



**ADHERENCE TO HEMODIALYSIS AMONG END STAGE
RENAL DISEASE PATIENTS (ESRD) IN SELECTED
NEPHROLOGY UNITS IN RWANDA**

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**ADHERENCE TO HEMODIALYSIS AMONG END STAGE RENAL DISEASE
PATIENTS (ESRD) IN SELECTED NEPHROLOGY UNITS IN RWANDA**

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a. Declaration by the Student

I do hereby declare that this *dissertation* submitted in partial fulfilment of the requirements for the degree of **MASTERS OF SCIENCE** in **NURSING**, at the University of Rwanda/College of Medicine and Health Sciences, is my original work and has not previously been submitted elsewhere. Also, I do declare that a complete list of references is provided indicating all the sources of information quoted or cited.

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.....**Chiranda 13/06/2017**.....

DEDICATIONS

To my family; my loving husband Prudence, my lovely children Gisèle ,Consolée and David.

Without you this work could not be achievable.

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ABSTRACT

Introduction

End stage renal disease (ESRD) becomes an alarming problem in the world increasing the number of patients maintained on dialysis and renal transplantation. Poor adherence to hemodialysis has been reported in other countries but less information is available in Rwanda and Africa continent. Factors contributing to non-adherence to hemodialysis are not well explained in literature.

Purpose of the study

The purpose of this study was to explore adherence to hemodialysis among end stage renal disease patients (ESRD) in selected nephrology units in Rwanda. The specific objectives were to assess the level of adherence to hemodialysis among end stage renal disease patients, to identify the barriers to adherence to hemodialysis among end stage renal disease patients and to identify motivating factors of adherence to hemodialysis among end stage renal disease (ESRD) patients.

Methods

A mixed method approach was used. An explanatory sequential mixed method design was employed where quantitative data was collected and analyzed first, then followed by collection and analysis of qualitative data. For the quantitative stage, a total sample of 41 participants was selected. Data for quantitative research was collected in the form of structured interview schedules into sections namely demographic data and adherence to haemodialysis. Quantitative data was collected to determine the level of adherence to hemodialysis among end stage renal disease (ESRD) patients. Descriptive statistics and inferential statistics of chi-square were used to analyse the data.

For the qualitative stage, a purposive sample of study participants was selected from the sample of quantitative. Those with high, moderate and low level of adherence to haemodialysis were selected. Data was collected using a semi-structured interview schedule which elicited barriers to and motivators of adherence to haemodialysis. Data for qualitative was analysed using a thematic framework approach. The health belief model was used as a conceptual framework to guide the study.

Results: Twenty one (51%) of ESRD participants scored above 80%, meaning that their adherence to HD scores was high. Seventeen (42%) scored between 70 and 79% meaning that

the level of these participants was moderate. Three (7%) scored below 70% meaning that their level of adherence to HD score was low. A significant association between age($p=.038$) and religion ($p=.003$) and adherence to hemodialysis was found. The identified motivators of adherence to hemodialysis were Family support, hope for renal transplant, alleviation of symptoms, to prolong life and improved quality of life, and fear of death. Barriers to adherence to hemodialysis were poverty, uncertain transport, treatment related complications and long distance.

Conclusion: Adherence to hemodialysis is a concern in Rwanda, these implying nurses in four aspects, nursing practice, nursing education, nursing research and nursing administration, for better management of ESRD.

ABBREVIATIONS

CAPD :	Continuous Ambulatory Peritoneal Dialysis (CAPD)
CBHI	Community based health insurance
CDC:	Center of disease control
CKD:	Chronic kidney disease
ESRD:	End stage renal disease
EU:	European Union
GFR:	Glomerular Filtration Rate
FARG	Fund for Neediest survivors of Genocide in Rwanda
GDP:	Gross domestic product
HD:	Hemodialysis
HBP:	High blood pressure
HTN:	Hypertension
HIV:	Human immunodeficiency virus
KDIGO:	Kidney disease improving global outcome
KFH:	King Faisal Hospital
PD:	Peritoneal dialysis
p.m.p:	per million populations
QOL:	Quality of life
R.R.T:	Renal replacement therapy

SPSS	Statistical Package for the Social Sciences
SSA:	Sub-Saharan Africa
US:	United State
UR:	University of Rwanda
USA:	United States of America
USRDS	United Sates renal data system
UTHK:	University teaching hospital of Kigali
UTHB:	University teaching hospital of Butare
WHO:	World Health Organization

TABLE OF CONTENTS

DEDICATIONS.....	ii
ACKNOWLEDGEMENT	iii
ABSTRACT.....	iv
ABBREVIATIONS	vi
List of Tables	xi
List of Figures.....	xii
CHAPTER ONE.....	1
1.1 Introduction.....	1
1.2 Background	1
1.3 Problem statement.....	3
1.4 Purpose of the study	5
1.4.1Main objective	5
1.4.2 Specific objectives	5
1.5 Research questions	5
1.6 Significance of the study.....	6
1.7. Definition of terms	6
1.7.1. Adherence.....	6
1.7.2. End Stage Renal disease:.....	6
1.7.3.Hemodialysis	6
1.8. Subdivision of the study.....	7
CHAPTER TWO: LITERATURE REVIEW.....	8
2.1. Introduction	8
2.2 Theoretical literature	8
2.2.1Prevalence of ESRD	8
2.2.1.1Causes of ESRD	9
2.2.1.2 Overview on the use of hemodialysis procedure.....	11
2.2. 2.Empirical literature	13
2.2.2.1Adherence to hemodialysis.....	13
2.2.2.3 Conceptual framework Health Belief Model (adapted from Rosenstock. 1960)	17
CHAPTER 3: METHODOLOGY	20

3.1 Research approach.....	20
3.2. Study Design	20
3.3. Study Area.....	20
3.4 Study Population	21
3.5 .Sample size for quantitative	21
3.6. Sample strategy for quantitative.....	21
3.7. Sample strategy for qualitative.....	22
3.8 Sample size for qualitative	22
3.9. Selection criteria for quantitative study	22
3.10. Selection criteria for qualitative	23
3.11. Inclusion criteria for cases of selected ESRD participants	23
3.12. Exclusion criteria for cases of selected ESRD study participants.....	23
3.13. Data collection procedure.....	23
3.14. Data Collection methods for quantitative.....	23
3.15. Instrument for qualitative study	24
3.16. Validity of the data collection instrument for quantitative	24
3.17. Reliability of the quantitative:.....	26
3.18. Trustworthiness in qualitative data	26
3.19. Data analysis for quantitative.....	27
3.20. Data analysis for qualitative.....	27
3.21. Ethical consideration	27
3.22. Data management.....	28
3.23. Dissemination.....	28
CHAPTER 4: STUDY RESULTS.....	29
4.1 Introduction	29
4.2 Quantitative findings.....	29
4.2.1 Demographic data of ESRD participants.....	30
4.2.2 Adherence to hemodialysis among ESRD participants	45
4.2. 3 inferential statistics on association between demographic variables and adherence to Hemodialysis.....	48
4.2.4 Conclusion of the quantitative findings.....	50

4.3 Qualitative findings	51
4.3.1 Introduction	51
4.3.2 Selected ESRD participants	51
4.3 Stages of the qualitative data analysis	53
4.3.1 Data organization.....	53
4.3.2. Familiarization:.....	53
4.3.4 Identifying a thematic framework :	53
4.3.5 Indexing:.....	53
4.3.6 Tabulation:.....	54
4.3.7. Interrelating and description of themes:	54
4.3.7.1 Motivators of adherence to hemodialysis	55
4.3.7.2 Barriers to adherence to hemodialysis.....	57
4.3.7.3 Conclusion of the qualitative findings.....	59
CHAPTER FIVE: DISCUSSIONS, RECOMMENDATIONS AND CONCLUSIONS	61
5.1 Introduction	61
5.2 Demographic characteristics of ESRD participants	61
5.3 Adherence to hemodialysis among ESRD participants.....	65
5.4. Study limitations	67
5.5. Recommendations	68
5.6. Conclusion.....	69
REFERENCES	70
APPENDICES	78

List of Tables

Table 3. 1: Construct validity measure for the study	25
Table 4.2: Adherence to hemodialysis among ESRD participants (N=41)	46
Table 4.3: Adherence to hemodialysis scores among ESRD participants (N=41)	47
Table 4. 4: Association between demographic characteristics and adherence to hemodialysis among ESRD participants.....	49
Table 4.5: selected ESRD participants for the qualitative study (n =7).....	52
Table 4.6: Predefined themes and subthemes	54

List of Figures

Figure 1: Adapted conceptual framework from health belief model (1960)	19
Figure 4. 2: Distribution of age among ESRD participants (N = 41)	30
Figure 4.3:Distribution of gender among ESRD participants(N=41).....	31
Figure 4.4: Distribution of marital status of ESRD participants (N=41).....	32
Figure 4.5: Distribution of the level of education among ESRD participants (N=41)	33
Figure 4.6: Religion of ESRD participants (N=41)	34
Figure 4.7: Occupation of ESRD participants(N=41).....	35
Figure 4.8: Monthly income of ESRD participants (N=41)	36
Figure 4.9: Area of residence of ESRD participants (N=41).....	37
Figure 4.10: Distributionof mode of transport among ESRD participants (N=41)	38
Figure 4.11: Distance between the hospital and home of ESRD participants(N=41)	39
Figure 4.12: Mode of water supply among ESRD participants (N=41)	40
Figure 4.13: Mode of sewerage system among ESRD participants (N=41).....	41
Figure 4.14: The availability of support system for ESRD participants(N=41).....	42
Figure 4.15: Distribution of duration of ESRD(N=41).....	43
Figure 4.16: Distribution of causes of ESRD among study participants(N=41)	44

CHAPTER ONE

1.1 Introduction

End stage renal disease (ESRD) is a known public health difficulty globally (Yusop et al. 2013, p.1). In the same study Yusop et al. (2013) showed that the increasing prevalence of ESRD is similar to the increasing prevalence of type 2 diabetes mellitus, and they added that the total number of people with diabetes is expected to grow from 336 million in 2012 to 522 million in 2030 . The increase of ESRD patients necessitates management on dialysis for better outcome and wellbeing thus , adherence to prescribed treatment is essential (Abo et al.,2015,p. 21). Therefore, adherence to hemodialysis for ESRD requires coordinated efforts and effective health providers' patient's interactions to minimize non adherence related risks and further improve the quality of life.

1.2 Background

End Stage Renal Disease (ESRD) occurs from the damage of normal kidney tissues over an extended period of time. Frequently there are no symptoms until the kidney has lost more than half its function. The loss of kidney function in ESRD is generally irreversible and permanent (Physician & Visits 2014,p.1).Kidney disease improving global outcome(KDIGO)explained the different stages of CKD that progress to renal failure as follows: In stage 1 there is a normal or high glomerular filtration rate(GFR) that is greater or equal to 90(ml/min/1.73 m²),in stage 2 , the GFR is mildly decreased between 60-89 (ml/min/1.73 m²), in stage 3a,the GFR is said to be mildly to moderately decrease and is equal to 45-59(ml/min/1.73 m²), the stage 3b is characterized by a moderately to severely decreased GFR 30-44(ml/min/1.73 m²),in stage 4, the GFR is severely decreased 15-29(ml/min/1.73 m²),and in stage 5 that is renal failure the GFR is less than 15(ml/min/1.73 m²) (Journal & Society 2013,p.5).

Centre for disease control (2014) highlighted diabetes mellitus and hypertension as the general causes of end stage renal disease (ESRD). Glomerulonephritis and congenital or hereditary diseases are additional important causes ,and other risk factors for ESRD include cardiovascular disease, obesity, high cholesterol, lupus, and a family history of ESRD (CDC, 2014,p.1).The study conducted by Stanifer et al. discovered also the use of toxic herbs as another risk factor for ESRD where they showed that up to 80% of the populations in sub-Saharan region are estimated to use herbal or traditional medicines (Stanifer et al. 2014, p.179). The risk of developing ESRD also increases with age, because these risk factors are more frequent at advanced age. Furthermore, in sub-Saharan Africa, ESRD essentially affects economically productive young society between the ages of 20 and 50 years with HTN, diabetes and infections (Annals of African Medicine, 2012,p.120). Gender is also a risk as men with chronic renal disease are 50% more likely than women to have renal failure (CDC 2014,p.1).

According to the study conducted by Fresenius medical care (2013,p.5), the number of patients who were on treatment for ESRD worldwide was estimated to be 3,200,000 at the end of 2013 and with an estimation of 6% growth rate, continued to grow at an important rate than the world population. ESRD prevalence was higher in Taiwan with approximately 3,170 p.m.p the next country was Japan with about 2,620 p.m.p. and the USA with around 2,080 p.m.p.The average was around 1,090 p.m.p. in the 28 countries that compose European Union (EU). A reduction is noted in countries where the GDP per capita is below a limiting value(Fresenius Medical Care AG & Co. KGaA 2013,p.5).

Two main types of renal replacement therapy, are dialysis and kidney transplantation(Al-Khattabi, 2014,p.592) as cited in (National Kidney Foundation, 2013). The two common forms of dialysis therapy for ESRD patients are hemodialysis(HD) and peritoneal dialysis(PD) (Yang et al.,2015,p.2).Hemodialysis is the preferred modality of treatment of ESRD patients in Rwanda. Dialysis centers are in the three referral hospitals (King Faisal Hospital, university teaching hospital of Kigali (UTHK), and the university teaching hospital of Butare (UTHB), one dialysis center in Gisenyi district hospital in western province and one private clinic, located at Kimihurura.The treatment of end-stage renal disease (ESRD) is expensive, particularly in case of hemodialysis. The accessibility to this modality is distant between low resource settings and

high resource settings (Gérard et al., 2016,p.30). Opportunities to get better in management of ESRD in SSA are restricted by low alertness, not enough access, poor detection, and late presentation for clinical care(Lunyera et al. 2016,p.1)as cited in (Kalyesubula et al., 2015)

Adherence is crucial in management of ESRD patients. World health organization(WHO) describes adherence as the extent to which a person's behaviour (taking medications, following a recommended diet, and /or executing life –style changes) corresponds with the agreed recommendations of health care provider (WHO, 2003, p.3).The definition of adherence was introduced to reduce the paternalistic nature of the expression compliance. The meaning of the term adherence includes also compliance definition that tends to influence the patient for agreement (Alikari, Zyga, 2014). Compliance and adherence are used interchangeably (Allen et al. 2011,p.129).Patient adherence with the recommendation and treatment of hemodialysis is critical. Unfortunately poor patient adherence to hemodialysis is a prevalent problem in health care that has considerable medical, social and economic consequences, predominantly among patients undergoing hemodialysis(Mersal et al .2016,p.35).

1.3 Problem statement

Informal observations and clinical experience in renal unit in the university teaching hospital of Kigali (UTHK) revealed poor adherence to hemodialysis. There is no previous study on adherence to hemodialysis in Rwanda. However, documented literature reveals that approximately 50% of individuals with ESRD undergoing hemodialysis (HD) do not adhere to their prescribed treatment regimen (Wells ,2011,p.155,Kemmerer 2015,p.479-480) as cited in (Kutner 2001).This statement was also confirmed by Ibrahim et al. (2015)where their study done in Egypt showed that non-adherence through skipping hemodialysis sessions varied from 7 to 32% among end stage renal disease patients. The study done in Zimbabwe has shown that more than 50% of patients were not adherent to scheduled hemodialysis plan where 93% of respondents had missed at least one session with 61% missing most of the scheduled sessions and only 7% attended all the hemodialysis sessions as scheduled. Sixty seven percent had rescheduled the prescribed hemodialysis sessions more than once (Chironda et al. 2014,p. 29).According to Duong et al.(2015,p.5) non adherence with treatment plan in their patients was

problematic as approximately half of patients missed their sessions while (11 %) required extra treatment and(12 %) shortened their sessions.

It was revealed that non adherence to treatment negatively affects patient outcomes and increases healthcare expenses. Not only patients themselves are affected, but non-adherence behavior influences the normal work-load of the hemodialysis unit(Duong et al. 2015,p.5)as cited in(Leggat et al. 1998). According to Allen et al.(2011,p.128), only 50% of patients in developed countries following the treatment prescribed for them by health care providers, non-adherence is commonly described as rising morbidity, hospitals visits and general health care costs.

According to Abo et al.(2015), dialysis treatment and shortening treatment time will result in physical problems which influence the decision to skip or shorten treatment time. The reported physical symptoms were hypotension (50%), cramps (23.08%), fatigue (19.23%), and clots in access site (33.33%) (Abo et al. 2015,p. 29).In short term, non- adherence to treatment regimen may increase the probability emergency and hospital admissions (Mersal et al.,2016,p.35) as cited in (Mohsen et al., 2013)

Factors contributing to non-adherence to hemodialysis are not well explained in literature. However, Amanpour F, Dadgari A, Hebrahimi H(2016,p.250)did a study which showed HD patients expressing high levels of anxiety and experiencing a numerous of physical, psychological, and social problems. Health care providers especially nurse can play an important role to evaluate the quality of life in HD patients. In the study conducted by Duong et al. (2015), they reported that young age, male and longer duration on hemodialysis to be associated with skipping and shortening the dialysis sessions. They added that patients new to dialysis were not at all times adherent with their treatment schedule. The reason for non-adherence was not explored but their personal observations argued that it might be due to lack of mental and physical preparation and the disturbance experienced from the first session of hemodialysis(Duong et al. 2015,p.5).

In Rwanda Studies on causes of ESRD are limited but according to health profile Rwanda 2014 (WHO update) renal diseases were the fourteenth leading cause of death among 50 top causes. One of the modalities of treatments of ESRD includes hemodialysis. There are no previous studies to provide clear data on adherence to hemodialysis and contributing factors in Rwanda. Therefore, the aim of this study is to determine the level of adherence and identify related factors to varying levels of adherence to hemodialysis in ESRD patients in selected hospitals of Rwanda.

1.4 Purpose of the study

The purpose of this study is to explore adherence to hemodialysis among end stage renal disease patients (ESRD) in selected nephrology units in Rwanda

1.4.1 Main objective

To investigate the **extent** of adherence to hemodialysis and factors influencing adherence among End Stage Renal Disease patients in Rwanda

1.4.2 Specific objectives

1. To assess the level of adherence to hemodialysis among end stage renal disease patients
2. To identify barriers to adherence to hemodialysis among end stage renal disease patients
3. To identify motivating factors of adherence to hemodialysis among end stage Renal Disease (ESRD) patients

1.5 Research questions

1. What is the level of adherence to hemodialysis among end stage renal disease patients in Rwanda?
2. What are the barriers to hemodialysis adherence among end stage renal disease patients in Rwanda?
3. What are motivating factors of hemodialysis adherence among End stage Renal Disease (ESRD) patients?

1.6 Significance of the study

This study will contribute to:

Nursing practice by helping nurses to put more effort in the clinical area with evidence in handling ESRD patient's varying issues.

Nursing research by providing new information that will be used in the future in the nursing field whereby nursing interventions may be tested for better practice in managing ESRD patients.

Nursing education: Future nurse students may use this study as a tool that may increase the awareness regarding end stage renal disease, and in turn take preventive measures to minimize the increase and severity of non-adherence to hemodialysis .Higher education provides more skills and gives better patient 's management outcomes .

Nursing management will rise the voice for advocacy and will use administrative measures, to address the seriousness of ESRD patient's problems. Also by making ways of possible solutions through close communication with all concerned governmental health parties, given the awareness about highlighted responsibility in managing ESRD patients in cooperation with policies, rules and regulations makers.

1.7. Definition of terms

1.7.1. Adherence. Adherence as defined by WHO is the extent to which a person's behavior (taking medications, following a recommended diet, and /or executing life –style changes) corresponds with the agreed recommendations of health care provider(WHO, 2003,p.3). In this study adherence refers to following a recommended hemodialysis plan.

1.7.2. End Stage Renal disease: End Stage Renal Disease (ESRD) is a total or almost total permanent kidney failure. It is progressive and frequently permanent decline in kidney function, which is in the end fatal without the intervention of intermittent dialysis and/or kidney transplantation (Mersal et al. 2016,p.35)as cited in(Mohsen et al., 2013). In this study the disease of focus is ESRD which is being treated by hemodialysis.

1.7.3.Hemodialysis: Hemodialysis (HD) utilizes countercurrent flow to complete extracorporeal removal of waste products from blood, counting urea, creatinine, and free water, when the

kidneys are in a state of failure (Li et al., 2016,p.1)as cited in(Goswami et al., 2014). In this study hemodialysis is a dialytic therapy which is used to treat ESRD in Rwanda.

1.8. Subdivision of the study

This study included introduction, review of the literature, methodology, study results, discussions, study limitations and recommendations, references and appendices

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

The literature review can motivate new research ideas, facilitate to set the foundation for studies, aid researchers to interpret their findings and offers readers with a background for understanding present knowledge on subject and clarifies the importance of the new study (Denise F. Polit & P. 2010 p.170). This chapter covered the theoretical literature that was composed of definition, causes and prevalence of ESRD as well as hemodialysis as management modality of ESRD, empirical literature that focused on studies on adherence to HD and factors affecting adherence to HD as well as the conceptual framework that guided the study.

2.2 Theoretical literature

2.2.1 Prevalence of ESRD

End Stage Renal Disease (ESRD) presents from the destruction of normal kidney tissues over a long period of time (Physician & Visits 2014, p1). Most of the time there are no symptoms until the kidney has lost more than half of its function, and in ESRD the loss of kidney function is irreversible and permanent (Physician & Visits, 2014, p.1). In 2013 there were 661,648 prevalent cases of ESRD in the United States (USRDS 2015, p.146). According to the study conducted by Fresenius medical care Fresenius Medical Care AG & Co. KGaA (2013), the number of patients who were treated for ESRD globally was around 3,200,000 at the end of 2013 and, with an estimation of 6% growth rate, that continued to increase at an important higher rate than the world population. ESRD prevalence was at a higher level in Taiwan with nearly 3,170 per million population, followed by Japan with approximately 2,620 p.m.p., then the USA with around 2,080 p.m.p. The average was about 1,090 p.m. in the 28 countries that compose the European **Union (EU)** (Fresenius Medical Care AG & Co. KGaA 2013). A decrease is noted in countries where the GDP per capita is below a limiting value (Fresenius Medical Care AG & Co. KGaA 2013).

In Africa, there is an inconsistency in accessibility through the reported prevalence. It was reported in 2015 a prevalence of 400 p.m.p in North Africa and 12.6 p m p in West Africa (Gérard et al.2016, p.1). According to the study conducted by Alashek et al. (2012,p.1) in Libya, the prevalence of dialysis-treated ESRD patients, 85% of prevalent patients were aged <65 years and 58% were male. In Sudan, the estimated incidence of new cases of ESRD patients was 70–140 per million inhabitants per year. There were limited data about causes of ESRD in Sudan population (Banaga et al. 2015,p.2)

Stanifer et al.(2014,p.179)mentioned poor quality data for the prevalence of CKD in sub-Saharan Africa, and their review identified that the main reasons were related to reduced sampling methods, changeable kidney function measurements, and variable data accessibility in every country. Stanifer et al.(2015,p.2), observed a high burden of ESRD in Northern Tanzania that was associated with low awareness. Also they identified demographic, lifestyle practices including traditional medicine use, socio economic factors, as well as NCDs to be accounted for a number of the increases ESRD risk observed with urban residence. The study conducted by (Lunyera et al. 2016,p.2) has shown that kidney disease was the 13th most common cause of death , and the estimated annual age-adjusted death rate was attributable to CKD in Uganda expressed as 27.8 per 100,000 population exceeding the global estimate that was 16.3 per 100,000 .There are no statistical data about the prevalence of ESRD in Rwanda but according to the ministry of health there were 1750cases of chronic kidney diseases that were operated among other NCDs treated in 2014 from all health facilities(Statistics 2014,p.70).

2.2.1.1Causes of ESRD

Diabetes causes 44% of all new cases of kidney failure. In 2012 it was the primary cause for 239,837 ESRD patients in America(American Kidney fund,2015,p.1).In Europe the diabetes also is the main common cause of ESRD(Kramer et al., 2016,p.3).

Patients who had diabetes mellitus like the cause of ESRD were comprising 24% of the incident RRT patients and 17% of the prevalent, RRT patients(Kramer et al. 2016,p.3). There were 135-million diabetics worldwide, with a projected increase to 300-million by 2025 and to increase by 170% in developing countries approximately 40% in developed countries(Sarala Naicker, 2013 ,p.162).

Diabetes mellitus was affecting 9.4-million people in Africa. The estimated increase in diabetes mellitus in Africa was anticipated to be 12.7-million, an increase of 140%, by 2025(Sarala Naicker, 2013,p.162). In the survey done in Rwanda on non-communicable diseases risk factors, diabetes was affecting 3.1% of the population(Ministry of health, 2015,p.15)

Other risk factors for ESRD include cardiovascular disease, obesity, high cholesterol, lupus, and a family history of ESRD (CDC,2014,p.1) .In addition to non-communicable diseases, communicable diseases especially infections (HIV, hepatitis ,glomerulonephritis) are common causes of ESRD in Africa(Halle et al. 2015, p.1; Ochwila et al. 2014,p.51; W. a Alashek et al. 2012,p.5). According to American Kidney fund(2015),high blood pressure (HBP) was noted to cause 28.4% of all new cases of kidney failure. In 2012 it was the primary cause for 159,049 kidney failure patients in US. An estimated 70 million (29%) people had hypertension (American Kidney fund, 2015,p1). The study conducted by Gerard et al. (2016) in Burkina Faso showed that the presumed causes of ESRD couldn't be identified in (22.1%), (77.9%) were hypertensive nephropathy ,(48.5%) chronic glomerulonephritis , 30.6% related to diabetes and viral origin 26.8%, chronic tubule interstitial nephropathy 19.4%, polycystic kidney disease (1.5%) (Gérard et al., 2016,p.33).According to Rwanda ministry of health ,15% of the population studied was having increased blood pressure (Ministry of health 2015,p.14)

Among the causes mentioned by American Kidney fund(2015,p.1),glomerulonephritis was representing (7,9%),cystic or hereditary congenital disease was responsible of (2.2%),urological disease (0.5%) ,other known causes(10.7%)missing Cause 3.2%, unknown Cause 3.1% in US. Stanifer et al. (2014,p.178) mentioned that CKD is a prevalent and potentially growing disease across sub-Saharan Africa with risk factors that include both communicable and non-communicable diseases. HIV also needs to be integrated in HIV and non-communicable diseases. Stanifer et al. (2014,p .179) mentioned also the use of traditional medicine where their study showed that up to 80% of the populations in sub-Saharan countries are estimated to use herbal or traditional medicines and some of the most commonly herbs used as drugs are *Securidacalongepedunculata* (African violet tree), Cape aloes, and *Euphorbia matabalensis*.

The risk of developing ESRD also rises with age, as these risk factors are commonly seen at older age(CDC 2014).Men who have chronic renal disease are 50% at risk than women to have renal failure (CDC,2014 p.1).The results of the study done in Palestine showed that 52.1% of ESRD participants were males(Zyoud et al.2016,p.3).Some racial and ethnic groups are at greater risk for ESRD. Compared to whites, the risk for African Americans is almost 4 times higher, Native Americans is 1.5 times higher, and Asians 1.4 times higher compared to non-Hispanics, Hispanics are about 1.5 times as likely to be diagnosed with kidney failure (American Kidney fund 2015, p.1). Studies oriented to causes of end stage renal diseases in Rwanda are lacking.

2.2.1.2 Overview on the use of hemodialysis procedure

Dialysis is the process of removing waste products from the body by diffusion from one fluid compartment to another across a semi-permeable membrane(Www.cms.gov ,2015).Dialysis procedures can include hemodialysis, peritoneal dialysis, hemofiltration and ultrafiltration. Among these types of dialysis procedures, two are mostly used to treat ESRD ,those are hemodialysis and peritoneal dialysis(Www.cms.gov, 2015).Hemodialysis is the preferred treatment of choice in Rwanda.

In hemodialysis, molecules diffuse in a solution crosswise a semi permeable membrane alongside an electrochemical concentration gradient(Himmelfarb, and T. Ikizler 2010 ,p.1833).Hemodialysis is achieved habitually in 3 to 5 hour sessions, 3 times a week(Www.cms.gov 2015,p.2 ask).The goals of hemodialysis are primarily also two functions. First hemodialysis removes renal failure-related toxins and second it removes surplus water and salt. In hemodialysis water is removed by hydrostatic ultrafiltration and this is a pressure phenomenon (Sam,2014p4). For hemodialysis to be done, blood and dialysate have to meet in the dialyzer despite the fact that the two fluids are separated by a semi-permeable dialyzer membrane (Sam,2014p1). By hemodialysis one supplements calcium and bicarbonate, at the same time as removing potassium, magnesium, and urea and extra toxins by diffusion water and sodium are removed by ultrafiltration(Sam, 2014,p.3).

According to Fresenius , more than half (50%) of the world dialysis patient population was treated in five countries that are the USA, China, Japan, Brazil and Mexico . The different values for the prevalence of dialysis in the five countries with the large number of dialysis patient populations, ranging from as little as 245 in China to 2,505 p.m.p. in Japan, are an indication of the widely varying situation regarding dialysis treatment practices (Fresenius Medical Care AG & Co. KGaA 2013p6).The following 10 countries considered by the number of patient population on dialysis were representing 23% of the global dialysis patient population and 25% of the world population. The remaining 25% of global dialysis patients were treated in approximately 135 different countries accounting nearly(43%)of the world population(Fresenius Medical Care AG & Co. KGaA 2013,p.6).

The study conducted by Sá(2013,p.9)revealed that Portugal was characterized by the highest incidence and prevalence of ESRD treated by dialysis or kidney transplantation in the European Union (EU) meaning that 235.9 and 1575.9 per million population (p.m.p) in 2010 and 226.49 and 1661.9 p.m.p in 2011.In 2011, there were 91,314 individuals on dialysis in Brazil, equivalent to a prevalence of 475 p.m.p. It was estimated that 50-70% of Brazilians who had ESRD died without being submitted to any type of treatment (Paulo, 2014,p.91)

Amanpour F, Dadgari A, Hebrahimi H (2016,p.250) in their study they found that there were more than 16,000 ESRD patients under dialysis treatment in Iran. In Singapore, the prevalence of ESRD was 1436.1 per million population in 2013 and the prevalence of dialysis patients increased at an average rate of 8% per year from 1999 to 2013(Yang et al. 2015, p.2). The dialysis population was expected to augment due to the population's aging and due to diabetes with a high prevalence (Yang et al., 2015,p.1). According to the study conducted by Kamau et al. (2012,p,75) in Kenya he showed that in Sub-Saharan Africa, an extent of 4000 ESRD patients were on maintenance hemodialysis and this number was representing less than 1% of the world total. Also he explained that the availability of renal replacement therapy in Sub-Saharan Africa (SSA) is restricted by elevated costs, deficiency of equipment and a small number of skilled personnel (Kamau et al. 2012,p.75).

In the study done by Stanifer et al. they projected an estimation of more than 70% with end stage renal disease patients to be in low income countries in 2030 such those in sub-Saharan Africa where the gross domestic product per person is classically less than US\$1500 per year (Stanifer et al., 2014p e174). There are no available information oriented to the use of hemodialysis in Rwanda but it might be difficult for ESRD patients to afford the hemodialysis cost considering that priority could be acute renal failure patients to be on hemodialysis for a period of 6 weeks using community based health insurance coverage after which they will be considered as chronic patients and will start to pay 100% of the whole package of hemodialysis, which is different in Europe and US where the coverage of ESRD is 100%(Kramer et al. 2016, p4,)This is different from Europe where the majority of ESRD patients on renal replacement therapy were covered at 100% (Kramer et al. 2016, p4, Tataradze et al. 2016 p.441, Hirth et al. 2008,p.91).

2.2. 2.Empirical literature

2.2.2.1Adherence to hemodialysis

Successful treatment of ESRD depends on patients adhering to their hemodialysis plan. However, this continues to be a persistent problem and a significant barrier to effective management of the population. Adherence is defined as the extent to which a person's behaviour of taking medication, following a diet, and/or executing lifestyle change, corresponds with agreed recommendations from a health care provider(WHO, 2003,p3).Adherence as defined by WHO is the extent to which a person's behavior (taking medications, following a recommended diet, and /or executing life –style changes) corresponds with the agreed recommendations of health care provider(WHO, 2003,p.3).

Hemodialysis (HD) patients are requested to adhere to a very complex treatment regimen consisting of fluid and diet restrictions, medications, and, generally, 3 or 4 hour hemodialysis (HD) sessions three times per week(Abo et al. 2015,p.21). Patients have to follow and adhere to the prescribed regimen for sustainable and best possible health and well- being(Abo et al. 2015). In the study conducted by Obialo et al.(2012,p.216) the treatment was defined as shortened if the length of dialysis was at least 10minutes shorter than the recommended length of dialysis or

missed if a patient missed one or more HD sessions in one month. The percentage of skipping \geq one dialysis session per month was 0.3 in France, 0.9 in Germany, 8.8 in Italy, 6.6 in Spain, and 12.6 in United Kingdom. For those who skipped at least one treatment, in Sweden:0, Japan:0, United State:2.3% of all sessions. About the percentage of patients who shortened dialysis sessions \geq 10 minutes, in France they were 7.3, Germany 9.5, Italy 8.8, United Kingdom 12.6 (Garzoni et al. 2007, p.231)

According to Wells (2015, p.1) positive influences given for adherence were including prolonged life, family, and hope of getting a transplant. Improved adherence to prescribed dialysis can reduce the morbidity and mortality (Obialo et al., 2012, p.315). The study conducted by Duong et al. in Vietnam revealed that (42 %) of patients missed hemodialysis session, and time on hemodialysis was associated with missed hemodialysis session. (Duong et al., 2015, p.1).

Nevertheless, few published studies in African countries have revealed non adherence as an issue. Ibrahim did the study in Egypt which showed that non-adherence through skipping hemodialysis sessions varied from 7 to 32% among end stage renal disease patients. The study done in Zimbabwe has shown that more than 50% of patients were not adherent to scheduled hemodialysis plan where 93% of respondents had missed at least one session with 61% missing most of the scheduled sessions and only 7% attending all the hemodialysis sessions as scheduled. Sixty seven percent had rescheduled the prescribed hemodialysis sessions more than once (Chironda et al., 2014, p.29). In Rwanda there are no available data exhibiting the picture of the level of adherence to hemodialysis among ESRD patients, reason for the present study.

2.2.2.2.1 Barriers to adherence to hemodialysis

Hemodialysis patients have to cope with many difficulties such as limitation of fluid intake and foods contained potassium, presence in HD session, diverse medications, social and economic problems, with changes in their work status or in family setting (Theofilou 2013, p.188). Theofilou (2011, p.2) emphasized patient education in maintaining the quality of life (QOL) and patient's survival. In the study conducted by Abo et al. (2015) in Egypt, it was shown that

patients under maintenance hemodialysis skipping a dialysis treatment and shortening treatment time were often caused by parallel types of problems.

The physical or other problems lead to the decision to skip a dialysis treatment or shorten treatment time. The physical problems reported included hypotension 50%, cramps 23.08%, fatigue 19.23%, and clots in access site ,33.33%(Abo et al. 2015,p.29).Recurrent muscle cramps frequently lead to non-compliance with the prescribed haemodialysis treatment (Rocco et al. 1993,p.1179) and impact patients' quality of life (Chironda and Bhengu 2016,p.5) as cited in(Fidan et al.2013).Perceived physical health has also been reported to cause reduced adherence to treatment regimen among CKD patients (Chironda et al., 2014p.29)

Kazley et al. (2014)conducted a study in South Carolina on Heath care provider perception of chronic kidney disease where they commented that adherence to available treatment options was found to be an issue in African American with CKD. The same authors reported patients to do not stay adherent to given treatment regimens because of deficient knowledge ,reaction of denial , fear, and they utilized frequently religion to deal with the situation (Kazley et al., 2014,p.1).

The study conducted by Abo et al.(2015,p.29) in Egypt has shown that more than half of the study sample reported the main cause of not taking medication was that it was costing a lot and more than three third 95% reported that their economic income was not sufficient for the plan while(3.64%)&(1.85%) shortened dialysis session by 4 to five times in one month and 6months follow up after program implementation respectively, and about 50 % of the study sample skipped one dialysis session with a month and only five patients in the study sample were died before two follow up times.

Ibrahim et al.(2015)stated that non-adherence to prescription is frequent among hemodialysis (HD) patients and has been associated with increased morbidity. They said that around 50% of HD patients are expected to be non-adherent to some part of their treatment. Their study showed that(36%) of HD patients were non-adherent to their dialysis treatment(Ibrahim et al. 2015,p.243)

In the study conducted by Maciel et al.(2015, p.544) the main obstacles to adhere to hemodialysis were difficulties with transport explained by the low socioeconomic rank, the deficit of knowledge concerning the disease, the restrictions resulting from the treatment and the disturbance experienced in the HD sessions. The study conducted by Day (2015, p.6) shows others considerations if hemodialysis has to be done in the hemodialysis unit and those are need to travel to the dialysis unit three times a week at a designed time, waiting time for the dialysis treatment and the work that may need to fit nearer the dialysis time. Other difficulties mentioned by Madeiro et al.(2010,p.548) included pain or anxiety during arteriovenous fistula puncture ,distance, care with the arteriovenous fistula , getting up early, water restriction, inability to work, dependency.

According to Chapman (2012, p.3) the majority of patients commencing dialysis in low income countries die or stop treatment within three months of initiating dialysis due to cost constraints.In Nigeria, a retrospective analysis by Ekrikpo et al.(2011,p.5) revealed that the main predictor of mortality was low dialysis frequency due to inability to pay for more than a few dialysis sessions. Poor adherence to hemodialysis in ESRD patients could be attributable to high cost as a major reason considering that the community based health insurance coverage can be used only for acute renal failure on hemodialysis , while ESRD patients on hemodialysis treatment pay out of their pockets.The lack of health care resources in low and middle income countries makes renal replacement therapy unavailable, with consequently low adherence to this therapy (Chironda and Bhengu 2016, p.5). Low awareness could be another factor contributing to poor adherence as the disease appears to be not well known and understood by many of Rwandan population. Rwanda as many of other African countries lack studies on factors influencing adherence to hemodialysis thus, some of those factors will be found out in this study.

2.2.2.2Motivating factors of adherence to hemodialysis

To be on hemodialysis will help ESRD disease patients to feel better and have lengthened life than if they are not under treatment (Day, 2015,p.6). The motivating aspects for therapeutic adherence were coexistence with the HD machine, the undertaking of laboratory tests, religious belief, and the existence of social support(Maciel et al.2015,p.544).Madeiro et al.

(2010p.548)showed factors that can promote adherence to hemodialysis treatment and those were fear of death, faith in God, and expecting a kidney transplant, resignation, family, hemodialysis professionals, work and indifference.

2.2.2.3 Conceptual framework Health Belief Model (adapted from Rosenstock,1960)

The Health belief model was used by Wells(2015) to guide her study entitled Determinants of Adherence to Living on Dialysis for Mexican Americans. The model was developed out of a set of independent and applied research problems with which a group of researchers in the Public Health Service were facing between 1950 and 1960. The theory and development of the model grew all together with the solution of problems that were practical (Rosenstock& Ph 1960,p.328).The components of health belief model were 1: individual perceptions explained by perceived susceptibility, modifying factors including demographic variables ,2: perceived threats and cues of action ,3:likelihood of action including perceived benefits and perceived barriers .The components of health belief model that were used in this study are modifying factors, perceived benefits, perceived barriers and behavior change

Modifying factors are defined like individual's characteristics that influence personal perceptions such as traditions,level of education ,experiences, expertise and incentive(Constructs &Concept 2003, p.33). In this study, modifying factors are demographic data for ESRD patients: age, sex, marital status, knowledge about ESRD.

Perceived benefits Perceived benefits are a person's opinions of the significance or the means to use a new behavior in reducing the threat of disease(Constructs & Concept 2003,p.32). In this study, perceived benefits are motivating factors of adherence to hemodialysis in ESRD in Rwanda.

Perceived barriers: They are obstacles of individuals in the method to accept a new behavior (Constructs & Concept ,2003, p33.). In this study perceived barriers will be constraints to adhere to hemodialysis plan in ESRD patients. Chan et al. (2014)mentioned some of obstacles that were depression, problems of transportation, demographic factors, and poor stimulus which were associated with missed dialysis treatment.

Behavior change Behavior is also influenced by cues to action that are defined as measures, community, or things that influence people to modify their behavior(Constructs & Concept 2003,p.33). In this study behavior change will be adherence to hemodialysis of ESRD patients.

Health belief model

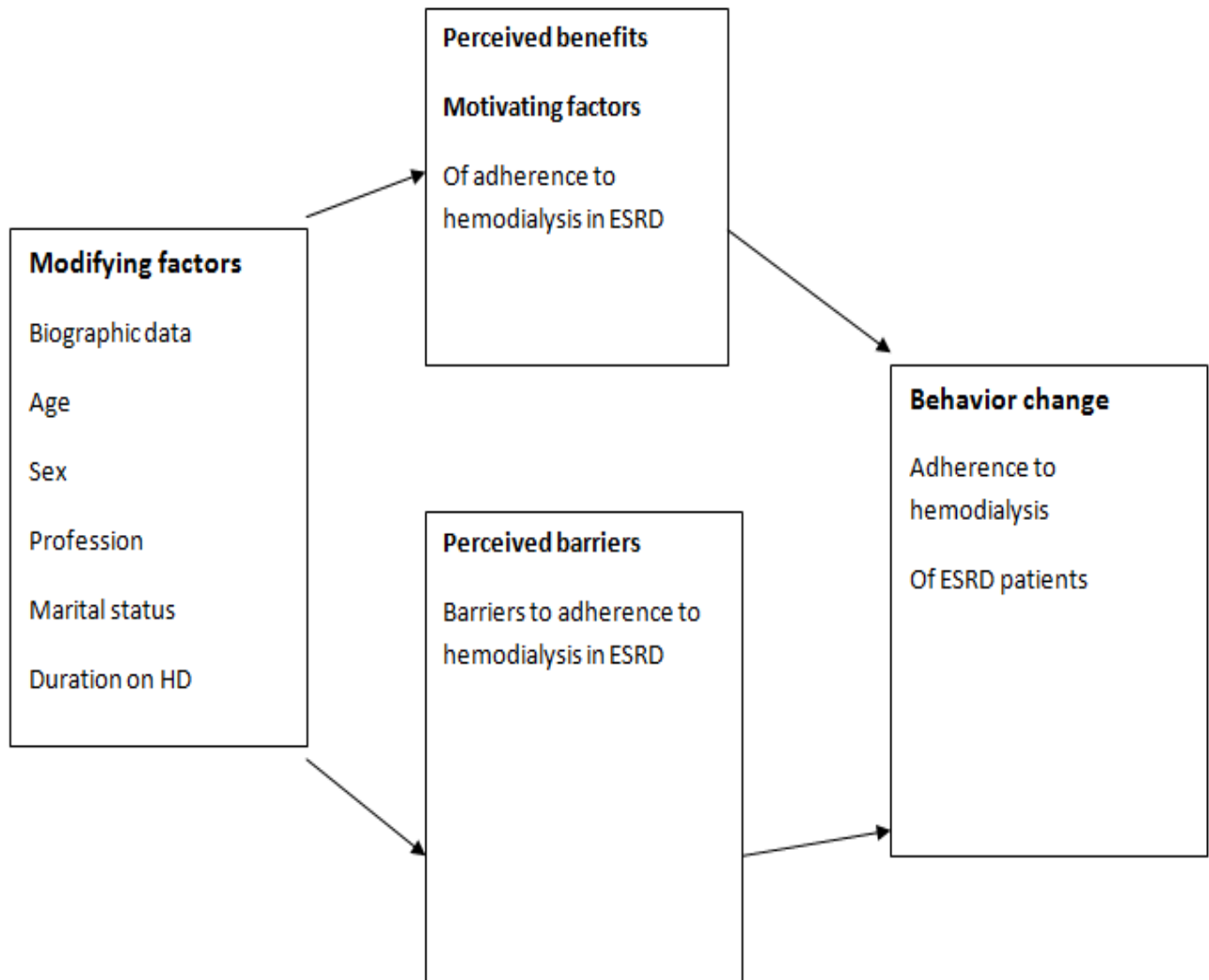


Figure 1: Adapted conceptual framework from health belief model (1960)

Conclusion:

The theoretical literature, empirical literature and adapted conceptual framework provided data to base on to build new ideas for the current study on adherence to hemodialysis among end stage renal disease in selected nephrology units in Rwanda

CHAPTER 3: METHODOLOGY

Burns N & Grove S. K. (2009) defined research methodology as the application of all the steps, strategies and procedures for gathering and analysing data in research investigation in a logical and systemic way. The methodology for this study was presented as follows:

3.1 Research approach

This study was a mixed method approach. According to Creswell (2014), mixed method research is an approach to inquiry involving both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks. The researcher used this approach as it involved both quantitative and qualitative to gain a complete understanding of the level of adherence to haemodialysis, elaborate and expand on the reasons behind the varying levels of adherence.

3.2. Study Design

The research design of a study outlines the basic approach that researchers use to answer their research question (Denise F. Polit & P. 2010, p.74). A sequential explanatory mixed method design was used for this study. Creswell defines sequential explanatory mixed method design as one in which the researcher first conducts quantitative research, analyses the results, and then is based on the results to explain them in more detail with qualitative research. In this study, the researcher collected and analysed quantitative data to determine the level of adherence to haemodialysis among end stage renal disease patients using descriptive cross sectional design. To further explain the varying adherence behaviours among ESRD participants, the researcher collected and analysed qualitative data from selected participants with high, moderate and low level of adherence to haemodialysis using qualitative descriptive design.

3.3. Study Area

The study was conducted at university teaching hospital of Kigali (UTHK) in dialysis unit during a period from September 2016 to March 2017. CHUK is the main public referral hospital in Rwanda located in the center of Kigali city in the district of Nyarugenge . University Teaching

Hospital of Kigali (UTHK) has 550 bed capacity. It was built in 1918. In 2028 it functioned as health center and later in 1965 as a hospital. From 1994 to 1996, UTHK has served as health center, a district hospital and as a referral hospital as well. It serves 1,000,000 people from a largely urban area and receives patients referred from different district hospitals in Rwanda for specialized care. It provides facilities for medical education, for nursing and other health and allied professionals education. The renal unit in UTHK was opened in 2015. King Faisal hospital (KFH), university teaching hospital of Butare (UTHB) constituted study areas in order to obtain needed sample size .

3.4 Study Population

Population is defined as all elements, such as individuals, events or objects that meet the sample criteria for inclusion in a study – sometimes referred to as target population (Grove et al.,2013). All hemodialysis patients in Rwanda constituted study population. The target population was patients attending hemodialysis at the selected study sites. Accessible population included the patients attending hemodialysis at the time of the study.

3.5 .Sample size for quantitative research.

According to Denise F. Polit & P.(2010, p.307), quantitative researchers should select the largest sample possible so that it is representative of the target population.

Therefore, the sample size for the quantitative study was equal to 41 studies participants.

3.6. Sample strategy for quantitative

The researcher used stratified sampling in quantitative stage. Stratified sampling means dividing the parent population into several types or layers and then sampling randomly from each layer, not sampling randomly directly from the parent population (Shi 2015, p.3). In this study, there were three strata namely UTHK, UTHB, and King Faisal hospital. Non probability sampling was used to select patients from each stratum (hospital). In non-probability sampling, randomization is not essential in selecting a sample from the population of interest, to a certain extent, subjective methods are used to decide which elements are included in the sample (Etikan et al., 2016, p.1). The researcher used the total population to select from each strata. This is where by the entire population that meet the criteria are included in the research being conducted. Total

population sampling is more usually used where the number of cases being investigated is relatively small (Etikan et al. 2016 ,p.3).

3.7. Sample strategy for qualitative

Study participants for qualitative case study were selected using a type of non-probability sampling called purposive sampling. According to Grove et al. (2013), non-probability sampling refers to non-random sampling in which not every element of the population has an opportunity for selection in the sample. Purposive sampling was used for the qualitative case study to follow those hemodialysis study participants from the quantitative phase with highest, moderate and lowest levels of adherence to hemodialysis for maximum variation. The researcher selected information-rich cases to find in-depth information on real reasons for varying adherence behaviors to hemodialysis.

3.8 Sample size for qualitative research.

The sample size for the qualitative part was determined by data saturation. Data saturation occurs when additional sampling provides no new information because new data yield redundant information (Creswell 2014). Therefore, the depth of information elicited one with on adherence behaviors to hemodialysis among CKD participants determined the sample size. The researcher started with two cases, one with high level, moderate and one with low level of adherence to hemodialysis, to give in-depth information on motivators and barriers to adherence to hemodialysis. More cases of ESRD participants were selected until data saturation was achieved. Data saturation was achieved at participant number 12.

3.9. Selection criteria for quantitative study

Inclusion criteria

- Patients on hemodialysis for more than 2 months,
- Adult aged 18 years and above
- Patients able to communicate effectively
- Conscious patients who agreed to participate

Exclusion criteria

- Acute renal disease patients
- Critically ill patients on hemodialysis who are unable to cooperate

- CAPD patients
- Hemodialysing patients for less than 2 months

3.10. Selection criteria for qualitative

3.11. Inclusion criteria for cases of selected ESRD participants

In this study, all ESRD participants on haemodialysis who met the inclusion criteria for the quantitative phase also met the criteria for the qualitative phase. Cases of participants with the highest, moderate and lowest levels of adherence to haemodialysis were included in the case study. These cases were selected until data saturation was achieved.

3.12. Exclusion criteria for cases of selected ESRD study participants

Cases of ESRD participants who were excluded in the quantitative phase were excluded in the case study. Cases of ESRD participants with average adherence to haemodialysis will not be included in the qualitative phase of the study.

3.13. Data collection procedure

After obtaining ethical clearance, ethical approval from respective hospitals that composed the study sites were delivered then copies were given to unit managers of dialysis units to facilitate the researcher to approach the patients. Once the researcher introduced, ESRD patients were individually explained the purpose of the study and those who accepted to participate were given informed consent form that then was signed. Interview schedule guide form was read and explained to the participants, with clarification where needed, then they were asked questions and were helped to tick their chosen answer for the quantitative study. Information given for the qualitative phase was audio recorded, observation notes, and field notes were taken. The interview was translated from Kinyarwanda to English before transcription.

3.14. Data Collection methods for quantitative

The research instrument for quantitative was developed using components of ESRD adherence questionnaire (Kim et al., 2011) and from literature. The English instrument was translated into Kinyarwanda instrument by specialists in the Department of Languages at the University of Rwanda. Self-reported method of collecting data was used. It was the structured interview guide which consisted of two sections namely demographics and level of adherence to hemodialysis.

The demographic section captured the personal descriptive data of ESRD participations. The second section asked questions that revealed the extent of adherence to hemodialysis among ESRD patients.

3.15. Instrument for qualitative study

In the qualitative phase, semi-structured interviews with open-ended questions were used to collect data. This was an interview situation in which the researcher had a list of topics to cover on barriers and motivators to adherence to haemodialysis. The English instrument was translated into Kinyarwanda instrument by specialists in the Department of Languages at the University of Rwanda. Self-reported method of collecting data was used. Use of open-ended questions in the qualitative phase allowed selected ESRD participants to respond narratively in their own words.

The instrument for motivators and barriers to adherence to haemodialysis among ESRD was developed from in-depth literature review. It consisted of three items. The semi-structured interview schedule was designed to elicit in-depth information on motivators and barriers to adherence to haemodialysis of ESRD participants who presented with low and high levels of adherence to the procedure. Selected ESRD study participants were asked questions on how they were managing their haemodialysis, motivators of adhering with their haemodialysis and barriers to adherence with haemodialysis.

3.16. Validity of the data collection instrument for quantitative

Polit and Beck(2012) define validity of a questionnaire as the degree to which the instrument measures what it is intended to measure. **Face validity** was ensured through structuring the instrument into two separate stages. Face validity is established when an individual (and or researcher) who is an expert on the research subject reviewing the questionnaire (instrument) concludes that it measures the characteristic or trait of interest. Face validity involves the expert looking at the items in the questionnaire and agreeing that the test is a valid measure of the concept which is being measured just on the face of it(Bolarinwa 2015,p.196).

Content validity was ensured through giving the instrument to experts in the nephrology field to assess whether all contents to be measured have been included. Content validity is the extent to

which the questions on the instrument and the scores from these questions represent all possible questions that could be asked about the content or skill (Mohamad et al.,2015)as cited in(Creswell, 2005). Again, inclusion of items from literature also enhanced content validity of the instrument.

Construct validity was achieved by checking items in the data collection tools against study objectives and concepts in the framework to ascertain whether all construct under study have been measured. Pre-testing the instrument was conducted to check for any ambiguities in the instrument. **Construct validity** is the degree to which an instrument measures the trait or theoretical construct that it is intended to measure. It does not have a criterion for comparison rather it utilizes a hypothetical construct for comparison. It is the most valuable and most difficult measure of validity. It is a measure of how meaningful the scale or instrument is when it is in practical use (Bolarinwa 2015,p.197)

Table 3.1: Construct validity measure for the study

Objectives of the study	Components of the conceptual framework	Interview schedule	Items in interview schedule
To determine the level of adherence among ESRD patients	Behaviour change	Appendix 1	Section A and B, all items
To identify motivating factors of adherence to hemodialysis among end stage Renal Disease (ESRD) patients	Perceived benefits	Appendix 2	Section A, item 1 and 2
To identify barriers of adherence to haemodialysis among ESRD patients	Perceived barriers	Appendix 2	Section A, items 1 and 3

3.17. Reliability of the quantitative:

Reliability refers to consistency, accuracy and dependability with which the instrument measures data (Polit and Beck,2012). Translating the research tool from English to local language ensured collection of reliable data, free from misinterpretation. Use of the structured interview schedule and following the items using the same wording and sequencing during the interview also enhanced the reliability of the data obtained through the instruments. A reliability analysis called Cronbach's alpha was performed to measure the internal consistency of the instrument.

3.18. Trustworthiness in qualitative data

The researcher took measures to improve the trustworthiness of qualitative data. According to Miles et al.(2014), defined quantitative analysis as manipulation of numeric data through statistical procedures for the purposes of describing phenomena or assessing the magnitude and reliability of relationships among them. Four measures of trustworthiness for this study were credibility, dependability, confirmability and transferability.

Credibility refers to how much the data collected accurately reflects the multiple realities of the phenomenon (Sikolia et al.,2013,p.2).In this study the credibility was achieved through prolonged engagement on the field that permitted to capture and well understanding the cultural context and believes of ESRD participants about hemodialysis treatment ,and gain the trust of given informations.

Triangulation was used through face to face interview and patients observation to capture their emotions. Also member checks were used to verify if recorded data were true.

Transferability is a trustworthiness concept that can be seen as external validity. Sikolia et al. (2013, p.2) explained transferability as the applicability of one set of findings to another setting. In this study, transferability was ensured by using purposive sampling where only ESRD patients on hemodialysis treatment were composing the sample for the qualitative research because they were possessing information of the phenomenon under study and this would allow the generalization of obtained findings from participants to the general population knowing that all referral teaching hospital dialysis centers were considered.

Dependability refers to the confirmation that the data represents the varying conditions of the phenomenon under study and should be consistent across time, researchers and analysis

techniques (Sikolia et al. 2013,p.3) as cited in(Brown et al.2002, Morrow ,2005). In this study, dependability was ensured by allocating another individual researcher in the field to evaluate the consistency of the instrument used. Interview records, observation notes, were kept for the audit trial.

Confirmability: Confirmability refers to the degree to which the results of an inquiry could be confirmed by other researchers (Anney 2015,p.279). In this study, confirmability was achieved by allowing the audit trial to verify all steps that were followed during the data analysis.

3.19. Data analysis for quantitative

Polit and Beck(2012) defined quantitative analysis as manipulation of numeric data through statistical procedures for the purposes of describing phenomena or assessing the magnitude and reliability of relationships among them. In this study, descriptive statistics were used to describe the extent of adherence to hemodialysis among ESRD patients. Inferential statistics of chi squared to test if there is any association between demographic variables and extend of adherence to hemodialysis among End stage Renal Disease Patients.

3.20. Data analysis for qualitative

Data analysis for qualitative method used thematic framework approach. Thematic analysis or qualitative content analysis see commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby looking for them to illustrate descriptive and/or explanatory conclusions clustered around themes (Gale et al., 2013,p.2). In this study, the stages of analysis for the qualitative data were: data organization, familiarization, identifying thematic framework, indexing, displaying data, interrelating and description of themes.

3.21. Ethical consideration

The permission was requested from ethical board and research committee to carry out the study then after ethical clearance, permission to collect data was requested and delivered by hospital research committees. Concerned hospitals were University Teaching Hospital of Kigali, University Teaching Hospital of Butare, and King Faisal Hospital and ethical approval was obtained from these study sites. Patient's rights were respected which include to refuse or to withdrawal from the study at any time, without any consequence to health care and they were prevented from discomfort and harm. Privacy was observed. Confidentiality was respected.

Informed consent and participant's authorization was sought. The purpose of the study was explained to the participants .Informed consent from participants was taken. The participation was voluntary.

3.22. Data management

Interview schedule completed forms were put in locked cupboard after every daily interview sessions, then entered and coded using computer where they were kept using a password to prevent any escape of participant's information. No identifying information was put on the data collection tools. Interview schedule hard copy completed forms will be kept for two years after which they can be destroyed.

3.23. Dissemination

The thesis will be presented to the library, and copies will be given to the study sites ,that are University Teaching Hospital of Kigali, University Teaching Hospital of Butare and King Faisal Hospital.

CHAPTER 4: STUDY RESULTS

4.1 Introduction

Chapter four focuses on study results. The study approach is a mixed method approach. The research design for this study was sequential explanatory mixed method, which involved collection and analysis of quantitative data followed by collection and analysis of qualitative data. The purpose of the study was to explore adherence to hemodialysis among end stage renal disease patients (ESRD) in selected nephrology units in Rwanda. The main objective was to investigate the extend of adherence to hemodialysis and associated factors among end stage renal disease patients in selected nephrology units in Rwanda .Specific objectives were to assess the extent of adherence to hemodialysis among end stage renal disease patient, identify barriers to adherence to and motivating factors of adherence to hemodialysis among end stage renal disease (ESRD) patients.

4.2 Quantitative findings

A total sample of 41 ESRD participants was selected for the quantitative phase. Data was collected through interviews using face-to-face interview schedule. Statistical Package for the Social Sciences (SPSS)/pc version 21 computer software was used to compute all statistical analysis. Presented below are results from the quantitative phase which includes descriptive statistics on demographic data, the level of adherence to haemodialysis, and inferential statistics of chi squared to identify associations between selected biographical characteristics and adherence to haemodialysis.

4.2.1 Demographic data of ESRD participants

Figure 4.2 shows the results on the age of ESRD participants. The total number of ESRD participants was 41. Eleven (26.83%) were aged between 51 and 60 years, 10 (24.39%) were having greater than 60 years, 9 (22%) were aged between 31 and 40 years, (14, 63%) between 41 to 50 years and 5 (12.20%) were aged between 18 and 31 years.

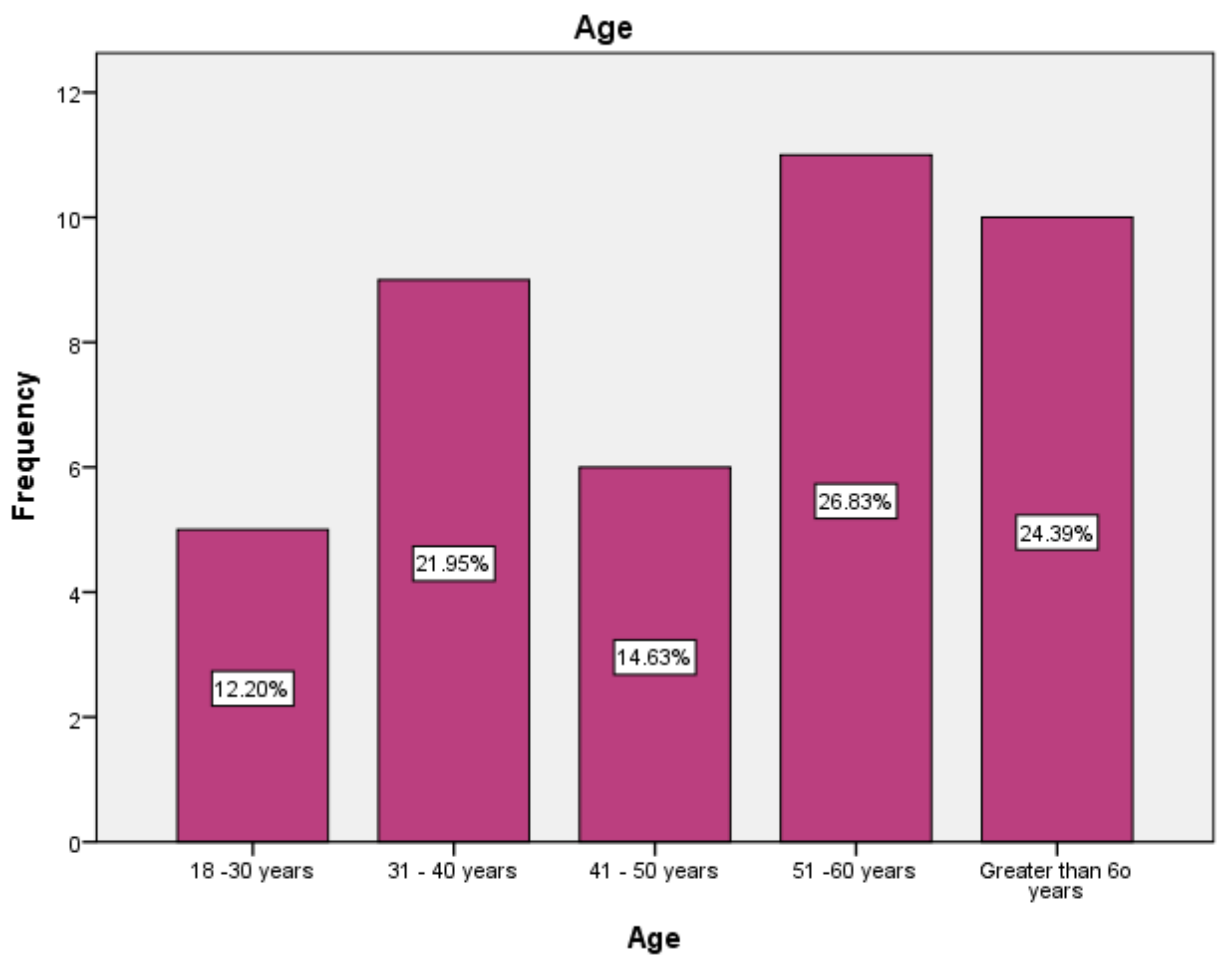


Figure 4.2: Distribution of age among ESRD participants (N = 41)

The figure 4.3 represents the distribution of gender .The majority of ESRD participants were males, 24(58,54%) , than females who were 17 (41 ,46%) among 41 respondents.

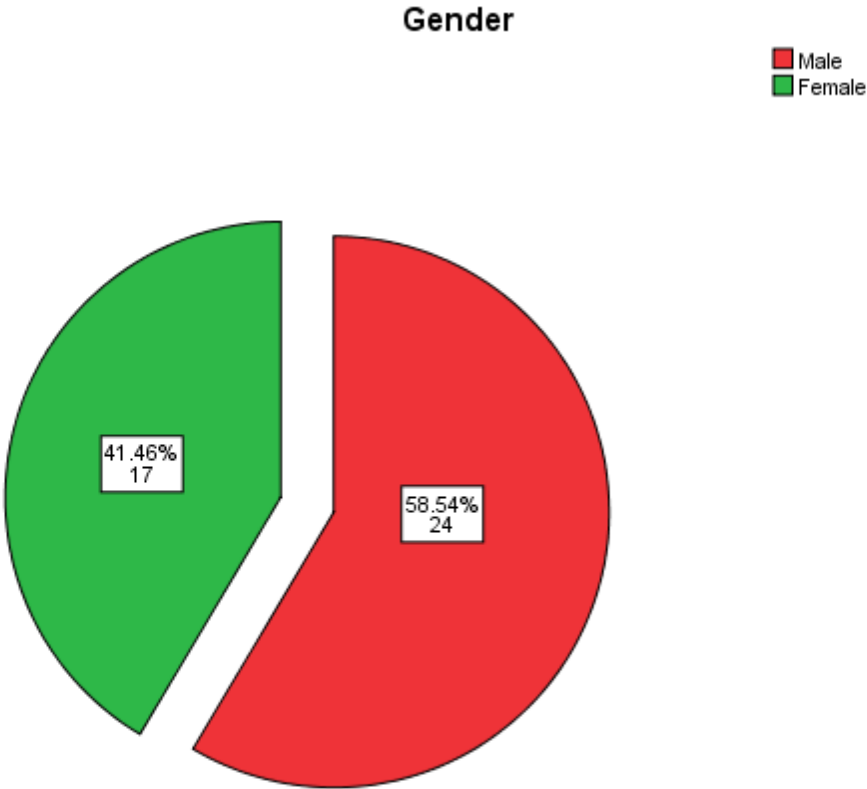


Figure 4.3:Distribution of gender among ESRD participants(N=41)

The figure 4.4 demonstrates the marital status of ESRD participants. Among 41 respondents, 28(68,29%) were married, 7(17,07 %) were single, 5(12,20%) were widowed and 1(2,44 %) was separated.

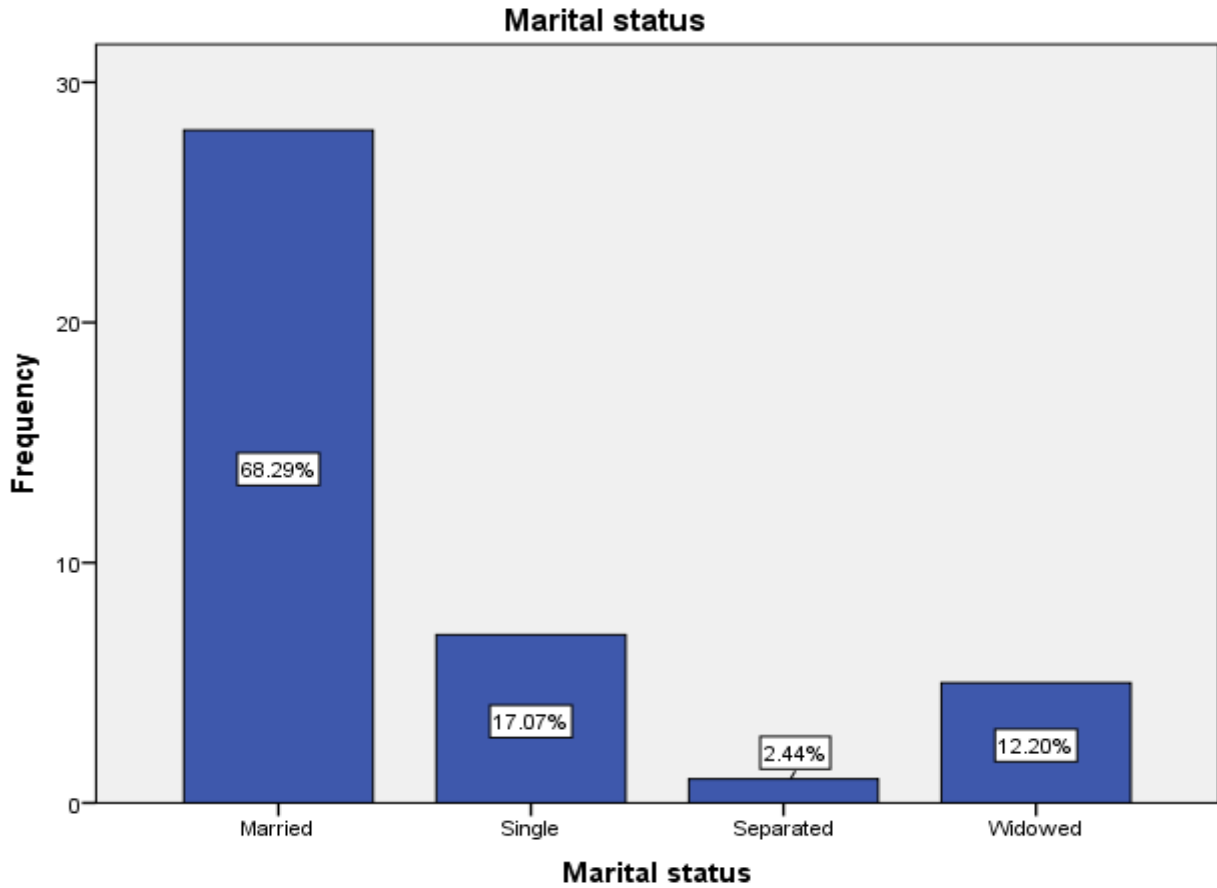


Figure 4.4: Distribution of marital status of ESRD participants (N=41)

The figure 4.5 displays the level of education of respondents .The figure shows that 16(39,02%) were secondary educated,13(31,71%) completed primary education, 8(19.51%)frequented colleges or universities and 4(9.76%)were not educated.

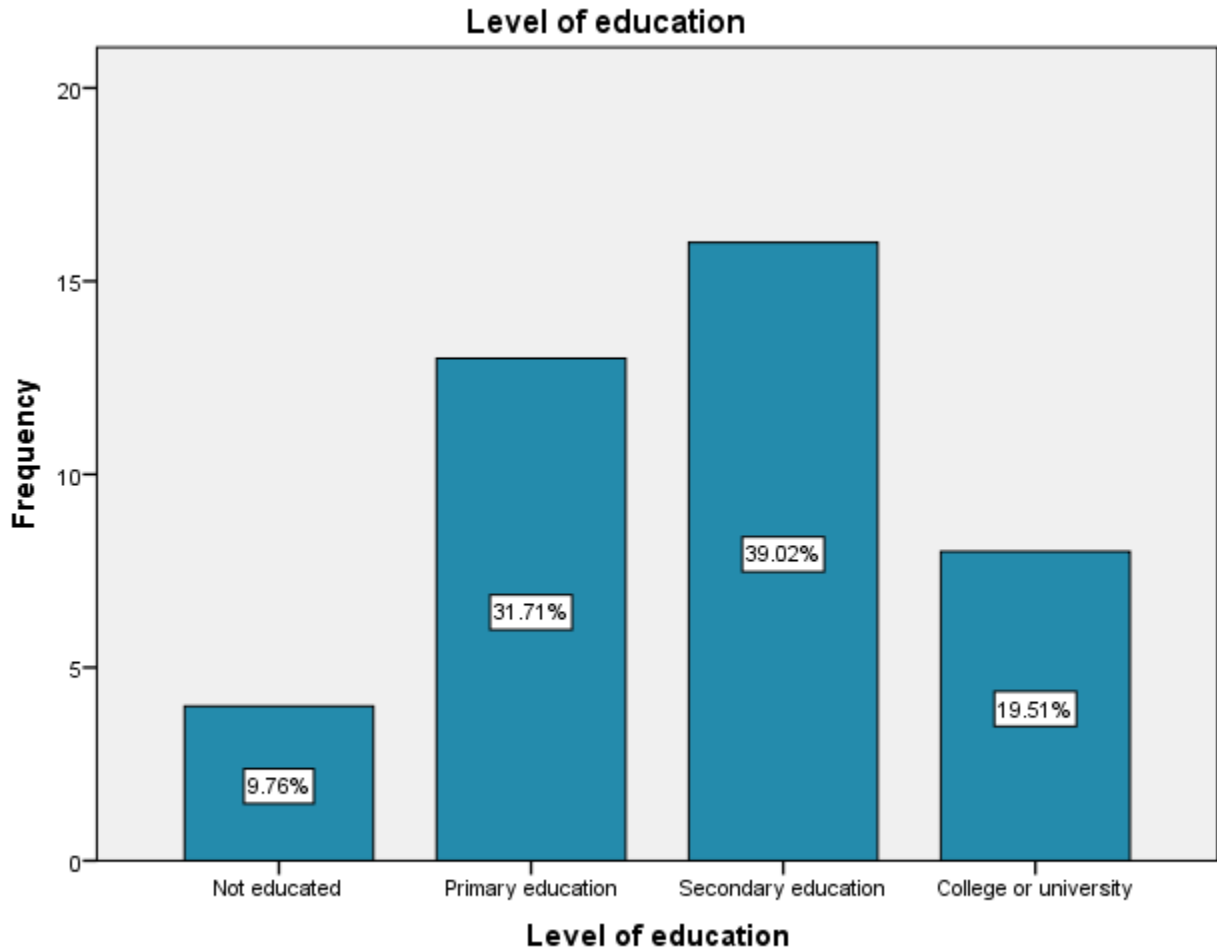


Figure 4.5: Distribution of the level of education among ESRD participants (N=41)

The figure 4.6 shows the religion of ESRD participants. Christians were representing 39(95.12 %) and Muslim were representing 2 (4.88%) among 41 participants.

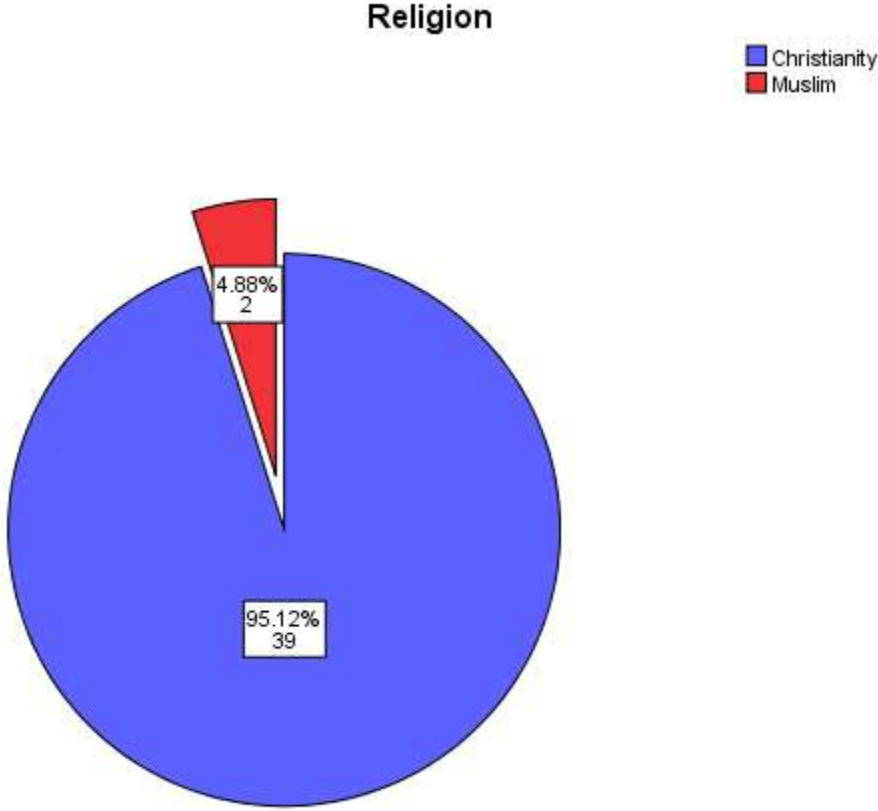


Figure 4.6: Religion of ESRD participants (N=41)

The figure 4.7 shows that in term of occupation, 31(75.61%) were unemployed, 6(14.63%) were self-employed and 4(9.76%) were public servants.

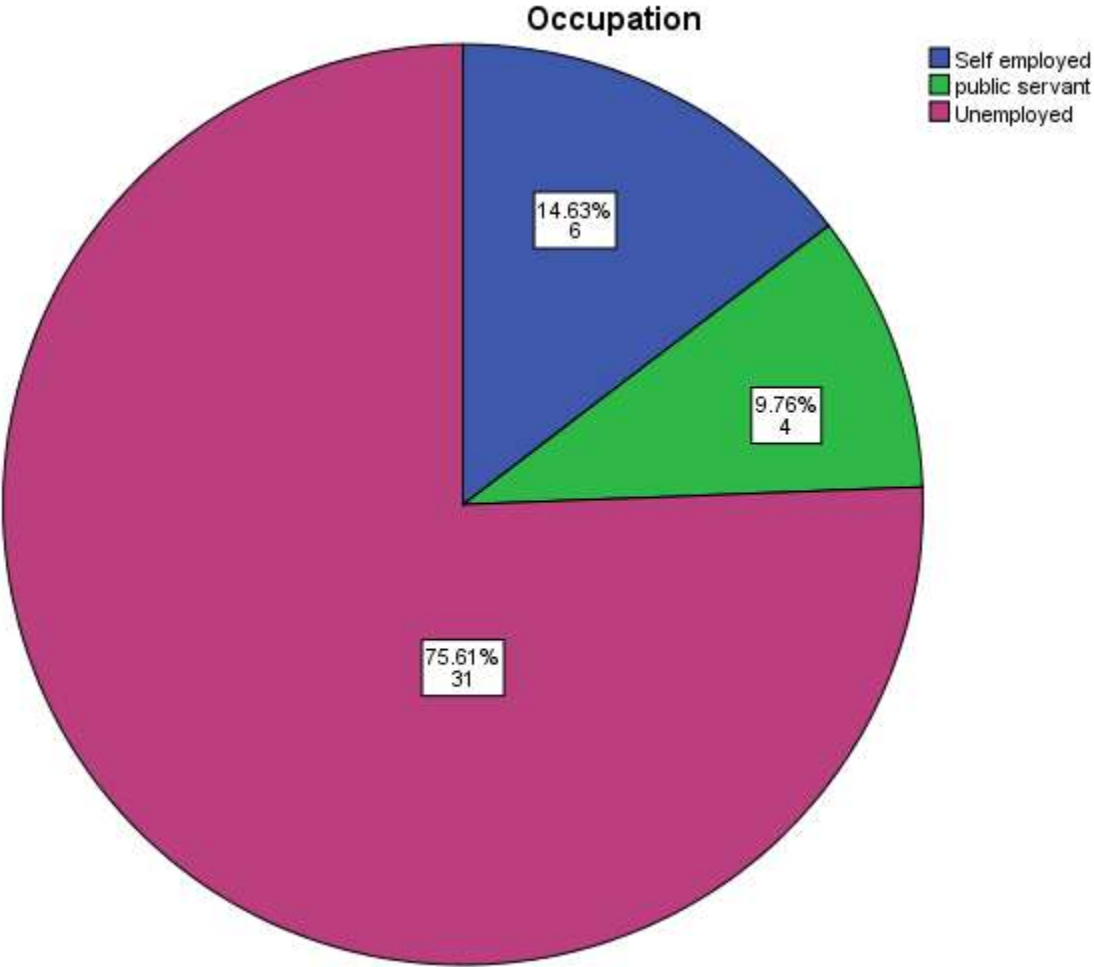


Figure 4.7: Occupation of ESRD participants (N=41)

Figure 4.8 demonstrates monthly income of ESRD participants. For 31(75.61%) participants, the monthly income was zero,4(9.78%) were having a monthly income of more than 200000 Rwanda francs, 3(7.32 %) had between 100 000 and 200000 Rwanda francs of monthly income, also 3(7.32 %) were having a monthly income of between 50000 and 100000 Rwanda francs.

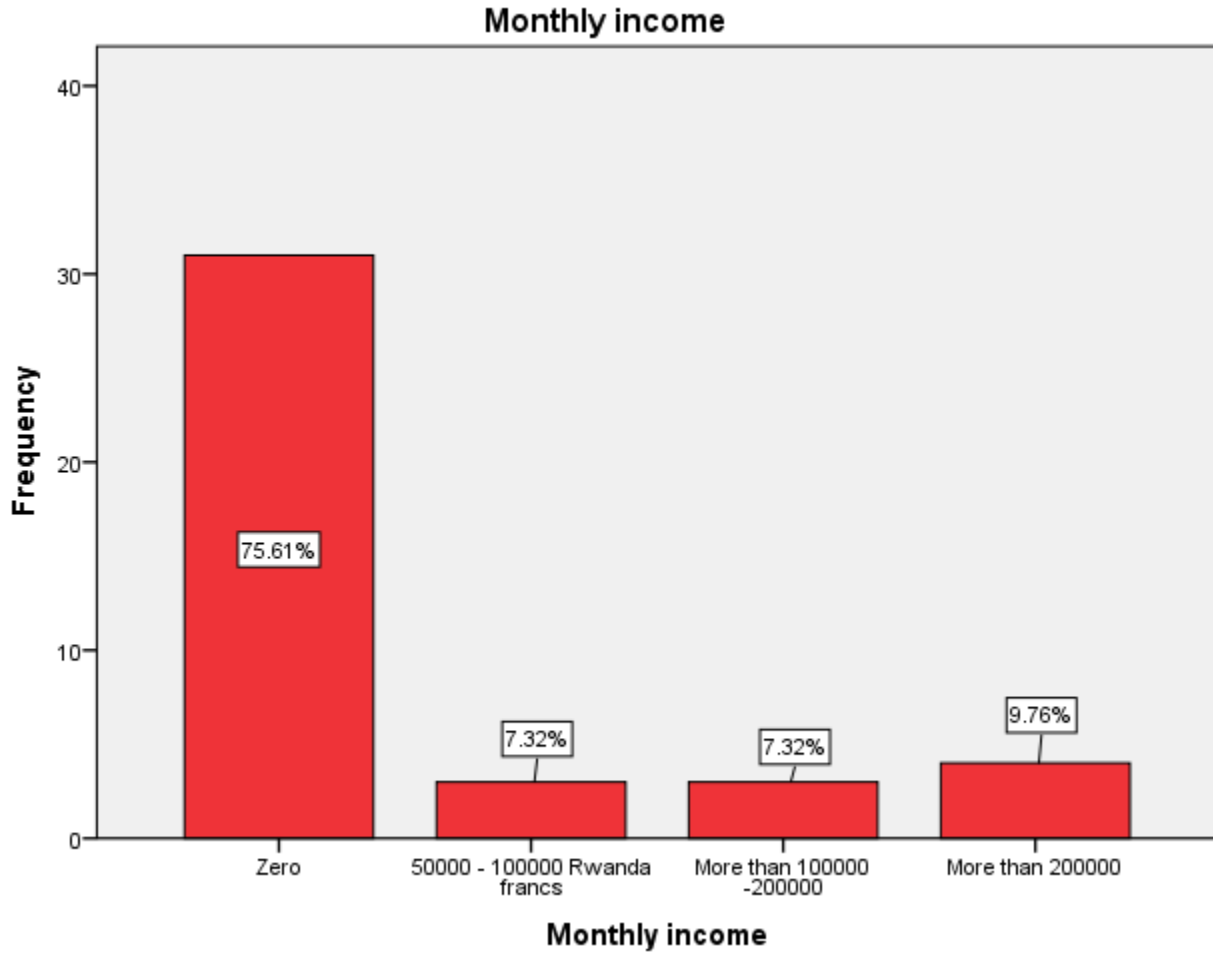


Figure 4.8: Monthly income of ESRD participants (N=41)

The figure 4.9 shows the areas of residence of ESRD participants. Twenty two (53.66%) were living in high density areas, 16(39%), were staying in medium density areas,2 (4.9%) were living in low density area and one (2,4%) was staying in rural area.

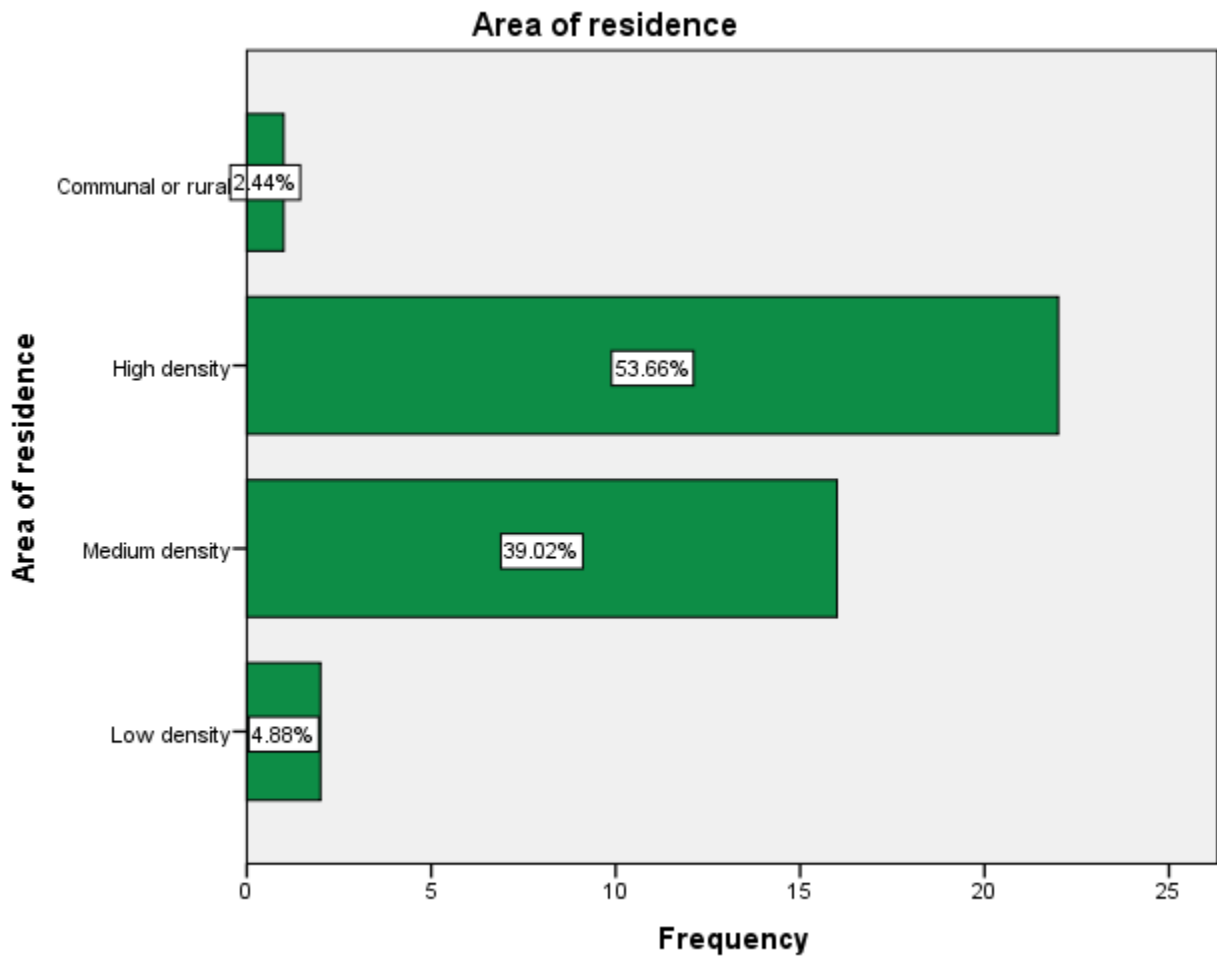


Figure 4.9: Area of residence of ESRD participants (N=41)

Figure 4.10 concerns the mode of transport used by ESRD participants .Sixteen (39.02%) were using taxis,11(26.83%) used public buses, 12(29.27%)had private cars and two(4.88%) used to come to the hospital by foot.

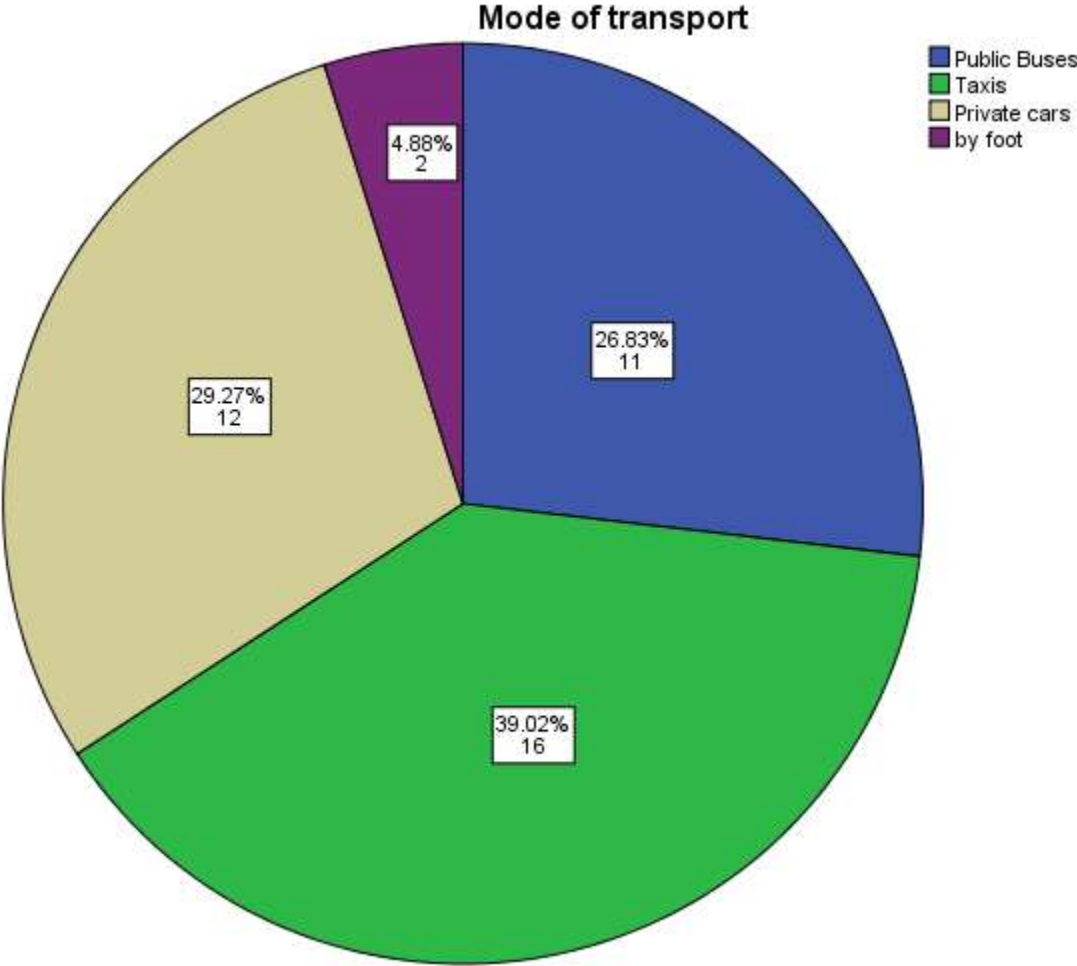


Figure 4.10: Mode of transport of ESRD participants (N=41)

The figure 4.11 demonstrates the distance existing between the hospital and home for ESRD participants .Twenty one(51.22%) were staying at a distance of between zero and ten kilometers 8(19.51%) were staying at a distance ranging between eleven and twenty kilometers,1(2.44%) participant was living at a distance between twenty one and thirty kilometers,3(7,3%) were staying at a distance between thirty one and fourty kilometers and 8(19.51%) participants were staying at a distance of greater than fourty kilometers.

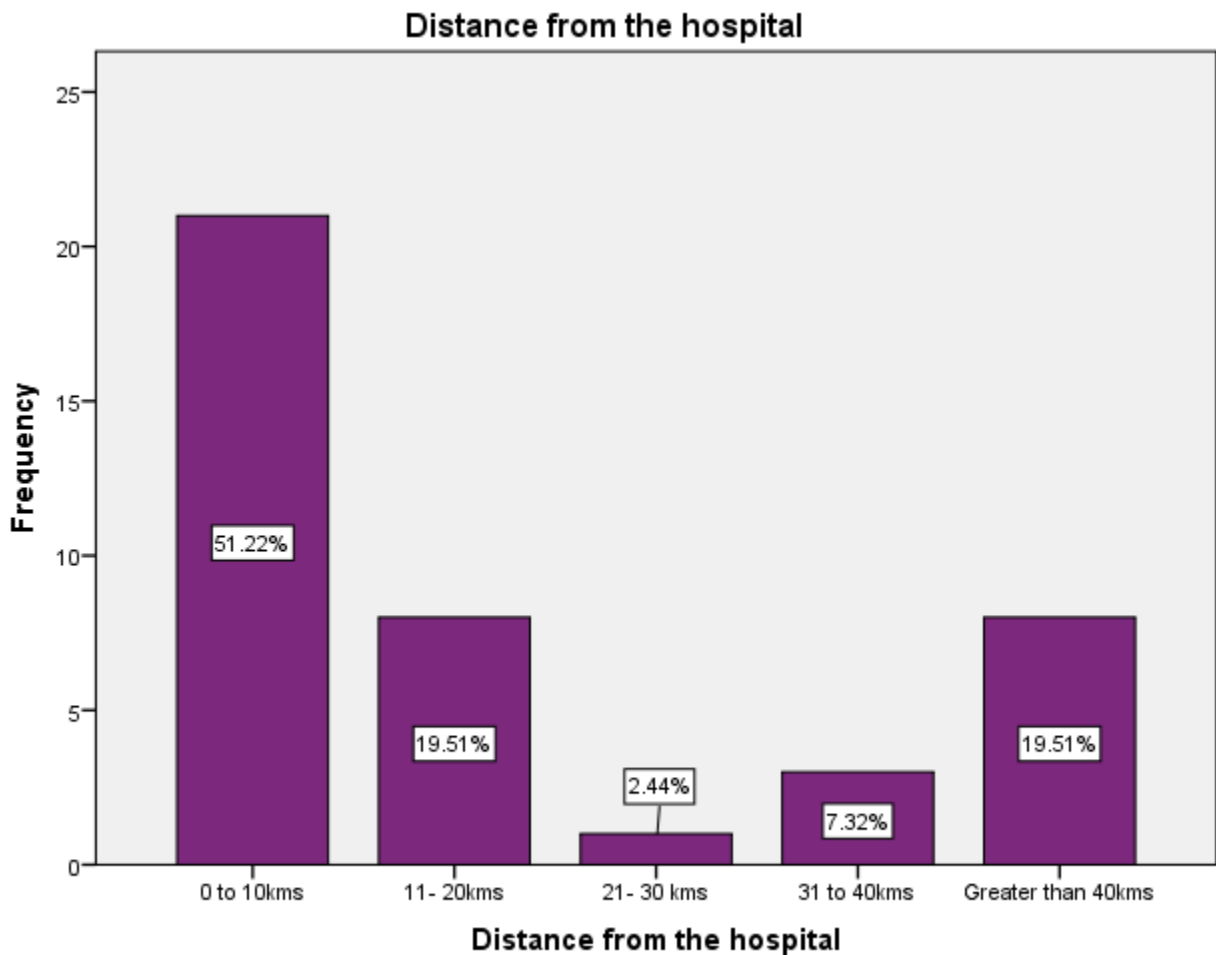


Figure 4.11: Distance between the hospital and home of ESRD participants (N=41)

The figure 4.12 shows the mode of water supply among ESRD. Thirty nine (95.12%) were able to use tap water and 2 (4.88%) were using water from river among ESRD participants.

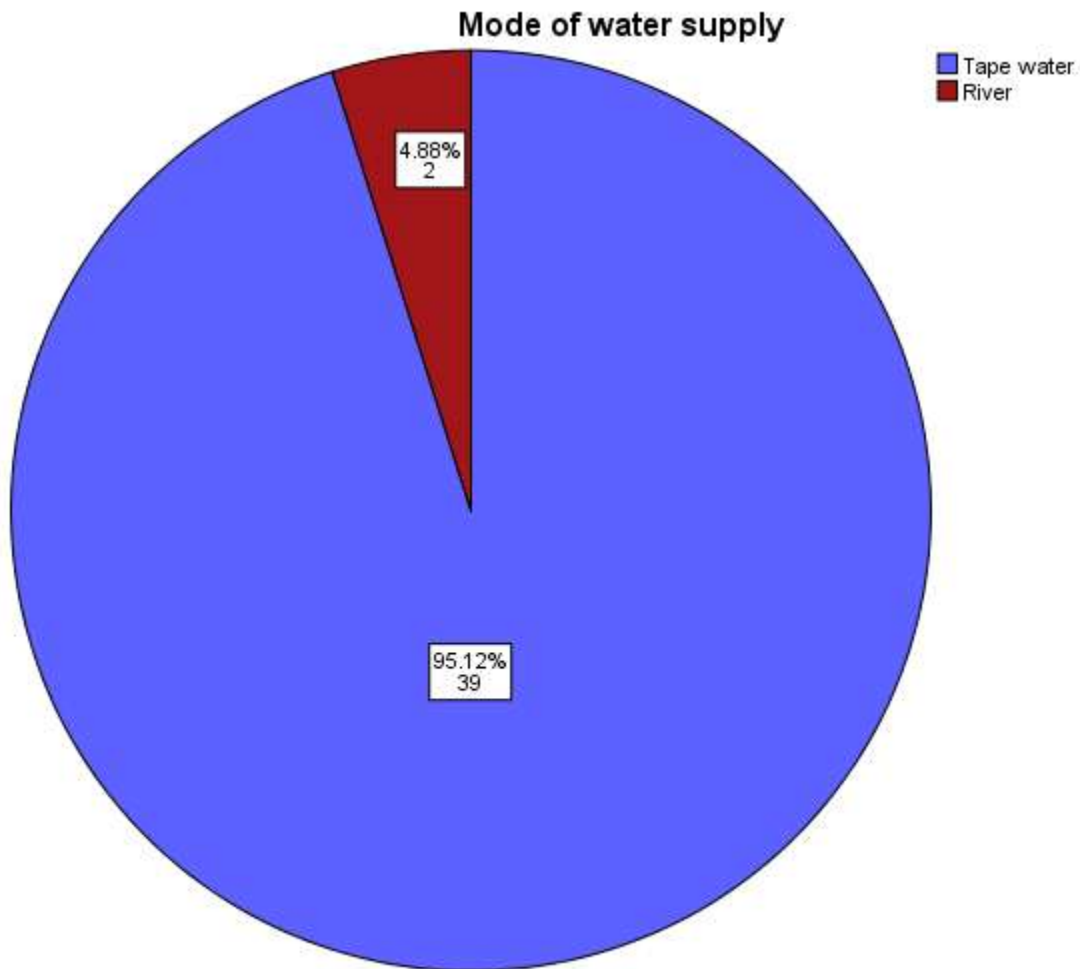


Figure 4.12: Mode of water supply among ESRD participants (N=41)

The figure 4.13 shows the mode of sewerage system .Twenty two (53.7%) were using flashing system while the remaining 19(46.3%) were using pit latrines.

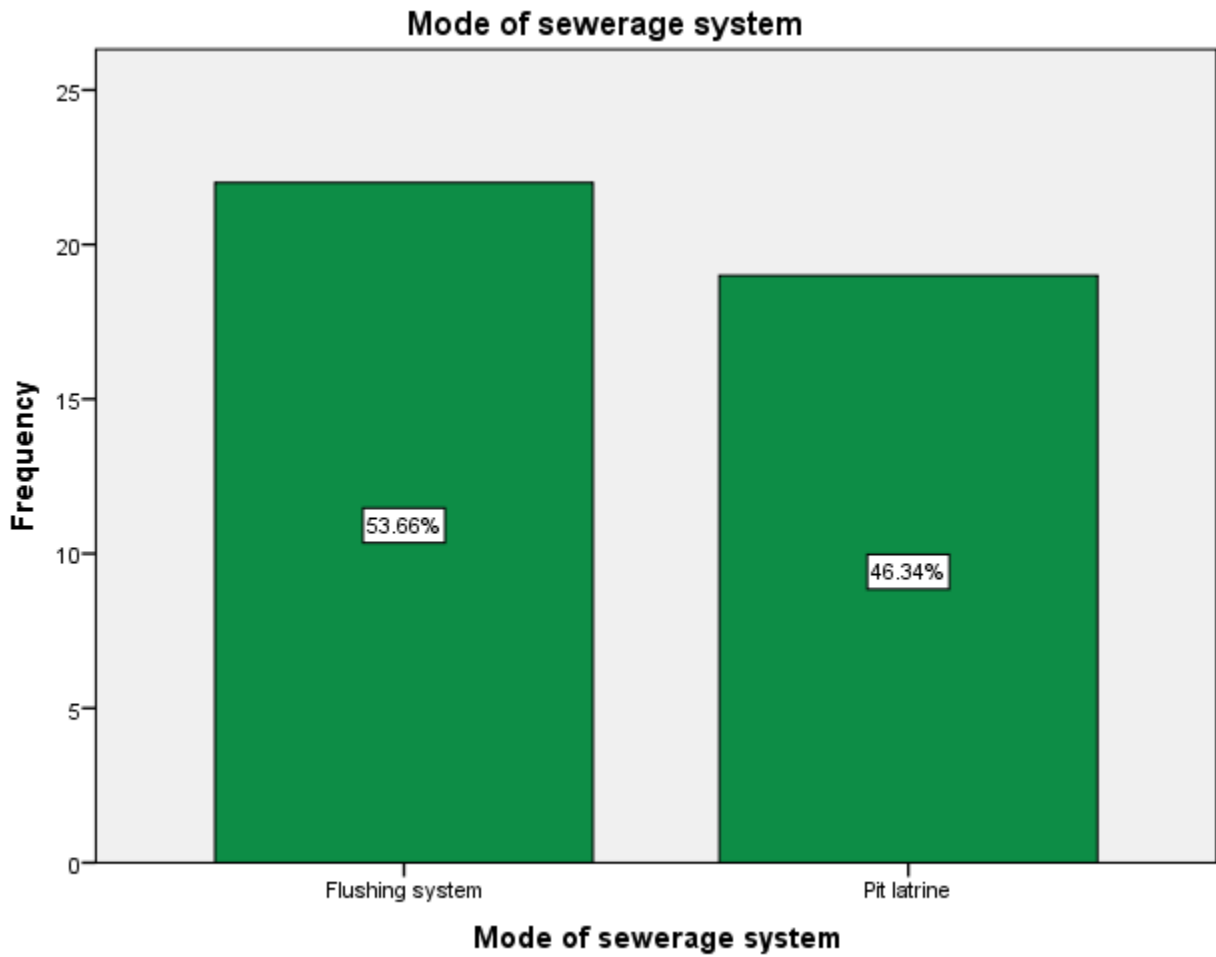


Figure 4.13: Mode of sewerage system among ESRD participants (N=41)

The figure 4.14 shows the availability of support system .Twenty(48,8% of ESRD participants were covered by FARG , 8(19.51%) were self-sponsored ,private medical insurances were covering 6(14.63%),4(9,76%) participants were covered by the community based health insurance and 3 (7.32 %)were assisted by the government.

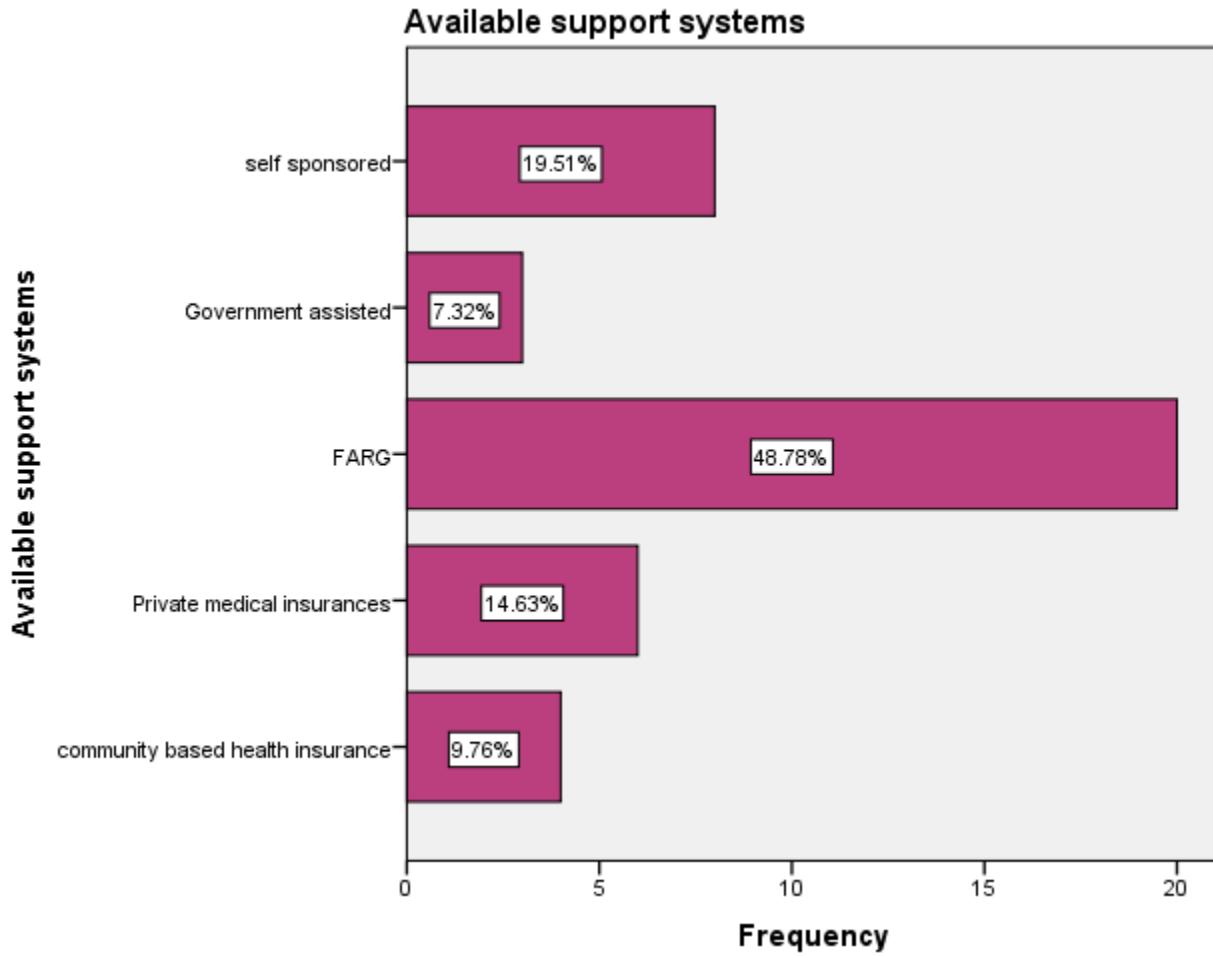


Figure 4.14: The availability of support system for ESRD participants (N=41)

The figure 4.15 concerns the duration of ESRD. The study results revealed that 12 (29.27%) participants were having ESRD for more than five years, 11 (26.83%) had ESRD for a period between three months and one year, 8 (19.51%) participants had ESRD for three to five years, 6 (14.63%) had ESRD for two to three years and 4 (9.76%) for one to two years.

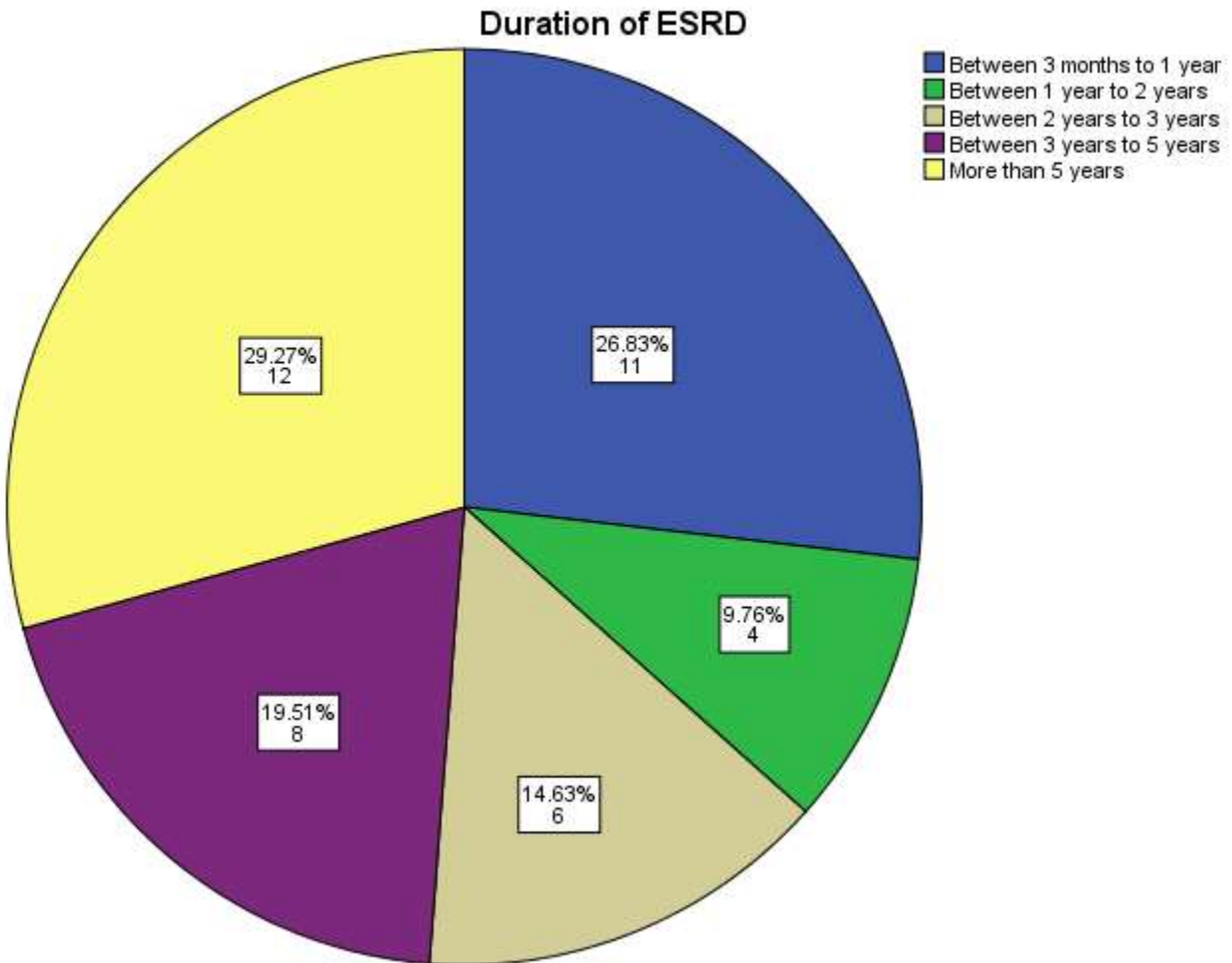


Figure 4.15: Distribution of duration of ESRD (N=41)

The figure 4. 16 demonstrates the causes of ESRD.Among 41 participants the results from the study showed that in 22 (53.66%) ESRD was caused by hypertension , 8(19.51%) had diabetes mellitus,4(9.76%)had diabetes and hypertension, for other 4 (9.76) the cause was unknown and for 3 (7.32%) the ESRD was attributed to other causes

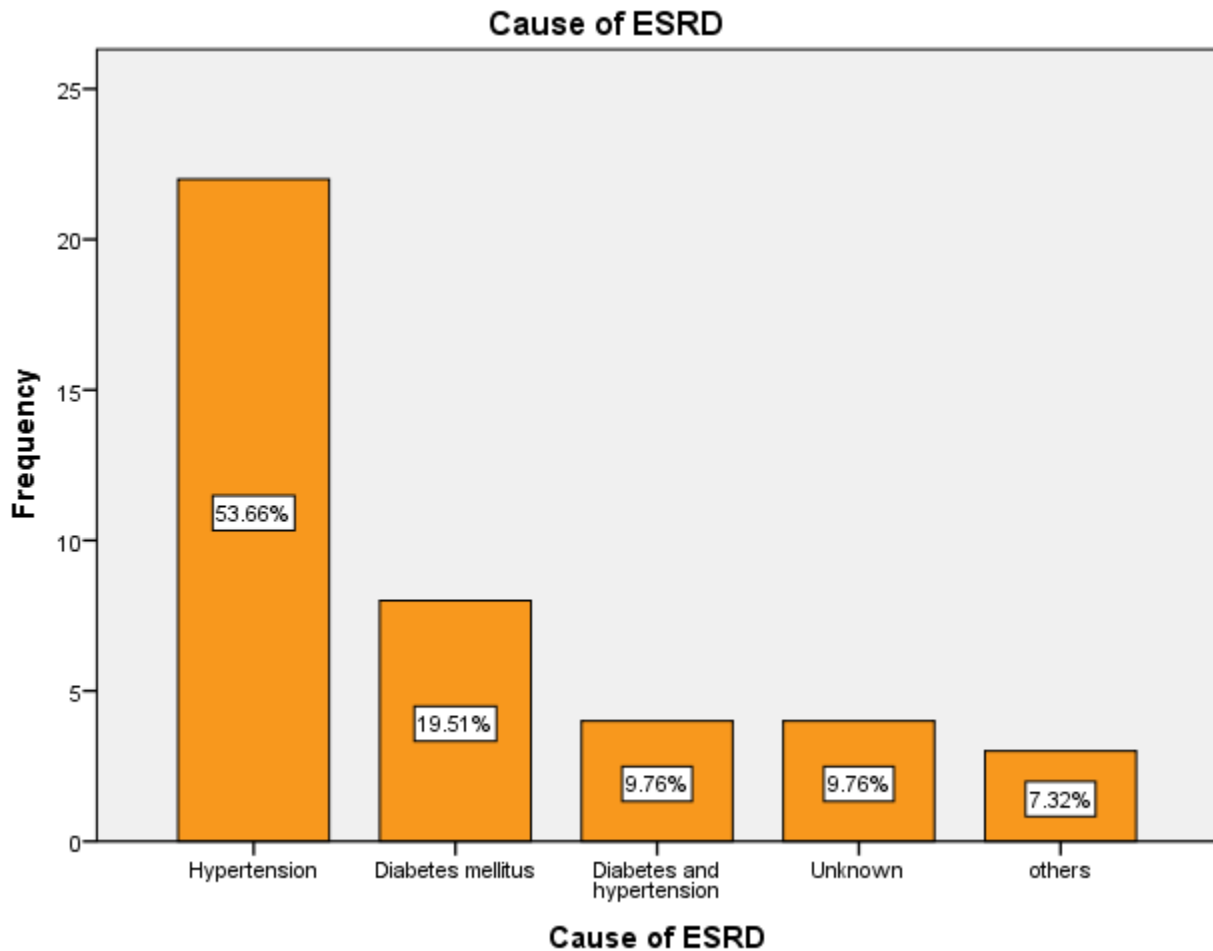


Figure 4.16: Distribution of causes of ESRD among study participants(N=41)

4.2.2 Adherence to hemodialysis among ESRD participants

The table 4.1 shows adherence to hemodialysis among ESRD Participants. Regarding the number of dialysis sessions received per week in ESRD participants, 14(34.1 %) were receiving two dialysis sessions, 26(63.4%) were receiving three sessions and 1(2.4%) was receiving four dialysis sessions per week. According to the number of hours for each dialysis session, 41(100%) of ESRD participants were staying on dialysis for 4 hours for each dialysis session. With regard to the convenience of dialysis schedule for ESRD participants, 39 (95.1%) respondents agreed that the dialysis schedule was convenient for them while 2(4, 9%) participants expressed that the dialysis schedule was not convenient for them.

On the importance of not missing hemodialysis session, one (2.4%) participant was never told the importance to not miss dialysis session, one (2.4%) was told the importance to not miss dialysis session for more than a month ago, one (2.4%) for one month ago, 2(4.9%) for the past one week, and 36 (87.8%) were told the importance to not miss dialysis session during the week they were interviewed. About the importance to follow dialysis schedule, one (2.4%) participant reported that it was moderately important to follow dialysis schedule, 6(14.6%) responded that it was very important and 34(83.9%) agreed that it was highly important to follow dialysis schedule. Six (14%) ESRD participants reported to have a lot of difficult to stay entire dialysis session, 3(7.3%) complained to have moderate difficulty, 11(26.8%) experienced little difficulty, while 21(51%) reported to have no difficulty to stay entire dialysis session.

On the number of dialysis sessions missed in the past month, the study results showed that 2(4.9%) ESRD participants missed 3 dialysis sessions, 5(12.2%) missed 2 dialysis sessions, 9(22%) missed one session, 25(61%) didn't miss any dialysis session in the last month. Two (4.9%) ESRD participants shortened dialysis session once, while 39(95.1%) didn't shorten dialysis session in the last month.

Table 4.2: Adherence to hemodialysis among ESRD participants (N=41)

Variable	Frequency	Percentage
Days to receive dialysis		
2 days or less	14	34.1%
3 days	26	63.4%
4 days	1	2.4%
Total	41	100%
Hours treated for each Session		
4 hours	41	100%
Convenience of dialysis schedule		
No	2	4.9%
Yes	39	95.1%
Last day to be told the importance to do not miss dialysis session		
Never	1	2.4%
More than a month ago	1	2.4%
One month ago	1	2.4%
Last week	2	4.9%
This week	36	87.8%
Importance to follow dialysis schedule		
Moderate important	1	2.4%
Very important	6	14.6%
Highly important	34	82.9%
Difficult to stay entire dialysis session		
A lot of difficulty	6	14.6%
Moderate difficulty	3	7.3%
Little difficulty	11	26.8%
No difficulty	21	51.2%
Missed Dialysis sessions during the last month		
Missed three	2	4.9%
Missed two	5	12.2%
Missed one	9	22%
None	25	61%
Shortened dialysis session during the last month		
Once	2	4.9%
None	39	95%

The table 4.2 shows adherence to hemodialysis scores among ESRD participants .The total adherence to HD score was 34 and the minimum expected adherence to HD score was 10 considering the obtained sample of the study(N=41) among ESRD participants. The maximum adherence to hemodialysis score obtained in the study sample was 29(85.29%) out of 34, and the minimum adherence to hemodialysis score was 19 (55.88%) out of 34. The mean, median, and mode adherence to HD score was 26.65, 28, and 28 respectively.

The researcher adopted an adherence scale to measure the level of adherence to HD among ESRD participants .Scale used was adopted from Chironda et al.2014, for high , moderate and low adherence(Adherence to hemodialysis scale).According to the scale, 80 to 100% was identified as high adherence, 70 to 79% was identified as moderate adherence and less than 70% was classified as low adherence.

Basing on the scale developed, 21(51%) of ESRD participants scored above 80%, means that their adherence to HD scores was high. Seventeen (42%) scored between 70 and 79% meaning that the level of these participants was moderate. Only 3 (7%) scored below 70% meaning that their level of adherence to HD score was low.

Table 4.3: Adherence to hemodialysis scores among ESRD participants (N=41)

Adherence to HD out of 34	Adherence score percentage	Level of adherence according to the scale	Frequency	Percentage frequency
19	55.88%	Low	1	2.4%
22	64.7%	Low	1	2.4%
23	67.64%	Low	1	2,4%
24	70.5%	Moderate	3	7.3%
25	73.5%	Moderate	5	12.2%
26	76.47%	Moderate	6	14.6%
27	79.41%	Moderate	3	7.3%
28	82.35%	High	14	34.1%
29	85.29%	High	7	17.1%
Total			41	100%

4.2. 3 inferential statistics on association between demographic variables and adherence to Hemodialysis.

The table 4.3 shows the association between demographic characteristics and adherence to hemodialysis among end stage renal disease participants. Concerning age, there was a statistically significant association between age and adherence to hemodialysis (Chi-square value=47.471^a, df=32, p=.038 < 0.05) among ESRD participants. Concerning marital status there was no significant association between marital status and adherence to hemodialysis among end stage renal disease participants (Chi square value =6.823^a, df=8, p=.971). In term of education there was no association between the level of education and adherence to hemodialysis among ESRD participants (Chi square value=12.670^a, df=24, p=.338)

On the religion it has been shown that there was a statistically significant association between religion and adherence to hemodialysis among end stage renal disease participants (Chi square value =26.306^a, df=8, p=.003 < 0.05). On occupation there was no significant association between occupation and adherence to hemodialysis among end stage renal disease participants (Chi square value =25.583^a, df=24, p=.375). Concerning monthly income, there was no association between monthly income and adherence to hemodialysis among end stage renal disease participants (Chi square value =25.562^a, df=24, p=.376). Concerning the distance from the hospital, it was shown that there was no significant association between the distance from the hospital and adherence to HD among end stage renal disease participants.

On the mode of transport there was no significant association between mode of transport and adherence to hemodialysis among end stage renal disease participants (Chi square value =24.927^a, df=32, p=.182). On the area of residence there was no significant association between area of residence and adherence to hemodialysis among end stage renal disease participants (Chi square value =14.318^a, df=24, df=24, p=.939). Concerning the distance from the hospital, it was shown that there was no significant association between the distance from the hospital and adherence to HD among end stage renal disease participants (Chi square value =24.927^a, df=32, p=.809)

On the available support system and duration of ESRD there was no significant association between either available support system either duration of end stage renal disease participants

respectively (Chi square value =32,df=32,p=.442) and (Chi square value=28.617^a ,df=32,p=.639) respectively.

Table 4.4: Association between demographic characteristics and adherence to hemodialysis among ESRD participants.

Demographic characteristics	Chi square	Value	Degree of freedom (df)	p- value
Age	Pearson Chi-Square	47.471 ^a	32	.038
	N of valid cases	41		
Gender	Pearson Chi-Square	6.823 ^a	8	.556
	N of valid cases	41		
Marital status	Pearson Chi-Square	12.670 ^a	24	.971
	N of Valid Cases	41		
level of education	Pearson Chi-Square	26.306 ^a	24	.338
	N of Valid Cases	41		
Religion	Pearson Chi-Square	23.759 ^a	8	.003
	N of Valid Cases	41		
occupation	Pearson Chi-Square	25.583 ^a	24	.375
	N of Valid Cases	41		
Monthly income	Pearson Chi-Square	25.562 ^a	24	.376
	N of Valid Cases	41		
area of residence	Pearson Chi-Square	14.318 ^a	24	.939
	N of Valid Cases	41		
Distance from the hospital	Pearson Chi-Square	24.927 ^a	32	.809
	N of Valid Cases	41		
Mode of transport	Pearson Chi-Square	30.078 ^a	24	.182
	N of Valid Cases	41		
Mode of water supply	Pearson Chi-Square	9.311 ^a	16	.900
	N of Valid Cases	41		
Available support system	Pearson Chi-Square	32.496 ^a	32	.442
	N of Valid Cases	41		
Duration of ESRD	Pearson Chi-Square	28.617 ^a	32	.639
	N of Valid Cases	41		

4.2.4 Conclusion of the quantitative findings

Basing on the scale developed, only 21(51%),of ESRD participants scored above 80%,meaning that their adherence to HD score was high, and 20(49% scored below 80% meaning that there was low adherence to hemodialysis among ESRD participants .In the most of demographic characteristics there was no evident significance ,a part from age($p=.038$) and religion ($p=.003$)respectively, that showed that there was a significant association between age and gender respectively, and adherence to hemodialysis among ESRD participants. The selection of the sample for qualitative study was depending on the results of the quantitative. In addition of what was highlighted, among ESRD participants who scored above 80%(with high adherence), there of them were selected for the qualitative stage, for those who scored between 70 and 79%(moderate adherence), three among them were selected for the qualitative study and only one participant was selected among those who scored below 70 % as having low adherence to hemodialysis.

4.3 Qualitative findings

4.3.1 Introduction

Qualitative sample was selected from the quantitative results. Three participants with high adherence, three with moderate adherence and one participant with low adherence were selected respectively to answer objective number 2 and objective number 3 focusing on motivating factors and barriers to adherence to hemodialysis among ESRD. The qualitative findings were presented as follows:

4.3.2 Selected ESRD participants

The table 4.4 shows selected ESRD participants for qualitative study. A sample of seven participants determined by data saturation was used for qualitative part of the study. The age of the selected ESRD participants ranged from 25 years to 72 years .About the gender, four (4) participants were male while three (3) were female. Concerning their marital status, five (5) were married, one (1) was widowed while one (1) was single. About the level of education, three (3) had primary education, one (1) had secondary education, while two (2) were not educated and one (1) had university.

About the religion one (1) was Muslim, six (6) were Christian. All of the participants seven (7) were unemployed. Concerning health insurance, four (4) were covered by FARG, two (2) were self-sponsored, and one (1) had community based health insurance (CBHI). About the adherence to hemodialysis scores ,three (3) had high adherence(scored 82.35%),three(3) had moderate adherence (2 scored 78,47% and 1 had a score of 73.5%),and only one(1) had a score of 55.88%(low adherence)

Table 4.5: selected ESRD participants for the qualitative study (n =7)

	P 1	P 2	P 3	P 4	P 5	P 6	P 7
Age	25	64	72	35	53	60	55
gender	F	F	M	M	M	F	M
Marital status	Single	Married	Widowed	Married	Married	Married	married
Level of education	Secondary education	Primary education	Primary education	Primary education	University	Not educated	Not educated
Religion	Christian	Christian	Christian	Christian	Christian	Christian	Muslim
Occupation	unemployed	Unemployed	Unemployed	unemployed	Unemployed	unemployed	unemployed
Support system	FARG	FARG	FARG	CBHI	Self-sponsored	FARG	Self-sponsored
Level of adherence	High 82.35%	High 82.35%	High 82,35%	Moderate 76.47%	Moderate 76.47%	Moderate 73.5%	Low (55.88%)

FARG- Fund for neediest survivors of genocide in Rwanda

CBHI-Community Based Health Insurance

P - Participant

4.3 Stages of the qualitative data analysis

4.3.1 Data organization: transcription: Transcript: A written verbatim (word-for-word) description of a verbal interaction, like an interview(Gale et al., 2013,p.2)First step of analyzing data, researchers write down the data, take notes and read them many times like to describe the tendency of the participants' perspectives that can be traced back using straight quotations from the transcription.(Jones et al. 2016,p.103). The transcription was done by writing word by word as they come out from ESRD participant's interview regarding motivators and barriers of and to adherence to hemodialysis, as well as using field notes taken while collecting data to be able to read and code them.

4.3.2. Familiarization: Active continual reading to become familiar with all aspects of the data. It is necessary to read the entire set of data, before coding, for obtaining a general understanding (Javadi & Zarea ,2016,p.36).During reading and rereading, transcripts, researchers achieve a general understanding of data in addition to the main issues in the phenomenon under study (Jones et al. 2016,.103). Familiarization was achieved through deep reading to understand and to be familiar with those data, generating initial codes and to determine possible relationships among them.

4.3.4 Identifying a thematic framework :Analytical framework is a place of codes organized into categories that have been together developed by researchers concerned in analysis that can be used to manage and organize the data (Gale et al., 2013,p.1). From data organization the main two predefined themes in this study were motivators and barriers of and to adherence to HD among end stage renal disease participants, then subthemes were identified.

4.3.5 Indexing:The organized application of codes from the decided analytical framework to the full dataset(Gale et al., 2013,p.2). The stage of indexing permitted to identify subthemes, from the two key themes identified in the initial coding of identifying a thematic framework. The key themes and subthemes that then were categorized to facilitate the capture of their similarities and possible interrelations. Two predefined themes were motivators of adherence to hemodialysis among ESRD participants, and barriers to adherence to hemodialysis among end stage renal disease participants .Important subthemes for motivators were hope for renal transplant, family

support, alleviation of symptoms, to prolong life and improved quality of life, and fear of death. Regarding barriers to hemodialysis, revealed subthemes were poverty, problems of transport, treatment related complications and long distance.

4.3.6 Tabulation: Approach used in advance to describe how narratively themes will be represented to analyze findings in qualitative research, in a form of a table like an addition to the discussions (Creswell 2014, p.249). Predefined themes and subthemes are displayed in the table to allow the identification of main themes and provide an organized approach to handle and interpret them. The table 4.5 represents predefined themes and summarized subthemes related to motivators of and barriers to hemodialysis among end stage renal disease participants in this study.

Table 4.6: Predefined themes and subthemes

	Main theme 1	Main theme 2
	Motivators of adherence to hemodialysis	Barriers to adherence to hemodialysis
Subthemes	1.Waiting for renal transplant 2.Alleviation of symptoms 3.Family support 4.To prolong life and improved quality of life 5.Fear of death	1.Lack of money/poverty 2..Difficult of transport 3.Long distance 4.Therapy related complications

4.3.7. Interrelating and description of themes: Identification of uniqueness and difference among the data, record and explore association between concepts (Gale et al. 2013, p.5). A final step in data analysis that involves building an interpretation in qualitative research of the findings. It captures the real meaning of the idea regarding the lesson learned. These lessons could be the researcher's own interpretation, understood that the inquirer brings to the study from an individual background, history, and experiences (Creswell, 2014, p.249).

4.3.7.1 Motivators of adherence to hemodialysis

Motivators of adherence to hemodialysis reported by ESRD participants, include family support, hope for renal transplant, alleviation of symptoms, and improved quality of life, fear of death, to prolong life.

Family support

In Rwanda the family assistance for every person in need is traditionally a common culture .The family support in ESRD participants was giving them force to cope with hemodialysis treatment. Two (2) participants expressed the importance of the family in their course of disease and treatment by hemodialysis.

One participant said: “The support from my family helps me they help me, I try to respect dialysis schedule, I use RAMA this is insurance from my family (p 5)

“Normally my home is in Butare, but I have a daughter who lives in Kigali, they help me I stay in the house of my daughter that facilitates me to come here, they try to help me” (p2)

The hope for renal transplant:

The hope for renal transplant was highlighted by two (2) participants as it giving them the force to continue dialysis because they were expecting stability once hemodialysis was no longer needed.

“I am waiting for renal transplant, but a donor is still a problem. If I have a chance to get a donor, it will be an answer, Let wait, it is hard... it is hard, but I am waiting” (p4)

“The first person who accepted to give me a kidney had problems in the following days. When they did exams, they found her pregnancy and she had difficulties in delivering, she delivered a dead baby .After delivery, her husband also died. Don’t you understand that her also she has problems? She has many problems and she has small children she has to take care of .She could give me a kidney like she accepted to do it but those children will miss someone to take care of them. so I can’t blame her because she wanted to save me with her kidney. hhh. I will wait for another one. If I have a chance to get someone I will accept the kidney .If I don’t get him I trust In God he will cure me.(P2)

You understand that someone accepted to give me a kidney without my demand , I didn't think about it she has taken the decision herself ,we didn't discuss about it before .I was her aunt ,It was a sacrifice, she said that I will give you a kidney. God has many ways to work ,even now I can get a donor ,because I didn't give anything for that first one .No, It is like you think about something in you ,to give someone an important thing. I hope that it will be resolved” (P2)

Alleviation of symptoms

Two (2) participants highlighted alleviation of symptoms as a motivator of adherence to hemodialysis treatment. Hemodialysis treatment was considered as a valuable mean to decrease the burden of physical problems that were making ESRD participants uncomfortable and compromising normal life.

One patient said: “

I came in bad condition but from the time it started (hemodialysis), I improve slowly, so that it is very important for me (part4)

Another participant said:

... I realized that it did help me; I was so bad when I came but now I am better. I was always dizzy but now it disappeared (p2)

Fear of death

ESRD participants were pushed to follow hemodialysis treatment because they didn't want to die

Another said: It is because hemodialysis helps me ,It replaces my kidneys that are not working , if I don't respect the schedule there are consequences including death. You have to be careful and respect doctor's instructions ...and I received renal transplant that was rejected and now I came back to dialysis (p.1).

To prolong life and improved quality of life

Four participants highlighted the need to adhere to hemodialysis for the purpose of prolonging their lives and improved quality of life. Hemodialysis treatment was considered as very helpful, where ESRD participants were expecting life and improvement of the quality of their life as well.

...What do you need me to tell you. It is because I need to push days of life because if hemodialysis is not done what will happen? (p3)

Health care providers give a good service, you see good results, and he said (p5)

“It is because dialysis is the one thing that helps me in my life” (P6)

4.3.7.2 Barriers to adherence to hemodialysis

Multiple obstacles or barriers to adherence to hemodialysis among end stage renal disease participants were a very big worry reported. Many of them were mentioned as reasons to miss dialysis sessions, problems to stay longer on dialysis machines or treatment related complications. The identified barriers are presented as follows:

Lack of money/poverty

Poverty was reported by six (6) participants as a big barrier that was affecting adherence to hemodialysis among ESRD participants at the time of the study.

One participant said:

The cost of that act (hemodialysis) is very (high), I missed two dialysis sessions last month because I didn't have money, lack of money, sometimes, you don't hope that you will get money for transport .If I have money I try to follow hemodialysis schedule (p5).

Another participant said:

“Poverty ...All problems I have are consequences of poverty. All problems. What can you do without money? Poverty, we try to look for money for transport to do not be absent (p2).

“When I have money, I come, if I don't have money I don't come. The reason why I missed hemodialysis session last month is that I didn't have money, that why you didn't see me “(p7) ‘

Information given about the reasons to miss hemodialysis sessions were of great importance

Uncertain transport

Four (4) participants reported the problem of transport. The lack of transport in ESRD participants was a factor that was increasing the chance to do not attend hemodialysis treatment and this was related to financial issues, traveling a long distance or coming from a place where taxis or buses are few and don't work every day. The problem of transport was mentioned by five (5) of the participants. One of the participants said:

“It is difficult to get a taxi for transport . . . Most of the times on holidays or sometimes during the week end and when I miss it I go back home, I don't come. I miss hemodialysis because there is no transport or when there is a rain because I wake up very early and I live very far. at Cyohoha nearest Burundi, It is very difficult for me because I lack money for transport”.(P6)

Another participant said:

“One thing that is difficult for me is that when I go to wait for a car and I found that it left me, and I use a moto .Eeee it is difficult for me to use a moto and it is expensive. When I came for dialysis I reach home after using 600 Rwanda francs because we have to use two different buses , but to come here I use 200 Rwanda francs ,there is a car that drops us near the hospital when we come”.(P2)

Treatment related complications

Seven participants highlighted treatment related complications such as catheter pain, headaches, increased hypertension, and tiredness. To feel tired was reported by four (4) participants, while three (3) reported to have headaches when staying on dialysis machine for four hours.

One participant said:

“Because the catheter was inserted on the femoral region, it caused me much difficulties and pain, to do not change position on the time of hemodialysis... It is very difficult.”(p4)

“One participant said “Of course difficulties are there because you feel tired, but because it is the program of the treatment you don't have any other choice.”(p7)

Another participant said: “There is no alternative but it makes me tired (hemodialysis) (p5)

Another said: “To feel tired and to have headaches” (p2)

“Sometimes the blood pressure increases, or I have headaches” (p1)

One (1) participant reported:” To deteriorate, weakness to breath, eating little, drinking little, to do not sleep.”(Part3)

Long distance

Of seven participants, 3 were traveling a distance of more than 40 km to get to the hospital for hemodialysis treatment, while they were not always sure that they will get many for transport and this was a limitation to adherence to hemodialysis.

“To stay far from the hospital, it is very far from here .more than 60 kilometers .It is a long distance between home and the hospital ... it is very difficult but... (p5)

“I live very far...at Cyohoha nearest Burundi, it is very difficult for me, taxis don’t come every day, like on Sunday ,or when it is a holiday, taxis are very rare or even don’t come” .(p6)

4.3.7.3 Conclusion of the qualitative findings

Among 7participants asked about motivators of adherence and barriers to adherence to hemodialysis, the findings revealed that waiting for renal transplant, alleviation of symptoms, family support to prolong life and improved quality of life, fear of death were the principle motivators of adherence to hemodialysis. Poverty or low financial status, problems of transport, treatment related complications, long distance, were the main identified barriers to adherence to hemodialysis among ESRD participants .This explains better the reason for decreased level of adherence to hemodialysis among ESRD in studied population.

CHAPTER FIVE: DISCUSSIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 Introduction

This study was exploring adherence to hemodialysis among end stage renal disease patients. Results from the quantitative phase include descriptive statistics on demographic data, the level of adherence to haemodialysis, and inferential statistics of chi square to identify associations and relationships between selected biographical characteristics and adherence to haemodialysis. The qualitative phase focuses on results on motivating factors and barriers to hemodialysis among ESRD participants

5.2 Demographic characteristics of ESRD participants

On the age of ESRD participants, the results have shown that of the total number of ESRD participants (N=41), eleven (26.83%) were aged between 51 and 60 years, 10 (24, 4%) were having greater than 60 years, 9 (22%) were aged between 31 and 40 years, (14, 63%) between 41 to 50 years and 5 (12, 20%) were aged between 18 and 31 years. The mean age was ranging between 41-50 years being a productive age group as it was confirmed by the literature in Africa. In the results of Gerard et al. (2016) the average age was 45.2, and in that of Chironda et al. (2014) the mean age was 45.67 to show that in developing countries CKD affects the population of under 50 years this being the economically productive age group that is affected as it was observed by (Ekrikpo et al. 2011). Contrary, the study results from Palestine in 2016 have shown that the mean age was 53.3 (Zyoud et al. 2016 p.3). ESRD is more frequent in adult above 70 years in US (CDC 2014). The increase in ESRD prevalence is attributed mainly to longer survival among ESRD patients in current years in US (USRDS 2015 p.149).

The majority of ESRD participants were males, 24 (58, 54%), than females who were 17 (41, 46%) among 41 respondents. This is similar to the study conducted by Ekrikpo et al. in 2011 where males were representing 57% and 43% were females. In opposition the findings of Burkhalter et al. (2014) showed the predominance of females who were representing 64.5%, and according to Duong et al. (2015) males were representing 47% of the study participants. On the marital status of ESRD participants among 41 respondents, 28 (68, 29%) were married, 7 (17, 07%) were single, 5 (12, 20%) were widowed and 1 (2, 44%) was separated. Another African study

revealed similar results 66.67% were married, 26.67 % were single and 6.67% were widowed (Abo et al. 2015)

The results of the study showed that 16 (39.02%) were secondary educated, 13 (31.71%) completed primary education, 8 (19.51%) frequented colleges or universities and 4 (9.76%) were not educated. ESRD affects both educated and non-educated people, but the decreased level of education can contribute to a reduced level of understanding, that can lead to a poor level of following medical instructions in favor of ESRD treatment, contrary to an increased level of education that facilitates to capture and convey the message about the concerns of the disease (ESRD) and the importance of its treatment including hemodialysis. In the study of Gerard et al. most of their participants were having middle and high school 35.5%, college and university were representing 18%, non-educated people were 24.4% and primary education was represented by 22.1%. In the study of Madeiro (2010) 64% were having poor education, and 11% were illiterate

The study results showed that 31 (75.61%) were unemployed, so they didn't have any monthly income, 6 (14.63%) were self-employed and 4 (9.76%) were public servants. 4 (9.78%) were having a monthly income of more than 200,000 Rwanda francs, 3 (7.32%) had between 100,000 and 200,000 Rwanda francs of monthly income, also 3 (7.32%) were having a monthly income of between 50,000 and 100,000 Rwanda francs. Three quarters of the participants were unemployed consequently didn't have any monthly income. This could be a limitation to the efficacy of adherence to hemodialysis treatment, considering that presently one session costs around or over 100,000 Rwanda francs, only few Rwandans in need can afford hemodialysis treatment. This is exceptional in Libya where the access to dialysis therapy is free for ESRD Libyan patients (W. A. Alashek et al. 2012).

On the areas of residence of ESRD participants, twenty-two (53.66%) were living in high density areas, 16 (39%), were staying in medium density areas, 2 (4.9%) were living in low density area and one (2.4%) was staying in rural area. The majority of the population was from urban living in high density area. Concerning the mode of transport used by ESRD participants. Sixteen (39.02%) were using taxis, 11 (26.83%) used public buses, 12 (29.27%) had private cars and two (4.88%) used to come to the hospital by foot.

The mode of transport can determine the time used and the facility or difficulty to attend dialysis session on time. In the situation of Rwanda if a public bus is the mode to be used, it appears to be less expensive but it takes longer depending on the availability of passengers compared with the taxis this could make ESRD participants in a hurry and stress to get to the hospital for hemodialysis treatment which is far different from patients who possess their own cars that facilitate the transport. Again for those who come to the hospital by foot they are not secured in case they have some physical problems like dizziness in way to come from or to go back home

In this study, the results showed that twenty one (51.22%) were staying at a distance of between zero and ten kilometers, 8 (19.51%) were staying at a distance ranging between eleven and twenty kilometers, 1 (2.44%) participant was living at a distance between twenty one and thirty kilometers, 3 (7.3%) were staying at a distance between thirty one and forty kilometers and 8 (19.51%) participants were staying at a distance of greater than forty kilometers. A long distance contributes to the increase of demands of money for transport for patients who are in poor position to pay for hemodialysis treatment as many of them are unemployed and the transport not assured, this again will decrease the level of adherence to hemodialysis treatment

On the availability of support system, twenty (48.8% of ESRD participants were covered by FARG, 8 (19.51%) were self-sponsored, private medical insurances were covering 6 (14.63%), 4 (9.76%) participants were covered by the community based health insurance and 3 (7.32%) were assisted by the government. Because of the high cost for hemodialysis treatment, participants who were fully covered or with increased financial status could afford the treatment. The number of those who possess a community based health insurance is very reduced, to explain that even if many Rwandan are insured, ESRD patients have to pay 100% from their pocket in case of hemodialysis, which they are unable to afford and this still remains a problem of limited accessibility to expensive health care like hemodialysis, as a procedure performed in referral hospitals including KFH that is a private, this making the treatment inaccessible for the community based health insurance holders. This situation is different from that of Europe where the majority of ESRD patients on renal replacement therapy were covered at 100% (Kramer et al. 2016, p4). In Georgia also RRT including hemodialysis therapy is covered by the state at 100% (Tataradze et al. 2016, p.441), as well as in US where ESRD patients

are covered by Medicare without considering their age (Hirth et al. 2008,p.91) . Concerning the duration of ESRD, the study results revealed that 12 (29.27%)participants were having ESRD for more than five years,11(26.83%)had ESRD for a period between three months and one year,8(19.51%) participants had ESRD for three to five years,6 (14.63%) had ESRD for two to three years , and 4(9.76%)for one to two years. This most was to meet the significance of the inclusion criteria while recruiting study participants. Regarding the causes of ESRD the results from the study showed that in 22 (53.66%) ESRD was caused by hypertension , 8(19.51%) had diabetes mellitus,4(9.76%)had diabetes and hypertension, for other 4 (9.76) the cause was unknown and for 3 (7.32%) the ESRD was attributed to other causes.This is in accordance with the literature .In the study of Banaga et al. (2015) the most common cause was hypertension (34.6 %).In patient aged between 40 to 60 years old the leading cause of ESRD was hypertension (38.5 %) followed by diabetes mellitus (14 %). In patient aged older than 60 years the leading cause of ESRD was hypertension (38.4 %) followed by diabetes mellitus (23.3 %) .In the study conducted in Cameroon the results showed that 88.4% had hypertension,28.4% had diabetes(Halle et al. 2015).

In the western world the most common cause of ESRD is diabetes(Kramer et al. 2016) . 21% to 51% of patients who start renal replacement therapy have diabetes(Narres et al. 2016). In addition, In US the primary cause of ESRD is diabetes followed by hypertensions. In 2012 diabetes was responsible for 44%, and hypertension for 28, 4% of new cases of new cases of ESRD(American Kidney fund 2015). In another study the prevalence of hypertension was 49.2% and 36.3% of patients were having the history of diabetes mellitus and 20.4% of patients suffered from diabetes mellitus and hypertension respectively(Burkhalter et al. 2014).

According to Madala et al. (2014) in the results of their study hypertension alone was accounting for 75.2% and 29.8 % were having diabetes. Diabetes and hypertension are the two causes on top of ESRD in seven of twelve Arab countries(Farag et al. 2012).Contrary , in a research done in central America ,in rural area of Nikaragua ,they found that 92% did not have diabetes and 64% did not have a history of hypertension, 57%–64% of the participants were having CKD of non-traditional etiology(Lozier et al. 2016).In Rwanda ,in 2015, diabetes was affecting 3.1% of the population and 15% of the population studied was having increased blood pressure (Ministry of health 2015,p.14).In this study the results shown can be a consequence of low awareness and let

consultation in most of the population studied as CKD and its causes appear to be not well known by most of Rwandan population. Basing on the results of the survey done by the Rwanda ministry of health in 2015, blood pressure and diabetes were rarely measured. The results of the study conducted in Senegal revealed unawareness of the disease in more than three quarter of CKD participants (Seck et al. 2014). The results of Stanifer et al. (2015) found that awareness was 10.5% of participants who had CKD. Unawareness and late consultation was also reported in Nigeria (Bello 2014) contrary to the population of developed countries where diabetes and hypertension can be related to the life style and advanced older age due to improved health care

5.3 Adherence to hemodialysis among ESRD participants

Basing on the scale developed 21 (51%), of ESRD participants scored above 80%, meaning that their adherence to HD score was high. Seventeen (42%) scored between 70 and 79% meaning that the level of these participants was moderate. Only 3 (7%) scored below 70% meaning that their level of adherence to HD score was low. This confirms what is evidenced by the literature that it has been estimated that 50% of patients on hemodialysis do not adhere to at least part of their dialysis regimen (Kutner, 2001). In the study of Duong et al. (2015) 42% of ESRD patients missed their dialysis sessions and 12% shortened their sessions. This results are similar to those of Al-Khattabi where attendance to hemodialysis accounted for 55.96%.

In the study of Ekrikpo et al. (2011) they noted that 13% completed at least 70% of the planned dialysis sessions. Another African study showed an evidence of non-adherence among ESRD patients where 93% of participants missed at least one session with (61%) of respondents who missed nearly all of the scheduled sessions, no more than 7% attended all the haemodialysis sessions as planned (Chironda et al. 2014). This African countries' results differ considerably from those of developed countries. The percentage of skipping \geq one dialysis session per month was 0.3 in France, 0.9 in Germany, 8.8 in Italy, 6.6 in Spain, and 12.6 in United Kingdom. For those who skipped at least one treatment, in Sweden: 0, Japan: 0, United State: 2.3% of all sessions. About the percentage of patients who shortened dialysis sessions \geq 10 minutes, in France they were 7.3, Germany 9.5, Italy 8.8, United Kingdom 12.6 (Garzoni et al. 2007, p.231). Shortening dialysis session in the present study was in 2 (4.8%) participants and mostly it was related to the technical problems, dialysis machines were not working.

Decreased adherence to hemodialysis is a big concern in Rwanda, affecting negatively ESRD patients themselves, and the treatment outcomes, and this becomes a burden for health care institutions and Rwandan community in general. In the most of demographic characteristics there was no evident significance, apart from age ($p=.038$) and religion ($p=.003$) respectively, that showed a statistical significant association between age and religion respectively, and adherence to hemodialysis among ESRD participants.

Discussion qualitative research

In this study, the aim of qualitative phase was to answer to two objectives namely barriers to adherence to hemodialysis and motivators of adherence to hemodialysis among end stage renal disease participants. The health belief model was the concept framework that guided the study. Family support was considered as very important to help ESRD participant to cope with the disease. The importance of the family was also noted by Madeiro (2010). Social support affects positively outcomes and is a connection between ESRD patient and adherence to HD treatment (Victoria et al. 2015). Family participation is essential, because of the role of protection and socialization of their members (Madeiro et al. 2010), Wells (2015) also supports the cultural value and the importance of the family in ESRD patients.

Hope for renal transplant, was mentioned by ESRD participants as a motivator of adherence to hemodialysis, as they were expecting to be better and stable if hemodialysis is no longer needed. Similar motivating factor was seen in the study of Wells (2015). In another study the perception of renal transplant had a different aspect where patients were not adequately informed to take decisions concerning transplant, were not sure if they will get support or if they will recover from surgery (Kazley et al. 2014). As explained in the literature, kidney transplantation is the mainly less expensive method of RRT (Tataradze et al. 2016 p.438) and according to Chapman (2012 p.4) kidney transplant, when correctly applied, is the treatment of choice for patients with ESRD because of decreased costs and superior outcomes.

Well done kidney transplantation is related with improved survival, better quality of life and healthcare cost investments when compared to dialysis (USRDS 2015, p.126).

Alleviation of symptoms, to prolong life and improved quality of life: ESRD participants were appreciating the positive effect of the treatment; to feel better, to have life to see good lab results

because of hemodialysis treatment. Similarly to other studies, Wells (2015) observed that ESRD patients confirmed that hemodialysis was giving them life and in the study of Maciel et al. (2015), the relief of symptoms and the monitoring of the disease by laboratory tests have been highlighted.

Fear of death was a motivator to adherence to hemodialysis, in the study of Wells (2015) patients well expressing to be between life and death .In this study the patient was scaring to do not attend to hemodialysis because there was a fear to die if medical instructions are not respected. Poverty, was mentioned by the majority of the participants to affect attendance to hemodialysis because most of the time missed dialysis sessions were related to financial constraints. These findings are similar to other documented literature done by Chironda and Bhengu, 2016 where low socioeconomic status was highlighted as a barrier to adherence to hemodialysis.

The problems of transport also, were related to financial issues, the distance to travel, availability of buses or taxis depending on where the patient stays. This confirms what was observed in the study of Maciel et al. (2015) that the difficult was caused by the financial cost. In the study of Madeiro (2010), poor quality of the road was noted to increase the difficulties of transport. The problem of transport in the study of Chan et al. (2014) was noted, not related to financial constraints but it was observed in patients who were going to dialysis unit using transportation van or who were driving over 17minutes to get to the clinic, or when the car was broken.

Treatment related complications comprised tiredness headaches, catheter insertion site pain, difficult of eating difficulty of drinking to not sleep and long distance. Similar complications were expressed in the studies of Maciel (2015) and Madeiro (2010).

5.4. Study limitations

1.A decrease of the study population was observed apparently due to the reduced financial status in ESRD participants that forced some of them to stop hemodialysis treatment few months after its initiation. Also some of the patients died ,and there were patients who shifted from the university teaching hospital of Kigali and King Faisal hospital to a private nephrology clinic, probably due to the decreased cost compared to the two previously mentioned

hospitals. The large sample size should be considered in future studies to obtain more information concerning ESRD patients.

2. Time was limited as the study was carried out to fulfill the requirement of the master's degree more observations with the extend time may complete the current study findings.

3. There was no funding for the study, more inputs from expert researchers that require financial support may be limited and should be availed in the future.

4. Delay to obtain permissions from different ethical committees of the hospitals composing study sites this imposing researcher to work in hurry to collect data, to meet the deadline of allocated time for data collection

5. The generalization in qualitative research is not possible, because it captures only diversities around the phenomenon under study.

6. The interview translation from Kinyarwanda to English language can omit or modify the meaning of some wards used by the study participants that, can lead to misinterpretation of the data.

5.5. Recommendations

Nursing practice :Increase effort in evidence based practice ,improve communication and education with and of ESRD patients ,to increase awareness and remove underestimation about the importance of adherence to hemodialysis among ESRD patients because non adherence to treatment affects negatively the quality of life and increases the mortality .

Nursing education: Increased knowledge in nurses increases better management of the patients. The number of specialized nurses in nephrology field should be increased through sustained education that will empower them to understand ESRD , and to achieve satisfactory outcomes in management of ESRD patients .

Nursing research: It was evident that the level of adherence to hemodialysis was low as only 51 % achieved a score of high adherence to hemodialysis of 82.35 % , 49% were qualified to have low adherence as long as they were below 80% based on the scale developed .Identified factors that affected negatively adherence to hemodialysis could be extended with more

studies. Nurses are invited to be engaged in more and urgent researches regarding adherence to hemodialysis and associated factors among ESRD patients

Nursing administration : Nursing administration is a channel and pillar for advocating for patients, its influence and involvement in policy development in favor of ESRD patients will lead to better understanding of the burden and negative effects of non-adherence to hemodialysis, consequently, more efforts will be made for better and durable solutions, toward adherence to hemodialysis among ESRD patients.

5.6. Conclusion

Adherence to hemodialysis is a concern in Rwanda and continues to be a worldwide problem among patients with ESRD. Around half (51%) of the participants were qualified for high adherence, the remaining 49% were classified for low adherence according to the scale used. In demographic characteristics there was statistical significant association between age ($p=.038$) and religion ($p=.003$) and adherence to hemodialysis. Family support, hope for renal transplant, alleviation of symptoms, to prolong life and improved quality of life, fear of death were motivators of adherence to hemodialysis. Enumerated constraints or barriers to adherence to hemodialysis found were poverty, uncertain transport, treatment related complications comprising tiredness headaches, catheter insertion site pain difficult of eating difficulty of drinking, to not sleep and long distance. In this regard, nurses should be advocates of ESRD patients in promoting adherence to hemodialysis.

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APPENDICES

APPENDIX 1. ADMINISTERED INTERVIEW SCHEDULE GUIDE FOR RESEARCH PARTICIPANTS

Instrument

The researcher will adopt ESRD adherence questionnaire which was developed by Kim et al. (2010)

SECTION 1- BIOGRAPHICAL DATA FOR ESRD PATIENTS

1-Age

- 1- 18-30 years
- 2- 31-40 years
- 3- 41-50 years
- 4- 51-60 years
- 5- Greater than 60 years

2- Sex

- 2.1 Male
- 2.2 Female

3- What is your marital status?

- 3.1 Married
- 3.2 Single
- 3.3 Divorced
- 3.4 Separated
- 3.5 Widowed

4- What is your level of Education?

- 4.1 Primary school
- 4.2 Secondary school
- 4.3 College or University

5- What is your religion?

- 5.1 Christianity
- 5.2 Muslim
- 5.3 Traditional

6- What is your occupation?

- 6.1 Self employed

6.2 Skilled worker

6.3 Unemployed

7- What is your monthly family income?

7.1 Zero

7.2 50 000 to 100 000 Rwanda franc

7.3 more than 100000 to 200 000 Rwanda franc

7.4 More than 200000 Rwanda Franc

8- Area of residence?

8.1 Low density

8.2 Medium density

8.3 High density

8.4 Communal or rural

9- What is your mode of transport from and to the hospital?

9.1 Public Buses

9.2 Taxis

9.3 Private cars

10- Distance from the hospital

10.1 0 to 10kms

10.2 11- 20kms

10.3 21- 30 kiss

10.4 31 to 40kms

10.5 Greater than 40kms

11- What is the mode of water supply?

11.1 Tape water

11.2 Borehole water

11.3 Open well

11.5 River

12- What is the mode of sewerage system?

12.1 Flushing system

12.2 Pit latrines

12.3 Bush system

13- What are the available support systems?

13.1 Community medical aid

13.2 Private medical insurances

13.3 Family support

13.4 Medical aid and family support

14 - What is the duration of ESRD?

14.1 Between 3 months to 1 year

14.2 Between 1 year to 2 years

14.3 Between 2 years to 3 years

14.4 Between 3 years to 5 years

14.5 More than 5 years

15- What was the cause of your ESRD?

15.1 Hypertension

15.2 Diabetes mellitus

15.3 Glomerulonephritis

15.4 Diabetes and hypertension

15.5 Diabetes and Glomerulonephritis

15.6 Glomerulonephritis and hypertension

15.7 Genetic

15.8 Unknown

QUANTITATIVE INTERVIEW SCHEDULE

Section 2: Adherence to hemodialysis

1- How many days a week do you receive dialysis treatment?

1.1 2 days or less

1.2 3 days

1.3 4 days

1.4 More than 4 days

2- How many hours are you treated for dialysis each week per session?

- 2.1 3 hours
- 2.2 4 hours
- 2.3 5 hours
- 2.4 More than 5 hours

3- Is your dialysis schedule convenient for you?

- 3.2 Yes
- 3.1 No

If no, comment _____

4- When was the last time a health-care worker talked to you about the importance of not missing dialysis sessions?

- 4.1 Never
- 4.2 More than a month ago
- 4.3 One month ago
- 4.4 Last week
- 4.5 This week

5-How important do you think it is to follow your dialysis schedule

- 5.1 Not important
- 5.2 Little important
- 5.3 moderate important
- 5.4 Very important
- 5.5 Highly important

6- How much difficulty have you had for staying your entire dialysis session as prescribed by your doctor?

- 6.1 A lot of difficulty
- 6.2 Moderate difficulty
- 6.3 Little difficulty

6.4 No difficulty

Comment:

7- During the last months, how many dialysis sessions did you miss?

7.1 Missed more than 3

7.2 Missed three

7.3 Missed two

7.4 Missed one

7.5 None

If missed dialysis session, why: _____

8- During the last month, how many times have you shortened the dialysis time?

8.1 More than thrice

8.2 Thrice

8.3 Twice

8.4 Once

8.5 None

Comment: _____

APPENDIX 2

Qualitative Semi-structured interview guide

MOTIVATORS AND BARRIERS TO ADHERENCE TO HEAMODIALYSIS

Section A – Information of selected ESRD Study participants

- 1- Age
- 2- Gender
- 3- Marital status
- 4- Level of education
- 5- Religion
- 6- Occupation

1. How do you manage your hemodialysis treatment?

2. What are the motivators to your adherence to hemodialysis?

APPENDIX 2: INVITATION TO PARTICIPATE IN A RESEARCH STUDY

INFORMED CONSENT FORM

Introduction

My name is MUKAKARANGWA Marie Claire; I am Rwandese, a student undertaking master's degree in critical care and trauma nursing. You are being asked to participate in a research study on adherence to hemodialysis. You were selected as a possible participant in this study because you are on hemodialysis.

Purpose of the study

The purpose of the study is to explore adherence to hemodialysis among End Stage Renal Disease (ESRD) patients in selected renal units in Rwanda.

Description of the study procedures

You are expected to be in the study for 15 to 20 minutes for each stage and notes taken as well with your permission. The questions asked in this study will assess your extend of adherence to hemodialysis, motivating factors of and barriers to adherence to hemodialysis.

Right to refuse or withdraw from the study

Participants are allowed to refuse or withdraw at any stage of the study. Also, you will have the option of not participating in any part or the full interview, without any consequences on your hemodialysis treatment at the study facility.

Minimal risk is expected in this study.

There may be unknown risks and reasonable foreseeable (or expected) risks. The researcher will ensure that there are no risks or harms associated with participating in this study as the human rights will not be violated. Risks will be minimized throughout the study. I realize you might be exhausted after your hemodialysis session and you are free to reschedule the interview.

Benefits of Being in the Study

By participating in the study, you will not receive any direct benefits. There will be no monetary compensation for participating and the study is for the academic achievement. However, you will receive the satisfaction of knowing that participation in this research may help patients on hemodialysis at all hospitals of Rwanda.

Confidentiality

Confidentiality will be assured as no names will appear on the interview schedule at any stage of data collection as they will be coded. Signed consent forms will not be attached to instruments to ensure anonymity. If you are willing to participate, a consent form will be signed to indicate acceptance. Data will be stored in a locked cabinet and not be accessible to any other person other than the investigator.

However, absolute confidentiality cannot be guaranteed and personal information may be disclosed if required by the law. The study staff will have access to all the information collected in this study. Moreover, there are organizations that may inspect or copy your research records for quality assurance and data analysis and these include the institutional review board (IRB). All the documents for the study will be destroyed after 2 years of study completion.

Contact details

For further information or reporting of study related adverse events, contact me or my supervisor on the following address and numbers:

University of Rwanda

College of medicine and Health Sciences

School of Nursing and Midwifery

Kigali, Rwanda

Mukakarangwa Marie Claire :0788597085

Dr Chironda – 00250 789924956.

In case of reporting complaints relating to the study, contact the IRB Chairperson

Institutional Review Board

Research Office

University of Rwanda

Kigali, Rwanda

Tel...+250 (0)7885-63312

Email...**fsunday@khi.ac.rw**

CONSENT TO PARTICIPATE

Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary by the researcher.

Subject's Name (print):_____

Sign.....Date.....

Researcher's sign.....Date.....

Contact of the researcher

MUKAKARANGWA Marie Claire

Mobile No :0788597085

Email :mariekarangwa@yahoo.com

APPENDIX 3:UBUTUMIRE MU KWITABIRA UBUSHAKASHATSI KU BURWAYI BW 'IMPYIKO

Inyandiko ihamya ko umurwayi yemeye kwitabira ubushakashatsi

Nitwa MUKAKARANGWA Marie Claire ndiumunyarwanda ,ndiumunyeshuriwiga mu kicioyakabiri muri kaminuza y'u Rwanda mu ishuriry' abafromo n'ababyaza ishamirishinze kwitakundembe n'inkomere.Ndi gukora ubushakashatsi ku buryo abarwayi bafite uburwayi bw' impyiko mu Rwanda bubahiriza gahunda yokwivuzah akoreshejwe imashini iyungurura amaraso(dialize).

Ndabatumira kuba mwakitabira ubushakashatsi musubiza ibibazo nanabahumurizak uko nta nkurikizi yabibamo.

Ubu bushakashatsi bugamije kureba no kumenya urugero abarwayi bafite uburwayi bw'impyiko bubahirizaho gahunda ya dialize ,ikazanabafasha kuyubahiriza.Buzafasha kandi n'abiga iby'ubuforomo kugiraicyo bahindura mu mikorere yabo mu masomo yabo mu bushakashatsi bakora mu byerekeranye no kwigisha abarwayi b'impyiko no kubasobanurira inyungu ziri mu kubahiriza gahunda yo kwivuzah hakohoreshejwe dialize.

Hateganyijwe ko uwitabiriye ububushakashatsi twamarana iminota irihagatiya cumi n'itanu(15) na makumyabiri(20) kandi amakuru atanzwe akandikwa ari uko mubitangiye uruhushya.

Kwitabira ubushakashatsi ni ubushake, kandi no kuba wabihagarika wabikora igihe ubishakiye nta nkurikizi.

Ntawe usabwa gushyiraho izina rye kandi amakuru atanzwe azaguma ari ibanga.

Nta mafaranga ateganyirijwe abazitabira ubushakashatsi ariko inyungu irimo ni uko bushobora gufasha abarwayi b'impyiko bivuzah hakoreshejwe dialize bari mu Rwanda hose.

Uwaba afiteikibazo yahamagara kuri telephone numero 0788597085 Cyangwa

Dr Chironda – 00250 789924956.

Cyangwa numero y'ishami rishinze ubushakashatsi muri kaminuza y'u Rwanda riri mu kigo kigisha iby'ubuzima i Nyarugenge(IRB)

Tel:+250 (0)7885-63312

Email :fsunday@khi.ac.rw

Maze gusoma no kumva uruhare rwanjye mu bushakashatsi, nemeye kuzitabira ubushakashatsi mbishyiraho umukono.

Umukono.....Itariki

Umukono w'ukora ubushshatsi...  Itariki

Aho ukoraubushakashatsi abarizwa

MUKAKARANGWA Marie Claire

Mobile No :0788597085

Email :mariekarangwa@yahoo.com

APPENDIX 4: WORK PLAN

Work to be done	Date to be completed	Personnel assigned to task	Person days required
1. Research Proposal preparation and submission	Week 1-26 1 July-23 Dec	2 persons	2 persons x 182 days =384
2. Ethical clearance and permission to do the work	Week 28 -30 24 th Dec 2016-14 Jan 2017	1 person	1 person x 21 days =21
3. Patients recruitment	Week 31-32 15 Jan-30 Jan 2017	1 person	1 person x 14
4. Pre-testing and questionnaires	Week 33-34 1 st -14 Feb /2017	1 person	1 x 14 days =14
5. Data Collection UTHK, UTHB, KFH	Week 35-38 15 Feb-7 March	2 persons	2 x 21 days =42
6. Data coding, and entry into computer and data analysis	Week 39 8 th -14 th March	2 persons	2 x 7 days =14
7. Report Writing (First draft) and report presentation	Week 40 15 th -21 st March	2 persons	2 x 7 days =14
8. Report presentation	Week 41	1 person	1 x 7 days =7
9. . Report Writing (Final draft) and finalizing the report	Week 42 2 nd -27 th March	1 person	1 x 7 days =7
10. Dissertation presentation preparation	Week 43 28 March -06 April 2017	1 person	1 x 7 days =7
11. Dissertation submission and oral presentation	Week 44 17-28 Apr 2017	1 person	1 x 7 days =7

APPENDIX 5: BUDGET

This study will not be funded but the proposed budget is as follows:

I Development of the proposal

No	Item	No of persons	No of days	No of persons-days	Cost/unit RWF	Total RWF
1	Internet	1	56	1x56	1000	56000
2	Transport	1	24	1x24	1000	24000
3	Restauration	1	24	1x24	1500	36000
4	Communication	1	56	1x56	1000	56000
	Sub total					172000

II .Data collection

	Items	Person/materials	No of days	No of person-days	Cost /unit	Total RWF
1	Papers	2 limes	1	1	4500	9000
2	Printing questionnaires	700	1	1	20x700	14000
3	Transport	2	21	2x21=42	3000	126000
4	Lunch	2	21	2x21=42	3000	126000
	Sub total					275000

III. Study supplies

1	Item	Quantity	Unit price	Total	
2	Notebooks	3	1500	4500	
3	Pens	5	100	500	
4	Pincils	3	100	300	
5	Rabber	1	100	100	
6	Eraser	1	100	100	
	Identification card		500	500	
	Sub total			6500	

IV .Production of the report

Items	Items	Quantity	No of days	Person -days	Cost /unit	Total
1	Cross check and verification of data	2	14	2x14	5000	140000
2	Data entering	2	14	2x14	5000	140000
3	Data analysis	2	21	2x21	5000	210000
4	Report Draft	1	35d	1x35	5000	35000
	Sub total					525000

V.Workshop for report validation

	Item	Quantity	No/day	Personnel per day	Unit Price RWF	Total RWF
1	Meeting	2	2	4	5000	20000
2	Lunch	2	2	4	5000	20000
3	Transport	2	2	4	5000	20000
	Subtotal					60000

Budget summary

No	Description	Total
1	Development of the proposal	172000
2	Data collection	275000
3	Study supplies	6500
4	Production of the report	575000
5	Workshop for report validation	60000
	Total budget	1068500

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 22/02/2017
Ref: CMHS/IRB/159/2017

MUKAKARANGWA Marie Claire
School of Nursing and Midwifery, CMHS, UR

Dear MUKAKARANGWA Marie Claire

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled "*Adherence To Hemodialysis Among End Stage Renal Disease Patients (ESRD) In Selected Nephrology Units In Rwanda*".

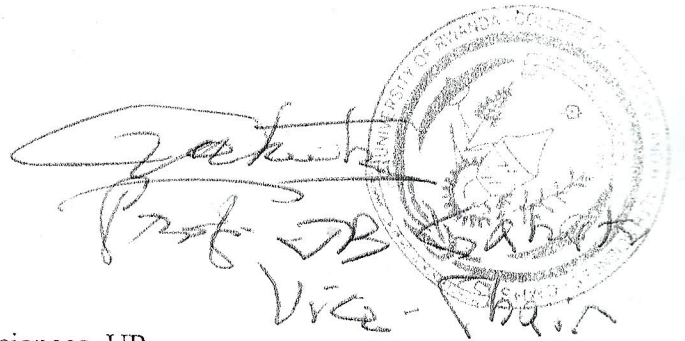
Having reviewed your protocol and found it satisfying the ethical requirements, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major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

We wish you success in this important study.

FOS Professor Kato J. NJUNWA
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate studies, UR





**CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL**

Ethics Committee / Comité d'éthique

March 17th, 2017

Ref.: EC/CHUK/325/2017

Review Approval Notice

Dear Mukakarangwa Marie Claire,

Your research project: "Adherence to Hemodialysis among end stage renal disease patients (ESRD) in selected Nephrology units in Rwanda."

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 17/03/2017 to evaluate your protocol of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your protocol.

You are required to present the results of your study to CHUK Ethics Committee before publication.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

John Nyirigira
The Secretary, Ethics Committee,
University Teaching Hospital of Kigali

<<University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations>>.

B.P. :655 Kigali- RWANDA www.chk.rw Tél. Fax : 00 (250) 576638 E-mail :chuk.hospital@chukigali.rw



KING FAISAL HOSPITAL, KIGALI

Patient Centered Care

19th April, 2017

MUKAKARANGWA Marie Claire
Postgraduate student: Masters Science Nursing
School of Nursing and midwifery
College of Medicine and Health science
University of Rwanda
Mobile phone: 0788597085

Dear Mukakarangwa,


We acknowledge receipt of your study protocol: **"Adherence to Hemodialysis among End Stage Renal Disease patient (ESRD) in selected nephrology units in Rwanda"**

After a thorough review by the KFH, K Ethics-Research Committee; the KFH Ethics Research Committee reviewers consider this study important which will yield very welcome information to improve care of ESRD patients in Rwanda and in particular at KFH.

Therefore, the reviewers recommended that the postgraduate student researcher should be permitted to commence her research immediately.

N.B. It is a requirement that you deposit a final copy of your research in the office of Continuous Quality Improvement in King Faisal Hospital, Kigali for our records.

Best Regards



Dr. Samuel Lutalo
Chief Consultant Physician
& Chairperson KFH, K Ethics Research Committee

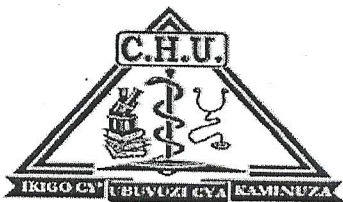


CC:

- Chief Executive Officer, KFH
- All KFH, K Ethics-Research Committee Members.

King Faisal Hospital, Kigali will become a Centre of Excellence in health services provision and clinical education in Africa

• TEL: +250 252 588888 • FAX: +250 252 583203 • EMAIL: info@kfh.rw • Website: www.kfh.rw
GASABO DISTRICT, P.O. Box 2534 KIGALI, RWANDA



**CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL**

**CENTRE HOSPITALIER UNIVERSITAIRE
DE BUTARE (CHUB)
OFFICE OF DIRECTOR GENERAL**

Huye,.....1..5..MAR..2017

N° Ref: CHUB/DG/SA/03/..506../2017


Marie Claire Mukakarangwa
University of Rwanda
College of Medicine and Health Sciences
School of Nursing and Midwifery
Phone: 0788597085
Email: mariekarangwa@yahoo.com

Dear Mukakarangwa

Re: Your request for data collection

Reference made to your letter requesting for permission to collect the data within University Teaching Hospital of Butare, for your research proposal entitled “**Adherence to hemodialysis among end stage renal disease patients (esrd) in selected nephrology units in Rwanda**”, and based on approvals Ref: CMHS/ IRB /159/2017 from University of Rwanda and No RC/UTH/B/016/2017 from our research committee, we are pleased to inform you that your request was accepted. Please note that your final document will be submitted in our Research department.

Sincerely,


Dr. Augustin SENDEGEYA
Director General of CHUB

Cc:

- Medical Director
- Nursing Director
- Training and Research Manager

CHUB