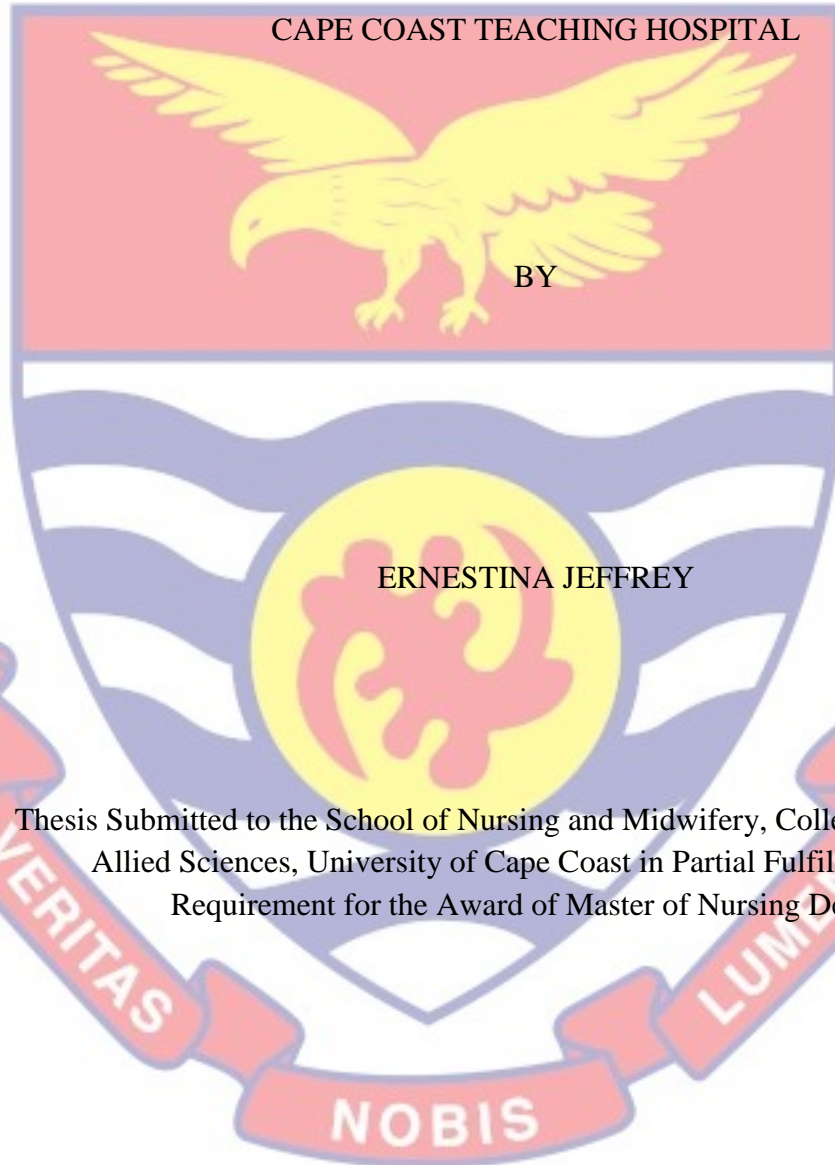


UNIVERSITY OF CAPE COAST

LIVED EXPERINCES OF PEOPLE WITH CHRONIC KIDNEY DISEASE IN

CAPE COAST TEACHING HOSPITAL



BY

ERNESTINA JEFFREY

Thesis Submitted to the School of Nursing and Midwifery, College of Health and Allied Sciences, University of Cape Coast in Partial Fulfilment of the Requirement for the Award of Master of Nursing Degree

JULY 2016

DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the results of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature..... Date.....

Name

Supervisor's Declaration

We hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidance on supervision of thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature Date.....

Name.....

Co-Supervisor's SignatureDate

Name.....

ABSTRACT

About ten percent of the population worldwide has chronic kidney disease (CKD), the majority of whom are women. A leading cause of CKD in sub-Saharan Africa (SSA) is hypertension. People living with CKD undergo multiple experiences as a result of the disease and its treatment, which can lead to depression. This study aims to examine the experiences of people living with CKD, with a view to gaining an in-depth understanding of the phenomenon. The study adopted exploratory qualitative approach in collecting and analyzing the data. Ten individuals aged 16 to 50 years were purposively sampled from the Cape Coast Teaching Hospital (CCTH) for the study. Semi-Structured interviews were used to collect data and the content was analysed thematically. Findings include: limited knowledge of CKD, psychological and emotional challenges associated with CKD. Financial implications regarding the treatment of CKD was reported as a major concern to most participants. In conclusion, it was evident that CKD patients may benefit from information and education regarding CKD including treatment options.

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Finally, to my wonderful friends and colleagues who are not mentioned.

DEDICATION

To my family: Dad, Mum and siblings



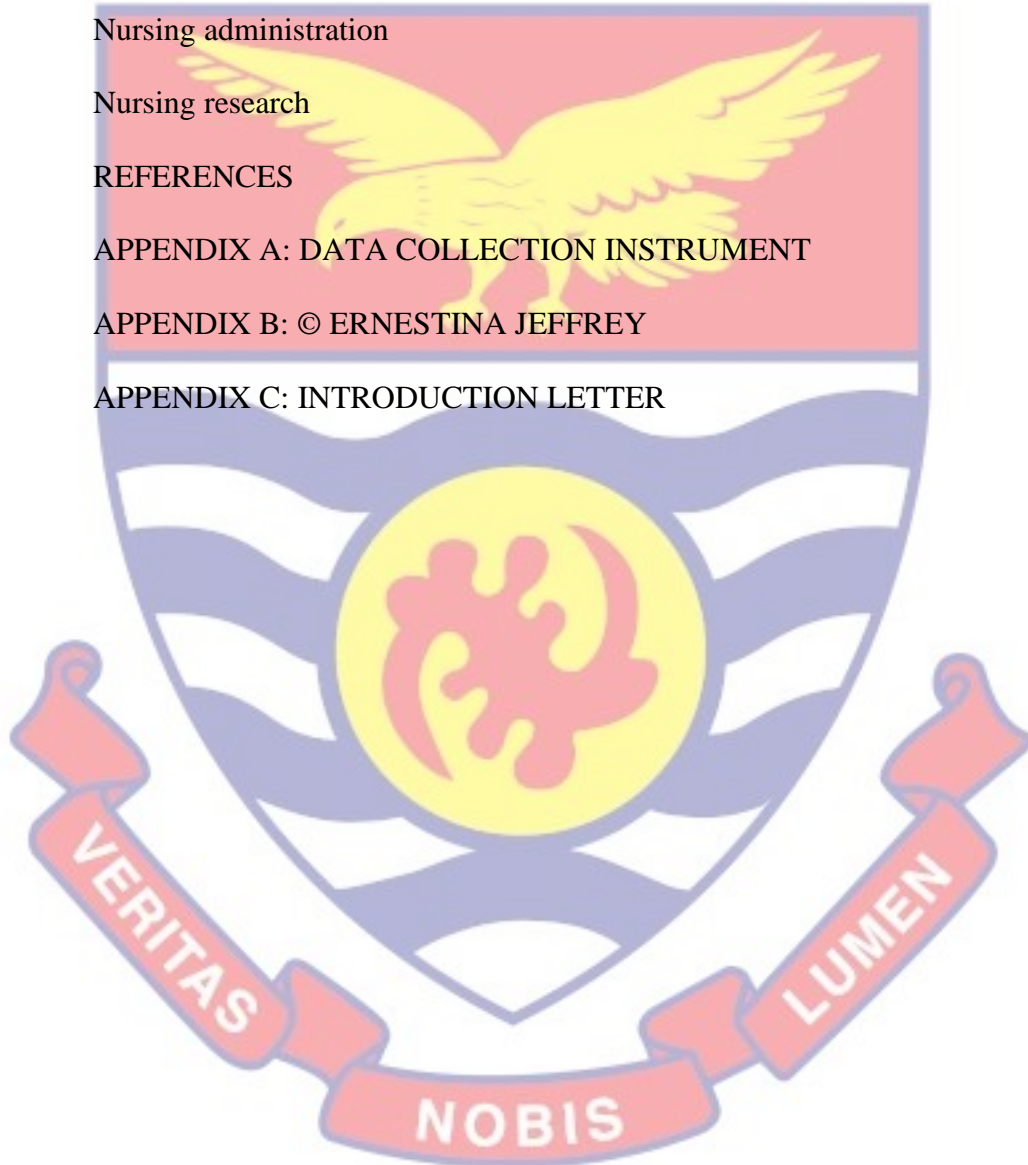
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ABBREVIATIONS

| | | |
|------------------|---|---|
| CCTH | : | Cape Coast Teaching Hospital |
| CKD | : | Chronic Kidney Disease |
| CVD | : | Cardiovascular Disease |
| DBP | : | Diastolic Blood Pressure |
| ESKD | : | End Stage Kidney Disease |
| eGFR | : | Estimated Glomerular Filtration Rate |
| HGB | : | Heamoglobin |
| LPD | : | Low Protein Diet |
| NKF-KDOQI | : | National Kidney Foundation- Kidney Disease Outcomes Quality Initiative |
| PTH | : | Parathyroid Hormone |
| TC | : | Total Cholesterol |
| RRT | : | Renal Replacement Therapy |
| SSA | : | sub-Saharan Africa |
| W.H.O. | : | World Health Organization |



CHAPTER ONE

INTRODUCTION

This chapter presents the background, problem statement, purpose of the study, research objectives, significance of the study, limitations and delimitation of the study.

Background to the Study

People living with Chronic Kidney Disease (CKD) undergo multiple experiences due to both the disease and its treatment (Finnegan-John & Thomas, 2013). These include physical, psychological, emotional and social experiences. Having CKD affects the lives of the people in each of those areas; therefore, the experience of having CKD is different for each person.

The kidneys play a fundamental role in fluid, electrolyte and acid-base homeostasis in the human body. Irreversible damage to the kidneys results in CKD which leads to the inability to perform vital homeostatic, excretory and synthetic functions. When this occurs, there is a manifestation in the form of abnormal albumin excretion or decreased kidney function that lasts longer than three months as quantified by measured or estimated glomerular filtration rate [eGFR] (Amoako, Laryea, Bedu-Addo, Andoh, & Awuku, 2014). Jha, Garcia-Garcia, Iseki, Li, Naicker, Platter, Saran, Wang and Yang (2013) demonstrated that, progressive renal disease, more often than not, leads to End Stage Kidney Disease (ESKD). The cost for renal replacement services for ESKD is enormous. It is claimed that in the United Kingdom (UK) and Italy, the population of ESKD clients accounts for an estimated 0.7%-1.8% of the health service budget (Xue,

Ma, Louis & Collins, 2001) whereas in the United States (US), the expenditure on ESKD was estimated at US \$28 billion in 2010 (Amoako et al. 2014). According to Preidt (2015), more than 2 million patients with kidney failure worldwide die prematurely every year. The 2010 Global Burden of Disease study indicated that, chronic kidney disease was ranked 27th in the list of causes of total number of deaths worldwide (Jha et al. 2013).

Globally, 10% of the population is reported to be affected with CKD (Donfrancesco, Palleschi, Palmieri, Rossi, Noce, PannoZZo, Spoto, Tripepi, Zoccal & Giampaoli, 2013). Reports from the American Kidney Statistics indicate that although CKD is more widespread among women, men with CKD are 50% more likely than women to progress to kidney failure. CKD affects between 5-15% of the adult population in the developed world (Amoako et al. 2014).

In Africa, CKD is estimated to affect about 10.4% of the population (Amoako et al. 2014) making it a significant public health concern. It has been found to account for 8-10% and 5% of medical admissions in Ghana and Nigeria respectively (Osafo, Mate-Kole, Afram & Adu, 2011). Statistics over the past five years from the National Kidney Foundation - Ghana (2011) indicate a continual increase in reported kidney cases in Ghana. In 2012, over 3,612 kidney malfunction cases were reported; in 2011, 2,687 cases; and in 2010, 2,593 cases; in the same way in 2009 2,387 cases; and in 2008 2,435 cases were reported at the Korle-Bu Teaching Hospital alone (Osafo et al. 2011). In Cape Coast Teaching Hospital (CCTH), there is an increment in CKD cases (CCTH, 2014). Naicker, (2013) argues that hypertension is a leading cause of CKD in SSA,

ranging from 48.7% in Ghana to 29.8% in Nigeria, and 25% in Senegal. Osafo et al. (2011) found a prevalence of 46.9% among hypertensive patients in a Ghanaian outpatient setting. Hypertension affects about 25% of the adult population and is the cause of ESRD in 21% of patients on Renal Replacement Therapy (RRT), which is required when the kidneys are functioning at less than 10–15 percent. RRT is accomplished in one of the following ways: Dialysis and Kidney transplant (Naicker, 2013). This situation is not different in CCTH since majority of CKD clients have hypertension (CCTH, 2014). Amoako et al. (2014) found that in Burkina Faso, 44% of hospitalized hypertensives have chronic kidney disease. Besides hypertension, other risk factors or contributory factors of CKD are reported. For example, chronic glomerulonephritis is an important cause of CKD in tropical Africa (Ojo, 2014). Other factors include: too much ingestion of alcohol, herbal medicines, aphrodisiacs of any kind, and smoking. Odenigbo, Oguejiofor, Onwubuya and Onwukwe (2009) claimed that, Diabetes mellitus and HIV infection are also notable contributors to CKD burden. Thus, any step to understand and formulate measures to control this condition should take into account the multiplicity of risk factors for CKD.

Chronic Kidney Disease clients in developing countries are often presented with severe or complicated conditions. As a result of late presentation, more than 75% of clients with ESRD require dialysis at a time when they are presented with complex and co-morbidities conditions. Although CKD remains a key cause of morbidity and mortality in many hospitals in Ghana, there is insufficient statistics to support a comprehensive understanding of the

epidemiology of CKD (Amoako et al. 2014).

In particular, the lived experiences of people with CKD remain unsolicited. Lack of awareness about CKD is one of the major obstacles to the global efforts used in preventing and controlling the health burden of CKD. It is claimed that, thousands of people throughout Ghana have limited knowledge on kidney diseases. The development of chronic kidney disease is increasing dramatically. As the population gets older, the prevalence of diseases such as diabetes and hypertension also increases (Osafu et al. 2011).

Although there is increasing incidence of CKD, the treatment and management of CKD remain a major health policy concern across the world. Management and treatment of CKD is expensive and thus difficult for people to access treatment especially in Africa. The cost of dialysis, initial laboratory investigations and medications is GH¢3,000. In Ghana, each session of dialysis ranges between GH¢190 – 300 (CCTH, 2014). Access to treatment is limited and in instances where treatment options are available, only the affluent in society can afford treatment and management due to high cost. Dialysis and kidney transplant remain the major treatment options for CKDs. Over two million people worldwide receive treatment with dialysis or a kidney transplant; yet, this number may only represent 10% of the populace who actually need treatment to survive (Couser, Remuzzi, Mendis, & Tonelli, 2011). Of the 2 million people who receive treatment globally, a majority are treated in only five countries, namely the United States, Japan, Germany, Brazil, and Italy. These five countries represent only 12% of the world population. This suggests that more than 80% of all patients who

receive treatment are in developed countries where there are better access to healthcare and high elderly populations (Jha et al. 2013). Globally, the need for renal health care and RRT is ever-increasing, but few countries can afford to meet the needs of all patients. While dialysis and transplantation consume an ever-increasing proportion of the health budget in countries such as the United States, Japan, and Taiwan, there is inadequate availability of these expensive therapies in the majority of emerging countries and more so in Africa (Naicker, 2013). It is suggested that, people affected with CKDs experience multiple complications which further exacerbate their health conditions. According to Courser et al. 2011, depression remains a common psychological problem in haemodialysis patients. Additional stressors that may be associated with CKD include biochemical imbalance, physiological changes, neurological disturbances, cognitive impairment, and sexual dysfunction. Finnegan-John and Thomas, (2013) also argued that all the above-named stressors can potentially play a role in depression. It is claimed that the point of access for dialysis via a fistula, neck line, or catheter and edema can all change clients' appearance which leads to low self-esteem and isolation. Therefore, clients are not present at social functions due to impact of dialysis treatment on relationships with family and friends; and the attitudes of family members towards patients (Finnegan-John & Thomas, 2013).

Ghafari, Farshid, Afahari, Sepehrvand, Rikhtegar, Ghasemi and Hatami (2010) suggested that sexual difficulties can sometimes occur as a result of erectile dysfunction among male patients with ESRD and can undermine intimacy especially when the individual affected is young, not married or has hope of

having children. Physical problems, such as insomnia, problems accessing the treatment site, weakness, loss of appetite, general bodily pains, dizziness and breathlessness all account to depression among CKD clients (Cruz, Andrade, Urrutia, Draibe, Nogueira-Martins & Sesso, 2011).

It is claimed that approximately 30% of children and adolescents with CKD experience mainly restless leg syndrome and periodic limb movements (Sinha, Davis & Matsuda-Abenedi, 2009). Davids, Greenbaum, Gipson, Wu, Sinha & Rosen (2012) hold that, 58.5% of patients with CKD have symptoms of a sleep disorder (restless leg syndrome, periodic limb movements, excessive daytime sleepiness, or sleep disordered breathing), which correlates with a decrease in quality of life, independent of the level of kidney function (Massengill & Ferris 2014).

Massengill and Ferris (2014) suggested that in a North American CKD cohort, parents of children and adolescents with lower levels of renal function were more likely to report low energy, severe weakness, or daytime sleepiness and, consequently, general poorer quality of life. Davis, Greenbaum Gipson and Wu (2012) believe that families with children who are diagnosed of CKD undergo emotional, physical, and financial stress (Ferris & Mahan, 2009). Additional psychological burdens to the family include increased school absences and missed opportunities for school activities due to low self-esteem and body image disturbance. Parental distractions related to their child's chronic condition can lead to feelings of neglect by other siblings which may affect the family's well-being (Ferris & Mahan, 2009). Financial burdens result from interrupted work

schedules, insurance copayments for medical visits or medications, and poor reimbursement for travel costs, meals, or parking. In general, parents of a chronically-ill child have higher marital distress and decreased marital harmony when compared with parents of healthy children (Massengill & Ferris, 2014).

CKD occurs gradually, and the consequences of non-adherence are palpable to patients who have such complex medical and dietary regimens. In fact, despite medical advances, kidney transplant failure in adolescents exceeds that of any other population (Morton, Devitt, Howard, Anderson, Snelling & Cass, 2010). There is an urgent need for CKD public policy programs in both developed and developing countries. In some countries however, the incidence of kidney failure owing to some types of CKD is stabilizing or declining, possibly reflecting early detection and treatment (Bello, Levin, Manns, Feehally, Druke, Faruque, Hemmelgarn, Kernahan, Mann, Klarenbach, Remuzzi & Tonelli, 2015). Braun, Sood, Hogue, Lieberman and Copley-Merriman (2012) demonstrated that although the prevalence of kidney failure varies significantly throughout the world, the number of patients and the cost of providing dialysis and transplantation continues to escalate. Attention on controlling and treating CKD remains poor across the globe and this is more pronounced in low and middle income countries of which Ghana is not an exception. Bello et al. (2015) assert that few countries have policies for CKD and most are ignorant of the high prevalence of CKD, its contribution to other diseases, or its economic burden. Early detection and intervention are the more cost-effective strategies for CKD. In 2010 alone, 3,281 patients were diagnosed of CKD at the renal clinic of the Korle

Bu Teaching Hospital, representing 38% increase of patients in 2009 (Ghana News Agency, 2011). This happened due to the awareness creation during World Kidney Disease 2009. According to Carroll (2006), 9 out of 10 people who have stage 3 CKD are unaware of it. This is common in Ghana because a majority of the population do not have any information on CKD or its complications; as a consequence, once they start experiencing any of the symptoms, they have no option than to obtain over-the-counter drugs or herbal preparations which can worsen the condition (Stanifer, Jing, Tolan, Helmke, Mukerjee, & Naicker, 2014). The above context highlights the need for research to investigate the lived experience of people with chronic kidney disease in CCTH, since there is no study conducted with respect to this topic. Information generated from such research has the potential to inform the formulation of policies and health interventions to improve health outcomes of people living with CKDs.

Statement of the Problem

Chronic Kidney Disease is a universal public health problem that influences mortality and morbidity rate. More than two million patients with chronic kidney disease die prematurely every year (Preidt, 2015). According to World Health Organization (WHO), Kidney Disease Deaths in Ghana reached 2,469 or 1.32% of total deaths in 2014. Osafo et al. (2011) believed that the age adjusted Death Rate is 15.74 per 100,000 of population, which ranks Ghana 74th in the world. It is believed that the burden of hypertension and diabetes associated CKD is 190,000 deaths per year in Ghana. Other CKD related deaths such as too much intake of alcohol, herbal medicines, smoking and aphrodisiacs consumption

are on the increase. Generally, it is claimed that one in every ten people have CKD in Ghana, that is 23% are in stages 1- 2, 48 % in stages 3-4 and 7% in stage 5 (Osafo et al. 2011). Hashiguchi (2015) also believes that CKD is on an increase. The prevalence of CKD increases with age and advancements in technology. The most common causes of CKD in Ghana are hypertension and diabetes (Amoako et al. 2014). These causes of CKD are preventable and only need awareness from the health systems and individual support with optimum cooperation to prevent CKD. Despite numerous measures such as periodic awareness creation, the situation seems not to improve as CKD is rated among the most prevalent cases in CCTH (CCTH, 2014).

Cukor, Peterson, Cohen and Kimmel (2006) argued that the diagnosis of CKD is traumatic to the client and is associated with negative feeling such as strain, distress and emotional pain, especially when almost all clients are dying due to associated complications and other issues such as financial constraints. However, a few studies investigate people's experience with CKD.

Another challenging issue faced by clients diagnosed with CKD is associated with lifestyle modification such as dietary and fluid restrictions in order to accommodate their ill health. These lifestyle restrictions have much impact on social functioning with patients performing a balancing act to ensure maintenance of vitamin, iron, and protein levels. Such restrictions can impact clients' illness, values, concept, beliefs, sense of personal control leading to anxiety and depression, inhibiting coping and adjustment, hence poor quality of life (Osafo et al. 2011).

Naicker (2013) argued that CKD affects mainly young adults aged 20–50 years in sub-Saharan Africa (SSA) and is primarily due to hypertension and glomerular diseases, contrasting with developed countries, where CKD is present in middle-aged and elderly patients and is predominantly due to diabetes mellitus and hypertension. Adherence to medical treatment among children with CKD and ESKD is challenging, particularly in the adolescent and young adult population who complete about 2% of CKD clients. This is because the young adult falls within the working age where they are expected to work to meet financial obligations, but once affected, all these goals are not met. Consequently, patients with CKD experience lifestyle modifications limitations (Christensen & Ehlers, 2002). According to Osafo et al. (2011), there are a number of patients with end-stage renal disease in Ghana who need haemodialysis but due to economic constraints, they cannot afford it. A majority have to depend on supportive organizations for financial assistance. In most of SSA countries, the vast majority of patients with CKD die because of lack of treatment. RRT is expensive, which makes it unaffordable for the inhabitants in the low-income regions (Krziesinski, Sumaili & Cohen, 2006). Financial burden with respect to CKD is also a problem in Ghana since the cheapest dialysis per session in Ghana is Ghana190 cedis (CCTH, 2014). People undergoing haemodialysis, the most common form of RRT, spend a minimum of eighteen hours per week during dialysis in addition to travelling to and from the treatment centre (Wadd, King, Bennett & Grant, 2011). Some of these patients are the primary wage earners of their family and occasionally their demise might compromise the finances of the whole family.

This issue is more difficult when clients have to rely on other people for financial support because of difficulties paying for the dialysis, expensive medications and diagnostic investigations (Krantz & McCeney, 2002).

Research on lived experiences of people with CKD worldwide is scanty especially in Africa. Studies are rare on the lived experiences of people with chronic kidney disease in Ghana. To provide individualized and specific nursing interventions, healthcare providers must better understand the lived experiences of patients with CKD. There is a need therefore to explore the lived experiences of people with chronic kidney disease in CCTH that will form the basis for recommendations to modify some of the experiences and this may result in quality care to clients.

Purpose of the Study

The purpose of this study is to explore the lived experiences of people with CKD in CCTH to have an improved understanding, which may lead to improved patient and family-centered holistic nursing care and provide individualized nursing interventions. Another purpose is to assist healthcare providers better understand the lived experiences of patients with CKD and to form the basis for recommendations to modify some of the experiences and ultimately result in quality care to clients.

Objectives

The main objective of the study is to investigate clients' experiences with CKD at the Cape Coast Teaching Hospital (CCTH).

Specific Objectives

1. To investigate the knowledge of clients with CKD on signs, symptoms and complications in CCTH.
2. To investigate the psychosocial experiences of clients diagnosed with CKD.
3. To investigate the challenges facing clients with CKD.
4. To explore the impact of CKD on the lives of clients in CCTH.
5. To investigate the support network for clients diagnosed with CKD.

Significance of the Study

It is hoped that the results of this study will be used by the CCTH Medical and Renal Units as well as other relevant stakeholders in health policy. The study will also help in developing strategies that will enhance achievement of good kidney health. Moreover, the study is intended to provide meaningful information which will enhance CKD control in CCTH. Finally, the findings of this study will be used to equip clients with the necessary knowledge and basic skills to help them cope with the untoward and devastating effects of CKD through the media.

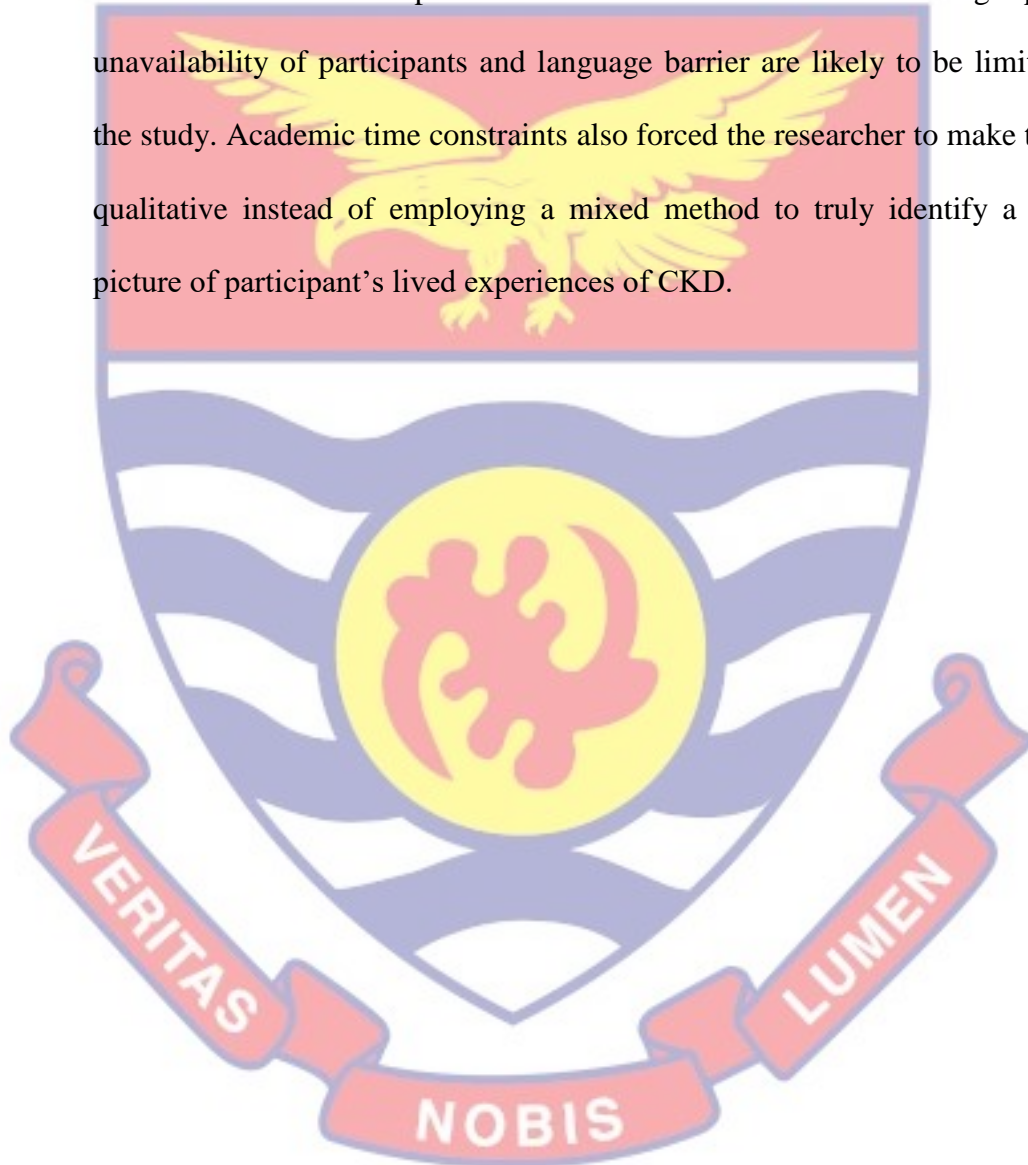
Delimitations

The establishment of exclusion and inclusion criteria, according to LoBiondo-Wood and Haber (2010), increases the precision of a study and strengthens evidence produced. In this study, the participants were clients diagnosed with CKD; and were receiving care at CCTH; who were capable of

giving consent. Exclusion criteria included clients who cannot give consent due to their condition.

Limitations

Limited time period and external factors including perceived unavailability of participants and language barrier are likely to be limitations to the study. Academic time constraints also forced the researcher to make this study qualitative instead of employing a mixed method to truly identify a complete picture of participant's lived experiences of CKD.



CHAPTER TWO

REVIEW OF LITERATURE

The purpose of this chapter is to identify studies that have been conducted on the lived experiences of people living with CKD. A literature review was conducted to cover the period of 2003 to 2016 to identify research undertaken in CKD globally as well as in Africa and Ghana. Key expressions used in the literature search included, “experiences of CKD on clients”, “experiences of CKD in Africa and West Africa,” and “experiences of CKD in Ghana”. Only articles written in English are peer-reviewed were considered for review. Books, printed articles and peer-reviewed journals on the subject under study were largely sourced from the Sam Jonah Library, UCC. Documents from the Ministry of Health, Ghana, Ghana Health Service, and CCTH data on CKD were also used in the process of the study. The following databases were searched for articles: Google Scholar, CINAHL, EBSCO HOST and Hinari. The literature review also considered technological, religious, philosophical, social, beliefs, economic, and educational factors in CKD that were in line with the framework of the study.

The literature review is presented under the following sub-headings: the trajectory theory, overview of CKD, psychological burden, issues of dialysis. Additional stress, financial and difficult lifestyle, effects of CKD on body image, malnutrition, social relations and support associated with CKD such as marital and familial issues are also addressed.

The Trajectory Theory

Also known as Corbin-Strauss-Model, the trajectory theory is a middle range nursing theory applicable in situations of people with chronic illness such as CKD, hypertension or diabetes. The theory was developed by Anselm L. Straus, and Juliet Corbin (1992). According to this model, chronic illnesses are serious diseases which could last the whole life of the concerned person affecting the person's mental, emotional and social well-being. The trajectory theory is relevant for this research since CKD affects the client emotionally, psychologically and physically.

McCorkle and Pasacreta, (2001) explain trajectory as *“a course of illness over time plus the actions taken by patients, families and health professionals to manage or shape the course”* (p. 1). Eight phases of chronic illness trajectory have been identified as follows:

- Initial or pretrajectory phase: This is the period before signs and symptoms are present. In the case of CKD, the initial stage is the period when the client is healthy with no sign of illness.
- Trajectory onset phase: This occurs with the first onset of signs and symptoms such as general unwellness, scanty urinary output. This phase also includes the diagnostic period where blood urea creatinine (BUE Cr) results are within abnormal ranges.
- The crisis phase: This is when a potentially life-threatening situation arises

such that no urine is produced for more than ten hours after intake of about four liters of fluids.

- The acute phase: This follows the crisis phase and refers to the period when symptoms can be controlled by a prescribed regimen. In the case of CKD, symptoms like uremic encephalopathy and anuria can be controlled by prescribed drugs and regimen like RRT.
- Stable phase: This phase starts once symptoms are controlled.
- Unstable phase: This period is when the patient's symptoms are uncontrolled by the previously adopted regimen. This happens when clients no longer benefit from treatment and RRT.
- Downward phase: This is characterized by progressive deterioration in mental and physical status such as hypertensive encephalopathy, uremic gastritis, uremic anemias, generalized oedma.
- Dying phase: This phase is the period of weeks, days, or hours preceding death.

Overview of CKD

The kidneys are a pair of organs found along the posterior muscular wall of the abdominal cavity (Wallace, 2016). The left kidney is located a little more superior than the right kidney due to the larger size of the liver on the right side of the body. The kidneys lie behind the peritoneum that lines the abdominal cavity and are thus well thought-out to be retroperitoneal organs. The ribs and muscles

of the back protect the kidneys from external damage. Adipose tissue known as perirenal fat surrounds the kidneys and acts as protective padding (Velho & Velho, 2013).

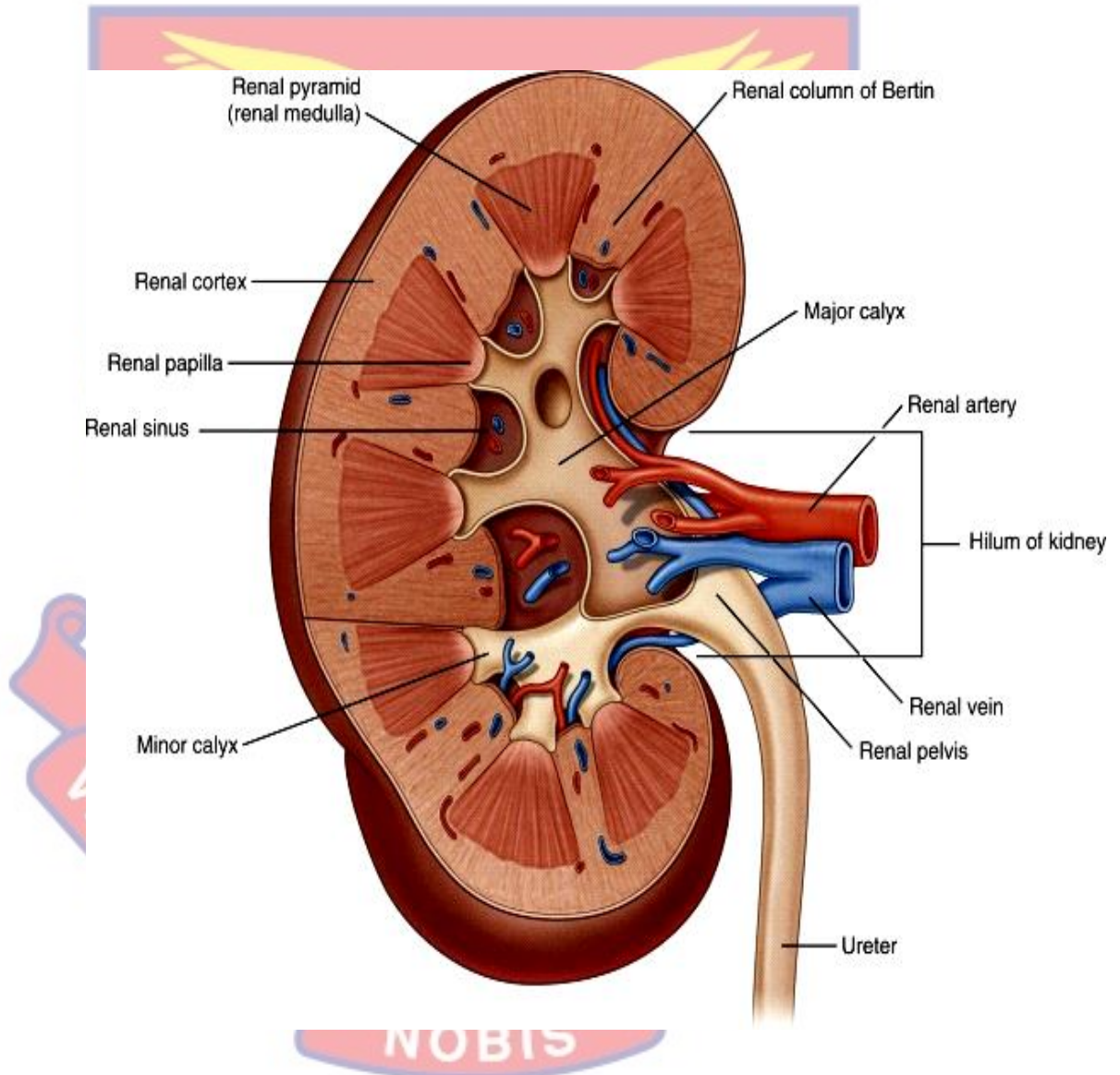


Figure 1 A Cross section of the kidney

(Velho & Velho, 2013)

Structure

The kidneys are bean-shaped with the convex side of each organ located laterally and the concave side medial (Wallace, 2016). The indentation on the concave side of the kidney, known as the renal hilus, gives space for the renal artery, renal vein, and ureter to enter the kidney. A thin layer of fibrous connective tissue forms the renal capsule surrounding each kidney. The renal capsule provides a stiff outer shell to keep the shape of the soft inner tissues. Deep to the renal capsule is the soft, dense, vascular renal cortex. Seven cone-shaped renal pyramids form the renal medulla and it is deep in the renal cortex. The renal pyramids are aligned with their bases facing outward toward the renal cortex and their apexes point inward in the direction of the center of the kidney (Kurts, Panzer, Anders & Rees, 2013). Each apex connects to a small calyx, a small hollow tube that collects urine. The minor calyces join to form three larger major calyces, which further merge to form the hollow renal pelvis at the center of the kidney. The renal pelvis exits the kidney at the renal hilus, where urine drains into the ureter (Velho & Velho, 2013).

The nephron as Amoako et al. (2014) note is the microscopic unit of the kidney. Each kidney has thousands of nephrons. When an individual is young and healthy, not all nephrons work at all times; some nephrons are held in reserve. As one ages or in the case of kidney damage, some nephrons die and other resting nephrons take over the work of those that die. When there are no extra nephrons outstanding and kidney damage continues, the individual begins showing signs of CKD. Because of this stepwise loss of nephrons, the kidneys are able to "hide" the

fact that they are damaged till the damage is severe. When two-thirds of the nephrons have been lost the person affected is no longer able to conserve water (Wallace, 2016). By the time there is elevation in the waste product creatinine in the blood, 75% of the nephrons in both kidneys have been lost. When blood flows through the kidneys, the kidneys act as a compound filter that removes wastes from blood that are generated from break down of food, old cells, toxins or poisons and many drugs that are administered for treatment of other diseases. The wastes are removed in the midst of water as urine. Waste products that can be measured in the blood include creatinine and urea nitrogen but there are many other waste products that are not measured by blood tests (Ephraim, 2010).

Functions of the Kidney

The kidneys play a vital role in the maintenance of normal body function. The fundamental and well known function of the kidneys has to do with the formation of urine through complex filtration, re-absorption and secretion mechanisms. To add to the above, the kidneys also excrete urea and uric acid which are the end products of protein and nucleic acid metabolism. The kidneys also control fluid, electrolyte and acid base balance of the body and create a steady environment for the metabolic processes of tissues and cells. This purpose is essential for life and it is realized by balancing solute and water transport, excreting metabolic waste products, conserving nutrients, and regulating acid-base balance in the body (Ephraim, 2010).

Causes of CKD

Wallace (2016) state that CKD is not a single disease. There are many diverse causes of CKD but by the time the signs of kidney disease show, the cause may no longer be noticeable. Some possible causes of CKD include: congenital malformation of the kidneys (birth defects), chronic bacterial infection of the kidneys with or without kidney stones (pyelonephritis), hypertension, diseases coupled with the immune system (e.g. glomerulonephritis, systemic lupus), acute kidney disease, for example poisoning with antifreeze that damages the kidneys. According to Biruck (2012), chronic glomerulonephritis and interstitial nephritis are currently the primary causes of CKD in developing countries. Yirsaw (2012) stated that CKD is associated with substantial cardiovascular morbidity and mortality. It has a major effect on healthcare expenses and world productivity, particularly in low-income countries where young people are the majority of afflicted inhabitants. An estimated 80% of challenges associated with CKD occur in low- or middle-income countries including Ghana, and 25% is among people younger than 60 years who fall within the working class (Couser et al. 2011).

Couser et al. (2011) suggest that, the most abundant acquired and congenital forms of CKD include glomerulopathies (33%); vesicoureteral reflux, obstruction, or infections (25%); hereditary nephropathies (16%); hypoplasia or dysplasia (11%); and vascular disorders (5%). African Americans and Latinos are disproportionately affected by CKD in part due to an elevated incidence of glomerular conditions. With the rising incidence of obesity and Type 2 Diabetes

Mellitus in youth, the incidence of CKD in adults is expected to amplify. The pediatric ESKD population is only 2% of all patients (Sekulic & Sekulic, 2013).

Wanner, Inzucchi, Lachin, Fitchett, Eynatten, Mattheus, Johansen, Woerle, Broedl and Zinman (2014) explained that diabetes is the principal cause of kidney failure. Diabetes causes 38.4% of all cases of kidney failure. In 2009, it was the primary diagnosis for 214,909 kidney failure clients in Ghana. An anticipated 25.8 million people had diabetes; 7 million of them were undiagnosed. It is estimated that, about 40% of people with diabetes will develop CKD (Ephraim, 2010). African Americans with diabetes are 2.5 to 5.6 times more likely than whites to develop kidney disease (Wallace, 2016). According to the United States (US) Renal Data System Annual Data Report (2010), the leading causes of CKD primary to kidney failure in the United States are diabetes (incident cases of ESRD of 153 per million population in 2009), hypertension (accounting for 99 per million population), and glomerulonephritis, (which accounts for 23.7 per million population). Cardiovascular disease is also a vital cause. However, in the United States, about 28% of patients with CKD stage 3 or worse are neither diabetic nor hypertensive. The proportion of people with CKD not explained by diabetes or hypertension is substantially higher in developing countries. In developing countries, diabetes and hypertension now appear to be the leading causes of ESRD with a prevalence of about 30% and 21%, respectively, but glomerulonephritis and CKD of unknown origin account for a larger fraction of the total, particularly in younger patients (Couser et al. 2011). For example, in a study of clients with CKD detected by International Society of

Nephrology-sponsored screening programs in China, Mongolia, and Nepal, 43% of people with CKD did not have diabetes or hypertension.

Thomas, Kanso and Sedor (2008) suggested that the combination of obesity, smoking, poor diet, and lack of exercise can increase a person's risk for kidney disease. The risk of chronic kidney disease was correlated to physical inactivity (Stengel, Tarver-Carr, Power, Eberhardt & Brancati, 2003). Smoking is a relevant risk factor, conferring a substantial increase in risk for renal function deterioration (Tonelli, Wiebe, Culeton & House 2006). Contrasting developed countries where CKD presents in middle-aged and elderly patients mainly due to diabetes mellitus and hypertension, in Africa and for that matter Ghana, CKD affects people between the ages of 20 to 50. Presentation is usually delayed, with greater than 75% in ESRD requiring dialysis during reporting or severely ill with co-morbidities (Naicker, 2013). Similar to the rest of the world, the need for renal health care and renal replacement therapy (RRT) is mounting, but only few countries in Africa can afford to meet the needs of all patients. While dialysis and transplantation consume an ever-increasing proportion of the health budget in countries such as the United States, Japan, and Taiwan, the expensive therapies in the majority of emerging countries and more so in African nations including Ghana is inadequate (Naicker, 2013).

Chawla, Eggers and Kimmel (2014) stated that acute kidney injury can lead to chronic kidney disease regardless of the cause of the acute injury. For example, it is established that there is the link between the diagnosis of preeclampsia and the later development of ESRD. Acute kidney injury is

associated with ESRD thirteen times as higher than clients without acute kidney injury and forty times if the clients had both acute kidney injury and preexisting CKD (Ishani, Xue, Himmelfarb, Eggers, Kimmel, Molitoris, & Collins, 2009). In one study, after adjustment for potential confounders such as the presence of diabetes and a low estimated GFR at baseline, acute kidney injury necessitating dialysis was independently associated with a risk of stage 4 or 5 chronic kidney disease that was twenty-eight times as high, and a risk of death that was more than twice as high, as the risks among hospitalized patients who did not require dialysis (Coca, Singanamala & Parikh, 2011). In a Canadian study involving patients with acute kidney injury who required in-hospital dialysis and survived without dialysis for at least thirty days after discharge, the risk of ESRD was three times as high as the risk in a matched cohort, but there was no increased risk of death (Chawla et al. 2014). Other less documented factors are also contributory factors. For example, there is a strong association that intrauterine events linked to poor nutrition alter prenatal programming and lead to low nephron number, which represents another considerable risk factor for CKD in later life. This is relevant to global health given the emerging food crises worldwide (Couser et al. 2011).

Risk Factors

Lights and Boskey (2015) believed that the risk of CKD runs in families, and increases for those over the age of 65. It is claimed to be more common among African-Americans, Native Americans, and Asian-Americans. Retnakaran, Cull, Thorne, Adler and Holman, (2006) demonstrated that, other risk factors for CKD include cigarette smoking, hypertension, obesity, high cholesterol, diabetes

(types 1 and 2), autoimmune disease, obstructive kidney disease, which includes bladder obstruction caused by benign prostatic hyperplasia (BPH) cirrhosis and liver failure, narrowing of the artery that supplies the kidney cancer atherosclerosis, bladder cancer, kidney stones, kidney infection, systemic lupus erythematosus (SLE), scleroderma, vasculitis and vesicoureter of the kidney.

Signs and Symptoms

Thomas (2012) argued that the kidneys have so many functions, when their function is altered; there are many signs that may show. By the time signs of CKD shows, the damage is severe. CKD is usually deadly in months to years but various treatments and therapy can keep the individual comfortable with a good quality of life for months to years. Because the kidneys perform a number of functions, the signs an individual affected with CKD show can vary. The signs may be severe or may be subtle and gradually be progressive. Despite the chronic nature of the disease, sometimes signs appear abruptly (Tonelli et al. 2016). Some of the more common signs of CKD include: nausea and or vomiting diarrhea, lack of appetite, weight loss, and general depression related to the elevation of waste products in the blood, anaemia resulting in pale gums and weakness due to a low blood count, generalized weakness from low blood potassium. Serebo and Nyan (2016) maps that less common signs include: weakened bones which can result in bone fractures, high blood pressure can lead to unexpected blindness, itchy skin from calcium and phosphorous depositing in the skin, bleeding into the stomach or gut or bruising of skin. Some signs evident during examination include: dehydration, weight loss, pale gums and ulcers in the mouth. The signs seen in

clients with CKD and the findings on examination are not definite for CKD and may be seen with many other diseases so blood and urine tests are required to make a diagnosis of CKD (Preidt, 2015).

Stages of CKD

CKD is classified into stages (Levey, Inker, Curhan & Forman, 2016). Stages 1 and 2, also called “moderate” or clinically important requiring the presence of kidney injury such as proteinuria as well as reduced GFR of (≥ 90 mL/min/1.73 m²) in stage 1 and GFR 60 to 89 mL/min/1.73 m² in stage 2. Stages 3 (GFR 30 to 59 ml/min) and 4 (GFR 15 to 29 ml/min), with less than 60 ml/min chosen as a cutoff because it represents loss of about 50% of normal renal function and 4 (GFR 15 to 29 ml/min), with less than 60 ml/min is chosen as a cutoff because it represents loss of about 50% of normal renal function, although there is an evidence of increased risk in earlier stages. The role of proteinuria as well as GFR measurements in assessing risk of CKD is particularly significant since clients who fall within stages 1 and 2 of CKD with high proteinuria have worse outcomes than those within stage 3 with no proteinuria. Moreover, the progression of both ESRD and cardiovascular disease is predicted much more accurately by proteinuria measurements than by GFR (Stanifer, Jing, Tolan, Helmke, Mukerjee & Naicker, 2014). A recent meta-analysis of eight cohorts of 845,125 general and high-risk people confirms the marked and graded increased risk for ESRD in those with a GFR less than 60 ml/min (stage 3) and in people with albuminuria at all levels independent of traditional cardiovascular risk factors. Stage 5 CKD is ESRD and is identified by GFR less than 15 ml/min or

the need for dialysis. In addition, Wu et al. (2015) believed that CKD is a progressive chronic disease divided into five stages base on patient's glomerular filtration rate (GFR). Untreated CKD will progress to ESRD, requiring lifelong dialysis or kidney transplantation. Late-stage CKD (stage 4 and 5) is significantly coupled with decreased quality of life, high morbidity rates, and increased mortality (Chen, Tsai, Sun, Wu, Lee, & Wu, 2011).

The pain associated with CKD cannot be expressed only by the individual affected but the relatives, friends and care givers (Wadd et al. 2011). With some of the clients, their physical appearance communicates that there are problems. A majority of the clients with CKD develop other reactions to the diseases such as depression, refusal of treatment and therapy and the notion of life not worth living due to the challenges associated with CKD. Problems may start from the day that the client is diagnosed with CKD or before. The experience is more problematic when kidney transplant has been successfully done and the recipient is required to comply with powerful drug therapy which prevents the body's immune system from rejecting the new organ. The medication may cause negative side effects and is necessary for as long as the kidney lasts. Since renal transplant is assumed as a return to kidney restoration, this reality is not widely recognized (Amerena & Wallace, 2009). People undergoing haemodialysis, the most common form of RRT, spend a minimum of eighteen hours per week during dialysis in addition to travelling to and from the treatment centre (Wadd et al. 2011). Although most clients wish for home dialysis, due to challenges such as sufficient social and physical supports at home, age, impaired dexterity, inadequate space to store

equipment and supplies, and the need for home modifications to make home dialysis possible (e.g. plumbing, electricity) it is impossible in countries such as Ghana (Walker, Howard, Morton, Palmer, Marshall, & Tong, 2015).

Diagnosis of CKD

CKD is traditionally assessed in terms of both overall renal function (glomerular filtration rate, GFR) and the presence of kidney damage ascertained by either kidney biopsy or other markers of kidney damage such as proteinuria (also termed albuminuria and defined by a urine albumin/creatinine ratio of greater than 30 mg/g or urine protein/creatinine ratio greater than 200 mg/g), abnormal urinary sediment, abnormalities on imaging studies, or the presence of a kidney transplant. GFR is projected in clinical practice using readily calculated equations that adjust serum creatinine values to age, sex, and ethnicity. It is important to recognize that both serum creatinine and albuminuria can be easily assessed using readily available, inexpensive laboratory testing (Couser et al. 2011). Laboratory studies used in the diagnosis of CKD may include the following: Complete blood count, Urinalysis, Serum albumin levels, Lipid profile, Serum calcium and phosphate, 25-hydroxyvitamin D, Alkaline phosphatase, Intact parathyroid hormone (PTH) levels, Serum and urine protein electrophoresis and free light chains, Antinuclear antibodies (ANA), double-stranded DNA antibody levels, Serum complement levels, Cytoplasmic and perinuclear pattern antineutrophil cytoplasmic antibody (C-ANCA and P-ANCA) levels Anti-glomerular basement membrane (anti-GBM) antibodies, Hepatitis B and C, human immunodeficiency virus (HIV), Venereal Disease Research Laboratory

(VDRL) serology. Renal ultrasonography, Retrograde Computed tomography (CT) scanning, Magnetic resonance imaging (MRI), Renal radionuclide scanning and Kidney Biopsy (Barsoum, 2003).

Prevalence and Incidence of CKD

Velho and Velho (2013) argues that the incidence and prevalence of kidney diseases differs substantially across countries and regions. More than 80% of all patients receiving treatment for end-stage kidney disease are estimated to be in affluent countries with large elderly populations and universal access to health care (Jha et al. 2013). Projected worldwide population changes suggest that the potential number of cases of end-stage kidney disease will increase excessively in developing countries where the numbers of elderly people are expanding (Stevens, Viswanathan, Weiner, 2010).

Braun et al. (2012) explained that CKD is an unbearable disease affecting approximately 7% of all people aged 30 years and older, which translates to more than 70 million people in developed countries worldwide. This number is likely to be much elevated given the unknown prevalence in developing countries including Ghana. The increased prevalence of diabetes, hypertension, obesity and an aging population will only propound the rise of CKD (Braun et al. 2012). Regardless of the fact that treating CKD is expensive, complicated medication regimes, and symptoms including nausea, pain, and fatigue lead to low quality of life. Patients may also experience negative outcomes including mortality or worsened morbidity (Amerena & Wallace, 2009). CKD is a universal public health problem that continues to rise in terms of prevalence and financial cost to

humanity (Wu et al. 2015). A national survey from the United States showed that the number of adults suffering from CKD had amplified from ten to thirteen percent of the national population. The estimated prevalence of moderate CKD in developed countries is variable but is generally between 5% and 7% of the total adult population and consistently increases over time within countries (Ephraim, 2010). Given projected increases in the prevalence of most important risk factors for CKD (including diabetes, hypertension, and cardiovascular disease), the prevalence of CKD in developing countries is anticipated to dramatically increase over the next two decades (Wanner, Inzucchi, Lachin, Fitchett, Eynatten, Mattheus, Johansen, Woerle, Broedl & Zinman 2014).

In 2012, Biruck put the prevalence among Nigerians in a family practice population at 10.7%. The prevalence of CKD in Ghana has varied over the years; from 1.6% per million people by Bamgboye (2006) to 4% among hypertensives in the Greater Accra region as documented in the study by Ado and Leon (2009). Recently, a prevalence of 46.9% has been recorded among hypertensives in Ghana (Osafo et al. 2011).

Demographic Factors Influencing CKD

Jha et al. (2013) argued that the demographics of people with chronic kidney disease vary widely worldwide. In the USA, African-American and the Hispanic reach end-stage kidney disease at younger ages than white people (with a mean age 57 and 58 years verse 63 years). Young adults aged 20–50 years in sub-Saharan Africa mainly develop chronic kidney disease owing to hyper-

tension and glomerulonephritis. In Ghana, patients with chronic kidney disease of unknown origin were younger, poorer, and more likely to present with advanced chronic kidney disease than were people with known causes (Ephraim, 2010).

Treatment Overview

The goal of treatment for CKD is to prevent or slow further damage to the kidneys (Powe, Peterson & Mark, 2015). Other conditions such as diabetes or hypertension usually cause kidney disease, so it is important to recognize and manage the underlying condition. It is also important to prevent diseases and avoid situations that can lead to kidney damage or make it worse.

Treatment to Control Kidney Disease

Fadem, Walker, Abbott, Friedman, Goldman, Sexton, Buettner, Robinson and Peters, (2011) have shown that in cases where the affected individual has diabetes, it is important to control blood sugar levels with diet, exercise and medicines. A persistently high blood sugar level can damage the blood vessels in the kidneys. On the other hand, where the individual affected has high blood pressure, it is also important to keep the blood pressure in an expected target range, for example less than 130/80mmhg (Gallagher & de Lusignan, 2010). If other conditions or diseases are causing kidney damage, such as a blockage (obstruction) in the urinary tract or long-term use of medication that can damage the kidneys, the client will be managed in view of that. Blood pressure medicine, such as an ACE inhibitor or an angiotensin II receptor blocker (ARB). These medicines are used to reduce protein in the urine and help manage high blood pressure may be prescribed (Berns, Jeffrey, Gray, Cuhan & Sheridan, 2015).

Medicines to Treat Symptoms and Complications of Chronic Kidney Disease

Preidt (2015) showed that symptoms associated with CKD are unbearable and need to be treated to prevent complications. Medicines used to treat symptoms and complications of CKD include: Erythropoietin (rhEPO) therapy and iron replacement therapy (iron pills or intravenous iron) for treatment of anaemia. Medicines for electrolyte imbalances such as insulin and calcium gluconate are used as well as diuretics to treat fluid overload caused by chronic kidney disease (Gutierrz, 2013). ACE inhibitors and ARBs are used to control blood pressure and or may be used when there is protein in urine (proteinuria) or have heart failure. Regular blood tests are required to make sure that these medicines do not raise potassium levels (hyperkalemia) or make kidney function worse (Motedayen, Nehrir, Tayebi, Ebadi, & Einollahi, 2014).

Dialysis

Lacson and Brunelli (2011) believed that, dialysis is a life-support treatment that uses a special machine to filter harmful wastes, salt, and excess fluid from the blood. This restores the blood to a normal, healthy balance. Dialysis replaces many of the kidney's important functions. There are two types of dialysis: Hemodialysis and Peritoneal dialysis. Hemodialysis is when blood is filtered using a dialyzer and dialysis machine (Holley, 2013). Peritoneal dialysis, on the other hand, is when blood is filtered inside the body after the abdomen is filled with a special cleaning solution (Hansson & Watnick, 2016). Dialysis is a necessary treatment for people with end-stage kidney disease or permanent kidney failure. It is needed when there is about 85% to 90% loss of the kidneys (Mandal,

2015). Dialysis treatment itself usually does not cause any pain or discomfort. However, some clients may develop low blood pressure, which can lead to headache, cramping, nausea, and vomiting (Ikizler, 2014). This usually goes away after a few treatments. Being on dialysis may also lead to tiredness and depression (Himmelfarb, 2005). Dialysis require strict scheduling and adjustments to lifestyle, which can disrupt work or everyday activities which may be frustrating hence counselors may be able to help so that clients cope (Tong, Palmer, Manns, Craig, Ruospo, Gargano, Johnson, Hegbrant, Olsson, Fishbane & Strippoli, 2013).

Kidney transplant

Orandi, Luo, Massie, Garonzik-Wang, Lonze, Ahmed and Segev (2016) have demonstrated that kidney transplant is another treatment option for kidney failure. A kidney transplant is a surgical procedure to place a healthy kidney from a live or deceased donor into a person whose kidneys no longer function properly. This may allow for a fairly normal life. Transplantation is rare due to lack of infrastructure on the other hand; survival can be complicated by the affordability of immunosuppressive drugs, malnutrition and infectious diseases (White, Chadban, Jan, Chapman & Cass, 2008).

Palliative Care

Tamura and Cohen (2010) have proposed that palliative care as a kind of care for people who have a chronic illness such as CKD. Patients receiving care on account of CKD have reduced life expectancy and high rates of chronic pain, depression, cognitive impairment, and physical disability. Its goal is to improve

quality of life-not just in body but also in the mind and spirit. Palliative care along with treatment is recommended. According to McCorkle and Pasacreta (2001), palliative care is ideal in managing CKD if treatment no longer seems like a good choice or when client choose conservative care (*i.e.*, no dialysis) (Davison, 2010).

End-of-Life Issues

Davison (2010) argued that CKD progresses to end stage kidney failure when damage to the kidneys is so severe that dialysis or a kidney transplant is needed to control symptoms and prevent complications and death. It is accepted for client to state a preferred health care choices in writing (with an advance directive such as a living will) while still able to make and communicate these decisions. On the other hand, a durable power of attorney or to choose a health care agent usually a family member or loved one, to make and carry out decisions in cases where the client become unable to speak. Option to refuse or stop treatment is also a right (Wadd et al. 2011).

Follow-up Visits

Levin Hemmelgarn, Culleton and Tonelli, (2008) believe that, this is important in managing CKD because regular blood and urine tests to check how well the kidneys are functioning is ideal to either change treatment plan or make amendment. These tests are critical to help monitor disease. Some of the tests include: GFR, to estimate how well the kidneys filter blood and to know the stage of kidney disease. Tests to measure the amount of protein in urine, to find out

whether medicines need to be adjusted or not (Gallagher & de Lusignan, 2010)

Restrictions Associated With CKD

Ikizler (2014) believed that clients diagnosed with CKD are educated on the need to avoid some food supplements such as the following: Salt (sodium) restriction includes: not adding salt to food at the table, not cooking with salt, avoiding most types of fast food, and minimizing the use of most canned foods. This is because, salt retains fluids; hence it must be avoided in cases where there is high blood pressure, swelling of the legs, or a tendency to accumulate of water elsewhere (such as in the lungs). Another supplement that is restricted is potassium; this is because as CKD progresses, high blood potassium levels may occur, and the intake of potassium-rich foods (such as potatoes, oranges, bananas, tomatoes, dried beans, and figs) is unsafe for client (Levin et al. 2008). Last but not least is protein. Protein restriction is not usually advised until the very late stages of CKD however, in general, patients with CKD should not be in the habit of consuming excessive high-protein meals because very high protein intake may actually accelerate the rate of kidney damage (Berns et al. 2015). Gutierrez (2013) has also demonstrated that clients are educated to avoid taking medications that can cause harm to the kidneys such as herbal preparations. Dehydration of any kind is avoided by promptly treating illnesses, such as diarrhea and vomiting. In addition, products containing magnesium such as antacids like mylanta, milk of magnesia or laxatives like citroma must be avoided since these products increase the risk of having abnormally high levels of magnesium (hypermagnesemia) which may cause vomiting, diarrhea or both. Lastly, clients are educated on the

need to avoid X-ray tests that require IV dye (contrast material), such as an angiogram, an intravenous pyelogram (IVP), and some CT scans because IV dye can cause more kidney damage (Tamura & Cohen, 2010).

Prevention of CKD

Thomas (2012) believes that the key to preventing chronic kidney disease is early detection through education and screening. Aggressive intervention for hypertension and diabetes clients is ideal. Medical care with early intervention can change the course of chronic kidney disease and help prevent the need for dialysis or a kidney transplant. Chen and Harris (2015) have suggested that chronic kidney disease may sometimes be prevented by controlling the other diseases or factors that can contribute to kidney disease. To them, people who have already developed kidney failure also need to focus on these things to prevent the complications of kidney failure. To add to the above, keeping blood sugar within a target range among those who have diabetes is encouraged as well as maintaining at a healthy weight. This can help prevent other diseases, such as high blood pressure and high cholesterol levels which can prone an individual of CKD (Mandal, 2015). Last but not least is quitting smoking or use of other tobacco products since smoking can lead to atherosclerosis which reduces blood flow to the kidneys and increases blood pressure.

Complications Associated with CKD

CKD is associated with many complications Thomas et al. (2008) have showed that as CKD gets worse, symptoms-such as fatigue, nausea, and loss of appetite may occur more often or severe. The National Kidney Foundation defines

anaemia as a hemoglobin of less than 13.5 g/dL in men and less than 12.0 g/dL in women. In cases of anaemia, one may need to take medicine called human recombinant erythropoietin (rhEPO) which helps the body form new red blood cells and help improve appetite and general sense of well-being. Iron supplement is recommended if there is an iron deficiency (Lerma, 2015). If uremic syndrome (uremia) is developed, there is the need to have wastes and fluids removed through dialysis or the kidney replaced through a kidney transplant (Powe et al. 2015). In addition, renal phosphate excretion is reduced. Together, both processes cause serum calcium levels to fall, resulting in increased secretion of parathyroid hormone (secondary hyperparathyroidism). Parathyroid hormone has a phosphaturic effect. It also increases the calcium levels by increasing bone resorption and promoting 1- α -hydroxylation of 25-hydroxy vitamin D synthesized by the liver (limited effect because of reduced kidney reserve from scarring). Rising phosphorus levels are almost universally observed in stage 3 CKD patients (Wang & Chen, 2012).

The increased cardiovascular risk associated with CKD has been well established, and estimated cardiovascular mortality rates are ten to one hundred fold higher among dialysis population. The cardiovascular risk associated with renal impairment increases earlier in the course of kidney disease progression than was initially hypothesized. More specifically, there is evidence that even mild to moderate degrees of renal impairment are associated with increased cardiovascular risk (Wanner et al. 2014). Diabetes is associated with adverse outcomes in all stages of CKD. Moreover, lower fasting plasma glucose and/or

glycated hemoglobin levels are associated with lower risk of all-cause mortality and reduced cardiovascular death of borderline significance in patients with moderate to severe renal impairment (Weiner, 2009).

Prognosis of CKD

In patients receiving continuity of care as a result of CKD, death has been a more frequent outcome than in stage 4 and 5, but not in stages 1, 2 and 3. Outcomes were predicted by modifiable risk factors specific to CKD. Proteinuria used in conjunction with estimated GFR refined risk stratification. These findings provide information; specific to CKD patients under regular outpatient nephrology care. Progression of CKD is predicted in most cases by the degree of proteinuria. Patients with nephrotic-range proteinuria (greater than 3 g/24 h or urine protein/creatinine greater than 3) usually have a poorer prognosis and progress to renal failure more rapidly. Progression may occur even if the underlying disorder is not active. In patients with urine protein less than 1.5 g/24 h, progression usually occurs more slowly if at all. Hypertension, acidosis, and hyperparathyroidism are associated with more rapid progression as well. Nicola, Chiodini, Zoccali, Borrelli... & Minutolo (2011).

Otero, Gayoso, Garcia and De Francisco (2005) have explored on the epidemiology of chronic renal disease in the Galician population and found out, baseline characteristics, socio demographic characteristics, and results of a clinical examination. Blood variables were collected from 237 patients who fulfilled the study's inclusion and criteria. The mean age of the sample was 49.58

years (95% confidence interval, 47.39-51.76). The prevalence of Kidney Disease Outcomes Quality Initiative Grade 3 CKD was 5.1%, but the coexistence of an albumin/creatinine ratio >30 mg/g with grade 1 to 2 CKD raised the final rate to 12.7% in this population. It was found that a high prevalence of hypertension (31.5%), isolated systolic hypertension (20.1%), diabetes mellitus (8%), obesity (13.1%), smoking habit (22.7%), high atherogenic index (30.8%), and high alcohol intake (24%) were risk factors significantly associated with renal disease. The researcher believes that, most CKD clients have been diagnosed with other chronic conditions most especially diabetes or hypertension.

The discomfort associated with CKD cannot be expressed by the physical appearance only (Wadd et al., 2011). With some of the clients, their appearance communicates that there are challenges. Majority of the clients with CKD develop other reactions to the diseases such as depression, refusal of treatment and therapy and the notion of life not worth living due to the challenges associated the CKD. The following give insight into some of these challenges.

Psychological and Emotional Burden

It is claimed that decreased marital agreement, strife in family dynamics, and lower socioeconomic status (SES) have been associated with poorer health outcomes and can affect patients' insight of social support and depressive affect. CKD patients who undertake treatment with regular interaction and observation by medical staff are potentially an ideal group for evaluation of the effects of psychosocial factors and stress on outcomes than others, as well as an excellent patient population for intervention to diminish morbidity and mortality. These

relations between potentially modifiable psychosocial risk factors for disease and medical aspects of illness form a paradigm for the study of interventions related to adjustment to chronic illness in the ESRD population (Cukor et al. 2007). A focus on psychological issues deserves consideration for two reasons. Firstly, transplant has psychological effects. Available studies on psychosocial aspects of organ transplantation (kidney, pancreas, lung, liver, and heart) indicate anxiety and negative feeling experienced pre- and post-transplant. Pre-transplant issues include concerns of possible psychological evaluation for transplant and fear of deselection, which may lead to failure to express frustration or concerns about the process. Patients may also anticipate negative outcomes which may include mortality or worsened morbidity, or worries about potential viability of the graft and the side-effects of immunosuppressant medication (Amerena & Wallace, 2009).

Shivani, Goldsmith and Anthenelli (2002) demonstrated that the most common psychiatric disorder in the population of ESRD patients on dialysis were depression and affective disorders (26%), organic brain syndromes and dementia (26%), schizophrenia other psychoses (22%), and drug and alcohol abuse (15%) in a review of hospitalization data from US Medicare. Bhatti, Ali, Siddique and Satti (2014) also maps that depression is common among CKD clients.

Smetanka (2006) explained that suffering is an expression used to describe the physical and emotional chaos of an individual. Finnegan-John and Thomas (2013) explained suffering as a focal point to explain the losses felt as a result of dialysis as a treatment which majority of CKD clients undergo,

discussing such aspects as loss of freedom, stress and strain on the entire family. It was explained that the concept of suffering as taking place at three levels, firstly is suffering in relation to sickness and treatment, secondly is suffering related to the care provided, and at the third level suffering related to each person's unique life and existence (Abdel-Kader, Unruh, M.L., & Weisbord, 2009). It was further described that the ultimate suffering as the fear of death, which is almost always present especially when the client is in the downward phase of the trajectory theory which is characterized by progressive deterioration in mental and physical status such as uremic encephalopathy, uremic gastritis, uremic anaemias, generalized oedema or when other clients are in unstable state of the disease process. Existential optimism that can be used to alleviate suffering may include hope and expectations, combined with fear of what may happen if the machine fails to function effectively. Thomas et al. (2008) explained that though the disease is challenging, major suffering is experienced when complications such as anaemias, fractures, encephalopathy and the need for a donor and waiting for a transplant as some examples of suffering. In the same way, Hashiguchi (2015) explained that suffering is associated with CKD with respect to the financial challenges encountered. Go, Chertow, Fan, McCulloch, R and Hsu (2004) believed that despite all these challenges discussed above, the risk of cardiovascular events and hospitalization also renders the individual to suffering.

The assessment of depression is complicated by overlap of depressive and uremic symptoms (Cukor et al. 2007). Using US administrative data, it was made known that hospitalization for depression among CKD was a late event, occurring

more frequently in clients treated for more than two years. It is believed that greater prevalence of depression was observed using subsets of Kidney Disease Quality of Life questions, in clients treated for ESRD for more than one year (Finkelstein & Finkelstein, 2000). In a study, Wang and Chen (2012) used the Veterans Administration database to identify 1588 male haemodialysis clients. The physician diagnosed rate of depression was 14.7%. It is revealed that depression affects CKD clients and has been related to increased mortality in the general medical population. CKD patients that are classified as depressed and those who report of frequent depressive affect have higher risk of mortality, withdrawal from therapy and hospitalization (Palmer, Vecchio, Craig, Tonelli, Johnson & Strippoli, 2013). Some examples of things that clients with CKD often feel powerless to control are: dietary changes, dialysis schedule, employment/income, medication regime just to mention but a few Mujais, Story, Brouillette, Takano & Finkelstein, 2009). The acts of receiving dialysis, administering medications and other treatment routines remind them of their renal disease, loss of personal control and being dependent on medication, individuals and dialysis machine (Finnegan-John, & Thomas, 2013). Recurrent performance of these acts makes them feel heated and offended. This anger can be directed towards many sources including dialysis, caregivers, family and friends. Anger may be inward, leading to depression and low self-esteem (Poppe, Crombez, Hanouille, Vogelaers, & Petrovic, 2013). It is demonstrated that alcohol and substance abuse are strongly associated with subsequent suicide in the CKD populace. This definitively indicates that populations that withdraw from

treatment and those that commit suicide represent different clinical entities, highlighting that suicide is linked with alcohol, drug dependency and the presence of mental illness. (Cukor et al. 2007).

Chiang, Livneh, Yen, Tsai-Chung Li and Tsai (2013) explored the prevalence and correlates of depression among chronic kidney disease patients in Taiwan with respect to the percentages of the 2000 World Standard Population; the age-standardized depression prevalence was established to be 20.6%. Thus, it was projected that about one out of five CKD patients met the criteria for depression in the study. Cheistiensen and Ehlers (2002) also argue that depressive and anxiety disorders are the most common mental health problems in the CKD population.

Similarly, Palmer (2013) conducted a study to support the fact that most CKD clients are depressed. Studies were principally conducted in dialysis settings. A total of 41 study populations provided data for the prevalence of depression according to diagnostic criteria identified by clinical interview. The participants were interviewed and diagnosed by a psychiatrist, nephrologists, psychologist or psychometrist researchers, trained interviewers (medical resident, nurse or social worker, or unspecified qualification) (Odenigbo, Oguejiofor, Onwubuya & Onwukwe, 2009)

Pagel, Söderkvist, Medin, Hylander and Heiwe (2012) conducted research on health-related quality of life in all the stages of CKD and at initiation of dialysis. All health-related quality of life dimensions deteriorated considerably

with CKD stages with the lowest scores in CKD Stage 5. Patients in CKD stages 2–3 showed significantly decreased HRQoL.

It is claimed that in comparison to depression, anxiety disorders have received little clinical attention in the CKD populace (Fasmer, Halmøy, Oedegaard & Haavik, 2011). The implication of high levels of anxiety or an anxiety diagnosis on outcomes is also unclear. Anxiety's harmful impact on QOL and its specific effect in CKD has not been widely studied. Clients with depression, anxiety or any other psychiatric disorder may represent a population at particular risk. Anxiety may exist when treatment is yet to begin, when it fails or if other clients die as a result of complication development. Clients diagnosed with CKD and other psychiatric disorders have low QOL due to financial, psychological and their general well-being. Regarding the effects of sociodemographic variables on patients' mental health, gender is reported to have an effect; so female patients present higher scores of anxiety and lower scores in positive affect. Male patients are reported of having more social activities and interests and better QOL (Theofilou, 2011).

According to Bruce, Beech, Sims, Brown, and Crook (2010), anger and hostility closely correlate negative affective dispositions. Anger refers to strong emotions coupled with perceived or actual unjust treatment or some other accusation. Hostility connotes an enduring disposition that expresses cynicism, suspicion, and/or resentment. Most clients diagnosed with CKD become hostile to treatment and therapy especially when they feel they should return back to their normal self or when things do not work as expected. A majority of them feel it is

unfair they became ill while others also feel angry about the loss of control over their lives. This is very common as it reflect in the unstable phase of the trajectory theory when the patient's symptoms are uncontrolled by the previously adopted regimen. This happens when clients do not benefit from treatment and RRT any longer. Not many studies to date have examined how these factors are correlated with kidney disease. However, research has established anger and hostility to be connected to hypertension, which is a major risk factor for CKD. This line of inquiry can display how psychonephrology aids in the understanding of the development and progression of CKD among high-risk populations such as African Americans. Performing daily activities such as administering prescribed drugs and other activities of daily living with respect to CKD can make them feel angry and resentful (Kimmel, 2002).

Issues of Dialysis

Hansson and Watnick (2016) map that the decision of managing clients on dialysis is a challenge that most clients face. Some decide to discontinue dialysis due to challenges of life such as being dependent on the machine as well as cultural and financial challenges (Wang & Chen, 2012). Most familiar reason for this decision may include failure to thrive, medical complications, and age (Morrow, 2014). Approximately, 20% of US dialysis patients gladly choose to discontinue ESRD therapy. Black clients are much less likely to vacate from care than white clients (Lights & Boskey, 2015). It is believed that depression is a predictor of the decision to withdraw from dialysis. Bhatti et al. (2014) believe that depression is one of the reasons why client withdraw from dialysis. Despite

the rate of withdrawal from dialysis, the extent to which it should be considered a suicide equivalent is uncertain and controversial. It is recognized that CKD clients have the potential to commit suicide with relative ease through noncompliance with higher rates in dialysis clients compared with the general population (Christensen & Ehlers, 2002) Some commit suicide due to the uncomfortable situations (Gupta, 2006). Lai, Tsai, Hsu, Chiang, Huang and Huang (2013) suggested that, withdrawal from dialysis is ethically suitable for some patients with numerous co morbidities and a shortened life expectancy. While some clients start RRT with no struggle, others do not want to start at all due to fear of the unknown (Smetanka, 2006).

Stress, Financial and Difficult Lifestyle

According to Essue et al. (2013), CKD poses a financial burden on patients and their entire households. In Ghana, the direct costs of medical care are partly covered by health insurance. However, self-management expenses are usually paid by patients. Most studies that estimate out-of-pocket costs only quantify straight costs for treatment overlooking the costs associated with self-management, which include medically related transport, home-care assistance, illness-related home modifications and assistive devices. As CKD disproportionately affects lower socioeconomically disadvantaged individuals, it can reasonably be expected that this patient population is also at risk of economic hardship (Jha et al. 2013).

Braun et al. (2012) state that CKD is associated with significant economic burden. Household economic hardship and out-of-pocket costs on medical and

health-related expenses was deliberated using the economic burden of CKD. The impact of CKD on employers is significant. As the general working population gradually more includes individuals older than 65 years, the working population with CKD may be increased, thereby placing a growing burden on employers and the nation at large (Braun et al. 2012).

Crimmins, Hayward, and Seeman (2004) claim that socioeconomic and cultural issues (SES) have been shown to have a significant impact on CKD. Socioeconomic factors such as low income, poor education, residence in low-income areas, and poor access to health care are strong predictors of the development of CKD. Higher SES was linked with improved survival, with enhanced survival (Crews, Greer, Evans, Zonderman & Powe, 2010). Saunders and Cagney (2010) found higher mortality rates among dialysis clients living in areas that were predominately black in USA. It was also established that there were lower rates of transplantation in communities that composed of blacks being the majority (Kerr, Medcalf, O'Donoghue & Matthews, 2012).

Another vital factor to consider is the relationship of the ethnicities of the client and the physician. Evidence indicates that, there is decreased trust on behalf of patients when they are of a different ethnicity than the physician (Hasnain-Wynia & Baker, 2006).

Plantinga, Tuot and Powe (2010) have demonstrated that culture also plays an important role in health care, how illness is perceived and treatment or therapy required. Cultural beliefs also affect lifestyle factors, such as diet,

exercise, and body image, contributing to differential rates of obesity, hypertension, and diabetes among racial and ethnic minorities. Some people have different attitudes towards illness that put them in intellectual conflict with the views of their physicians. These attitudes may be based on various beliefs, and there may even be a general doubt towards western medicine. The relationship between psychosocial functioning, culture, and SES have links to health outcomes in the CKD populace (Bruce et al. 2010).

Finnegan-John and Thomas (2013) believe that added stressors coupled with CKD leads to biochemical imbalance, physiological changes, neurological disturbances, cognitive impairment, and sexual dysfunction which can potentially play a role in causing depression. Tong Palmer, Manns, Craig, Ruospo...and Strippoli (2013) found that patients with CKD receiving haemodialysis developed a new identity and sense of self. This new and upward psychological state identified that clients became watchful of a new set of circumstances which includes an uncertain future, demands of illness, dependence of machinery, medication, and healthcare providers (Bruce et al. 2010). Negative insight of illness is strongly linked to poorer survival rates. To add to the above, client's perceptions of treatment control predict survival risk factors, including co morbidity and illustrations of the negative impact of maladaptive illness perceptions on clinical outcomes. Decreased QOL is associated with limited personal freedom and control. On the whole, the loss of freedom had wider effects, has negative impact on clients family, marital and social relationships. Impaired self and body image are familiar psychological consequences of living

with CKD. It is also proven that self-image and self-esteem have a bearing on aspects of QOL, which encompasses the physical, social, and emotional well-being. Clients might have to adjust to their changing appearance by the way clients dress. Benefiting from dialysis treatment can considerably have impact on body image, as clients might recognize themselves as unattractive. For example, procedures to create a point of access for dialysis via a fistula, neck line, or catheter can all change the appearance of the client (Osafo et al. 2011). Immunosuppressant drugs administered to prevent organ rejection after transplant can also add to obvious bodily changes impairing self-acceptance.

The roles within marital relationships change when a partner becomes a carer and can give rise to depression in the care as a consequence. There is the probability that the patient may become the focus of negative emotions (Cohen, 2004). In addition, sexual difficulties can occasionally occur as a result of erectile dysfunction in male clients with CKD and can undermine intimacy. It is noticeable that a number of disease and treatment-related factors that restrict lifestyle and undermine QOL in people with CKD affect them emotionally (Finnegan John & Thomas, 2013). Psychological support to help patients cope with lifestyle restrictions and to enhance personal control through self-management strategies are therefore necessary (Cukor, Scott, Cohen, Rolf, Peterson & Kimmel, 2007).

Odden, Whooley and Shlipak (2005) explained that CKD is coupled with QOL, due to the effects of uremia. ESRD leads to loss in mobility, exercise capacity, self-assessed physical function, and is further allied with reduced ability

to work and function effectively leading to stress. Stress is a condition whereby environmental factors surpass the adaptive capacity of a person to a point where psychological and physiological responses may place them at risk for disease (Velho & Velho, 2013). Vecchio, Palmer, Tonelli, Johnson and Strippoli (2012) observed that stress can have implications for the development and progression of CKD. Clients with CKD go through stress in cases where there is no or limited support be it financial, psychological or emotional (Osafo et al. 2011). Due to the stress clients undergo, some of them result to comorbid behaviors such as alcohol, tobacco, and drug abuse (Theofilou, 2011). It is believed by the researcher that, good culture and socioeconomic support must be encouraged since there is a signal that it prevents complications and prolongs client's life hence improvement in client's quality of life. The research also believes that CKD is associated with multiple discomforts as evidence by this literature.

Impact of CKD on Body Image

Morton, Devitt, Howard, Anderson, Snelling and Cass (2010) have stated that there is a profound effect on the general appearance of clients affected with CKD which is characterized by the presence of fistula in clients benefiting from dialysis. Due to associated signs and symptoms with CKD, clients develop different alterations in their looks. While some lose weight due to malnutrition, others gain weight due to edema especially in those who default and those yet to start dialysis (Tong et al., 2013). There may also be a more existential concept of the body, as it is sometimes noted that due to dependency on the machine, a client does not own his body. This relates specifically to the body as a physical entity in

the world of dialysis. The lived body relates to the medical discourse and practice that transforms the bodily experience of the clients (Levey et al. 2016). Levey and co make reference to the power of the medical–functional discourse, in particular over bodily feelings and sensations. Since dialysis affects so many features of the body, mainly in terms of the access (fistula and lines) and the machine itself, this is quite an established experience (Levey et al. 2016). Thomas et al. (2008) also refer to the concept of the body in a study, related to the changes of bodily sensation through the process of CKD progression which includes dialysis, in particular the effects of the fistula in dialysis and the physical feelings and pains experienced by clients. Benefiting from dialysis treatment can considerably have impact on the physical appearance of the client, as clients may recognize themselves as unattractive. For example, procedures to create a point of access for dialysis via a fistula, neck line, or catheter can all change the appearance of the client (Kimmel, 2001).

Impact of CKD on Nutrition

According to Thomas et al. (2008) depression preceded the decrease in serum albumin concentration in dialysis patients, this implies that depression causes malnutrition since depressed client refuse to eat. To add to the above, because CKD clients are being restricted as to what to eat, majority become malnourished. Lai, et al. (2013) believed that as clients advance through the stages of CKD, there is alteration in nutritional requirements and metabolism of protein, water, salt, potassium, and phosphorous. These changes lead to fruitless energy generation despite adequate ingestion of protein and carbohydrate

substrates. According to Ikizler (2014), in more severe cases, these alterations in nutrient utilization cause uremic malnutrition, a syndrome that is distinct from malnutrition caused by insufficient nutrient consumption. There has also been increasing evidence of cachexia that occurs in majority of CKD clients (Weiner, 2009). Levels of stress hormone associated with depression and dysregulated carbohydrate metabolism, as well as other such mediators have also been shown to be high in CKD patients treated with HD (Mansour, Youssef, Salameh & Yaseen, 2014). The researcher believes that, good renal nutrition support must be encouraged since there are evidence that renal diet prevent complications and prolongs client's life despite nutritional challenges associated with CKD; hence, improvement in client's quality of life.

Social Relations and Support

Cohen, Sharma, Acquaviva, Peterson, Patel and Kimmel (2007) believed that increased social support has the potential to positively have an effect on outcome of CKD through a number of mechanisms, together with decreased levels of depressive affect, amplified patient awareness of quality of life, increased access to health care, improved patient compliance with prescribed therapies, and direct physiologic effects on the immune system. Advanced levels of social support have been linked to survival in more than a few studies of patients with renal disease. To add to the above, higher spousal support among women on dialysis was coupled with improved compliance and survival in subgroup analyses (Cohen et al. 2007). Again, having good intimacy in relationship with a life partner diagnosed with CKD is found to be a sign of good

health. Such relationships have positive aspects such as associations with better social support (Perz, Ussher & Gilbert 2013). Pole, Crowther and Schell (2004) claimed that marital stability, contentment, and comfort have been associated with positive health outcomes in the general inhabitants. Hawkins and Booth (2005) also state that unhappily married individuals report poorer health than do happily married or divorced people with comparable demographic and health characteristics. Declines in reported marital satisfaction have been associated with subsequent poorer health evaluations. Marital conflicts mostly affect insight of illness and hamper with the ability of a patient to comply with the difficult regimen (Finkelstein & Finkelstein, 2000). Cukor et al. (2007) have also stated that patients undergoing dialysis as well as their spouses had strong psychological distress of marital strain. Out of the whole twenty percent of spouses of dialysis patients who had considerable depressive symptoms Spouses' level of grief was not related to level of patient function or depression. Social support received by the patient as well as financial support by the spouse accounted for a large proportion of comfort. Another study suggested by Walker et al. (2015) women caregivers of ESRD patients apparent good QOL and no evidence of burden, but these two parameters were interrelated. It was noted that there is decreased level of anxiety, depression, and marital troubles in a group of carefully screened home dialysis spouse partners than the rest. Krantz and McCeney (2002) found that, even though there was a high predominance of sexual dysfunction among dialysis patients, marital and social adjustment scores were comparable to those of the general population. Daneker, Kimmel, Ranich and Peterson (2001) found a

correlation between patient and spouse Beck Depression Inventory (BDI) scores. It was found that spousal levels of depression linked with extent of dialysis clients' depressive affect, and the greater the level of social support the spouse reported, the less strain they recognized in the marriage (Palmer, Vecchio, Craig, Tonelli, Johnson, Nicolucci, Pellegrini, Saglimbene, Logroscino, Fishbane & Strippoli 2013).

Marital conflict has been associated with endocrinological and immunologic alterations in women, but not men, in participants without renal disease. Kimmel (2001) explored a study of 68 Israeli prevalent hemodialysis patients and the study revealed high levels of distress compared with normative groups and high correlations between distress scores of spouses. Married female patients had less anxiety than married male patients. However, male spouses had elevated levels of pain as compared to female spouses. Giving and receiving of social support within a marriage may also vary during the ESRD life cycle. Among Canadian couples, female patients felt that family support declined after the onset of illness, but no change in alleged support was noted by male ESRD patients. The study explored the relationships between medical factors, neuro-endocrinological and immunologic factors, and outcome in a subset of male and female hemodialysis patients performing in dyadic relationships. Dyadic satisfaction scores were as good as those of normative populations, although the women had more negative assessments of their marriages than the men. Marital contentment and conflict scores correlated with medical risk factors and psychosocial parameters only in women in the study. To add to the above, neurologic,

immunologic, and marital indices predicted differential survival in the study group, but the dyadic indices were associated with outcome in the women only. It appears that strong negative emotion, such as perception of dyadic conflict, may be a principally important stressor in women undergoing HD, activating physiological and neuroendocrinological pathways (Cukor et al. 2007). From this literature, it can be anticipated that women with CKD benefiting from HD are in difficult marital relationships and are at risk of developing particular risk which can lead to mortality. This risk may relate to their roles as females or other expectations. Because stress, inflammatory responses, and depressive symptoms are greater in women; possibly, these factors mediate outcomes for women more than men with CKD (Holley, 2013). The researcher believes that, sound marriage and family support must be encouraged since there is an indication that it prevents complications such as depression among CKD clients and improves quality of life.

It is claimed that social support encompasses to a social network's provision of psychological and material resources which is intended to benefit an individual's ability to cope with stress associated with CKD (Cohen et al. 2004). Levin, Hemmelgarn, Culleton, Tobe, Tonelli, (2008) have demonstrated that, social support and integration are now recognized as vital factors in adjustment to chronic and acute illness of which CKD is not an exception. In fact, through social support groups clients tend to learn from each other which build their self-esteem. In addition, suggestions underling differences in individual experiences will be addressed (Cukor et al. 2007).

It is believed by social science that diseases affect an individual's social relationships as well as her total well-being. It has been well established that clients with thin social networks and low levels of social support have an increased risk for death (Poppe, Crombez, Hanouille, Vogelaers & Petrovic, 2013). Individuals living alone or have minimum contact with friends, relatives, or acquaintances, single and do not belong to any social group have been found to have elevated rates of cardiovascular disease morbidity and mortality than persons who are integrated in social networks (Kimmel, 2001). Bruce et al. (2010) claimed that the involvement in dense social networks and psychologically supportive relationships can be a protective factor against environmental threats to physiological health. However, the impact of social support has been assessed principally in patient populations. Research has determined the impact of social support to the chronically ill client. The degree to which social support has had positive implications on clients diagnosed of CKD cannot be overemphasized (Go, Chertow, Fan, McCulloch & Hsu, 2004).

Several studies have shown a relationship between survival and perception of social support in CKD patients of different ethnic backgrounds. Psychologists have found that, QOL measure include social support, which predicts survival of hemodialysis patients strong family unity, as a social support indicator measured by the Family Environment Scale and predicted survival in HD clients. Support from family and caregivers correlated with a composite compliance measure in HD patients in an urban area. Moreover, one could not ascertain contact between measures of social support from family and friends and compliance measures of

CKD clients, and have also failed to show a correlation between greater perception of social support and conformity. Kimmel (2001) also found that inadequate social support correlated with depressive symptoms, negative perception of illness outcome, and unsatisfied with life. Mujais, Story, Brouillette, Takano, Soroka, Franek, Mendelssohn and Finkelstein (2009) explained that optimism was the mediating pressure between social support and depression and highlighted the need to account for the role of individual differences in the connection between support and depression. Social support may have an effect on psychological, medical, and biochemical factors in other unknown ways to cause better health outcomes. The researcher believes that, social support groups must be encouraged since previous studies indicate that it prevents depression among clients and improves QOL.

Summary

The purpose of this review was to explore the lived experiences of people with CKD. There are common elements across all modes of clients in all studies regarding the experiences of CKD. There is however an over-representation of participants with ESKD compared to those who are not; in fact, there is a clear lack of studies of stages 1, 2 and 3 patients alone because it is believed that such clients undergo less stress (Finnegan-John & Thomas, 2013). Studies of clients underwent dialysis reported experiences relating to time spent on the machine, the environment and the side-effects. The studies in this review provided useful insights into the psychosocial burdens, stress, financial and difficult lifestyle for individuals living with CKD. The coping and adaptation strategies reported in

these studies covers the diagnosis to the point of starting dialysis and their continued lifetime on dialysis. The review suggests that participants attach different meanings of various experiences; some studies have concentrated on the negative aspects of CKD while others have focused on value and positive features of the adaptive process. These conflicting views can be assigned to the different theoretical and methodological approaches, and experience of long term condition was also a common element.

There is however some important points in this review that deserve further study. The literature review provides a focus and context for the current study. There is a clear need to expand the current knowledge base of CKD. A greater understanding of the implications of CKD is required, including how information should be disseminated.

Perico and Remuzzi (2014) found that Africa is experiencing an increase incidence of hypertension (60 million people) and type 2 Diabetes Mellitus (greater than 12 million people), which are the underlying causes in greater than 15% of CKD cases. According to Ojo (2014), none of the 54 countries in Africa will be able to afford the cost of medical care associated with pre-dialysis CKD for their populations (estimated to be \$2500 to \$20,000 per patient annually). Even more out of reach is the annual price tag of dialysis treatment which amounts to \$20,000 to \$30,000 per person per year in sub-Saharan Africa. Medicare covers this cost expenditure for the 500,000 US citizens with ESRD but in Ghana, dialysis is not covered by NHIS making its management quite complicated. In contrast, fewer than 5% of the 500,000 new cases of ESRD in

SSA gain access to even a limited period of dialysis (Abu-Aisha & Elamin, 2010). In Africa, kidney disease imposes disproportionate, untold human suffering and a catastrophic economic burden on the African continent in several respects: less than 2% of the patients with ESRD have access to RRT, making ESRD traumatic for majority of the patients (Hingorani & Ingelfinger, 2016).

CKD is very expensive to be treated in Ghana. A weekly dialysis of a patient cost GH¢ 900.00 (USD\$ 300.00) excluding prescribed drugs that are used to control blood pressure and sugar levels just to mention but a few (Osafo et al. 2011). The high cost of treatment coupled with terminal nature of the disease move the therapy from a medical to a socio-economic situation as most patients eventually die after their resource can no longer support the cost of treatment (Finkelstein & Finkelstein, 2000). In CCTH, one dialysis session cost 190 Ghana cedis the cheapest in the country currently (CCTH, 2014). Emotional and physical symptoms in CKD patients, including symptoms that the patients rate as being severe including sexual dysfunction and psychological distress. Sexual dysfunction and depression are both common in people with CKD. Approximately, one-quarter of people with CKD fulfill the criteria for a diagnosis of depression, and approximately 70% of men with CKD face erectile dysfunction. These estimates are higher than in the general populace, where the prevalence of depression is between 5 to 9% for women and 2 to 3% for men and the prevalence of sexual dysfunction is 31% in men (Suzuki, Nishimatsu, Oba, Takahashi, & Homma, 2014).

Vecchio et al. (2012) have shown that people with chronic kidney disease

(CKD) experience markedly poorer quality of life as compared to the general population. Individuals with CKD and particularly those with an advanced kidney disease, frequently experience: fatigue (71%), itching (55%), constipation (53%), low appetite (49%), pain (47%), sleep disturbances (44%), anxiety (38%) and restless legs (30%). Harms related with CKD include both those that impact the health of an individual as well as those that impact society as a whole. The most obvious societal effects are the tremendous financial cost and loss of productivity associated with kidney failure.

The difficulty of care also includes procedures such as fistula catheterization, fluid and dietary restrictions, blood pressure measurements daily, injectables such as erythropoiesis-stimulating agents once to thrice weekly, growth hormone daily for children, or insulin administration for diabetics, and or peritoneal dialysis or hemodialysis thrice weekly in ESKD cases which affect the quality of life of the affected client (Hashiguchi, 2015). According to Osafo (2011), 10% of all deaths in medical wards at the Korle-Bu Teaching Hospital are due to chronic kidney diseases. Unfortunately, most patients are young and belong to the economically active group.

Morton et al. (2010) conducted a qualitative study in 2010 on Patient Views about Treatment of Stage 5 CKD in Australia. A qualitative analysis of semi structured interviews was adopted. Ninety five participants were interviewed. Freedom, convenience, self-care, effectiveness, and simplicity were commonly cited positive characteristics, whereas confinement, risk, family burden, pain, and time commitment were negative characteristics associated with

RRTs. The characteristics were not specific to dialysis modalities, and some examples, self-care were seen as both positive and negative. It was concluded that patients preferred RRTs that enhanced their freedom and autonomy and were convenient, effective, and simple. Treatments that minimized confinement and risk also were viewed positively. Our analysis suggests that patients might choose between therapies based on their perception regarding which therapy most embodies particular characteristics that minimize impact on their lifestyle. Presentation of information regarding RRTs should focus on these characteristics and the potential impact of alternative treatments on the patients and how they wish to lead their lives.

Wu et al. (2015) conducted a study on lived experiences and illness representation of Taiwanese patients with late-stage chronic kidney disease. A qualitative study was designed to identify patients' experiences and perceptions related to living with late-stage chronic kidney disease. Interviews were held for 15 patients with late-stage chronic kidney disease from two medical centers in Taiwan. Five themes were identified using content analysis: experiencing moderate to severe symptoms and signs; tracing back to causes; realizing the long-term, irreversible nature of the disease; facing the consequence of unavoidable deterioration; and coping with the disease. At the end of the study, the themes and concepts described from the findings of these studies can help to provide understanding of the multidimensional and complex experiences of individuals living with CKD. Also, the findings will present the lived experiences of clients with CKD in CCTH and highlight the need for healthcare providers to

assess clients' illness representation before offering interventions for patients coping with chronic kidney disease.



CHAPTER THREE

METHODOLOGY

This chapter presents research design, study setting, population, sampling technique, instrument, and procedures that were used to address the research objectives for this study. The main objective of the study is to investigate the experiences of clients with CKD at CCTH.

Research Design

An exploratory qualitative with a phenomenological overtone approach was used in carrying out this study. Phenomenology, rooted in a philosophical tradition is an approach to exploring and understanding people's everyday life experiences (Polit & Beck, 2010). The qualitative study design was chosen because the researcher wanted to explore the lived experiences of people with CKD in CCTH.

Study Setting

CCTH was selected for this research because there was no study found in literature as for as the researcher is concern about the lived experiences of people with CKD. To add to the above, CCTH is the only hospital in both the Western Region and Central Region of Ghana with a renal center; hence, all renal cases from all other regions are referred to the facility for management. The study was done in the two units which were located in the hospital.

CCTH is located in Cape Coast. It is a 400-bed capacity hospital and is the main referral point for all other health facilities in the region and sometimes beyond (CCTH, 2014). The hospital was originally built to provide tertiary care for referred patients but it currently provides primary health care service for the people of the region and beyond.

The hospital was commissioned in 12th August 1998, as the regional hospital with the following wards: Male Medical Ward, Female Medical ward, Pediatric Ward, Obstetrics and Gynecology Ward, Neonatal Intensive Care Unit (NICU), Emergency Unit, Intensive Care Unit (ICU), Executive Suite, Delivery Suite, Surgical Suite, and a Renal Unit (CCTH, 2014). Until the commissioning of a new ultra-modern hospital designed as a regional hospital in 2013, CCTH played the role of a regional hospital. Even though the hospital continues to render valuable services to many people within the catchment area, it lacks adequate specialized staff, residential accommodation for both staff and patients relatives. The mission of the hospital is to provide advanced clinical tertiary health service to support primary and secondary health care. It also serves as a renal unit for both the Western and Central Regions of Ghana and beyond.

Study Population

A research population is generally a large collection of individuals or objects that is the main focus of a scientific query (Polit & Beck, 2010). A research population is also known as a well-defined collection of individuals and objects known to have similar characteristics. All individuals or objects within a certain population usually have a common, binding characteristic or trait.

The target population for this study were clients diagnosed with CKD and are receiving care at CCTH. Participants were sampled to participate in the study.

Sample and Sampling Technique

The medical wards were selected for the study and ten participants were sampled for data collection, following data saturation. Mason (2010) believed that qualitative research is concerned with meaning and not making generalizable hypothesis. Also, because qualitative research is very labor-intensive, analyzing a large sample can be time-consuming and is often simply impractical. In addition, if the sample is too large, data becomes repetitive and eventually superfluous.

Access to the wards were facilitated by the ward in-charges, clients who fell within the inclusive criteria were consulted and their consent sought before they took part in the study. Clients who were willing to participate voluntarily were recruited for the study.

The Male Medical ward was sampled because the researcher wanted to explore the experiences of males who were living with CKD and have not yet started dialysis. The Female Medical ward was selected to explore the experiences of people not yet on dialysis but living with CKD from a feminine perspective. The Renal Unit was also selected to examine the experiences of clients on RRT. Participants were purposively selected for semi-structured interviews. Clients who were diagnosed of CKD and were receiving treatment at CCTH had more experiences to share, thus their inclusion in the study. The researcher went to both male and female medical wards as well as the renal unit and requested for a list of clients who met the inclusion criteria. The purpose of the research was explained

to selected clients. Clients who were willing to participate in the study were required to sign a consent form. The mobile phone numbers of participants were collected and a convenient time and place for the interview was arranged between researcher and participants. Participants were selected for interview until saturation was reached.

Inclusion and Exclusion Criteria

Clients who were diagnosed with CKD and those who consented were selected. However, exclusion criteria included clients who could not communicate effectively due to their condition such as unconsciousness and encephalopathy were excluded in the study.

Instrument

In-depth interviews were used to collect the data. Interviews were guided by an interview schedule which was formulated to address research objectives. Follow up questions were asked when clarification was needed. A pre-test of interview schedule was done in the Cape Coast Municipal Hospital where two clients diagnosed of CKD were interviewed and the interaction was recorded in order to address any problems in the interview schedule and also verify the validity of the work. Results of pretest were shown to the supervisor who proposed some modification to be done to the interview questions. It was observed that clients had minimum knowledge on CKD and had psychological and financial challenges as a result of CKD. Data collection started after supervisor and researcher were satisfied that the new interview guide explored the lived experiences of people with CKD.

Data Collection

Participants were called on phone and a meeting place and time for the interview was scheduled. Three participants in male medical ward, three in the Female Medical ward and four in renal unit (two males and two females) were interviewed. Most interviews were done in the homes of participants and others were done at a designated side ward in the ward the hospital. The language used for the interview were English and Fante. Interviews were audio recorded and were transcribed verbatim by the researcher. In this study, it was ensured that participants told their stories with minimal interruption. Six interviews ranged from 45 to 60 minutes while four lasted for 30 minutes. However saturation was not determined in the medical wards. Four additional participants were interviewed in the renal unit to determine 'saturation'. 'Saturation' occurs when the researcher finds that no new themes are emerging from the analysis of data (Rebar, Gersch, Macnee & McCabe, 2011). Participants were debriefed to ensure reliability of data collected to avoid researcher bias.

Data Analysis

In-depth-interviews were analyzed thematically (Ritchie & Lewis, 2003). The content of the interview were transcribed verbatim from audio tape recordings and were read several times to identify key concepts and codes. Codes were developed to describe identified key concepts. Codes with similar meanings were collated as themes. Similar themes were grouped together to form categories. The data from male and female medical wards as well as those from the renal unit were analyzed according to themes developed and reviewed by

supervisor to facilitate content validity. Participants were also debriefed about themes to make sure it represented their lived experiences. Themes developed were: a) psychological and emotional challenges associated with CKD such as, depression and anxiety, b) financial challenges associated with CKD and c) social and physical effects of CKD; Body image.

Ethical Considerations

The research proposal was submitted to and approved by the University of Cape Coast Institutional Review Board (UCCIRB). Additionally, the study received approval from CCTH where the research was conducted. All principles of research ethics were adhered to as expected. Participants were briefed about the study's aim and about the procedures before their written informed consents were obtained. Participants were informed about their rights to refuse to participate in the study or to opt out from continuing their participation in the study at any time without giving any reason. Also, participants were informed that their refusal to participate in the study would not be used against them in any form. The confidentiality of participants was thus enforced, and they were assured that the data would be used for research purposes only. Transcribed interviews were stored in electronic folders that were created and labeled appropriately for easy identification by the researcher. These folders were kept on a pendrive solely meant for the purpose of this study and kept under lock and key. The study process did not entail any harmful effects on participants

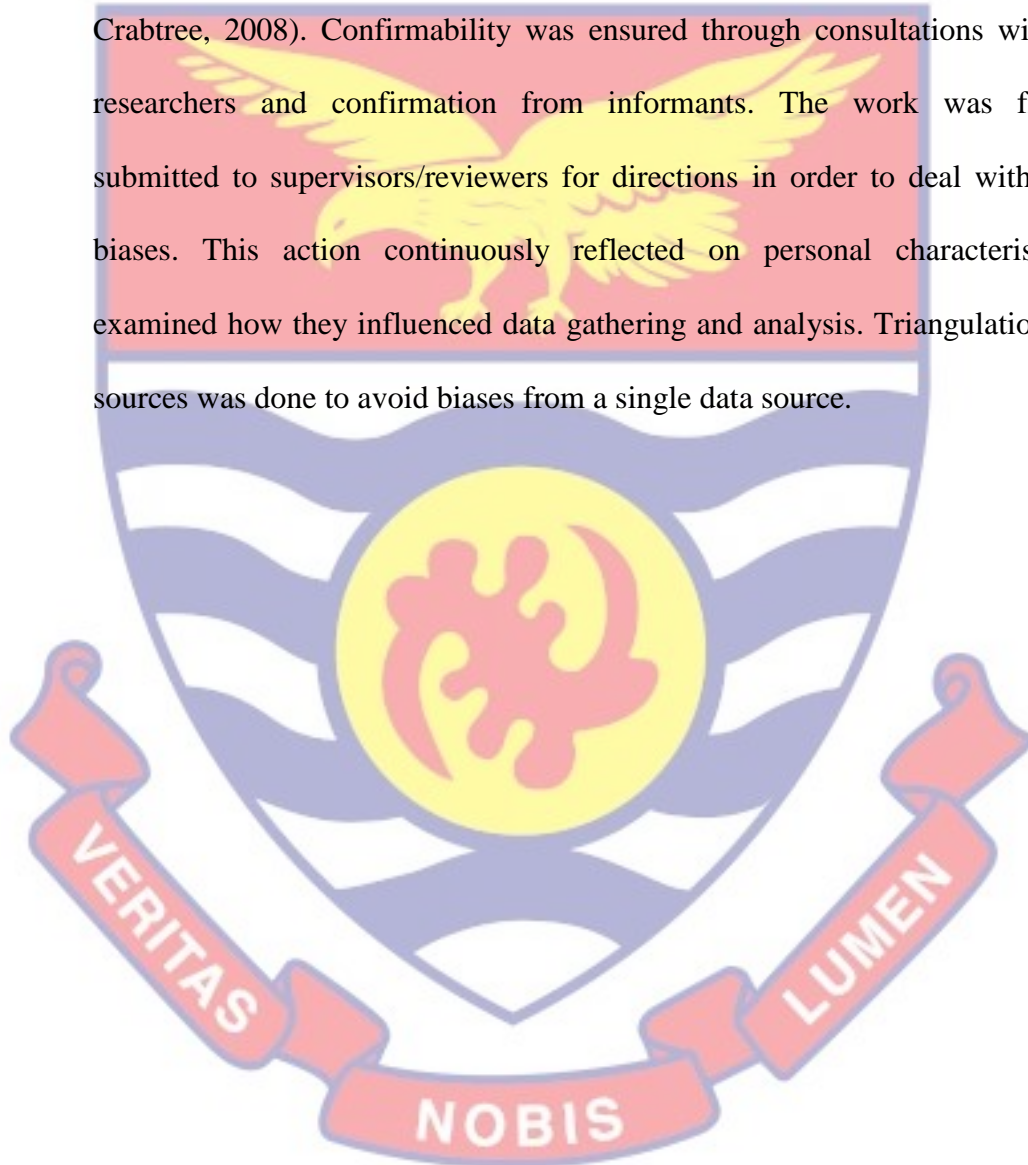
Rigor

A challenge relates to how one may know if he or she can trust the outcome of a qualitative study. The core concepts of validity, reliability and generalizability that are essential markers of sound quantitative research apply to some degree in qualitative studies as well. Those concepts in qualitative research are called credibility, dependability and transferability (John, 2014).

Credibility refers to the confidence in the truth, value or believability of the findings of the study (Polit & Beck, 2010). Credibility is demonstrated through strategies such as data and method triangulation, repeated contacts with participants, peer-briefing and member checking (Jeanfreau, 2010). Credibility in this research was ensured through search for confirmation and clarification and from informants, consistency in data collection, and completion of data cleaning, running validity checks, auditability, and consistency in coding.

Transferability or fittingness refers to the possibility that the findings would have meaning to another group or could be applied in another context (Streubert-Speziale, 2007). Jeanfreau (2010) believed that accurate and rich description of research findings demonstrates fittingness or transferability by providing adequate information for evaluating the analysis of data. Detailed descriptions and verbatim quotations were presented so that a person who wants to use the findings of this research could judge the appropriateness of transferring the study findings to another group.

Cohen and Crabtree (2008) explained dependability as showing that findings are consistent and could be repeated with a different researcher. Confirmability refers to a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias (Cohen & Crabtree, 2008). Confirmability was ensured through consultations with expert researchers and confirmation from informants. The work was frequently submitted to supervisors/reviewers for directions in order to deal with possible biases. This action continuously reflected on personal characteristics and examined how they influenced data gathering and analysis. Triangulation of data sources was done to avoid biases from a single data source.



CHAPTER FOUR

RESULTS AND DISCUSSIONS

This chapter presents results of the study and also discusses results in line with the literature reviewed and the objectives of the study. The purpose of the study was to explore the lived experiences of people with chronic kidney disease (CKD).

The results of the study are presented in two sections. The first section presents demographic results and the second section presents thematic categories that were arrived at after content analysis of data. The summary of demographic data is found in Table 1 and the summary for thematic categories is presented in Table 2.

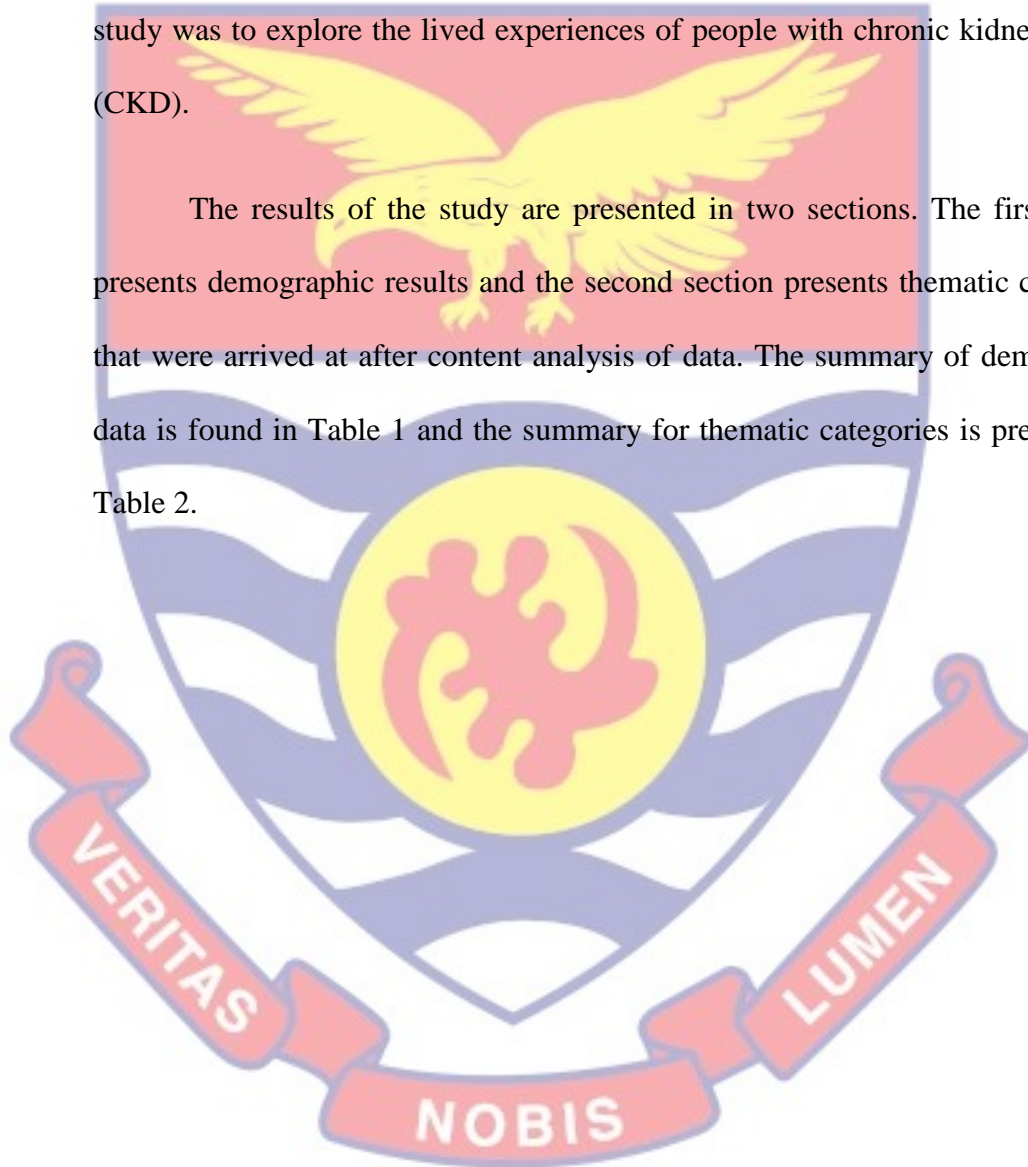


Table 1 - Demographic Characteristics of Participants

| Demographic Information | N=10 | Frequency | Percentage |
|---|------|-----------|------------|
| Age (in years) | | | |
| 15-24 | | 2 | 20% |
| 25-34 | | 3 | 30% |
| 35-44 | | 3 | 30% |
| 45-54 | | 2 | 20% |
| Geographical location | | | |
| Western Regional | | 5 | 50% |
| Asante Region | | 2 | 20% |
| Central Region | | 3 | 30% |
| Length of Time on treatment or RRT | | | |
| 1 year | | 5 | 50% |
| 2 years | | 2 | 20% |
| 3 years | | 2 | 20% |
| 4 years | | 1 | 10% |
| Marital Status | | | |
| Single | | 3 | 30% |
| Married | | 7 | 70% |
| Gender of Respondents | | | |
| Male | | 5 | 50% |
| Female | | 5 | 50% |
| Education of Respondents | | | |
| None | | 1 | 10% |
| Primary | | 1 | 10% |
| JHS/Middle School | | 1 | 10% |
| SHS | | 2 | 20% |
| College | | 3 | 30% |
| University first degree | | 2 | 20% |

Ten clients diagnosed with CKD participated in the research. The demographic data in Table 1 indicates that the respondents were between ages 16 to 50 years. Five interviewees had been on treatment for one year. Two had been on treatment for the past two years while another two had been on treatment for three years now. Only one had been on treatment for four years. Five males and five females participated in the study. Three were single while seven were married. Five of the participants were from Western Region while three were from Central Region. Two participants were from the Ashanti Region. Two of the participants had completed university while three had completed college. Two had completed SHS (Senior High School), one had completed middle school while one had completed primary education. One had no formal education. Seven respondents obtained knowledge about CKD from the media. Only one respondent had obtained knowledge from health personnel while two had obtained knowledge from various hospitals via OPD education. Of the ten clients interviewed, five of them were on dialysis, while five were not yet on RRT. The table also reveals that none of the respondents had received a transplant.

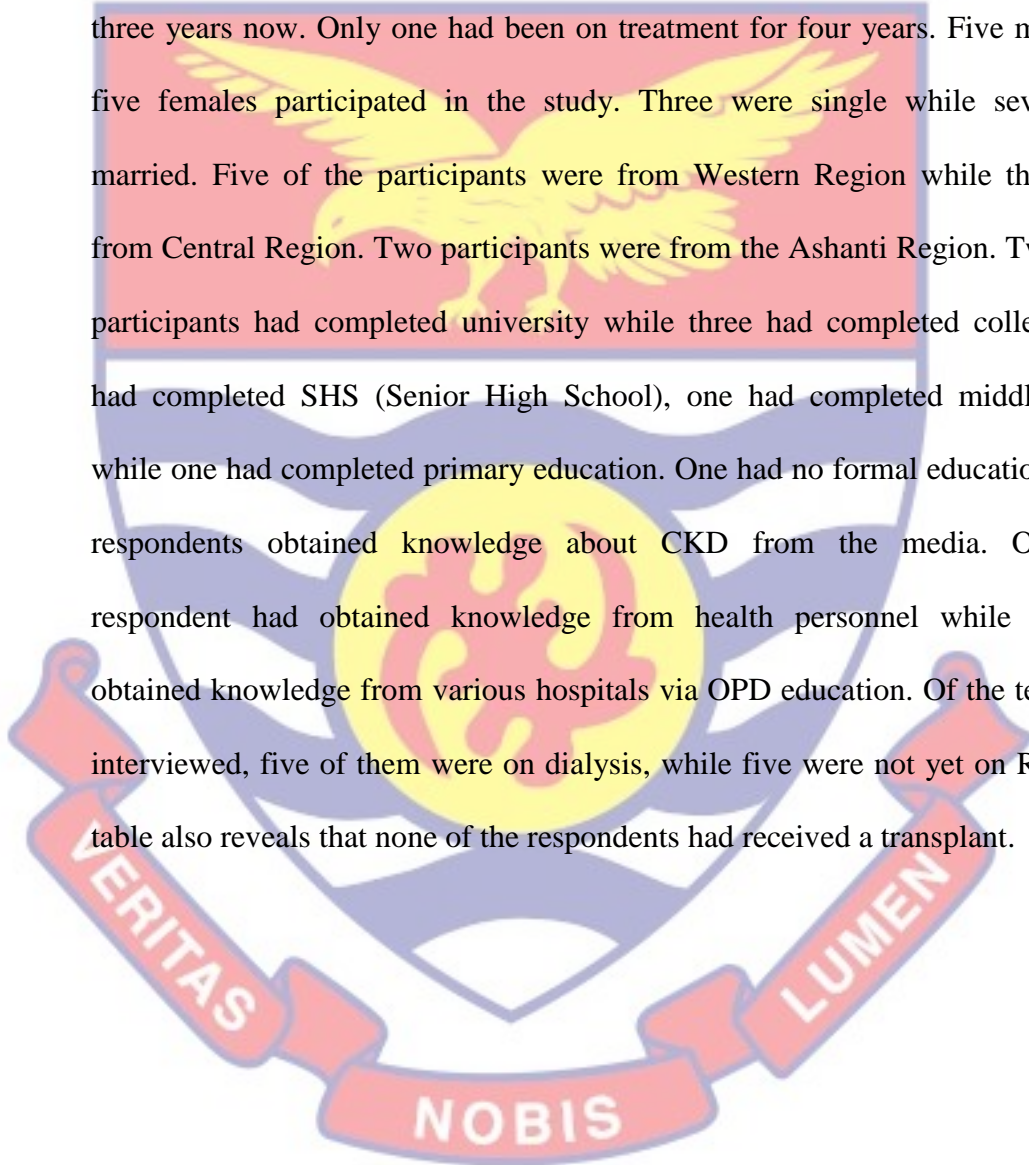


Table 2 - Results of Thematic Categories

| THEME | SUB-THEME |
|--|--|
| Theme one: Knowledge of CKD | Inadequate knowledge on causes and treatment of CKD Inadequate knowledge on CKD |
| Theme two: Psychological and emotional challenges associated with CKD. | Psychological impact Dependence and support. Sexual challenges. Negative feeling. Coping responses, faith and religion. |
| Theme three: Financial challenges associated with CKD | |
| Theme four: Impact of CKD on social life | |
| Theme five: Physical impact of CKD | |
| Theme Six: Impact on activities of daily living | |
| Theme seven: Availability of social support system | |

The table above present a summary of the main themes identified in this study. The seven thematic categories that emerged from data analysis are indicated in Table 2.

Theme one: Inadequate knowledge.

The first category was knowledge of CKD. The challenges that were encountered by clients were: inadequate knowledge of the causes, treatment regimen of CKD and inadequate knowledge of CKD.

The first challenge was inadequate knowledge of the causes and treatment regimen of CKD. Three of the participants did not know names of their drugs nor the time of administration of such drugs. All that they knew was that the medications have been prescribed for them to take. One said

“My children who support me know everything about CKD so even if I do not know; I am not bothered” (Participant 1).

Another said: *“My husband knows the names of the drugs and when I should administer them. He always reminds me when to take those drugs especially the epo”* (Participant 2).

One participant who was an illiterate lamented:

“I cannot have those English names at hand but I can identify them” (Participant 3). Three of the participants knew a majority of the type of the drugs but not the desired effect

“I know Epo, nifedipine, aldomet and so on but I do not know what they do” (Participant 4).

Two had knowledge on the side effects of the drugs as well as desired effect while two knew the desired effects as well as side effects of the drugs. They knew the names of the drugs at hand, which one can be gained with or without prescription and when and when not the drugs should be taken or otherwise.

These participants knew when to start dialysis, what to eat and what not to eat as well as fluid the restrictions. All participants knew about what to eat and what not to eat. They also knew about fluid intake and output measurement or balancing.

“What I know is that the drugs that control the blood pressure such as nifedipine is effective but at the end of the day, one may experience dizziness, tremor and flushing” (Participant 6).

I am not allowed to take in canned foods, salt, more than 500mls of water, high potassium food and so on” (Participant 10).

“Epo is for blood production just like iron.” (Participant 9).

I do not eat bananas, potatoes, oranges because of the high potassium content. I also do not add salt to food at the table, I do not cooking with salt, I avoid all fast and canned foods. This is because, salt retains fluids hence must be avoided” (Participant 9).

The second challenge encountered was inadequate education around CKD. Two of the respondents said they were not educated on CKD. Five participants had education on the causes but not the complications of CKD. Two of the participants said they had education on the causes, treatment and complications of

CKD via the media. One participant was well educated on CKD. A participant lamented:

"It is a bad disease which occurs when one cannot make urine"
(Participant 5).

"Once it is a chronic disease that means I will battle till death. All I need to do is to comply with treatment" (Participant 6).

"I know it means my kidneys are diseased but I do not know what the main issue is" (Participant 2).

"All I know is that I am ill. That is all. I am yet to ask the nurses questions. Moreover, they are busy and I do not want to disturb them" (Participant 3).

"I had a shock of my life when the nurse told me I needed to start dialysis immediately looking at my laboratory results, because nothing had been explained....."(Participant 8).

"Though I was gradually educated about dialysis by one of the young nurses, I still have some fear of unknown whenever I am to start the process It is a disease that affects the kidneys, rendering the individual unable to make enough urine" (Participant 9).

"I understand it is a chronic disease in which the kidneys are affected resulting in scanty urine production. I also know I must

be on treatment till a change is seen in my state” (Participant 10).

Theme two: Psychological and emotional challenges associated with CKD.

All participants indicated that CKD had affected them psychologically. They all added that CKD had lowered their self-esteem in one way or the other. It was identified that the psychological impact that differs in some stages of the disease were more traumatic than others. These traumas had an impact on their ability to cope with the disease and treatment required. The following are some of the excerpts from some patients:

“This disease is a challenge which I do not wish for anybody because, if you do not encourage yourself you will die, I attempted suicide but did not succeed” (Participant 2).

“I cry always, looking at the tablets I take every day” I always ask myself many questions, I am not a happy person” (Participant 4).

“I feel left out, I know I am not part of my age group, I feel bad about that (crying)” (Participant 7).

“I need no one to tell me I am fine, I am not in fact I am very ill” participant 6.

I am not comfortable at all, I wish I am no more, because life has become very bitter, I think till day break; I do not sleep well” (Participant 5).

” I feel sad about my current state, HIV is even better, than this disease” (Participant 9).

“I sometimes ask myself if it is really me, I am really suffering. This challenge is just too much. I always have trouble night before dialysis, I feel God has forgotten about me. Why should I go through all these problems, I hate to depend on that machine” (Participant 10).

“I feel I am left behind. My mates are in school learning.....I feel useless and hopeless” (Participant 5).

“I need no one to tell me there is hope, I know there is not because almost all the people I know who have this disease are dead, I feel and fear I am the next to die (crying) ” [Participant 1].

“I had to defer my schooling due to this disease” (Participant 8).

Dependence and support was a sub-theme participants expressed. All ten participants lamented that CKD had made them depend on other people in one way or the other. It was identified that at a point in time, one will be totally dependent according to the disease process. These traumas had an impact on their ability to cope with the disease and treatment required. The following are some of the excerpts from some patients:

“I thank God for the lives of my siblings; they have been very supportive” (Participant 3).

“I think I am useless without the dialysis machine” (Participant 9).

“I have become dependent on friends and relatives, some even avoid me because they know no matter what, I will die (Participant 5).

” The media is helping me because; I always listen to words of encouragement from radio and TV (Participant1).

“My co-workers used to help but have given up on me” (participant 10).

“My elder siblings who are outside the country have been supportive but I know God watches over me, He is my dependable father” (Participant 6).

“I feel the dialysis machine controls me and has become part of me because I always assume that the machine is my kidney just that I pay before I urinate” (Participant 7).

“I have become dependent on various medications, I cannot go a day without any, I feel very bad about that” (Participant 8).

“I depend solely on my husband who has gone for loan to see to it that I become well, I am trusting God heals me because, He is the great physician” (Participant 3).

“I depend on pastors, have been to Nigeria for Prophet TB

Joshua's water and I am believing in God's own time, he will heal me" (Participant 2).

Sexual challenge was the third subtheme. Four of the male participants and two women indicated that CKD had affected their sexual life rendering them to have low or no libido. They all added that CKD had diminished their desire for sex in one way or the other. These challenges had various impact on their ability to cope with the disease and treatment required. The following are some of the excerpts from some patients:

"My sexual life has been affected by haemodialysis, I am not able to have sex as I used to. My wife seems not worried, but I am"
(Participant 10).

"My marriage has not been stable since I started taking these medication, this disease has really worried me because my wife is young, I am afraid someone may win her" (Participant 9)

"I do not have the desire for sex any longer but my problem is who to satisfy my husband sexually" (Participant 2).

"I do not think I am being able to satisfy my husband sexually, the treatment has decreased my sexual activity" (participant 3).

"The desire to have sex is always there, but I am not able to perform well" (Participant 1).

“My erections are not normal as I want it to be, I feel bad about that because I fear my wife may be worried. My problem is that, everything about sex is out of memory now, I do not know why”
(Participant 9).

“I am not able to have sex any longer; I know I am disturbing my husband” (Participant 7).

“With this disease, there is nothing like desire for sex, it won’t even come in mind” (Participant 8).

Negative feelings were the fourth challenge and sub theme. All participants indicated that once a while they have negative thought. They all added that the challenges associated with CKD had diminished their entire life. They added that the challenges had various impact on their individual lives. Depression was a common psychological response experienced by all of the participants. Participants spoke of a variety of losses and treatment burdens experienced. The following quote described a loss of freedom.

“I felt like I have no control over my own body, my kidneys are rotten” (Participant 9)

“I cannot go out alone, unless someone goes with me” (Participant 7)

The majority of the participants expressed feelings of depression as a result of reduced quality of life. While some spoke of the fact that they cannot take in

normal diet, others spoke of the fluid restrictions. The following are some of the lamentations:

“The difficult lifestyle is my major challenge. All the food I love to eat are what I am told not, to drink small amount of water a day, and it is really difficult” (Participant 7).

“What really depresses me is the number of drugs that I take every day, the amount and the financial burden on my family” (Participant 3).

“When I think of other things I probably would have been doing now that I am unable to do because of this disease, I feel all hope is lost, will be a dependent till I die” (crying) (Participant 5).

“At times I feel very depressed” (Participant 2).

“I am too young and innocent to have this disease” (participant 4)

A sense of hopelessness was also expressed as a challenge associated with CKD. They added that the state of hopelessness rises most especially when complications arise. They further added that the challenges had various impact on their individual lives. The following quote described a loss of freedom.

“Not even a single call from a friend to check on me..... Oh, this life..... (Shaking his head) (Participant 6)

“I have been doing this dialysis for years now, and I wonder, am I

going to get a transplant? I am thinking if I can really do dialysis for 5 or 10 years” (Participant 9).

“I am afraid of the complications associated with CKD, I feel I will not survive when I experience one because I know myself
“(Participant 1).

Death, thoughts about dying and death featured in my interviews. The participants added that the state of hopelessness rises especially when complications arises. They further added that the thought of they dying had various impact on their individual lives. The following excerpt described a loss of freedom:

“Having this renal failure disease is so bad, I used to see people in the unit and few weeks later they are dead” (Participant 10).

“It is a bad feeling when all your mates are healthy and moving forward and you are not” (Participant 8).

” As head of my family, look at how I look, I am not well. My son once asked me what the main problem was and I was so down, I feel when I die things will be okay because I am always on admission, all the staff know me, I do not feel comfortable” (Participant 1).

Coping responses, faith, and religion was the fifth sub-theme. All participants expressed faith as a means of coping and adjusting to CKD. Some described how their faith linked them to a religious community that offered some

support. Many said their faith enabled them to keep an existential perspective over their condition. The participants talked about faith as having a protective effect:

“I will say my religion and strong faith in the Almighty God has probably stopped me committing suicide” (Participant 8).

“... I have seen my faith as a way of supporting the reality of this condition, rather than blaming God, others and myself for having it” (Participant 9).

Many participants also discussed how religious beliefs helped them to cope with their situation. This type of reflection appeared to help some patients focus on the bigger picture.

“Well, there is a God, without Him, maybe I would not have even been here. I could have been dead. So even though I am here in this chair he is still working with me, He is still there.... I think if you have faith, it all makes sense; it fits into some sort of pattern” (Participant 8).

“If you do not have any faith at all, I suppose it must be very frustrating. But if you have a feeling that it is all part of a big plan, then you get on with it I think...” (Participant 4).

“I depend on pastors, have been to Nigeria for Prophet TB Joshua’s water and I am believing God for healing” (Participant

2).

“I feel so depressed about this disease, but I am trusting God for healing” (Participant 5).

“This disease has really increased my faith in Christ Jesus. I know God will heal me. It is just a matter of time” (Participant 2).

Theme Three: Financial Challenges Associated with CKD

All participants stated that the disease is associated with financial challenges. It was added that the CKD had made them to depend on other people in one way or the other. It was noted that at a point in time, one may need financial support no matter what, especially when dialysis is ongoing. These were some of their lamentations:

“My family cannot boast of property because, all has been sold to get a transplant done but to no avail” (Participant 9).

“I do not have any property due to this challenge” (Participant 1).

“I feel the financial burden on my children is just too much” (Participant 2).

“The laboratory investigations are too expensive as well as the drugs, I had to sell my land at a cheaper rate” (Participant 3).

“This disease is very stressful and expensive to manage I spend twice my salary in two weeks” (Participant 10).

“I feel I am a burden because I cannot work to repay the money involved in the treatment” (Participant 4).

“My husband has gone for loan, and looking at the situation, the money is even not enough because the drugs and investigations are just too expensive because of that, I sometimes omit some of the drugs to save money” (Participant 7).

“The NHIS does not support enough, everything about this disease is expensive, the cost involved in travelling from my house to the hospital, food to eat, drugs, laboratory investigations and above all dialysis” (Participant 8).

“I owe a lot of people and I do not think I can pay back because I do not have any one to support me financially again since all the people around me have given up” (Participant 8).

“I wish I could pay my parent and siblings for their financial support but I cannot. Everything about CKD is expensive” (Participant 6).

“My parents are really struggling to assist me to survive but, it is not easy. We have sold every property in the house” (Participant 5).

Theme four: Impact of CKD on social life

A majority of the participants (nine out of ten) stated that the disease has affected their social life. They indicated how CKD has affected their social lives as individuals. All participants spoke about different reasons why CKD has affected their social lives as compared to the pre trajectory phase. The following are some of the lamentations:

“I am not able to attend social functions (such as funerals, parties, church services) as I previously do, “I personally do not feel comfortable going out any longer because I have observed most people stare at me and give the same answer over and over again”

(Participant 3)

“I do not go out because friends will question why I am not drinking any beverage” (Participant 4).

“I do not want a situation whereby I will be tired on least exertion in public so I do not go anywhere. Some friends’ visit of which I hate because some people are inquisitive and want to ask so many questions” (Participant 10).

“I cannot continue education because of this challenge” (Participants 5 and 7).

“I am an outgoing person, but due to the dizziness associated with this disease, I am not able to go out neither am I able to attend

meetings, which is really affecting me as a member of dressmakers' association” (Participant 2).

“I do not attend choir practice and church because of this challenge” (Participant 1).

“As a camera man and head of my family, due to vision problems associated with CKD, I have stopped working” (Participant 9).

“I do not want people to see me due to the disease, because of that I do not go anywhere. I wish I could go out but I don't” (Participants 6 and 8).

Theme Five: Physical Impact of CKD

All participants spoke about different physical impacts of CKD on their lives. All of the ten participants indicated that physical symptoms such as weakness, loss of appetite, general bodily pains, dizziness and breathlessness were experienced. The majority of the participants stressed that they encountered many problems, such as sleep disturbances, fluid, and diet restrictions. All the 10 patients indicated that they had problems with food and fluid restrictions. This finding is in line with a study carried out by Mok and Tam (2001) in Hong Kong which reported that haemodialysis patients experience fluid and food restrictions as stressors. The following are some of the outcome of the interviews:

“Once a while, I experience severe joint pains. I feel dizzy especially after dialysis” (Participant 9).

“I feel weak mostly” (participant 1). “I feel sleepy always and as a teacher, I am not able to teach, a student once asked if I am okay that made me very sad because I realized I was very sick and the outside world has observed that” (Participant 10).

“I mostly experience general weakness. I feel so weak that I cannot even carry my own baby. When I make an attempt to do so, I feel as though I am about falling” (Participant 6).

“I often lose appetite and sometimes have to force myself to eat due to the restrictions. I mostly experience nausea, and do not have appetite for food especially when urea high” (Participant 7).

While some spoke of fatigue and decreased energy levels, others spoke of change in physical appearance having a significant impact on their lives. The following quote illustrates how CKD-related fatigue has compromised social interactions and family life.

“Currently, I cannot do what I used to do any longer. Because I do not have the energy anymore and I get really tired as well. Before this illness I used to meet with my friend and have a drink or come home quite late. But now I do not have that energy to visit friends” (Participant 7).

“The need to have a permanent internal fistula to facilitate treatment is a burden; it undermines body image and self-esteem

everyone who sees it ask a question” (Participant 8).

“It is uncomfortable displaying fistula and I always need to disguise it under clothing even when the weather is hot” (Participant 9).

With a sad facial expression, one lamented:

“My physical appearance has changed, I look bigger than previous, people hardly recognize me,” (Participant 5).

“I hate how I look, because I have really changed, my feet are swollen, my face has changed as well as every part of my body.”(Participant 2).

“My skin has become dark, unable to walk fast as I used to and becomes tired easily all because of this disease” (Participant 3).

“My body has changed, I easily become tired on least exertion, I was not like this” (Participant 4).

“I do not see well, sometimes, I feel I will die soon” (Participant 8).

“I do not have a problem with it because I am aware that other people think about the fistula” (participant 10).

“I became fat as a result of CKD. I was always really slim, always fit, and healthy, I wore everything that was nice then I put on

weight. And I am now walking around in clothes I cannot identify myself in” (Participant 7).

Theme Six: Impact on Activities of Daily Living (ADL)

Impact on activities of daily living was the sixth theme and a challenge faced by clients with CKD. Participants spoke about different impacts of CKD on ADL. Participants indicated that the impact of CKD had affected their various ADL. The following were gained from the interviews:

“I am a dressmaker and I am not able to sew enough dresses as I used to hence, I do not get much money, this is the period of my life that I need money most” (Participant2).

“I cannot study because I feel sleepy almost all day; My GPA is affected” (Participants 5 and 7).

“I cannot join other teachers who are fit to do extra classes, because I am always tired. “To give up employment was another source of stress because dialysis three or four hours a session, three days a week for dialysis and my district director did not understand me. It is a challenge” (Participant 10).

“I cannot perform normal home duties as I used to, I feel I have become lazy” (Participant 4).

“I had to stop schooling because of this disease. I should have been in tertiary by now but, look at me here.....I wonder if I can learn, I

am always thinking about dialysis and when all will be over the physical symptoms of CKD also affect employment. As we talk, if I go out to look for a job, I am ignored because I need days to attend to the hospital of time off work.” (Participant 6).

“I was a regular member in church but due to this disease, I cannot act in church as I used to” (Participant 8).

“I cannot sell I used to because no one buys from me I look ill” (Participant 3).

“I cannot take good pictures also, I do not get contract again because of my sickness” (Participant 9).

“Sometimes I become too weak and worried that I am bathed by my wife” (Participant 1).

Theme Seven: Availability of Social Support System.

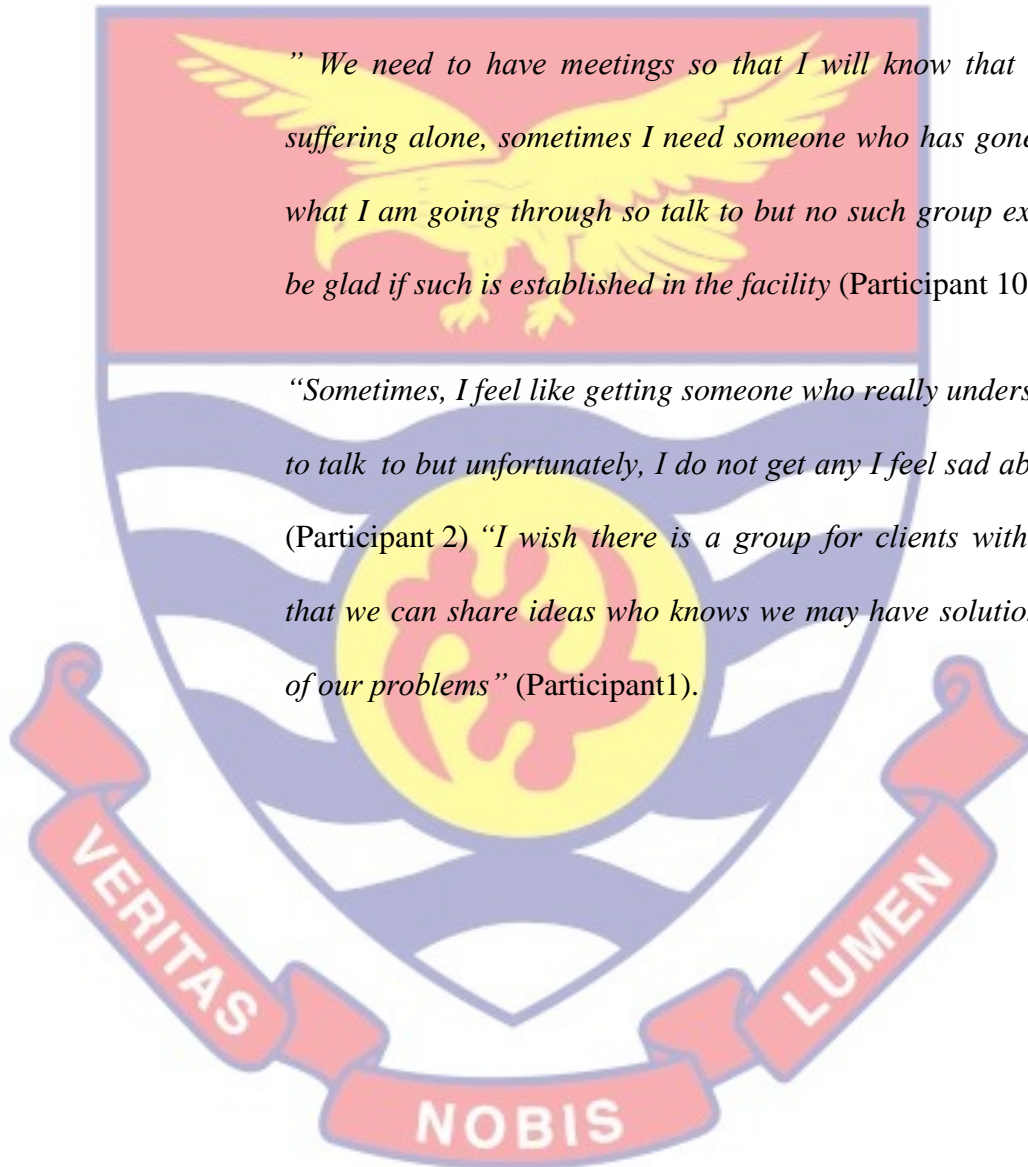
Participants spoke of the view that they were often in need of additional help after they left the hospital. The following statement indicated that there was a significant need for better partnership between health and social support in order to assist clients in the best possible way.

“I think that social support system is missing; the hospital can setup something like a support system in a form of group for us which can make an easier route for us all, we will all benefit from that” (Participant 7).

“The hospital must organize a general meeting in a form of a group so that we can find comfort among ourselves, I am anticipating something like this will benefit us since we all suffer individually” (Participant 9).

” We need to have meetings so that I will know that I am not suffering alone, sometimes I need someone who has gone through what I am going through so talk to but no such group exist, I will be glad if such is established in the facility (Participant 10) .

“Sometimes, I feel like getting someone who really understands me to talk to but unfortunately, I do not get any I feel sad about that” (Participant 2) “I wish there is a group for clients with CKD so that we can share ideas who knows we may have solution to most of our problems” (Participant1).



Discussion

The findings of the study suggest that a majority of the participants had limited knowledge on CKD. Plantinga et al. (2010) explained that patient level of CKD knowledge includes general knowledge of CKD, its risk factors, and consequences and understanding of individual risk and CKD status. Thomas et al. (2008) define CKD as the presence of kidney damage, manifested by abnormal albumin excretion or decreased kidney function, quantified by measured or estimated GFR that persists for more than three months. This suggests that the participant had an idea what CKD is but not the complications and treatment available. This finding is also in agreement with Wright, Wallston, Elasy, Ikizlerand & Cavanaugh (2010) who conducted a research on development and results of a kidney knowledge survey given to patients with CKD. According to the research, participants had poor knowledge. There is therefore the need for nurses and medical officers to give recurrent education to clients on the overview of CKD so that clients will be updated on issues bothering them to prevent complications and CKD progression leading to mortality.

The data from the study also identified that living with a chronic illness such as CKD can greatly compromise the value systems that patients hold relating to what gives their lives quality and to what they attribute meaning in their lives. It is clear from the participants that CKD has affected them mentally and emotionally and has undermined every area of their lives and this findings in agreement with the trajectory theory which holds that every chronic disease affects the patient emotionally and psychologically. This study has been valuable

in illustrating the ways in which CKD destabilizes the quality of life. Vecchio et al. (2012) argue that psychological impact is the effect caused by environment and or biological factors on individual social and or psychological aspect. This is in support with Vecchio et al. (2012) who demonstrated that people with CKD experience markedly poorer quality of life as compared to the general population. Some participants with psychological burden such as considerable impact on quality of life also spoke about experiencing grief for the loss of their kidney. Participants with psychological distress can be addressed by health psychologists, with an aim to improving coping mechanisms and enhancing quality of life. This could be done by establishing services or multidisciplinary care approaches which incorporate a holistic framework. In cases where participants with psychological issues are not addressed, the client would not comply with the management or commit suicide since one may assume life is not worth it.

Stresses associated with CKD are discussed by all participants in the findings. This is in support with work done by Cukor et al. (2007). According to Cukor et al. (2007), stress is a concomitant of chronic illness and its treatment, and may have meaningful influences on psychological or medical outcomes. To add to the above, all the eight phases of the trajectory theory indicate a type of stress. All of the participants in this study reported various stressful situations as a result of CKD, supporting the fact that every chronic disease really affects the affected person emotionally, resulting in stressful situations. If clients continuously become stressed up due to the challenges associated with CKD, there is the like hood that they may give up on medical management and may fall

in the hands of people who cannot assist in any way as far as managing CKD is concern. Management must ensure that clients with stressful situations must be addressed by health psychologists, with an aim to improving coping mechanisms and enhancing quality of life. This could be done by multidisciplinary care approaches which incorporate a holistic framework.

Morton et al. (2010) conducted a qualitative study on patient's views about treatment of Stage 5 CKD in Australia. Freedom, convenience, self-care, effectiveness, and simplicity were commonly cited positive characteristics, whereas confinement, risk, family burden, pain, and time commitment were found as negative characteristics associated with managing CKD. The above research is similar to the work done since all the clients reported negative feelings such as pain, treatment burden, loss of control, resulting in depression and effect of CKD on their social life, limiting the majority to be confined in their various homes. Negative emotions can be described as any feeling which causes an individual to be miserable and sad. These emotions make an individual to dislike him/herself and others, and take away their confidence. The clinical psychologist as well as a religious person must be invited to talk to the client according to his or her faith to build up their hope and trust accordingly. In cases where nothing is done about such issue, clients may give up on management or may end up with the wrong people who may not be of help to them.

Of all the five men who were interviewed, four of them spoke of sexual challenges with an exception of one who was not sexually active. A majority of men with CKD reported having erectile dysfunction. Erectile dysfunction in CKD

is multi factorial and includes decreased arterial blood flow, venous leakage due to shunts, altered penile smooth muscle function, hormonal disturbances, side effect of medications, and neurogenic dysfunction. The etiological factors are often classified into organic and psychological causes; however, the two factors are interwoven (Rathi & Ramachandran, 2012). Suzuki et al. (2014) defined erectile dysfunction (ED) as an inability to attain and/or maintain penile erection sufficient for satisfactory sexual performance. Suzuki et al. (2014) report concluded that erectile dysfunction is a very common disease in CKD patients, which is in support with this research and it is a multi-factorial disease whose causes include hormonal, metabolic, nutritional, and psychological factors. Issues of erectile challenges can cause additional psychological problems and or breakdown of relationship. Testosterone replacement therapy together may be useful, particularly for CKD patients with hypogonadism. Renal transplantation may restore erectile function, particularly for young patients. Sufficient dialysis and adequate nutritional intake are necessary to improve the general condition of uremic patients. In addition, control of anemia using Epo and control of secondary hyperparathyroidism using phosphate binders, an active form of vitamin D and/or cinacalcet hydrochloride are required. Zinc supplementation may be necessary when zinc deficiency is suspected. If a psychological problem is suspected, psychotherapy and/or antidepressant medications may be necessary. Other options for the treatment of erectile dysfunction include injecting prostaglandin E1 into the shaft of the penis, vacuum constriction devices and constriction bands, and penile prostheses. These treatments are beyond the scope of this review, and have

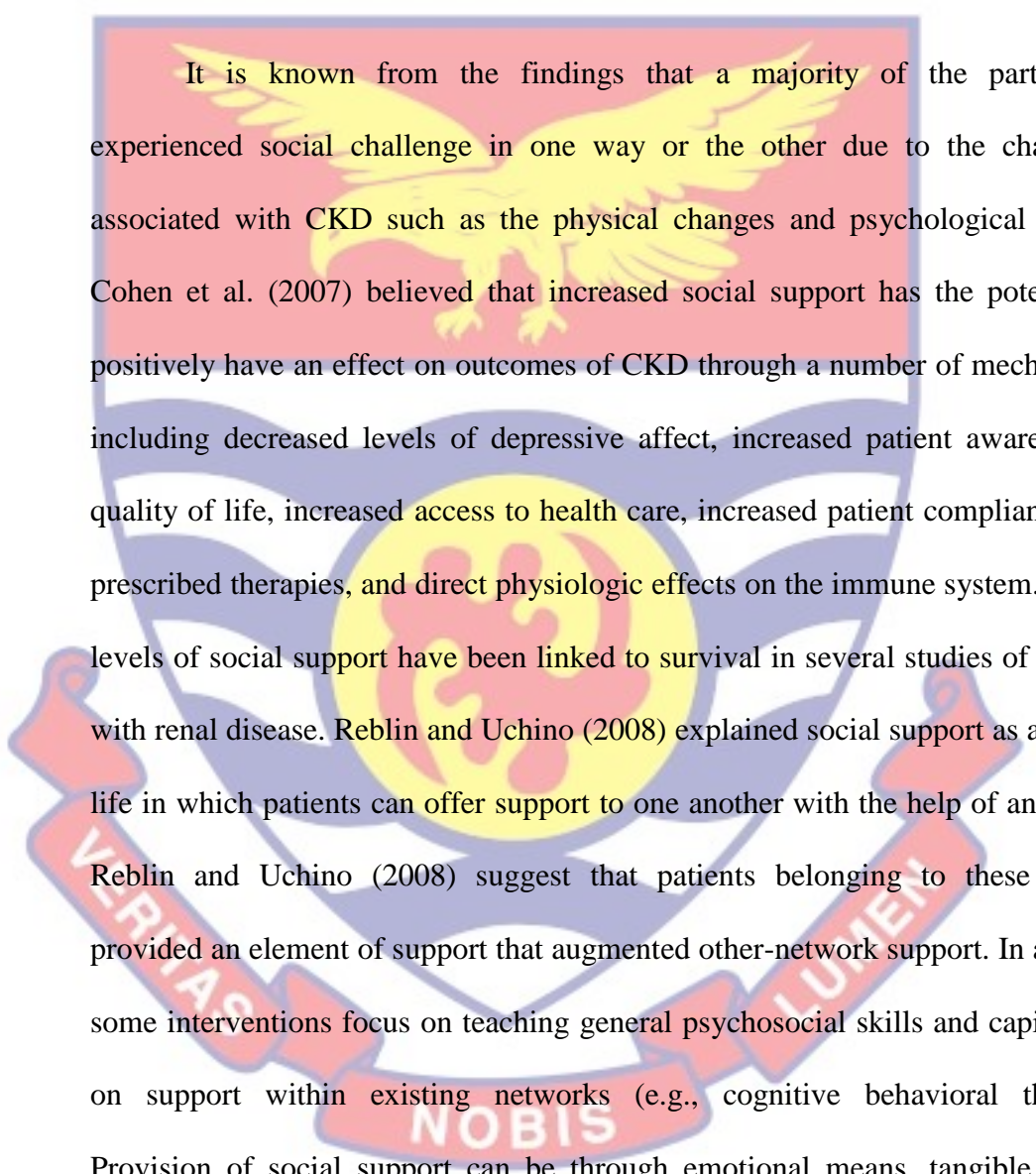
not been discussed in detail.

All participants in the study experienced physical impact of CKD in one way or the other. Thomas et al. (2008) explained physical impact of CKD as negative changes that take place in the physiology of an individual battling with CKD. This corresponds to the downwards phase of the trajectory theory where the affected person exhibits progressive deterioration in mental and physical status such as hypertensive encephalopathy, ureamic gastritis, uremic anaemias, generalized oedma.

Physical effect vary taking into consideration the stage of the disease. Taking the trajectory theory into consideration, one will note that each phase of the phases gives different physical challenge. Physical challenges associated with CKD as expressed by the participants is in agreement with Thomas et al. (2008) who found that CKD client's experience various unpleasant physical effects such as anaemia which results in dizziness. Physical signs and symptoms that can be treated must be treated with immediate effect such as through the administration of erythropoetin to clients to increase their heamoglobin level. The management must also recognize complication as early as possible to avoid mortalities. Clients must also be educated on the need for drug compliance because some of these physical signs and symptoms occur as a result of non-compliance.

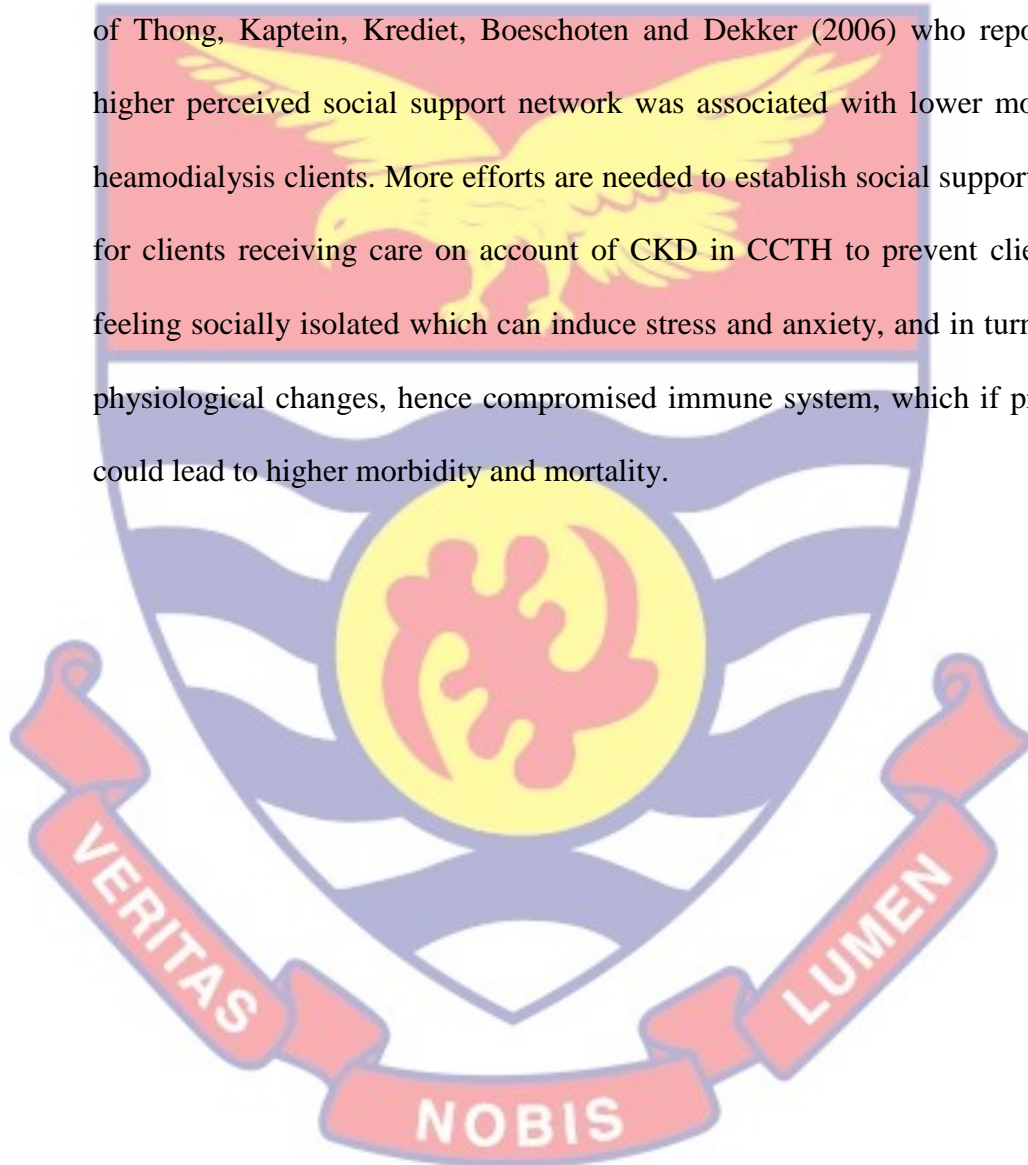
Evidence exists that all participants faced financial challenges in one way or the other. This is in accordance with Essue et al. (2013) who conducted a research on how clients are managed with the cost of CKD, it was found that a majority of

clients go through financial difficulties. This challenge was mentioned by participants who participated in this study as well indicating that financial challenge is a problem at CCTH. The hospital must set up renal fund to support client in their care so to reduce financial burden on the client they manage.

The logo of the University of Cape Coast is a watermark in the background. It features a shield with a yellow eagle at the top, a central yellow circle with a red figure, and a red banner at the bottom with the Latin motto "VERITAS LIBERABIT VOS A NOBIS".

It is known from the findings that a majority of the participants experienced social challenge in one way or the other due to the challenges associated with CKD such as the physical changes and psychological trauma. Cohen et al. (2007) believed that increased social support has the potential to positively have an effect on outcomes of CKD through a number of mechanisms, including decreased levels of depressive affect, increased patient awareness of quality of life, increased access to health care, increased patient compliance with prescribed therapies, and direct physiologic effects on the immune system. Higher levels of social support have been linked to survival in several studies of patients with renal disease. Reblin and Uchino (2008) explained social support as a way of life in which patients can offer support to one another with the help of an expect. Reblin and Uchino (2008) suggest that patients belonging to these groups provided an element of support that augmented other-network support. In addition some interventions focus on teaching general psychosocial skills and capitalizing on support within existing networks (e.g., cognitive behavioral therapy). Provision of social support can be through emotional means, tangible efforts, information sharing or advice giving. Belonging to a social support network improves quality of life and peer relationships, and decreases loneliness and the perceived impact of the disease. Feeling socially isolated can induce stress and

anxiety, which in turn can produce physiological changes, such as a compromised immune system, which if prolonged, could lead to higher morbidity and mortality. The results suggest an increased mortality risk amongst patients who perceive that they have insufficient supportive interactions. The results are consistent with that of Thong, Kaptein, Krediet, Boeschoten and Dekker (2006) who reported that higher perceived social support network was associated with lower mortality in hemodialysis clients. More efforts are needed to establish social support network for clients receiving care on account of CKD in CCTH to prevent clients from feeling socially isolated which can induce stress and anxiety, and in turn produce physiological changes, hence compromised immune system, which if prolonged, could lead to higher morbidity and mortality.



CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter presents the summary, conclusions, and recommendations of the study. The purpose of the summary section is to briefly describe the processes used in conducting this research. Based on study results and discussion, conclusions are drawn. The recommendation section presents suggestions by the researcher on the improvements needed in the experience of people living with CKD.

Summary

This research sought to explore the lived experiences of people with CKD in CCTH. The specific objectives were:

1. To investigate the knowledge of clients with CKD on signs, symptoms and complications in CCTH.
2. To investigate the psychosocial experiences of clients diagnosed with CKD.
3. To investigate the challenges facing clients with CKD.
4. To explore the impact of CKD on the lives of clients in CCTH.
5. To investigate the support network for clients diagnosed with CKD.

The Cape Coast Teaching Hospital was purposive sampled for the study. Approval for the study was received from the Institutional Review Board of the University of Cape Coast. Again, pre-test of work for validity was done at the Cape Coast Metropolitan Hospital. Here again, the participants were purposively selected. Written informed consent was also obtained from participants. The data was obtained through an administration of semi-structured interview until saturation was achieved. The results were analysed through content analysis. Results were presented, using descriptive statistics and displayed with tables. Seven thematic categories were identified and discussed. Key findings of the study were as follows:

Two of respondents were between ages 15 to 24 years. Three of the respondents were between 25 to 34 years. Another three of the respondents ranged between ages 35 to 44 years while two were aged between 45 to 54 years. Of the ten clients interviewed, five of them were on dialysis, while five were not. None of the respondents had a transplant done. Also, half of the participants interviewed had been on treatment for a year. Two had been on treatment for the past two years while another two had been on treatment for three years. Only one had been on treatment since four years. Five of the participants were males and the other five, females. Three were single while seven were married. Five of the participants were from Western Region while three were from Central Region. Two participants were from the Ashanti Region. Two of the participants had completed University. Three of the participants had completed college. Two had completed and SHS (Senior High School), while one participant had completed

middle school. One had primary education and one had no formal education. Seven themes were derived from interview: knowledge on CKD, psychological, and emotional challenges associated with CKD, impact of CKD on social life, physical impact of CKD on participant, impact on Activities of Daily Living (ADL), availability of social support system and financial challenges associated with CKD.

Conclusion

This study provides empirical evidence of significant changes in the illness representation in clients with CKD. The findings from the study indicate that living with a chronic illness such as CKD can greatly compromise the “value systems” that patients hold relating to what gives their lives quality and to what they attribute meaning in their lives. It is clear from those who participated in this study that CKD undermines every area of a patient’s life. Also, the participant’s perception to their illness indicates they realize that CKD is incurable. Thus, most of them proactively changed their lifestyle and adopted balancing therapies to maintain good health. They also prepared themselves to face future treatment. Qualitative data from this study found that current CKD patient illness representation and coping patterns differ significantly from those of previous study (Wu et al. 2015). In earlier studies, misconceptions about CKD encouraged patients to conceal or deny the disease, which made the coping process difficult. Fortunately, public attitudes towards kidney disease have changed in Ghana. The shift of the illness trajectory from concealment to self-adjustment should contribute to the effort of health workers. Findings in this study indicate that

education can correct cultural-based misconceptions about CKD and influence coping behaviors. Although participants clearly understood the necessity of eventual treatment, they still felt uneasy about the consequences of having CKD. Health workers should thus raise their sensitivity to patients' complex feelings of uncertainty and distress caused by the prospect of CKD and the struggle to regain normalcy in daily life. Nurses may leverage this desire for normalcy to encourage clients diagnosed with CKD to reflect on the successful coping-related changes they have made in their life and lifestyle as a way of finding meaning in living with the disease. This positive perspective may further help motivate patients maintain their new healthy lifestyle. Nurses should take this opportunity to help clients with CKD integrate recommended regimens into daily life as one way to achieve a new normal life. It has also added to existing data, on the experience of clients with CKD. Additionally, the data from this study has created an evidence, based upon which future health psychology services can be built within hospitals nationwide to address psychological needs of the renal population.

Recommendations

Recommendations are discussed under the following sub-headings: nursing practice, nursing education, nursing administration and nursing research.

Nursing practice

Unit heads of renal and the medical wards should organize frequent internal workshops on renal care for nurses and medical officers so that recurrent education to clients on the overview of CKD can be done to update clients and address issues bothering them, to prevent complications and CKD progression. To

add to the above, the management should ensure that public education on CKD is given in order for the general public to report to health facility earlier.

The management of health facilities should have plans of involving psychologist in the care of the clients in their care so that clients with psychological distress can be addressed by health psychologists, with an aim to improving coping mechanisms and enhancing quality of life. This could be done by establishing services or multidisciplinary care approaches which incorporate a holistic framework. The clinical psychologist as well as a religious person must be invited to counsel the clients according to their faith to build up their faith and trust accordingly.

Nursing education

Formal education in renal nursing is necessary in the practice of renal nursing. The universities should introduce renal nursing as a specialist course for nurses so that we can have more renal nurses in Ghana. Orientation in the form of workshops or conferences in care of renal clients must be given to staff members who nurse such clients. Further studies should be conducted to find the incidence and prevalence of CKD among the general population in Ghana.

Nursing administration

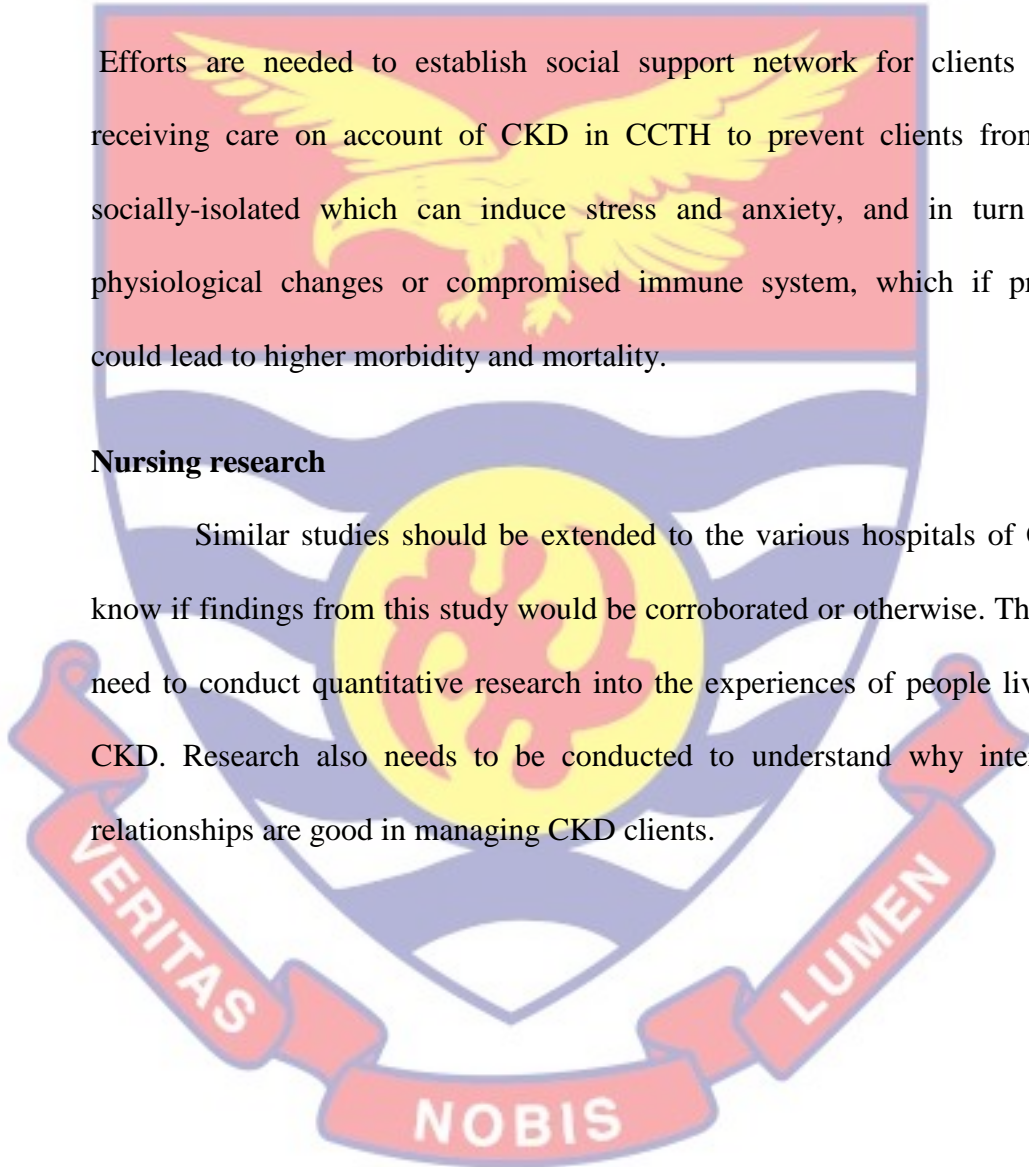
Hospital administration should organize workshops for staff working in the renal unit and other units where renal patients are being treated to improve therapeutic relationship. To add to the above, it will be beneficial if the renal unit gets a fund which will be made known to the general public so that contributions

can be made by the general public to support clients since all participants complained bitterly about the financial challenges being faced. Also, it will be best if government takes away with taxes on renal consumables so that the cost will be reduced or better still renal treatment be made free to all clients.

Efforts are needed to establish social support network for clients who are receiving care on account of CKD in CCTH to prevent clients from feeling socially-isolated which can induce stress and anxiety, and in turn produce physiological changes or compromised immune system, which if prolonged, could lead to higher morbidity and mortality.

Nursing research

Similar studies should be extended to the various hospitals of Ghana to know if findings from this study would be corroborated or otherwise. There is the need to conduct quantitative research into the experiences of people living with CKD. Research also needs to be conducted to understand why interpersonal relationships are good in managing CKD clients.



REFERENCES

- Abdel-Kader, K., Unruh, M. L., & Weisbord, S. D. (2009). Symptom Burden, Depression, and Quality of Life in Chronic and End-Stage Kidney Disease *Clinical Journal of American Society of Nephrology*, 4 (6), 1057-1064.
- Abu-Aisha, H., & Elamin, S. (2010). Peritoneal dialysis in Africa. Peritoneal dialysis International, *Journal of the international Society of Peritoneal dialysis*, 30 (1), 23-8.
- Addo, J., Smeeth L., & Leon, D. A. (2009). Hypertensive target organ damage in Ghanaian civil servants with hypertension. *The Pan African Journal*, 4 (8), 66-72.
- Amerena, P & Wallace, P. (2009). Psychological experiences of renal transplant patients: A qualitative analysis. *Counselling and Psychotherapy Research*, 9 (4), 273-279
- Amoako, Y. A., Laryea, D. O., Bedu-Addo, G., Andoh, H., & Awuku, Y. A. (2014). Clinical and demographic characteristics of chronic kidney disease patients in a tertiary facility in Ghana. *The Pan African Medical Journal*, 4 (18), 274.
- Bamgboye, E.L. (2006). End-stage renal disease in sub-Saharan Africa. *Ethnicity and Disease*, 16 (22), 2-5-9.
- Barsoum, R. S. (2003). End-stage renal disease in North Africa *Kidney International Supplement*, 55 (83), 111-4.

Bello, A. K., Levin, A., Manns, J. B. Feehally, J., Drueke, T., Faruque, L., Hemmelgarn, B. R., Kernahan, C., Mann, J., Klarenbach, S., Remuzzi, G., & Tonelli, M. (2015). Effective CKD Care in European Countries: Challenges and Opportunities for Health Policy. *American Journal of Kidney Disease*. 65 (1), 15-25.

Berns, J. S., Jeffrey, S., Gary, C., Curhan, D., & Sheridan, A. M. (2015). Patient information: Chronic kidney disease (Beyond the Basics) *International Journal of Nephrology and Renovascular Diseases archives*, 5 (2), 151-163.

Bhatti, A. B., Ali, F., & Siddique A. Satti, S.A. (2014). Association between Chronic Kidney Disease and Depression. *Open Journal of Nephrology*, 4 (2), 15-20.

Biruck, Y. (2012). Chronic kidney disease in sub-Saharan Africa: Hypothesis for research demand. *American Journal of Kidney Disease*, 11 (2), 119-120.

Bleyer, A., Berns, J. S., & Sheridan, A.M. (2016). Urine output and residual kidney function in kidney failure. *International Journal of Nephrology and Renovascular Diseases*, 11 (6), 37-503 171-3.

Braun, L. A, Sood, V., Hogue, S., Lieberman, B. & Copley-Merriman, C. (2012). High burden and unmet patient needs in chronic kidney disease *International Journal of Nephrology and Renovascular disease*, 5 (5), 151-163

Bruce, M. A., Beech, B. M., Sims, M., Brown, T. N., Wyatt, S. B., Taylor, H. A., Williams, D. R. & Crook, E. (2010). Social environmental stressors, psychological factors, and kidney disease. *Journal of Investigative Medicine*, 57 (4), 583-9.

Bucharles, S. G. E., Varela, A. M., Barberato, S. A., & Pecoits-Filho, R. O. (2010). Assessment and management of cardiovascular disease in patients with chronic kidney disease *Jornal Brasileiro de Nefrologia*, 32 (1), 18-108

Cape Coast Teaching Hospital. (2014). Annual Performance Review, Cape Coast

Carroll, L. E. (2006). The Stages of Chronic Kidney Disease and the Estimated Glomerular Filtration Rate. *The Journal of Lancaster Hospital*, 4 (2), 19-22.

Chawla, L. S., Eggers, P. W., Star, R. A., & Kimmel, P. L. (2014). Acute Kidney Injury and Chronic Kidney Disease as Interconnected Syndromes: A literature review. *The New England journal of medicine*, 3,371 (1), 58-66.

Chen, S. H., Tsai, Y. F., Sun, C.Y., Wu, I. W., Lee, C. C., & Wu, M. S. (2011). The Impact of Self-management Support on the Progression of Chronic Kidney Disease. A Prospective Randomized Controlled Trial. *Nephrology Dialysis Transplantation*, 26 (11) 3560-6.

Chen, T & Harris, C. D. (2015). Challenges of chronic kidney disease prevention. *The Medical Journal of Australia*, 7203 (5), 209-10.

Chiang, H. H., Livneh, H., Yen, M. L., Tsai-Chung, L & Tsai, T. Y. (2013). Prevalence and correlates of depression among chronic kidney disease patients in Taiwan. *Bio Med Central Nephrology*, 80 (14), 78-102

Chien, W. T., Mui, J. H. C., Cheung, E. F. C & Gray, R. (2015). Effects of motivational interviewing-based adherence therapy for schizophrenia spectrum disorders: a Randomized Controlled Trial. *American Journal of Nephrology*, 14 (16), 2-70.

Christensen, A. J & Ehlers, S. L. (2002). "Psychological factors in end-stage renal disease: an emerging context for behavioral medicine research," *Journal of Consulting and Clinical Psychology*, 70 (3), 712-24.

Coca, S. G., Singanamala, S. & Chirag, R. Parikh, C. R. (2011). Chronic Kidney Disease after Acute Kidney Injury: A Systematic Review and Meta-analysis, *Kidney International*, 81 (5), 442-448.

Cohen, D. J., & Crabtree, B. F. (2008). Evaluating criteria for qualitative research in health care: conversation and recommendation. *Annals of Family Medicine*, 66 (6), 331-339

Cohen, S. (2004). Social Relationships and Health. *Clinical Journal of the American Society of Nephrology*, 59 (6), 676-684

Cohen, S. D., Sharma, T., Acquaviva, K., Peterson, R. A., Patel, S. S & Kimmel, P. L. (2007). Social Support and Chronic Kidney Disease: An Update. *Advances in Chronic Kidney Disease*, 14 (4), 335-44.

Couser, W. G., Remuzzi, G., Mendis, S & Tonelli, M. (2011). The Contribution of Chronic Kidney Disease to the Global Burden of Major Non Communicable Diseases. *Kidney International*, 80 (12), 1258-70.

Crews, D., Greer, R. C., Evans, M. K., Zonderman, A., & Powe, N. R. (2010). Poverty, Race, and CKD in a Racially and Socioeconomically Diverse Urban Population. *American Journal of Kidney Disease*, 55 (6), 992-1000.

Crimmins, E. M., Hayward, M.D., & Seeman, T. E. (2004). Race/Ethnicity, Socioeconomic Status and Health. *Kidney International*, 60 (7), 1156-70.

Cruz, M. C., Andrade, C., Urrutia, M., Draibe, S., Nogueira-Martins, L. A. and Sesso, R. C. (2011) Quality of life in patients with chronic kidney disease Clinics (Sao Paulo), 66 (6), 991–995.

Cukor, D., Peterson, R. A., Cohen, S. D & Kimmel, P. L. (2006). Depression in end-stage renal disease hemodialysis patients. *Nature Clinical Practice Nephrology*, 2 (12), 678-87.

Cukor, D., Scott, D., Cohen, S. D., Rolf, A., Peterson, R. A. & Kimmel, P. L. (2007). Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness. *Journal of the American Society of Nephrology*, 18 (12), 3042-55.

Daneker, B., Kimmel, P. L. Ranich, T., Peterson, R. A. (2001). Depression and marital dissatisfaction in patients with end-stage renal disease and in their spouses. *American Journal of Kidney Disease*, 38 (4), 839-46.

Davis, I. D., Greenbaum, L. A., Gipson, D., Wu, L. L., Sinha, R., Matsuda-Abedini, M., Emancipator, J. L., Lane, J. C., Hodgkins, K., Nailescu, C., Barletta, G. M., Arora, S., Mahan, J. D., & Rosen, C. L. (2012). Prevalence of sleep disturbances in children and adolescents with chronic kidney disease. *Pediatric Nephrology*, 27, (3), 451-9.

Davison, S. N. (2010). End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease. *Clinical Journal of American Society of Nephrology*, 5 (2), 195-204.

Davita Health Center, 2016. Retrieved from www.davita.com

Donfrancesco, C., Palleschi, S., Palmieri, L., Rossi, B., Noce, C., Pannozzo, F., Spoto, B., Tripepi, G., Zoccal, C., & Giampaoli, S. (2013). Estimated Glomerular Filtration Rate, All-cause mortality and cardiovascular Diseases in a low risk population. *Journal of negative result in biomedicine Nephrology*, 10 (13), 71- 5.

Edwards, J.G. (2016). The Formation of Urine. Literature Review. *Journal of American Medical Association. Arch Internal Medicine*, 65 (4), 800-824

Ekart R., Bevc, S., Hojs N., Knehtl, M., Dvoršak B., & Hojs, R. (2015). Albuminuria is Associated with Subendocardial Viability Ratio in Chronic Kidney Disease Patients. *Kidney Blood Press Research*, 40 (6), 565-74.

Ephraim, R .K. D. (2010). Predictive Equations, Oxidative and Metabolic Risk Factors among Ghanaian Patients Presenting With Chronic Kidney Disease. *The Pan African Medical Journal*, 120 (5), 18-27.

Essue, B. M., Wong, G., Chapman, J., Li, Q., & Jan, S. (2013). How are patients managing with the costs of care for chronic kidney disease in Australia? A cross-sectional study. *Journal of negative result in biomedicine Nephrology*, 14 (4), 5-7.

Fadem, S. Z., Walker, D. R., Abbott, G., Friedman, A. L., Goldman, R., Sexton, S., Buettner, K., Robinson, K & Peters, T. G. (2011). Satisfaction with renal replacement therapy and education: the American Association of Kidney Patients survey. *Clinical Journal of American Society of Nephrology*, 6 (3), 605-12.

Fasmer, O. B., Halmøy, A. Oedegaard, K. J., & Haavik J. (2011). Adult attention deficit hyperactivity disorder is associated with migraine headaches. 261 (8), 595-602.

Ferris, M. E., & Mahan, J. D. (2009). Pediatric Chronic Kidney Disease and the Process of Health Care Transition. *Seminars in Nephrology*, 29 (4), 435-44.

Finkelstein, F. O., & Finkelstein, S. H. (2000). Depression in chronic dialysis patients: assessment and treatment. *Nephrology, Dialysis, Transplantation*, 15 (12), 1911-3.

Finnegan-John, J & Thomas, V.J. (2013). The Psychosocial Experience of Patients with End-Stage Renal Disease and Its Impact on Quality of Life: Findings from a Needs Assessment to Shape a Service. *American Journal of Nephrology*, 30 (8), 986-8.

Galea, S. & Vlahov, D. (2005). Urban health: evidence, challenges, and directions. *Annual Review of Public Health*, 26 (12), 341-65.

Gallagher, H., & de Lusignan, S. (2010). Quality-improvement strategies for the management of hypertension in chronic kidney disease in primary care: a systematic review *British Journal of General Practice*, 60 (575), 258-65.

Ghafari, A., Farshid, B. A., Afahari, A. T., Sepehrvand, N., Rikhtegar, E K., Ghasemi, E. K., & Hatami, S. (2010). Sildenafil citrate can improve erectile dysfunction among chronic hemodialysis patients. *Indian Journal of Nephrology*, 20 (3), 142-5.

Ghana News Agency. (2011). Chronic kidney disease on the increase in Ghana. Retrieved from ghananewsagency.org/health/chronic-kidney-disease-on-the-increase-in-ghana-26432ord.

Go, A. S., Chertow, G. M., Fan, D., McCulloch, C. E, & Hsu, C. (2004). Chronic Kidney Disease and the Risks of Death, Cardiovascular Events, and Hospitalization. *The New England journal of medicine*, 35 (1), 1296-1305.

Gupta, N. E. (2006). Pulling the Plug on Dialysis Patients. *Health Service Research*, 22 (3), 24-31.

Gutierrz, O. M. (2013). Sodium and phosphorus-based food additives: persistent but surmountable hurdles in the management of nutrition in chronic kidney disease. *Advances in Chronic Kidney Disease*, 20 (2), 150-6.

Hansson, J. H., & Watnick, S. (2016). Update on Peritoneal Dialysis: Core Curriculum. *American journal of kidney disease*, 67 (1), 151-64.

Hashiguchi, L. (2015). Visualizing the rise of chronic kidney disease worldwide. 7th edition. Mosby Elsevier, St. Louis.

Hasnain-Wynia, R., & Baker, D. W. (2006). Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions. *Health Service Research*, 41(41), 1501-18

Hawkins, D. N., & Booth, A. (2005). Unhappily Ever After: Effects of Long-Term, Low-Quality Marriages on Well-Being. *Social Factors*, 84 (1), 451-471.

Himmelfarb, J. (2005). Hemodialysis Complications. *American Journal of Kidney Diseases*, 45 (6), 1122-31.

Hingorani, S. & Ingelfinger, J. R. (2016). Renal Complications of Hematopoietic-Cell Transplantation. *New England Journal of Medicine*, 37 (4), 2256-2267.

Holley, J. L. (2013). General Medical Care of the Dialysis Patient: Core Curriculum University of Illinois, Urbana-Champaign and Carle Physician Group, Urbana, IL *American Journal of Kidney Disease*, 61 (1), 171-83.

Ikizler, T.A. (2014). Optimal Nutrition in Hemodialysis Patients. *Advance Chronic Kidney Disease*, 20 (2), 181–189.

Ishani, A., Xue, J. L., Himmelfarb, J., Eggers, P. W., Kimmel, P. L., Molitoris, B. A. & Collins, A. J. (2009). Acute Kidney Injury Increases Risk of ESRD among Elderly. *Journal of American Society of Nephrology*, 20 (1), 223–228.

Jeanfreau, S. G. (2010). Appraising qualitative research in health education: Guidelines for public health educators. *Health Promotion Practice*, 11 (5), 612-617.

Jha, V., Garcia-Garcia, G., Iseki, K., Li, Z., Naicker, S., Platter, B., Saran, R., Wang, A.Y., & Yang, C.W. (2013). *Chronic kidney disease: global dimension and perspectives*, 382 (9888), 260-72.

John, M. (2014). Qualitative Research. Cape Coast: University of Cape Coast.

Kerr, M., Bray, B., Medcalf, J., O'Donoghue, D. J., & Matthews, B. (2012). Estimating the financial cost of chronic kidney disease to the NHS in England. *Nephrology Dialysis Transplantation*, 27 (3), 73-80.

Kimmel, P. L. (2001). Psychosocial factors in dialysis patients. *Kidney International*, 59 (4), 1599-613.

Kovesdy, C. P., Sterns, R. H. & Forman, J. P. (2016). Pathogenesis, consequences, and treatment of metabolic acidosis in chronic kidney disease. *American Journal of Kidney Disease*, 61 (2), 161-73.

Krantz, D. S., & McCeney, M. K. (2002). Effects of Psychological and Social Factors on Organic Disease: A Critical Assessment of Research on Coronary Heart Disease. *Annual Review Psychology*, 53 (3), 341-69.

Krzesinski, J. M., Sumaili, K. E., & Cohen, E., (2006). How to tackle the avalanche of chronic kidney disease in sub-Saharan Africa: the situation in the Democratic Republic of Congo as an example. *Nephrology. Dialysis. Transplantation*, 22 (2), 332-335.

Kurts, C., Panzer, U., Anders, H. J., & Rees, A. J. (2013). The immune system and kidney disease: basic concepts and clinical implications. *Nature Reviews. Immunology*, 13 (10), 738-53.

Lacson, E & Brunelli, S.M. (2011) Hemodialysis Treatment Time: A Fresh Perspective. *Clinical Journal of the American Society of Nephrology*, 6 (10) 2522-2530.

Lai, C. F., Tsai, H. B., Hsu, S. H., Chiang C. K., Huang, J. W., & Huang, S. J., (2013). Withdrawal from long-term hemodialysis in patients with end-stage renal disease in Taiwan. *Journal of the Formosan Medical Association, 112* (10), 589-99.

Lehma, E. V. (2015). Anemia of Chronic Disease and Renal Failure. *Clinical Journal of the American Society of Nephrology, 6* (10), 2522-2530

Levey, A.S., Inker, L. A., Curhan, G. C. & Forman, J.P. (2016). Definition and staging of chronic kidney disease in adults. *American Journal of Kidney Disease, 35* (1), 16-29.

Levin, A., Hemmelgarn, B., Culeton, B., Tobe, S., McFarlane, P., Ruzicka, M., Burns, K., Manns, B., White, C., Madore, F., Moist, L., Klarenbach, S., Barrett, B., Foley, R., Jindal, K., Senior, P., Pannu, N., Shurraw, S., Akbari, A., Cohn, A., Reslerova, M., Deved, V., Mendelssohn, D., Nesrallah, G., Kappel, J., & Tonelli, M. (2008). Guidelines for the management of chronic kidney disease. *Canadian Society of Nephrology, 179* (11), 1154-62.

Lights, V & Boskey, E. (2015). Chronic Kidney Disease. *Nephrology Dialysis Transplantation, 26* (1), 116-21.

Lo Biondo-Wood, G. & Haber, J. (2010). Nursing Research: Methods and Critical Appraisal for Evidence- Based Practice, 7th edition. Mosby Elsevier, St. Louis.

Mandal, A. K. (2015). Pathogenesis and Prevention of Progression of Chronic Kidney Disease. *Open Journal of Internal Medicine*, 5 (3), 23-27.

Mansour, M. A .M, Youssef, H. A. M., Salameh, T. N., and Yaseen, R. W. (2014). Impact of Education Program on Protein Balance among Hemodialysis Patient. *World Journal of Medical Sciences*, 11 (1), 69-77,

Mason, M. (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Academic Journal*, 11 (3), 1

Massengill, S. F. & Ferris, M. (2014). Chronic Kidney Disease in Children and Adolescents. *Pediatrics in Review*, 35 (1), 16-29.

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McCorkle, R., & Pasacreta, J. V. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control. Journal of the Moffitt Cancer Center*, 8 (1), 36-45.

McMillan, J. I. (2016). Merck Manual Professional Version, Chronic Kidney Disease (Chronic Renal Failure; CKD) New Jersey, USA: New Jersey Press

Morrison, J. (2015) Dialysis. Florida, USA: West Florida Press.

Morrow, A. (2014). Making the Decision to Stop Dialysis: Dialysis at the End of Life. Florida, USA: Pensacola Press.

Morton, R. L., Devitt, J., Howard, K., Anderson, K., Snelling, P., & Cass, A. (2010). Patient Views About Treatment of Stage 5 CKD: A Qualitative Analysis of Semi structured Interviews. *American Journal of Kidney Disease*, 55 (3), 431-40.

Motedayen, Z., Nehrir, B., Tayebi, A., Ebadi, A., & Einollahi, B. (2014). The Effect of the Physical and Mental Exercises During Hemodialysis on Fatigue: A Controlled Clinical Trial. *Clinical Journal of American Society of Nephrology*, 6 (4), 14686.

Mujais, S. K., Story, K., Brouillette, J., Takano, T., Soroka, S., Franek, C., Mendelsohn, D., & Finkelstein, F. O. (2009). Health-related Quality of Life in CKD Patients: Correlates and Evolution over Time. *Clinical Journal of American Society of Nephrology*, 4 (8), 1293-301.

Naicker, S. (2013). End-stage renal disease in Sub-Saharan Africa. *Ethnic Disease*, 19 (11), 1-13-5.

National Kidney Foundation of Ghana. (2016). Chronic Kidney Disease on an increase in Ghana. Retrieved from ghananewsagency.org National Kidney Foundation, 2016

Nicola, L. D., Chiodini, P., Zoccali, C., Borrelli, S., Cianciaruso, B., Di Iorio, B., Santoro, D., Giancaspro, V., Abaterusso, C., Gallo, C., Conte, G., & Minutolo, R. (2011). Prognosis of CKD Patients Receiving Outpatient Nephrology Care in Italy. *Clinical Journal of American Society of Nephrology*, 6 (10), 2421-8.

Odden, M.C., Whooley, M. A., & Shlipak, M.G. (2005). Depression, Stress, and Quality of Life in Persons with Chronic Kidney Disease: The Heart and Soul Study. *Nephron Clinical Practice*, 103 (1), c1–c7.

Odenigbo, C. U., Oguejiofor, O. C., Onwubuya, E. I. & Onwukwe, C. H. (2009). Prevalence of Chronic Kidney Disease in a Nigerian Family Practice Population. *Annual Medical Health Science Research*, 4 (2), S128–S132.

Ojo, A. (2014). Addressing the Global Burden of Chronic Kidney Disease Through Clinical and Translational Research. *Transactions of the American Clinical Climatological Association*, 125, 229-43.

Orandi B. J., Luo, X., Massie, A. B., Garonzik-Wang, J. M, Lonze, B. E., Ahmed, R., Segev. D. L. (2016) .Survival Benefit with Kidney Transplants from HLA-Incompatible Live Donors. *The New England Journal of Medicine*, 374 (10), 940-950.

Osafo, C. Mate-Kole, M., Afram, K., Adu, D. (2011). Prevalence of chronic kidney disease in Hypertensive patients in Ghana, 33 (4), 388-92.

Otero, A., Gayoso, P., Garcia, F., & De Francisco, A. L. (2005). Epidemiology of chronic renal disease in the Galician population: Results of the pilot Spanish study. *Kidney International Supplement*, 23 (9), 16-9.

Pagel, A. A., Söderkvist, B. K., Medin, C., Hylander, B. & Heiwe, S. (2012). Health-related quality of life in different stages of chronic kidney disease

and at initiation of dialysis treatment. *Health and Quality of Life Outcomes*, 18 (4), 10-71.

Palmer, S., Vecchio, M., Craig, J. C., Tonelli, M., Johnson, D. W., Nicolucci, A., Pellegrini, F., Saglimbene, V., Logroscino, G., Fishbane, S., & Strippoli, G. F. M. (2013). Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. *Kidney International*, 84 (1), 179-91.

Perico, N & Remuzzi, G. (2014). Chronic kidney disease in sub-Saharan Africa: a public health priority. *Canadian Journal of Kidney Health and Disease*, 16 (2), 40.

Perz, J., Ussher, J. M. & Gilbert, E. (2013). Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *Bio Medical Center Cancer*, 16 (3), 270-272.

Plantinga, L. C., Tuot, D. S., & Powe, N. (2010). Awareness of Chronic Kidney Disease among Patients and Providers. *Advances in Chronic Kidney Disease*, 17 (3), 225-36.

Pole, M., Crowther, J. H., & Schell, J. (2004). Body dissatisfaction in married women: The role of spousal influence and marital communication patterns. *Body Image*, 1 (3), 267-78.

Polit, D. F. & Beck, C.T. (2010). Essentials of Nursing Research: Appraising Evidence for Nursing Practice, 7th edition. Lippincott, Williams and Wilkins, Philadelphia.

Poppe, C., Crombez, C; Hanouille, I, Vogelaers, D., & Petrovic, M. (2013). Improving Quality of Life in Patients with Chronic Kidney Disease. *Nephrology Dialysis Transplantation*, 28 (1), 116-21.

Powe, N. R., Peterson, P. G., & Mark, E. K. (2015). Case of 78-Year-Old Man with Hypercalcemia and Renal Failure. *The New England Journal of Medicine*, 373 (9), 864-73.

Preidt, R. (2015). Millions of kidney failure patients die for lack of treatment: Study received from consumer, 4th edition. North Florida.

Rathi, M & Ramachandran, R. (2012). Sexual and gonadal dysfunction in chronic kidney disease: Pathophysiology. *Indian Journal of Endocrinology and Metabolism*, 16 (2), 214–219

Rebar, C.R., Gersch C.J., Macnee, C.L., & McCabe, S. (2011). Understanding Nursing Research (3rd Ed), London: Lippincott Williams & Wilkins.

Reblin, M., & Uchino, B.N. (2008) Social and Emotional Support and its Implication for Health. *Current Opinion in Psychiatry*, 21 (2), 201-5.

Reid, J., Noble, H.R., Porter, S & Shields, J.S. (2013). A Literature Review of End-Stage Renal Disease and Cachexia: Understanding Experience To Inform Evidence-Based Healthcare 39 (1), 47–51.

Retnakaran, R., Cull, C.A., Thorne, K.I., Adler, A.I & Holman, R.R. (2006). Risk Factors for Renal Dysfunction in Type 2 Diabetes. 55 (6), 1832-9.

Ritchie, J & Lewis, J. (2003). Qualitative Research Practice: A Guideline for Social Science Student and Researchers, 7th edition. Trowdrige, Wilshire.

Saunders, M.R Cagney, K.A, Ross, L.F, & Alexander, G.C. (2010). Neighborhood Poverty, Racial Composition and Renal Transplant Waitlist *American Journal of Transplantation*, 10 (8), 1912-7.

Seck, S. M., Doupa, D., Gueye, L. & Dia, C. A. (2014). Prevalence of Chronic Kidney Disease and Associated Factors in Senegalese Populations: A Community-Based Study in Saint-Louis. *Iranian Journal of Kidney Diseases*, 8 (4), 286-91.

Sekulic, M & Sekulic, S. P. (2013). A Compendium of Urinary Biomarkers Indicative of Glomerular Podocytopathy. *Pathology Research International*, 8 (18) 32-35.

Selye, H. (2013). The Stress of Life. 7th edition, New York: McGraw Hill.

Serebo, L., & Nyan, B. (2016). Kidney health, ultimate health joy FM, Accra Ghana.

Shah, A. J., Wadoo, O., & Latoo, J. (2010). Psychological Distress in Carers of People with Mental Disorders. *British Journal of Medical Practitioners*, 3 (3), 32-7

Shivani, R., Goldsmith, R. J., & Anthenelli, R. M. (2002). Alcoholism and Psychiatric Disorders: Diagnostic Challenges. *Alcohol Research*, 26 (2), 22-26.

Shutto, Y., Shimada, M., Kitajima, M., Yamabe, H., Saitoh, Y., Saitoh, H., & Razzaque, M.S. (2013) Inadequate Awareness among Chronic Kidney Disease Patients Regarding Food and Drinks Containing Artificially Added Phosphate *Iranian Journal of Kidney Diseases*, 10 (13) 71-78

Silva¹, S. M., Braido, N. F., Ottaviani, A. C., Gesualdo, G. D., Zazzetta S. M., Orland, F. S. (2016). Social support of adults and elderly with chronic kidney disease on dialysis. *Journal of Advance Chronic Kidney Disease*, 24 (9), 27-52

Sinha, R., Davis, I. D., Matsuda-Abedini, M. (2009). Sleep disturbances in children and adolescents with non-dialysis-dependent chronic kidney disease. *Arch Pediatric Adolescent Medicine*, 163 (9), 850-855.

Smetanka, S. L. (2006). Who Will Protect the "Disruptive" Dialysis Patient?

Srivastava, R. (2016). The Sharing of Loss. *The New England Journal of Medicine*, 37 (4), 2309-2311.

Stanifer, J. W., Jing, B., Tolan, S., Helmke, N., Mukerjee, R., & Naicker, S. (2014). The epidemiology of chronic kidney disease in sub-Saharan Africa: a systematic review and meta-analysis. *The Lancet Global Health*, *14* (3), 174-81

Stengel, B., Tarver-Carr, M. E., Powe, N. R., Eberhardt, M. S., & Brancati, F. L. (2003). Lifestyle factors, obesity and the risk of chronic kidney disease. *Epidemiology*, *14* (4), 479-87

Stevens, L. A., Viswanathan, G., Weiner, D. E. (2010). Chronic kidney disease and end-stage renal disease in the elderly population: current prevalence, future projections, and clinical significance. *Journal of Advance Chronic Kidney Disease*, *17* (4), 293-301.

Streubert-Speziale, H. J. (2007). *Qualitative Research in Nursing*. Philadelphia: Lippincott Williams & Wilkins.

Suzuki, E., Nishimatsu, H., Oba, S., Takahashi, M., & Homma, Y. (2014). Chronic kidney disease and erectile dysfunction *World Journal of Nephrology*, *63* (4), 220–229.

Tamura, M. K & Cohen, L. M. (2010). Should there be an expanded role for palliative care in end-stage renal disease? *Current Opinion in Nephrology and Hypertension*, *19* (6), 556-60.

Tayyem, R. F., Mrayyan, M. T., Heath, D. D. & Bawadi, H. A. (2008). Assessment of nutritional status among ESRD patients in Jordanian hospitals. *Journal of Renal Nutrition*, 18 (3), 281-7.

Theofilou, P. (2011). Depression and Anxiety in Patients with Chronic Renal Failure: The Effect of Socio-demographic Characteristics. *International Journal of Nephrology*, 51 (4) 60-70

Thomas, N. (2012). Recognizing early signs of chronic kidney disease. 140 London Wall, London.

Thomas, R., Kanso, A., & Sedor, J. R. (2008). Chronic Kidney Disease and Its Complications. *Primary Care*. 35 (2), 329-44.

Thong, M. Y., Kaptein, A. A., Krediet, R. T., Boeschoten, E. W., & Dekker, F. W. (2006). Social support predicts survival in dialysis patients for the Netherlands Cooperative Study on the Adequacy of Dialysis *Nephrology Dialysis Transplantation*, 22 (3), 845-50.

Tonelli, M., Wiebe, N., Culeton, B & House, A. (2006). Chronic Kidney Disease and Mortality Risk: A Systematic Review *Journal of the American society of nephrology*, 17 (7), 2034-47.

Tong, A., Palmer, S., Manns, B., Craig, J. C., Ruospo, M., Gargano, L., Johnson, D. W., Hegbrant, J., Olsson, M., Fishbane, S & Strippoli, G. F. Strippoli, G. F (2013). The beliefs and expectations of patients and caregivers about home haemodialysis: an interview study. *British Medical Journal Open*,

24 (31), 0021-48

Vecchio, M., Palmer, S. C., Tonelli, M., Johnson, D. W., & Strippoli, F. M. G (2012). Depression and sexual dysfunction in chronic kidney disease: a narrative review of the evidence in areas of significant unmet need. *Nephrology Dialysis Transplantation*, 27 (9), 3420-8.

Velho, A. M., & Velho, R. M. (2013). Anatomy and physiology series: looking at the kidney as a whole. *Journal of Renal Nursing*, 5 (1), 20-23

Wadd K., King L., Bennett P., & Grant J. (2011). Being a parent on dialysis: a literature review. *Journal of Renal Care*, 37 (4), 208-215.

Walker, R. C., Howard, K., Morton, R. L., Palmer, S. C., Marshall, M. R & Tong, A. (2015). Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study. *Nephrology Dialysis Transplantation*, 31 (1), 133-41.

Wallace, M. A. (2016). Anatomy and Physiology of the Kidney. *Association of perioperative Registered Nurses Journal*, 68 (5), 800, 803-16.

Wang, L. J & Chen, C. K. (2012). The Psychological Impact of Hemodialysis on Patients with Chronic Renal Failure, Renal Failure. *Nephrology Dialysis Transplantation*, 51 (6), 953-978.

Wanner, C., Inzucchi, S. E., Lachin, J. M., Fitchett, D., Eynatten, M., Matthews, M., Johansen, O. E., Woerle H. J., Broedl, U.C., & Zinman, B. (2014). Empagliflozin and Progression of Kidney Disease in Type 2 Diabetes. *The New England Journal of Medicine*, 37 (5), 323-334

Weiner, D. E. (2009). Public Health Consequences of Chronic Kidney Disease. *Clinical Pharmacological Therapy*, 86 (5), 566-569.

White, S. L., Chadban, S. J., Jan, S., Chapman, J. R., & Cass, A. (2008). How can we achieve global equity in provision of renal replacement therapy? *Bulletin of the World Health Organization*, 86 (3), 229-37

Wright, J. A., Wallston, K. A., Elasy, T. A., Ikizer, T. A. & Cavanaugh, K. L. (2010). Development and Results of a Kidney Disease Knowledge Survey Given to Patients with CKD. *American Journal of Kidney Disease*, 57 (3), 387-95.

Wu, C. C, Lin, C. C, Hsieh, H. F., & Chang, S. H. (2015). Lived experiences and illness representation of Taiwanese patients with late-stage chronic kidney disease. *Journal of health psychology*, 59 (4), 1599-613.

Xue, J. L., Ma, J. Z., Louis. T.A., & Collins, A. J. (2001). Forecast of the number of patients with end stage renal disease in the United States to the year 2010. *Journal of American Society of Nephrology*, 12 (12), 2753-8

Yirsaw, B. D. (2012). Chronic kidney disease in sub-Saharan Africa: Hypothesis for research demand. *Annual African Medicine*, 11 (2), 119-120.



APPENDIX A: DATA COLLECTION INSTRUMENT

Information for participants.

Study title: LIVED EXPERIENCES OF PEOPLE WITH CHRONIC KIDNEY DISEASE IN CAPE COAST TEACHING HOSPITAL.

Brief information about the research

Invitation

We would like you to take part in a study. If you approve of it you will be required to fill out a questionnaire regarding the research

Why are we doing this project?

We want to find out your views regarding the lived experiences of people with chronic kidney disease in Cape Coast Teaching Hospital. This project will be written up by the researcher for a research degree (MN). In the future we hope the research will lead to people knowing more about the lived experiences of people with chronic kidney disease in Cape Coast Teaching Hospital.

Why have I been chosen?

You have been asked to take part because staff thinks that, as a service user, your experiences in our facility would be helpful to the study. **Do I have to take part?**

No. You can choose whether you want to say yes or no. You do not have to give reasons. If you do take part, but then change your mind you are allowed to do so.

What will happen to me if I take part?

We will ask you questions regarding your views and lived experiences of people with chronic kidney disease in Cape Coast Teaching Hospital. Interview will last for 45 to 60 minutes.

Will my taking part be confidential?

Yes. Anything you tell us will be used without using your name. We will not use your name if we share anything you tell us.

What will happen to the results of the research study?

We will send you a short report, work will be published to the benefit of all.

Who is organising and funding this research?

The University of Cape Coast

Who has checked or reviewed this study?

IRB, UCC

IRB, university of Cape coast (contacts details)

For further information contact:

(Address and contact details)

Ernestina Jeffrey

0205889294

Thank you for agreeing to take part in the study.

Participant signature.....



SECTION A. BIOGRAPHICAL INFORMATION

The purpose of this study is to explore the lived experiences of people living with CKD in CCTH. You are invited to participate. If you agree to be in this study, an interview will be conducted with you. The interview will include questions about your condition (CKD), how it has affected your health and general well-being. The interview will take about 45 to 60 minutes to complete. With your permission, the interview will be taped. You may skip any questions that you do not want to answer. The records of this study will be kept confidential and destroyed after the study

Age category

- 5-14
- 15-24
- 25-34
- 35-44
- 45-54

Marital Status

- Single
- Married
- Widow
- Widower
- Divorced
- Co-habiting

Gender

Male

Female

Living Conditions

Where do you live?

Do you live alone?

Any contact with your neighbors?

Educational Background

Primary

JHS/ Middle school

WACE

SSCE

O- Level

A-Level

College

Tertiary

Non



SECTION B. INTERVIEW GUIDE

Knowledge

Do you have any idea about CKD?

What are some of the signs and symptoms of CKD?

What do you think causes of CKD?

Are you aware of any treatment?

Do you take medications for your condition?

How long have you been on medication?

Are your medications easy to get?

How do you feel after taking the medication?

Do you think the treatment is helpful?

What are some of the challenges associated with treatment?

Do you sometimes feel like giving up on the treatment?

Psychosocial / Emotional Experiences

Tell me how you feel about this condition?

How do you cope when sad about you current state?

Do you think there is any hope?

What is your major fear?

How do you feel when you hear about the death of someone with CKD?

ACTIVITIES OF DAILY LIVING

Physical

How has CKD affected your physical appearance?

How do you feel when people observe you closely?

How has CKD affected your performance in bed?

Do you sleep well?

Are you able to work effectively?

Do you get any help?

Social

Tell me about your social life?

Do you or have friends visiting you?

Do you attend church / mosque regularly?

How has your eating habit affected you and your family as a result of your condition?

How do you cope with fluid and diet restrictions?

How has CKD affected your school/ work attendance?

Financial Experience

How has the treatment of chronic kidney disease affected your finance?

How expensive are the treatments e.g. drugs, fistula and lab investigations?

Are you able to afford the prescribed drugs?

How affordable are the lab investigations?

Do you get any financial support?

How do you feel when you do not have money?

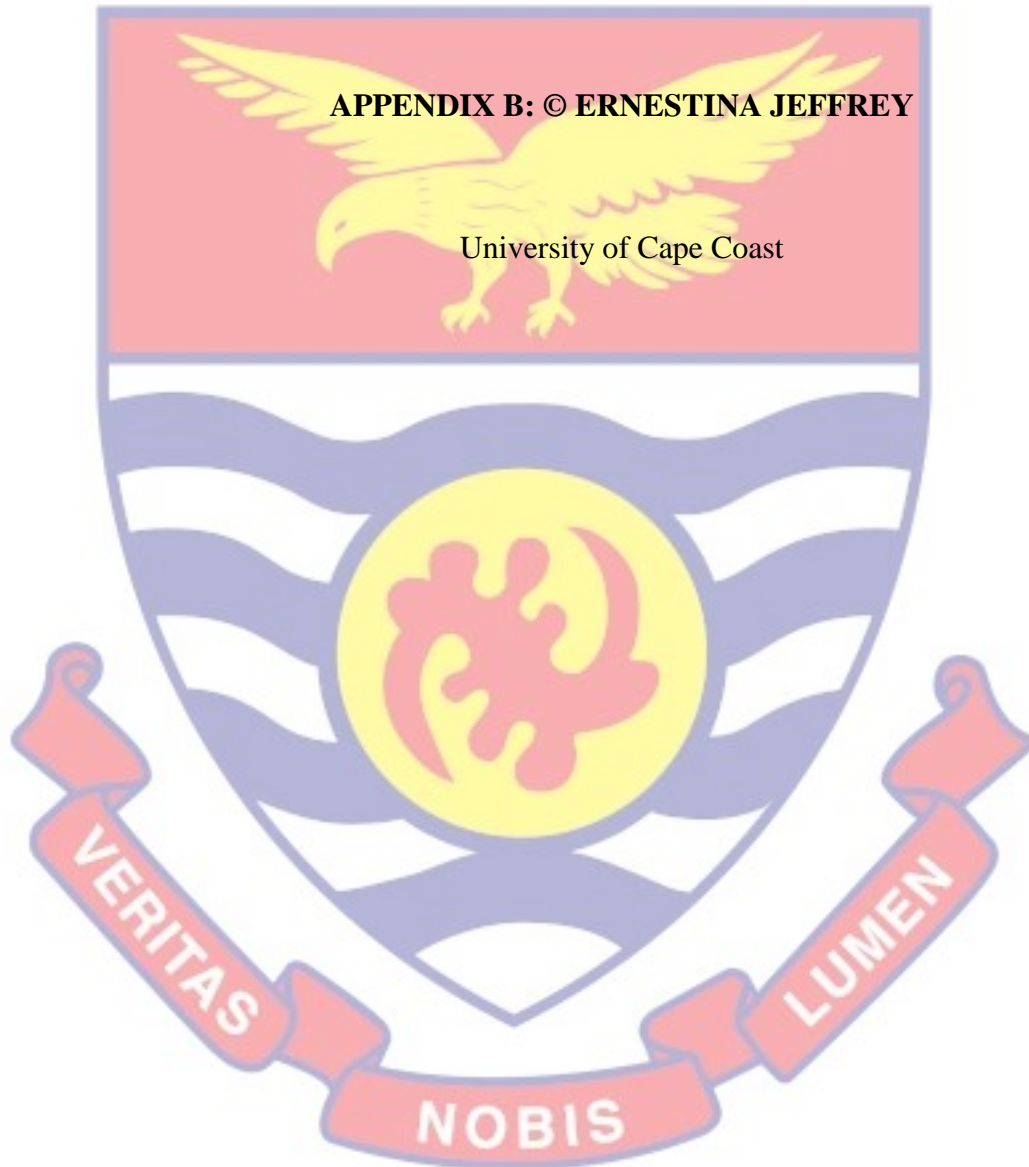
How do you meet other responsibilities like paying utility bills, feeding the family, and learning?

Are you still working?

Do you get full payment at the end of the month?

How does your employer support you financially?





APPENDIX C: INTRODUCTION LETTER

UNIVERSITY OF CAPE COAST
INSTITUTIONAL REVIEW BOARD SECRETARIAT

TEL: 03321-33172/3 / 0207355653/ 0244207814

C/O Directorate of Research, Innovation and Consultancy

E-MAIL: irb@ucc.edu.gh

OUR REF: UCC/IRB/3/41

YOUR REF:



9TH MARCH, 2016

Ms. Ernestina Jeffrey
School of Nursing and Midwifery
University of Cape Coast

Dear, Ms. Jeffrey,

ETHICAL CLEARANCE –ID NO: (UCCIRB/CHAS/2015/106)

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for implementation of your research protocol titled: **“Lived experiences of people with chronic kidney disease in Cape Coast Teaching Hospital.”**

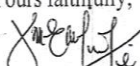
This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol

Yours faithfully,


for: (Samuel Asiedu Owusu)
ADMINISTRATOR

cc: The Chairman, UCCIRB

ADMINISTRATOR
INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF CAPE COAST
Date: 09-03-16

*In case of reply the reference number
and the date of this
Letter should be quoted*

Our Ref.: CCTH/MD—G/16-38
Your Ref.:



P. O. Box CT.1363
Cape Coast
Tel: 03321-34010-14
Fax: 03321-34016
Website: www.ccthghana.com
www.ccthghana.org
email: info@ccthghana.org

13th April, 2016

**MS. ERNESTINA JEFFREY
NURSING OFFICER
CAPE COAST TEACHING HOSPITAL**

Dear Madam,

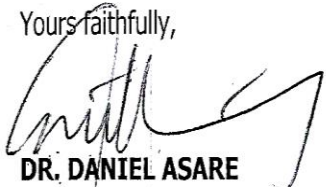
RE: APPLICATION FOR ETHICAL CLEARANCE

With reference to your letter dated 11th April 2016 on the above subject, I write to inform you that the Cape Coast Teaching Hospital (CCTH) has granted approval to conduct research in partial fulfilment of the condition for the award of Master of Nursing Programme.

The hospital would also appreciate to have a copy of any relevant findings.

Thank you.

Yours faithfully,



**DR. DANIEL ASARE
(CHIEF EXECUTIVE OFFICER)**



UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEAN'S OFFICE



Telephone: 233-3321-33342/93372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref:

Your Ref: 77/Vol. 2/

10th March, 2016

To The CEO
CCH



Dear Sir/Madam,

LETTER OF INTRODUCTION: MISS ERNESTINA JEFFREY

The above named person is a level 850 student of the School of Nursing and Midwifery, University of Cape Coast with ID number BS/MNS/14/0005.

Miss Jeffrey is in her final year, pursuing a Master of Nursing. She is conducting a research on the topic: "the lived experiences of people with chronic kidney disease in Cape Coast Teaching Hospital."

We would be very grateful if you could offer her the necessary assistance and support.

Thank you.

Yours faithfully,

Dr. Samuel Victor Nuvor
VICE-DEAN

For Dir of Nursing to handle
Meet Dir/ERC
Dir of nursing
Ms the nurse must pay her fees & secure for the money for the clearance
5/4/16