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SCHOOL OF MEDICINE & PHARMACY

HEALTH RELATED QUALITY OF LIFE OF PATIENTS UNDERGOING IN-CENTRE MAINTENANCE HEMODIALYSIS IN RWANDA: A CROSS SECTIONNAL STUDY

Dissertation submitted in partial fulfillment of the requirements for the award of the degree of Master of Medicine in Internal Medicine, University of Rwanda.

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DECLARATION

I, SHUMBUSHO Gloria, declare that this dissertation entitled "Health related quality of life of patients undergoing in-centre hemodialysis in Rwanda", a cross sectional study realized in four referral hospitals CHUK, CHUB, KFH, RMH, is the result of my own work and have not been submitted for any other degree at the University of Rwanda or any other institution.

It is submitted to the College of medicine and health sciences in partial fulfillment of the requirements for the award of the degree of Master of medicine in Internal medicine atUniversity of Rwanda.

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DEDICATION

To the almighty God

To my husband

To my son

To my dear Parents

To my dear sisters and brothers

To my Supervisors

To my Patients

I dedicate this work.

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LIST OF ABREVIATIONS

AKI: Acute Kidney Injury

BMI: Body Mass Index

BKD: Burden of Kidney Disease

CKD: Chronic Kidney Disease

CHUK: Centre Hospitalier Universitaire de Kigali

CHUB: Centre Hospitalier Universitaire de Butare

CBHI: Community Based Health Insurance

DOPPS: Dialysis Outcomes and Practice Patterns Study

EKD: Effect of Kidney Disease

ESKD: End Stage Kidney Disease

ESA: Erythropoietin Stimulating Agents

GFR: Glomerular Filtration Rate

HRQOL: Health Related Quality of Life

HD: Hemodialysis

HIV: Human Immunodeficiency Virus

IDF: International Diabetes Federation

KDIGO: Kidney Disease Improving Global Outcome

KDQOL: Kidney Disease Quality of life

KFH: King Faisal Hospital

LMIC: Low and Middle Income Countries

MCS: Mental Composite Score

MMI: Military Medical Insurance

NCD: Non Communicable Disease

PD: Peritoneal Dialysis

PCS: Physical Composite Score

QOL: Quality of life

RRT: Renal Replacement Therapy

RMH: Rwanda Military Hospital

RSSB: Rwanda Social Society Board

SSA: Sub Saharan Africa

SPKD: Symptoms and Problem of Kidney Disease

USA: United States of America

ABSTRACT

Background: The limited access to renal replacement therapy increases the burden of end stage kidney disease (ESKD) in resource limited setting. For the majority of patients reaching hemodialysis, there are environmental and individual factors which affect their health related quality of life (HRQOL). Improving the quality of life should be the primary outcome of end stage kidney disease patients on hemodialysis in Rwanda.

Objectives: To describe the health related quality of life of patients undergoing in-centre maintenance hemodialysis in Rwanda using the KDQOL™-36 and determine sociodemographic and clinical characteristics associated with their quality of life.

Methods: The study was a multicenter prospective cross-sectional study of 89 patients on maintenance hemodialysis at the hospitals—CHUK, CHUB, RMH and KFH—where in-centre hemodialysis is provided. Demographic and clinical information were collected between September 2020 and March 2021 for all patients aged >18 years receiving in-centre hemodialysis for at least three months and health related quality of life scores was measured using the KDQOL™-36 questionnaire which assesses physical (PCS) and mental (MCS) health functioning, the effect, burden and symptoms and problem of kidney disease. Mixed effects linear regression models were fitted to explore factors associated with overall KDQOL and its domains, while accounting for clustering of patients within hemodialysis units.

Results: The overall mean (SD) quality of life score was 48.92 (18.84), PCS score 37.33 (10.66) and MCS 44.74 (9.98). Symptoms and problem of kidney disease, effect of kidney disease, and burden of kidney disease scored 58.22 (27.44), 53.48 (17.14) and 20.01 (18.27) respectively. The majority of participants were younger than 60 years old (69.7%), male (66.3%), married or living with a partner (53.9%) and unemployed (56.2%). Approximately 70% had secondary school education or greater and 67.4% were fully covered by medical insurances bearing no out of pocket payments for dialysis. Factors associated with overall quality of life include male sex (a ß: 8.54, 95% CI: 2.77, 14.26); being employed (a ß: 8.16, 95% CI: 2.18, 14.29); dialysis vintage of 13-24 months (a ß: 10.47, 95% CI: 3.57, 17.58), hemoglobin of 10-11g/dl (a ß: 7.27, 95% CI (0.70, 13.72)) and comorbidities (e.g., 4 comorbidities vs none; a ß: -29.76, 95% CI: -41.47, -18.32).

Conclusion: Patients on in-centre hemodialysis in Rwanda have reduced HRQOL scores with the burden of kidney disease and physical composite domains being most affected. Higher overall KDQOL mean score was associated with male sex, being employed, dialysis vintage of 13-24 months, hemoglobin of 10-11g/dl and absence of comorbidities.

Key words: Health related quality of life, end stage kidney disease, in-centre hemodialysis, kidney disease quality of life.

CHAPTER I: INTRODUCTION

1.1. Background

Chronic kidney disease (CKD) is a common and important non-communicable disease (NCD). The burden of kidney disease worldwide is substantial, growing and poses significant challenges for governments responding to the health of their populations, particularly in low and middle income countries (LMIC).(1) Worldwide, the leading cause of CKD is diabetes followed by hypertension and glomerulonephritis.(2)(3) In low resourced settings, it is projected that approximately ten percent of NCD are related to infectious diseases and it is plausible that this is the case with kidney disease.(4) Access to renal replacement therapy (RRT) is estimated at 9%-16% worldwide, the lowest access is in middle and eastern Africa (1-3%) mainly due to the cost.(5) Based on 2010 estimates, approximately 2.6 million people with ESKD received dialysis or transplantation while an additional 2.3-7.1 million people are projected to have died owing to lack of access to renal replacement therapy, predominantly in low resource settings.(6) By 2030, the number of person receiving RRT will increase up to 5.4 million.(7) Currently, hemodialysis is the most common modality available in sub-Saharan Africa (SSA) where renal transplant and dialysis are a challenge with cost and human resources constraints impacting availability.(8) Generally, the outcome of dialysis patients in SSA is poor, and marked by premature mortality in the first year after dialysis initiation.(9)(10) A high mortality rate following initiation of dialysis may be related to late presentation to a nephrologist or kidney care center, affordability, lack of access to treatment for metabolic complications and poor education.(10)

Rwanda is one of the smallest central African countries with an approximately 13 million population and only about 17.6% living in urban areas.(11) The gross domestic product (GDP) per capita is approximately 820 US dollars.(12) Over 90% of Rwandan population have access to health care through community based health insurance (CBHI), while 6% use civil servant and military personnel insurances and other private health insurances.(13)(14)(15) Based on estimates from World Health Organization, NCDs including renal diseases were predominant cause of mortality in Rwanda accounting for 58% of the total since 2016.(16) The prevalence of ESKD is not well studied, but kidney failure is among the top 10 leading cause of death from non-communicable diseases and injuries in Rwanda.(16) Currently, in-centre maintenance hemodialysis is available at three public, university affiliated tertiary referral centers, Kigali University Teaching Hospital (CHUK), Butare University Teaching Hospital (CHUB), and Rwanda Military hospital (RMH) and at

King Faisal Hospital (KFH), which is a public-private quaternary hospital. The African Health Network, a private company provides outpatient, community based hemodialysis at three units located in Kigali and western province.(17) CBHI covers hemodialysis for only six weeks for patients with acute kidney injury (AKI) and does not cover costs associated with chronic RRT for CKD.(18) Maintenance dialysis is covered by employer and private health insurances or special funds (eg Genocide Victims Fund GVF) at 85 to 100% of HD cost, thus, for the majority of Rwandans, there are substantial out of pocket costs and financial hardship associated with hemodialysis.(17)

Access to dialysis is limited by its cost, a shortage of specialized medical staff with training in nephrology and renal replacement therapy and geographic distribution of in-centre hemodialysis units.(17)(19) Despite challenges, the survival rates have improved in patients with kidney failure treated with acute hemodialysis in Rwanda.(18)

It has been reported that ESKD decreases the HRQOL of affected patients.(20) Health related quality of life (HRQOL) measurements may provide a reasonable metric of patients' status in resource limited settings.(21)(22) In Africa, there are few studies assessing the QOL of patients with CKD, less again of dialysis patients. Thokozani Masina et al. (23) in Malawi and Kamau et al. (24) in Kenya found reduced HRQOL of dialysis patients.

This study aim is to determine the health related quality of life of patients with ESKD undergoing in-centre maintenance hemodialysis in Rwanda and the factors associated with quality of life. To our knowledge, this will be the first study, about the HRQOL of dialysis patients in the country and we hope that it will pave a way for the improvement of the concerned population and for future studies.

1.2. Problem statement and study justification

Given the high health burden of ESKD and increasing access to dialysis, assessing HRQOL of patients on hemodialysis in Rwanda will help to determine mental, physical and kidney disease specific difficulties patients are facing and identify modifiable factors associated with quality of life. This is the first study evaluating the quality of life of end stage kidney disease patients on hemodialysis in Rwanda. The study will bring additional descriptive information to the existing literature regarding the demographic and clinical features of patients undergoing chronic hemodialysis in sub-Saharan Africa. It has the potential to influence hemodialysis protocols for in-centre and outpatient community dialysis units in Rwanda and other low-income countries scaling up hemodialysis to address the growing burden of ESKD.

1.3. Research questions and hypothesis

1.3.1. Research questions

What is the HRQOL of patients on maintenance in-centre hemodialysis in Rwanda as measured by the KDQOL™-36?

What factors are associated with the QOL of patients on maintenance in-centre hemodialysis in Rwanda?

1.3.2. Research hypothesis

Sociodemographic factors affect the HRQOL of patients on hemodialysis in Rwanda.

1.4. Objectives

1.4.1. General objective

To describe the HRQOL of patients on maintenance in-centre hemodialysis in Rwanda.

1.4.2. Specific objectives

1. To determine demographic and clinical characteristics of patients on in-centre maintenance hemodialysis in Rwanda.

2. To document the HRQOL of patients on maintenance in-centre hemodialysis in Rwanda using the KDQOL™-36 instrument.

3. To determine sociodemographic and clinical factors that are associated with the quality of life of patients on in-centre maintenance hemodialysis in Rwanda.

CHAPTER II: LITERATURE REVIEW

2.1. Definition of Chronic kidney disease

The 2012 Kidney Disease: Improving Global Outcomes (KDIGO) Chronic Kidney Disease guidelines define chronic kidney disease (CKD) as an abnormal kidney structure or function for more than three months with health implications.(25) CKD is classified according to its causes, glomerular filtration rate (GFR) category, or albuminuria category.(25) Evaluation based on GFR classifies CKD into five stages. The fifth stage encompasses end-stage kidney disease (ESKD) defined by GFR less than 15 mL/min/1.73m^2.(26)

Based on World Health Organization (WHO) global health estimates, kidney diseases are the 10th cause of death worldwide.(27) CKD is a strong predictor of cardiovascular diseases and often results from communicable and non-communicable diseases.(26) While there is limited information regarding prevalence of CKD in low-income contexts, recent studies in SSA estimate the prevalence of CKD to be 13.9% with a mean age of 41 years.(6)

2.2. Causes and risk factors of chronic kidney disease

2.2.1. Diabetes mellitus

Diabetes is the most common cause of chronic kidney disease worldwide.(1) The risk of ESKD is tenfold higher in patients with diabetes.(2) According to the International Diabetes Federation (IDF) report of 2019, sub-Saharan Africa accounts for 19.4 million people with diabetes and is predicted to have the highest prevalence worldwide by 2045 with an increase of 143%.(2) This increase is related to the growing rates of obesity, poor diet and increased life expectancy.(2) Diabetes related chronic kidney disease results from hyper filtration induced by hyperglycemia which increases urinary albumin excretion, podocytes damage and reduction of GFR.(2) The increase risk to ESKD is associated with recurrent urinary tract infections in diabetes patients, neurogenic bladder, macrovascular angiopathy and hypertension.(2)

2.2.2. Hypertension

Hypertension can be a cause, a contributory factor or a consequence of chronic kidney disease. Sixty to 90% of CKD patients have hypertension and is more prevalent in black population.(28)(29) CKD from hypertension results from unregulated glomerular hydrostatic pressure that increases albumin excretion responsible for glomerular filtration barrier.(30) CKD can also lead to hypertension through endothelial dysfunction, renin angiotensin

aldosterone system (RAAS) overactivity, sympathetic system stimulation and fluid and sodium retention which worsen renal dysfunction. Renin angiotensin aldosterone system interruption may help to slow the progression to kidney failure.(2)(31)(32)

2.2.3. Infections

In sub-Saharan Africa, the burden of NCD is related to the high rate of infectious diseases.(4) There is a link between infectious diseases and non-communicable diseases particularly in low resourced settings.(4) Infectious diseases are causes and risk factors of CKD by various mechanisms: chronic glomerulonephritis and interstitial nephritis secondary to both viral, bacterial and parasitic infections such as HIV, hepatitis, staphylococcus, tuberculosis and malaria, and obstructive uropathy from parasitic infection such as schistosomiasis.(33) The high prevalence of HIV and tuberculosis in Sub-Saharan Africa also contributes to the large burden of CKD.(6)

2.2.4. Acute kidney injury

Acute infectious diseases such as malaria, pneumonia, and sepsis are common causes of acute kidney injury (AKI) requiring dialysis.(18) Acute kidney injury is a risk factor and an accelerator of chronic kidney disease. The risk of developing CKD is almost nine fold higher in patients who had had AKI and 28- fold higher in patients who had AKI requiring dialysis.(34) Chronic kidney disease results from maladaptive repair following acute renal injury marked by fibrosis, loss of tubular function, chronic interstitial inflammation, vascular rarefaction, and glomerulosclerosis.(34)

2.2.5. Other risk factors

Sociodemographic factors: A 2021 report from the Centers for Disease Control and Prevention (CDC) stated that CKD is more common in people over 65, in women and in Hispanic black adults.(35) In sub-Saharan Africa, the mean age of chronic kidney disease is approximately 40 years and the burden of CKD is higher in urban residents.(6)(36)(37)

Environmental factors such as exposure to heavy metals (mercury, lead, cadmium), smoking and second hand smoke, herbicides and pesticides, air pollution, nephrotoxic phytochemicals present in some plants and herbs and unregulated food additives are associated with development of CKD. (38)

Non-steroidal anti-inflammatory drugs (NSAID) use and other nephrotoxic drugs are also risk factors of CKD.(31)(26)

2.3. Complications of end-stage kidney disease

ESKD is associated with poor quality of life, excessive cost of care and poor health outcomes.(9)(5)(39) ESKD results in progressive loss of kidney function and may lead to premature death.(25) CKD can affect all organs; it is a major risk factor of cardiovascular diseases (CVD), endocrine and metabolic abnormalities, infections, physical and cognitive function impairment.(40)

2.4. Treatments of end-stage kidney disease

The main treatment is renal replacement therapy (RRT) that includes renal transplant, hemodialysis and peritoneal dialysis.(31) Indications for initiation of dialysis include symptoms and signs of kidney failure, inability to control fluid status or blood pressure and decline in nutritional status not responding to interventions.(41)

For decades, measurement of small solute clearance using Kt/V calculation index defined "dialysis adequacy".(41) Kt/V determines the effective renal urea clearance by volume of distribution during dialysis session. However urea clearance is a part of endpoints to achieve dialysis adequacy.(42) In January 2018, KDIGO participants suggested use of the term "goal directed dialysis" instead of "dialysis adequacy". Goal directed dialysis shares decision-making between patient and clinician to help patients to achieve their individual goals and allows the clinician to provide individualized, high-quality dialytic care.(41) Goals include small solute clearance, electrolytes, fluid, nutrition status, dialysis related symptoms and patients social and work capacity.(41)

The 5-year survival rate on dialysis varies by country and is highest in high-income countries.(43) Complications associated with dialysis vary depending on type of dialysis, age, and comorbidities.(44) Dialysis may be associated with catheter or mechanical problems, infection and frailty.(41) Early mortality is common in patients receiving in-centre hemodialysis compared to those on peritoneal dialysis, community and home hemodialysis.(45)(44)

2.5. Burden of end stage kidney disease in low-income countries

The annual cost of dialysis per person is USD 3,424 to USD 42,785 for hemodialysis, USD 7,974 to USD 47,971 for peritoneal dialysis in LMICs.(46)

In sub-Saharan Africa, hemodialysis is the most common RRT modality available.(8) Globally, there is significant variability in the delivery of hemodialysis and outcome data for patients on HD in low-income countries (LIC) is limited, generally poor and marked by a

high premature mortality.(9)(10) Economic and human resource constraints affect the ability to initiate and monitor patients on HD according to international recommendations. In many low-income countries, access to Erythropoietin stimulating agents, intravenous iron, phosphate binding medications, activated Vitamin D and vascular access surgery is limited.

2.6. Situation in Rwanda

2.6.1. Health system in Rwanda

There have been improvement in access to health services, reduction of child and maternal mortality, reduction of HIV prevalence and reduction of endemic disease incidence in Rwanda.(19)(47) Most (92%) Rwandans access health care using community based health insurance (CBHI) which is linked to ubudehe category and managed by the Rwanda social society board (RSSB).(13) Currently, the socioeconomic life standing of Rwandan households is classified into four "Ubudehe categories".(14) According to Rwanda Population and Housing Census (2012 RPHC), 10.1% of the population were classified as severely poor (category 1), 27.2% moderately poor and 26.8% and 35.9% categorized as vulnerable and non-poor respectively.(48) Patients in category 1, are exempt from premiums; category 2 and 3 pay a fixed 10% co-pay for health center and hospital visits.(15) Approximately 6% of the total population have civil servant health insurance also managed by Rwanda social society board (RSSB) and military medical insurance (MMI).(15) In addition, there are private health insurance schemes available for purchase, and funds that cover medical care for vulnerable groups, such as genocide victim funds (GVF). The out-of-pocket cost ranges between 0 and 18% of total health expenditure depending on type of insurance coverage.(15)

Despite the effort made to improve the health system in Rwanda, the increasing incidence of non-communicable diseases (NCDs), including kidney disease is increasing the socioeconomic burden. NCDs Disability-adjusted life years (DALYs) in Rwanda approximated 35% with less than 1.7% of the health budget spent on NCDs in 2016. Since 2021, a budget of USD 53.9 million was released by the national strategy for the prevention and control of NCDs in Rwanda.(16)

2.6.2. Kidney diseases in Rwanda

There are insufficient data on the prevalence of kidney diseases in Rwanda. Approximately ten percent of the Rwandan population had a positive urine albumin in 2012.(17) In-centre

hemodialysis is the predominant renal replacement therapy in Rwanda. There are very few patients currently on peritoneal dialysis with costs often exceeding that for HD and limited peritoneal dialysis infrastructure in the health system. Transplantation is not performed in Rwanda. Patients access transplantation through the Ministry of Health funded transplantation performed out of country or through out-of-pocket payments abroad.(17) Same as other specialized care centered in urban areas, dialysis centers are located in cities, particularly Kigali City; however, the majority of Rwandans live in rural areas.(11) Patients will have to travel long distances or move from their residence to live near dialysis units. RRT first became available at the university teaching and tertiary referral hospitals and expanded between 2007 and 2015. The annual cost of hemodialysis per patient ranges between Int$13,260 and Int$20,592. In addition to the cost and the distribution of in-centre hemodialysis, a shortage of specialized medical staff in kidney diseases limits the access to RRT.(17)(19) A retrospective study done by Bitunguhari et al. looking at the outcome of hemodialysis patients at CHUK between 2014 and 2017 found a mortality rate of approximately 47% within four months of initiation of dialysis.(49)

2.7. Quality of life measures

There is increasing recognition by the international community that there are dialysis dependent and non-dialysis dependent factors that impact patient experience and outcomes beyond dialysis adequacy.(41) Those factors include socioeconomic status, age, comorbidities, vascular access, dialysis session duration and adequacy, dialysis session frequency, and symptoms associated with dialysis such as muscle spasms, skin dryness and itching, changes in blood pressure, sleep disorders, pain, sexual dysfunction, anorexia, and feeling dependent on medical personnel.(50)(51)(52)(53)(54)(55)

2.7.1. Definition of quality of life

WHO defines quality of life as an individual's perception of his position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.(56) To assess patients status properly, their perception of QOL should be considered.(22) Health related quality of life is a multidisciplinary concept that describes how disease or its treatment affect physical, social and emotional status according to patient’s perspectives.(21)(22)

There are several measures of HRQOL designed to evaluate the impact of chronic diseases and their treatments on a patient.(21)(57) Health related quality of life depends on various

variables. It is known that the HRQOL is poor in patients with history of chronic non-communicable diseases.(58) Measuring HRQOL in chronic NDCs patients can help to identify valuable information on their health problem, to improve communication between patient-clinician and improve patient care.(21)

2.7.2. Kidney disease quality of life short form

The Kidney Disease Quality of Life (KDQOL) instrument was designed by RAND Health Care for patients with kidney diseases on dialysis or not.(59) It is a validated tool used in multiple studies and recommended by the National Kidney Foundation for assessing quality of life in adult patients with ESKD.(20)(60)

The KDQOL-36™ is a short form that includes 36 items distributed into four scales: SF-12 scale (12 items) which reflect physical and mental composite scales, burden of kidney disease scale BKD (4 items), symptoms/problems of kidney disease scale SPKD (12 items), and effects of kidney disease scale EKD (8 items).(59) Each item is scored from 0 to 100 representing the percentage of total possible score achieved. The higher score, the better the quality of life.(59) A higher score in the BKD domain reflects lower perceived burden of kidney disease.(45) (Appendix 2)

ESKD decreases the quality of life of affected patients.(20) Low score in dialysis patients is associated with high hospitalization rate and mortality.(22)

To promote high-quality services in renal dialysis facilities, routine measurement of HRQOL in dialysis patients using the KDQOL-36™ is now mandatory in the United States. Measurement should be done four months after initiation of dialysis and at least every year.(22)(61) Three months after starting dialysis are considered as a period of transition from AKI recovery, early mortality and registries. Symptoms associated with ESKD may resolve within three months after initiation of dialysis.(41)

In Africa, studies assessing the quality of life of patients with CKD are not many, even fewer have looked at dialysis patients. Thokozani Masina et al (23) found that the mean overall quality of life of 22 Malawians on maintenance hemodialysis was low, at 59.9%. In a study done in 2011 at Kenyata National Hospital, Nairobi, Kamau et al(24) revealed that HRQOL of patients on maintenance hemodialysis is poor, physical component lower than mental health. There were no specific significant risk factors of this poor quality of life.

CHAPTER III: METHODOLOGY

3.1. Study design

We conducted a multicenter cross-sectional study on all patients with end-stage kidney disease on in-centre hemodialysis in Rwanda between September 2020 and March 2021. We obtained ethical clearance from the Institutional Review Board (IRB) Nº 053/CMHS IRB/2020 (Appendix 1), as well as the hospital ethical committees. All study participants signed written informed consent prior to study enrollment. (Appendix 3)

3.2. Study setting

The study was conducted at all four in-centre hemodialysis units located in referral hospitals: CHUB, CHUK, RMH which are all within the public health system and King Faisal Hospital which is a public-private hospital. All four centers offer hemodialysis for acute kidney injury and CKD patients on daily basis. Butare University Teaching Hospital is built in the south province of Rwanda. It has a bed capacity of 500 with five beds in hemodialysis unit available since 2007. Kigali University Teaching Hospital is the biggest referral hospital in the country that receives the majority of patients referred from district hospitals, and is sited in the capital city, Kigali, Nyarugenge district. It has a capacity of 550 beds including five beds in hemodialysis unit and offers hemodialysis services since 2014. Rwanda military hospital, also located in Kigali, Kicukiro district, has a bed capacity of 500 and six hemodialysis beds with service offered beginning in 2017. King Faisal Hospital (KFH) is a semi private and first accredited hospital located in Kigali in Gasabo district, was the second hemodialysis unit in Rwanda, established in 2010 and has nine beds in hemodialysis center. We did not include African Health Network dialysis unit, a private clinic with three community hemodialysis unities located at Kimihurura (Kigali), Rubavu and Rusizi (Western province) offering dialysis to approximately 70 CKD patients with similar cost, insurance coverage and out of pocket expenses as in-centre hemodialysis.

3.3. Study population

We enrolled all patients with ESKD on in-centre maintenance hemodialysis for at least three months at four teaching hospital dialysis units. Three months following initiation of dialysis are considered as a transition period between AKI and CKD with high mortality and possible recovery from symptoms related to kidney failure.(41)

3.3.1. Inclusion criteria

- Patient with ESKD on maintenance hemodialysis at all in-centre hemodialysis unit in Rwanda for ≥3 months.
- Patients aged 18 years and above.
- Patients accepting to participate in the study.

3.3.2. Exclusion criteria

- Patients on hemodialysis for acute kidney injury.
- Patients hospitalized within the last four weeks
- Patients with neurological disability making them unable to respond to the questions.

3.3.3. Sample size

Given the relatively small number of patients on maintenance hemodialysis in Rwanda, we collected data on all eligible participants on in-centre maintenance hemodialysis between September 2020 and March 2021. In total, 89 patients from all four dialysis units were included.

3.4. Data collection and measures

HRQOL data were collected using the KDQOL36-Item Short Form questionnaire (appendix 2). Instructions and documentations on scoring were obtained from RAND Health Care.(59) Because of small number of participants at CHUK and CHUB, results from these two in-centre hemodialysis units were aggregated for analysis. To determine factors associated with HRQOL of hemodialysis patients, sociodemographic and clinical data were collected and all cutoffs were based on distribution of the data: age (<45 years, 45-60 years and >60 years), gender (female or male), marital status (married living together, never married and separated-widow), level of education (primary school or less, secondary school level and post-secondary school), and employment status (employed, retired and unemployed). Health insurance coverage was categorized into <100% coverage and 100% coverage, poverty index was collected based on ubudehe category. We also collected data on current district of residence of patients on hemodialysis. We collected all comorbidities associated with ESKD which were categorized into 0, 1, 2, and 3 comorbidities. We collected information on number of medications taken per day by the patient and was distributed into < 3 drugs, 3-4 drugs, >4 drugs based on the distribution of data, and if a patient has been hospitalized in the

last six months of HD (yes or no). Hemoglobin level (<10g/dl, 10-11g/dl, >11g/dl), albumin level (<35g/l, 35-40g/l, >40g/l) were taken from patients' files.

We collected data regarding hemodialysis: dialysis vintage categorized into <12 months, 13-24 months and >24 months, number of hemodialysis per week as thrice weekly or twice weekly hemodialysis; number of HD in the past 30 days categorized into ≤10 sessions and > 10 sessions, type of HD access which can be fistula or graft, semi-permanent catheter or temporary catheter. We did not collect data about small solutes clearance using Kt/V as it was not measured in most dialysis centers.

A questionnaire (Appendix 2) was administered to each participant during their regularly scheduled dialysis in person by one study investigator to ensure clarifying questions that can be asked by the participant. For patients not fluent in English, questions were translated by the study team into local language before administration. After obtaining informed consent, participants anonymously and privately completed the questionnaire in person or with help of an investigator. Approximately 10 minutes were required to a patient to fill the survey.

3.5. Data entry and analysis

3.5.1. Data entry

Responses on quality of life questionnaire were exported to excel scoring tool of KDQOL-36^{TM} which provided patients' score in five domains (PCS, MCS, BKD, EKD and SPKD). The overall KDQOL score was obtained from a programed KDQOL-36^{TM} survey.(62) All demographic and clinical information were collected on paper, entered into excel with independent double entry by two study investigators to minimize data entry errors.

3.5.2. Data analysis

Descriptive statistics were used to describe the study sample including demographic and clinical characteristics overall and by KDQOL. Mean and standard deviation (or median with inter-quartile range) were used as appropriate for continuous variables and frequency (and percentage) for categorical variables. As described earlier, the outcomes were overall KDQOL and the five domains of the KDQOL-36 ™ questionnaire (PCS, MCS and BKD, SPKD, and EKD) presented as a mean score and standard deviation. Visual presentation was used to show variations of score by overall KDQOL, by domain and by hemodialysis center. Mixed effects linear regression models were fitted to explore factors associated with overall KDQOL and its five domains, while accounting for clustering of patients within hemodialysis

centers. First, unadjusted (crude) models were fitted to assess the association between each independent variable (e.g., sex, age, vintage, and comorbidity) and overall KDQOL (and its five domains) to check which variables pass an initial screening at α set at 0.20 as model entry significance level. All potential factors associated with overall KDQOL (and its five domains) were retained for further exploration in multivariate (adjusted) models. Stepwise approach was used to select the most parsimonious models. Patients' sex and age were retained in all models regardless of their α. Parameter estimates are reported as ß coefficients along with their 95% confidence interval (CI) and p values. All analyses were conducted using R version 4.0.2.

3.6. Data security

All data were anonymous, stored in locked cabinets to be restricted to the study team. The electronically generated data were deidentified and files were password protected. The principal investigator was in charge of data security.

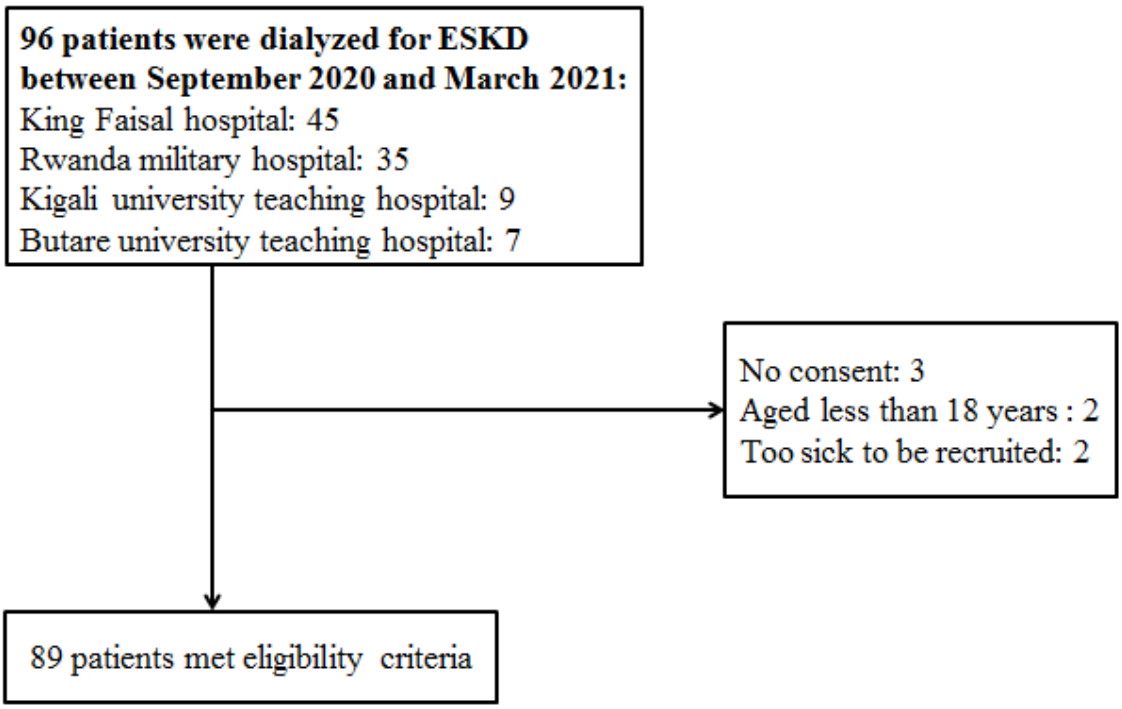
3.7. Conflict of interest

Study collaborators declare no conflicts of interest.

CHAPTER IV: RESULTS

4.1. Study participants selection

During the study period, 96 patients were on hemodialysis for ESKD at CHUK, CHUB, RMH, and KFH. A total of 89 patients met the inclusion criteria and participated in the study.



ESKD: End stage kidney disease

Figure 1. Patients selection flow

4.2. Demographic and clinical characteristics of study participants

Table 1. Demographic characteristics of study participants

Variable	Category	Sample n= 89	%
Sex	Female	30	33.7
	Male	59	66.3
Age	< 45 years	29	32.6
	45-60 years	33	37.1
	> 60 years	27	30.3
Education	Post-secondary	36	40.4
	Secondary school	26	29.2
	Primary or less	27	30.3
Marital status	Married/ living together	48	53.9
	Never married	23	25.8
	Separated or widowed	18	20.2
Ubudehe category	1	7	8.0
	2	18	20.5
	3	63	71.6
	4	0	0
Insurance coverage	<100% coverage	29	32.6
	100% coverage	60	67.4
Hemodialysis centers	CHUK-CHUB	14	15.7
	King Faisal Hospital	43	48.3
	Rwanda Military Hospital	32	36.0
Employment status	Employed	27	30.3
	Retired	12	13.5
	Unemployed	50	56.2

#Ubudehe category: economic life standing of households of Rwandan population

CHUK-CHUB: Kigali University Teaching Hospital and Butare University Teaching Hospital

Majority of participants were young. Only 30.3% were over 60 with male to female ratio of nearly 2:1. Almost half of participants were married (53.9%) and unemployed (56.2%). Approximately 70% had secondary school level or higher, 71.6% of patients were in the 3rd category of ubudehe and 67.4% were fully covered by medical insurance. Sixty-one

participants were living in Kigali and the majority of study participants on hemodialysis were receiving treatment at King Faisal Hospital.

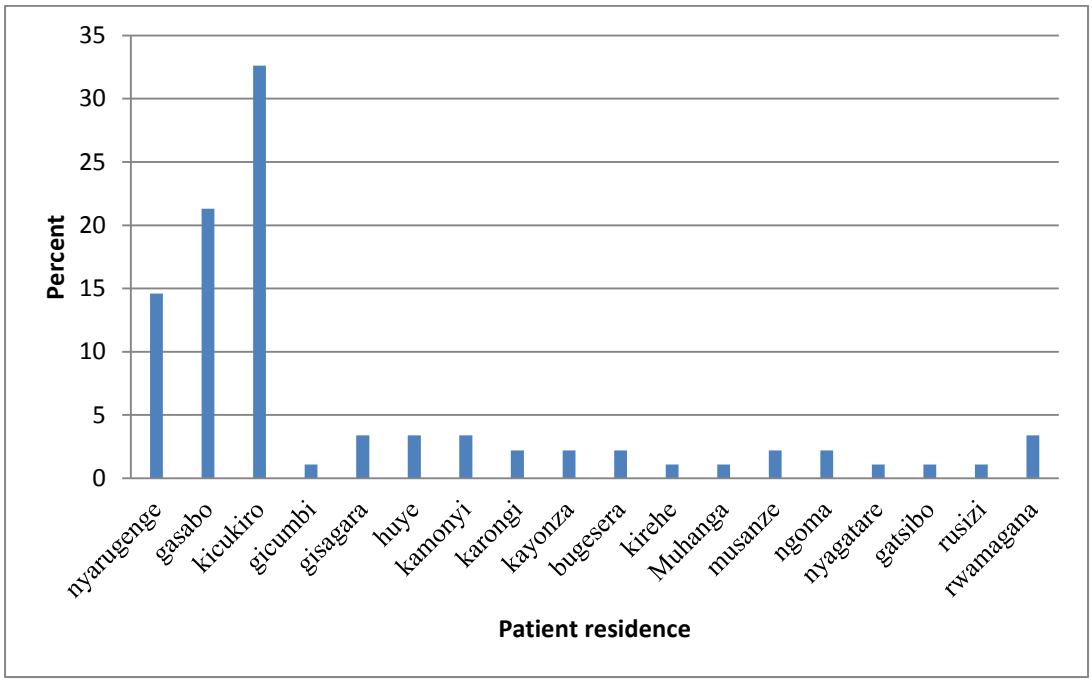


Figure 2. Distribution of participants residence by district

The majority of participants (61%) were living in Kigali districts (Nyarugenge, Gasabo and Kicukiro), where three in-centre hemodialysis are located.

Table 2. Clinical characteristics of study participants

Variable	Category	Population n=89	%
Number of comorbidities	0	8	9.0
	1	44	49.4
	2	28	31.5
	3	9	10.1
Number of medications	<3 drugs	18	20.2
	3-4 drugs	38	42.7
	>4 drugs	33	37.1
Hospitalized in the last 6 months (n=87)	No	40	46.0
	Yes	47	54.0
Albumin g/l	<35	21	23.6
	35-40	40	44.9

Variable	Category	Population n=89	%
Hemoglobin g/dl	>40	28	31.5
	<10	38	42.7
	10-11	24	27.0
	>11	27	30.3
Number of HD per week	2	17	19.1
	3	72	80.9
Number of HD in past 30 days	≤10 sessions	28	31.5
	>10 sessions	61	68.5
Hemodialysis access	Fistula/ graft	30	33.7
	Semi-permanent dialysis catheter	34	38.2
	Temporary dialysis catheter	25	28.1
Dialysis vintage	<12 months	36	40.4
	13-24 months	22	24.7
	>24 months	31	34.8

HD Hemodialysis

Almost all participants (91%) had comorbidities and 79.8% were taking > 3 medications per day. Half of participants had been hospitalized within the last six months. Most participants had normal or higher hemoglobin and serum albumin level. Regarding dialysis, more than half (59.5%) had been on hemodialysis for more than 12 months, 80.9% had thrice weekly hemodialysis and 33.7% had a fistula for hemodialysis access.

4.3. Health related quality of life data

4.3.1. Kidney disease quality of life score

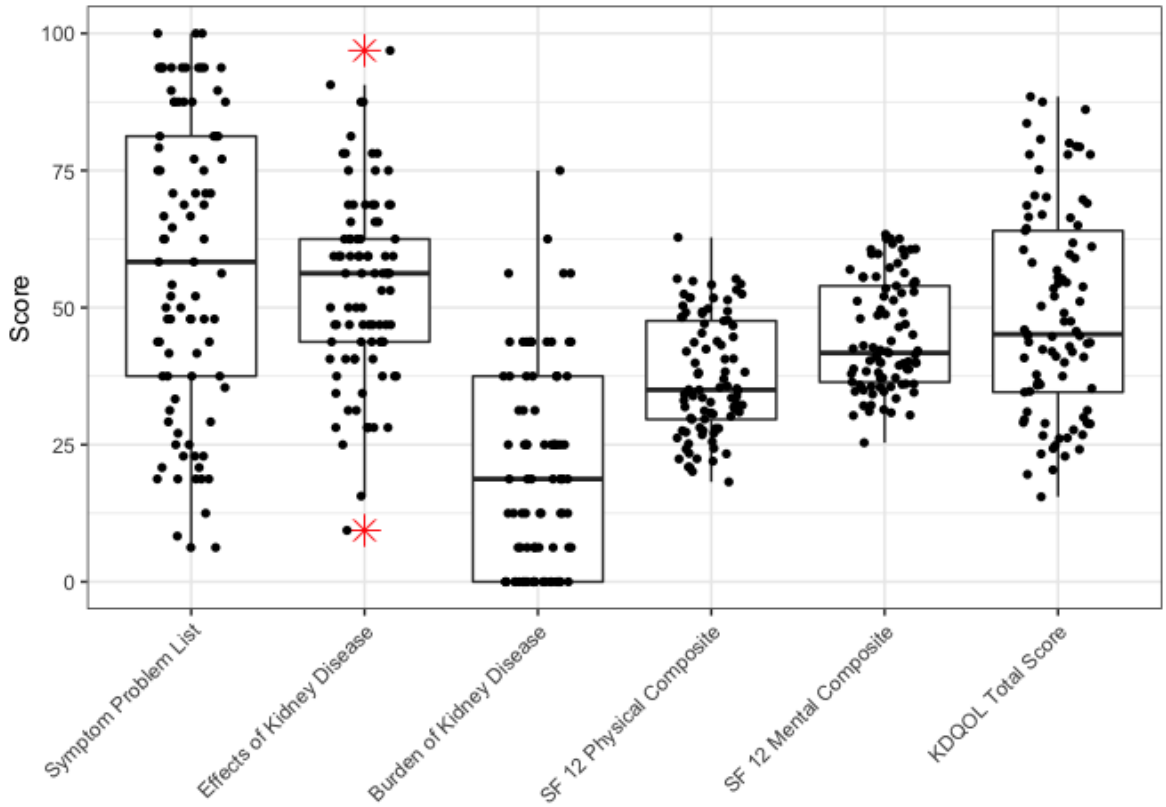


Figure 3. Distribution of HRQOL patients scores by KDQOL-36^{TM} domains

The overall mean ± SD quality of life score was 48.92 ±18.84.

Using the KDQOL-36 ^{TM} instrument, the mean physical composite summary score was 37.33 ± 10.66, the mental composite summary had a mean score of 44.74 ± 9.98 and symptoms and problems of kidney disease, effect of kidney disease, and burden of kidney disease had respectively a mean ±SD of 58.22 ± 27.44, 53.48 ± 17.14 and 20.01 ± 18.27. (Figure 3)

Among five subscales of KDQOL-36 ^{TM}, the burden of kidney disease had the lowest mean score of 20.01 ± 18.27. Questions related to BKD included questions regarding how kidney disease interferes with patient's life regarding time spent dealing with the disease, self-esteem and relationship between the patient and his family.

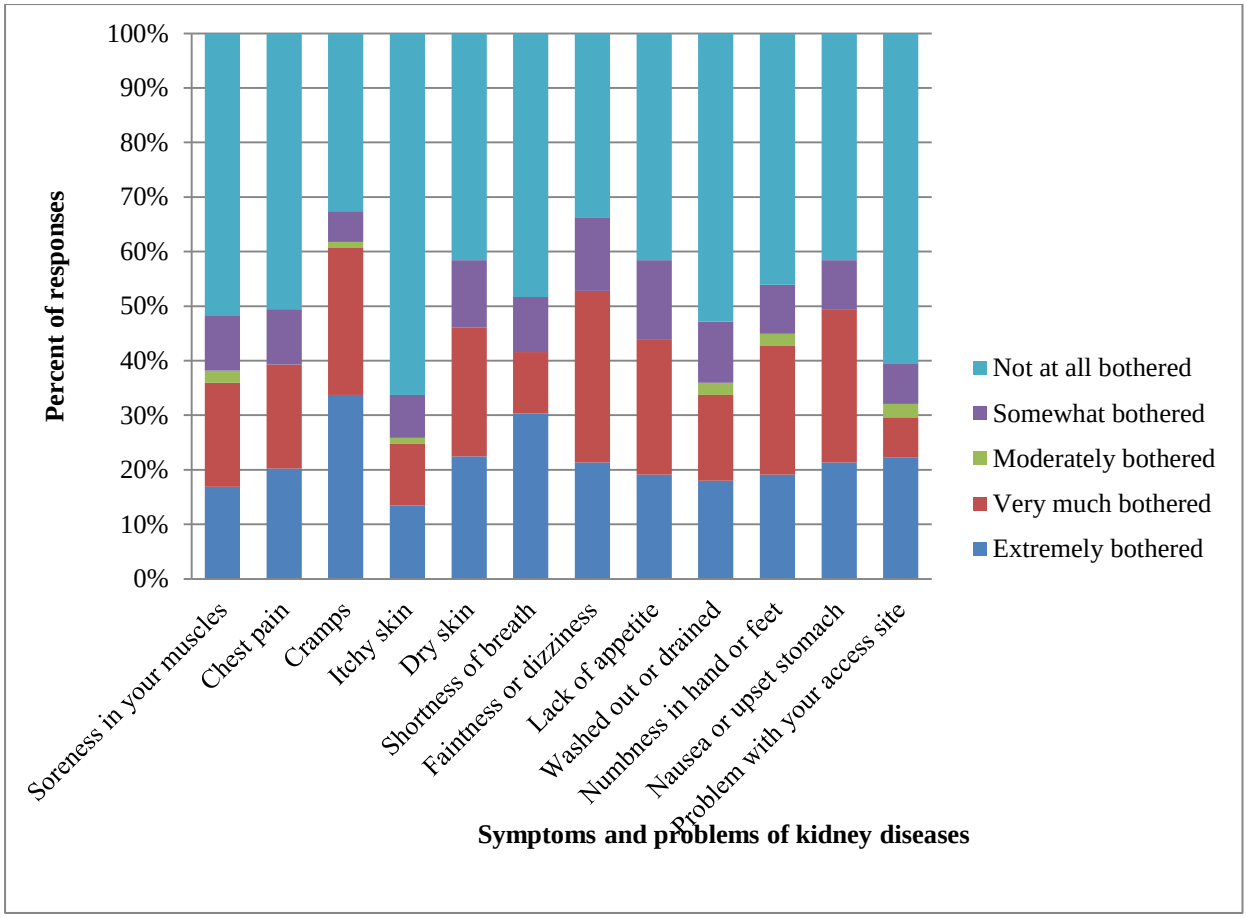


Figure 4. Symptoms and problems of kidney disease among patients treated with in-center hemodialysis at CHUB, CHUK, KFH, and RMH.

Symptoms and problem of kidney disease scale had the highest mean score of 58.22 ±27.44 The study question for all symptoms was: "During the past 4 weeks, to what extent were you bothered by each of them?" Possible responses were: "not at all bothered, somewhat bothered, moderately bothered, very much bothered, and extremely bothered". For all 12 items surveyed, the majority of patients responded "not at all bothered"; four items scored more than 50% (item 17, 18, 25, and 28). Less than 35% of patients indicated being "extremely bothered" by each of the 12 symptoms.

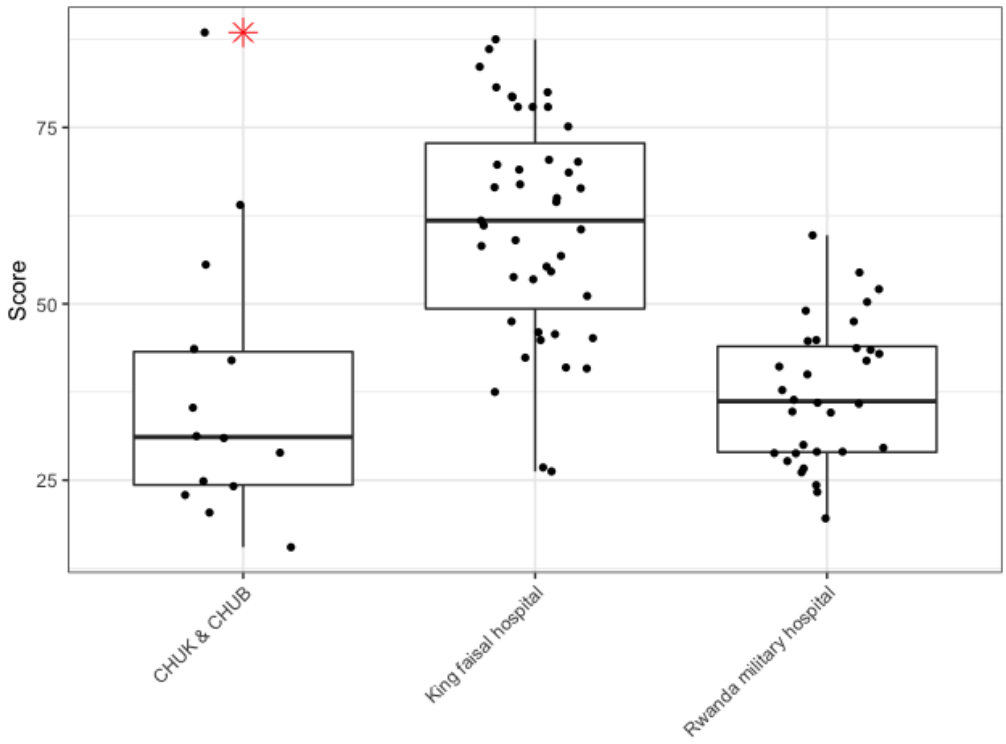


Figure 5. Distribution of HRQOL scores by hemodialysis center

King Faisal Hospital hemodialysis unit had the highest HRQOL mean in all domains with an overall quality of life mean (SD) score of 61.21 (15.71). Rwanda military hospital and Kigali-Butare teaching hospitals overall mean (SD) scores were 37.31 (10.02) and 37.70 (19.95) respectively. (Figure 5)

Comparison between hemodialysis centers showed significant difference of HRQOL scores between hemodialysis centers and the overall KDQOL score and its four domains; SPKD, BKD, PCS and MCS with P value <0.001. No significant difference of effect of kidney disease subscale between HD units observed.

4.3.2. Distributions of KDQOL by independent variables

Table 3. KDQOL-36^{TM} by sociodemographic and clinical characteristics (n=89)

	Symptom problem list Mean (SD)	Effects of kidney disease Mean (SD)	Burden of kidney disease Mean (SD)	SF12 Physical Composite Mean (SD)	SF12 Mental Composite Mean (SD)	KDQOL Total score Mean (SD)
Sex						
Female	57.08 (23.76)	49.38 (17.24)	16.67 (16.11)	33.91 (8.11)	45.80 (9.23)	46.68 (17.00)
Male	58.79 (29.31)	55.56 (16.85)	21.72 (19.19)	39.07 (11.42)	44.20 (10.37)	50.06 (19.75)
P value	**0.783**	**0.108**	**0.220**	**0.030**	**0.479**	**0.427**
Age						
<45 years	45.91 (26.71)	51.72 (17.94)	16.16 (19.08)	36.31 (9.79)	39.88 (7.68)	40.79 (14.85)
45-60 years	64.84 (26.81)	53.98 (16.50)	22.16 (18.29)	39.24 (10.59)	47.41 (9.84)	53.39 (17.67)
>60 years	63.35 (25.35)	54.75 (17.51)	21.53 (17.36)	36.09 (11.66)	46.71 (10.72)	52.19 (21.65)
P value	**0.011**	**0.791**	**0.386**	**0.435**	**0.005**	**0.016**
Education						
Primary school and less	61.96 (23.49)	50.35 (18.80)	19.91 (19.15)	38.65 (9.79)	44.37 (9.86)	50.81 (17.43)
Secondary school	57.06 (30.15)	57.81 (15.78)	23.61 (19.31)	37.67 (10.49)	45.66 (10.63)	49.93 (20.09)
Post-secondary	55.93 (27.94)	50.72 (16.50)	15.14 (15.12)	35.48 (11.86)	43.86 (9.45)	45.57 (18.72)
P value	**0.693**	**0.144**	**0.199**	**0.546**	**0.767**	**0.555**
Marital status						
Never married	52.63 (31.45)	53.12 (14.87)	20.11 (21.23)	38.31 (11.20)	43.45 (8.17)	45.78 (17.41)
Married/living together	61.55 (27.96)	53.19 (18.66)	22.01 (18.14)	38.57 (10.24)	45.83 (11.25)	51.94 (20.93)
Separated/widowed	56.48 (19.46)	54.69 (16.44)	14.58 (13.89)	32.76 (10.40)	43.49 (8.47)	44.87 (13.29)
P value	**0.425**	**0.946**	**0.343**	**0.125**	**0.542**	**0.261**
Employment						
Unemployed	55.92 (24.59)	48.88 (16.96)	15.12 (15.88)	34.62 (10.07)	42.65 (8.16)	44.79 (16.14)
Employed	58.56 (31.71)	61.23 (15.07)	26.16 (21.37)	40.49 (10.41)	45.76 (12.18)	52.92 (20.42)
Retired	67.01 (29.04)	55.21 (16.87)	26.56 (14.87)	41.51 (11.13)	51.16 (9.07)	57.12 (22.40)
P value	**0.457**	**0.008**	**0.015**	**0.022**	**0.022**	**0.051**

	Symptom problem list Mean (SD)	Effects of kidney disease Mean (SD)	Burden of kidney disease Mean (SD)	SF12 Physical Composite Mean (SD)	SF12 Mental Composite Mean (SD)	KDQOL Total score Mean (SD)
Ubudehe category						
1	46.13 (19.93)	50.00 (18.49)	9.82 (10.11)	31.66 (6.23)	44.09 (7.03)	39.18 (15.30)
2	57.87 (24.19)	53.65 (15.17)	19.79 (19.79)	32.17 (11.19)	42.21 (9.44)	43.22 (18.12)
3	60.48 (28.36)	53.37 (17.52)	20.93 (18.42)	39.17 (10.19)	45.50 (10.47)	51.58 (19.06)
P value	**0.41**	**0.877**	**0.316**	**0.015**	**0.47**	**0.093**
Health insurance coverage						
<100% coverage	51.65 (32.72)	54.96 (15.68)	20.04 (15.07)	37.98 (10.68)	44.70 (10.37)	47.30 (20.19)
100% coverage	61.39 (24.15)	52.76 (17.88)	20.00 (19.76)	37.01 (10.73)	44.77 (9.88)	49.70 (18.27)
P value	**0.117**	**0.574**	**0.992**	**0.69**	**0.975**	**0.576**
Number of HD per week						
Twice	63.11 (29.74)	63.05 (16.02)	23.90 (16.57)	40.42 (11.58)	47.09 (10.71)	55.19 (21.33)
Thrice	57.06 (26.96)	51.22 (16.71)	19.10 (18.64)	36.60 (10.38)	44.19 (9.80)	47.44 (18.04)
P value	**0.416**	**0.01**	**0.333**	**0.185**	**0.284**	**0.128**
Number of HD in the past 30 days						
≤ 10	60.04 (28.35)	59.71 (15.08)	21.21 (17.46)	37.82 (10.70)	45.02 (10.78)	51.04 (20.91)
>10	57.38 (27.21)	50.61 (17.38)	19.47 (18.75)	37.11 (10.72)	44.62 (9.68)	47.95 (17.90)
P value	**0.673**	**0.019**	**0.679**	**0.772**	**0.862**	**0.476**
Hospitalized in the last 6 months						
No	57.29 (31.80)	57.89 (18.70)	21.41 (18.56)	39.68 (11.19)	45.53 (10.24)	50.33 (20.41)
Yes	57.76 (23.34)	49.60 (15.26)	17.55 (17.27)	34.89 (9.66)	43.47 (9.52)	46.64 (17.00)
P value	**0.938**	**0.025**	**0.319**	**0.035**	**0.335**	**0.36**
Number of medications taking						
<3 drugs	69.68 (29.12)	58.16 (19.50)	23.61 (22.84)	42.05 (10.77)	47.19 (10.15)	53.82 (23.24)
3-4 drugs	58.28 (24.98)	52.47 (14.26)	16.45 (17.10)	36.24 (10.51)	43.17 (9.93)	48.35 (15.72)
>4 drugs	51.89 (27.99)	52.08 (18.84)	22.16 (16.62)	36.01 (10.36)	45.22 (9.93)	46.91 (19.62)
P value	**0.085**	**0.434**	**0.275**	**0.108**	**0.355**	**0.447**
Albumin						
<35 g/l	53.97 (23.66)	51.64 (15.89)	11.61 (17.49)	32.94 (10.45)	41.72 (9.52)	39.29 (17.04)
35-40 g/l	58.85 (28.46)	53.83 (17.64)	21.56 (18.72)	38.36 (10.36)	45.48 (10.18)	51.55 (19.67)
>40 g/l	60.49 (29.14)	54.35 (17.81)	24.11 (16.73)	39.15 (10.70)	45.96 (9.92)	52.39 (16.96)
P value	**0.703**	**0.85**	**0.045**	**0.092**	**0.281**	**0.025**
Hemoglobin						
<10 g/dl	52.52 (28.43)	51.32 (17.54)	16.78 (17.86)	36.64 (10.48)	42.32 (9.16)	44.86 (18.62)
10-11 g/dl	63.63 (25.72)	56.12 (19.54)	25.78 (20.71)	38.50 (9.67)	47.33 (11.35)	54.49 (19.24)
>11 g/dl	61.42 (26.97)	54.17 (14.32)	19.44 (15.82)	37.26 (11.99)	45.85 (9.36)	49.68 (18.08)
P value	**0.232**	**0.549**	**0.165**	**0.803**	**0.123**	**0.141**

	Symptom problem list Mean (SD)	Effects of kidney disease Mean (SD)	Burden of kidney disease Mean (SD)	SF12 Physical Composite Mean (SD)	SF12 Mental Composite Mean (SD)	KDQOL Total score Mean (SD)
Vintage						
≤12 months	45.08 (25.14)	53.21 (17.89)	16.15 (18.32)	34.76 (9.75)	40.31 (8.28)	41.09 (16.45)
13-24 months	72.16 (22.05)	58.10 (17.51)	26.14 (19.64)	38.36 (10.41)	50.41 (9.76)	56.63 (15.31)
>24 months	63.58 (27.40)	50.50 (15.77)	20.16 (16.51)	39.58 (11.52)	45.87 (9.85)	52.55 (20.75)
P value	**<0.001**	**0.284**	**0.13**	**0.16**	**<0.001**	**0.003**
HD access						
Fistula/graft	68.47 (29.24)	54.90 (19.86)	28.96 (18.09)	43.37 (10.65)	48.79 (10.76)	58.40 (19.77)
Semi-permanent dialysis catheter	49.02 (25.68)	52.02 (14.92)	15.44 (18.09)	33.24 (8.99)	41.69 (9.15)	41.81 (15.89)
Temporary dialysis catheter	58.42 (23.86)	53.75 (17.00)	15.50 (15.11)	35.64 (9.80)	44.04 (8.72)	47.22 (17.17)
P value	**0.016**	**0.799**	**0.004**	**<0.001**	**0.014**	**0.001**
Number of comorbidities $						
0	88.54 (11.19)	62.50 (19.76)	35.94 (13.67)	44.59 (7.75)	56.05 (4.09)	68.80 (13.32)
1	53.98 (29.56)	56.18 (18.01)	20.17 (19.20)	39.04 (10.46)	42.42 (9.42)	47.70 (17.53)
2	57.74 (22.70)	49.33 (11.26)	16.29 (17.12)	34.55 (10.17)	45.87 (10.13)	47.91 (19.05)
3	53.47 (26.25)	45.14 (21.37)	16.67 (14.99)	31.15 (11.02)	42.54 (9.51)	40.38 (19.58)
P value	**0.009**	**0.067**	**0.054**	**0.018**	**0.003**	**0.01**

$ Comorbidities include hypertension, heart failure, hepatitis B or C, cerebrovascular disease, HIV/AIDS and gout.
T-test or ANOVA were used to compare mean KDQOL within groups.
HD hemodialysis

KDQOL varied by independent variables (Table 3). Significantly higher mean quality of life scores were observed in patients 45-60 years (53.39±17.67), with a serum albumin level above 40g/dl (52.39±16.96), on hemodialysis for 13-24 months (56.63±15.31)), with a fistula for hemodialysis access (58.40±19.77) and without comorbidities (68.80±13.32).

4.4. Factors associated with health related quality of life

In adjusted model; sex, employment status, dialysis vintage, number of comorbidities, and hemoglobin level were significantly correlated with overall kidney disease quality of life. (Table 4)

Men had higher overall quality of life score than women (a ß: 8.54 95% CI: 2.77, 14.26), adjusting for age, dialysis vintage, employment status, comorbidities, albumin and hemoglobin levels. Being employed was statistically associated with higher overall quality of life than unemployed patients (a ß: 8.16 95% CI: 2.18, 14.29), adjusting for age, sex, vintage, comorbidities and albumin and hemoglobin levels. Patients with hemoglobin level of 10-11g/dl had higher overall KDQOL compared to those with hemoglobin less than 10g/dl (a ß: 7.27 95% CI: 0.70, 13.72), adjusting for age, sex, employment status, dialysis vintage, comorbidities and albumin level. Patients on hemodialysis for 13-24 months had higher overall mean quality of life than those on HD for 12 months or less (a ß: 10.47 95% CI:3.57, 17.58), adjusting for age, sex, employment status, comorbidities and albumin and hemoglobin levels. Patients with three comorbidities, on average, had overall KDQOL lower than those without comorbidities (ß: -29.97 95% CI: -41.47, -18.32), adjusting for age, sex, vintage, employment status and albumin and hemoglobin levels.

In adjusted model; sex, employment status, type of hemodialysis access and comorbidities were statistically significantly associated with physical composite summary domain. (Table 4)

Men had higher PCS score than women (a ß: 4.62; 95% CI: 1.02, 8.21), adjusting for age, employment status, type of hemodialysis access and number of comorbidities. Employed patients had higher mean PCS score than unemployed (a ß: 3.88; 95% CI: 0.39, 7.39), adjusting for age, sex, type of hemodialysis access and number of comorbidities. Patients having a semi-permanent catheter for hemodialysis access had lower PCS score than those using a fistula or graft (a ß: -6.11; 95% CI: -10.38, -1.94), adjusting for age, sex, employment status and comorbidities. Patients with three comorbidities, on average, had lower PCS than those without comorbidities (a ß: -9.06; 95% CI: -16.42, -1.84), adjusting for age, sex, vintage, employment status and type of hemodialysis access.

Employment status, dialysis vintage and number of comorbidities were significantly associated with mental composite summary domain in the adjusted model. (Table 4)

Employed (a ß: 5.76; 95% CI:2.09, 9.53) and retired patients (a ß: 8.18; 95% CI: 2.66, 13.86) had higher MSC scores than unemployed patients, adjusting for age, sex, vintage, and number of comorbidities. Dialysis vintage of 13-24 months (a ß: 9.10; 95% CI: 5.03, 13.46) and dialysis vintage above 24 months (a ß: 6.30; 95% CI: 2.54, 10.30) had higher MSC score than those on hemodialysis for 12 months or less, adjusting for age, sex, employment status and number of comorbidities. Patients with comorbidities, on average, had mean MCS score lower than those without comorbidities (eg. three comorbidities vs one a ß: -12.55; 95% CI: -19.97, -5.60), adjusting for age, sex, vintage, and employment status.

The burden of kidney disease subscale correlated significantly with employment status, type of hemodialysis access and number of comorbidities in the adjusted model. (Table 5) Being employed was associated with higher BKD score compared to unemployed patients (a ß: 10.29; 95% CI: 3.20, 17.49) adjusted for age and sex, employment status, type of hemodialysis access and number of comorbidities. Patients with temporary HD catheter had lower BKD score compared to those having a fistula (a ß: -10.71; 95% CI: -19.48, -2.32) adjusted for age, sex, employment status, and number of comorbidities.
Patients with one comorbidity or more had lower BKD score compared to those without comorbidity (a ß: -17.32; 95% CI: -29.95, -5.63) adjusted for age, sex, employment status, and hemodialysis access type.
In the adjusted model, number of hemodialysis in the past 30 days and number of comorbidities were significantly associated with the effect of kidney disease. (Table 5) Patients who underwent more than 10 sessions of hemodialysis in the past 30 days had lower KDQOL score in effect of kidney disease domain compared to those with less than 10 sessions in the past 30 days (a ß: -7.70; 95% CI: -14.81, -0.59), adjusting for age, sex, and number of comorbidities. Two or more comorbidities was associated with lower EKD score than those without comorbidities (a ß: -15.53; 95% CI: -27.99, -3.06), adjusting for age, sex, and number of HD sessions in past 30 days.
In the adjusted model, age, sex, dialysis vintage and number of comorbidities were significantly associated with symptoms and problems of kidney disease subscale. (Table 5) Male sex had higher score in SPKD than female (a ß: 11.98; 95% CI: 2.82, 21.18), adjusting for age, health insurance, dialysis vintage and number of comorbidities. Age above 60 years correlated with higher SPKD score (a ß: 13.611; 95% CI: 1.42, 26.29), adjusting for sex, health insurance, dialysis vintage and number of comorbidities. Dialysis vintage of 13-24 months correlated with higher SPKD score than those on hemodialysis for 12 months or less

(a ß: 16.28; 95% CI: 5.20, 27.82), adjusted for age, sex, health insurance, and number of comorbidities. Patients with three comorbidities had lower SPKD score than those without comorbidities (a ß: -33.27; 95% CI: -53.11, -14.20), adjusting for age, sex, and dialysis vintage.

Table 4. Factors associated with overall KDQOL, PCS and MCS

Independent variables (reference group)	Overall KDQOL				Physical.Composite Summary				Mental.Composite Summary			
	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value
Sex (Female)												
Male	6.57 (0.02, 13.04)	0.04	8.54 (2.77, 14.26)	0.008	6.84 (3.24, 10.41)	<0.001	4.62 (1.02, 8.21)	0.01	-0.45 (-4.39, 3.42)	0.81	0.61 (-2.86, 4.12)	0.74
Age (<45 years)												
45-60 years	3.35 (-4.32, 11.49)	0.40	6.23 (-0.37, 13.14)	0.09	-2.76 (-7.19, 1.91)	0.23	-1.32 (-5.40, 2.96)	0.55	4.04 (-0.37, 8.85)	0.08	3.83 (-0.17, 8.39)	0.08
>60 years	5.37 (-2.43, 13.47)	0.18	6.68 (-1.67, 15.17)	0.15	-3.92 (-8.42, 0.74)	0.09	-4.19 (-9.50, 1.20)	0.14	4.56 (0.05, 9.31)	0.05	1.09 (-3.86, 6.36)	0.68
Education (Primary school and less)												
Secondary school	2.38 (-6.06, 10.56)	0.56			0.75 (-4.16, 5.52)	0.75			2.58 (-2.24, 7.45)	0.24		
Post-secondary	2.17 (-5.33, 9.57)	0.57			0.62 (-3.76, 4.93)	0.77			2.70 (-1.81, 6.89)	0.27		
Marital status (Never married)												
Married/living together	3.59 (-3.63, 10.89)	0.33			-1.09 (-5.17, 3.01)	0.60			1.37 (-2.94, 5.75)	0.53		
Separated/widowed	-4.77 (-13.75, 4.31)	0.30			-7.61 (-12.67, -2.49)	0.004			-1.48 (-6.84, 3.96)	0.59		
Employment (Unemployed)												
Employed	5.99 (-0.85, 12.89)	0.09	8.16 (2.18, 14.29)	0.01	4.85 (0.92, 8.80)	0.01	3.88 (0.39, 7.39)	0.04	2.32 (-1.66, 6.34)	0.25	5.76 (2.09, 9.53)	0.005
Retired	6.93 (-2.32, 16.37)	0.14	4.23 (-5.01, 13.70)	0.41	4.18 (-1.12, 9.58)	0.12	5.68 (0.05, 11.40)	0.06	6.45 (1.07, 11.96)	0.02	8.18 (2.66, 13.86)	0.007
Ubudehe category (1)												
2	1.78 (-10.99, 14.66)	0.78			-0.75 (-7.75, 6.30)	0.83			-2.87 (-10.46, 4.80)	0.46		
3	6.84 (-4.62, 18.56)	0.25			4.41 (-1.87, 10.83)	0.17			-1.04 (-7.84, 5.96)	0.76		
Health insurance coverage (<100% coverage)												
100% coverage	4.77 (-1.84, 11.28)	0.15			0.34 (-3.55, 4.17)	0.86			1.08 (-2.86, 4.93)	0.58		
Number of HD per week (Twice)												
Thrice	-1.47 (-9.67, 6.46)	0.71			-0.48 (-5.26, 4.13)	0.83			-0.30 (-5.15, 4.35)	0.89		
Number of HD in the past 30 days (≤ 10)												
>10	-2.53 (-9.19, 4.09)	0.45			-0.39 (-4.27, 3.47)	0.84			-0.15 (-4.08, 3.74)	0.93		
Hospitalized in the last 6 months (No)												
Yes	-3.61 (-9.88, 2.63)	0.25			-4.68 (-8.22, -1.15)	0.01			-1.97 (-5.66, 1.68)	0.29		
Number of medications taking (<3 drugs)												
3-4 drugs	-2.32 (-10.76, 6.01)	0.58			-4.22 (-9.06, 0.54)	0.08			-2.75 (-7.67, 2.08)	0.27		
>4 drugs	-2.74 (-11.48, 5.80)	0.53			-3.72 (-8.74, 1.16)	0.14			-0.12 (-5.23, 4.83)	0.96		
Albumin (<35 g/l)												
35-40 g/l	8.36 (0.65, 16.27)	0.03	6.29 (-0.39, 13.17)	0.09	3.07 (-1.47, 7.76)	0.19			1.97 (-2.65, 6.77)	0.41		

Independent variables (reference group)	Overall KDQOL				Physical.Composite Summary				Mental.Composite Summary			
	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value
>40 g/l	8.86 (0.66, 17.27)	0.03	2.47 (-4.92, 10.01)	0.54	3.76 (-1.07, 8.75)	0.13			2.36 (-2.55, 7.46)	0.35		
Hemoglobin (<10 g/dl)												
10-11 g/dl	9.44 (2.03, 16.82)	0.01	7.27 (0.70, 13.72)	0.04	1.84 (-2.59, 6.26)	0.41			5.05 (0.66, 9.40)	0.02		
>11 g/dl	2.39 (-4.75, 9.59)	0.51	2.09 (-3.94, 8.13)	0.53	-0.59 (-4.89, 3.71)	0.78			2.65 (-1.58, 6.91)	0.22		
Vintage (≤12 months)												
13-24 months	8.65 (0.83, 16.80)	0.03	10.47 (3.57, 17.58)	0.008	-0.44 (-5.09, 4.40)	0.85			7.48 (3.04, 12.19)	0.001	9.10 (5.03, 13.46)	<0.001
>24 months	5.70 (-1.36, 13.03)	0.12	9.71 (3.33, 16.30)	0.007	1.52 (-2.68, 5.87)	0.48			3.40 (-0.6, 7.63)	0.107	6.30 (2.54, 10.30)	0.003
HD access (Fistula/graft)												
Semi-permanent dialysis catheter	-8.44 (-16.35, -0.89)	0.03			-6.20 (-10.69, -1.90)	0.006	-6.11 (-10.38, -1.94)	0.008	-3.88 (-8.62, 0.57)	0.09		
Temporary dialysis catheter	-6.75 (-14.71, 1.01)	0.09			-5.59 (-10.12, -1.17)	0.01	-5.30 (-9.51, -1.16)	0.02	-3.00 (-7.75, 1.59)	0.21		
Number of comorbidities (0) [$]												
1	-11.40 (-22.62, -0.52)	0.04	-15.31 (-25.17, -5.76)	0.005	-0.12 (-6.52, 6.08)	0.96	-3.28 (-9.11, 2.40)	0.29	-10.04 (-16.60, -3.74)	0.003	-9.55 (15.58, -3.82)	0.003
2	-11.14 (-22.79, 0.13)	0.06	-13.20 (-23.30, -3.46)	0.01	-4.55 (-11.20, 1.88)	0.17	-3.36 (-9.64, 2.72)	0.31	-6.51 (-13.33, 0.021)	0.059	-6.51 (-12.96, -0.57)	0.04
3	-21.49 (35.22, -8.03)	0.002	-29.97 (-41.47, -18.32)	<0.001	-9.49 (-17.33, -1.81)	0.01	-9.06 (-16.42, -1.84)	0.02	-10.81 (-18.84, -3.012)	0.009	-12.55 (-19.97, -5.60)	0.001

*Adjusted for clustering of patients within hemodialysis centers.

[$] Comorbidities include hypertension, heart failure, hepatitis B or C, cerebrovascular disease, HIV/AIDS and gout

Table 5. Factors associated with BKD, EKD and SPKD domains

Independent variables (ce) group)	Burden of kidney disease				Effects of kidney disease				Symptom problem of kidney disease			
	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value
Sex (Female)												
Male	7.17 (-0.11, 14.32)	0.05	2.95 (-4.49, 10.29)	0.46	6.51 (-1.27, 13.78)	0.09	6.84 (-0.35, 14.03)	0.07	5.51 (-4.75, 15.66)	0.29	11.98 (2.82, 21.18)	0.01
Age (<45 years)												
45-60 years	-0.71 (-9.23, 8.55)	0.87	1.16 (-7.12, 10.49)	0.80	2.25 (-6.31, 10.82)	0.61	7.24 (-0.98, 15.47)	0.10	7.30 (-4.46, 19.91)	0.23	11.49 (0.50, 23.35)	0.05
>60 years	0.99 (-7.68, 10.15)	0.82	-1.70 (-12.81, 9.70)	0.78	3.02 (-5.98, 12.02)	0.51	9.09 (-0.42, 18.61)	0.07	9.87 (-2.10, 22.39)	0.11	13.611 (1.42, 26.29)	0.04
Education (Primary school and less)												
Secondary school	0.11 (-9.22, 9.02)	0.98			0.51 (-8.69, 9.44)	0.91			3.75 (-9.30, 16.34)	0.87		
Post-secondary	5.68 (-2.58, 13.77)	0.17			7.51 (-0.93, 15.87)	0.08			-0.94 (-12.55, 10.45)	0.56		
Marital status (Never married)												
Married/living together	0.17 (-7.86, 8.32)	0.96			0.04 (-8.49, 8.62)	0.99			5.81 (-5.53, 17.27)	0.32		
Separated/widowed	-8.12 (-18.10, 2.02)	0.11			1.52 (-9.05, 12.18)	0.78			-0.87 (-14.96, 13.41)	0.90		
Employment (Unemployed)												
Employed	9.78 (2.34, 17.31)	0.01	10.29 (3.20, 17.49)	0.009	12.35 (4.72, 19.98)	0.002			-0.12 (10.91, 10.76)	0.98		
Retired		0.12	10.57 (-0.96,	0.10	6.33 (-3.93,	0.23			4.01 (-10.56,	0.59		
8.12 (-1.92, 18.43)			22.57)		16.60)				18.91)			
Ubudehe category (1)												
2	8.34 (-5.78, 22.63)	0.25			3.51 (-11.22, 18.52)	0.64			8.71 (-11.00, 28.62)	0.39		
3	7.09 (-5.54, 20.15)	0.28			3.06 (-9.93, 16.67)	0.65			6.89 (-10.77, 25.05)	0.45		
Health insurance coverage (<100% coverage)												
100% coverage	1.60 (-5.85, 8.88)	0.66			-2.18 (-9.81, 5.42)	0.57			13.03 (3.06, 22.81)	0.01	9.57 (0.01, 18.74)	0.05
Number of HD per week (Twice)												
Thrice	-0.56 (-9.74, 8.20)	0.90			-11.83 (-20.59, -3.07)	0.009			2.21 (-10.46, 14.46)	0.72		
Number of HD in the past 30 days (≤ 10)												
>10	-1.34 (-8.75, 6.02)	0.72			-9.08 (-16.56, -1.62)	0.01	-7.70 (-14.81, -0.59)	0.04	-1.91 (-12.22, 8.34)	0.71		
Hospitalized in the last 6 months (No)												
Yes	-3.73 (-10.62, 3.11)	0.28			-8.30 (-15.42, -1.15)	0.025			0.75 (-9.08, 10.53)	0.87		

Independent variables (reference group)	Burden of kidney disease				Effects of kidney disease				Symptom problem of kidney disease			
	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value	Crude ß coefficient (95% CI)	P value	Adjusted ß coefficient (95% CI)	P value
Number of medications taking (<3 drugs)												
3-4 drugs	-5.10 (-14.33, 3.96)	0.27			-5.69 (-15.26, 3.87)	0.25			-7.48 (-20.31, 5.16)	0.25		
>4 drugs	1.64 (-7.95, 10.92)	0.73			-6.07 (-15.87, 3.72)	0.23			-12.43 (-25.73, 0.52)	0.06		
Albumin (<35 g/l)												
35-40 g/l	7.24 (-1.29, 16.14)	0.10			2.19 (-6.89,11.27)	0.64			-1.02 (-13.24, 11.61)	0.87		
>40 g/l	9.62 (0.51, 19.08)	0.04			2.71 (-7.01, 12.44)	0.58			0.36 (-12.65, 13.77)	0.95		
Hemoglobin (<10 g/dl)												
10-11 g/dl	9.03 (0.74, 17.25)	0.03			4.80 (-3.93, 13.54)	0.28			11.12 (-0.50, 22.68)	0.06		
>11 g/dl	1.17 (-6.81, 9.21)	0.77			2.84 (-5.58, 11.29)	0.51			6.05 (-5.16, 17.34)	0.29		
Vintage (≤12 months)												
13-24 months	5.10 (-3.66, 14.44)	0.26			4.82 (-4.16, 13.88)	0.30			18.70 (6.97, 31.03)	0.002	16.28 (5.20, 27.82)	0.008
>24 months	-0.01 (-7.95, 8.35)	0.99			-2.76 (-10.89, 5.44)	0.51			11.61 (1.001, 22.68)	0.03	9.74 (-0.35, 20.31)	0.07
HD access (Fistula/graft)												
Semiparmanent dialysis catheter	-8.59 (-17.38, -0.37)	0.04	-8.01 (-16.95, 0.51)	0.09	-2.87 (-11.30, 5.64)	0.50			-8.89 (-21.34, 2.92)	0.15		
Temporary dialysis catheter	-10.78 (-19.59, -2.28)	0.01	-10.71 (-19.48, -2.32)	0.02	-1.14 (-10.26, 7.97)	0.80			-4.32 (-16.83, 7.84)	0.49		
Number of comorbidities (0)$												
1	-9.66 (-22.58, 2.62)	0.13	-17.32 (-29.95, -5.63)	0.009	-6.32 (-18.76, 6.12)	0.32	-5.89 (-18.13, 6.34)	0.36	-22.96 (-40.51, -6.03)	0.01	-19.93 (-36.47, -4.05)	0.02
2	-13.45 (-26.87, -0.69)	0.04	-14.96 (-28.29, -2.676)	0.03	-13.17 (-26.14, -0.18)	0.05	-15.53 (-27.99, -3.06)	0.02	-19.00 (-37.23, -1.43)	0.04	-19.16 (-36.56, -2.71)	0.03
3	-14.78 (-30.54, 0.46)	0.06	-17.62 (-33.01, -2.97)	0.03	-17.36 (-33.09 - 1.62)	0.03	-19.66 (-34.92, -4.41)	0.01	-26.47 (-47.96, -5.51)	0.01	-33.27 (-53.11, -14.20)	0.001

*Adjusted for clustering of patients within hemodialysis centers.

$ Comorbidities include hypertension, heart failure, hepatitis B or C, cerebrovascular disease, HIV/AIDS and gout

CHAPTER V: DISCUSSION

In this study, we aimed to describe HRQOL of patients undergoing in-centre maintenance hemodialysis in Rwanda using the KDQOL™-36 and determine associated sociodemographic and clinical characteristics. Eighty-nine patients from all in-centre hemodialysis units at the four referral hospitals (CHUK, CHUB, KFH and RMH) were included.

We found reduced overall quality of life mean score (48.92 ±18.84) and reduced PCS, MCS, burden of kidney disease composite, effect of kidney disease composite and symptoms and problems of kidney disease composite scores. These mean scores are similar to Kamua et al's findings (24). Our results are lower compared to studies from middle and higher income countries that have used the same KDQOL-36™ tool (Table 6). (63)(45)(64)

Other studies from SSA, showed reduced QOL of dialyzed patients, though they used the KDQOL-SF 1.3 version. T. Masina et al in Malawi (23) and Bagasha et al in Uganda (65) found an overall HRQOL score of 59.9 (±8.8) and 41.71 (±4.42) respectively.

Table 6 Health related quality of life of patients treated with hemodialysis from different studies using the KDQOL-36™

	Country				
	Rwanda #	**Kenya(24)**	**Saudi Arabia**(64)	**USA**(63)	**USA**(45)
PCS	37.33	39.09	37.4	38	36.6
MCS	44.74	41.87	43.5	51.8	49.0
BKD	20.01	16.15	31.5	53.2	51.3
EKD	53.48	67.63	56.5	76.6	78.1
SPKD	58.22	73.46	74	80.7	73.0

PCS physical component summary, **MCS** mental component summary, **BKD** burden of kidney disease component summary, **EKD** effect of kidney disease component summary, **SPKD** symptoms and problem of kidney disease component summary **USA** United States of America #present study

In this study, the BKD domain had a lower score (20.01±18.27). This low score reflects the impact of kidney disease on patient's daily activities, and their relationship with others. Symptoms and problem of kidney disease domain had relatively higher mean score of 58.22±27.44. However, a SPKD score less than 70 generally reflects a high symptom burden.(45) Similar findings of low scores in the burden of kidney disease sub-scale and

relatively higher score in the symptoms and problem of kidney disease sub-scale have been noted in studies conducted Africa.(23)(24)(65)

We found that 61% of participants were living in Kigali's districts where three of four studied hemodialysis units are located therefore patients and their family have to travel long distances or move to near dialysis centers. Our results showed higher overall KDQOL score and all five domains scores in patients on in-centre maintenance hemodialysis at King Faisal Hospital and lower scores at CHUK-CHUB in-centre hemodialysis unit. This discrepancy might be related to patient's choice due to the fact that KFH is the most accredited hospital of the country, was the first to have HD unit in Kigali with more HD beds than other centers, specialized medical staff, sufficient human resources and materials. In addition, the national referral board office that transfers patients for kidney transplantation is located at KFH and there is a possibility to access HD using health insurance coverage as in other in-centre dialysis units. The majority of patients managed at CHUK and CHUB are referred from rural areas with lesser socioeconomic status makes their dialysis unit less frequented for chronic maintenance HD.

The majority of our study sample (69.7%) was 60 years old or less. Similar studies from LMIC found that dialysis patients were young. The mean or median age is 44 years ±13.98 in Kenya, 45.9 years in Uganda, 44.8 years ± 16.0 years in Malawi, 51.66 years ±14.02 years in Tunisia, 55.75 years ±10.25 in India years, and 57.1 years ±11.9 in Singapore.(24)(65)(23)(66)(67)(54) In contrast, the Dialysis Outcomes and Practice Patterns Study (DOPPS), an international cohort study from mainly developed countries, found an overall higher mean age of 62 ± 14 years.(51) This difference of age may be explained by the pattern of causes and risk factors of kidney disease by region, the lack of strategies of prevention and management of communicable and non-communicable diseases and the poor socioeconomic status that make NCDs including kidney diseases more prevalent in young population of resource limited countries.(43)(17) In addition, dialyzed patients from countries with access to transplantation are relatively older.(43) Age is associated with HRQOL depending on patients perception and believe.(68) Our results showed a significant association between age above 60 years and higher symptoms and problem of kidney disease score (ß: 13.611; 95% CI: 1.42, 26.29).

Male sex was the most predominant at 66.3%. The majority of studies from both developing and developed countries found a male sex predominance in patients on in-centre hemodialysis: 59% in DOPPS(51), 60.2% in Uganda(65), and 59.1% in Malawi(23). Male to

female ratio were 1.91:1 and 1.73:1 in Kenya and Tunisia respectively.(24)(67) There is no clear explanation on the exact cause of lower proportion of females with ESKD on hemodialysis but same in Rwanda, women are responsible of numerous domestic tasks that they cannot overcome and at increased risk of depression and negative perception of ESKD which lead them to choose palliative care instead of dialysis in fear of being a burden to their families.(68)

The socioeconomic status is an important predictor of QOL.(50) Among our study participants, 53.9% were married living together with the partner, 68.5% were living in urban area and 70.7% had secondary school level or post-secondary. Despite that a small proportion of Rwandan population is categorized in ubudehe category three or above based on the economic life standing of households (14), 71.6% of our study sample were classified in third category. All participants had health insurance coverage, with 67.4% covered at 100%. These findings reflect the financial constraints and the social impact to access and maintain RRT in resource limited settings. The majority of patients on hemodialysis have higher socioeconomic status as it is described in other African publications.(23)(24)(65)(68)(17)

Our results showed that the overall HRQOL of patients on in-centre maintenance hemodialysis was significantly associated with sex, employment status, dialysis vintage, number of comorbidities, and hemoglobin level. Being employed was associated with higher physical (p value =0.04), and mental (p=0.005) functioning, and less burden of kidney disease (p=0.009). Having a health insurance that covers all medical care was associated with high symptoms and problem of kidney disease score (p value=0.05). T Masina et al (23) in Malawi, showed that low yearly total household income was associated with lower MCS scores, and no other demographic factors were significantly associated with HRQOL. The poor correlation between the sociodemographic factors and the HRQOL score was also found by Kamau et al (24) in Kenya. These findings may be linked to small sample size of studied population. Other studies showed a correlation statistically significant between sociodemographic factors including age, gender, employment, socioeconomic status, education level and HRQOL scores.(67)(54)(50) L. Zouari et al (67) in Tunisia showed that age of 60 years and above, a low economic status and living in rural area were associated with poor quality of life

More than a half of our study participants (59.5%) have been on hemodialysis for more than 12 months. Higher qol score was seen in patients on dialysis for 13 to 24 months in MCS ($p<0.001$) and SPKD (p=0.008) domains. Dialysis vintage above 24 months was significantly

associated with high SPKD (crude ß:11.61 95%CI: 1.001, 2.98), higher overall KDQOL (adjusted ß: 9.71 95%CI: 3.33, 16.30) and high MCS score (adjusted ß: 6.30 95%CI: 2.54, 10.30). Alqahtani et al. (64) in Saudi Arabia, found a mean dialysis vintage of 52 months ± 50 with a weak negative correlation between overall quality of life score and increasing dialysis vintage. In contrast, F. Yang et al (54) in Singapore showed that long dialysis vintage more than 3.5 years was significantly associated with high MCS; the suggested explanation was the cognitive adaptation of patients dialyzed for a long period. Sesso et al (50) in Brazil who showed that after a mean of 8 months on dialysis, the physical and mental health improve over time.

The mean dialysis vintage was 49.06 months in Tunisia, 12 months in Malawi. None of the two publications showed significant association between dialysis vintage and HRQOL.(67)(23)

Patients who had an arterio-venous fistulae had higher scores in all HRQOL domains compared to those using semi-permanent or temporary hemodialysis catheter. Results showed significant positive effect of fistula or graft on physical functioning (P=0.008) and BKD scale (p=0.04). Domenick Sridharan et al (53) showed a higher HRQOL in patients having an arteriovenous fistula compared to tunneled catheters and grafts. Whereas Ajeebi A et al (69) in Saudi Arabia showed a non-significant correlation between the PCS and HD access (p=0.07) with 48.8%, 47.6% of patients having permanent catheter and arterio- venous fistula respectively.

Normal hemoglobin improves the HRQOL of CKD patients.(22)(70) Underweight (BMI <18.5 kg/m2) and lower serum albumin are markers of high mortality and poor QOL in of CKD patients on maintenance hemodialysis.(71) In the current study, patients with serum albumin level of >40g/l had higher quality of life score. We did not find statistically significant correlation of quality of life domains with serum albumin level in adjusted model. Our results show significant positive correlation between hemoglobin level of 10-11g/dl and overall KDQOL (a ß7.27 95% CI (0.70, 13.72) and burden of kidney disease with ß: 9.03 (95% CI: 0.74, 17.25). Kamau et al (24) in Kenya did not find significant association between HRQOL and hemoglobin or albumin level. F Yang et al (54) in Singapore showed an association between high albumin and hemoglobin level with high PCS. Murali R et al (66) in India found a significant positive correlation of normal hemoglobin and the HRQOL. L Zouari et al (67) in Tunisia showed a significant association between poor QOL and anemia. Registered dietitian nutritionist should intervene to improve the nutrition status of dialyzed patients and reduce adverse clinical outcome.(71)

Eighty percent of study participants had thrice weekly hemodialysis sessions. This adherence to standard recommended practice on dialysis frequency (72) may be explained by the 100% insurance coverage of the majority of our study population. In contrast to other regional studies where patients prefer twice weekly dialysis to reduce expenditures such as transport, accommodation as shown by Bagasha et al. in Uganda (65) and Masina et al in Malawi (23). Our results showed higher scores in patients on twice weekly compared to thrice weekly hemodialysis in all domains, and statistically significant in EKD domain (p value=0.01). We identified a negative correlation between thrice weekly hemodialysis (a crude ß: -11.83, 95% CI: -20.59, -3.07) and more than ten hemodialysis in past 30 days (adjusted ß:-7.70 95% CI (-14.81, -0.59)) and the effect of kidney disease domain. The reason why thrice weekly hemodialysis or more than ten HD per month would negatively correlate with the effect of kidney disease in our study sample is not clear but it might be due to small studied sample, long period spent on hemodialysis, frequent travel and limited employment opportunities. Bagasha et al (65) found the association between insufficiency dialysis frequency and reduction of quality of life mainly for symptom burden and physical health subscale.

In this study, the number of comorbidities was in direct proportion with worse quality of life score, affecting all HRQOL domains. The number of comorbidities goes with the number of medications making affected patients' QOL poor.(73) It has been reported that type 2 diabetes itself reduces the HRQOL.(74) Diabetes is the main and common cause of ESKD found in many studies from LMIC and developed countries to be associated significantly or not with HRQOL.(24)(65) (66)(67)(69)(63) Jieun Cha et al (52) in Korea demonstrated a significant poor HRQOL associated with the high number of comorbidities ($p < 0.001$).

Study strengths

This is the first study evaluating the HRQOL of dialysis patients realized in Rwanda. The use of KDQOL-36™, an internationally validated tool added credibility to our findings and facilitated the comparison with other studies from different settings.

The KDQOL-36™ tool is relatively short in comparison to other QOL tools which makes it slightly easier to administer and answer to avoid participant disengagement in the process.(59)

This study was conducted on all eligible patients of the in-centre hemodialysis units of Rwanda which makes our results representative of in-centre hemodialysis patients.

We were able to identify significant association between socioeconomic and clinical characteristics and HRQOL scores.

Study limitations

KDQOL-36^{TM} instrument is not validated in Rwandan context, and there is no validated translation form of KDQOL-36^{TM} survey into the local language (Kinyarwanda) therefore there might be misinterpretations in the translated questionnaire.

Being a cross-sectional study makes difficult the determination of causes of low HRQOL found. Only associated factors could be determined.

It is difficult to reduce confounding in observational data, especially with a small sample size. Our analysis did not thoroughly explore some metrics that clinicians frequently report as barriers to care and to QOL such as financial constraints (out of pocket costs or yearly income) and travel to HD units.

Our study included patients on in-centre maintenance hemodialysis we did not include community dialysis units.

CHAPTER VI: CONCLUSION AND RECOMMANDATIONS

6.1. Conclusion

Patients on in-centre hemodialysis in Rwanda have a significantly low HRQOL scores compared to those reported by other settings. The lowest score was found on burden of kidney disease and physical composite summary domains. There is a notable difference of HRQOL scores between hemodialysis units. Factors associated with overall HRQOL found were sex, employment status, number of comorbidities, dialysis vintage, and hemoglobin level.

6.2. Recommendations

Awareness of health professionals about the importance of routine assessment of HRQOL on all ESKD patients on dialysis might help to properly assess patients' status and engage them in improving their management.

Optimizing medical and biomedical management of dialysis patients by physicians, nurses, physiotherapist, nutritionist, and psychologist in parallel with social and spiritual support may help to improve their HRQOL because patients with more comorbidities had lower QOL.

Finding ways to make dialysis less obstructive to maintain employment; eg by providing options to dialyze in the evening as opposed to during the working hours so patients are able to remain employed may improve their HRQOL.

Further research questions regarding patients with ESKD in both in-centre publicly funded units as well as community based private clinics are recommended. These include comparison between using internationally accepted measures of dialysis adequacy (Kt/V) and QOL measures which are cheap and easy to administer could be used as proxies for HD adequacy in low income countries.

Validation of the KDQOL survey instrument in Rwandan context to ensure outcomes of the survey are reliable and could help clinical decision making routinely.

Utilize a different validated poverty index to further evaluate the impact of poverty on quality of life.

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APPENDIX 1: Institutional review board (IRB) approval

UNIVERSITY of RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

DIRECTORATE OF RESEARCH & INNOVATION

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 18th/March/2020

Dr SHUMBUSHO Gloria
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 053/CMHS IRB/2020

Your Project Title ***"Assessment of Health Related Quality Of Life of Patients On Maintenance Hemodialysis In Referral Hospitals, Rwanda"*** has been evaluated by CMHS Institutional Review Board.

		Involved in the decision		
		Yes	No (Reason)	
Name of Members	**Institute**		**Absent**	**Withdrawn from the proceeding**
Prof Kato J. Njunwa	UR-CMHS		X	
Prof Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS	X		
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS		X	
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 12th March 2020, **Approval has been granted to your study**.

Please note that approval of the protocol and consent form is valid for **12 months**.

Email: researchcenter@ur.ac.rw P.O Box 3286 Kigali, Rwanda www.ur.ac.rw

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 18th March 2020

Expiration date: The 18th March 2021

Professor GAHUTU Jean Bosco
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:
- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR

APPENDIX 2: Study questionnaire

1. Name initial:
2. Study number:
3. Date of birth/ Age:
4. Gender:
5. Residence: District:
6. Marital status: Never married○ Married/living together○ Divorced/separated/widowed○
7. Ubudehe category: I II III IV
8. Employment status: Unemployed○ Employed with monthly income○ Daily based payment○ Retired○
9. Annual household income (Rwandan francs):
10. Level of education: No education○ Primary school○ secondary school○ Post-secondary○
11. Health Insurance: Yes○ No○ If yes, specify the insurance:
12. Comorbidities:
    a. Diabetes○
    b. Hypertension○
    c. Coronary artery disease○
    d. Cerebrovascular disease○
    e. Congestive heart failure○
    f. Lung disease○
    g. Neurological diseases○
    h. peripheral vascular diseases○
    i. HIV/AIDS○
    j. Hepatitis B or C○
    k. Cancer○
    l. Gastrointestinal bleeding○,
    m. Recurrent cellulitis/skin infection○
13. Number of Medications that you currently take:
14. Dialysis vintage/ Date HD initiation:
15. Type of HD access: fistula/graft/tunneled○, semi-permanent dialysis catheter○ temporary dialysis catheter○
16. Number of hemodialysis/week (dialysis prescription): 3HD/week○ 2HD/week○
17. Number of hemodialysis sessions in the past 30 days:
18. Number of hospitalization during the last 6 months:
19. Date of last hospitalization:
20. Hemoglobin level:
21. Albumin level:
22. BMI:

23. Kt/V:

24. Complications associated with HD: carpal tunnel syndrome○ amyloidosis (ß2-microglobulin) ○ parathyroidectomy○

KIDNEY DISEASE QUALITY OF LIFE 36-ITEM SHORT FORM QUESTIONNAIRE

Your Health

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

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

Excellent○ Very good○ Good○ Fair○ Poor○

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

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

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

	Yes	**No**
4. Accomplished less than you would like		
5. Were limited in the kind of work or other activities		

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	**No**
6. Accomplished less than you would like		
7. Didn't do work or other activities as carefully as usual		

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

Not at all○ A little bit○ Moderately○ Quite a bit○ Extremely○

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

How much of the time during the past 4 weeks

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

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

All of the time○ Most of the time○ Some of the time○ A little of the time○ None of the time○

<u>Your Kidney Disease</u>

How true or false is each of the following statements for you?

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

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

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

<u>Effects of Kidney Disease on Your Daily Life</u>

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

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

Thank you for completing these questions

APPENDIX 3: Informed consent form

This consent form is for those who are invited to participate in our study on "**Health related quality of life of patients on in-centre maintenance hemodialysis in Rwanda.** Meaning finding out how is the quality of life of patients on maintenance hemodialysis.

This form comprises of two sections:

1. Introduction to the study.
2. Consent form.

SECTION I: **Introduction to the study:**

We are going to explain and invite you to participate in this study. You will think about it and ask questions if necessary so that you understand the whole process, benefits and possible risks (although there are no expected risks) before you decide to accept to participate in this study.

My name is **SHUMBUSHO Gloria**, a medical doctor by profession, I am also a senior student in Internal medicine specialization program (master's degree) at University of Rwanda College of Medicine and Health Sciences. Me and my supervisors are carrying out a research on quality of life of patients who are on in-centre maintenance hemodialysis for end stage renal disease at Butare University Teaching Hospital, Kigali University Teaching Hospital, Rwanda Military Hospital and King Faisal Hospital so that we can evaluate modifiable risks to improve their quality of life.

Objective of the study:

The aim of this study is to release the knowledge on health related quality of life of patients on in-centre maintenance hemodialysis and awareness for possible modifiable factors that affect their quality of life.

Methods of the study intervention:

During the study, we will use a questionnaire, which will be given to participants to fill in their demographics and problems related to their illnesses including physical symptoms, social problems, and even economic issues. At the end will be put- together and analyzed to know the magnitude and characteristics of all patients and that will help us to make an appropriate conclusion.

Participant selection:

We invite all patients with end stage kidney disease on in-centre maintenance hemodialysis at CHUK, CHUB, RMH and KFH to participate in the study.

Right to participation:

Your participation in this study is fully voluntary. You will continue to get same management as you have been receiving even if you choose not to participate. You are allowed to refuse to participate. This will not affect in anyway your deserved management.

Duration of study:

Survey questionnaire filling will take not more than 10 minutes.

Risks:

This study is entirely safe there are no expected risks.

Benefits and reimbursement:

There is no reimbursement for any one's participation in this study.

Confidentiality:

Information that will be recorded from your charts or collected from you will be highly confidential. This information will be stored on a secured file in a password protected computer. Our questionnaire files have not included a NAME to protect the participant and only the researchers will have access to them.

Sharing the results:

We plan to publish the results for academic and research purposes and we shall feed back to the treatment team for self-evaluation. Your confidentiality will always be protected throughout.

CONTACTS

Door for questions is always open and in case you can contact the following:

SHUMBUSHO Gloria: +250788804882, glorishu@gmail.com.

KABAHIZI Jules: +250788824874, jukabahizi@yahoo.fr

CMHS IRB Chair Person: +250788490522.

CMHS IRB Deputy Chair Person: +250783340040.

SECTION II**: consent form.**

I have understood information provided all my questions have been answered to my satisfaction. I consent voluntarily to participate in this study.

Printed name of participant: …….

Signature/ thumb print of participant: …….

Date: ……..

Statement by the researcher/individual obtaining consent:

I have accurately read out the information sheet to the potential participant, and made sure that the participant understands the above information to my best of ability.

I confirm that the participant was given opportunity to ask questions about the study, and all the questions have been answered correctly to best of my knowledge.

I confirm that the individual has not been forced into giving consent; the consent has been given freely.

A copy of this consent form has been provided to the participant.

Print name of Researcher/ person obtaining consent: …….

Signature of Researcher/ person obtaining consent: ……

Date: ……