UNIVERSITY of RWANDA

Dissertation

LIVED EXPERIENCES OF KIDNEY TRANSPLANT PATIENTS AT SELECTED REFERRAL HOSPITAL IN RWANDA

By

RUDASHIRIKAKA JEAN DE DIEU

Registration number: 221027863

A dissertation submitted in partial fulfillment of the requirement for the degree of

MASTERS IN SCIENCES OF NURSING/ Nephrology

College of medicine and health science

Supervisor: Dr. Lakshmi Rajeswaran

Co-supervisor: Mr. Emile MUNYEMBARAGA

27th June,2023

DECLARATION

I, RUDASHIRIKAKA Jean de Dieu, hereby declare that this dissertation is my original work and has not been submitted and reported elsewhere. It has been submitted in partial fulfillment of the criteria for the Master's Degree in Nursing/Nephrology track at the University of Rwanda. I now further certify that a comprehensive list of references, including all information mentioned or quoted therein, has been submitted.

Signature: 

RUDASHIRIKAKA Jean de Dieu Date: 10.07/2023

Signature: 

Co-Supervisor: Mr Emile MUNYEMBARAGA Date: 10.07.2023

Signature: 

Supervisor: Lakshmi Rajeswaran Date: 10.07.2023

DEDICATION

This work is dedicated to all kidney transplant recipients as well as my family, who have supported me greatly and prayed for me the entire two-year journey.

ACKNOWLEDGEMENT

I want to sincerely thank and appreciate my supervisor, Dr. LAKSHMI Rajeswaran, for her excellent guidance and support during the planning and writing of my project. Additionally, I value the advice provided by my co-supervisor, Mr. MUNYEMBARAGA Emile. I am appreciative of all the professionals at the University of Rwanda's College of Medicine and Health Sciences, School of Nursing and Midwifery, Masters of Science in Nursing, and Nephrology Track. My sincere gratitude goes out to my exceptional classmates for helping me complete my two years of master's study in nursing, especially my classmate on the nephrology track. I'd also like to thank my coworkers for permitting the change to the duty schedule that allowed me to go to class. And finally, I'm grateful for my parents and other relatives for encouragement.

ABSTRACT

Background: A kidney transplant is the greatest treatment option for people with end-stage renal disease, but in addition to a higher quality of life, there are additional problems that could interfere with everyday activities because a kidney transplant necessitates ongoing contact with medical facilities. A kidney transplant patient will also need to alter their daily routines and engage in activities like self-checking, medication compliance, good hygiene, and drinking enough fluids. It was preferable to hear directly from the patients in order to better understand their experiences and get their opinions on medical care, wellbeing, and life adaptation following transplantation.

The study's aim: This study ‘s aim was to explore the actual experiences of kidney transplant recipients at a selected referral hospital in Rwanda.

Methodology: In this research, the experiences of kidney transplant recipients were explored. The phenomenology exploratory qualitative design was used to investigate the kidney transplant patients ‘experiences. To select and interviewing respondents undergone kidney transplantation, the Purposive sampling was used. The collection of data was done by using semi-structured interview guide and the content analysis method was used to analyze the data by the examination of narrative information to adequately represent every part of each piece of content, data has been arranged, coded and categorized to describe all aspect of each content and identify key themes.

Results: from the transcripts analysis, five major themes were emerged “Improved quality of life”, “Emotional challenge”, “Medical management”, “Healthcare system challenge” and “Cross cultural challenge”.

Conclusion: The kidney transplant patients face many challenges, and the management of medication is one among the main stressors along with the financial challenges and monthly hospital visits. The healthcare system should try to provide appropriate support for the kidney transplant patients for them to maintain the survival of the allograft for a longer period.

Keywords

Lived experiences, kidney, transplantation, Rwanda

ABLE OF CONTENTS

LIST OF SYMBOLS AND ABBREVIATIONS

CBHI: Community based Health insurance

CHUB: University teaching Hospital of Butare

CHUK: University teaching Hospital of Kigali

CKD: Chronic Kidney Disease

DBD: Dead Brain Donor

DCD: Dead Circulatory Donor

ESRD: End Stage Renal Diseases

GFR: Glomerular Filtration Rate

GVF: Genocide Vulnerable Fund

HD: Hemodialysis

ISN: International Society of Nephrologists

KFH: King Faisal Hospital

MBI: Body Mass Index

MMI: Military Medical Insurance

MoH: Ministry of Health

NCDs: Non-Communicable Diseases

RMH: Rwanda Military Hospital

RRT: Renal replacement therapy

RSSB: Rwanda Social Security Board

USA: United State of America

UTI: Urinary Tract Infection

LIST OF FIGURES

LIST OF TABLES

CHAPTER I: INTRODUCTION

1.1. Introduction

End-stage renal failure (ESRD) is best treated with a renal transplant, but in addition to a higher quality of life, there are additional problems that could interfere with daily activities because a kidney transplant necessitates ongoing contact with medical facilities. In addition, kidney transplant patient will need daily behaviors change and activities like self-checking, adherence to medicine, best hygiene and taking enough fluids. In order to understand better the patients 'experiences, it is mandatory to hear from them so that they express their thoughts on life adaptation after transplantation, medical provision and wellbeing.(1)

However, the experiences of kidney transplant patients in Rwanda are not yet identified. The current research will help to find out their experiences which in return may contribute to the quality of care provided to them.

1.2. Background

The end stage renal diseases (ESRDs) have an alerting rate regarding the prevalence where about 2 million are reported globally and about1.4 million are on renal replacement therapies. Due to the rise in Non-Communicable Diseases (NCDs) like diabetes and hypertension, it is predicted that the incidence increment rate will climb by 8% annually in low- and middle-income countries like Rwanda. Glomerular filtration rate (GFR) is less than 15ml per minute in ESRD, a condition in which the kidneys have lost all function. Then renal replacement therapy is needed which include hemodialysis, peritoneal dialysis and renal transplant.(2)

For many ESRD patients, kidney transplantation is the best course of treatment as it improves quality of life, reduces hemodialysis machine dependence, eliminates fluid and nutritional restrictions, restores the sexual function, allows the fertility and the potential of having children. For the cost it is estimated at one- fifth of annual cost of dialysis (3)

In the phenomenological analysis study conducted in United Kingdom, the participants revealed that the experiences post kidney transplant are influenced by the personal history of illness. They emphasized the difference between before and after transplantation as fatigue and inability to perform physical activity while able to work after. Many receivers also find it challenging to fully accept the generosity of donation due to their bond with their donor and the donated organ.

Uncertainty around the motivations of donors makes it challenging for the recipient to make sense of the experience because they are unable to envision reciprocity in this situation. After receiving an organ, one feels obligated to live a good life. Even the terminology used to describe the procedure—"gift" or "donation"—had an effect on the receivers' emotional connection to their donor.(4)

Although the kidney transplant is better than other RRTs (Renal Replacement Therapies), the patients 'daily life is affected because of continuing medical visits for follow up, medical prescription for life, instructions to prevent infection such as self-monitoring, hygiene and enough fluid taking.(5)

In qualitative explorative study conducted in Denmark, it was revealed that the kidney transplantation procedure was difficult and had an impact on daily life as well as to balance hope, promising future and concerns related to health. The challenges were related to waiting time where patient were thinking every time on the day they will get a donor to be free of disease suffering, transformation within the time of transplantation like hospitalization days and post-operative discomfort like pain, limited movement and finally the outpatient's consultations for follow-up but due to life restriction caused by renal disease they tried to balance return to normal life post-transplant and then hope outweighed the challenges (6)

Another study conducted in Iran, the participants showed improvements in quality of life, a return to normalcy, improved health, and increased vitality as changes after transplantation. Concerns included the length of graft survival, worries about to have another kidney transplant or go back on dialysis in the future, comorbidities, future quality of life, and the price of their medical treatment. Many transplant recipients were appreciative of their new organs, but some were concerned about the strain transplantation would have on their family members.(5)

In Pakistan, the patients claimed that their coping and adjustment processes both before and after the transplant were ultimately influenced by the attitudes and behaviors of their family, friends, partners/spouses, relatives, and coworkers. In the case of high scorers, a good connection helped their coping, whereas for low scorers, estranged relationships and sentiments of being a liability and undesired led to a sense of being distant and unwanted as well as a lower level of quality of life satisfaction. (7) Success narratives, revealed a favorable opinion of medical experts and how they were seen as saviors who restored their health and allowed them to resume their normal lives

while the less happy recipients, on the other hand, accused the medical staff of being ineffective because, in their opinion, the doctors failed to properly diagnose and treat them, forcing the patients to need a transplant as a result. (7)

According to the same study, having a strong commitment to following the recommendations for a lifelong immunosuppressant and nutrition plan helped patients' grafts stay healthy and last a long time. However, those who were less satisfied with their quality of life thought that taking their medications was a duty that would be too demanding for the rest of their lives. They also stated their worries about the harmful effects of taking these medications as prescribed and linked the unfavorable prescription side effects to the continued usage of immune-suppressants. (7)

In the qualitative study conducted in 2020 in sub-Saharan African countries, showed that in 10 out of the 53 nations, renal transplantation is carried out, although only five of them (Egypt, South Africa, Tunisia, Algeria, and Sudan) have ongoing programs that carry out more than 50 cases annually. Kenya, Nigeria, and South Africa had renal transplantation programs among the 47 sub-Saharan African nations, and they reported rates per million people of 0.60, 0.23, and 5.12, respectively. Unfortunately no studies regarding kidney transplant patients ‘experiences identified in this region (8)

Summary

Studies conducted in different countries revealed that following renal transplant, patients have different experiences in which some are positive, other negative such as physical, emotional, financial and behavioral changes. Some get improved physical as they got energy compared to the period pre-transplantation, other raised concern where immunosuppressive drugs for whole life is taken as burden, other feel guilt of the generosity of their donors to miss how to show them the reciprocity of the showed kindness; following medical visits and fear of graft rejection as concern too etc. In Rwanda, patients might have similar experiences but no study yet identified so this study is embarked on exploring the kidney transplant patients ‘experiences post kidney transplantation in Rwanda.

1.3. Problem statement

ESRD patients are often hopeful about the improvements that renal transplantation will bring to their quality of life in all areas of their lives (9). Having a functioning kidney transplant is one way that many patients expect to recover a sense of "normalcy" in their life. Although they may be thankful for their new kidney, kidney transplant recipients frequently experience guilt and feelings of fear after the operation. Changes in family dynamics, food limits, time constraints, functional limitations, drug side effects, changes in work, changes in sexual function, cognitive impairment, and awareness of imminent death are just a few examples of stressors. (10).Understanding patient experiences is essential to making sure they are taken into account when developing important strategies and future plans for renal services. Ignoring these crucial patient opinions increases the likelihood that improper renal service delivery and a lack of adequate support may negatively affect general health.(11)

However, in Rwanda kidney diseases especially renal failure are managed locally with dialysis in teaching hospitals (CHUB, CHUK, KFH/R, RMH) and currently in the private clinic known as Africa Healthcare Network (AHN): and more than 10 patients annually are referred to India for kidney transplant via medial referral board. The ministry of health is still looking for how in collaboration with foreign surgeons, transplantation may be performed in the country. (12) It is still unknown how those who have had a kidney transplant recipients adapt to the life after kidney transplantation in Rwanda which motivated the researcher to conduct this study in order to explore all experiences lived in daily life post kidney transplantation then taken into consideration by health care providers especially in nephrology care.

1.4. The aim of the study

This study was having the aim of exploring the experiences of kidney transplant patients in Rwandan context.

1.5. Research objectives

1.5.1. Main objective

To investigate the kidney transplant patients 'experiences in Rwanda context

1.5.2. Specific objectives

- To explore the patients' physical changes after kidney transplant
- To explore the patients' emotional changes after kidney transplant
- To identify the patients concerns regarding the self-care after kidney transplant.
- To identify the patients concerns regarding medical adherence after kidney transplant.
- To identify the needs or suggestions of kidney transplant patients for improving the quality healthcare provision.

1.6. Research questions

- What are the patients' physical status after kidney transplant?
- What are the patients' emotional status after kidney transplant?
- What are the patients' concerns regarding the self-care after kidney transplant?
- What are the patients' concerns regarding the medical adherence after kidney transplant?
- What are the needs of kidney transplant patient for improving the quality healthcare provision?

1.7. Significance of the study

The outcomes of this study will have a great importance in informing the health care providers especially in nephrology field about lived experiences of patients with kidney transplant in Rwanda and this may influence the healthcare providers how they provide appropriate holistic care to kidney transplant patients. The results will also allow researchers to use the currents information for future studies and the government to establish the ways of continuing the support of transplanted patients to avoid graft rejection considering the expenses spent for organ transplant process.

For nursing education: this research's results will contribute to find the gaps in transplanted patients care so that they use them in student nurses training for better patients 'holistic care.

For nursing practice: from understanding the experiences of kidney transplant patients, the health care providers especially nurses will be able to fill the gaps regarding the kidney transplant patients 'holistic care.

For nursing research: the research's findings will be the source of information for the future researchers.

For nursing administration: this research will provide the basic information for police makers so that they make some policies, protocols and guidelines for better management of kidney transplant patients.

In concluding, the researcher is expecting to find the information that would bring additional knowledge to health care providers especially nurses to support or advocate for better management of patients with kidney graft.

1.8. Definition of the concepts

Experiences: is the procedure of learning new things or improving the one's abilities by exposure, such as touching, doing, seeing, or feeling something.(13)

Lived experiences: are well-defined as personal knowledge about the world increased over direct, personally participation in everyday proceedings or actions. It may also refer to knowledge of people gained from direct face-to-face interaction.(14)

In phenomenology: Lived experiences are situated immediate activities and encounters in everyday experience taken for granted as reality.(14)

In this study, lived experience is defined as any change either positive or negative whether be it physical, psychological, social, financial and concerns gained due to kidney transplantation in Rwanda.

Kidney transplant: is when a healthy kidney is surgically removed from one individual and transplanted into a patient with end stage renal disease. The donor of kidney may be alive or dead and most experts agree that the best course of treatment for persons with ESRD is transplantation.(15)

1.9. Organization of the study

There are six chapters in this thesis:

The description of essential words, background information, a problem statement, objectives, and the significance of the study are all included in Chapter 1's introduction.

The examination of theoretical and empirical literature reviews is included in chapter two.

The research approaches employed are described in depth in chapter three.

Chapter 4: According to the goal of the study, this chapter presents the demographic information about the participants as well as the findings.

In Chapter 5, the research findings are compared to those of other studies on the experiences of kidney transplant recipients.

Sixth chapter: this chapter includes conclusion and recommendations.

1.10. Conclusion

The patients with end stage renal disease continues to increase as the leading risk factors are increasing too. so, the need for kidney transplant will also be in need continuously this is why it is important to be prepared and plan for a better management of kidney transplant patien

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

The researcher will synthesize the reading from many articles published on end-stage renal disease and kidney transplant patients' experiences in this chapter. These will be discussed under theoretical and empirical literature accessed from search data base such as Google scholar, PubMed etc. For most of the articles, the publication date is below 5 years. Search terminologies were related to the research topic the experiences of kidney transplant patients.

2.2. Theoretical literature

2.2.1. Introduction

In this literature, the researcher will go in the details about kidney transplant, indications, contra indication, types of donors, preparation for transplant and the complications. The search engines such as Hinari, Google Scholar, PubMed and NIH library utilized for literature review. The key words like live experiences, challenges, perception and barriers were utilized to identify relevant scientific studies. Studies conducted between 2012 and 2022.

2.2.2. Kidney transplantation

Since 60 years ago the kidney transplantation has been taken as the renal replacement therapy preferred comparing to other modalities due to their showed survival rate among patients suffering from end stage renal disease comparing to those on dialysis.(15) successfully done by Dr Joseph in 1954 ,kidney transplant evolves significantly as advancements regarding immunology and transplantation allowed for a wide variety of eligible kidney recipients. This brought high quality of life and survivorship even over 10 years than dialysis.(5)

Kidney transplant is considered the best course of treatment for those who develop end stage renal disease or CKD stage five “A complex and widespread illness, chronic kidney disease(CKD) affects over 37 million adult American and is associated with significant levels of mortality and mortality, increased prevalence and large public health expenditures(7) Stage five chronic kidney disease (CKD) where eGFR is <15 ml/min/1.73 m2,the need for RRT to survive is mandatory as severe alarming manifestations such respiratory distress ,itching, restlessness and nausea already installed with other consequences like disruptions or abnormal functioning of nervous system such as peripheral, gastrointestinal tract hemorrhage, tissue inflammation of the layers around the heart and changing in brain tissue or its functioning.(9)

2.2.3. Indications

End-stage renal disease (ESRD) which is becoming more increasing from Diabetes and hypertension; the two most typical etiologies of renal failure. Other reasons can be classified as post-renal (obstruction, reflux nephropathy), intrinsic renal (glomerulonephritis, focal-segmental glomerulosclerosis), pre-renal (chronic or acute ischemia), or intrinsic renal (glomerulonephritis). When a patient's chronic kidney disease (CKD) progresses to stage 4, which is indicated by a glomerular filtration rate (GFR) of less than 30 mL/min/1.73 m2, they should consult a nephrologist and receive information regarding kidney failure and treatment options, including transplantation. (16)

2.2.4. Contra indications

There two absolute and relative contra indications: The inability to endure surgery due to severe cardiac or pulmonary disease, active cancer, active infection, active drug misuse, or uncontrolled mental illness are absolute contraindications to kidney transplantation while relative contraindications include frailty, psychiatric issues, a short life expectancy, morbid obesity with a recommended body mass index (BMI) less than 40 kg/m, history of noncompliance with dialysis schedules or medication regimens, and others that may vary depending on the institution and geographical area (defined as less than the anticipated waiting time for a kidney).(16)

2.2.5. Patient selection

A big number of ESRD patients have many comorbidities and mostly are the ones led to kidney disease so it mandatory to well screen them before transplant in order to make sure if they will tolerate surgery or post-transplant immunosuppressant drugs.(10)

Three sub-patient populations are found as a result of the screening:

- Patients with a standard risk profile are those without complex co-morbidities like diabetes or heart disease within two years before the transplant.
- High-Risk Patients: These individuals are chosen by transplant centers based on the recipient's medical history, which may include obesity, diabetes, liver illness, or heart disease.
- kidney-pancreas patients: Patients who need a combined kidney and pancreas transplant(18)

2.2.6. Donor selection/allocation

Donors of kidneys might be either living or deceased.

Brain dead donors (DBD) and donors who donated after cardiac death are the two categories of deceased donors (DCD).

As the name implies, brain dead donors are those who have successfully met the requirements for a brain death test.

Despite not reaching the criteria for official brain death, patients who are identified as DCD donors are those who neurologists believe are unlikely to make a meaningful recovery from their neurological condition. When it comes to DCD donation, procurement can't start until the patient has been declared terminally extubated by a third party doctor and the heart has stopped beating.(16)

2.2.7. Complications

They can install as early or late complications such as hemorrhage always a possible during vascular surgery, both during the procedure and immediate post operatively. There may not be classic bleeding symptoms as tachycardia because most patients with end stage renal disease mostly take beta-blockers so may not react to hypovolemia apparently.

Thrombosis: Renal vein thrombosis carries a significant risk of transplant loss and may manifest as new-onset hematuria, abrupt-onset oliguria/anuria, and/or graft failure in the early postoperative phase. Arterial thrombosis is uncommon but often harmful and manifests similarly in the recipient, characterized by a sharp decline in urine output in a previously functioning allograft. Since ultrasound is widely used as a diagnostic technique, it should be requested in this situation.(16)

For late complications there may be infection: Since patients are immediately put on immunosuppression following surgery, infections are common. They are most severely immunosuppressed in the first three to six months following surgery, which increases their risk of infection at that time. The traditional nosocomial and bacterial infections that are most usually discovered in the first month after donation include urinary tract infections and surgical site infections. Other complications are Arterial Stenosis which installs later and most of the time has no symptoms. When graft function is compromised, ultrasonography evaluation frequently leads

to its identification. Angiography can be used for transluminal angioplasty and is both diagnostic and therapeutic.(16)

Lymphocele: During the exposure of the iliac vessels, the concomitant lymphatics are disrupted, which results in this complication. Therefore, careful ligation of lymphatic tissue should be carried out. Lastly, Urinoma often appears one week after transplantation and patients may experience pain and edema on the incision site, reduced graft function from compression, or infection, similar to lymphocele. An increased creatinine level in the fluid aspirate may help to confirm.(16)

2.2.8. Enhancing the results of kidney transplantation

Patients are first evaluated by nephrologists and hepatologists before being sent to a transplant surgeon because transplant is a multidisciplinary operation. After a referral is made and the patient is added to a transplant list, there are a number of further steps before an organ is allocated. When an organ becomes available, the transplant coordinators help with matching and allocation. Following admission, the patient undergoes surgery with the assistance of surgeons, anesthesiologists, operating room staff, and eventually, doctors from the intensive care unit.(16)

Changes in lifestyle, adherence to medicine, and medical monitoring are crucial for kidney transplantation success. As some medications, such as prednisolone, mycophenolic acid, and tacrolimus, have a tendency to cause high blood pressure, hyperglycemia, and hyperlipidemia, adopting a healthier lifestyle would help ensure the success of kidney transplantation. Immunosuppressive medications help prevent immune system rejection of the graft by the recipient..(19)

Additionally, patients must maintain good personal cleanliness, follow up with their doctor, and take their immunizations on schedule. Additionally, for some medications like tacrolimus, assessing the levels of medicines or their metabolites in the patient's bodily fluids may serve to assess medication adherence. Take into account variables including age, gender, family support, patient trust in the healthcare system, prescription side effects, and recommended diet types that may hinder medication or lifestyle adherence. Eliminating unneeded prescriptions, improving patient happiness, treating depression, and including patients in treatment selection are a few strategies that could improve adherence.(19)

2.3. Empirical literature

The empirical literature used in this study will concentrate on kidney transplant patients' experiences.

Renal replacement therapy is necessary for patients with end-stage renal disease since their kidneys can no longer properly operate to eliminate waste and excess water from the body. Kidney transplantation is one of the treatments.

According to a qualitative study conducted in the United States in 2019, the patients showed that following a lifelong routine of drugs, lifestyle modifications, treatment burden with a variety of components of care, the cost of medications and monitoring, interpersonal problems, and financial difficulties affect their wellbeing.(20)

Participants in a phenomenological analysis study carried out in the United Kingdom disclosed that a person's medical history affects how they feel life after a kidney transplant. The contrast between before and after transplantation was highlighted as being weariness and an inability to engage in physical activity, whilst being able to work after. Many receivers also find it challenging to fully accept the generosity of donation due to their bond with their donor and the donated organ. Uncertainty around the motivations of donors makes it challenging for the recipient to make sense of the experience because they are unable to envision reciprocity in this situation. After receiving an organ, feeling an obligation to live a good life becomes a moral burden. It was discovered that the emotional connection between beneficiaries and their donor was impacted by the language used to describe the transaction (either "gift" or "donation").(4)

In the qualitative study conducted in 2020 in United Kingdom , revealed that after transplant the recipient would be happy and content but in contrast they reported the emotional issues such worries related to the graft like not be sure or asked themselves about the duration of new kidney's survivorship, having acquired the new diseases from the donors, feeling guilt for those who are not yet be able to be transplanted while they were together at hemodialysis, felt isolated because no longer in touch with dialysis team and requested for psychological support from peers to psychologist.(21)

In Italy (2021), it was reported that the sexual activity in kidney transplant patents is not prioritized where it might be caused by the felling of fear of graft rejection and are not yet confident of the

guarantee of future life. all these stressing concerns impact on sexuality. Participants reported poor interest in sexuality and most of time they postpone it which lead to the family relationship disturbance among partners. although the sexual issues among kidney transplant patients is a concern , is not valued or taken in attention by health workers in their routine activities.(22)

In a qualitative study conducted in 2012 in Iran, it was revealed that patients had trouble finding information to help them manage their condition and protect their new kidney because the education they received before to transplantation was not in a consistent manner. Before transplantation, there was inadequate information about treatment, kidney transplantation, and supportive systems. After transplantation, there was inadequate information about post-operative care medications and complications, which resulted in a lack of knowledge about drugs used specifically for transplantation, how to avoid their side effects, the signs and symptoms of infections, or post-surgery care, as well as a lack of knowledge about help support in an emergency. Patients must therefore struggle on their own to increase their awareness and knowledge of maintaining grafts on one's own (23).

Kidney transplant patients transplanted after having used dialysis for a long time, develop complex changes physically, psychologically, socially and in self-management post-surgery. Patients have become able to participate in daily productive activities after the transplant procedure, but they have got many difficulties in the process of returning back to life. In this trajectory, they encounter with the dual character of physiology, mixtures of emotions, complicated social networks and postoperative self-management.(24)

Advanced renal disease patients describe a sense of loss and a shift in their future goals. Recipients of kidney transplants reported greater independence and a return to practically normal living, as well as an improvement in quality of life, physical activity, and function as compared to their pre-transplant lives. But in addition, the kidney transplant patients mentioned their concern for the condition of their allograft and worry that it would malfunction. (25)

The changes after transplantation comprises: improvements in quality of life, the back to the normal life, good health and strong. Distresses encompasses: duration of graft survival, fears about returning back to dialysis one day or necessitating another kidney transplant, comorbidities, future quality of life, the cost and quality of their healthcare. Most transplant patients were thankful for

their transplant, but few were concerned about the burdens transplantation engaged to their loved ones.(5)

In the qualitative study conducted in 2020 in sub-Saharan African countries, showed that in 10 out of the 53 nations, renal transplantation is carried out, although only five of them (Egypt, South Africa, Tunisia, Algeria, and Sudan) have ongoing programs that carry out more than 50 cases annually. Kenya, Nigeria, and South Africa had renal transplantation programs among the 47 sub-Saharan African nations, and they reported rates per million people of 0.60, 0.23, and 5.12, respectively. Unfortunately no studies regarding kidney transplant patients 'experiences identified in this region (8)

Summary: Even though different literatures revealed that the kidney transplant patients experience various changes and concerns such physical, emotional, behavioral, social-economical, the majority took place in developed nations, whereas patients in low-income developing nations like Rwanda may have similar experiences. So, this study is for exploring the kidney transplant patients 'experiences at selected referral hospital in Rwanda.

2.4. Research gap identified

According to a study of the literature, it was found that kidney transplant patients go through both positive and negative experiences. Due to the lack of research among patients who underwent kidney transplants in Rwanda, there is a significant information gap. The majority of studies were carried out in developed countries.

2.5. Conceptual framework

A conceptual framework is a collection of abstract and broad concepts put together to address a phenomenon of interest. It stands for connected concepts to explain an area of interest.(26)

Diagram 1: showing the application of conceptual framework

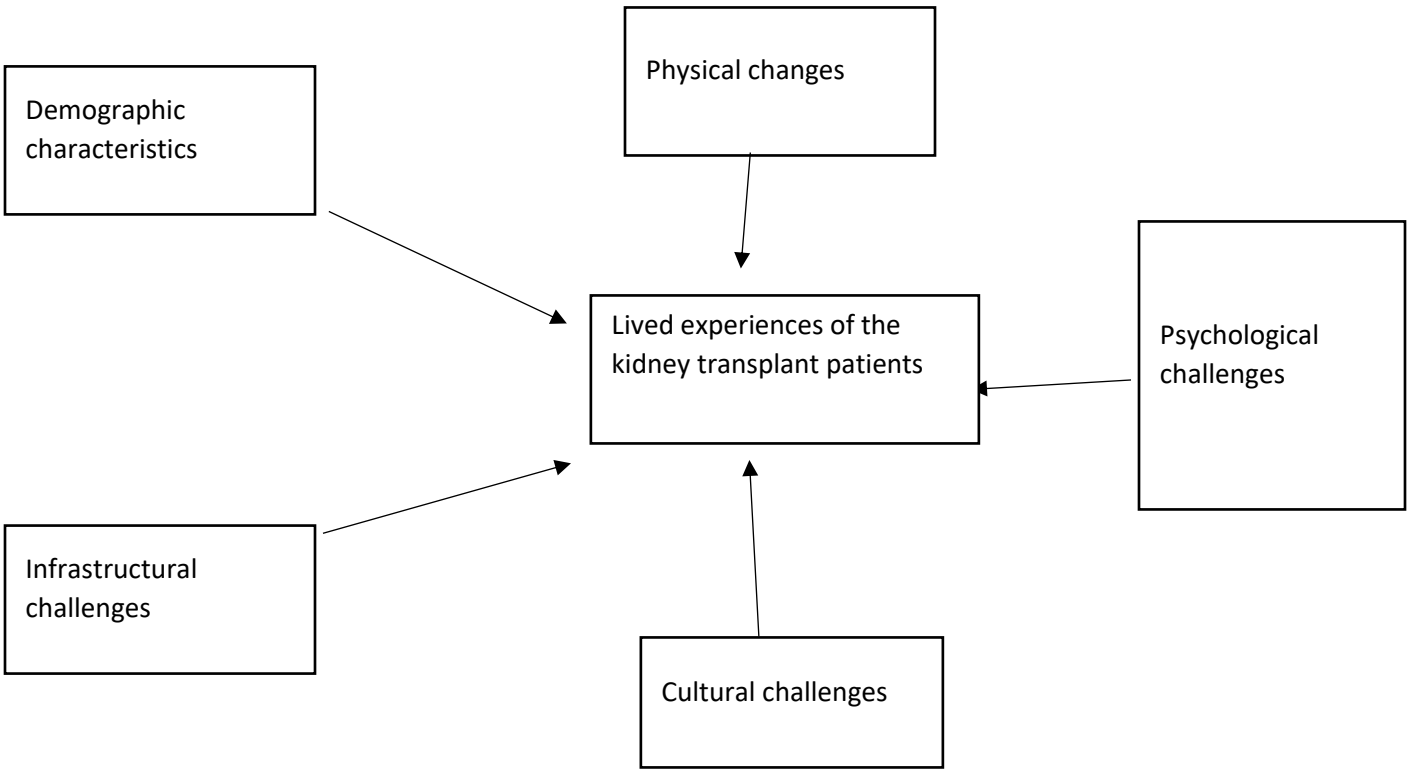

Figure 1. Application of conceptual framework

In this study the researcher evaluated the physical changes such as the return of physical strength, emotional challenges such as psychological changes related to life post-transplant, medical concerns such as medication adherences and affordability, cultural challenges especially how they lived in India and healthcare infrastructures challenges such as healthcare facilities accessibility ; all to find out the experiences of the kidney transplants patients at selected referral hospital in Rwanda.

2.6. Conclusion

Most of the studies have been conducted in developed countries. There is a paucity of literature on kidney transplant patients' experiences in context of Africa as well as in Rwanda particularly.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. Introduction

Under chapter three, it was discussed about the methodology used in the study including the research design, population, setting, sample size and sampling process, data collection tools, ethical considerations, data collection procedure, data analysis and study limitations.

3.2. Research design

A study's plan that establishes the primary framework for data collecting with the goal of producing reliable results is known as a research design. It is a process for selecting study participants, study sites, and data collection methods to address the research question. (27)

Phenomenology is a qualitative research method that explores the nature of daily experiences.(28).In this study, the experiences of kidney transplant patients were explored using the qualitative research method with the phenomenology exploratory design. The results of this study are descriptive. The design was chosen as it was utilized to explore and get the thorough understanding of experiences, concerns of kidney transplant patients and opinions for improving their healthcare.

3.3. Research setting

The location where the data for the study will be collected is referred to as the research setting.(29) This study was carried out in King Faisal Hospital Rwanda, a national specialized hospital located in Gasabo District , Kacyiru Sector, Kigali City. It is Self-managed hospital under government authority. It has been preferred because as the specialized hospital the government builds on day to day its capacity. It is the one which refers all patients abroad for kidney transplantation and is equipped for being able to manage them when they come back. In terms of specialized staff, medicines, laboratory and other investigations facilities. The bed strength is 160 beds.

The kidney transplant patients follow up facilities are laboratory able to analyze tacrolimus level, imaging facilities like CT scan and MRI to identify any allograft issue as early as possible and the availability of immunosuppressant drugs in the pharmacy.

3.4. Study population

The group of persons, objects, events, or elements that will be studied or elements in which the researcher will be interested during the investigation is referred to as the population. You might refer to it as a research or a target audience.(28)(29)

The study population in this research was composed by all kidney transplant patients doing post kidney transplant follow up at King Faisal Hospital/Rwanda within the study period. The total number was 97 patients as found from nephrology unit ‘s data base in collaboration with unit manager.

3.5. Sampling

Sampling is defined as the design which specifies the sampling method, sample size and process to recruit elements or subjects or the procedure used to select study participants so that they do representation of the population from where they were chosen(28)(29)

3.5.1. Sampling method

Purposive sampling was used in this study as sampling method and is defined as the procedure used to select and interviewing participants the researcher is sure that have been experiencing the event or phenomenon in interest.(28)

3.5.2. Accessible Population

Thirty-five (35) patients in all met the inclusion criteria, and they were included as research participants at the King Faisal Hospital's renal unit.

3.5.3. Inclusion criteria

Participants were post-kidney transplant patients on follow-up at a nephrology unit / KFH who

- could express themselves in Kinyarwanda or English language,
- able to communicate verbally,
- mentally healthy and able to consent,
- volunteering to participate,
- aged over 18 years.

3.5.4. Exclusion criteria

The researcher excluded all patients

- diagnosed with kidney rejection,
- who didn't consent,
- unable to communicate verbally,
- mentally unstable and
- under 18 years old because are not mature enough to consent on their own decision.

3.5.5. Sample size

13 participants made up the sample size for this study, which was based on the idea of data saturation. The saturation, according to Polite and Beck, is the moment at which a qualitative study has amassed enough data to feel complete because additional data just produce duplicate information.(29).

After the thirteenth interview, where individuals repeated information from earlier interviews, the data became saturated because no new information was arriving from the participants.

3.5.6. Sampling strategy

Choosing and interviewing people who have really experienced the phenomenon of concern is a procedure known as purposeful sampling.(28)

Purposive sampling was employed in this study to identify participants who had undergone kidney transplantation. Patients with kidney transplants who matched the inclusion requirements for this study were chosen by the researcher. Copy of ethical permission from KFH/IRB was provided to the unit manager of the renal unit, and information was made apparent to all of the unit's nurses. The nephrology unit nurse manager provided the list of patients who were in follow up. In collaboration with unit manager the list of 35 patients who were assumed to collaborate well was extracted then through the call center of hospital all phone contacts were found and the researcher approached the participants one by one for consent and interview.

3.6. Trustworthiness of the Instrument

In this study, the researcher employed an open-ended, semi-structured interview guide to encourage patient discussion of their experiences. Together with the supervisors, the tool was created based on the literature review. The development of the instrument benefited from the assistance of another qualified qualitative researcher.

The first component of the study included the demographics of the participants, while the second section focuses on the experiences of kidney transplant recipients. Interviews were recorded on audiotape, and field notes were collected all throughout the session. To evaluate the tool's reliability and validity, a pretest with only two participants was conducted. So, after two interviews the researcher realized that the questions were well understood and provided the appropriate and consistent information according to the research question. The reason why after two participants the tool was decided to be used for whole data collection.

Credibility, dependability, confirmability, and transferability were highlighted by Lincoln and Guba as factors ensuring the reliability of qualitative research.(30).

Every requirement was taken into account in this study, and the following table shows the methods that were employed to meet each rigor. It demonstrates the steps the researcher took to achieve each in order to make the study worthwhile.

Table 1**: Strategies adjusted from Lincoln and Guba**

RIGOR CRITERIA	**DEFINITION**	**STRATEGY USED TOATTAIN THE RIGOR**
Credibility	It is the procedure used to establish confidence that the results are accurate or true, realistic and convincing.	The researcher spent enough time with participants to create good rapport and co-operation. The interview was done by the researcher himself, as he has the appropriate knowledge and research expertise or skills to do his research activities. he used the field notes, analyze them and store them

		correctly. The supervisor and co-supervisor were contacted regularly for debriefing. The data were transcribed and the patients was asked if the data are reflective of their own lived experiences.
Dependability	This is defined as study ability to provide stable data over time and outcomes repeatable within the same cohort of participants, coders and context.	The detailed drafts of study protocol were prepared during the study. The detailed record of the data collection procedure and the documentation of all the data were done throughout the data collection process.
Confirmability	This is the neutrality or the degree of study's findings to be consistent once repeated by other researchers.	The researcher provided the journals and meet often with the supervisor.
Transferability	The degree to which the study results can be attributed to other settings or generalized in other context or setting.	The researcher used participants who really lived the experience as kidney transplanted under follow-up and data collection continued until the saturation reached. To make sure that the member enrolled in the study were ones interviewed and reminding them what the study was about before interview.

Source.(30)

3.7. Data collection

3.7.1. Data collection instrument

Introduction: Hello, I am RUDASHIRIKAKA Jean de Dieu, a Masters in nursing student specializing in Nephrology Nursing. In order to better understand the experiences of kidney transplant recipients at a particular referral hospital in Rwanda, I am undertaking a study. It is my hope that this study's findings may help kidney transplant recipients obtain the proper care they need from medical professionals. I am aware that everyone's post-kidney transplant daily life is going to be different. I would appreciate it if you could give me the best possible answer to the questions I will be asking you. Your entire response will only be used for research purposes.

Ice breaking question

1. Tell me "Are you happy that you have got kidney transplant"?

   Major Interview Questions, the researcher probed and prompted the participants to understand deeply:
2. Can you please share your experiences after transplant?

   The researcher probed with some questions regarding physical (Fitness, exercise, daily work, and emotional status (sleeplessness, mood changes, upset with self, etc.); about the medications taking ordered after transplant? (Adherence, availability, accessibility, assistance from family members)
3. Can you please share about self-care in maintaining your kidney healthy? E.g. I may probe on barrier if not mentioned related to Health system access, doctors' appointment, getting medications, dietary consultations, counselor and financial.

4. Can you please share how you get the family support after kidney transplant? (socially and financially)
5. Can you please share how was the process to find the donor and your relationship?
6. Can you please share how was your mind set while you were preparing for the kidney transplant?
7. Can you please share how was the life or your experiences while you were in India?
8. Do you have any suggestions to the hospital or the ministry of health regarding providing care for the renal transplant patients?

3.7.2. Data collection

An in-depth face-to-face interview was performed to allow participants to communicate their feelings and opinions in order to cover the study's objectives. The record of kidney transplant patients being followed up was collected from the renal nurse in charge after getting the appropriate authorities' ethical approval, and the patient with the best communication was then picked. After obtaining their phone numbers, the researcher gave the participants a brief explanation of the study's objectives before giving them the option to continue or discontinue participation. Thirteen (13) individuals consented to the interview and gave their consent.

The researcher arranges the room for interview for those interviewed at KFH in the internal medicine ward in separate room and others held at participants 'home they were arranging the meeting like in their living room without interruption. No disturbance sign was hanged outside the interview room.

After obtaining the participant's consent, the researcher probed and prompted questions during the interview to allow for explanations and recorded the conversation on audiotape. Additionally, nonverbal communication field notes and observations were noted. One person was interviewed for 30 to 45 minutes. All exchanges took place in Kinyarwanda. Due to budgetary restrictions, there was no research assistant.

3.8. Data analysis

In order to comprehend the data at the lowest level of abstraction possible in order to address the research topic, the researcher employed the content analysis method to summarize the data's observable and intelligible components. Data were organized, classified, and categorized to describe every feature of each piece of content.

The qualitative content analysis is the evaluation of narrative information to discover significant themes and accurately portray every component of each piece of content.(28)(29)

The data was arranged, coded and categorized in order to describe all aspects of each content.

The data was coded using three levels of coding.

Level 1 coding: The researcher and the supervisors went line by line through the data and created codes based on the language used by the study participants.

Level 2 coding: After grouping the coded data as a result of level 1 coding being compressed, categories were produced. We compared the coded data and developed categories after the supervisor also created categories and coded data.

Level 3 coding: From the categories that appeared during coding, the main themes were formed.

3.9. Ethical consideratio

In order to gain access to the study settings, permission was granted by the King Faisal Hospital's research committees with approval letter referred as **KFH/2023/054/IRB** and the University of Rwanda's (UR) college of medicine and health sciences' internal review board (reference: **CMHS/IRB/577/2022).** All prospective participants were given the assurance that participation is entirely voluntary and that declining to participate will not result in any consequences. Additionally, it was made clear to participants that they might stop taking part at any time. To keep the information anonymous, a name was not required.

Only those subjects signed the consent form were interviewed for the study and only the researcher and the supervisors had access to the written notes and audio recordings, which were both stored behind locked doors.

Privacy

The interview was conducted in a separate room.

Protection from harm

In order to prevent any issue which may raise during the interview such as the emotional crisis, the researcher used non emotional exciting questions.

Confidentiality and anonymity

Only the researcher accessed to the written notes and audio recordings as they were kept in locked places and names were not required to ensure the confidentiality of the data. All the participants were identified by the code numbers.

Informed consent

All participants were given the reassurance that participation is voluntary and that declining to participate didn’t result in any consequences.

Only those participants who choose to take part in the study signed the consent form and negotiate the time for the interview.

3.10. Data management

After the interview was over, the recorded information was transferred from the recorder to the computer, played back, and then transcribed into a word document. English version was translated from the Kinyarwanda version. The participants received the code number until the last participant (PART I – PART XIII). The recorded interview after being coded was kept in computer and folder protected with password.

3.12. Limitation of the study

Methodological limitation

- **Lack of prior research:** During the literature review, the researcher experienced the lack of previous studies conducted in the context of Rwanda on experience of kidney transplant patients.
- **Measure used to collect the data:** The researcher used the tool developed based on literature review because there was no tool used in other settings to be borrowed and contextualized.
- **Self-reported data:** Because the researcher explored the experience of kidney transplant patients, the data that were given cannot be verified, it is believed to be true. they may remember or not remember the experience that occurred in the past. They can also attribute positive actions to his own and attribute negative to someone else.
- The researcher met the difficulties related to the skills in the qualitative study as was the first time to conduct it, to overcome this limitation the researcher met as frequent as possible with the supervisors to share the work and challenges in order to corrects any mistake as soon as possible

Study site limitation

- The researcher met the problem of not getting the permission for data collection at one of the planned sites of the study.

Sample size limitation

- The participant might not respect the appointment of interview due to different challenges or daily life activities to overcome this limitation, the researcher adapted to the participant convenient time and joined him/her at his or her convenient place.

Financial limitation: the researcher was self-sponsored; so, met some challenges like recruiting the assistant researcher.

CHAPTER FOUR: RESULTS

4.1. Introduction

In this chapter, the data generated from participants on lived experiences of kidney transplant patients were described. The researcher conducted a face to face interview by means of interview guide then data were transcribed verbatim then translated to English. The categories and themes which emerged were created and quotations from participants were presented under each. Demographic characteristics and different themes are presented.

4.2. Demographic characteristics of respondents

The study used 13 study participants; they were between the ages 25 to 63 years old. Only three of them were female while ten others were male. On marital status nine were married legally, three singles, 1 cohabitants or illegal marriage. On education level, 1 had primary; 3 secondaries,5university and other 4 didn't finish secondary school. On Ubudehe 9 were in category 3; 3 were in category 2 while 1 was in category 1.

Regarding occupation of the participants 3 were farmers, 4 had no occupation, 1 teacher, 1 soldier,1 student and 3 technicians. on kidney transplant duration it was ranging from 1 year to 11 years, and to their home residence were coming from rural area and Kigali city. Most participants were from Kigali City where four (4) were from Gasabo, four (4) from Kicukiro and one (1) from Nyarugenge districts. The Eastern province, participants were from kirehe (one participant) and Western province (three participants). For insurance the majority use CBHI (Community Base Health Insurance) and GVF (Genocide Vulnerable Fund) with 4 for each; 2 used RSSB (Rwanda Social Security Board); 1 for Military medical insuarance(MMI) and Ministry of Defense(MoD); 1 used UAP and the last used the Ministry of Health support(MoH). For the place of kidney transplant the majority went at Yashoda Hospital with 7; others went at Global Hospital, Mumbai Hospital, Bangarore Hospital, Miote hospital and Continental hospital and Madalas medical mission hospital. The summarized details are in the attached table of characteristics of participants.

Table 2: Socio demographic characteristics

	Age of patients		
Gender	**N**	**Minimum**	**Average**	**Maximum**
Female	3	34	39	48
Male	10	25	46	63
Total/Average	**13**	**25**	**44**	**63**

Marital status	**N**	**Duration PT**	**N**
Married	9	Less than 5 years	5
Single	4	5 years and above	8
Total	**13**	**Total**	**13**

Educational level	**N**	**Ubudehe category**	**N**
Bachelor	4	Category 1	1
Diploma (A1)	1	Category 2	3
Primary	1	Category 3	9
Secondary	7	**Total**	**13**
Total	**13**		

Table 2: Socio demographic characteristics (con't)

Occupation	**N**	**District**	**N**

Farmer	3	Gasabo	4
None	4	Kicukiro	4
Student	1	Kirehe	1
Technician	3	Nyarugenge	1
Employed	2	Rubavu	1
Total	**13**	Rutsiro	2
		Total	**13**

Insurance	**N**
CBHI	4
GVF	4
MMI	1
MOH	1
RSSB	2
UAP	1
Total	**13**

4.3. Emerging themes

The aim of this study was to explore the lived experiences of kidney transplant patients at selected referral hospital in Rwanda.

After analysis, the themes and categories which emerged are summarized below

Table 3: Themes and Categories

CATEGORIES	THEMES
Happy/hope Satisfaction/Return to normalcy	Improved quality of life
Fear of rejection Frustration Lack of medical insurance Guilt	Emotional challenge
Cost of the medicines Post-transplant regime Non-availability of the drugs Transport issues	Medical management
Non availability of the Nephrologist Cost of the investigations Counselling facilities Non availability renal nutritionist	Health system challenges
Food Language Foreign land	Cross cultural challenge

Lived experiences of kidney transplant patients

4.3.1. Improved quality of life

The quality of life is defined as the individual's perception regarding his/ her ability to participate in or enjoy life events; when is feeling healthy, comfortable and refers to both the experiences and the conditions in which he or she lives. It can be defined also considering the individual wealth or level of satisfaction or capabilities; it encompasses emotional, physical, material and social wellbeing.(31)

Most of the patients expressed their gratitude of having received the kidney transplant which helped them to be free of hemodialysis and associated suffering. It helped them to eliminate normally and drinking water freely. They got stronger than before the transplantation at the level they are able to work, to perform daily living activities such as continuing schools, wedding and giving birth etc.

To describe these experiences, they have said in the following words

Happy and hope

Participant 1 said how he is feeling after kidney transplant compared to the pre transplantation status.

"Comparing with the status before the transplant when I was on Hemodialysis now I am good and I feel stronger. I go to work and I feel better; I am happy because before I felt incapable for everything and when you are not able to do things you don't think well but now there is hope, I can work at tolerable level according to instructions given after transplant and I am caring for myself". (PART 1)

Participant 2 stated how to get kidney transplant made him very happy and hope of life comparing to the status before while on hemodialysis

The patient said "starts laughing a lot: hhhhh, When I was sick I was depressed with no hope of life but after kidney transplant I am so happy because it added my days of life, I participated in my children's weds, I drive myself and supervise my projects (farms, motel etc.)". (PART 8)

Another participant describes his life while was on Hemodialysis and the one after kidney transplant

"It is of great value to have been given the kidney because before I was hopeless life, it was like I lived at hospital: dialysis every 2 days but after I got kidney the life continued, I came back to school from secondary to university level, I got married and getting child, I work and now I only come at hospital for medicines and medical follow up" (PART 4)

Satisfaction and return in normalcy

One participant reported how the life before transplant was very challenging than after getting kidney transplant

"Before the transplant I was too tired, sleeping all the time and unable to go to work with weight loss. I spent more time at hospital on peritoneal dialysis which was only done at hospital in that time but after kidney transplant I felt the life back, the pain went away and after 3 months I went back at work, so I am happy of having got the kidney transplant; in brief the life has been restored (PART6)."

Second participant narrated how was the life before and after kidney transplant

"Before transplant I was very weak, suffering from hemodialysis and other complications but after transplant my life returned normal; I am very happy because it cured my disease, I have given birth now my child is 2.6years old, I resumed my work as a teacher and I even sometimes cultivate in my banana plantation" (PART 11)

Another participant said how he was about dying before transplant but after he has hope of life for a long time:

"It is amazing to have got the kidney transplant because before I was hopeless of living but the transplant helped me to return in good life; physically there is good improvement because before I was no longer working at the level my employer had stopped my job but now he found that I get stronger and resumed my work even though the working hours are reduced as I am not yet at the same level as before I got sick but I try my best." (PART 2)

4.3.2. Emotional challenge

Emotional challenge is very distressing situation which causes strange and unusual behavior with irresistible feelings of anguish and irritation, which can sometimes make a person lose touch with reality, self-harm, or ruin or destroy relationships.(32)

The participants expressed the emotional effects related to the life post kidney transplants where some had the fear of rejection, frustration at their working place, fear of not be able to afford the immunosuppressant drugs and guilt of putting the donors at the risks during transplantation process.

Fear of rejection

First participant describes how is felling about the future of his new kidney

"when I get sick like lastly where I was told that my kidney was not working well, I started to think where I was before transplant and what if I return in the same life so I got anxiety but when I get healed the life continued normally". (PART 4)

Second participant described what affects him and causing to think on possible kidney rejection:

"I think about the future of my family if one day the drugs are not available or being attacked by other disease leading to my kidney failure that will affect my family so the thoughts like those come always in my mind otherwise I hope that if I respect instructions as required my kidney will not fail. I always pay attention to undertake my kidney as I remember how to find a donor is difficult" (PART 5)

Another participant reported how is thinking about the kidney rejection

"Because at the time the drugs were so expensive and my insurance didn't cover the medicines so I always thought about if I miss the medicines. I paid around 200k monthly without insurance so sometimes I miss doses and medical follow up which cause me to be in worry of my kidney rejection". (PART 6)

Frustration

One participant describes the situation that is challenging at the working place

"The issue is that where I work sometimes they appoint me to work as normal person because they see me physically stable or fit which worries me that can harm my kidney and even rejection, they don't give me the motivation or promotion as other people thinking that I am handicapped while I do the same work as my coworkers". (PART 1)

Second participant described how her relationship with husband has been changed since she got kidney disease until post transplantation

For family relationship in post kidney transplantation life the patient said "there is big problem with my family because my husband doesn't support me appropriately since during time I was on

Hemodialysis. Sometimes the nurses contributed for my transport to go home from Hemodialysis. My husband doesn't help me, if he was having to choose he would reject me." (PART 13)

Another participant reported how thinks about working for others so that even to look for a job is challenging for her

"We need that the government avails the fund for the kidney transplant patients. They can start their own business because to work for other persons sometimes is difficult where they can give you hard work while in your own business you can manage yourself." (PART 7)

Lack of medical insurance

The participants described problems related to the lack of medical insurance as below;

One participant said how to not having the medical insurance affect him as doesn't get the medicines appropriately

"I may not sleep well due to many thoughts regarding the medicines that one day I will not afford them as must be taken for life which may lead to the rejection and returning on Hemodialysis so all those disturb my sleeping". (*PART 10)*

Another participant describes how to maintain kidney healthy without medical insurance is a big problem

The patient said "the medications are expensive and we struggle to get them the reason why since 9 months my kidney is still healthy but without support it is not sustainable for whole life while we know the risk of not taking them regularly". (*PART 2)*

Third participant reported the issue of not having the medical insurance and how it makes him to be worried of his kidney health if it continues so.

"I always think about if I miss the medicines. I pay around 200k monthly without insurance so sometimes I miss doses and medical follow up which cause me to be in worry of my kidney rejection". (*PART 6)*

Guilt

The participants described how while waiting for being transplanted they were worried of the risks of death or other complications related to surgery and anesthesia to their donors

One participant said that was happy to go for kidney transplant but worried of her sister who might be having the surgery related complications even death

While preparing to go for transplant the patient said" I was very excited with too much joy even though it was something strange to me there was no other way to heal but sometimes I thought about my sister who was going to be operated while was not sick" (PART 1)

Another participant reported how was afraid of the life of her sister put at surgical risk while healthy

While preparing to go for transplant the patient said" I felt very happy, I didn't have the fear because of suffering on Hemodialysis. I only waited the date of doing it but I thought on my sister's life which was put at risk until I tried to rend her afraid by asking some questions like if she was not afraid of surgical and anesthesia risk such as dying but she replied that she had already taken decision and was ready for everything might happen" (PART 11)

Third participant reported that was afraid to come back in Rwanda behind the dead donor while was the one who was healthy. *While preparing to go for transplant the patient said" I thought about healing but later I thought on the risk of the donor. I wondered if she dies from surgical complication how I can come back behind the dead body while is me who should die" (PART 13)*

4.3.3. Medical management

Medical management refers to a coordinated process or system that ensures the appropriate use of healthcare resources over the course of care (from preventative to end-of-life care), in the quantity and for the length of time required to accomplish targeted health outcomes.(32)

The most participant described the issue related to medical management in post kidney transplant where some mentioned the problem of not having the insurance that cover the medicines and laboratory analysis which are normally mandatory every month while others reported issue of the price at extent even some who use insurance are unable to afford the percentage must be paid and lastly other reported the transport fees to reach the specialized healthcare facilities in Kigali all without counting the fees for eating and other daily living needs such as healthy diets..

Cost of the medicines

One participant reported how is difficult for kidney transplant to afford medicines whatever financial status because they are very expensive

One participant said" before I respected the instructions regarding medication and medical checkup but after my work was ended and my medical insurance expired I do no longer respect them regularly because without insurance I spend around 100k for consultation and laboratory analysis and to find nephrologist appointment with CBHI system of transfer is not easy. All of them affect me in respecting medication and follow-up instructions". (PART 6)

Another participant described how is difficult to afford medicines despite insurance

The participant said "the money for buying medicines is a big issue because are expensive, there is a time I missed money to buy them and I requested for the support at my district authorities. they bought medicines of 3 months while I was trying to look for capacity. Imagine, if that happens to me while I have a job(Teacher) and RSSB insurance what about the private patients. Even 15% is heavy plus other expenses like transport and medical checkup." (*PART 11)*

The third participant reported how is difficult to respect the medication instruction due to financial limitations

"the main issue is about finding money to buy them because no insurance. My mum spends more than 230 k monthly so sometimes we don't get money where for not missing the doses I try to borrow from my colleagues while waiting to find money." (PART 10)

Post-transplant regime

Most participants revealed an issue regarding to find healthy diet after kidney transplant due to huge amount of expenses for medical services and lack of financial support.

One participant describes the challenges regarding appropriate feeding while needed for staying healthy, said *"For nutrition it not easy to respect the required regimens because it is expensive because, if I don't have enough money to buy potatoes how I shall buy an apple for example! So, even though I have medical insurance but I have Limitation to other daily livings needs due to finance issues thus I use the normal diet". (PART 4)*

The second participant reported how is difficult to afford healthy diet despite the good medical insurance

"I have financial limitation paying the daily needs like healthy nutrition. I live here at Kigali supported by government with 50 k per month so rent the house and solving other daily financial problems is not easy". (PART 7)

Another patient described how is unable to respect the protocol of taking medicine as told while was in India to prevent some drugs effects like stomach irritation due to financial limits

"The challenge is about the finance as the protocol I had from India stated that morning at 6 am, I should take 500 ml of hot milk, at 7am water like 1 liter or more then at 8 am you take tacrolimus, then at 9 am taking breakfast (tea, eggs and bread or fresh food) plus MMF and prednisolone all for preventing stomach irritation. Unfortunately, me I don't get them due to lack of money and financial support from any one". (PART 13)

Non-availability of the drugs

The participants described the challenges regarding the availability of the immunosuppressant drugs in both private pharmacies and in hospital

One participant said that sometimes the drugs may be out of stock and you risk to miss the doses

"Sometimes you can go to pharmacy and some of them are stoke out, you try to borrow from colleagues but if it delays to be available that can affect the patients with risk of rejection". (PART 1)

Another patient reported the stock out of the medicine which make him worried that one day they may miss the drugs and lose their kidney

"In life as transplanted we have to have discipline; to respect the given instructions but some challenges are there because those drugs are not available in many pharmacies especially at district hospital level or rural areas so to find them require to do long distance to Kigali or at Gisenyi in one military pharmacy (Mediasol pharmacy). These drugs are mostly in 4 pharmacies only in Kigali and at King Faisal Hosptal, some drugs may be out of stock which lead to run up and down in different pharmacies in Kigali". (PART 9)

The third participant reported that the drugs are important for them to continue in normal life but some challenges like process of renewing the covering letter provided by ministry of health which is his insurer delayed and cause the risk of medical interruption

"During the renewal of the medical assistance, the process also delays which can cause the lack of medicines and sometimes the drugs may not be available in the pharmacies". (PART 5)

Transport issues

The participants described how to access the nephrology services is challenging especially regarding transport fees from the rural area to Kigali

One participant said that can sometimes not respect medical instruction due to the transport issues

"To try to respect the medical checkup and medical prescription when I don't Have enough money for transport, I go at Kibuye hospital to look for the internist. Post-transplant medication is a big problem because are not covered by community health insurance while is used by the majority of Rwandese, even me using RSSB(RAMA) 15% is not easy; I spend more than 50k monthly for medicines so plus medical checkup, transport etc". (PART 9)

Another participant reported how transport fees are challenging for medical management

"I have a job(Teacher) and RSSB insurance but even 15% is heavy plus other expenses like transport and medical checkup. For medical checkup I don't respect, I can do it once in 2 or 3 months because no enough money at the level my Doctor nephrologist can call me saying that has missed me. Most of time I negotiate the internist here at Kibuye Provincial hospital to get some prescriptions or lab request for checking some tests as creatinine only". (PART 11)

The third participant stated how the transport fees used in his trajectory process of disease has affected the family life balance especially financially

"My family supports me as they can but the issue is about the family expenses used for my medical services and due to long time of disease from the time of Dialysis, the transport and accommodation fees in India, to buy medicine after transplant all caused me to sale my different things of value which affected the family daily living style". (PART 6)

4.3.4. Healthcare system challenge

The participants described the issue in accessing health facilities both for medication and medical follow-up. Most participants reported the insufficient of health services in different level of healthcare in Rwanda where the lack of enough nephrologists and specialized staff cause them to spend more money to go where they are and risks of skipping some medication doses and medical checkups due to lack of transport fees. They would request for availing the nephrology services and post kidney transplant medicines at District and Provincial hospitals.

One participant reported the difficulties met during covid – 19 due to the unavailability of nephrology service at the nearest hospital

"Regarding post-transplant medication, the patient said "I try to respect medical instruction appropriately but during covid- 19 I got a big problem of getting the medicines due to lock downs and lack of public transport and I started to divide the doses by two for prolonging them then I started having some health problems". (PART 11)

Non availability of the Nephrologist

First participant reported the challenge met when gets sick and reports at accident and emergency where was received by other doctors and spent the whole week without nephrologist visit in the ward

The patient said" in Rwanda we don't have the nephrologist to help us appropriately; you can get sick and going at emergency received by the other doctors who are not knowledgeable in nephrology domain and they treat you at their level but there is a risk of harming your kidney. Even when admitted no nephrologist for daily follow-up, for example last time I got urinary infection, at A/E the nephrologist ordered medication and admission via phone. After 5 days of injection no improving I decided to go back home. I called my nephrologist who then sent the doctor in nephrology fellowship to discharge me. When he checked the results of admission lab analysis found the bacteria not sensible to the antibiotics I was put on. So Imagine if didn't call! That showed how we need permanent nephrologists". (PART 13)

Second participant stated that not having the nephrologist at peripheral level is challenging in post kidney transplant healthcare services especially for those who live in rural far from Kigali

"The nephrologists are too few as well as the internist while they are only ones allowed to prescribe the medicine and laboratory requests for some medical insurances. To try to respect the medical checkup and medical prescription when I don't Have enough money for transport, I go at Kibuye hospital to look for the internist. For medical checkup I spend fees for transport and the lodge for 2 days for nephrology consultation at Kigali, I Spend. For tacrolimus level test: the first day I do consultation for getting lab request, to be ready for sample taking next day as the sample might be taken as aery as possible in morning at 8 am while the nephrologists start working at around 10am. All these require me a big amount of money which then cause me to do medical checkup once in three months". (PART 10)

Third participant reported how the lack of nephrologist permanently is challenging in the kidney transplant patients especially in medical follow-up

"The nephrologists are still few which cause the problem that once you miss the Doctor, you don't have other alternative easily and out of appointment you can't find the nephrologist, this sometimes causes the delays in medical checkups or medicines prescription renewing". (PART 5)

Cost of the investigations

The participant described how medical checkups are cost and that handicaps their capacity to do medical checkups appropriately

One participant said that when he had medical insurance respected the follow- ups but nowadays does not because uses community bas health insurance (CBHI) which doesn't cover it

"I respected the instructions but after my work was ended and my medical insurance expired I do no longer respect them regularly even medical checkup because without insurance I spend around 100k for consultation and laboratory analysis and to find nephrologist appointment with CBHI system of transfer is not easy. All of them affect me in respecting medication and follow-up instructions". (PART 6)

Another participant reported that would like to respect all post kidney transplants instructions but has financial limitations.

For self-care to maintain the kidney healthy, the patient said "I try to respect the advices given except the medical follow-up that some - times I don' t respect due to lack of money which cause me to skip like one month." (PART 12)

Third participant reported how the cost of investigation doesn't respect the required medical follow-up and investigation especially tacrolimus level.

"With RSSB, I spend more than 50k monthly for medicines without transport and lab tests. To ease it for medical checkup I can do tacrolimus level one in 4 months while for other tests I go at Gisenyi and negotiate the internist for some selected lab tests: urea and creatinine only". (PART 11)

Counselling facilities

The participants describe how important to avail specific counselors for kidney transplant patients;

One participant reported the experience got from the colleague who was misbehaving after the transplant thinking that had cured him at the extent he felt free for whatever he wanted either in drinking or eating.

"We need specific counselors for kidney transplant patients because after transplant the patients think that they are cured and start to take all things freely such as too much alcohol taking, red meats in the bars then after 1 to 2 months the weight increase, the creatinine raises that is due to ignorance because there is not information and close follow-up. I know many people who their kidneys rejected in that manner. On friend came from the India and his coworkers received him by buying drinks, meats etc. then few days he got raised creatinine fortunately after telling me his behavior, I counselled him and now is ok". (PART 13)

Other participant stated that they need appropriate counselors because they may have psychological problems especially when the family members are not supporting the patients because it is not an easy life when alone

"In order to maintain good life as kidney transplant patients, we would request for availing the medicines at peripheral level like district and provincial hospitals, increase the nephrologists and train the kidney transplant counsellors because till now we don't have them while some can have psychological issues. Imagine if in this life you are in conflict with the relatives like your husband, you can't tolerate this difficulty journey of life so we may need the counselors". (PART 11)

Third participant stated how there is a gap in their management here in Rwanda as they consult the nephrologist only while they don't deal with other health aspects than medicine prescription and laboratory analysis

"The nutrition is not well addressed about education here in Rwanda because I respect the advices from Indian but here I only meet the nephrologist and I think that when we meet nephrologist is enough for all health aspects but he mostly deals with the medical prescriptions and laboratory analysis only". (PART 10)

Non availability of renal nutritionists

The participants have reported an issue related to the unavailability of specialized renal nutritionists and its impact on their wellbeing and financial burden.

One participant declared how after transplant has struggled to control the diabetes due to poor nutritional discipline while consulted the nutritionist at King Faisal hospital

"She said my glycaemia was not controlled for a long time but one day I met a private nutritional specialist and has advised me for the kind of food to use which I already knew but educated me how to prepare them to prevent the hyperglycemia. Since then, my glycaemia is controlled. This showed how our nutritional management is poor especially in public health facilities while to consult the private nutritional clinic is too expensive". (PART 2)

Another participant reported how is difficult to find a specialized renal nutritionist to adjust diet according to the laboratory results.

He said "as I do medical checkup every month, sometimes the laboratory results come with the variety values either high or low so that there should be the nutritional adjustment for example you may have high cholesterol, low sodium. So, in that case no adapted advices from nutritionist I can get". (PART 5)

Third participant reported that there is not a formal way of nutritional follow-ups for maintaining our body healthy as kidney transplant patients from our healthcare facilities. We do arrangement ourselves about nutritional behaviors.

He said" when I was On Hemodialysis I was told not take some food like Banaba, restricting drinks and water but after transplant no one told me about nutritional discipline to prevent kidney

rejection, I can use the information heard from colleagues and what told from India. So, if there is a change needing special nutritional attention or adjustment is not easy to get". (PART 10)

4.3.5. Cross cultural challenge

The most participants underwent the kidney transplant in India so they described how they lived there and the challenges they met. They reported the problem associated with the unfamiliar food such spicy and non-cow milk; difficult in communication due to the language barriers and improper environmental sanitations.

Food

First participant described how to eat was too difficult due to unfamiliar food

"we have got problem of language what caused us to eat badly as we were not able to communicate well for ordering the food so they could bring the same food two times in one day and very spicy briefly we have been protected by God otherwise we lived bad conditions". (PART 7)

Second participant stated how he spent 2 weeks without eating and being operated for intestine collation due to the unfamiliar food and cooking style.

"I didn't eat until they operated my intestine due to their collation. I had the appetite but the food was very spicy, the milk of camel or I don't know etc. all these and other many unfamiliar ingredients like the leaves of the eucalyptus I was so challenged about food. So, it caused to spend there several days with the unplanned budget". (PART 1)

Another participant reported how to eat was difficult until they got discharged and started to cook themselves.

"The main issue was the spicy but l tried to adapt until after operation we went in the apartment and starting to cook ourselves and the food are cheaper". (PART 8)

Communication Language

The participants described how the language was a big issue for communication

First participant stated how they had a problem of communication until they got an interpreter

"First problem was about the language, from the flight process as we were not familiar but assisted by different people at airports we reached the hospital. When Doctor realized that we are

not able to communicate in English he showed us the Rwandan who was there to help us". (PART 13)

Another participant reported the problem of communication due to language constraint

"In the India the main problem was about the language for communication but there was one friend who lived there, has helped us for communication until we came back home without problem". (PART 12)

Third participant reported how to communicate was a challenge for treatment due to language barrier

"Living in the foreign country was not easy but there were few patients like cancer patients. so, suffering with challenge to communicate is problem; for the food when you are not able to communicate for complaining on what they brought while you didn't order while there was phone number that you can use for kitchen etc. Main issue there was the language leading to poor communication even during the pain". (PART 5)

Foreign land

In this study some participants described the unfamiliar environment that they mostly reported as poor hygiene.

One participant said" once we reached at hospital, the Doctors had forbidden us to go outside the hospital or outside the apartments where we were showed; saying that we risked to contract the severe infection and dying due to poor hygiene we might meet while walking around". (PART 9)

Another participant reported how spent more time in India because of flood which caused them to be transferred at the other hospital until our hospital became functional

He said" I had had the challenges because I spent there more than a year due the flood from the heavy rain which caused us to be transferred from Yashoda to Apollo until the hospital became ready to refunction; there it can rain for 2 months and causing the flood; So, it caused me to spend there several days and using the unplanned budget". (PART 1)

Third participant described how to live in India was a problem due to dirty environment

She stated that in the India the main problem was the poor hygiene:" you might find the stool in the streets/ways while walking, or find the shops surrounded by bushes. So if not pay attention you can contract the infection easily". (PART 11)

4.4. Conclusion

These findings are coming from data of kidney transplant patients doing follow-ups at king Faisal hospital in nephrology unit. These findings reflect what the kidney transplant patients are experiencing especially challenges and suggestions for what are needed to improve their healthcare services, where experiencing Increased freedom or Improved quality of life emotional challenges, medical management issue, Healthcare system challenge and Cross cultural challenge. All suggested needs regard the facilitation to access the medicines and laboratory analysis such as enhancing CBHI capacity to pay medicines and other nephrology healthcare services or ease the access of their healthcare services as done for non-communicable disease, tuberculosis or viral hepatitis where most services are provided for free. Avail nephrology service from peripheral health facilities and fund for enhancing their financial capacity through generating income projects so that they may become able to solve their daily needs themselves.

The kidney transplant patients experience Increased freedom or Improved quality of life, emotional challenge, Medical management issue, Healthcare system challenge, cross cultural challenge and suggest the needs to facilitate accessing the medicines and other kidney health related services.

The next chapter comprises the discussion of the study results comparing to the other studies.

CHAPTER FIVE: DISCUSSION

5.1. Introduction

The discussion of the study's findings was done in comparing to other earlier researches under this chapter. The purpose of this study was to explore the actual lived experiences of kidney transplant recipients at selected referral hospital. Improved quality of life, emotional challenges, medical management issues, healthcare system obstacles, and cross-cultural challenges were the emerging themes from the data. For this research there were following objectives:

- To explore the patients' physical and emotional changes after kidney transplant
- To identify the patients concerns regarding the self-care and medical adherence after kidney transplant.
- To identify the needs or suggestions of kidney transplant patients for improving the quality healthcare provision.

5.2. Experiences of kidney transplants patients

In this chapter, the interpretation of the study's findings was contrasted with other earlier researches. Exploring the actual lived experiences of kidney transplant recipients at a selected referral hospital in Rwanda was the aim of this study. Themes that emerged from the data included increased improved quality of life, emotional difficulties, problems with medical treatment, difficulties with the healthcare system, and cross-cultural difficulties.

5.2.1. Improved quality of life

Most of the kidney transplant patients expressed their gratitude of having received the kidney transplant which helped them to be free of hemodialysis and associated suffering. It helped them to eliminate normally and drinking water freely. They got stronger than before the transplantation at the level they are able to work, to perform daily living activities such as continuing schools, wedding and giving birth etc.

These findings are consistent with the finding of Mohamed Younis H, Thabet Mohammed G, and Sayed Khalil S. where they showed that for many ESRD patients, kidney transplantation is the best course of treatment as it improves quality of life, reduces machine dependence, eliminates

fluid and nutritional restrictions, restores the sexual function, allows the fertility and the potential of having children. For the cost it is estimated at one- fifth of annual cost of dialysis.(3)

The similarities about the return to the normalcy were also found in the study of Wiltshire et al. where the participants revealed that the experiences post kidney transplant are influenced by the personal history of illness. They emphasized the difference between before and after transplantation as fatigue and inability to perform physical activity while able to work after.(4)

5.2.2. Emotional challenge

The participants expressed the emotional effects related to the life post kidney transplants where some had the fear of rejection, frustration at their working place, fear of not be able to afford the immunosuppressant drugs and guilt of putting the donors at the risks during transplantation process.

These findings regarding emotional effect of kidney transplant especially regarding the guilt of putting the donors on the risks while were healthy were found in the study of Wiltshire et al. where the participants revealed that it is not easy to understand the generosity of their donors and it was stated as followed: many receivers find it challenging to fully appreciate the generosity of donation due to their relationship with their donor and their donated organ. Uncertainty around the motivations of donors makes it challenging for the recipient to make sense of the experience because they are unable to envision reciprocity in this situation. After receiving an organ, feeling an obligation to live a good life becomes a moral burden. It was discovered that the emotional connection between beneficiaries and their donor was impacted by the language used to describe the procedure (either "gift" or "donation").(4)

The other study of Tucker et al. the participants showed improvements in quality of life, a return to normalcy, improved health, and increased vitality as changes after transplantation. Concerns included the length of graft survival, worries about to have another kidney transplant or go back on dialysis in the future, comorbidities, future quality of life, and the price of their medical treatment.(5)

The similarities in the study of Jones et al. revealed that after transplant the recipient would be happy and content but in contrast they reported the emotional issues such worries related to the graft like not be sure or asked themselves about the duration of new kidney’s survivorship, having

acquired the new diseases from the donors, feeling guilt for those who are not yet be able to be transplanted while they were together at hemodialysis, felt isolated because no longer in touch with dialysis team and requested for psychological support from peers to psychologist. (21)

Another study of Abarca-Durán et al. revealed emotional problems among the kidney transplant where it was reported that the sexual activity in kidney transplant patents is not prioritized where it might be caused by the felling of fear of graft rejection and are not yet confident of the guarantee of future life. all these stressing concerns impact on sexuality. Participants reported poor interest in sexuality and most of time they postpone it which lead to the family relationship disturbance among partners. although the sexual issues among kidney transplant patients is a concern, is not valued or taken in attention by health workers in their routine activities.(22)

About frustration related to working hours reductions, fear of heavy works, fear of working for others thinking that they can be given hard work which may harm the kidney allograft and family relationship disturbances mentioned in this study are similar to the finding of the study of McKeaveney et al. where it revealed that dietary limits, time restraints, functional limitations, drug side effects, changes in employment, changes in sexual function, cognitive dysfunction, and awareness of imminent death can all be stressors.(33)

5.2.3. Medical management

Most participants in this study revealed the issue of medical management in the life post kidney transplantation such as inaccessibility of the medicines which are very expensive and not found countrywide; the diet helping to stay healthy and prevent drugs side effect and transport issues to reach the nephrology services at Kigali for medical checkups and medical prescriptions etc. all raised the financial problem affecting the whole daily living situation.

The similar findings were reported in the of Lorenz et al. where the patients showed that following a lifelong routine of drugs, lifestyle modifications, treatment burden with a variety of components of care, the cost of medications and monitoring, interpersonal problems, and financial difficulties affect their wellbeing.(5)

In the other study of Tucker et al. the participants revealed that although the kidney transplant is better than other RRTs (Renal Replacement Therapies), the patients ‘daily life is affected because

of continuing medical visits for follow up, medical prescription for life, instructions to prevent infection such as self-monitoring, hygiene and enough fluid taking.(5)

5.2.4. Healthcare system challenge

In this study most of the participant showed the challenge regarding the healthcare system where all services related to kidney transplant are only found in Kigali while the patients are from all over the country so this affects them in respecting the post kidney transplant instruction like doing irregular medical follow-ups and lack of medicines other spend too much money in prioritizing their life but affects the family's life. They should leave it but the risks overweigh the challenges like fearing the kidney rejection and try to go at those specialized healthcare facilities at whatever price even though it may be irregularly. They also mentioned the lack of specific counselors for kidney transplants' issues.

The similar issues of balancing the risks and the challenges were reported in the study of Nielsen et al. it was revealed that the kidney transplantation procedure was difficult and had an impact on daily life as well as to balance hope, promising future and concerns related to health. The challenges were related to waiting time where patient were thinking every time on the day they will get a donor to be free of disease suffering, transformation within the time of transplantation like hospitalization days and post-operative discomfort like pain, limited movement and finally the outpatient's consultations for follow-up but due to life restriction caused by renal disease they tried to balance return to normal life post-transplant and then hope outweighed the challenges.(6)

About the lack of counselors and specialized health workers, it was the same in the other study of Ghadami et al. where it was revealed that patients had trouble finding information to help them manage their condition and protect their new kidney because the education they received before to transplantation was not in a consistent manner. Before transplantation, there was inadequate information about treatment, kidney transplantation, and supportive systems. After transplantation, there was inadequate information about post-operative care medications and complications, which resulted in a lack of knowledge about drugs used specifically for transplantation, how to avoid their side effects, the signs and symptoms of infections, or post-surgery care, as well as a lack of knowledge about help support in an emergency. Patients must therefore struggle on their own to increase their awareness and knowledge of maintaining grafts on one's own .(23)

5.2.5. Cross cultural challenge

The participants were all Rwandan in this study, they reported different challenges met due to the foreign culture where they underwent kidney transplantation. Some had long admission due to complication of non-eating due to unfamiliar food, fear of being operated by foreign doctors, problem of expressing felling/pain due communication problem/language, poor eating due to unfamiliar food etc. Briefly, the culture coping was a challenging.

These finding are not far from the finding of the study of Kamran where participants revealed different copying factors after kidney transplant for maintaining normal life. the patients claimed that their coping and adjustment processes both before and after the transplant were ultimately influenced by the attitudes and behaviors of their family, friends, partners/spouses, relatives, and coworkers. In the case of high scorers, a good connection helped their coping, whereas for low scorers, estranged relationships and sentiments of being a liability and undesired led to a sense of being distant and unwanted as well as a lower level of quality of life satisfaction. So this showed how the unfamiliar surrounding can influence your quality of life.(7)

5.4. Conclusion

The purpose of this study was to investigate the experiences of kidney transplant recipients at selected referral hospital in Rwanda. The conclusion reached during the debate is that the finding sheds light on the diverse demands and experiences of kidney transplant recipients. The emergent themes suggested that kidney transplant patients may encounter a wide range of problems, including those relating to cross-cultural challenges, medical treatment, emotional challenges, and healthcare system challenges.

The following chapter will present the study's conclusion and the recommendations.

CHAPTER SIX: CONCLUSION AND RECOMMENDATION

6.1. Introduction

The conclusion of this research is included in this chapter whereas the fourth chapter's description of the study's findings is followed by a description of the important recommendations for nursing practice, nursing education, policymakers, and future research in the fifth chapter.

6.2. Conclusion

In this study on the lived experiences of kidney transplant recipients at selected referral hospital in Rwanda, improved quality of life, emotional challenges, medical management issue, Healthcare system challenge and Cross cultural challenge themes emerged. It improves quality of life, reduces machine dependence, eliminates fluid and nutritional restrictions, restores the sexual function, allows the fertility and the potential of having children as positive impact but on the other hand the patients showed that following a lifelong routine of drugs, lifestyle modifications, treatment burden with a variety of components of care, the cost of medications and monitoring, interpersonal problems, and financial difficulties affect their wellbeing. all raised issues support the need of support in different aspects of life such as financial, social and psychological.

Patients who have undergone kidney transplants have reported a variety of varied experiences that are consistent with other studies. There were few, nevertheless, that were specific to Rwanda: The kidney transplant patients face many challenges, and the management of medication is one among the main stressors along with the financial challenges and monthly hospital visits. The healthcare system should try to provide appropriate support for the kidney transplant patients for them to maintain the survival of the allograft for a longer period.

6.3. Recommendations

- **To the healthcare professionals**

The following recommendations are made in light of the study's findings:

- Nurses should be aware of the issues that kidney transplant recipients face and make plans to address those issues.
- It is advised that nurses provide kidney transplant patients with the same level of care and attention as they provide to ESRD patients receiving hemodialysis.

- Nurses organize the regular meetings with the kidney transplant patients for identifying any health concerns to provide education, advices and allow them to share the experiences or challenges met on daily basis to find together the appropriate solutions or doing advocacy to the concerned authorities.
- In order to provide kidney transplant patients with the best possible assistance for their healthcare needs, healthcare professionals should work together with them.

➢ **To the Stakeholders**

It is recommended that

- The authority collaborates with stakeholders to change the CBHI policy for covering the post kidney transplant services to reduce the burden regarding the access of the medicines and other related health services such as regular medical checkups.
- The authority collaborates with stakeholders to train the kidney transplant patients in small businesses that can generate money and avail the fund for assisting those without capital because they spend more money on daily living needs such special diet as some have other chronic diseases like Diabetes and HTN while most of them are unemployed or worried to look for the jobs fearing the heavy or hard works that may be given to them.

➢ **To the Future research**

- It is advised to apply these findings to subsequent investigations. To learn more about these experiences, such as psychological status or patients' perceptions of the kidney transplantation process in Rwanda, one could further research the categories that resulted from the study.

➢ **To the Nursing Education**

- Based on the results of this study, it is advised that nursing education teach and educate nurses, so that when the nurses are trained, they should also train the students who also focus on the treatment of kidney transplant patients.

➢ **To the Government**

It is recommended to the government:

- To train enough healthcare personnel specialized in nephrology field such as nephrologists, nurses specialized in nephrology, specific nutritionists and counselors to be able to provide appropriate care to kidney transplant patients.
- To decentralize the nephrology services at primary level to help patents living out of Kigali to access the medical follow-ups and medicines without long travels and much transport fees expenses that would reduce the financial burden to patient and family.
- To provide a system aimed at reducing the cost of post-transplant medicines and laboratory analysis as is the main source of financial issues experienced by kidney transplant patients.

REFERENCES

1. Tucker EL, Smith AR, Daskin MS, Schapiro H, Cottrell SM, Gendron ES, et al. Life and expectations post-kidney transplant: A qualitative analysis of patient responses. BMC Nephrol. 2019;20(1):1–10.

2. Claire Mukakarangwa M, Chironda G, Nkurunziza A, Ngendahayo F, Bhengu B. Motivators and barriers of adherence to hemodialysis among patients with end stage renal disease (ESRD) in Rwanda: A qualitative study. Int J Africa Nurs Sci [Internet]. 2020;13(March):100221. Available from: https://doi.org/10.1016/j.ijans.2020.100221

3. Mohamed Younis H, Thabet Mohammed G, Sayed Khalil S. Infection control: effect of nursing teaching protocol on nurses' knowledge and practice regarding kidney transplantation patients. Int J Adv Nurs Stud. 2018;7(1):21.

4. Wiltshire G, Clarke NJ, Phoenix C, Bescoby C. Organ Transplant Recipients' Experiences of Physical Activity: Health, Self-Care, and Transliminality. Qual Health Res. 2021;31(2):385–98.

5. Tucker EL, Smith AR, Daskin MS, Schapiro H, Cottrell SM, Gendron ES, et al. Life and expectations post-kidney transplant: A qualitative analysis of patient responses. Iran J Nurs Midwifery Res [Internet]. 2019;17(2 Suppl 1):1–10. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23833599%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3696978

6. Nielsen C, Clemensen J, Bistrup C, Agerskov H. Balancing everyday life—Patients' experiences before, during and four months after kidney transplantation. Nurs Open. 2019;6(2):443–52.

7. Kamran F. Living with a Kidney Transplant: Perceptions and Experiences. Am J Appl Psychol [Internet]. 2014;2(1):5–12. Available from: http://pubs.sciepub.com/ajap/2/1/2

8. Kobayashi S, Hidaka S. Can we still ignore renal replacement therapy in sub-Saharan Africa ? All living beings are created equal. 2020;6:1–13.

9. El-Agroudy AE, Taher AA, Alshehabi KM, Alalwan AA, Arekat MR. Quality of Life among Renal Transplant Recipients in Bahrain: A Single-Center Experience. Saudi J Kidney Dis Transplant. 2021;32(3):774–85.

10. McKeaveney C, Noble H, Courtney AE, Gill P, Griffin S, Johnston W, et al. Understanding the holistic experiences of living with a kidney transplant: An interpretative phenomenological study (protocol). BMC Nephrol. 2020;21(1):1–5.

11. McKeaveney C, Noble H, Courtney AE, Gill P, Griffin S, Johnston W, et al. Understanding the holistic experiences of living with a kidney transplant: An interpretative phenomenological study (protocol). BMC Nephrol. 2020;21(1):1–6.

12. Rwanda Ministry of Health. ANNUAL REPORT July 2012-June 2013. Obstet [Internet]. 2013;4(3):1–9. Available from: http://mhnpjournal.biomedcentral.com/articles/10.1186/s40748-016-0033-x%5Cnhttp://www.ncbi.nlm.nih.gov/pubmed/17437200%5Cnhttp://informahealthcare.com/doi/abs/10.1080/14767050601134645%5Cnhttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=140005&to

13. Dictionary C. experiences. Cambridge Univ Press Assess. 2016;

14. Dictionary O. Lived experiences. Oxford Learn Dictionaries. 2022;

15. Wang Y, Snoep JD, Hemmelder MH, van der Bogt KEA, Bos WJW, van der Boog PJM, et al. Outcomes after kidney transplantation, let's focus on the patients' perspectives. Clin Kidney J. 2021;14(6):1504–13.

16. INOUE H. Kidney Transplantation. Rinsho Geka. 1964;19:725–31.

17. Aziz F, Clark DF. Introduction to Kidney Transplantation. Kidney Transpl Manag. 2019;1–3.

18. Burns G, Dumont D, Gould L. Clinical Handbook for Kidney Transplantation. 2017;(June).

19. Kenawy AS, Gheith O, Al-Otaibi T, Othman N, Atya HA, Al-Otaibi M, et al. Medication compliance and lifestyle adherence in renal transplant recipients in Kuwait. Patient Prefer Adherence. 2019;13:1477–86.

20. Lorenz EC, Egginton JS, Stegall MD, Cheville AL, Heilman RL, Nair SS, et al. Patient experience after kidney transplant : a conceptual framework of treatment burden. 2019;4.

21. Jones J, Damery S, Allen K, Nicholas J, Baharani J, Combes G. You have got a foreign body in there': Renal transplantation, unexpected mild-to-moderate distress and patients' support needs: A qualitative study. BMJ Open. 2020;10(3):1–7.

22. Abarca-Durán X, Fernández-Medina IM, Jiménez-Lasserrotte MDM, Dobarrio-Sanz I, Martínez-Abarca AL, Fernández-Sola C. Sexuality in kidney transplant recipients: A qualitative study. Healthc. 2021;9(11):1–12.

23. Ghadami A, Memarian R, Mohamadi E, Abdoli S. Patients' experiences from their received education about the process of kidney transplant: A qualitative study. Iran J Nurs Midwifery Res [Internet]. 2012;17(2 Suppl 1):S157-64. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23833599%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3696978

24. Chunyan L, Zhuofeng Y. The experience of adults patients in daily life after kidney transplantation A descriptive literature review. 2022;

25. Antoun J, Brown DJ, Clarkson BG, Shepherd AI, Sangala NC, Lewis RJ, et al. Experiences of adults living with a kidney transplant—Effects on physical activity, physical function, and quality of life: A descriptive phenomenological study. J Ren Care. 2022;(April):1–8.

26. Nkuranyabahizi M, Rajeswaran L, Ngendahayo F, Umuhire L, Shyaka JC, Dushimiyimana V, et al. Caring experiences and support needs among family caregivers of patients with End Stage Renal Disease (ESRD) in Rwanda: A descriptive qualitative study. Int J Africa Nurs Sci. 2021 Jan;15.

27. Oshagbemi T. Chapter 4. Research Design and Methodology. Leadersh Manag Univ. 2017;(2003):67–95.

28. James AF. Reading, understanding, and applying Nursing searserch. Fifth Edit. Rhyner S, West S, editors. Philadelphia: Davis Company; 2017. 1–353 p.

29. Polite FD, Beck TC. Nursing Research: Principles and Methods. Seveth. 2003. 1–746 p.

30. Forero R, Nahidi S, Costa J De, Mohsin M, Fitzgerald G, Gibson N, et al. Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. 2018;1–11.

31. Encyclopedia Britannica. Quality Of life. 2023;

32. Robinson. WHAT DO WE MEAN BY EMOTIONAL DIFFICULTIES? Little, Brown B Gr Ltd. 2023;(Hachette Carmelite House, London).

33. Mckeaveney C, Noble H, Courtney AE, Gill P, Griffin S, Johnston W, et al. Understanding the holistic experiences of living with a kidney transplant : an interpretative phenomenological study (protocol). 2020;1–5.

ANNEXURES

ANNEXE A. INTERVIEW QUESTIONNAIRE / ENGLISH

Introduction: Hello, I am RUDASHIRIKAKA Jean de Dieu, a Masters in nursing student specializing in Nephrology Nursing. In order to better understand the experiences of kidney transplant recipients at a particular referral hospital in Rwanda, I am undertaking a study. It is my hope that this study's findings may help kidney transplant recipients obtain the proper care they need from medical professionals. I am aware that everyone's post-kidney transplant daily life is going to be different. I would appreciate it if you could give me the best possible answer to the questions I will be asking you. Your entire response will only be used for research purposes.

SECTION A: DEMOGRAPHIC AND OTHER CHARACTERISTICS

Date of Interview: …….

1. Age …...
2. Gender: …….
3. Marital status……

a. Single

b. Married

c. Living with partner

d. Widowed

e. Separated

f. Divorced

4. Educational level …….
5. Occupation …….

In not employed, how do you earn daily income? Elaborate

6. Residence/ District

7. Medical insurance……...

8. Country you underwent kidney transplant?.....

9. Year of renal transplant?.....

10. Current living location…….

SECTION B: EXPERIENCES OF KIDNEY TRANSPLANT PATIENTS

Ice breaking question

1. Tell me "Are you happy that you have got kidney transplant"?

   Major Interview Questions, the researcher will probe and prompt to understand deeply
2. Can you please share your experiences after transplant?

   The researcher may probe with some questions regarding physical (Fitness, exercise, daily work, and emotional status (sleeplessness, mood changes, upset with self, etc.); about the medications taking ordered after transplant? (Adherence, availability, accessibility, assistance from family members)
3. Can you please share about self-care in maintaining your kidney healthy? E.g. I may probe on barrier if not mentioned related to Health system access, doctors' appointment, getting medications, dietary consultations, counselor and financial.
4. Can you please share how you get the family support after kidney transplant? (socially and financially)
5. Can you please share how was the process to find the donor and your relationship?
6. Can you please share how was your mind set while you were preparing for the kidney transplant?
7. Can you please share how was the life or your experiences while you were in India?
8. Do you have any suggestions to the hospital or the ministry of health regarding providing care for the renal transplant patients?

ANNEXE B. CONSENT FORM/ENGLISH

Participant ‘s consent in the study regarding experiences of kidney transplant patients at selected nephrology units in Rwanda.

Hello! I am RUDASHIRIKAKA Jean de Dieu, a Masters student of Science in Nursing, 2nd year at University of Rwanda in nephrology track. I am conducting this research project in order to explore the lived experiences of kidney transplant patients in Rwanda.

Purpose of the research: to explore the experiences of kidney transplant patients in Rwanda

Study participation: Once you consent to participate in this research, it will be necessary to answer questions which will be asked during interview that will be done face to face. As in the interview there is no right or wrong answers do not hesitate to be involved.

Confidentiality: the collected information will be kept thoroughly confidential and not revealed to anybody else.

Risks: no harm expected from this research unless you feel tired during the interview but you may stop momentarily at any time if you become so uncomfortable.

Rights to withdraw and alternatives: to be part of this study is voluntarily. Once you feel better not to participate or to discontinue participation it will not affect your usual care from the institution. You are allowed to discontinue the involvement in this study even though you have signed the consent.

Benefits: No direct benefit to you from participation in this study rather the information from the participants will help the healthcare personnel to understand well the perspectives and challenges of kidney transplant patient so that they could set the care plan accordingly.

Contacts: if any inquiry regarding this study, don’t hesitate to contact me as principal investigator RUDASHIRIKAKA Jean de Dieu via Tel. 0788800570/07, University of Rwanda, College of Medicine and Health Sciences, School of Nursing and Midwifery, Remera- Kigali-Rwanda.

Signature:

I _____ have read the contents in this form. My questions have been answered. I agree to participate in this study.

Signature of participant _____

I _____ have read the contents in this form. My questions have been answered. I do not agree to participate in this study.

Signature _____

Signature of witness (if patient cannot read) _____

Signature of researcher _____

Date of signatures _____

ANNEXE C. INTERVIEW IN KINYARWANDA

Intangiriro

Bwana/Madamu, nitwa Rudashirikaka Jean de Dieu, ndi umunyeshuli muri kaminuza y' u Rwanda mu ishami ry'ubuvuzi n'ubuzima mu agashami kita ku barwayi b'impyiko; ndashaka gukora ubushakashatsi mukureba imibereho y'abarwayi bahawe impyiko mu Rwanda.Niteze ko ibizava mu ubushakashatsi bizagirira akamaro abarwayi bahawe impyiko mubijyanye no kubafasha kwita kubibazo bahura nabyo mubuzima bwabo bwabo bwa buri munsi cyane cyane hagamijwe no gukurikiza amabwiriza ateganyijwe mu gufata neza impyiko bahawe. Ikindi kandi abakora mu buvuzi nabo bazabona amakuru abafasha gushyiraho gahunda ihamye yo kubitaho hakurikijwe ubuzima babayeho nyuma yo guhabwa impyiko. Ndabizi ko abarwayi bafiete byinshi bagomba gukora no kwitwararika nyuma yo guhabwa imyiko haba mu buzima bwa buri munsi n'ibijyanye no kwikurikirana kwa muganga,niyo mpamvu ngirango ndebe ese haba harimo ibibazo cyangwa ibintu bimeze neza. Ndashimishwa no kumva musubiza ibibazo uko mubyumva. Ibisubizo mutanga bizakoreshwa gusa kugirango intego y"ubushakashatsi igerweho.

IGICE CYA A: AMAKURU ARANGA USUBIZA:

Aya makuru azuzuzwa nyuma yo guhura n'abarwayi bemeye kugira uruhare mu bushakashatsi

Itariki: …….

A1. Imyaka …...……

A2. Igitsina: …….

A3. Irangamimerere

a) Ingaragu…….

b) Ndubatse…….

c) Mbana n'inshuti yanjye tutarasezeranye…….

d) Umupfakazi…….

e) Twaritandukanije……

f) Twatandukanijwe n’amategeko……

A4. Amashuri wize …….

A5. Icyiciro cy’ubudehe…….

A6. Icyo akora …….

A7. ubwishingizi……

A8. Aho utuye.

A9. Aho waherewe impyiko……...

A10. Igihe waherewe impyiko……..

IGICE CYA B

Ibibazo bijyanye n’imireho ya buri munsi kuva umurwayi yamara guhabwa impyiko kugeza uyu munsi. (ubaza azajya abaza neza kugirango umurwayi yumve ikibazo kandi nawe atege amatwi neza kugirango yumve icyo umurwayi ashaka kuvuga):

Mbateze amatwi kubijyanye n’ibyo mwahuye nabyo kuva mwahabwa impyiko kugeza ubu.

1. Ese mwiyumva mute kuba mwarahawe impyiko?
2. Twifuzaga ko mwadusangiza ubuzima mubayemo cg uko mubayeho nyuma yo guhabwa impyiko.
    A. Twifuzaga ko mwatubwira niba hari ibibazo mwahuye nabyo haba ku mubiri cyangwa ku mitekerereze (Mbese nko gukora sport, gukora akazi kaburi munsi, gusinzira cg se kubura ibitotsi, guhinduka mu mimerere no kwivumbura)
    B. Twifuzaga ko mwadusangiza uko mubasha gukurikiza amabwiriza kubijyanye n’imiti mwandikiwe nyuma yo guhabwa impyiko. Mwadusangiza ibibazo muhura nabyo mubijyanye n’imiti,mbese nko kuyifata neza, kuyifatira kugihe, uruhare rw’abo mubana mu muryango)

3. Twifuzaga ko mwadusangiza uko mwiyitaho kugirango mukomeze kubungabunga imyiko mwahawe itazangirika niba hari n' imbogamizi muhura nazo (kubona abaganga, kubona imiti, kubona abashinzwe imirire n'abajyanama kubahawe impyiko).
4. Twifuzaga ko mwadusangiza uko mubanye n'abagize umuryango nyuma yo guhabwa impyiko n'uko babafasha mubuzima bwa buri munsi.
5. Twifuzaga ko mwadusangiza urugendo rw'uko mwabonye ubaha impyiko n'icyo mupfana.
6. Twifuzaga ko mwadusangiza uko mwiyumvaga cg uko mwatekerzaga igihe mwiteguraga kujya guhabwa impyiko.
7. Twifuzaga ko mwadusangiza uko mwari mubayeho igihe mwari mu buhinde mwaragiye guhabwa impyiko.
8. Hari ibitekerezo mufite mubona byafasha ku mavuriro na Leta by'umwihariko kugirango abarwayi bahawe impyiko barusheho kwitabwaho neza?

ANNEXE D. CONSENT FORM/KINYARWANDA

Urwandiko rugamije gutanga amakuru ku ubushakashatsi bwitwa “ubunararibonye cg imibereho y’abarwayi bahawe impyiko mu Rwanda”

Muraho! Nitwa RUDASHIRIKAKA Jean de Dieu, ndi umunyeshuli muri kaminuza y’ u Rwanda mu ishami ry’ubuvuzi n’ubuzima mu gashami kita ku barwayi b’impyiko; ndigukora ubushakashatsi murwego rwo kurangiza icyiciro cya gatatu cya Kaminuza. Ubu bushakashatsi bwemewe ni ikigo gishinzwe ubushakashatsi muri Kaminuzay’u Rwanda ishamiry’ubuvuzin’ubuzima

Integoy’ubu bushakashatsi: Ubu bushakashatsi bugamije kumenya byimbitse imibereho y’abarwayi bahawe impyiko kuva babwiwe ko bagiye guhabwa impyiko na nyuma yaho. **Kwitabira ubushakashatsi**: Niba wiyemeje kugira uruhare muri ubu bushakashasti, murasabwa gusa gusubiza ibibazo muri bubazwe imbona nkubone. Ntimugire ikibazo kuko nta gisubizo kiricyo cyangwa kitaricyo musubiza.

Ibanga: Amakuru yose azafatwa muri ubu bushakashatsi azagirwa ibanga rikomeye kuburyo ntamuntu wundi azabwirwa, azafasha gusa mu ubushakashatsi.

Ingorane n’ingaruka zishobora kuvuka: Ubu bushakashatsi ntangaruka bufite usibye umwanya wanyu muzaduha. Rimwe na rimwe ushobora kumva bigukoze ahantu(unaniwe) bitewe n‟ibyo wahuye nabyo mu burwayi, kandi biramutse bigenze gutyo twahagarikaho ibiganiro.

uburenganzira mu kuva mu ubushakashatsi: Kugira uruhare mu ubushakashatsi ni ubushake bwawe. Wahitamo kuguma cyangwa kuva mu ubushakashatsi uzaguma guhabwa serivisi nkuko wazihabwaga. Ushobora kwivana mu ubushakashatsi igihe cyose ubishatse, niyo waba wamaze kwemera.

Inyungu: Nta inyungu z’ako kanya uzabona mu ukugira uruhare mu ubushakashatsi. Gusa amakuru azatangwa azafasha abavura kumenya ibibazo abahawe impyiko bahura nabyo babishakire ibisubizo ndetse no kurushaho gutanga service nziza.

Uwo wabaza ku bindi bisobanuro: Uramutse ugize ikibazo, ushobora kubaza Mr. RUDASHIRIKAKA Jean de Dieu Tel: 0788800570/0739301638, Kaminuza y’u Rwanda, ishami ry’ubuvuzi n’ubuzima, Remera-Kigali-Rwanda. Ushobora kandi no guhamagara umuyobozi

ushinzwe kwemerera no kwemeza iby'ubushakashatsi muri Kaminuza y"u Rwanda ishami ry'ubuvuzi n'ubuzima kuri 0788586768, cyangwa ugahamagara umwungirije kuri 0788215863.

Umukono:

Njyewe _____ Namaze gusoma no gusobanukirwa iby'ubu bushakashatsi. Ibibazo byanjye byasubijwe, nemeye kugira uruhare mugutanga amakuru. Umukono w"utanga amakuru _____

Njyewe _____ Namaze gusoma no gusobanukirwa iby'ubu bushakashatsi. Ibibazo byanjye byasubijwe, nanze kugira uruhare mugutanga amakuru. Umukono w"uwanze gutanga amakuru. _____

Umukono w"uhagarariye utanga amakuru (igihe umurwayi atazi gusoma) _____

Umukono wa nyiri ubushakashatsi _____

Itariki __/____/2023

ANNEXE E: ETHICAL CLEARANCES

ETHICAL CLEARANCE FROM UNIVERSITY OF RWANDA CMHS/IRB

UNIVERSITY of RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

DIRECTORATE OF RESEARCH & INNOVATION

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 22/12/2022
Ref: CMHS/IRB/577/2022

RUDASHIRIKAKA JEAN DE DIEU

Postgraduate Studies Program,
School of Nursing and Midwifery, CMHS, UR

Dear RUDASHIRIKAKA JEAN DE DIEU,

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled **"Lived experiences of kidney transplant patients at selected nephrology units in Rwanda"**.

Having reviewed your application and been satisfied with your protocol, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

Assoc. Prof. Stefan Jansen (PhD)
Acting 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

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

IRB NOTIFICATION OF APPROVAL KING FAISAL HOSPITAL RWANDA

KING FAISAL HOSPITAL KIGALI

KING FAISAL HOSPITAL RWANDA

INSTITUTIONAL REVIEW BOARD

Patient Centered Care

IRB Notification of Approval

Ref: KFH/2023/ 054/IRB

Date: February 28, 2023
Protocol Title: Lived experiences of kidney transplant patients at selected nephrology units in Rwanda
Principal Investigator:
Rudashirikaka Jean de Dieu **Email:** jrudashirikaka1@gmail.com
Protocol Reference #: KFH/2023/ 054/IRB
Date of IRB Initial Review: February 22, 2023
Review Type: Full Review
IRB Review Decision: Approved
Date of Effectiveness: February 28, 2023
Date of Expiry: February 27, 2024

Dear Rudashirikaka Jean de Dieu,

King Faisal Hospital Rwanda's Institutional Review Board (KFH IRB) reviewed your resubmission. This letter is to notify you that the KFH IRB approved your resubmission, and this approval is valid for one (1) year and then must be renewed according to the KFH IRB Standard Operating Procedures.

Please note the following considerations:

1. Please review the KFH IRB Standard Operating Procedures and ensure compliance with all requirements, including participant content, changes or amendments to the protocol, and reporting requirements.
2. All project materials, including signed consent forms, must be retained and are subject to review in case of a routine audit
3. Notify the KFH Directorate of Research once data collection is completed
4. The Principal Investigator is requested to submit a hard copy of his/her final manuscript to the Directorate of Research upon completion.
5. Principal Investigators must follow the appropriate study continuing review and closure procedures as indicated in the Standard Operating Procedures Manual.

Please contact us at irb@kfhkigali.com in case of any questions or clarifications.

Sincerely,

Dr. Jean Marie Vianney D[illegible]ana
Consultant ENT Surgeon
Chair, Institutional Review Board

KING FAISAL HOSPITAL RWANDA

L