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# Kidney transplant related knowledge and health education needs of patients with chronic kidney failure in two academic hospitals in Gauteng

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# KIDNEY TRANSPLANT RELATED KNOWLEDGE AND HEALTH EDUCATION NEEDS OF PATIENTS WITH CHRONIC KIDNEY FAILURE IN TWO ACADEMIC HOSPITALS IN GAUTENG

**MMABJE CALVIN NKADIMENG**

A research report submitted to the Faculty of Health Sciences,

University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements

for a Master of Science Degree in Nursing.

**Johannesburg 2021**

# DECLARATION

I, Mmabje Calvin Nkadimeng, declare that the research report on **"**Kidney transplant related knowledge and health education needs of patients with chronic kidney failure in two academic hospitals in Gauteng,**"** is my own unaided work. It is being submitted for the Degree Master of Nursing Science at University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.



31 Mar 2021

…… …….

Signature Date

Protocol number: **M171028**

## DEDICATION

This research study is dedicated to:

- My parents, Goodman and Mashibihle Nkadimeng
- My late uncle, Mmakgari Nkadimeng

## ACKNOWLEDGEMENTS

My appreciation and sincere thanks to the following people who supported me throughout this study:

My supervisor, Dr. Nokuthula Nkosi-Mafutha, for her guidance and support.

The statistician and the University of the Witwatersrand Health Sciences library staff.

My parents, Goodman and Mashibihle Nkadimeng

My family members, Nthabiseng, Mpho, Kholofelo, Surprise, Helen, Mogau, Koketso and Lebogang

My fiancé, Lerato Mohlala, for her support

My friends, Glen Malape, Sipho Mbuyane, Caswell Seloane and Mashoro Phasha

The renal unit patients and staff members of the two hospitals for their support; they made it easier for me to conduct my study in their units. Thank you very much.

Above all, l made it this far through God's Grace.

# ABSTRACT

**Background:** Patients living with chronic kidney failure endure a lot of stress, as they have to adjust their lifestyle, stop smoking, eat a healthy diet, and refrain from self-medication. Currently, South Africa has dearth in literature regarding the knowledge of these patients about kidney transplant, which is so far the best treatment for chronic kidney failure. Patients are provided with health education before any transplant, this is done to equip them with adequate knowledge regarding the disease and its management. However, there are no methods to examine whether the patient comprehended the information or not.

**Purpose**: The purpose of this study was to describe the kidney transplant related knowledge and health education needs of patients with Chronic Kidney Failure on haemodialysis awaiting kidney transplant in two hospitals in Gauteng.

**Methods:** The study was a quantitative, descriptive and cross-sectional survey and data was collected using a kidney transplant understanding tool (K-TUT) questionnaire.

**Data analysis:** Data was analysed using the statistical package for Social Science computer Programme and quantitative content analysis.

**Setting:** The setting for this study was the renal units at two academic hospitals in Gauteng, South Africa.

**Results:** Of the n=124 aimed sample size**,** n=70 patients gave consent to participate in the study, based on the set objective of describing the knowledge of patients on dialysis about their knowledge on kidney transplant, a large number n=58 (82.86%) scored above 50% indicating adequate knowledge and n=12 (17.14%) scored below 50%, which is regarded as inadequate knowledge. However, at the mean score of 55%, only half (n=35; 50%) of the participants had adequate knowledge. When considering the 55% as adequate knowledge indicator, half of the participants had inadequate knowledge regarding kidney transplant. The health education needs revealed three themes: firstly, the health education needs related to kidney transplant (quality of life, reproductive health and risks and side effects). Secondly the additional information needs to understand kidney transplant process such as donors and support system and lastly the family member involvement theme which entailed their family member understanding of the risk of rejection and infection.

**Conclusion:** The results of the study highlighted the need for tailor-made health education to equip patients and family member involvement with knowledge before they undergo haemodialysis and kidney transplant.

**Key words: Chronic kidney failure, Health education needs, Kidney transplant; knowledge.**

# TABLE OF CONTENTS

**DECLARATION** ..... i
**DEDICATION** ..... ii
**ACKNOWLEDGEMENTS** ..... iii
**ABSTRACT** ..... iv
**LIST OF ANNEXURES** ..... ix
**LIST OF FIGURES** ..... x
**LIST OF TABLES** ..... xi
**NOMENCLATURE** ..... xii
**CHAPTER ONE** ..... 1
**OVERVIEW OF THE STUDY** ..... 1
**1.1 INTRODUCTION** ..... 1
**1.2 BACKGROUND & RATIONALE** ..... 1
**1.3 PROBLEM STATEMENT** ..... 4
**1.4 RESEARCH QUESTION** ..... 5
**1.5 PURPOSE OF THE STUDY** ..... 5
**1.6 OBJECTIVES:** ..... 5
**1.7 SIGNIFICANCE OF THE STUDY** ..... 5
**1.8 DEFINITION OF TERMS** ..... 6
**1.9 RESEARCH SETTING** ..... 7
**1.10 OVERVIEW OF RESEARCH METHODOLOGY** ..... 7
**1.11 OUTLINE OF THE RESEARCH REPORT** ..... 7
**1.12 SUMMARY** ..... 8
**CHAPTER TWO** ..... 9
**LITERATURE REVIEW** ..... 9
**2. 1 INTRODUCTION** ..... 9
**2.2 THE ANATOMY OF THE KIDNEY** ..... 9
**2.3 A BRIEF PHYSIOLOGY OF KIDNEY FAILURE** ..... 10
**2.3.1.1 Acute kidney failure** ..... 11
**2.3.1.2 Chronic kidney failure** ..... 11
**2.4 PREVALENCE OF KIDNEY FAILURE** ..... 13
**2.5 RISK FACTORS FOR KIDNEY FAILURE** ..... 14
**2.5.1 HIV and AIDS** ..... 14
**2.5.2 Hypertension and diabetes** ..... 15
**2.5.3 Poor infrastructure and kidney failure detection** ..... 16

**2.6 MANAGEMENT OF CHRONIC KIDNEY FAILURE** ..... 17
**2.6.1 Health education** ..... 17
**2.6.2 Lifestyle adjustment** ..... 18
**2.6.3 Dialysis** ..... 20
**2.6.4 Kidney transplant** ..... 21
**2.7 STRATEGIES TO PROMOTE KIDNEY DONATION** ..... 23
**2.8 SELF-CARE MANAGEMENT** ..... 24
**2.9 KNOWLEDGE ABOUT KIDNEY TRANSPLANT** ..... 25
**2.10 SUMMARY** ..... 26
**CHAPTER THREE ..... 27**
**RESEARCH DESIGN AND METHODS** ..... 27
**3.1 INTRODUCTION** ..... 27
**3.2 RESEARCH DESIGN** ..... 27
**3.3 RESEARCH METHODS** ..... 28
**3.3.1 POPULATION AND SAMPLING** ..... 28
**3.3.1.1 Population** ..... 28
**3.3.1.2 Sample and sampling** ..... 28
**3.3.2 RESEARCH CONTEXT** ..... 29
**3.3.4 DATA COLLECTION PROCEDURE** ..... 30
**3.3.4.1 Data collection instruments** ..... 30
**3.3.4.2 The recruitment procedure** ..... 31
**3.3.4.3 Realisation of data collection** ..... 32
**3.3.5 DATA ANALYSIS** ..... 32
**3.4 VALIDITY AND RELIABILITY** ..... 34
**3.5 HUMAN RESEARCH ETHICS COMMITTEE** ..... 34
**3.6 SUMMARY** ..... 35
**CHAPTER FOUR ..... 36**
**PRESENTATION AND DISCUSSION OF THE RESULTS** ..... 36
**4.1 INTRODUCTION** ..... 36
**4.2 RESULTS AND DISCUSSION** ..... 36
**4.2.1 Demographic profile** ..... 36
**4.2.2 Knowledge about kidney transplant** ..... 43
**4.3 SUMMARY** ..... 53
**CHAPTER FIVE ..... 54**
**SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION** ..... 54
**5.1 INTRODUCTION** ..... 54
**5.2 SUMMARY OF THE STUDY** ..... 54

**5.3 LIMITATIONS** ..... 55
**5.4 RECOMMENDATIONS** ..... 55
**5.4.1 Recommendations for nurses practicing in dialysis units** ..... 55
**5.4.2 Recommendations for Nursing Research** ..... 56
**5.4.3 Recommendation for Nephrology Nursing Practice** ..... 56
**5.5 CONCLUSION** ..... 57
**LIST OF REFERENCES** ..... **59**

# LIST OF ANNEXURES

**Annexure 1: demographic profile** **70**

**Annexure 2: questionnaire** **71**

**Annexure 3: information leaflet** **78**

**Annexure 4: informed consent** **81**

**Annexure 5: e-mail permission to use the k-tut** **82**

**Annexure 6a: permission to conduct study at hospital** **83**

**Annexure 6b: permission to conduct study at the hospital** **84**

**Annexure 7: ethics clearance** **85**

**Annexure 8: postgraduate approval letter** **86**

# LIST OF FIGURES

**Figure 2.1: Kidney structure** **9**

**Figure 4.1: Gender** **38**

**Figure 4.2: Educational status** **39**

**Figure 4.3: Tobacco use** **40**

**Figure 4.4: Alcohol consumption** **41**

**Figure 4.5: Hypertension** **42**

**Figure 4.6: Diabetes** **43**

**Figure 4.7: Knowledge about kidney transplant** **44**

# LIST OF TABLES

**Table 2.1:** Kidney failure based on Glomerular Filtration Rate and management 13

**Table 3.1:** Descriptive data analysis 33

**Table 4.1:** Demographic profile 36

**Table 4.2:** Health education needs of the participants 45

# NOMENCLATURE

| | |
|---|---|
| **AIDS** | Acquired Immunodeficiency Syndrome |
| **ART** | Antiretroviral Treatment |
| **CKD** | Chronic Kidney Disease |
| **HIV** | Human Immunodeficiency Virus |
| **ICU** | Intensive Care unit |
| **K-TUT** | Kidney transplant understanding tool |
| **SANC** | South African Nursing Council |
| **SPSS** | Statistical Package for Social Science |
| **WHO** | World Health Organization |
| **CKF** | Chronic Kidney Failure |
| **GFR** | Glomerular Filtration Rate |

# CHAPTER ONE

# OVERVIEW OF THE STUDY

## 1.1 INTRODUCTION

This chapter provides an overview of the study, which includes the background, problem statement, purpose of the study, research questions and significance of the study. A brief description of the research methods and design is given as well as the clarification of concepts used in the study. Kidneys form part of the vital organs in the body, it helps the body to eliminate waste products from the blood. Patients suffering from kidney failure are deprived of this normal physiological benefit. They only rely on artificial methods for removal of waste products from their blood.

## 1.2 BACKGROUND & RATIONALE

Kidney failure is a worldwide public health problem that affects millions of people from all racial and ethnic groups (Levey et al., 2009). Kidney failure can be fatal, it is distinguished as either acute or chronic. Acute kidney failure is a clinical syndrome characterised by an acute fall in glomerular filtration rate, resulting in decreased clearance of metabolic waste products from the blood (Kellum et al., 2012). Chronic kidney failure is described as the decreased level of kidney function or existence of kidney damage for a duration of three months or above, regardless of diagnosis (National Kidney Foundation, 2015). Once a person is diagnosed with Chronic kidney failure (CKF), the management involves renal replacement therapy, which is haemodialysis, peritoneal dialysis or kidney transplantation (Levin & Stevens, 2013). An individual is placed on one of these procedures while awaiting kidney transplant. Kidney transplant is a scarce procedure and very expensive. In South Africa the cost to the government for kidney transplant procedure has been estimated at approximately R200 000 per patient annually (Muller, 2013)

The World Health Organization (WHO) cites that up to 69 400 kidney transplants are performed annually worldwide, and 46% are from living donors. Globally there is a lack of kidney donors (Matas, 2012), and Africa suffers from this scarcity too (Muller, 2013). This makes a kidney a

scarce resource to those in need of one or receiving one. As with all scarce resources, their use should be optimised. In order to adequately take care of the of the kidney, health education needs to be clear and understood. Those who receive a kidney therefore need to be adequately educated to decrease the possible chances of rejection related to poor self-management.

According to the Transplant Foundation (2014), there were up to 4 300 adults and children awaiting transplants in South Africa. The South African Renal Registry (2014) shows that approximately 4 328 kidney transplants were performed, and up to 26 990 patients suffering from kidney failure were on haemodialysis between 2012 to 2014. The centre for disease control and prevention states that approximately one in three adults with diabetes and one in five adults with hypertension that is uncontrolled, are at risk of kidney failure (Center for Disease Control and Prevention, 2014). These two conditions place people at higher risk of developing kidney failure compared to those who do not suffer from them (Matas, 2012). The challenge for South Africa is that there is poor control and management of hypertension and diabetes (Steyn et al., 2008). Poor management and control of hypertension and diabetes leads to kidney failure, and the best, cost effective management is kidney transplant. A systemic review study done by Kayima et al. (2013) reveal that in Africa generally the control of hypertension was poor even among subjects that were aware of their status and those that were treated.

Rosaasen et al. (2017) cite that kidney transplant is the renal replacement therapy of choice for patients suffering from chronic kidney failure. Kidney transplantation is a procedure whereby a normal kidney is surgically placed into a body where it will relieve the kidneys that lost their function by performing all the functions of a normal kidney (National Kidney Foundation, 2015). Kidney transplant is more cost-effective especially for the healthcare system and provides the patient with fivefold quality-adjusted life-years than dialysis (Low et al., 2015). A person can receive a kidney from a living donor or from an individual who has died (cadaver) (National Kidney Foundation, 2015).

However, it is important to note that not every patient is eligible for a kidney transplant, those who are eligible undergo an extensive evaluation by a transplant team to identify factors that may have an adverse effect on the kidney transplant outcome and select medically suitable candidates to place on the waiting list (Kaufman et al., 2015). This team consist of nephrologists, surgeons, transplant coordinator nurse, kidney recipient and living donor (where possible) and a social worker (Mendes et al., 2012).

As a standard procedure, patients who are eligible for a kidney transplant, and their families, are given health education about kidney transplant even before they are placed on the waiting list. They receive written (printed) pamphlets, one-on-one and group health education about the transplantation process, which outlines the programme options, risks and benefits of receiving a kidney from both live and deceased donors, and the need for an immunosuppressive medication regimen. Furthermore, they are educated on lifestyle adjustments (diet, fluid restriction and lifelong prescribed medication such as immunosuppressive), effects of transplantation on existing medical conditions and the caring of the graft after transplantation (Mendes et al., 2012).

The challenge is the waiting period for a kidney transplant, which can be longer than a year, putting patients at risk of forgetting the health education they had received. It is therefore significant to evaluate patient's kidney transplant knowledge and health education needs in order to intervene effectively. If patients are assessed of their kidney transplant related knowledge, information to update their understanding could be provided. However, assessment tools that determine adequate or inadequate knowledge of patients with CKF are scarce in South Africa. Nevertheless, a study by Rosaasen et al. (2017) used Kidney Transplant Understanding Tool (K-TUT) to assess the knowledge of the patients regarding kidney transplant and discovered that the K-TUT appears to be a promising tool to measure kidney transplant knowledge.

According to authors (Gordon & Wolf 2009; Skelton et al., 2015) patients with chronic kidney failure have inadequate knowledge about kidney transplant in general. Inadequate knowledge can lead to non-adherence, which has adverse clinical outcomes (Clark et al., 2013). Also, Skelton et al. (2015) highlight that patients with inadequate knowledge may be non-adherent and can make unintentional errors due to misunderstanding of medical instructions. Adequate knowledge is critical for successful renal replacement therapy (RRT) because it relies on the patient's adherence to therapy requirements such as lifestyle changes and use of immunosuppressive treatment (Clark, Farrington & Chilcot, 2014).

Adequate knowledge enables patients to be adherent to medical regimens, solve problems related to CKF symptoms, know when to seek help and who to contact for assistance which reduces unnecessary casualty visits, hospitalisation, improving kidney transplant outcomes (Skelton et al., 2015). Van Camp et al. (2012) in their interventional research conducted in Belgium, which was a nurse-led education and counselling intervention study aimed at improving adherence to phosphate binders among patients with chronic kidney failure,

discovered increased adherence among the control group that was given health education related to the group that was not given health education. This study indicates the significance of tailor-made health education in improving adherence.

Tailor-made education is necessary to improve patient's knowledge about kidney transplant (Skelton et al., 2015). Tailor-made education is reported to have a positive influence on patient empowerment that is required for self-care management before and after kidney transplant (Low et al. ,2015). This is also emphasised by Howe et al. (2015), who mention that healthcare providers should introduce, educate and discuss the transplantation procedure, and invite patients to ask questions about kidney transplant. Tailor-made health education can improve patient's knowledge about kidney transplant, which seem to be less researched (Gordon & Wolf, 2009; Skelton et al., 2015).

## 1.3 PROBLEM STATEMENT

Patients living with Chronic Kidney Failure are expected to be knowledgeable regarding kidney transplant. However, these patients have inadequate knowledge about the procedure, which is the preferred choice of treatment due to its relative cost-effectiveness (Low et al., 2015). Inadequate knowledge about kidney transplant can lead to poor self-care management and subsequent transplanted kidney rejection or acquiring infections (Gordon & Wolf, 2009). Currently, South Africa is struggling with the control of hypertension and diabetes (Ndou et al., 2013), and with an approximate number of 900 000 South Africans who live on ARVs, which also contributes to kidney failure (Simelela & Venter, 2014). Therefore, for those diagnosed with Chronic Kidney Failure and eligible for kidney transplant, it is crucial to prevent the risks of kidney transplant rejection by continuously assessing their level of health education and identifying health education needs.

There seems to be a dearth in studies concerning the knowledge and health education needs of patients diagnosed with kidney failure and awaiting kidney transplant about the procedure and their educational needs. Moreover, in the two South African academic hospitals in Johannesburg, no studies have been conducted regarding knowledge and health education needs of patients on haemodialysis awaiting kidney transplant. This information is necessary, as literature indicates patients who have received effective tailor-made health education are empowered and adhere to therapy compared to those who were not provided with health education (Van Camp et al., 2012). For healthcare providers to prepare individualised health

education for patients they need to be aware of the knowledge and health education needs of the patient with Chronic Kidney Failure. This study describes the level of knowledge and health education needs of patients on haemodialysis awaiting kidney transplant in two academic hospitals in Johannesburg.

## 1.4 RESEARCH QUESTION

The research question for the study was:

What is the kidney transplant related knowledge and health education needs of patients with Chronic Kidney Failure on haemodialysis awaiting kidney transplant?

## 1.5 PURPOSE OF THE STUDY

The purpose of this study was to describe the kidney transplant related knowledge and health education needs of patients with Chronic Kidney Failure on haemodialysis awaiting kidney transplant at two academic hospitals in Gauteng.

## 1.6 OBJECTIVES:

The objectives of the study were to:

- describe the demographic profile of patients on haemodialysis;
- describe the kidney transplant related knowledge of patients on haemodialysis;
- identify the kidney transplant related health education needs of patients with CKF.

## 1.7 SIGNIFICANCE OF THE STUDY

Adequate knowledge about kidney transplant is important as patients will be able to care for themselves adequately and the risks of kidney rejection related to poor self-care management will be minimised. The findings of this study will bring awareness to the healthcare providers

caring for patients on haemodialysis awaiting kidney transplant about the knowledge level and health education needs of their patients and enable them to decide on the type of tailor-made health education that could be provided to patients prior to kidney transplant.

## 1.8 DEFINITION OF TERMS

1.8.1 Kidney transplant - is a procedure whereby a normal kidney is surgically placed into a body where it will relieve the kidneys that lost their function by performing all the functions of a normal kidney (National Kidney Foundation, 2015). In this study, kidney transplant means surgically inserting a normal kidney in the body and allowing it to perform all its functions.

1.8.2 Haemodialysis – is an artificial membrane that is used to help eliminate waste products and correcting fluid and electrolyte imbalances at the same time in chronic kidney failure patients (Grant et al., 2017). In this study, haemodialysis means the use of artificial membrane to correct fluid and electrolyte imbalances and remove waste products in kidney failure patients.

1.8.3 Healthcare provider – is a person that helps to identify, prevent, or treat illness or disability (Joseph & Joseph, 2016). In this study, a healthcare provider is a professional who either diagnose, provide nursing care, health education and manage patients with kidney failure.

1.8.4 Adherence – is the action of continuing to obey a rule, law, or agreement (Mafutha & Wright, 2013). In this study, to adhere means a patient's actions to obey the required self-care management for individuals on haemodialysis awaiting kidney transplant.

1.8.5 Tailor-made health education – it is health education specially designed for a particular person or purpose (Schapira et al., 2017). In this study, tailor-made health education will mean health education that is specifically prepared to meet the individual needs of patients diagnosed with kidney failure, on haemodialysis awaiting kidney transplant.

1.8.6 Immunosuppressive – is medication that is used to prevent or suppress the body's immune response. This kind of medication is used to stop the body from rejecting the transplanted organ and for treatment of autoimmune diseases (Hartono, Muthukumar & Suthanthiran, 2013). Immunosuppressives in this study are medications taken by patients to prevent infections.

1.8.7 Graft – is a healthy tissue extracted from a certain part of the body to replace another tissue that is failing to perform its expected functions in other part of the body (Dahl et.al, 2011).

In this study, a graft means healthy tissue that is taken from one part of the body to replace diseased or injured tissue in another part of the body.

1.8.8 Chronic Kidney Failure - is a progressive and irreversible deterioration of the renal excretory function (López-Novoa et al., 2010). In this study Chronic Kidney Failure (CKF) means the damage to the kidneys that cannot be reversed, but only require dialysis or kidney transplant.

1.8.9 Patient 's Knowledge - is described by Bolisani & Bratianu (2018) as theoretical or practical understanding of a subject. In this study knowledge refers to the attributes displayed by the patients with CKF on haemodialysis awaiting kidney transplant to show understanding of their condition and treatment plan.

## 1.9 RESEARCH SETTING

The research settings were two renal units in two academic hospitals in Gauteng. One hospital had 64 patients and the other had 60 patients, so in total is 124. The researcher chose the two hospitals conveniently, and because they are part of University of Witwatersrand training centres and again, they had target population for the study.

## 1.10 OVERVIEW OF RESEARCH METHODOLOGY

This study was a non-experimental descriptive quantitative and cross-sectional survey. The target population included all the patients with chronic kidney failure, on haemodialysis awaiting kidney transplant in the dialysis units in both academic hospitals. The target population was n=124 patients in the two units combined, but only n=70 patients gave consent to take part. Data was collected by the researcher using Kidney Transplant Understanding Tool (K-TUT), some participants opted to fill the questionnaires by themselves. A detailed description of the research methods is provided in Chapter 3.

## 1.11 OUTLINE OF THE RESEARCH REPORT

The research report is divided into five chapters:

Chapter 1: Overview of the study

Chapter 2: Literature review

Chapter 3: Research design and methods

Chapter 4: Research results and discussion

Chapter 5: Conclusions, limitations and recommendations of the study

## 1.12 SUMMARY

This chapter outlined the overview of the study, and how the study was executed, the problem statement, the research question, the objectives, and all the terms included in the study were explained.

# CHAPTER TWO

# LITERATURE REVIEW

## 2. 1 INTRODUCTION

This chapter presents the literature review of the study. It is crucial to have a better understanding of this phenomenon in order to contribute towards the lives of individuals suffering chronic kidney failure. In this chapter, a description of the anatomy of the kidney, physiology of the kidney, acute and chronic kidney failure, the prevalence of kidney failure, the risk factors, as well as its management is provided.

The literature presented was published between 2008 and 2018 and accessed through the following search engines: Google Scholar, PubMed, Science Direct, and Scopus using search terms such as kidney failure, risk factors, pathophysiology, self-management, prevalence, kidney transplant, haemodialysis, and peritoneal dialysis. Figure 2.1 depicts the anatomy of the kidney, it depicts the anatomical structure of the kidneys.

## 2.2 THE ANATOMY OF THE KIDNEY

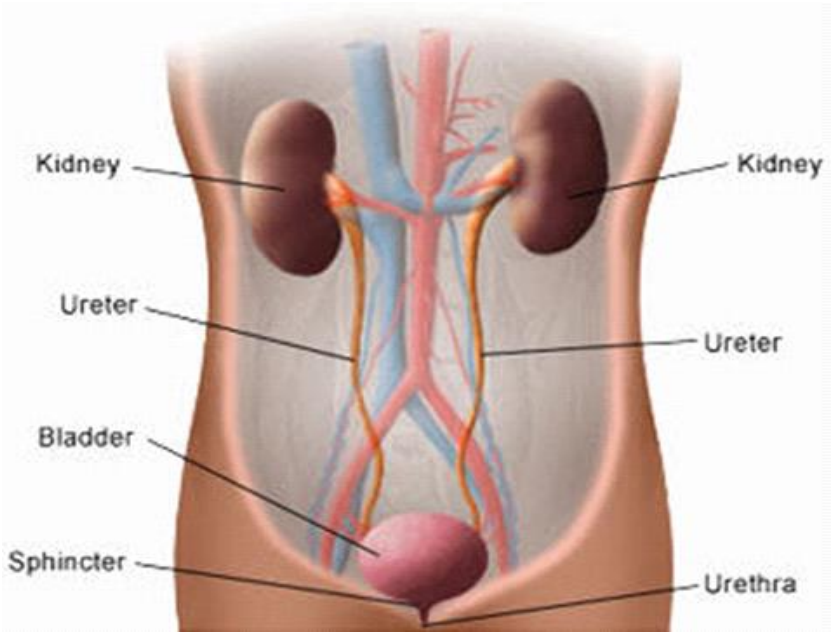



**Fig 2.1: Kidney structure** (Ishii, Aboumarzouk & Van Poppel, 2019).

As displayed in Figure 2.1, kidneys are bean-shaped, paired organs that are situated outside the peritoneal cavity behind the upper abdomen, each on the side of the vertebral column at the level of the 12th thoracic to third lumbar vertebrae (National Kidney Foundation, 2015). According to Mbeje (2013), kidneys are in the lumbar region, and decontaminate the blood and discharge urine. The right kidney normally is situated lower than the left, this is due to the position and size of the liver. For adults, one kidney weighs approximately 113 to 170 g, about 2.5 cm, 5 to 6 cm wide and about 10 to 12 cm long.

## 2.3 A BRIEF PHYSIOLOGY OF KIDNEY FAILURE

The main function of a kidney is to eliminate waste products from the blood, help with balancing fluids in the body, formation of urine, is explained below by described by Rayner, Thomas and Milford (2016) includes:

- Waste elimination: The kidneys filter out toxins, excess salts and urea, a nitrogen-based waste created by cell metabolism. Urea is synthesised in the liver and transported through the blood to the kidneys for removal.
- Fluid balance: the kidneys help in the chemical breakdown of urine, they react to changes in the body's water level throughout the day. If there is decreased fluid intake, the kidneys adjust accordingly and leave water in the body instead of helping to excrete it.
- Blood pressure regulation: there is a need for constant pressure in the kidneys to filter blood; when the pressure goes down, the kidneys increase the pressure. The kidney produces angiotensin that also signals the body to retain sodium and water. Both the constriction and retention help restore normal blood pressure.
- Red blood cell regulation: when there is a lack of oxygen in the blood, the kidneys triggers the erythropoietin release, a hormone that helps in stimulating the release red blood cells carrying oxygen from the bone marrow.
- Acid regulation: when cells metabolise, acid is produced. Foods eaten may increase or neutralise acid in our body. For the body to maintain its healthy functioning capacity, acid must be properly regulated.

### 2.3.1 PATHOPHYSIOLOGY OF KIDNEY FAILURE

It is critical to note that if at any point a person's normal kidney function is altered, the person becomes at risk of kidney failure or suffer from kidney failure. There are two types of kidney failure and they will be discussed in terms of acute and chronic kidney failure.

#### 2.3.1.1 Acute kidney failure

Rahman, Shad & Smith (2012) describe acute kidney failure as a sudden decline in kidney function, manifested by an elevated serum creatinine level, with or without reduced urine output. Creatinine is an important kidney function marker, which if high, it symbolises decreased kidney function. Meanwhile, Varrier, Fisher & Ostermann (2015) emphasise that acute kidney failure comprises of dysfunction or inability of the kidney to remove waste products from the blood, balance fluid, acid-base and electrolyte regulation. These occur at varying degrees, and prognosis depending on the extent and nature of the failure. Moreover, the patient has a chance of opening up, which means regaining independent kidney function which can be seen after kidney function tests were done. It is reported that, acute kidney failure in developing and developed countries is on the rise and causes high morbidity and mortality in adults, as well as the subsequent development of chronic kidney failure (Al-Saqladi, 2016).

#### 2.3.1.2 Chronic kidney failure

Mbeje (2013) defines chronic kidney failure as dynamic and irreversible, with markable crumbling in kidney functioning, as the body's capacity to look after metabolic, fluid and electrolyte balance becomes unsuccessful. Furthermore, Chronic Kidney Failure (CKF) is described as a medical condition in whereby there is an irreversible loss of kidney functioning, so the patient depends permanently on renal replacement therapy to extract wastes and excess fluid from the body (Mullins et al., 2016). CKF manifests in reduced functioning of the kidney, higher excretions of albumin, and evidenced by persistent lower estimated glomerular filtration rate (GFR) for more than three months (Thomas, Kanso, & Sedor, 2008). The measure of the kidney’s function is referred to as GFR. GFR can be calculated using the Cockroft-Gault formula as follows (Solini & Ferrannini, 2011):

GFR (mL/min) = (140-age [y]) x body weight (kg) [72 x creatinine (mg/dL)] x 0.85.

There are different stages of kidney failure based on GFR, Table 2.1 describes each stage and its management.

**Table 2.1: Kidney failure based of GFR and management** (Thomas et al.,2008; Solini & Ferrannin, 2011)

| Stage | Description | GFR mL/min/1.73m$^2$ | Clinical manifestation | Management |
|---|---|---|---|---|
| 1 | Slight kidney failure with normal or increased filtration. | >90 | The kidneys are healthy and working well, but the patients may have other symptoms of kidney failure. For example, protein in urine or physical damage to the kidneys. | Eat healthy diet. Keep control of blood glucose level if diabetic. Keep blood pressure at normal ranges. |
| 2 | Mild decrease in kidney function | 60-89 | Like stage 1; there are no present physical symptoms. | Patients are advised to adhere to their treatments, eat healthy diet, exercise regularly. |
| 3 | Moderate decrease in kidney function | 30-59 | Backpain, passing more or less urine than normal. Swelling on the limbs. | At this stage, patients are advised to adhere to proper diet and take medication strictly as prescribed. |
| 4 | Severe decrease in kidney function | 14-29 | The patients present with swelling on the limbs, difficulty in breathing, back pains and reduced urine output. | Management includes control of the condition led to decrease in kidney function. |

| | | | | |
|---|---|---|---|---|
| 5 | Kidney failure | <15 | The patient has diminished kidney function; there is a build-up of wastes in the blood. The symptoms can be itching, nausea, vomiting, general malaise, difficulty in breathing, loss of appetite. | Dialysis or kidney transplant are the treatment of choice. |

## 2.4 PREVALENCE OF KIDNEY FAILURE

Kidney failure is a non-communicable disease that is prevalent in both developed and developing countries and it will be discussed here in terms of international and national prevalence. Internationally, acute kidney failure is responsible for approximately 2 million deaths annually (Chawla & Kimmel, 2012). Yearly, new cases rate of early rate of end-stage kidney failure in Hong Kong (1115 people), reflected in their renal registry information, shows an overall pattern of dynamically expanding numbers (Cheung et al, 2015). Likewise, the rates have been expanding in the United States, and it is anticipated that by 2020, there will be 700,000 patients on dialysis in the United States, costing US$30 million (R430 404 002.73) a year for their dialysis treatment. Recent surveys have shown a marked diversity of CKD prevalence in the general population, from 5% to 13% worldwide (De Nicola & Minutolo, 2016) and it is now recognised as a public health priority worldwide.

Literature further reveals that the estimated prevalence of chronic kidney failure in sub-Saharan Africa is 13.9%, which is like global estimates of 13.4% (Etheredge & Fabian, 2017). The management and treatment of HIV and AIDS is a major contributor to the current state of kidney failure (Ekrikpo et al., 2018). The number of people infected with HIV is estimated at approximately 35 million, sub-Saharan Africa has 68% of those who are infected and are on Antiretroviral treatment (Moosa et al., 2015). Because of this situation, in South Africa the

number of patients on renal replacement therapy has continued to increase gradually, and was 10 360 in December 2015 (Davids, Marais & Jacobs, 2017). Furthermore, Gauteng holds the largest population (3238) of people with kidney failure on dialysis therefore, this study will highlight the educational needs of these patients and their knowledge levels, which are pivotal in the dialysis journey as well as in post-transplant.

## 2.5 RISK FACTORS FOR KIDNEY FAILURE

The World Health Organization (WHO, 2015) describes a risk factor as "any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury". Meyers (2015) elaborates that risk factors include ageing, family history of CKD, constant use of non-steroidal anti-inflammatory drugs (NSAIDs), and history of abnormal kidney function, abnormal morphology of the kidney, dyslipidaemia, hyperuricaemia, obesity, metabolic syndrome, autoimmune diseases, kidney infections, nephrotic syndrome and kidney stones. Varrier et al. (2015) outline the most common causes of kidney failure as sepsis, decreased blood flow to the kidneys, haemodynamic instability, and nephrotoxic injury. Naicker (2013) mentions hypertension, HIV and Diabetes Mellitus as the major risk factors of kidney failure, especially in South Africa and the African continent at large. The risk factors will further be discussed in terms of HIV and AIDS, hypertension and diabetes, and poor infrastructure as literature reveals they are the main contributors to kidney failure (Etheredge & Fabian, 2017).

### 2.5.1 HIV and AIDS

Literature shows that since ART (antiretroviral treatment) was initiated, a prospective study on kidney injury in HIV patients who access to ART found that more severe immunosuppression (CD4 <200 cells/mm3 and/ or HIV RNA level >10 000 copies/mL) is still the major risk factor for kidney failure (Moosa et al., 2015). There is increasing evidence that ART (Adefovir and tenofovir) can lead to a wide variety of nephrotoxic effects and acute kidney failure (Soto et al., 2019). According to Achhra et al. (2016), some selected antiretroviral drugs, especially tenofovir disoproxil fumarate (TDF), and some ritonavir-boosted protease inhibitors have been related with increased risk of CKD due to their tubular nephrotoxicity effect; nephrotoxicity will be shown by decrease in kidney function of a patient.

### 2.5.2 Hypertension and diabetes

Judd and Calhoun (2012) define hypertension as the systolic blood pressure of >140mmHg and diastolic pressure of >90mmHg, checked on two different occasions or visits to the Healthcare provider. Chronic elevated blood pressure cause renal vasodilation, inflammation and metabolic derangements eventually causes kidney failure which in turn, further impairs kidney excretion of sodium and worsens kidney failure and hypertension (Hall et al., 2014). Furthermore, systemic hypertension is diffused to intraglomerular capillary pressure leading to glomerulosclerosis and impaired kidney function (Kazancioğlu, 2013). Basically, with time, persistent elevated blood pressure causes the narrowing, weakening and hardening of arteries around the kidneys. Damaged arteries are unable to transport enough blood to the kidney tissue. Kidney failure results from nephrons being unable to receive oxygen and nutrients supply needed for them to function well due to damaged blood vessels.

Diabetes is a disease in which the body is unable to respond or produce to the hormone insulin, resulting in irregular breakdown of carbohydrates and high levels of the blood glucose (Zaccardi et al., 2016). Diabetes Mellitus is responsible for about one third of chronic kidney failure patients who undergo dialysis. It is the leading cause of chronic kidney failure worldwide. Persistent high glucose levels in the diabetic patients is more likely to cause kidney failure. This happens when the glomerular basement membrane thickens due to high blood glucose levels and cause obstruction on the renal veins and arteries (Shahbazian & Rezaii, 2013). Moreover, more albumin leaks into the urine, this happens as the disease progresses further, it is a stage known as macroalbuminuria or proteinuria. The increased amount of albumin in the urine is usually followed by the decrease in filtering function of the kidneys, resulting in waste retention in the body (Dabla, 2010).

Both hypertension and diabetes are chronic diseases that depend on effective self-care management, just like when a person is on dialysis or just had a kidney transplant. The need for effective health education and adequate knowledge cannot be over-emphasised on people with these two conditions because usually they co-exist. Moosa et al. (2015) viewed hypertension as a reason for CKD and aggravating present CKD, resulting in a vicious cycle. According to Mnukwa (2015), in a study done in Ethiopia, the occurrence of CKD was observed to rise due to hypertension and diabetes mellitus. In addition, Mnukwa (2015) emphasised that

hypertension (13.6%) and diabetes (7.0%) were observed to be the highest comorbidities recorded in the 100 patients' files observed.

In a study conducted by Brewster, Panday & Van Montfrans (2020), it was reported that more effort should be focused on the prevention of hypertension and diabetes in lower- and middle-income countries. Nevertheless, with low control rates and the high prevalence of the two conditions, adequate drug treatment is imperative to lessen illness and death rates. This means essential part of population health strategies is to improve drug treatment. Studies conducted in South Africa (SA) (Katz, 2007; Meyers, 2015) demonstrated that hypertension is by far the greatest reason for CKD in Black African patients, while diabetes is most diagnosed among White and Asian patients. According to Meyers (2015), the most important risk factor in South Africa's Black population for CKD is the development of essential hypertension not diagnosed early, and often poorly treated. Kaze et al. (2016) confirmed that worldwide there is a growing prevalence of hypertension, particularly Sub-Saharan Africa because it is where most people are undiagnosed, inadequately treated or not treated at all.

### 2.5.3 Poor infrastructure and kidney failure detection

Etheredge and Fabian (2017) emphasise that poor infrastructure, such as the absence of screening and prevention programmes in the hospitals and community healthcare centres for kidney disease, are systemic factors that further increase this risk. Patients who are eligible for screening are those diagnosed with hypertension, diabetes, HIV positive and on antiretroviral medications (ARVs). Also, those who present with signs and symptoms of kidney failure, a physician may recommend for other tests and procedures to confirm the diagnosis (Rahman, Shad & Smith, 2012). According to Rahman, Shad & Smith, 2012 these may include:

- Urine output measurements

  The amount of urine excreted in a day may help a doctor determine the cause of kidney failure. Patients are given 2 or 5L bottle to collect 24 hours' urine specimen for measuring how much urine is passed in 24 hours.

- Urine tests

Analysing a urine sample, using a urinalysis procedure, abnormalities may be revealed that indicate kidney failure. Those abnormalities include blood and protein in the urine.

• Blood tests

A blood sample is collected and sent to the laboratory for assessment, a rapid rise in the levels of urea and creatinine may be noted from the blood results — kidney function is measured through those two substances.

• Imaging tests

Tests such as ultrasound and computerised tomography are used to help a doctor view the kidneys. This can be done in the hospital.

• Biopsy (Removing a sample of kidney tissue for testing)

In some situations, a doctor may recommend a kidney biopsy to remove a small sample of kidney tissue for lab testing. A needle is used to penetrate the skin and into the kidney to remove a tissue sample.

Nephrologists and medical students were educating communities about chronic kidney disease (CKD) prevention through the kidney Disease Screening and Awareness Program, founded at Harvard University in the USA (Hsiao, 2018). The nephrologists and students visited churches, community centres, shopping centres and residential areas to educate people about kidney disease and take history for screening. Therefore, nurses get to be exposed to all the specialties, including nephrology nursing, during their training to become professional nurse. Furthermore, after the undergraduate course, a person can register for the postgraduate course in nephrology nursing, which is where they get to learn intensively about nephrology.

## 2.6 MANAGEMENT OF CHRONIC KIDNEY FAILURE

During the screening for CKD, if the kidneys are unable to clear waste products and fluid on their own and the patient develops total kidney failure, then this is regarded as end-stage kidney disease. At this point, lifestyle adjustments, dialysis and a kidney transplantation are recommended as part of the management, and these will be discussed below.

### 2.6.1 Health education

According to the World Health Organization (2015) health education is an intervention that aims to communicate health information and provide skills to support patients to adopt healthy behaviours voluntarily. Health education can be provided in various teaching methods, such as individual interaction with the health care provider, mass and group media, target specific groups such as people living with similar health condition e.g., kidney failure patients. Moreover, health education uses materials such as printed pamphlets and are displayed in health facilities mostly. Also, media such as internet, television and social medias are used as source of health education.

For patients with kidney failure their health education comprises of self-care, adherence to treatment, and lifestyle adjustment. The challenges faced by the healthcare providers include inability to explain kidney failure because of language barrier, especially to non-English speakers and patients who have no understanding of the roles of the kidney in the body (Narva, Norton & Boulware, 2016). When the patients are empowered or provided with health education on their condition, compliance to their treatment and self-care is expected to improve (Royani et al, 2013). The same authors further mentioned that healthcare providers should consider basing patients' education on empowerment programme which is a modern educational method in which the patients can exchange their experiences in addition to having active participation in learning.

### 2.6.2 Lifestyle adjustment

It is important to note with CKF patients, health education is often provided in terms of individualised or group methods. The individualised education helps the healthcare providers to monitor the level of knowledge and health education needs of each patient regarding their condition, and what is entailed. The group education makes sure that all the patients and well informed about how they should conduct themselves and be knowledgeable about their condition and promotes sense of belonging (Narva, Norton & Boulware, 2016).

If a patient always come for their treatment with fluid overload; in this instance, it is the fluid intake health education that they need. However, they challenge comes when they are being educated about fluid intake continuously when they attend their dialysis session, they respond by saying they get dry and there is nothing they can do about it but to have water (Palmer et al., 2016). While if the same education is provided in a group session, patients can share how they

personally navigate the thirsty challenges that leads to others taking fluids more that recommended.

As part of the treatment for kidney failure, the nephrologist may suggest a special diet to help support the kidneys and reduce the work they must do. The nephrologist will refer the patient to a dietician who can analyse the current diet and educate patients on individual bases regarding their unique diet which can make it easier for their kidneys to function (Kalantar-Zadeh & Fouque, 2017). According to Kalantar et al. (2017), in terms of dietary practise patients are taught to:

• Avoid products with added salt.

Reduce the amount of salt intake each day (<5g) by not consuming products with added salt, including many convenience foods, such as frozen dinners, canned soups and fast foods. Foods with added salt include salty snack foods, canned vegetables, and processed meats and cheeses. Food containing high salt may cause high or uncontrolled blood pressure. Most of the patients have a low level of education hence adherence is not expected to be high.

• Choose lower potassium foods.

Lower potassium foods may be recommended at each meal. High-potassium foods include bananas, oranges, potatoes, spinach and tomatoes. Some examples of low-potassium foods include apples, cabbage, carrots, green beans, grapes and strawberries. A lot of salt substitutes contain potassium, so they should be avoided in kidney failure. In this case, hypertensive patients are educated to eat five portions per day of fruits and vegetables (Ozcariz et.al, 2015), however now because they are diagnosed with kidney failure, they are taught to avoid these fruits; this will not only confuse a patient but might lead to distrust of the healthcare providers (Cupisti et al., 2018).

• Limit the amount of protein taken.

The dietician will give an estimate of the appropriate number of grams of protein needed each day and make recommendations for a patient's suitable consumption based on that amount (Yan et al., 2018). examples of high-protein foods include lean meats, eggs, milk, cheese and beans; low-protein foods include vegetables, fruits, breads and cereals. The challenge with this kind of diet is that people, especially the illiterate, do not know how to measure the grams of protein or amount to be consumed per day, therefore health education will need to be structured in a way that the patient can relate to their situation at home and be able to adjust their dietary practice, that is if the health education was received well and understood. In the literature, Nkosi

& Wright (2010) discovered that hypertensive patients were educated about diet, but they could not remember exactly what the Healthcare provider said. Therefore, the chances of behaviour change are unlikely in such situations.

- Not to use un-prescribed medications or over the counter medications

According to the WHO, there are more people using complementary alternative therapies and herbal medications to treat diseases worldwide, most of which were found to be nephrotoxic (Hsieh et al., 2012). The effects of herbal medicines on the kidneys are complex because they are frequently used as compound mixtures (Hsieh et al., 2012). This use of traditional medicine is not only unique to the Chinese, as in South Africa most people still consult the traditional healer or use alternative complementary methods to cure themselves from different illness (Marais, Steenkamp & Du Plooy, 2015). Regardless of reasons patients have, they are discouraged from using traditional medicine but to consult medical health centre.

### 2.6.3 Dialysis

Dialysis is a procedure that uses artificial membranes to removes waste products and extra excess fluid from the blood when the kidneys cannot function. Types of dialysis are classified as haemodialysis and peritoneal (Nissenson & Fine, 2016). In haemodialysis, a machine filters excess fluids and waste products from the blood (Vadakedath & Kandi, 2017) taking the role of the kidneys; a patient is required to attend a four-hours session of haemodialysis three times a week. In peritoneal dialysis, a thin sized tube (catheter) is placed into the abdomen, fills the patient's abdominal cavity with a solution that absorbs excess fluids and waste (Sow et al., 2018). After a while, the solution is drained from the body, carrying the waste with it, into a collection bag. Peritoneal dialysis is done every four hours in a day, therefore the patients have to be at home in order to do it, however there a machine can be provided to the patients, mostly those who are working, to connect themselves overnight and only disconnect in the morning the following day (Roumelioti et al., 2016). The machine helps in infusing the solution into the abdominal cavity and then draining it.

In Johannesburg, Gauteng Province, there are selected government hospitals that offer dialysis, namely the Charlotte Maxeke Academic Hospital, Helen Joseph Hospital, Leratong Hospital and Chris Hani Baragwanath Hospital (Davids, Marais & Jacobs, 2017). The financial burden of dialysis can be overwhelming for the public hospital, as mentioned previously currently it is

estimated to cost approximately R200 000 per annum per patient in South Africa (Moosa et al., 2015). Furthermore, not all the patients with kidney failure get to have a slot for dialysis due to the shortage of state facilities that offer dialysis, therefore many people die while on a waiting list (Moosa et al., 2015). Due to limited state resources, patients remain on the waiting list for a long time.

### 2.6.4 Kidney transplant

According to the National Kidney Foundation (2015), kidney transplant involves surgically placing a healthy kidney from a donor into the body. Some of the kidney failure patients are not eligible for a kidney transplant, this includes older aged patients (>65 years old) and those with severe heart or vascular disease who can remain on dialysis rather than undergoing kidney transplantation (Berns, 2018; National Kidney Foundation, 2015). Other exclusion criteria for kidney transplantation are as follows:

- Being diagnosed with cancer or being on cancer treatment
- A chronic illness or infection that cannot be cured and could lead to death within a few years.
- Dementia
- Uncontrolled mental illness
- A body mass index greater than 40 (severe obesity)
- Current substance (alcohol and drug) abuse

It is important to note that before kidney transplant process is initiated, the client is provided with health education and family members are involved. During this process, the transplant coordinator is in close contact with the patient and their family, to explain the procedure and what it entails (National Kidney Foundation, 2015). The patients are then required to go through the transplant work-up programme to make sure they are not among those who do not qualify. Tests to determine whether patients can receive a kidney or not are listed below as described by the Kidney Foundation (National Kidney Foundation, 2015):

- Blood tests: These are used to check the function of the heart, kidneys, liver, thyroid and immune system. Blood sugar control and electrolyte balance will also be checked. Special tests to look for certain viruses (EBV, hepatitis and HIV/AIDS) will also be done.
- Chest X-ray: This is done to check the lungs for infection, lung disease, or other abnormalities. It is also used to see the size of the heart.
- Echocardiogram: This is an ultrasound of the heart, used to check the chambers of the heart, valves, and pumping function for any signs of problems, such as blockage or thrombosis.
- Electrocardiogram: This test looks at the heart's rhythm and will show if there are any abnormalities.
- Cardiac stress test: This is to measures the ability of the heart to respond to stress in a controlled environment. It can show if the heart is strong enough for a transplant surgery.
- Cancer screening: a patient must not be having cancer or treating cancer before undergoing a kidney transplant. Some cancer screening tests, which may include a colonoscopy, skin cancer screening, prostate exam (men), and mammography (women), will be done. If a patient had cancer in the past, they will be checked thoroughly to ensure it has not returned.
- Dental evaluation: This is done to exclude any infections, cavities on the teeth, or gingivitis (gum disease). If any of these dental problems are identified, it is best to treat them before transplant as they can cause infections that may cause rejection after kidney transplant.

Furthermore, Rosaasen et al. (2017) cite that kidney transplant is the renal replacement therapy of choice for patients suffering from CKF. Kidney transplant is more cost-effective, especially for the healthcare system and provides the patient with fivefold quality-adjusted life-years than dialysis (Low et al., 2015). Globally, there are challenges in getting people to donate a kidney, because willingness to donate depends on several variables, the level knowledge, attitude and cultural or religious values of the potential donor (Bello & Raji, 2016). A person can receive a kidney from a living donor or from an individual who has died (cadaver) (National Kidney Foundation, 2015). However, to date, people are still sceptical about donating their kidneys even after their death. In Africa and South Africa, the cultural and religious beliefs related to donating still need to be broken (Bello & Raji, 2016); for example, it is believed "the ancestors will not recognise you, should you die with incomplete organs" (Taghavi et al., 2019).

A study done by Gordon & Wolf (2009) in Chicago, reveals that many participants identified inadequate knowledge about living kidney donation, expressing doubt about the differences between living kidney donation and deceased donation. In this study participants believed that

donors are unable to bear children, have reduced life expectancy and are at risk of developing kidney failure after donating. While Irving et al. (2012) conducted a study in Mexico and discovered that some participants felt no one should intervene, therefore discouraging kidney donation. The participants believed they need to maintain their body as a 'whole' to enter the next life. Others also believed that their body belongs to God not to them and were therefore unable to donate. Others highlighted the importance of certain rituals that has to do with the grieving process and that organ donation was perceived to interfere in this process (Irving et al.,2012).

Furthermore, some cultures believed that the spirit transferred from the donor to the recipient and others discussed the need for ancestors to approve before donating the kidney, so that the remaining family may still have protection from the ancestors (Muwanga, 2018). Therefore, due to the lack of proper and effective strategies in education to the public, those who require kidney transplant continue to live on dialysis, although kidney transplant would yield a better quality of life.

## 2.7 STRATEGIES TO PROMOTE KIDNEY DONATION

A possible strategy was highlighted in a study conducted in the USA on Health care professional regarding kidney donation. It is reported that the healthcare providers support the government to introduce incentives for living donors in order to increase the number of kidney donations (Story, Eyck & Kuppachi, 2018). Kidney donation is mostly affected by the attitudes, lack of knowledge and socioeconomic factors like fears of male and females being unable to bear children after kidney donation, and fears that donating would reduce their life expectancy (Gordon & Wolf, 2009). There should be cultural education to enhance kidney donation, additionally structurally incorporates cultural values into the program. For example, the healthcare providers at the dialysis centres must ask the patients to come with their family members to the education sessions to be taught and be able to understand kidney donation and give their blessing to family members to pursue it (Gordon & Wolf, 2009).

It is the transplant centre's responsibility to overcome barriers to living Kidney donation by taking an active role and the community should launch a campaign distributing information about living kidney donation's risks and benefits and encouraging the public to consider donating a kidney either to a family member or a stranger with chronic kidney failure (Allen &

Reese, 2016). Furthermore, same authors mentioned that the focus of discussions about increasing living kidney donation was on financial incentives, but ethical objections make widespread adoption of payment for donation impossible.

Organizations like National Kidney Foundation can play an important role in promoting kidney donation because they operate beyond the healthcare infrastructure and play no role in the consent process, they are free to promote donation without challenging ethical norms underlying the physician–patient relationship (Allen & Reese, 2016). Also, introducing home-based education to target the recipient and potential donors of their choice, such as family members or friends (Barnieh et.al., 2017). In this case the education should be given to individuals rather than in groups.

## 2.8 SELF-CARE MANAGEMENT

Self-care management is defined as the decisions and behaviours that patients with chronic illness engage in that affect their health and wellbeing daily for the rest of their lives (Grady & Gough, 2014). Furthermore, the WHO defines self-care as the ability for individuals to use information and knowledge available to them to look after their own health. It is a decision-making process, which empowers individuals to look after their own health proficiently and conveniently (Wong et al., 2018).

According to Wong et al. (2018) self-care has been related with positive mental and physical health outcomes across patient populations. The patient's self-care confidence affects their performance of self-care management behaviours, for example, the amount of stress and anxiety that they experience, and the decision-making in self-care management. The same authors reported that interventions can increase self-care self-efficacy, therefore, it is important for healthcare providers to understand factors that influence patients' self-care so that educational interventions can be initiated.

In a study done by Hafezieh et al. (2020) among patients on haemodialysis in Yazd, Iran. It was evident that self-management was associated with knowledge, if the patient was knowledgeable, then they were more likely to have a high self-management skill.

When considering self-care management in terms of kidney failure, self-care management refers to the ability of a patient to take medication properly, manage fluid intake, adhere to a proper diet and attend their dialysis sessions as scheduled (Green et al., 2013). According to

Hernández et al. (2018), CKD patients are subjected to high levels of stress, about the restriction of diet and control of fluids, exhaustion, limitation of physical activities and poor self-care. It is crucial therefore, that healthcare providers have a deeper understanding of the patients' perception of their illness and treatment, and how they view the significant changes to their lives due to kidney failure (Sadala et al., 2012).

## 2.9 KNOWLEDGE ABOUT KIDNEY TRANSPLANT

Bolisani and Bratianu (2018) define knowledge as theoretical or practical understanding of a subject. Knowledge about kidney transplant is crucial because patients living with CKD will have to use it should they receive a kidney. Health education should be comprehensive enough and inform them about the benefits of receiving a kidney and how to live healthy and prevent rejection at all costs. According to Poorgholami, Javadpour, Saadatmand & Jahromi (2016) involving patients in their treatment programme to effectively manage the disease complications and improve their self-esteem is a very important. This is because educating patients did show to be effective in self-esteem improvement in patients undergoing haemodialysis.

Regardless of the importance of knowledge about kidney transplant; Beaumont and Waterman (2019) reported insufficient knowledge among CKF patients awaiting transplant among patients on dialysis in dialysis centres throughout Missouri. This lack of knowledge can be curbed by providing tailor-made health education and group discussions for the patients to comprehend and have adequate knowledge. In a study done to explore the knowledge and advance care needs of patients who have CKF, it was revealed that it is essential to engage patients and educate them of their condition, also involve the family members for support (Phillips, MacNab & Loewen, 2018). Most importantly proper health education enhances the knowledge adequacy, patient's adherence to medication, scheduled dialysis treatments, and quality of life (Alikari et al., 2019). Healthcare providers should know that It is essential to detect the patients' health educational needs and equally be able to help the patient meet those needs.

There is a need for interventions to address informational gaps and focus on emotions to improve patients' experiences and ability to understand kidney transplant (Reed et al., 2018); those interventions include exposing patients to the kidney transplant recipients, providing health education on kidney transplant and involving family members for support. According to

Slesnick et al. (2015), patients with chronic conditions can cope well emotionally when they are knowledgeable about their condition. Furthermore, these patients capable of developing the knowledge, skills, and confidence to appropriately address, or self-manage problems related to their condition (Ghadam et al., 2016).

Engaging patients with transplant education will help identify gaps in patient transplant knowledge and to make informed decisions about the implementation of interventions for patients with low transplant knowledge. Dialysis and transplant centres should consider giving more education in their respective institutions to increase provider awareness about the range in transplant knowledge among their patient population, and to identify at which step in the transplant process patients are most in need of additional educational resources (McPherson, Hamoda & Patzer, 2019). Knowledge Assessment of Renal Transplantation could help to inform use of more targeted educational interventions to supplement routine patient care, which may improve access to kidney transplant. Furthermore, Educational interventions that seek to increase patient kidney transplant knowledge should also focus on increasing confidence about this knowledge (Gupta et al., 2014). According to Iqbal et al. (2017), in a study done in morocco, it was reported that Knowledge, attitude and perception towards kidney transplantation is positively influenced by person's educational level. Until there is improvement in personal education level along with widespread transplantation campaigns, there will still be lack of kidney transplant knowledge amongst the patients.

## 2.10 SUMMARY

This chapter discussed kidney failure, the prevalence from global to South Africa as a country, risk factors for Chronic kidney failure, management and types of dialysis in context. Health education to improve knowledge and promote quality of life of the patients, self-care, kidney donation in terms of strategies to enhance donation, as well as barriers for kidney donation and knowledge regarding kidney transplant was also outlined. The kidney structure was described as well. Pathophysiology of kidney failure was briefly discussed in this chapter.

# CHAPTER THREE

# RESEARCH DESIGN AND METHODS

## 3.1 INTRODUCTION

The previous chapters established the foundation of academic research, and different research studies in the field of nephrology and transplant were presented. In this chapter, the research methods, design, data collection and analysis are described.

The study was aimed at describing the kidney transplant related knowledge and health education needs of patients with Chronic Kidney Failure on haemodialysis awaiting kidney transplant at two academic hospitals in Gauteng.

The objectives of the study were to:

- describe demographic profile of patients on haemodialysis;
- describe the kidney transplant related knowledge of patients on haemodialysis;
- identify the kidney transplant related health education needs of patients with CKF.

## 3.2 RESEARCH DESIGN

Hakim (2012) describes research design as the overall strategy that a researcher chooses to integrate the different components of the study in a comprehensible and reasonable way, thus making sure that the research problem is addressed effectively. It constitutes the plan for the measurement, collection, and analysis of data. This study was a non-experimental descriptive quantitative and cross-sectional survey.

### 3.2.1 Non-experimental descriptive design

Non-experimental research is usually descriptive, meaning the researcher is either describing a situation or phenomenon simply as it stands, or describing a relationship between two or more variables, all without any interference from the researcher (Radhakrishnan, 2013). This means there is no manipulation of any variables or randomly assign participants to a control or treatment group. In this study the researcher had no control group, hence the use of the non-experimental descriptive design.

### 3.2.2 Cross-sectional design

A cross sectional design is a non-current study, done at a specified time, at the same time and with the same participants (Brink, van Der Walt & Van Rensburg, 2015). The advantages of a cross-sectional design are it is faster and not costly, and it paves the way for further study (Setia, 2016), thus the decision to use it in this study to describe the knowledge of patients on haemodialysis regarding kidney transplant and to explore their health education needs related to kidney transplant.

## 3.3 RESEARCH METHODS

A research method is a strategy used to implement the plan for answering the research question (Christensen et al., 2011). The research methods for this study will be described in terms of population, sampling, inclusion and exclusion criteria, research context, data collection and analysis methods.

### 3.3.1 POPULATION AND SAMPLING

The population, sampling and recruitment procedure will be described.

#### 3.3.1.1 Population

Target population means the whole set of individuals displaying some common characteristics (Polit & Beck, 2008). The target population included all the patients with chronic kidney failure, on haemodialysis awaiting kidney transplant in the dialysis units in both academic hospitals. The academic hospital A had 64 patients and academic hospital B had 60 patients during the data collection period. The target population was n=124 patients in the two units combined, but only n=70 patients gave consent to take part in the study.

#### 3.3.1.2 Sample and sampling

A sample is a subset of the population that is selected to represent the population (Brink et al., 2015). The sample was selected on the following inclusion criteria:

- Older than 18
- Diagnosed with chronic kidney failure and on haemodialysis
- Awaiting kidney transplant
- These patients were provided with health education before being put on the kidney transplant waiting list so they are expected to be familiar with the information on the questionnaire

Exclusion criteria for sampling was:

- A person who received kidney transplant before

According to Polit & Beck (2008), sampling is a set of elements considered representative of the target population, while sampling technique is further described by the same authors as the procedure and process of selecting a part of the population as a sample from the total research population or the accessible population.

Convenience sampling was to select the population in this study. Brink et al. (2015) define convenience sampling as a type of sampling technique where the first available primary data source will be used for the research without additional requirements. The advantages of convenience sampling are that it is cheap, efficient, and simple to implement (Jager et al., 2017). Using the Raosoft sample calculator at 5% margin error and confidence level of 95%, a sample size of 94 participants was decided on. The sample was found using the following formula:

Sample size (n) = population (N) ÷ (1+population×margin error$^2$ (e))

$n=N \div (1+Ne^2)$

$n=124 \div (1+124\times0.05^2)$

$n=124 \div (1.31)$

n=94 participants

### 3.3.2 RESEARCH CONTEXT

The study was done at two academic hospitals in Gauteng, both hospitals are associated with the University of Witwatersrand's Faculty of Health Sciences and responsible for teaching and clinical training of healthcare providers. Each hospital has a renal unit for kidney failure, they

provide haemodialysis to patients suffering from either chronic or acute kidney failure. Acute kidney failure patients are being administered haemodialysis while admitted in hospital, then the CKF patients are being scheduled for haemodialysis coming from home (Outpatient).

Hospital A is based at Park Town Johannesburg, it is equipped with all the specialties, thus welcomes referrals from all over South Africa. This renal unit has 64 chronic kidney failure patients who are on haemodialysis. Service is provided between Monday and Saturday in the chronic side, and Monday to Sunday in the acute side. Patients on Dialysis patients who are accommodated are those who reside in and around Hillbrow, Yeoville, Berea, Park town, Braamfontein, Alexander, Sandton and Fourways.

While hospital B is based at Auckland Park, it provides tertiary health services to the Johannesburg community. It has two admission wards, nine medical wards, four surgical wards, two orthopaedic wards, a psychiatric unit, ICU, high-care unit, a dialysis unit and 11 functioning operating units. The dialysis unit is situated on the ground floor of the building and there are 60 patients on haemodialysis. The operating times are same as the first hospital. The catchment areas include Roodepoort, Cosmo City, Honeydew, Florida and Diepsloot.

### 3.3.4 DATA COLLECTION PROCEDURE

The data collection procedure is described in terms of recruitment procedure and realisation of data collection.

#### 3.3.4.1 Data collection instruments

Data was collected through self-report using structured interviews guided by a demographic profile questionnaire **(Annexure 1)** and the validated questionnaire (researcher administered **Annexure 2**). The questionnaire for demographic data was developed by the researcher, and it consisted of:

- Gender
- Age
- Cultural group
- Education
- Lifestyle

- Medical history
- Occupation
- Marital status

The K-TUT has been tested and validated in Canada (Jones et al., 2016); in their study, their main objective was to create a tool to measure patient knowledge of kidney transplantation and to evaluate its validity. The K-TUT tool section about kidney transplant knowledge, which consist of the following information:

- Nine (9) true or false questions about kidney transplant knowledge
- Twelve (12) multiple choice questions about kidney transplant knowledge
- One (1) yes or no question, asking the participant if this questionnaire is adequate for assessing a person's knowledge about kidney transplant

The second section of the K-TUT consist of three open ended questions about the health education needs of the patients:

- what else would you like to know about kidney transplant?
- is there any other information that you need, and you think can help you to understand this process?
- should your family be involved in this process; what information do you think they will need in order to assist you?

In summary, the section A consisted of multiple choice, true or false and yes or no questions about kidney transplant knowledge (22 questions) and the second section had open ended questions (3 questions) about the health education needs of the patients.

### 3.3.4.2 The recruitment procedure

The healthcare providers were informed about the study and assisted in identifying potential participants. Potential participants were informed that this study forms part of the normal procedures of health education in relation to kidney transplant and does not have an influence on whether a patient will or will not receive a kidney. The contents of the study were explained to the patients **(Annexure 3)**, and informed consent **(Annexure 4)** was obtained from those who were willing to participate.

### 3.3.4.3 Realisation of data collection

In this study, the researcher attempted to answer the research question *"What is the kidney transplant related knowledge and health education needs of patients who are on haemodialysis awaiting kidney transplant?"*

- The researcher arranged with the unit managers about specific dates suitable for data collection. A specific private room was organised for the data collection. The researcher administered the questionnaire and those who chose to answer the questionnaire without assistance were allowed to do so.
- Data was collected through self-report. In literature, self-report is described as using structured and semi-structured interviews to get a person's perspective on a given topic (Barker, Pistrang & Elliott, 2015). In this study self-report was guided by **Annexure 1**, demographic profile and the Kidney Transplant Understanding Tool (K-TUT) questionnaire (**Annexure 2)** as explained in **Chapter 3 – (3.3.4.1).** It took up to 45 minutes to complete the questionnaire. The tool was initially tested and validated in Canada only. The permission to use the tool was granted by the developer of the K-TUT **(Annexure 5)**. The researcher asked the questions and wrote the answers. The completed questionnaires were collected by the researcher on the same day for data capturing on the excel spreadsheet. Data was collected between June and September 2018.

### 3.3.5 DATA ANALYSIS

Data was captured in an excel spreadsheet, and the researcher manually cleaned the data and used the statistical package for social science (SPSS) computer programme to analyse it. Descriptive statistics were used to describe and summarise the results in this study, as they allow the researcher to organise the data in ways that give meaning and insight and to examine a phenomenon from a variety of angles (Burns & Grove, 2009).

Central tendency (mean, mode and median) was used to determine average scores in section one of the questionnaire, the knowledge of the participants about kidney transplant. In order to determine the relationship between demographics and knowledge about kidney transplant, the simple linear regression was done. This is a statistical method that allows the researcher to summarize and study relationship between two continuous(quantitative) variables (Polit & Beck, 2008).

Bivariate testing (Spearman's rho) was used to test whether there was a relationship between gender and knowledge about kidney transplant, educational levels and knowledge about kidney transplant, marital status and knowledge of kidney transplant and medical history and knowledge of kidney transplant all the variables were significantly different from zero. Table 3.1 is the descriptive statistics used in this study.

Table 3.1 Descriptive data analysis

| Descriptive data analysed | Methods |
|---|---|
| • **describe demographic profile of patients on haemodialysis;**<br>• **describe the kidney transplant related knowledge of patients on haemodialysis;** | Central tendency (mean, mode and median) |
| • **Determine relationship between demographics and knowledge about kidney transplant** | Simple linear regression |

To determine, adequate knowledge, a participant that scored 50% and above, had adequate knowledge and below 50%, had inadequate knowledge. However, the cut-off point to determine knowledge was increased to 55% to also see whether participants will be deemed as having adequate kidney transplant related knowledge

Qualitative content analysis was used for section two of the questionnaire, which had open-ended questions. Qualitative content analysis is described as an approach to analysis that focuses on interpreting and describing, meaningfully, the topics and themes that are evident in the contents of communications when framed against the research objectives of the study (Williamson et al., 2018). Qualitative content analysis was used to determine the presence of certain words, concepts, themes, phrases, characters, or sentences within texts or sets of texts and to quantify this presence in an objective manner.

To use qualitative content analysis, firstly the researcher read from the questionnaire, of the participant number one. Highlighted certain words, concepts, themes, phrases, characters, or sentences within texts in different colours and repeat the same strategy until to the last participants. Certain categories were identified and grouped together and themes were formulated and these were confirmed by the supervisor.

## 3.4 VALIDITY AND RELIABILITY

Validity and reliability of the study was determined throughout the study as explained here:

- Validity refers to the degree to which the measuring instrument measures what it is supposed to measure (Rossouw, 2001:133); in this study the K-TUT was tested and validated in Canada (Jones et al, 2016).

- Reliability refers to the consistency and accuracy of information attained in a study (Polit & Beck, 2014); it was pre-tested in five participants who did not form part of the study, no adjustments were required.

- Face validity indicates that the instrument appears to measure what is it is designed to measure (Polit & Beck, 2008:753). Content validity, is the degree to which the items in an instrument adequately represent the universe of the content for the concept being measured, as suggested by Polit and Beck (2008:750). The tool was hand delivered to experts in nephrology and a transplant coordinator to ensure face validity and content validity before the study commenced. They gave their input in terms of cut off points regarding what would be adequate and or inadequate knowledge regarding kidney transplant knowledge.

- During the qualitative content analysis, the supervisor confirmed the formulated categories and themes.

## 3.5 HUMAN RESEARCH ETHICS COMMITTEE

The following ethical considerations outlined by Brink et al. (2015) were applied prior to conducting the study.

- Permission to use the tool was sought and granted by the instrument developer **(Annexure 5).**
- The study commenced after ethical clearance was obtained from the Human Ethics Committee (Medical) at the University of the Witwatersrand **(Annexure 7).**
- Permission was sought from the Department of Health, which then gave permission for the research to access the clinical facilities and the hospitals also gave permission as well

**(Annexure 6a and 6b).** Approval from one of the hospitals could not be retrieved since the student's computer crushed. The hospital was approached and then issued a 2021 approval instead **(Annexure 6b).**

- Informed consent was obtained before participation in the study **(Annexure 4).** The participation in the study was voluntarily, so participants had the right to withdraw from the study during the interview process.
- Anonymity was enhanced by allocating numbers in all the questionnaires.

## 3.6 SUMMARY

This chapter gave an in-depth overview of the research design and method used in answering the research question, and a description of the accessible target population and the sampling method utilised. The planning of the empirical research, the design of the data collection instrument and data collection procedure, including methods to ensure reliability and validity of the instruments, were discussed. The chapter also presented and discussed the ethical procedures followed to ensure protection of the human rights of the research participants taking part in this study.

# CHAPTER FOUR

# PRESENTATION AND DISCUSSION OF THE RESULTS

## 4.1 INTRODUCTION

This chapter is the presentation and discussion of the results of this study. The research results will be presented and discussed in terms of response rate, demographic profile, knowledge about kidney transplant, as well as health education needs of the participants regarding kidney transplant.

## 4.2 RESULTS AND DISCUSSION

The results will be discussed in terms of response rate, demographic profile,

### 4.2.1 Demographic profile

The demographic profile of the participants is illustrated below in table 4.1 and will be discussed in detail.

Table 4.1 Demographic profile

| | **Frequency** | **Percentage** |
|---|---|---|
| **Gender** | | |
| Male | n=38 | 54.29% |
| Female | n=32 | 45.71% |
| **Education status** | | |
| Grade 1-3 | n=1 | 1.43% |
| Grade 4-7 | n=9 | 12.86% |
| Grade 8-12 | n=40 | 57.14% |

| | | |
|---|---|---|
| Tertiary education | n=20 | 28.57% |

| **Tobacco use** | **Frequency** | **Percentage** |
|---|---|---|
| Yes | n=3 | 4.62% |
| No | n=67 | 95.38% |
| Alcohol consumption | | |
| Yes | n=4 | 5.80% |
| No | n=66 | 94.20% |
| Hypertension | | |
| Yes | n=53 | 76.81% |
| No | n=17 | 23.19% |
| Diabetes | | |
| Yes | n=10 | 14.29% |
| No | n=60 | 85.71% |

#### 4.2.1.1 Gender

The demographic profile of the participants in this study revealed that of the 70 (n=70) participants 32 (n=32; 45.71%) were females and 38 (n=38; 54.29%) males. These results are similar to a study done by Brar & Markell (2019), from data obtained from the National Health and Nutrition Examination survey, and all the participants were CKD (Chronic Kidney Disease) patients on renal replacement therapy, where they reported that there are fewer women compared to men on renal replacement therapy. Furthermore Chang et al. (2016) wrote that male patients show a substantially higher prevalence of CKD and end-stage renal disease (ESRD) than female patients, and this is because females have Estrogen hormone. Estrogen has deep sound effects on converting growth factor-β signal transduction and on the renin-angiotensin system. These effects may contribute to changes in kidney haemodynamics and affect kidney disease progression (Neugarten & Golestaneh, 2013).

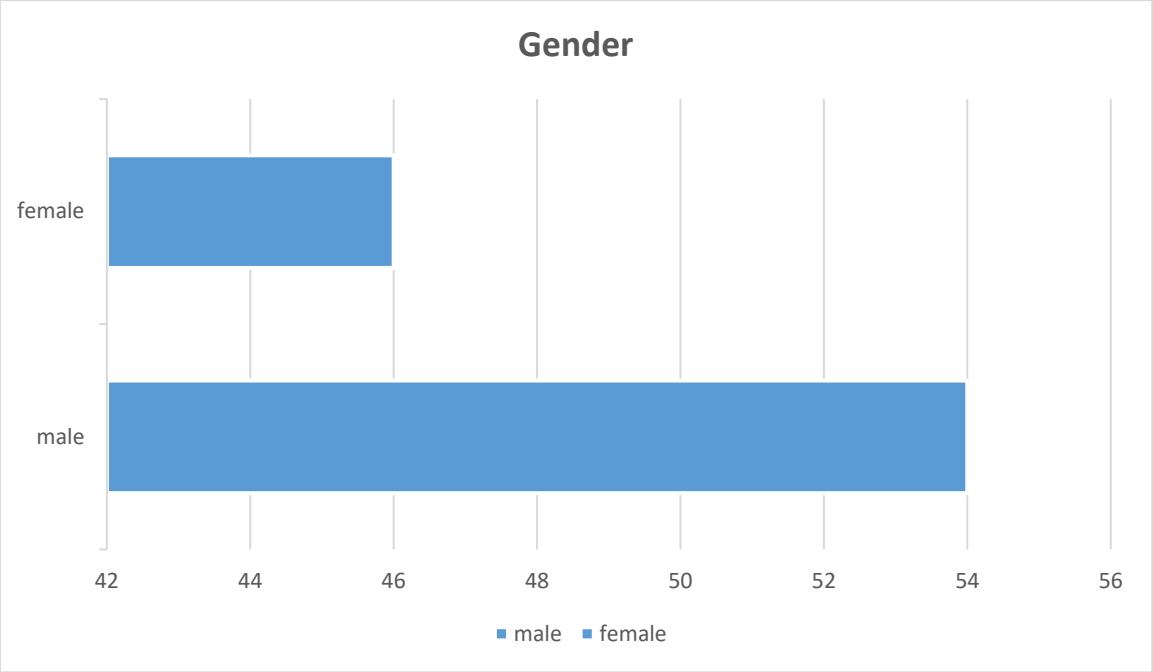



Figure 4.1 Gender

#### 4.2.1.2 Education status of the participants

As depicted in Figure 4.1, more than half of the participants (n=40; 57.14%) went to high school, and 20 (28.57%) had tertiary education training, as described in table 4.1; only 10 (14.29%) of the participants left school at primary level. The participants in this study were all functional literate. The results of this study are similar to those of Waterman et al. (2015) in the USA (United States of America), who conducted a study among 540 participants, where assessment regarding knowledge about kidney transplant was done and it is evident that those with higher education and tertiary education had more knowledge about kidney transplant. There is currently no study done in South Africa on education status of people with kidney failure.

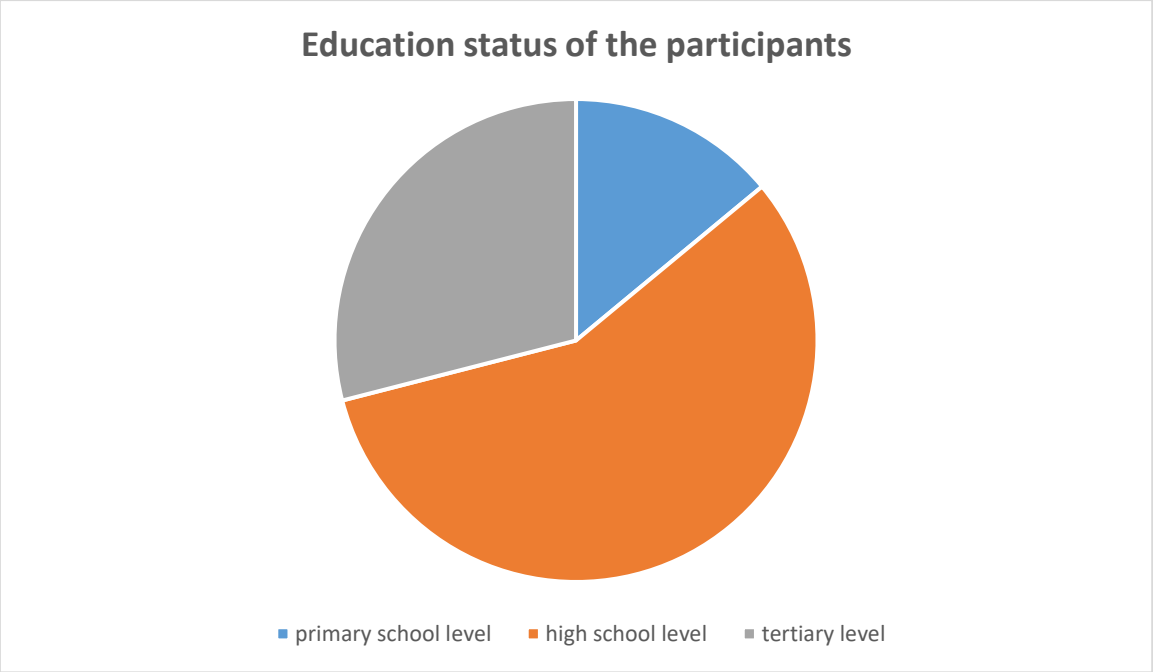



Figure 4.2 educational status of participants

#### 4.2.1.3 Tobacco use

As part of the demographics, lifestyle habits data were collected from the participants, n=70 used either tobacco or alcohol. The tobacco use is described and only three (4.62%) of the n=70 participants reporting smoking see, Figure 4.2. Patients knows that tobacco use is prohibited for those on haemodialysis and awaiting kidney transplant and this is taught during haemodialysis as patients wait for a kidney to be donated. This could have affected the response rate leading to them to a risk of desirability bias on this item, as only three participants in our study revealed that they used tobacco.

Research conducted regarding smoking at Toronto General Hospital by Tang et al., (2019), on n=3223 participants who were referred to the hospital for kidney transplant, reported that those agreed to habits of tobacco use had a decreased likelihood of being legible for receiving a kidney transplant. The exact reason for this is that smoking causes vasoconstriction which may lead to the new kidney being unable to get enough blood supply, so the patients were advised to stop or reduce on their smoking habits so that they could remain on the transplant list.

It is important to note that there are consequences of smoking beyond eligibility for transplantation. Another study conducted in Hong Kong outlined the concerns about smoking among patients awaiting kidney transplantation which are health concerns beyond transplantation inclusion criteria, and these included vasoconstriction effect, increased

malignancy chances, major cardiovascular events, and reduced graft survival post kidney transplant (Fung, Chau, & Chow, 2019).

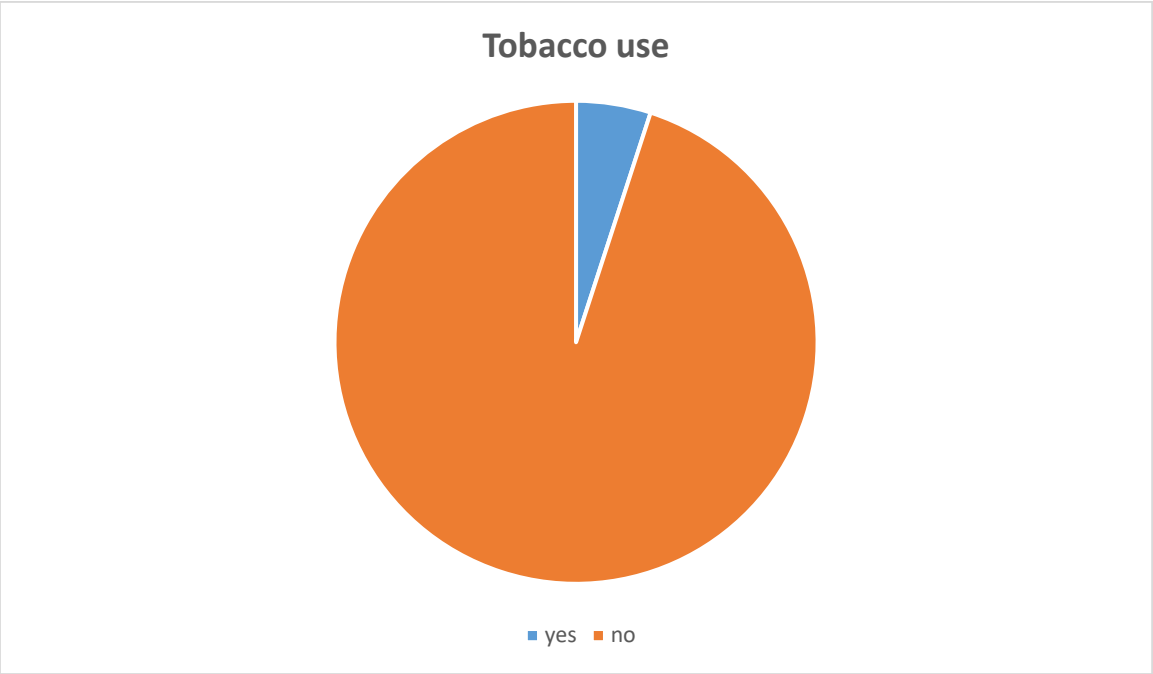



Figure 4.3 Tobacco use

#### 4.2.1.4 Alcohol consumption

Similar to the tobacco use, for alcohol use only four participants (5.80%) self-reported to be consuming alcohol while on haemodialysis and awaiting kidney transplant. As discussed in Chapter 2 (2.6.2), prior to kidney transplant each patient has to meet a certain criterion to be part of the therapy, and health education is provided by the therapy team regarding alcohol consumption and substance abuse. The results of this study are not unique, as Monfared et al. (2019) reported that 8% of their participants agreed to consuming alcohol in their study which was aimed to investigate lifestyle, sleep quality, and related factors among patients on haemodialysis at a hospital in Rasht City, Iran. It seems the knowledge that it is prohibited to consume alcohol while on haemodialysis awaiting kidney transplant could lead to desirability bias in this study.

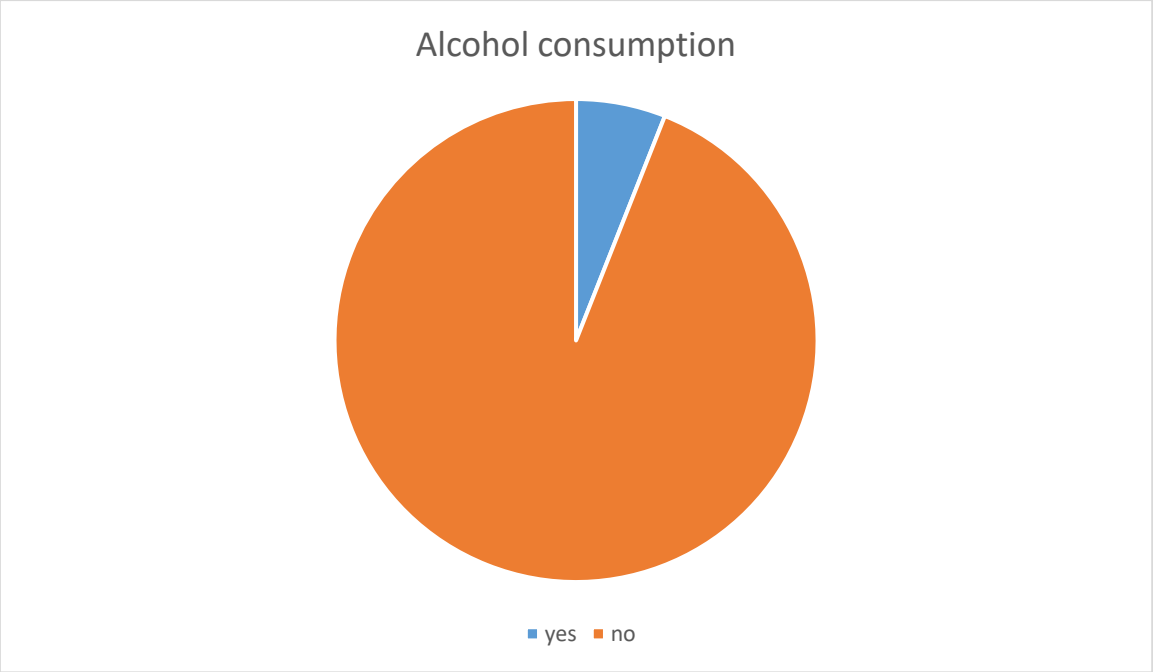



Figure 4.4 Alcohol consumption

In addition, medical history was collected also

#### 4.2.1.5 Hypertension

Hypertension complication is the major contributor to kidney failure. In this study, about n=53 (76.81%) participants were hypertensive and on treatment; however, there is no difference in level of knowledge between those with and without hypertension. These results are almost similar to a local study done at Zandspruit, South Africa, by Rheeder et al. (2016), where it was found that the prevalence of hypertension was at 58% amongst adults of 45 years and older with kidney disease. Globally, Mills et al. (2016) discovered that with the high and increasing burden of hypertension worldwide, it is becoming a major health concern because morbidity and mortality rate from cardiovascular and kidney diseases, as well as the financial costs to society goes high.

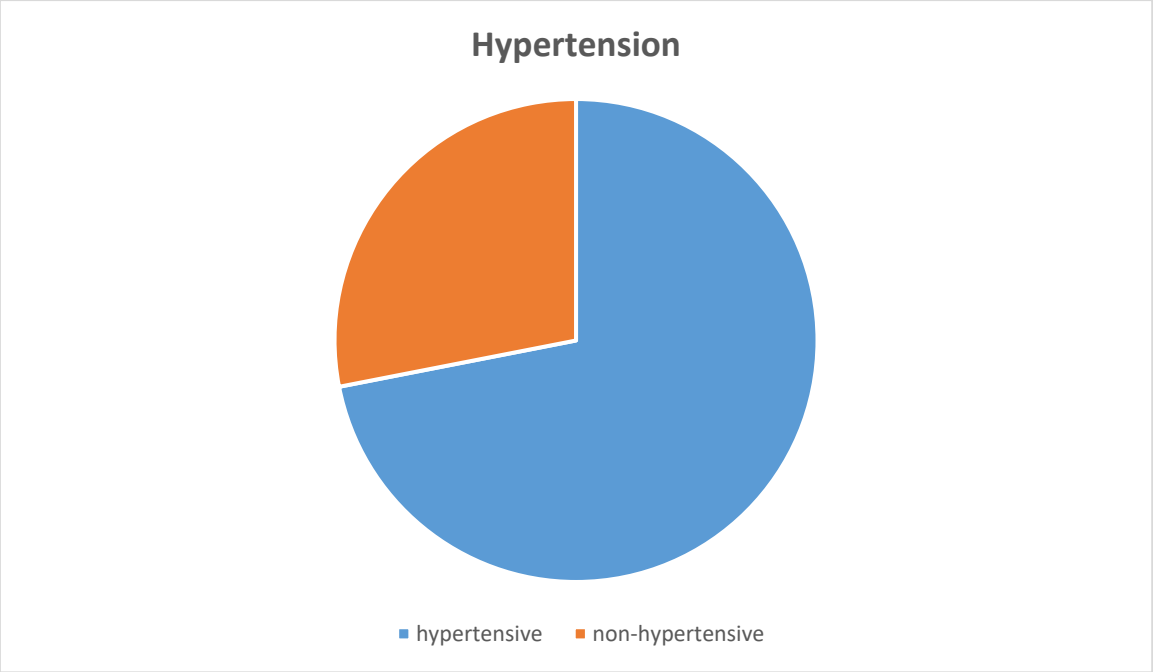



Figure 4.5 Hypertension

#### 4.2.1.6 Diabetes

Based on research results, only n=10 (14.29%) participants reported they were living with diabetes and on treatment. In South Africa, as discussed in Chapter 2 (2.5.2), chronic kidney failure was observed to be on the rise due to high prevalence and poor control of diabetes and hypertension (Meyer, 2015). Wadee, Rekhviashvili & Gangat (2018) conducted a record review study in Johannesburg on n=357 patient's files from a dialysis centre. The authors revealed a prevalence rate of 30% for diabetes and 31% for hypertension and indicated that these two conditions were the most common cause of kidney failure. According to the study done in Yaoundé(Cameroon),hypertension and diabetes are on the rise and the poor management and complications accompanied with these conditions contributes to the burden of diseases, especially kidney failure (Kaze et al., 2016).

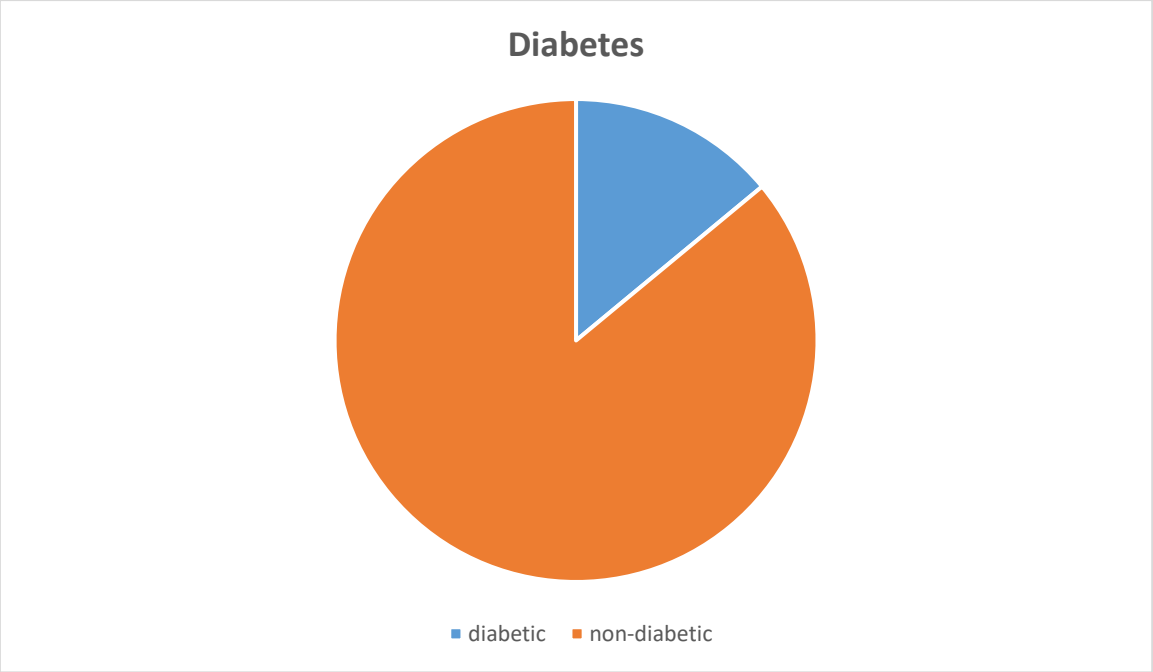



Figure 4.6 Diabetes

#### 4.2.1.7 Use of over the counter medication

It is well recorded in literature that patients with chronic diseases mostly use over the counter medication (Moore et al., 2015). When exploring the use of over the counter medication, only one (1.43%) participant agreed to using such medication, similar to the question regarding smoking and alcohol use. It is possible that the patients answered in their favour because they understand that over the counter medication is prohibited in their condition, they are only allowed to take prescribed medication.

In summary the demographic data of the participants, revealed that more men than women are on haemodialysis; only n=10 left school at primary level, had n=10 had diabetes and a higher number of n=53 participants had hypertension. A few, less than five participants respectively smoked tobacco, consumed alcohol, and used over the counter medication. Below is the knowledge of the participants regarding kidney transplant and their education needs relating to kidney transplant.

### 4.2.2 Knowledge about kidney transplant

Using the Kidney Transplant Understanding Tool (K-TUT) we explored the participant's kidney transplant knowledge using both multiple choice and true or false and yes or no questions to a total of 69 points. In order to have adequate knowledge the participant had to score 50%, this was suggested by the experts consulted during proposal development, confimed

by postgraduate assessors and WITS statistician. Based on the set objective of describing the knowledge of patients on dialysis about their knowledge on kidney transplant, a large number (n=58; 82.86%) scored above 50% indicating adequate knowledge and n=12 (17.14%) scored below 50% which is regarded as inadequate knowledge. However, at the mean score of 55%, only half (n=35; 50%) of the participants had adequate knowledge and half had inadequate knowledge regarding kidney transplant.

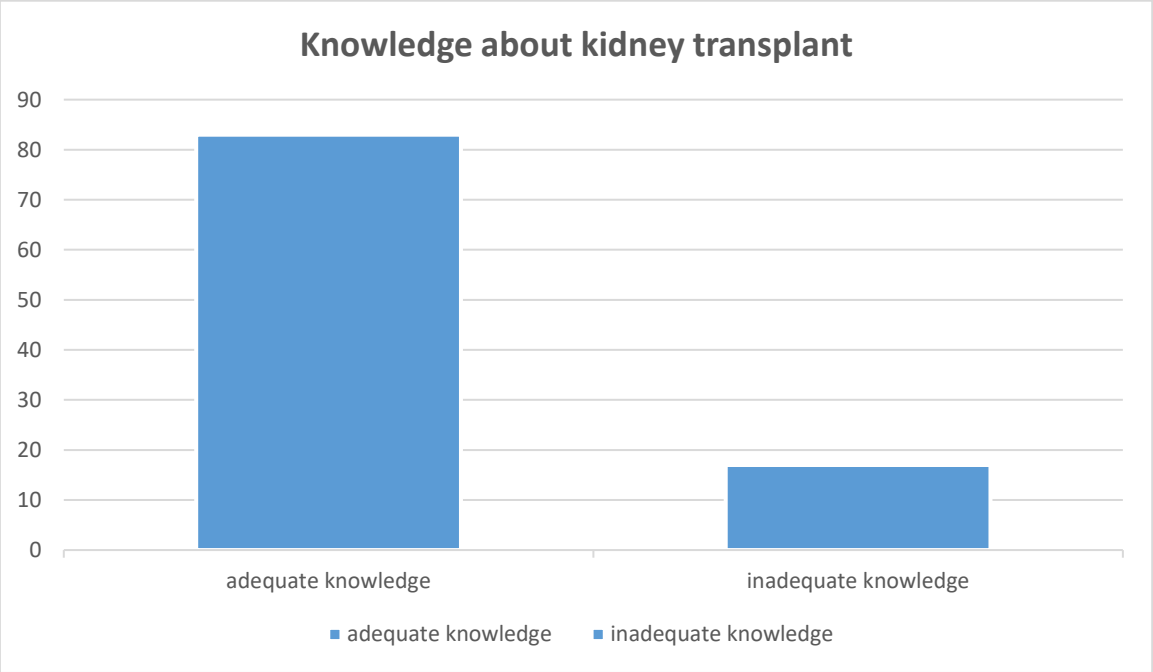



Figure 4.7 Knowledge about kidney transplant

The inadequate knowledge was observed in elderly patients (n=23; 30.86%) and those who never went to high school (n=10; 14.29%). The inadequate knowledge discovered among the participants in this study is not unique to the South African population only. An international study by Keddi, Finnie & Kim (2019) also revealed lack of knowledge about kidney transplantation and fear of surgery as factors that had an impact on patients' attitudes about kidney disease and transplant.

Even though this study did not explore the satisfaction of patients with regard to health education and how the health education was provided to the patients by the team, literature does reveal that health education should be tailor-made to a level of grade 4 (Garofyllou et al., 2017). Moreover, our findings are supported by a study conducted in the USA by Karlin, Chesla and Grubbs (2019), where the participants reported that the healthcare providers do not explain to them thoroughly about their condition and all the treatment options included.

Another study reported that patients awaiting kidney transplant have limited knowledge regarding treatment options and outcomes on the kidney transplant waiting list. They recommend personalised risk information and intellectual approaches that recognise how patients process information and balance competing risks may improve informed decision making (Schmajuk, DeGuzman & Allen, 2018). However, Rosaasen et al. (2017) discovered that patients were not satisfied regarding the education provided to them before a kidney transplant, because they believed the health education was not tailor-made for them. In this study, the researcher further investigated the health education needs of the participants in this study in section two of the K-TUT questionnaire, which is presented in section 4.4.

In terms of relationship between kidney transplant related knowledge and demographics all the variables were statistically significant from zero.

### 4.2.3 Health education needs

This section aimed to respond to the third objective of the study, exploring the knowledge needs of the participants. The participants responded to the qualitative questions part of the questionnaire in section 3, and three themes emerged as presented in Table 4.2.

**Table 4.2 Health education needs of the participants**

| THEMES | CATEGORIES |
|---|---|
| 4.2.3.1 Personal health related needs | • Self-care and Quality of life |
| | • Reproductive health |
| | • Kidney transplant and donors |
| | • Information about donors |
| | • Personal support |
| 4.2.3.2 Family related | • Family involvement |
| | • Family as support system |
| | • Family to understand the risks for rejection |

As depicted in Table 4.2, from the qualitative data, two themes were generated and will be described below:

#### 4.2.3.1 Personal health related needs

On the theme health and education needs, n=26 (37.14%) participants indicated that this question was not applicable to them, while n=24 (34.29%) revealed they would like to know

everything about kidney transplant, and only eight (n=8; 11.43%) indicated they did not have a need for information. From those who indicated a need for information, these needs ranged from information on self-care to quality of life, reproductive health, risk for rejection and infection and support system. Stipulated in the quotes below is the quality of life information needs from the participants.

- **Self-care and quality of life**

Patients stated their self-care and quality of life health education needs as:

*P12 "How to take care of yourself before and after transplant."*

*P21 "How to take care of your kidney transplant to make you live longer."*

While P6 said they would like to know:

*"How to take more precaution to avoid my kidney transplant to reject."*

About four (n=4; 5.71%) of the participants wanted to know more about their quality of life after the transplant. This was narrated as:

*P1 "How long does it take for a rejection to occur."*

Others seemed anxious about the future after the transplant:

*P31 & P33 "After kidney transplant, how many years can you live?"*

The participants concern about their self-care and quality of life after kidney transplant is not surprising. Self-care is described as an individual's ability to take action to improve or preserve their own health (Bressi & Vaden, 2017). Therefore, among patients with kidney failure, it means taking care of one's health, in terms of attending dialysis sessions as scheduled, proper diet and taking medications as prescribed after the kidney transplant.

In terms of self-care, authors Paterson, Thorne and Russell (2016) revealed that everyday self-care decision-making in chronic illness is a complex, individualised and dynamic process. The complexity is experienced by these individuals, as they must make decisions daily, in relation to medication, diet and overall lifestyle changes.

With regards to the participants concern about their quality of life after the kidney transplant, Tamura et al. (2018) conducted a study at Mie University Hospital in Japan. The authors were

evaluating the quality of life of the recipients after kidney transplantation by comparing their values with those of haemodialysis patients, and identifying the physical, mental, and socio-economic factors associated with quality of life among kidney transplant recipients. Tamura et al. (2018) they discovered that patients felt that the quality of life after kidney transplant is better than that of patients on haemodialysis; kidney transplant can be beneficial, not only physically but also emotionally and socially.

Another study by Sandwijk et al. (2019) on the quality of life revealed that fatigue and depression are common in haemodialysis patients, resulting in a low quality of life, while kidney transplant recipients had improved quality of life. It is therefore critical that patients on haemodialysis awaiting kidney transplant are informed and educated about the benefits of haemodialysis and that of kidney transplant in relation to self-care and the quality of life after the transplant.

- **Reproductive health**

It is also important to educate patients who are at childbearing age about their reproductive health after kidney transplant. In this study, one (1.43%) participant, 38 years old, was worried about her reproductive health and indicated that she would like to know,

> *P8 "Can you still have babies after transplant?"*

Patients undergoing dialysis and of reproductive age must be educated about reproductive health while on dialysis, especially because they have diminished sexual desire, veganism, failure of achieving orgasm, vaginal dryness, menstrual irregularities, and infertility (Abozead et al., 2018). However, kidney transplant may improve fertility and a woman can give birth to a healthy baby (Ahmed, Vitek & Holley, 2017).

- **Kidney transplant information**

In terms of participants wanting to know more about kidney transplant:

P51 mentioned that:

> *"To be educated more about kidney transplant especially on herbal medicines, anti-rejections and creatinine levels. Given more information will certainly decrease failure problems.''*

Considering the kidney transplant knowledge level of the participants in this study, this participant's knowledge needs are valid. It is within the policy of the two hospitals that before patients are put on dialysis and on the waiting list for kidney transplant, they are thoroughly educated about the lifestyle changes, which includes not using any over the counter medicines or herbal medicines. The challenge with the use of OTC and herbal medicines, as indicated by Touiti et al. (2019), is that the use of herbal medication by patients with kidney disease may promote or worsen pre-existing kidney disease. This is basic knowledge that any patient regardless of their level of education should know. With kidney disease, every patient is educated about it by the transplant team, however these findings may reveal that attention that needs to be given to these patients on how the education is provided, furthermore the healthcare professionals might have to assess whether the patients understood their health education.

The chronic kidney failure patients who are on dialysis awaiting kidney transplant, lack knowledge on what they have to do or how they have to conduct themselves before and after kidney transplant. This was outlined in some of the quoted replies by the participants:

*P12"How to take care of yourself before and after transplant,"*

*And P6 "How to take care of your kidney transplant to make you live longer," and*

*P45"How to take more precaution to avoid my kidney transplant to reject."*

The participants direct quotes above reveal lack of knowledge regrading self-care. Self-care among patients who have undergone kidney transplant is crucial. Li, Ma and Wang (2020) implemented a program to enhance selfcare of patients (n=100) that have received kidney transplant. These patients were followed up via outpatient care, telephone calls, home and family visits, as well as support group. The pre-post test results revealed an increased level of knowledge related to self-monitoring, correct medication, proper exercise, and overall self-care abilities.

- **Information about donors;**

Some participants wanted to know about donors and said:

*P49 "Can my 21 years' old son donate his kidney for me?''*

Another said:

*P56 "'Can my friend donate?"*

These participants indicated inadequate knowledge as to who was eligible to donate a kidney, in terms of age and relation. This lack of knowledge could be a contributory factor to lack of kidney donors in the country and worldwide. However, anyone is eligible for donating a kidney, if they are a match in terms of tissue type and do not meet the exclusion criteria outlined in Chapter 2 of this study (2.6.2). But it is essential for potential donors to go through counselling regarding both long and short-term risks associated with being a living kidney donor, including risks related to the surgery and long-term health risk (Sawinski & Locke, 2018). The long- and short-term risks as outlined by O'Keeffe et al. (2018) are as follows:

- Risk for acute kidney failure
- Pre-eclampsia during pregnancy in females
- Bone fractures

In a study conducted in the USA by Delmonico et al. (2015) it was suggested that financial incentive for organ donors should be implemented to reduce the waiting list for transplantation. Many people are willing to donate only if there is financial incentive.

This theme, health education needs does indicate a need for information which is in line with our quantitative data that we presented earlier in this chapter.

- **Personal support**

On this subtheme n=14 (20%) indicated that they needed more information but were not specific as to which information, while some participants mentioned support system as follows:

One participant mentioned emotional support:

*P67 "No, just emotional support.''*

another one mentioned group discussions:

*P3 said "Yes, if we could have team discussions at least once a month to prepare you when time comes for transplant."*

Emotional support is crucial for patients with kidney failure awaiting kidney transplant, because these patients experience the distress and anxiety associated with uncertainties of the future, the pain and fear about risks associated with transplantation (Koons & Smeltzer, 2018). Chen et al.

(2018), in a study done in Taiwan, defined social support as resources provided by a network of individuals and social groups, including family members, friends, healthcare providers and religious affiliation members. Moreover, studies of social support on chronic diseases have indicated that social support can be influential in improving self-management behaviours and reducing factors affecting the progression of disease (Bale, Douglas et al., 2016).

### 4.4.2 Family related information

Approximately nine (12.86%) participants wrote yes, only one (1.43%) (P58) said the family members must not be involved, while 14 (20%) participants said the question was not applicable to them. Others n=46 (65.71%) indicated their family members should be involved and be educated about quality of life after transplant, understanding kidney transplant, support systems, risk of rejection and infection.

- **Family involvement**

Family involvement was narrated in terms of quality of life of the donors after the transplant. Others wanted their family members not to be involved.

Participants narrated quality of life of donor after transplant as:

P7 "*They need to be assured that donating a kidney is not a health risk. Most people think they are going to be sick just like you do.''*

While others indicated that the family members should be involved in understanding a kidney transplant:

P4 "*They have to be given health education on kidney transplant so that they can understand better.*''

*P15 "They need to be involved for workshops and other meetings about renal failure and transplant process.''*

*P17 "They should know how to help me during and after transplant.''*

*P18 "They need to understand that kidneys wont regenerate when its ESRD, therefore dialysis is mandatory until kidney transplant is done.''*

The participants indicating that their family needed to be involved and informed about the kidney transplant process, could be also indicating a need for support with regard to information, especially when considering the fact that most of them had inadequate knowledge

about kidney transplant. Therefore, health education should be comprehensive and continuously provided to family members.

According to Narva, Norton and Boulware (2016), family and other caregivers' involvement in CKD patient education may better prepare them to support the patients they care for and eventually, yield improved patient outcomes. Patient treatment and dietary adherence will be much improved as well.

- **Family as support system**

Furthermore, other participants expressed their needs for family as a support system as described in the quotes below:

P6 *"My family is needed to be involved in this process to assist to take care of every step you have to follow.''*

*P9 "To give me support in everything in my journey to transplant.''*

*P40 "How they should help me to be transplanted.''*

*P55 "Yes, because of my diet, be with me and my appointments.''*

Family support was also expressed in terms of realisation that they might depend fully on their family members and maybe have complications after the transplants was expressed as:

P29 *"Yes, they need to know how to take care of me at home.''*

P45 *"Yes, because if it happens, I get unconscious, they are the ones to assist me and they should also be able to see the signs, so they take precautions.''*

Tannor et al. (2017), in their study on quality of life in patients on chronic dialysis in South Africa, conducted in cape town in Cape Town on 106 patients, reported the patients mentioned appreciating more family support. Furthermore, they wish the family members could better understand kidney failure and kidney donation, so they could be able to donate for them. This Cape Town, South Africa study confirms a need for family support specifically as mentioned by the participants in this study.

The participants in this study also seemed to be concerned about their family understanding and involvement in their dietary practice. This reveals what Baines et al. (2018) discovered in 2018, that patients had not been having a good social life (not attending weddings, funerals and parties) while on dialysis, because they believed they would not enjoy it as they have dietary restrictions and are not allowed to drink more fluids.

- **Family members to understand the risk for rejection**

Participants further related that their families needed to know more about their risk of rejection and infection:

*P5 "They need to know when the kidney is rejected and why. They must be told about the risks of infections.''*

*P18 "They also need to understand the risks related to the kidney transplant, surgically, medically and anaesthesia, as well as rejection risks.''*

The possibility of kidney rejection and infection is very high after kidney transplant. According to Cippa et al. (2015), the prevalence of infections is high after kidney transplantation and it is a major thread for recipient of the kidney in the first year post-transplantation. Therefore, family members need informing about the anti-rejection medications to make sure they encourage the patients to take them constantly to avoid rejection. Patients must adhere to anti-rejection medication post-transplant to prevent rejection of the new kidney (Cossart et al., 2019).

Reading the above quotes, the participants have some level of anxiety about the future; they anticipate being unconscious and realise they might be dependent on their family members immediately after the transplant. Goh & Griva (2018), in their study about Anxiety and depression in patients with end-stage renal disease: the impact and management challenges, found that several risk factors for developing depression in patients undergoing renal transplantation include gender, sleep quality, employment, and financial status. Anxiety can be an overwhelming feeling to someone who is constantly waiting for a call to be transplanted, therefore Healthcare providers need to be aware this need and allay the fears of the patients and reassure them continuously. The study was conducted amongst patients with chronic kidney failure.

## 4.3 SUMMARY

Demographic profile and kidney transplant related knowledge were described in this chapter. The themes that emerged were crosschecked by the supervisor of the researcher. In the study, it is revealed that patients have inadequate knowledge about kidney transplant, especially on self-care, quality of life and medications taken after transplant. The findings of this study will assist healthcare professionals as to which tailor-made health education to provide to the patients. In this regard, the health education should be more about self-care, quality of life and medication after transplant. The data and interpretations were supported by the literature.

# CHAPTER FIVE

# SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

## 5.1 INTRODUCTION

A summary of the study and a description of the limitations and recommendations are provided. The conclusion is also stated in this chapter.

## 5.2 SUMMARY OF THE STUDY

The aim of the study was to describe the kidney transplant related knowledge and health education needs of patients with Chronic Kidney Failure on haemodialysis awaiting kidney transplant in two academic hospitals in Gauteng.

The objectives of the study were to describe the kidney transplant related knowledge, describe demographic profile and identify the health education needs of patients with chronic kidney failure on haemodialysis. The kidney transplant understanding tool (K-TUT), with added qualitative component that explored the health education needs of the participants, was used to collect data. A cross-sectional study was conducted from June to September 2018, among chronic kidney failure patients in dialysis units in two academic hospitals in Johannesburg. Of the potential 124 patients, only 70 gave consent to participate in the study. The summary of the study is as follows:

**In summary**:

Section one of the questionnaire was made up of true or false and multiple-choice questions, which were to assess the kidney transplant knowledge of the patients. There were more males (54.29%) than females (45.71%) who participated in the study, and males showed to be scoring higher than females. Based on the set objective of describing the knowledge of patients on dialysis about their knowledge on kidney transplant, a large number (n=58; 82.86%) scored above 50% indicating adequate knowledge and 12 (17.14%) scored below 50%, which is regarded as inadequate knowledge. However, at the mean score of 55% only half (n=35; 50%)

of the participants had adequate knowledge and half had inadequate knowledge regarding kidney transplant.

Section two of the questionnaire had open-ended questions. Patients expressed their needs and pointed out the areas that needed more attention so they could be equipped with more knowledge regarding kidney transplant. Quality of life after kidney transplant, family member's involvement, risks of rejection and infections, understanding kidney transplant, reproductive health after transplant and support system were the themes formulated during data analysis of the study.

Participants displayed lack of knowledge regarding kidney transplant and displayed fear of kidney rejection after transplant. Other participants were concerned about not having support at home due to family members not being involved in their care, so they are suggesting that family members be involved in patient's condition management by the healthcare professionals.

## 5.3 LIMITATIONS

The study was restricted to renal units of the two academic hospitals in Gauteng, thus the results cannot be generalised to include patients in other hospitals in Gauteng or South Africa. The sample size was not achieved, this is one of the limitations of the study. Data was collected by means of K-TUT questionnaire; therefore, no triangulation took place by means of focus groups or individual interviews. The participants were on haemodialysis and knowledgeable of the fact that smoking and use of over-the-counter medication was unadvisable, therefore the participants in this study could have been exposed to desirability bias.

## 5.4 RECOMMENDATIONS

The following recommendations are made based on the results from this study with regard to nurses practicing in dialysis units, nursing research and nephrology nursing practice.

### 5.4.1 Recommendations for nurses practicing in dialysis units

With the growing burden of chronic kidney disease, the dialysis units in the hospitals are busier and patient numbers are increasing. In the light of this, the following recommendations for nurses practicing in dialysis unit are made.

- Attend workshops and conferences on kidney failure and transplant so they can be equipped and updated with knowledge on kidney failure. The National Kidney Disease Education Programme is prioritising the development of resources such as clinical encounter tools, patient education aids, and training programmes that help healthcare professionals better identify and care for patients with CKD (Narva & Briggs, 2009)
- Establish a support groups for patients on dialysis. In a study done by Hughes, Wood and Smith (2009), at two hospitals in south London, it was reported that peer support helped patients adapt to chronic illness by normalising adherence to demanding treatment regimens and increasing patients' sense of empowerment and agency.
- Advocate for the patients and provide tailored health education for them. According to Murray et al. (2009), variable factors, such as knowledge gaps, uncertainty regarding outcomes and lack of clarity about what matters most, can influence their decision-making. Therefore, patient advocacy is vital for these patients. The patients and their families rely on the expertise, knowledge and honesty of their healthcare team to make informed decision (Doss, DePascal & Hadley, 2011)

### 5.4.2 Recommendations for Nursing Research

The current study focused on the description of kidney transplant related knowledge and health education needs of patients with chronic kidney failure in two academic hospitals in Johannesburg. Therefore, replication of this study in different settings such as in other provinces or in the private sector is recommended to provide additional evidence. The follow-up to this study should be based on the relationship between the health-care professionals and the chronic kidney failure patients. This may be the reason why there is the existence of the kidney transplant knowledge gap.

### 5.4.3 Recommendation for Nephrology Nursing Practice

Based on the findings of this study, for patient's kidney transplant related knowledge and health education needs to be improved, the nephrology nurses should provide the following to the patients:

- Involve the patient's immediate family members in the treatment plan of the patient, so they can have an insight of what the patient is going through, and what they have to do in order to contribute to the patient's wellbeing. According to a research done by Miller and Dimatteo (2013), it is suggested that social support can benefit patients' health by buffering stress, changing affective states, increasing self-efficacy, and influencing change in negative health behaviours. Family members are the most significant source of that support.

- Nephrology nurses should make it a point to give health education to the patients on a regular basis, so that the patients can be equipped with up-to-date knowledge after their dialysis sessions. When delivering health education, healthcare providers are to ensure it is understood, that they explain well and give clarity where required, and lastly the messages must be consistent, meaning they need to speak and share same content with participants (Bear & Stockie, 2014)

- Tailor-made health education will be more beneficial to every patient, as this will address the individual health education needs. According to Lingerfelt & Thornton (2011), one-on-one structured education can improve knowledge about CKD medical and self-management for patients on haemodialysis.

- Attend in-service training workshops on nephrology nursing to gain more knowledge on how to manage kidney failure patients. Moreover, Jackson et al. (2019) mentioned that in-service training has been adapted internationally to meet the demands of evolving nursing practice, and for this reason it remains relevant and essential to nurses.

## 5.5 CONCLUSION

In this study, it was discovered that only half of the participants had adequate knowledge and the other half had inadequate knowledge regarding kidney transplant. The inadequate knowledge was observed in elderly patients and those who never went to high school. Moreover, males scored higher compared to their female counterparts. According to Finkelstein et al. (2008), in a study done in the United States of America on Chronic CKD patients, about one-third of patients reported limited or no understanding of their chronic kidney disease and no awareness regarding their treatment options. A significant and substantial number of patients indicated they had no familiarity with transplant. Furthermore, patients felt healthcare providers

did not explain things properly, they mention terms they do not understand and provide lengthy explanations that are difficult to understand (Lederer et al, 2015).

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**LIST OF ANNEXURES**

**ANNEXURE 1: DEMOGRAPHIC PROFILE**

| **Demographic profile** | | |
|---|---|---|
| Age: | | |
| Gender: | | |
| Cultural group: | | |
| **Marital status: *Tick*** √ | | |
| Single | | |
| Married | | |
| Cohabiting | | |
| Divorced | | |
| **Employment status: *Tick*** √ | **Yes** | **No** |
| Employed | | |
| Unemployed | | |
| Self employed | | |
| State grant/pensioner | | |
| **Educational level: *Tick*** √ | | |
| Grade 1-3 | | |
| Grade 4-7 | | |
| Grade 8-12 | | |
| Tertiary education | | |
| Never went to school | | |
| **Do you drink alcohol?** | | |
| **Do you smoke?** | | |
| **Medical History:** | | |
| Hypertension | | |
| Diabetes | | |
| List other medication that you take other than what the Doctor prescribed for you: | | |

| | | |
|---|---|---|
| | | |

**ANNEXURE 2: QUESTIONNAIRE**

**DATE_____**

**Section 1: K-TUT - KIDNEY TRANSPLANT UNDERSTANDING TOOL**

**TRUE OR FALSE: CHOOSE THE BEST ANSWER**

**1. Every person who receives a kidney transplant feels better than before the transplant.**

- True
- False

**2. Transplant pills must be taken to help prevent rejection.**

- True

¨ False

**3. Some diseases that cause kidney failure can come back in the kidney transplant.**

- True

¨ False

**4. Anti-rejection medications are also called immunosuppressants.**

- True
- False

**5. Your kidney transplant is also called a graft.**

- True
- False

**6. You should always take your anti-rejection medications unless instructed by your transplant team.**

- True
- False

**7. You will need to do blood testing at least monthly for as long as the kidney transplant is functioning.**

- True
- False

**8. Herbal supplements are generally safe to take with your transplant, since they are natural.**

- True
- False

**9. Most people can to return to work after receiving a kidney transplant.**

- True
- False

**CHECK THE CORRECT ANSWERS <u>(YOU MAY CHOOSE MORE THAN ONE)</u>**

**10. When thinking about herbal or traditional therapies, which of the following are true? (check all the correct answers)**

___ Traditional treatments are safe for a kidney transplant because they are natural.

___ Herbal medications recommended in the media (i.e. internet, TV) are generally safe for your transplant.

___ Pills that boost your immune system are safe for people with a transplant.

___ Family and friends may suggest herbal remedies or natural products - you should check with your transplant team before trying them out.

**11. If you are experiencing a side effect from your anti-rejection pills, what should you do? (check all the correct answers)**

___ Continue taking the pills as prescribed.

___ Contact your transplant team.

___ Decrease the dose of your antirejection pills to see if that helps.

___ Stop your antirejection pills until you can see your doctor.

___ Try to manage the side effects with over the counter medications.

**12. What precautions should you take to prevent colds or flu illness? (check all the correct answers)**

___ Wash your hands.

___ Get vaccinations such as your yearly flu shot.

___ Avoid unnecessary contact with others who are unwell.

___ Quit your job because at work you are with sick people.

___ Wear a mask when out in a crowd.

**13. It is important to tell all your doctors that you received a kidney transplant because: (check all the correct answers)**

___ Other pills may not mix well with anti-rejection pills.

___ Anti-rejection pills make it easier for you to catch infections.

___ Anti-rejection pills increase your cancer risk, so regular check-ups are important.

___ Some pills may harm your transplant.

___ Anti-rejection pills may affect how you heal after surgery.

___ You do not need to tell your doctors that you have a transplant.

**14. It is important to tell your pharmacist that you received a kidney transplant because: (check all the correct answers)**

___ Other pills may not mix well with anti-rejection pills.

___ Your pharmacist can help you decide if you should treat common problems (such as heartburn or (cold sores) with over the counter medications.

___ Some over the counter medications can harm your transplant.

___ You do not need to tell your pharmacist that you have a transplant.

**15. Which statements are true about creatinine? (check all the correct answers)**

___ Creatinine is measured by a blood test.

___ Creatinine levels can tell us how your kidney is working.

___ Your creatinine will always be normal after your kidney transplant.

___ If your creatinine goes up, it always means there is rejection.

**16. When thinking about transplant rejection, which of the following are true? (check all the correct answers)**

___ Rejection cannot be treated.

___ Stronger anti-rejection pills can sometimes treat rejection.

___ You have a good match, so rejection cannot occur.

___ If you take your anti-rejection pills correctly, rejection will not occur.

___ You will know if you have rejection because you will feel sick.

**17. In the first few months after your kidney transplant, which of the following are true? (check all the correct answers)**

___ You can catch infections easier because your anti-rejection pills are stronger.

___ You should avoid changes to your glasses or contact lenses because your eyesight may change.

___ Regular blood testing is not important.

___ Out of country travel is encouraged.

**18. Years after your kidney transplant, which of the following are true? (check all the correct answers)**

___ Some anti-rejection pills can hurt the kidney transplant.

___ High blood pressure can hurt the kidney transplant.

___ More pills may be needed to treat complications from the transplant.

___ Your transplant team may decrease your anti-rejection pills.

___ Your transplant team may need to increase your anti-rejection pills.

**19. Which statements are true about pregnancy in women who have received a kidney transplant? (check all the correct answers)**

___ Some antirejection pills can cause birth defects.

___ Antirejection pills can be stopped during pregnancy.

___ Pregnancy may cause an increase in creatinine.

___ A kidney transplant will always make it possible to have a baby.

___ You should discuss your wish to become pregnant with your transplant team.

**20. Which statements are true about men who have received a kidney transplant? (check all the correct answers)**

___A kidney transplant will always let you father a child.

___A kidney transplant will always fix your erection problems.

___Some pills taken by the father may harm the baby.

___You should discuss your wish to father a child with your transplant team.

**21. When thinking about sexually transmitted infections (STIs) after kidney transplant, which of the following are true? (check all the correct answers)**

___ Birth control pills can prevent STIs.

___ Condoms can prevent all types of STIs.

___ All sexually transmitted infections can be cured.

___ Anti-rejection pills increase the risk of catching STIs during sexual activity.

**22. Do you think this questionnaire is adequate for assessing a person's knowledge about kidney transplant?**

**Pease tick appropriate box**

| | | | |
|---|---|---|---|
| **Yes** | | **No** | |

**END OF SECTION 1**

**SECTION 2 of the K-TUT**

**2.1 What else would you like to know about kidney transplant?**

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**2.2 Is there any other information that you need, and you think can help you to understand this process?**

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**2.3 Should your family be involved in this process, what information do you think they will need in order to assist you?**

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**ANNEXURE 3: INFORMATION LEAFLET**

**KIDNEY TRANSPLANT RELATED KNOWLEGDE AND HEALTH EDUCATION NEEDS OF PATIENTS WITH CHRONIC KIDNEY FAILURE AWAITING KIDNEY TRANSPLANT IN TWO ACADEMIC HOSPITALS IN GAUTENG**

Greetings.

My name is Mmabje Calvin Nkadimeng, a student at the University of the Witwatersrand enrolled for a Master of Science in Nursing (Nephrology nursing). I am conducting a study as part of the requirements for my studies, on kidney transplant related knowledge and health education needs of patients with chronic kidney failure awaiting kidney transplant in two academic hospitals in Johannesburg. I would like to invite you to consider participating in my study titled "*Kidney transplant related knowledge and health education needs of patients with chronic kidney failure awaiting kidney transplant in two academic hospitals in Johannesburg"*

Before you decide, it is important to understand why this study is being conducted and what it involves. Please take time to read the information as it explains what the study seeks to achieve.

The main purpose of the study is to investigate the kidney transplant related knowledge and health education needs of patients on haemodialysis awaiting kidney transplant, to bring awareness to the healthcare providers regarding knowledge and health education needs of patients on haemodialysis awaiting kidney transplant.

The Objectives are to:

- describe the characteristics of the patients
- describe the kidney transplant related knowledge of patients on haemodialysis.
- describe the kidney transplant related health education needs of patients on haemodialysis.

The study focuses on all the chronic kidney failure patients on haemodialysis awaiting kidney transplant. Should you wish to take part, you will be assisted to complete the attached Kidney

Transplant Understanding Tool questionnaire, which comprises 22 questions and an additional three open-ended questions

Participation in the study is purely voluntary and no penalties will be imposed on you should you decide not to participate. If you wish to participate, please sign the consent form and complete the questionnaire. Your name will appear only on the consent form but not on the questionnaire for confidentiality. Permission to conduct the study has been sought from the relevant departments and approval was granted. Please feel free to contact me for further information on my cell phone number, 0795158877 or email, mmabjecalvin@yahoo.com, or my supervisor, Dr. Nkosi-Mafutha, on (011) 488 4718 during office hours.

Yours faithfully

Mmabje Calvin Nkadimeng

**ANNEXURE 4: INFORMED CONSENT**

**CONSENT FORM**

**KIDNEY TRANSPLANT RELATED KNOWLEDGE AND HEALTH EDUCATION NEEDS OF PATIENTS WITH CHRONIC KIDNEY FAILURE IN TWO ACADEMIC HOSPITALS IN GAUTENG**

I _____ (full name) give consent to take part in the above study.

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. I understand that my participation in this study is voluntary and that I can withdraw from at any time, without any penalties enforced on me.

SIGNATURE: _____ DATE: _____

## ANNEXURE 5: E-MAIL PERMISSION TO USE THE K-TUT

Hi Dr. Mafutha,

Thanks so much for providing the context. I actually thought you were referring to another paper that we have published using the K-TUT aimed at assessing health literacy, knowledge and satisfaction of kidney transplantation, so this helps.

I think this sounds like a very exciting study and wish you well with this endeavour. I only ask that you keep me posted on your results, and kindly cite our paper in your work.

If you need any further clarification on how we used or interpreted the K-TUT, please do not hesitate to let me know.

Thanks,

Holly

-- Holly Mansell, BSP, PharmD

Assistant Professor

College of Pharmacy & Nutrition, University of Saskatchewan

Health Sciences Building (Room 3132)

104 Clinic Place, Saskatoon, SK, SZN 2Z4

ph: (306) 966-1512

Email: holly.mansell@usask.ca

## ANNEXURE 6A: PERMISSION TO CONDUCT STUDY AT HOSPITAL

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

**Gauteng Department of Health**
Helen Joseph Hospital
Enquiries: Dr. M.R. Billa
Chief Executive Officer
Tel :( 011) 489-0306/1087
Fax :( 011) 726-5425
E mail: Raymond.Billa@gauteng.gov.za
Date: 2 March 2018

Dr.M.R.Billa
Chief Executive Officer
Helen Joseph Hospital

Dear Dr.Billa

**STUDY:** Kidney transplant related knowledge and health Education needs of patients with chronic Kidney failure in two academic hospital in Gauteng

**RESEARCHERS:** Mr Calvin Nkadimeng

**Ethic: M171028**

The above was discussed at the Research Committee Meeting. We recommend that permission be granted for Helen Joseph Hospital to be used as a site for the above research. However, since this is a research project involving voluntary participation. We cannot guarantee participation of individuals/patients

As this is all independent research project it remains the responsibility of the researcher to recruit participants from the relevant department within the hospital and acquire their individual voluntary consent to participate in your study.

Thankyou

Dr. Murimisi Mukansi
CHAIRPERSON
DATE:

Approved

Dr. M.R. BILLA
CHIEF EXECUTIVE OFFICER
DATE: 02.03.2018

## ANNEXURE 6B: PERMISSION TO CONDUCT STUDY AT THE HOSPITAL

The original copy was lost when the researcher's computer was stolen, and this is a re-issue from the institution to be included in the report as requested by the examiners.

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

**MAXEKE JOHANNESBURG ACADEMIC HOSPITAL**

**Office of the Nursing Director**
**Enquiries:** Mr. Moses Tshabuse
**Tel:** (011) 488-4558
**Email:** Moses.Tshabuse@gauteng.gov.za
01 March 2021

NHRD Ref: GP 201801 012

**Dear Mr. M Nkadimeng**

**STUDY TITLE: Kidney transplant related knowledge and Health Education needs of patients with chronic kidney failure in two academic hospital in Gauteng**

Permission is granted for you to conduct the above-mentioned study as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the HOD and Unit Manager or sister in charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

**Supported / ~~not supported~~**

**Ms. M.M Pule**
**Nursing Director**
**Date:** 01/03/2021

**~~Approved~~/not approved**

**Ms. G.M Bogoshi**
**Chief Executive Officer**
**Date:** 02.03.2021

## ANNEXURE 7: ETHICS CLEARANCE




R14/49 Mr MC Nkadimeng

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M171028

| | |
|---|---|
| **NAME:** (Principal Investigator) | Mr MC Nkadimeng |
| DEPARTMENT: | School of Therapeutic Sciences<br>Department of Nursing Education<br>Medical School<br>University |
| PROJECT TITLE: | Kidney transplant-related knowledge and health education needs of patients with chronic kidney failure in two academic hospitals in Gauteng |
| **DATE CONSIDERED:** | 27/10/2017 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | |
| **SUPERVISOR:** | Dr N Mafutha |
| APPROVED BY: | Professor CB Penny, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 09/11/2018 |

**This clearance certificate is valid for** 5 years from date of approval. **Extension may be** applied for.

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and ONE COPY returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, J/we undertake to resubmit to the Committee. I agree to submit a yearly progress report. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed, in this case, the study was initially reviewed in October and will therefore be due in the month of October each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

**PLEASE** QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

## ANNEXURE 8: POSTGRADUATE APPROVAL LETTER

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

03 January 2020
Person No: 1225838
PAG

Mr MC Nkadimeng
P O Box 239
Sekhukhune
1124
South Africa

Dear Mr Mmabje Nkadimeng

**Master of Science in Nursing: Approval of Title**

We have pleasure in advising that your proposal entitled *Kidney transplant related knowledge and health education needs of patients with chronic kidney failure in two academic hospitals in Gauteng* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences