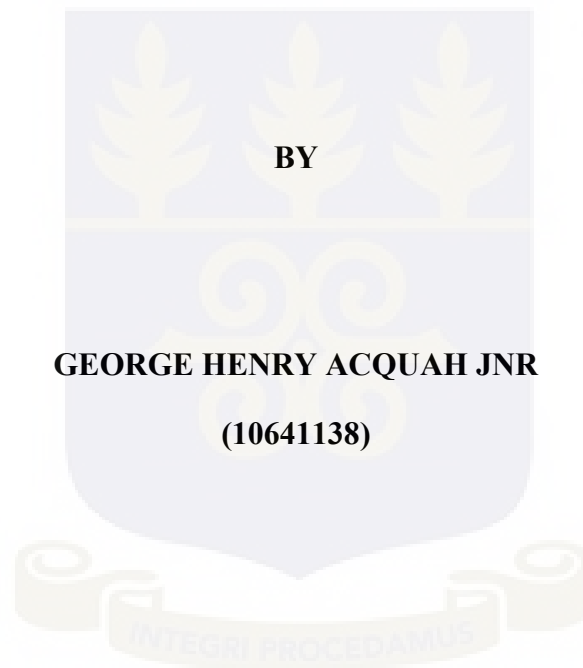


**SCHOOL OF PUBLIC HEALTH
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA**

**ECONOMIC COST OF END STAGE RENAL DISEASE: A STUDY OF PATIENTS
ATTENDING THE RENAL DIALYSIS UNIT OF THE KORLEBU TEACHING
HOSPITAL**



**A DISSERTATION SUBMITTED TO THE SCHOOL OF PUBLIC HEALTH ,
UNIVERSITY OF GHANA IN PARTIAL FULFILLMENT FOR THE AWARD OF
THE MASTER OF PUBLIC HEALTH(MPH) DEGREE.**

JULY, 2018

DECLARATION

I, George Henry Acquah Jnr, declare that except for the other people's investigations which have been duly acknowledged, this work is the result of my own original research, and that this dissertation, either in whole or in part has not been presented elsewhere for another degree.

.....

GEORGE HENRY ACQUAH JNR

(STUDENT NAME)

.....

Date

.....

DR JUSTICE NONVIGNON
(ACADEMIC SUPERVISOR)

.....

Date

DEDICATION

This work is dedicated to my late mother, Mrs Veronica Acquah. May her soul rest in perfect peace.

ACKNOWLEDGEMENT

I give thanks to the almighty God, my father in Heaven for His unflinching love and support in my life.

Special thanks too to my family for their care and support towards the success of this project.

I give great thanks to my Supervisor, Dr Justice Nonvignon for his patience, guidance and care for me.

Finally, I give great thanks too to my mentors Dr Patrick Adjei, Dr Archibold Buah-Kwofie, Dr Josephine Nsafu and Dr Winfred Baah, for their enormous support towards the success of the project

May God bless you all.

ABSTRACT

BACKGROUND: End Stage Renal Disease is the condition of total and permanent kidney failure, in which dialysis or kidney transplantation is vital for survival. The economic burden of ESRD is enormous and is borne not only by the patient but also society and the nation at large.

OBJECTIVES: To determine the economic cost of care of patients with ESRD undergoing haemodialysis.

METHOD: A cross-sectional study of patients at the Dialysis Unit of the Korle-Bu teaching hospital was undertaken using cost of illness approach. The direct cost comprised medical and non-medical costs. Indirect cost was determined by valuing the productivity time of unpaid caregivers using national daily minimum wage. The intangible cost was assessed with a descriptive approach by use of a Likert scale.

RESULTS: The study estimated average monthly direct cost to be GHS 3,585.73 (USD 753.00) and the average indirect cost being GHS 580.41 (USD121.89) monthly. The total economic cost per patient per month was found to be GHS 4,166.15 (USD 874.89) per month.

CONCLUSION: The direct cost of ESRD is enormous(86% of the total cost), loss of productivity measured as indirect cost is also substantive(14% of the total cost). The intangible costs associated with ESRD is also considerable, as the disease poses considerable psychosocial disturbance to the patient.

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ABBREVIATIONS

COI	-Cost of Illness
CKD	-Chronic Kidney Disease
ESRD	-End Stage Renal Disease
HD	-Hemodialysis
KBTH	-Korle Bu Teaching Hospital
KT	-Kidney Transplantation
LMIC	-Lower and middle income countries
NHIS	-National Health Insurance Scheme
PD	-Peritoneal dialysis
Sub-BMC	-Sub budgetary management committee
UG	-University of Ghana
UN	-United Nations
WHO	-World Health Organisation

CHAPTER ONE

1.0 INTRODUCTION

1.1: Background

End stage Renal disease(ESRD) is the condition of total and permanent kidney failure, in which dialysis or kidney transplantation is vital for survival. End stage kidney disease represents the climax of a sequence of events in kidney damage, known as chronic kidney disease(CKD). Following an insult to the kidney, there may be sudden or temporary loss of kidney function, known as Acute kidney injury (AKI). If the insult persists, loss of function may continue for many years leading to CKD and eventually ESRD, which is the final stage of CKD.

Leading causes of CKD include Diabetes Mellitus and Hypertension. In sub saharan Africa, infection, particularly HIV and herbs are notable causes, with diabetes mellitus being the commonest cause across the globe. Complications of chronic kidney disease include anemia, stroke, heart failure and metabolic bone disease. Stroke and heart failure are the major contributors to death from CKD

About 10% of the population worldwide is affected by chronic kidney disease (CKD), and many die each year because they do not have access to affordable treatment. Its prevalence in Sub Saharan Africa(SSA) is estimated to be about 14%(Stanifer et al, March 2014).

According to the 2010 Global Burden of Disease study, chronic kidney disease was ranked 27th in the list of causes of deaths worldwide in 1990, but rose to 18th in 2010. This degree of movement up the list was second only to that for HIV and AIDs. Over 2 million people worldwide currently receive treatment with dialysis or a kidney transplant to stay alive, yet this number may only represent 10% of people who actually need treatment to live. Of the two million people who receive treatment for kidney failure, the majority are treated in only

five countries – the United States, Japan, Germany, Brazil, and Italy. These five countries represent only 12% of the world population. Only 20% are treated in about 100 developing countries that make up over 50% of the world population. More than 80% of all patients who receive treatment for kidney failure are in affluent countries with universal access to health care and large elderly populations.

Worldwide, an estimated 200 million people have chronic kidney disease (CKD). In the United States, African Americans (AAs) have a four-fold excess risk of CKD compared to non-Hispanic white people and globally, people in the low-to-middle income countries of Asia and Sub-Saharan Africa have the highest rates of CKD. Annually, more than 500,000 individuals develop end-stage renal disease (or CKD stage 5) in Sub-Saharan Africa alone and the vast majority of these patients suffer premature mortality. The health care costs and economic burden of CKD are huge and not sustainable even in advanced Western countries(Ojo et al, 2014)

1.2: Problem statement

The growing prevalence and progression of chronic kidney disease (CKD) raises concerns about our capacity to manage its economic burden to patients, caregivers, and society. The societal direct and indirect costs of CKD and end-stage renal disease are substantial and increase throughout disease progression.

According to the 2010 Global Burden of Disease study, In the US, treatment of chronic kidney disease is likely to exceed \$48 billion per year. Treatment for kidney failure consumes 6.7% of the total Medicare budget to care for less than 1% of the covered population. In Canada, by the end of year 2000, an estimated 24,921 people were living with ESRD. The total economic burden of ESRD in Canada in 2000 was \$1.9 billion(Zelmer, 2007). In China, the economy will lose US\$558 billion over the next decade due to effects on death and disability attributable to heart disease and kidney disease. In England, according to a recent report published by NHS Kidney Care, chronic kidney disease costs more than breast, lung, colon and skin cancer combined. In Australia, treatment for all current and new cases of kidney failure through 2020 will cost an estimated \$12 billion. In the united states Medicare fee-for-service spending for ESRD beneficiaries rose by two percent, from \$30.4 billion in 2012 to \$30.9 billion in 2013, accounting for seven percent of the overall Medicare paid claims costs(USRDS).

There is paucity of data on the economic burden of ESRD in Ghana and SSA. The current minimum daily wage for Ghanaians in the public sector is GHS 9.68 and a session of hemodialysis at the Renal dialysis unit of the Korlebu Teaching Hospital costs GHS 260 and this is not covered under the NHIS.

1.3: Research Questions

1. What is the direct cost of ESRD to patients?
2. What is the indirect cost of ESRD to patients?
3. What are the intangible costs associated with ESRD to patients?

1.4: Objectives

1.4.1 General Objective:

The General Objective of the study was to determine the cost of ESRD borne by households of patients at the Renal dialysis unit of The Korle-Bu Teaching hospital.

1.4.2 Specific Objectives:

The specific objectives of the study were to :

1. Estimate the direct cost of ESRD to patients
2. Estimate the indirect cost of ESRD to patients
3. Determine the intangible costs associated with ESRD to patients

1.5: Conceptual framework on Household cost of ESRD

The conceptual framework as illustrated in Figure 1 generally describes the components of household cost of ESRD. The costs associated with the management of ESRD are divided into three major components; direct, indirect and intangible costs. With End Stage Renal Disease, the patient incurs expenditure in the form of transportation, communication and cost of renal replacement therapy. These constitute the direct cost. Indirect costs refer to productivity loss incurred by an illness and are very important in cost of illness studies as they can be substantial, sometimes even being more than the Direct cost. Intangible costs on the other hand are the pain and sufferings of patients as a result of a disease. These in totality make up the household cost of ESRD.

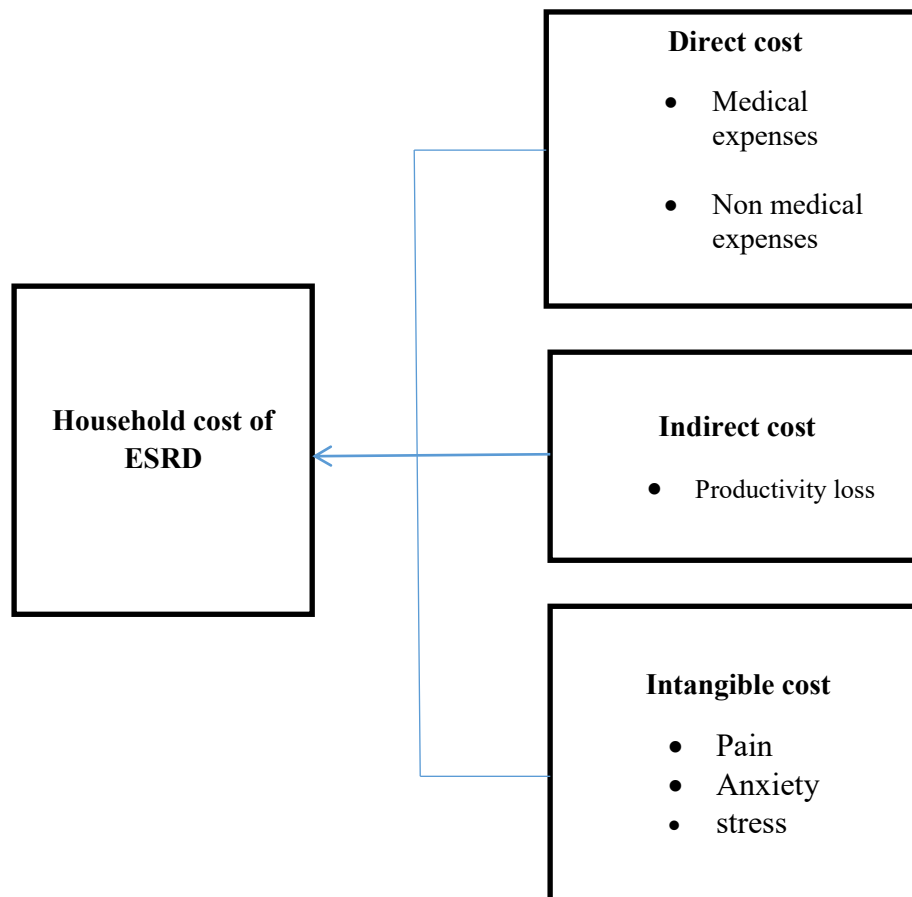


Figure 1: Conceptual framework of Household cost of ESRD

1.6: Justification

In view of scarce available data regarding cost of ESRD in Ghana, this study will come to fill in the knowledge gap with respect to cost of this illness borne by patients with their households at a typical tertiary hospital in the country. This study, aside filling in this gap, will inform health policy making, planning and budgetary allocation. It will also give a current perspective and inform economic framework for program evaluation regarding kidney failure. It would in addition, be a necessary tool for policy and institutional assessment. Cost analyses will also highlight the magnitude of the burden ESRD has on patients, thus informing the need for insurance coverage among others.

CHAPTER TWO

2.0: LITERATURE REVIEW

2.1: Introduction

ESRD is the condition of total and permanent kidney failure and dialysis or kidney transplantation is essential for survival. The disease is a terminal medical condition with expensive health and financial consequences on the patient, family and society at large. The direct cost of the disease usually forms the greater part of the total economic cost, and this is mainly from the cost of hemodialysis, medication and laboratory investigations. Loss of productivity is also substantive as several hours of productivity are spent by patients and caregivers on transportation to health facilities and in receiving treatment for ESRD and this makes the indirect cost of the disease enormous. The intangible cost of the disease is also appreciable as the disease exerts a considerable toll on the emotional and psychological needs of the patient.

2.2: Epidemiology of CKD

According to the 2010 Global Burden of Disease study, chronic kidney disease was ranked 27th in the list of causes of deaths worldwide in 1990, but rose to 18th in 2010. About 10% of the population worldwide is affected by chronic kidney disease (CKD), and many die each year because they do not have access to affordable treatment. The prevalence in sub Saharan Africa(SSA) is estimated to be about 14%(Stanifer et al, March 2014).

2.3: Definition and scope of CKD

The Kidney Disease Outcomes Quality Initiative (KDOQI) of the National Kidney Foundation (NKF) established a definition and classification of CKD in 2002. The KDOQI and the international guideline group on Kidney Disease Improving Global Outcomes (KDIGO) have subsequently updated these guidelines.

The guidelines define CKD as either kidney damage or a decreased glomerular filtration rate (GFR) of less than 60 mL/min/1.73 m² for at least 3 months. Whatever the underlying etiology, once the loss of nephrons and reduction of functional renal mass reaches a certain point, the remaining nephrons begin a process of irreversible sclerosis that leads to a progressive decline in the GFR.

Staging

The different stages of CKD form a continuum. The stages of CKD are classified as follows :

- Stage 1: Kidney damage with normal or increased GFR (>90 mL/min/1.73 m²)
- Stage 2: Mild reduction in GFR (60-89 mL/min/1.73 m²)
- Stage 3a: Moderate reduction in GFR (45-59 mL/min/1.73 m²)
- Stage 3b: Moderate reduction in GFR (30-44 mL/min/1.73 m²)
- Stage 4: Severe reduction in GFR (15-29 mL/min/1.73 m²)
- Stage 5: Kidney failure (GFR <15 mL/min/1.73 m² or dialysis)

Signs and symptoms

Patients with CKD stages 1-3 are generally asymptomatic. Typically, it is not until stages 4-5 (GFR <30 mL/min/1.73 m²) that endocrine/metabolic derangements or disturbances in water or electrolyte balance become clinically manifest.

Signs of late stage CKD (4&5)

- Loss of lean body mass
- Muscle weakness
- Body swelling from fluid retention in tissues

- Hypertension
- Fatigue
- Reduced exercise capacity
- Impaired cognitive and immune function
- Reduced quality of life
- Development of cardiovascular disease
- New onset of heart failure or the development of more severe heart failure
- Increased cardiovascular mortality
- Gastrointestinal symptoms: nausea, vomiting, diarrhea
- Skin manifestations: Dry skin, itchiness, bleeding into skin
- Fatigue, increased somnolence, failure to thrive
- Malnutrition
- Erectile dysfunction, decreased libido, amenorrhea
- Platelet dysfunction with tendency to bleed

Treatment of ESRD

Treatment for ESRD is by kidney replacement. This can be by Kidney transplant or dialysis. ESRD is treated by dialysis at the KorleBu Teaching Hospital. Each ESRD patient requires averagely three sessions of dialysis a week to maintain good health. Periodically Laboratory investigations are done to assess kidney function . Medication is also required to control causative factors such as hypertension and diabetes mellitus and as disease progresses patient will also require blood transfusion. Surgical procedures such as Femoral catheterization are also carried out to connect the dialysis machines to patients circulation for the dialysis procedure.

2.4 Economic burden of CKD:

2.4.1: Direct cost

Chronic Kidney Disease is an expensive medical condition owing to the complexity of the disease and its large socio-economic demands. The direct cost of the disease increases as the disease progresses and at end stage renal disease when renal replacement is required could lead to catastrophic spending in some households.

Kim et al, (2013) used a population based design to estimate the socioeconomic burden of CKD in Korea. The costs of CKD stages III, IV , V, hemodialysis (HD) and peritoneal dialysis (PD) were estimated with a prevalence-based method. The costs of kidney transplantation (KT) and post kidney transplantation were estimated using an incidence-based method. The estimates were direct medical cost, productivity loss cost due to hospitalization and outpatient visit, caregiver cost, and transportation cost. They found that the direct medical cost per year per patient with CKD stages III, IV, and V were 1205, 1963, and 8035 Euros respectively. The direct medical cost per year per patient receiving HD and PD was 34,554 and 25,806 Euros respectively. Medical cost per year per KT patient was 68,798 Euros. Direct medical cost accounted for 70% of the total cost of CKD IV and 87% of the total cost of post KT.

In China, Wu et al (2012), performed a cost of illness analysis on 401 CKD Patients at Beijing, Shanghai, Guangzhou and Chengdu. 281 of them were at CKD stage 3 to 4 and 120 at CKD stage 5. Prevalence data on chronic kidney disease for the Chinese population was collected from literatures. An observational retrospective study was conducted to collect the economic data between November 2012 and December 2012.

From the societal perspective, total costs per patient over 1 year amounted to Chinese Yuan (CNY) 34205 (median: CNY24246, IQR: CNY16271 - CNY 34958) for patients in 3-4 stage

of CKD with direct cost accounting for 97.7% of the total, and Chinese Yuan (CNY) 128231 (median: CNY 103450, IQR: CNY 85351 -CNY 159726) for patients in 5th stage of CKD with direct cost accounting for 82.3% of the total.

A retrospective cross-sectional study of 25,576 CKD patients was done using their electronic medical records, at the Kaiser Permanente, a health consortium in California by Vupputuri et al, (2005) on the direct cost of disease progression from CKD stage 1 to stage 4 among type 2 diabetics with CKD. The mean age of patients was 60.6 years, 51% were men, and mean diabetes duration was 5.3 years. At baseline, 17.9% of patients with T2D also had stage 3 or 4 CKD. Incremental adjusted costs that occurred over follow-up (from baseline) was on average \$4569, \$12,617, and \$33,162 per patient per year, higher among patients who progressed from baseline stage 0–2, stage 3, and stage 4 CKD, respectively, compared to those who did not progress. Across all stages of CKD, those who progressed to a higher stage of CKD from baseline had follow-up costs that ranged from 2 to 4 times higher than those who did not progress. They concluded that, progression of CKD in type 2 diabetics drives substantial medical care costs. Interventions designed to minimize decline in progressive kidney function, particularly among patients with stage 3 or 4 CKD, may reduce the economic burden of CKD in type 2 diabetics.

Strengths of the study included the the large sample size and longitudinal data that allowed estimation of progression rates and changes in costs associated with progression of CKD. One limitation of the study was that the observational nature of the study precludes the assertion that the relationship between CKD progression and increasing medical care cost is causal.

2.4.2: Indirect cost

The indirect cost of the illness could also constitute a huge economic burden on industries, as the cost of absenteeism due to illness and also for treatment, as well as presenteeism could be enormous. The indirect costs are the costs of valued productive time lost to employers of ESRD patients as a result of time spent travelling to the hospital for treatment, time spent receiving treatment and waiting time at the hospital.

Again, Kim et al (2013) above, using the population based design to estimate the socioeconomic burden of CKD in Korea, found that cost associated with productivity loss was approximately 8–20% of total economic cost.

Also in China, Wu J et al (2012) above interviewed patients and caregivers about resource utilization and absenteeism from work in the past year. Indirect cost was estimated to be \$3,176.24 and this constituted 17.7% of total economic cost.

2.4.3: Intangible cost

There is a paucity of data on studies on the intangible cost of CKD worldwide, but Le et al, (2012) in an estimate of the economic burden of hypertension, a major cause of CKD among 9396 adults in a cross sectional study in rural south west china found the overall mean unit intangible cost associated with hypertension to be \$417.4

2.5: Conclusion

In conclusion, the management of end stage kidney disease consumes a significant portion of patients' financial and social resources and affects productivity. The cost of treatment increases as the disease progresses from CKD stage 1 to 4, escalating at CKD stage 5 or ESRD. Studies have been carried out in Asia, America and other developed countries to estimate the socioeconomic burden of the disease and there is the need to make these estimates in Ghana and Africa, to avail information for policy making.

CHAPTER THREE

3.0: METHOD

3.1: Study Design

The study was a descriptive cross-sectional, Cost-of-illness (COI) study of ESRD patients on dialysis at the renal unit of the Korlebu teaching hospital. It was intended to be a cost of illness study to estimate the economic cost of ESRD.

3.2: Study Area

The Korle Bu Teaching Hospital was built in 1923 and is currently the third largest Hospital in Africa and the leading patient referral centre in Ghana. The 2000-bed capacity Hospital currently has over 4,000 medical and paramedical staff with an average daily attendance of 1,500 patients (KBTH, 2014).

The Korle-Bu Teaching Hospital is located at the Guggisburg Avenue, within the Ablekuma locality of Accra Metropolis, in the Greater Accra region of Ghana. The hospital has 21 clinical and diagnostic departments/units which includes the Renal dialysis unit where the study took place (KBTH, 2014).

The Renal dialysis Unit of the hospital sees both emergency and outpatient clinic CKD cases in the Metropolis as well as other regions in the Ghana and sometimes from the West African Sub region and works in relation with other Sub budgetary management committees

(Sub-BMCs) in the Hospital. The unit also sees to the management of all in-patients in the hospital, with kidney impairment.

The renal unit of the Korlebu teaching hospital is the major center for treatment of CKD in the country.

The unit at present has at least 3 nephrologists, various physician trainee nephrologists, medical officers and specialized nurses who attend to patients round the clock.

The unit has 17 functioning haemodialysis machines and sees patients on outpatient clinic basis, patients on admission as well as emergencies. The unit currently manages an average of 200 ESRD patients on hemodialysis monthly and it runs four sessions of dialysis daily, with all 17 hemodialysis machines, and therefore carries out hemodialysis for an average of 40 to 60 ESRD patients daily.

At least 10 new cases are seen each week at the opd, 2 emergencies each day and over thirty cases on admission at the medical block of the hospital daily, as well as few other cases in other departments of the hospital.

3.3: Study population

Patients: The study population was patients with ESRD of all ages on hemodialysis at the renal dialysis unit of the KorleBu Teaching Hospital.

3.3.1 Inclusion Criteria:

1. Patients with ESRD on hemodialysis at the renal dialysis unit of the KorleBu Teaching Hospital, who consented to be a part of the study
2. Caregivers of the ESRD patients who consented to be a part of the study.

3.3.2 Exclusion Criteria

Patients:

1. Patients who were medically unfit to avail information or give consent.

3.4: Sample size Calculation

Patients: The sample size, determined at a confidence level of 95% using the Yamane's single sample for finite population formula:

$$n = \frac{N}{1 + N(e^2)}$$

Where n = sample size, N=population size and e = margin of error

Using a population size of 200 ESRD patients on dialysis monthly at the hospital and a margin of error of 0.05 this gives us a sample size of 133.

3.5: Sampling Method

Using Google's random digit generator, 133 patients were selected from the records of the average monthly 200 ESRD patients seen. Patients were approached daily by the research assistants and educated about the study. Their consent was then sought and questionnaires administered.

3.6: Study Variables

The variables used in the study were the total economic cost of ESRD, direct, indirect and intangible costs. These have been described together with their measurements in tables 1-3.

Direct cost: This was made up of medical and non-medical costs (i.e. cost of transport, food and consumables, communication)

Indirect cost: This was made up of the cost of the number of days the patients and caregivers were absent from work and the waiting and travel times to and from the Renal Dialysis Unit.

Intangible cost: Perception of patient's fear, discomfort and emotional sufferings was assessed. This was done with the use of a Likert scale. The individual choices were graded and an average score obtained.

The sociodemographic characteristics for each participant was also obtained, including marital status, monthly income, NHIS beneficiary status, number of children, religious affiliation, age and educational status.

3.7: Data Collection Techniques and Tools

Patients and caregivers: Structured questionnaires were employed for data collection. The questionnaire was made up of both open and closed ended questions covering relevant information and patients' demographic information. The questionnaire had sections covering the duration of treatment. It further elicited information on the intangible cost such as fear, discomfort and emotional suffering endured by patients.

The questionnaire (Appendix 2) was generally in five (5) sections: The first part being the part that captured the sociodemographic characteristics of the patient and coding information. The second section described the duration of illness. The third part, in finding direct cost, obtained estimates for direct medical cost and non medical cost. The fourth and fifth sections had variables used in estimating indirect and intangible costs respectively.

Patients and their caregivers were interviewed by the PI and research assistants and information was obtained to fill the questionnaires

3.8 Quality Control

Adequate mechanisms were put in place to safeguard and guarantee data accuracy and make it devoid of any bias. The measures included training of research assistants, pre-testing of questionnaires, editing of completed questionnaires, and data entry. Research assistants were

also monitored on the data collection on a daily basis. All completed data were validated and entered on a daily basis. Also the dataset was cleaned before analysis. Completed questionnaires were kept under lock and key to prevent unauthorized people from gaining access to them. Also the questionnaires will be discarded 5years after publication of the findings of the study.

Training of field workers: Three (3) research assistants were recruited to help with data collection. These individuals were clinical year medical students of the University of Ghana School of Medicine and Dentistry. They were fluent in English, Akan and Ga and were trained for two (2) days on the questionnaires and on how to obtain consent, as well as how to handle the information collected. They were also educated on ESRD, the study and approach to patients for data collection, ethics and courtesy. Their work was additionally supervised and reviewed daily.

Pre-testing of questionnaires: The questionnaire was pre-tested prior to final administration to the participants. Pre-testing was conducted on ESRD patients on dialysis at the renal dialysis unit of the Korle-Bu Teaching Hospital. However this sample was not part of the sample for the main study.

Editing completed questionnaires: Exposed errors and inconsistencies from the pre-testing were amended and reviewed before commencement of the study.

Follow up interviews: Follow up interviews were carried out at subsequent patient visits, to gather any information in the questionnaire not captured at first contact.

3.9 Data Entry and Processing

The information collected was validated, serialized and coded within 24 hours before entry into Microsoft Excel 2010. After entry, the data set was crosschecked for errors with the hard copies. The data was analyzed using Microsoft Excel 2010.

3.9.1: Data Analysis

Data analysis involved estimation of the direct, indirect and intangible costs of ESRD.

Socio-economic status variables were generated for patients based on their educational status, occupation and income.

A sensitivity analysis was also done. This was to examine the robustness of the study by looking out for the effects of a change in the value of an input about which there may be uncertainty, on the output. This improved the accuracy of the study.

3.9.2: Estimation of direct costs

This was the summation of direct medical cost (cost of consultation, hospital admission, hemodialysis, cost of medication and consumables, cost of surgical procedures) and direct non-medical cost i.e cost of transportation, communication, cost of food etc. .

Direct Medical cost: This included cost of consultation, hospital admission, medication, dialysis, laboratory investigations, cost of folders, and allied treatment such as dietherapy and surgical procededures. These were summed for each patient and an average determined.

The direct non-medical costs included the following:

Transport cost: This covered the cost of conveying the patient to and from the hospital while on admission and for treatment on OPD basis.

Food: This estimated the cost of food and drinks the ESRD patient consumed in the period of treatment.

Miscellaneous: These came from the cost of items like communication

The total direct cost was ascertained by a summation of all components of direct medical and direct non-medical expenses.

Table 1: Estimation of Direct cost of ESRD

No.	VARIABLE NAME	DESCRIPTION	UNIT OF MEASUREMENT
1.	DIRECT MEDICAL COST	consultation, hospital admission, medication, dialysis, laboratory investigations, cost of folders, allied treatment , cost of surgical interventions	GHS
2.	DIRECT NON-MEDICAL COST	cost of conveying the patient to and fro the hospital while on admission and for treatment on OPD basis, cost of food and drinks the ESRD patient would use in the period of treatment	GHS

3.9.3: Estimation of indirect costs

Indirect cost was calculated by multiplying the daily minimum wage rate by the number of days of workdays lost for the patient, as the human capital method (HCM) is designed to ascertain the value of human capital as the present value of the patient's future earnings. Productivity loss was therefore valued using the 2016 national minimum wage in the country (that is GH¢ 9.68 per day). The estimation of indirect cost is shown in the Table 2

Table 2: Estimation of indirect cost of ESRD

No	Category	Cost estimation approach
1.	Days lost to patients	This was the summation of days lost to patients who have ESRD, due to treatment per month
2.	Productivity loss to patients due to traveling and waiting times	This was the summation of the total number of hours spent by the patient and travelling time to seek treatment for ESRD per month
3.	Days lost to caregivers	This was the summation of days lost to caregivers of patients with ESRD, due to treatment per month

4.	Productivity loss to caregivers due to traveling and waiting times	This was the summation of the total number of hours spent by the caregiver and travelling time to seek treatment for ESRD patient per month.
5.	Total Indirect cost	This was the overall aggregation of the total valued productivity, obtained by multiplying the total time spent by the minimum daily wage.

3.9.4: Total cost estimation

The overall cost was estimated by the summation of the total direct cost and total indirect cost. The average cost per patient was determined by dividing the overall cost by the number of ESRD patients sampled.

3.9.5: Determination of intangible costs

The Intangible cost was assessed with the Likert scale. A five dimensional Likert scale was used, in which patients were asked to rate statements under each dimension as (1) 'not at all' (2) 'a little' (3) 'moderately' (4) 'quite a bit' (5) 'extremely' in respect of the fear, pain and emotional sufferings. The mean of the responses for each dimension and their individual items under them was estimated for patients. The composite intangible score was obtained by adding the dimensions in each domain and multiplying by the number of questions. This score was reclassified into low, moderate and high intangible cost with the corresponding ranges using descriptive statistic tertile as shown in table 2. Cross tabulations and Chi-square test were done to test the differences in intangible cost between males, females and among different educational levels and age groups.

Table 3: Composite intangible score ranges

No.	Dimension	Upper range limit
1.	Low	1/3
2.	Moderate	2/3
3.	High	3/3

3.9.6: Ethical Considerations

The study was carried out at the Renal dialysis unit of the Korle-Bu Teaching Hospital. Ethical approval was sought from the IRB-KBTH, who also introduced the PI to the Head of the Renal Dialysis Unit. Participants involved in the study were ESRD patients on dialysis at the renal unit of the Hospital.

There was no harm from the study. The questionnaire (Appendix 2) was well structured to facilitate the data collection. The participants were told about the general nature of the study and assured of no potential harm as well as of confidentiality with regards to the information to be collected. They were told of their freedom to decline participation, with no consequences should they decide to do so. Participants signed to indicate their consent (Appendix 1) and guardians of minors also signed a consent form. For ESRD patients who were minors, their assent was sought after guardians had signed the consent form. All patients were allowed to ask any questions they had, in relation to the study. Regarding privacy and anonymity, the information provided will be treated with strict confidentiality. Filled questionnaires have been kept under lock and key to prevent unauthorized people from gaining access to them. Also the questionnaires will be discarded five years after publication of the findings of the study and no participant's name shall appear or be mentioned in any report that will come out from this study. No payment was made to the respondents for their time spent. There was no conflict of interest declared.

This study was self-sponsored in partial fulfillment for a Master of Public Health Degree from the University of Ghana.

CHAPTER FOUR

4.0 RESULTS

4.1: Background characteristics

A total of 134 patients participated in the study, representing a response rate of 67% of all the patients who attended the Dialysis unit of Korle-Bu Teaching hospital in the study period. The respondents consisted of 56% (75) males and 44% (59) females. The ages of the respondents ranged from 11 to 74 years, with mean and median ages of 42.2 (± 14.6) and 41.5 years respectively. The ages of most of the respondents, as shown in Table 4 was between 20 and 50 years, while a majority (46.3%) of the patients were employed and the median monthly income was GHS 1,000 . In contrast, only 7 of the respondents were at the extremities of age, representing 5% of the entire population of respondents. Most of the employed participants were employed in the formal sector, while 69.4% (93) have had at least Senior High school education. Table 4 shows the background characteristics of patients diagnosed with end-stage renal disease having haemodialysis within the study period.

About 4% of the respondents fully sponsor their haemodialysis themselves, with 96% of them requiring financial support from various sources (Figure 5). Those obtaining financial help from 'other' sources were made up of people receiving financial support from Non-Governmental Organisations (NGO) (5), Media houses (4), Churches (4), employers (3), and Parliamentarians (1). Two respondents did not disclose their source of financial help.

Table 4: Background characteristics of respondents

	Background characteristics	Number	Percent
Sex	<i>Male</i>	75	56.0
	<i>Female</i>	59	44.0
Age	<i>less than 20</i>	3	2.2
	<i>20-29</i>	28	20.9
	<i>30-39</i>	33	24.6
	<i>40-49</i>	29	21.6
	<i>50-59</i>	19	14.2
	<i>60-69</i>	18	13.4
	<i>70 +</i>	4	3.0
Marital status	<i>Married</i>	72	53.7
	<i>Not married</i>	62	46.3
Employment	<i>Employed</i>	62	46.3
	<i>Unemployed</i>	37	27.6
	<i>Student/ Apprentice</i>	16	11.9
	<i>Housewife</i>	1	0.8
	<i>Retiree</i>	18	13.4
Employment sector	<i>Formal</i>	37	27.6
	<i>Informal</i>	24	17.9
	<i>Non-workers</i>	73	54.5
Educaton	<i>No education</i>	4	3.0
	<i>Primary</i>	6	4.5
	<i>Middle/JSS/JHS</i>	31	23.1
	<i>SSS/SHS/Vocational/Technical</i>	45	33.6
	<i>Tertiary</i>	48	35.8
NHIS	<i>Beneficiary</i>	125	93.3
	<i>Non-Beneficiary</i>	9	6.7

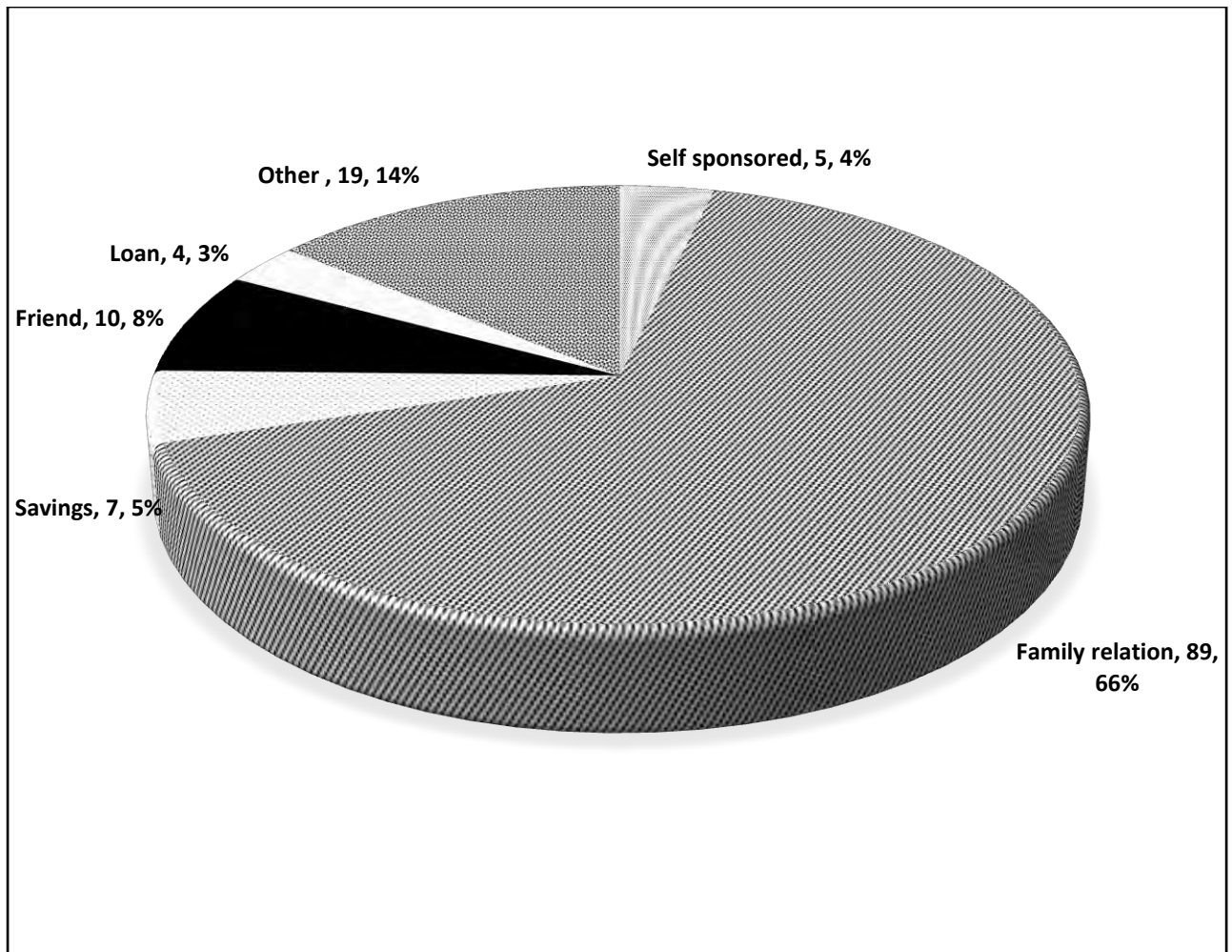


Figure 2: Distribution of sources of financial help

4.2: Direct cost of ESRD per month

The average monthly direct cost of ESRD was found to be GHS 3,585.73 ($\pm 1,373.71$). Of this, GHS 2,995.60(83.5%) was due to medical expenses and GHS 590.13(16.5%) was due to non medical expenses.

Table 5: Direct monthly cost of patients with ESRD undergoing haemodialysis

Cost components	Average Cost		Total Population cost (n=200)		Cost Profile
	GHS (SD)	USD ^a (SD)	GHS	USD ^a	
Medical Cost	2,995.60 (1,212.06)	629.08 (254.53)	599,119.85	125,815.17	83.5
<i>Dialysis</i>	2,396.04 (521.97)	503.17 (109.61)	479,208.96	100,633.88	66.8
<i>Surgical</i>	298.51 (1,131.57)	62.69 (237.63)	59,701.49	12,537.31	8.3
<i>Registration/ Consultations</i>	2.61 (30.24)	0.55 (6.35)	522.39	109.70	0.1
<i>Medication</i>	176.70 (291.15)	37.11 (61.14)	35,339.25	7,421.24	4.9
<i>Laboratory investigations</i>	163.75 (190.29)	34.39 (39.96)	32,750.75	6,877.66	4.5
<i>Imaging</i>	7.24 (47.45)	1.52 (9.96)	1,447.76	304.03	0.2
<i>Allied treatment</i>	6.72 (69.58)	1.41 (14.61)	1,343.28	282.09	0.2
Non-medical	590.13 (443.25)	123.93 (93.08)	118,026.87	24,785.64	16.5
<i>Travel cost</i>	434.43 (393.36)	91.23 (82.61)	86,886.57	18,246.18	12.1
<i>Food/ Drinks</i>	140.54 (74.30)	29.51 (15.60)	28,108.96	5,902.88	3.9
<i>Miscellaneous</i>	15.16 (33.66)	3.18 (7.07)	3,031.34	636.58	0.4
Total	3,585.73 (1,373.71)	753.00 (288.48)	717,146.72	150,600.81	100.0

^aUS\$1.00 equivalent to GHS 4.79 (Bank of Ghana average monthly interbank exchange rate, June 2018)

4.3: Indirect monthly cost

The average indirect economic cost was estimated to be GHS 580.41 ($\pm 1,438.55$). As shown in Table 6, most of the indirect cost to the household was accounted for by the sum of the valued care-giver's time lost.

Table 6: Indirect monthly cost of patients with ESRD undergoing haemodialysis

Indirect Cost	Average monthly cost		Population monthly		Cost Profile
	GHS (SD)	USD ^a (SD)	Total GHS	Total USD ^a	
<i>Valued productive time lost</i>	91.82 (23.58)	19.28 (4.95)	18,363.10	3,856.25	15.8
<i>Valued travel and waiting time</i>	73.88 (39.99)	15.52 (8.40)	14,776.81	3,103.13	12.7
<i>Valued caregiver's time lost</i>	414.71 (1,165.62)	87.09 (244.78)	82,942.48	17,417.92	71.5
Total	580.41 (1438.55)	121.89 (302.10)	116,082.40	24,377.30	100.0

^aUS\$1.00 equivalent to GHS 4.79 (Bank of Ghana average monthly interbank exchange rate, June 2018)

4.4: Total economic cost of patients with ESRD undergoing haemodialysis per month

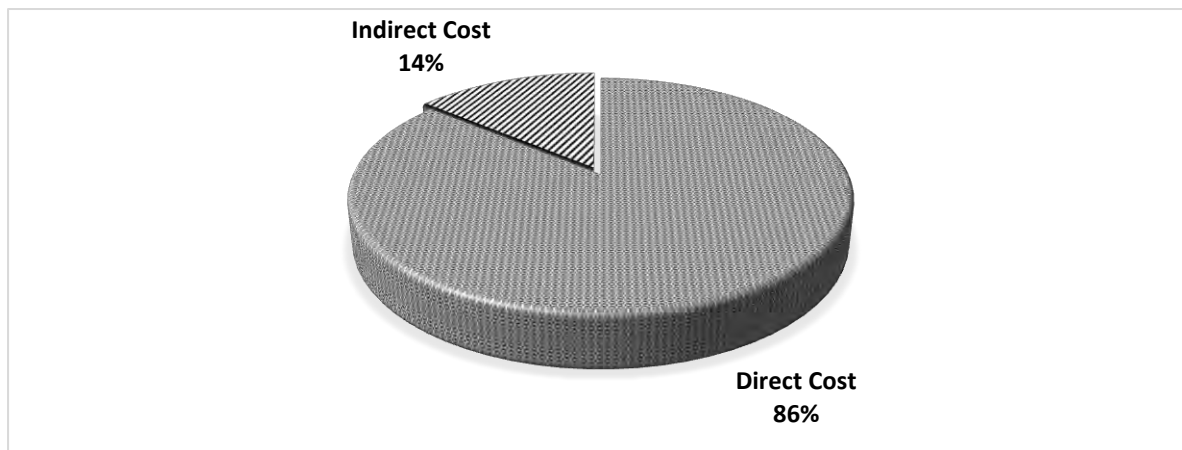


Figure 3: Proportion of direct and indirect cost in the total economic cost of ESRD borne by patients undergoing haemodialysis per month

The total economic cost of end-stage renal disease undergoing haemodialysis at the Dialysis unit of Korle-Bu Teaching Hospital was found to be GHS 833,229.12 (USD 174,978.12)

Most (86%) of this was accounted for by the direct cost, making up nearly six times the cost of the indirect cost borne by the households.

4.5: Sensitivity Analysis

Table. 7 Summary table showing sensitivity analysis of direct and indirect costs

Scenario	Cost component	Percentage change in parameter	Total cost		Percentage change in total cost	Proportion of total cost		Percentage change in proportions of cost	
			GHS	USD		Direct	Indirect	Direct	Indirect
Base scenario		0	4,222.11	881.44	0.0	86.3	13.7	0	0
Variation (One-way Sensitivity Analysis)	Medication	3	4,827.62	1,007.85	14.3	86.3	13.7	0.0	0.0
		5	4,827.76	1,007.88	14.3	86.3	13.7	0.1	-0.1
		7	4,827.91	1,007.91	14.3	86.3	13.7	0.1	-0.1
Variation (One-way Sensitivity Analysis)	Wage rate	3	4,455.62	930.19	5.5	81.7	18.3	-4.5	4.5
		5	4,471.42	933.49	5.9	81.4	18.6	-4.8	4.8
		7	4,487.23	936.79	6.3	81.2	18.8	-5.1	5.1
Multi-variation (Multi-way Sensitivity Analysis)	Medication and Wage rate	3	4,466.05	932.37	5.8	81.8	18.2	-4.5	4.5
		5	4,495.89	938.60	6.5	81.5	18.5	-4.7	4.7
		7	4,529.86	945.69	7.3	81.3	18.7	-4.9	4.9

^aUS\$1.00 equivalent to GHS 4.79 (Bank of Ghana average monthly interbank exchange rate, June 2018)

Table 7 above is a summary table showing the sensitivity analysis of direct and indirect costs. At the base scenario the average monthly economic cost of ESRD per patient is GHS 4,222.11. This is made up of direct and indirect costs. On varying the cost of medication by 7% we realize a 10% drop in indirect cost and a 10% increment in direct cost. On varying the wage rate by 7% we realize a 5% drop in direct cost and a 5% increment in indirect cost. On varying both the wage rate and cost of medication by 7% we realize a 5% reduction in direct cost and a 5% increment in indirect cost, with an overall percentage change in total cost being less than 10%.

4.6: Intangible cost associated with ESRD among patients on haemodialysis

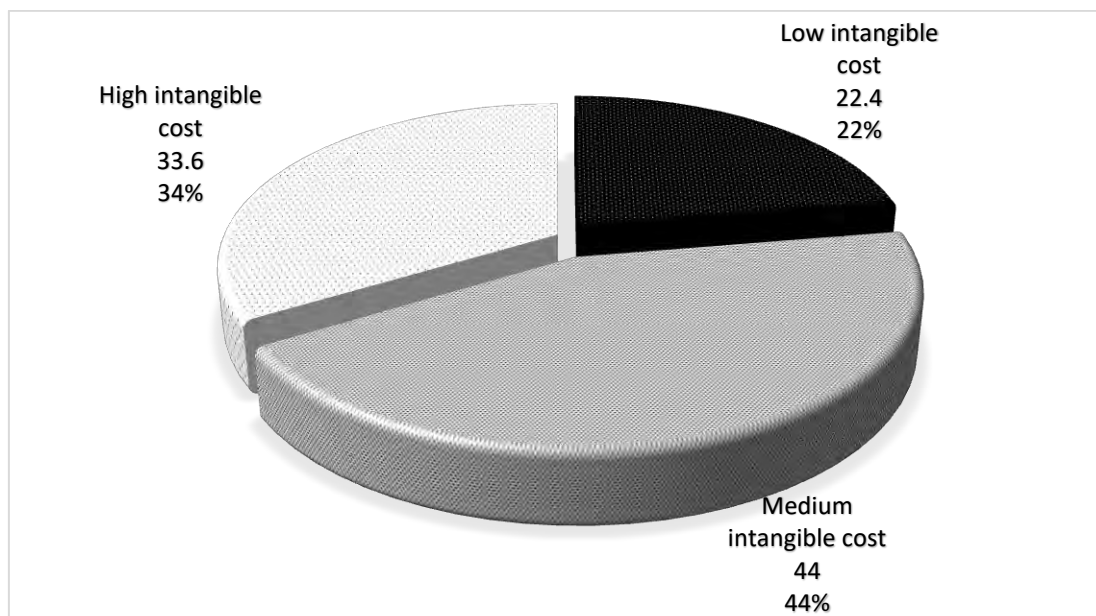


Figure 4: Intangible costs associated with ESRD borne by patients undergoing haemodialysis

Figure 7 shows that 34% of the ESRD patients had high intangible cost while 44% were in the moderate range. There was however no statistically significant difference in intangible cost with sex ($p=0.152$) education ($p=0.163$) and employment status ($p=0.248$).

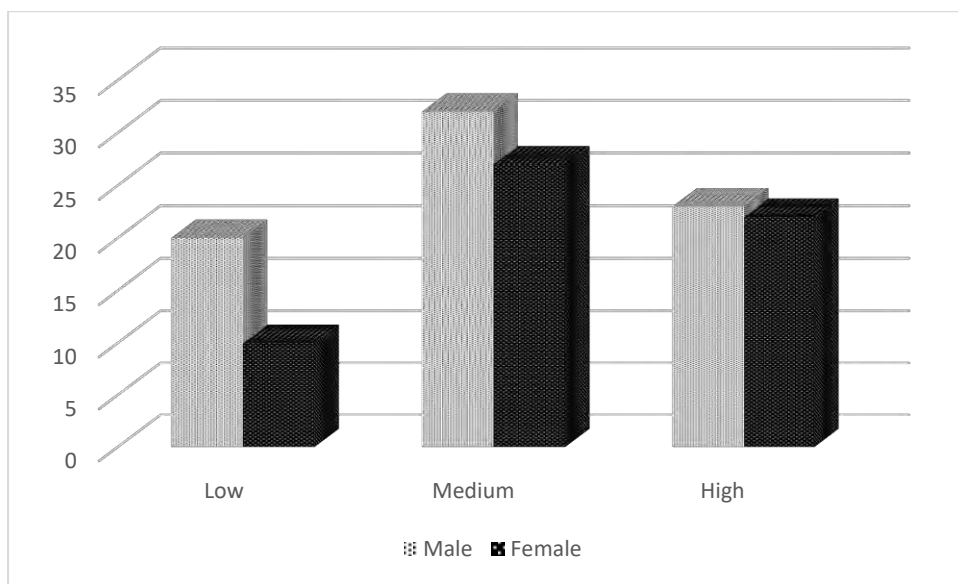


Figure 5.: Intangible cost among the sexes

CHAPTER FIVE

5.0 DISCUSSION

This study set out to determine the household costs of patients diagnosed with end-stage renal disease who are having dialysis at the Korle-Bu Teaching Hospital. The study estimated the average direct cost of the disease to be GHS 3,585.73 (USD 753.00) and the average indirect cost to be GHS 580.41 (USD121.89) monthly per patient. The median monthly income was estimated to be GHS 1,000 and therefore the proportion of the direct cost of the disease relative to income is 3.6/1

The current study estimated the average monthly direct cost of ESRD to be GHS 3,585.73(USD 753.00) Mushi, Marschall, & Fleßa, (2015) in their systematic review found the direct cost of haemodialysis among ESRD patients in LMIC to range from USD 285.33 to USD 3,565.42 monthly per patient. Ahlawat et al. also estimated a monthly direct expenditure of USD 265.08 per person in India. It was however found to be equivalent to USD 872.24 in Italy (Turchetti et al., 2017). Most of the total direct cost was accounted for by the cost of the haemodialysis itself, making 66.8% of the entire direct cost. This is consistent with all papers reviewed, and serves as a cost element to target, should there be a consideration for any kind of social intervention of the sort. This is also evident in the finding that a disproportional 96% of the respondents in this study have to seek additional source of help to foot their bill for care of ESRD although 93.3% of them were beneficiaries of the National Health Insurance scheme. This may go to suggest that patients may benefit from a wider coverage of the NHIS.

Generally it is well known that the direct cost estimates associated with chronic diseases are higher than those of acute diseases or communicable diseases on condition that they are

effective and efficacious (Jo, 2014). Such chronic diseases, as is for ESRD need a certain continuous care which may be burdensome to patients annually. Similar observations have been made for obesity (Ricci et al., 2005), schizophrenia (Tajima-Pozo et al., 2015), and stroke (Joo et al., 2014).

Economic evaluation of smoking in Vietnam showed a proportionate 49.5% of total cost being accounted for by indirect cost (Yang et al., 2011). Indirect cost comprised 9% of the total social cost by Turchetti et al., though their actual annual estimate was comparatively larger than was found in this study. The indirect cost from this current study accounted for 14% of the total cost. This comparatively larger representation reflects the substantive loss in productivity of the patients, most of whom are workers in formal employment.

Many of the participants experienced medium to high intangible cost, reflected by the comparative proportions found. The components investigated were fear and emotional suffering which seem to be fairly common among the participants.

5.1 Study Limitations

1. The study was limited by the paucity of data on studies on economic cost of ESRD in Ghana and SSA for comparison and improvement.
2. The economic cost of co morbid conditions such as diabetes mellitus which has an effect on ESRD could also not be assessed owing to the short duration of the study.
3. There was also a lack of an adequate tool to measure productivity loss among patients and caregivers who worked in the informal sector.

CHAPTER SIX

6.0: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The average direct cost incurred monthly by ESRD patients at the renal dialysis unit of the Korlebu Teaching Hospital was GHS 3,585.73 (USD 753.00) and the average indirect cost was GHS 580.41 (USD121.89) monthly per patient.

83.5% of the direct costs was due to medical expenses and the remaining 16.5% was from non medical expenses. The average monthly cost of dialysis was GHS 2,396.04 which constituted about 67% of the average monthly direct cost. The average monthly indirect cost per patient was GHS 580.41. Indirect costs constituted 14% of the total economic cost. There is a palpable level of perceived psychological and emotional distress among patients with ESRD on haemodialysis in Ghana.

Majority of ESRD patients were in the reproductive age group and majority of ESRD patients financed their treatment through financial support from family.

6.2 Recommendations

1. **Expansion of NHIS coverage :** Patients with ESRD could benefit from a widening of the NHIS coverage to contain some of the high cost components such as the cost of hemodialysis.
2. **Health promotion targets:** This study shows that majority of end-stage renal disease patients were in the productive age group. It is recommended that health promotion programs regarding kidney diseases targets this age bracket as well as the young and elderly .

3. **Provision of more renal dialysis centres:** The cost of transportation and loss of productivity can be reduced if more renal dialysis units are made available in each region across the country
4. **Psychosocial support:** The moderate intangible cost of the disease among majority of the participants can be met if families and societies support ESRD patients with their presence and encouragement. Clinical psychologists should also be deployed to assist patients with their emotional distress. The study also showed that a large number of participants obtained financial support from their families and thus family support is crucial in successful management of ESRD.

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APPENDIX 1:

ECONOMIC COST OF END STAGE RENAL DISEASE: A STUDY OF PATIENTS

ATTENDING THE RENAL DIALYSIS UNIT OF THE KORLE-BU TEACHING

HOSPITAL

CONSENT FORM

My name is GEORGE HENRY ACQUAH JNR, a post-graduate student from the school of Public Health, University of Ghana. I am carrying out a study in this department to find out the general cost incurred by End stage renal disease patients , who report to this hospital and I would be very glad if you could participate in it. Your participation would involve granting us fifteen minutes of your time, to provide answers to a structured questionnaire on yourself and how much you have spent on treating yourself.

You may not have any immediate or direct benefits from the survey, but your responses would be helpful in policy planning and formulation and recommendations to appropriate authorities to help reduce the economic burden of End stage renal disease in general and to inform reimbursement procedures.

If you indeed decide to take part, you are allowed to withdraw whenever you wish to, and are also allowed to skip answering any of the questions that you are not very comfortable with.

The information you would provide is going to be treated with strict confidentiality. Apart from my research team and members of the Ethics Committee of this hospital, no body shall have access to the information since it shall be under lock and key. We also assure you that your name shall not appear or be mentioned in any report that will come out from this study.

Before taking Consent

Do you have any questions you wish to ask about the study? Yes No

If yes, please, indicate the questions

below).....
.....

In case you have any questions later please, do not hesitate to contact

George Henry Acquah Jnr, Department of Health Policy, Planning and Management,
School of Public Health, University of Ghana. (Tel: 0244-056901) Email:
geo_acqjnr@yahoo.com.

Also, if you need further clarifications about this study kindly contact : The Secretary,
Research Office, Korle-Bu Teaching Hospital. (0302739510)

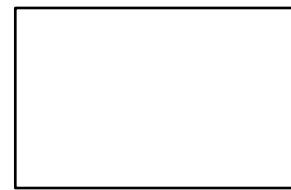
PATIENT'S CONSENT

I have read or I have let somebody read or translated all the necessary information that I need to know concerning this study and have fully understood it. I have decided on my own accord without any coercion to take part in this study. However by deciding to participate in this study, I am not waiving any of my personal rights by signing or thumb printing this consent form.

Signature:

.....

OR



L/R Thumb Print

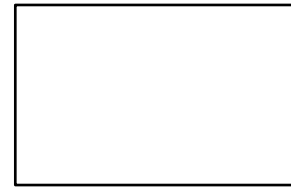
CAREGIVER'S CONSENT

I have read or I have let somebody read or translated all the necessary information that I need to know concerning this study and have fully understood it. I have decided on my own accord without any coercion to take part in this study. However by deciding to participate in this study, I am not waiving any of my personal rights by signing or thumb printing this consent form.

Signature:

.....

OR



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APPENDIX 2:**DRAFT QUESTIONNAIRE****ECONOMIC COST OF ESRD: A STUDY OF PATIENTS AT THE RENAL DIALYSIS UNIT OF KORLE-BU TEACHING HOSPITAL**

Dear Respondent,

This is a research carried out on *cost of End stage renal disease: A study of patients at the Renal Dialysis Unit of Korle-Tu Teaching Hospital*. I will therefore like to take some minutes of your precious time to answer these questions. You are assured that the answers you give will be strictly confidential and your name will not be mentioned in our research reports. Thank you.

Qn. No.	Questions	Response
Respondent ID: <input type="text"/> <input type="text"/> <input type="text"/>		
Section 1	SOCIO-DEMOGRAPHIC INFORMATION	
1	What is your gender 1. Male 2. Female	<input type="text"/>
2	What was your age at your last birthday?	<input type="text"/> <input type="text"/> years
3	What is your highest level of formal education? 1. No formal education 2. Primary 3. Middle/JSS/JHS 4. SSS/SHS/Secondary/Vocational/Technical 5. Tertiary	<input type="text"/>
4	What is your marital status? 1. Married 2. Not married	<input type="text"/>
5	What is your employment status? 1. Employed 2. Unemployed (<i>If Unemployed, answer Qs. 6 & 7</i>) 3. Student/Apprentice 4. Housewife 5. Retiree	<input type="text"/>
6	If Unemployed, why are you not working now? 1. Unable to work due to illness 2. Other (please specify).....	<input type="text"/>
7	If Unemployed, have you been looking for a job within the past 6 months? 1. Yes 2. No	<input type="text"/>

8	If employed, in which sector are you? 1. Formal sector 2. Informal sector	<input type="text"/>
9	If Employed, what is your average monthly income? (i.e., salary plus other monies from other sources)	GHS
10	Are you an NHIS beneficiary? 1. Yes 2. No	<input type="text"/>
Section 2	DETAILS OF ILLNESS	
12	How long have you been on dialysis? 	<input type="text"/>
Section 2	DIRECT COST INFORMATION	
13	<i>Medical & Surgical cost: how much have you spent during your hospital visit or stay in the management of the illness?</i>	GH¢
	(a) Surgical interventions(femoral catheterization, A-V fistula etc)	
	(b) Dialysis	
	(c) Registration	
	(d) Consultation	
	(e) Laboratory investigations	
	(f) Medicines/drugs	
	(g) Other diagnostic tests (such as scan etc.)	
	(h) Any allied procedures such as dietherapy, etc	
	(i) Other, specify: _____	
14	<i>Non-medical cost: how much did you spend/pay for (you and accompanying relative)?</i>	GH¢
	(a) Estimate of total travel cost (to and from the facility)	
	(b) Food cost	
	(c) Drinks/water cost	

	(d) Other miscellaneous costs (i.e., phone calls/phone credits, other consumables used due to this illness)	
	(e) Others, kindly specify: _____	
15	Did you rely on financial help from other source(s) for treatment, aside your income? 1. Yes 2. No	<input type="checkbox"/>
16	What are the sources (multiple responses possible)? 1. Relative 2. Friend 3. Savings 4. Loan/Grant 5. Other (Specify)	<input type="checkbox"/>
17	How much money did you receive from the identified source(s)?	GH¢.....
Section 4	INDIRECT COST INFORMATION	
18	How many days in total have you absented from work (if applicable) as a result of the illness?	_ _ _ days
19	How many minutes in total do you estimate to have spent travelling to and from the health facility?	_ _ _ Mins.
20	How many minutes did you spend waiting before you were called to see the doctor or health professional for treatment?	_ _ _ Mins.
21	Did anyone from your household accompany you from home to the health facility? 1. Yes 2. No	<input type="checkbox"/>
22	If anyone did accompany you to the health facility, what is his or her employment status? 1. Employed 2. Unemployed 3. Student 4. Housewife 5. Retired 6. Other, specify: _____	<input type="checkbox"/>

23	<p>Did the person who accompany you, come with you from the house and stay with you for treatment and take you back home?</p> <p>1. Yes 2. No</p>	<input type="text"/>
If yes in Q26 above, use same time as the patient's in Q 21 & 22 for Q 27 & 28		
24	<p>How many hours/minutes in total did he/she travel to and from to be with you in the health facility?</p>	<input type="text"/> <input type="text"/> <input type="text"/> Mins.
25	<p>How many hours/minutes/days in total did he/she spend with you when you were receiving treatment in the health facility?</p>	<input type="text"/> <input type="text"/> <input type="text"/> Mins/hours/Days
26	<p>Total time spent</p>	
Section 5	INTANGIBLE COST INFORMATION	
	<p><i>Please, rate the following statements concerning FEAR from the illness, from “not at all” to „extremely” depending on how it applies to you.</i></p>	
27	<p>I think about my health now more than before since I was diagnosed with End stage kidney disease.</p> <p>1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely</p>	<input type="text"/>
28	<p>Because of the illness, my future is of concern to me</p> <p>1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely</p>	<input type="text"/>
29	<p>I am always worried about getting another illness</p> <p>1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely</p>	<input type="text"/>

30	<p>When I think about my future health, I feel some uneasiness</p> <ol style="list-style-type: none"> 1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely 	<input style="width: 50px; height: 20px;" type="text"/>
<p><i>Now kindly rate again, the following statements concerning EMOTIONAL SUFFERING from the illness, from “not at all” to „extremely” depending on how it applies to you.</i></p>		
34	<p>I suffer emotionally because I constantly worry about my condition</p> <ol style="list-style-type: none"> 1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely 	<input style="width: 50px; height: 20px;" type="text"/>
35	<p>I think I am a burden to others because of my illness</p> <ol style="list-style-type: none"> 1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely 	<input style="width: 50px; height: 20px;" type="text"/>
36	<p>I am constantly worried about exhibiting the loss of function resulting from the illness down in public</p> <ol style="list-style-type: none"> 1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely 	<input style="width: 50px; height: 20px;" type="text"/>
37	<p>I feel embarrassed in social situations</p> <ol style="list-style-type: none"> 1. Not at all 2. A little 3. Moderately 4. Quite a bit 5. Extremely 	<input style="width: 50px; height: 20px;" type="text"/>