

**PERSPECTIVES OF YOUTHS AT KENYATTA NATIONAL HOSPITAL  
LIVING WITH END STAGE KIDNEY DISEASE ON THE IMPACT OF THE  
DISEASE**

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REQUIREMENTS FOR THE AWARD OF DEGREE OF MASTERS OF  
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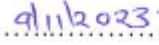
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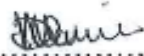
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## **DEDICATION**

This work is dedicated to my husband Shadrack Langat and my entire family for their care, motivation and spiritual support.

## **ACKNOWLEDGEMENT**

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## **LIST OF ABBREVIATIONS AND ACRONYMS**

<b>ACR:</b>	Albumin Creatinine Ratio
<b>CAKUT:</b>	Congenital anomalies of the kidney and urinary tract
<b>CKD:</b>	Chronic Kidney disease
<b>CVD:</b>	Cardiovascular Disease
<b>DALYs:</b>	Global Disability-Adjusted Life-Years
<b>eGFR:</b>	Estimated glomerular filtration rate
<b>ERC:</b>	Ethics Review Committee
<b>ESKD:</b>	End Stage Kidney Disease
<b>GBD:</b>	Global Burden of Disease
<b>GFR:</b>	Glomerular Filtration Rate
<b>GKHA:</b>	Global Kidney Health Atlas
<b>HD:</b>	Hemodialysis
<b>HIV:</b>	Human Immunodeficiency Virus
<b>ISN:</b>	International Society of Nephrology's
<b>KDIGO:</b>	Kidney Disease: Improving Global Outcomes
<b>KNH:</b>	Kenyatta National Hospital

<b>KRT:</b>	Kidney Replacement Therapies
<b>MI:</b>	Myocardial Infarction
<b>NCD:</b>	Non-Communicable Diseases.
<b>NHIF:</b>	National Health Insurance Funds
<b>PD:</b>	Peritoneal dialysis
<b>SDGs:</b>	Sustainable Development Goals
<b>SPSS:</b>	Statistical Package for Social Science.
<b>U o N:</b>	University of Nairobi
<b>USA:</b>	United States of America
<b>WHO:</b>	World Health Organization

## OPERATIONAL DEFINITIONS

**Chronic Kidney disease (CKD):** is a medical condition whereby the kidney experiences permanent structural and functional irregularities lasting longer than three months.

**Impact:** refers to marked effects or influence associated with End stage kidney disease

**Perspectives:** youths' attitudes views or opinions towards or views the biopsychosocial impact of living with End stage kidney disease

**Physical impact:** refers to the bodily effect rather than the mind. In this study, it refers to the impacts of End stage kidney disease on the youth's body

**Psychological impact:** Refers to the mental and emotional states of youths with End stage kidney disease.

**Social impact:** refers to how the disease affects the youths and their communities including social interaction and relationships

**Youth:** The World Health Organization defines youth as a transition period between childhood and adulthood from age 15 to 24.

## ABSTRACT

**Background:** End-stage kidney disease (ESKD) is a public health concern that occurs as a complication of chronic kidney disease (CKD) in which the kidneys have lost almost all of their function. Chronic kidney disease is a leading cause of death worldwide, Kenya included with its increasing burden associated to rise in non-communicable diseases (NCDs) such as diabetes and hypertension and HIV/AIDS. ESKD requires multidisciplinary approaches in its management and its treatments are complex and expensive. Youths are particularly vulnerable to the effects of ESKD due to their unique developmental needs which can interfere with their treatment compliance and general well-being. There was need therefore to explore their perspectives regarding the impacts of the disease.

**Study objective:** To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the impact of the disease

**Methodology:** A descriptive phenomenological qualitative study was used to explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the impact of the disease. Purposive sampling was used to identify the potential participants for the study. The study sample size of 11 participants was established on the basis of data saturation. Data from the study participants was collected using in-depth interviews with an interview guide. The interviews were audio-taped, then transcribed verbatim. The data was probed using the NVivo software then thematic analysis was done.

**Results:** The study participants were youths aged 15-24 years living with ESKD most of whom were single and lived with their families. In relation to the participants' perspectives regarding the physical impacts of the end stage kidney disease, body changes emerged as the main theme with extreme weakness and fatigue, weight loss and body pains as its sub-themes. In relation to the participants' perspectives regarding the psychological impacts of the end stage kidney disease, uncertainties emerged as the main theme with anxiety and stress and feeling frustrated and sad as its sub-themes. In relation to the participants' perspectives regarding the social impacts of the end stage kidney disease, biographical disruption emerged as the main theme with reliance on social capital and disrupted social life as its sub-themes.

**Conclusion:** Youths living with ESKD did experience a wide range of adverse physical, psychological and social impacts of the ailment.

**Recommendation:** Health practitioners at KNH's renal unit should accord due consideration to the physical, mental and social wellbeing of youths receiving treatment for the condition in the hospital. Youths receiving treatment for ESKD should also be encouraged to seek help for any adverse physical, mental and social effects of ESKD that they experience.

## CHAPTER ONE: INTRODUCTION

### 1.1 Introduction

Chronic Kidney disease (CKD) is a medical condition in which the kidney experiences permanent structural and functional irregularities lasting longer than three months (Agarwal, 2016). CKD can progress to End-Stage Kidney Disease (ESKD), which is the final stage where the kidneys have lost almost all of their function. End stage kidney disease (ESKD) is a severe disease that demands medical intervention, such as dialysis or kidney transplantation, to restore the impaired kidney function that has been lost (Hashmi, Benjamin and Lappin, 2023). In addition to its progression to ESKD, CKD can have other adverse outcome which include cardiovascular diseases (CVD) such as Myocardial Infarction (MI) and premature death (Hemmelgarn et al., 2010).

The Kidney Disease: Improving Global Outcomes (KDIGO 2012) has suggested CKD diagnostic methods such as laboratory testing. The most often used is the estimated glomerular filtration rate (eGFR) or urine test for the presence of albumin. The KDIGO guideline has outlined the five stages of CKD based on the eGFR and Albumin creatinine ratio (ACR) as shown in the table below.

**Table 1.1: Stages of CKD**

Stages of CKD	GFR (ml/min/1.73m <sup>2</sup> )	ACR (mg/g)	Qualitative description of kidney function
<b>G1</b>	≥ 90	< 30	High or Normal
<b>G2</b>	60 to 89	<30	Mild decrease
<b>G3a</b>	44 to 59	30 - 300	Mild or moderate decrease
<b>G3b</b>	30 to 44	30 - 300	Moderate to severe decrease
<b>G4</b>	15 to 29	>300	Severe decrease
<b>G5</b>	<15	>300	Kidney failure/ESKD

The management of ESKD is a complex process that requires a team-based approach involving various healthcare professionals, including nephrologists, dietitians, social workers, and other multidisciplinary teams (St Peter et al., 2013). The goal is to provide comprehensive care that addresses the physical, emotional and social needs of the patient and improves their quality of life. ESKD requires Kidney Replacement Therapy (KRT) such as dialysis and kidney transplantation for survival(Thurlow et al., 2003). Dialysis is a common treatment for ESKD that removes waste and excess fluids from the blood (Reddenna et al., 2014). There are two types of dialysis: hemodialysis and peritoneal dialysis. The current study mainly focused on youths receiving hemodialysis as well as those seeking transplant services at Kenyatta National Hospital.

## **1.2 Background Information**

Globally, Chronic Kidney Disease (CKD) and End Stage Kidney Disease (ESKD) are public health concerns. According to the Global Burden of Disease (GBD) Study 2019, CKD was the 16th leading cause of global disability-adjusted life-years (DALYs) and the 18th leading cause of death worldwide, responsible for approximately 1.3 million deaths in 2019 (Abbafati et al., 2020).

The prevalence of CKD is increasing globally with an estimated 9% of the world's population (approximately 700 million people) affected by CKD and a significant proportion progressing to ESKD resulting in approximately 697,000 deaths (Bikbov et al., 2020).According to the 2019 Global Kidney Health Atlas (GKHA) by the International Society of Nephrology (ISN), there were 144 newly diagnosed cases of



End Stage Kidney Disease (ESKD) per one million individuals in the global population (Oguejiofor et al., 2021).

The increasing burden of CKD and its progression to ESKD is attributed to the rise in non-communicable diseases (NCDs) such as Diabetes, hypertension, and Human Immunodeficiency Virus and Acquired immunodeficiency syndrome (HIV/AIDS) (WHO, 2021, 2022). Other predisposing factors include glomerulonephritis genetics, familial predisposition, advancing age, smoking, and exposure to nephrotoxic substances such as exposure to heavy metals (Kazanciog & Lu, 2013). Middle-income and low-income countries are mainly affected by the disease (Kovesdy, 2022; Levey et al., 2007; Liyanage et al., 2015a, 2015b). This is due to their inability to provide adequate care to those at risk for and those in need of ESKD treatment.

In the United States (US), CKD is responsible for the highest number of fatalities, with an estimated 37 million people affected by the disease and more than half progressing to ESKD (Centers for Disease Control and Prevention in the United States, 2021). Children and adolescents aged between 12-19 years are also affected by kidney disease with approximately 6427 children diagnosed with ESKD (United States Renal Data System, 2022). The adolescents diagnosed with ESKD since childhood and had been on dialysis had a life expectancy of 38 years and 63 years for those who had received kidney transplant (Kramer et al., 2009).

In Africa, the burden of CKD is at 15.8% with the majority progressing to ESKD as shown in a systematic review that included a total of 98 studies conducted in various African countries (Kaze et al., 2018). The majority of CKD cases were due to underlying predisposing factors such as diabetes, hypertension, and HIV infection.

The challenge of ESKD in Africa is intensified by the restricted availability of dialysis and transplant facilities, coupled with inadequate infrastructure for the treatment of ESKD (Luyckx et al., 2017).

In sub-Saharan Africa, ESKD poses a significant health concern due to inadequate access to renal replacement therapy (dialysis or kidney transplantation) services (Luyckx et al., 2017). As reported in a systematic review and meta-analysis that appeared in the *Lancet Global Health* in 2014, the estimated prevalence of chronic kidney disease (CKD) in sub-Saharan Africa is 13.9%, which is higher than the global prevalence of 10.6%. The prevalence of ESKD in the region is estimated to be 13.9 per million population (PMP), which is significantly lower than the global average of 279 Per million population (PMP) (Stanifer et al., 2014).

According to the *Global Burden of Disease Study 2019*, CKD was the 12th leading cause of death in Kenya, accounting for 4,724 deaths. The age-standardized CKD mortality rate in Kenya was 9.9 per 100,000 population, which is higher than the global age-standardized rate of 7.2 per 100,000 population (Abbfati et al., 2020). At Kenyatta National Hospital (KNH), the prevalence of CKD among inpatients is at 36.8% (Mwenda et al., 2019). Data on the burden of ESKD among youths globally, regionally and nationally is limited, but the available evidence suggests that ESKD is an increasing concern for public health in the region, with a significant burden on pediatrics and young adults (Bikbov et al., 2020; Cockwell & Fisher, 2020; Jager et al., 2019; Kaze et al., 2018; Massengill & Ferris, 2014; Stanifer et al., 2014).

Youths often experience significant physical, emotional and social changes as they transition from childhood to adulthood. They develop their identities and navigate

various challenges and opportunities (Spano, 2004). This affects their feelings, thinking, decision-making and interaction with the world. As well, these factors require various information and services, including but not limited to age-appropriate comprehensive sexual education, chances to develop life skills, fair, proper, and efficient health services, as well as a secure and supportive setting for optimal growth and development.

End stage kidney disease like other chronic conditions among youths affects their growth and development. Poor growth in youths and children with ESKD is mainly contributed to various factors such as abnormalities of the growth hormone (insulin-like growth factor 1) metabolic acidosis, malnutrition and renal osteodystrophy (Rodig et al., 2014). The leading causes of ESKD among young people include primary glomerular disease (21.7%), congenital anomalies of the kidney and urinary tract (CAKUT) (29.3%), cystic/hereditary/congenital diseases (12.7%), secondary glomerular disease/vasculitis (8.2%), interstitial nephritis/pyelonephritis (4.5%), transplant complications (1.3%), diabetes (0.4%) and neoplasms/tumors (0.7%) according to a study by Johansen et al. (2021).

The condition poses significant difficulties to the overall well-being of young people, leading to negative impacts on their daily activities as well as that of their families. Most caregivers of children with ESKD experience great financial hardship, and physical and psychological stress. Their work is disrupted since they play a role of a primary caregiver and still should gather for the treatment modalities (Darwish et al., 2018). The disease significantly impacts the survival rate and quality of life of youths, affecting their physical, psychological and social well-being to a greater extent than

those without the disease (El-gamasy & Eldeeb, 2017; Gerson et al., 2010; L. Tjaden et al., 2012; L. A. Tjaden et al., 2015).

The burden of ESKD is increasing globally and Kenya is not an exception. ESKD is a critical public health issue and requires prompt attention due to its severe impact on their well-being. Youths face different challenges when dealing with ESKD and more so due to concurrent developmental changes that occur at this stage (Nair et al., 2023). They need proper support to be able to overcome these challenges and survive. There was no available literature on the perspectives of youths with ESKD in Kenya on the impacts of the disease. The study was important in filling this research gap and its findings are useful in developing targeted strategies that help the youths in dealing with various challenges.

### **1.3 Problem Statement**

End stage kidney disease burdens not only the general population but also those afflicted by it. While for a long time, the greatest percentage of patients with ESKD was older, more and more younger patients are presenting for care in failure. This rising prevalence is related to the emergence of non-communicable diseases (NCDs) such as diabetes and hypertension in this population in addition to congenital causes (Bikbov et al., 2020; Kazanciog & Lu, 2013). As the cases continue to rise in the 0-15 years age group, its significance and implications on the lives of children the young people are of concern.

The youth face challenges in compliance with medication and treatments. Mohamedi and Mosha (2022) reported that in addition to financial constraints, the young patients did not adhere to treatment due to physical impacts such as fatigue and weakness

following hemodialysis. They associated the hemodialysis sessions with bad experiences. Additionally, since ESKD is a life-altering illness, many patients were still in denial. Usri, Djunadi and Iskandarsyah (2018) reported depression among those patients who had not accepted the condition. This resulted in failure to comply with the treatment.

End stage kidney disease (ESKD) has a significant impact on youths, making them particularly vulnerable to its effects, as they are in a crucial developmental stage of their lives and facing many developmental changes. This period is often characterized by increased exploration and experimentation, as well as the formation of their personal and social identity (Spano, 2004). This can be stalled and disrupted in youths with ESKD due to their unique health care needs which demands continuous dependence at a stage where they should be focusing on developing independence and their career.

Youths with ESKD experience a variety of physical, psychological, and social challenges that can impact their overall well-being (L. A. Tjaden et al., 2015). Research on the perspectives of youths with ESKD has shown that these individuals often face physical limitations related to their condition, such as fatigue, muscle weakness, and increased susceptibility to infections (El-gamasy & Eldeeb, 2017). Living with ESKD can also have adverse effects on one's social relationships, including those with family and friends, leading to feelings of loneliness and isolation (Tong et al., 2013). This makes it essential to understand the specific experiences and perspectives of youths with ESKD, to ensure that their needs are effectively addressed and to promote their overall well-being. Despite the increasing burden of ESKD in Kenya, the experiences of youths with ESKD have not been fully explored. The lack

of knowledge on the perspectives of youths with ESKD in Kenya hinders the development of targeted interventions to improve their quality of life.

In Kenya, no study had been done on the perspectives of youths living with ESKD on the impact of the disease. There was a need for a study in Kenyatta National Hospital (KNH) which is the largest referral hospital in Kenya, and one of the largest kidney care centers in East Africa. KNH Renal Unit offers both hemodialysis and kidney transplant services to the patients and hence is a key health provider of care for youths with ESKD. It is estimated that approximately 8 youths receive their hemodialysis services per week at the Renal unit with approximately 20 seeking transplant services. The institution ensures that the youths and other populations receive their treatments by ensuring that the National Health Insurance Funds (NHIF) caters for their services. However, in trying to meet their needs, the institution fails in making timely procurement of dialysis items, shared dialysis unit resulting long dialysis waiting time due to the larger population seeking care and limited dialysis machines and also the frequency of dialysis session which is 2 days a week disrupt the school attendance for the youths. Due to the limited research on the perspectives of these youths in Kenya, it was important to understand their unique challenges and needs. This study therefore aimed to address this gap by exploring the perspectives of youths with ESKD on the impact of the disease in KNH.

#### **1.4 Justification of the Study**

Addressing the impacts of ESKD on youth is an important step in reducing the burden of ESKD and associated NCDs such as diabetes and hypertension. Youth are a particularly vulnerable population when it comes to chronic diseases, and addressing

ESKD in this group is essential for achieving the Sustainable development goals (SDGs), specifically Goal 3 (Good Health and Well-being) and Goal 10 (Reduced Inequalities).

The perspectives of the youths with ESKD are fundamental in providing holistic care. Holistic approach in healthcare management cannot be met without factoring in the individual perspective. The youths with ESKD have both developmental milestones as well as challenges in dealing with ESKD. These challenges are likely to affect their overall health. The youths are still in the developmental stage where they cannot manage some of the challenges alone and they require support in dealing with such challenges. Although there was little knowledge of the perspectives of the youths with ESKD in different countries, no previous studies had been done on the topic in Kenya's Kenyatta National Hospital.

Therefore, this study helps fill in existing knowledge gap and collecting sufficient evidence recommending the formulation and use of evidence-based clinical guidelines for supporting youths with different experiences and perceptions. It may also advocate setting up counseling programs to help improve some of the psychological challenges faced by adolescents.

Findings from this study may be useful in sensitizing and educating youths on the importance of some of the precautionary measures such as fluid and diet restriction and treatment adherence. This study's findings may offer new insight into on youths' perspectives on ESKD and provide useful reference information for other populations living with ESKD.

This study may be the first step towards improving youths' experiences on their physical functioning psychosocial impact and their perspectives on the social impact of the disease and form a foundation for future studies that can influence and reduce mortalities associated with ESKD.

This study sought to address a critical gap in the literature by exploring the perspectives of youths with ESKD in KNH, Kenya. Understanding the challenges and needs of these youths would inform the development of policies and programs that better support their health and well-being. By exploring the physical, psychosocial, and social effects of ESKD, this study contributes important new knowledge to the field and helps to improve the lives of youths with this chronic illness.

### **1.5 Research Questions**

1. What are the perspectives of youths at Kenyatta National Hospital living with ESKD on the physical impact of the disease?
2. What are the perspectives of youths at Kenyatta National Hospital living with ESKD on the psychological impact of the disease?
3. What are the perspectives of youths at Kenyatta National Hospital living with ESKD on the social impact of the disease?

### **1.6 Study Objectives**

#### **1.6.1 Main Objective**

To explore the perspectives of youths at Kenyatta National Hospital living with ESKD the on impact of the disease



### **1.6.2 Specific Objectives**

1. To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the physical impact of the disease.
2. To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the psychological impact of the disease.
3. To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the social impact of the disease

### **1.7 Study Scope**

This study focused on the perspectives of youths living with ESKD. It sought to determine youths' perspectives in the sense of: 1) physical functioning 2) psychological effects 3) social effects at Kenyatta National Hospital. A qualitative study was undertaken to assess the perspectives among the youths with ESKD at KNH regarding the impacts of ESKD.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This section reviewed the literature on the perspectives of youths living with ESKD on the impact of the disease. This chapter comprises literature on the key subtopics related to the objectives of this study, research gaps and theoretical framework for the study. It aimed at providing a comprehensive understanding of the perspectives and experiences of youth with ESKD and identified gaps in the existing research that could inform future research and interventions. By addressing the unique needs of youth with ESKD, we can improve their quality of life and reduce the burden of this condition on individuals.

### **2.2 Physical Impacts among Patients with End Stage Kidney Disease**

Physiological challenges have also been linked to ESKD. This is shown in a qualitative study conducted by EL-Gamasy and Eldeeb (2017) to assess the physical status of children with ESKD. The results showed that children with ESKD had abnormal nutritional habits such as diet and fluid restriction, disturbed sleep patterns such as interrupted sleep due to difficulty in breathing and decreased daily physical exercise due to fear of injury, tampering with the vascular access and tiring easily.

Similar observations have been made in cross-sectional studies done among hemodialysis patients. Patients reported reduced physical functioning compared to the healthy population, with lower limb muscles more affected which increased the risk of falls. Difficulty with mobility and performance of activities of daily living was also reported by the patients. In addition, an increased risk of falls pain, stress, fatigue and disturbed sleep patterns were also reported. (Vanden Wyngaert et al., 2020).

Additionally, Tong et al (2009) reported various challenges associated with ESKD treatment. The treatment itself was complex, endless, tiresome and time-consuming. Furthermore, it was associated with physical symptoms such as cramping, restless leg syndrome, nausea and vomiting. Diet and fluid restriction was difficult to achieve especially in gatherings and this affected their way of living. Nevertheless, patients acknowledged kidney transplants as a resolution to fluid and diet restriction.

### **2.3 Psychological Impacts among Patients with End Stage Kidney Disease**

Psychological challenges are common among individuals undergoing the management of chronic conditions such as ESKD. This is seen in a qualitative study done in London (2013) which aimed at assessing the psychosocial experience of patients with ESKD. The study reported depression as the main psychological challenge among almost all the participants. This was supported by (Han et al., 2019) in a study done among elderly ESKD patients in Singapore. Depressive symptoms such as sadness, low mood and suicidal thoughts affected most of the participants. Depression can lead to a decrease in quality of life and may also impact a patient's ability to comply with their treatment regimen, leading to poorer health outcomes (Kimmel et al., 1998).

Anxiety also affects individuals with ESKD. This is seen in a study conducted by (Yu et al., 2020) to investigate the prevalence and associated factors of anxiety among patients with ESKD undergoing hemodialysis. The study included 184 patients, and the results showed that 52% of the participants had anxiety symptoms. The factors associated with anxiety in this study included female gender, lower education level, longer duration of dialysis, and a history of psychiatric illness.

Other psychological issues included stress and fear of pain and treatment outcomes (Finnegan-John & Thomas, 2013; Taylor et al., 2008; Usri et al., 2018). ESKD can be a stressful and traumatic experience for young people, affecting their mental health and well-being. They may experience stress related to their diagnosis, treatment, and prospects, which can lead to post-traumatic stress disorder (PTSD) or other mental health conditions (Cukor et al., 2007).

The physical changes associated with the disease undermine the confidence and self-esteem of those with ESKD. This is seen in a study conducted among adolescents and young adults aged 12-24 years with advanced CKD. The results showed that adolescents and youths with advanced CKD experienced impaired body image, sick identity, and inferiority. Other key elements reported from the study were experiences of insecurity, injustice and mental challenges (Nicholas et al., 2011; Taylor et al., 2008; Tong et al., 2009).

#### **2.4 Social Impacts among Patients with End Stage Kidney Disease**

Several sociological consequences associated with ESKD have been documented. Nicholas et al (2011) in a study conducted in Canada reported some social impacts of ESKD. Most children and adolescents with ESKD missed attending school which resulted in poor performance. Disturbed body image and difficulty in disclosing their ESKD to their peers in fear of shame and disconnection was also reported. Despite the negative experiences from most of the participants, the older adolescents described themselves as being responsible in their treatment plan and felt included in decision-making and which prompted them to learn more about some of the ESKD medications.

Similarly, a qualitative study by EL-Gamasy and Eldeeb (2017) and (Tong et al., 2013) found abnormal emotional and behavioral activities such as loneliness and isolation among children with ESKD. The children felt some sense of difference from the rest in that they have the disease. This resulted in self-isolation. More than half of the children did not participate in religious practices like praying. This was due to repeated hospitalization and fatigue associated with the disease and its treatment which hindered them from attending church services. Sibling favoritism and parental overprotectiveness were also reported among the children with ESKD and this affected their self-esteem and social interaction with their parents (El-gamasy & Eldeeb, 2017; Tong et al., 2013).

In addition, educational disruptions by the weekly dialysis sessions and repeated hospitalization led to underachievement. This also affected their employment and career ambitions. Impaired body image and fatigue associated with the treatments compromised their social interactions and intimate relationships. The males felt less masculine than the rest of the population. This as well negatively impacts their productivity and social relationships (Bailey et al., 2018; Nicholas et al., 2011)

## **2.5 Research Gaps**

Several studies had been conducted globally on the experiences of individuals with ESKD; however, there was limited research that specifically focused on the perspectives of youths with ESKD in Kenya in relation to impacts of the ailment. The existing literature highlighted the psychological, physical and social impacts of ESKD on affected individuals. The studies also indicated that ESKD significantly impacted the quality of life, including physical and mental health, education and employment

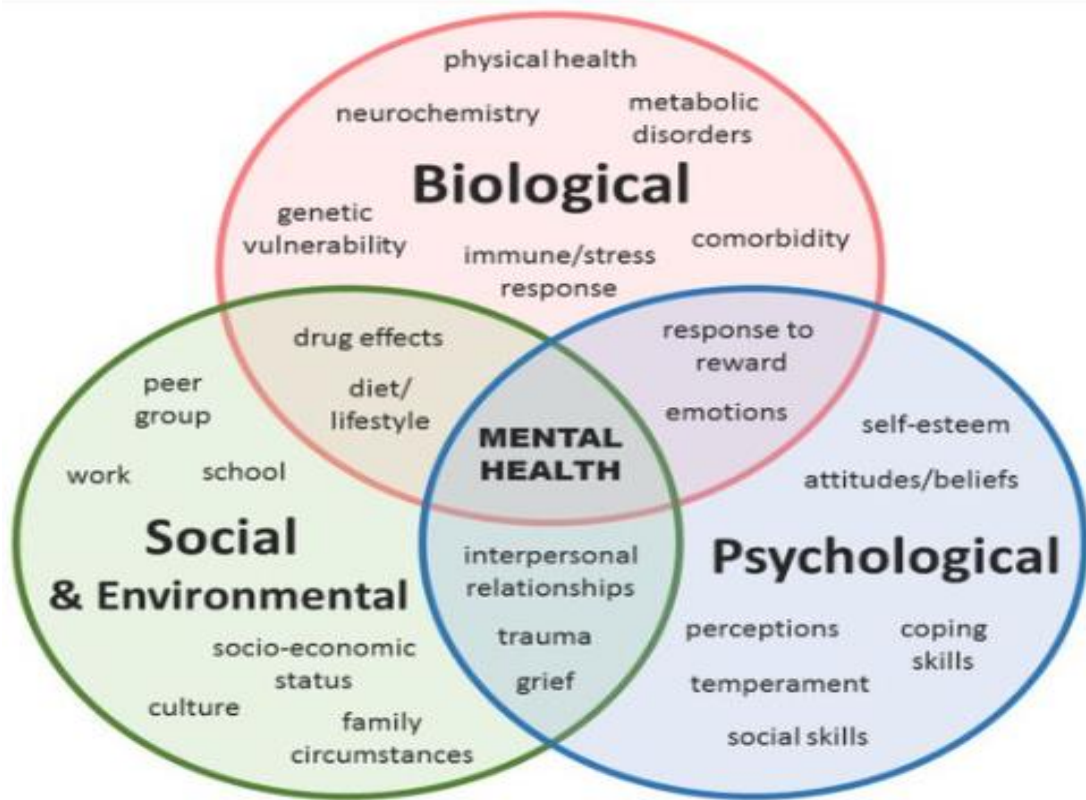
opportunities, and overall well-being. While there had been some research on the perspectives of youth living with ESKD on the impacts of the disease, there were still significant gaps in Kenya in the understanding of lived experiences and the most effective interventions to support youths with ESKD. Additionally, this study explored the unique experiences of youths from different cultural backgrounds and with different levels of social support attending the KNH. By addressing these research gaps, we could improve our understanding of the lived experiences of adolescents with ESKD and provide more effective care and support for this vulnerable population.

## **2.6 Theoretical Model of the Study**

### **2.6.1 The Bio-Psychosocial Model**

Theoretical frameworks refer to a group of ideas that offer structure to a theory (Varpio et al., 2020). The theoretical framework helps in discovering and analyzing new perspectives. It provides a basis for understanding different phenomena such as diseases, for example, ESKD, its causes and impact.

The biopsychosocial model was adapted in 1977 by George L. Engel and it is based on three aspects of health and illness; the biological, psychological, and social aspects. The theory stress on the relationship between the three aspects and their role in health and illness (Engel, 1977).



**Figure 2.1: The bio-psycho-social model**

**Source: Engel (1977)**

The biological aspect involves the link between the disease and bodily health, while the psychological aspect such as mental and emotional wellness relates to behavior. The interpersonal factors such as social interactions and community activities form the social aspects.

The biopsychosocial model recognizes that ESKD is influenced by a complex interplay of biological, psychological, and social factors. Understanding and addressing these various factors can lead to a more holistic approach to managing ESKD patients, taking into account not only the biological aspects of the disease but also the psychological and social factors that impact patients' well-being and disease outcomes.

This model emphasizes the importance of interdisciplinary care, involving healthcare professionals from different disciplines, to provide comprehensive care for ESKD patients.

#### **2.6.1.1 Biological Influences on Health**

Biological factors play a central role in ESKD. Genetic predisposition, physiological changes, and underlying medical conditions such as diabetes and hypertension can all contribute to the development of CKD and its progression to ESKD (Wang et al., 2020). Genetic mutations, kidney anatomy, and function, as well as other physiological factors, can influence an individual's susceptibility to CKD and impact disease severity and progression.

ESKD treatment requires fluid and diet restrictions which can have a profound impact on the nutritional habits of an individual. The vascular access used for dialysis predisposes patients to infection and limits their physical activities. Some of the medications used in the management of ESKD such as steroids causes facial puffiness, nausea and vomiting, cramping, and weight gain. These factors associated with ESKD may affect the psychological and social aspects of an individual. For instance, weight gain may impair the body image of an individual which in turn is likely to affect social interaction.

#### **2.6.1.2 Psychological Influences on Health**

Psychological factors, including cognitive, emotional, and behavioral aspects, can significantly impact ESKD. Guerra et al., (2021) found that psychological distress, such as depression, anxiety, and stress, can have a negative impact on CKD patients' overall well-being and may contribute to disease progression. Adherence to treatment



plans, lifestyle changes, and coping mechanisms play a significant role in managing ESKD. Individuals with ESKD are likely to exhibit low self-esteem due to bodily changes as a result of some of medications used in the management of ESKD. This increases the risk of depression and may negatively affect social interaction among the youths. In addition, it affects the treatment compliance among the youths.

### **2.6.1.3 Social Influences on Health**

Social factors, such as socioeconomic status, cultural beliefs, social support systems, and access to healthcare, are important determinants of ESKD. Socioeconomic status and limited access to healthcare may affect ESKD patients' ability to access timely and appropriate medical care, adhere to treatment plans, and make necessary lifestyle changes. Social support systems, including family, friends, and community support, can also influence ESKD patients' coping strategies and disease management. ESKD treatments cause educational disruption due to frequent and continuous dialysis and repeated hospitalization which result in underachievement, employment difficulties, compromised social interactions and intimate relationships among the youths. This may influence an individual to develop depression, which may, in turn, contribute to physical health problems.

## **CHAPTER THREE: METHODOLOGY**

This chapter entailed a discussion of the methods that were used during the study. The following subtitles are illustrated at large; study design, study area, study population, inclusion criteria, exclusion criteria, sample size determination, sampling procedure, participants' recruitment procedure, participant consenting procedure data collection instruments, data collection procedure, data management plan and finally, data analysis and presentation.

### **3.1 Study Design**

In this study, a qualitative research design was applied and this involved the use of descriptive phenomenology to explore the perspectives on the biopsychosocial impact of ESKD on youths with ESKD at Kenyatta National Hospital, Renal unit.

### **3.2 Phenomenology**

Phenomenology is a theoretical model that explores people's lived experiences and perspectives and focuses on the phenomena that have impacted an individual (Hallett, 1995). It is used to explore the unique experiences of each individual, including their subjective interpretations of their symptoms, their emotional and psychological responses to their illness, and their perceptions of the impact of their illness on their social relationships and identity (Sundler et al., 2019).

In this study, descriptive phenomenology was used to explore the perspectives of youths living with ESKD on the impact of the disease. This involves exploring and describing the essential features of a particular phenomenon as they are experienced

by individuals. It can help uncover the essence of their experiences and provide a deep understanding of the lived reality of this population (Husserl, 1927).

To conduct a descriptive phenomenology study on the perspectives of end-stage kidney disease (ESKD) among youths on the impacts of the disease, the following steps were taken.

**Select a sample:** Identifying a group of youths with ESKD who were willing to participate in the study.

**Conduct interviews:** Conducting open-ended in-depth interviews with each participant. The interviews focused on exploring the participants' experiences of ESKD, including their physical, psychological, and social impacts. The interviews were audio-recorded with the consent of the participants.

**Transcribe and analyze the data:** Transcribing the audio-recorded interviews and analyzing the data using a phenomenological approach. The analysis involved a careful examination of the participants' experiences and perspectives, identifying common themes and patterns that emerged from the data.

**Identify essential features:** Identifying the essential features of the participants' experiences of ESKD. The description was grounded in the participants' experiences and perspectives and was written in a way that was accessible to others.

**Write up the findings:** Writing up the findings of the study clearly and concisely. The write-up included a detailed description of the phenomenon as well as a discussion of the implications of the findings for practice and future research.

### **3.3 Study Area**

The research was conducted at the Renal Unit of Kenyatta National Hospital (KNH), which is the primary teaching and referral hospital serving not only the nation but also the broader East African Community. KNH has more than 6,000 employees and can accommodate more than 2,000 beds. It is situated in the upper western area of Nairobi's central business district. The hospital offers corporate services such as Dialysis and kidney transplant treatments, Cancer Treatment Center, dental services, psychiatric clinic, diabetic clinic, maternal and child health clinic, laboratory, general outpatient services, Pharmacy, Comprehensive, Care and TB clinic. The KNH Renal Unit has the largest hemodialysis units in the country. Approximately 22 hemodialysis machines were serving approximately 45 patients per day and approximately 135 patients were dialyzed monthly. The renal unit offers both the inpatients and outpatient services and patients on hemodialysis attended 2 sessions per week. The renal unit worked closely with the transplant unit in organizing clinics which were done on Mondays and Tuesdays for their clients. Youths with ESKD are not exceptionally from other populations they get their Kidney Replacement Therapies (KRT) at the Renal Unit.

### **3.4 Study Population**

The study population included youths aged 15-24 years diagnosed with ESKD and receiving their kidney replacement therapies (KRT) at Kenyatta National Hospital Renal Unit. The World Health Organization's (WHO) definition of youth was utilized in the study (WHO, 2023). This was in line with the research objectives which focused on understanding or addressing issues that were pertinent to late adolescence

and early adulthood. Participants within this age range are in a critical developmental stage and may encounter unique challenges and opportunities that warrant investigation or intervention. There were approximately 8 youths receiving hemodialysis services and about 20 seeking kidney transplant services at Kenyatta National Hospital.

#### **3.4.1 Inclusion Criteria**

- i. Youths with ESKD who had been on hemodialysis for more than 3 months
- ii. Youths aged 15-24 years
- iii. Youths above 18 years who individually consented to be interviewed
- iv. Youths aged below 18 years whose parent/guardian gave consent and the participant signed the assent form.

#### **3.4.2 Exclusion Criteria**

- i. Youths who were very sick and those unable to give written consent were excluded.
- ii. Youths with ESKD who had been on hemodialysis for less than 3 months.
- iii. Youths with any form of cognitive disorder.
- iv. Youths aged below 18 years whose parent/guardian did not give consent and the participant did not sign the assent form.

### **3.5 Sample Size Determination**

The study participants comprised of 7-12 persons. This number was based on the guidelines for phenomenological studies. Morse proposed 6-10 participants for phenomenological research. However, because of the iterative relationship between the sample and data analysis, Faulkner and Trotter (2017) recommended that recruitment should continue until there was a saturation of themes. Mason proposed that to ensure the right sample was achieved, multiple and complementary recruitment strategies should be applied. In this study, data saturation was achieved after interviewing the 11<sup>th</sup> participant.

### **3.6 Sampling Procedure**

Purposive sampling was used to select participants for the study because it was the most appropriate method for recruiting individuals who could provide rich and detailed information that was relevant to the descriptive phenomenological design. With this sampling technique, participants were selected based on their unique characteristics or experiences that were relevant to the research question rather than being selected randomly. The researcher analyzed the participants' medical records and identified those who had been on hemodialysis for more than 3month, mixed gender and participants with different levels of education. The researcher also used her judgment to determine eligible participants who could participate in-depth interviews. This increased the likelihood of selecting participants who could provide rich information about the phenomenon being studied, which was crucial for a descriptive phenomenological study. Therefore, purposive sampling was considered the most effective technique for this type of research (Korstjens and Moser, 2018).

### **3.7 Participants' Recruitment Procedure**

Following ethical approval from the Kenyatta National Hospital/University of Nairobi Ethics and Research Committee (KNH/UON-ERC) and authorization from Kenyatta National Hospital, the researcher requested permission from both the head of the Renal Unit department and the nurse in charge of the unit to access the participants. The researcher notified the staff about the study, eligibility of the participants, method of data collection and the duration of data collection. The participants were identified from the registration books at the renal unit. Their files were obtained to determine their medical records and clinical history. The participants' files were also analyzed to omit those with any exclusion criteria. The study included youths with ESKD aged 20-24 years who had been on hemodialysis for more than 3months, youths at different levels of education and both the employed or unemployed youths visiting or admitted at KNH Renal Unit for hemodialysis or kidney transplant services. The eligible participants who could engage in an in-depth interview were invited to participate in the study. Participants who accepted to take part in the study were taken through a consenting procedure.

### **3.8 Participant Consenting Procedure**

The researcher approached the eligible participants verbally to seek consent after they had been screened and selected for the study. The participants were provided with information on the research topic, the research objectives, method of data collection and the duration of data collection. Those who agreed to participate in the study were provided with a participant's information sheet and consent form to go through it. All the participants were able to go through it at the unit. For participants aged below 18

years, their parents/guardians were also provided with participant's information and parental/guardian informed consent form to go through it. Two participants below 18 years did not consent because of parental decline and the other minor experienced complications after dialysis. The researcher together with the eligible participant scheduled a day, time and venue convenient to the participant. All the participants chose to be interviewed at the hospital and the researcher liaised with the unit in-charge and was allocated a private room for the interview.

### **3.9 Data Collection Instruments**

The researcher used a demographic form (see Appendix viii) to collect demographic data information from the participants. An interview guide was used as the primary tool to facilitate data collection during the interviews. The interview guide (see Appendix V) outlined how the interview was conducted; it contained structured questions and prompts guided by the study objectives. A digital audio recorder was also used to record the data during the in-depth interviews.

### **3.10 Pretest**

The questionnaires were pretested with 4 youths aged 15-24 years receiving treatment at KNH Renal Ward (7A) before the actual data collection. This was done to detect any form of bias that could affect the study. The main study did not include the results obtained during the pre-test.

### **3.11 Data Collection Procedure**

Eligible participants selected for the study and who offered their consent were invited to participate in an interview. Appointments were made for those who agreed to



participate in the study. The interviews were conducted at participants' convenient place. Those who chose to be interviewed at the hospital were allocated a private room.

The demographic form for each participant was filled out before beginning the interview. The researcher conducted individual interviews with each participant, ensuring that each participant was interviewed only once. To maintain confidentiality, only the researcher and the study participant were present in the room.

The researcher provided a thorough explanation of the research details to the participants and obtained their informed consent for the interview and recording purposes. Once consent was obtained, the interview was recorded using audio tape. An interview guide was used to facilitate the conversation and ensured that all relevant information was covered. During the interview, the researcher established rapport with the participant, actively listened to their responses and encouraged them to elaborate on their experiences. Detailed notes were taken based on the researcher's observation.

Data collection was done until saturation was reached. Each participant was assigned a unique code after the interview based on the date of the interview and the position during the interview. The data collected was then transcribed verbatim and pseudo names were used during findings reporting.

### **3.12 Data Management Plan**

#### **3.12.1 Data Storage**

To maintain anonymity, interview notes, transcripts, and audio recordings received consecutive serial codes and were kept in a secure, lockable drawer. The information was saved on a laptop protected by a password.

#### **3.12.2 Data Analysis, Presentation and Measurement**

The study participants' socio-demographic data was analyzed using descriptive statistics. The transcribed data and noted findings were promptly organized and filed according to the study objectives. This helped prevent any confusion during the analysis phase. Thematic analysis with the aid of NVivo software was used to analyze the data as per the study objectives. This thematic analysis of the youths' perspectives on the impacts of ESKD included these six steps as recommended by Braun and Clarke (2006):

**Familiarization:** To enhance the familiarity with the data, the researcher engaged in various activities such as listening to the audio recordings, reviewing their notes, and re-reading the transcriptions. These actions were aimed at gaining a deeper understanding of the content and breadth of the collected data and comprehensively grasping the entire phenomenon under study. The researcher also reviewed the audio recordings multiple times to ensure the accuracy of the transcriptions. Furthermore, during each interview, the researcher took notes to capture nuances that could not be conveyed solely through recordings. These nuances included factors such as the participants' mood, facial expressions, tone of voice, body language and physical positioning. These notes supplemented the audio and textual data, providing

additional context and insights during the analysis.

**Coding:** The initial coding was based on the interview guide, but new codes emerged during the analysis. The codes were continually created and modified throughout the entire coding process. After coding, the data was categorized into various themes, and then the codes were assigned to describe the content. Throughout this analysis, the researcher engaged in constant comparisons to identify patterns and themes based on the frequently used terms or verbatim expressions. Special attention was paid to the language, beliefs, and opinions expressed by the participants during the interviews. The researcher condensed these aspects into concise phrases serving as codes, which captured the participants' experiences and feelings as conveyed in the transcripts. The researcher focused on segments that were relevant and of interest in addressing the research questions.

**Generating themes:** The researcher reviewed the initial codes and grouped them into potential themes. These themes were coherent, distinct and related to the research questions.

**Reviewing themes:** The researchers reviewed the themes and ensured that they accurately reflected the data. Researchers revised the themes or combined them into overarching themes. Related themes were consolidated into a single meaningful theme. Themes that possessed distinct meanings were not altered to promote diversity within the descriptive data. By preserving these distinctive themes, the descriptive data accurately reflected the diverse range of perspectives and experiences captured during the interviews.

**Defining themes:** Each theme was named based on the data they represented. When

merging themes, the resulting overarching themes were named to reflect the data covered by each theme. To ensure the validity and reliability of the emergent themes, the researcher conducted a thorough review of the data by examining if there were any instances of outliers. When determining the themes, the researcher prioritized their importance to the overall research question so as to ensure that the themes selected for analysis aligned with the research objectives and provided a comprehensive understanding of the research topic.

**Writing up:** The researcher wrote up the findings clearly and in a concise manner, providing evidence to support each theme and using quotes from the data to illustrate the themes.

### **3.13 Dissemination Plan**

The researcher shall share the study results with the UoN Department of Nursing Sciences, institution's library and eventually upload them in the University of Nairobi's repository. Furthermore, the researcher shall also endeavor to present the findings at suitable academic and scientific conferences and publish them in reputable scientific journals to ensure their broad dissemination.

### **3.14 Ethical Considerations**

The researcher followed the appropriate procedures for reviewing, obtaining clearance, and obtaining approval to conduct the study by submitting an application and presenting the research proposal to the KNH-UoN ERC. The researcher then requested permission to carry out the study at Kenyatta National Hospital.

The researcher obtained voluntary informed consent from the participants and a parental/guardian signed consent with assent form for those below 18 years before beginning the data collection procedure. The consent contained the purposes of the study, the procedure of collecting data, the risk and benefits of participating in the study and measures to ensure confidentiality. The participant's autonomy and dignity were respected throughout the research process. Their decisions to participate in research were considered and respected. The researcher maintained privacy and confidentiality of the participants. Participant's details were not indicated anywhere in the interview guide. The interview notes, transcripts, and audio recordings were kept in a secure, lockable drawer and protected by a computer password

The research had the potential to introduce emotional harm, breach of privacy, breach of participants' autonomy during consenting procedure and power imbalances. Efforts were put in place to minimize the risks. In case of emotional harm, the participants were offered debriefing sessions after the interview and were allowed to stop the interview. Participants' privacy and confidentiality were maintained throughout the data collection procedure. The participants were made aware of their willingness to participate and their freedom to withdraw from the study at any given time. There was no coercion or incentives for participants. Power imbalances were reduced by engaging the participants in the study through member checks. The study was conducted under guidelines from KNH-UoN ERC to protect the participants from harm. Additionally, referrals were made according to the KNH protocols.

## **CHAPTER FOUR: RESEARCH FINDINGS**

### **4.1 Introduction**

This chapter presents findings of the study in line with the study objectives. It describes identified themes and subthemes that emanated from interviews with the study participants relating to their perspectives on the the physical, psychological and social impacts of end stage kidney disease.

An aggregate of 11 youths aged 15-24 years receiving treatment for ESKD at Kenyatta National Hospital's Renal Unit took part in the study. The study participants were selected using purposive sampling technique and the study sample size was determined on the basis of the principle of data saturation. Data saturation in the study was reached when data obtained from further interviews with the participants did not yield new insights or meanings.

The chapter begins by highlighting the demographic characteristics of the study participants under Section 4.2. The remaining parts of the chapter are organized as per the study objectives. Hence, section 4.3 highlights results on the perspectives of the youths living with ESKD on the physical impacts of the illness; section 4.4 highlights results on the perspectives of the youths living with ESKD on the psychological impacts of the illness while section 4.5 highlights results on the perspectives of the youths living with ESKD on the social impacts of the illness.

### **4.2 Demographic Characteristics of the Participants**

The participants' demographic attributes were evaluated. From the findings, all (100%, n = 11) of the participants were aged 20 - 24 years, lived with their families

and were unemployed. In addition, all the study participants were Christians and hypertension was the most prevalent comorbidity. Results are presented in Table 4.1.

**Table 4.1: Demographic characteristics of the participants**

Demographic attributes		Frequency (N)	Percentages
Gender	Male	7	63.6
	Female	4	36.4
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Age	20 - 24 years	11	100.0
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Level of education	Secondary	6	54.5
	Tertiary	5	45.5
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Marital status	Single	9	81.8
	Married	2	18.2
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Number of children	None	8	72.7
	One	2	18.2
	Two	1	9.1
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Time since diagnosis with ESKD	3 - 12 months	2	18.2
	13 -24 months	4	36.4
	> 24 months	5	45.5
	<b>Total</b>	<b>11</b>	<b>100.0</b>
Comorbidities	Hypertension only	9	81.8
	Hypertension and diabetes	1	9.1
	Hypertension and systemic lupus erythematosus (SLE)	1	9.1
	<b>Total</b>	<b>11</b>	<b>100.0</b>

NB: ESKD - End stage kidney disease

### **4.3 Participants' Perspectives on Physical Impacts of the Disease**

The study explored the perspectives of the youths regarding the physical impacts of the end stage kidney disease for which they were under treatment. In this study, perspectives on the physical impacts of ESKD were defined as the experiences of the youths on the physical functioning status as a result of living with ESKD and aimed to find out how the youths' physical wellbeing had been impacted by the illness. Therefore, a review of the youths' perspectives on the physical impacts of ESKD explored the participants' views regarding how living with ESKD affected them physically including their capacity to engage in normal activities of daily living. According to Bailey et al. (2018) and Nair et al. (2023), perspectives on the physical impacts of ESKD in the context of young adults signifies the young adults' physiological experiences while living with the disease and therefore denotes any limitations imposed on their physical wellbeing including their physical functioning ability by the disease.

The primary focus of discussions with the participants was on how living with ESKD had affected them physically. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the participants' views regarding the physical impacts of the disease are summarized in Table 4.2.



**Table 4.2: Theme and sub-themes on participants’ perspectives on the physical impacts of ESKD**

<b>Research objective</b>	<b>Codes [5 top ranked codes]</b>	<b>Theme and sub-themes</b>
To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the physical impact of the disease	<ul style="list-style-type: none"> <li>▪ Feeling tired (n=11)</li> <li>▪ Low energy levels (n=11)</li> <li>▪ Lost weight (n=10)</li> <li>▪ Body pains (n=8)</li> <li>▪ Disrupted sleep (n=4)</li> </ul>	<p><i>Theme:</i> Body changes</p> <p><i>Sub themes</i></p> <p>Extreme weakness and fatigue</p> <p>Weight loss</p> <p>Body pains</p>
<p><b>Definition of the theme &amp; sub-themes</b></p> <p><i>Body changes</i> which signified experiences of extreme body weakness and fatigue, loss of weight and body pain leading to increased difficulties in performing normal activities of daily living among the participants due to the illness.</p> <p><i>Extreme weakness and fatigue</i> signifying experiences of increased body frailty (or low energy levels) and tiredness among the participants due to the illness.</p> <p><i>Weight loss</i> signifying lower than desirable body weight or notable decrease in participants’ body weight due to the illness.</p> <p><i>Body pains</i> signifying experiences of physical body pain including joint pain and headaches among the participants due to the illness.</p>		

During the discussions with the study participants regarding their views as to the physical impacts of ESKD, body changes emerged as the overarching theme and signified experiences of extreme body weakness and fatigue, loss of weight and body pain leading to increased difficulties in performing normal activities of daily living among the participants due to the illness. Three sub-themes emerged that related to how living with ESKD affected the participants physiologically. These were *extreme weakness and fatigue* which signified experiences of increased body frailty (or low energy levels) and tiredness among the participants due to the illness; *weight loss* which signified notable decrease in participants’ body weight due to the illness and

*body pains* which signified experiences of physical body pain including joint pain and headaches among the participants due to the illness. The three sub-themes are as described in the following subsections.

#### **4.3.1 Extreme Weakness and Fatigue**

The first sub-theme to emerge from the data on the physical impacts of living with ESKD among the study participants was extreme weakness and fatigue. This sub-theme related to experiences of general body frailty and tiredness among the study participants as a result of the ailment more so when undertaking any activities requiring physical strength/energy. According to the findings, the study participants acknowledged experiencing persistent episodes of extreme fatigue and general body weakness attributable to living with kidney failure. The participants indicated that they experienced difficulties in undertaking normal activities of daily living such as standing, walking, house chores and hobbies requiring physical strength like football and cycling due to persistent feelings of extreme tiredness and low energy levels. Indeed, the participants attributed their diminished physical functioning status to the persistent feelings of excessive fatigue, low energy levels and general body weakness that they frequently experienced. It was therefore evident from the interactions with the participants that increased body fatigue and weakness was a major physical impact attributable to living with kidney failure. The extreme weakness and fatigue among the study participants could be as a result of the diet restrictions and effects of the illness such as vomiting and nausea. The participants' shared perspectives in relation to experienced feelings of fatigue and weakness are as illustrated in the following verbatim excerpts;

“I can say that my body strength has really reduced, like I do not usually do the normal things that I used to do like carrying heavy things, walking and engaging in physical sporting activities because of getting very tired a lot all the time.” (Salim\*)

“At times I feel very tired and it (*referring to the disease - ESKD*) makes me weak. I am barely able to perform activities that are physically demanding like I used to before I got sick.” (Lydia\*)

“In terms of energy levels, I feel my physical energy is too low. There are things that I cannot do like helping my mum carry two jerricans of 20 liters, walking long distances or going for hikes, which I could do earlier without lots of difficulties.” (Steve\*)

“Yes, there are changes in my body. Like now I cannot play like I used to. My energy level has reduced and I get tired pretty quickly because my kidneys are not working well.” (Wayne\*)

“I have difficulties doing hard jobs (*referring to tasks that are physically strenuous*). When I do such jobs, it reaches a point that I get overwhelmed. Often, I will start well but after like 5 to 10 minutes my energy gets depleted. I feel very exhausted and weak and I cannot continue.” (Stacy\*)

“I have become very weak. I cannot do anything. I cannot do anything by myself. I feel I have no energy left. Whenever I try to do normal tasks like washing and walking, I keep stopping as I quickly get exhausted and feel weak.” (Ann\*)

“...It has affected me a lot. Before I got this disease, I would be able to work and not feel tired like the way I do now. But now, I cannot stand for long hours or walk for long distances. Often, I do not have the energy even to go out to meet friends or maybe go to play games like football or something like that. I cannot as I feel excessively weak and tired.” (Ken\*)

“I am less productive compared to before in terms of working. All my strength is gone. I just feel overly weak and tired, all because of the weekly dialysis sessions.” (Francis\*)

“You know, when you have this disease, it is hard to do any work because you always feel tired and weak. Even walking, nowadays I cannot walk for long. Even, going to church is not every day. Sometimes you want to go but feel overly tired and you do not have the strength to go. So, things like that.” (Anton\*)

### 4.3.2 Weight Loss

From the findings, weight loss emerged as another leading physiological impact of living with ESKD among the study participants. This sub-theme related to how the participants' body weight had been affected by the ailment and signified a lower than desirable body weight or a notable decrease in body weight among the study participants as a result of the illness. From the findings, majority of the study participants acknowledged that their body weight had notably decreased following being diagnosed and treated for end stage kidney disease. Particularly, most of the participants indicated that their current body weight was far lower than were previously, that is, before the ESKD diagnosis. Most of the participants acknowledged that their bodyweight had adversely been affected by the ailment attributing their significantly reduced body weight to effects of the ailment's treatment such as vomiting, nausea and diarrhea, loss of appetite and restricted diets. The participants also espoused the view that their reduced body weight contributed to their diminished physical functioning. It was therefore evident that the participants' body weight was adversely impacted by the ailment. This is illustrated in the ensuing verbatim excerpts;

“Loss of weight due to vomiting and diarrhea is the other physical challenge I have had due to the kidney failure. Before this disease, I was much bigger in size and weighed much more. Now look at me.” (*Salim\**)

“For me, I can say, living with this disease has really changed my physical appearance. Like now I am 20 years and unlike my friends who are 20 years, they are like big and I am small. I was told my growth will be stunted because I have one kidney. So, many people confuse me for a baby. They say like I am in primary school or high school; so, you feel uncomfortable with it. You are not confident with your body. For me I feel like this is not the body I deserve.” (*Steve\**)

“Yes, there are changes in my body due to the kidney problem. Yeah, I have lost a lot of weight. Some people discriminate me thinking I have HIV; simply because I have lost a lot of weight and they do not know the cause. Some say it is witchcraft and such things, so it’s really sad.” (*Lucy\**)

“Yes, there are changes; I have lost quite a bit of weight. I have slimmed. I am not like the way I used to be before.” (*Wayne\**)

“People say I look like a baby. I look like a 12 years old baby. My body is so small. I was not always like this. So, this disease has really ‘eaten’ me up and of course I am not comfortable looking this small. Maybe it is due to the highly regulated diet I have to adhere to.” (*Dan\**)

“You look at me. See, I look small. I was not always like this. It is because I have lost a lot weight since I became ill and was put under dialysis. In my estimation, I think I could have lost as much as 10kgs.” (*Ann\**)

“Yes, it has really affected me. I have lost a lot of weight. Initially, I was around 60 - 62 kgs, but right now I am 55 kgs.” (*Ken\**)

“Yes, I have lost a lot of weight since beginning dialysis. I think I am not able to eat well; I do struggle with appetite for food. I have no much interest in feeding, may be because of the stringent dietary regulations we are required to observe.” (*Francis\**)

“Yeah, there is a lot of differences. For one, I have shed lots of weight. We have been restricted a lot of food. We have also been restricted to take a little amount of water and you know water is life. So, feeding becomes a challenge.” (*Anton\**)

### **4.3.3 Body Pains**

Body pains emerged as the other leading physiological impact of living with ESKD among the study participants. This sub-theme related to the participants’ views on whether the ailment caused them bodily pain and signified experiences of physical body pain including joint pain and headaches among the participants occasioned by the illness. From the findings, majority of the study participants expressed the view that they did experience occasional bodily pains which they attributed to living with kidney failure. According to the findings, the most common reported forms of body pain were joint pains, pain in the knees and headaches, with a significant proportion

of the participants acknowledging that they relied on pain relieving medication to alleviate or deal with the body pains. The study participants also agreed that the body pain experiences impaired their quality of life. It was therefore evident that, among youths living with ESKD, body pain constituted a major physical impact of the ailment. This is illustrated in the ensuing verbatim excerpts;

“Yes, there are numerous physical challenges I do face as a result of the condition. The most significant is joint pains which worsen while walking to the point that I cannot even walk.” (*Ann\**)

“Many times, I have difficulties in walking due to episodes of moderate to severe joint pains that I experience from time to time.” (*Stacy\**)

“I do experience pain in my knees which was not the case before I got this disease. At times, the pain is so much that I have to take pain killers to get it under control.” (*Dan\**)

“Sometimes my feet hurt. They are really painful sometimes. Yeah, particularly the knees and the bones in the legs (*pointing at the knees and legs*) which makes walking really difficult and painful.” (*Steve\**)

“Yeah, I do experience many physical challenges including bone pains and joint pains which at times are so painful that I feel incapacitated. I however manage the pains using furnished pain-relieving medications.” (*Lydia\**)

“Recurrent body pains are a real challenge. Sometimes, I do complain of headaches. Walking is also an issue because of knee pains, though that is being monitored. I do take painkillers a lot to manage the pain, without which I would not be able to do anything.” (*Salim\**)

“I usually experience a lot of pain after the dialysis. I do not know why. It is usually on my joints. I do also get headaches after dialysis. At times, it resolves without taking pain killers but most of the time I have to use the pain-relieving drugs to get rid of the pain.” (*Francis\**)

“Another challenge I face is pain on the knees, joints and feet which at times can be severe making walking unbearable. I take medication to relieve the pain, but the pain bothers me.” (*Ken\**)

#### **4.4 Participants' Perspectives on Psychological Impacts of the Disease**

The study explored the perspectives of the study participants regarding the psychological impacts of the end stage kidney disease for which they were under treatment. In this study, perspectives on the psychological impacts of ESKD were defined as the aggregation of mental feelings, thoughts and emotions that the youths experienced as a result of living with ESKD. It thus aimed to find out the study participants' views as to how their psychological wellbeing was impacted by the illness. Therefore, a review of the youths' perspectives on the psychological impacts of ESKD explored their views regarding how living with ESKD affected them mentally including their thoughts, feelings and emotions. According to Nicholas et al. (2011), psychological impacts of ESKD among young adults signifies the young adults' mental wellbeing following diagnosis and treatment for kidney failure and focuses on the ailment's effects on their individual thoughts, emotions and feelings.

The primary focus of discussions with the participants was on how living with kidney failure affected them psychologically/mentally. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the participants' perspectives regarding the psychological impacts of the ailment are summarized in Table 4.3.

**Table 4.3: Theme and sub-themes on participants’ perspectives on the psychological impacts of ESKD**

<b>Research objective</b>	<b>Codes [5 top ranked codes]</b>	<b>Theme and sub-themes</b>
To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the psychological impact of the disease	<ul style="list-style-type: none"> <li>▪ Anxiety (n=10)</li> <li>▪ Stress (n=10)</li> <li>▪ Frustrations (9)</li> <li>▪ Sadness (n=9)</li> <li>▪ Feeling overwhelmed (n = 4)</li> </ul>	<p><i>Theme: Uncertainties</i></p> <p><i>Sub themes</i></p> <p>Anxiety and stress</p> <p>Frustrations and sadness</p>
<p><b>Definition of the theme &amp; descriptors</b></p> <p><i>Uncertainties</i> signifying experiences of doubts (not knowing what to expect in relation to the illness outcome) and frequent negative/worrying thoughts among the participants due to the illness.</p> <p><i>Anxiety and stress</i> signifying feelings of mental strain, fear and worry that the participants experienced due to the illness.</p> <p><i>Frustrations and sadness</i> signifying feelings of sorrow, despondency and futility with living that the participants experienced due to the illness.</p>		

During the discussions with the study participants regarding their views on the psychological impacts of ESKD, uncertainties emerged as the overarching theme and signified experiences of doubts (not knowing what to expect in relation to the illness outcome) and frequent negative/worrying thoughts among the participants due to the illness. Two sub-themes emerged that related to how living with ESKD affected the participants psychologically. These were *anxiety and stress* which signified feelings of mental strain, fear and worry that the participants experienced due to the illness and *frustrations and sadness* which signified feelings of sorrow, despondency and futility with living that the participants experienced due to the illness. The two sub-themes are as outlined in the following subsections.



#### 4.4.1 Anxiety and Stress

One of the leading psychological impacts of living with kidney failure experienced by the study participants was feelings of anxiety and stress. This sub-theme represented feelings of mental strain, fear and worry that the participants experienced due to the illness and therefore signified how living with kidney failure affected their emotional and mental wellbeing. From the findings, majority of the participants indicated that they suffered anxiety and stress as a result of their diagnosis largely due to the hassles and rigidities of dialysis treatment as well as fear of losing their life. From the findings, it was apparent that being diagnosed with kidney failure, its disruptive effects on their normal life and the rigors of its treatment were a traumatising experience to majority of the study participants which made them feel anxious and stressed. From the findings, it was apparent that the emotional and mental wellbeing of the study participants had adversely been affected by the ailment. This is illustrated in the following verbatim excerpts;

“I do have lots of thoughts mainly around the fate of the disease. Will it just be like this? Will I ever go back to my usual self, like I were before? And now that I am still young, how will I marry with this condition and will the person accept me as I am? You know, such thoughts which make me feel worried and stressed up.” (*Anton\**)

“Yes, I do sometimes feel anxious and stressed. I wonder what will happen after dialysis. I also feel stressed up because I am less productive, I cannot sleep well and have to all the time watch what I am eating. I have also lost some of my friends who had similar illness, which leaves me quite fearful that I too will face similar fate.” (*Francis\**)

“It has really affected me because it came at a time when I was just beginning my career. I used to work as a TV host and a DJ. So, my career was starting to pick up then I got this disease. So, you can imagine the way I was feeling seeing that my career is taking off and here I am now I cannot be able to work anymore. I felt like now this is the end for me. So, at first, I was very stressed and worried. It took me quite a while to accept it.” (*Ken\**)

“Obviously I cannot avoid thinking too much. Many times, I get anxious and feel quite stressed. When I think about the situation that I am in now and compare it with before (*referring to when she used to be okay or not ill*), you cannot fail to feel worried and stressed.” (*Ann\**)

“When I was diagnosed with kidney failure, I was very worried and stressed until I wished that I could just die. I was just wishing death could just come. I waited for death but it never came. I used to stay in the ward all alone. My mother who was to be with me, was with my kids and my husband has left me because of my illness. So, I could come to the ward and stay alone then go back home alone. I think this contributed to me being highly stressed and unease. To be honest, I do not think I have ever fully recovered from that distressing experience.” (*Stacy\**)

“The disease (*referring to the kidney failure diagnosis*) does affect me mentally because I keep wondering how it will all end, like am I approaching my death. Also, the hassles of dialysis treatment, you know, the weekly visits to the hospital for dialysis and not being able to enjoy the things I used to like before I got sick like playing football with my friends. It is all very difficult and distressing.” (*Dan\**)

“Indeed, I have suffered lots of mental distress due to this illness. I am very worried about my family. Because we (*referring to himself and his wife*) have a child, I am very worried that when the mother is all alone, she will not be able to manage looking after the kid by herself. So, for me, the stress and anxiety is mainly due to concerns about my family which makes me feel on the edge.” (*Wayne\**)

“For me, it is mostly fear because sometimes you think that when they say ‘*end stage*’ so you think I will soon die. You also get stressed by when you hear that patients you have been with in dialysis are dead. Sometimes, they (*referring to the care providers*) also tell you that your catheters are failing and you have to buy others. All this is quite stressful.” (*Lucy\**)

#### **4.4.2 Frustrated and Sad**

Frustrations and sadness also emerged as another leading psychological impact of living with kidney failure experienced by the study participants. This sub-theme related to experiences of sorrow, gloom, hopelessness and vainness among the study participants as a result of living with kidney failure. It therefore represented feelings of desperation, dissatisfaction, irritation and sorrow linked to living with kidney failure among the study participants. From the findings, a significant number of the participants shared the view that they did experience feelings of irritation, discontent

and sadness which they attributed to the rigours of dialysis treatment, restrictions on their normal life imposed by the illness and to the significant adverse effects of the illness on their social life. The frustration and unhappiness also emanated from various other experiences linked to living with the illness such as the adverse physical impacts of the illness including diminished physical functioning status, disrupted sleep, losing weight and frequent body pains; disrupted social relations such as not being to spend more time with friends or not being able to actively participate in social events as before and individual concerns over overcoming the illness. Hence, it was evident that feelings of sadness and frustration were a notable psychological impact of ESKD that the study participants experienced, as is demonstrated in these ensuing verbatim excerpts;

“I am deeply disturbed by this condition (*referring to the kidney failure*). Mostly, what frustrates me so much about the disease is being unable to do things that I used to before such as long walks and hikes. Also, I cannot go anywhere far from home, say like visiting relatives may be for 3 days or 4 days, for I have to be here for dialysis twice every week. I am also frustrated with the many diet restrictions, pain on my feet and knees and the weight loss. That’s what mostly makes me feel down.” (*Steve\**)

“Honestly, I feel like this disease has made me to lag behind. I have seen my TV hosting and Deejaying careers fail to take off. I feel like I am slowly losing my dreams which disturb me a lot. Also, I was diagnosed at a point when the disease had gone too far (*meaning advanced*) which really made me feel dejected.” (*Ken\**)

“Sometimes, I feel overwhelmed. What makes me most sad is knowing that I will live with this condition to the end. I feel frightened that my end is near. I am also deeply disturbed by the fact that most of the things that I used to do normally like playing and working, nowadays I cannot do them. I think I am also sad that I am not able to help my wife and kid as much as I could because of the illness” (*Wayne\**)

“I most frustrated and sad when I hear that a patient or patients I knew and with whom we were receiving similar treatment(s) have died. It makes you wonder, am I next? It really hurts.” (*Lucy\**)

“Yeah, there are times I feel very frustrates and unhappy. For example, maybe I want to go to a place where I could get held up for a couple of days. Then I

remember i must come here twice a week for dialysis. So, I get frustrated because I cannot go somewhere for like many days. Maybe I only go there for one day and come back because the next day I will be on dialysis.” (*Ann\**)

“Most of the times I do feel unhappy and frustrated as I feel life has not given me a fair chance compared to other people. Also tiring so fast whenever I attempt to do anything, not being able to walk for long, I cannot play with my peers as I used to before, looking like a 12 years old baby because of excessive weight lost and so on. All these leave me feeling frustrated with life.” (*Dan\**)

“Being left by my husband because of ailing with kidney failure and therefore having no one to support me and not being able to care for my baby was really challenging and pushed me to the edge. Add to that a disrupted work life, disrupted sleep, so many food and fluid intake restrictions and general body fatigue and weakness. Tell me, with all these and other difficulties, how can one not be frustrated with this illness?” (*Stacy\**)

“I feel frustrated because I am now less productive. See, most of my peers have been employed and achieved many things and I am here on a hospital bed. So, I would say, the frequent hospitalizations, not being able to sleep well, always watching out for what and how much to eat and drink and the frequent headaches and joint pains make me feel gloomy and upset.” (*Francis\**)

“With this disease, a lot is disheartening and frustrating including stalled personal plans and goals, regular hospital visits for the weekly dialysis sessions, reduced physical functioning due to diminished physical strength, disrupted sleep and curtailed social interactions among numerous other challenges.” (*Anton\**)

#### **4.5 Participants’ Perspectives on Social Impacts of the Disease**

The study also explored the perspectives of the study participants regarding the social impacts of the end stage kidney disease for which they were under treatment. In this study, perspectives on the social impacts of ESKD were defined as the nature of social relations and interactions that the youths had with other people at family and community levels while living with ESKD. It therefore signified how the youths’ social life and relationships had been impacted by the disease. Therefore, a review of the youths’ perspectives on the social impacts of ESKD explored their views

regarding how living with kidney failure affected the youths' social life meaning their social interactions with other members of the family and the larger community.

The primary focus of discussions with the participants was on how living with end stage kidney disease had affected their social relations with others. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the participants' views regarding the social impacts of the ailment are summarized in Table 4.4.

**Table 4.4: Theme and sub-themes on participants' perspectives on the social impacts of ESKD**

<b>Research objective</b>	<b>Codes [5 top ranked codes]</b>	<b>Theme and sub-themes</b>
To explore the perspectives of youths at Kenyatta National Hospital living with ESKD on the social impact of the disease	<ul style="list-style-type: none"> <li>▪ Support from family (n=9)</li> <li>▪ Support from other relatives (n=8)</li> <li>▪ Feeling socially isolated (n=7)</li> <li>▪ Lesser social interactions / activities (n=7)</li> <li>▪ Fewer friends</li> </ul>	<p><i>Theme:</i> Biographical disruption</p> <p><i>Sub themes</i></p> <p>Reliance on social capital</p> <p>Disrupted social life</p>
<p><b>Definition of the theme &amp; descriptors</b></p> <p><i>Biographical disruption</i> signifying how the kidney failure diagnosis and treatment influenced the social relations and interactions of the study participants.</p> <p><i>Reliance on social capital</i> signifying nature of the participants' social relations and interactions and support received from family and friends while living with kidney failure.</p> <p><i>Disrupted social life</i> signifying experiences of disrupted social relationships and social isolation among the participants due to the illness.</p>		

During the discussions with the study participants regarding their views on the social impacts of ESKD, biographical disruption emerged as the overarching theme and signified how the participants' social relations and interactions with others including family, friends and community were affected by their kidney failure diagnosis and treatment. This theme therefore represented effects on the participants' social relations and interactions at family and community level attributable to living with the end stage kidney disease. Two sub-themes emerged that related to how living with ESKD affected the participants socially.

These were *reliance on social capital* which signified nature of the participants' social relations and interactions and support received from family and friends while living with kidney failure and *disrupted social life* which signified experiences of disrupted social relationships and social isolation among the participants attributable to the illness. The two sub-themes are as described in the following subsections.

#### **4.5.1 Reliance on Social Capital**

Reliance on social capital emerged as one of the leading social impacts of living with ESKD among the study participants. This sub-theme reflected the nature of social relations and interactions that the study participants had with others including family members and friends while living with the ESKD. It also reflected the kind of support that the study participants received from family and friends while living with the kidney failure. From the findings, it was evident that support from family and friends whether financial or in non-financial forms including physical, emotional, psychological and social, was instrumental and had a positive influence on helping the study participants cope with the illness. Majority of the participants indicated that

they had strong and positive social relations with their families and close friends and that they received lots of support, material and otherwise, from them. Most of the participants did also acknowledge that support received from their families and friends was helpful and kept them going. The findings pointed to the important role that support from family and friends served in aiding the participants better cope with the illness, its effects and its treatment. This is illustrated in the following verbatim quotes;

“The illness has not affected my relations with my family. I do get lots of support from my parents and siblings. For instance, it is my parents who settle all my treatment costs and any other costs that arise. When I feel low, they are quick to cheer me up and to encourage me to soldier on. So, I would say they are loving, caring and understanding.” (*Salim\**)

“My family has always been there for me, before I was ill and even now, nothing has really changed in terms of our relations. My parents help me financially to meet the costs of treatment while my siblings help me out with chores when I am unable to do them. So, I relate well with them because they understand my condition and are very supportive.” (*Lydia\**)

“I must say I have been able to come this far because of my family. They give me total support. I relate very well with them. Like my elder brother keeps on checking on me. He always helps me when I am in need. My parents are also keen in helping me to avoid foods, drinks or any aspects that may worsen my condition. My parents also allow my friends from school and church to come to our home to be with me so I am not very lonely. I am happy I have a good and reassuring family.” (*Steve\**)

“My family is the best. They console me when I feel down. When I am down or when they see that I am not on the mood, they try to make me happy. When lonely, they keep me company. When I need to go to the hospital for dialysis, my parents organize on how I get to the hospital and ensure I have a person to accompany to the hospital. I would say they are always there for me every step of this journey. I thank God because I have them” (*Lucy\**)

“I do not have any challenges relating with my parents. Our relations are good. I would also add that they are caring and supportive. They meet most of my needs particularly those to do with treatments. My mother also got someone to counsel me when I was diagnosed with the ailment. So, yeah, they have been good to me and continue to help me out.” (*Dan\**)

“My parents are always positive. They just talk to me nicely. Whenever I ask for something, I need for my schooling or for my treatment, they gladly

support me whenever they are able to. Even when I feel like I am disturbing them, they are kind because they do not scold or dismiss my views.” (*Ann\**)

“With my family, I get along with them very well. They help me where they can. My parents continue to support me in my work, in my family. When I have financial challenges to do with my treatment, my parents, elder siblings and a few of my close friends always come to my aid. I would therefore say they are great.” (*Ken\**)

“My relationship with my family and a few of my friends has become strong. They (*referring to his family and close friends*) have been very supportive. I understand that dialysis and related expenditures are costly, so I am thankful that my parents and some of my friends have helped me with that. My siblings also keep in touch, they encourage me not to give up and lend me a hand when I am in need.” (*Francis\**)

“My family is okay; they do support me in treatment like covering the costs of dialysis and other costs like transport and lunches. They are also keen to involve me in family events despite my illness. I feel they value my contributions in various family affairs despite my illness. Indeed, they have been very supportive.” (*Anton\**)

However, a few of the participants indicated that they did not receive adequate support from their family and lamented that they felt deserted even by their very own people, as is illustrated in the following verbatim quote;

“For family and close friends, I do not know whether it is because a lot of money has been used to support me until other times, they see like you are lying. But lately, I have noted they are reluctant to help me. Like this time, I just called to ask for the money to use to buy catheter and they refused to give it. Again, I called them to come and donate me blood so that I can be transfused and they refused. So, it is like they are even tired of me. They even see it is better if you could die so that you can relief them or you are finishing family property. Now if you hear that, you know the relationship has decreased.” (*Wayne\**)

“When I became sick, my family and friends came to support me. They supported me until a point they started asking themselves ‘why is she not getting well? When will she recover?’ They literally gave up. The challenge with kidney failure is that it requires a lot of money. You need money for the medication, clinic, transport, rent and food. It reached a point they were asking” Why is she not coming out of Kenyatta? Others said ‘you got well long ago but you like stay’. So, I no longer receive much support from them today.” (*Stacy\**)



#### 4.5.2 Disrupted Social Life

Disrupted social life as a sub-theme under social support reflected disruptions on the study participants social relations and interactions with members of their communities occasioned by the illness. It signified experiences of disrupted social relationships and social isolation among the participants due to the illness. It also reflected the effect of the illness on how the study participants interacted with other members of their communities such as friends, neighbours, members of their church and social circles, among others socially. This also included how the study participants were treated by these members of their community in light of their health condition. From the findings, most of the study participants indicated that living with ESKD had significantly altered their social life in an adverse manner. Most of the participants lamented that being sick with kidney failure had significantly disrupted their social lives and expressed as having experienced challenges or difficulties in their social relations and interactions with peers at the community level as a result of the illness. Such difficulties included being socially isolated by their friends due to the illness, reduced participation in social activities/events, being stigmatized because of the illness, being treated differently (with unnecessary excess caution) by their friends due to the illness and being gossiped about by their peers due to the health condition.

This is illustrated in the following verbatim excerpts;

“Yes, I have experienced changes in how peers treat me because of the illness. It is mainly about attracting pity. I can call it pity because if you tell them, you are on dialysis and it is helping you, instead of them seeing it as normal, it attracts some kind of pity or excessive unnecessary compassion. Sometimes they downgrade you like you are not supposed to do this. For instance, there was a day we were planting trees in school and they could say ‘you know you are sick, just stay aside. Just watch or take a video.’ Maybe they are just caring but sometimes I feel like this is too much. There is a lot of pity and it makes me feel downgraded.” (*Salim\**)

“For my friends our relationship is not that good so I often keep to myself. It is because some think I cannot be able to do anything because I am sick. And when I request them to do something with me like I suggest we walk for 1 km, they decline and say ‘what if something happens to you, we will be held responsible’. Sometimes they make me to feel like am down. Some also talk to me rudely and accuse me of pretending or excusing myself because I am sick. Some also think I am showing off like when I come to class late and look at me and wonder why I am treated differently or in a special way by the teachers. When in social gatherings, I cannot take given sodas, cakes, they again think I am pretending or I have pride. So, they do not understand and often treat me badly.” (*Lydia*\*)

“Yes, they always remind you that you are sick. I hate to be reminded that I am sick. Like when you are in a party, they tell you ‘You should not eat those ones because you are sick’ or when you meet someone and they ask you ‘how is dialysis’. I really hate this question so much. I am also not able to do much in social events which some of peers see as pretense or pride yet you want to help but you cannot because of the condition.” (*Steve*\*)

“Some friends tend to part ways with me. When you call them, they just don't pick your call. It rings but no one is picking Maybe they think you want to borrow some money for your medication. I don't know. It is challenging. Again, I cannot hang out with my friends anymore. I cannot go to some places because they are so crowded and my immunity is not such strong. So, most of the times I stay inside the house not outside.” (*Lucy*\*)

“You know, for friends, at this time, I do not have any friends. They all left me because I am sick. You know when I was not sick you could find people requesting you even for 50 shillings or telling you to come and visit them. But since I got sick, they see maybe if I visit them or go near them, they might also get infected with that disease. So, you see, my social relations have greatly reduced.” (*Wayne*\*)

“You see I cannot do many of the things my peers do because of my illness. So, I have only a few friends mainly because most of the time I stay indoors. I am also not able to take part in many social events like parties, weddings and attending church. So, the illness has seriously curtailed my social life.” (*Dan*\*)

“When I attend those events (*referring to social events*), be it funerals, weddings, parties or church, I am the one who feels where it pinches most. I know where the needle is pricking me. That kind of meal we are given, I will not celebrate with people freely. I find myself isolating from people because if I indulge past the requirements set by the doctors, I will find myself in a bad situation.” (*Stacy*\*)

“Most of them (*referring to her friends*) we parted because some came with negative energy and for me, I do not want that because I know my condition or you do not want any stress. You see like in church, I am a dancer, but they will not allow me to dance because of the condition. So, you have to sit aside and

watch as others dance. So, some of them you have to eliminate them so that your health can be good.” (*Ann*<sup>\*</sup>)

“Take for instance football; I cannot play because I cannot be able to run like the way I used to before I became sick. For social events like parties and weddings, even those I cannot attend or even if I attend, I cannot eat at these parties, because I have to check what I am eating as advised by the doctors. So, for now, I have stopped going to events and I have stopped working, I am just focusing on my treatment.” (*Ken*<sup>\*</sup>)

## **CHAPTER FIVE: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS**

### **5.1 Introduction**

This chapter highlights discussion of findings, conclusions and recommendations of the study in accordance with the identified themes and sub-themes. The study explored the perspectives of youths living with end stage kidney disease, at Kenyatta National Hospital, regarding the impacts of the disease.

### **5.2 Discussion of Findings**

#### **5.2.1 Participants' Perspectives on Physical Impacts of the Disease**

Body changes, signifying experiences of extreme body weakness and fatigue, loss of weight and body pain leading to increased difficulties in performing normal activities of daily living among the participants due to the illness, emerged as the major theme under the perspectives on the physical impacts of ESKD among the study participants. Its sub-themes included extreme weakness and fatigue, weight loss and body pains, a discussion on which herein follows.

The first sub-theme, extreme weakness and fatigue, signified experiences of general body fatigue and frailty/weakness among the study participants as a result of the ailment more so when undertaking any activities requiring physical strength/energy. In this study, a significant proportion of the participants acknowledged experiencing persistent episodes of excessive general body weakness and tiredness attributable to living with kidney failure. The participants indicated that they experienced difficulties in undertaking normal activities of daily living such as standing, walking, house

chores and hobbies requiring physical strength like football and cycling due to persistent feelings of extreme tiredness and low energy levels. Indeed, the participants attributed their diminished physical functioning status to the persistent feelings of extreme fatigue, low energy levels and general body weakness that they frequently experienced. Similarly, El-Gamasy and Eldeeb (2017) in a study assessing the physical status of children with ESKD reported that these children experienced adverse physical impacts due to the illness including persistent body fatigue and general body weakness in turn decreasing their physical activity levels. In a study by Vanden Wyngaert et al. (2020) elevated levels of fatigue and general body weakness were noted among patients on hemodialysis in turn leading to difficulties with mobility and performance of activities of daily living. Similar observations were made by Tong et al. (2009) who noted that most of the patients receiving kidney replacement therapies complained of elevated levels of tiredness and physical body weakness which they attributed to the ailment.

The second sub-theme, weight loss, signified experiences of lower than desirable body weight or notable decrease in participants' body weight due to the illness. In this study, majority of the study participants acknowledged that their body weight had notably decreased following being diagnosed and treated for end stage kidney disease. Particularly, most of the participants indicated that their current body weight was far lower than were previously, that is, before the CKD diagnosis. Most of the participants acknowledged that their body weight had adversely been affected by the ailment attributing their significantly reduced body weight to effects of the ailment's treatment such as vomiting, nausea, diarrhea, loss of appetite and restricted diets. The participants also espoused the view that their reduced body weight contributed to their

diminished physical functioning. Likewise, in a review of young adults' perspectives on living with kidney failure, Bailey et al. (2018) also identified notable loss of weight as one of the leading physical impacts of kidney failure among affected young adults. While assessing the physical status of children with ESKD, El-Gamasy and Eldeeb (2017) also pointed to loss of weight as being a common physiological effect of ESKD on the surveyed patients physical health status. Taylor et al. (2008) in a study exploring the experiences of living with advanced CKD during adolescence also noted that majority of the surveyed adolescents identified loss of weight as one of the physical effects of advanced CKD that they had experienced.

The third sub-theme, body pains, signified experiences of physical body pain including joint pain and headaches among the participants occasioned by the illness. In this study, majority of the study participants expressed the view that they did experience occasional bodily pains which they attributed to living with kidney failure. According to the findings, the most common reported forms of body pain were joint pains, pain in the knees and headaches, with a significant proportion of the participants acknowledging that they relied on pain relieving medication to alleviate or deal with the body pains. The study participants also agreed that the body pain experiences impaired their quality of life. It was therefore evident that, among youths living with ESKD, body pain constituted a major physical impact of the ailment. Tong et al (2013) in a study examining challenges experienced by patients with ESKD did also identify pain in joints, feet, limbs and knees as some of the physical symptoms commonly reported by these patients. Nicholas et al. (2011) in a qualitative study exploring the lived experiences of children and adolescents with end stage kidney disease did also report body pain in areas such as the feet and joints as being a

common contributor to impaired physical functioning among these category of patients. Nair et al. (2023) in a study examining the challenges and unique considerations of adolescents with chronic kidney disease also identified body pain including headaches and joint pains as being a common physical effect of living with kidney failure among affected adolescents.

### **5.2.2 Participants' Perspectives on Psychological Impacts of the Disease**

Uncertainties, signifying experiences of doubts (not knowing what to expect in relation to the illness outcome) and frequent negative/worrying thoughts among the participants due to the illness, emerged as the major theme under the study participants' views on the psychological impacts of end stage kidney disease. Its sub-themes included anxiety and stress and frustrations and sadness, a discussion on which herein follows.

The first sub-theme, anxiety and stress, signified feelings of mental strain, fear and worry that the participants experienced due to the illness. It represented feelings of mental strain, fear and worry that the participants experienced due to the illness and therefore signified how living with kidney failure affected their emotional and mental wellbeing. Study findings demonstrated that majority of the participants indicated that they suffered anxiety and stress as a result of their diagnosis largely due to the hassles and rigidities of dialysis treatment as well as fear of losing their life. From the findings, it was apparent that being diagnosed with kidney failure, its disruptive effects on their normal life and the rigors of its treatment were a traumatising experience to majority of the study participants which made them feel anxious and stressed. It was therefore apparent that the emotional and mental wellbeing of the

study participants had adversely been affected by the ailment. Han et al. (2019) in a study done among patients with ESKD in Singapore did also observe that majority of the patients suffered from mental distress manifesting as anxiety and stress which in turn led to poorer health outcomes and impaired quality of life. Similar observations were made by Yu et al. (2020) who in a study investigating the prevalence of anxiety among patients with ESKD undergoing hemodialysis did also report apparent anxiety symptoms in more than half of the patients and which they attributed to the difficulties and demands associated with dialysis. Psychological symptoms including anxiety and elevated stress levels among patients with ESKD were also reported in a study by Finnegan-John and Thomas (2013) which noted that ESKD can be a stressful and traumatic experience for young people adversely affecting their mental health and wellbeing.

Frustrations and sadness which signified feelings of sorrow, despondency and futility with living that the participants experienced due to the illness constituted the second sub-theme under the participants' perspectives regarding the psychological impacts of ESKD. The sub-theme represented feelings of desperation, dissatisfaction, irritation and sorrow linked to living with kidney failure among the study participants. From the findings, a significant number of the participants shared the view that they did experience feelings of irritation, discontent and sadness which they attributed to the rigours of dialysis treatment, restrictions on their normal life imposed by the illness and to the significant adverse effects of the illness on their social life. The frustration and unhappiness also emanated from various other experiences linked to living with the illness such as the adverse physical impacts of the illness including diminished physical functioning status, disrupted sleep, losing weight and frequent body pains;



disrupted social relations such as not being to spend more time with friends or not being able to actively participate in social events as before and individual concerns over overcoming the illness. Hence, it was evident that feelings of sadness and frustration were a notable psychological impact of ESKD that the study participants experienced. This was also seen in a study done by Usri et al. (2018) which assessed the psychosocial experiences of patients with ESKD and reported irritation and sorrow as the main psychological challenges that the participants experienced. This was attributed to the chronic nature of the illness and its various adverse effects on their physical and social wellbeing. In a study by Taylor et al. (2008) adolescents living with advanced CKD were also found to suffer from various mental challenges including elevated levels of gloom and irritation. Similarly, Nicholas et al. (2011) did also report frustrations and unhappiness as some of the common mental effects of ESKD among affected adolescents.

### **5.2.3 Participants' Perspectives on Social Impacts of the Disease**

Biographical disruption, signifying how the kidney failure diagnosis and treatment influenced the social relations and interactions of the study participants, emerged as the overarching theme under study participants' perspectives regarding the social impacts of ESKD. This theme therefore illuminated effects on the participants' social relations and interactions at family and community level attributable to living with the end stage kidney disease. The two sub-themes that emerged under this theme were reliance on social capital and disrupted social life and are as hereby discussed.

The first sub-theme, reliance on social capital, signifying nature of the participants' social relations and interactions and support received from family and friends while

living with kidney failure emerged as one of the leading social impacts of ESKD that was experienced by the study participants. Reliance on social capital reflected the nature of social relations and interactions that the study participants had with family members and friends while living with ESKD. It also reflected the kind of support that the study participants received from family and friends in the course of treatment. From the findings, it was evident that support from family and friends whether financial and in non-financial form including physical, emotional, psychological and social, was instrumental and had a positive influence on helping the study participants cope with the illness. Majority of the participants indicated that they had strong and positive social relations with their families and close friends and that they received lots of support, material and otherwise, from them. Most of the participants did also acknowledge that support received from their families and close friends was helpful and kept them going. The findings pointed to the important role that support from family served in aiding the participants better cope with the illness, its effects and its treatment. Similarly, Nicholas et al. (2011) in a study conducted in Canada reported support from the immediate family, whether material or non-material, as one of the social impacts of ESKD among adolescents living with the condition. This support was found to be instrumental in helping the adolescents cope with the illness particularly the treatment aspect. Likewise, Tong et al. (2013) reported that support from family profoundly influenced how children with ESKD coped with the effects of the illness both emotionally and physically.

The second sub-theme, disrupted social life, signified the nature of social relations and interactions that the study participants within their communities while living with kidney failure. It signified experiences of disrupted social relationships and social

isolation among the participants due to the illness. It depicted how the participants' social life was adversely affected by their kidney failure diagnosis and treatment. This also included how the study participants were treated by these members of their community in light of their health condition. From the findings, most of the study participants indicated that living with ESKD had significantly altered their social life in an adverse manner. Most of the participants lamented that being sick with kidney failure had significantly disrupted their social lives and expressed as having experienced challenges or difficulties in their social relations and interactions with peers at the community level as a result of the illness. Such difficulties included being socially isolated by their friends due to the illness, reduced participation in social activities/events, being stigmatized because of the illness, being treated differently (with unnecessary excess caution) by their friends due to the illness and being gossiped about by their peers due to the health condition.

Similar observations were reported by El-Gamasy and Eldeeb (2017) who found abnormal social behaviors such as loneliness and self-isolation among children with ESKD which they attributed to stigmatization, low self-esteem and parental overprotectiveness of these children. Bailey et al. (2018) also reported that living with ESKD adversely impacted social relationships among affected adolescents due to its effects such as impaired body image, increased body weakness and fatigue. Nicholas et al. (2011) reported similar findings among young adults with ESKD most of whom complained that living with kidney failure had significantly disrupted their social lives while acknowledging that they experienced increased difficulties in maintaining their social relations and interactions. In contrast, participants in the study by Han et al.

(2019) reported no significant disruptions on their social relations as a result of living with ESKD.

### **5.3 Conclusions**

Based on the findings of the study, the study concludes that;

Physically, the youths living with ESKD at KNH experienced body changes which manifested largely as feelings of extreme weakness and tiredness, weight loss and body pains which in turn impaired their physical functioning status

Psychologically, the youths living with ESKD at KNH experienced uncertainties over their illness outcome which manifested through episodes of anxiety and stress and feeling frustrated and sad.

Socially, reliance on social capital from family and friends and disrupted social life formed the major social impacts of ESKD among youths living with ESKD at KNH.

### **5.4 Recommendations**

#### **5.4.1 Recommendations for Practice**

Health practitioners at KNH's renal unit should accord due consideration to the physical, mental and social wellbeing of youths receiving treatment for the condition in the hospital. This includes provision of painkillers to those in pain and counselling services to those with uncertainties about the disease and its treatment

Youths receiving treatment for ESKD should also be encouraged to seek help for any adverse physical, mental and social effects of ESKD that they experience.

#### **5.4.2 Recommendations for Policy**

The structures and policies at KNH's renal unit should meet the needs of youths living with ESKD be they physical, psychological and/or social.

Peer mentorship programs should be developed to help the youth in dealing with diverse challenges associated with ESKD. This includes fostering their communication through various social media platforms such as WhatsApp and Telegram.

#### **5.4.3 Recommendations for Research**

The current study only focused on the perspectives of youths at Kenyatta National Hospital living with End stage kidney disease on the impact of the disease. An exploration of the impacts of ESKD on the affected youths from the perspectives of their caregivers, both at home and in the hospitals, would equally be informative. Further, an exploration of the self-management challenges and care needs of youths living with ESKD at KNH would also be enlightening.

## REFERENCES

- Bailey, P. K., Hamilton, A. J., Clissold, R. L., Inward, C. D., Caskey, F. J., Ben-Shlomo, Y., & Owen-Smith, A. (2018). Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. *Population Health Sciences*, 8, 19926. <https://doi.org/10.1136/bmjopen-2017-019926>
- Bikbov, B., Purcell, C. A., Levey, A. S., Smith, M., Abdoli, A., Abebe, M., Adebayo, O. M., Afarideh, M., Agarwal, S. K., Agudelo-Botero, M., Ahmadian, E., Al-Aly, Z., Alipour, V., Almasi-Hashiani, A., Al-Raddadi, R. M., Alvis-Guzman, N., Amini, S., Andrei, T., Andrei, C. L., ... Murray, C. J. L. (2020). Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 395(10225), 709–733. [https://doi.org/10.1016/S0140-6736\(20\)30045-3](https://doi.org/10.1016/S0140-6736(20)30045-3)
- Centers for Disease Control and Prevention in the United States. (2021). Chronic Kidney Disease in the United States, 2021. *Cdc*, 1, 1–6. <https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html> <https://www.cdc.gov/kidneydisease/publications-resources/2019-national-facts.html>
- Cockwell, P., & Fisher, L. A. (2020). The global burden of chronic kidney disease. *The Lancet*, 395(10225), 662–664. [https://doi.org/10.1016/S0140-6736\(19\)32977-0](https://doi.org/10.1016/S0140-6736(19)32977-0)
- Cukor, D., Cohen, S. D., Peterson, R. A., & Kimmen, P. L. (2007). Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *Journal of the American Society of Nephrology*, 18(12), 3042–3055. <https://doi.org/10.1681/ASN.2007030345>
- Darwish, M. M., Hassan, S. H., Fathy Taha, S., Said, H., El-Megeed, A., Abdul-Aziz, T., & Ismail, M. (2018). *Family impact and economic burden among caregivers of children with chronic kidney disease in Assiut, Egypt*. <https://doi.org/10.1186/s42506-020-00058-7>
- El-gamasy, M. A., & Eldeeb, M. M. (2017). International Journal of Pediatrics and Assessment of physical and psychosocial status of children with ESRD under regular hemodialysis , a single centre experience. *International Journal of Pediatrics and Adolescent Medicine*, 4(2), 81–86. <https://doi.org/10.1016/j.ijpam.2017.01.001>
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>

- Faulkner, S. L., & Trotter, S. P. (2017). Data Saturation. *The International Encyclopedia of Communication Research Methods*, 1–2. <https://doi.org/10.1002/9781118901731.IECRM0060>
- Gerson, A. C., Wentz, A., Abraham, A. G., Mendley, S. R., Hooper, S. R., Butler, R. W., Gipson, D. S., Lande, M. B., Shinnar, S., Moxey-Mims, M. M., Warady, B. A., & Furth, S. L. (2010). Health-Related Quality of Life of Children with Mild to Moderate Chronic Kidney Disease. *Pediatrics*, 125(2), e349. <https://doi.org/10.1542/PEDS.2009-0085>
- Guerra, F., Di Giacomo, D., Ranieri, J., Tunno, M., Piscitani, L., & Ferri, C. (2021). Chronic Kidney Disease and Its Relationship with Mental Health: Allostatic Load Perspective for Integrated Care. *Journal of Personalized Medicine*, 11(12). <https://doi.org/10.3390/JPM11121367>
- Hallett, C. (1995). Understanding the phenomenological approach to research. *Nurse Researcher*, 3(2), 55–65. <https://doi.org/10.7748/NR.3.2.55.S6>
- Han, E., Shiraz, F., Haldane, V., Koh, J. J. K., Quek, R. Y. C., Ozdemir, S., Finkelstein, E. A., Jafar, T. H., Choong, H. L., Gan, S., Lim, L. W. W., & Legido-Quigley, H. (2019). Biopsychosocial experiences and coping strategies of elderly ESRD patients: A qualitative study to inform the development of more holistic and person-centred health services in Singapore. *BMC Public Health*, 19(1), 1–13. <https://doi.org/10.1186/s12889-019-7433-6>
- Husserl, E. (1927). Phenomenology \* by Edmund Husserl Pure Natural Science and Pure Psychology. *Encyclopedia Britannica*, 1927, 1–11.
- Jager, K. J., Kovesdy, C., Langham, R., Rosenberg, M., Jha, V., & Zoccali, C. (2019). A single number for advocacy and communication—worldwide more than 850 million individuals have kidney diseases. *Kidney International*, 96(5), 1048–1050. <https://doi.org/10.1016/J.KINT.2019.07.012>
- Kazanciog, R., & Lu, Y. (2013). *Risk factors for chronic kidney disease: an update*. <https://doi.org/10.1038/kisup.2013.79>
- Kaze, A. D., Ilori, T., Jaar, B. G., & Echouffo-Tcheugui, J. B. (2018). Burden of chronic kidney disease on the African continent: A systematic review and meta-analysis. *BMC Nephrology*, 19(1), 1–12. <https://doi.org/10.1186/s12882-018-0930-5>
- Kimmel, P. L., Peterson, R. A., Weihs, K. L., Simmens, S. J., Alleyne, S., Cruz, I., & Veis, J. H. (1998). *Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients I*. <https://doi.org/10.1046/j.1523-1755.1998.00989.x>
- Kovesdy, C. P. (2022). Epidemiology of chronic kidney disease: an update 2022.

- Kramer, A., Stel, V. S., Tizard, J., Verrina, E., Rönnholm, K., Pálsson, R., Maxwell, H., & Jager, K. J. (2009). Characteristics and survival of young adults who started renal replacement therapy during childhood. *Nephrology, Dialysis, Transplantation : Official Publication of the European Dialysis and Transplant Association - European Renal Association*, 24(3), 926–933. <https://doi.org/10.1093/NDT/GFN542>
- Levey, A. S., Atkins, R., Coresh, J., Cohen, E. P., Collins, A. J., Eckardt, K. U., Nahas, M. E., Jaber, B. L., Jadoul, M., Levin, A., Powe, N. R., Rossert, J., Wheeler, D. C., Lameire, N., & Eknoyan, G. (2007). Chronic kidney disease as a global public health problem: Approaches and initiatives - A position statement from Kidney Disease Improving Global Outcomes. *Kidney International*, 72(3), 247–259. <https://doi.org/10.1038/sj.ki.5002343>
- Lincoln, Y., & Guba, E. G. (1985). The Disturbing and Disturbed Observer. *Naturalistic Inquiry*, 92–109, 357–367.
- Liyanage, T., Ninomiya, T., Jha, V., Neal, B., Patrice, H. M., Okpechi, I., Zhao, M. H., Lv, J., Garg, A. X., Knight, J., Rodgers, A., Gallagher, M., Kotwal, S., Cass, A., & Perkovic, V. (2015a). Worldwide access to treatment for end-stage kidney disease: A systematic review. *The Lancet*, 385(9981), 1975–1982. [https://doi.org/10.1016/S0140-6736\(14\)61601-9](https://doi.org/10.1016/S0140-6736(14)61601-9)
- Liyanage, T., Ninomiya, T., Jha, V., Neal, B., Patrice, H. M., Okpechi, I., Zhao, M. H., Lv, J., Garg, A. X., Knight, J., Rodgers, A., Gallagher, M., Kotwal, S., Cass, A., & Perkovic, V. (2015b). Worldwide access to treatment for end-stage kidney disease: a systematic review. *The Lancet*, 385(9981), 1975–1982. [https://doi.org/10.1016/S0140-6736\(14\)61601-9](https://doi.org/10.1016/S0140-6736(14)61601-9)
- Luyckx, V. A., Tuttle, K. R., Garcia-Garcia, G., Gharbi, M. B., Heerspink, H. J. L., Johnson, D. W., Liu, Z. H., Massy, Z. A., Moe, O., Nelson, R. G., Sola, L., Wheeler, D. C., & White, S. L. (2017). Reducing major risk factors for chronic kidney disease. *Kidney International Supplements*, 7(2), 71–87. <https://doi.org/10.1016/j.kisu.2017.07.003>
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung*, 11(3).
- Massengill, S. F., & Ferris, M. (2014). Chronic Kidney Disease in Children and Adolescents. *Pediatrics In Review*, 35(1), 16–29. <https://doi.org/10.1542/PIR.35-1-16>
- Morse, J. M. (2000). Determining Sample Size. *Qualitative Health Research*, 10(1),



3–5. <https://doi.org/10.1177/104973200129118183>

- Nair, N., Prashant Kadatane, S., Yaacoub, R. M., Sandhu, J. M., Bhavaraju, S., & Raina, R. (2023). Challenges and unique considerations of adolescents with chronic kidney disease. *Acta Paediatrica*. <https://doi.org/10.1111/APA.16752>
- Nicholas, D. B., Picone, G., & Selkirk, E. K. (2011). The lived experiences of children and adolescents with end-stage renal disease. *Qualitative Health Research*, 21(2), 162–173. <https://doi.org/10.1177/1049732310382789>
- Reddenna, L., Ayub Basha, S., Siva, K., & Reddy, K. (2014). *Dialysis Treatment: A Comprehensive Description*. 3(1), 1–13. [www.ijpras.com](http://www.ijpras.com)
- Rodig, N. M., Mcdermott, K. C., Schneider, M. F., Hotchkiss, H. M., Yadin, O., Seikaly, M. G., Furth, S. L., & Warady, B. A. (2014). *Growth in Children With Chronic Kidney Disease: A Report From the Chronic Kidney Disease in Children Study*. <https://doi.org/10.1007/s00467-014-2812-9>
- Spano, S. (2004). *Stages of Adolescent Development f s and ACT for Youth Upstate Center of Excellence FINDINGS FINDINGS*.
- St Peter, W. L., Wazny, L. D., & Patel, U. D. (2013). New Models of CKD Care Including Pharmacists: Improving Medication Reconciliation and Medication Management. *Curr Opin Nephrol Hypertens*, 22(6), 656–662. <https://doi.org/10.1097/MNH.0b013e328365b364>
- Stanifer, J. W., Jing, B., Tolan, S., Helmke, N., Mukerjee, R., Naicker, S., & Patel, U. (2014). The epidemiology of chronic kidney disease in sub-Saharan Africa: A systematic review and meta-analysis. *The Lancet Global Health*, 2(3), e174–e181. [https://doi.org/10.1016/S2214-109X\(14\)70002-6](https://doi.org/10.1016/S2214-109X(14)70002-6)
- Sundler, A. J., Lindberg, E., Nilsson, C., & Palmér, L. (2019). Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open*, 6(3), 733–739. <https://doi.org/10.1002/NOP2.275>
- Taylor, R. M., Gibson, F., & Franck, L. S. (2008). The experience of living with a chronic illness during adolescence: A critical review of the literature. *Journal of Clinical Nursing*, 17(23), 3083–3091. <https://doi.org/10.1111/j.1365-2702.2008.02629.x>
- Thurlow, J. S., Joshi, M., Yan, G., Norris, K. C., Agodoa, L. Y., Yuan, C. M., & Nee, R. (2003). Global Epidemiology of End-Stage Kidney Disease and Disparities in Kidney Replacement Therapy. *Depth Topic Review Am J Nephrol*, 52, 98–107. <https://doi.org/10.1159/000514550>
- Tjaden, L. A., Grootenhuis, M. A., Noordzij, M., & Groothoff, J. W. (2015). *Health-related quality of life in patients with pediatric onset of end-stage renal disease:*

*state of the art and recommendations for clinical practice.*  
<https://doi.org/10.1007/s00467-015-3186-3>

- Tjaden, L., Tong, A., Henning, P., Groothoff, J., & Craig, J. C. (2012). Children's experiences of dialysis: A systematic review of qualitative studies. *Archives of Disease in Childhood*, 97(5), 395–402. <https://doi.org/10.1136/archdischild-2011-300639>
- Tong, A., Henning, P., Wong, G., McTaggart, S., MacKie, F., Carroll, R. P., & Craig, J. C. (2013). Experiences and perspectives of adolescents and young adults with advanced ckd. *American Journal of Kidney Diseases*, 61(3), 375–384. <https://doi.org/10.1053/j.ajkd.2012.09.024>
- Tong, A., Sainsbury, P., Chadban, S., Walker, R. G., Harris, D. C., Carter, S. M., Hall, B., Hawley, C., & Craig, J. C. (2009). Patients' Experiences and Perspectives of Living With CKD. *American Journal of Kidney Diseases*, 53(4), 689–700. <https://doi.org/10.1053/j.ajkd.2008.10.050>
- United States Renal Data System. (2022). Epidemiology of kidney disease in the United States. In *National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases*. <https://usrds-adr.niddk.nih.gov/2022>
- Vanden Wyngaert, K., Van Craenenbroeck, A. H., Eloot, S., Calders, P., Celie, B., Holvoet, E., & Van Biesen, W. (2020). Associations between the measures of physical function, risk of falls and the quality of life in haemodialysis patients: A cross-sectional study. *BMC Nephrology*, 21(1), 1–10. <https://doi.org/10.1186/s12882-019-1671-9>
- Varpio, L., Paradis, E., Uijtdehaage, S., & Young, M. (2020). The Distinctions Between Theory, Theoretical Framework, and Conceptual Framework. *Academic Medicine: Journal of the Association of American Medical Colleges*, 95(7), 989–994. <https://doi.org/10.1097/ACM.0000000000003075>
- Wang, M., Li, J., Li, Y., Yao, S., Zhao, M., Wang, C., Wu, S., & Xue, H. (2020). The effects of hypertension and diabetes on new-onset chronic kidney disease: A prospective cohort study. *The Journal of Clinical Hypertension*, 22(1), 39. <https://doi.org/10.1111/JCH.13768>
- WHO. (2021). *HIV/AIDS*. <https://www.who.int/data/gho/data/themes/hiv-aids>
- WHO. (2022). *Diabetes*. [https://www.who.int/health-topics/diabetes#tab=tab\\_1](https://www.who.int/health-topics/diabetes#tab=tab_1)
- Yu, I.-C., Fang, J.-T., & Tsaiid, Y.-F. (2020). *Exploring demands of hemodialysis patients in Taiwan: A two-step cluster analysis*. <https://doi.org/10.1371/journal.pone.0228259>

## APPENDICES

### Appendix I: Work Plan

Activity/months/ Year	DEC 2022- Mar 2023	APRIL 2022- JUNE 2023	JULY 2023	AUG 2023	SEP 2023	OCT 2023	NOV 2023
Proposal development							
Submission to KNH-UoN ERC							
Action on ERC recommendation							
Pre-testing							
collection and cleaning of data							
Processing and Analysis of data							
Report Writing							
Presentation of the draft report and corrections to the supervisor							
Presentation of the final report and submission to the supervisor							
Thesis defense							

## Appendix II: Budget

Aspect of Budget	Explanation	Particulars	Measurement Unit	Expense (Kshs)	Overall expense (kshs)
Review of the Literature	Personal literature search, transport and use of data bundles	A literature search in articles, books, and dissertations.	12 weeks	@1000 per Week	12,000
Stationary	A ream of A4 papers	1	@800 per ream	800	800
Digital voice recorder		1		5000	5000
Proposal Printing	Printing	3 copies	70 pages @	@20 per page	4200
Photocopy charges	70 pages	3 copies @70 pages	210 pages	@5 per page	1050
Ethical Approval	KNH/UON Ethics	1	@2000	2000	2000
Data Collection and Data Analysis	Interview Guide for Pretesting	Printing photocopy, and Transport	4 copies 7 days	@10 @1000	40 7000
Participants information sheet	Photocopy	30 copies	@50	1500	1500
<b>Subtotal</b>					<b>35000</b>

Report	Draft report with 150 pages@	printing and photocopy	150 pages, 5 copies	@20 @5	3000 3750
Final document	Printing	150 pages	@20	3000	3000
Final document	Printing	150 pages	@20	3000	3000
Photocopying	Final document 5 copies	5@150pages	@ 5	3750	3750
Binding	5 copies	@500	2500		2500
Photocopying	10 copies @ 150 pages	@5	7500		7500
Binding	10 copies	@500	500		5000
Publication fee					70000
<b>Subtotal</b>					<b>101500</b>
Contingencies (10%)	13650				13650
<b>Total</b>					<b>150,150</b>

### **Appendix III: Letter to Ethics Committee**

Chepkorir Truphena

Reg. No.: H56/40898/2021

School of Nursing Sciences

College of Health Sciences

University of Nairobi

16th March 2023

To

The Chairman

The KNH-UoN ERC,

P.O Box 20723-00202

Nairobi

Dear Sir/Madam

**RE: PERMISSION TO CONDUCT RESEARCH AT KENYATTA NATIONAL HOSPITAL.**

My name is Truphena Chepkorir a second-year student at the University of Nairobi, School of Nursing Sciences pursuing a Master of Science in Nursing (Renal Nursing).

I am undertaking qualitative research **to Explore the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease.** I am seeking permission to conduct my research at Kenyatta National Hospital.

The study participants will be recruited from the Kenyatta National Hospital Renal unit. The data collection using in-depth interviews will be done by Chepkorir Truphena as the principal investigator.

I look forward to your positive feedback.

Thank you.

Yours Faithfully

Chepkorir Truphena

Reg. No, H56/40898/2021

Email: [truphena.uonbi@student.uonbi.ac.ke](mailto:truphena.uonbi@student.uonbi.ac.ke)

Mobile No: 0706598064

#### **Appendix IV: Letter to Institution (Department)**

Chepkorir Truphena

Reg. No, H56/40898/2021

School of Nursing Sciences

College of Health Sciences

University of Nairobi

16th March 2023

To

The Deputy Director of Medical Research

Kenyatta National Hospital

P.O Box 20723-00202

Nairobi

Dear Sir/Madam

#### **RE:PERMISSION TO CONDUCT RESEARCH AT KENYATTA NATIONAL HOSPITAL.**

My name is Truphena Chepkorir, a second-year student at the University of Nairobi, School of Nursing Sciences nursing a Master of Science in Nursing (Renal Nursing).I am undertaking a qualitative study to **explore the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease.** I am seeking permission to conduct my research at Kenyatta National Hospital.

The study participants will be recruited from the Kenyatta National Hospital Renal unit. The data collection using in-depth interviews will be done by Chepkorir Truphena as the principal investigator.



The letter of approval from the ethics review committee and a summary of the study's content will be attached.

I look forward to your positive feedback.

Thank you in advance.

Yours Faithfully

Chepkorir Truphena

Reg. No, H56/40898/2021

Email: [truphena.uonbi@student.uonbi.ac.ke](mailto:truphena.uonbi@student.uonbi.ac.ke)

Mobile No: 0706598064

## **Appendix V (a): Participants Information Sheet and Consent Form**

### **Participants Information Sheet**

**Study title:** Exploring the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease.

**Researcher:** Chepkorir Truphena. Tel: 0706598064.

#### **Introduction:**

My name is Truphena Chepkorir, a student at the University of Nairobi pursuing a Master of Science Degree in Renal Nursing. I am conducting research titled **"Exploring the Perspectives of Youths at Kenyatta National Hospital Living with End Stage Kidney Disease on the Impact of the Disease"** The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in medical research:

- i) Your decision to participate is entirely voluntary
- ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal

- iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue?

**YES .... NO....**

This study has been approved by The Kenyatta National Hospital-University of Nairobi Ethics and

Research Committee Protocol No. \_\_\_\_\_.

### **The Purpose of the Study**

The study intends to determine the perspectives of youths living with End Stage Kidney Disease on the impact of the disease in Kenyatta National Hospital. The findings of the study will be used in the formulation and use of evidence-based clinical guidelines for supporting youths with different experiences and perceptions.

### **RISKS**

The research has the potential to introduce emotional harm, breach of privacy, breach of participant's autonomy during the consenting procedure and power imbalances. Efforts will be put in place to minimize the risks. In case of emotional harm, the participants will be offered debriefing sessions after the interview and will be allowed to stop the interview. Participants' privacy and confidentiality will be maintained throughout the data collection process. The participants will be made aware of their willingness to participate and their freedom to withdraw from the study at any given

point. There will be no coercion or incentives for participants. Power imbalances will be reduced by engaging the participants in the study through member checks. The study will be conducted under guidelines from KNH/UoN-ERC to protect the participants from harm. Additionally, referrals will be made according to the KNH protocols.

## **BENEFITS**

You may benefit from counseling services. We will refer you to a hospital for care and support if necessary. Also, the information you provide will help us better understand your experiences of living with ESKD and its impact. This information is a major contribution to science and overall patient outcome.

## **CONSENT FORM.**

### **Participant's statement**

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

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

**I agree to participate in this research study: Yes .....No.....**

**Participant name:** \_\_\_\_\_

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

**Researcher's statement**

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

**Researcher's Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature** \_\_\_\_\_

## **Appendix V (b): Informed Consent (Swahili Version)**

### **Kichwa cha Mradi: Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo**

Mtafiti: Chepkorir Truphena Tel: 0706598064.

#### **Utangulizi:**

Jina langu ni Truphena chepkorir, mwanafunzi katika Chuo Kikuu cha Nairobi anayefuata Shahada ya Uzamili ya Sayansi katika Uuguzi wa Figo. Ninafanya utafiti unaoitwa "**Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo**" Madhumuni ya fomu hii ya idhini ni kukupa maelezo utakayohitaji ili kukusaidia kuamua kama au la kuwa mshiriki katika utafiti. Jisikie huru kuuliza maswali yoyote kuhusu madhumuni ya utafiti, nini kitatokea ikiwa utashiriki katika utafiti, hatari na manufaa yanayoweza kutokea, haki zako kama mtu aliyejitolea, na kitu kingine chochote kuhusu utafiti au hili fomu ambayo haiko wazi. Tunapojibu maswali yako yote kwa kuridhika kwako, unaweza kuamua kuwa katika utafiti au la. Mchakato huu unaitwa 'ridhaa iliyoarifiwa'. Ukishaelewa na kukubali kuwa katika utafiti, nita nakuomba utie sahihi jina lako kwenye fomu hii. Unapaswa kuelewa kanuni za jumla zinazotumika kwa washiriki wote katika utafiti wa matibabu.

i) Uamuzi wako wa kushiriki ni wa hiari kabisa

ii) Unaweza kujiondoa kwenye utafiti wakati wowote bila ya kutoa sababu ya kujiondoa kwako

iii) Kukataa kushiriki katika utafiti hakutaathiri huduma unazostahili kupata katika kituo hiki cha afya au vituo vingine. Tutakupa nakala ya fomu hii kwa rekodi zako.

Naweza kuendelea?

**NDIYO.... HAPANA....**

Utafiti huu umeidhinishwa na Hospitali ya Kitaifa ya Kenyatta-Chuo Kikuu cha Maadili cha Nairobi na

Itifaki ya Kamati ya Utafiti Na. \_\_\_\_\_.

### **MADHUMUNI YA UTAFITI**

Utafiti huo unanua kubainisha mitazamo ya vijana wanaoishi na ugonjwa wa Figo kuhusu athari za ugonjwa huo katika hospitali ya kitaifa ya Kenyatta. Matokeo ya utafiti yatautumika katika uundaji na matumizi ya miongozo ya kliniki yenye msingi wa ushahidi kwa ajili ya kusaidia vijana walio na uzoefu na mtazamo tofauti

### **HATARI**

Utafiti una uwezo wa kuanzisha madhara ya kihisia, uvunjaji wa faragha, uvunjaji wa uhuru wa washiriki wakati wa utaratibu wa idhini na usawa wa mamlaka. Juhudi zitawekwa ili kupunguza hatari. Katika kesi ya madhara ya kihisia, washiriki watapeleka vikao vya majadiliano baada ya mahojiano na wataruhusiwa kusitisha mahojiano. Faragha na usiri wa washiriki vitadumishwa katika mchakato wote wa kukusanya data. Washiriki watafahamishwa kuhusu utayari wao wa kushiriki na uhuru wao wa kujiondoa kwenye utafiti wakati wowote. Hakutakuwa na shuruti au motisha kwa washiriki. Ukosefu wa usawa wa nguvu utapunguzwa kwa

kuwashirikisha washiriki katika utafiti kupitia ukaguzi wa wanachama. Utafiti huo utafanywa chini ya miongozo kutoka kwa hospitali ya taifa ya kenyattata/Chuo Kikuu cha Nairobi - bodi ya maadili na ukaguziili kuwalinda washiriki dhidi ya madhara. Zaidi ya hayo, marejeleo yatafanywa kulingana na itifaki za Hospitali ya taifa ya Kenyatta

## **FAIDA**

Unaweza kufaidika na huduma za ushauri. Tutakuelekeza kwa hospitali kwa huduma na usaidizi ikibidi. Pia, maelezo utakayotoa yatatusaidia kuelewa vizuri zaidi mitazamo yako ya kuishi na ugonjwa wa figo na athari zake. Habari hii ni mchango mkubwa kwa sayansi na matokeo ya jumla ya mgonjwa

## **FOMU YA IDHINI.**

### **Kauli ya mshiriki**

Nimesoma fomu hii ya idhini au nimesomewa maelezo. Nimepata nafasi ya kujadili utafiti huu na mtafiti. Nimejibiwa maswali yangu kwa lugha ninayoielewa. Hatari na faida zimeelezwa kwangu. Ninaelewa kuwa ushiriki wangu katika utafiti huu ni wa hiari na kwamba ninaweza kuchagua kujiondoa wakati wowote. Ninakubali kwa uhuru kushiriki katika utafiti huu. Ninaelewa kuwa juhudi zote zitafanywa ili kuweka maelezo kuhusu utambulisho wangu wa kibinafsi kuwa siri

Kwa kutia saina fomu hii ya idhini, sijaacha haki zozote za kisheria nilizo nazo kama mshiriki katika utafiti wa utafiti.

**Ninakubali kushiriki katika utafiti huu: Ndiyo ..... Hapana .....**



**Jina la mshiriki:** \_\_\_\_\_

**Sahihi** ya **mshiriki** / **mhuri** ya **kidole** **gumba**

\_\_\_\_\_ **Tarehe** \_\_\_\_\_

**Kauli ya mtafiti**

Mimi, aliyetia sahihi hapa chini, nimeeleza kikamilifu maelezo muhimu ya utafiti huu kwa mshiriki aliyetajwa hapo juu na ninaamini kuwa mshiriki ameelewa na ametoa ridhaa yake kwa hiari na kwa uhuru.

**Jina la Mtafiti:** \_\_\_\_\_ **Tarehe:** \_\_\_\_\_

**Sahihi** \_\_\_\_\_

## **Appendix VI (a): Parent/Guardian Consent Form and Participant Information**

### **Participants' information sheet**

**Title of Study:** Exploring the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease.

**Researcher:** Truphena Chepkorir

#### **Introduction:**

My name is Truphena Chepkorir, a student at the University of Nairobi pursuing a Master's of Science Degree in Renal Nursing. I am conducting research titled "**Exploring the Perspectives of Youths at Kenyatta National Hospital Living with End Stage Kidney Disease on the Impact of the Disease**". The purpose of this consent form is to give you the information you will need to help you decide whether or not your child should participate in the study. Feel free to ask any questions about the research that is not clear. Once you understand and agree for your child to be in the study, I will request you to sign your name on this form. You should also understand that your child's decision to participate is entirely voluntary and he or she may withdraw from the study at any time without necessarily giving a reason for his/her withdrawal. In addition, your refusal to participate in the research will not affect the services your child is entitled to in this health facility or other facilities.

May I continue?

**YES ..... NO.....**

For children below 18 years of age we give information about the study to parents or

guardians. We will give you a copy of this form for your records. If your child is at an age that he/she can appreciate what is being done then he/she will also be required to agree to participate in the study after being fully informed and provided with an ascent form to sign.

### **PURPOSE OF THE STUDY**

The study intends to determine the perspectives of youths living with End Stage Kidney Disease on the impact of the disease in Kenyatta National Hospital. The findings of the study will be used in formulation and use of evidence-based clinical guidelines for supporting youths with different experiences and perceptions. We are asking for your consent to consider your child to participate in this study.

### **RISKS**

The research has the potential to introduce emotional harm, breach of privacy, breach of participants' autonomy during the consenting procedure and power imbalances. Efforts will be put in place to minimize the risks. In case of emotional harm, the participants will be offered debriefing sessions after the interview and will be allowed to stop the interview. Participants' privacy and confidentiality will be maintained throughout the data collection process. The participants will be made aware of their willingness to participate and their freedom to withdraw from the study at any given point. There will be no coercion or incentives for participants. Power imbalances will be reduced by engaging the participants in the study through member checks. The study will be conducted under guidelines from KNH/UoN-ERC to protect the participants from harm. Additionally, referrals will be made according to the KNH protocols.

## **BENEFITS**

Your child may benefit from counseling services. We will refer your child to a hospital for care and support if necessary. Also, the information you provide will help us better understand their experiences of living with ESKD and its impact. This information is a major contribution to science and overall patient's outcome.

## **PARENT/GUARDIAN CONSENT FORM**

The person being considered for this study is unable to consent for him/herself because he or she is a minor (a person less than 18 years of age). You are being asked to give your permission to include your child in this study.

### **Parent/guardian statement**

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with the researcher. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation and that of my child in this study is voluntary and that I may choose to withdraw at any time. I understand that all efforts will be made to keep information regarding me and my child's personal identity confidential. By signing this consent form, I have not given up my child's legal rights as a participant in this research study.

**I voluntarily agree to my child's participation in this research study:**

**Yes ..... No....**

**Parent/Guardian signature/Thumb stamp:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Parent/Guardian printed name:** \_\_\_\_\_

**Researcher's statement**

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

Printed Name: \_\_\_\_\_ Date: \_\_\_\_\_

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

**Appendix VI (b): Parent/Guardian Consent Form and Participant Information  
(Swahili Version)**

**Kichwa cha Mradi: Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo.**

Mtafiti: Chepkorir Truphena. Tel: 0706598064.

**Utangulizi:**

Jina langu ni Truphena chepkorir, mwanafunzi katika Chuo Kikuu cha Nairobi anayefuata Shahada ya Uzamili ya Sayansi katika Uuguzi wa Figo. Ninafanya utafiti unaoitwa "**Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo**" Madhumuni ya fomu hii ya idhini ni Madhumuni ya fomu hii ya idhini ni kukupa taarifa utakayohitaji ili kukusaidia kuamua kama mtoto wako atashiriki au la. Jisikie huru kuuliza maswali yoyote kuhusu utafiti ambayo hayako wazi. Ukishaelewa na kukubali mtoto wako awe kwenye utafiti, nitakuomba utie sahihi jina lako kwenye fomu hii. Unapaswa pia kuelewa kwamba uamuzi wa mtoto wako kushiriki ni wa hiari kabisa na anaweza kujiondoa kwenye utafiti wakati wowote bila kutoa sababu ya kujiondoa kwake. Aidha, kukataa kwako kushiriki katika utafiti hakutaathiri huduma anazostahili mtoto wako kupata katika kituo hiki cha afya au vituo vingine.

Naweza kuendelea?

**NDIYO..... HAPANA.....**

Kwa watoto walio chini ya umri wa miaka 18 tunatoa taarifa kuhusu utafiti kwa wazazi au walezi. Tutakupa nakala ya fomu hii kwa rekodi zako. Iwapo mtoto wako yuko katika umri ambao anaweza kufahamu kile kinachofanywa basi atahitajika pia kukubali kushiriki katika utafiti baada ya kufahamishwa kikamilifu na kupewa fomu ya idhini ya vijana ili atie sahihi.

## **MADHUMUNI YA UTAFITI**

Utafiti huo unanua kubainisha mitazamo ya vijana wanaoishi na ugonjwa wa Figo kuhusu athari za ugonjwa huo katika hospitali ya kitaifa ya Kenyatta. Matokeo ya utafiti yatautumika katika uundaji na matumizi ya miongozo ya kimatibabu yenye msingi wa ushahidi kwa ajili ya kusaidia vijana walio na uzoefu na mtazamo tofauti. Tunaomba idhini yako ya kuzingatia mtoto wako kushiriki katika utafiti huu.

## **HATARI**

Utafiti una uwezo wa kuanzisha madhara ya kihisia, uvunjaji wa faragha, uvunjaji wa uhuru wa washiriki wakati wa utaratibu wa idhini na usawa wa mamlaka. Juhudi zitawekwa ili kupunguza hatari. Katika kesi ya madhara ya kihisia, washiriki watapelelewa vika vya majadiliano baada ya mahojiano na wataruhusiwa kusitisha mahojiano. Faragha na usiri wa washiriki vitadumishwa katika mchakato wote wa kukusanya data. Washiriki watafahamishwa kuhusu uhuru wao wa kushiriki na uhuru wao wa kujiondoa kwenye utafiti wakati wowote. Hakutakuwa na shuruti au motisha kwa washiriki. Ukosefu wa usawa wa nguvu utapunguzwa kwa kuwashirikisha washiriki katika utafiti kupitia ukaguzi wa wanachama. Utafiti huo utafanywa chini ya miongozo kutoka kwa hospitali ya taifa ya kenyattata/Chuo Kikuu cha nairobi -bodi ya maadili na ukaguzi ili kuwalinda washiriki dhidi ya madhara. Zaidi ya hayo,

marejeleo yatafanywa kulingana na itifaki za Hospital ya Taifa ya Kenyatta

## **FAIDA**

Mtoto wako anaweza kufaidika na huduma za ushauri. Tutampeleka mtoto wako hospitali kwa matunzo na usaidizi ikibidi. Pia, maelezo utakayotoa yatatusaidia kuelewa vyema uzoefu wao wa kuishi na ugonjwa wa figo na athari zake. Habari hii ni mchango mkubwa kwa sayansi na matokeo ya jumla ya mgonjwa

## **FOMU YA IDHINI YA MZAZI/MLEZI.**

Mtu anayezingatiwa kwa utafiti huu hana uwezo wa kujikubali kwa sababu yeye ni mtoto mdogo (mtu aliye chini ya miaka 18). Unaombwa kutoa idhini yako ya kujumuisha mtoto wako katika utafiti huu.

### **Kauli ya mzazi/mlezi**

Nimesoma fomu hii ya idhini au nimesomewa maelezo. Nimepata nafasi ya kujadili utafiti huu na mtafiti. Nimejibu maswali yangu kwa lugha ninayoielewa. Hatari na faida zimeelezwa kwangu. Ninaelewa kuwa nitapewa nakala ya fomu hii ya idhini baada ya kuitia saini. Ninaelewa kuwa ushiriki wangu na wa mtoto wangu katika utafiti huu ni wa hiari na kwamba ninaweza kuchagua kuuondoa wakati wowote. Ninaelewa kuwa juhudi zote zitafanywa ili kuweka maelezo kunihusu na ya mtoto wangu kuwa siri. Kwa kutia saini fomu hii ya idhini, sijaachana na haki za kisheria za mtoto wangu kama mshiriki katika utafiti huu

**Ninakubali kwa hiari ushiriki wa mtoto wangu katika utafiti huu:**



**Ndio .....hapana....**

**Sahihi ya Mzazi/Mlezi/Muhuri wa kidole gumba:**

\_\_\_\_\_ **Tarehe** \_\_\_\_\_

**Jina lililochapishwa la Mzazi/Mlezi:** \_\_\_\_\_

**Kauli ya mtafiti**

Mimi, aliyetia sahihi hapa chini, nimeeleza kikamilifu maelezo muhimu ya utafiti huu kwa mshiriki aliyetajwa hapo juu na ninaamini kuwa mshiriki ameelewa na ametoa ridhaa yake akijua.

**Jina Lililochapishwa:** \_\_\_\_\_ **Tarehe:**

\_\_\_\_\_

**Sahihi:** \_\_\_\_\_

## **Appendix VII(a): Assent Form for the Adolescent**

**Project Title: Exploring the Perspectives of Youths at Kenyatta National Hospital Living with End Stage Kidney Disease on the Impact of the Disease**

**Researcher: Truphena Chepkorir**

We are doing a research study about the experiences among youths with kidney disease and how the disease affects them.

Permission has been granted to undertake this study by the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee (KNH-UoN ERC)

If you decide that you want to be part of this study, you will be asked to describe your experiences of having kidney disease and its effects. This will take approximately 30minutes.

Your response will be recorded in an audio tape and will be kept in a computer with a password protected. No one will be allowed to access the recording except the researcher. You might feel some discomfort during the interview but we will put up measures to reduce the discomfort.

Not everyone who takes part in this study will benefit.

A benefit means that something good happens to you. Some benefits might include the provision of counseling services. If you do not want to be in this research study, free to withdraw from the study at any point without any consequences.

### **Participant's statement**

I \_\_\_\_\_(NAME OF ADOLESCENT) acknowledge that I have received an explanation of the study, and I understood all the information provided to me. I have had all my questions answered satisfactorily. I acknowledge that I am free to withdraw from the study at any point without any consequences.

**Yes, please tick I agree to take part in this research**

**No, please tick I don't agree to take part in this research**

**Participant's signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**Participant's name** \_\_\_\_\_ **Time** \_\_\_\_\_

**Researcher's statement**

I confirm that I have thoroughly explained the study's purpose and the contents of the assent form to the participant. They have voluntarily agreed to participate in the study without any coercion or undue pressure from me. I have adhered to the study's guidelines for obtaining consent from participants, and they have been provided ample opportunities to ask questions. All their queries have been adequately addressed to their satisfaction.

**Designee/investigator's signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Designee/investigator's name:** \_\_\_\_\_ **Time** \_\_\_\_\_

## **Appendix VII (b): Assent Form for the Adolescent (Swahili Version)**

**Kichwa cha Mradi: Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo.**

Mtafiti: Chepkorir Truphena

Tunafanya utafiti kuhusu uzoefu miongoni mwa vijana wenye ugonjwa wa figo na jinsi ugonjwa huo unavyowaathiri.

Ruhusa imetolewa kufanya utafiti huu na Hospitali ya Kitaifa ya Kenyatta-Kamati ya Maadili na Utafiti ya Chuo Kikuu cha Nairobi (KNH-UoN ERC)

Ukiamua kuwa ungependa kuwa sehemu ya utafiti huu, utaulizwa kueleza uzoefu wako wa kuwa na ugonjwa wa figo na madhara yake. Hii itachukua takriban dakika 30. Majibu yako yatarekodiwa katika kanda ya sauti na yatawekwa kwenye kompyuta na nenosiri lililohifadhiwa. Hakuna mtu atakayeruhusiwa kufikia rekodi isipokuwa mtafiti. Unaweza kuhisi usumbufu wakati wa mahojiano lakini tutaweka hatua za kupunguza usumbufu.

Sio kila mtu atakayeshiriki katika utafiti huu atafaidika. Faida inamaanisha kuwa kitu kizuri kinatokea kwako. Baadhi ya manufaa yanaweza kujumuisha utoaji wa huduma za ushauri nasaha. Iwapo hutaki kuwa katika utafiti huu, huru kujiondoa katika utafiti wakati wowote bila matokeo yoyo

### **Kauli ya mshiriki**

MIMI \_\_\_\_\_ (JINA LA KIJANA) ninakubali kwamba nimepata maelezo ya utafiti, na ninaelewa maelezo yote niliyopewa. Nimejibiwa maswali yangu yote kwa njia ya kuridhisha. Ninakubali

kwamba niko huru kujiondoa kwenye utafiti wakati wowote bila madhara yoyote.

**Ndiyo**, (tafadhali weka alama) Ninakubali kushiriki katika utafiti huu

**Hapana**,( tafadhali weka alama) kuwa sikubali kushiriki katika utafiti huu

**Saini ya mshiriki:** \_\_\_\_\_ **Tarehe:** \_\_\_\_\_

**Jina la Mshiriki:** \_\_\_\_\_ **Saa:** \_\_\_\_\_

**Kauli ya mtafiti**

Ninathibitisha kuwa nimeeleza kwa kina madhumuni ya utafiti na yaliyomo kwenye fomu ya idhini kwa mshiriki. Wamekubali kwa hiari kushiriki katika utafiti bila shuruti yoyote au shinikizo lisilostahili kutoka kwangu. Nimezingatia miongozo ya utafiti ya kupata kibali kutoka kwa washiriki, na wamepewa fursa za kutosha za kuuliza maswali. Maswali yao yote yameshughulikiwa vya kutosha kwa kuridhika kwao.

**Sahihi** ya **aliyebuniwa/mchunguzi:** \_\_\_\_\_ **Date:**

\_\_\_\_\_

**Jina la aliyebuniwa/mchunguzi:** \_\_\_\_\_ **Saa** .....

## **Appendix VIII: Demographic Form**

### **Demographic data**

I express my gratefulness to you for giving your consent to participate in this study. I would be glad to by asking you a number of questions about yourself. I would like to start by knowing you.

1. How old are you?.....
2. Indicate the Gender..... Male/Female
3. What is your marital status?..... Single/Married/divorced/widow/widower
4. How many children do you have?.....none/1,2 ,3, more than 3
5. Are you living alone or with your family? .....alone/with the family
6. Tell me about your level of education?.....primary/secondary/Tertiary
7. What is your occupation.....Employed/unemployed
8. What is your religion? ..... Christian/Muslim/Hindu
9. For how long have you been with Kidney failure.... (0-6 months),(6-12months),(12-24 months),(more than 24months)
10. Do you have any other medical condition?.....yes/no
11. If yes, state the condition.....

## **Appendix IX (a): Study Interview Guide**

**Title:** Exploring the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease.

Your truthful responses to the following questions will significantly help me in trying to identify the impacts of ESKD on you. All answers given will be documented and coded, with the assurance that they will remain confidential and will not reveal any personal information. The interview is expected to last for about 30 minutes.

### **Introduction:**

- Researcher introduction and review of the following:
- Who am I and what I'm trying to do?
- What will be done with these responses?
- Reasons for participating in the study

I am grateful to you for the information you have provided about yourself. Now, do you grant me permission to proceed with the taping?

### **I agree to participate in this research**

**Yes.....**                      **No.....**

### **I agree to audio-recording of the interview**

**Yes.....**                      **No.....**

[If No, thank the respondent for the time and end the session]. [If yes, proceed with interviewing them] Now that the recording has commenced, kindly say “Yes” to confirm your approval of me recording of this interview.

### **Youths’ Perspectives on ESKD**

<b>Serial</b>	<b>Questions</b>	<b>Prompts</b>
<b>1</b>	<b>What are your experiences on the physical impacts of kidney failure?</b>	<p>How has living with kidney failure affected your day-to-day physical functioning and overall energy levels?</p> <p>What are some of the physical challenges you face as a result of the condition?</p> <p>Are there any changes in your body since you were diagnosed with kidney failure?</p> <p>Has dialysis treatment affected you? In what ways?</p> <p>Please tell me how well you believe you are managing these physical challenges</p>
<b>2</b>	<b>What are your experiences on the psychological impacts of kidney failure</b>	<p>How has living with kidney failure affected your emotional well-being and mental health?</p> <p>Can you describe any specific psychological challenges you've encountered since your diagnosis?</p> <p>Has the disease changed your attitude toward others?</p> <p>If yes, in what ways?</p> <p>Are there times when you feel frustrated or overwhelmed with kidney failure?</p> <p>How do you manage these feelings, and what helps you stay positive?</p>



3	<p><b>What are your experiences on the social impacts of kidney failure?</b></p>	<p>How has living with kidney failure affected your social life and relationships with friends and family?</p> <p>Have you experienced any changes in the way people interact with you since the diagnosis?</p> <p>Has the disease affected people's attitudes towards you?</p> <p>Can you share any challenges you've faced in maintaining social activities or participating in events due to your condition?</p> <p>How have you coped with these changes?</p>
<p>Is there something you think I should have asked? Would you like to add anything else?</p>		

**Thank you very much for your participation in this study**

## **Appendix IX (b): Study Interview Guide (Swahili Version)**

### **Kichwa cha Mradi: Kuchunguza Mitazamo ya Vijana katika Hospitali ya Kitaifa ya Kenyatta Wanaoishi na Ugonjwa wa Figo wa Hatua ya Mwisho juu ya Athari za Ugonjwa huo**

Majibu yako ya ukweli kwa maswali yafuatayo yatanisaidia sana katika kujaribu kutambua athari za ugonjwa wa figo kwako. Majibu yote yatakayotolewa yatarekodiwa na kuwekwa msimbo, kwa uhakika kwamba yatabaki kuwa siri na hayatafichua taarifa zozote za kibinafsi. Mahojiano hayo yanatarajiwa kudumu kwa takriban dakika 30.

#### **Utangulizi:**

- Utangulizi wa mtafiti na mapitio ya yafuatayo:
- Mimi ni nani na ninajaribu kufanya nini?
- Nini kitafanyika kwa majibu haya?
- Sababu za kushiriki katika utafiti

Ninakushukuru kwa habari uliyotoa kukuhusu. Sasa, je, unanipa ruhusa ya kuendelea na kurekodi?

#### **Ninakubali kushiriki katika utafiti huu**

**Ndio .....Hapana.....**

#### **Ninakubali kurekodi sauti ya mahojiano**

**Ndio..... Hapana....**

[Kama **Hapana**, mshukuru mhojiwa kwa muda na umalize kipindi]. [Kama **ndiyo**, endelea kuwahoji] Kwa vile sasa kurekodi kumeanza, tafadhali sema “**Ndiyo**” ili kuthibitisha idhini yako ya mimi kurekodi mahojiano haya

### Mitazamo ya vijana kuhusu Ugonjwa wa Figo

Msururu	Maswali	Ushawishi
1	<b>Je, una uzoefu gani kuhusu athari za kimwili za ugonjwa wa figo?</b>	<p>a) Je, kuishi na ugonjwa wa figo kumeathiri vipi utendaji kazi wako wa kila siku wa kimwili na viwango vya jumla vya nishati?</p> <p>b) Je, ni zipi changamoto za kimwili unazokabiliana nazo kutokana na hali hii?</p> <p>c) Je, kuna mabadiliko yoyote katika mwili wako tangu ulipogundulika kuwa na ugonjwa wa figo?</p> <p>d) Je, matibabu ya dialysis yamekuathiri? Kwa njia zipi?</p> <p>e) Tafadhali niambie jinsi unavyoamini kuwa unasimamia changamoto hizi za kimwili</p>
2	<b>Je! una uzoefu gani juu ya athari za kisaikolojia za ugonjwa wa figo</b>	<p>a) Je, kuishi na ugonjwa wa figo kumeathiri vipi hali yako ya kihisia na afya ya akili?</p> <p>b) Je, unaweza kuelezea changamoto zozote mahususi za kisaikolojia ambazo umekumbana nazo tangu utambuzi wako wa ugonjwa wa figo?</p> <p>c) Je, ugonjwa umebadilisha mtazamo wako kwa wengine? Kama ndiyo, kwa njia zipi?</p> <p>d) Je, kuna nyakati ambapo unahisi kuchanganyikiwa au kuzidiwa na ugonjwa wa figo?</p> <p>e) Je, umekabiliana vipi na mabadiliko haya ya kisaikologia?</p>
2	<b>Je, una uzoefu gani kuhusu athari za kijamii za ugonjwa wa figo</b>	<p>a) Je, kuishi na ugonjwa wa figo kumeathiri vipi maisha yako ya kijamii na mahusiano na marafiki na familia?</p>

		<p>b) Je, umepitia mabadiliko yoyote katika jinsi watu wanavyowasiliana nawe tangu utambuizi?</p> <p>c) Je, ugonjwa huo umeathiri mtazamo wa watu kwako?</p> <p>d) Je, unaweza eleza changamoto zozote ambazo umekumbana nazo katika kudumisha shughuli za kijamii au kushiriki katika matukio kutokana na hali yako?</p> <p>e) Je, umekabiliana vipi na mabadiliko haya?</p>
<p>Kuna kitu unadhani nilipaswa kuuliza? Je, ungependa kuongeza kitu kingine chochote?</p>		

**Asante sana kwa ushiriki wako katika utafiti huu**

## Appendix X: Approval Letter from KNH-UoN ERC



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

Ref: KNH-ERC/A/458

Truphena Chepkorir  
Reg. No. H56/40898/2021  
Dept. of Nursing Sciences  
Faculty of Health Sciences  
University of Nairobi

Dear Truphena,

**ETHICAL APPROVAL-RESEARCH PROPOSAL: EXPLORING THE PERSPECTIVES OF YOUTHS AT KENYATTA NATIONAL HOSPITAL LIVING WITH END STAGE KIDNEY DISEASE ON THE IMPACT OF THE DISEASE (P402/04/2023)**

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P402/04/2023**. The approval period is 29<sup>th</sup> August 2023 –28<sup>th</sup> August 2024.

This approval is subject to compliance with the following requirements;

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

Protect to discover



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

29<sup>th</sup> August, 2023



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

Yours sincerely,



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

c.c.     The Dean, Faculty of Health Sciences, UoN  
          The Senior Director, CS, KNH  
          The Chairperson, KNH- UoN ERC  
          The Assistant Director, Health Information Dept., KNH  
          The Chair, Dept. of Nursing Sciences, UoN  
Supervisors: Dr. Eunice Omondi, Dept. of Nursing Sciences, UoN  
              Dr. Dorcas Maina, Dept. of Nursing Sciences, UoN

## Appendix XI: Approval Letter from Kenyatta National Hospital



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

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






### Study Registration Certificate

1. Name of the Principal Investigator/Researcher  
CHEPKORIR TRUPHENA
2. Email address: shepkorirtruphena@gmail.com Tel No. 0706 598064
3. Contact person (if different from PI).....
4. Email address: ..... Tel No. ....
5. Study Title  
EXPLORE THE PERSPECTIVES OF YOUTH AT KENYATTA NATIONAL HOSPITAL  
LIVING WITH END STAGE KIDNEY DISEASE ON THE DISEASE
6. Department where the study will be conducted RENAL  
(Please attach copy of Abstract)
7. Endorsed by Research Coordinator of Department where study will be conducted.  
Name: Nancy Mwangi Signature [Signature] Date 18/1/23
8. Endorsed by KNH Head of Department where study will be conducted.  
Name: Dr. P. Mwangi Signature [Signature] Date 4/9/23
9. KNH UoN Ethics Research Committee approved study number \_\_\_\_\_  
(Please attach copy of ERC approval)
10. I CHEPKORIR TRUPHENA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.  
Signature [Signature] Date 4/9/2023
11. Study Registration number (Dept/Number/Year) RENAL 1210/2023  
(To be completed by Medical Research Department)
12. Research and Program Stamp \_\_\_\_\_

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



## Appendix XII: Research Permit from NACOSTI

 REPUBLIC OF KENYA	 <b>NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY &amp; INNOVATION</b>
Ref No: <b>988506</b>	Date of Issue: <b>16/October/2023</b>
<b>RESEARCH LICENSE</b>	
	
<b>This is to Certify that Miss. Truphena Chepkorir of University of Nairobi, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Nairobi on the topic: Exploring the perspectives of youths at Kenyatta National Hospital living with End Stage Kidney Disease on the impact of the disease for the period ending : 16/October/2024.</b>	
License No: <b>NACOSTI/P/23/30376</b>	
<b>988506</b> Applicant Identification Number	 Director General <b>NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY &amp; INNOVATION</b>
Verification QR Code	
	
NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.	
<b>See overleaf for conditions</b>	



**THE SCIENCE, TECHNOLOGY AND INNOVATION ACT, 2013 (Rev. 2014)**  
Legal Notice No. 108: The Science, Technology and Innovation (Research Licensing) Regulations, 2014

The National Commission for Science, Technology and Innovation, hereafter referred to as the Commission, was established under the Science, Technology and Innovation Act 2013 (Revised 2014) herein after referred to as the Act. The objective of the Commission shall be to regulate and assure quality in the science, technology and innovation sector and advise the Government in matters related thereto.

**CONDITIONS OF THE RESEARCH LICENSE**

1. The License is granted subject to provisions of the Constitution of Kenya, the Science, Technology and Innovation Act, and other relevant laws, policies and regulations. Accordingly, the licensee shall adhere to such procedures, standards, code of ethics and guidelines as may be prescribed by regulations made under the Act, or prescribed by provisions of International treaties of which Kenya is a signatory to
2. The research and its related activities as well as outcomes shall be beneficial to the country and shall not in any way;
  - i. Endanger national security
  - ii. Adversely affect the lives of Kenyans
  - iii. Be in contravention of Kenya's international obligations including Biological Weapons Convention (BWC), Comprehensive Nuclear-Test-Ban Treaty Organization (CTBTO), Chemical, Biological, Radiological and Nuclear (CBRN).
  - iv. Result in exploitation of intellectual property rights of communities in Kenya
  - v. Adversely affect the environment
  - vi. Adversely affect the rights of communities
  - vii. Endanger public safety and national cohesion
  - viii. Plagiarize someone else's work
3. The License is valid for the proposed research, location and specified period.
4. The license any rights thereunder are non-transferable
5. The Commission reserves the right to cancel the research at any time during the research period if in the opinion of the Commission the research is not implemented in conformity with the provisions of the Act or any other written law.
6. The Licensee shall inform the relevant County Director of Education, County Commissioner and County Governor before commencement of the research.
7. Excavation, filming, movement, and collection of specimens are subject to further necessary clearance from relevant Government Agencies.
8. The License does not give authority to transfer research materials.
9. The Commission may monitor and evaluate the licensed research project for the purpose of assessing and evaluating compliance with the conditions of the License.
10. The Licensee shall submit one hard copy, and upload a soft copy of their final report (thesis) onto a platform designated by the Commission within one year of completion of the research.
11. The Commission reserves the right to modify the conditions of the License including cancellation without prior notice.
12. Research, findings and information regarding research systems shall be stored or disseminated, utilized or applied in such a manner as may be prescribed by the Commission from time to time.
13. The Licensee shall disclose to the Commission, the relevant Institutional Scientific and Ethical Review Committee, and the relevant national agencies any inventions and discoveries that are of National strategic importance.
14. The Commission shall have powers to acquire from any person the right in, or to, any scientific innovation, invention or patent of strategic importance to the country.
15. Relevant Institutional Scientific and Ethical Review Committee shall monitor and evaluate the research periodically, and make a report of its findings to the Commission for necessary action.

National Commission for Science, Technology and  
Innovation(NACOSTI),  
Off Waiyaki Way, Upper Kabete,  
P. O. Box 30623 - 00100 Nairobi, KENYA  
Telephone: 020 4007000, 0713788787, 0735404245  
E-mail: [dg@nacosti.go.ke](mailto:dg@nacosti.go.ke)  
Website: [www.nacosti.go.ke](http://www.nacosti.go.ke)