

**ASSESSING THE PALLIATIVE CARE NEEDS OF END STAGE KIDNEY DISEASE
PATIENTS IN A TERTIARY HOSPITAL IN NIGERIA**

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LIST OF ACRONYMS

AIDS -Acquired Immune Deficiency Syndrome
APCA - African Palliative Care Outcome Scale
CARI -Caring for Australasians with Renal Impairment
CKD - Chronic Kidney Disease
ECF - Extracellular fluid
ESKD - End-stage Chronic Kidney Disease
GFR - Glomerular Filtration Rate
HIV - Human Immunodeficiency Virus
HTN - Hepatitis Neuritis
IBM SPSS - International Bases Machine Statistical Package for Social Sciences
ISN- International Society of Nephrologists
NSAIDs - Nonsteroidal Anti-inflammatory Drugs
POS-S - Palliative Outcome Scale-symptoms
APCA - POS- African Palliative Care Association- Palliative Outcome Scale
UNAIDS - United Nations Programme on HIV/AIDS
USA - United State of America
WHO -World Health Organization
LMICs - Low- and Middle-Income countries
UCH- University College Hospital

ABSTRACT

Background: Worldwide, end-stage kidney disease (ESKD) is associated with high morbidity and mortality. Currently, the incidence of ESKD in Nigeria is about 1.6% -12.4% and is higher amongst 25-45 year-olds, implying that ESKD indirectly affects the economic productivity of the nation negatively. ESKD is a condition that may progress rapidly from a chronic to a terminal phase and is responsible for about 2-3% of all hospital admission worldwide while in Nigeria the proportion of admissions is as high as 10%. This high symptom and disease burden of ESKD warrants implementation of a palliative care program that is able to assess and manage the needs of patients with this condition and to support their families.

Methods: A descriptive study was undertaken to assess the palliative care needs of patients. A random sample of 110 ESKD patients attending University College Hospital (UCH) Ibadan were interviewed using published standardized and validated questionnaire over a period of 3-months. The questionnaire was a combination of the Integrated Palliative Outcome Scale-Renal Patient Version (IPOS-R) and Hope Spiritual Assessment Tool (HOPE). The socio-demographic characteristics comprising of gender, age, place of residence and knowledge of palliative care were determined. IPOS-R was used to explore the patients' symptom-burden, psychological and social palliative care needs and quality of life while the HOPE was used to explore patients' spiritual needs. Ethical approval was obtained from the relevant organizations. Data was analyzed using the IBM SPSS version 23.0.

Results: More than half of the participants (57%) were female, 92% had co-morbidities, 86% had formal education, 60% were self-employed and their median age was 43.5years. Half (51%) reported experiencing severe symptoms and poor quality of life. More than half (50%) of the patients complained of shortness of breath, pain, general body malaise, sore mouth, restless with more than 80% reporting nausea, poor appetite, difficulty in sleeping and weakness. Fifty-three percent reported experiencing anxiety most of the time and reported that their families and friends were worrying about them. The majority (98%) said their source of hope was God. Most patients (93%) said they were not aware of palliative care medicine.

Conclusion: There is a huge need for palliative care for patients with ESKD in Nigeria. This study has developed a framework that can be used by a palliative care team, in collaboration with nephrologists, to provide a person-centered care for these patients and their families.

Keyword: Palliative care, End-Stage Kidney Disease (ESKD), Integrated Palliative Outcome Scale (IPOS), Nigeria

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of the study

Chronic kidney disease (CKD) is defined as structural or functional kidney damage of three months or more, with or without decreased Glomerular Filtration Rate (GFR) (Jassen 2012). Globally, the increase in prevalence of chronic kidney disease (CKD) is one of the reasons that has brought about more attention and research for this condition. CKD was declared a global public health crisis over a decade ago (Levey et. al., 2007); (WHO report, 2005) and a large proportion (60%) of it was associated with non-communicable diseases like cancer, cardiovascular disease, chronic respiratory disease, and diabetes. CKD is one of the leading causes of premature mortality worldwide, taking 27th position in the world (NKF, 2019) and the 8th leading cause of death in women (The Guardian, 2018); (WHO, 2005).

The prevalence of kidney disease in many low- and middle-income countries (LMICs) remains unknown but it is anticipated to be higher than in affluent countries mainly because of financial constraints in prevention strategies in LMICs (Liyanage et al., 2015); (Naicker, 2009). CKD is considered one of the most cost-draining diseases. In Australia, a higher income country (HIC), kidney failure treatment was budgeted an estimated of \$12 billion in 2020. In the United States of America (USA), another developed country, its treatment is estimated to exceed \$48 billion per year and consuming 6.7% of the total Medicare budget (IFKF and ISN, 2019). This is equivalent to the overall annual health expenditure of Nigeria (Ifeoma et. al., 2010). Nigeria is one of the LMIC that has witnessed increased prevalence rate of end stage kidney disease with 14% of the population having this disease (Ifeoma et. al., 2010); (Oyebola et. al., 2017).

CKD may progress rapidly from stage one to stage five. The stage 5 disease is also known as end-stage kidney disease (ESKD) or kidney failure which is associated with various complications such as hypertension, anaemia, malnutrition, bone disease and neuropathy (Jassen, 2012) thereby requiring specialised management by nephrologists. The management comprises of conservative management and/or renal replacement therapy (RRT) also referred to as kidney

replacement therapy (KRT), comprising of either dialysis or kidney transplantation. Dialysis treatment is an artificial filtering system that removes excess water and toxins from the blood. This treatment often requires visiting a treatment facility/hospital several times a week where the patient's blood is diverted to a machine to be cleaned (IFKF and ISN, 2019). Kidney transplantation is a surgical procedure to replace one of the patient's poorly functioning kidneys with a human-donor's well-functioning kidney (IFKF and ISN, 2019). In HICs, many ESKD patients often opt for either kidney transplantation or dialysis treatments despite the exorbitant costs because their countries have good infrastructure and health-budgets in place and are able to assist to carry the costs. As part of the 1972 Amendments to the Social Security Act, the US Congress extended coverage under Medicare, the public insurance program funded by the Federal Government, to people with ESKD (HCFA, 1993). However, in Nigeria, most ESKD patients are self-funded, and they often opt out from dialysis or renal replacement therapy after an average of three months of treatment due to financial constraints (Ifeoma et. al., 2010). Government funded Palliative care service becomes an alternative option to manage such patients. Unfortunately, ESKD patients in Nigeria do not have access to Palliative and supportive care (Fitzsimons et. al., 2007), as this service (which is not adequately developed) is accessed through referral by nephrologists. Many patients present very late to nephrologists, usually at advanced stage when renal replacement therapy is required (PNRCP, 2018). Out of this 75-80 % who present to the nephrologists, very few are referred for palliative care service and support. Poverty, lack of education by patients and lack of basic knowledge of palliative care by physicians are other factors that contribute to lack of palliative care delivery (Oyebola et. al., 2017). It is therefore necessary to introduce an adequate and accessible Palliative Care service for patients with ESKD in Nigeria.

Palliative care is a multidisciplinary approach to care, that includes advanced care planning for patients with end-of-life needs (Wang D. , 2011), (Alvin, 2016). The program was initially set up for cancer patients but as time went on the scope of the practice was widened to cover for other life-threatening diseases such as chronic kidney disease, a condition that incidentally has similar symptoms-burden as cancer (Alvin, 2016). Palliative care is an intervention that can be offered alongside potentially curative treatment. World Health Organization (WHO) defines palliative

care as an approach that improves the quality of life of patients facing the problems associated with life-threatening diseases and their families through the prevention and relief of suffering by means of early identification, comprehensive assessment and treatment of pain and other physical, psychological, and spiritual problems (WHO, 2011). According to Oyebola et. al.(2017), palliative care and its policies are still at the developmental stages in Nigeria despite a long history of identified need for this care. For example, there was an estimated 4.6million people in 2005 that required palliative care service. Palliative Care had been introduced in the country by Dr. Anne Merriman and Mrs. Fatumbi. Oyebola as far back as 1993 with the first hospital-based Palliative Care service becoming established in Nigeria more than a decade later in 2006 by Dr. Oyebola (Oyebola et. al., 2017). To date these services have not developed sufficiently to cover the needs of majority of patients with ESKD.

1.2 Problem statement

There is a high burden of CKD & ESKD in Nigeria. The country's health insurance scheme is unable to cover the costs of renal replacement therapy (Ifeoma et. al., 2010). Most patients are of low economic status and are unable to afford out-of-pocket payments for such a service (Ijoma et. al., 1998). We propose that public hospitals should implement a robust multidisciplinary, cost-efficient, and accessible Palliative Care service that is funded by Government.

1.3 Rationale for the study

The study-site (where the researcher is working as a medical doctor) is a tertiary institution that sees a significant number of patients with CKD, averaging 2,500 patients/ year and yet it has no palliative care service for this group of patients. Currently, the nephrologists (kidney-specialists) at this facility are solely responsible for managing these patients without the support of a necessary palliative care team. This poses difficulty with meeting the needs of this group of patients and their families.

The primary outcome of this study, therefore, is to do a situational analysis of the palliative care needs of these patients and develop a systematic framework for a comprehensive palliative care service that will promote collaboration between multidisciplinary stakeholders in order to provide support for the physical, social, psychological and spiritual needs of patients and their

family members living with ESKD at the study-site, University College Hospital, Ibadan, Nigeria.

1.4 Aim & Objectives

Aim

- To make a comprehensive assessment of the palliative care needs of ESKD patients at this tertiary hospital in Nigeria using published validated tools and to use the findings of this assessment to adapt these published tools to make them feasible to be readily used by a multidisciplinary Palliative Care team to support ESKD patients and their families in this hospital.

Objectives

- To determine the symptom-burden of these ESKD-patients
- To assess the psychological, social and spiritual needs of these ESKD-patients using a validated published tool
- To assess the quality of life of these ESKD-patients using a validated published tool
- To assess available support systems in homes of ESKD-patients using a validated published tool
- To explore the current use of the palliative care services available for these ESKD-patients.
- To adapt the published tools used above to make them feasible to be readily used at this setting in Nigeria.

1.5 Significance and expected outcomes of the study

The study will produce the first home-grown palliative-care framework that is contextualized for use for ESKD patients attending a tertiary public hospital in Nigeria. It is envisaged that in time, with government support, the program will expand and be offered throughout the country. Palliative Care as a philosophy, like Family Medicine, is a multidisciplinary service that is driven by ethical principles such as utilitarianism, social justice and fairness. Because of this, it is not difficult to imagine that patients suffering from other life-threatening medical conditions will also benefit through the same comprehensive assessment of their needs using the tools produced in this study, which may or may not need minor adaptations for different settings.

This study is likely to propel the Nigerian Government to speed up engagement with the already adopted principle of WHO Public Health Approach to Palliative Care to provide the service to all who need it. Although Nigeria has gone somewhat in implementation of palliative care services compared to other neighboring in West Africa countries, the service has not been extended to the majority of indigent patients many of whom suffer with ESKD. (Oyebola et. al., 2017); (WHO, 2011).

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Epidemiology of Chronic Kidney Disease and End-Stage Chronic Kidney Disease

Chronic Kidney Disease (CKD) is one of the non-communicable diseases that has gained significant public health interventions (Levey et al., 2007); (Obrador et. al., 2002) due to its high global incidence rate. The National Kidney Foundation (NKF) reported that CKD affected 10% of the world's population (NKF, 2019). It is estimated that the overall prevalence is 8%-16% globally. This corresponds to nearly 500 million affected individuals, of whom 78% (387.5 million) reside in low-income to middle-income countries (LMICs) (ElHafeez et al., 2018)

Globally one in ten people live with CKD, and 90% of those affected are unaware of the condition (ISN, 2016). According to a 2019 NKF's community survey known as the Kidney Early Evaluation Program (KEEP), people unaware that they are living with ESKD were identified amongst the more than 150,000 high-risk individuals with diabetes and/or hypertension. These consistent findings underscore high health costs associated with missed opportunities to prevent , recognise and reduce CKD (Henryford Health System, 2011).

CKD is at least three to four times more prevalent in Africa than in developed countries (Naicker,2009), particularly in sub-Saharan Africa, where there is an increased prevalence of risk factors such as acute kidney injury, diabetes mellitus and hypertension (Liyanage et al., 2015); (Naicker, 2009). Out of the overall CKD cases in Africa, 2% - 41% are attributed to the West and Central-West Region, 12% - 17% are attributed to Central Region, 6% - 29% are attributed to the Southern Region, 7% - 15% are attributed to the Eastern Region, 3% - 13% are attributed to the North Region while 2% - 14% are attributed to Sub-Sahara Africa (ElHafeez et. al., 2018). Of the cases in sub-Sahara, 2%-10% are in Nigeria (Ifeoma et. al., 2010). In USA about 30 million people or 15% of adults are estimated to have CKD (CDCP, 2017), in China 119.5 million people or 11% (The Lancet, 2012), in Australia 12% , in Thailand 6.8% (Domrong et al., 2005), in India 17.2% (Singah et. al., 2013), in Italy 6% (Cirillo et. al., 2006), in Switzerland 8.1% (Nitsch et. al., 2006) and in Iceland 7.2% (Viktorsdottir et. al., 2005)

Nigeria is the most populous country in Africa and the seventh most populous country in the world, with an estimated population of over 198 million (Osakwe, 2018). Currently, the annual incidence of CKD is between 1.6% and 12.4% and the proposed national care registry estimated the prevalence of CKD to be about 11.4%-30% of the adult population (PNRCP, 2018; Odubanjo et. al., 2015). ESKD, on the other hand, affects about 25,000- 50,000 people in Nigeria, which is about 0.025 percent of the total population (Uzukwu, 2018). Patients who become dialysis-dependent have a mortality of 90-100% after 3 months due to late presentation, lack of funds, and paucity of centers offering renal replacement therapy (PNRCP, 2018; Odubanjo et. al., 2015). The high rate of kidney decline in Nigeria is a result of different factors, which include late recognition of the disease, poor awareness on the part of healthcare workers, low access to healthcare facilities, and a high level of illiteracy (Oyebola et. al., 2017). In 2018, The Guardian reported that kidney failure in Nigerian women could be attributed to hypertension, diabetes, chronic renal nephritis, and complications arising from pregnancy.

It is estimated that 2-3% of hospital admissions in tropical countries hospital are due to renal related diseases such as diabetic nephropathy, whereas the rate in Nigeria is higher, with ESKD accounting for more than 10% of hospital admissions (PNRCP, 2018; Naicker, 2003). The disease burden is enormous in Nigeria, with the age-band of 25-40 years old being mostly affected (Odubanjo et. al., 2015). This population constitutes the nation's workforce. ESKD therefore, has a negative impact on the nation's productive capacity, economy, and national development.

2.2 Pathophysiology of end-stage chronic kidney disease

According to the NKF, the definition of CKD is a yardstick to its management and is based on the estimated glomerular filtration rate (eGFR). Kidney damage is defined by pathologic kidney abnormalities such as persistent proteinuria, hematuria; imaging abnormalities and/or eGFR <60 mL/min/1.73 m² on two occasions separated by ≥ 90 days which is not associated with a transient, reversible condition such as volume depletion (NKF 2019).

Table 1; Stages of CKD and their descriptions

Stage	Estimated GFR (mL/min/1.73 m ²)	Comment
1	Greater than or equal to 90	Normal GFR with or without proteinuria
2	Between 59 and 89	Age-related decline in GFR with proteinuria
3A 3B	Between 30 and 60	Low risk of progression to kidney failure
4	Between 15 and 30	High risk of progression to kidney failure
5 5D 5T	Less than 15	Kidney failure

Source; International Society of Nephrology (ISN, 2016)

Chronic kidney disease is a non-communicable disease that progresses rapidly from stage 1 through to the advanced stage (stage 5) which is also known as End Stage Kidney Disease (ESKD). Fortunately, most patients do not progress from CKD Stage 3 to 5, but 17% of CKD Stage 4 patients will progress to Stage 5 and 1% of CKD Stage 3 patients will progress to stage 5 (ISN, 2016); (IFKF and ISN, 2019). The transition to CKD Stage 4 is often insidious and under-recognized. Specifically, this transition represents a clinical event like a stroke or acute myocardial infarction because CKD Stage 4 is marked by a major increase in cardiovascular mortality and progression to advanced Stages. During CKD Stage 4, death is a competing risk for progression to ESKD. At this advanced stage, the kidneys lose their filtering capabilities, dangerous levels of fluid, electrolytes and waste accumulate in the body (MFMER, 2019). Comprehensive systems targeting early recognition, prevention and management, and treatment by primary care physicians and physician extenders are required at this critical stage in collaboration with nephrologists.

The progression of CKD to ESKD is increasing globally, especially in developing countries, where a high prevalence rate of risk factors such as hypertension and diabetes is experienced. ESKD is fast becoming an epidemic all over the world. It is a chronic disease that is associated with a lot of morbidity and mortality despite medical intervention. Worldwide, the prevalence of ESKD is estimated to be about 3,010,000 with a high growth rate of 7% per annum (TNAN, 2018). Mortality for patients on dialysis is about 20% annually worldwide, with the elderly

population having a worse prognosis and the one-year survival after commencing dialysis is about 73% (Axelsson et. al., 2018).

2.3 Risk factors for chronic kidney disease and end-stage chronic kidney disease

Risk factors for the progression of CKD can be classified as non-modifiable and modifiable according to Henryford Health System (2011). Non-modifiable factors are factors that cannot be reduced or controlled by altered behaviour. These factors cannot be changed and are a combination of genetic and lifestyle factors. They include male gender, advanced age, ethnicity (African-American, Native-American, Hispanic, and Asian), family history of kidney disease (e.g., cystic kidney disease), low birth weight, congenital or acquired solitary kidney, and prior kidney damage (trauma, infection). It is, however, possible to develop ESKD with or without the risk factors (Winchester Hospital, 2013).

Modifiable factors are factors that existed before the onset of CKD and, if prevented, may alter the progression to ESKD. Modifiable factors can be classified into three categories depending on their ability to modify disease progression. Category 1 is factors which specific intervention will reduce risk such as, Diabetes, hypertension, obesity, metabolic syndrome, and hyperlipidaemia. Category 2 is factors in which specific interventions are likely to reduce risks, such as smoking, nephrotoxic exposure, certain drugs (non-narcotic analgesic preparations), kidney stones, prostatic hypertrophy (obstruction), and radiocontrast media. The third category is factors which specific modifications may or may not lower risk and they include high protein intake, low income and/or educational level, chemical and environmental hazards like lead. Screening for these risk factors is highly crucial, especially for individuals with a family history of CKD, hypertensive, and /or diabetic patients, because early intervention lowers the risk of progression to ESKD in these patients.

Risk factors for ESKD identified in different parts of the world vary. In India and Pakistan, chronic glomerulonephritis is the commonest cause, followed closely by diabetes (Sakhuja et. al., 2003). The average age affected is about 42years, the same as in Nigeria (Sakhuja et. al., 2003). A study in China identified IgA nephropathy (a type of glomerulonephritis) as the major cause of ESKD (Lin, 2008). In the five North Africa countries, Egypt, Algeria, Libya, Morocco, and

Tunisia, interstitial nephritis, usually due to environmental pollution and drug abuse/misuse is the commonest cause, followed closely by glomerulonephritis and diabetes. Other risk factors identified in these countries include urolithiasis, obstructive uropathy, and schistosomiasis (Barsoum, 2003). In South Africa, hypertension and glomerulonephritis are the commonest causes of ESKD (Sakhuja et. al., 2003). In addition to hypertension and glomerulonephritis, obstructive uropathy and diabetes are also factors identified in tropical Africa and East Africa (Sakhuja et. al., 2003). In West Africa, mainly Nigeria, the etiology for the majority of the population is due to 3 main factors: hypertension, diabetes, and chronic glomerulonephritis (Sakhuja et. al., 2003).

Human immunodeficiency virus (HIV) is another major cause of various types of kidney disease, ranging from acute, chronic, and end-stage (Swanepoel, 2018). Currently, the prevalence of HIV is 37million worldwide and annual incidence of 2million worldwide (Swanepoel, 2018). HIV-associated nephropathy (HIVAN) is due primarily to HIV infection and other co-infections (such as hepatitis B, hepatitis C, etc.) It is due secondarily to the effect of prolonged use of Highly Active Antiretroviral Therapy (HAART) on the kidney. HIV-positive individuals with kidney disease have a 2 to 3-fold increased risk of progression to ESKD than the normal population (Swanepoel, 2018). A tiny percentage (3.7%) of Nigeria's population is HIV-positive (UNAIDS, 2013). The prevalence of kidney disease in HIV-positive individuals in Nigeria is estimated to be about 22.9% to 51.8% (Ekrikpo et. al., 2018).

2.4 Symptoms of end-stage kidney disease

As kidney failure progresses, patients become sicker and might develop a variety of signs and symptoms: loss of appetite, nausea, vomiting, fatigue, weight loss, itchy skin, confusion, difficulty concentrating, swelling throughout the body, low urine output, generalized weakness, multiple bruises, numbness and tingling in the extremities, irritability, decreased desire for sexual activity (Rak et. al., 2017). Others include menstrual irregularities, constipation, diarrhea, muscle cramps and twitches, shortness of breath, chest pain, weak and brittle bones, restless legs syndrome, yellowish-brownish skin tone, headache, and frequent hiccups (Saini et. al., 2006); (Brown et. al., 2008) (Winchester Hospital, 2013). Symptoms identification, which is the subject of study, and management, are critical parts of Kidney Supportive Care.

2.5 Palliative care for end-stage kidney disease.

There is an increasing rate of withdrawal from dialysis treatment by CKD patients and the reasons are diverse among patients. Some CKD patients withdraw from the dialysis section due to increased comorbidities/symptoms and lack of financial support (Ifeoma et. al., 2010). They perceive that it may not outweigh likely survival and quality of life benefits (Noble, 2013); (Rajiv, 2016) and it hinders the right of freedom. There have been various studies examining symptoms prevalence in dialysis patients and separately, in patients managed on a non-dialysis (conservative) pathway.

The National Consensus Project defined Palliative care as ‘patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering’ (Dahlin et. al., 2004). According to NKF, palliative care is a specialized type of medical care in which palliative care specialists collaborate with CKD patients, their families, caregivers, nephrologists, and other professionals to alleviate pain and suffering of patients and their families whilst patients are still receiving treatment to cure or manage their disease/s.

Palliative care is, therefore, a holistic care that prevents physical, intellectual, emotional, social, and spiritual suffering in patients living with life-limiting disease and enhances patients’ autonomy, knowledge about the disease condition and decisions about mode of treatment (Dahlin et. al., 2004). The goal of palliative care is primarily prevention of suffering, management of suffering, and improving the quality of life for a patient living with a life-threatening illness such as ESKD (Axelsson et. al., 2018). Palliative care can offer an extra layer of support to CKD patients through managing pain and other conditions related to CKD, which include high blood pressure, heart diseases, diabetes, and coronary diseases; aiding communication with patients’ doctors and evaluating treatment options; and explaining what to expect, i.e., prognosis throughout the illness (NKF,2019). It is critical to educate nephrologists and other medical staff on how to effectively communicate and address these patients’ and

families concerns through the establishment of interdisciplinary goals that will result in more patient-centered care plan (Vandecasteele et. al., 2014). (Rak et. al., 2017), suggested the involvement of consultants, or ancillary services, i.e. palliative care, ethics consultants or hospital chaplains, as a helpful step in the shared decision-making process.

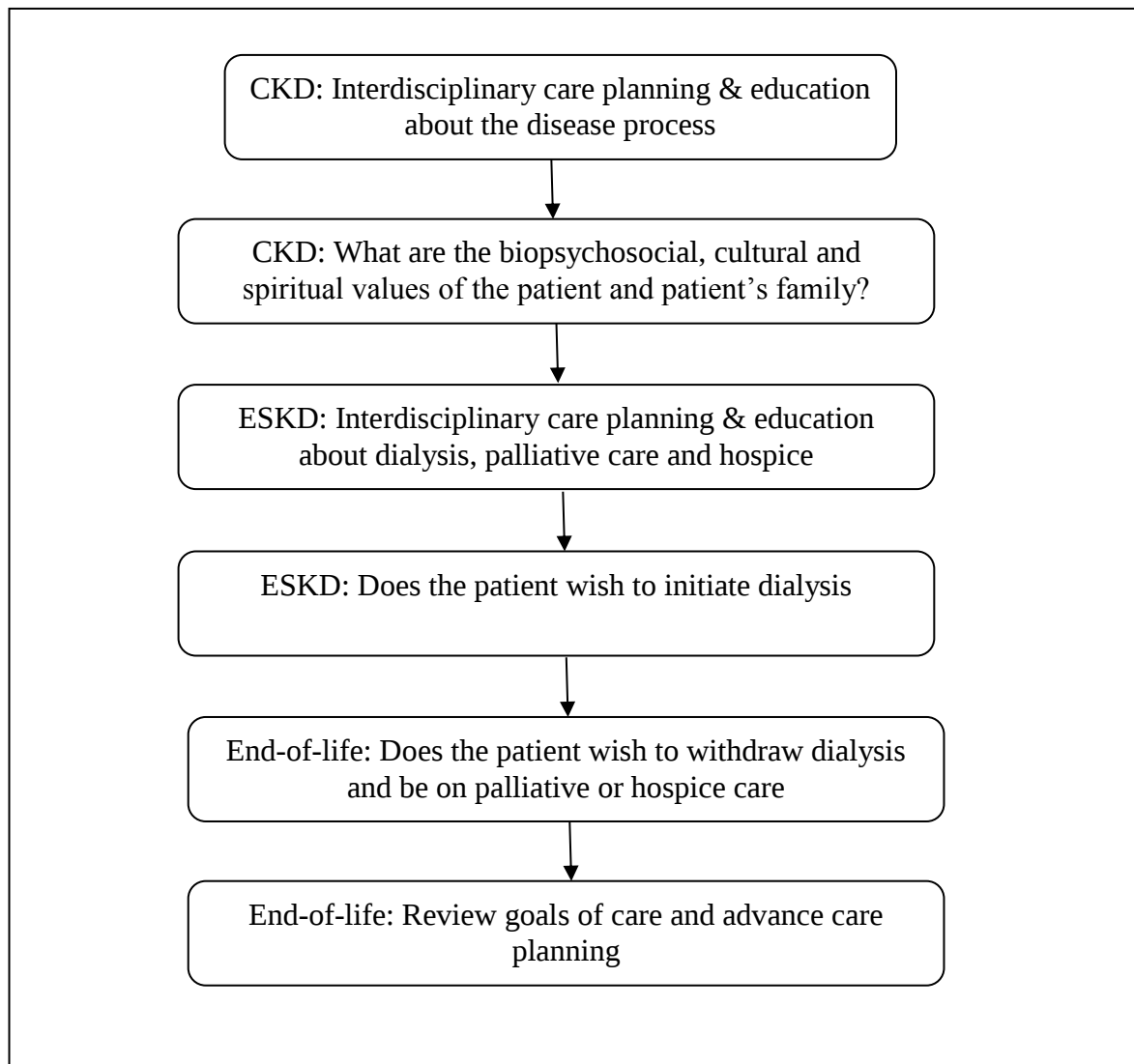


Figure 1: Proposed question and intervention flow chart to guide palliative care for ESKD and end-of-life (Rak et. al., 2017)

The WHO public health model approach to palliative care has significantly improved palliative care delivery in countries that have used it to align palliative care reform in their national health policy to foster drug availability, adequate education, and implementation of palliative care.

The palliative care system includes the following components: Advance Care Planning (ACP) is an essential component of palliative care, as identified by numerous articles in the literature as well as end-of-life care frameworks from various jurisdictions (Dobbins, 2005). Terminal care is care provided to the patient in the last days or weeks of the patient's life, which largely involves focusing on comfort care and symptom management, as well as allowing the family to say their goodbyes. Conservative management; care provided to patients who have an ESKD diagnosis but have decided not to initiate dialysis or go through kidney transplantation for various personal reasons. These patients have an average of 6.3 months to live (Smith et al., 2003) and therefore have urgent palliative care needs. Supportive care is the non-pharmacological aspect of helping patients cope with an ESKD diagnosis, such as helping patients to express and understand emotions and facilitating patient empowerment through giving patients choice and control (Pereira & Bruera, 2001). It may also include helping patients with the financial aspects of managing their health care. Spiritual care: services that address the spiritual needs of patients, which can vary widely among individuals. For some patients, it involves having a healthcare provider to be there for them as they explore the meaning of what is happening to them (Department of Health, 2008). For other patients, spiritual care may be a way to help them delve deeper into their faiths. Specialist palliative care is palliative care services provided by healthcare providers who have received full training in palliative care and work specifically with patients with palliative care needs (e.g., physicians who specialize in palliative care). Non-specialist palliative care is palliative care services provided by healthcare providers who are not specialized in palliative care but may have received some form of palliative care education or training.

Application of palliative medicine principles and practices to management of patient with kidney disease, a growing modern concept is known as Kidney Supportive Care (KSC). This concept whose goal is alleviation of suffering through treatment of symptoms, empathic communication, and support for psychosocial distress. Provision of primary palliative care includes primary

palliative care by the nephrologist, as well as referral of patients with complex distress for comanagement by an interprofessional specialty palliative care team, when available (Davison SN, 2015) (Harris D et al 2019). Symptoms identification, the subject of this thesis, and management are critical parts of KSC.

2.6 Palliative care needs of end-stage kidney disease

ESKD is a disease associated with a lot of physical, emotional, psychological, and spiritual suffering. It constitutes one of the diseases, which may progress rapidly. There have been various studies examining symptom prevalence in dialysis patients and, separately, in patients managed on a non-dialysis, conservative pathway, but few identifying their palliative care needs. Patients with ESKD have many palliative care needs, which according to a study by Axelsson and colleagues comprise comprehensive symptoms assessment, management, and communication about prognosis and end of life issues (Axelsson, L. et. al., 2018).

A study by Bates in Malawi identified four major domains of palliative care needs in patients with ESKD, which include chronologically change in functional status, i.e., loss of independence due to overwhelming physical symptoms; financial challenges and their impact on hospital care; loss of role within the family and strain on the relationship and, lastly, the importance of spiritual and cultural beliefs (Bates et al., 2017). A newsletter on ESKD patients' needs and hospice care shows that ESKD has poor life expectancy with only one-third living as long as a patient without renal disease, while patients on dialysis live only half as long as a cancer patient. While 70% of cancer patients have a life expectancy of 5 years, only about 35% of ESKD patients survive for more than five years. With 96% of patients who withdraw from dialysis due to varying factors dying within 4 weeks (HMA, 2007). Another study by Fassett et al identified the multidimensional role of palliative care in the control and management of symptoms for patients either on dialysis, conservative care, or withdrawing from active therapy (Fassett et. al., 2011). This study revealed that patients on dialysis do not necessarily have a better quality of life compared to patients who prefer to forgo dialysis from the outset. There is therefore a great need to identify the palliative care needs of all ESKD patients early in the disease trajectory. This

study also compared symptoms burden in ESKD patients and cancer patients concluding that both have a high symptom burden with a marked decrease in the activity of daily living and quality of life. As a result, pre-dialysis education to addressing palliative care multidisciplinary management for both clinicians and ESKD patients in palliative care is critical. The multidisciplinary team included the patient, family/caregivers, a palliative care physician, a palliative care nurse, dietician, social worker, chaplain, and/or rehabilitation specialist (physical therapy, occupational therapy, or rehabilitation medicine (Fassett et. al., 2011). A study from Hong Kong explored the prevalence of symptoms in this disease either with conservative or any form of renal replacement therapy (Yong, D. S.et. al, 2009). The most common symptoms identified in this study are fatigue, cold aversion, pruritus, lower torso weakness, and difficulty sleeping. Axelsson identified pain (66%) as the most prevalent symptoms, followed by respiratory secretion (46%), anxiety (41%), confusion (30%), shortness of breath (32%), and nausea (17%) (Axelsson et. al.2018).

Murtagh F.et.al. (2007) declares that the symptom burden associated with ESKD is often undermanaged because the condition is under-diagnosed. Ten symptoms were identified in this study but the commonest five were fatigue/tiredness, pruritus, constipation, anorexia, and pain. A study by Abdel-kaher et.al (2009) found that the symptom burden of ESKD that includes depression contributed to an enormous reduction in the quality of life. Axelsson said that even if death is expected, most patients dying with ESKD have unmet palliative care needs regarding symptoms management, advance care planning, and bereavement support (Axelsson et. al., 2018).

CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 Background of the Research area

Nigeria is a developing African country, the most populous and one of the largest economies; it has the third-largest youth population in the world after India and China with more than 90 million of its population under age 18. The estimated population is 200,962,417 and according to the 2006 census, its population was 140,431,790. Nigeria has population density of 215/km² (556.8/sq mi) and total land area of 923,768km² (356,669 sq mi). Nigeria was officially named the Federal Republic of Nigeria in 1963 and it is a nation with thirty-six (36) States with Abuja as its Capital. It borders Niger in the North, Chad in the Northeast, Cameroon in the East, and Benin in the West, and its coast in the South is located on the Gulf of Guinea in the Atlantic. It is geographically located at 9°41'N 7°29'E/9.06°N 7.483°E. There are three main ethnic groups which are Hausa, Igbo, and Yoruba. The country is also divided into six geopolitical zones namely North-east, North-west, North-central, South-east, South-south, and South-west. The people are predominantly Christian, Muslim, and Traditional believers. The people were known for their rich culture, agriculture, art, and craft. The official language of the people is English and they have many native languages. The nation enjoyed significant developments and one of these is the construction of prominent public institutions' buildings. Among the public institutions are schools, hospitals, Government houses/secretariats, Radio stations e.tc. The nation has many tertiary hospitals which include University College Hospital, Ibadan (UCH), Lagos University Teaching Hospital (LUTH), Obafemi Awolowo University Teaching Hospital (OAUTH) among many others.

3.2 Research site

University College Hospital, Ibadan is the first University College Hospital and Federal Government-owned tertiary health institution in Nigeria established by the act of parliament in November 1952 and it is affiliated with the University of Ibadan. It is situated at Ibadan North Local Government of Ibadan, Oyo State.

The hospital was established to provide training for health professionals, organize research and provide quality curative and preventive healthcare services. The hospital has a large workforce comprising of healthcare practitioners who include doctors, nurses, pharmacists, medical laboratory scientists, nephrologists among others. It has a bed capacity for over 863 inpatients and has 96 consultative outpatient clinics in 50 specialties and sub-specialty disciplines. A pain clinic and a hospice service are also on-site for the care of terminally ill patients. The hospital also houses the first and only geriatric centre in Sub-Sahara Africa named the Chief Tony Anenih Geriatric Centre (CTAGC). The Hospital has trained over 6,000 Doctors, 501 Dentists, 4,513 Nurses, 2307 Mid-wives, 471 Peri-Operative nurses, 1,062 Laboratory Scientists, 576 Environmental Health Officer Tutors, 451 Nurse/Midwives/Public Health Educators, 326 Primary Health Care Tutors, 590 Community Health Officers, 640 Physiotherapists, 531 Health Information Management Personnel since 1957 (Wikipedia , 2019).

3.3 Research population

The research population consisted of ESKD patients aged 18years and above receiving dialysis or on conservative treatment at UCH, Ibadan. These patients had eGFR less than $15\text{mL}/\text{min}/1.73\text{m}^2$. They were seen at the medical outpatient, dialysis unit and emergency department within the period of study, December 2018 - February 2019.

3.4 Research design

The design for this research study was observational and descriptive.

3.5 Sample size

The average population with ESKD in Nigeria is 50,000 (Uzukwu, 2018).

Sample size was determined using Quantitative Research Sample Size Calculator. (Flex MR 2021)

Table 2: Sample size calculator

Estimated population with ESKD in Nigeria	Confidence level	Margin of error	Sample size
250 000	99%	5%	664
50 000	99%	10%	166
50 000	95%	5%	385
50 000	95%	10%	97
50 000	90%	5%	271
50 000	90%	10%	68

We chose a feasible sample size of 97 that would give results with a confidence interval of 95% and a margin of error of 10%. In the end, we sampled 110 (more participants than were required) in order to accommodate possible data sheets that could be discarded as a result of incomplete information.

3.6 Sampling technique

A two-stage sampling technique was used. Firstly, a sampling frame of patients with ESKD was developed. Secondly a simple random sample of 110 participants was selected from this list.

3.7 Inclusion criteria

1. Patients at fifth stage of chronic kidney disease
2. ESKD patients undergoing dialysis or conservative care
3. ESKD patients who were 18 years old and above

3.8 Exclusion criteria

1. ESKD patients who were under 18 years' old
2. Patients who did not give consent to participate in the study.
3. Patients who were acutely ill, and too weak to respond to questions.

3.9 Instrument for data collection

Data was collected using questionnaire (see appendix A), Part A of the questionnaire captured the socio-demographic characteristics of the participants and Part B assessed the palliative care needs of participants using the Integrated Palliative Outcome Scale (IPOS) (Murtagh ,2019). IPOS is a new measure that incorporates the best of Palliative Outcome Scale (POS), Palliative Outcome Scale-Symptoms (POS-S) and African Palliative Care Association POS (APCA-POS). It is specifically developed for use among people severely affected by diseases such as cancer, neurological diseases, respiratory, heart, renal or liver failures. It has been welcomed by patients and professionals as it is comprehensive and captures both the symptoms and psychosocial factors.

The IPOS is a validated instrument that can be used in clinical care, audit, research, and training. It incorporates enquires about physical symptoms, psychological, emotional and financial. HOPE approach to Spiritual Assessment tool was also used for patient's spiritual assessment (Gowry 2001). In this research study, IPOS Renal Patient Version was used (Rajesh 2018) with slight adjustment to fit the Nigeria population. The Likert scale was further simplified to 3-4 variables instead of 5 as necessary to make the answers less cumbersome. Words like mild, moderate severe were utilized to assist with easy translation to the local languages. The Likert scale was further simplified to 3-4 variables instead of 5 as necessary. Words like mild moderate were used to assist with easy translation to the local language.

3.10 Ethical considerations and ethics principles

Ethics approval was obtained from both the Human Research Ethics Committees of the University of Cape Town, South Africa and University College Hospital before embarking on fieldwork. Permission was also received from the heads of palliative care, medical outpatient, emergency and dialysis unit.

The data and information that were collected from the participants were kept secure and confidential both during and after the research study. Data collected by the research team was securely held under authority of the research assistant and a secure code for logging the information into the software of the computer system. Such information did not include names,

addresses and contact of participants or of close people hence no person will be traced to the data or information given in the course of the research work. The research team ensured that there were no elements in the study that could impose harm or risk on the participants. During the interview, if any of the participants were noticed to have any distressing symptoms or became too ill to continue, the physician or attending nurse was notified promptly for care.

An informed consent (see Appendix B) was taken using the language spoken by the patient. It was read or given to each randomly selected ESKD patient at the dialysis centre at UCH who meets the inclusion criteria, and this was done by the research assistant that are recruited for the research study. The participants were free to withdraw from participating in the research study during and after the collection of data but not after compilation and analysis of data.

3.11 Data collection techniques

Research assistants were recruited and trained on the sensitivity and research ethics of the study. They were also educated about the study, the research methodology, different aspect of the questionnaire how to obtain informed consent and questionnaire administration. The aim and methodology of the study were explained to participants in simple terminology and their mother tongue for those who do not understand English, after which informed consent was obtained. After taking consent, the trained research assistant read the questionnaire and gave it to the participants and escorts, if they were available. The questionnaires were completed with the assistance of the research assistant, family member, friend, relative and or an appropriate staff member of the institution. The filled questionnaires were collected from the participants by the research assistants and given to the record officer in the Palliative Care department.

3.12 Data analysis and management

The collected questionnaires were pre-checked for completion by the investigator and the research assistants before the data was entered by the palliative care record officer on the Microsoft Office Excel spreadsheet 2017. The validated data was further exported to an analytical software named IBM Statistical Package for Social Sciences (SPSS) version 23.0 to analyze the descriptive statistics. Frequencies, percentages, mean and median were calculated. The results are represented by pie charts, bar charts, percentages, and frequency tables.

CHAPTER FOUR

4.0 RESULTS

4.1 Socio-demographic characteristics of respondents

The total number of participants was 110, with a 57%: 43% female to male ratio. The mean age was 45.13. with median 43.50 and age range of 20.00 to 80.00 years old. Most respondents were married 69(62.72%) and mostly Christians 62(56.36%). About 14(12.73%) of ESKD patients did not have any formal education, 23(20.91%) had primary education, a few 42(38.18%) had secondary education while very few 31(28.18%) had tertiary education. Majority of the respondents 87(79.09%) were Yoruba, and more than half were self-employed 66(60.00%) whilst 19(17.27%) were unemployed.

The majority 87(79.09%) of the ESKD patients lived in the urban settings and 23(20.91%) lived in rural area. Regarding referrals, just over a half 59 (53.64%) of the participants were referred by private hospitals, about a third 41(37.27 %) from public hospital and only a few, 10 (9.09%) were self-referred.

In terms of co-morbidities, the majority 92(83.64%) had one or more co-morbidities, with most 58(63.04%) being afflicted with hypertension and less than 10% had diabetes.

Table 3: Socio-demographic characteristics of patients with end stage kidney diseases

Variables	Frequency N (%)
<i>Age (years):</i>	median age = 43.5 (20.00 -80.00)
18-30	20(18.18)
31-60	72 (65.46)
>60	18 (16.36)
<i>Sex</i>	
Male	47 (42.73)
Female	63 (57.27)
<i>Marital status</i>	
Single	20 (18.18)
Married	69 (62.73)
Divorced	12 (10.91)
Widowed	8 (7.27)
Separated	1 (0.91)
<i>Religion</i>	
Christianity	62 (56.36)
Islam	48 (43.64)
<i>Level of Education</i>	
None	14 (12.73)
Primary	23 (20.91)
Secondary	42 (38.18)
Tertiary	31 (28.18)
<i>Ethnicity</i>	
Yoruba	87 (79.09)
Igbo	14 (12.73)
Hausa	5 (4.55)
Others	4 (3.63)

Occupation

Employed	25 (22.73)
Self-employed	66 (60.00)
Not working	19 (17.27)

Location

Urban	87 (79.09)
Rural	23 (20.91)

Place being referred from

Public hospital	41 (37.27)
Private hospital	59 (53.64)
Self-referred	10 (9.09)

Table 4: Comorbidities in participants with end stage kidney disease.

Comorbidities	Frequency N (%)
Hypertension only	58 (52.73)
Glomerulonephritis	8 (7.27)
Diabetes only	3 (2.73)
Cancer only	2 (1.82)
Sickle cell nephropathy	2 (1.82)
HIV nephropathy	1 (1.10)
Hypertension & Diabetes	7 (6.40)
Hypertension & Cancer	2 (1.82)
Hypertension & HIV	2 (1.82)
Others	7 (6.40)
No comorbidities	18 (16.36)

4.2 The level of awareness of respondents.

Table 5. shows that majority 102(93%) of the respondents were not aware of palliative care as a service in the hospital. The few that were aware mentioned their source of information as friends or the University College Hospital.

Table 5: Level of awareness of Palliative Care service by respondents

Variables (N = 110)	Frequency n (%)
Have you heard of Palliative Care?	
Yes	8(7.30)
Source:	
Friend	2(25.00)
Newspaper	1(12.50)
University College Hospital	2(25.00)
Not mentioned	3(37.50)
No	102(93.73)

4.3 The symptom-burden of participants.

Participants experienced many symptoms (Table 4) with the top 5 being weakness 99 (90.00%), difficulty in sleeping with 94(85.45%), poor appetite 89(80.90%), nausea 80(80%) and shortness of breath 78(78%). The rest of the symptoms experienced were pain (70%), general body malaise (70%), sore dry mouth (68 %), restless leg syndrome (68%), drowsiness (64%), vomiting (60%), drowsiness (64%), change in skin (55%), constipation (46%) and itching (49%). The least common symptom experienced among this cohort was diarrhea at 25%.

Table 6: The symptoms burden in end-stage kidney disease patients

Symptoms N (110)	Frequency n (%)
<i>Weakness (99)</i>	
Mild	25(23.00)
Moderate	31(28.00)
Severe	43(39.00)
No Weakness	11(10.00)
<i>Difficulty in sleeping (94)</i>	
Mild	19(17.00)
Moderate	30(27.00)
Severe	45(41.00)
No Difficulty in Sleeping	16(15.00)
<i>Poor appetite (89)</i>	
Mild	23(21.00)
Moderate	34(31.00)
Severe	32(29.00)
No Poor Appetite	21(19.00)
<i>Nausea (80)</i>	
Mild	31(28.00)
Moderate	21(19.00)
Severe	28(26.00)
No Nausea	30(27.00)
<i>Shortness of Breath (78)</i>	
Mild	11(10.00)
Moderate	40(36.00)
Severe	27(25.00)
No Shortness of Breath	32(29.00)
<i>Pain (77)</i>	
Mild	18(16.00)
Moderate	25(23.00)
Severe	34(31.00)
None	33(30.00)
<i>General body malaise (76)</i>	
Mild	25(23.00)
Moderate	27(25.00)

Severe	24(22.00)
None	34(31.00)
<i>Sore Dry Mouth (74)</i>	
Mild	27(25.00)
Moderate	24(22.00)
Severe	23(21.00)
None	36(33.00)
<i>Restless leg syndrome (74)</i>	
Mild	19(17.00)
Moderate	27(25.00)
Severe	28(26.00)
None	36(33.00)
<i>Drowsiness (70)</i>	
Mild	24(22.00)
Moderate	25(23.00)
Severe	21(19.00)
None	40(36.00)
<i>Vomiting (65)</i>	
Mild	25(23.00)
Moderate	12(11.00)
Severe	28(26.00)
None	45(41.00)
<i>Change in Skin (60)</i>	
Mild Change in Skin	14(13.00)
Moderate Change in Skin	22(20.00)
Severe Change in Skin	24(22.00)
None	50(46.00)
<i>Constipation (50)</i>	
Mild	17(16.00)
Moderate	25(23.00)
Severe	8(7.00)
None	60(55.00)
<i>Itching (53)</i>	
Mild	25(23.00)
Moderate	12(11.00)
Severe	16(15.00)

None	57(52.00)
<i>Diarrhea (22)</i>	
Mild	11(10.00)
Moderate	9(8.00)
Severe	8(7.00)
None	82(75.00)

4.4 Assessment of the psychological and social needs of ESKD-patients using integrated palliative care outcome scale- renal patient version (IPOS-RENAL), a validated & published tool.

4.4.1 The psychological needs of ESKD patients

The majority of respondents 59(53.6%) said most of the time they felt anxious or worried about their illness whilst 34(30.9%) expressed that they sometimes feel anxious. A minority 17(15.5%) of ESKD patients reported that they did not have any friends or family who were worried or anxious about them but more than half 68(61.8%) reported that their family and friends most of the time felt anxious or worried about their illness. It was also revealed that about 40(36.4%) respondents sometimes felt depressed while a few 50 (45.5%) most of the time did not feel depressed.

Results from table 7 show that a noticeable proportion, 44 (40.0%) of ESKD patients did not feel at peace at all. Over half of the respondents 63(57.3%) were able to share how they felt most of the times with their families or friends. A significant number 73(66.4%) of the respondents had as much information as they wanted and only a few 14(12.7%) of them did not have access to any information at all.

Table 7: The psychological needs of ESKD patients

Variable	Frequency (n) (%)	
<i>Feeling anxious or worried about your illness</i>		
Not at all	17	(15.45)
Sometimes	34	(30.91)
Most of the time	59	(53.64)
Total	110	(100.0)
<i>Any friends or family worried or anxious about you</i>		
Not at all	17	(15.45)
Sometimes	25	(22.73)
Most of the time	68	(61.82)
Total	110	(100.00)
<i>Feeling depressed</i>		
Not at all	20	(18.18)
Sometimes	50	(45.46)
Most of the time	40	(36.36)
Total	110	(100.00)
<i>Have you felt at peace?</i>		
Not at all	44	(40.00)
Sometimes	39	(35.46)
Most of the time	27	(24.55)
Total	110	(100.00)
<i>Able to share how you feel with family or friends</i>		
Not at all	11	(10.00)
Sometimes	36	(32.73)
Most of the time	63	(57.27)
Total	110	(100.00)

Had as much information as you wanted

Not at all	14	(12.73)
Sometimes	23	(20.91)
Most of the time	73	(66.36)
Total	110	(100.00)

4.4.2 The assessment of social needs of ESKD patients

Some of the respondents 33(30.00%) had their practical problems mostly addressed as far as their illness was concerned but more still thought that their practical problems pertaining to their illness were hardly addressed 39(35.46%). (Table 6)

Many of the respondents 52(47.3%) reported that their time were not being wasted on appointments in the renal clinic while some of them 31(28.2%) said more than half a day of their time was wasted on appointments.

Table 8: The assessment of social needs of ESKD patients

Variable	Frequency (n) %
<i>Responses by patients on whether practical problems resulting from their illness had been addressed or not</i>	
No problems	13 (11.82)
Problems hardly addressed	39 (35.46)
Problems partly addressed	25 (22.73)
Problems mostly addressed	33 (30.00)
Total	110 (100.00)

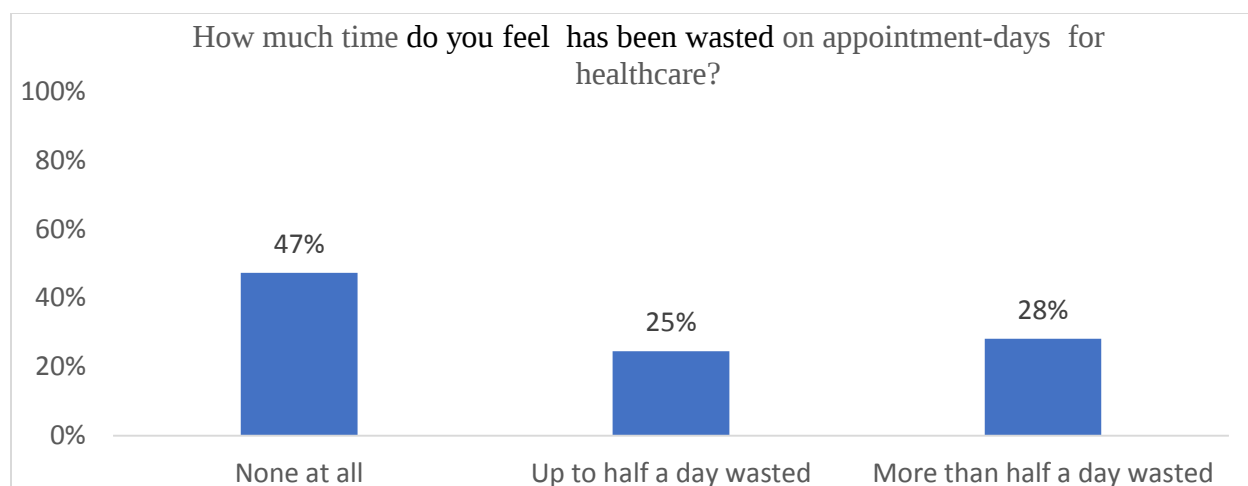


Figure 2: Proportion of responses to a question about the length of time wasted on appointment for healthcare sought for ill-health related to ESKD visits for ESKD.

4.5 An assessment of spiritual needs using the Hope Spiritual tool

Pertaining to their spiritual assessment, a third of the respondents 36(32.7%) were members of an organized religion, only 2 (1.82%) had spiritual beliefs that were not related to organized religion and many 107(97.27%) did not think that spiritual beliefs could affect their care as illustrated with table 7. Figure 4 shows that about a third of the respondents 42 (38.18%) wish to consult a spiritual leader whenever they are ill.

The majority (98%) responded that God is their source of hope or comfort while 2% responded that family members were their sources of hope or comfort. Figure 2 depicts that the majority of the respondents (89%) responded that praying is what helps them in difficult times while 7% responded that family member(s) helped them in difficult times. Two percent of the respondents responded that being in the midst of people help them in difficult times, 1% responded that both family and friends helped them in difficult times, while others reported that listening to music, praising God and singing helped them in difficult times.

It was observed also that 54% of the respondents stated that there were no spiritual practices that are most helpful to them, 45% responded that praying is the spiritual practices that is most helpful, 1% share the beliefs that everything, listening to music or worshipping God is most helpful spiritual practices.

In addition, all the respondents reported that there is no conflict between their belief and the care they are receiving as depicted with figure 3.

Table 9: The assessment of spiritual needs of ESKD patients

Variable	Frequency (n) (%)
<i>A member of an organized religion</i>	
Yes	36 (32.73)
No	74 (67.27)
Total	110 (100.00)
<i>Have spiritual belief separate from organized religion</i>	
Yes	2 (1.82)
No	108 (98.18)
Total	110 (100.00)
<i>A belief that spiritual practice can affect your care</i>	
Yes	3 (2.73)
No	107(97.27)
Total	110 (100.00)

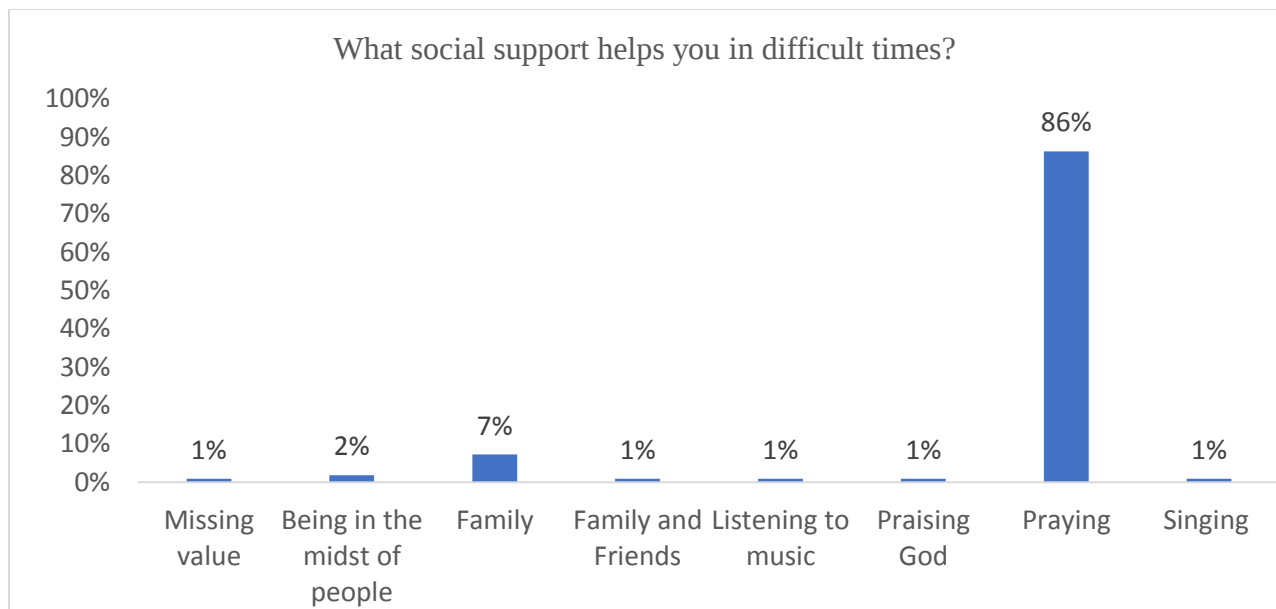


Figure 3: Proportion of respondents with respect to what helps them in difficult times



Figure 4: Proportion of respondents to a question of whether there was any conflict between their belief and the care they were receiving

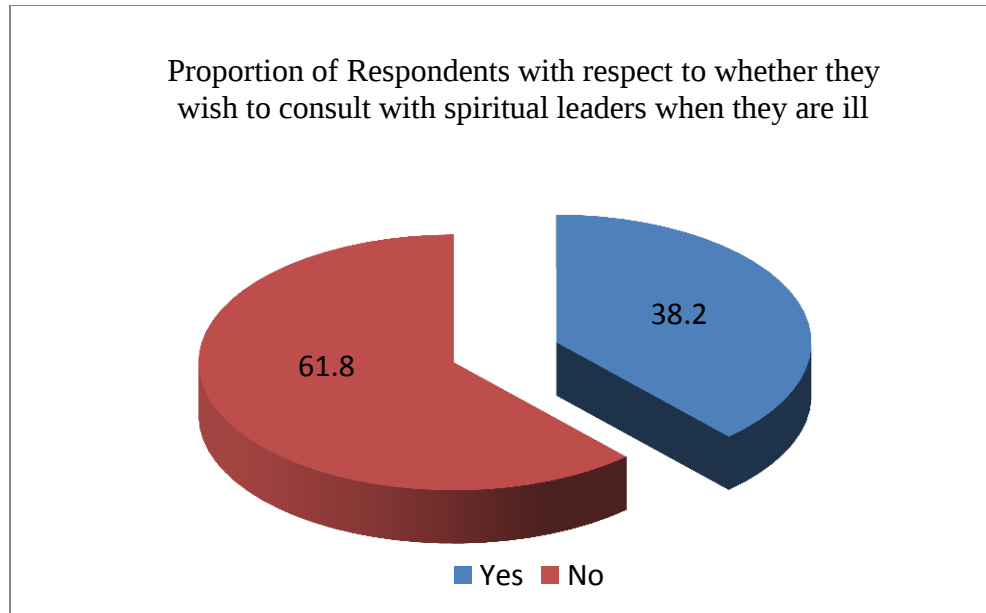


Figure 5: Proportion of respondents wishing to consult with a spiritual leader when they are ill.

4.6 Assessment of the quality of life of respondents.

The level of symptoms of EKSD patients were of three levels depending on the gravity of the illness. It was discovered that level of symptoms experienced by more than half 56(50.91%) of the respondents were severe while some 37(33.6%) have moderate symptom but few 17(15.46%) have a mild level of symptoms (*table 8*).

Table 10: Self-reported level of symptoms experienced by participants

Variable	Frequency (n) (%)
Mild	17 (15.46)
Moderate	37 (33.64)
Severe	56 (50.91)

4.7 The assessment of mental health and psychosocial support by family, friends and health-service providers.

In general, the vast majority of respondents felt supported by their families to a greater or larger extent (Table 9). Whilst the respondent also expressed that they mostly felt their friends and family showed concern for them and healthcare workers offered counselling, half of them expressed that their psychosocial problems were not addressed. Eighty-two percent indicated that they felt depressed either sometimes (45, 46%) or most of the time (36, 36%)

Table 11: Availability of family support for ESKD patients

Variable	Frequency (n) (%)
Not available	4 (3.6)
Sometimes	60 (54.5)
Always	46 (41.8)
Total	110 (100.0)

Table 12: Assessment of mental health and psychosocial support of participants.

	Not at all n (%)	Sometimes n (%)	Most of the time n (%)	Total (N)
Feeling anxious?	17 (15.46)	34 (30.91)	59 (53.64)	110 (100.00)
Any friends of family worried or anxious about you?	17(15.46)	25(22.73)	68 (61.82)	110(100.00)
Feeling depressed?	20 (18.18)	50 (45.46)	40 (36.36)	110(100.00)
Have you felt at peace?	44 (40.00)	39 (35.56)	27 (24.55)	110(100.00)
Are you able to share how you feel with family or friends?	11 (10.00)	36 (32.72)	63(57.27)	110(100.00)
Were you provided with sufficient information that you required about your illness?	14 (12.73)	23 (20.91)	73 (66.36)	110 (100.00)
Were psychosocial problem/s the addressed?	52 (47.27)	25 (22.73)	33 (30.00)	110(100.00)

CHAPTER FIVE

5.0 DISCUSSION, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

In developing countries chronic kidney disease is often diagnosed or managed late because of reasons such as, late presentation of patients to nephrologists, scarce dialysis programs and high cost of treatment (Po-Ya Chang et. al, 2016); (Kher, 2002) e.tc. While affluent countries are focusing on how to improve the quality of life and increasing the long-term survival of ESKD patients, most developing countries like Nigeria are still struggling with short-term survival and the high cost of therapy that limit continuation of treatment.

Our study confirms that Nigeria has not given serious attention to the epidemiology and management of CKD. Developed countries have an advantage over LMICs such as Nigeria because they have favourable economic conditions, better political-social structures, better overall health care facilities and sustainable health care funding strategies to address issues surrounding public threats like ESKD (Eggers, 2011) & (Kher, 2002).

The median age of our participants with ESKD was 45 years old. This is close to the ESKD incidence age mentioned by (Vinay et al., 2010); (Kher, 2002) but is much lower than the mean age of 60years in developed countries (Kher, 2002).

Previous numerous studies observed higher incidence rate of ESKD in women than men in developing countries which is also supported by our study with female to male ratio of 63:47. The higher incidence of CKD and ESKD in women could be as a result of poor glycemic control, poor blood pressure control and family income (Kher, 2002). Most of the ESKD patients in developing countries experienced hypertension and glomerulonephritis as the most common comorbidity and risk factor, the same as in our study.

The majority of our participants experienced re-occurring physical symptoms, and psychological, emotional and financial issues. Prior to entering the study, the patients had not been offered palliative care to alleviate physical and psychosocial suffering related to their life-threatening

disease. Compared to symptoms prevalence data from HIC (Eggers, 2011), our cohort reported higher symptoms prevalence plus they also suffered from the two main mental conditions namely anxiety and depression. They suffered with weakness, difficulty in sleeping, poor appetite, nausea, shortness of breath and pain. What was unanticipated was that vast majority, despite mental and physical suffering, expressed that they were able to find peace which they found in God.

Financial stress was another burden brought about by loss of earnings, especially because many participants had been self-employed. Some published studies have found that the overburdening illness symptoms cause patient to become less active in many spheres of their lives (financial, sexual and social). In the course of meeting or addressing the end-of-life needs of victims, close members are sometimes overwhelmed and stressed by the burden that are transferred by the victims just as corroborated by (Wang, 2011) that patients with ESKD and their families often face uncertainties and complex emotion, and have difficult decisions to make concerning end-of-life needs. The weights of responsibilities of close members of ESKD patients on average or low standard of living are greater in developing countries where the economic and environment structure are unfavourable.

Palliative care is still under-developed in Nigeria despite it having been introduced in the country in 1993 (Oyebola et. al., 2017) & (Ifeoma I. U. et. al., 2010). In our study, all the participants were unaware of Palliative Care medicine as a medical discipline. An education drive is necessary to familiarize patients and caregivers about the support that palliative care gives (Wang, 2011). Almost more than two decades ago, the Nigerian department of health stated that all CKD patients and their care-givers were entitled to information that would enable them to make informed decisions and achieve the best possible quality of life (Department of Health, 2004) & (Department of Health, 2005). The following framework illustrates what the department envisaged for palliative care.

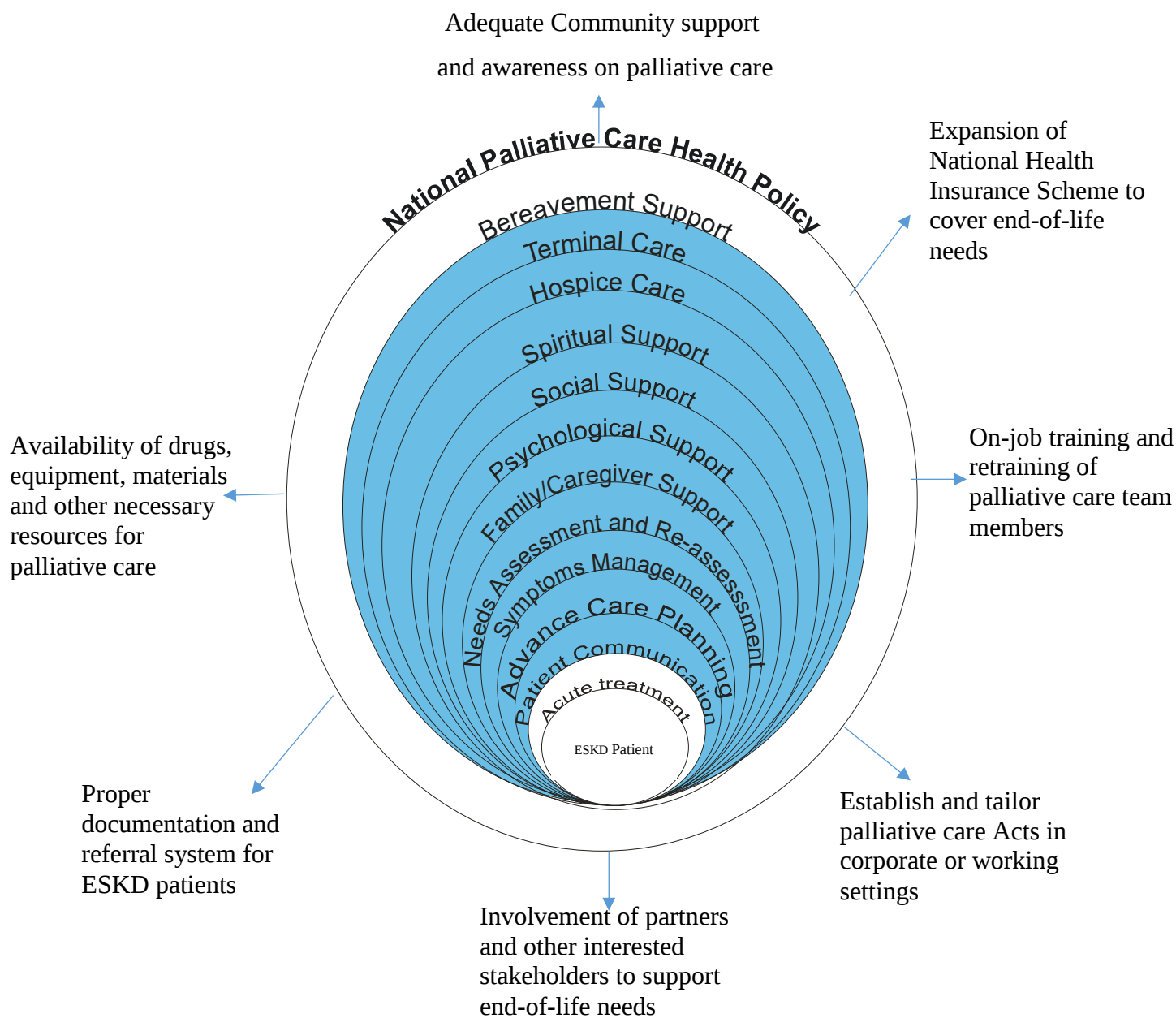


Fig 6: Planned comprehensive palliative care management of patients with end-stage kidney disease in Nigeria

Source: The Researcher

The above planned comprehensive palliative care management programme of patients with ESKD in Nigeria encompasses the cardinal components of a holistic assessment

and management of a patient requiring palliative care. It is in line with WHO public health model approach to palliative care (WHO, 2004), International Society of Nephrologist (ISN) integrated ESKD care framework (David H. et. al., 2019), New South Wales Health End of Life and Palliative Care Framework (NSW , 2019), Best Practices in Palliative Care for Patients with End Stage Renal Disease (Wang D. , 2011). We are therefore suggesting that both this original framework and the findings of this study be incorporated when a new evidence-based version is developed.

5.2. Limitation of the study.

The study is self-sponsored. Not only did this cause financial stress, it also led to the scope of some elements within the study being shortened or abandoned.

5.3. Conclusion.

This study has shown that the prevalence of symptoms in kidney failure patients is high which represent great suffering in these patients. This result clearly shows that there is an urgent need to address and meticulously manage these symptoms best provided by an alliance between Nephrology and Palliative Care and best met through the establishment of a Kidney Supportive Care Clinic within the Nephrology department focusing on these symptoms.

5.4 Recommendations

- i. Our study has shown that the IPOS-tool-renal version together with Hope-tool (with minor changes to adjust for local setting) were able to comprehensively assess for the palliative care needs of patients with ESKD. We recommend that the study-site hospital assemble a multidisciplinary team (including patients and their care-givers) to develop a person-centred framework for palliative care delivery.
- ii. The developed palliative care programme, should be capacitated to provide training to others.

- iii. Non-profit organisations (NPOs) including other relevant community stakeholders should be invited to participate.
- iv. Guidelines and referral pathways should be established to allow for continuum of care across all levels of care (in the private and in the public sectors)
- v. The study findings should be disseminated through publication and presentations to encourage palliative care to take up at the study site and beyond.
- vi. Further studies on ESKD including monitoring and evaluation of this project should be encouraged by Nigerian stakeholders, also further studies to compare symptoms prevalence in patients on dialysis and those on conservative care is also needed.

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APPENDIX 1:

1. INFORMED CONSENT FORM (ENGLISH)

IRB Research approval number: ++++++

This approval will elapse on: dd/mm/yyyy

TITLE OF RESEARCH

ASSESSING THE PALLIATIVE CARE NEEDS OF END-STAGE KIDNEY DISEASE PATIENTS IN A TERTIARY HOSPITAL IN NIGERIA

NAME OF RESEARCHER

The study is being conducted by Adetayo J. Adebayo (Principal researcher and can be contacted on 08034069302). The supervisors of the study, Prof Mosedi Namane, mosedi.namane@uct.ac.za and Dr. Samuel Ajayi, soajayi@hotmail.com can also be contacted.

This form aims to explain to you about the study, that you may wish to participate in. Please feel free to ask questions from the principal researcher or clinical team and you can use the telephone number on this form. Take your time to make a decision whether to participate or not in the study.

Thank you for giving your time to hear about this research.

PURPOSE OF THE STUDY

The purpose of the study is to assess the palliative care needs of patient with diagnosis of End-Stage Kidney Disease and see how access to palliative care service can help to improve their quality of life.

PROCEDURE OF THE RESEARCH

If you agree to be part of the study, we will ask you to sign an informed consent form after adequate explanation has been given to you. We will ask you to answer questions to obtain information for this research. This will take about 30 minutes of your time. There will be no procedures like taking blood in this study.

WHAT IF I DON'T WANT TO TAKE PART IN THE STUDY?

Taking part in this study is absolutely voluntary. You are not obliged to participate in the study and you are free to withdraw at any time in the course of the study. Your participation will not

affect your care in the hospital in anyway if you decide to withdrawal from the study. Take time to think about participation and discuss with your caregivers / family members and doctors.

WHAT HAPPENS IF I AGREE TO PARTICIPATE IN THE STUDY

Once you agree to take part in the study, a consent form will be given to you to sign. An experienced researcher will give you a questionnaire to fill (which takes between 5-10 minutes) and you can ask questions on areas not clear to you. It is a one-time interview but we may need to contact you to clarify certain matters if they come up. However this is unlikely. After filling the questionnaire, please, kindly return it to the researcher who will wait patiently for you to finish. In case you came to the clinic alone, and might need help with your questionnaire. Please, feel free to call on the researcher for help.

COST OF PARTICIPATION

Your taking part in the study, will not cost you anything or any amount.

BENEFITS OF PARTICIPATION

There are no direct benefits for participating in the study.

RISK OF PARTICIPATION

There are no risks of participation although, some questions might cause emotional discomfort. If this occurs, the interviewer will stop and you can choose to withdraw from the study or to restart at a time of your choosing.

CONFIDENTIALITY

All information collected in this study will be confidential. You will not be identified in anyway.

WILL YOU LIKE TO BE INFORMED ABOUT THE RESULTS OF THE STUDY?

A report on the findings from this study will be sent to participants and to the clinic where you were seen.

STATEMENT OF PERSON GIVING CONSENT;

1. I confirm that I have read and understand the information on the consent form and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason and without my care being affected.

3. I agree to take part in the above study.

Name _____

Signature _____

Date _____

Name of person witnessing; _____

STATEMENT OF PERSON OBTAINING INFORMED CONSENT:

I have fully explained this research to _____ and have given sufficient information, including about risks and benefits, to make informed decision.

Signature _____

Date: _____

Name: _____

CONTACT PERSONS FOR THE STUDY

Please if you have questions about this research, kindly contact the Chairman of the Ethics Committee of the University of Ibadan, at Biode Building, Room 210, 2nd Floor, Institute for Advanced Medical Research and Training, College of Medicine, University of Ibadan, E-mail: uiuchrc@yahoo.com and uiuchec@gmail.com

In addition, if you have any questions about your participation in this research, you can contact the principal investigator, DR ADETAYO J.ADEBAYO, Hospice & Palliative care unit, UCH. E-mail.drade.adebayo@gmail.com. 08034069302

APPENDIX 2

INFORMED CONSENT FORM (YORUBA)

Nọmba itẹwọgbà IRB: #####

Igba ti ibuwọlu iwadi yio pari: ọjọ/osu/ọdun

AKORI IWADI: SISAGBEYEWỌ ITOJU TI AWON TI N'JE IRORA LORI IGBEYIN IPELE AISAN KIDIRIN LE NILO NI ILE IWOSAN AKOSEMOSE ISEGUN OYINBO NI NIGERIA.

ORUKO OLUWADI: Iwadi yii yio wa ye nipase Adetayo J. Adebayo. Ohun si tun ni o je oluwadi agba. ero ibanisoro: 08034069302. Awon olutomisona Dr. Mosedi Namane, mosedi.namane@uct.ac.za ati Dr. Samuel Ajayi, soajayi@hotmail.com a le kan si won naa..

E se pupo fun akoko yin ti e fi sile lati mo nipa eto iwadi yii.

Foomu yi wa lati se alaye ni kikun nipa iwadi yii ki elebaa kopa ninu re. Jowo o ni anfaani lati beere ounkohon lowo adari oluwadi agba, awon igbimo onisegun, o si tunle lo ero ibara eni soro ti o wa lori foomu yii.

Lo asiko re yi lati se ipinu bi oba wu oo lati kopa tabi ko ba wu oo. Ese pupo.

IDI FUN IWADI

Idi pato fun iwadi yii ni lati sagbeyewo itoju ti awon ti n je irora lori igbeyin ipele aisan kidirin le nilo ati lati mo boya iru itoju sise be le je ki igbe aye won o gbe peeli si.

ILANA IWADI

Ti o ba gba lati kopa ninu iwadi yii, a o ro oo lati buwo lu foomu iyonda lati kopa yii leyin igba ti a ti se alaye ni kikun fun oo daradara. A o beere awon ibeere lowo re lati fun wan i idahun ti o ni se pelu iwadi yii. Eyi yio gba ogbon iseju ninu akoko re. Ko si ilana Kankan ti o je mo gbigba eje re ninu iwadi yii.

BI KO BA WU MI LATI KOPA NINU ETO IWADI YII

Kikopa ninu eto iwadi yii je ohun ti o wuni lokan. A o fi ipa mu o lati kopa ninu eto iwadi yii, osi ni eto lati so pe oko se mo ni asiko ti o ba wu oo lasiko ti iwadi yii baa an lo lowo. Kikopa re ko ni pa itoju re lara rara ni ile iwosan ti o ba si ti pinnu lati kuro ninu eto iwadi yii, o lee se be gege

lai si wi pe a un kan nipa tabi fi inira fun oo. Jowo fi akoko ti oni lati ro oo daradara ki o si jiroro pelu awon olutoju/ ebi re /dokita

KINI YIO SELE TI MO BA GBA LATI KOPA NINU ETO IWADI YII

Bi o bati pinnu lati kopa ninu eto iwadi yii, a o fun o ni foomu olukopa ti iwo yio bu owo lu. Akosemose oluwadi yio fun oo ni eda iwe ibeere ti iwo yio bawa dahun (eyi ko ni gba ju iseju marun-un si mewa lo.) o si ni anfaani lati beere ibeere ti o ba ru o loju. O je iforowanilenu wo elekan soso sugbon a maa nilo lati ke pe oo fun awon oro ti oba ru wa loju. Sibe, iru sise eyi, ko wopo. Lehin igba ti o bati bawa dahun awon ibeere, jowo da iwe ibeere na pada fun awon asewadi wa ti won o fi suru duro de oo titi iwo yio fi se tan, Bi iwo basi dawa si ile iwosan ti onilo eniti yio ran oo lowo lati koo awon idahun re sile, Jowo oni aaye lati ke si oluwadi fun iranlowo

IDIYELE LATI KOPA

Kikopa re ninu eto iwadi yii ko ni na oo ni owo re.

EWU:

Ko si ewu kan pato ninu iwadi yii. Sugbon, awon ibeere kan le je ki o ni edun okan. Ti eyi ba waye, a o da wo ibeere duro lesekeke, o si le yan lati ma se kopa mo ninu iwadi yii tabi ki o sese bere fun kikopa.

ASIRI IWADI

Gbogbo asiri awon ohun ti a ba gba lati odo olukopa ninu iwadi yi ni a o fi pa mo ti eni kokan ko si ni anfaani lati ri rara. A ko ni fi idanimu han jade bi oti wu ki o mo.

NJE IWO YIO MO NIPA GBOGBO ABAJADE ETO IWADI YII BI?

A o jabo gbogbo abajade ohun ti o jeyo ninu eto iwadi yii fun awon olukopa ati si awon ile iwosan ibi ti olukopa wa lasiko tie to iwadi naa n lo lowo.

Gbólóhùn ti eni ti fifun ni ase:

1. Mo ti mo daju pe mo ti ka o si ye mi yekeyeke gbogbo ohun oro lori foomu iyonda lati kopa mosi tunle ni anfaani lati bere ibeere ti ko ba ye mi.

2. O ye mi yekeyeke pe kikopa mi je atinuwa mo si ni anfaani lati jawo ni akoko ti o ba wu mi laisi awawi ati lai si ni da titoju mi duro tabi da a lagara.

3. Mo gba lati kopa ninu eto iwadi yii.

Oruko _____

Ibuwolu _____

Ojo _____

Oruko asoniduro -----

Gbólóhùn ti eni ti gba ase fun:

Mo ti ni kikun alaye fun iwadi si _____ ki o si ti fi to alaye, pẹlu nipa ewu ati awọn anfaani, lati se ohun nipa ipinnu.

Ojọ: _____ Ibuwọlu: _____

Oruko Olukopa: _____

AWON TI A LE KAN SI LORI ETO IWADI YII.

Jowo, ti o ba ni ibeere nipa eto iwadi yii, e le kan si Alaga igbimo ti o buwolu iwadi yii lati kese jari ni Iyara 210, aja keji, BIODÉ BUILDING, IAMRAT, COLLEGE OF MEDICINE, UNIVERSITY OF IBADAN, ero ayelukara: uiuchrc@yahoo.com ati uiuchec@gmail.com. Ni afikun, ti o ba ni eyikeyi ibeere nipa kikopa rẹ ninu iwadi yi, o le kan si awọn oluwadi agba. Oruko: DR ADETAYO J.ADEBAYO ti ẹka awon ti n'se itoju alaisan ti n'je irora ni ile iwosan UCH, ero ibanisoro: 08034069302, Ero Ayelukara: drade.adebayo@gmail.com

APPENDIX 3:

QUESTIONNAIRE

Assessing the Palliative Care Needs of End-Stage Kidney Disease Patient in a Tertiary Hospital in Nigeria

Dear Respondent,

Good day. My name is Adetayo Adebayo, a postgraduate student in the department of Palliative Medicine, Faculty of Public Health and Family Medicine, University of Cape Town, South Africa. I am carrying out a study on assessing the palliative care needs of end stage kidney disease patients at the University College Hospital, Ibadan. All information given will be used to improve the quality of life of patient living with end stage kidney disease. It is voluntary.

Section A: SOCIO-DEMOGRAPHIC DATA ACCORDING TO PARTICIPANTS

Date (dd/mm/yyyy) :

Study No

A.

QUESTIONS	POSSIBLE RESPONSES
Q1. Age at last birthday (years)	
Q 2. Sex	1 ☐ Male 2 ☐ Female
Q 3. Marital status	single 1 ☐ 2 ☐ married ☐ 3. divorced ☐ 4 ☐ widowed 5 ☐ separated
Q4. Religion	1 ☐ Christianity 2 ☐ Islam 3 ☐ Traditional 4 ☐ others 5 ☐ specify
Q5. Ethnicity	1 ☐ Yoruba 2 ☐ Igbo 3 ☐ Hausa 4 ☐ Others 5 ☐ specify
Q 6. Level of education	1 ☐ none 2 ☐ primary 3 ☐ secondary [] university [] others, specify
Q7. Where do you live?	1 ☐ Urban 2 ☐ Rural
Q8. Where were you referred from?	1 ☐ UCH 2 ☐ private hospital 3 ☐ self 4 ☐ others. Specify.....
Q9. Have you heard of palliative care?	1 ☐ yes 2 ☐ No, if yes where.....
Q10. Any comorbidities? How many?	List

B.
International Palliative Outcome Scale-Renal Patient Version (IPOS)

Q1. What has been your main problems or concerns related to your kidney disease over the past week?

1.
2.
3.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Mildly	Moderately	Severely	
Pain	0 ☐	1 ☐	2 ☐	3 ☐	
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	
Itching	0 ☐	1 ☐	2 ☐	3 ☐	
Difficulty Sleeping	0 ☐	1 ☐	2 ☐	3 ☐	
Restless legs syndrome or difficulty keeping legs still	0 ☐	1 ☐	2 ☐	3 ☐	
Changes in skin	0 ☐	1 ☐	2 ☐	3 ☐	

Diarrhoea	0●	1●	2●	3●	
-----------	----	----	----	----	--

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1. _____	0●	1●	2●	3●
2. _____	0●	1●	2●	3●
3. _____	0●	1●	2●	3●

<u>Over the past week:</u>					
	Not at all		Sometimes	Most of the time	
Q3. Have you been feeling					
anxious or worried about your illness or treatment?	0●		2●	3●	
Q4. Has any of your family or friends been anxious or worried about you?	0●		2●	3●	
Q5. Have you been feeling depressed?	0●		2●	3●	
	Not at all		Sometimes	Most of the time	
Q6. Have you felt at peace?	0●		2●	3●	
Q7. Have you been able to					
share how you are feeling with your family or friends as much as you wanted?	0●		2●	3●	
Q8. Have you had as much information as you	0●		2●	3●	

wanted?					
	No problems	Problems hardly addressed	Problems partly addressed	Problems mostly addressed	
Q9. Has any practical problems resulting from					
your illness been addressed? (such as financial or personal)	0 ●	1 ●	2 ●	3 ●	
	None at all		Up to half a day wasted	More than half a wasted	
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g., waiting around for transport or repeating tests	0 ●		1 ●	2 ●	
Q11. How did you complete this questionnaire?	On my own ● With help from a relative ● With help from a member ●				

1.

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

APPENDIX 4

SPIRITUAL ASSESSMENT (HOPE ASSESSMENT TOOL)

Table 5.1	HOPE Approach to Spiritual Assessment
H Spiritual Resources	What are your sources of hope or comfort? What helps you during difficult times?
O Organized Religion	Are you a member of an organized religion? What religious practices are important to you?
P Personal Spirituality	Do you have spiritual beliefs, separate from organized religion? What spiritual practices are most helpful to you?
E Effects on Care	Is there any conflict between your beliefs and the care you will be receiving? Do you hold beliefs or follow practices that you believe may affect your care? Do you wish to consult with a religious or spiritual leader when you are ill or making decisions about your healthcare?
Source: Anandarajah, G., & Hight, E. (2000). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. www.aafp.org/ .	

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UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room 253-48 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6626
Email: stuart.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

24 October 2018

HREC REF: 685/2018

Dr M Namane
Public Health & Family Medicine
2nd floor, Entrance 5
Falmouth Building

Dear Dr Namane

PROJECT TITLE: ASSESSING PALLIATIVE CARE NEEDS OF END-STAGE KIDNEY DISEASE PATIENTS IN A TERTIARY HOSPITAL IN NIGERIA (Masters Candidate - A.J. Adebayo)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 October 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledges that the student, Dr Adebayo Adebayo will also be involved in this study.

Yours sincerely


PROFESSOR M. BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

MOF 685/2018



INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)

College of Medicine, University of Ibadan, Ibadan, Nigeria.

Director: **Prof. Catherine O. Falade**, MBBS (Ib), M.Sc., FMCP, FWACP

Tel: 0803 326 4593, 0802 360 9151

e-mail: cfalade@comui.edu.ng lillyfunke@yahoo.com



UI/UCH EC Registration Number: **NHREC/05/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

Re: Assessing the Palliative Care Needs of End Stage Kidney Disease patients in a Tertiary Hospital in Nigeria.

UI/UCH Ethics Committee assigned number: UI/EC/18/0397

Name of Principal Investigator: **Dr. Adetayo J. Adebayo**

Address of Principal Investigator: School of Public Health and Family Medicine,
Faculty of Health Sciences,
Rondebosch, Cape Town, South Africa

Date of receipt of valid application: 28/08/2018

Date of meeting when final determination on ethical approval was made: **N/A**

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and *given full approval by the UI/UCH Ethics Committee.*

This approval dates from **13/11/2018 to 12/11/2019**. If there is delay in starting the research, please inform the UI/UCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the UI/UCH EC assigned number and duration of UI/UCH EC approval of the study.* It is expected that you submit your annual report as well as an annual request for the project renewal to the UI/UCH EC at least four weeks before the expiration of this approval in order to avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the UI/UCH EC. No changes are permitted in the research without prior approval by the UI/UCH EC except in circumstances outlined in the Code. The UI/UCH EC reserves the right to conduct compliance visit to your research site without previous notification.



Professor Catherine O. Falade

Director, IAMRAT

Chairperson, UI/UCH Ethics Committee

E-mail: uiuchec@gmail.com



UNIVERSITY COLLEGE HOSPITAL, IBADAN

The pioneer Teaching Hospital in Nigeria.

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November 27, 2018

Dr. Adebayo Adetayo J,
Department of Hospice and Palliative Care,
University College Hospital,
Ibadan.

Dear Dr. Adebayo,

Re: Permission to Conduct Research

Please refer to your letter dated November 26, 2018 on the above subject. I hereby inform you that approval has been given for you to collect data by means of administering questionnaires to end stage kidney disease patients seen at the Nephrology Unit of the Department of Medicine in this hospital for your study titled: **"Assessing the Palliative Care Needs of End Stage kidney Disease Patients in a Tertiary Hospital in Nigeria."**

Please liaise with the Head of Medicine Department, who by a copy of this letter, is being informed of the need to give you the necessary assistance and cooperation in this regard. Please endeavor to acknowledge the University College Hospital, Ibadan in the final report of your research. **Also, note that submission of a copy of the report to the office of the Chairman, Medical Advisory Committee of this Hospital is highly important.**

Yours sincerely,

Dr. V. I. Akinmoladun
Director of Clinical Services, Research & Training
Chairman, Medical Advisory Committee
For: Chief Medical Director

Prof. Temitope O. Alonge
- MBBS (Ibadan), FRCS Edinburgh, FWACS, MD Leicester, FPA
- Chief Medical Director

Dr. V. I. Akinmoladun
- BChD, MSc, FDSRCS (Eng.), FFDRCS (Ire), FWACS
- Chairman, Medical Advisory Committee; Director of Clinical Services, Research & Training

Mr. A. K. Shiyabola
- B.Sc, M.Sc, MPA, GD LSCM, FHAM, MNIM, ACIPM, CIPSMN, MNPA
- Director of Administration & Secretary to the Board

