DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE POST KIDNEY TRANSPLANTATION AT KENYATTA NATIONAL HOSPITAL

A dissertation presented as part fulfilment of postgraduate fellowship in clinical nephrology.

Dr. Caroline M Gituku

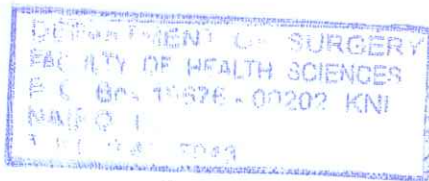**H114/42140/2022**

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This is my original work; it has not been presented to any other university or institution for academic credit.

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DEDICATION

I dedicate this work to my family for your support and for always believing in me. To my colleagues Ben, Kakai and Kibe for always keeping me on my toes. To the kidney transplant recipients at Kenyatta National Hospital without whom I could not have accomplished this study. May God bless you all.

ACKNOWLEDGEMENTS

ABSTRACT

Background:

Prevalence of chronic kidney disease has been rising globally causing a substantial burden on healthcare resources across the globe. ESRD is coupled with reduced functional capacity and quality of life. Kidney transplantation is the recommended treatment; however, it necessitates lifelong use of immunosuppressive agents that are associated with side effects.

Objective: Study aim was to determine the HRQoL in kidney transplant recipients and its determinants.

Methods: Descriptive cross-sectional study conducted at KNH transplant outpatient clinic. Questionnaires collected data on social, economic and demographics. Clinical and laboratory characteristics derived from medical records. HRQoL determined using the WHOQoL–BREF and KDQoL36 questionnaire. Variables summarised using, mean and standard deviation for continuous variables while percentages and proportions for categorical variables. HRQoL Scores vis-a-vis continuous variables analysed using Pearson correlation. HRQoL scores versus categorical variables analysed using the student T test /ANOVA. A 0.05 level of significance was adopted.

Outcomes: Seventy-three participants were recruited,75% were males with a mean age 46.6 (SD14.4), 65% resided in an urban setup and 42% had tertiary level education. Majority (63%) were very satisfied with their overall HRQoL. Male participants had higher physical health scores (65.9±7.1 vs 58.9±10.3 p0.002) while residing in an urban setup was associated with high environmental scores (79.5±14.2 vs 71.8±12.0 p0.025). Participants with well controlled blood pressure had high scores in social and environmental (89.7±12.9 vs 80.5±14.6 p0.016) (80.0±12.2 vs 66.5±14.6 p<0.001) respectively. Participants with HB>12g/dl had high physical and psychological scores (59.4±12.2 vs 65.9±6.1 p0.004) (69.7±10.8 vs 77.4 ±7.3 p0.001) respectively. High scores in physical, psychological, and environmental for participants with eGFR>45ml/min (65.9±6.4 vs 58±11.9 p0.001) (77.3±7.4 vs 68.4±10.7 p<0.001) (79.1±13 vs 68.8±14.5 p0.007) respectively. KDQoL and WHOQoL-BREF questionnaires correlated poorly in physical (0.295 p0.011), psychological (0.415 p <0.001) and social domains (0.298 p0.011).

Conclusions: Transplant recipients on follow-up at KNH transplant clinic are satisfied with their HRQoL. Factors associated are male gender, residing in urban setup, eGFR>45ml/min, HB>12g/dl and BP<130/80. The KDQoL and WHOQoL- BREF questionnaires correlate poorly and should be used separately.

Recommendations: Better HRQoL in KTR thus transplantation should be recommended for eligible patients with ESRD. Further longitudinal studies are required to test for these associations.

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ABBREVIATIONS AND ACRONYMS

CKD: Chronic Kidney Disease

ESRD: End Stage Renal Disease

GFR: Glomerular Filtration Rate

KTR: Kidney Transplant Recipient

KNH: Kenyatta National Hospital

QoL: Quality of Life

HRQoL: Health Related Quality of Life

RRT: Renal Replacement Therapy

SPSS: Statistical Package for Social Sciences

WHO: World Health Organisation

WHOQoL – BREF: World health Organisation Quality of Life Brief

KDQoL- Kidney Disease Quality of Life instrument

KDIGO- Kidney Disease Improving Global Outcomes

CHAPTER ONE: INTRODUCTION

1.0 Background

Chronic Kidney disease (CKD) is global health burden with increased prevalence in the last decade. It is associated with high morbidity and mortality, ranking amongst top ten causes of mortality globally for the year 2019. This was a rise from 13th in 2000, with a mortality increase from 813,000 to 1.3 million cases according to World Health Organisation(W.H.O) data of 2022.

End stage renal disease (ESRD) is coupled with decreased functional capacity and quality of life of the patient. The recommended renal replacement modalities for patients with ESRD are dialysis (haemodialysis and peritoneal) and kidney transplantation.

Advances have been made to improve the adequacy of dialysis and in treatment of associated complications, however despite these advances, this has not translated in improved life quality.

Kidney transplantation improves the renal function, the life quality and survival, however it necessitates the lifelong use of immunosuppressive agents that are associated with side effects.

A study by Evans et all compared the quality of life (QoL) of patients on haemodialysis versus kidney transplant recipients (KTR). KTR had a better functional capacity, more satisfaction with life and better life quality in comparison to those on haemodialysis (1).

A study conducted at the Kenyatta national hospital dialysis unit, participants on dialysis, were found to have a reduced quality of life, with the physical being more affected than mental(2).

Immediate post-transplant period has a high complication rate, thus an increased mortality. Nevertheless, on the long-term KTR have a better survival benefit when compared with their counterparts on dialysis(3, 4).

Several hypotheses have been postulated to explain the improved quality of life post-transplantation. One, the correction of anaemia is associated with resolution of symptoms like fatigue, which a definite impact on the physical component. There is also normalization of substances like urea and phosphate that further improves their physical component. The fluid and diet restrictions that were in place when the patient was on dialysis are lifted thus

contributing further to their quality of life. Reduced dependency on the dialysis machine gives them freedom of movement that translates to improvement in their psychological and social component. Resumption of work also has a positive impact; however, it is influenced by the availability of work that further affects the quality of life(5, 6).

Despite the improved survival and quality of life, KTR require the lifelong use of immunosuppressive agents. The side effects of these therapy coupled with patient's characteristics have been postulated to negatively impact HRQoL of KTR(7).

Physical, mental and kidney disease variables in HRQoL scores are associated with high risk of mortality and morbidity while on renal replacement therapy, regardless of the demographic and comorbid factors(8, 9).

According to the Global Observation on Donation and Transplantation 80,926 kidney transplants were done in the year 2020, with 32% of them being living kidney donation.

Kenyatta national hospital has been conducting kidney transplantation for over 10 years now with over 200 transplants done.

1.1 Justification

World Health Organisation(W.H.O) defines QoL as one's perception of their life influenced by their culture and their value systems in relation to ones' goals, expectations, standards, and concerns.

Health related quality of life (HRQoL) determines impact that health status has on quality of life (QoL). It is a measure of patient's wellbeing in terms of their physical, psychological, and social domains. It is used to determine the effectiveness of a treatment modality and help clinicians make rational decisions on the optimal choice of treatment(10).

Renal transplantation is advantageous than dialysis in terms of cost-effectiveness, extended survival and better HRQoL. However, life after transplantation may have its' positive as well as negative aspects.

Clear identification of personal, environmental, and clinical factors that negatively impact HRQoL is paramount. This will help develop interventions that mitigate these factors and elevate recipients HRQoL.

1.2 Problem statement

The last two decades, has seen a rise of patients with comorbidities on dialysis. When assessing their eligibility of transplantation one factor considered is the quality of life.

Comparison of HRQoL between patients on dialysis and kidney transplant recipients have shown better functional and general wellbeing of life post-transplantation(1).

However, majority of these comparison studies there was no matching of participants in terms of their age, comorbidities, and socioeconomic status. Yet these same factors determine whether one is transplanted or not, thus the transplant population can be considered as a preselected group, making the generalizability of these studies is difficult.

Currently in our set up there are no studies evaluating quality of life post-kidney transplantation and factors that influence it.

1.3 Research question

What is the HRQoL of kidney transplant recipients on follow up in Kenyatta National Hospital and what factors determine it?

1.4 Broad objective

To determine health-related quality of life and factors associated in kidney transplant recipients on follow-up at Kenyatta National Hospital.

Specific objectives

1. To describe the health-related quality of life in kidney transplant recipients on follow up at Kenyatta National Hospital.
2. To determine the socio-demographic factors associated with the health-related quality of life of kidney transplant recipients on follow up at Kenyatta National Hospital.

Secondary objectives

1. To compare the clinical characteristics and quality of life scores.

2. To compare the agreeability of KDQoL 36 questionnaire and WHOQoL-BREF questionnaire.

1.5 Research hypothesis

The hypothesis for the study was:

1.   Kidney transplant recipients have an improved quality of life.
2.   The improved quality of life is influenced by sociodemographic and clinical factors.

1.6 Scope and delimitation of the study

This study aimed to describe the quality-of-life post-kidney transplantation and factors associated. It was not powered to assess for correlation of the factors and quality of life. Geographically, the study focused on the patients attending outpatient transplant clinic at the Kenyatta National Hospital, located in Nairobi, Kenya. It was a cross-sectional descriptive study, hence only provide a snapshot view of the recipients.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

Chronic kidney disease (CKD) defined as either presence of damage to kidney or reduced estimated glomerular filtration rate (eGFR) <60ml/min for at least 3 months. According to W.H.O global data of 2020, the global prevalence of CKD has been on an upward trend in the last decade. This has been associated due to increased survival of patients with CKD and increased prevalence of conditions associated with CKD.

Kidney Disease Improving Global Outcomes (KDIGO) defines end stage renal disease (ESRD) as eGFR less than 15ml/min. Globally, leading cause of ESRD is diabetic kidney disease. The range of chronic conditions that progress to ESRD is broad ranging from parenchymal diseases, obstructive uropathy and systemic conditions. ESRD is associated with increased prevalence of cardiovascular disease, decreased functional capacity and quality of life(4).

The renal replacement therapies available for ESRD eligible patients is dialysis and kidney transplantation. Dialysis involves the removal of solutes and water through a semi-permeable membrane that can be artificial or biological. Dialysis is thus sub-classified into haemodialysis and peritoneal dialysis. It is associated with inadequate urea removal thus a substantial functional incapacity. This is despite the advances that have been made to improve the adequacy of dialysis and to treat ESRD associated complications.

Kidney transplantation on the other hand restores the kidney function; however, it necessitates the lifelong use of immunosuppressants that are associated with adverse effects. It is thus the recommended treatment modality for eligible ESRD patients.

Patients with ESRD their quality of life is influenced by the disease, the associated comorbidities and renal replacement therapy modality.

The effectiveness of a treatment modality can be determined in various ways, the survival of the patient, the clinical outcomes, and the quality of life.

2.1 Quality of life

Quality of life (QoL)is one's perception of their position in life influenced by ones' culture, value systems in relation to ones' goals, expectations, standards, and concerns (W.H.O).

Health related quality of life (HRQoL) is thus the impact a chronic disease and its treatment has on ones' perceptions of their own physical and mental function.

HRQoL is the wellbeing of the patient in terms of the physical, psychological, and social. It may be affected by several factors that include, side effect of treatment, patient's relationships with caregivers and health care workers, and the clinically the disease process(11)

2.1.1 Health related quality of life of on maintenance haemodialysis

Patients on haemodialysis have a lower QoL in comparison to the general population and post-kidney transplantation. This is further coupled by sociodemographic factors, with female participants having lower scores in psychological and environmental domains than their male counterparts(12).

The low physical domain in patients on dialysis has the same mortality predictive value as the urea clearance ratio, with higher values associated with increased likelihood of survival(13).

A Study conducted at Kenyatta National Hospital (KNH) dialysis unit, had similar results with low score in physical and mental domain. However, there was no correlation with sociodemographic variables despite it being a young, unemployed, and uneducated population(2).

Factors associated with the low physical scores in patients on dialysis included low haemoglobin levels, increase in age and higher degree of comorbidity.

2.1.2 Health related quality of life in kidney transplant recipients (KTR) transplantation

KTR have improved functional capacity and psychological wellbeing in comparison to maintenance haemodialysis(1).

A Palestinian study compared quality of life in KTR compared to patients on maintenance haemodialysis, KTR had higher scores in social and physical domain(14).

A Portugal study unlike the Palestinian study, KTR had low physical scores with high environmental scores(15).

Kidney transplant recipients do have a higher HRQoL scores in all domains in comparison to patients on maintenance dialysis. However, on evaluation of KTR sociodemographic variables they tend to be younger, of a higher educational level and socioeconomic level; and

these factors are associated with higher HRQoL scores. However, sociodemographic factors are a strong determinant whether one is transplanted(14).

The Palestinian study, older patients (above 60 years) with low level of education (primary level) and female gender on dialysis had lower physical domain scores in comparison to their counterpart. While in the transplant recipient arm, being of male gender, younger in age and of higher education level was associated with high scores in all domains(4, 14).

The Portugal study had an almost similar patient population with high proportion being male, younger (less than 60 years) and had a higher literacy level. Low literacy level was associated with low physical and social domain, though the other variables had no statistically significant correlation(15).

Another study conducted in France evaluated factors associated with HRQoL in KTR, had almost similar patient groups. The mean age was 55 years, with 60% being males, majority having a higher level of education (secondary level and above) and higher socioeconomic status. On multivariate regression having advanced age, female gender, and low socioeconomic status was associated with low scores(16).

Thus, kidney transplant recipients can be considered as a pre-selected population in terms of their socio-demographic variables. These same variables do determine suitability for transplantation making the generalisation of these studies difficult. Gaylin et al analysed 4118 participants initiated on dialysis, persons with advanced age, females, black race, low financial status, and presence of cardiovascular disease had the lowest transplantation rates(17).

Several studies have tried to overcome this by following the same patient population from dialysis to post-transplantation period thus each participant acts as their own control. One study conducted on 93 Spanish participants; there was improvement in the global, physical, and psychological domains. However, older age and greater degree of prior comorbidities diminished the effect of transplantation (18).

A Canadian study that similarly followed up patients from the dialysis to two years post-transplantation, had marked improvement in the quality of life with majority of participants being able to return to work. In contrast to the Spanish study these improvements cut across all socio-demographic groups even in the elderly. Thus, though the elderly, have a higher mortality and morbidity in comparison to younger recipients; they should not be excluded

from transplantation based on age alone, rather exclusion should account their quality-of-life post-transplantation(19).

The improved quality of life in transplant recipients has been attributed to several factors that occur simultaneously with none outweighing the other. A positive association between correction of anaemia and physical domain has been defined. Similarly, the correction of metabolic derangements that are only partially corrected with dialysis leads to better physical domain scores. The freedom that comes with lack of dependency on the dialysis machine has also been attributed to improve psychological and social domains. Other factors like normalisation and restoration of fertility in women, recovery of sexual potency and libido in men have also been shown to positively influence the general quality of life(18).

Socio-economic factors do influence the quality-of-life post-transplantation. These include the availability of work and welfare benefits that vary from country to country. A study in a Swedish cohort 1-year post-transplant, 62% of the participants considered themselves fit to work but only 43% of them had a job. On further evaluation, participants who were employed prior to transplantation had a high chance of being employed post-transplant. Thus, transplantation did not increase employment status but only helped maintained the prior employment status. On evaluation of those employed and not employed post-transplantation, lack of a job was associated with high depression levels despite overall increase in the quality of life(6, 20).

Length of time post-transplantation also affects the QoL. Approximately 50% of participants in a Portuguese study received a transplant within the last 5 years, they however had low scores in their physical and psychological domains(15). Thus, the early post-transplant period is associated with increased anxiety and muscles loss that translates to reduced scores in the psychological and physical domains(21).

Despite the improved quality of life, the post-transplant period is a phase complexed by the need of immunosuppressive drugs that are associated with risk of opportunistic infections and adverse effects. Generally, transplant recipients with a longer duration post-transplant are thought to have a better quality of life in comparison to those with a shorter duration. The improvement could be attributed to adaptations that are made over time and the decreasing need of immunosuppressants that occur over time (15, 18).

Advances in the immunosuppressive therapies has led to better graft and patient survival. Tacrolimus is associated with better physical appearance and reduced incidence of acute

rejection episodes in comparison to cyclosporine-based therapy(22). The reduced acute rejection episodes however do not correspond with increased graft survival especially so if the episode completely resolves. Thus cyclosporine versus tacrolimus have no difference in terms of long-term graft survival it's the mere presence of an acute rejection episode that is associated with reduced quality of life(23, 24).

Presence or absence of comorbidities also significantly impact on the quality-of-life post-transplantation and are factors considered whether one is eligible for transplant or not(18).

Diabetes mellitus patients present a double challenge since their quality of life on dialysis is lower than non-diabetic patients and they have a higher risk of cardiovascular disease increasing their mortality and morbidity risk. Hence, the option available for diabetic patients more so for the type 1 diabetic patients is a double kidney-pancreas transplantation. The double transplants have been associated with better glycaemic control, better quality of life, improved survival, and reduced progression of microvascular complications(25). However, this option is not available in most transplant centres and is associated with high morbidity in the immediate post-transplant period.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

Techniques used to carry out this study are described in this chapter. Study design, area, population, sampling population and sample size are thus described. Study instruments used and data collection procedures are detailed. Data analysis is presented. Also presented are the validity, reliability, and ethical considerations.

3.1 Study design

Descriptive cross-sectional study. Descriptive cross-sectional design provides an observation at a point in time. Thus, this study was able to have an idea of the current HRQoL in KTR and form a build up for more longitudinal designs.

3.2 Study site

Undertaken at Kenyatta national hospital(KNH) transplant outpatient clinic.

KNH a tertiary level hospital in Nairobi Kenya, 3 km from the city centre. Largest hospital not only in Kenya but also in East and Central Africa. It serves as research, teaching, and referral hospital with a bed capacity of 2000.

The renal department is one of the specialized services offered in the hospital, it offers dialysis and transplant services to both inpatient and outpatient. As from the year 2010 the number of transplants conducted in the unit per year increased from 3 to 20 per year due to the '*interlife*' program. Approximately, in the past decade the unit has conducted 200 living kidney donation transplants.

The unit conducts a weekly transplant clinic whereby kidney transplant recipients are followed up. It has a weekly review of approximately 20 -30 patients per week.

3.3 Study population

This study included kidney transplant recipients on follow up at the KNH transplant outpatient clinic with at least 3 months post-transplantation.

Thus, ensuring research questions and objectives are met.

3.4 Sample size

Calculated using Fisher's formula:

$$n = \frac{Z^2 x\, P(1-P)}{d^2}$$

Where:

n = Desired sample size

Z = value from standard normal distribution corresponding to desired confidence level (Z=1.96 for 95% CI)

P = expected true proportion

Estimated at 0.95, from a study conducted in Egypt(26)

d = desired precision (0.05)

$$n = \frac{1.96^2 x\, 0.96(1-0.95)}{0.05^2} = 73$$

3.4.1 Sampling Procedure

Convenience sampling technique utilised to recruit recipients. Participants were recruited as they attended their regular weekly clinic follow up.

3.4.2 Inclusion criteria

1. Participants on follow up at KNH transplant clinic

2. Participants who consent to be included.

3.4.3 Exclusion criteria

1. Participants who transplanted less than 3 months prior.
2. Participants diagnosed with cognitive deficit and / or active psychiatric disease.

3.5 Data collection

3.5.1 Study Variables

The independent variables were socio-demographic, economic, clinical and laboratory.

The dependent variable was Health Related Quality of Life (HRQoL) that was expressed through, psychological, physical, environmental, and social variables.

3.5.2 Study instruments and collection

Consent was obtained after a detailed explanation by the principal investigator on the study aim. The participants were then given the KDQoL, WHOQoL- BREF and sociodemographic questionnaires to fill. Participants were given privacy and time to fill the questionnaires at their own discretion as their waited the clinic review. This helped maintain privacy and confidentiality of the participants. Participants who were unable to read the principal investigator translated and helped them fill the questionnaires.

Direct questioning and recording of the responses in a <u>data collection questionnaire</u> was done to obtain data on socio-demographic, clinical and laboratory variables.

The primary diagnosis prior to transplantation, duration on dialysis pre-transplantation, need of dialysis post-transplantation, co-morbidities and post-transplant treatment history was derived by review of patients' medical record.

Laboratory findings for haemoglobin and serum creatinine were retrieved from the medical records, and an average of three most recent was utilised.

An average blood pressure of three different readings was utilised.

HRQoL was assessed using the <u>KDQOL-36 questionnaire</u> and <u>WHOQOL-BREF.</u>

KDQOL-36 questionnaire is a survey that was issued in the year 2000 based on a prior questionnaire created in 1994. It has 5 items that includes the physical, mental, the kidney disease in view of symptoms, problem, burden, and effects. Two components measure general HRQoL while the other three are specific to kidney disease.

WHOQoL-BREF questionnaire was created by WHO in 1998 and it has been validated for the East African community in 2021(27). A shorted version has 26 items. Twenty-four items are classified into four domains and each item is rated on a 5-point Likert scale. They include physical health, psychological well-being, social relationships, and environment health. These four domains determine ones' perception of QoL. Question one and two are examined separately and they asses the individual's overall perception of their QoL and their overall health respectively.

 An identification mark was placed against the participant's response. Questions not answered were left blank.

3.5.3 Data cleaning

The principal investigator reviewed the data collection questionnaires for completeness. The raw data was inspected for any missing data.

3.5.4 Data entry

Data processing was done with Statistical Package for Social Science (SPSS) 20.0.

3.5.5 Data protection and safety

The completed questionnaires were stored under lock and key accessible only by the principal investigator. Confidentiality was maintained via anonymity, de-identification, and data encryption.

A password protected computer was utilised to store the data. The questionnaires shall be shredded after 3 years or on publication of the study.

3.5.6 Data analysis

The study variables that were evaluated in this study included the age, gender, residential area, occupation, and education level were collected with the data collection questionnaire. The KDQoL and WHOQoL- BREF questionnaires collected variables that include the overall HRQoL, the social, environmental, physical, and psychological domains that influence the overall HRQoL. Clinical variables that include duration on haemodialysis, duration post-transplantation, any comorbidities pre- or post-transplantation were collected using the data collection questionnaire.

Standard deviation was utilized to summarize continuous variables. Proportions and percentages summarised categorical data. Relationships of HRQoL Scores and the continuous variable analysed by Pearson correlation or Spearman rank correlation. Relationships of HRQoL scores and categorical variables analysed using the student T test /ANOVA. Univariate analysis done using Kruskal Wallis test for continuous variables and Fisher's exact for categorical variables. A p level of 0.05 was adopted.

3.6 Ethical Consideration

All the prerequisite authorizations and approval to conduct the study was sought from the Institutional Research and Ethics Committee (IREC) at KNH before conducting the study. Permission to collect data was also obtained from KNH's hospital directors. Confidentiality and privacy were maintained through-out this study. Consent was obtained from each participant.

3.7 Benefits of the study

Findings from the study will be beneficial to the transplant community as it will enlighten on QoL in KTR. Information gained will identify recipients who will highly benefit from transplantation from their socio-demographic and clinical characteristics and thus prioritize them. The study will also inform intervention programs aimed at improving QoL of patients with ESRD. Participants who partook in this study were also be informed of their HRQoL and factors that affect it, they were advised on how to modify their factors to improve their HRQoL.

3.8 Study limitation

This was a descriptive study, thus not able to test for any associations.

3.9 Confidentiality

Confidentiality was be maintained throughout the study. To ensure anonymity and confidentiality, the principal investigator used codes for patient identification as opposed to using names.

3.10 Budget

The budget for the study was as tabulated below.

Item	Price
Printing	30,000
Ethics	3,000
Miscellaneous	30,000
Total	63,000

Table 1: Budget of the study.

CHAPTER FOUR: STUDY FINDINGS

4.0 Introduction

This chapter reports this study's findings and analysis as per the methodology. The study was undertaken at KNH transplant outpatient clinic between the months of May to September 2022. A total of 75 questionnaires were administered with a response rate was of 97.3% (n=73).

4.1 Overall health related quality of life

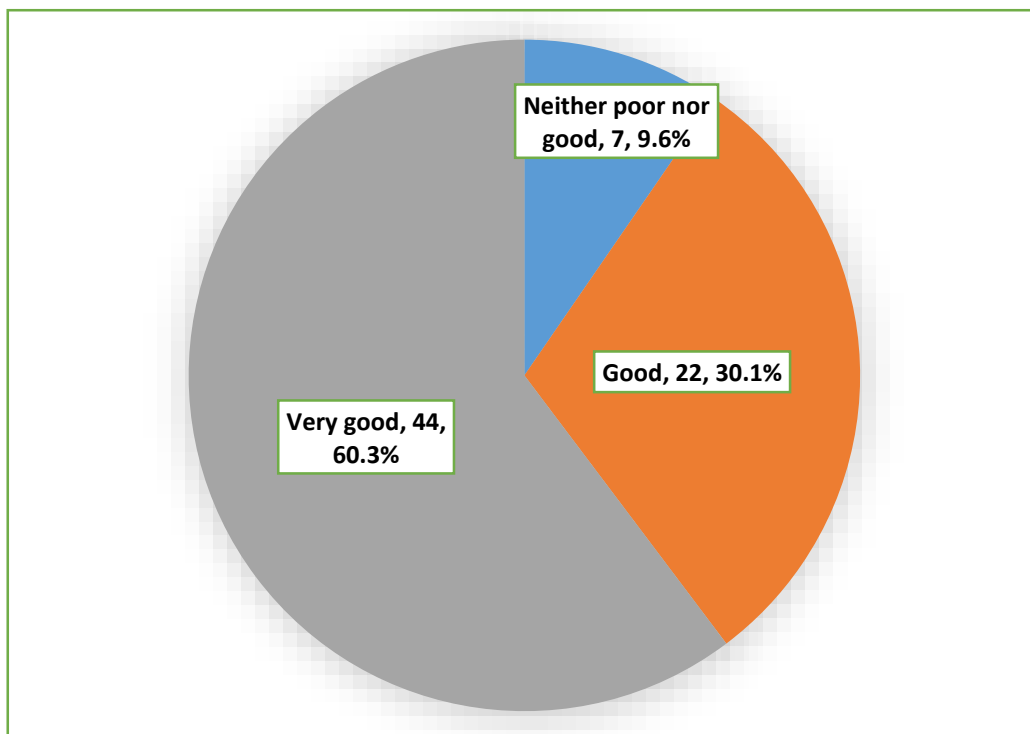The overall HRQoL was rated using a Likert scale by WHOQoL-BREF questionnaire. The results are as shown:

Figure 1: Overall rate of quality of life using WHOQOLBREF questionnaire.

Majority of the participants rated their overall HRQoL as very good, with only a small fraction being dissatisfied.

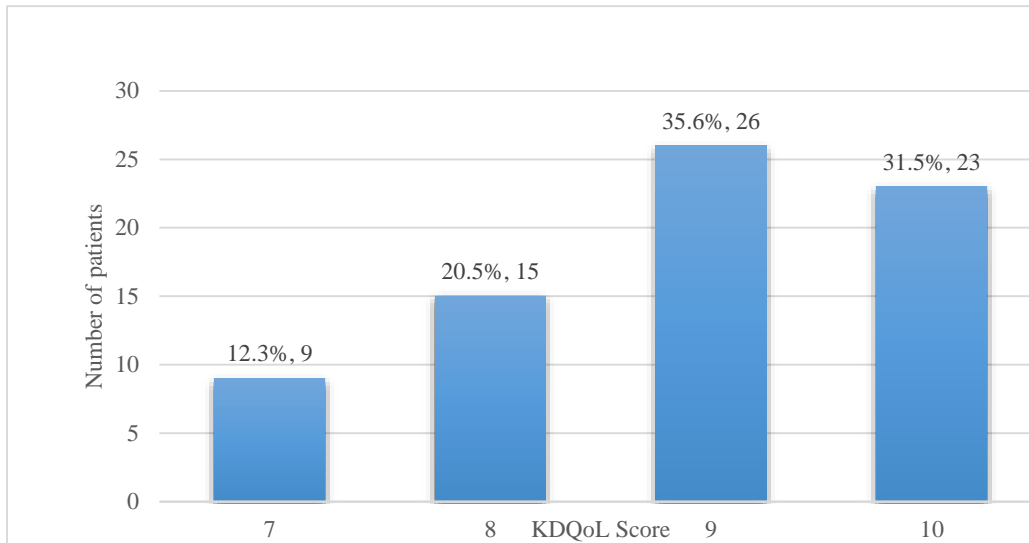Overall health related quality of life using KDQoL questionnaire was as shown below.

Figure 2: Overall health related quality of life using KDQoL.

The overall mean for health-related quality of life was 8.9 (SD 1.0), with minimum of 7.0, maximum 10 and median score of 9.0 (IRQ 8.0 – 10.0).

4.1.1 Overall satisfaction with their health

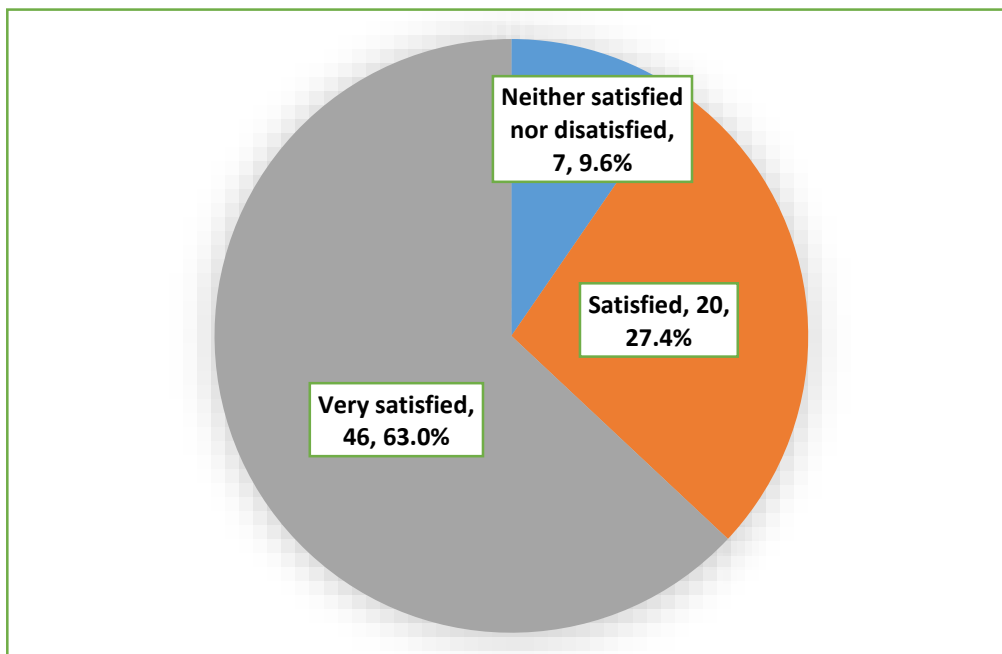Participants satisfaction with their health was shown on figure 2.

Figure 2: Overall satisfaction with health using WHOQoL-BREF questionnaire.

Majority of the participants were satisfied with their quality of life, similarly only 10% were neither satisfied nor dissatisfied.

4.1.2 Health related quality of life (WHO-QOL BREF) domains

The HRQoL domains highest mean scores were reported in the social domain, followed by environment, psychological, and finally physical health in that order.

4.2 Sociodemographic variables

Section one of the study instrument was used to collect data concerning sociodemographic, results are as shown below.

Age	N	Physical health	Psychological	Social relationship	Environment
<30	12	62.3±10.8	74.9±8.7	86.5±20.2	75.6±16.1
30 – 39	11	64.6±7.4	75.0±10.3	90.4±13.5	76.7±12.8
40 – 49	16	63.9±8.9	74.9±10.2	87.2±12.4	73.6±15.8
50 – 59	17	64.9±8.5	73.9±8.4	87.5±12.3	79.8±11.2
≥60	17	64.8±7.8	77.9±7.9	86.8±12.5	78.1±14.4
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.936	0.764	0.966	0.770
Gender					
Male	55	65.9±7.1	76.4±7.9	87.5±13.4	78.4±13.0
Female	18	58.9±10.3	72.2±11.3	87.6±15.3	72.3±15.9
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.002**	0.078	0.994	0.112
Residence					
Rural	25	64.7±8.7	75.5±8.1	86.0±11.6	71.8±12.0
Urban	48	63.9±8.5	75.3±9.4	88.3±14.8	79.5±14.2
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.690	0.926	0.496	**0.025**
Education					
Not educated	3	69.0±6.0	81.0±0.0	83.3±14.4	71.0±20.2
Primary	13	64.7±5.4	74.5±7.5	88.9±12.6	73.7±10.8
Secondary	26	63.4±7.9	75.4±7.9	84.9±16.2	77.0±14.0
Tertiary	31	64.1±10.2	75.2±10.7	89.6±12.1	78.7±14.7
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.752	0.732	0.579	0.641
Occupation					

Employed	54	63.7±8.0	75.0±8.7	88.5±12.1	76.9±13.7
Retired	8	68.8±10.0	79.6±9.2	83.6±12.5	77.4±9.8
Not employed	11	63.4±9.9	74.3±9.8	85.8±21.6	76.1±18.1
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.273	0.358	0.595	0.978
Marital status					
Married	54	64.5±8.3	75.6±8.9	87.7±12.2	76.3±13.5
Single	18	63.1±9.5	74.6±9.5	86.5±18.1	77.5±15.1
Widowed	1	63.0±-	81.0±-	100.0±-	94.0±-
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.824	0.757	0.636	0.448

Table 2: Sociodemographic characteristics and HRQoL domains

Male gender was the dominant gender in this patient population, with high physical health domain scores.

Majority resided in an urban setup and had high environmental domain scores.

The level of education in most participants was secondary and higher and most were employed at the time of this study.

4.3 Clinical and laboratory characteristics

Clinical and laboratory characteristics are as tabulated below.

BP	N	Physical health	Psychological	Social relationship	Environment
<130/80	56	65.1±7.9	76.2±8.1	89.7±12.9	80.0±12.2
>130/80	17	61.2±10.1	72.7±11.2	80.5±14.6	66.5±14.6
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.099	0.160	**0.016**	**<0.001**
Glomerular filtrate					
Stage 1- 3a	57	65.9±6.4	77.3±7.4	89.1±13.3	79.1±13.0
Stage 3b-5	16	58.0±11.9	68.4±10.7	82.1±14.4	68.8±14.5
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.001**	**<0.001**	0.072	**0.007**
Haemoglobin level					
<12	19	59.4±12.2	69.7±10.8	84.3±14.4	72.8±16.9
≥12	54	65.9±6.1	77.4±7.3	88.7±13.5	78.3±12.6
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.004**	**0.001**	0.231	0.139
Haemodialysis duration					
<24	24	67.3±6.8	76.3±6.4	88.6±11.9	79.2±11.6
≥24	49	62.6±8.9	75.0±10.0	87.0±14.7	75.7±14.9
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.027**	0.565	0.652	0.317

Table 3: Clinical and laboratory characteristics and HRQoL domains

High environmental and social scores in participants with well controlled blood pressure, while those in CKD stage 1-3a had high scores in the physical, psychological, and environmental. Similarly, those with hemoglobin levels above 12g/dl had higher physical and psychological domains than their counterparts.

Participants with pre-transplant dialysis duration less than 2 years had higher physical health domains scores.

4.4 Transplant related characteristics

Transplant related characteristics are as shown below.

Duration since transplant (years)	N	Physical health	Psychological	Social relationship	Environment
<10	65	64.3±8.6	75.4±9.1	87.3±14.1	76.9±14.5
≥10	8	63.3±8.0	75.0±8.5	89.9±11.1	76.6±8.6
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.750	0.899	0.614	0.960
Episodes of acute graft dysfunction					
Yes	15	59.0±12.6	71.3±10.8	86.7±15.5	69.5±15.4
No	58	65.5±6.6	76.5±8.2	87.8±13.4	78.8±13.0
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.007**	**0.044**	0.786	**0.021**
Comorbidities post-transplantation					
Yes	20	64.6±5.2	76.2±5.7	91.0±11.0	82.3±14.9
No	53	64.0±9.5	75.1±9.9	86.3±14.6	74.8±13.1
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.790	0.635	0.195	**0.039**
Complications post transplantation					
Yes	29	63.8±8.7	75.4±11.0	84.7±14.6	73.1±15.0
No	44	64.4±8.5	75.4±7.4	89.4±13.0	79.4±12.7
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.764	0.997	0.158	0.058

Table 4: Transplant related characteristics and HRQoL domains

Participants with episodes of acute graft dysfunction had lower physical, psychological, and environmental domains scores. While those post-transplantation with comorbidities, had reduced scores in their environmental domain.

4.5 Comparison of scores and domain

Scores and domains in the questionnaires were compared as shown below.

WHOQOL-BREF Overall QoL	N	Physical health	Psychological	Social relationship	Environment
Poor	7	58.3±14.6	63.4±12.7	81.3±19.4	66.1±19.8
Good	66	64.8±7.5	76.7±7.5	88.2±13.1	78.0±12.8
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		0.054	**<0.001**	0.209	**0.031**
KDQoL Score					
<9	24	59.9±11.2	72.1±10.5	84.4±13.8	73.5±15.5
≥9	49	66.3±5.9	77.0±7.7	89.1±13.6	78.5±12.9
Overall	73	64.2±8.5	75.4±8.9	87.5±13.8	76.9±13.9
p-value		**0.002**	**0.026**	0.172	0.145

Table 4: Comparison of highest and lowest HRQoL scores in the questionnaires

Participants with good overall QoL using WHOQOL-BREF questionnaire had higher scores in the psychological and environmental domain. QoL above nine using KDQOL, had high scores in their physical and psychological domains.

4.6 Correlation of the WHOQoL-BREF and KDQoL questionnaires

Correlation between the two questionnaires was determined using Pearson correlation coefficient.

KDQOL			
WHO Domain	**Physical health**	**Psychological domain**	**Social domain**
Physical health	0.295		
Psychological		0.415	
Social relationship			0.298
N	73	73	73
p-value	**0.011**	**<0.001**	**0.011**

Table 5: Correlation of WHOQoL-BREF and KDQoL questionnaires.

There was a weak correlation between the KDQoL and WHOQoL-BREF questionnaires on the physical health and social domain. There was a moderate correlation on the psychological domain.

CHAPTER FIVE: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction.

Discussion of the study findings as per the research objectives is done in this chapter. Findings from this study are compared with others both from the local region and globally. Conclusions drawn from the findings; recommendation and limitations are further outlined in this chapter.

5.1 Demographic characteristics

The mean age was 46.6 (SD14.4) with only 23% being above 60 years of age. This corresponds to earlier studies done on the hemodialysis population where the mean age was 44 years (±13)(2).

Males dominated in this study with them compromising 75% of all participants. This gender predominance is in contrast to earlier study that had been done in the dialysis population where it was a more 1:1 distribution(2).

Approximately 80% of the participants in this study had a secondary and higher level of education. Kamau et al also reported a high-level education with 70% of the participants having a secondary and higher level of education(2).

The high level of education also corresponded with an equal high level of employment at 74% in this study. Despite having a high level of education in an almost similar population in the Kamau et al study, there was a high level of unemployment at approximately 50%(2).

This study majority (66%) resided in an urban set-up. However, in contrast, a study conducted in Palestinian majority of the participants were residing in a village setting at the time of the study(14)

5.1.1 Demographics characteristics and HRQoL

Male kidney transplants recipients had higher physical health domain scores in comparison to their female counterparts (65.9 ±7.1 versus 58.9±10.3 p value0.002). However, had more male than female participants.

Participants from an urban dwelling had a better environmental domain than those from a rural dwelling (79.5 ±14.2 versus 71.8±12.0 p value 0.025). This could be due to better social economic status in the urban dwellers.

Antunes et al had slightly different findings with no difference between gender and the four domains of quality of health. They did not evaluate the occupation status; however, the differences they reported were in literacy level, whereby participants with low literacy level had lower mean score in the environmental and psychological domains(15).

Sarhan et al on evaluation of the sociodemographic variables and quality of life domains found that age, gender, education level and residential area were all associated with better quality of life in all the domains(14).

Hwang et al reported that younger participants (<49years), higher education level (tertiary) and were employed had higher physical health domains. While participants who were married with a tertiary level of education had higher mental/psychological domains(28).

However, Mouelhi et al being of advanced age, female gender, unemployment, having dependents and living alone were all associated with low quality of life scores(16).

Rasheed et al gender, marital status, and social class, in contrast to this study, had no association with quality-of-life domains. However, age was negatively associated with physical and psychological domains, whereby younger participants had lower scores in these domains. Education was positively associated with psychological domain, whereby participants with a tertiary level of education had a higher psychological domain score(26).

Considering that this was a descriptive study, and discrepancy between this studies and studies in the region, further studies are thus required to evaluate these sociodemographic variables and their correlation with quality of life.

5.2 Overall Quality of life

Using the KDQoL questionnaire 67% of the participants gave an overall QoL score of 9 out of 10. Similarly, using the WHOQoL-BREF questionnaire, 60% reported their QoL to be very good.

Several studies have shown that the overall QoL improves in KTR in comparison to counterparts on dialysis(1, 29).

Though this study did not compare HRQoL between transplants and dialysis, 90% of them reported their overall HRQoL to be good and they were satisfied with their health.

Gorlen et al in their study population, 66% reported their QoL as good and very good, with only 6% reporting it as poor(30).

In contrast, a study in Egypt by Rasheed et al, 97.8% of the participants were unsatisfied with their overall QoL, highest dissatisfaction being social domain. However, this population was younger in comparison to our study (mean age 37.3 ± 7.6 versus 46.6 ±14.4) and the longest duration post transplantation was 18 months(26).

Villeneuve et al followed transplants recipients over 36 months, quality of life steadily increased from the third post-transplant month and by the 6th month was no difference with that of general population(21).

Difference between this study and the Egyptian study by Rasheed at al, could be explained by the shorter duration post-transplantation and the difference in age.

WHOQoL-BREF questionnaire groups quality of life in four domains: physical, psychological, environmental, and social.

Using WHOQoL-BREF questionnaire, the highest quality of life mean scores was in the social domain at 87.5±13.8 and the lowest scores was in physical domain at 64.2±8.5.

Kamau et al, used the KDQoL to evaluate quality of life in patients undergoing hemodialysis at Kenyatta National Hospital, lower scores were in the physical domain at 39.09±9.49(2). It should be noted, this was not the same population study, hence longitudinal studies are required to further evaluate if the physical domain does improve with transplantation.

Antunes et al used the WHOQoL-BREF questionnaire; physical had lowest score at 58.51±9.54 and highest scores in the environmental domain at 74.94±11.98. The environmental domain was the second highest score in our study at 76.9±13.9. Findings in this study were thus similar to Antunes et al in Lisbon(15).

Kamal et al in Nepal, similarly, highest scores were in the social domain and the lowest score in the environmental domain(29).

Mouelhi et al in France used SF 36 questionnaire, which has 8 domains; lowest scores were in the mental health and vitality, while highest score in the physical and social functioning(16). Though this study, and the Mouelhi et al used different questionnaires, social domain had highest scores in both.

Sarhan et al like Mouelhi et al, used SF 36 questionnaire and they too had highest score in the social domain(14).

This study thus does correlates well with similar studies.

5.3 Clinical characteristics

This study, participants with hemoglobin above 12g/dl had high physical and psychological scores.

Anemia (HB <13g/dl for men and <12g/dl for women) has been identified as an independent predictor of mortality in ESRD. Thus, correction of anemia is paramount and has cardiovascular and non-cardiovascular benefits. The non-cardiovascular benefits include reduced fatigue, increased exercise tolerance and work capacity due to better skeletal muscle oxygenation. This improved oxygenation has been associated with a feeling of better wellbeing and improved cognitive function(10).

This study had well preserved renal function with approximately 80% of the participants being between CKD stage 1 and 3a. Further supported by the fact that 75% participants had well controlled blood pressure measurements and a hemoglobin level above 12g/dl.

This study utilized the CKD EPI calculation, which factors in race and gender to calculate the eGFR. KDIGO classifies chronic kidney disease (CKD) into 5 classes depending on the eGFR.

Glomerular filtration rate and quality of life have a positive correlation whereby persons with high GFR have high quality of life score. Similarly, patients with low GFR have increased symptoms and low quality of life(31).

Mouelhi et al on multivariate analysis found that having a higher serum creatinine level and chronic graft dysfunction was associated with low quality of life scores(16).

Participants with poorly controlled BP had low physical and environmental scores while having anemia was associated with low physical and psychological scores. Similarly, participants with low GFR had low physical, psychological and environmental domains. These findings could thus be explained by the fact that participants with low GFR are more likely to have poorly controlled BP, more likely to be anemic and also with low HRQoL.

This finding does correlates with other studies done and could be explained by the increased symptomology seen in this group(21).

5.4 Hemodialysis related characteristics

This study had a very small proportion of recipients being transplanted less than one year on dialysis. This could be explained by the lack of accessibility to resources like suitable donors, a transplant center, and lack of knowledge to those requiring the service.

Despite the lack of high uptake of pre-emptive dialysis, there has been a reduction in the average duration on dialysis. Kamau et al had a maximum duration of 156 months while this study had less than 20% being on dialysis for more than 36 months (2).

Kidney transplantation is recommended for the eligible patient in CKD, with pre-emptive transplantation having superior outcomes in terms of patient and graft survival(32). Pre-emptive transplantation is the transplantation of a CKD patient before initiation of dialysis. Despite its superior outcomes, it is inhibited by availability of suitable donors among other factors(32).

Similar results were in the Mouelhi et al study, despite being a developed country, 87% of all participants were on dialysis prior to transplantation with a median duration of 24 months. The low number of participants in this French population with pre-emptive transplantation could be explained by the fact that 91% of the transplants were deceased donation that have a longer waiting period in comparison to living kidney donation(16).

This study association of dialysis duration and HRQoL domains, participants with a duration less than 2 years had higher scores in all domains but statistically significant in the physical health domain.

 Kamau et al study there was no correlation of dialysis duration and HRQoL domains(2).

Hwang et al 37 out of the 123 participants had pre-emptive transplantation, though they had high physical and psychological scores this was not statistically significant(28).

 Rasheed et al the longest dialysis duration was 7 years, participants with shorter dialysis duration (<1 year) majority were unsatisfied with their overall, physical, and psychological domains in comparison to those with longer duration. However, this study 96% reported to be unsatisfied with their overall health(26).

Discrepancy between this study and the above studies could be explained by the small sample sizes. Thus, further studies are required to assess whether dialysis duration does really correlate with quality-of-life domains.

5.5 Transplant related characteristics

This study 43% of the participants had a graft less than 5 years. Several studies reported similar results, the Lisbon study 51% participants had a graft less than 5 years, while the Palestinian study the median graft duration was 7.1 years and the Hwang et al 34% had a graft less than 5 years(14, 15, 28).

This study had no correlation with post-transplant period and HRQoL.

Similarly, several other studies found no correlation between the duration post-transplant and HRQoL domains(26, 28).

However, Antunes et al study participants with a short post-transplant period had low physical and psychological scores(15).

The immediate post-transplant period has been associated with low scores in the physical and psychological domains due to associated anxiety and muscle weakness experienced in the first year(21).

Incidence of acute graft dysfunction in this study was at 21%. Mouelhi et al reported slightly lower incidence rate at 15%(16). The difference could be due to mode of diagnosis whereby was defined as baseline rise of serum creatinine by 25% in this study. Thus, lack of a kidney biopsy may lead to misdiagnosis of other conditions that may mimic acute rejection.

Participants in this study with reported incidence of acute graft dysfunction had low physical, psychological, and environmental scores. Similarly, Simmons et al correlates lower incidence of rejection with high social and psychological scores(33). Unlike this study, Mouelhi et al study found no correlation of acute rejection episodes and quality of life(16).Further studies are thus required to explore this association.

Most common anti-rejection medications were calcineurin inhibitors (CNI) at 86%, followed by mycophenolic acid derivatives at 71%, all the participants were on glucocorticoids. Similar results were reported by Mouelhi et al, whereby 82% of the participants were on CNI, 65% were on mycophenolic acid derivatives and only 58% were on glucocorticoids(16).

The use of tacrolimus in this patient population could thus explain where the most common post-transplant comorbidity was new onset diabetes mellitus at 19%. Post-transplant diabetes mellitus previously called new onset diabetes mellitus, defined as a recipient not prior diabetic now requiring insulin more than 30 days after transplantation.

This study, KTR with comorbidities post-transplant had low environmental domains scores. Similar results were reported by several studies(16, 18).

The most common post-transplant complication was infection in this study at 30%. There was no correlation of post-transplant complication and quality of life. However, unlike this study, Simmons et al there was a correlation of post-transplant infections and low QoL domains(33).

5.6 Comparison of high and low quality of life scores

Using WHOQOL-BREF participants with good and very good overall QoL had high psychological and environmental scores. While high physical and psychological scores in participants with overall QoL greater than nine using KDQOL and was statistically significant in physical, psychological, and environmental domains.

Kidney transplantation is associated with improved physical health due to the correction of anemia with reduced fatigue and increased exercise tolerance, and correction of metabolic derangements(10, 34).

Similarly, the freedom that comes with reduced dependence on the dialysis machine has been associated with improved psychological domains. Though the immediate post-transplant period is associated with increased anxiety due to fear of loss of graft, depression levels are lower than the dialysis population with improved psychological domain(34).

Kidney transplantation has been associated with increased job seeking behavior with increased employment rate post-transplantation. The improved employment rates and dependence could attribute to the improved environmental domain(19).

5.7 Correlation of the WHOQOL-BREF and KDQOL questionnaires

The KDQOL-36 questionnaire has five items that includes the physical, mental, the kidney disease in view of symptoms, problem, burden, and effects. Two components measure general HRQOL while the other three are specific to kidney disease.

WHOQOL-BREF questionnaire has 24 items classified into 4 domains i.e., physical, psychological, social, and environment. These determine ones' view on quality of life.

This study had a weak correlation between the KDQoL and WHOQoL-BREF on the overall health and the social domain and a moderate correlation on the psychological domain.

This could be explained by the fact that the KDQOL questionnaire had a high rate of un-responded items in comparison to the WHOQOL-BREF questionnaire. This high rate of un-responded items was attributed to the fact that most participants had no symptoms they attributed to be a burden on their kidney disease.

However further studies are necessary.

5.8 Conclusion

The post-transplant period is associated with good QoL in majority of KTR.

Socio-demographics variables associated with good QoL are male gender and residing in an urban setup.

Clinical characteristics associated with good quality of life include a high GFR, well controlled BP and absence of anemia.

The post-transplant period presence of acute graft dysfunction and comorbidities are associated with low quality of life scores.

5.9 Limitation

This descriptive study was not able to test the strength of any of the associations.

5.10 Recommendations

Further studies are required to test further these associations.

Kidney transplantation should be recommended to eligible patients with ESRD for it is associated with improved QoL.

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Appendix

DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE POST KIDNEY TRANSPLANTATION AT KENYATTA NATIONAL HOSPITAL

Data collection questionnaire

Serial number……………………………….

SECTION A: DEMOGRAPHIC DATA

1. What is your age in years? [   ]

2. What is your gender?

   Male [   ]

   Female [   ]

3. Residence

   Rural [   ]
   Urban [ ]

4. Level of education
   Not educated [   ]
   Primary [   ]
   Secondary [   ]
   Tertiary [   ]

5. Occupation
   Employed [   ]
   Retired [   ]
   Not employed [   ]

SECTION B: CLINICAL MEASURE

(As at the time of the interview)

6. Glomerular filtration rate [   ]

(Using CKD epi formula)

Stage 1: GFR >90 mL/min/1.73 m ^{2} [   ]

Stage 2: GFR 60-89 mL/min/1.73 m ^{2} [   ]

Stage 3a: GFR 45-59 mL/min/1.73 m ^{2} [   ]

Stage 3b: GFR 30-44 mL/min/1.73 m ^{2} [   ]

Stage 4: GFR 15-29 mL/min/1.73 m ^{2} [   ]

Stage 5: GFR < 15 mL/min/1.73 m ^{2} [   ]

7. Haemoglobin level (average of three measurements)

Anaemia: haemoglobin < 12 [   ]

Normal: haemoglobin ≥12 [   ]

8. Blood pressure (average of three readings)

Hypertensive >130/80 [   ]

Normal <130/80 [   ]

SECTION C: HAEMODIALYSIS

9.   What was the dialysis duration prior to transplantation in months [   ]

10. Was the cause of the ESRD known?

Yes [   ]

No [   ]

12b. If known, state the cause of the ESRD.

Hypertension [   ]

Diabetes mellitus [   ]

Chronic glomerulonephritis [   ]

Obstructive uropathy [   ]

Polycystic kidney disease [   ]

Lupus nephritis [   ]

Others [   ]

Please specify……………………………………………………………

11. Were there any comorbidities pre-transplantation.

      Yes [   ]

      No [   ]

      4a. If yes state them

      Hypertension [   ]

      Diabetes mellitus [   ]

      Others [   ]

         If   others,   please specify…………………………………………………

SECTION D: POST TRANSPLANT PERIOD

12. What is the duration since transplantation?

      0-1 Year [   ]
      1-5 years [   ]
      5-10 years [   ]
      10-15 years [   ]
      15-20 years [   ]
      >20 years [   ]

15. Has there been any episodes of acute graft rejection? [   ]
      (Defined as a serum creatinine rise >25% from baseline)

16. Presence of comorbidities that occurred post-transplant.
      Hypertension [   ]
      Post-transplant diabetes [   ]
      Neoplasia [   ]

BMI > 30 (kg/m^2) [   ]

Others [   ]

    If   others,   please specify…………………………………………………………

17. Presence of complications that occurred post-transplant.

Infections [   ]

    If   yes,   please specify…………………………………………………………

Drug related complications [   ]

    If   yes,   please specify…………………………………………………………

Surgically related complications [   ]

    If   yes,   please specify…………………………………………………………...

Others [   ]

    If   others,   please specify………………………………………………………….

DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE POST KIDNEY TRANSPLANTATION AT KENYATTA NATIONAL HOSPITAL

Kidney Disease and Quality of Life (KDQOL™-36)

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.

   [Mark an ☒ in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

3. 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? [Mark an ⊠ in a box on each line.]		Yes, limited a lot	Yes, limited a little	No, no limited at all
a	Vigorous activity, such as running, lifting heavy objects, participating in strenuous sports	......☐ 1........... ☐ 2 ....☐ 3		
b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	......☐ 1........... ☐ 2 ....☐ 3		
c	Lifting or carrying groceries..	......☐ 1........... ☐ 2 ....☐ 3		
d	Climbing several flights of stairs..	......☐ 1........... ☐ 2 ....☐ 3		
e	Climbing one flight of stairs..	......☐ 1........... ☐ 2 ....☐ 3		
f	Bending, kneeling, or stooping..	......☐ 1........... ☐ 2 ....☐ 3		
g	Walking more than a kilometer	......☐ 1........... ☐ 2 ....☐ 3		
h	Walking 500 meters..	......☐ 1........... ☐ 2 ....☐ 3		
i	Walking 100 meters..	......☐ 1........... ☐ 2 ....☐ 3		
j	Bathing or dressing yourself..	......☐ 1........... ☐ 2 ....☐ 3		

4. 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
			☐	☐
a	Cut down on the amount of time you spent on work or other activities..		..... ☐ 1 .... ☐ 2	
b	Accomplished less than you would have liked.		..... ☐ 1 .... ☐ 2	
c	Were limited in the kind of work or other activities?..................		..... ☐ 1 .... ☐ 2	
d	Had difficulty performing the work or other activities (for example, it took extra effort)?		..... ☐ 1 .... ☐ 2	

5. 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
		☐	☐
a	Cut down on the amount of time you spent on work or other activities?...	.... ☐ 1 .... ☐ 2	
b	Accomplished less than you would like?	.... ☐ 1 .... ☐ 2	
c	Didn't do work or other activities as carefully as usual?	.... ☐ 1 .... ☐ 2	

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or clubs?

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

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
☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

9. 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 □
a	Did you feel full of life?..	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
b	Have you been a very nervous person?........................	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
c	Have you felt so down in the dumps that nothing could cheer you up?	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
d	Have you felt calm and peaceful?............................	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
e	Did you have a lot of energy?	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
f	Have you felt downhearted and unhappy?.........................	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
g	Did you feel worn out?.............	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
h	Have you been a happy person?.....................................	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6
i	Did you feel tired?..................	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6

10. 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
☐	☐	☐	☐	☐
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

11. Please choose the answer that best describes how true or false each of the following statements is for you.

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to catch things a little more easily than other people	☐	☐	☐	☐	☐
		☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	I am as healthy as anybody I know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	I expect my health to get worse..................................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	My health is excellent..................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Your Kidney Disease

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

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	My kidney disease interferes too much with my life	☐ ☐ 1	☐ ☐ 2	☐ ☐ 3	☐ ☐ 4	☐ ☐ 5
b	Too much of my time is spent dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	I feel frustrated dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	I feel like a burden on my family....................................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

13. These questions are about how you feel and how things have been going 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…

		None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
		☐	☐	☐	☐	☐	☐
a	Did you isolate yourself from people around you?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
b	Did you react slowly to things that were said or done?............	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
c	Did you act irritable toward those around you?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
d	Did you have difficulty concentrating or thinking?....................................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
e	Did you get along well with other people?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
f	Did you become confused?....................................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

14. 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 ☐
a	Soreness in your muscles?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Chest pain?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	Cramps?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	Itchy skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e	Dry skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f	Shortness of breath?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g	Faintness or dizziness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h	Lack of appetite?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
i	Washed out or drained?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
j	Numbness in hands or feet?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
k	Nausea or upset stomach?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Effects of Kidney Disease on Your Daily Life						

15. 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 ☐
a	Fluid restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Dietary restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	Your ability to work around the house?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	Your ability to travel?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e	Being dependent on doctors and other medical staff?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f	Stress or worries caused by kidney disease?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g	Your sex life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h	Your personal appearance?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

16. The next two questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

How much of a problem was each of the following in the past 4 weeks?

	Not a problem	A little problem	Somewhat of a problem	Very much a problem	Severe problem
	☐	☐	☐	☐	☐
a Enjoying sex?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Becoming sexually aroused?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

17. For the following question, please rate your sleep using a scale ranging from 0 representing "very bad" to 10 representing "very good".

If you think your sleep is half-way between "very bad" and "very good," please mark the box under the number 5. If you think your sleep is one level better than 5, mark the box under 6. If you think your sleep is one level worse than 5, mark the box under 4 (and so on).

On a scale from 0 to 10, how would you rate your sleep overall?

[Mark an ☒ in one box.]

Very bad										Very good	
☐										☐	
0	1	2	3	4	5	6	7	8	9	10	
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐		

18. How often during the past 4 weeks did you...

		None of the time	A Little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
a	Awaken during the night and have trouble falling asleep again?............................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
b	Get the amount of sleep you need?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
c	Have trouble staying awake during the day?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

19. Concerning your family and friends, how satisfied are you with...

		Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
a	The amount of time you are able to spend with your family and friends?..................	☐ 1	☐ 2	☐ 3	☐ 4
b	The support you receive from your family and friends?........	☐ 1	☐ 2	☐ 3	☐ 4

20. During the past 4 weeks, did you work at a paying job?

Yes	No
☐	☐
☐ 1	☐ 2

21. Does your health keep you from working at a paying job?

Yes	No
☐	☐
☐ 1	☐ 2

22. Overall, how would you rate your health?

Worst possible (as bad or worse than being dead)			Half-way between worst and best								Best possible health		
☐			☐								☐		
	0	1	2	3	4	5	6	7	8	9	10	
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐		

DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE POST KIDNEY TRANSPLANTATION AT KENYATTA NATIONAL HOSPITAL

WHOQoL-BREF questionnaire

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

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

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

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

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5

24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 † + † + † + † + † + † + †	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) † + † + † + † + † + †	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 † + † + †	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 † + † + † + † + † + † + † + †	a. =	b:	c:

WHOQoL –BREF KISWAHILI

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

'Maswali yafuatayo yanajaribu kuchunguza jinsi wewe unavyohisi hali yako ya afya na maisha yako kwa jumla. Nitakusomea maswali na vile hiari za majibu ambazo unazo. Tafahdahli chagua jibu ambayo inalingana na maoni yako au ni karibu na jibu lako'

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

'Ukijibu maswali tafadhali jaribu ukumbuke kanuni, ridhaa, na shaka zako. Vile tungeuliza ukijibu wasali ukumbuke vitu ambazo zimefanyika maishani mwako kuanzia sasa na kurudi
nyuma wiki nne vilizo pita'

Codes:

Very poor (**Mbaya sana)**

Poor (**Mbaya)**

Neither poor nor good (**Sio mbaya wala sio mzuri)**

Good (**Nzuri)**

Very good (**Nzuri sana)**

1. How would you rate your quality of life?

 Je, ukikaripia hali ya maisha yako, je waweza kusemaje?

1 2 3 4 5

Codes:

Very dissatisfied (**Hai ridhishi sana)**

Dissatisfied (**Hai ridhishi)**

Neither satisfied nor dissatisfied (**Hai ridhishi wala haipendezi)**

Satisfied (**Inaridhisha)**

Very satisfied (**Inaridhisha sana)**

2. How satisfied are you with your health?

Je, unaridhiswa na hali yako ya afya?

1 2 3 4 5

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

'Maswali yafuatayo yana jaribu kupima maarifa zako kuhusu vitu mbali mbali katika wiki nne

zilizo pita'

Not at all (**Hakuna hata kidogo)**

A little (**Kidodgo)**

A moderate amount (**Kadiri)**

Very much (**Sana)**

An extreme amount (**Kabisa)**

3. To what extent do you feel that physical pain prevents you from doing what you need to do? **Ni kwa kiasi gani ambayo unaona kwamba maumivu ya mwili imekuzuiya kufanya vitu ambazo ungependa kuyafanya?**

       5 4 3 2 1

4. How much do you need any medical treatment to function in your daily life?
Ni kwa kiasi gani ambayo unahitaji matibabu katika maisha yako ya kila siku?

       5 4 3 2 1

5. How much do you enjoy life?
Ni kwa kadiri/kiasi gani ambayo wewe unafurahia maisha?

       1 2 3 4 5

6. To what extent do you feel your life to be meaningful?
Ni kwa kiasi gani ambayo wewe unaona kwamba maisha yako ina muhimu?

       1 2 3 4 5

Codes:

Not at all (**Hakuna hata kidogo**)

A little (**Kidodgo**)

A moderate amount (**Kadiri**)

Very much (**Sana**)

An extreme amount (**Kabisa**)

7. How well are you able to concentrate?

65

Ni kwa kiasi gani ambayo wewe unaweza kukaza fikira ju ya jambo?

1 2 3 4 5

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

Ni kwa kiasi gani ambayo wewe unahisi usalama wako katika shughli zako za kila siku?

1 2 3 4 5

9. How healthy is your physical environment?

Je, sifa za mazingira yako unayaonaje?

1 2 3 4 5

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

Maswali yanayofuata yanauliza uwezo wako wakupima maarifa yako au kufanya vitu fulani kwa wiki nne zilizopita.

<u>Codes:</u>

Not at all (**Hakuna hata kidogo)**

A little (**Kidodgo)**

A moderate amount (**Kadiri)**

Very much (**Sana)**

An extreme amount (**Kabisa)**

10. Do you have enough energy for everyday life?

Je, una nguvu ya kutosha kufanya shughli za kawaida za kila siku?

1 2 3 4 5

11. Are you able to accept your bodily appearance?

   Je, una ridhika na umbo lako au hali yako ya kimwili?

         1 2 3 4 5

12. Have you enough money to meet your needs?

   Je, una pesa za kutosha kutimiza mahitaji yako?

         1 2 3 4 5

13. How available to you is the information that you need in your day-to-day life?

   Je, maelezo ambazo unazotaka katika maisha yako ya kila siku unayapata?

        1 2 3 4 5

14. To what extent do you have the opportunity for leisure activities?

   Je, ni kwa kiasi gani ambayo unapata nafasi ya kupumzika na kufaragha?

         1 2 3 4 5

         <u>Codes:</u>
         Very poor (**Mbaya sana)**

          Poor (**Mbaya)**

          Neither poor nor good (**Sio mbaya wala sio mzuri)**

Good (**Nzuri)**

Very good (**Nzuri sana)**

15. How well are you able to get around?

Je, ni kwa kiasi gani ambayo unaweza kuwasiliana/kutembea?

1 2 3 4 5

Codes:

Very dissatisfied (**Hai ridhishi sana)**

Dissatisfied (**Hai ridhishi)**

Neither satisfied nor dissatisfied (**Hai ridhishi wala haipendezi)**

Satisfied (**Inaridhisha)**

Very satisfied (**Inaridhisha sana)**

16. How satisfied are you with your sleep?

Je, ni kwa kiasi gani ambayo unaridhishwa na uwezo wako wa kulala?

1 2 3 4 5

17. How satisfied are you with your ability to perform your daily living activities?

Je, ni kwa kiasi gani ambayo wewe unaridhishwa na uwezo wako wa kjiendelza katika maisha yako ya kila siku?

1 2 3 4 5

18. How satisfied are you with your capacity for work?

Je, ni kwa kiasi gani ambayo wewe unaridhiswa na uwezo wako wa kufanya kazi?

1 2 3 4 5

19. How satisfied are you with yourself?

 Je, ni kwa kiasi gani ambayo unaridhishwa na maisha yako?

1 2 3 4 5

20. How satisfied are you with your personal relationships?

   Je, ni kwa kiasi gani ambayo unridhishwa na uhusiano yako na watu wengine?

1 2 3 4 5

21. How satisfied are you with your sex life?

   Je, ni kwa kiasi gani ambayo unridhishwa na maisha yako ya kimapenzi?

1 2 3 4 5

22. How satisfied are you with the support you get from your friends?

   Je, ni kwa kiasi gani ambayo unridhishwa na usaidizi ambayo unpata kutoka marafiki   zako?

1 2 3 4 5

23. How satisfied are you with the conditions of your living place?

   Je, ni kwa kiasi gani ambayo unridhishwa na hali ya makao ambayo unaishi?

1 2 3 4 5

24. How satisfied are you with your access to health services?

Je, ni kwa kiasi gani ambayo unridhishwa na uwezo wa kupata huduma za matibabu?

1 2 3 4 5

25. How satisfied are you with your transport?

Je, ni kwa kiasi gani ambayo unridhishwa na huduma za usafirishaji?

1 2 3 4 5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

'Swali linalofuata linahusu mara ngapi wewe umehisi au kuarifu vitu mbali mbali katika wiki nne zilizo pita'

Never (**Hakuna hata kidogo)**

Seldom (**Kidogo)**

Quite often (**Mara kwa mara)**

Very often (**Sana)**

Always (**Kila mara)**

26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Je, kuhisi ya kuwa na hali ya moyo mzito, taruki au wasi wasi huja kwako mara ngapi?

5 4 3 2 1

Do you have any comments about the assessment?

Je, una maoni yeyote kuhusu maswala ambayo yameulizwa?