

**ASSESSING HEALTH LITERACY IN PROMOTION OF SELF-MANAGEMENT
AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE ATTENDING KENYATTA
NATIONAL HOSPITAL**

HELDA NEKESA WAFULA

REG: H56/11890/2018

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR
THE AWARD OF DEGREE OF MASTERS OF SCIENCE IN RENAL NURSING OF
THE UNIVERSITY OF NAIROBI**

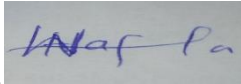
NOVEMBER 2020

DECLARATION

I, Helda Nekesa Wafula, the undersigned, declare that this is my original work and has not been submitted for any award to any other University or institution of higher learning

Registration Number: H56/11890/2018

Signature ...



Date...01/12/2020.....

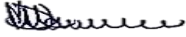
CERTIFICATE OF APPROVAL

We, the undersigned certify that this thesis is submitted for partial fulfillment of the award of the degree of Master of Science in Nursing (Renal Nursing) of the University of Nairobi with our approval as internal supervisors.

Dr. Dorcas Maina

Lecturer, School of Nursing Sciences

University of Nairobi

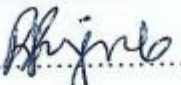
Signature: ... 

Date: ...01/12/2020.....

Mrs. Eve Rajula

Lecturer, School of Nursing Sciences

University of Nairobi

Signature... 

Date... 1/12/2020

ACKNOWLEDGEMENT

I sincerely express my gratitude to all those who have assisted me in this work. To my supervisors; Dr. Dorcas Maina and Mrs. Eve Rajula for their invaluable guidance, support and follow up. My heartfelt appreciation also goes to my lecturers at the University of Nairobi, School of Nursing Sciences for their encouragement and support. In addition, my gratitude goes to my classmates for allowing discussion and occasional consultations and the librarian for helping me access references for secondary data to get appropriate literature.

DEDICATION

I would like to dedicate this achievement to my family for their continued support throughout.

TABLE OF CONTENTS

| | |
|--|------|
| ACKNOWLEDGEMENT | 2 |
| DEDICATION | v |
| LIST OF ABBREVIATIONS..... | x |
| LIST OF FIGURES | xi |
| LIST OF TABLES | xii |
| OPERATIONAL DEFINITION OF TERMS | xiii |
| 1.0 CHAPTER ONE: INTRODUCTION..... | 1 |
| 1.1 Background..... | 1 |
| 1.2 Problem statement..... | 7 |
| 1.3 Justification of the study | 9 |
| 1.4 Significance of the study..... | 9 |
| 1.4 Research objectives..... | 10 |
| 1.4.1 Broad objective | 10 |
| 1.4.2 Specific Objectives | 10 |
| 1.5 Research questions..... | 11 |
| 1.6 Hypothesis..... | 11 |
| 2.0 CHAPTER TWO: LITERATURE REVIEW..... | 12 |
| 2.1 Introduction..... | 12 |
| 2.2 Kidney disease | 12 |
| 2.3 Chronic kidney disease (CKD)..... | 13 |
| 2.4 Self-management | 14 |
| 2.5 Health education | 16 |
| 2.6 Health literacy..... | 17 |
| 2.7 Assessment of health literacy in promotion of self-management behavior..... | 19 |
| 2.8 Level of health literacy on kidney disease among patients with chronic kidney disease ... | 22 |
| 2.9 Association between health literacy and self-management behaviors among patients with chronic kidney disease | 25 |

| | |
|--|----|
| 2.10 Effectiveness of targeted health education sessions on health literacy in self-management among patients with chronic kidney disease..... | 28 |
| 2.11 Gaps in literature review..... | 31 |
| 2.12 Theoretical framework..... | 31 |
| 2.13 Conceptual framework..... | 33 |
| Figure 1 Conceptual framework | 33 |
| 3.0 CHAPTER THREE: METHODOLOGY | 35 |
| 3.1 Introduction..... | 35 |
| 3.2 Study design..... | 35 |
| 3.3 Study area..... | 35 |
| 3.4 Sampling and Sample size calculation..... | 36 |
| 3.4.1 Sample size calculation..... | 36 |
| 3.4.2 Inclusion criteria | 37 |
| 3.4.3 Exclusion criteria | 37 |
| 3.4.4 Sampling method | 37 |
| 3.5 Data collection instruments..... | 39 |
| 3.6 Data collection procedure | 39 |
| 3.7 Data management and statistical analysis..... | 40 |
| 3.8 Ethical consideration..... | 41 |
| 3.9 Study findings/ dissemination plan..... | 41 |
| 4.1: Introduction..... | 42 |
| 4.2 Socio-demographic characteristics | 43 |
| Table 1. Socio-demographic information | 43 |
| 4.3 Other medical conditions and duration of CKD | 43 |
| Table 2. Other medical conditions and duration of chronic kidney disease. | 44 |
| 4.4.1 The level of health literacy and self-management | 44 |
| Table 3. Assessing the level of health literacy..... | 45 |
| Table 4. Symptoms of chronic kidney disease..... | 46 |

| | |
|--|----|
| 4.4.2 Assessment of perceived self-management | 46 |
| Table 5. Assessment of perceived self-management | 47 |
| 4.5 Association between health literacy and self-management behaviors..... | 47 |
| Table 6. Model summary | 48 |
| Table 7. Analysis of variance (ANOVA) | 48 |
| Table 8. Coefficients affecting self-management | 49 |
| 4.6 Effectiveness of targeted health education sessions on health literacy in self-management practices among patients with chronic kidney disease | 49 |
| Table 9. Assessing the level of health literacy..... | 50 |
| Table 10. Symptoms of chronic kidney disease..... | 51 |
| Table 11. Assessment of perceived self-management. | 52 |
| Table 12. Group statistics for health literacy | 53 |
| Table 13. Group statistics for self-management | 53 |
| Table 14. Assessing the level of health literacy..... | 54 |
| Table 15. Symptoms of chronic kidney disease..... | 55 |
| Table 16. Assessment on perception of self-management..... | 56 |
| Table 17. Group statistics for health literacy | 57 |
| Table 18. Group statistics for self-management | 57 |
| 5.1 Discussion | 58 |
| 5.2 Conclusion | 61 |
| 5.3 Recommendation | 62 |
| APPENDICES | 76 |
| APPENDIX I: TIME FRAME..... | 76 |
| APPENDIX II: BUDGET..... | 77 |
| APPENDIX III: Consent form..... | 78 |
| APPENDIX IV: Participant Demographic Information Questionnaire..... | 81 |

| | |
|---|----|
| APPENDIX V: Kidney Disease Knowledge Survey..... | 83 |
| APPENDIX VI: Perceived Kidney Disease/Dialysis Self-Management Scale..... | 85 |
| APPENDIX VII: Targeted Health Education Tool | 86 |
| APPENDIX VIII: LETTER OF APPROVAL FROM ETHICS | 87 |
| APPENDIX IX: LETTER OF APPROVAL FROM KENYATTA NATIONAL HOSPITAL | 89 |

LIST OF ABBREVIATIONS

| | |
|---------------|---|
| AKI | Acute Kidney Injury |
| BP | Blood pressure |
| CKD | Chronic kidney disease |
| EGFR | Estimated glomerular filtration rate |
| ESRD | End-stage renal disease |
| GFR | Glomerular filtration rate |
| HE | Health education |
| HeLMs | Health Literacy Management Scale |
| HL | Health literacy |
| KDIGO | Kidney disease improving global outcome |
| Kgs | Kilograms |
| KIKs | Kidney disease knowledge survey |
| KNH | Kenyatta national hospital |
| LHE | Low health education |
| LHL | Limited health literacy |
| NCDs | Non communicable diseases |
| NHANES | National health and nutrition survey tool |
| WHO | World health organization |

LIST OF FIGURES

Figure 1: Conceptual framework.....34

LIST OF TABLES

| | |
|---|----|
| Table 1: Socio-demographic information..... | 44 |
| Table 2: Other medical conditions and duration of chronic kidney disease..... | 45 |
| Table 3: Assessing the level of health literacy..... | 46 |
| Table 4: Symptoms of chronic kidney disease..... | 47 |
| Table 5: Assessment of perceived self-management..... | 48 |
| Table 6: Model summary..... | 49 |
| Table 7: Analysis of variance (ANOVA)..... | 49 |
| Table 8: Coefficients..... | 50 |
| Table 9: Assessing the level of health literacy..... | 51 |
| Table 10: Symptoms of chronic kidney disease..... | 52 |
| Table 11: Assessment of perceived self-management..... | 53 |
| Table 12: Group statistics for health literacy..... | 54 |
| Table 13: Group statistics for self-management..... | 54 |
| Table 14: Assessing the level of health literacy..... | 55 |
| Table 15: Symptoms of chronic kidney disease..... | 56 |
| Table 16: Assessment on perception of self-management..... | 57 |
| Table 17: Group statistics for health literacy..... | 58 |
| Table 18: Group statistics for self-management..... | 58 |

OPERATIONAL DEFINITION OF TERMS

Chronic kidney disease: Damage to the kidneys for 3 months or more, or structural or functional abnormalities of the kidneys

Dietary recommendations: Changes made to the diet of a person with chronic kidney disease such as eating a low protein diet, reducing salt intake, phosphorus, potassium, and other electrolytes

End stage renal disease: This is also called stage five of chronic kidney disease or kidney failure is defined as the terminal stage of chronic kidney disease

Fluid restrictions: Limit on fluid intake for patients with ESRD to amounts that can safely be removed during dialysis or urination

Health education: This is the social, intellectual and psychological dimensions which involve fostering skills and motivation to articulate health issues in order to make an informed choice.

Health literacy: This is the ability to obtain, process, and understand basic health information and services to help make informed decisions. In this study the level of health literacy was assessed using kidney disease knowledge survey tool.

Hemodialysis: This is the process of purifying blood of a person with kidney disease using extracorporeal circuit

Kidney transplantation: This is the organ transplant of a kidney into a patient with end-stage kidney disease

Self-management: This is the care taken by individuals towards their own health and wellbeing. In this study, perceived motivation in self-management was assessed using perceived kidney/dialysis self-management scale.

Therapy adherence: Strictly follow prescribed management

ABSTRACT

Chronic kidney disease (CKD) is a major health problem with a prevalence of 11 to 14% globally. CKD progresses slowly, causing a reduction in the renal function. The patient needs to adopt effective self-management strategies and therefore should be health literate in his condition. Health literacy plays a big role in influencing access and utilization of basic health information. Despite health literacy being shown to promote self-management, most renal units still focus on generalized health education which may not be appropriate for each patient.

Broad objective: To assess the effects of health literacy in promoting self-management practices among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital

Methodology: The study adopted Quasi-experimental study design, and purposive sampling method was utilized to identify patients presenting with chronic kidney disease. The study utilized kidney disease knowledge survey tool to assess health literacy while self-management was assessed using the perceived kidney/dialysis self-management scale. The sample population was divided using systematic random sampling. Targeted group education sessions were administered to 30 participants, while other participants received standard healthcare protocol offered at the unit. The two groups were later evaluated to assess the effectiveness of health education sessions. Categorical data was analyzed using percentages and continuous data by getting the mean, and standard deviation. Chi square was used to determine the association between health literacy and self-management while T-test was used to compare the difference between the two populations.

Results: The level of health literacy among CKD patients was 70.4%, and the level of self-management was 49%. Association between health literacy and self-management had (F-value = 2.967, with a $p \leq 0.12$) and targeted health education sessions provided to participants had (M = 0.83, SD = 0.01) T- value of 0.038.

Conclusion: The findings of this survey show that the level of health literacy among patients with CKD was high, but the level of self-management was low. There is significant association between health literacy and self-management behaviors among patients with chronic kidney disease, and provision of targeted health education sessions in groups significantly increased the level of health literacy in promotion of self-management.

1.0 CHAPTER ONE: INTRODUCTION

1.1 Background

Non-communicable diseases are on the high rise globally derailing the achievement of health for all. Consequently, the third Sustainable development goal (SDG) aims at ensuring health for all by the year 2030. According to WHO (2019) and United Nations (2017), one of the specific goals is to reduce premature mortality from non-communicable diseases (NCDs) through promoting, preventing and treating mental health thus improving the wellbeing of a person. The non-communicable diseases are increasingly causing high morbidity and mortality in the affected patients, (Gowshall & Taylor-Robinson, 2018). In sub-Saharan Africa, NCDs is among the leading causes of mortality with chronic kidney disease (CKD) presenting as one of the major NCD, (Hodel et al., 2018).

There is marked increase in the prevalence of CKD among general population. Hill et al., (2016) found a prevalence of 11 to 13% globally. This compares with the figures given by WHO (2017) who gave a global estimate of the prevalence of CKD across different populations of about 11 to 14%. ElHafeez et al., (2018), found a prevalence of 12.1% among general population in the continent of Africa, while in Tanzania, estimated prevalence of CKD is 13.6%, (Hodel et al 2018). No official figures have been provided for the prevalence of CKD in Kenya.

Chronic kidney disease (CKD) progresses slowly, causing a reduction in renal function. This reduction progresses to End Stage Renal Disease (ESRD), (Vaidya & Aeddula, 2018). In order to slow down the progression, patients suffering from CKD should self-manage during the course of their illness. This is done by effectively taking medications and changing lifestyle which includes diet and fluid intake restrictions, (Maoliosa et al., 2018), exercises, alcohol, and

smoking cessation, (Havas, Clint & Bonner, 2017; Schrauben, Hsu & Rosas, 2018). This is essential in prolonging life and ensuring the patient is able to perform necessary activities of living. Wakasugi and Kazama, (2017) stipulate that self-care behaviors are associated with improved health outcome among individuals with chronic diseases. The patient is able to take full control of his health which will help in delaying disease progression.

Self-management is the cornerstone in management of kidney diseases. Self-management strategies are core in managing chronic kidney disease, (Devraj, Borrego et al., 2018). In order to live with a chronic illness, an individual undertakes tasks to manage their health. It fosters self-care and builds problem solving skills of the patient. The patient becomes confident in making lifestyle changes and following treatment regimens, (Maoliosa & Gil, 2018; Indino, Sharp & Esterman, 2019). The lifestyle changes focus on illness needs by developing skills, knowledge, and confidence of the patient. The patient should be considered as a whole, thus self-management interventions should be geared towards taking care of the social, emotional, physical and mental health of the patients, (Maolisa, Bhavneet & Heather, 2017). This is important in meeting the individual's desires through collaborating with different stakeholders and is dependent on multiple patient characteristics including health literacy (HL).

During care, the patient should be able to carry on with his daily routine without depleting family resources. The patients focus on illness needs by developing skills and knowledge, (Chen and Chang, 2018), mobilizing resources and support, (Javier et al., 2018) and also learning how to cope or live with the disease and its impact on their lives, (Grey, Schulman-Green & Knafl, 2015; Lin et al., 2017). These approaches will help increase the engagement of the patient who will be able to make adjustments in his life and focus on his condition.

Chronic kidney disease (CKD) is divided in stages based on deterioration of kidney function. The Kidney disease improving global outcomes KDIGO (2012) has divided CKD into 5 stages. Stage one signifies normal or GFR greater than 90ml/min. Patients in stage two are having mild form of CKD with GFR = 60 to 89 ml/min, stage three have moderate form with GFR = 30 to 59 ml/min, stage four is the severe form of CKD with GFR= 15 to 29 ml/min, while stage five GFR is less than 15 and is considered end stage renal disease (ESRD). The stages are useful in planning care for the patient with CKD. In stage 1 kidney disease, the focus is on preventing the progression to ESRD and prevention of the risk of developing cardiovascular complications, (Campbell et al., 2016). Managing kidney functions, hypertension and diabetes is essential to improve prognosis.

The patient should be encouraged to effectively self-manage during the early stages of CKD. During stages 1-4, patient shows no significant signs of kidney damage and might assume the severity of CKD is not a concern and therefore consider self-management unnecessary, (Joboshi & Oka, 2017). The patients should then be supported to understand the complexity of the condition and encouraged to manage the disease to slow down its progression and improve the quality of life. In the early stages of CKD, self-management is critical during patient's care. Identifying ways in which the patients should be motivated to effectively manage their own illness is important, (Havas, Clint & Bonner, 2017). This is done by ensuring that the patient is knowledgeable about the disease process and the expected outcome. This necessitates a need for targeted health education interventions which will help improve the patient outcomes, (Hoerger et al., 2015). Creating kidney disease awareness is important in engaging patients and ensuring adherence to treatment.

Health education is a powerful moderator between communication and health outcomes. It facilitates an individual's ability to make changes that are going to affect his life (Parnell et al., 2019). It affects the patient's behavior in utilizing health services, which will have an impact on health outcomes. Health education creates conditions for change and growing competency of groups and individuals' health literacy, (Przybylska, et al., 2014). This helps a person improve his abilities to manage the condition.

The patient should be involved in decision making and implementation of care, which is paramount for long-term management of CKD. The patient must be health literate to be able to understand and use health information in order to perform self-management, (Campbell, et al., 2016). Health literacy encompasses the knowledge and skills of an individual, which will enable him to understand what is happening to him and why he is receiving a certain intervention. This is the social and cognitive skills, which helps individuals to access, process, understand and utilize information in the maintenance and promotion of good health, (Mirczak 2017; Rasu, et al., 2015). A health literate individual can obtain, understand and utilize health information to assist him in making appropriate decisions about his health.

Health literacy is more than just the ability to read and write. It does not entail only having the ability to read pamphlets, and make medical appointments, (WHO, 2016), or comply with doctor's prescription, (Budhathoki & Pokharel, 2017). It also includes the ability to understand the health information and utilize it in making decisions related to their health. Any person can experience health literacy issues. The Centre for disease control (CDC, 2016) reports that even the elite people can face health literacy issues when the medical terms are used, or when they are diagnosed with a scary illness, which causes confusion. This could be attributed to lack of

understanding of what is happening to their bodies as they are having a health condition which requires complicated care.

Health literacy plays a critical role in promoting self-management of chronic kidney disease. The complexity of chronic kidney disease means that the individual should have the skills and confidence to make critical decisions about his health without undue pressure or coercion. Detailed intensive coordination between different players is required to optimize care during ongoing treatment of kidney disease in order to prevent progression to end stage renal disease (ESRD), (Dageforde & Cavanaugh, 2018). Health literacy plays a role in promoting communication between different stakeholders responsible for the care of the patient. These are patients, health providers, and the social networks within health system with intentions of promoting an understanding and engagement in patient's care, (Moreira 2018). Adequate health literacy will lead to improved patient communication, adherence to treatment, engaging in self-care, which will improve the health status of the patient and save the costs to the healthcare systems, (Kasesmap 2019). This will improve the patient outcome; however it is affected by low health education among patients with CKD.

Low health education can lead to poor self-management of CKD. The patient has poor health outcome when health education and numerous skills of the patient are poorly matched with technically complex information which is provided at the health facilities, (Stanifer et al., 2016; CDC 2016). Low health education increases the chances of low health literacy which increases patient vulnerability to health issues. According to Gardiner (2019), low health education will make patients vulnerable to health problems, causing lower treatment adherence. This commonly affects patients in all stages of kidney disease leading to poor health outcomes. Low health literacy is also associated with decreased levels of adherence, increased hospitalization, and

reduced uptake of kidney transplantation, (Dageforde & Cavanaugh, 2013). This contributes to a high incidence of patient missing dialysis treatments and increased visit to the emergency department. Taylor et al., (2019) found out that there was reduced access to renal transplantation services among patients with limited health literacy. The patient with low health literacy does not understand the treatment modalities available and therefore is not able to choose on other available options.

Health care providers (HCPs) have a greater role to play during patient education and management. They should not assume that all patients who attend CKD clinic are knowledgeable about the disease. Devraj et al., (2018) found out that performance in CKD-specific behaviors or participation in the follow up clinics by patients does not imply that patients are knowledgeable about CKD. This could simply mean the patient is complying with health care providers' instructions. The patients should be educated to understand the complexity, prognosis of the disease and consequently be aware of self-managing skills. Self-management activities will be performed by the patient after appropriate information has been provided, (Duprez, et al., 2018). This will help in improving prognosis.

Some patients possess health information to some extent while others have none at all. Information and support should be geared towards health literacy skills on individual patients, as they differ in their level of health literacy, without focusing on the medical context alone, (Heijmans et al., 2015). This information should be individualized to meet patient's needs. Communication should be in a language the patient understands. Walker et al., (2016) found that poor communication leads to difficulty translating clinical information and the patients felt inadequate during clinical encounters. Health care providers should ensure that the patient understands what he is being taught.

Patients with CKD should be managed as individuals with unique needs. The care provided should be individualized to meet the patient's needs at that time, (O'Hare, 2017). This will ensure prioritization of patients' needs. Patients who are not motivated and lack confidence should be supported to ensure effective continuity of care, (Bowling & Hare, 2012; Stevenson et al., 2018). Once they have confidence that they are doing the right thing, they are more likely to be compliant. Therefore, patient-centered care is essential and patients' care should be tailored to the specific needs arising at that time. Health education will become beneficial to the patient by increasing the level of health literacy which will increase the uptake of self-management.

Planning of care should be done with the patient as an active participant. Unfortunately, consulting persons with CKD regarding the support that they desire to effectively manage their condition is rarely done, (Havas, Clint & Bonner, 2017; Maoliosa et al., 2018). The patient should be engaged and supported during self-management interventions in order to be part of the process.

1.2 Problem statement

Self-management (SM) strategies are core in the management of chronic illnesses like kidney disease. It is the daily management of a chronic condition by the individual throughout the course of his illness, (Anekwe & Rahkovsky, 2018). Health literacy plays a role in promoting the self-management process, which includes symptom recognition, taking actions during emergencies, adherence to medication, fluids, and diet. Mirczak (2017) found out that knowledge on health literacy of the patient with chronic disease helps to design a therapeutic education session for the individual patient.

Health literacy can be affected by limited health education (LHE). This increases health risks to the patients by interfering with their health maintenance and self-care if health education, and

instructions are not clearly understood, (Rasu, Bawa, & Suminski, 2015; Mendoza, 2019). As part of routine kidney care, there is a need to create a culture of patient empowerment and education with continued support on the patient management, (Kayser et al., 2019; Jain & Green, 2016). Engaging with the patients increase awareness and understanding of the disease condition and they are educated on different treatment modalities.

Health care providers (HCPs) have a greater role in communicating the complexity of CKD. They should educate and discuss with the patients about the disease condition, (Rajah, Hassali & Lim, 2017). However, HCPs have traditionally focused on offering CKD related health messages and facts to patients. This may be due to time constraints, competing tasks, and lack of an agreement on the timing and appropriateness of initiating CKD education, (Barton et al., 2018; Narva, Norton & Boulware, (2016). Time should be created during patient care to ensure that the patient is given more CKD information which will be of importance during the course of illness.

Despite health literacy being shown to promote self-management, most renal units still focus on generalized health education which may not be appropriate for each patient, and most patients still depend on the health care providers to provide their wholesome care. In KNH renal unit, the provision of targeted health education sessions to patients with CKD is rarely provided in groups, instead the patients are provided education by the counselor and nutritionist during end stage renal disease when preparing for renal replacement therapy and are only referred back to a nutritionist and a counselor less often during their follow-up care in renal unit. Most of the patients come in with increased weight of more than 3 kgs and high blood pressure every follow-up visit, (data from patient's files, unpublished observations). This necessitates intervention to find out how they perceive their self-management activities during their care. The purpose of this study is therefore to assess the effects of health literacy in promoting self-management, assess

the patient perception on self-management strategies, and evaluate the effectiveness of targeted group educational sessions among patients presenting with CKD.

1.3 Justification of the study

Renal failure and End-stage renal disease are becoming common health care concerns in Kenya. Health literacy helps increase the level of uptake of services and improves self-management. There is limited information available on health literacy and promotion of self-management strategies among patients with chronic diseases. Health literacy is also poorly understood, there are regional disparities in the levels of health literacy with differences in definitions. Self-management is not appreciated by the patient and relatives; this makes most patients to depend on health care providers for wholesome care. Self-management provides a better approach in improving the quality of life among patients with chronic kidney disease. Thus knowledge of the current health literacy levels will inform healthcare stakeholders on the efforts that need to be considered to promote positive health among these patients.

In KNH there is no documented evidence on the level of health literacy in promotion of self-management, and yet it is important to describe it. This study, therefore, aimed to give an opportunity for patients to share their challenges regarding CKD and self-management.

1.4 Significance of the study

Identifying the level of health literacy among patients with CKD aimed at enabling the renal team; especially the nurses, who spend most of their time with the patients talking to, and health educating them to understand their level of health literacy. This will help the renal team design appropriate measures on areas they are supposed to improve.

Assessing the level of self-management aimed at identifying the strengths of the patient and his perception about his condition which will help in improving the quality of care among patients with chronic kidney disease.

The findings also aimed at providing a background for developing an assessment tool for assessing the level of health literacy and self-management. These findings will also inform policy makers and curriculum planners at KNH and national level in the Ministry of Health in designing protocols and educative programs that will facilitate training on health literacy and self-management for patients and health care providers.

Most studies on health literacy have been done outside Kenya and there is no data available on self-management strategies among patients presenting with chronic diseases. This study will provide data on level of health literacy in self-management among patients locally and internationally, and will form a reference for other related studies.

1.4 Research objectives

1.4.1 Broad objective

To assess the effects of health literacy in promoting self-management practices among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital

1.4.2 Specific Objectives

1. To assess the level of health literacy on kidney disease among patients with chronic kidney disease attending renal unit at Kenyatta National hospital
2. To determine the association between health literacy and self-management behaviors among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital
3. To evaluate the effectiveness of targeted health education group sessions on health literacy in self-management practices among patients attending renal unit at Kenyatta National Hospital.

1.5 Research questions

1. What is the level of health literacy on kidney disease among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital?
2. What is the association between health literacy and self-management behaviors among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital?
3. What is the effectiveness of targeted health education sessions on health literacy in self-management practices among patients with chronic kidney disease attending renal unit at Kenyatta National Hospital?

1.6 Hypothesis

There is no relationship between targeted health education sessions and level of health literacy in promoting self-management among patients with CKD

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter focuses on reviewing the definition of chronic kidney disease, the effects of CKD on self-management strategies and the role of health literacy in promoting self-management. There is a discussion focusing on the tools used in chronic disease management. Further discussion deals with utilization of targeted health education sessions on health literacy and finding out the associations between health literacy and promotion of self-management among CKD patients. The databases searched included Google scholar, Hinnari, and PubMed, while key words used include chronic kidney disease, self-management, health education and health literacy.

2.2 Kidney disease

Kidney disease is the process whereby the kidneys fail to perform their functions which leads to retention of waste products. This causes retention of water and nitrogenous waste products in blood (Bindroo & Challa, 2019). Kidney disease affects the process of excretion. Waste products like urea are retained in the body because the kidneys cannot filter blood efficiently, (Fraser & Blakeman 2016). This causes the build-up of toxic waste products in the body.

All patients who present with conditions that may predispose them to develop renal insufficiency are assessed for renal function during screening. An estimate of glomerular filtration rate (GFR) evaluates the degree of renal impairment, (Rosenberg 2019; Gounden & Jialal 2019). The degree of renal impairment is then used to classify the disease depending on severity. Other studies may also be done to help in the diagnosis, which include urinalysis, radiological studies and kidney biopsy, (Inker & Perrone 2019). The patient may present with acute renal injury. Acute renal

injury (AKI) also called acute renal failure, is an abrupt decline in renal function, (Makris & Spanou 2016). Kidney Disease Improving Global Outcomes (KDIGO 2012) defines AKI as either an increased serum creatinine to 1.5 times baseline, or more within the last 7 days, or an increased serum creatinine of 0.3mg/dL or more within 48 hours, or urine output less than 0.5 ml/kg/h for 6 hours. AKI causes a build-up of waste products in the patient's blood. The build-up makes it hard for the kidneys to keep the right balance of the body (Horino, 2020). The build-up of substances can be massive, and worsen the outcome of AKI leading to chronic kidney disease.

2.3 Chronic kidney disease (CKD)

Chronic kidney disease is marked by a progressive decline in renal function for more than three months. The Centre for disease control CDC (2019) defines CKD as declining of the renal function more three months with an estimated glomerular filtration rate (eGFR) less than 60ml/min/1.73m³. This can lead to end stage renal disease. Similarly, Kidney Disease Improving Global Outcome (KDIGO 2012) defines CKD as damage to the kidneys for 3 months or more, or abnormalities in the structure or functions of the kidneys, with or without decreased GFR, or with or without damage to the kidneys. Patients with chronic kidney disease may present with either some degree of decreased renal function or severe chronic renal failure, (Arora 2020)

Chronic kidney disease is a common form of kidney disease. CKD is associated with an increase in cardiovascular risks, which increases the risk of developing End stage kidney disease. Damien, Lanham, Parthasarathy & Shah (2016) in a study to assess the key cost drivers associated with caring for patients with CKD, found 90% of patients with CKD had hypertension, 44% diabetes and 61% had heart disease. An analysis of CURE-CKD registry by Tuttle et al., (2019) found two thirds of the patients with chronic kidney disease had

hypertension, and diabetes. Patients who present with CKD may have other comorbidities affecting their health, or had previous AKI which complicated to CKD.

Chronic kidney disease is a lifelong disease necessitating long term care, which makes the patient to become a key player in his care. Onge et al., (2013) found out that management of CKD poses ongoing challenges among health care professionals, and patients suffering from it have to bear the responsibility of managing themselves. Effective management depends on the person's performance as they are needed to take responsibility for their care. Fostering self-care through supporting self-efficacy of the patient may produce long term benefits, (Fraser & Blakeman 2016). This is dependent on self-management.

2.4 Self-management

Self-management is the care which individuals undertake to maintain their health and wellbeing, (Barlow et al., 2002). Self-management does not only include symptom management and treatment of the chronic conditions but also the physical and psychosocial support including the advancement of changes in lifestyle. Self-management is not simply giving health educational sessions or providing information but individuals undertake self-management in order to lead a healthy life as they address their physical, psychological, social, and emotional needs, (Kenning et al., 2015)., It is the ability of a person to manage his condition.

Self-management is the decision, strategies and activities individuals undertake to manage long-term health conditions, (Boger et al., 2015). These strategies are the tasks an individual will strive to undertake in order to modify the course of a chronic illness. They include taking medications, reducing weight, cessation of smoking, reducing of alcohol consumption and increasing physical activity, (Sharaf, Salem & Abdulaziz 2016). In addition, the patient should be able to monitor and manage himself. He should have the ability to monitor his weight, blood

pressure and blood sugar which creates and maintains new healthful behaviors, (Welch et al., 2015). Adjustments should be made by the patient to ensure he maintains his normal hemodynamic status.

Patients have to be supported during illness to manage their emotions. This requires them to deal with feelings of despair, fear, frustration and anger which cause depression, (Javalk et al., 2014). This will help in adjusting to living with a chronic illness. Therefore, patients should receive social and psychological support. This will help them live positively by taking care of their mental and physical health, (Havas, Clint & Bonner 2017). The individual has to strive and actively participate in self-management to optimize health and reduce complications.

Patients presenting with CKD have improved health outcomes during self-management. Bonner et al., (2014) found out that self-management behavior can help to slow down CKD progression. The progression is slowed because the risk factors to further organ damage is slowed or even halted. This will lead to a delay in disease progression and improved life expectancy. Similarly, Lin et al., (2013) found that self-management improves health outcomes and increases the quality of life. Self-management behaviors may delay CKD progression which reduces morbidity. Dhea et al., (2019) found that patients on self-management had good adherence to treatment. This reduced the number of patient hospitalizations. Furthermore, Garofalo et al., (2018) found that there was a decrease in blood pressure after moderate restriction of daily intake of sodium. This resulted in improved cardiac functions.

Self-management of the patients improves urinary excretion. Donald et al., (2018) found that self-management interventions decreased urinary excretion of proteins. The decrease in excretion of the proteins is related to further reduction of risk factors that damage the glomeruli. In addition, patients who perform self-management have a reduction in the levels of blood glucose

and blood pressure, (Peng et al., 2019). This helps increase the capacity to carry out exercises and improves kidney function which reduces hypertension and diabetes, the main risk factors of CKD progression.

The patients should be able to effectively self-manage themselves during all stages of CKD. There should be a focus on early stages to improve CKD prognosis and delay progression to ESRD, (Bonner, 2014). This will help improve health outcomes and lower the burden on healthcare systems. Welch (2015) concludes that patients should be motivated to effectively manage themselves. This will slow down the disease progression, and reduce the number of emergency admissions and hospitalization.

2.5 Health education

Health education is the knowledge and understanding of health related issues. Mishra (2017) defines health education as social, intellectual and psychological dimensions that help someone make an informed choice. This directly affects a person's life. Health education is not merely information dissemination but involves fostering skills and motivation to articulate health issues, (Hou 2014). This will help the patient make informed choices about their health actions.

Health education is effective in improving people's health and promoting a person's wellbeing and quality of life. Health education has a goal of promoting, maintaining and improving the health of individuals and communities, (Capozzi 2018). This is done through health education programs. To adopt healthy behaviors, health education should be provided to gain information, knowledge, and skills, (Kumar & Preetha 2012). This helps individuals and communities increase their knowledge and attitudes towards their health.

Health education helps in empowering people to define their health problems, set priorities and look for solutions about their health problems. Health care providers who provide education to

their patients should help them understand the condition better and enable them to interact with the healthcare industry, (Kennedy et al., 2017). Increasing patient health education improves the health outcome of the patient. The end goal of strong patient education is to increase the health literacy of the patient in order to help him get engaged in shared decision making and self-management behaviors (Packard & Paakkari 2012). Health education helps the patient understand the choices and consequences of his actions.

Health literacy and health education are closely interconnected. Stars (2018) defines health education as an outcome of health educational activities, policies and interventions which increase the health literacy of the patient. Health literacy helps to define learning outcomes delivered from health education interventions, (Paakkari & Paakkari 2012). Health education helps increase the patient's ability to engage with health care systems and improves health literacy.

2.6 Health literacy

Health literacy is the ability of a person to engage with health information and services. Health literacy is defined by the WHO (2016) as the ability of a patient to obtain, process, and comprehend basic health information and services in order to make informed choice. Moreover, health literacy is more than just reading and writing. Sorensen et al., (2012) defined health literacy as possession of literacy skills, which is reading and writing, where the patient is motivated and competent to access, understand and utilize health information. Health literacy promotes self-management. Health literacy plays a mediating role between health and education which is essential in promoting self-management and has different challenges for health education, (Stars 2018). Health education can improve health literacy. Health literacy can be

used as a measure to evaluate the outcome of health education, (Nutbeam 2015). This is important in measuring the level of knowledge which has been acquired by the patient.

There is a difference in the level of health literacy skills. Nutbeam, McGill and Premkumar (2017) and Ishikawa et al., (2018) categorized HL into functional, interactive and critical literacy levels. The patient's ability to make decisions is dependent on the literacy level. Functional literacy is the basic skills used to obtain accurate information on health risks, (Bouya et al., 2018). This includes using medication and health care services. On the other hand, functional health literacy is described as basic skills for individuals to obtain health information and use of the knowledge on prescribed activities, (Ishikawa et al., (2018). Basic skills are important for patients to understand some information required during management.

Interactive health literacy helps patients get meaning in health information. It deals with advanced literacy skills for individuals to understand the meaning of the available information to help in making decisions, (Ishikawa et al., 2018). Furthermore, communication between health care providers and the patient is important during care. Interpersonal communication between health providers and the patient will lead to a patient receiving factual information, (Parmer et al., 2015). This increases patient participation through patient voicing concerns and provider checking patient understanding.

Critical health literacy deals with the analysis and use of information to control, and support life events affecting patients. Sykes, Willis. Rowlands and Popple (2013) describe critical health literacy as the ability of a patient to critically analyze all the available options in his care. This will help him to choose the most feasible option to take. Similarly, Broder et al., (2018) defined critical health literacy as the ability of a patient to analyze available information which increases his participation in making decisions. This ensures a patient makes an informed decision and it is

therefore necessary to assist the patient follow treatment recommendations. Interventions should be designed to facilitate a multidimensional concept of health literacy, (Indino, Sharp & Esterman 2019). This will further enable a patient to analyze health information and apply it to his health.

2.7 Assessment of health literacy in promotion of self-management behavior

Health literacy can be assessed in varied ways. As a result, different tools were developed and used in the assessment of health literacy in chronic diseases. These tools vary in the approach and design, with a few focusing on comprehensiveness in health literacy among populations. The Rapid Estimate of Adult Literacy in Medicine (REALM) tool focuses on recognizing words by assessing the ability of a patient to read and pronounce health related words. Patients are given words to read aloud starting from the easiest and progressing to the most difficult. They are then scored depending on the number of words correctly pronounced, (Kazley et al., 2015). The advantages of REALM tool include a short administration time and simplicity in the scoring, (Dumenci et al., 2013). It is a faster way to recognize the participant's reading ability. However, despite the tool being short, it may require much time during clinical studies, and does not assess understanding and listening skills, (Manganello et al., 2017). The patient is simply assessed on pronunciation of words.

The Test of Functional Health Literacy in adults (TOFHLA) is an assessment test tool designed to assess the health literacy of adults in a health care setting. The researcher asks the participant to read a total of 36 words from the easiest to most difficult about labels on prescriptions, diagnostic procedures, and medical terms. The total number of words correctly read is counted and grading provided with TOFHLA score of 0-16 being inadequate, 17-22 is marginal and 23-36 is adequate functional health literacy. This tool is not feasible for use in a clinical setting due

to limited time and may be difficult for older individuals than younger people, (Houston et al., 2018). This may be due to demands on knowledge, fluency in speaking and working memory that decline with age.

The Newest Vital Sign (NVS) is a brief, 6-item screening tool that was developed for assessing the ability of a patient to read and understand information on nutritional labels. The tool is used to assess whether a patient can perform tasks assigned to him, (Weiss 2018). A person is given oral questions and his responses are recorded on a sheet containing correct answers. The researcher assesses health literacy based on correct responses. The NVS tool is easy and quick to administer, but on the other hand, a single label is used to assess comprehension, where the wordings can be confusing while some participants may have difficulty in doing mathematics, (Saad, 2016). The ability of the patient to read and have numeracy skills does not mean that he understands the consequences and outcome of the choices he is going to make during his care.

The Health Literacy Management Scale (HeLMS) is an 8 scale with 4-5 items. The tool is used to measure the person's ability to seek, understand, and utilize health information within the health facility, (Jordan et al., 2012). The scale tests four dimensions: information acquisition, communication and interaction, willingness to improve health and economic support. The patient later gains knowledge of where to seek health information. The tool helps identify the individual's capacity to gain and utilize information with the focus lying on the patient and the family. The tool is used to assess a range of health literacy constructs for example how patient communicates with health care providers, use of health information and how the patient is proactive.

The Health literacy questionnaire is a multidimensional tool that explores health literacy in nine dimensions/scales and is composed of 44 items. The tool was developed using a theoretical

definition of health literacy by the WHO. The validation of the tool was done by Debussche, et al., (2018) on patients with diabetes and cardiovascular diseases who found the tool had internal consistency and reliability in all the 9 scales. Hawkins, Gill and Batterham, (2017) used a health literacy questionnaire to assess health literacy among CKD patients using the multidimensional approach. The tool can be used in standard surveys and outcome assessments to derive health literacy profiles. Nolte et al., (2017) noted that the tool had strong psychometric properties. It was used to facilitate the development of interventions, improve services and evaluate the outcomes of patients.

The Kidney disease knowledge (KIKs) was developed in the United States to assess CKD specific knowledge, (Wright et al., 2011). The tool was used to identify risk factors for poor kidney knowledge in non-transplant CKD patients. The tool measures the objective knowledge of kidney disease on self-care practices of the patients, identifies risk factors for poor kidney knowledge and preventive measures of CKD progression, (Park et al., 2018). It has a maximum score of 28, (Schrauben 2019). The score is determined as a percentage of the correct response. The KIKs tool was validated by Nguyen, Douglas & Bonner (2016) and it had a Cronbach alpha of 0.82. The tool has been used in a study by Wembenyui, Bonner and Clint (2016) to measure the level of kidney disease knowledge, where patients had limited knowledge about CKD. The study adopted this tool to measure the level of health literacy among patients with chronic kidney disease.

The Perceived Kidney/Dialysis Self-Management Scale (PKDSMS) is an eight item scale, a tool which was adopted from perceived medical condition self-management scale. It was formulated to assess the ability of a patient to perform CKD self-management (Chang, Hsieh & Tsai 2019). It was designed to measure perceived competences among CKD and dialysis patients and can be

modified for use in various chronic diseases (Wild, Wallston & Cavanaugh 2017). The tool was used among patients with HIV/AIDS, diabetes, and rheumatologic conditions. It uses a Likert response options range from 1 for strongly disagree to 5 for strongly agree. Total scores range from 8 to 40, the higher score represents greater perceived ability of patients to perform self-management activities on kidney conditions. The tool was validated by Wild, Wallston and Cavanaugh 2017 and found a Cronbach alpha of 0.83. The tool measures self-efficacy specifically related to CKD and helps to screen patients who are presenting with CKD or those receiving dialysis quickly in order to identify patients who have low perceived competence in self-management. The tool was adopted in this study to assess perceived self-management of individual participant with CKD who were either on dialysis or not.

Review of the tools was done to identify a tool that would be appropriate for the study. The study assessed the level of health literacy on kidney disease among patients using the kidney disease and knowledge survey tool, where patients were rated using percentages of the score they got. The study also looked at the effectiveness of targeted health education sessions on health literacy among CKD patients and found out the associations between health literacy and self-management behaviors among patients with CKD attending the renal unit. Self-management was assessed using the perceived kidney/dialysis self-management scale, where the score was calculated from a range of 8-40, with a higher score signifying higher level of self-management.

2.8 Level of health literacy on kidney disease among patients with chronic kidney disease

The patient should find a necessity of accessing, appraising and utilizing health related information during his management. This is affected by the level of health literacy of the patient. Different populations of patients with CKD have different level of health literacy during the course and duration of treatment which affects the uptake of health services. An assessment of

patients with CKD attending medical outpatient clinic on CKD knowledge in Malaysia showed that 71% had limited health literacy (Yann et al., (2019). This was not associated with gender, education level and duration of CKD diagnosis. Similarly, Bahadori, Najari and Alimohammadzadeh (2018) in a study among hemodialysis patients of Baharlu Hospital in Tehran found that 80% of the patients had limited health literacy. Patients with higher health literacy scores had better general health.

The socio-economic status of the patient also affects the uptake of services. In a study by Wong et al., (2018) among low income patients with CKD, the results showed that they had increased tobacco use, poor dietary habits and a low health literacy of 26%. This may have been due to inability of the patient to follow treatment recommendations due to inconsistencies in attending follow-up visits. Tuller et al., (2010) found that the cost of transportation to attend routine clinics was a potential barrier to treatment adherence among chronic disease patients. This may be due to lack of funds and competing demands between transport and other basic necessities. Health insurance status may also affect the uptake of services. Chisholm-Burns, Spivey and Pickett (2018) found that persons with a medical insurance cover had higher health literacy compared to those not insured at all. This may be attributed to increased accessibility of the services without much financial burden.

Inadequate health literacy leads to the patient having difficulty in understanding health information. This is because most doctors use medical terms when communicating with the patient. In examining the role of health literacy in patient knowledge and adherence in medical care among patient diagnosed with ESRD, Qobadi, et al., (2015) found out that 75% had some difficulty understanding and reading information. Patients with low level health literacy have lower kidney knowledge and may not understand the consequences of the choices they make.

The patient's awareness and knowledge may affect health literacy on self-management behaviors. Devraj et al., (2018) assessed health literacy using the Newest Vital Sign tool and found that 63% had low health literacy. Furthermore, a patient who had adequate health literacy had an increased level of knowledge and good self-management practices. In addition, Shrestha et al., (2018) through exploring disease-specific knowledge among patients with CKD in Nepal found 73% of the respondents had inadequate health literacy. Health literacy is strongly associated with patient knowledge about CKD. However, Bouya et al., (2018) found out that despite increasing awareness on CKD, 23 % of the patients had limited health literacy. Therefore awareness and knowledge about CKD did not translate to adequate health literacy

Adequate health literacy is associated with adherence of the patient to treatment and lowered treatment costs. Gardiner (2019), in a study on the effects of health literacy on treatment adherence and health optimism among patients with CKD found that 50% of participants who were non-adherent to medications had low levels of health literacy. The patients who have good adherence to medication are more likely to have better prognosis. Galura and Barton (2017) found that patients who had 100% adherence had a 37% risk reduction of developing ESRD. Adequate health literacy promotes greater knowledge on CKD which favors patient adherence to treatment.

Information, education and communication (IEC) materials should be availed for patients to read. There are limited resources which should reach high risk populations with relevant, useful and understandable information (Narva, Norton & Boulware 2016). However, IEC material displayed on notice boards and other places are not fully accessed by the patients. Gray et al., (2016) found 50% of patients after one year of follow up and sitting near the notice board displayed with IEC materials had low levels of health literacy. Therefore, providers should not

have an assumption that the patients will read and understand the information displayed on the board.

Conversely, some studies have shown that there is an adequate level of health literacy in some patients who regularly attend clinic. Tuot et al., (2019), in a study on CKD awareness among community dwelling adults with CKD found out that 83.1% had adequate health literacy. Similarly, Stomer, et al., (2019), found that 85% had adequate health literacy. This helped increase utilization of services. In addition, Dominic (2018) found that 75% of patients with advanced kidney disease had adequate health literacy. This may have been due to regular clinic attendance which offers an opportunity for health education and improves the health literacy of the patients.

Studies in hemodialysis and kidney transplant patients have reported better health literacy scores. Warsame, et al., (2019) evaluated health literacy among adult kidney transplant patients and found that 91% had adequate health literacy. Similarly, Wong et al., (2018) found 74% of patients undergoing hemodialysis had adequate health literacy. This may be due to three weekly visits to the renal unit for dialysis and patients on transplantation are closely followed up and intensive education provided to patient before undergoing transplantation.

2.9 Association between health literacy and self-management behaviors among patients with chronic kidney disease

Health literacy has an effect on the quality of life of the patients. This improves if the patients are knowledgeable on how to self-manage the disease. Moktan, Leelacharas and Prapaipanich (2019) found there is a relationship between CKD knowledge and self-management behaviors among pre-dialytic patients. Patients who had moderate health literacy had a higher level of self-management. Schrauben (2019) found that an increased level of self-care/management is

associated with higher objective scores in knowledge among ESRD patients who have adequate health literacy. This may be because sufficient health information improved their level of self-care.

The patient with adequate health literacy is knowledgeable about CKD prognosis and can perform self-care after acquiring adequate health information. Nguyen, Douglas and Bonner (2018) found that patients with adequate health literacy have significant improvement in knowledge on self-management activities. Moreover, patients with adequate HL have increased self-efficacy. Wang, Chen and Tsai (2019) found that self-care behavior was positively related to disease knowledge among elderly patients living with CKD. This may enhance the self-optimism of the patient, which will help the patient adapt to his situation and cope well with complications that may arise due to poor prognosis.

Individuals expect positive outcomes, which include improved physical and mental health. Gardiner (2019) explained that patients with adequate health literacy positively influenced health optimism and treatment adherence. This is because optimism may play an important role in accommodating stressful events and situations, which enhance self-management of the patient. Optimism is related to life satisfaction and perceived quality of life among patients with CKD, (Masood et al., 2017). This may be due to the ability of patients to cope with their condition. Furthermore, optimistic patients show resilience when confronted by a challenging situation.

Patients participate in managing CKD and other comorbidities like hypertension and diabetes by taking up responsibilities assigned to them by their health care providers. Patients develop resilience to help them cope with the stressors during diagnosing and management of CKD, (Roberti et al., 2018). Similarly, they should look for ways of coping with the diagnostic investigations and management of the condition. Agarwal and Malhotra (2019) defined resilience

as a process where an individual adapts to unimaginable stressful situations. Patients with adequate health literacy may develop resilience which will help in self-management interventions and this affects every patient irrespective of the level of education.

Optimizing wellness and health are critical goals for patients after kidney transplant. Health literacy has an important implication on wellness and health which reduce the negative outcomes after transplantation, (Chisholm-Burns, Spivey & Pickett, 2018). Adequate health literacy in kidney transplant patients promotes healthy behaviors. (Costa-Requena et al., 2017) found that patient with adequate health literacy had increasing levels of adherence to immunosuppressive therapy which prevents graft rejection. This improved the outcome of transplantation through self-management by the patient taking prescribed medications.

The level of education of a patient alone does not affect how he will adapt and perform self-management strategies. While patient education is necessary, it is not sufficient alone, but patient should be provided skills to facilitate behavior change, (Pearson, Mattke, Shaw, Ridgely & Wiseman 2007). Furthermore, Geboers et al., (2016) found that there was low self-management strategies in highly educated than low educated older adults. This may be due to the complexity of the diagnosis and use of medical terms in patient management which necessitates patient training on the skills to be performed.

Limited health literacy levels prevent the patients with CKD from engaging and making informed decisions about their health. Limited health literacy affects survival and increases waitlist mortality due to a lengthy evaluation process among patients with CKD, (Warsame et al., 2018). This may be due to multiple steps before the patient is booked for surgery which can be a barrier for patients with low health literacy. Furthermore, there is a relationship between the patient's clinical outcomes and health literacy. Taylor (2019) found out that adult patients with

ESRD who had inadequate health literacy had reduced accessibility to kidney transplantation. This may be due to the fact that patients with limited health literacy do not understand other treatment modalities and are not able to make choices of transplantation.

Some studies have equally shown that health literacy levels do not directly affect self-management practices but other factors influence the uptake of self-care. Levine et al., (2017) found there was no difference in health care utilization outcomes among low and adequate health literacy groups. This does not affect adherence to treatment. Similarly, Wong et al., 2018 found that lower medication adherence is not associated with health literacy. To engage in self-care behaviors, adequate skills may also be needed in addition to acquiring disease-related knowledge

2.10 Effectiveness of targeted health education sessions on health literacy in self-management among patients with chronic kidney disease

During the early stages of CKD, patients are advised to take medication and change their lifestyle in order to reduce the risk of CKD progression, while those in advanced stages are advised to prepare for renal replacement therapy or conservative management. The motivation to actively engage in care is influenced by the patient understanding the risks of disease, and the benefits of different treatment modalities.

The intention of self-management education is not only to make patients live better but also improve patient prognosis. It also reduces the cost of managing the disease by increasing patient's skills, knowledge and understanding to deal with the illness, (Mahjubian, Bahraminejad & Kamali 2018). This may help improve patient outcome. Moreover, knowledge of CKD helps increase their active participation in their own care, (Ann, Lynch & Vincerooy 2019). This may help increase self-management interventions. Therefore, there is need for patients with CKD to

have an understanding of their condition and how to manage themselves, (Narva, Norton & Boulware 2016). This is necessary during planning for patient care to enhance self-management. Adequate health literacy is essential during self-management of the patient. Zimbudzi et al., (2019) found that patients with high level of knowledge and skills are keen to take action which help in slowing down the progression of kidney disease. It is therefore important to increase patient knowledge on CKD. Patients educated about the disease are likely to follow proper treatment, cope better, and participate in healthcare decision- making, (Yann, Shiun, & Goh 2016). This helps to increase self-management activities.

Patients with CKD have similar challenges which affect their health literacy. Stomer et al., (2019) found that patients have the same health literacy levels with the same challenges irrespective of the type and stage of the disease. This makes them vulnerable to deficient knowledge which reduces health literacy. Lederer et al., (2015) found that 28% of patients did not understand the physician's explanation of medical terms and got confused during a lengthy discussion. During the management of a patient, care and education should target individual needs at that time. Therefore, health providers should tailor communication to individual patients according to their needs and level of understanding, (Lederer et al., 2015). This will help patients understand health information and help improve health literacy.

Patients need support from peers during health education sessions. They benefit from group learning which reduces the drawbacks of each treatment modality, (Cassidy et al., 2018). Moreover, group discussion is an effective way of learning how to promote health literacy. Mahjubian, Bahraminejad and Kamali (2018) found holding group discussions improved health literacy and reinforced self-management among hemodialysis patients. A successful form of informal education is learning in a group and supporting one another, (Wongwiseskul &

Chinnapan 2014). It may be appropriate to ask others what they do in order to maintain their health through changing lifestyle and managing uncomfortable symptoms.

To make an informed decision, patient should be provided with education, but these interventions are limited due to the timing of education sessions. The more time the patient has to acquire knowledge, the better the clinical outcome, (Bosch, Warren & Rutherford 2015). Limited time availability during routine clinic visits affects CKD education provided to the patient, (Narva, Norton & Boulware 2015). Therefore, patients encourage attending group classes outside clinic time as they wait to be served, (Cassidy et al., 2018). Outside clinic time is appropriate to avoid interruptions during sessions as patients need time and continuous education sessions to share personal experiences with peers

Continuous education is necessary for the patient to ensure that he understands the disease prognosis. Many patients with CKD have lower perception on susceptibility to the disease because of the asymptomatic nature of early CKD, which limits their motivation to seek CKD knowledge, (Narva, Norton & Boulware 2015). This makes patients not ready to receive all information at once. Aggarwal and Meel (2018) emphasized the need for the provision of continuous education to increase knowledge on medication and improve their adherence to treatment. This was important in ensuring medication adherence in chronic kidney disease patients. Moreover, repeatedly providing education sessions using different teaching styles may be effective in maintaining the knowledge of the patient, (Gray et al., 2016). Education combined with training in self-management behaviors helps the patient become a partner in advocating for his care.

2.11 Gaps in literature review

From the literature review, there was still scarce information on health literacy. In East Africa one study has been documented in Tanzania on the prevalence of CKD. No documented data on any research which had been done in Kenya on the effectiveness of health education on health literacy among patients with chronic kidney disease and neither had the research been done in Kenyatta National Hospital. There was, therefore, a need to carry out a study at KNH on health literacy and self-management among CKD patients

2.12 Theoretical framework

The study adopted the self-care deficit model of nursing by Dorothea Orem's as a conceptual framework to evaluate the self-management of patients. Dorothea Orem began her work in 1959 and made her publication in 1971. She revised her work until 2001. Dorothea Orem's theory defines Nursing as the art of assisting others in providing and managing self-care in order to maintain or improve the functioning of human. The goal of nursing is to ensure that the patient meets self-care needs and control, stabilizes and minimizes the effects of chronic poor health or disability, (Duke 2002). The focus of Nursing is on the ability of an individual to perform self-care, which is the practice of activities that individuals will initiate and perform on their own behalf to facilitate in maintaining their health and wellbeing.

According to Orem, the model comprises of three interrelated theories. This includes the theory of self-care, self-care deficit and theory of nursing system. Theory of self-care focuses on activities undertaken by an individual independently to sustain his wellbeing, (Teston et al., 2017). The study adopted self-care to entail the ability of an individual diagnosed with CKD to adhere to treatment and preventive services and also learn how to live with the effects of pathologic conditions. This is important during the disease process as the patient is supposed to

perform lifestyle modifications and make a follow-up in the clinic. Patients require nurses' service when they have some limitations in the provision of self-care during rehabilitation services.

Self-care deficit comes about when the patient cannot sufficiently address self-care demands. She describes this when nursing is needed and how a patient can be helped through nursing. This involves acting for or doing for the patient, guiding the patient, offering support and providing an environment that will help to promote personal development to help patients to meet future goals and also help in teaching the client, (Gordon, Walker & Carrick-Sen 2014). The nurse is supposed to establish deficits and take appropriate actions to address the demands of an individual. In this study, a patient has a self-care deficit when he has low levels of health literacy to undertake self-management at home or at the facility and is not able to adhere to all treatment regimens. The nursing system includes the art of providing nursing care that restores an individual's self-care abilities while dealing with therapeutic self-care needs, (Baulita 2010). This will include assessment of health literacy and offering education sessions to the patient depending on their needs.

Orem's theory describes nursing interventions in three categories; wholly compensatory where an individual is not able to engage in self-care actions. This requires him to fully depend on others as he is unable to care for himself, during his continued existence and wellbeing. In partly compensatory, an individual can partly meet some of the self-care needs but requires nurse's assistance in taking care of manipulative tasks or other ambulation. In supportive education, an individual can take responsibility for his self-care, meet self-care needs but will require minimal assistance to gain knowledge and make decisions, (Abou-hafs 2018). The nurse offers

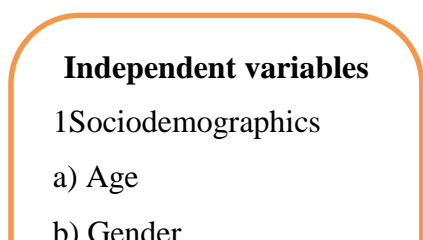
consultancy services through teaching. The study recommends patients to be offered continuous education and support to reduce risk factors which can worsen prognosis to ESRD.

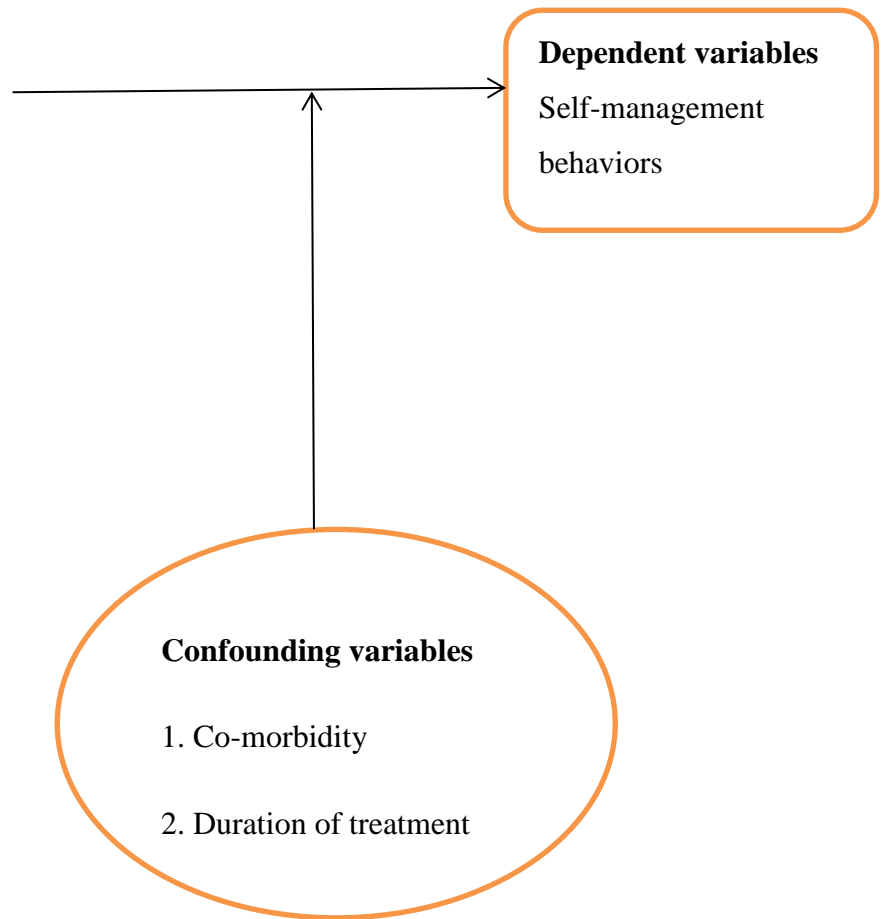
CKD is a condition in which the patients need to learn and take care of themselves by participating in their care. The study demonstrates the patient's self-management abilities by adhering to prescribed care and management. Recommendations have been made on the utilization of nursing systems in order to reinforce a patient's self-care agency which is the ability of the person to engage in self-care.

The study adopted research variables as follows; the dependent variable was self-management behaviors while the independent variables included health education and health literacy. Confounding variables included the presence of comorbidities and duration since diagnosis.

2.13 Conceptual framework

Figure 1 Conceptual framework





3.0 CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter provides a review of the methods used to carry out a successful study. The major concept highlighted includes the study design, study area and the study population. The chapter also describes the sample population, sample size calculation, sampling technique used and the study instruments, which were used for collecting data. Data management process, dissemination plan and the limitations are also discussed.

3.2 Study design

The study utilized a quasi-experimental study design among patients with chronic kidney disease to assess participants who were provided targeted health education sessions against those who received standard health education provided at the facility. The study population was identified and given a questionnaire to complete. Health literacy was measured using the Kidney disease knowledge survey (KIKs) tool while self-management was assessed using perceived kidney disease/dialysis self-management scale. Later the sample population was divided into two groups. A targeted group health education session was administered to one group while the other group received standard health care protocol sessions offered by service providers (staff). The two groups were later assessed using the Kidney disease knowledge survey (KIKs) tool and perceived kidney disease/Dialysis self-management scale to evaluate the outcome.

3.3 Study area

The study was conducted in the renal unit at the Kenyatta National Hospital (KNH). This is the biggest national referral facility in the republic of Kenya. Patients with complicated conditions who need specialized care that cannot be managed in the lower level facilities are referred from

across the country to seek care at KNH. Patients with renal conditions across the country also come for the services as KNH has a renal unit with specialized personnel who are running the unit, and attends to approximately 30 patients per day, (Kenyatta National Hospital 2015). The study population was the specific group within study area which was relevant to the present study. The target population was patients above 18 years attending renal unit at Kenyatta National Hospital for chronic kidney disease management who had met the inclusion criteria.

3.4 Sampling and Sample size calculation

3.4.1 Sample size calculation

Sample size determination and formula used

KNH renal unit attends to approximately 30 patients daily. The researcher adopted the (Krejcie & Morgan, 1970) formula

$$n_0 = \frac{X^2 * N * P * (1 - P)}{(ME^2 * (N - 1) + (X^2 * P * (1 - P)))}$$

n_0 = sample size

X^2 = Chi-square for the specified confidence level set at 3.8708 since the confidence interval is 95%. The confidence level is the probability that a measured quantity will fall within a given confidence interval.

N= Population size of 240

p= Population proportion (.50 in this case)

ME=desired margin of Error (expressed as a proportion). The margin of error statistic was expressed as the amount of random sampling error in a survey's results (0.08 in this case).On substitution of values,

$$n_0 = \frac{3.8708^2 * 240 * 0.50 * (0.50)}{(0.08^2 * (240 - 1) + (3.8708^2 * 0.50 * (0.50))}$$

$n_0=93$

The sample size was 93

3.4.2 Inclusion criteria

- All patients with chronic kidney disease who attended renal unit
- The patient were 18 years and above
- Gave an informed consent

3.4.3 Exclusion criteria

- Patients who had cognitive impairment and were unable to give informed consent
- Patients who were very sick, and needed immediate attention.

3.4.4 Sampling method

Non probability purposive sampling method was employed. All participants who undertook the study were patients with CKD, attending renal unit at KNH.

Participants were recruited daily and a separate list of those who had participated was made to avoid participant bias. On a daily basis, a list of all participants who had consented and willing to participate in the study was written down continuing from the last number of the previous day and the sampled population completed the health literacy and self-management tools. Later the group was divided into two, one group (case) was offered targeted health education session and the other control group received standard health care protocol sessions offered by service providers (staff) attending to the clients at the facility. The group which was offered targeted health education was selected through systematic random sampling from a sample of participants. This depended on the number of participants who consented daily. The sampling

interval was first calculated by dividing the total number of participants (93) by the number we wanted in the sample (30). In this case, the sampling was 4. In every 4th participant, 1 participant formed a population which was provided targeted health education and 3 participants formed a population provided with standard health care protocol. A number was selected randomly between 1 and 4 in the list of sampled participants, which may have been 3. Participant number 3 was the first participant selected. The next participant to be selected was the 4th participant from number three. This means from the 3rd participant, the next would be 7th, then 11th until the whole list was completed and desired sample of 30 participants achieved. This sample only received targeted health education session in groups. The remaining participants formed the control group who received standard health care sessions which is provided at the facility. Daily, the two identified groups were interviewed, until the entire sample was achieved.

Kidney disease knowledge survey (KIKs) tool was used to find out the level of health literacy and the Perceived kidney disease/Dialysis self-management scale used to assess self-management practices among both groups of participants before and after the intervention.

The intervention group was grouped in a group of six according to their age cohorts, and a targeted group health education session on the basic information about CKD was provided to help patients gain knowledge on CKD.

Follow up of the two groups was done after 1 month where health literacy was assessed by measuring the changes in CKD knowledge using kidney disease knowledge survey (KIKs) tool and results compared with the initial study. Self-management was assessed by measuring perceived self-management and motivation levels using Perceived kidney disease/Dialysis self-management scale.

3.5 Data collection instruments

The study used standardized questionnaires which comprised of three sections. A socio-demographic questionnaire collected data of the participants. Health literacy was assessed using the Kidney Disease Knowledge Survey (KIKs) tool. The score was determined by getting a percentage of the correct response. Kidney disease knowledge survey tool was modified, where some difficult questions were omitted from the questionnaire. The questionnaire was pretested at KNH hospital ward 7A, among 10 in-patients with chronic kidney disease. The tool was validated among chronic kidney disease patients and had a Cronbach's alpha of 0.8.

Self-management was assessed using the Perceived kidney disease/Dialysis self-management scale which assessed the patient's perceived ability to self-manage their condition. Response options ranged from 1 for strongly disagree to 5 for strongly agree. The tool had been previously used and validated by Wild, Wallston and Cavanaugh (2017) among patients with CKD and found a Cronbach alpha of 0.83

3.6 Data collection procedure

The researcher administered the questionnaire with the help of research assistants (2 nurses from different departments). Data collection started at 8 am in the morning targeting patients who had come to the unit. Participants who participated in the study met the inclusion criteria and signed an informed consent. The sampled population completed the socio-demographic questionnaire.

The researcher got a list of all participants who had consented to participate in the study, divided them into two groups and made a list of the two groups.

The kidney disease knowledge survey (KIKs) tool was used to find out the level of health literacy and the Perceived kidney disease/Dialysis self-management scale used to assess self-management practices among both groups of participants. The intervention group was put in a

group of six, and provided targeted group health education session on the basic information about CKD to help patients gain knowledge on CKD. A session took a maximum of one hour where a teach-back (show me) method was used to ensure the patient understood. The researcher was available to oversee the whole process and ensure that research assistants were providing the respondents with accurate information through constant review of the filled questionnaires.

A follow up of the two groups was done after 1 month. Health literacy was assessed by measuring the changes in CKD knowledge using kidney disease knowledge survey (KIKs) tool and results compared between the two groups. Participants with higher educational scores were considered to have gained in health literacy. Self-management was assessed by measuring perceived self-management and motivation levels using Perceived kidney disease/Dialysis self-management scale where the score was calculated from a range of 8-40, with a higher score signifying higher level of self-management

3.7 Data management and statistical analysis

Sorting and editing of questionnaires for completeness was done by the researcher with the help of a qualified statistician to ensure they were accurate and complete. Questionnaires which were incomplete were excluded and the data entered in the Statistical Package for Social Scientists (SPSS) version 25 for analysis.

Descriptive statistics was used to describe the socio-demographic characteristics of the sample population. The variables included age, marital/education status which was analyzed using percentages and outcome presented in form of tables. Level of health literacy was assessed using continuous data by getting the mean and standard deviation.

To determine the association between health literacy and self-management behaviors among patients with chronic kidney disease, chi square was used and the P-value was less than 0.05

Two samples T-test was used to get the difference between the population provided a targeted health education session and the group which was provided with standard health care sessions. There was a statistical significance where the calculated t exceeded critical t value at 0.05.

3.8 Ethical consideration

Review of the proposal, clearance and approval to conduct the study was sought by presenting the study proposal to The University of Nairobi- Kenyatta National Hospital Ethics and Research Committee (KNH/ UoN- ERC) who approved the research. Reference number is P101/102/2020. Clearance to conduct the study was obtained from KNH department of research. Both verbal and written consent was sought from KNH administration and the participants. The study was non-invasive and participants' privacy and confidentiality was observed throughout the study by ensuring personal data was kept safe in a lockable cupboard and data in computer was protected with a password.

3.9 Study findings/ dissemination plan

The study findings will be presented as a thesis in partial fulfillment of the requirements for the award of Masters of Science in Renal Nursing Degree of The University of Nairobi, which will be available in the University repository and a hard copy will be available in the library.

The report will be published in medical journals and will also be presented in scientific conferences like seminars and symposiums. The summary of results/ recommendations will be presented to staff at Kenyatta National Hospital renal unit/ clinics and relevant authorities at KNH in order to inform decisions and policy which may lead to an improvement in the self-management of patients.

4.0: CHAPTER FOUR: RESULTS

4.1: Introduction

The study was conducted to assess the role of health literacy in promoting self-management practices among patients with chronic kidney disease. The objectives that were being investigated included assessing the level of health literacy on chronic kidney disease, to evaluate the effectiveness of targeted health education group sessions on health literacy in self-management practices, and to determine the association between health literacy and self-management behaviors among patients with chronic kidney disease. The data collection process began on 28th July 2020, and was concluded by 28th September 2020, which took a period of two months. Approximately fifteen respondents were recruited daily, participants were divided into two groups and a list of the two groups made. The intervention group was put in a group of six, and provided a targeted group health education session after completing the questionnaire. A follow up of the second group was done after 1 month from 31st August 2020 till 28th September 2020. A total of 96 participants were recruited, who were issued 96 questionnaires but 93 questionnaires were completed, representing a response rate of 97%. These were included in the analysis. A pilot study was performed at KNH ward 7A (renal medical ward), among 10 in-patients with chronic kidney disease. 3 questions (medications which could be prescribed that patients with CKD should avoid, what GFR stands for and does kidney disease keep your red blood cells normal) were difficult for the patient to understand and therefore were removed from the questionnaire. The tool was validated among chronic kidney disease patients and had a Cronbach's alpha of 0.8

4.2 Socio-demographic characteristics

Majority of the respondents who were interviewed were married at 58 (61.7%), 51 (39.1%) respondents have some form of employment, with 69 (75.4%) having a health insurance cover and only 1 (1.1%) had never attained any level of basic education as summarized in table 1.

Table 1. Socio-demographic information

| | | Frequency | Percentage |
|-----------------------|---------------------|-----------|------------|
| Gender | Male | 59 | 62.8 |
| | Female | 35 | 37.2 |
| | Total | 94 | 100.0 |
| Marital status | Single | 25 | 26.6 |
| | Married | 58 | 61.7 |
| | Widow/widower | 5 | 5.3 |
| | Divorced/ separated | 6 | 6.4 |
| | Total | 94 | 100.0 |
| Education status | Primary | 30 | 32.3 |
| | Secondary | 42 | 45.2 |
| | College/university | 20 | 21.5 |
| | None | 1 | 1.1 |
| | Total | 93 | 100.0 |
| Employment Status | Employed | 15 | 16.3 |
| | Self Employed | 36 | 39.1 |
| | Unemployed | 41 | 44.6 |
| | Total | 92 | 100.0 |
| Presence of Insurance | Yes | 69 | 75.4 |
| | No | 23 | 25.5 |
| | Total | 92 | 100.0 |

4.3 Other medical conditions and duration of CKD

Respondents presenting with CKD had other medical conditions. According to the study, 53 (63.1%) presented with hypertension and 20 (23.8%) had diabetes. Most of the patients 40 (43.6%) had been diagnosed with CKD within one year as summarized in table 2

Table 2. Other medical conditions and duration of chronic kidney disease.

| | | Frequency | Percentage |
|------------------------------------|------------------------------|-----------|------------|
| Other Medical Conditions | Hypertension | 53 | 63.1 |
| | Diabetes | 20 | 23.8 |
| | Human immunodeficiency virus | 2 | 2.2 |
| | Hepatitis B | 2 | 2.2 |
| | Arthritis | 1 | 1.2 |
| | Cardiac Condition | 3 | 3.2 |
| | Cancer | 2 | 2.2 |
| | Total | 83 | 100 |
| Duration of Chronic kidney disease | Less than one year | 40 | 43.6 |
| | 1 to 2 years | 19 | 20.2 |
| | >2-< 5 years | 25 | 26.6 |
| | More than 5 years | 9 | 9.6 |
| | Total | 93 | 100.0 |

4.4.1 The level of health literacy and self-management

Health literacy is an individual's capacity to obtain, process, understand and use health information to make health related decisions and actions for themselves. In this study health literacy was assessed by ascertaining their response to several measures of health literacy according to the study tool. Most of the components on health literacy rated above 70%. The level of health literacy was measured by creating dummy variables for each of the health literacy variables and indicating 1 for the correct answer and 0 for a wrong answer. Summation of health literacy was 65.2, with an average health literacy developed resulting in a score of 0.704 which was converted to percentage. Therefore the level of health literacy in the survey was 70.4%.

An analysis of different components of health literacy was assessed by asking general questions about CKD and symptoms related to CKD. The study shows that, 57 (61.3%) of the patients understood that on average their blood pressure should be lower than 130/80. 65 (69.9%) confirmed that there are certain medications that can be prescribed to them in order to keep a

healthy condition. 56 (60.2%) confirmed that CKD increases a person's chance of getting a heart attack, while 80 (86%) of participants indicated that there was a chance of CKD increasing a chance of death from any cause. According to the respondents, in case of kidney failure, it can be seen from the survey that 64 (68.8%) of the patients will choose the kidney transplant, while 16 (17.2%) will choose hemodialysis as their treatment plan as summarized in table 3.

Table 3. Assessing the level of health literacy

| | | Frequency | Percentage |
|--|----------------------|-----------|------------|
| Average blood pressure | Greater than 170/100 | 21 | 22.6 |
| | 169/100-150/90 | 9 | 9.7 |
| | 149/89-130 81 | 5 | 5.4 |
| | Less than 130/80 | 57 | 61.3 |
| | Missing value | 1 | 1.1 |
| | Total | 93 | 100.0 |
| Medication prescribed | Yes | 65 | 69.9 |
| | No | 28 | 30.1 |
| | Total | 93 | 100.0 |
| Treatment in case of kidney failure | Lung biopsy | 1 | 1.1 |
| | Bronchoscopy | 3 | 3.2 |
| | Kidney transplant | 64 | 68.8 |
| | Hemodialysis | 16 | 17.2 |
| | Colonoscopy | 1 | 1.1 |
| | Missing value | 8 | 8.6 |
| | Total | 93 | 100.0 |
| Chronic disease increases a person's chance of heart attack | Yes | 56 | 60.2 |
| | No | 37 | 39.8 |
| | Total | 93 | 100.0 |
| Chronic kidney disease increases chances of death from any cause | Yes | 80 | 86 |
| | No | 12 | 14 |
| | Total | 92 | 100 |

In regards to the symptoms of chronic kidney disease, 79 (84%) of the respondents indicated that a patient with CKD would experience increased fatigue, with 73 (77.7%) indicating that the patient may experience shortness of breath as presented in table 4.

Table 4. Symptoms of chronic kidney disease

| Symptoms of chronic kidney disease | Response [n, (%)] | | N |
|------------------------------------|-------------------|-----------|----|
| | Yes | No | |
| Increased Fatigue | 79(84%) | 15(16%) | 93 |
| Shortness of breath | 73(77.7%) | 20(22.3%) | 93 |
| Unusual Itching | 64(68.1%) | 29(31.9%) | 93 |
| Nausea and/ vomiting | 69(73.4%) | 24(26.6%) | 93 |
| Increased trouble sleeping | 67(71.3%) | 26(28.7%) | 93 |
| Hair loss | 34(36.2%) | 59(63.8%) | 93 |
| Weight loss | 67(71.3%) | 26(28.7%) | 93 |
| No symptom at all | 17(18.1%) | 76(81.9%) | 93 |

4.4.2 Assessment of perceived self-management

Self-management is the care individuals undertake to maintain their health and wellbeing. Self-management was assessed by measuring perceived self-management and motivation levels using the perceived kidney disease/Dialysis self-management scale, where the score was calculated using a categorical scale from 8 to 40. The researcher first computed an average scale score of each questionnaire. Thereafter, a summation of all the averages was done before dividing the summation by the number of questionnaires to get the overall average scale at 0.49, which was converted to a percentage. This means that self-management was at 49% for all the respondents sampled.

An analysis of different components of self-management perception was assessed with majority of the respondents perceiving having some difficulties during their self-management, with 54 (58%) agreeing that it was difficult finding effective solutions to problems that occur in managing dialysis, 42 (45.1%) of the respondents disagreeing that they are able to effectively find efforts in changing things they don't like in their kidney disease as shown in table 5

Table 5. Assessment of perceived self-management

| Statements | Response [n, (%)] | | | | | N |
|--|-------------------|-----------|------------------------|-----------|----------------|----|
| | Strongly disagree | Disagree | Neither agree/disagree | Agree | Strongly agree | |
| When managing my kidney disease (dialysis), It is difficult finding effective solutions for problems that occur. | 15(16%) | 21(22.3%) | 4(4.3%) | 46(49.4%) | 8(8.6%) | 93 |
| It is ineffective to find efforts to changing things I dislike about my kidney disease (dialysis) | 10(10.6%) | 32(34%) | 7(7.4%) | 37(39.8%) | 8(8.6%) | 93 |
| With regards to my kidney disease (dialysis), am able to handle myself well | 1(1.1%) | 9(9.7%) | 7(7.4%) | 63(67%) | 14(14.9%) | 93 |
| I have the ability to manage things and people related to my kidney disease (dialysis) | 5(5.4%) | 20(21.5%) | 9(9.6%) | 53(56.4%) | 7(7.4%) | 93 |
| I am successful in the projects i undertake in managing my kidney disease (dialysis) | 4(4.3%) | 21(22.6%) | 10(10.6%) | 48(51.1%) | 11(11.7%) | 93 |
| My kidney disease (dialysis) management plans typically do not work out well | 13(13.8%) | 35(37.2%) | 7(7.4%) | 30(32.5%) | 9(9.7%) | 93 |
| Managing my kidney disease (dialysis) turns out the way I don't like, despite trying hard | 10(10.8%) | 27(29%) | 9(9.6%) | 40(42.6%) | 8(8.5%) | 93 |
| I have the ability to accomplish my goals regarding my kidney disease (dialysis) management | 8(8.6%) | 18(19.4%) | 3(3.2%) | 52(55.3%) | 13(13.8%) | 93 |

4.5 Association between health literacy and self-management behaviors

In the study, the researcher sought to determine if there is an association between health literacy and self-management behaviors among patients with chronic kidney disease. A multiple linear

regression was performed to ascertain the effects of average blood pressure, medication that can be prescribed by doctor to keep kidneys healthy, treatment in case of kidney failure, presence of stages of chronic kidney disease, if chronic kidney disease increases a person’s chances of heart attack and death from any cause on self-management behaviors among patients with chronic kidney disease.

The model explained 38.8% ($R^2 = 0.388$) of the variance in self-management behaviors among patients with chronic kidney disease but since we have more than one independent variable we will instead consider the adjusted R^2 and conclude that the model explains 24.5% of variation in self-management behaviors among patients with chronic kidney disease (Adjusted $R^2 = 0.245$) as presented on model summary in table 6.

Table 6. Model summary

| Model summary | | | | | | |
|----------------------|-------------------|----------|-----------------|---|----------------------------|---------------|
| Model | R | R Square | Adjusted Square | R | Std. Error of the Estimate | Durbin-Watson |
| 1 | .433 ^a | .388 | .245 | | .10792 | 2.190 |

To assess the level of significance, analysis of variance (ANOVA) was used. The regression model was statistically significant, (F-value = 2.967, with a $p \leq 0.012$) as summarized in table 7

Table 7. Analysis of variance (ANOVA)

| ANOVA^a | | | | | | |
|---|------------|----------------|----|-------------|-------|-------------------|
| Model | | Sum of Squares | df | Mean Square | F | Sig. |
| 1 | Regression | 3.457 | 6 | .576 | 2.967 | .012 ^b |
| | Residual | 14.956 | 77 | .194 | | |
| | Total | 18.413 | 83 | | | |
| a. Dependent Variable: Dialysis Self-Management | | | | | | |
| b. Predictors: (Constant), If chronic kidney disease increases a person’s chances of death from any cause, average blood pressure, medication that can be prescribed by doctor to help keep kidneys healthy, presence of stages of chronic kidney disease, treatment in case of kidney failure, and if increases a person’s chances of heart attack and death | | | | | | |

The study found out that, the presence of stages of chronic kidney disease, whether CKD increases chance of heart attack and death influenced the level of self-management as summarized in table 8 on coefficients.

Table 8. Coefficients affecting self-management

| Coefficients^a | | | | | | |
|---------------------------------|--|-----------------------------|------------|---------------------------|-------|------|
| Model | | Unstandardized Coefficients | | Standardized Coefficients | T | Sig. |
| | | B | Std. Error | Beta | | |
| 1 | (Constant) | 2.067 | .392 | | 5.269 | .000 |
| | Average blood pressure | -.025 | .038 | -.069 | -.666 | .507 |
| | Medication that can be prescribed by doctor to help keep kidneys healthy | -.018 | .106 | -.017 | -.167 | .868 |
| | Treatment in case of kidney failure | .138 | .090 | .161 | 1.538 | .128 |
| | Presence of stages of chronic kidney disease | .214 | .108 | .207 | 4.977 | .025 |
| | chronic kidney disease increases a person's chances of heart attack | .198 | .102 | .204 | 3.947 | .045 |
| | chronic kidney disease increases chances of death from any cause | .275 | .146 | .198 | 2.882 | .046 |

a. Dependent Variable: Dialysis Self-Management

4.6 Effectiveness of targeted health education sessions on health literacy in self-management practices among patients with chronic kidney disease

The researcher sought to find out if offering targeted health education sessions was effective in improving the level of health literacy in promotion of self-management among patients with CKD. 30 participants who were recruited from 93 participants were given targeted health education sessions in groups. Follow-up was done after one month on the 27 participants; the other 3 were lost to follow-up.

The initial survey before provision of targeted education session showed that 12 (44.4%) respondents indicated that normal blood pressure should be lower than 130/80 and 15 (55.6%) respondents acknowledged that there are medications which can be prescribed to patients who have chronic kidney disease. 20 (74.1%) respondents indicated that they would choose kidney transplant as a treatment modality in case of kidney failure while 11 (40.7%) would choose hemodialysis as presented in table 9.

Table 9. Assessing the level of health literacy

| | | Frequency | Percentage |
|--|-------------------|-----------|------------|
| Average blood pressure | 160/90 | 6 | 22.2 |
| | 150/100 | 3 | 11.1 |
| | 170/80 | 5 | 18.5 |
| | Lower than 130/80 | 12 | 44.4 |
| | Missing value | 1 | 1.1 |
| | Total | 27 | 100.0 |
| Presence of medication prescribed in treatment of chronic kidney disease | Yes | 15 | 55.6 |
| | No | 12 | 44.4 |
| | Total | 27 | 100.0 |
| Treatment in case of kidney failure | Lung biopsy | 1 | 1.1 |
| | Bronchoscopy | 0 | 0 |
| | Kidney transplant | 20 | 74.1 |
| | Hemodialysis | 11 | 40.7 |
| | Colonoscopy | 3 | 11.1 |
| | Missing value | 3 | 11.1 |
| | Total | 27 | 100.0 |
| Presence of stages of chronic kidney disease | Yes | 17 | 63 |
| | No | 10 | 37 |
| | Total | 27 | 100.0 |
| Chronic disease increases a person's chance of heart attack | Yes | 14 | 51.9 |
| | No | 13 | 48.1 |
| | Total | 27 | 100 |
| Chronic kidney disease increases chances of death from any cause | Yes | 11 | 40.7 |
| | No | 16 | 59.3 |
| | Total | 27 | 100 |

Chronic kidney disease may present with or without symptoms. According to the study, 12 (44.4%) respondents indicated that a person with CKD can present with increased fatigue while 11 respondents indicated that patients with CKD would present with shortness of breath, with 15 (55.6%) respondents indicating that the patient can present with nausea and vomiting and unusual itching as presented in table 10

Table 10. Symptoms of chronic kidney disease

| Symptoms of chronic kidney disease | Response [n, (%)] | | N |
|------------------------------------|-------------------|-----------|----|
| | Yes | No | |
| Increased Fatigue | 12(44.4%) | 15(55.6%) | 27 |
| Shortness of breath | 11(40.7%) | 16(59.3%) | 27 |
| Unusual Itching | 15(55.6%) | 12(44.4%) | 27 |
| Nausea and/ vomiting | 15(55.6%) | 12(44.4%) | 27 |
| Increased trouble sleeping | 12(44.4%) | 15(55.6%) | 27 |
| Hair loss | 9(33.3%) | 18(66.7%) | 27 |
| Weight loss | 13(48.1%) | 14(51.9%) | 27 |
| No symptom at all | 7(25.9%) | 20(74.1%) | 27 |

Patients presenting with chronic kidney disease have different perceptions on the effectiveness of self-management. In the study, 22 respondents perceived that they had difficulty in finding effective solutions and 14 respondents indicating that they find efforts in changing things they do not like about their kidney disease as summarized in table 11.

Table 11. Assessment of perceived self-management.

| Statements | Response [n, (%)] | | | | | N |
|---|-------------------|-----------|------------------------|-----------|----------------|----|
| | Strongly disagree | Disagree | Neither agree/disagree | Agree | Strongly agree | |
| When managing my kidney disease (dialysis), It is difficult finding effective solutions for problems that occur | 3(11.1%) | 2(7.4%) | 0 | 20(74.1%) | 2(7.4%) | 27 |
| It is ineffective to find efforts to changing things I dislike about my kidney disease (dialysis) | 1(3.7%) | 11(40.7%) | 1(3.7%) | 12(44.4%) | 2(7.4%) | 27 |
| With regards to my kidney disease (dialysis), am able to handle myself well | 0 | 10(37%) | 2(7.4%) | 13(48.1%) | 2(7.4%) | 27 |
| I have the ability to manage things and people related to my kidney disease (dialysis). | 1(3.7%) | 10(37%) | 3(11.1%) | 10(37%) | 3(11.1%) | 27 |
| I am successful in the projects I undertake in managing my kidney disease | 3(11.1%) | 7(25.9%) | 1(3.7%) | 12(44.4%) | 2(7.4%) | 27 |
| My kidney disease (dialysis) management plans typically do not work out well | 2(7.4%) | 7(25.9%) | 1(3.7%) | 14(51.9%) | 3(11.1%) | 27 |
| Managing my kidney disease (dialysis) turns out the way I don't like, despite trying hard | 1(3.7%) | 5(18.5%) | 3(11.1%) | 16(59.3%) | 2(7.4%) | 27 |
| I have the ability to accomplish my goals regarding my kidney disease (dialysis) management. | 2(7.4%) | 12(44.4%) | 4(14.8%) | 8(29.6%) | 1(3.7%) | 27 |

In the study, the group which received standard health care protocol sessions offered by service providers at the facility had a mean of 0.64 in health literacy before the intervention was instituted in the study, compared to 0.59 after the intervention respectively as summarized in table 12.

Table 12. Group statistics for health literacy

| Health literacy | Group | N | Mean | Std Deviation |
|-----------------|--------|----|------|---------------|
| | Before | 27 | 0.64 | 0.2 |
| | After | 27 | 0.59 | 0.14 |

The study also showed that the group provided standard health care protocol sessions by service providers at the facility, had a mean of 0.53 in self-management during the beginning of the study compared to 0.51 at the end of the study respectively as presented in table 13.

Table 13. Group statistics for self-management

| Self-management | Group | N | Mean | Std Deviation |
|-----------------|--------|----|------|---------------|
| | Before | 27 | 0.53 | 0.67 |
| | After | 27 | 0.51 | 0.69 |

After the intervention, 14 (51.9%) of the respondents indicated that on average the blood pressure should be less than 130/80, 21 (77.8%) respondents had medication that could be prescribed by doctor to keep their kidneys healthy. The majority 24 (88.9%) of the respondents needed a kidney transplant, 20 (74.1%) needed Hemodialysis, while 1 (3.7%) respondent needed colonoscopy and lung biopsy each in case they developed kidney failure. It can also be seen that 26 (96.3%) of the respondents indicated that there are stages of chronic kidney disease, 25 (92.6%) respondents indicating that there was a chance of developing a heart attack if chronic kidney disease worsened, and 25 (92.6%) respondents indicated that there are chances of death from chronic kidney disease as summarized in table 14.

Table 14. Assessing the level of health literacy

| | | Frequency | Percentage |
|--|-------------------|-----------|------------|
| Average blood pressure | 160/90 | 5 | 18.5 |
| | 150/100 | 3 | 11.1 |
| | 170/80 | 5 | 18.5 |
| | Lower than 130/80 | 14 | 51.9 |
| | Total | 27 | 100.0 |
| Presence of medication prescribed in treatment of chronic kidney disease | Yes | 21 | 77.8 |
| | No | 6 | 22.2 |
| | Total | 27 | 100.0 |
| Treatment in case of kidney failure | Lung biopsy | 1 | 1.1 |
| | Bronchoscopy | 0 | 0 |
| | Kidney transplant | 24 | 88.9 |
| | Hemodialysis | 20 | 74.1 |
| | Colonoscopy | 1 | 1.1 |
| | Missing value | 3 | 11.1 |
| | Total | 27 | 100.0 |
| Presence of stages of chronic kidney disease | Yes | 26 | 96.3 |
| | No | 1 | 3.7 |
| | Total | 27 | 100.0 |
| Chronic disease increases a person's chance of heart attack | Yes | 25 | 92.6 |
| | No | 2 | 7.4 |
| | Total | 27 | 100 |
| Chronic kidney disease increases chances of death from any cause | Yes | 25 | 92.6 |
| | No | 2 | 7.4 |
| | Total | 27 | 100 |

After offering of targeted health education sessions, 25 respondents said that the patient with CKD would present with increased fatigue, 23 respondents indicated that CKD may cause shortness of breath, and an increased trouble in sleeping, while 25 indicated that the patient with CKD may experience unusual itching as summarized in table 15.

Table 15. Symptoms of chronic kidney disease

| Symptoms of chronic kidney disease | Response [n, (%)] | | N |
|------------------------------------|-------------------|-----------|----|
| | Yes | No | |
| Increased Fatigue | 25(92.6%) | 2(7.4%) | 27 |
| Shortness of breath | 23(88.5%) | 3(11.5%) | 27 |
| Unusual Itching | 25(92.6%) | 2(7.4%) | 27 |
| Nausea and/ vomiting | 26(96.3%) | 1(3.7%) | 27 |
| Increased trouble sleeping | 23(88.5%) | 3(11.5%) | 27 |
| Hair loss | 12(44.4%) | 15(55.6%) | 27 |
| Weight loss | 25(92.6%) | 2(7.4%) | 27 |
| No symptom at all | 8(29.6%) | 19(70.4%) | 27 |

During assessment of patient's perception on self-management after provision of targeted group health education sessions among 27 participants, 15 (55.6%) respondents still perceived that it was difficult finding effective solutions for problems occurring during management of dialysis, but 19 (70.4%) respondents agreed that they find effective efforts to change things they don't like about their kidney disease. 21 (77.8%) respondents stated that they were able to handle themselves and others well with respect to their kidney disease, while 16 respondents are successful in projects undertaken in managing their kidney disease as presented in table 16.

Table 16. Assessment on perception of self-management

| Statements | Response [n, (%)] | | | | | N |
|---|-------------------|----------|------------------------|-----------|----------------|----|
| | Strongly disagree | Disagree | Neither agree/disagree | Agree | Strongly agree | |
| When managing my kidney disease, it is difficult to find effective solutions for problems that occur. | 3(11.1%) | 8(29.6%) | 1(3.7%) | 5(18.5%) | 10(37%) | 27 |
| It is ineffective to find efforts to changing things I dislike about my kidney disease (dialysis) | 0(0%) | 7(25.9%) | 1(3.7%) | 15(55.6%) | 4(14.8%) | 27 |
| With regards to my kidney disease(dialysis), am able to handle myself well | 2(7.4%) | 4(14.8%) | 0(0%) | 17(63%) | 4(14.8%) | 27 |
| I have the ability to manage things and people related to my kidney disease (dialysis) | 1(3.7%) | 4(14.8%) | 1(3.7%) | 19(70.4%) | 2(7.4%) | 27 |
| I am successful in the projects I undertake in managing my kidney disease (dialysis) | 1(3.7%) | 7(25.9%) | 3(11.1%) | 14(51.9%) | 2(7.4%) | 27 |
| My kidney disease (dialysis) management plans typically (dialysis) do not work out well | 4(14.8%) | 8(29.6%) | 1(3.7%) | 13(48.1%) | 1(3.7%) | 27 |
| Managing my kidney disease (dialysis) turns out the way i don't like, despite trying hard | 1(3.7%) | 6(22.2%) | 1(3.7%) | 18(66.7%) | 1(3.7%) | 27 |
| I have the ability to accomplish my goals regarding my kidney disease (dialysis) management | 1(3.7%) | 7(25.9%) | 2(7.4%) | 13(48.1%) | 4(14.8%) | 27 |

The study found after assessing the effectiveness of targeted health education sessions that the participants who received a targeted health education session had higher levels of health literacy (M =0.83, SD =0.01) than the population which was provided standard care in the facility (M =0.64, SD =0.2). The group demonstrated significantly higher scores, p = 0.038 as summarized in table 17. (M= mean, SD=standard deviation)

Table 17. Group statistics for health literacy

| Health literacy | Group | N | Mean | Std deviation | Levene's test of equality of variance | |
|-----------------|---------|----|------|---------------|---------------------------------------|-------|
| | | | | | Equal variance assumed | |
| | Group 1 | 27 | 0.83 | 0.01 | F | sig |
| | Group 2 | 27 | 0.64 | 0.2 | 7.156 | 0.038 |

After the intervention, the participants who received a targeted health education session had higher levels of self-management (M =0.68, SD =0.48) than the population which was provided standard care in the facility (M =0.53, SD =0.67). The group demonstrated significantly higher scores, p = 0.021 as summarized in table 18. (M= mean, SD=standard deviation)

Table 18. Group statistics for self-management

| Self-management | Group | N | Mean | Std deviation | Levene's test for equality of variance | |
|-----------------|---------|----|------|---------------|--|-------|
| | | | | | Equal variance assumed | |
| | Group 1 | 27 | 0.68 | 0.48 | F | Sig |
| | Group 2 | 27 | 0.53 | 0.67 | 3.276 | 0.021 |

5.0 CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

The study shows that majority of the respondents were married, with most of them having some form of employment and an insurance cover. The respondents therefore had some social support from their partners. The health insurance also reduced the cost of accessing services. This may have enabled the patients to keep appointments because they were only supposed to plan for transport and some money to be remitted to the insurance scheme in order to cater for the treatment costs. This correlates to a study by Wong et al., (2018) among medium income patients with CKD who found that over half of the patients had access to health care with high levels of health literacy. Similarly, Chisholm-Burns, Spivey & Pickett (2018) found that persons insured with a medical insurance cover had higher health literacy level compared to those with no insurance at all.

Patients with chronic kidney disease have other underlying health conditions. The study showed that, majority of the respondents had been diagnosed with CKD within one year, and most of them presented with hypertension and diabetes. This corresponds with a study by Campbell et al., (2016), where hypertension and diabetes were the main cause of kidney disease. Similarly, an analysis of CURE-CKD registry by Tuttle et al., (2019) found that two thirds of the patients with chronic kidney disease had hypertension, and diabetes.

The patient with CKD should be able to monitor and manage self. According to this survey, most patients understood the normal blood pressure (BP) reading. Patients also understood that there are medications that they are supposed to be taking in order to keep their kidneys healthy. This corresponds to a study by Welch et al., (2015), who found out that the patient should understand the normal BP readings and should be able to monitor his weight, blood pressure and blood sugar. In this study, more than half of the participants indicated that chronic kidney disease

would increase a person's chance of death. This correlates with a study by Taylor et al., (2018) who found that low health literacy level has adverse clinical events which increase in-patient hospitalization and death. The study also showed that majority of respondents indicated that CKD would increase a person's chance of developing a heart attack. This correlates with a study by Matsuoka et al., (2016) who found that there was risk of dying from heart attack among patients with CKD.

From the study, the average level of health literacy among patients with CKD was 70.4 percent. This findings corresponds to a study by Dominic (2018) who found that the level of health literacy among patients with CKD was 75%. Similarly, a study by Wong et al., (2018), among medium income patients with CKD found that the level of health literacy was at 74%. Moreover, Stomer, et al., (2019) found that 85% had adequate health literacy. In addition, Tuot et al., (2019), in a study on CKD awareness among community dwelling adults with CKD found that 83.1% had adequate health literacy.

Most of the respondents who participated in the study were patients undergoing hemodialysis or were attending renal transplant clinic sessions. This study correlates with a study by Warsame, et al., (2019) to evaluate health literacy level among adult kidney transplant patients who found that the level of health literacy was high. Similarly, Wong et al., (2018) found that patients undergoing hemodialysis had adequate health literacy. This may be due to two weekly visits to the renal unit for dialysis, or patients on transplantation are closely followed up. Patients who have low health literacy are often not booked and assessed for renal transplantation unless they show an increased understanding of the condition. This correlates with a study by Taylor (2019) who found that inadequate health literacy was associated with reduced accessibility to kidney transplantation among adults with ESRD. Conversely, Devraj et al., (2018) found out that

patients with CKD had low levels of health literacy. Similarly, Shrestha et al., (2018) in a study among patients with CKD in Nepal found respondents had inadequate health literacy.

Health literacy affects the quality of life of the patients and improves the outcome if the patients are knowledgeable about how to perform self-management. The study shows that there is an association between health literacy and self-management behaviors among patients with chronic kidney disease. This study corresponds with a study by Moktan, Leelacharas and Prapaipanich (2019) who found there was a relationship between CKD knowledge and self-management behaviors among pre-dialytic patients. In addition, Schrauben (2019) found that an increased level of self-management was associated with higher objective scores in knowledge among ESRD patients who have adequate health literacy. Patients with high level of health literacy showed enhanced self-optimism and resilience when confronted by a challenging situation, which helped them adapt and cope well with situations arising during their care. This correlates with a study by Gardiner (2019) who found that patients with adequate health literacy positively influenced health optimism and treatment adherence.

The level of health literacy of a patient alone does not affect how the patient will adapt and perform self-management strategies. Health literacy levels do not directly affect self-management practices but other factors influence the uptake of self-care. The survey found out that despite the level of health literacy being at 70.4%, the level of self-management was low at 49%. This correlates with a study by Levine et al., (2017) who found there was no difference in health care utilization among low and adequate health literacy groups. Similarly, a study by Wong et al., (2018) among low income patients with CKD, found that despite increased tobacco use and poor dietary habits, the level of health literacy was adequate. While adequate health

literacy is necessary, it is not sufficient alone. Patients should be provided continuous education to improve their self-management.

Kidney disease knowledge is important in engaging patients and ensuring adherence to treatment and self-management. In the study, we found that a planned and interactive targeted health education sessions provided to the 27 respondents in groups was highly effective, and increased the level of health literacy and self-management compared to the population that was provided the standard care at the facility. This correlates with a study by Lopez-Vargas et al., (2016) who found that a well-planned and designed, frequent and interactive educational session to individuals or groups improved patient knowledge. Similarly, Gray et al., (2016) found that repeatedly providing education sessions using different teaching styles effectively maintains the knowledge of the patient. The study also found that, group education sessions encouraged participants to learn from their peers on how they changed their lifestyle, and in management of symptoms which improved their level of health literacy. This compares to a study by Mahjubian, Bahraminejad and Kamali (2018) who found that holding group discussions improved health literacy and reinforced self-management among hemodialysis patients. In addition, Wongwiseskul and Chinnapan (2014) found that a successful form of informal education is learning in a group and supporting one another.

5.2 Conclusion

The level of health literacy among patients with CKD attending the renal unit was 70.4%. Most of the components on health literacy rated higher above 70%. Generally, both groups of participants were knowledgeable but, those who were provided with targeted education sessions rated higher. Self-management among patients with CKD is statistically significant to the level of health literacy. However, there are other factors which increase the patient's perception of

self-management. Continuous targeted health education sessions in groups significantly increased the respondent's perception on self-management behaviors.

5.3 Recommendation

Assessment of health literacy in promotion of self-management should be incorporated to patient's management during all stages of CKD, and continuous targeted health education sessions should be provided to patients in groups to help patients learn from one another and increase patient self-management. There is also a need to formulate a standardized tool for assessing the level of health literacy and self-management behaviors. Further research is necessary to find out how knowledge on the normal average blood pressure and treatment options in case of kidney failure influences self-management.

REFERENCES

- Abha S, Suman B. S, Vijay K. K, Sailesh B, Robin M, and Paras K Pok (2018). Health Literacy and Knowledge of Chronic Diseases in Nepal Health literacy, Research and Practice 2(4): e221–e230.doi: [10.3928/24748307-20181025-01](https://doi.org/10.3928/24748307-20181025-01)
- Abou-Hafs, A., 2018. Nurse´ s role in diabetes management: Challenges and facilitators.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48(2), 177–187. doi:10.1016/s0738-3991(02)00032-0
- Bo, A., Friis, K., Osborne, R.H. and Maindal, H.T., 2014. National indicators of health literacy: ability to understand health information and to engage actively with healthcare providers- a population-based survey among Danish adults. *BMC public health*, 14(1), p.1095.
- Boger, E., Ellis, J., Latter, S., Foster, C., Kennedy, A., Jones, F., & Demain, S. (2015). Self-management and self-management support outcomes: a systematic review and mixed research synthesis of stakeholder views. *PloS one*, 10(7), e0130990.
- Bouya, S., Allahyari, J., Hesarakı, M., Koochakzai, M. and Maleknejad, A., 2018. The Importance of Health Literacy in Patients with Chronic Kidney Disease: A Literature Review.
- Bowling, C.B., Vandenberg, A.E., Phillips, L.S., McClellan, W.M., Johnson, T.M. and Echt, K.V., 2017. Older patients’ perspectives on managing complexity in CKD self-management. *Clinical journal of the American Society of Nephrology*, 12(4), pp.635-643.
- Cassidy, B.P., Harwood, L., Getchell, L.E., Smith, M., Sibbald, S.L. and Moist, L.M., 2018. Educational Support around Dialysis Modality Decision Making in Patients with Chronic

- Kidney Disease: Qualitative Study. *Canadian journal of kidney health and disease*, 5, p.2054358118803323.
- Chironda, G. and Bhengu, B., 2019. Barriers to management of Chronic Kidney Disease (CKD) CKD in a renal clinic in KwaZulu-Natal Province, South Africa–A qualitative study. *International Journal of Africa Nursing Sciences*, 10, p.116-123.
- Chisholm-Burns, M. A., Spivey, C. A., & Pickett, L. R. (2018). Health literacy in solid-organ transplantation: a model to improve understanding. *Patient preference and adherence*, 12, 2325.
- Collister, D., Russell, R., Verdon, J., Beaulieu, M. and Levin, A., 2016. Perspectives on optimizing care of patients in multidisciplinary chronic kidney disease clinics. *Canadian journal of kidney health and disease*, 3, p.122.
- Dageforde, L. A., & Cavanaugh, K. L. (2018). Health Literacy: Emerging Evidence and Applications in Kidney Disease Care. *Advances in chronic kidney disease*, 20(4), 311.
- Damien, P., Lanham, H. J., Parthasarathy, M., & Shah, N. L. (2016). Assessing key cost drivers associated with caring for chronic kidney disease patients. *BMC health services research*, 16(1), 690.
- Debussche, X., Lenclume, V., Balcou-Debussche, M., Alakian, D., Sokolowsky, C., Ballet, D., Elsworth, G.R., Osborne, R.H. and Huiart, L., 2018. Characterization of health literacy strengths and weaknesses among people at metabolic and cardiovascular risk: Validity testing of the Health Literacy Questionnaire. *SAGE open medicine*, 6, p.2050312118801250.

- Devraj, R., Borrego, M.E., Vilay, A.M., Pailden, J. and Horowitz, B., 2018. Awareness, self-management behaviors, health literacy and kidney function relationships in specialty practice. *World journal of nephrology*, 7(1), p.41.
- Donald, M., Gil, S., Kahlon, B., Beanlands, H., Straus, S., Herrington, G., Manns, B. and Hemmelgarn, B.R., 2018. Overview of self-management resources used by Canadian chronic kidney disease clinics: a national survey. *Canadian Journal of Kidney Health and Disease*, 5, p.2054358118775098.
- Donald, M., Kahlon, B.K., Beanlands, H., Straus, S., Ronksley, P., Herrington, G., Tong, A., Grill, A., Waldvogel, B., Large, C.A. and Large, C.L., 2018. Self-management interventions for adults with chronic kidney disease: a scoping review. *BMJ Open*, 8(3), p.e019814.
- Dumenci, L., Matsuyama, R., Riddle, D.L., Cartwright, L.A., Perera, R.A., Chung, H. and Siminoff, L.A., 2014. Measurement of cancer health literacy and identification of patients with limited cancer health literacy. *Journal of health communication*, 19(sup2), pp.205-224.
- El Din, U.A.A.S., Salem, M.M. and Abdulazim, D.O., 2016. Stop chronic kidney disease progression: Time is approaching. *World journal of nephrology*, 5(3), p.258.
- Feinberg, Iris,. 2016, Health Literacy in High-Risk Populations. Dissertation, Georgia State University. https://scholarworks.gsu.edu/sph_diss/6
- Fraser, S.D. and Blakeman, T., 2016. Chronic kidney disease: identification and management in primary care. *Pragmatic and observational research*, 7, p.21.
- Galura, G. and Pai, A.B., 2017. Health Literacy and Medication Management in Chronic Kidney Disease. *HLRP: Health Literacy Research and Practice*, 1(3), pp.e109-e115.

- Hill, N.R., Fatoba, S.T., Oke, J.L., Hirst, J.A., O'Callaghan, C.A., Lasserson, D.S. and Hobbs, F.R., 2016. Global prevalence of chronic kidney disease—a systematic review and meta-analysis. *PloS one*, *11*(7).
- Inese Stars, 2018. Health literacy as a challenge of health education: SHS Web of Conferences 40, 02004 (2018) -<https://doi.org/10.1051/shsconf/20184002004>Int. Conf. SOCIETY. HEALTH. WELFARE 2016.
- Garofalo, C., Borrelli, S., Provenzano, M., De Stefano, T., Vita, C., Chiodini, P., Minutolo, R., Nicola, L.D. and Conte, G., 2018. Dietary salt restriction in chronic kidney disease: a meta-analysis of randomized clinical trials. *Nutrients*, *10*(6), p.732.
- Gordon, C., Walker, M. and Carrick-Sen, D., 2014. Diabetes knowledge in patients' adult offspring. *Nursing times*, *110*(26), pp.24-26.
- Gounden V, Jialal I., 2019 Renal Function Tests. [Updated 2020 Mar 31]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2020 Jan-.Available from: <https://www.ncbi.nlm.nih.gov/books/NBK507821>
- Gowshall, M., & Taylor-Robinson, S. D. (2018). The increasing prevalence of non-communicable diseases in low-middle income countries: The view from Malawi. *International journal of general medicine*, *11*, 255.
- Green, J.A., Mor, M.K., Shields, A.M., Sevick, M.A., Arnold, R.M., Palevsky, P.M., Fine, M.J. and Weisbord, S.D., 2013. Associations of health literacy with dialysis adherence and health resource utilization in patients receiving maintenance hemodialysis. *American Journal of Kidney Diseases*, *62*(1), pp.73-80.

- Havas, K., Douglas, C. and Bonner, A., 2017. Person-centred care in chronic kidney disease: a cross-sectional study of patients' desires for self-management support. *BMC nephrology*, 18(1), p.17.
- Heijmans, M., Waverijn, G., Rademakers, J., van der Vaart, R. and Rijken, M., 2015. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Education and Counseling*, 98(1), p.41-48.
- Hodel, N.C., Hamad, A., Praehauser, C., Mwangoka, G., Kasella, I.M., Reither, K., Abdulla, S., Hatz, C.F. and Mayr, M., 2018. The epidemiology of chronic kidney disease and the association with non-communicable and communicable disorders in a population of sub-Saharan Africa. *PloS one*, 13(10).
- Hoerger, T.J., Simpson, S.A., Yarnoff, B.O., Pavkov, M.E., Burrows, N.R., Saydah, S.H., Williams, D.E. and Zhuo, X., 2015. The future burden of CKD in the United States: a simulation model for the CDC CKD Initiative. *American Journal of Kidney Diseases*, 65(3), pp.403-411.
- Horino, T. (2020). Acute Kidney Injury: Definition and Epidemiology. In *Acute Kidney Injury and Regenerative Medicine* (pp. 3-20). Springer, Singapore.
- Housten, A.J., Lowenstein, L.M., Hoover, D.S., Leal, V.B., Kamath, G.R. and Volk, R.J., 2018. Limitations of the S-TOFHLA in measuring poor numeracy: a cross-sectional study. *BMC public health*, 18(1), p.405.
- Inese Stars, 2018. Health literacy as a challenge of health education: SHS Web of Conferences 40, 02004 (2018) -<https://doi.org/10.1051/shsconf/20184002004>Int. Conf. SOCIETY. HEALTH. WELFARE 2016.

- Ishikawa, H., Yamaguchi, I., Nutbeam, D., Kato, M., Okuhara, T., Okada, M. and Kiuchi, T., 2018. Improving health literacy in a Japanese community population—a pilot study to develop an educational programme. *Health expectations*, 21(4), pp.814-821.
- Jain, D., Aggarwal, H.K. and Meel, S., 2018, Assessment of Medication Adherence in Chronic Kidney Disease Patients: A Tertiary Care Experience. *International Journal of Health Sciences and Research*.
- Lim, J.H., Zacharia, N.F., Chinna, K., Karupaiah, T., Daud., Zam., Exploring the relationships between health literacy, dietary adherence and its mediators in hemodialysis patients in Malaysia. Sun 313. <https://doi.org/10.1016/j.ekir.2019.05.720>
- Luyckx, V.A., Tonelli, M. and Stanifer, J.W., 2018. The global burden of kidney disease and sustainable development goals. *Bulletin of the World Health Organization*, 96(6), p.414.
- Joboshi, H. and Oka, M., 2017. Effectiveness of an educational intervention (the Encourage Autonomous Self-Enrichment Program) in patients with chronic kidney disease: a randomized controlled trial. *International journal of nursing studies*, 67, pp.51-58.
- Kasemsap, K., 2019. Challenges and implications of health literacy in global health care. In *Advanced Methodologies and Technologies in Medicine and Healthcare* (pp. 185-197). IGI Global.
- Kayser, L., Karnoe, A., Duminski, E., Somekh, D. and Vera-Muñoz, C., 2019. A new understanding of health related empowerment in the context of an active and healthy ageing. *BMC health services research*, 19(1), p.242.
- Kennedy, B.M., Rehman, M., Johnson, W.D., Magee, M.B., Leonard, R. and Katzmarzyk, P.T., 2017. Healthcare providers versus patients' understanding of health beliefs and values. *Patient experience journal*, 4(3), p.29.

- Kenning, C., Coventry, P. A., Gibbons, C., Bee, P., Fisher, L., & Bower, P. (2015). Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care? *Family Practice*, 32(3), 311–316. <http://doi.org/10.1093/fampra/cmz002>
- Levine, R., Javalkar, K., Nazareth, M., Faldowski, R.A., de Ferris, M.D.G., Cohen, S., Cuttance, J., Hooper, S.R. and Rak, E., 2018. Disparities in health literacy and healthcare utilization among adolescents and young adults with chronic or end-stage kidney disease. *Journal of pediatric nursing*, 38, p.57-61.
- Lin, M.Y., Liu, M.F., Hsu, L.F. and Tsai, P.S., 2017. Effects of self-management on chronic kidney disease: a meta-analysis. *International journal of nursing studies*, 74, pp.128-137.
- Lopez-Vargas, P.A., Tong, A., Howell, M. and Craig, J.C., 2016. Educational interventions for patients with CKD: a systematic review. *American Journal of Kidney Diseases*, 68(3), p.353-370.
- Mahjubian A, Bahraminejad N, Kamali K 01 Dec 2018 The Effects of Group Discussion Based Education on the Promotion of Self-Management Behaviors in Hemodialysis Patients. *Journal of Caring Science*, 7(4): p 225-232
- Makris, K., & Spanou, L. (2016). Acute kidney injury: definition, pathophysiology and clinical phenotypes. *The clinical biochemist reviews*, 37(2), 85.
- Masood, A., Kamran, F., Rashid, S. and Mazahir, S., 2017. Life-orientation, subjective well-being and social support as predictors of quality of life in patients with end stage renal disease. *Bangladesh Journal of Medical Science*, 16(3), pp.346-353.
- Matsuoka, S., Tsuchihashi-Makaya, M., Kayane, T., Yamada, M., Wakabayashi, R., Kato, N.P. and Yazawa, M., 2016. Health literacy is independently associated with self-care

- behavior in patients with heart failure. *Patient education and counseling*, 99(6), p.1026-1032.
- Mendoza, Tram., 2019, Enhancing Health Literacy Using Teach Back Method to Increase Patient Adherence to medication regime. Doctor of Nursing Practice (DNP) Projects. 164. <https://repository.usfca.edu/dnp/164>
- Mirczak, A., 2017. Health literacy level among elderly and chronic disease self-management. *Journal of Education, Health and Sport*, 7(3), p.72-85.
- Moktan, S., Leelacharas, S., & Prapaipanich, W. (2019) Knowledge, Self-Efficacy, Self-Management Behavior of the Patients With Predialysis Chronic Kidney Disease. *Ramathibodi Medical Journal* 42(2) p 38 - 48
- Monique A.M., Lynch and Geovanni V. F, 2019. Health Literacy An Intervention to Improve Health Outcomes: DOI: 10.5772/intechopen.86269
- Moreira, L., 2018. Health literacy for people-centred care. Directorate for employment, labour and social affairs health committee, OECD Health Working Paper No. 107
- Narva, A.S., Norton, J.M. and Boulware, L.E., 2016. Educating patients about CKD: the path to self-management and patient-centered care. *Clinical Journal of the American Society of Nephrology*, 11(4), p.694-703.
- Nguyen, N.T., Douglas, C. and Bonner, A., 2019. Effectiveness of self-management programme in people with chronic kidney disease: A pragmatic randomized controlled trial. *Journal of advanced nursing*, 75(3), pp.652-664.
- Nutbeam, D., 2019. Health education and health promotion revisited. *Health Education Journal*, 78(6), pp.705-709.

- Nutbeam, D., McGill, B. and Premkumar, P., 2018. Improving health literacy in community populations: a review of progress. *Health promotion international*, 33(5), pp.901-911.
- O'Hare, A.M., 2018. Patient-centered care in renal medicine: five strategies to meet the challenge. *American Journal of Kidney Diseases*, 71(5), p.732-736.
- Park, J. M., Koerschner, C., Mawby, J., Selman, S., Kwon, H. K., Sonnenday, C. J., Wright Nunes, J. A., & Sharma, P. (2018). Knowledge of Chronic Kidney Disease Among Liver Transplant Recipients. *Liver transplantation: official publication of the American Association for the Study of Liver Diseases and the International Liver Transplantation Society*, 24(9), 1288–1292. <https://doi.org/10.1002/lt.25302>
- Parmer, J., Furtado, D., Rubin, D.L., Freimuth, V., Kaley, T. and Okundaye, M., 2015. Improving interactive health literacy skills of older adults: Lessons learned from formative organizational research with community partners. *Progress in community health partnerships: research, education, and action*, 9(4), pp.531-536.
- Parnell, T.A., Stichler, J.F., Barton, A.J., Loan, L.A., Boyle, D.K. and Allen, P.E., 2019, July. A concept analysis of health literacy. In *Nursing forum* (Vol. 54, No. 3, pp. 315-327).
- Pearson, M. L., Mattke, S., Shaw, R., Ridgely, M. S., & Wiseman, S. H. (2007). Patient self-management support programs: an evaluation. *Rockville, MD: Agency for Healthcare Research and Quality*, 08-0011.
- Peng, S., He, J., Huang, J., Lun, L., Zeng, J., Zeng, S., Zhang, L., Liu, X. and Wu, Y., 2019. Self-management interventions for chronic kidney disease: a systematic review and meta-analysis. *BMC nephrology*, 20(1), p.142.

- Pradeep Arora, MD (2020). Chronic kidney disease: University of Buffalo State University of New York School of Medicine and Biomedical Sciences; <https://emedicine.medscape.com/article/238798-overview>
- Qobadi, Mina & Besharat, Mohammad Ali & Rostami, Reza & Rahiminezhad, Abbas. (2015). Health Literacy and Medical Adherence in Hemodialysis Patients: The Mediating Role of Disease-Specific Knowledge. *Thrita*. 4. 10.5812/thrita.26195.
- Rajah, R., Hassali, M.A. and Lim, C.J., 2017. Health literacy-related knowledge, attitude, and perceived barriers: a cross-sectional study among physicians, pharmacists, and nurses in public hospitals of Penang, Malaysia. *Frontiers in public health*, 5, p.281.
- Rasu, R.S., Bawa, W.A., Suminski, R., Snella, K. and Warady, B., 2015. Health literacy impact on national healthcare utilization and expenditure. *International journal of health policy and management*, 4(11), p.747.
- Roberti, J., Cummings, A., Myall, M., Harvey, J., Lippiett, K., Hunt, K., Cicora, F., Alonso, J.P. and May, C.R., 2018. Work of being an adult patient with chronic kidney disease: a systematic review of qualitative studies. *BMJ open*, 8(9), p.e023507.
- Sarah J. S, Kerri L. C, Angela F. T, Alp I, Ana C. R, Nwamaka D. E, and Julie W N. (2019) The Relationship of Disease-Specific Knowledge and Health Literacy With the Uptake of Self-Care Behaviors in CKD. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6943760/>
- Stanifer, J.W., Muiru, A., Jafar, T.H. and Patel, U.D., 2016. Chronic kidney disease in low-and middle-income countries. *Nephrology Dialysis Transplant* Rosenberg, M., 2018. Overview of the management of chronic kidney disease in adults. *UpToDate [Internet]*.31(6), p.868-874.

- Stanifer, J.W., Turner, E.L., Egger, J.R., Thielman, N., Karia, F., Maro, V., Kilonzo, K., Patel, U.D. and Yeates, K., 2016. Knowledge, attitudes, and practices associated with chronic kidney disease in northern Tanzania: a community-based study. *PloS one*, 11(6), p.e0156336.
- Stevenson, J., Tong, A., Campbell, K.L., Craig, J.C. and Lee, V.W., 2018. Perspectives of healthcare providers on the nutritional management of patients on hemodialysis in Australia: an interview study. *BMJ open*, 8(3), p.e020023.
- Sykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: a concept analysis. *BMC public health*, 13(1), 1-10.
- Taylor, Dominic M. (2018) Health literacy and its relationship with process and outcome *eprints.soton.ac.uk*
- Taylor, D.M., Fraser, S., Dudley, C., Oniscu, G.C., Tomson, C., Ramanan, R., Roderick, P. and ATTOM investigators, 2018. Health literacy and patient outcomes in chronic kidney disease: a systematic review. *Nephrology Dialysis Transplantation*, 33(9), pp.1545-1558.
- Teston, E.F., Sales, C.A. and Marcon, S.S., 2017. Perspectivas de indivíduos com diabetes sobre autocuidado: contribuições para assistência. *Escola Anna Nery Revista de Enfermagem*, 21(2), pp.1-8.
- Tuller, D. M., Bangsberg, D. R., Senkungu, J., Ware, N. C., Emenyonu, N., & Weiser, S. D. (2010). Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: a qualitative study. *AIDS and Behavior*, 14(4), 778-784.

- Tuot, D.S., Wong, K.K., Velasquez, A., Crews, D.C., Zonderman, A.B., Evans, M.K. and Powe, N.R., 2019. CKD Awareness in the General Population: Performance of CKD-Specific Questions. *Kidney Medicine*, 1(2), p.43-50.
- Vaidya SR, Aeddula NR. 2019, Chronic Renal Failure. StatPearls. StatPearls Publishing. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK535404>
- Van den Bosch, J., Warren, D. S., & Rutherford, P. A. (2015). Review of predialysis education programs: a need for standardization. *Patient preference and adherence*, 9, 1279.
- Wang, S.L., Chen, H.C. and Tsai, Y., 2019. SP817 The interaction between self-care behavior and disease knowledge in poor renal outcomes in elderly with chronic kidney disease. *Nephrology Dialysis Transplantation*, 34(Supplement_1), p.gfz103-SP817.
- Warsame, F., Haugen, C.E., Ying, H., Garonzik-Wang, J.M., Desai, N.M., Hall, R.K., Kambhampati, R., Crews, D.C., Purnell, T.S., Segev, D.L. and McAdams-DeMarco, M.A., 2019. Limited health literacy and adverse outcomes among kidney transplant candidates. *American Journal of Transplantation*, 19(2), pp.457-465.
- Weiss, B.D., 2018. The Newest Vital Sign: Frequently Asked Questions. *HLRP: Health Literacy Research and Practice*, 2(3), pp.e125-e127.
- Wembenyui, C. F. (2017). *Examining knowledge and self-management of chronic kidney disease in a primary health care setting: Validation of two instruments* (Doctoral dissertation, Queensland University of Technology).
- Wembenyui, C.F., Bonner, A. and Douglas, C., 2016. 70: Examining patient's knowledge about chronic kidney disease in a primary health care setting. *Renal Society of Australasia Journal*, 12, p.43-43.

- Wild, M.G., Wallston, K.A., Green, J.A., Beach, L.B., Umeukeje, E., Nunes, J.A.W., Ikizler, T.A., Steed, J. and Cavanaugh, K.L., 2017. The Perceived Medical Condition Self-Management Scale can be applied to patients with chronic kidney disease. *Kidney International*, 92(4), pp.972-978.
- Wong, K.K., Velasquez, A., Powe, N.R. and Tuot, D.S., 2018. Association between health literacy and self-care behaviors among patients with chronic kidney disease. *BMC nephrology*, 19(1), p.1-8.
- Wongwiseskul, S. and Chinnapan, W., 2014. Program of health education through group learning and 'buddy' support on reducing excessive salt consumption among the aging with hypertension. In *The 1st International Nursing Conference Nursing Innovation: A Key To Promote The Humanized Health In ASEAN Economic Community (AEC) Era* (p. 21)

APPENDICES

APPENDIX I: TIME FRAME

| Activity | Oct 2019 | Nov 2019 | Dec 2020 | Jan 2020 | Feb 2020 | Mar 2020 | Apr 2020 | May 2020 | Jun 2020 | Jul 2020 | Aug 2020 | Sep 2020 | Oct 2020 | Nov 2020 |
|--|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Development of the concept | | | | | | | | | | | | | | |
| Proposal writing and presentation | | | | | | | | | | | | | | |
| Submission of proposal to Ethics Board | | | | | | | | | | | | | | |
| Data collection and analysis | | | | | | | | | | | | | | |
| Report writing and corrections | | | | | | | | | | | | | | |
| Presentation of the project | | | | | | | | | | | | | | |
| Project results dissemination | | | | | | | | | | | | | | |

APPENDIX II: BUDGET

| NO | ITEM | COST |
|----|----------------------------|---------|
| 1 | INTERNET | 10,000 |
| 2 | STATIONARY | 5,000 |
| 3 | ACCESS TO RECORD FEE | 2,000 |
| 4 | ERC FEE | 2,000 |
| 6 | STATISTICIAN FEE | 35,000 |
| 7 | PRINTING AND BINDING | 10,000 |
| 8 | PUBLICATION/ DISSEMINATION | 45,000 |
| 9 | CONTINGENCY | 10,000 |
| | | |
| | TOTAL | 120,000 |

JUSTIFICATION OF THE BUDGET

Internet- to facilitate literature search by accessing information needed for the study

Stationary- one rim of full scaps, pencil, biro pens, eraser, and 2 hand books

Printing and binding- three copies of proposal and research documents will be printed and binded. Printing of the Questionnaire will also be done

ERC fee- the amount will be paid to KNH/UON ERC for approval of the proposal

Data access fee- amount paid to KNH to be allowed access patient information as required by KNH policy

Contingency allowance- will cater for any unforeseen expenses

Statistician fee- this fee will be paid to facilitate data analysis.

APPENDIX III: Consent form

Study title: Role of health literacy in promoting self-management among patients with chronic kidney disease attending renal clinic at Kenyatta National Hospital

Introduction to the study and research

My name is Helda Nekesa Wafula, I'm a postgraduate student at the university of Nairobi, School of Nursing Sciences, pursuing a Master of Science in Nursing (MScN) degree. I'm conducting a research at the Kenyatta National Hospital Renal Clinic to find out the effectiveness of health education on self-management among patients with chronic kidney disease.

For the study to be successful, I request for your participation by assisting in completing a questionnaire that will be availed to you by the researcher. You will be required give the most appropriate response to the best of your knowledge. Since you are already attending renal clinic for CKD management, i am interested in collecting information on how you are managing yourself.

Assurance of confidentiality

Confidentiality will be observed in all information that you will give in this study. You are required to voluntarily consent to participate in this study. You will be given a consent form to fill, on which you will be assigned a code. You will not be required to write your name on the questionnaire. The questionnaires will be kept under key and lock and will only be accessed by the researcher.

Your participation in this study is voluntary and your refusal to participate will not affect the provision of service that you deserve. Even after consenting to participate, you are free to withdraw from the study at any time. No monetary incentive will be given to the participants in this study.

Benefits/Risks of the study

Findings from this study will be utilized in determining the effectiveness of health education interventions on health literacy in self-management of CKD. This will inform the care givers at KNH Renal Unit on areas that require improvement during assessment of self-management interventions among patients with CKD. The national policy makers will also be informed on areas of priority in planning for self-management of CKD. This will be of great assistance in resource allocation both at the KNH and the National level. The study findings will also be utilized for future research in the study field.

During the study process no invasive procedures will be performed. You may experience minimal risks that could be psychological in nature on realization of possible areas of inadequate health literacy. In case you experience these challenges, you are advised to get in touch with the researcher for assistance. No punitive measures will be applied in case of not participating in self-management.

Duration of participation

You are required to give information to the researcher, who will fill in your responses in a questionnaire. There will be a follow up interviews after one month, and the process will take about an hour of your time.

Contact information

For any queries or clarifications concerning this study, you are advised to contact Helda Nekesa Wafula, MScN student at the University of Nairobi, School of Nursing Sciences on mobile phone number 0722573223, or Chairperson KNH-UON ERC on P.O Box 20723-00202, tel. 0202725272

Consent Form

The above details concerning the study have been explained to me. I agree to participate in the study. I understand my participation in the study is voluntary. I willingly give my consent to divulge the necessary information that is required.

Participant's signature/thumb mark_____

Researcher's signature _____

Date _____

APPENDIX IV: Participant Demographic Information Questionnaire

CODE NO:

1. What is your gender?

- a. Male b. Female

2. What is your age?years

3. What is your marital status?

- a. Single c. Widowed
b. Married d. Divorced/ Separated

4. What is the highest level of education completed?

- a. Primary school c. College/University
b. Secondary school d. Other: please specify.....

5. Are you currently...?

- a. Employed d. Retired
b. Self-employed e. Other: please specify.....
c. Unemployed

6. Do you have an insurance cover?

- a. Yes b. No

7. Do you have any other medical condition?

- a. Yes b. No

8. If yes, which one?

- a. Diabetes c. HIV
b. Hypertension c. others specify_____

9. For how long have you been diagnosed of chronic kidney disease?

a. Less than one year c. Two to five years

b. One to two years d. More than five years

APPENDIX V: Kidney Disease Knowledge Survey

This survey aims to find out how well you understand chronic kidney disease.

1. On average, your blood pressure should be:

- 160/90 150/100 170/80 Lower than 130/80

2. Are there certain medications your doctor can prescribe to help keep your kidney(s) as healthy as possible?

- Yes No

3. If the kidney(s) fail, treatment might include (PICK up to TWO ANSWERS):

- Lung biopsy Bronchoscopy Kidney transplant
Hemodialysis Colonoscopy

4. Are there stages of CHRONIC kidney disease?

- Yes No

5. Does chronic kidney disease increase a person's chances of heart attack?

- Yes No

6. Does chronic kidney disease increase a person's chance of death from any cause?

- Yes No

This section is about the symptoms of chronic kidney disease

7. Increased fatigue?

- Yes No

8. Shortness of breath?

- Yes No

9. Unusual itching?

- Yes No

10. Nausea and/vomiting?

Yes No

11. Increased trouble sleeping?

Yes No

12. Hair loss?

Yes No

13. Weight loss?

Yes No

14. No symptom at all?

Yes No

APPENDIX VI: Perceived Kidney Disease/Dialysis Self-Management Scale.

Scores 1 ‘Strong disagree’, 2 ‘Disagree’ 3 ‘Neither agree/disagree’ 4 ‘Agree’ 5 ‘Strongly agree’

1. It is difficult for me to find effective solutions for problems that occur with managing my kidney disease (dialysis).
2. I find efforts to change things I don't like about my kidney disease (dialysis) are ineffective.
3. I handle myself well with respect to my kidney disease (dialysis).
4. I am able to manage things related to my kidney disease (dialysis) as well as most other people.
5. I succeed in the projects I undertake to manage my kidney disease (dialysis).
6. Typically, my plans for managing my kidney disease (dialysis) don't work out well.
7. No matter how hard I try, managing my kidney disease (dialysis) doesn't turn out the way I would like.
8. I'm generally able to accomplish my goals with respect to managing my kidney disease (dialysis).

APPENDIX VII: Targeted Health Education Tool

1. Chronic kidney disease

- Definition
- Stages of chronic kidney disease
- Causes of chronic kidney disease
- Signs and symptoms
- Investigations done

2. Management of CKD

- Conservative
- Renal replacement therapy
 - dialysis
 - kidney transplant

3. Complications of CKD

APPENDIX VIII: LETTER OF APPROVAL FROM ETHICS



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UoN ERC

Email: uonknh_erc@uonbi.ac.ke
Website: <http://www.erc.uonbi.ac.ke>
Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

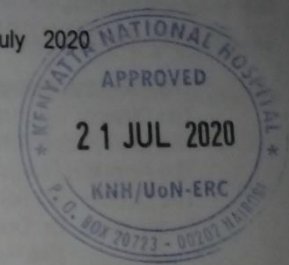


KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/233

Helda Nekesa Wafula
Reg. No.H56/11890/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

21st July 2020



Dear Helda

RESEARCH PROPOSAL – ASSESSING HEALTH LITERACY IN PROMOTION OF SELF-MANAGEMENT AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE ATTENDING KENYATTA NATIONAL HOSPITAL (P101/02/2020)

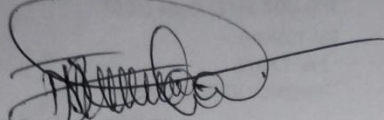
This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 21st July 2020 – 20th July 2021.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

- c.c. The Principal, College of Health Sciences, UoN
 The Director, CS, KNH
 The Chairperson, KNH- UoN ERC
 The Assistant Director, Health Information, KNH
 The Director, School of Nursing Sciences, UoN
 Supervisors: Dr. Dorcas Maina, School of Nursing Sciences, UoN
 Eve Rajula, School of Nursing Sciences, UoN

APPENDIX IX: LETTER OF APPROVAL FROM KENYATTA NATIONAL HOSPITAL

KNH/R&P/FORM/01



KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
HELDA NEKESA WAFULA
2. Email address: billywarf@gmail.com Tel No. _____
3. Contact person (if different from PI) _____
4. Email address: _____ Tel No. _____
5. Study Title
ASSESSING HEALTH LITERACY IN PROMOTION OF SELF
MANAGEMENT AMONG PATIENTS WITH CHRONIC KIDNEY
DISEASE ATTENDING KENYATTA NATIONAL HOSPITAL
6. Department where the study will be conducted RENAL UNIT
(Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.
Name: Nancy Hanyombe Signature: [Signature] Date: 19/8/2020
8. Endorsed by KNH Head of Department where study will be conducted.
Name: Dr. J.W. Njiru Signature: [Signature] Date: 20.8.2020
9. KNH UoN Ethics Research Committee approved study number _____
(Please attach copy of ERC approval)
10. I HELDA WAFULA NEKESA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.
Signature: [Signature] Date: 20/8/2020
11. Study Registration number (Dept/Number/Year) Renal 20 AUG 2020 136/2020
(To be completed by Medical Research Department)
12. Research and Program Stamp _____



All studies conducted at Kenyatta National Hospital **must** be registered with the Department of Research and Programs and investigators **must commit** to share results with the hospital.

Turnitin Originality Report

- Processed on: 24-Nov-2020 10:13:44
- ID: 1455877591
- Word Count: 21539
- Submitted: 1

ASSESSING HEALTH LITERACY IN PROMOTION OF SELF-MANAGEMENT
AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE ATTENDING KENYATTA
NATIONAL HOSPITAL By Helda Wafula

Similarity Index

6%

Similarity by Source

Internet Sources:

5%

Publishers:

4%

Student Papers:

N/A

2% match (Internet from 09-May-2020)

<https://www.scribd.com/document/443450831/Chi-Nguyen-Nguyen-Thesis>

1% match (Internet from 19-Jun-2018)

https://eprints.qut.edu.au/114075/1/Coletta_Wombonyai_Thesis.pdf

1% match (publications)

Marcus G. Wild, Kenneth A. Watson, Jamie A. Green, Lauren B. Beach et al. "The Perceived Medical Condition Self-Management Scale can be applied to patients with chronic kidney disease", *Kidney International*, 2017

1% match (Internet from 22-Jul-2020)

http://erepository.uonbi.ac.ke/bitstream/handle/11295/100279/Phoebes_Utilization%20of%20Catheter%20Associated%20Urinary%20Tract%20Infection%20Bundle%20Among%20Critical%20Care%20Nurses%20-%20Kenya%20National%20Hospital.pdf?seq=1&lower_layer&sequence=1

1% match (Internet from 03-Sep-2020)

<https://scholarworks.walden.edu/cgi/viewcontent.cgi?article=7090&context=dissertations>

1% match ()

<http://hdl.handle.net/10034/345902>

Dr Ducas Mwa

[Signature]

1-12-2020



[Signature]
Prof. Mengesha Mwa