and Bhengu, 2016b). A study in Egypt found a 36% prevalence on non-adherence to HD and it was associated with poor quality of life, depression and malnutrition (Ibrahim, Hossam and Belal, 2015). A study in Nigeria documented 40% mortality rate in 90 days of commencing HD and 63% after one year (Alasia and Emem-Chioma, 2012).

At the Renal Unit of KNH, newly diagnosed ESRD patients undergo counselling sessions concerning their therapy modalities prior to commencement of therapy. The aim of the counselling sessions is to ensure that patients understand and accept their disease condition and the therapeutic modalities that are involved. This forms the basis for positive adherence behaviour towards therapy among the patients. However studies that have been done at KNH have demonstrated high morbidity among ESRD patients on HD. The prevalence of malnutrition among ESRD patients on HD at this hospital has been documented to be at 61.2% (Giabe, Kayima, Were and Kigondu, 2016). A study done by Gitari and McLigeyo (2011) found out that anaemia and iron deficiency were common despite the therapeutic measures; 87.9% of the patients had haemoglobin less than 11 g/dl, the recommended minimum target for anaemia and 34.5% had iron deficiency anaemia. Rajula, Kayima, Ogola and Maritim (2009) established a 76% prevalence of hypertension in this group of patients out of which only 16.6% had achieved the target BP of <130/80 mmHg. Quality of life among patients with ESRD is affected by non-adherence to therapy (Chiu, Teitelbaum, Misra, de Leon, Adzie and Rajnish, 2009). A study done by Kamau, Kayima and Otieno (2011) on health related quality of life of patients on HD at KNH found that quality of life of patients was reduced.

From the above findings it is evident that morbidity and poor quality of life is high among ESRD patients at KNH; however data on adherence to therapy is lacking, which is a key determinant of the treatment outcomes. This study therefore seeks to establish the level of

adherence to therapy in ESRD patients. This will provide an insight in success or failure of therapy in ESRD patients.

#### 1.3 Justification of the study

The sustainable development goal 3 aims at ensuring health for all by the year 2030 and among the specific goals is to reduce mortality from non-communicable diseases (Mechta, Juhl, Feldt-Rasmussen andThomsen, 2017). This is not possible when there is an increase in people suffering from ESRD. ESRD leads to increase in disease burden, morbidities and mortalities. Management of ESRD should be focused on adherence to medication prescription, diet and fluid restrictions and HD session attendance. Non adherence to treatment increases the risk of morbidity, mortality and even lengthy hospital stay (Chironda and Bhengu, 2016a). Quality of life among patients with ESRD is affected by non-adherence to therapy (Chiu, Teitelbaum, Misra, de Leon, Adzie, and Rajnish, 2009). Despite the importance of adherence to therapy in ESRD patients, there have been few studies to describe it (Naalweh, Mohammad, Moutaz, and Samah, 2017).

KNH is the largest referral hospital in Kenya which receives a large number of clients requiring renal care. However, there are no documented studies on adherence to therapy; therefore it is important to conduct this study. Assessing the adherence levels is important since it will unearth the interventions that can be used by health care professionals to increase adherence levels among ESRD clients. The study findings will go a long way in determining the success or failure rate of ESRD management. This will inform the care givers at KNH Renal Unit on areas that they should emphasize on while giving individualized care. The findings of the research will also be of benefit to policy makers at the KNH and at the national level and thus assist in resource allocation. The findings will also be used as a library resource for reference as well as a basis for future research.

#### **1.4 Research Objectives**

#### **1.4.1 Broad Objective**

To determine the level of adherence to therapy amongst patients with ESRD at KNH.

#### 1.4.2. Specific Objectives

- 1. To establish the level of adherence to haemodialysis session attendance amongst patients with ESRD at KNH.
- 2. To determine the extent of adherence to prescribed medications amongst patients with ESRD at KNH.

- 3. To assess the level of adherence to fluid restrictions and diet recommendations amongst patients with ESRD at KNH.
- 4. To determine the knowledge and attitude on therapy amongst patients with ESRD at KNH.

# **1.5. Research Questions**

- 1. What is the level of adherence to haemodialysis session attendance amongst patients with ESRD at KNH?
- 2. What is the extent of adherence to prescribed medications amongst patients with ESRD at KNH?
- 3. What is the level of adherence to fluid restrictions and diet recommendations amongst patients with ESRD at KNH?
- 4. What is the knowledge and attitude on therapy amongst patients with ESRD at KNH?

# **1.6 Hypothesis**

Age, gender, marital status, education level and duration of haemodialysis have no influence on adherence to therapy among ESRD patients at KNH.

# **1.7 Research Variables**

# **1.7.1 Independent Variables**

This study considered independent variables to be: age, gender, marital status, level of education and duration of HD therapy.

# **1.7.2 Dependent Variables**

The dependent variables considered in this study were adherence to: HD session attendance; prescribed medications; diet and fluid restrictions. Also considered were the knowledge and the attitude on therapy.

# 1.7.3 Confounders

Co-morbidity, family support, the distance from the dialysis centre, availability of drugs and finances were considered as the confounders in this study.

#### **1.8 Theoretical Framework.**

This study adopts Orem's Self-Care deficit Model as a conceptual framework to evaluate adherence to therapy in ESRD patients. Dorothea Orem, the founder of this model had begun her work in 1958 and published in 1971. Consecutive publications of her work were done in the years 1980, 1985, 1991, 1995 and 2001(Paech, 2007). According to Orem, Nursing entails the administration of self-care which is beneficial in sustaining life and health, in recuperating from illness or trauma, or managing their effects. "Self-Care deficit Model" concerns an individual's deprivation for self-care (actions that one performs with the motive of sustaining life, health and well-being). Individuals require self-care action which should be provided and managed continuously so as to sustain life, recuperate from illnesses and manage their effects. The model comprises of three connected theories of; self-care, self-care deficit and the nursing system. Self-care entails the actions one performs independently to aid and sustain personal well-being all through life. In this study, self-care refers to the ability of an individual diagnosed with ESRD to adhere to the four components of therapy. Persons gain from nursing when they have health-related limitations in the provision of self-care. These limitations may be as a consequence of illness, injury, medical tests or treatment. Selfcare deficit comes about when self-care actions are not sufficient to address the known selfcare demands. It describes when nursing is needed and how people can be helped through nursing. The action of the nurse entails establishment of the limitation / deficit and the implementation of appropriate interventions to address the demands of the individual. In this study, a patient with ESRD is considered to have self-care deficit when s/he is not able to adhere to all the components of therapy.

Nursing systems entail the act of nurses prescribing, designing and providing nursing care that restore an individual's self-care abilities while addressing therapeutic self-care needs. The nurse's ability to aid an individual in addressing current and potential self-care needs involves a series of actions. The theory describes the support modalities utilised by the nurse in three categories: Wholly Compensatory (an individual's self-care agency is compromised enough to rely on others for well-being and it encompasses total nursing care whereby a client is unable to care for themselves); partly Compensatory (an individual can meet some self-care needs but requires the nurse's assistance in meeting others and it entails sharing of the self-care needs between the nurse and the patient) and supportive-educative (an individual can meet self-care needs but requires assistance in making decisions, controlling of behaviour, or acquiring knowledge. The patient takes responsibility for their own self care

and the nurse offers assistance on consultancy basis by teaching). In this study the supportive educative system is applicable since ESRD patients require support and education on their care modalities and this is a key factor in developing positive adherence behaviour to therapy.

ESRD is a lifetime condition and patients are expected to learn and participate in their own care. This study will evaluate: patient self-care ability demonstrated by adherence to prescribed therapy and patient self-care deficit demonstrated by non-adherence to prescribed therapy. Recommendations will be made on utilization of the Nursing system to either reinforce self-care agencies in the case of adherence or improve them in the case of non-adherence.





Adapted from Paech (2007)

Figure 1: Orem's Self-Care Theory Framework

# **1.9 Conceptual Framework**



Source: Author's, 2018.

**Figure 2: Conceptual Framework** 

#### **CHAPTER TWO: LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter discusses renal failure and renal replacement therapy modalities: Conventional Haemodialysis (HD), Haemofiltration, Haemodiafiltration, Continuous Renal Replacement Therapy (CRRT) and Peritoneal Dialysis (PD). HD will be emphasised on, since it is the most commonly used modality in the management of renal failure. Also discussed are therapeutic modalities associated with HD that include medication prescription, dietary and fluid recommendations, and a review of literature in view of adherence to these modalities. Renal failure refers to the inability of the kidneys to perform their functions which include: maintenance of the body's internal equilibrium of water and electrolytes, excretion of acidic metabolic end products of metabolism and the endocrine function of erythropoietin and 125-dihydroxycalciferol production. Renal failure can either be acute or chronic (Porth and Matfin, 2009).

#### 2.2 Acute Kidney Failure (AKF)

Acute Kidney Failure (AKF) also referred to as Acute Kidney Injury (AKI) refers to the sudden loss of kidney function that can be reversible. Reduction in GFR, nitrogenous waste build-up in the blood (azotemia) and body fluids and electrolytes alterations are characteristic of AKI. Porth and Matfin (2009) classify the causes of AKI as: pre-renal (by reduced blood flow to the kidneys e.g. due to haemorrhage), post-renal (by obstruction of urine output e.g. by renal stones) and intrinsic (by disorders within the kidneys e.g. acute tubular necrosis). AKI is common and is associated with high morbidity and mortality with rates between 22% and 67% of patient admission in intensive care units (ICUs) being reported (Thakar, 2009). AKI can be reversed by identifying and correcting the underlying cause in time and hence aversion of progression to CKD or death (Porth and Matfin, 2009).

#### 2.3 Chronic Kidney Disease (CKD)

CKD refers to gradual loss of kidney function that occurs over a period of time; can be in months or years. Porth and Matfin (2009) explain that CKD can result as a complication of renal diseases (such as glomerulonephritis and pyelonephritis) or other system diseases such as diabetes and hypertension. These complications result in destructive effects on the nephrons with the end result of alterations in kidney functions. Porth and Matfin (2009) further explains that CKD affects almost every body system, resulting in azotemia, altered excretion of sodium and water and altered regulation of electrolytes: potassium, phosphate, calcium and magnesium. Other system disorders include: blood (e.g. anaemia),

cardiovascular, skeletal, neurologic, gastrointestinal and skin. CKD is classified into five stages, based on Glomerular Filtration Rate (GFR): Stage 1(Kidney damage with normal or increased GFR (>90ml/min/1.73m<sup>2</sup>); Stage 2 (Mild reduction in GFR (60-89 ml/min/1.73m<sup>2</sup>); Stage 3 (Moderate reduction in GFR (30-59 ml/min/1.73m<sup>2</sup>); (Stage 4: Severe reduction in GFR (15-29 ml/min/1.73m<sup>2</sup>) and Stage 5 (Kidney failure (GFR<15ml/min/1.73m<sup>2</sup>) (NKF/KDOQI, 2013). A decrease in GFR characterizes the five forms of CKD and this reflects the corresponding decrease in the number of nephrons that are functioning. The NKF in the updated classification system advised on the use of levels of GFR and albumin together as a way of improving accuracy in the assessment of CKD and the prognosis. Patients in stages 1-3 of CKD are often without symptoms. Low kidney function clinical manifestation typically appears in stages 4-5 (NKF/KDOQI, 2013).

#### 2.3.1 Pathophysiology of Chronic Kidney Disease

Nephrons are the microscopic structural and functional units of the kidney with a million being the approximate number contained in a normal kidney; each contributing to GFR. GFR is the best overall index of kidney function since it reflects the total filtration rates of the functional nephrons contained in the kidney. It is calculated as an estimate (eGFR) from serum creatinine levels (NKF/KDOQI, 2013). The normal GFR has variations depending on age, sex and body size and it reduces as one ages. In the new born GFR is about 40 ml/min/1.73m<sup>2</sup>: increasing to about 66 ml/min/1.73m<sup>2</sup> by the second week of life. The adult levels of 100-125 ml/min/1.73m<sup>2</sup> are achieved at around 2 years of age with the maturity of the kidneys (Mustafa, 2013). GFR remains steady up to the third decade of life and then it declines at approximately 1ml/min/1.73m<sup>2</sup> in the absence of damage to the kidneys may be normal in the elderly (NKF/KDOQI, 2013).

In renal injury irrespective of the aetiology, the healthy nephrons hyper filtrate and undergo hypertrophy as compensatory mechanisms. This maintains the GFR, irrespective of the progressive nephron damage, allowing for continued normal clearance of plasma solute; however it is a major cause of progressive damage of renal function. The compensatory mechanisms are also associated with the case to case differing rates of nephron destruction that can range from months to years. This explains the gradual occurrence of the signs and symptoms of CKD that become evident in advanced disease with the destruction of the few remaining nephrons (Porth and Matfin, 2009). Accumulation of urea (the principle nitrogenous waste product of metabolism, generated from protein breakdown) in blood is an

early sign of CKD. It is eliminated from the body through kidney glomerular filtration in urine. The normal range of blood urea nitrogen (BUN) is 7 to 20 mg/dL and it increases progressively as CKD progresses, to levels as high as 800 mg/dL in kidney failure, a clinical syndrome referred to as uraemia. Uraemia appears in the later stages of CKD when at least two thirds of nephrons have been destroyed and it affects almost every organ in the body. Creatinine is another nitrogenous waste product of muscle metabolism, that is filtered in the glomeruli and it is not reabsorbed by the renal tubules; hence it's use as an indirect method of measuring GFR and kidney damage extent in CKD (Porth and Matfin, 2009).

In CKD, the kidneys' function of regulation of fluid, electrolyte and acid base balance is compromised. Failure to excrete sodium and free-water results in extracellular volume expansion and total-body volume overload which in general is clinically manifested as GFR decreases to 10-15 mL/min/1.73 m<sup>2</sup> (CKD stage 5) and below, with the exhaustion of compensatory mechanisms. Volume overload in the late stages of CKD manifests in peripheral and pulmonary oedema, hypertension and congestive heart failure. Excessive intake of sodium and water could result in volume overload if the ingested amounts surpass the available potential for compensatory excretion even at higher GFR (Porth and Matfin, 2009).

Hyperkalaemia is not a common feature in the early stages of CKD because action of aldosterone (a hormone secreted by the adrenal (cortex) glands with the role of potassium, sodium and water regulation in the kidneys) is maintained. Aldosterone also causes increased excretion of potassium in the gastrointestinal tract. Hyperkalaemia usually develops in CKD stage 4 with the decreased ability of the kidneys to excrete potassium; however it can present in earlier stages with ingestion of potassium-rich diets. It can also be seen in patients with low serum aldosterone levels that are common in diabetes mellitus and in the use of medications such as Angiotensin Converting Enzyme Inhibitors (ACEIs), beta-blockers or Non-steroidal Anti-Inflammatory Drugs (NSAIDs). Extracellular shift of potassium secondary to acidemia or from lack of insulin can also cause manifestation of hyperkalaemia in the early CKD stages (Porth and Matfin, 2009).

Metabolic acidosis is observed generally with stage 5 CKD. This is because the kidneys at this stage are incapable of producing adequate ammonia in the proximal tubules that converts endogenous acid into ammonium and excreted in urine. Consequently ammoniagenesis results as a compensatory mechanism by the kidneys to intensify hydrogen excretion in metabolic acidosis and it is associated with rapid progression of kidney disease. Metabolic acidosis causes increased protein degradation, oxidation of essential amino acids, reduced synthesis of albumin and loss of adaptation to a low-protein diet resulting in negative nitrogen balance and consequently protein-energy malnutrition, loss of lean body mass, and muscle weakness. Metabolic acidosis also can contribute to renal osteodystrophy development, because bone acts as a buffer for excess acid, with resultant loss of mineral. Acidosis may interfere with vitamin D metabolism resulting in osteomalacia (Porth and Matfin, 2009).

Uraemia in CKD affects the kidney function of production of erythropoietin; the hormone that stimulates the bone marrow to produce red blood cells (RBC), resulting in anaemia. Anaemia manifests in the early stages of CKD and worsens as the viable renal mass shrinks and with the progressive reduction of GFR. Uraemia also has a role on formation of bone marrow suppression in CKD; hence further lowering production of RBCs. Anaemia of renal failure therefore results in reduced blood viscosity resulting in peripheral vasodilation and decreased vascular resistance. This results in compensatory increase in heart rate and cardiac output to maintain tissue perfusion. This results in cardiac manifestations that include high blood pressure, left ventricular hypertrophy which could complicate to heart failure. Symptoms associated with anaemia in CKD include dyspnoea, fatigue and reduced tolerance to exercises. Anaemia in CKD is also caused by: platelet dysfunction (due to uraemia) which increases the tendency to bleed and blood loss that occurs during haemodialysis; resulting in chronic blood loss, and iron deficiency resulting from anorexia and dietary restrictions that limit intake (Porth and Matfin, 2009).

Reduction of GFR in CKD, leads to less filtration and excretion of phosphate resulting in phosphate retention. This results in increased parathyroid hormone (PTH) secretion by parathyroid gland, to increase excretion of phosphate by the kidneys; hence serum levels of phosphate barely rise in the early CKD stages. In stages 4-5 of CKD as GFR reduces, the kidneys are unable to excrete the excess dietary intake of phosphate and hyperphosphatemia develops. Hyperphosphatemia has a negative feedback mechanism on the parathyroid glands; hence reduced PTH secretion. It also has suppressive effects on kidney hydroxylation of inactive 25-hydroxyvitamin D to calcitriol, its active form. This results in low plasma calcitriol levels which in turn cause decreased intestinal calcium absorption resulting in hypocalcaemia. Hypocalcaemia can also result from increased binding of calcium to the elevated serum phosphate (Porth and Matfin, 2009).

Low plasma calcitriol levels, hypocalcaemia, and hyperphosphatemia activate synthesis and secretion of PTH. Persistence of this activation especially in the late stages of CKD causes maladaptive PTH secretion, with the parathyroid glands initially hypertrophying and becoming hyperplastic and the end result is secondary hyperparathyroidism. PTH levels in secondary hyperthyroidism persistently remain elevated resulting in bone resorption of calcium resulting in hypercalcaemia and reduced bone volume and mineralization. The end result is CKD–mineral and bone disorder (CKD-MBD); characterized by bone fractures and tenderness and vascular calcification (Porth and Matfin, 2009).

Cardiovascular manifestations in CKD are common and they lead in the cause of death in CKD (Semin, 2003). The increased risk for cardiovascular disease (CVD) is attributable to the cumulative effects of several factors that include fluid overload, uraemia and abnormalities of the endocrine system such as those associated with anaemia. CVD involve the heart; Left ventricular hypertrophy (LVH) and cardiomyopathy and the vascular system (atherosclerosis and arteriosclerosis). LVH is the commonest in ESRD and results from hypertension and fluid overload. Pericarditis is also common in ESRD and it is associated with uremic toxins and inadequate haemodialysis. Effects of uraemia on the gastrointestinal system manifest in anorexia, nausea, vomiting, metallic taste, ulceration and bleeding of gastrointestinal mucosa and hiccups (Porth and Matfin, 2009).

Effects on the peripheral nervous system (PNS) manifest in peripheral neuropathy secondary to atrophy and demyelination of nerve fibres by uremic toxins. This is characterized by restless leg syndrome (poorly localized sense of discomfort and involuntary movements of lower extremity), muscle weakness and atrophy. Effects on the central nervous system (CNS) result in uremic encephalopathy, characterized by reduced alertness and awareness in the early stages. As the disease progresses inability to fix attention, loss of recent memory and perceptual errors in identifying objects and persons manifest. In late disease, seizures, delirium and coma are evident as complications (Porth and Matfin, 2009).

#### 2.4 Renal Replacement Therapy (RRT)

RRT is important for the survival of ESRD patients. Forms of RRT that are available are dialysis and kidney transplantation. Brunner and Day (2011) describe various forms of dialysis to include: Conventional Haemodialysis (HD), Haemofiltration, Haemodiafiltration, Continuous Renal Replacement Therapy (CRRT) and Peritoneal Dialysis (PD). Kidney transplantation is the RRT of choice for ESRD management because it replaces kidney

endocrine function. However the limited availability of organ donors and the cost implications makes HD the most popular RRT modality for majority of ESRD patients (Abecassis, Barlett, Collins, Davis, Delmonico, *et al.*, 2008).

#### 2.4.1 Conventional Haemodialysis (HD)

HD refers to the process of purifying blood of a person with renal failure by removing waste products such as creatinine and urea and free water through an extracorporeal circuit (Brunner and Day, 2011).

#### 1. Vascular access for Haemodialysis

A vascular access provides a reliable site where the bloodstream can be easily accessed allowing adequate blood flow rate for HD. Brunner and Day (2011) describe three major types of vascular access as: arteriovenous (AV) fistula, arteriovenous (AV) graft, and venous catheter. A catheter is inserted into the subclavian, internal jugular, or femoral vein, providing an instant access to the circulation of the patient; hence it is useful in acute indications of HD. A fistula is more permanent than a catheter. It is created through a surgical intervention where by an artery is anastomosed to a vein either side to side or end to side and the usual site is the forearm. It takes about 4 to 6 weeks for the fistula to mature before it can be used. Needles are usually inserted into the vessels to create adequate blood to flow through the dialyzer. The arterial segment draws blood from the patient to the dialyzer and the venous segment returns the dialyzed blood back to the patient. A graft is created by interposing a graft material between an artery and vein subcutaneously; usually in the forearm, upper arm, or upper thigh (Brunner and Day, 2011).

#### 2. Haemodialysis apparatus

HD apparatus comprise of a blood circuit, a HD solution circuit and a dialyzer or artificial kidney (Daugirdas, 2015). The blood circuit runs from the vascular access; the point where blood is pumped out from the patient via an "arterial (inflow) blood line" to the dialyzer. Blood is then rein fused to the patient from the dialyzer via a "venous (outflow) blood line." Affixed to the inflow and outflow blood lines are a variety of chambers, side ports, and monitors. The side ports are for purposes of infusing saline or heparin. Priming of the dialyzer circuit before HD and rinsing back of the contents of the blood circuit at the end of HD is done by use of saline. Heparin (an anticoagulant) is infused before blood enters the dialyzer to prevent blood from clotting within the HD circuit. Sampling ports are useful for drawing predialysis and postdialysis blood for biochemical measures. Pressure monitors

ensure maintenance of pressure gradient across the dialyzer membrane for adequate flow of compounds into and out blood. Before reinfusion of blood back to the patient, blood is passed through an air trap that removes bubbles and it has a sensor that ensures no air bubbles remain. The HD solution circuit comprises of the HD solution (dialysate) supply system. The system prepares the solution online by mixing concentrated acid solutions; that contain electrolytes such as sodium, potassium, calcium and magnesium; with purified water. The concentrated acid solution has various concentrations of the components and it is prescribed according to the needs of the patient. Bicarbonate is added to the dialysate bath to maintain the body's buffer system. The system also has several monitors that ensure the solution is at the right temperature and the concentration of the dissolved components is safe for the patient. A blood leak detector stops HD on detection of blood products in the outflow dialysate. The dialyzer comprises of two compartments: dialysate and blood, separated from each other by a semi-permeable membrane, through which the dialysate is then pumped (Daugirdas, 2015).

#### 3. Principles of Haemodialysis

HD is based on the principles of diffusion, osmosis and ultrafiltration (Daugirdas, 2015). Diffusion removes toxins and wastes in the blood where their concentration is higher to the dialysate where their concentration is lower. The dialysate comprises of all the essential electrolytes in their ideal extracellular concentrations. The dialysate bath is properly adjusted so as to control the electrolyte levels of the blood. The semipermeable membrane hinders diffusion of red blood cells and proteins whose molecules are large. Osmosis removes excess water from the blood by moving from the blood where solute concentration is higher to the dialysate bath where solute concentration is lower. Ultrafiltration is the movement of water from an area where its pressure is high to an area where it's lower and it is much more efficient than osmosis. Negative pressure (suctioning force) is applied to the HD membrane; hence accomplishing ultrafiltration, a force that is necessary in removal of excess fluid in renal failure (Daugirdas (2015).

#### 4. Forms of Haemodialysis

Daugirdas (2015) describes two forms of HD: Sustained low-efficiency haemodialysis (SLED) and Sustained low-efficiency haemodiafiltration (SLED-F). SLED is a form of HD that has an extended (6 to10 hour) session length with decreased blood and dialysate flow rates of about 200 mL/min and 100–300 mL/min respectively. Regular HD equipment can be used with the application of low blood and dialysate flow rates. This can be achieved through

application of software update for certain HD machines such that the machine used for HD during the day can be updated for delivery of SLED during the night. SLED-F requires additional infusion of replacement fluid unless replacement fluid can be made from dialysis solution online by the dialysis machine (Daugirdas (2015).

#### 5. Indications of Haemodialysis

Acute indications of HD include: acidemia due to metabolic acidosis in cases where correction with sodium bicarbonate is not practical; abnormalities of electrolyte balance such as severe hyperkalaemia, common in AKI; acute poisoning or intoxication with substances that can be dialyzed such as salicylic acid and lithium; fluid overload that doesn't respond to diuretics and complications of uraemia such as pericarditis, gastrointestinal bleeding or encephalopathy (Irwin, 2008). Chronic HD is indicated in patients with symptomatic kidney failure and low GFR < 15 mL/min (Tattersall, 2011).

### 2.4.2 Haemofiltration

Hemofiltration is similar to HD, except that the principle utilized is varied. Just like in HD pumping of blood is done through a dialyzer or hemofilter with no dialysate being utilized. Application of a pressure gradient results in rapid movement of water through the membrane that is so permeable that many dissolved substances are dragged along with the water. This includes substances whose molecular weights are large and are usually not filtered by HD. In the process blood loses salts and water and infusion of a substitution fluid is usually done into the extracorporeal circuit to replace those (Brunner and Day, 2011).

#### 2.4.3 Haemodiafiltration

Haemodiafiltration combines the principles of HD and hemofiltration (Brunner and Day, 2011).

#### 2.4.4 Continuous Renal Replacement Therapy (CRRT)

CRRT apply the same principles with HD. The major difference is that HD removes large amounts of wastes and water in a short period (usually over 2 to 4 hours) and CRRT remove wastes and water at a slow and a steady state (Brunner and Day, 2011).

#### 2.4.5 Peritoneal Dialysis (PD)

In PD, the peritoneum (a serous membrane that covers the abdominal organs and lines the abdominal wall) serves as the semipermeable membrane. An abdominal catheter is used to introduce the dialysate solution that is sterile into the cavity of the peritoneum at intervals.

The principles of diffusion and osmosis are applied to remove urea, creatinine and water from the blood supply of the peritoneum where their concentration is high into the cavity of the peritoneum where their concentration is low. This happens across the membrane of the peritoneum that is semipermeable. The principle of ultrafiltration is also utilized in PD to remove water. This is usually done by use of dialysate solution that has a high concentration of glucose to create an osmotic gradient (Brunner and Day, 2011).

#### 2.5 Haemodialysis session attendance in ESRD management

The NKF/KDOQI Clinical Practice Guideline for Haemodialysis adequacy recommends 3-4 HD sessions in a week lasting 4 hours (240 minutes) each, to achieve best survival outcomes (NKF/KDOQI, 2015). Skipping or shortening of HD sessions decreases the delivered HD dose and hence the adequacy of the HD. Studies have shown that missed and shortened HD treatment poses a challenge to providers due to increased morbidity and mortality ( Obialo, Hunt, Bashir and Zager, 2012). A study based on electronic medical records and Medicare claims in the USA found out that a single absence from HD sessions was associated with an increased risk of hospitalization of 1.4 fold and an increased risk of death of 2.2 fold in subsequent 30 days (Gray, Cohen, and Brunelli, 2017). In Australia, Smyth and Harting (2015) reported that at least 43% of patients missed at least one scheduled session and younger patients were less likely to adhere. Another study in Saudi Arabia also documented 45% non-adherence to HD (Al-Khattabi, 2014). High rates of adherence to HD however have been realized. A study done in Malaysia observed self-reported adherence rates of 91% and the findings were consistent with records of attendance to HD sessions of the participants (Chan, 2012). Another study in Palestine by Naalweh, Mohammad, Moutaz, and Samah, (2017) observed 88% adherence to HD attendance.

#### 2.6 Prescribed medication in ESRD management

Given the many functions of the kidneys in the body, it is difficult for HD to replace all of these functions in renal failure. A variety of medicines are therefore usually prescribed in ESRD to supplement some of these functions. Other medications that are prescribed for patients with ESRD on HD are associated with comorbidities that are common in this group of patients such as hypertension.

#### 2.6.1 Treatment of hypertension in ESRD

Hypertension is a common comorbidity in ESRD with an estimate of 86% of patients being diagnosed with hypertension and it is associated with increased cardiovascular morbidity and

mortality (Agarwal, Flynn, Pogue, Mahboob, Efrain et al., 2014). The NKF/KDOQI Clinical Practice Guidelines for cardiovascular diseases in CKD recommend blood pressure measurements of <140/90 and <130/80 mmHg before and after HD respectively. Besides strict attention to fluid status by minimizing intradialytic fluid accumulation and limitation of dietary sodium intake, adequate control of blood pressure in ESRD often requires pharmacologic therapy which should be modified according to the patient's physiological needs and the presence of other disease comorbidities as well as end organ damage (NKFKDOQI, 2005). All classes of antihypertensive drugs can be used to manage hypertension in patients on HD, except diuretics. Diuretics such as furosemide have been found to be ineffective at very low GFR even when given at high doses (Agarwal, Flynn, Pogue, Mahboob, Efrain et al., 2014). Drugs that block the renin-angiotensin-aldosterone system (RAAS): Angiotensin-converting enzyme inhibitors (ACEIs) e.g. fosinopril and Angiotensin II receptor blockers (ARBs) e.g. candesartan are the recommended first-line therapy for HD patients. This is because they are easily tolerated and they have been found to reduce cardiovascular morbidity. Others include Calcium channel blockers e.g. amlodipine and Beta-Blockers e.g. carvedilol (Agarwal, Flynn, Pogue, Mahboob, Efrain et al., 2014).

#### 2.6.2 Treatment of Anaemia in ESRD

The NKF/KDOQI Clinical Guidelines for anaemia in CKD defines anaemia as haemoglobin level <13.0g/dl in males and <12.0g/dl in females (NKF/KDOQI, 2008). Anaemia is highly prevalent in renal failure. Data from the National Health and Nutrition Examination Survey (NHANES), by Stauffer and Fan (2014) found that anaemia was twice as prevalent in people with CKD (15.4%) as in the general population (7.6%). The prevalence of anaemia increased with stage of CKD, from 8.4% at stage 1 to 53.4% at stage 5. It is central to symptoms associated with compromised kidney function that include dyspnoea, fatigue, reduced tolerance to exercises and depression. Anaemia leads to increased morbidity and mortality related to cardiovascular diseases and increased risk of hospitalization and hospital length of stay.

Screening for and treating anaemia forms a routine part of care in HD patients. The treatment of anaemia in ESRD typically entails erythropoietin and iron to prevent severe anaemia and the need for blood transfusions. The preferred route of erythropoietin administration is the subcutaneous route which has been found to have a longer time of bioavailability hence use of lower doses than the intravenous route. Blood count should be done before administration to determine whether the patient needs erythropoietin or not, or whether the dose requires adjustment. This is because erythropoietin has been associated with high blood pressure due to its effect of increased haematocrit which increases blood viscosity and peripheral resistance, especially in chronic use. Iron is commonly administered intravenously because the oral route is associated with poor efficacy and troublesome side effects, such as constipation, dyspepsia, bloating, or diarrhoea (Daugirdas, 2015).

#### 2.6.3 Treatment of Hyperphosphatemia in ESRD

Phosphate retention is a common feature of ESRD since the kidneys are unable to excrete excess phosphate. Hyperphosphatemia consequently is a common complication of ESRD and it is associated with increased risk of cardiovascular complications and subsequent mortality (Ketteler and Biggar, 2013). The NKF/KDOQI Clinical Practice Guidelines for Bone metabolism and disease in CKD recommends maintenance of serum phosphorous levels between 3.5 and 5.5 mg/dl in order to improve patient quality of life and longevity (NKF/KDOQI, 2017). Hyperphosphatemia is managed with phosphate binders to reduce dietary phosphorous since it is difficult to control dietary intake. Patients are educated on the importance of taking phosphate binders and also on the proper way of taking them; chewing just before or with meals. Phosphate binders form the cornerstone of drug therapy in ESRD and controlled serum phosphate level is an indicator of adherence to prescribed drugs. Calcitriol, a synthetic vitamin D analog is also prescribed for prevention of the renal osteodystrophy in ESRD (Waheed, Pedraza, and Lenz, 2013).

#### 2.6.4 Adherence to prescribed medications in ESRD

A major universal challenge in management of chronic diseases is poor long term adherence to drug therapy (WHO, 2003). Drug therapy in ESRD is mainly focused on prevention of complications such as hyperphosphatemia and anaemia and management of comorbidities such as hypertension that are highly associated with mortality. Management of complications and comorbidities associated with ESRD is analogous with a high burden of daily pill intake. A study done in the USA reported a median daily pill burden of 19 with one quarter of the participants exceeding 25 medications per day ( Chiu, Teitelbaum, Misra, de Leon, Adzie, and Rajnish, 2009). High pill burden has been associated with poor drug adherence of as low as 3% (Schmid, 2009).

Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed medication non-adherence was associated with high serum phosphorous levels above 5.5 mg/dL. The USA was found to have the highest non-adherence at 24%. Belgium, Japan, Germany and

Spain had the lowest at 12% each. Unmarried patients were found to have a higher likelihood of non-adherence (Fissell, Karaboyas, Bieber, Sen, Li, et al., 2016). A systematic review on adherence to phosphate binders revealed non-adherence rates that ranged between 22 and 74% with a mean of 51%. Younger age was found to be consistently associated with nonadherence (Karamanidou, Clatworthy, Weinman, and Horne, 2008). A study done in Malaysia on determinants of compliance behaviours among patients undergoing HD identified 66.5% compliance to medication. Perceived barriers to compliance were lack of adequate knowledge at 55.4%, side effects/complications at 78.3%, forgetfulness at 80.6% and large tablet burden at 60.6% (Chan, 2012). A study that was conducted in Saudi Arabia on medication adherence among adult patients on haemodialysis found out that 71.91% were non adherent. Being older (p = 0.012) and being married (p = 0.012) were associated with higher levels of adherence. The study also found that a medium level of education (high school) was associated with lower levels of adherence (P = 0.024) as opposed to low (primary) and high (college) levels that were associated with high levels of adherence. However gender, availability of a care giver and employment status were found to have no effect on compliance to medication (Alkatheri and Alyousif, 2014). Ahlawat, Tiwari, and Cruz, (2016) conducted a study in India on prevalence and predictors of medication nonadherence in patients with chronic kidney disease. In this study 22%, 23% and 55% of the patients were found to have high, medium and low levels of adherence respectively.

#### 2.7 Diet recommendations in management of ESRD

Diet recommendations in ESRD are essential components of therapy. This is largely because of the compromised function of the kidneys and the effects of dialysis. The aim of therapy is to ensure that patients maintain optimum nutrition with minimal complications while maintaining tolerable levels of metabolic wastes that can be safely removed during HD (NKF/KDOQI, 2008).

#### 2.7.1 Protein-Calorie requirements in ESRD

Patients with ESRD have higher protein requirements that are related to higher losses of amino acids (building blocks of proteins) that occur during dialysis. Malnutrition has been documented to be prevalent in ESRD patients with 50% of them being affected (Zha and Qian, 2017). To prevent malnutrition in renal failure, NKF/KDOQI recommends intake of dietary protein in patients who are clinically stable on HD of 1.2 g/kg body weight per day out of which 50% of it should be of high biologic value and energy intake of 30-35 kcal/kg. (NKF/KDOQI, 2008). Proteins of high biologic value are those that contain the nine essential

amino acids (not synthesised by the body) and they are highly absorbed hence having less nitrogenous waste formation. Sources of these proteins include animal proteins such as lean meat, poultry, eggs, milk and milk products, fish and seafood. Proteins of low biological value are deemed to be incomplete because their content of the essential amino acids is low or one or more are missing. They include plant proteins such as grains, legumes, fruits and nuts. All patients with ESRD on HD should therefore have their nutritional status assessed by a dietician and provided with a diet plan based on their individual nutritional needs. It is also important that they have continuous nutritional counselling and screening schedules so as to enhance adherence to diet therapy and hence prevent malnutrition related morbidity and mortality.

#### 2.7.2 Electrolyte Balance in ESRD

Maintenance of electrolyte balance in ESRD patients is crucial; of importance are sodium, potassium and phosphorous. Positive sodium balance and the consequent volume expansion have been associated with hypertension in ESRD (Lee, 2012). A low sodium diet (2g) and low sodium (130 mmol) dialysate therefore are recommended for control of blood pressure. A high potassium diet is contraindicated in ESRD patients because kidneys' ability to excrete potassium is compromised and examples include: fruits (e. g. avocados, bananas, mangos, oranges & orange juice); vegetables (e.g. pumpkin, potatoes, sweet potatoes, tomatoes, and tomato sauce) and dairy products (e.g. milk, yogurt and ice cream). Patients with renal failure should be counselled by a dietician on the kind of foods to avoid, the recommended food portions, and on the methods of preparing their foods so as to reduce the potassium levels. This helps in averting life threatening hyperkalaemia induced arrhythmias that are associated with high mortality (Nakhoul, Huang, Arrigain, Jolly, Schold et al., 2015). Increased morbidity and mortality in ESRD patients is associated with elevated phosphorous due to increased cardiovascular events especially due to vascular calcification (Cannata-Andía and Martin, 2016). It is therefore important that foods high in phosphorous added to food in the form of an additive or preservative (inorganic phosphorus) in foods such as fast foods, ready to eat foods, canned and bottled beverages, enhanced meats, and most processed foods are avoided in ESRD so as to prevent these complications. The NKF/KDOQI recommends maintenance of serum phosphorous levels between 3.5 and 5.5 mg/dL in order to improve patients' quality of life and longevity (NKF/KDOQI, 2015).

#### 2.7.3 Micronutrients requirements in ESRD

Deficiencies of micronutrients that include vitamins A, C, B6, B9, E, and D and elements such as calcium, iron and zinc are common in ESRD. These deficiencies have been associated with anti-oxidant deficient state (Kosmadakis, Da Costa Correia, Charles, Somda, and Aguilera, 2014). It is recommended that patients should achieve 100% of the dietary reference intakes (DRI) for vitamins A, C, E, K, thiamine (B1), riboflavin (B2), pyridoxine (B6), B12, and folic acid and 100% of the DRI for copper and zinc. However, due to the restricted nature of dietary intake and losses of water-soluble vitamins during HD, the recommendations are unfeasible. Hence dietary supplements come in handy for these patients (NKF/KDOQI, 2015).

#### 2.7.4 Adherence to diet recommendations in ESRD

Adherence to appropriate dietary regimen can reduce morbidity and mortality and enhance quality of life in ESRD. An international comparison study that was done on non-adherence to diet and fluid restrictions among adults having HD found high levels of non-adherence to diet of 84.4%. Germany had 81.6% level of non-adherence while that of the USA was at 68.1%. Levels of education (p<0.01) and smoking (p<0.01) were factors that were associated with non-adherence (Kugler and Maeding, 2011). A similar study done in Turkey elicited a 98.3% non-adherence level to diet recommendations (Efe and Kocaöz, 2015). A study done on fluid and dietary restriction among CKD patients in South Africa found out that 16% had high level of adherence to diet. 42.2 % were found to have moderate and another 42.2% had low levels of adherence. Factors that were associated were low income (p<0.027) and education levels (p>0.013) (Chironda and Bhengu, 2016b).

#### 2.8 Adherence to fluid restriction in ESRD

Fluid restriction in ESRD is essential since the kidney function of regulating fluid levels is compromised. In addition there is a limited amount of fluid that can be safely removed from the body during HD. Excessive fluid intake increases morbidity and mortality in ESRD (Kalantar-Zadeh, Regiodor, Kovesdy, Van Wyek, Bunnapradist, *et al.*, 2009). Restriction of fluids varies in individuals and it is determined by weight gain between HD treatments referred to as Inter Dialytic Weight Gain (IDWG), urine output and oedema. IDWG refers to the weight difference of the patient between the one taken at the beginning of a HD session and the one taken at the end of the previous HD (Leggat, Orzol, Hulbert-Shearon, Golpler, Jones, *et al.*, 1998). The NKF/KDOQI recommends an inter dialytic fluid gain of 1.5 to 2kg as a reference range for ESRD patients on HD (NKF/KDOQI, 2015). Kalantar-Zadeh,

Regiodor, Kovesdy, Van Wyek, Bunnapradist, *et al.*, (2009) identified a 28% increased death risk in a weight gain of 4kg or more over two consecutive dialysis sessions. A minimal fluid retention (between 0.5 and 1kg) was associated with a 26% reduction in death risk. The total amount of liquid a patient can consume in a day is calculated based on a 24 hour urine collection. The measured amount of urine is added to the insensible loss (daily amount of fluid lost from the lungs, skin, respiratory tract and faeces) of 500 - 600 ml to give the fluid restriction per day. A patient's urine output depends on the residual renal function which can decrease over time and thus fluid goals may change as a result. A fluid is anything that is liquid and/or melts at room temperature to include water, beverages and ice cream. It is important that patients are educated on how to deal with thirst without intake of fluids. Proposals that have been made towards this include sucking on ice chips, cold sliced fruit or sour candies. Others include chewing gum and use of artificial saliva (Smith, Coston, Glock, Elasy, Wallston, *et al.*, 2010).

Studies on adherence to fluid therapy have identified high levels of non-adherence with 61.1% and 79% rates being identified in USA and Germany respectively. Single marital status (p<0.008) and male sex (p<0.04) were found to be independent predictors for non-adherence to fluid (Kugler and Maending, 2011). Higher non-adherence levels of 95% have been documented in Turkey (Efe and Kocaöz, 2015). Chironda and Bhengu (2016b) documented 11% and 88.9% moderate and low levels of adherence respectively in South Africa. No association was found between biographical data and engagement with fluid restriction in this study.

#### 2.9 Patients' knowledge and attitude on therapy

Knowledge of patients on ESRD and the therapeutic modalities is critical to successful selfmanagement and better adherence outcomes. Through educational interventions or counselling, kidney disease patients get to acquire the necessary knowledge of the causes, manifestations and therapy of their condition. Attitude is a speculative construct representing personalized likes or dislikes for an item. Attitudes are described as positive, negative or neutral perspectives of a person, conduct or occurrence and they are modulated by knowledge (Ajzen, 2001). Absence of information and false information about disease conditions among patients may culminate in negative attitudes consequently influencing adherence outcomes.

Educational interventions for patients on HD have been elicited as important in their management. Sharaf (2016) conducted a study to determine the impact of educational
interventions on HD patients' adherence to fluid and sodium restriction in Egypt. High levels of knowledge and adherence to fluid and sodium restriction were associated with educational interventions. Patients' knowledge increased from 24.39+/-8.6 to 96.36+/-6.04 and adherence increased from 15.56+/-8.06 to 86.67+/-9.63 one month after interventions. Thus it is important that ESRD patients are educated on treatment modalities. A study by Naalweh, Mohammad, Moutaz, and Samah, (2017) on treatment adherence and perception in patients on maintenance HD in Palestine elicited positive attitude of the patients towards all the therapeutic modalities of ESRD. Attitude towards adherence to HD had the highest score at 96.4% followed by that of fluid restriction at 88.6%. The attitudes towards adherence to medication and diet were at 85.5% and 77.7% respectively. A study done in Tanzania by Stanifer, Maro, Egger, Karia, Thielman, et al. (2016) on knowledge, attitudes, and practices related to CKD found knowledge of the causes, manifestations and therapy for kidney disease was suboptimal (mean score 3.28 out of 10). Attitudes were marked by incessant worry over health (27.3%; 20.2, 36.0%), economic (73.1%; 68.2, 77.5%), and social impact (25.4%; 18.6, 33.6%) of kidney disease. A study done by Mutiso, Kayima, and Amayo, (2012) to determine knowledge attitudes and practices among CKD patients at KNH demonstrated that 70.9% had very little/no knowledge. These findings could translate to low levels of adherence to therapeutic modalities among the ESRD patients on HD. Management of ESRD ought to be comprehensive with the patients being made aware of their condition and being involved in the management plan. The patient's significant others should also be involved.

## **CHAPTER THREE: METHODOLOGY**

## **3.1 Introduction**

This chapter describes the study design, study area and the study population. It also describes the sample size calculation, sampling technique and the study instruments used for data collection. Also described are the ethical considerations, data management process and dissemination plan. Minimization of errors and bias and the limitations of the study are also considered.

# 3.2 Study Design

In this study, data was collected at a specific point in time and analysed to give a description of adherence behaviour to therapy among End Stage Renal Disease (ESRD) patients on conventional haemodialysis (HD) at Kenyatta National Hospital (KNH) Renal Unit. Hence a cross –sectional descriptive study was the most suitable for this study.

# 3.3 Area of Study

The study was conducted at the Renal Unit of KNH. KNH is the largest referral and teaching hospital in Kenya and East Africa. Located in Upper Hill area of the capital city Nairobi, it has a bed capacity of 1800. KNH receives the highest number of patients with CKD requiring renal replacement therapy (RRT) in the country. The Renal Unit has 27 HD machines providing inpatient and outpatient services, out of which about 20 machines are in good working condition at any given time. On average 60 sessions of HD are performed in a day, 7 days a week. According to the KNH statistics 240 clients undergo HD every week, out of which 140 are patients with ESRD.

In the Renal Unit, a multidisciplinary team comprising of: 6 doctors (3 consultant nephrologists and 3 registrars), 60 nurses, 1 nutritionist and 1 counsellor handle the clients and explain to them all that they need to know concerning ESRD. Patients are also guided on RRT modalities and on how to adhere.

# **3.4 Study Population**

Clients diagnosed with ESRD on HD at the Renal Unit- KNH formed the study population in this study. Data obtained from the Statistics Department of KNH indicate that approximately 140 clients with ESRD seek HD services per week.

### 3.5 Sampling and Sample Size

### 3.5.1 Calculation of sample Size

The study participants consisted of patients with ESRD. The study size was determined using the formula by Fisher et.al, (1998) as shown below.

$$n = \frac{Z^2 p q}{d^2}$$

Where;

n=the desired sample size when the target population is more than10, 000.

Z = normal deviation at the desired confidence interval (95%) = 1.96

p=the proportion of patients with ESRD attending Renal Unit was assumed to be 50%.

q = proportion of the population without the desired characteristics (1-p)

d=the level of statistical significance

Substitution for the formula:

$$n = \frac{1.96^2[0.5][0.5]}{[0.05][0.05]} = 384$$

Since the study population of 140 is less than 10,000, the formula below was therefore utilized to adjust the sample size estimate.

$$nf = n/[1 + n/N]$$

Where;

nf = the adjusted sample size

n = the sample size calculated

N = total population (the estimated attendance of end stage renal disease clients on haemodialysis at the renal unit).

$$nf = 384/[1 + 384/140]$$

= 384 / [1 + 2.7429]

= 384 / 3.7429

= 102.5942

103 was the sample size for the study.

## 3.5.2 Inclusion Criteria

Participants included in this study comprised of patients diagnosed with ESRD and had been undergoing HD sessions at the Renal Unit for at least 3 months. The patients were adults above 18 years of age and agreed to participate in the study by giving an informed consent.

## 3.5.3 Exclusion Criteria

Excluded from the study were the newly diagnosed ESRD patients because they were assumed to be still in the process of learning on their therapeutic modalities hence maybe non-adherent. Patients who were dependent in performing self-care activities such as the critically ill, those on peritoneal dialysis and those who declined to give informed consent of participation were also excluded.

## 3.5.4 Sampling method

Multistage sampling method was used in this study. This involves a combination of two or more types of probability sampling technique. Cluster sampling was used in the first stage to categorize patients into acute and chronic renal failure. The second stage entailed simple random sampling using yes/no to select patients who met the inclusion criteria from the chronic renal failure cluster. The procedure was repeated until the 103 questionnaires were filled.

# 3.5.5 Selection of study subjects

Information from the KNH- Renal Unit indicates that most of the ESRD patients are usually prescribed for two HD sessions in a week. The arrangement is such that the patients are scheduled for the first HD sessions on Monday, Tuesday and Wednesday with repeat sessions on Thursday, Friday and Saturday respectively. In total, 140 ESRD patients undergo HD sessions in a week. On average therefore, 140/3= 47 ESRD patients undergo HD sessions every day. The investigator collected data from the 103 participants in a period of 4 weeks, thus every week, 103/4=26 participants were interviewed. Data was collected for six (Monday to Saturday) days in a week; hence 26/6=4 questionnaires were filled each day. Simple random sampling was applied to select the four from the cluster of ESRD attending HD sessions each of the six days in the week during the study period. On being recruited into

the study, clients' files were marked with a sticker/code unique to this study so that they were not clustered in the consecutive days of the study. This gave each of the 140 ESRD patients an equal opportunity of being included in the study.

### **3.6 Study Instruments**

### **3.6.1 Questionnaire**

A structured questionnaire was used as the principle tool of data collection. It was in three parts: the first part elicited information on demographic data of the participants; the second part captured patient's biochemical data from medical records and the third part was an adopted End Stage Renal Disease-Adherence Questionnaire (ESRD-AQ) (Kim, Evangelista, Phillips, Pavlish, and Kopple, 2010). ESRD-AQ is a validated and reliable 46 item instrument. It was used to assess self- reported adherence behaviour and knowledge and attitude on therapy among ESRD patients on HD. ESRD-AQ addresses the four typical constituents of therapy adherence behaviour of individuals with ESRD on HD that entail adherence to: attendance of HD sessions; prescribed medications, fluid and dietary recommendations. The 46 items are divided into 5 sections with the first section consisting of 5 items addressing patient's general information on ESRD and RRT related history. The other 4 sections consist of 14, 9, 10 and 8 items addressing adherence to HD, medication, fluid restriction and diet recommendations respectively. The 4 sections directly measure adherence behaviours (item 25, 28, 29, 37, 44, and 57), and patients' knowledge and attitude about treatment (item 22, 23, 33, 34, 45, 46, 52, and 53).

The ESRD-AQ has responses that are a mixture of Likert scales, "yes/no" answer format, closed and open ended questions with higher scores being indicative of better adherence (Kim, Evangelista, Phillips, Pavlish, and Kopple, 2010). The score for adherence to HD session attendance was obtained by summing up the scores of items 25, 28 and 29. Each of the three items had five responses that were scored at 100, 75, 50, 25, and 0 respectively, with the most appropriate response attracting a score of 100 and the least a score of 0. A summation of the three scores was then done. Participants with scores of 300 were considered to have high levels of adherence to HD session attendance, those with scores of 150-299 as moderate and below 149 as low. The score for adherence to prescribed medications, fluid restrictions and diet recommendations were obtained from scores of items 37, 44, and 57 respectively. Each of the three items had five response attracting a score of 100 and the least a score of 100 and the least a score of 0. Participants with scores of 100 and the least a score of 100 and the least a score of 0. Score spectively. Each of the three items had five responses that were scores of items 37, 44, and 57 respectively. Each of the three items had five response attracting a score of 100 and the least a score of 0. Participants with scores of 100 were considered to have high levels of

adherence, those with scores of 50-99 as moderate and below 49 as low. To obtain the overall level of adherence, the sum of the scores for all the items (25, 28, 29, 37, 44, and 57) was obtained for each of the participants. Participants with scores of 550 to the maximum 600 were considered to have overall high level of adherence whereas those with scores of 500-549 and below 499 were considered to have moderate and low levels of adherence respectively.

The ESRD-AQ tool has an advantage over other tools in that it assesses the four typical constituents of therapy adherence behaviour of ESRD individuals on HD. The Dialysis Diet and Fluid Non -Adherence Questionnaire (DDFQ) is another tool that has established validity and reliability in evaluating therapy adherence in ESRD patients (Vlaminck, 2001). It evaluates the levels of adherence to fluid and dietary recommendations; hence it has limitations in measurement of adherence since it does not address attendance of HD sessions and use of medication. Therefore ESRD-AQ was used because it is the most appropriate tool that is consistent with the study title of this research. The questionnaire was self-administered for participants who could read and write. For those who could not read and write, a questionnaire guided interview using the same tool was given.

## **3.6.2 Medical Records**

Patients participating in the study through consenting had their records reviewed to check for biochemical data. These included pre-dialysis serum phosphate and potassium levels that were used as clinical indicators of adherence to medication and diet respectively and interdialysis weight gain (IDWG) as an indicator of fluid adherence. Also checked from the records were the appointments (HD sessions) not attended compared to the prescribed in the previous one month as a measure of adherence to HD session attendance.

## 3.6.3 Pretesting of the Questionnaire

The questionnaire was pretested at Machakos Level Five Hospital Renal Unit. This hospital was selected because the patients' characteristics are similar to those of the patients at KNH. This enabled the researcher to evaluate the clarity of questions asked, the general flow and the sensitivity of the tool. This was done by administering the questionnaires to 10 patients with ESRD selected randomly after giving an informed written consent to represent 10%  $(10\times103/100=10 \text{ patients})$  of the sample projected for the larger parent study (Connelly, 2008).

### **3.7 Ethical Considerations**

The research proposal was submitted to the Kenyatta National Hospital-University of Nairobi ethics and research committee (KNH-UON ERC) for approval. Permission was sought from the KNH Renal Unit and the Records department to access patients' files. Informed written consent was sought from the study participants before data collection at their free will without coercion. Questionnaires were coded, with no names written on them and confidentiality was assured on the information given by the participants.

### 3.8 Data Management

#### **3.8.1 Research assistants**

Data was collected by the principle investigator and one research assistant with qualification of a post basic training in nephrology nursing and working in the renal unit. This is because she is well versed with management of ESRD patients on HD. The assistant was trained for one day on the questionnaire, data collection procedure, consenting process and on evaluation of the questionnaire for completeness. The principal investigator also worked with the assistant in data cleaning and data entry. The researcher analysed the data with the assistance of a statistician.

### 3.8.2 Data collection

Multistage (cluster then simple random) sampling was used to select patients after which a narration of the study aim and expectations was done. Consenting process was voluntary with the recruited participants signing the consent forms. Participants had a choice of consenting in either English or Kiswahili. The questionnaires were self-administered. Literate patients were given the questionnaire to fill in. Those who could not read and write were taken through a questionnaire guided interview by the researcher and the research assistant. After filling of the questionnaire, each of the participants' files was reviewed for the latest 3 biochemical data to include pre-dialysis serum potassium and phosphate levels and interdialysis weight gain (IDWG). An average of each was then calculated and recorded. Also checked from the records were the appointments (HD sessions) not attended compared to the prescribed in the past one month. The parameters were then filled in the relevant questionnaires.

### **3.8.3 Data entry and cleaning**

Filled questionnaires were collected and checked for completeness and consistency. Inconsistent information was eliminated and unclear responses clarified from the respondents. Data from the completed questionnaires was entered using SPSS version 20 and protected with a password.

## 3.8.4 Data analysis and presentation

SPSS computer software, version 20 was used to analyse data. Data was summarized using descriptive statistics to include the mean, standard deviation, frequency distribution and percentages. Inferential statistics; the chi-square test was used to generate P-values that were used to test the study hypothesis. Frequency distribution tables, bar graphs and pie charts were used to present the results and scientific conclusions drawn from them.

## 3.8.5 Data Storage

The data collected was stored in a locked cabinet accessible by the researcher only. The researcher was responsible for safeguarding the data from being accessed by other people hence curbing chances of malicious use. Data was retrieved for analysis and kept under safe custody until completion of the study after which it was disposed of professionally to minimise unethical use.

## **3.7 Dissemination plan**

Research findings will be submitted to the University of Nairobi – School of Nursing Sciences through defence and the website. The final research copy will be submitted to the KNH and University of Nairobi main library for repository and references. A manuscript of the study will be published in a peer reviewed journal.

# 3.8 Minimizing errors and bias

The questionnaire was pretested and reviewed to ensure consistency and participants were selected by multistage (cluster then simple random) sampling. All eligible subjects were allowed to participate irrespective of literacy levels.

# 3.9 Limitations of the Study

The study was based on self reports to measure adherence to therapy hence it was subject to recall bias. This was mitigated by validating the self reports of adherence with the results of biochemical values of pre-dialysis potassium and phosphate levels and inter-dialytic weight gain (IDWG).

## **CHAPTER FOUR: RESULTS**

## 4.1 Introduction

This chapter presents the results of the study on evaluation of therapy adherence among patients with End Stage Renal Disease at Kenyatta National Hospital. The questionnaires were completed by 103 participants with a response rate of 100%. The information that was obtained is presented in tables and figures.

# 4.2 Social demographic characteristics of the study participants

Table 1 illustrates that the mean age of the participants was  $43.5 \pm 17$  years with 57.3 % (n= 59) aged 40 years and above. The females were more than the males accounting for 52.4% (n=54) of the study participants. The percentage of those married and living with spouses was 66.0% (n=68) while 34% (n=35) had no spouses and were single, separated or widowed. Majority of the study participants had attained secondary school education and above accounting for 70.5% (n=73) of the respondents. Patients who had dialyzed for less than 12 months were the majority accounting for 67% (n=69) of the study participants. The mean duration of haemodialysis of the participants was  $14.8 \pm 16.3$  months.

Demographic Characteristic	Categories	Frequency	Percentage (%)
Age in years	18 - 29	16	15.5
	30 - 39	28	27.2
	40 - 49	26	25.2
	50 - 59	16	15.5
	60 and above	17	16.5
Gender	Male	49	47.6
	Female	54	52.4
Marital Status	Single	30	29.1
	Married	68	66.0
	Widow/Widower	3	2.9
	Separated	2	1.9
Education Level	None	10	9.7
	Completed primary	20	19.4
	Completed	57	55.3
	secondary	16	15.5
	College/University		
Duration of Hemodialysis in	3-12	69	67
months	13-24	16	15.5
	25-36	11	10.7
	37-48	6	5.8
	Over 49	1	0.9
Total		103	100

Table 1: S	Social dem	ographic cha	racteristics of	f the stud	y participants
		01			

## 4.3 General information of the study participants

Table 2 illustrates that the most common type of comorbidity among ESRD patients attending HD at KNH was hypertension (75.5%; n=71) followed by hypertension and diabetes combined (14.9%; (n=14). More than half (52.4%; n=54) of the study participants reported they were assisted in management of their condition by their spouses. Less than half (41.7%; n=43) live within a radius of 0-20 km from the dialysis center and 67% (n=69) use public means to get to the center. More than half (54.45; n=54) of the participants were not employed and 99% (n=102) had a health insurance cover with the National Hospital Insurance Fund (NHIF)

Item	Responses	Frequency	Percentage
		(n)	(%)
Presence of comorbidity	No	9	8.7
	Yes	94	91.3
	Total	103	100
Type of comorbidity	Hypertension	71	75.5
	Diabetes	6	6.4
	Hypertension and diabetes	14	14.9
	Hepatitis B	2	2.1
	Cardiac disease	1	1
	Total	94	100
Assistance in management of	Myself	7	6.8
kidney failure	Parent	18	17.5
	Spouse	54	52.4
	Child	15	14.6
	Siblings/relatives	9	8.7
	Total	103	100
Distance from home to	0–20 km	43	41.7
dialysis centre	21–40 km	38	36.9
	41–60 km	12	11.7
	61–80 km	2	1.9
	81-100 km	2	1.9
	>100 km	6	5.8
	Total	103	100
Type of transportation used	Personal	21	20.4
to go to the dialysis center	Bus	69	67
	Taxi	13	12.6
	Total	103	100
Employment status	Employed	12	11.7
	Self	37	35.9
	Not	54	54.4
	Total	103	100
National Hospital Insurance	No	1	1
Fund (NHIF) member	Yes	102	99
	Total	103	100

### Table 2: General information of the study participants

### 4.4 Adherence to Haemodialysis (HD) session attendance

Majority of the study participants (67%; n=69) reported a high level of adherence to HD session attendance, whereas 29.1 % (n=30) and 3.9% (n=4) reported moderate and low levels respectively as illustrated on figure 3. These findings were validated by records of haemodialysis session attendance retrieved from the medical records whereby 76.7% (n=79) of the study participants had attended all the prescribed sessions of HD in a period of one month, whereas 23.3 % (n=24) had missed one or more of the prescribed sessions.



Figure 3: Adherence to haemodialysis session attendance

From table 3, the relationship between age of the study participants and adherence to HD session attendance was statistically significant (P-value = 0.001). Participants older than 40 years were more likely to adhere highly to HD session attendance than the younger ones. There was no statistical significance between gender, marital status, level of education and duration of HD of the participants and adherence to HD session attendance.

Study Porticipants'		Levels	Levels of adherence to HD			Dyalua
characteristics	Categories	Low	Moderate	High	n (%)	r value
		n (%)	n (%)	n (%)		
Age in years	18 - 29	3 (18.8)	1 (6.2)	12 (75.0)	16 (15.5)	0.001
	30 - 39	1 (3.6)	14 (50.0)	13 (46.4)	28 (27.2)	
	40 - 49	0	10 (38.5)	16 (61.5)	26 (25.2)	
	50 - 59	0	1 (6.3)	15 (93.8)	16 (15.5)	
	60 and above	0	4 (23.5)	13 (76.5)	17 (16.5)	
Gender	Male	3 (6.1)	11 (22.4)	35 (71.4)	49 (47.6)	0.233
	Female	1 (1.9)	19 (35.2)	34 (63.0)	54 (52.4)	
Marital status	Married	1 (11.5)	22 (32.4)	45 (66.2)	68 (66.0)	0.345
	Single	3 (10.0)	8 (26.7)	19 (63.3)	30 (29.1)	
	Widow/Widower	0	0	3 (100)	3 (2.9)	
	Separated	0	0	2 (100)	2 (1.9)	
Education level	None	0	4 (40.0)	6 (60.0)	10 (9.7)	0.378
	Primary	1 (5.0)	6 (30.0)	13 (65.0)	20 (19.4)	
	Secondary	3 (5.3)	17 (29.8)	37 (64.9)	57 (55.3)	
	College/University	0	3 (18.8)	13 (81.2)	16 (15.5)	
<b>Duration of HD</b>	1-12	4 (5.7)	20 (29)	45 (65.2)	69 (67)	0.399
(months)	13-24	2 (12.5)	3 (18.8)	11 (68.8)	16 (15.5)	
	25-36	3 (27.3)	3 (27.3)	5 (45.5)	11 (10.7)	
	37-48	0	2 (33.3)	4 (66.7)	6 (5.8)	
	Over 49	0	0	1 (100)	1 (0.9)	

Table 3: Study participants' characteristics and haemodialysis

# 4.4.1 Information related to Haemodialysis schedule

Table 4 illustrates that majority of the study participants (95.1%; n=98) receive 2 HD treatments per week. All the patients are treated for 4 hours each HD treatment (100%; n=103). Ninety per cent of the participants indicated that their HD schedule was convenient. Majority (76.7%; n=79) of the participants indicated that they did not miss any HD session. Among the participants who missed HD sessions, more than half (54.2%; n=13) reported transport problems as the main reason of missing.

Item	Responses	Frequency (n)	Percentage (%)
Days per week receives HD	2 days or Less	98	95.1
treatment	3 days	5	4.9
	Total	103	100
Hours treated for each HD	4 hours	103	100
treatment			
Convenience of HD schedule	No	10	9.7
	Yes	93	90.3
	Total	103	100%
Missed HD sessions	No	10	9.7
	Yes	93	90.3
	Total	103	100%
Missed HD sessions	No	79	9.7
	Yes	24	90.3
	Total	103	100%
Missed HD sessions	No	79	76.7%
	Yes	24	23.3%
	Total	103	100%
Main reason for missing	Transport problems	13	54.2
dialysis	Had other things to do	1	4.2
	HD access clotted	2	7.3
	Was hospitalized	2	8.3
	Did not want to go	2	8.3
	Travelled upcountry	2	8.3
	No return date indicated	1	4.2
	Tired of attending the sessions	1	4.2
	Total	24	23.3%

# Table 4: Information related to haemodialysis schedule

# 4.4.2 Information about counselling on Haemodialysis session attendance

Table 5 illustrates that 25.2% (n=26) of the study participants had never been counseled by a health professional (doctor, nurse, dietician or other medical staff) on the importance of not missing dialysis, while 74.8% (n=77) reported having been counseled at various intervals ranging from one week to when they first began dialysis. Those who had been counseled at various intervals on the importance of staying the entire dialysis time during treatment comprised 62.1% (n=64) of the participants whereas 37.9% (n=39) had never been counseled. Table 5: Information about acunselling on Hapmodialysis

Item	Responses	Frequency	Percentage
		<b>(n)</b>	(%)
Last time counseled	This week	9	8.7
on importance of not	Last week	15	14.6
missing dialysis	One month ago	8	7.8
treatment	More than one month ago	18	17.5
	When first began dialysis	27	26.2
	Never	26	25.2
	Total	103	100
Frequency of	Every dialysis treatment	6	5.8
counseling on	Every week	7	6.8
importance of staying	Every month	6	5.8
the entire dialysis	Every $2-3$ months	7	6.8
time during treatment	Every $4 - 6$ months	2	1.9
	When blood/ other tests are abnormal	14	13.6
	Rarely	6	5.8
	Irregularly	16	15.5
	Never	39	37.9
	Total	103	100

# Table 5: Information about counselling on Haemodialysis

# 4.5 Adherence to prescribed medications

Majority of the study participants (69.9%; n=72) reported a high level of adherence to prescribed medication whereas 23.3 % (n=24) and 6.8% (n=7) reported moderate and low levels respectively as illustrated on figure 4. These findings were validated with pre-dialysis phosphate levels whereby 52.4% (n=44) were found to have normal levels of 0.9-1.67 mmol/L with a mean of 1.58 mmol/L. participants whose levels were below normal accounted for 8.3% (n=7) and those above normal accounted for 39.3% (n=33). Participants whose reports of pre-dialysis phosphate levels were unavailable accounted for 17.5% (n=18) of the respondents.



# Figure 4: Adherence to prescribed medication

From table 6; there was no statistical significance between the study participants' characteristics and adherence to prescribed medications.

Study		Leve	ls of adheren	ice to		
Participants'	Categories		Medication		Total	Р
characteristics		Low	Moderate	High	n (%)	value
		n (%)	n (%)	n (%)		
Age in years	18 - 29	4 (25.0)	2 (12.5)	10 (62.5)	16 (15.5)	0.162
	30 - 39	1 (3.6)	8 (28.6)	19 (67.9)	28 (27.2)	
	40 - 49	1 (3.8)	5 (19.2)	20 (76.9)	26 (25.2)	
	50 - 59	0	5 (31.3)	11 (68.8)	16 (15.5)	
	60 and above	1 (5.9)	4 (23.5)	12 (70.6)	17 (16.5)	
Gender	Male	2 (4.1)	10 (20.4)	37 (75.5)	49 (47.6)	0.413
	Female	5 (9.3)	14 (25.9)	35 (64.8)	54 (52.4)	
Marital status	Married	3 (4.4)	16 (23.5)	49 (72.1)	68 (66.0)	0.564
	Single	4 (13.3)	7 (23.3)	19 (63.3)	30 (29.1)	
	Widow/Widower	0	0	3 (100)	3 (2.9)	
	Separated	0	1 (50.0)	1 (50.0)	2 (1.9)	
Education level	None	1 (10.0)	2 (20.0)	7 (70.0)	10 (9.7)	0.461
	Primary	1 (5.0)	8 (40.0)	11 (55.0)	20 (19.4)	
	Secondary	3 (5.3)	10 (17.5)	44 (77.2)	57 (55.3)	
	College/University	2 (12.5)	4 (25.0)	10 (62.5)	16 (15.5)	
Duration of HD	1-12	9 (13.1)	10 (14.5)	50 (72.5)	69 (67)	0.787
(months)	13-24	3 (18.8)	3 (18.8)	10 (62.5)	16 (15.5)	
	25-36	2 (18.1)	3 (27.3)	6 (54.5)	11 (10.7)	
	37-48	1 (16.7)	1 (16.7)	4 (66.7)	6 (5.8)	
	Over 49	0	0	1 (100)	1 (0.9)	

# Table 6: Study participants' characteristics and prescribed medications

# 4.5.1 Information related to prescribed medication

From table 7; majority of the study participants (86.4%; n=89) reported that they had no difficulties in taking their prescribed medication while 13.6% (n=14) reported difficulties. Among the participants who missed their prescribed medicines, 41.9% (n=13) reported medicine cost as the main reason of missing.

Item	Responses	Frequency	Percentage
		( <b>n</b> )	(%)
Difficulties with prescribed	No	89	86.4
medication	Yes	14	13.6
	Total	103	100
Magnitude of difficulty with taking	No difficulty	89	86.4
prescribed medication	A little difficulty	5	4.9
	Moderate difficulty	1	1.0
	A lot of difficulty	8	7.8
	Total	103	100
Missed medications	No	72	69.9%
	Yes	31	30.1%
	Total	103	100%
Main reason for not taking	Forgot to take	7	22.6
prescribed medication	Forgot to order	5	16.1
	Medicine cost	13	41.9
	Side effects	6	19.4
	Total	31	30.1%

**Table 7: Information related to prescribed medication** 

# 4.5.2 Information about counselling on prescribed medication

As illustrated on table 8; 25.2% (n=26) of the study participants reported that they had never been spoken to by a health professional (doctor, nurse, dietician or other medical staff) about their medicines, while 74.8% (n=77) reported having been spoken to at various intervals ranging from one week to when they first began dialysis. Those who had been counseled at various intervals on the importance of taking medicines as scheduled comprised 79.6% (n=82) of the participants whereas 20.4% (n=21) had never been counseled.

Item	Responses	Frequency	Percentage
		( <b>n</b> )	(%)
Last time spoken to	This week	11	10.7
about your medication	Last week	10	9.7
	One month ago	18	17.5
	More than one month ago	22	21.4
	When first began dialysis	16	15.5
	Never	26	25.2
	Total	103	100
Frequency of	Every dialysis treatment	6	5.8
counseling on	Every week	9	8.7
importance of taking	Every month	11	10.7
medicines as scheduled	Every $2-3$ months	4	3.9
	Every $4-6$ months	46	44.7
	When blood/ other tests are abnormal	2	1.9
	Irregularly	4	3.9
	Never	21	20.4
	Total	103	100

Table 8: Information about counselling on prescribed medication

# 4.6 Adherence to fluid restriction

Less than half (42.7%; n=44) of the study participants reported high level of adherence to fluid restriction whereas 35% (n=36) and 22.3% (n=23) reported moderate and low levels respectively as illustrated on figure 5. The findings were validated with measurements of Inter-dialytic weight gain (IDWG) whereby 54.4% (n=56) of the respondents had an IDWG of above the normal 2kg with a mean of 2.8 kg; while 45.6% (n=47) had below 2Kg with a mean of 1.5kg.



Figure 5: Adherence to fluid restriction

Table 9 illustrates a statistically significant relationship between marital status of the study participants and adherence to fluid restriction (P-value = 0.004). The married participants reported higher levels of adherence (52.9%; n=36) than the single (13.3%; n=4). The relationship between duration of HD and adherence to fluid restriction was statistically significant (P= 0.001). Participants who had dialyzed for less than twelve months reported high levels of adherence (59%; n=41) compared with those who had more than 12 months of dialysis. There was no statistical significance between gender, age and level of education of the participants and adherence to fluid restriction.

Study Participants'	<b>C</b> 4	Levels of adherence to fluid restriction			Total	Р
cnaracteristics	Categories	Low n (%)	Moderate n (%)	High n (%)	n (%)	value
Age in years	$     18 - 29 \\     30 - 39 \\     40 - 49 \\     50 - 59 \\     60 and above $	5 (31.3) 6 (21.4) 8 (30.8) 1 (6.3) 3 (17.6)	9 (56.3) 6 (21.4) 9 (34.6) 5 (31.3) 7 (41.2)	2 (12.5) 16 (57.1) 9 (34.6) 10 (62.5) 7 (41.2)	16 (15.5) 28 (27.2) 26 (25.2) 16 (15.5) 17 (16.5)	0.085
Gender	Male Female	11 (22.4) 12 (22.2)	14 (28.6) 22 (40.7)	24 (49.0) 20 (37.0)	49 (47.6) 54 (52.4)	0.378
Marital status	Married Single Widow/Widower Separated	12 (17.6) 10 (33.3) 0 0	20 (29.4) 16 (53.3) 0 1 (50.0)	36 (52.9) 4 (13.3) 3 (100) 1 (50.0)	68 (66.0) 30 (29.1) 3 (2.9) 2 (1.9)	0.004
Education level	None Primary Secondary College/University	0 3 (15.0) 17 (29.8) 3 (18.8)	4 (40.0) 9 (45.0) 19 (33.3) 4 (25.0)	6 (60.0) 8 (40.0) 21 (36.8) 9 (56.3)	10 (9.7) 20 (19.4) 57 (55.3) 16 (15.5)	0.297
Duration of HD (months)	1-12 13-24 25-36 37-48 Over 49	8 (11.6) 2 (12.5) 4 (36.4) 1 (16.7) 1 (100)	20 (29) 6 (37.5) 3 (27.3) 3 (50) 0	41 (59) 8 (50) 4 (36.4) 2 (33.3) 0	69 (67) 16 (15.5) 11 (10.7) 6 (5.8) 1 (0.9)	0.001

 Table 9: Study participants' characteristics and fluid restriction

# 4.6.1 Information related to fluid restriction

From table 10; more than half of the study participants (55.3%; n=57) reported that they had no difficulties in limiting their fluid intake while 44.7% (n=46) reported difficulties. Among the study participants who reported difficulties with fluid restriction, 97.8% (n=45) reported that they were unable to control fluid intake.

Item	Responses	Frequency	Percentage
		<b>(n)</b>	(%)
Difficulties with fluid	No	57	55.3
restriction	Yes	46	44.7
	Total	103	100
Magnitude of difficulty	No difficulty	57	55.3
with fluid restriction	A little difficulty	23	22.3
	Moderate difficulty	13	12.6
	A lot of difficulty	10	9.7
	Total	103	100
Types of difficulties	Was unable to control fluid intake	45	97.8
with limiting fluid	Do not understand how to follow		
intake	fluid restrictions	1	2.2
	Total	46	44.7%

Table 10: Information related to fluid restriction

# 4.6.2 Information about counselling on fluid restriction

Table 11 illustrates that 98% (n=101) of the study participants had been counselled by a health professional (doctor, nurse, dietician or other medical staff) on importance of limiting fluid intake at various intervals. All the study participants had been counselled at various intervals on the importance of limiting fluid intake.

Item	Responses	Frequency	Percentage
		( <b>n</b> )	(%)
Last time counseled on	This week	14	13.6
fluid restriction	Last week	33	32.0
	One month ago	14	13.6
	More than one month ago	18	17.5
	When first begun dialysis	22	21.4
	Never	2	1.9
	Total	103	100
Frequency of counseling	Every dialysis treatment	21	20.4
on importance of fluid	Every week	13	12.6
restriction	Every month	19	18.4
	Every $2-3$ months	6	5.8
	Every $4 - 6$ months	4	3.9
	Rarely	10	9.7
	Irregularly	12	11.7
	When blood/ other tests are	13	12.6
	abnormal		
	Total	103	100

# Table 11: Information about counselling on fluid restriction

# 4.7 Adherence to diet recommendations

A high level of adherence to diet recommendations was reported by 57.3% (n=59) of the study participants compared with 32% (n=33) and 10.7% (n=11) who reported moderate and low levels respectively as illustrated on figure 6. The findings were validated by pre-dialysis potassium levels whereby 65.9% (n=58) of the study participants had normal values of 3.5-5 mmol/L with a mean of 4.5 mmol/L. Participants whose reports of pre-dialysis potassium levels were unavailable accounted for 14.6% (n=15) of the respondents.



Figure 6: Adherence to diet recommendations

As illustrated on table 12; the relationship between age and level of adherence to diet recommendations was statistically significant (P-value = 0.015). Study participants older than 40 years were more likely to have higher levels of adherence than the younger ones. Participants aged 60 and above had the highest score of 88.2% (n= 15) in the category that reported high levels of adherence to diet recommendation. There was no statistical significance between gender, marital status, level of education and duration of HD of the study participants and adherence to diet recommendation.

Study		Levels of adherence to diet				
Participants'	Categories	recommendations			Total	P value
characteristics		Low	Low Moderate High		n (%)	
		n (%)	n (%)	n (%)		
Age in years	18 – 29	2 (12.5)	9 (56.3)	5 (31.3)	16 (15.5)	0.015
	30 - 39	6 (21.4)	7 (25.0)	15 (53.6)	28 (27.2)	
	40 - 49	0	11 (42.3)	15 (57.7)	26 (25.2)	
	50 - 59	2(12.5)	5 (31.3)	9 (56.3)	16 (15.5)	
	60 and above	1 (5.9)	1 (5.9)	15 (88.2)	17 (16.5)	
Gender	Male	4 (8.2)	21 (42.9)	24 (49.0)	49 (47.6)	0.078
	Female	7 (13.0)	12 (22.2)	35 (64.8)	54 (52.4)	
Marital status	Married	7 (10.3)	21 (30.9)	40 (58.8)	68 (66.0)	0.521
	Single	4 (13.3)	12 (40.0)	14 (46.7)	30 (29.1)	
	Widow/Widower	0	0	3 (100)	3 (2.9)	
	Separated	0	0	2 (100)	2 (1.9)	
<b>Education level</b>	None	0	0	10 (100)	10 (9.7)	0.115
	Primary	2 (10.0)	6 (30.0)	12 (60.0)	20 (19.4)	
	Secondary	7 (12.3)	23 (40.4)	27 (47.4)	57 (55.3)	
	College/University	2 (12.5)	4 (25.0)	10 (62.5)	16 (15.5)	
Duration of HD	1-12	5 (7.2)	20 (29)	44 (63.8)	69 (67)	0.513
(months)	13-24	3 (18.8)	5 (31.2)	8 (50)	16 (15.5)	
	25-36	1 (9)	4 (36.4)	6 (54.4)	11 (10.7)	
	37-48	1 (16.7)	2 (33.3)	3 (50.0)	6 (5.8)	
	Over 49	0	1 (100)	0	1 (0.9)	

 Table 12: Study participants' characteristics and diet recommendations

### 4.7.1 Information related to diet recommendations

From Table 13; more than two thirds of the study participants (72.8%; n=75), reported no difficulties with following the diet recommendations while 27.2% (n=28) had difficulties. Among the participants who reported difficulties with following diet recommendations, 78.6% (n=22) reported that they were unable to avoid certain un-recommended foods.

Item	Responses	Frequency	Percentage
		<b>(n)</b>	(%)
Difficulties with diet	No	75	72.8
recommendations	Yes	28	27.2
	Total	103	100
Magnitude of difficulty	No difficulty	75	72.8
with dietary	A little difficulty	8	7.8
recommendations	Moderate difficulty	20	19.4
	Total	103	100
Types of difficulties	Not willing to control what I eat	4	14.3
with dietary	Unable to avoid certain un-		
recommendations	recommended foods	22	78.6
	Do not understand what type of diet		
	to follow	2	7.1
	Total	28	27.2

# **Table 13: Information related to diet recommendations**

# 4.7.2 Information about counselling on dietary recommendations

From table 14; 96.1% (n=99) of the study participants reported that they had been counseled by a health professional (doctor, nurse, dietician or other medical staff) on importance of following the diet recommendations at various intervals. The participants who had been talked to on the importance of following a proper diet at various intervals comprised of 95.1% (n=98) compared to 4.9% (n=5) who had never.

Fable 14: Information abou	it counselling on dieta	ry recommendations
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Item	Responses	Frequency	Percentage
		<b>(n)</b>	(%)
Last time counseled on	This week	10	9.7
diet	Last week	26	25.2
	One month ago	22	21.4
	More than one month ago	20	19.4
	When first begun dialysis	21	20.4
	Never	4	3.9
	Total	103	100
Frequency of	Every dialysis treatment	9	8.7
counseling on	Every week	27	26.2
importance of following	Every month	21	20.4
a proper diet	Every $2-3$ months	8	7.8
	Every $4-6$ months	8	7.8
	Rarely	6	5.8
	Irregularly	13	12.6
	Never	5	4.9
	When blood/ other tests are abnormal	6	5.8
	Total	103	100

# 4.8 Overall Adherence

Overall adherence was considered to be full adherence to the four therapeutic modalities in ESRD: HD session attendance, prescribed medications, fluid restrictions and diet recommendations. The study participants that demonstrated overall adherence to therapy were 51.5% (n=53) compared to 25.2 % (n=26) and 23.3% (n=24) who exhibited moderate and low adherence as illustrated on figure 7.



**Figure 7: Overall Adherence** 

# 4.9 ESRD Patients' Knowledge on therapy

The study participants were asked to indicate why it is important to: follow their dialysis schedule, take their medicines as scheduled, limit their fluid intake and watch their diet daily. Table 15 illustrates that 62.1% (n=64); 48.5% (n=50); 62.1% (n=64) and 65% (n=67) of the study participants indicated that it is because they fully understood that their kidney condition required them to: follow dialysis schedule; take medications as scheduled; limit fluid intake and watch their diet daily respectively.

Item/ Responses	Frequency	Percentage
	(n)	(%)
Importance of following my dialysis schedule		
I fully understand my kidney condition requires dialysis	64	62.1
To keep my body healthy	20	19.4
Medical professional told me to do so	12	11.7
I was sick after I missed dialysis	5	4.9
I was hospitalized after I missed dialysis	1	1.0
Dialysis schedule is not very important to me	1	1.0
Total	103	100
Importance of taking medication as scheduled		
I fully understand my kidney condition requires medicines	50	48.5
To keep my body healthy	37	35.9
Medical professional told me to do so	4	3.9
I was sick after I missed medicines	9	8.7
I was hospitalized after I missed medicines	3	2.9
Total	103	100
Importance of limiting fluid intake		
I fully understand my kidney condition requires limiting fluid	64	62.1
To keep my body healthy	24	23.3
Medical professional told me to do so	7	6.8
I was sick after I drank lots of fluid	1	1.0
I was hospitalized after I drank lots of fluid	7	6.8
Total	103	100
Importance of watching my diet daily		
I fully understand my kidney condition requires to watch my diet	67	65.0
To keep my body healthy	26	25.2
Medical professional told me to do so	5	4.9
I was sick after eating un-recommended food	3	2.9
I was hospitalized after eating un-recommended food	2	1.9
Total	103	100

Table 1	15:	ESRD	Patients'	Knowledge	on tl	herapy

# **4.10 ESRD** patients' attitude towards therapy

The study participants were asked how important they thought it was to: follow their dialysis schedule; take their medications as scheduled; limit their fluid intake and watch their diet recommendations. Table 16 illustrates that 60.2% (n=62); 61.2% (n=63); 58.2% (n=60) and 69.9%; n=72) indicated that it was highly important to: follow dialysis schedule; take medications as scheduled; limit fluid intake and watch their diet daily respectively.

Item/ Responses	Frequency (n)	Percentage (%)
Importance of following haemodialysis schedule	62	60.2
Highly important	30	29.1
Very important	11	10.7
Moderately important		
Total	103	100
Importance of taking medication as scheduled		
Highly important	63	61.2
Very important	30	29.1
Moderately important	10	9.7
Total	103	100
Importance of limiting fluid intake		
Highly important	60	58.2
Very important	36	35.0
Moderately important	7	7
Total	103	100
Importance of watching the daily diet		
Highly important	72	69.9
Very important	31	30.0
Moderately important	0	0
Total	103	100

# Table 16: ESRD patients' attitude towards therapy

### **CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS**

### **5.1 Introduction**

The aim of this study was to evaluate therapy adherence among patients with End Stage Renal Disease (ESRD) at Kenyatta National Hospital (KNH). Generally, patients with ESRD attending haemodialysis (HD) at KNH had varied levels of adherence to the various therapeutic modalities. The highest levels of adherence were reported in the haemodialysis session attendance modality followed by prescribed medications and diet recommendations modalities. Sub optimal levels of adherence were observed in the fluid restriction modality. Overall adherence was 51.5% (n=53) which compares with the global adherence in ESRD (Griva, Lai, Lim, Yu, Foo, and Newman, 2014).

## **5.2 Discussion**

### 5.2.1 Adherence to haemodialysis session attendance

Self-reported adherence to HD session attendance by the study participants was rated highly; the findings being consistent with the records of HD session attendance that indicated that majority had attended all the prescribed HD sessions. High adherence to HD session attendance in this set-up could be associated with the findings that majority of the study participants reported that their dialysis schedule was convenient for them. Secondly, almost all the participants had enrolled for a health insurance cover with the National Hospital Insurance Fund (NHIF), which catered for the cost of HD treatment. In addition most of the patients had also attended counselling sessions on the importance of not missing HD and that of staying for the entire HD time although disparities on the frequency of the counselling sessions were noted. These findings were consistent with those of a study done in Malaysia among patients undergoing HD where Chan, (2012) observed high levels of adherence. The findings were also consistent with those of a study done in Palestine among patients on maintenance HD where majority of the participants reported high levels of adherence (Naalweh, Mohammad, Moutaz, and Samah, 2017). However these findings contradict results that were obtained in a study done in Australia where levels of HD session attendance were found to be suboptimal despite the high level of access to healthcare (Smyth and Harting, 2015). This contrast may be linked to differences in the population attributes; the perception of the Australian population towards management of ESRD may be divergent from that of the Kenyan population. In the developed world due to enhanced accessibility to health care, patients are prescribed for 3 or more HD sessions in a week; hence patients are more likely to miss attendance of all the sessions. This is unlike in our set up where majority of the patients are prescribed for 2 sessions due to limited resources; NHIF covers a maximum of 2 sessions per week; hence patients are unlikely to miss. In this current study, age was significantly associated with high adherence to HD session attendance with participants older than 40 years having better adherence than the younger ones. The Australian study also associated non-adherence with younger age. This could be because older patients may have more organized lifestyles that allow for the demands of the therapeutic regimen than the young. The discovery that younger patients had a higher likelihood of non- adherence to HD session attendance may result in poorer quality of life and higher rates of morbidity and mortality in future.

### **5.2.2** Adherence to prescribed medications

Adherence to prescribed medication was rated highly by majority of the study participants; with the self-reported adherence being consistent with the clinical findings of pre-dialysis phosphate levels that were used as clinical indicators of adherence to medication in this study. More than half of the participants had their pre- dialysis phosphate levels within the normal range and a few had levels below normal. The low levels could be associated with the chronic use of phosphate binders in ESRD and hence this group of patients was considered to be adherent to medication in this study. There was a slight overestimation of adherence by the participants which could be explained by the study methodology since serum phosphate was used as the indicator of adherence to medication yet most of the ESRD patients were on a variety of medications due to comorbidities. High adherence to prescribed medication in this current study could be associated with the fact that majority of the participants indicated that they did not have difficulties with taking their prescribed medications. In addition to this, most of the participants also reported having been counselled about their medications and on the importance of taking them, however wide variations in the frequencies of counselling were elicited. Cost of medications came up as the main challenge patients had with their medication and it is because NHIF does not cover the cost of these medicines. This finding was consistent with that of a study done at KNH among CKD patients by Mutiso, Kayima, and Amayo, (2012) where a high level of adherence to prescribed medication was observed. Also a study in Malaysia by Chan, (2012) among patients undergoing HD realized high levels of adherence to prescribed medication. Similarly a study done in Palestine among patients on maintenance HD discovered high levels of adherence to prescribed medication (Naalweh, Mohammad, Moutaz, and Samah, 2017). Various studies however contradict these findings. Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed medication non-adherence was high and it was associated with high pre-dialysis serum phosphate levels with the USA being the most affected (Fissell, Karaboyas, Bieber, Sen, Li, et al., 2016). A systematic review on adherence to phosphate binders revealed high non-adherence rates to medications (Karamanidou, Clatworthy, Weinman, and Horne, 2008). Alkatheri and Alyousif, (2014) also observed high levels of non-adherence to medication in a study conducted in Saudi Arabia among adult patients on HD. These variations may be attributed to differences in patient characteristics and study methodologies. This study did not elicit any statistically significant association of the study participants' characteristics with adherence to medication.

### 5.2.3 Adherence to fluid restriction and diet recommendations

More than half of the study participants were found to be non-adherent to fluid restriction with the self report being consistent with the clinical findings of high Inter Dialytic Weight Gain (IDWG) among the participants. IDWG was used in this study as a clinical indicator of adherence to fluid restriction where more than half of the study participants were found to have high levels; indicating low adherence to fluid restriction. The findings were explained by the high number of patients who gave reports of having difficulties in limiting fluid intake with inability to control fluid intake due to thirst being the most common reported problem. This is despite most patients having reported high frequencies of counselling sessions on importance of fluid restrictions. Excessive fluid intake increases morbidity and mortality in ESRD due to volume overload manifesting in peripheral and pulmonary oedema, hypertension and congestive heart failure. These observations are consistent with those of a study by Kugler and Maending, (2011); an international comparison study among patients on chronic HD where high levels of non-adherence to fluid restriction were realized. High nonadherence levels to fluid restriction were also documented in Turkey by Efe and Kocaöz, (2015) and by Chironda and Bhengu, (2016b) in South Africa among CKD patients on HD. A significant statistical relationship was elicited between adherence to fluid restriction and marital status with the married reporting higher adherence levels than their single counterparts. Similar findings were made in the study by Kugler and Maending (2011). This finding is associated with moral support provided to the patients by their spouses. Duration of HD of the participants also demonstrated a statistically significant relationship with fluid restriction. Participants who had dialyzed for less than 12 months had better adherence to fluid restriction than those who had dialyzed for a longer period. This finding concurs with that of a study done in Palestine among patients on maintenance HD by Naalweh, Mohammad, Moutaz, and Samah, (2017). Newly diagnosed ESRD patients may be keen to take up new habits in their fluid intake with an aim of meeting the demands of life-saving HD

therapy. However with time, they may experience lack of enthusiasm hence getting frustrated with the need to adhere. New ESRD patients may also have an advantage of receiving more social support hence being more compliant than the old.

More than half of the study participants had high level of adherence to diet recommendations with the findings of the self report being consistent with those of pre-dialysis potassium levels. Pre-dialysis potassium levels were used as clinical indicators of adherence to diet recommendations in this study, where majority of the participants were found to have favourable levels; indicating high level of adherence. These findings are explained by the fact that majority of the study participants reported no difficulties with following diet recommendations. Additionally most patients reported high frequencies of counselling sessions on importance of diet. Inability to avoid certain un-recommended foods was the most common reported problem among the patients who reported difficulties with diet recommendations. These findings were consistent with those of a study done in Saudi Arabia among patients on HD where majority of the patients had high levels of adherence to diet recommendations (Al-Khattabi, 2014). The findings of this current study contradict those of a study by Kugler and Maending, (2011) among patients on chronic HD where low levels of adherence to diet recommendations were realized. Low levels of adherence to diet recommendations were also documented in Turkey by Efe and Kocaöz, (2015) and in South Africa by Chironda and Bhengu (2016b) among CKD patients on HD treatment. Differences in the study subjects' characteristics may have contributed to these variations. Age was significantly associated with high adherence to diet recommendations where participants older than 40 years had better adherence than the younger. This could be because older patients may have more organized lifestyles that allow for the demands of the therapeutic regimen than the young.

# 5.2.4 ESRD patients' knowledge and attitude on therapy

Knowledge on diet recommendations had the highest score with 65% of the participants indicating that they fully understood that their kidney condition requires them to watch their diet. This was followed by a tie between knowledge on HD and fluid restriction with 62.1% of the participants indicating that they fully understood that their kidney condition required them to follow their dialysis schedule and limit their fluid intake respectively. Knowledge on medication was the lowest with less than half of the respondents (48.5%) indicating that they fully understood that their medicines as scheduled. Since majority of the participants in this current study had hypertension with or without diabetes as comorbidity, it is possible that they did not understand the association

between hypertension and ESRD (hypertension can be a cause or an effect of ESRD), hence explaining this finding. A number responded to this question by indicating that they took the medicines to keep their bodies healthy.

Attitude towards diet recommendations had the highest score with 69.9% of the participants believing that it is highly important to watch the type of food taken daily. The attitudes towards adherence to HD sessions and medication were close with 60.25% and 61.20% of the participants believing that it is highly important to follow their dialysis schedule and take their medicines as scheduled respectively. Attitude towards fluid restriction was the lowest with 58.3% of the participants believing that it is highly important to follow their dialysis schedule and take their medicines. This finding could further explain the suboptimal levels of adherence to fluid restriction that were observed in this current study. A study done in Palestine on treatment adherence and perception in patients on maintenance HD by Naalweh, Mohammad, Moutaz, and Samah, (2017) observed higher scores of attitude than those realized in the current study. Attitude towards adherence to HD had the highest score at 96.4% followed by that of fluid restriction at 88.6%. The attitudes towards adherence to medication and diet were at 85.5% and 77.7% respectively. Differences in the study subjects' characteristics may have contributed to these variations.

## **5.3 Conclusion**

Majority of ESRD patients attending haemodialysis at KNH Renal Unit had relatively high levels of adherence to haemodialysis session attendance, diet recommendations and prescribed medications. This was validated by the clinically measured adherence indicators of haemodialysis, diet and medication (records of haemodialysis session attendance, Pre-dialysis potassium and phosphate levels respectively). However, adherence to fluid restriction was suboptimal and was validated with high Inter Dialytic Weight Gain (IDWG) that was observed among the study participants. Generally the study participants were found to be knowledgeable on their therapeutic modalities and had a positive attitude on the same. Most of the Socio-demographic factors had no statistical significance in relation to adherence to the four therapeutic modalities. Therefore the null hypothesis that 'Age, gender, marital status, education level and duration of haemodialysis have no influence on adherence to therapy among ESRD patients at KNH' is not rejected.

### **5.4 Recommendations**

### **5.4.1 Policy and Action Recommendations**

There is need for health care providers to enhance emphasis on the importance of adhering to haemodialysis session attendance and of staying for the entire time of treatment especially among patients aged below 40 years. This will help improve their quality of life and reduce rates of morbidity and mortality that are associated with missed haemodialysis sessions. Inability to control thirst was singled out as a major challenge in adhering to fluid restriction among the study participants. It is therefore important that patients are educated on how to deal with thirst without intake of fluids. Proposals that have been made towards this include: sucking on ice chips, cold sliced fruit or sour candies; chewing gum and use of artificial saliva. Challenges of inability to avoid certain un-recommended foods among the study participants affected the outcomes of adherence to diet recommendations. On account of this, healthcare professionals should single out individual patient's perceived barriers; explore their preparedness to alter their dietary practices so as to attain optimal outcomes of adherence. There is need for health care providers to give patients adequate information on causes, manifestations and management of ESRD. This should be done in scheduled educational sessions to ensure standardized frequencies of counselling for all the patients besides identifying individual patient needs. Emphasis on holistic adherence to all forms of therapy to include haemodialysis session attendance, medication prescription, and fluid restriction and diet recommendations is imperative. There is a need for health care providers to ensure that pre-dialysis potassium and phosphate levels are monitored monthly with proper filing of the laboratory reports so as to detect hyperkalaemia and hyperphosphatemia that are associated with arrhythmias and cardiovascular events; the commonest causes of morbidity and mortality among ESRD patients. There is need for the National Hospital Insurance Fund (NHIF) to offer a comprehensive package for the ESRD patients to besides catering for haemodialysis treatment, cover the cost of medicines, laboratory investigations and counselling sessions.

### 5.4.2 Recommended studies

- 1. Evaluation of clinical outcomes in ESRD.
- 2. Self-regulation of fluid intake among ESRD patients.
- 3. Diet intake patterns among ESRD patients on haemodialysis.
- 4. Fluid and dietary counselling in ESRD by healthcare providers.

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### APPENDICES

### **APPENDIX 1: RESEARCH BUDGET**

COMPONENTS	UNIT OF	NUMBER/	COST	TOTAL
	MEASURE	DURATION	(KSH)	(KSH)
<u>Personnel</u>				
Research assistant	1	24	1,000.00	24,000.00
Statistician	1			30,000.00
Printing				
Proposal	1	70	10.00	700.00
Consent form	1	2	10.00	20.00
Questionnaires	1	9	10.00	90.00
ERC application form	1	6	10.00	60.00
Final report	1	100	10.00	1,000.00
Photocopying				
Proposal	3	75	3.00	675.00
Consent form	115	2	3.00	690.00
Questionnaires	115	9	3.00	3,105.00
ERC application form	2	6	3.00	36.00
Final report	5	100	3.00	1,500.00
Binding				
Proposal	3	1	100.00	300.00
Final report	6	1	500.00	3,000.00
Other costs				
ERC fees				2,000.00
Records access fees				1,500.00
Report dissemination fees				60,000.00
Subtotal				128,676.00
Miscellaneous (10% of subtotal)				12,867.60
Grand total				141,543.60

### **APPENDIX 2: WORK PLAN GANTT CHART**

ACTIVITY	Dec. 2017	Jan. 2018	Feb. 2018	Mar. 2018	Apr. 2018	May. 2018	Jun. 2018	Jul. 2018	Aug. 2018	Sept. 2018	Oct 2018	Nov. 2018
Proposal writing	2017	2010	2010	2010	2010	2010	2010	2010	2010	2010	2010	2010
Approval by ERC												
Pre-testing and correction of tool												
Data collection												
Data management												
Report writing												
Defence of project report												
Report dissemination												

### APPENDIX 3: INFORMED CONSENT (ENGLISH VERSION)

### Study information sheet for study participants and consent form

### Study title: Evaluation of therapy adherence among patients with End Stage Renal Disease at Kenyatta National Hospital

#### Introduction to the study and the researcher

My name is Polly Gichoni. I'm a postgraduate student at the University of Nairobi, School of Nursing Sciences, pursuing a Master of Science in nursing (MScN) degree. I'm conducting a research study at the Kenyatta National Hospital Renal Unit to evaluate adherence to therapy among End Stage Renal Disease (ESRD) patients.

For the study to be successful, I request your participation by completing a questionnaire that will be availed to you. You will be required to tick on the most appropriate response to the best of your knowledge. Since you are already on management of ESRD, I'm interested in collecting information on how you adhere to the prescribed medicines, diet and fluid recommendations and also on attendance to haemodialysis sessions.

#### Assurance of confidentiality

Confidentiality will be observed in handling of all the information that you will give in this study. You are required to voluntarily consent to participate in this study after which you will be provided with a copy of the consent form to fill. Neither your name nor any form of identification will be included in the questionnaire. An identification number will be allocated instead and it shall remain confidential to the researcher only.

### **Rights of the Participant**

Your participation in this study is voluntary. Your refusal to participate will not affect the provision of services that you deserve. Even after consenting to participate, you'll be free to withdraw from the study at any time. No monetary incentive will be given to the participants in this study.

#### **Benefits/ Risks of the study**

Findings from this study will be utilised in determining the success or failure rate of ESRD management. This will inform the care givers at KNH Renal Unit on areas that require improvement or sustenance in management of ESRD patients. This will be of great importance towards reduction of complications amongst the patients. The national policy makers will also be informed on areas of priority in planning of management of ESRD. This will be of great assistance in resource allocation both at the KNH and at the national level. The study findings will also be utilized for future research in the study field.

During the study process no invasive procedures will be performed. You may experience minimal risks that could be psychological in nature on realization of possible areas of non-adherence to therapy. In case you experience these challenges, you are advised to get in touch with the researcher for assistance. No punitive measures will be applied in case of non-adherence.

### **Duration of participation**

You are required to fill in a questionnaire if you are able to read and write. If otherwise the researcher will be of assistance in reading the questions to you and filling in your responses. There will be no follow up interviews after, and the process will take about 45 minutes of your time.

### **Contact information**

For any queries or clarifications concerning this study, you are advised to contact Polly Gichoni, MScN student at the University of Nairobi, School of Nursing Sciences on mobile number 0722 797 497, or the Chairperson, KNH-UON ERC on P.O. Box 20723-00202. Tel. 020 2725272.

### **Consent form**

The above details concerning the study have been explained to me. I agree to participate in the study. I understand my participation in the study is voluntary. I willingly give my consent to divulge the necessary information that is required.

Participant's signature/thumb mark \_\_\_\_\_

Researcher's signature

Date \_\_\_\_\_

### **APPENDIX 4: INFORMED CONSENT (KISWAHILI VERSION)**

### Karatasi ya habari ya utafiti kwa washiriki na ridhaa ya kushiriki kwenye utafiti

## Mada ya utafiti: Tathmini ya uzingatiaji wa tiba miongoni mwa wagonjwa wanaougua ugonjwa sugu wa figo katika hospitali kuu ya Kenyatta

### Dibaji ya utafiti na mtafiti

Jina langu ni Polly Gichoni. Mimi ni mwanafunzi wa shahada ya uzamili katika Shule ya Sayansi ya Uuguzi ya Chuo Kikuu cha Nairobi. Ninafanya utafiti wa kutathmini uzingatiaji wa tiba miongoni mwa wagonjwa wanaogua ugonjwa sugu wa figo katika Hospitali Kuu ya Kenyatta.

Ili kuweza kufaulu katika utafiti huu, naomba kushiriki kwako kwa kukamilisha dodoso utakalopatiwa. Utahitajika kutia alama ya pata ( $\sqrt{}$ ) kwenye jibu sahihi zaidi kwa kadri ya ufahamu wako. Kwa kuwa wewe unapata tiba ya ugonjwa sugu wa figo, nina nia ya kukusanya taarifa juu ya jinsi ya uwezo wako wa kuzingatia matumizi ya dawa zilizopendekezwa na maagizo ya vyakula na vinywaji, na pia mahudhurio ya vikao vya usafishaji damu.

### Uhakika wa usiri

Unahakikishiwa usiri kwa taarifa zote ambazo utatoa katika utafiti huu. Unatakikana kukubali kushiriki katika utafiti huu kwa hiari yako mwenyewe bila kulazimishwa na kwa kujaza nakala ya ridhaa ya idhini. Unahakikishiwa ya kwamba jina lako au aina yoyote ya utambulisho hayatajumuishwa katika hojaji, na badala yake, nambari ya utambulisho itatengwa na itabaki siri kwa mtafiti tu.

### Haki za mshiriki

Kushiriki kwako katika utafiti huu ni kwa hiari. Kukataa kushiriki hakutaathiri utoaji wa huduma unazostahili. Hata baada ya kuridhia kushiriki, utakuwa huru kujitoa kwa utafiti wakati wowote. Hakuna motisha ya fedha itatolewa kwa washiriki katika utafiti huu.

### Faida / hatari ya utafiti

Matokeo ya utafiti huu itatumika katika kuamua kiwango cha mafanikio katika matibabu ya ugonjwa sugu wa figo. Hii taarifa itatumika kuwaarifu wahudumu wa afya katika kitengo cha figo cha Hospitali Kuu ya Kenyatta katika maeneo ambayo yanahitaji kuboreshwa au kuendelezwa katika tiba ya ugonjwa huu. Hii itakuwa ni ya umuhimu mkubwa kuelekea kupunguza matatizo miongoni mwa wagonjwa. Watunga sera ya taifa pia wataangaziwa katika maeneo ya kipaumbele katika mipango ya usimamizi wa ugonjwa huu. Huu utakuwa ni msaada mkubwa katika ugawaji wa rasilimali katika Hospitali Kuu ya Kenyatta na katika ngazi ya taifa. Matokeo pia yatatumika kwa ajili ya utafiti wa baadaye.

Katika wakati wa mchakato wa utafiti huu hakuna taratibu vamizi zitafanywa. Unaweza pata hatari ndogo ambazo zinaweza kuwa za kisaikolojia katika asili juu ya utambuzi wa maeneo ya uwezekano wa kutozingatia tiba. Iwapo utapatana na changamoto hizi, unashauriwa kuwasiliana na mtafiti. Hakuna hatua za kutoa adhabu zitatekelezwa katika kesi ya kutozingatia matibabu.

### Muda wa kushiriki

Unahitajika kujaza dodoso kama una uwezo wa kusoma na kuandika. Kama vinginevyo mtafiti atakusaidia kusoma maswali na kujaza majibu yako. Hakutakuwa na mahojiano ya kufuatilia baada ya hojiano hili, na mchakato huu utachukua dakika 45 ya muda wako.

### Taarifa ya mwasiliano

Kwa maswali yoyote au ufafanuzi kuhusu utafiti huu, unashauriwa kuwasiliana na Polly Gichoni, mwanafunzi wa shahada ya uzamili katika Shule ya Sayansi ya Uuguzi ya Chuo Kikuu cha Nairobi, kwa nambari ya simu: 0722 797 497; au Mwenyekiti wa Kamati ya maadili ya utafiti katika Hospitali Kuu ya Kenyatta na Chuo Kikuu cha Nairobi kwenye S.L.P. 20723-00202, nambari ya simu: 020 2725272.

### Ridhaa ya kushiriki kwenye Utafiti

Nimeelezwa kuhusu utafiti unaonuiwa kufanywa. Nimekubali kushiriki kwa utafiti huu. Nimeelezwa kushiriki kwangu ni kwa hiari yangu. Nakubali kutoa habari zote zitakazotakikana kwa utafiti huu.

Sahihi/kidole gumba cha mshiriki \_\_\_\_\_

Sahihi ya mtafiti \_\_\_\_\_

Tarehe \_\_\_\_\_

### **APPENDIX 5: RESEARCH INSTRUMENT**

# Evaluation of therapy adherence among patients with End Stage Renal Disease at Kenyatta National Hospital

#### Questionnaire number \_\_\_\_\_

### **INSTRUCTION TO THE INTERVIEWER**

- i. Ensure that the participants are ESRD adult patients as per the inclusion and exclusion criteria.
- ii. Do not suggest responses to the participant.
- iii. Do not write the name of the participant on the questionnaire.

### SECTION I: SOCIO-DEMOGRAPHIC DATA

<b>1. Age in years:</b> $\Box$ 18-29 <sub>(1)</sub> $\Box$ 30-39 <sub>(2)</sub> $\Box$ 40-49 <sub>(3)</sub> $\Box$ 50-59 <sub>(4)</sub> $\Box$ 60 and above <sub>(5)</sub>
<b>2. Gender:</b> $\Box$ Male <sub>(1)</sub> $\Box$ Female <sub>(2)</sub>
<b>3. Marital status:</b> $\Box$ Married <sub>(1)</sub> $\Box$ Single <sub>(2)</sub> $\Box$ Widow/widower <sub>(3)</sub> $\Box$ Separated <sub>(4)</sub>
4. What is your highest education?
$\square None_{(1)} \square Primary completed_{(2)} \square Secondary completed_{(3)} \square College/university_{(4)}$
SECTION II: BIOCHEMICAL DATA
5. Last 3 pre-dialysis Potassium levels i) ii) iii) Average
6. Last 3 pre-dialysis Phosphate levels i) ii) iii) Average
7. Last 3 Inter-dialysis weight gains (IDWG) i) ii) iii) Average
8. Haemodialysis session appointments for the last one month
9. Haemodialysis sessions attended in the last one month

### SECTION III: End- Stage Renal Disease Adherence Questionnaire (ESRD-AQ)

This is a self- administered questionnaire with 48 items. The questions ask for your opinion about how well you follow your dialysis treatment schedule and recommendations related to medication, fluid restriction and recommended diet as well as your knowledge and attitude on treatment. This information will help us understand if you have difficulty following your haemodialysis treatment, medication regimen, fluid restriction and recommended diet. Please answer questions by marking the appropriate box with a tick ( $\sqrt{}$ ). If you are unsure about how to answer, please choose one best answer that applies to you.

Note: Numbers in parenthesis are the response codes.

### A. General information

10. How long have you been receiving haemodialysis treatment?
$\Box$ 3 to 12 months <sub>(1)</sub> $\Box$ 13 to 24 months <sub>(2)</sub> $\Box$ 25 to 36 months <sub>(3)</sub> $\Box$ 37 months and more <sub>(4)</sub>
<b>11.</b> Apart from kidney failure, do suffer from any other condition? $\Box$ No <sub>(1)</sub> $\Box$ Yes <sub>(2)</sub> (please answer below)
$\Box$ Hypertension <sub>(1)</sub> $\Box$ Diabetes <sub>(2)</sub> $\Box$ Hypertension <sub>(3)</sub> and diabetes
Other (specify) <sub>(4)</sub>
12. What type of transportation do you use to go to the dialysis centre?
$\Box \ Personal_{(1)} \qquad \Box \ Bus_{(2)} \qquad \Box \ Taxi_{(3)} \qquad \Box \ Medical \ transportation \ van_{(4)}$
Other (specify) (5)
13. Who assists you in the management of kidney failure?
$\square Myself_{(1)} \square Parent_{(2)} \square Spouse (husband or wife)_{(3)} \square Child_{(4)} \square Friend_{(5)}$
$\Box$ Other (specify the person) <sub>(6)</sub>
14. How far is your home from Kenyatta National Hospital?
$\Box \ 0 \text{ to } 20 \text{ km}_{(1)} \ \Box \ 21 \text{ to } 40 \text{ km}_{(2)} \ \Box \ 41 \text{ to } 60 \text{ km}_{(3)} \ \Box \ 61 \text{ to } 100 \text{ km}_{(4)}$
$\Box$ 101 km and more <sub>(5)</sub>
15. What is your employment status?
$\square \ Employed_{(1)} \ \square \ Self-employed_{(2)} \ \square \ Unemployed_{(3)} \ \square \ Other(specify)_{(4)}$
16. Are you a member of the National Hospital Insurance Fund (NHIF)?
$\Box$ No <sub>(1)</sub> $\Box$ Yes <sub>(2)</sub>
II. Adherence to Haemodialysis
17. How many days a week do you receive haemodialysis treatment?
$\Box$ 2 days or less <sub>(1)</sub> $\Box$ 3 days <sub>(2)</sub> $\Box$ 4 days <sub>(3)</sub> $\Box$ More than 4 days <sub>(4)</sub> $\Box$ More than 5 days <sub>(5)</sub>
18. How many hours are you treated for each haemodialysis?
$\Box$ Less than 3 hours <sub>(1)</sub> $\Box$ 3 hours <sub>(2)</sub> $\Box$ 3 hours and 15 minutes <sub>(3)</sub> $\Box$ 3 hours and 30 minutes <sub>(4)</sub>
$\Box$ 3 hours and 45 minutes <sub>(5)</sub> $\Box$ 4 hours <sub>(6)</sub> $\Box$ More than 4 hours <sub>(7)</sub>
□ Other (specify hours) <sub>(8)</sub>

### **19.** Is your dialysis schedule convenient for you?

- $\Box$  Yes<sub>(1)</sub>  $\Box$  No, because I have to come to the dialysis center too early<sub>(2)</sub>
- $\Box$  No, because I have to come to the dialysis center too late<sub>(3)</sub>
- $\Box$  No because of my work schedule<sub>(4)</sub>
- $\Box$  No, because it is my meal time and I get hungry during the dialysis treatment<sub>(5)</sub>
- $\Box$  No, because it is my medication time and I have to take medicines/insulin<sub>(6)</sub>

# 20. When was the last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about the importance of not missing your dialysis treatment?

 $\Box$  This week<sub>(1)</sub>  $\Box$  Last week<sub>(2)</sub>  $\Box$  One month ago<sub>(3)</sub>  $\Box$  More than a month ago<sub>(4)</sub>

 $\Box$  When I first began dialysis treatment<sub>(5)</sub>  $\Box$  Never<sub>(6)</sub>  $\Box$  Other (specify)<sub>(7)</sub>

# 21. How often does a medical professional (your doctor, nurse, dietician, or other medical staff) talk to you about the importance of staying for the entire dialysis time during your dialysis treatment?

- $\Box$  Every dialysis treatment<sub>(1)</sub>  $\Box$  Every week<sub>(2)</sub>  $\Box$  Every month<sub>(3)</sub>  $\Box$  Every 2 to 3 month<sub>(4)</sub>
- $\Box$  Every 4 to 6 months<sub>(5)</sub>  $\Box$  When I have abnormal blood or other test results<sub>(6)</sub>
- $\square$  Rarely<sub>(7)</sub>  $\square$  Irregularly<sub>(8)</sub>  $\square$  Never<sub>(9)</sub>  $\square$  Other (Specify) (10): \_\_\_\_\_

### 22. How important do you think it is to follow your dialysis schedule?

- $\Box$  Highly important<sub>(1)</sub>  $\Box$  Very important<sub>(2)</sub>  $\Box$  Moderately important<sub>(3)</sub>
- $\Box$  A little important<sub>(4)</sub>  $\Box$  Not important<sub>(5)</sub>

## 23. Why do you think it is important to follow your dialysis schedule? (Please choose one best answer that applies to you.)

- $\Box$  Because I fully understand that my kidney condition requires dialysis as scheduled<sub>(1)</sub>
- $\Box$  Because following the dialysis schedule is important to keep my body healthy<sub>(2)</sub>
- $\Box$  Because medical professional (my doctor, nurse, or dietician) told me to do so<sub>(3)</sub>
- $\Box$  Because I had an experience that I was sick after I missed dialysis<sub>(4)</sub>
- $\Box$  Because I had an experience that I was hospitalized after I missed dialysis<sub>(5)</sub>
- $\Box$  I don't think following the dialysis schedule is very important to me<sub>(6)</sub>

□ Other (Specify)(7):

# 24. How much difficulties have you had staying for your entire dialysis treatment as ordered by your doctor?

$\square \text{ No difficulty}_{(1)} \ \square \text{ A little difficulty}_{(2)} \ \square \text{ Moderate difficulty}_{(3)} \ \square \text{ A lot of difficulty}_{(4)}$
$\Box$ Extreme difficulty <sub>(5)</sub>
25. During the last month, how many dialysis treatments did you miss completely?
$\Box$ None (I did not miss any treatments) (1) $\Box$ Missed one dialysis treatment <sub>(2)</sub>
$\Box$ Missed two dialysis treatments <sub>(3)</sub> $\Box$ Missed three dialysis treatments <sub>(4)</sub>
$\Box$ Missed four or more dialysis treatments <sub>(5)</sub>
26. What was the main reason you missed your dialysis treatment last month?
$\Box$ Not applicable: I did not miss any treatment <sub>(1)</sub> $\Box$ Transportation problems <sub>(2)</sub>
$\Box$ I had other things to do (Please explain) (3):
$\Box$ Haemodialysis access (graft, fistula, or catheter) clotted <sub>(4)</sub>
$\Box$ Physician (medical or surgical) appointment <sub>(5)</sub> $\Box$ I had to go to the emergency room <sub>(6)</sub>
$\Box$ I was hospitalized <sub>(7)</sub> $\Box$ Forgot <sub>(8)</sub>
$\Box$ "Didn't want to go" or "Couldn't go" (Go to the next question: Question #28) <sub>(9)</sub>
□ Other (Please specify) (10):
27. (Answer this question when you marked the above question as "Didn't want to go Couldn't go.") Why didn't you want to go to the dialysis center? (Please choose one best answer that applies to you)

 $\Box$  Because dialysis treatment makes me anxious<sub>(1)</sub>  $\Box$  Because I had vomiting/diarrhea<sub>(2)</sub>

$\Box$ Because I had cramping <sub>(3)</sub>	$\Box$ Because I often get hungry	during dialysis treatment(4)
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□ Because I was	physically	v uncomfortable (S	Specify the	condition) (5)
	physican	y unconnortuole (c	peen y une	

 $\Box$  Because I was sick due to other conditions (Specify the conditions) (6)

□ Because I was emotionally depressed<sub>(7)</sub> □ Other<sub>(8):</sub>

### 28. During the last month, how many times have you shortened your dialysis time?

Not omnligghla	I have not chartanad	my dialyzin time		Truico
$\square$ inot applicable.	. I have not shortened	1  Inv  unarysis  und(1)	$\Box$ Once(2)	
TT TT			(-)	

 $\Box$  Three times<sub>(4)</sub>  $\Box$  Four to five times<sub>(5)</sub>  $\Box$  Other (Specify frequency)<sub>(6)</sub> : \_\_\_\_\_

# 29. During the last month, when your dialysis treatment was shortened, what was the average number of minutes?

 $\Box$  Not applicable: I have not shortened my dialysis time<sub>(1)</sub>

 $\Box$  Less than 10 minutes or 10 minutes<sub>(2)</sub>  $\Box$  11 to 20 minutes<sub>(3)</sub>  $\Box$  21 to 30 minutes<sub>(4)</sub>

 $\Box$  More than 31 minutes<sub>(5)</sub>  $\Box$  Other (Specify) <sub>(6)</sub>

### (If you need to write two or more different time because you shortened dialysis more than once, please use this space): \_\_\_\_\_\_

### 30. What was the main reason you have shortened your dialysis treatment?

□ Not applicable: I	have not shortened	my dialysis	time(1)
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 $\Box$  Cramping<sub>(2)</sub>  $\Box$  Bathroom use<sub>(3)</sub>  $\Box$  Restlessness<sub>(4)</sub>  $\Box$  Low blood pressure<sub>(5)</sub>

 $\Box$  Access (graft, fistula, or catheter) clotted<sub>(6)</sub>  $\Box$  Personal business or emergency<sub>(7)</sub>

 $\Box$  Physician (medical or surgical) appointment<sub>(8)</sub>  $\Box$  Did not feel like staying<sub>(9)</sub>

 $\Box$  Work schedule<sub>(10)</sub>  $\Box$  Transportation problems<sub>(11)</sub>

 $\Box$  Staff decision (Why? Please explain: For example, poor blood flow, clotting dialyzer, machine malfunction, etc.) (12):

Other (Please specify) (13):

### **III. Adherence to Medication**

## **31.** When was the last time a medical professional (your doctor, nurse, dietician or other medical staff) spoke to you about your medicines?

 $\Box$  This week<sub>(1)</sub>  $\Box$  Last week<sub>(2)</sub>  $\Box$  One month ago<sub>(3)</sub>  $\Box$  More than a month ago<sub>(4)</sub>

 $\Box$  When I first began dialysis treatment<sub>(5)</sub>  $\Box$  Never<sub>(6)</sub>  $\Box$  Other (Specify) (7): \_\_\_\_\_

## **32.** How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of taking medicines as ordered?

 $\Box$  Every dialysis treatment<sub>(1)</sub>  $\Box$  Every week<sub>(2)</sub>  $\Box$  Every month<sub>(3)</sub>

 $\Box$  Every 2 to 3 months<sub>(4)</sub>  $\Box$  Every 4 to 6 months<sub>(5)</sub>

 $\Box$  When I have abnormal blood or other (for example, blood pressure) test results<sub>(6)</sub>

 $\square$  Rarely<sub>(7)</sub>  $\square$  Irregularly<sub>(8)</sub>  $\square$  Never<sub>(9)</sub>  $\square$  Other (Specify) (10): \_\_\_\_\_

### 33. How important do you think it is to take your medicines as scheduled?

 $\Box$  Highly important<sub>(1)</sub>  $\Box$  Very important<sub>(2)</sub>  $\Box$  Moderately important<sub>(3)</sub>

 $\Box$  A little important<sub>(4)</sub>  $\Box$  Not important<sub>(5)</sub>

# 34. Why do you think it is important to take your medicines as scheduled? (Please choose one best answer that applies to you.)

 $\hfill\square$  Because I fully understand that my kidney condition requires to take medicines as  $\mathsf{scheduled}_{(1)}$ 

 $\Box$  Because taking medicines is important to keep my body healthy<sub>(2)</sub>

 $\Box$  Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do  $so_{(3)}$ 

 $\Box$  Because I had an experience that I was sick after I missed medicines<sub>(4)</sub>

 $\Box$  Because I had an experience that I was hospitalized after I missed medicines<sub>(5)</sub>

 $\Box$  I don't think taking medicines is very important to me<sub>(6)</sub>

□ Other (Specify) (7): \_\_\_\_\_

35. Have you had any difficulty with taking your medicine	$2 \square No_{(1)}$	$\Box$ Yes <sub>(2)</sub>
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### 36. How much difficulty have you had with taking your prescribed medicines?

 $\Box$  No difficulty<sub>(1)</sub>  $\Box$  A little difficulty<sub>(2)</sub>  $\Box$  Moderate difficulty<sub>(3)</sub>

 $\Box$  A lot of difficulty<sub>(4)</sub>  $\Box$  Extreme difficulty<sub>(5)</sub>

### 37. During the past week, how often have you missed your prescribed medicines?

 $\Box$  None of the time: I did not miss my medicines<sub>(1)</sub>  $\Box$  Very seldom<sub>(2)</sub>

 $\Box$  About half of the time<sub>(3)</sub>  $\Box$  Most of the time<sub>(4)</sub>  $\Box$  All of the time<sub>(5)</sub>

### 38. What was the main reason for not taking your prescribed medicines this past week?

- $\Box$  Not applicable: I did not miss medicines<sub>(1)</sub>  $\Box$  Forgot to take medicines<sub>(2)</sub>
- $\Box$  Forgot to order medicines<sub>(3)</sub>  $\Box$  Medicine cost<sub>(4)</sub>  $\Box$  Inconvenience<sub>(5)</sub>

 $\Box$  I was hospitalized<sub>(6)</sub>  $\Box$  Side effects<sub>(7)</sub> (Go to question #41)

□ Other<sub>(8):</sub> \_\_\_\_\_

# 41. (Answer this question when you have marked the above question as "Side effects.") What kind of side effect(s) to the medication(s) did you have? (Please choose one best answer that applies to you.)

$\Box$ Loss of appetite <sub>(1)</sub>	$\Box$ Nausea/vomiting/diarrhoea/constipation <sub>(2)</sub>	$\Box$ Stomach pain <sub>(3)</sub>
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 $\Box$  Dizziness<sub>(4)</sub>  $\Box$  Headache<sub>(5)</sub>  $\Box$  Itching/skin problems<sub>(6)</sub>

Other (Specify symptoms) (7):\_\_\_\_\_

### **IV. Adherence to Fluid restriction**

## 42. When was the last time a medical professional (your doctor, nurse or dietician or other medical staff) spoke to you about your fluid restrictions?

 $\Box$  This week<sub>(1)</sub>  $\Box$  Last week<sub>(2)</sub>  $\Box$  One month  $ago_{(3)}$   $\Box$  More than a month  $ago_{(4)}$ 

 $\Box$  When I began dialysis treatment<sub>(5)</sub>  $\Box$  Never<sub>(6)</sub>  $\Box$  Other (Specify)<sub>(7):</sub>

43. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of fluid restriction?

 $\Box$  Every dialysis treatment<sub>(1)</sub>  $\Box$  Every week<sub>(2)</sub>  $\Box$  Every month<sub>(3)</sub>  $\Box$  Every 2 to 3 month<sub>(4)</sub>

 $\Box$  Every 4 to 6 months<sub>(5)</sub>  $\Box$  Rarely<sub>(6)</sub>  $\Box$  Irregularly<sub>(7)</sub>  $\Box$  Never<sub>(8)</sub>

 $\Box$  When I have abnormal blood or other (for example, blood pressure) test results<sub>(9)</sub>

 $\Box$  Other (Specify)<sub>(10):</sub>

# 44. During the past week, how often have you followed the fluid restriction recommendations?

 $\Box$  All of the time<sub>(1)</sub>  $\Box$  Most of the time<sub>(2)</sub>  $\Box$  About half of the time<sub>(3)</sub>  $\Box$  Very seldom<sub>(4)</sub>

 $\Box$  None of the time<sub>(5)</sub>

### 45. How important do you think it is to limit your fluid intake?

 $\Box$  Highly important<sub>(1)</sub>  $\Box$  Very important<sub>(2)</sub>  $\Box$  Moderately important<sub>(3)</sub>

 $\Box$  A little important<sub>(4)</sub>  $\Box$  Not important<sub>(5)</sub>

## 46. Why do you think it is important for you to limit your fluid intake? (Please choose one best answer that applies to you).

Because I fully understand that my kidney condition requires limiting fluid intake<sub>(1)</sub>

 $\Box$  Because limiting fluid intake is important to keep my body healthy<sub>(2)</sub>

 $\Box$  Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do  $so_{(3)}$ 

 $\Box$  Because I got sick after I drank lots of fluid<sub>(4)</sub>

Because I was hospitalized after I drank lots of fluid(5)

 $\Box$  I don't think limiting fluid is very important to me<sub>(6)</sub>

Other (Specify)(7): \_\_\_\_\_

### **47.** Have you had any difficulty with limiting your fluid intake? $\Box$ No<sub>(1)</sub> $\Box$ Yes<sub>(2)</sub>

48. How much difficulty have you had following your fluid restriction recommendations?

 $\Box$  No difficulty<sub>(1)</sub>  $\Box$  A little difficulty<sub>(2)</sub>  $\Box$  Moderate difficulty<sub>(3)</sub>  $\Box$  A lot of difficulty<sub>(4)</sub>

 $\Box$  I was unable to follow any recommendations at all<sub>(5)</sub>

## 49. If you had difficulty following your fluid restriction recommendations, what type of difficulty have you had?

 $\Box$  No difficulty<sub>(1)</sub>  $\Box$  Not interested<sub>(2)</sub>  $\Box$  I was unable to control fluid intake<sub>(3)</sub>

 $\Box$  I don't understand how to follow the fluid restriction<sub>(4)</sub>  $\Box$  Other<sub>(5):</sub> \_\_\_\_\_

### V. Adherence to Diet recommendations

50. When was last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about your diet?

 $\Box$  This week<sub>(1)</sub>  $\Box$  Last week<sub>(2)</sub>  $\Box$  One month ago<sub>(3)</sub>  $\Box$  More than a month ago<sub>(4)</sub>

 $\Box$  When I began dialysis treatment<sub>(5)</sub>  $\Box$  Never<sub>(6)</sub>  $\Box$  Other (Specify)<sub>(7):</sub>

## 51. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of following a proper diet?

 $\Box$  Every dialysis treatment<sub>(1)</sub>  $\Box$  Every week<sub>(2)</sub>  $\Box$  Every month<sub>(3)</sub>  $\Box$  Every 2 to 3 months<sub>(4)</sub>

 $\Box$  Every 4 to 6 months<sub>(5)</sub>  $\Box$  Rarely<sub>(6)</sub>  $\Box$  Irregularly<sub>(7)</sub>  $\Box$  Never<sub>(8)</sub>

 $\Box$  When I have abnormal blood or other (for example, blood pressure) test results<sub>(9)</sub>

 $\Box$  Other (Specify)<sub>(10):</sub>

### 52. How important do you think it is to watch the types of food you eat each day?

 $\Box$  Highly important<sub>(1)</sub>  $\Box$  Very important<sub>(2)</sub>  $\Box$  Moderately important<sub>(3)</sub>

 $\Box$  A little important<sub>(4)</sub>  $\Box$  Not important<sub>(5)</sub>

# 53. Why do you think it is important for you to watch your diet daily? (Please choose one best answer that applies to you.)

 $\Box$  Because I fully understand that my kidney condition requires to watch my diet<sub>(1)</sub>

- $\Box$  Because watching my diet is important to keep my body healthy<sub>(2)</sub>
- $\Box$  Because a medical professional (my doctor, nurse, or dietician) told me to do so<sub>(3)</sub>
- $\Box$  Because I got sick after eating certain food that I was not supposed to eat<sub>(4)</sub>
- $\Box$  Because I was hospitalized after eating certain food that I was not supposed to eat<sub>(5)</sub>

 $\Box$  I don't think watching my diet is important to me<sub>(6)</sub>

□ Other (Specify) (7): \_\_\_\_\_

54. Have you had any difficulty following your dietary recommendations?

 $\Box$  No<sub>(1)</sub>  $\Box$  Yes<sub>(2)</sub>

### 55. How much difficulty have you had following your dietary recommendations?

 $\Box$  No difficulty<sub>(1)</sub>  $\Box$  A little difficulty<sub>(2)</sub>  $\Box$  Moderate difficulty<sub>(3)</sub>  $\Box$  A lot of difficulty<sub>(4)</sub>

 $\Box$  I was unable to follow any recommendations at all<sub>(5)</sub>

### 56. What type of difficulty have you had keeping your dietary recommendations?

- $\Box$  Not applicable: No difficulty<sub>(1)</sub>
- $\Box$  I was not willing to control what I want to eat<sub>(2)</sub>

 $\Box$  I was unable to avoid certain un-recommended food<sub>(3)</sub>

- $\Box$  I don't understand what type of diet to follow<sub>(4)</sub>
- □ Other (Specify) (5): \_\_\_\_\_

# 57. During the past week, how many times have you followed the diet recommendations?

 $\Box$  All of the time<sub>(1)</sub>  $\Box$  Most of the time<sub>(2)</sub>  $\Box$  About half of the time<sub>(3)</sub>  $\Box$  Very seldom<sub>(4)</sub>

 $\Box$  None of the time<sub>(5)</sub>

#### **APPENDIX 6: KNH/UON ETHICS AND RESEARCH COMMITTEE APPROVAL**



UNIVERSITY OF NAIROBI COLLEGE OF HEALTH SCIENCES P 0 BOX 19676 Code 00202 Telegrams: varsity Tel:(254-020) 2726300 Ext 44355

Ref: KNH-ERC/A/194

Polly Muthoni Gichoni Reg. No.H56/88368/2016 School of Nursing Sciences College of Health Sciences <u>University of Nairobi</u>

Dear Polly

RESEARCH PROPOSAL – EVALUATION OF THERAPY ADHERENCE AMONG PATIENTS WITH END STAGE RENAL DISEASE (ESRD) AT KENYATTA NATIONAL HOSPITAL (KNH) (P159/03/2018)

KNH-UON ERC

Email: uonknh\_erc@uonbi.ac.ke

Website: http://www.erc.uonbi.ac.ke

Facebook: https://www.facebook.com/uonknh.erc Twitter: @UONKNH\_ERC https://twitter.com/UONKNH\_ERC

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above research proposal. The approval period is from 29th May 2018 – 28th May 2019.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
   b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN
- ERC before implementation. c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events
- whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- f) Submission of an <u>executive summary</u> report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover



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

May 29, 2018

### **APPENDIX 7: KNH REGISTRATION CERTIFICATE**

	KNH/R&P/FORM/01
KENYATTA NATIONAL HOSPITAL P.O. Box 20723-00202 Nairobi	Tel.: 2726300/2726450/2726565 Research & Programs: Ext. 44705 Fax: 2725272 Email: <u>knhresearch@gmail.com</u>
Study Registration	on Certificate
1. Name of the Principal Investigator/Researcher POLLY GICHONI	
2. Email address:pgichoni 1407@gmail.co	M. Tel No. 0782797497
3. Contact person (if different from PI)NIA	
4. Email address:	Tel No
Hage Ranal bisease (ESAB) at Department where the study will be conducted	y among patients with Eng Kenyatta National Hospital (KNH) engl Uwit
(Please attach copy of Abstract)	
7. Endorsed by Research Coordinator of the Departme	nt where the study will be conducted.
Name: Signature	e Date
Name: M. JTHN JGG Signature	e Date plat
<ul> <li>Endorsed by KNH Head of Department where study Name: M. Thur Tangan Signature</li> <li>KNH UoN Ethics Research Committee approved stud (Please attach copy of ERC approval)</li> </ul>	will be conducted. Pate plan pate plan plan plan plan plan plan plan plan
<ul> <li>Endorsed by KNH Head of Department where study Name: M. JMLJ. JGG. Signature</li> <li>KNH UoN Ethics Research Committee approved stud (Please attach copy of ERC approval)</li> <li>I. POLLY GICHONI findings to the Department where the study will be and Programs.</li> </ul>	by numberDate 
<ul> <li>Endorsed by KNH Head of Department where study Name: M. Thur Targen Signature</li> <li>KNH UoN Ethics Research Committee approved stud (Please attach copy of ERC approval)</li> <li>I POLLI GICHONI findings to the Department where the study will be and Programs.</li> <li>Signature Main Date</li> </ul>	by number $\frac{p_{159} _{03} _{20} _{8}}{20}$ commit to submit a report of my study conducted and to the Department of Research $31 _{05} _{20} _{8}$
<ol> <li>Endorsed by KNH Head of Department where study Name: M. JMLJ. JGG. Signature</li> <li>KNH UoN Ethics Research Committee approved stud (Please attach copy of ERC approval)</li> <li>I <u>POLUT</u> <u>GICHON</u></li> <li>I <u>POLUT</u> <u>GICHON</u></li> <li>findings to the Department where the study will be and Programs.</li> <li>Signature <u>Mathematication</u> Date</li> <li>Study Registration number (Dept/Number/Year) <u>f</u></li> <li>(To be completed by Research and Programs Depart</li> </ol>	a 31 [06] 2018 2000 2018 2000 2018 2000 2018 2000 2018 2000 2018 2000 2018 2000 2018 2000 2018 2000 2018