

UNIVERSITY OF CAPE COAST

PERCEPTION OF PATIENTS/FAMILY AND HEALTHCARE  
PRACTITIONERS ON PALLIATIVE CARE AS ALTERNATIVE TO  
DIALYSIS IN THE TREATMENT OF END-STAGE KIDNEY DISEASE IN  
KUMASI METROPOLIS

BY

CATHERINE SARFO-WALTERS

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

SEPTEMBER 2016

## DECLARATION

### Candidate's Declaration

I hereby declare that this thesis is the result 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: .....

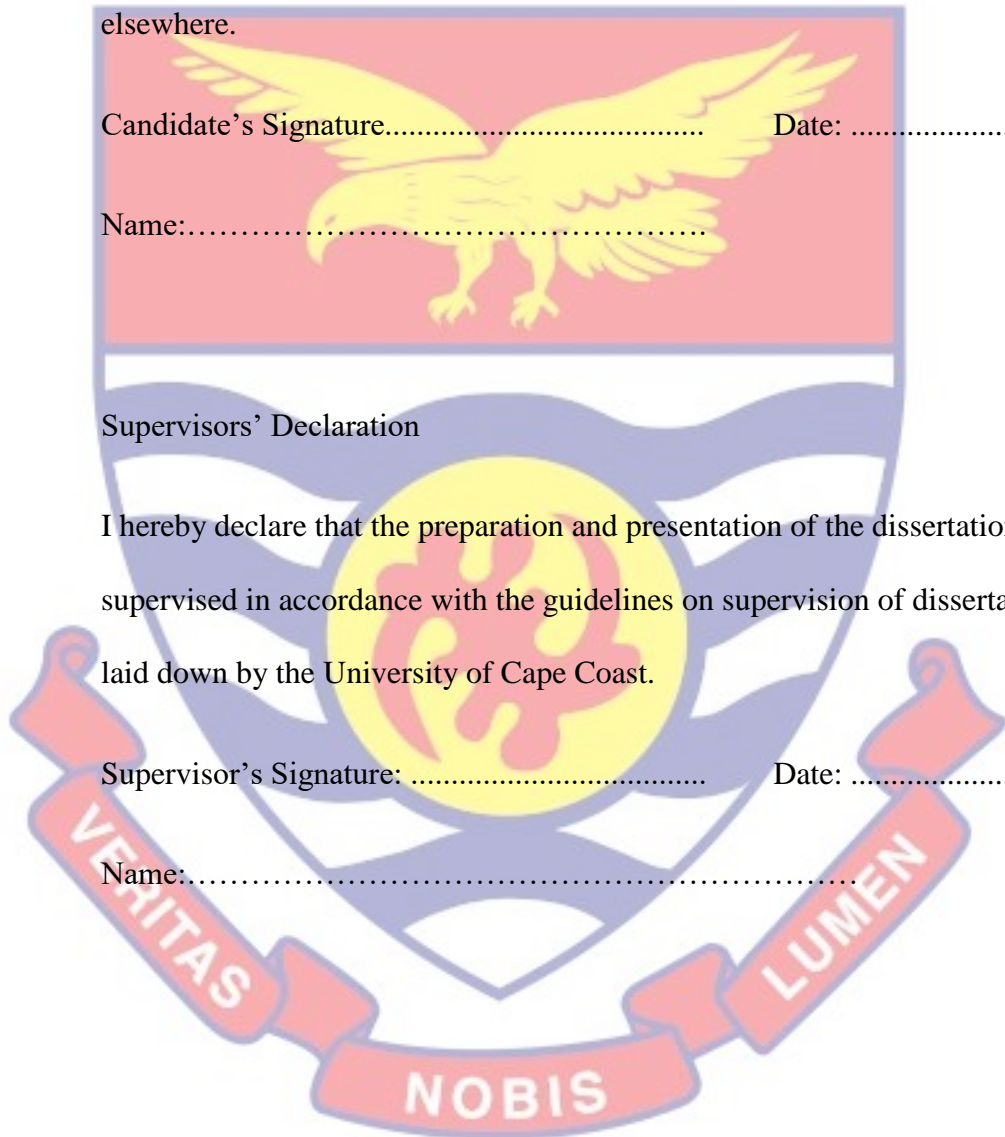
Name:.....

### Supervisors' Declaration

I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of dissertation laid down by the University of Cape Coast.

Supervisor's Signature: ..... Date: .....

Name:.....



## ABSTRACT

The main aim of this study was to establish patients/family and healthcare practitioners' perception on palliative care as alternative to dialysis in the treatment of End Stage Kidney Disease (ESKD) in Kumasi Metropolis. A descriptive qualitative with phenomenological overtone research design was used for this study. A purposive sampling technique was used to obtain 17 participants (8 health care practitioners, 6 patients and 3 family members) out of 30 healthcare practitioners and 32 patients in all the three centres in Kumasi Metropolis. The respondents' perception on palliative care as alternative to dialysis in the management of ESKD was evaluated using face to face interview. The findings of the study indicated most respondents elaborated that, palliative care is the treatment given to patients whose disease is not responsive to curative treatment. Most of the respondents perceived that patients' living with chronic diseases will die but to promote peaceful death, quality of life should be offered through palliative care. It is concluded that at the advanced stage of ESKD where dialysis will not improve quality of life, palliative nursing care is the alternative treatment to dialysis in the management of ESKD. It is recommended that treatment options should be made available for patient/family to make informed choice. Palliative care as an alternative management for ESKD should be part of the treatment options in the management of all patients/family with ESKD.

KEY WORDS

Perception

Patients/Family

Healthcare Practitioners

Palliative Care

Dialysis

Treatment

End-Stage Kidney Diseases (ESKD)

Kumasi Metropolis



## ACKNOWLEDGEMENTS

I offer my sincere gratitude to many individuals who have assisted me in completing this thesis. It was a challenging progress and I am grateful to say I am finally done. I would like to thank my supervisors Prof. Funmilayo Okalanwon and Dr. Jerry Ninnoni all of School of Nursing and Midwifery.

Thank you for sharing your knowledge, your amazing dedication and guidance, your constant encouragement, support and objective criticisms. To the man behind this thesis, the Dean of School of Nursing and Midwifery Prof. Adu-Oppong Ahmed, you deserve to be praised for the hard work for the success of this Masters Programme. I thank Dr. Peter Mate Siakwa for his encouragement and support. God richly bless you Dr. Mate Siakwa and to all the lecturers and administrative staff of the School of Nursing and Midwifery, UCC, Cape Coast.

I would like to thank all the nurses, doctors, patients and their families who have shown kindness, care and dedication to me and their patients/relatives. I would like to thank my husband Richard Sarfo-Walters for the support, advice and encouragement. To my mother Beatrice Mensah Bonsu, thank you for supporting me throughout my life in whatever I wanted to pursue.

Furthermore my sincere thanks goes to all the authors of the literature used as reference for this study. To all my collages in this programme, I say thank you for your encouragement.

DEDICATION

To my husband and children

Richard, Kwakye, Osei and Serwaa



TABLE OF CONTENTS

	Page
DECLARATION	ii
ABSTRACT	iii
KEY WORDS	iv
ACKNOWLEDGEMENTS	v
DEDICATION	vi
LIST OF TABLES	xi
LIST OF FIGURES	xii
LIST OF ACRONYMS	xiii
<b>CHAPTER ONE: INTRODUCTION</b>	
Background to the Study	1
Statement of the Problem	4
Objective of the Study	6
Specific Objectives	6
Significance of the Study	7
Delimitations of the Study	7
Limitations of the Study	8
Definition of terms	8
Organisation of the Study	9
Chapter Summary	10
<b>CHAPTER TWO : LITERATURE REVIEW</b>	
Introduction	11
Chronic Kidney Disease	12
Artificial Kidney	18

Quality of Life	20
Renal Disease and Quality of Life	25
Dialysis Adequacy and Quality of Life	26
Palliative Approach to Dialysis Care	31
The Need for Palliative Approach to Dialysis	35
Appropriate use of a Palliative Approach to Dialysis	38
Barriers to a Palliative Approach to Dialysis	39
Provider Barriers	39
Care Delivery Barriers	41
Implementing a Palliative Approach to Dialysis Care	42
Decision Making Regarding Conservative Care	45
Facilitating Shared Decision Making	49
Theoretical Framework of the Study	50
Chapter Summary	52
<b>CHAPTER THREE: RESEARCH METHODS</b>	
Research Design	53
Study Area	54
Population	54
Sampling Procedure	55
Ethical Considerations	55
Data Collection Instruments	56
Data Collection Procedures	57
Data Processing and Analysis	58
Trustworthiness	59
Reflexivity	60



Chapter Summary	60
CHAPTER FOUR: RESULTS AND DISCUSSION	
Introduction	61
Results	61
Demographic characteristic of the respondents	63
Objective One	65
Objective Two	73
Objective Three	81
Objective Four	86
Discussion	94
CHAPTER FIVE: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	
Introduction	99
Summary	99
Conclusions	101
Recommendations	102
Suggestions for further Research	102
REFERENCES	103
APPENDICES	
A Interview Guide	120
B Ethical Clearance	122
C Introductory Letter	123
D Approval from KATH	124
E Approval from Naghe Clinic	125

LIST OF TABLES

Table	Page
1. Demographic characteristics of Health Care Practitioners (N=8)	63
2. Demographic Characteristics of Patients/Family (N=9)	64



## LIST OF FIGURES

Figure	Page
1. Patient on the Haemodialysis Machine	19
2. Dialyzer (Artificial Kidney)	20
3. Comfort Theory	52



## LIST OF ACRONYMS



AKI	Acute Kidney Injury
ANNA	American Nurses' Association
ARC	Advanced Renal Care
ARF	Acute Renal Failure
CKD	Chronic Kidney Disease
CMS	Centre for Medicare and Medicaid
DHSSPS	Department of Health, Social Services and Public Safety
EOL	End of Life
ESKD	End-Stage Kidney Disease
HD	Haemodialysis
KATH	Komfo Anokye Teaching Hospital
NHS	National Health Service
NKF	National Kidney Foundation
QIL	Quality Incentive Programme
QOL	Quality of Life
RS	Resident Specialist
SMO	Senior Medical Officer
SSN	Senior Nursing Officer
WHO	World Health Organisation

## CHAPTER ONE

### INTRODUCTION

#### Background to the Study

Most End-Stage Kidney Disease (ESKD) patients want to learn about End-of-Life (EOL) issues, such as treatment options (including withdrawal from dialysis), and the availability of hospice (palliative) services (Davison, 2010). Discussing prognosis is a key step in EOL planning, but this occurs infrequently or late in the dying process among patients with ESKD. In two studies, 95 % and 97 % of patients with ESKD preferred to be given life-expectancy information—even if their prognosis was poor (Davison, 2010; Fine, Fontaine, Kraushar, & Rich, 2005). Furthermore, patients specifically want their physicians to disclose this information without prompting (Davison, 2010). A validated prognostic tool exists for dialysis patients (Cohen, Ruthazer, Moss, & Germain, 2010), yet both uncertainty regarding individual prognosis and a lack of training about how to communicate prognostic data has limited EOL discussions between healthcare practitioners and patient/family.

The annual mortality rate of dialysis patients approaches 20%–24% (Weiner, 2010). This is higher than that of prostate, breast or colorectal cancer. Many kidney patients are not aware of this and consider renal failure as curable with transplantation or treatable with dialysis (Davison, & Torgunrud, 2007). It has been proposed that open prognostic information to counter this should be offered even before dialysis is started (Davison, & Torgunrud, 2007), but this infrequently occurs. As a minimum, advance care planning should start when the answer to the surprise question is ‘no’ (would I be

surprised if this patient died within the next 6-12 months?). Optimal supportive care for end-stage renal disease (ESRD) patients starts with honest prognostic information, tailored to the patient's information preferences. However, this is not always achieved (Weiner, 2010).

For individuals with ESRD, palliative care can provide support in a number of areas. These include symptom management, advance care planning and in the provision of psychological support and education to both families and patients. There are three main patient groups who may benefit from palliative and supportive care. One group are those who prefer to forgo dialysis to follow the conservative care pathway (Chandna, Da Silva-Gane, & Marshall, 2011; Carson, Juszczak, Davenport, & Burns, 2009; Murtagh, Marsh, & Donohoe, 2007). A second group are those who begin dialysis in somewhat good health. Over time, they become more symptomatic and less well able to tolerate dialysis. A third group are those with relentlessly progressive conditions causing renal failure, such as severely poorly controlled diabetes.

There are great variations in the types of palliative care services for patients with CKD with the development of standards for renal palliative care associated with limited evidence (Murtagh et al. 2007). However, there is growing recognition in high acuity care areas that a holistic approach best supports decisions concerning the use of life-supporting treatments (Fassett, Robertson, Mace, Youl, Challenor, & Bull, 2011). There is increased awareness of the role that palliative care can play in the effective management of patients with CKD (Murtagh et al. 2007) and the urgency around implementing such pathways is of global concern.

Kidney disease is defined as end-stage when a patient's glomerular filtration rate has fallen to  $<15 \text{ ml/min/1.73 m}^2$  (Davison, 2010; Fine, Fontaine, Kraushar, & Rich, 2005). Mortality associated with end-stage kidney disease (ESKD) is high (Fine et al., 2005). The incidence of treated ESKD is rising in the western world, with a corresponding increase in the incidence of diabetes and cardiovascular disease, especially in ethnic minority groups. Survival on dialysis has been shown to be poorer in the older age group, especially in patients with increased comorbidity and in those whose functional status at the start of dialysis is poor (Cohen, Ruthazer, Moss, & Germain, 2010).

Advance care planning is a dynamic process. It involves understanding the patient, their life and their families before having discussions about future priorities and preferences for care. The focus is on improving quality of life as end of life approaches, while addressing family relationships and conflict (Hines, Glover, & Babrow, 2001). These are all priorities that patients themselves rate highly. Advance care planning allows for a more patient-centred approach rather than the focus being primarily on disease, for instance, centred around dialysis decisions (Hines, et al., 2001).

Davison and Torgunrud (2007), on researching advanced care planning, showed that patients wanted more information and in non-medical language on prognosis, disease process and the impact of treatment on daily life, although renal teams may find this difficult, particularly when discussing end-of-life issues, which are less often part of their routine practice. Renal professionals often need prompts to help them open up discussion about the future, as they are much less familiar with how to do this than palliative care

professionals. But when sensitive, open exploration of concerns for the future is achieved, the opportunity for discussion is often appreciated by patients (NHS Kidney Care GMMKC, & Advanced Renal Care (ARC) Project, 2012).

There is limited evidence about the duration of survival of conservatively managed patients. One study showed that median survival from entry into Stage 5 chronic kidney disease (CKD) was less for conservatively managed patients (21.2 months) than for those on dialysis (67.1 months,  $p < 0.001$ ), but for patients over 75 years of age with high co-morbidity and diabetes, this survival advantage was lost (Chandna, Da Silva-Gane, & Marshall, 2011). The decision to follow dialysis or conservative management pathway is individual to each patient.

A national observational study in Australia found that about 14% (one in seven) of patients with ESKD referred to nephrologists plan not to dialyze (Morton, Turner, & Howard, 2012). A change in service provision, with greater systematic inclusion of palliative and supportive care needs, is essential to address the needs of this growing group in Australia (Morton et al., 2012).

#### **Statement of the Problem**

Chronic kidney diseases have been identified as a major public health concern worldwide. It has even been suggested that the world is in the midst of an 'epidemic' with data from USA indicating that a massive 16.6% of the USA population aged  $\geq 20$  years have CKD (Karger, 2009). The CKD burden is increasing rapidly worldwide. At the end of 2004, 1,783,000 patients worldwide were receiving treatment for ESRD of which 77% were dialysis and 23% had a functioning renal transplant (Karger, 2009). The number of



patients with ESRD is increasing at a rate of 7% every year. The average incidence of ESRD in developing countries is 150 per million population (Karger, 2009). Other study conducted in central Sudan in 2009 among 224 ESRF patients found that hypertension (14.3 %) is a leading cause of ESRF followed by obstructive uropathy (11.6 %), glomerulonephritis (9.8 %), diabetes mellitus (8 %), however in 53.57 percent no cause was found (Elsharif, & Elsharif, 2011).

When people are living with chronic illness, quality care should be focused on the patient's own choices and definitions of quality and provide comfort measure to enhance well-being. Hence the needs for palliative care for chronic illness. Palliative care promotes independence and physical function as long as possible and as chosen by the patient (Scanlan, Gure, Jungbluth, Old, & Chen, 2002). A palliative system will continue active medical treatment with proven effectiveness while offering an individually customized plan to provide comfort, ensure continuity of care and emphasize end-of-life planning. But dialysis units often disregard the advance care planning and fail to address the palliative needs of patients and families (Renal Association, 2003).

There is growing awareness of the need for research into the palliative care needs, and relevant interventions to address these needs, for patients with ESKD. Greater awareness of those being managed conservatively is also occurring, and systematic study of this population is now beginning to take place. Research has been undertaken looking at patient's experience of conservative management (Noble, Meyer, Bridges, Kelly & Johnson, 2008) and its impact on families and carers (Low, Smith, & Burns, 2008). The

majority of the research until now has been UK based (Murtagh, Addington-Hall, & Higginson, 2011), but requires replication internationally. Although great strides have been made, the opportunity for maximizing palliative care for the individual patient who withdraws from dialysis is needed.

There is no known published study on dialysis discontinuation and palliative care for chronic kidney diseases in Ghana. In spite of the terminal nature of chronic kidney disease (CKD), end-of-life care planning is often inconsistent and pathways to palliative care are unclear from both patient/family and health care practitioners. Health professionals' and patient/family's perceptions of palliative care and the discontinuation of dialysis may influence their end-of-life decision making. Therefore, the need to evaluate palliative care for end-stage kidney diseases (ESKD) from health care practitioners and patient/family perspectives in Kumasi Metropolitan.

### **Objective of the Study**

The aim of the study is to evaluate perception of patient/family and healthcare practitioners on palliative care as alternate to dialysis in the treatment of end-stage kidney diseases in Kumasi Metropolitan.

### **Specific Objectives**

The specific objectives to this study were to:

1. explore perceptions of healthcare practitioners on palliative care for ESKD,
2. investigate patients' views and beliefs on palliative care for ESKD,
3. investigate patient family's views and beliefs on palliative care for ESKD and

4. examine healthcare practitioners' attitudes towards patients on palliative care for ESKD.

### **Significance of the Study**

Most end-stage kidney disease (ESKD) patients want to learn more about end-of-life (EOL) issues, such as treatment options (including withdrawal from dialysis), and the availability of hospice services (Davison, 2010). Consequently, quality of life is paramount in end-stage renal disease. This study is hopes to create awareness of quality of life after discontinuation from dialysis. Findings from the study may help policy makers in the health service to develop measures and policies to facilitate conservative management during ESKD in the health care system in Ghana.

The findings from the study may also provide guides in the nursing care when caring for patients who discontinue dialysis treatment. It will help health care practitioners to appreciate the need for quality assurance and incorporation of palliative care in ESKD. It will also help the nursing board in Ghana to appreciate the need to integrate quality assurance and good palliative management measures in the pre-registration training. The findings from this research may serve as a platform for other researchers to study palliative nursing in the hospitals where this study will be conducted. The study can also contribute to discussion of palliative care as alternate treatment for ESKD.

### **Delimitations of the Study**

The study was done in only Komfo Anokye Teaching Hospital (KATH), and Naghe Clinic. These hospital and clinic are in Kumasi, Ashanti Region of Ghana and as such the results cannot be generalized to the entire nation, Ghana. The researcher used only six (6) months to conduct the entire

research which could have been better if using longer period have been devoted to the study. The research was conducted only in the Medicine Department of KATH and dialysis centres of the other sites. Healthcare practitioners and patient/family who had ESKD and were willingly to participate in the study were involved in the study. Rotation nurses and other nursing staff categories were excluded from the study. Comparing the entire population of the studied areas (KATH, and Naghe Clinic), the researcher used only 17 respondents to conduct the study. The educational interventions, pre-tests, and post-tests were conducted at only three hospitals. Therefore generalization of study findings is limited to these hospitals and clinic.

#### **Limitation of the Study**

Financial restraint was on the main challenges that limited the researcher since the study was self-sponsored. Secondary, it was also difficult to chase respondents in all the three shift-duty run by the centres and this limited the researcher in getting respondents readily available to be interviewed.

Information from the Biostatistics Units in the various centres also limited the researcher to use more than two centres, this is because the researcher found it difficult getting information.

#### **Definition of Terms**

- End-Stage Kidney Diseases (ESKD): Progressive loss of renal or kidney functions over a period of time.
- Palliative care: Is the care rendered to patients to alleviate pain without curing.

- Dialysis: Method for removing waste products such as creatinine and urea, as well as free water from the blood when the kidneys fail to function.
- Healthcare Practitioners: these are both professional nurses and doctors who take care of patients with ESKD. They include dialysis nurses, general nurses, doctors, dieticians.
- Treatment: It is care rendered to patients to relieve them of their symptoms and signs.
- Patient/Family: Any person or group of people and their relatives who receive care from healthcare practitioners.

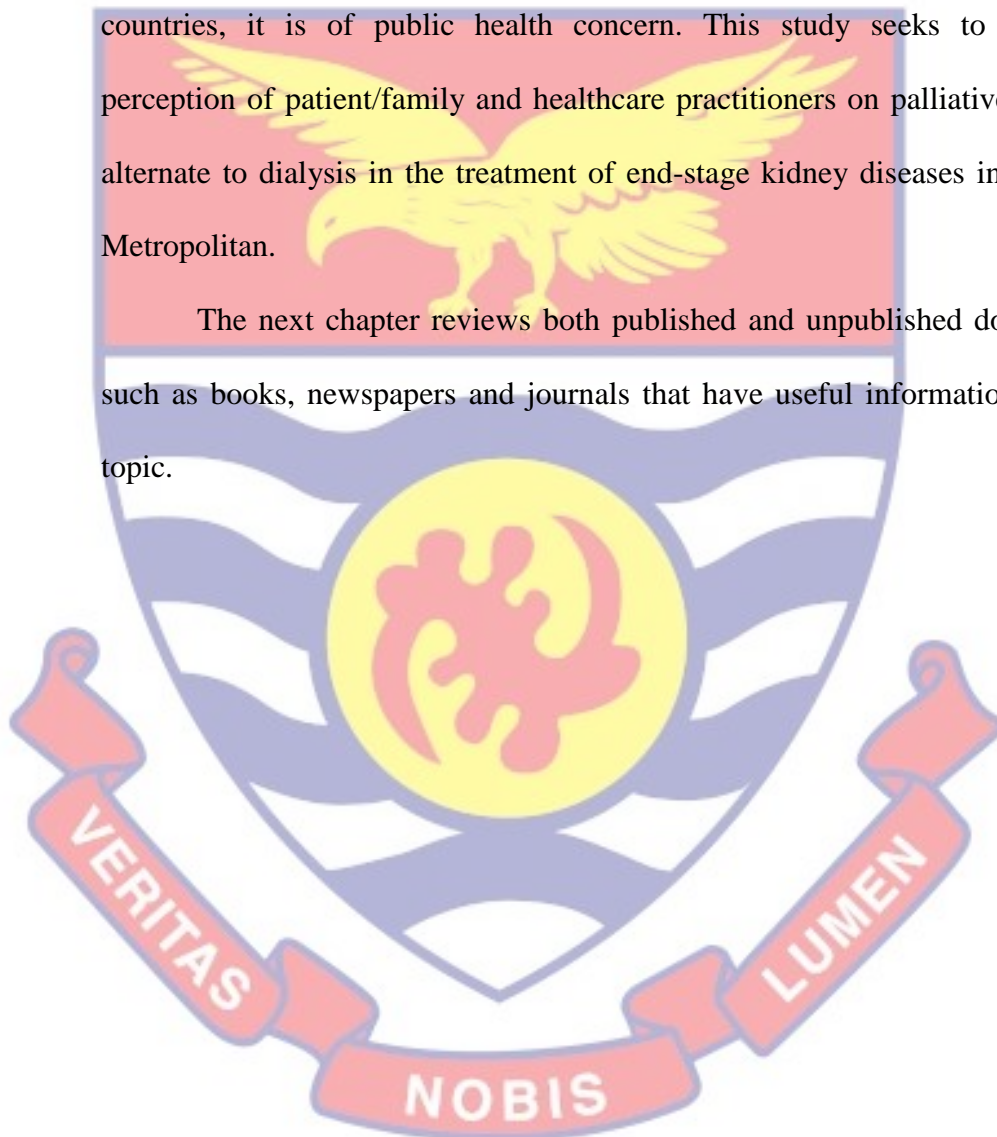
### **Organization of the Study**

This research report or thesis is organized in five chapters. Chapter one is made up of the following: background to the study, statement of the problem, purpose of the study, research questions, significance of the study, delimitation, limitations, definition of terms and the organization of the study. Chapter two dealt with the review of related literatures. This comprises both published and unpublished documents such as books, newspapers and journals that have useful information on the topic. Chapter three consists of the research methods and how the study is organized. The content of the chapter include: research design, population, sample and sampling technique, instruments used in the data collection, data collection procedure, ethical consideration and data analysis procedure. Chapter four highlights on the data presentation, analysis and discussion. The chapter five gives a summary of the study, draws conclusion and makes suggestions and recommendations for further studies.

## Chapter Summary

This chapter dealt with end-stage kidney diseases (ESKD) treatment options as a global issue which represents the largest and the most persistent gap between developed and developing countries. Countries have made progress in treating patients with ESKD but in most developed and developing countries, it is of public health concern. This study seeks to evaluate perception of patient/family and healthcare practitioners on palliative care as alternate to dialysis in the treatment of end-stage kidney diseases in Kumasi Metropolitan.

The next chapter reviews both published and unpublished documents such as books, newspapers and journals that have useful information on the topic.



## CHAPTER TWO

### LITERATURE REVIEW

In this chapter, related literature and research studies regarding definition of chronic kidney (renal) diseases (CKD), palliative care and nursing, and dialysis were reviewed. Both qualitative and quantitative studies on chronic kidney diseases were reviewed. Patients with CKD have a mortality rate of approximately 23% per (Hackett, & Watnick, 2007). Patients' deteriorating towards CKD are often counselled about their options for therapy including different dialysis modalities and/or kidney transplantation. In some circumstances, but not routinely, patients with advanced age and multiple co-morbidities may be offered a conservative pathway supported with palliative care. Despite this, end-of-life care planning is not consistently instigated (Hackett, & Watnick, 2007).

The importance of providing patient-centred palliative care for patients with advanced illnesses is gaining attention but standard dialysis delivery may not be consistent with the goals of care for many patients with ESKD. Many dialysis patients with life expectancy of <1 year may desire a palliative approach to dialysis care, which focuses on aligning patient treatment with patients' informed preferences (Tamura, & Meier, 2013). This observation explicates what comprises a palliative approach to dialysis care and describes its potential and appropriate use. It also reviews the barriers to incorporating such an approach into the current clinical standard of care and existing structure and outlines system-level changes needed to accommodate such an approach (Tamura, & Meier, 2013).

In retort to the high burden of physical and psychologic symptoms among individuals with ESRD, current commentary has called for policies to promote palliative care (Tamura, & Meier, 2013). However, among the ESRD population undergoing maintenance dialysis, much of the symptom burden may be attributable to dialysis therapy itself, particularly for those nearing the end of life. Also necessary, then, is a palliative approach to how dialysis delivery itself is provided, but the current system of dialysis delivery and regulatory oversight even in the United States is not well suited to accommodate such an approach (Tamura, & Meier, 2013).

### **Chronic Kidney Diseases**

Chronic kidney disease, also known as chronic renal disease, is a progressive loss of renal function over a period of months or years (National Kidney Foundation, 2006). The symptoms of worsening kidney function are unspecific, and might include feeling generally unwell and experiencing a reduced appetite (National Kidney Foundation, 2006). Often, chronic kidney disease is diagnosed as a result of screening of people known to be at risk of kidney problems, such as those with high blood pressure or diabetes and those with a blood relative with chronic kidney disease. Chronic kidney disease may also be identified when it leads to one of its recognized complications, such as cardiovascular disease, anaemia or pericarditis (National Kidney Foundation, 2006).

The global population of persons 60 years and older is approximately 605 million, accounting for 10 percent of the world's people. It is expected that this percentage will more than double by 2050, to 21 percent, when the older population will be nearly 2 billion, surpassing the population of children



(National Kidney Foundation, 2006). Fifty-four percent of the world's older population lives in Asia followed by Europe at 24 percent, with the United States, a relatively young country, at just over 12 percent. Life expectancy among the industrialized nations continues to increase. In 2004 the United Kingdom reported that 19 percent of their population was over 65 and projected an increase to nearly 20 percent over the next two decades (National Statistics, 2005). Population ageing is a concern of health care policy makers and providers. The World Assembly on Ageing adopted an International Plan of Action on Ageing in 2006 targeted at ensuring that people everywhere age with security and dignity (Global Action on Ageing, 2002). In the United States one of the major goals of Healthy People, 2020 is to increase quality and years of healthy life (Global Action on Ageing, 2002).

Chronic kidney disease is identified by a blood test for creatinine. Higher levels of creatinine indicate a falling glomerular filtration rate and as a result a decreased capability of the kidneys to excrete waste products. Creatinine levels may be normal in the early stages of CKD, and the condition is discovered if urinalysis shows that the kidney is allowing the loss of protein or red blood cells into the urine. To fully investigate the underlying cause of kidney damage, various forms of medical imaging, blood tests and often renal biopsy (removing a small sample of kidney tissue) are employed to find out if there is a reversible cause for the kidney malfunction (National Kidney Foundation, 2006). Professional guidelines classify the severity of chronic kidney disease into five stages, with stage 1 being the mildest and usually causing few symptoms and stage 5 being a severe illness with poor life expectancy if untreated. Stage 5 CKD is also called established chronic kidney

disease and is synonymous with the now outdated terms end-stage renal disease (ESRD), chronic kidney failure (CKF) or chronic renal failure (CRF) (National Kidney Foundation, 2006).

There is no specific treatment unequivocally shown to slow the worsening of chronic kidney disease. If there is an underlying cause to CKD, such as vasculitis, this may be treated directly with treatments aimed to slow the damage. In more advanced stages, treatments may be required for anaemia and bone disease. Severe CKD requires one of the forms of renal replacement therapy; this may be a form of dialysis, but ideally constitutes a kidney transplant.

CKD is initially without specific symptoms and can only be detected as an increase in serum creatinine or protein in the urine. As the kidney function decreases:

- \* Blood pressure is increased due to fluid overload and production of vasoactive hormones, increasing one's risk of developing hypertension and/or suffering from congestive heart failure
- \* Urea accumulates, leading to azotemia and ultimately uraemia (symptoms ranging from lethargy to pericarditis and encephalopathy). Urea is excreted by sweating and crystallizes on skin ("uremic frost").
- \* Potassium accumulates in the blood (known as hyperkalaemia with a range of symptoms including malaise and potentially fatal cardiac arrhythmias)
- \* Erythropoietin synthesis is decreased (potentially leading to anaemia, which causes fatigue)
- \* Fluid volume overload - symptoms may range from mild oedema to life-

threatening pulmonary oedema

\* Hyperphosphataemia - due to reduced phosphate excretion, associated with hypocalcaemia (due to vitamin D3 deficiency). The major sign of hypocalcaemia being tetany.

Later this progresses to tertiary hyperparathyroidism, with hypercalcaemia, renal osteodystrophy and vascular calcification that further impairs cardiac function.

\* Metabolic acidosis, due to accumulation of sulfates, phosphates, uric acid etc. This may cause altered enzyme activity by excess acid acting on enzymes and also increased excitability of cardiac and neuronal membranes by the promotion of hyperkalaemia due to excess acid (acidemia) (National Kidney Foundation, 2006).

People with chronic kidney disease suffer from accelerated atherosclerosis and are more likely to develop cardiovascular disease than the general population. Patients afflicted with chronic kidney disease and cardiovascular disease tend to have significantly worse prognoses than those suffering only from the latter. End-stage renal disease (ESRD) is a progressive, debilitating, chronic illness requiring nursing and medical interventions that include dialysis, education on lifestyle alterations, and dietary and fluid restrictions. The disease also affects body image because of oedema and the presence of arteriovenous fistulae or a central venous catheter. The disease can have an impact on patients' quality of life, potentially affecting their physical and mental health, functional status, independence, general well-being, personal relationships and social functioning (Suet-Cging, 2001; Bakwell, Hinggin, & Edmunds, 2002). In Ireland, approximately 780 patients depend on

haemodialysis for the maintenance of life (Irish Kidney Association, 2003).

In many CKD patients, previous renal disease or other underlying diseases are already known. A small number presents with CKD of unknown cause. In these patients, a cause is occasionally identified retrospectively (National Kidney Foundation, 2006).

It is important to differentiate CKD from acute renal failure (ARF) because ARF can be reversible. Abdominal ultrasound is commonly performed, in which the size of the kidneys are measured. Kidneys with CKD are usually smaller (< 9 cm) than normal kidneys with notable exceptions such as in diabetic nephropathy and polycystic kidney disease. Another diagnostic clue that helps differentiate CKD and ARF is a gradual rise in serum creatinine (over several months or years) as opposed to a sudden increase in the serum creatinine (several days to weeks). If these levels are unavailable (because the patient has been well and has had no blood tests) it is occasionally necessary to treat a patient briefly as having ARF until it has been established that the renal impairment is irreversible (National Kidney Foundation, 2006).

Additional tests may include nuclear medicine MAG3 scan to confirm blood flows and establish the differential function between the two kidneys. DMSA scans are also used in renal imaging; with both MAG3 and DMSA being used chelated with the radioactive element Technetium-99 (National Kidney Foundation, 2006).

In chronic renal failure treated with standard dialysis, numerous uremic toxins accumulate. These toxins show various cytotoxic activities in the serum, have different molecular weights and some of them are bound to other

proteins, primarily to albumin. Such toxic protein bound substances are receiving the attention of scientists who are interested in improving the standard chronic dialysis procedures used today.

Healthcare practitioners should always make treatments options available for patient/family to make an informed choice. Palliative as an alternate management for ESKD should be part of treatment options in the management of all patient/family with ESKD (National Kidney Foundation, 2006) in patients treated by these conventional methods.

Currently, several compounds are in development for CKD. These include, but are not limited to, bardoxolone methyl, olmesartan medoxomil, sulodexide, and avosentan. Replacement of erythropoietin and vitamin D3, two hormones processed by the kidney, is usually necessary in patients with CKD, as is calcium. Phosphate binders are used to control the serum phosphate levels, which are usually elevated in chronic kidney disease. When one reaches stage 5 CKD, renal replacement therapy is required, in the form of either dialysis or a transplant. In some cases, dietary modifications have been proven to slow and even reverse further progression. Generally this includes limiting a person's intake of protein. The normalization of haemoglobin has not been found to be of any benefit (Levin, Hemmelgarn, & Culeton, 2008).

The prognosis of patients with chronic kidney disease is guarded as epidemiological data has shown that all cause mortality (the overall death rate) increases as kidney function decreases (Perazella, & Khan, 2006). The leading cause of death in patients with chronic kidney disease is cardiovascular disease, regardless of whether there is progression to stage 5 (Perazella, & Khan, 2006; Sarnak, Levey, Schoolwerth, Coresh, Culeton, Hamm, &

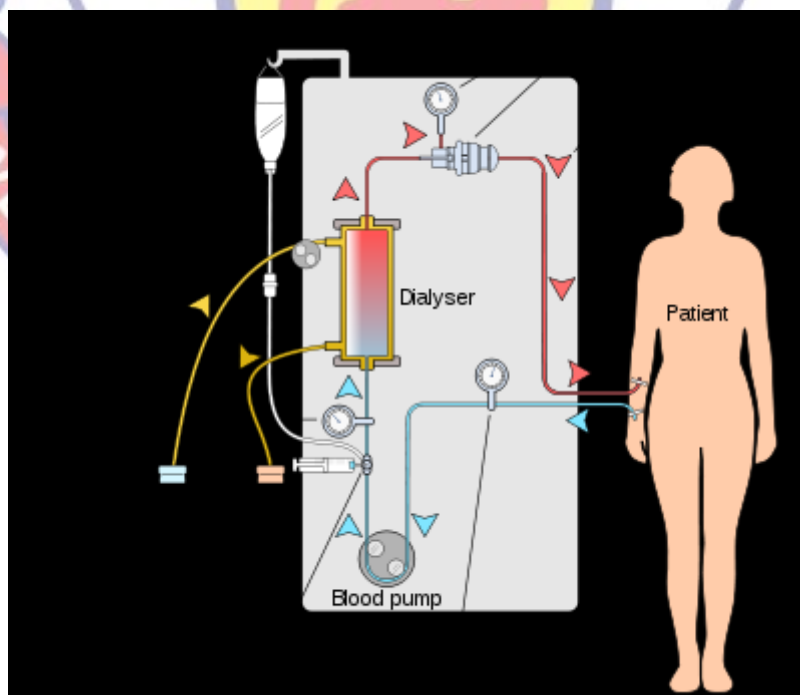
Parfrey, 2003; Marcello, Wiebe, Culleton, Lee, Klarenbach, Shrive, & Manns, 2007). While renal replacement therapies can maintain patients indefinitely and prolong life, the quality of life is severely affected (Heidenheim, Muirhead, Moist, & Lindsay, 2003). Renal transplantation increases the survival of patients with stage 5 CKD significantly when compared to other therapeutic options; (Groothoff, Grootenhuis, Offringa, Stronks, Hutten, & Heymans, 2005; Giri, 2004) however; it is associated with an increased short-term mortality (due to complications of the surgery). Transplantation aside, high intensity home haemodialysis appears to be associated with improved survival and a greater quality of life, when compared to the conventional three times a week haemodialysis and peritoneal dialysis (Pierratos, McFarlane & Chan, 2005).

### **Artificial Kidney**

Hemodialysis is a method for removing waste products such as creatinine and urea, as well as free water from the blood when the kidneys are in renal failure. The mechanical device used to clean the patients' blood is called a dialyser, also known as an artificial kidney. Modern dialysers typically consist of a cylindrical rigid casing enclosing hollow fibers cast or extruded from a polymer or copolymer, which is usually a proprietary formulation. The combined area of the hollow fibers is typically between 1-2 square meters. Intensive research has been conducted by many groups to optimize blood and dialysate flows within the dialyzer, in order to achieve efficient transfer of wastes from blood to dialysate (Gunda, Thomas, & Smith, 2005).

End-stage renal disease (ESRD) is a progressive, debilitating, chronic illness requiring nursing and medical interventions that include dialysis, education on lifestyle alterations, and dietary and fluid restrictions. The disease also affects body image because of oedema and the presence of arteriovenous fistulae or a central venous catheter. The disease can have an impact on patients' quality of life, potentially affecting their physical and mental health, functional status, independence, general well-being, personal relationships and social functioning (Gunda, Thomas, & Smith, 2005).

In Ireland, approximately 780 patients depend on haemodialysis for the maintenance of life (Irish Kidney Association, 2003). A study on national survey of palliative care in in ESRD suggested that palliative is needed to improve patients' quality of life by controlling symptoms as well as addressing social, psychological and spiritual issues (Gunda, Thomas, & Smith, 2005)



*Figure 1:* Patient on the Haemodialysis Machine; extracted from

www.gogglescholar.com



Figure 2: Dialyzer (Artificial Kidney): extracted from [www.gogglescholar.com](http://www.gogglescholar.com)

Evaluating the treatment of renal disease is important to enable the targeting of effective interventions by nurses by to improve patients' quality of life (Gunda, Thomas, & Smith, 2005). Urea Kinetic modeling is used to measure the adequacy of haemodialysis treatment. However, while most of the literature on urea kinetic modeling focuses on survival, morbidity and mortality rates, few people consider the effects of urea kinetic modelling or dialysis dose on patients' quality of life (Gunda, Thomas, & Smith, 2005) proposes to measure the results of treatment in terms of survival fails to consider the quality of that survival. Therefore it is important to measure the quality of life of patients with ESRD, as well as their quantity of life.

### **Quality of Life**

As a multidimensional concept, QOL can be described using subjective indicators such as sense of wellbeing and satisfaction with life. Objective indicators of QOL include functional status and mental health. The World



Health Organisation Quality of Life Group (Gunda, Thomas, & Smith, 2005) defined QOL as the 'individual's perceptions of their position in life in the context of the culture and value systems in which they live and with regard to their goals, expectations, standards and concerns' (p. 1403). Population specific cultural and age differences can only be identified when the QOL of these groups is specifically assessed. With the growing number of elders living alone, it is important to identify predictors of QOL to inform health care providers and policy makers.

Living arrangements are one indicator of wellbeing. Many elders desire to maintain independence and choose to live alone. As age increases, the percentage of the population living alone increases proportionately. With a longer life expectancy, older women are more likely to live alone, a percentage that is growing every year (Department of Health and Human Services, 2002). In 2002, 30.8 percent (9.8 million) of all non-institutionalized elders in the United States lived alone, 70 percent of these were women (Department of Health and Human Services, 2002). In Taiwan, ROC, the percentage of elders living alone rose from 10.5 percent in 1993 to 12.3 percent in 1996 (Department of Statistics, 1997). Living alone places elders at a higher risk for substandard health care quality than that of institutionalized elders. Health contributes to quality of life (QOL).

Several researchers have investigated elderly's QOL (Bowling, Banister, Sutton, Evans, & Windsor, 2002), reported on a national survey to measure QOL in 1999 British elders over 65-years old. Using a global QOL item, predictors included higher income, more education and fewer chronic illnesses. Gender or age did not significantly correlate with QOL ratings. Of

interest, only one third of the elders sampled lived alone. Hellstrom and Hallberg (2001) measured the QOL of 448 elders, 75 years and older, in Sweden. Using a mailed survey, QOL was measured using an investigator developed eight-item questionnaire. Factors associated with a low QOL were age and the number of health care symptoms. Not found to influence QOL were gender and the number of chronic diseases. Sixty-three percent of those surveyed lived alone.

Tseng and Wang (2001) explored perceived QOL and related factors in 161 older Taiwanese who lived in nursing homes. Using the QOL Index – Nursing Home Version the findings revealed a significant influence of education and socioeconomic status. Elders who had more interactions with family members reported higher QOL scores. There was no relationship with age. Thirty-five percent of the respondents indicated that they had lived alone before entering the nursing home. In a similar study Lia, Tzeng, Wang, Lee and Amidon (2005) used the WHOQOL-BREF to explore QOL among 488 Taiwanese elders also living in long term care facilities. Demographic variables associated with QOL include educational level and the number of chronic diseases. The researchers suggested that elders' depression might contribute to QOL differences. This finding supported Naumann and Byrne (2004) who studied older depressed male patients using the WHOQOL-BREF. Despite a small sample size ( $n = 39$ ), elders' QOL scores were strongly correlated with depression severity and physical symptoms.

Tsai, Chi and Chou (2004) used the SF-36 to measure QOL in three groups of elders in Taiwan, rural dwelling, urban dwelling and island dwelling. Using a structured questionnaire and personal interviews, 4424 elders over 65-years

old participated. Significant differences were found across the eight QOL scales with the older rural people reporting the lowest QOL. Additional factors contributing to QOL differences were age, gender, number of chronic illnesses, income and education. Less than 30% of the sample studied lived alone.

In a study to determine if QOL and living alone impacted mortality, Crockett, (2002) surveyed 157 chronic respiratory patients who were followed in an outpatient clinic. Data revealed, 'living with a partner was associated with an additional 12 months of life' (p. 309).

In one of the few studies of elder QOL in the United States, Mowad (2004) surveyed 135 veterans between 65-85 years old. The QOL Profile: Seniors Version asked subjects to rate satisfaction and importance with 54 items on a Likert-type scale. Weak, but significant, relationships were found between QOL and health status and QOL and number of illnesses. No differences in QOL were found based on age or education. There is little consensus as to the factors that influence elder's QOL. Further, there is a lack of research on a growing population, elders who live alone and their QOL. A study by Al-Arabi (2006) on "descriptions of challenges to patients with ESRD" in the USA, gave three conceptual findings: 1) Life Restricted with sub-themes "tied down, "left out, and "doing without;" 2) "Stay Alive with sub-themes "love from others", "accept it as part of life" and "trust in God;" and 3) Feeling Good with sub-themes "personal satisfaction" and "being happy." The study concluded that nurses can use holistic care required by patients with ESRD in order to meet the challenges presented to them each day.

For over 20 years, nephrologists and other researchers studying the Medicare ESRD Program have been concerned about the quality of medical care and the quality of life of patients on dialysis (Parker, Hakim, Nissenson, Steinman, & Glassock, 2011; Nissenson, 2014). The Centers for Medicare and Medicaid Services (CMS) have implemented value-based purchasing to improve quality in patient care (Conway, Mostashari, & Clancy, 2013). The CMS calls the ESRD Quality Incentive Program (QIP) their most recent step in fostering improved patient outcomes by establishing incentives for dialysis facilities to meet or exceed performance standards that the CMS has established (Conway et al., 2013). The ESRD QIP measures have been criticized, because they are disease oriented (Nissenson, 2014) and use easy-to-obtain laboratory-based indicators, such as Kt/V and hemoglobin, that do not reflect outcomes that are important to patients and that have had a minimal effect on survival or quality of life (Nissenson, 2014). For example, the CMS has been criticized for the continuing inclusion in the ESRD QIP of dialysis adequacy, when 98% of dialysis facilities are already meeting the target adequacy measure (Nissenson, 2014). In fact, the CMS have recognized that quality measures need to increasingly transition from setting-specific, narrow snapshots to meaningful, broad-based, patient-centered assessments of care along the continuum of treatment (Conway, Mostashari, & Clancy, 2013). They acknowledge that the primary purpose of quality measurement is the delivery of patient-centered, outcome-oriented, quality health care.

A key goal for nephrology clinicians is to provide optimal patient care to maximize patient quality of life (Kimmel, 2013). However, patient perception of quality of life is multifactorial and composed of objective and

subjective physical, emotional, and social aspects (Kimmel, 2013). Sadly, numerous studies suggest that the quality of life of patients with ESRD is below that of general age-, race-, and sex-matched populations (Nissenson, 2014; Kimmel, 2013). Disease-oriented approaches to improve patient quality of life, such as more intense and frequent hemodialysis, which have had disease-related benefits like reducing left ventricular mass and hypertension, have not had a major effect on the quality of life of patients on dialysis. Palliative care is patient centered. Use of palliative care quality metrics is feasible, and palliative care can improve patient quality of life and quality of care (Aldridge, & Meier, 2013).

### **Renal Disease and Quality of Life**

As outlined in the National Quality Strategy, the CMS is holding providers accountable in six priority domains, in which quality measures have been and are being developed for value-based purchasing (Nissenson, 2014; Kimmel, 2013). Three domains—patient experience and engagement, clinical care, and care coordination—are particularly relevant to quality care in the ESRD QIP. The In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) measures patient experience and engagement, but it does not assess patient quality of life or the most important concerns that patients report about living on dialysis. Particularly relevant to the experience and engagement of patients on dialysis is a recent thematic synthesis of 26 papers on perceptions of care of patients with CKD or ESRD and caregivers, which found that patients suffered from bodily deterioration, unyielding fatigue and pain, and loss of freedom and independence. They felt personally vulnerable and were negotiating existential tensions feeling that

they were living on borrowed time. Patients on dialysis reported being ambivalent about continuing it (Tamura, & Meier, 2013).

Another recent paper identifying priorities for research of patients on dialysis and caregivers found that one of their top 10 research questions was what is the psychological and social impact of kidney failure on patients their family, and other caregivers, and can this be reduced? None of the present or proposed ESRD QIP measures tap into patient and caregiver psychosocial and existential experiences of illness or measure the success of interventions to improve them. Again, none of the present or proposed ESRD QIP measures assess the provision of palliative care to patients with ESRD, although most patients on dialysis have multiple comorbidities, a high symptom burden, and a shortened life expectancy. Much like the advance care plan measure, the surprise question could begin as a reporting measure and transition to a clinical measure with one of several outcomes required for a, no, it would not be surprised if the patient died in 6 months, response: advance care planning as described above, palliative care consultation, patient declined palliative care consultation, and referral for hospice evaluation (Nissenson, 2014).

### **Dialysis Adequacy and Quality of Life**

Quality of life is a patient-important quality measure of care that often matters more to patients on dialysis than survival (Nissenson, 2014). Researchers have found that patient-reported quality of life is inversely proportional to the number of troublesome symptoms that patients report, such as pain, and treatment of symptoms improves patient quality of life (Davison, 2010). Although there are limited numbers of studies examining treatment of depression and targeted intervention for psychosocial stressors on the quality

of life of patients on dialysis, researchers believe that it is reasonable to speculate that treatment of these problems holds the promise for improving patient quality of life (Kimmel, 2013). Because quality of life is a uniquely personal perception, it is not a one size fits all concept, and the best assessments of patient quality of life are self-reports (Kimmel, 2013). None of the ESRD QIP measures assess patient-reported quality of life.

The CMS have recognized the need to develop more patient-centered quality metrics in the ESRD QIP. In 2013, the CMS convened a Technical Expert Panel (TEP) to recommend metrics for the Comprehensive ESRD Care initiative. In addition to their disease-oriented measures, this TEP recommended the inclusion of several patient-centered measures: the Kidney Disease Quality of Life, which includes a patient self-report of health; an advance care plan; and an assessment of patient functional status. The nephrology community has raised numerous concerns regarding the TEP-recommended measures (Nissenson, 2014), and the CMS is conducting additional research on the feasibility, usability, and technical considerations of the TEP-proposed measures. Dialysis facility-specific scoring on quality measures will also need to be adjusted for the population served by the facility, because patients who are ethnic minorities and those from impoverished areas vary in their self-reported health ratings and care satisfaction (Nissenson, 2014).

In addition, the CMS reported in the July 11, 2014, Federal Register that they propose in Payment Year 2018 to implement the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) as a clinical measure as well as depression screening, follow-up

for depression, pain assessment, and pain follow-up as reporting measures (Kimmel, 2013). The ICH CAHPS measures patient attitudes toward the quality of care that they receive from nephrologists, other dialysis staff, and the treatment center. In this regard, it is patient centered, but the ICH CAHPS has 58 questions, and it is not clear how the CMS plans to analyze it to further patient-centered care. Because treating pain and depression is known to improve quality of life (Davison, 2010), these measures are potentially among the most promising of the ones proposed for the ESRD QIP if transitioned to clinical measures.

Reporting measures are process measures, and clinical measures are outcome measures. As currently proposed, the pain and depression measures are process measures and not outcome measures. The weakness in this approach is that, although it provides incentives for compliance with the process of screening, it does not do so for ensuring optimal patient outcomes, such as effective management of pain and depression. Process measures may also increase overall costs, discourage innovation in health care delivery, and not add value for patients. For example, for the reporting measure of infection-related dialysis events, dialysis personnel need to enroll, complete training, and report data on events, such as central line-associated blood infections, to the National Healthcare Safety Network (Nissenon, 2014). They also need to contract with a vendor for the administration of the ICH CAHPS. Unless additional detail is provided to fulfill the Payment Year 2018 ESRD QIP measures, dialysis facilities will be free to use a number of different tools. For example, the proposed measure to assess pain does not require use of validated measures in ESRD, such as the numeric 10-point pain scale, which is used in



the Edmonton Symptom Assessment System–revised: Renal and World Health Organization Analgesic Ladder algorithm (Kimmel, 2013). The proposal to measure depression also does not require one of the well validated depression scales for patients with ESRD: the Beck Depression Inventory, the Hospital Anxiety and Depression Scale, or Patient Health Questionnaire-9 (Davison, 2010). Because pain and depression are major contributors to poor quality of life for patients on dialysis, it is important that these symptoms be managed effectively.

However, the use of process measures will allow the various tools to be evaluated for feasibility and ease-of-use in the clinical setting. Starting with process measures will also allow time for a consensus to be reached on which tools adequately guide clinicians to provide quality care, the frequency with which screening should be performed, and potential action measures to be used for positive screens. The CMS, Kidney Care Partners, the American Nephrology Nurses Association, and the Renal Physicians Association all agree that quality measures for patients on dialysis should be reliable, feasible, specific, and actionable. We recognize that there is a relative lack of data on interventions that dialysis providers can undertake to improve quality of life for patients with ESRD and measures to document benefit from the interventions. In addition to the experience that will be gained with the use of process measures to aid the development of outcome measures, federal funding for additional research in this area is urgently needed (ANNA, 2014). Compounding the problems with the ESRD QIP one size fits all approach is that patients on dialysis are a heterogeneous population (Reuben, & Tinetti, 2012). Three groups of patients with ESRD have been described in an article

on a vision for patient-centered care: (1) dialysis as a bridging or long-term maintenance treatment, (2) dialysis as a final treatment destination for patients with a poor prognosis, whose treatment goals are focused on maximizing quality of life with continuation of dialysis as long as physical and psychosocial symptoms are controlled adequately, and (3) active medical management without dialysis (conservative care). Optimal treatment, especially for groups 2 and 3, requires a patient-centered rather than a disease-oriented approach focusing on patients' values, preferences, and goals in light of their prognosis and encouraging informed choices about treatment as a result of shared decision making. Shared decision-making discussions, including advance care planning that focuses on end of life care, have been recommended by the American Society of Nephrology (Reuben, & Tinetti, 2012) and the Renal Physicians Association as a priority before the initiation of chronic dialysis and continuing through the illness trajectory, but, thus far, they have not been incorporated into the ESRD QIP and are not in the planning for the next 3 payment-years.

Advance care planning could begin as a process measure with attestation, which has been proposed by the National Quality Forum in Endorsed Measure 0326. With study, it could transition to an outcome measure with documentation of one of several outcomes: patient declined to participate in advance care planning, patient completed an advance directive, patient agreed to a do not resuscitate order, and/or patient agreed to and participated in the completion of a physician orders for life-sustaining treatment or similar form depending on the state (Tamura, & Meier, 2013).

The clinical practice guideline Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis (Tamura, & Meier, 2013) also recognized that patients with advanced kidney disease represent a heterogeneous population. The guideline noted three groups of patients whose treatment goals are distinctly different: (1) patients who choose aggressive therapy with dialysis without limitations on other treatments; (2) patients with a poor prognosis who choose dialysis but with limitations on other treatments, such as cardiopulmonary resuscitation, intubation, and mechanical ventilation, because they want to balance life prolongation and comfort; and (3) patients who decline dialysis and prefer that the primary goal of care be their comfort. These groups correspond well with those mentioned in the article on a vision for patient-centered care for patients on dialysis described above (Reuben, & Tinetti, 2012). The consistent recognition of distinct groups of patients with advanced kidney disease who have different goals of care underscores the need for advance care planning as a quality metric in this population.

### **Palliative Approach to Dialysis Care**

Palliative approach to dialysis care is a transition from a conventional disease-oriented focus on dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden for maintenance dialysis patients in their final year of life (Centres for Medicare & Medicaid Services, 2012). This transition aligns with palliative care in general as well as with the current demographic of the United States dialysis population.

The chronicity of end-stage renal disease and the uncertainties surrounding the course of the disease and its treatment dictate ongoing

psychosocial assessment of these patients. This study explored the psychosocial and physical involvements of haemodialysis patients. A qualitative study was conducted in one medical unit of a teaching hospital in Accra, Ghana. A sample of 10 females and a male end-stage renal disease patients, undergoing haemodialysis, were recruited. Interviews were audio taped. Data were transcribed verbatim and were analyzed through content analysis, coding and categorization (Achempim-Ansong & Donkor, 2012).

From the experiences narrated by the participants, four main themes emerged, which were divided into sub-themes. These included: psychological experiences (anxiety, depression, anger, worrying, and fear of death); social experiences (intentional isolation, inability to attend social functions, and effect of dialysis on marriage); economic encounters (difficulty in financing the treatment, loss of income, lowered productivity); and physical experiences (problems with sleeping, with fluid and diet restrictions, and with accessing the treatment site). Based on these findings, it is recommended that counselling centers should be attached to dialysis units in order to counsel patients and their families before haemodialysis commences (Achempim-Ansong & Donkor, 2012).

The Centres for Medicare & Medicaid Services (CMS) recognize palliative care as patient- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering (Centres for Medicare & Medicaid Services, 2012). Provision of palliative care is suitable at any age and at any stage in serious illness and it is not exclusively reserved for patients who have exhausted or decided to forgo life-prolonging therapies (Centre to Advance Palliative Care). CMS further explains that as age or illness progress,

and cure or rehabilitation are no longer realistic expectations, care focuses increasingly on palliation (Centres for Medicare & Medicaid Services, 2012).

ESKD is a unique illness in that while there is no cure and it portends a higher mortality rate than do some cancers, some patients with ESKD survive decades while receiving dialysis or following transplantation (U.S. Renal Data System, 2013). Therefore, a one-size-fits-all approach to dialysis care cannot be expected to meet the needs of such a heterogeneous demographic. This heterogeneity reflects a dramatic change in the ESKD patient population over the past 4 decades. A similar shift in how we approach dialysis care should follow suit.

At the inception of the ESKD Medicare Entitlement Program in 1972, the ESKD population was predominantly young and not experiencing progressive comorbid disorders, such as diabetes. Accordingly, the primary goal of care beyond merely extending life was rehabilitation—to enable patients disabled by ESKD to return to work or normal activities. Currently, however, more than half of patients initiating dialysis are >60 years of age and have multiple chronic illnesses in addition to ESRD, so the predominant goal is often restricted to prolongation of life. Patients have a wide spectrum of prognoses, including many with a life expectancy of <1 year (U.S. Renal Data System, 2013; Kurella, Covinsky, Collins, & Chertow, 2007). For this group, the burdens of dialysis care may outweigh its benefits, thus making desirable a palliative approach to dialysis care in which the emphasis is shifted toward minimizing physical and psychologic burdens of standard maintenance dialysis schedules such as fatigue and travel to and from dialysis (Trivedi, 2011).

As the patient nears the end of life, there is an increasing focus on symptom control and patient goals of care and a shift in the approach to dialysis care from conventional to palliative (Institute of Medicine, 2003).

Several domains of care apply within a palliative approach to dialysis care. While the rigorous quality measurement framework outlined by National Quality Forum (NQF) is directly applicable to developing standards of care for conventional dialysis, the current specific measures endorsed by the organization have less relevance to a palliative approach to dialysis (The National Quality Forum, 2013). Patient-centered metrics, such as those focused on quality of life, psychosocial health, and satisfaction with care, are not currently established by CMS or NQF for patients with CKD or ESKD in USA.

However, broad palliative care metrics endorsed by NQF and reported by the Centre to Advance Palliative Care could be adapted to a palliative approach to dialysis care (Tamura, & Meier, 2013; Weissman, Morrison, & Meier, 2010). Potential key domains include eliciting patient goals of care; physical, psychological, and spiritual symptom (symptoms without medical affiliation) management; patient and caregiver satisfaction; and caregiver support (Weissman et al., 2010). Within this framework, dialysis care providers must assume responsibility for initiating discussion of goals and prognosis and encouraging patient-family communication, with the broad understanding that the goals of a palliative approach to dialysis care are to ameliorate symptoms and minimize suffering (Holley, 2005).

Patient and caregiver satisfaction with care is also an important patient-centered domain for maintenance dialysis but has only recently been

evaluated. Studies suggest patient satisfaction with care correlates with perceived quality of life and disease burden, thus supporting its relevance to a palliative approach to dialysis care (Kimmel, 2000; Kirchgessner, Perera-Chang, Klinkner, Soley, Marcelli, Arkossy, Stopper, & Kimmel, 2006).

Finally, social support for caregivers is linked to improvements in psychological health, adherence with treatment, and survival among dialysis patients (Patel, Peterson, & Kimmel, 2005). Whether the patient is undergoing in-center or home dialysis, the quality of life for the caregiver correlates strongly with the patients' level of dependency (Patel et al., 2005; Belasco, Barbosa, Bettencourt, Diccini, & Sesso, 2006). Patients choosing a palliative approach to dialysis care may be in the midst of substantial functional decline, and as this process unfolds, there will likely be more demands and stress on their caregivers (Kurella Tamura, Covinsky, Chertow, Yaffe, Landefeld, & McCulloch, 2009).

### **The Need for Palliative Approach to Dialysis**

In justifying the need for a palliative approach to dialysis care, it is important to underscore the substantial morbidity and mortality among maintenance dialysis patients. The mean age for prevalent dialysis patients in the United States is now 62.7 years, and the prevalence of maintenance dialysis among patients  $\geq 75$  years of age has doubled during the last 2 decades (U.S. Renal Data System, 2013). The dialysis population has an adjusted 76% 1-year survival rate and only a 36% 5-year survival rate (U.S. Renal Data System, 2013). The adjusted mortality rate of maintenance dialysis patients is nearly twice that of adults with cancer and more than twice that of adults with congestive heart failure or stroke (U.S. Renal Data System, 2013).

Patients treated with maintenance dialysis have a high prevalence of debilitating symptoms, which are multifactorial in origin and include uremia, other complications of ESRD, demands of routine dialysis, or comorbid conditions (Cohen, Moss, Weisbord, & Germain, 2006). Physical and emotional symptoms are highly prevalent, are often severe and undertreated, and correlate directly with impaired quality of life among maintenance dialysis patients (Cohen et al., 2006; Feldman, Berman, Reid, Roberts, Shengelia, Christianer, Eiss, & Adelman, 2013).

In addition to the burdens of the dialysis procedure itself, initiation of dialysis often means that patients are committing themselves to intensive patterns of health care utilization, in many instances without full understanding and adequate discussion of the implications (Wong, Kreuter, & O'Hare, 2014). Only 6%–35% of dialysis patients complete advance directives planning; the default then becomes intensive care patterns, including multiple admissions, surgical procedures, and resuscitation attempts at the end of life (Davison, 2006).

Older dialysis patients initiate dialysis in the hospital, and many experience high rates of subsequent hospitalization (Wong et al., 2014). In a study of older Medicare patients starting dialysis, patients were classified into five levels of intensity of care, with the highest level being those who had longer than a 2-week hospital stay and received at least one intensive procedure, such as cardiopulmonary resuscitation, mechanical ventilation, or a feeding tube. In patients  $\geq 85$  years who received the highest intensity of care, the median duration of survival after dialysis initiation was  $<6$  months, with more than a third of that time spent in the hospital (Wong et al., 2014).



Many older adults treated with maintenance dialysis in the United States continue to receive aggressive care focused on life prolongation toward the end of their lives. Almost half (45%) of older United States dialysis patients die in a hospital setting as compared with 35% of Medicare beneficiaries with other severe chronic illness (including congestive heart failure, advanced liver disease, dementia, and chronic obstructive pulmonary disease) (Wong, Kreuter, & O'Hare, 2012). Rates of hospitalization (76%) and intensive care unit (ICU) admission (49%) during the final month of life are also substantially higher than reported for other older Medicare beneficiaries, including those with cancer (of whom 61% are hospitalized and 24% are admitted to an ICU) and heart failure (of whom 64% are hospitalized and 19% are admitted to an ICU) (Wong et al., 2012).

Additionally, older dialysis patients spend twice as many days in the hospital during the last month of life as do Medicare recipients with cancer (9.8 versus 5.1 days) and are three times more likely to undergo an intensive procedure (29% versus 9%). In contrast, rates of palliative care and hospice utilization among dialysis patients at the end of life are extremely low (Wong et al., 2012). Compared with hospice use in patients with terminal cancer (55%) and heart failure (39%), hospice is used in only 20% among dialysis patients and is often only initiated within the last days of life (Wong et al., 2012; O'Connor, Dougherty, Harris, & Casarett, 2013).

These current patterns of death and treatment intensity do not appear congruent with patient wishes when actively elicited. In a study of United States maintenance dialysis patients, only 18% preferred to live as long as possible even if suffering (Hines, Glover, Babrow, Holley, Badzek, & Moss,

2001). Similarly, in a study of patients with advanced CKD in Canada, a majority preferred their care to focus on decreasing pain and suffering, while only 18% favored dialysis to extend their lives (Davison, 2010). More patients wished to die at home (36%) or in an inpatient hospice (29%) than in a hospital (27%) (Davison, 2010).

### **Appropriate use of a Palliative Approach to Dialysis Care**

Given the high prevalence of advanced age, severe comorbid conditions, and high mortality rate among the ESRD population, a substantial proportion of patients undergoing maintenance dialysis may be nearing the end of life and could be candidates for a palliative approach to dialysis care (U.S. Renal Data System, 2013; Kurella et al, 2007; Cohen et al., 2006). Such patients may have difficulty tolerating conventional dialysis regimens, and conversations with patients about preferences and goals of care are warranted. While a discussion of dialysis withdrawal may be considered, many patients and family members may not feel ready to discontinue dialysis completely because of concerns about suffering from ESRD-related symptoms or death within the mean 8-day time frame following dialysis cessation in patients with no residual kidney function (O'Connor et al., 2013; Baumrucker, Carter, Stolick, Oertli, Sheldon, & Morris, 2009; Murtagh, Addington-Hall, Edmonds, Donohoe, Carey, Jenkins, & Higginson, 2007). A palliative approach would not inevitably lead to withdrawal but could provide a transition to this option.

Specific clinical scenarios of maintenance dialysis patients with limited life expectancy in which a palliative approach to dialysis care may be considered include (1) the maintenance dialysis patient who develops a severe illness that causes an abrupt decline in life expectancy, (2) the patient started

on dialysis in the setting of acute kidney injury (AKI) with unclear life expectancy and goals of care, and (3) the maintenance dialysis patient with progressive functional or cognitive decline. In a palliative approach to dialysis care, the transition of care for each of these scenarios would begin with a conversation about the goals of care (O'Connor et al., 2013; Baumrucker et al., 2009; Murtagh et al., 2007).

## **Barriers to a Palliative Approach to Dialysis**

### **Provider Barriers**

Several factors pose barriers to a palliative approach to dialysis care for appropriate patients. For example, while patients with ESKD prefer to be given information about their prognosis by their physicians and those who participate in end-of-life discussions tend to prefer less aggressive care, few dialysis patients report having had even limited discussions about their wishes (Davison, 2010; Wright, Zhang, Ray, Mack, Trice, Balboni, Mitchell et al., 2008; Fine, Fontaine, Kraushar, & Rich, 2005). The dearth of discussions is likely fuelled by provider uncertainty about prognosis and a lack of attention during training (Davison, Jhangri, Holley, Moss, 2006; Quill, & Abernethy, 2013). However, reliable instruments have been developed to identify dialysis patients at highest risk of death, and fellowship training programs have been encouraged to attend more to building this skill (Cohen, Ruthazer, Moss, & Germain, 2010; Moss, Ganjoo, Sharma, Gansor, Senft, Weaner, Dalton et al., 2008).

A lack of understanding of palliative care and/or negative perceptions among patients, caregivers, and providers alike may also function as a barrier to a palliative approach to dialysis care (Davison, Jhangri, & Koffman, 2014;

Thompson Bhargava, Bachelder, Bova-Collis, & Moss, 2008). While current guidelines and practice standards have resulted in most dialysis staff being highly trained to recognize signs of under dialysis and fluid overload, few if any are trained to identify or manage symptoms that may be addressed with palliative care. Even small changes in protocols, such as relaxation of biochemical targets (*e.g.*, for serum phosphorus) or flexibility around dialysis time/prescription, may be viewed as improper or inadequate care, thus leading to conflict among providers who strictly adhere to standard dialysis quality metrics versus those advocating for treatment aligned with the patient's goals.

Economic and regulatory factors also pose barriers. As the payer of 90% of prevalent dialysis patients, the establishment for the targets for dialysis care through its performance standards and frequently includes incentives to ensure an acceptable level of care (U.S. Renal Data System, 2013; Chambers, Weiner, Bliss, & Neumann, 2013). Within the ESRD Prospective Payment System, these incentives exist in the Quality Incentive Program, which is composed of performance metrics that include measures of dialysis dose, avoidance of high hemoglobin levels, and maximizing arteriovenous fistula use while minimizing central venous catheter use (Centres for Medicare & Medicaid Services, 2013a; Centres for Medicare & Medicaid Services, 2013b). End-of-life goals seldom conform to disease-focused incentivized metrics but the failure of a facility to achieve adequate performance on the Quality Incentive Program measures can result in up to a 2% loss of reimbursement for all Medicare beneficiaries in the facility (Weiner, 2011). Therefore, the juxtaposition of incentivized metrics and individualized, patient-centred care may create conflict among the facility management (who

bear the financial penalty for unmet metrics), physicians and other dialysis staff (who have an interest in seeing the facility succeed financially but are also charged with advocating for the best interests of the individual patient), and the patient (for whom goals may not align with quantifiable metrics) (Weiner, 2011).

### Care Delivery Barriers

The lack of wide-scale infrastructure or universal reimbursement for providing staff-assisted home haemodialysis or peritoneal dialysis (PD) contributes to the underuse of a palliative approach to dialysis. Staff-assisted home dialysis, which involves the delivery of haemodialysis or PD with the aid of visiting nurses who assist to varying degrees in the tasks needed for the patient and/or caregiver to safely and effectively perform maintenance dialysis at home, is well established and supported by governments in Canada, France, Belgium, and Denmark, but not in the United States (Castrale, Evans, Verger, Fabre, Aguilera, Ryckelynck, & Lobbedez, 2010; Brown, Dratwa, & Povlsen, 2007; Brown, 2009; Oliver, Quinn, Richardson, Kiss, Lamping, & Manns, 2007). Staff-assisted home dialysis may be particularly attractive over facility-based haemodialysis for elderly, frail patients who would need varying degrees of assistance to perform dialysis at home, thus serving as a palliative approach to dialysis care by avoiding potentially lengthy transportation to and from the dialysis facility and potentially allowing the dose of dialysis to be better tailored to the needs of patients with variable uremic symptoms.

Finally, Centres for Medicare & Medicaid Services (CMS) policy regarding provision of hospice benefits for patients in whom ESRD is the primary terminal condition contributes to the underuse of a palliative approach

to dialysis care by requiring that hospice agencies pay for the costs of continuing dialysis care in such cases (Centres for Medicare & Medicaid Services, 2013a; Centres for Medicare & Medicaid Services, 2013b). Such a proposition is not financially tenable for hospice providers, thus potentially depriving such patients who have a life expectancy consistent with hospice requirements (<6 months) an important aspect of supportive care services.

### **Implementing a Palliative Approach to Dialysis Care**

Reliable instruments have been developed to help identify dialysis patients at highest risk of death within a 6- and 12-month time frame and should be used widely (Cohen et al., 2010; Moss et al., 2008). Nephrology organizations have long advocated shared decision-making and discussion of prognosis for patients with AKI, advanced CKD, and ESRD (Renal Physicians Association & American Society of Nephrology, 2010). Palliative care physicians have recommended that nephrologists and other physicians providing primary care to specific disease populations develop generalist palliative care skill sets (Quill, & Abernethy, 2013). These skill sets include basic management of symptoms and comfort with discussions about patients' preferences for goals of treatment.

It is commonly assumed by clinicians that they do not have the time to discuss end-of-life issues with their patients and families and that sufficient space and privacy are not possible in the open dialysis unit. However, improved expertise would allow clinicians to facilitate such discussions with greater ease and efficiency. Further, patient and family members could be invited to have such discussions as part of care plan conferences that are already required by CMS.

Improving knowledge gaps in this area would require incorporation of skill sets into training program curricula for fellows (such as NephroTalk) and could be achieved through continuing medical education requirements for practicing nephrologists (Schell, Green, Tulsy, Arnold, 2013). Dialysis social workers and nursing staff may be tasked with following up with end-of-life discussions, the assignment of health care proxies, and completion of living wills, but nephrologists must remain primarily responsible for discussion of prognosis and goals of care with patients and families. Involvement of the dialysis team can facilitate the implementation of a palliative approach into dialysis care (Thompson et al., 2008; Singh, Germain, Cohen, & Unruh, 2014).

Although important guidelines, working group publications, and initiatives focusing on palliative care in the ESRD population have increased awareness among nephrology providers, additional research and evidence is needed to inform appropriate standards of care for patients undergoing a palliative approach to dialysis care (Renal Physicians Association & American Society of Nephrology, 2010; Germain, & Cohen, 2007). Many questions remain unanswered, including better identification of patients who could benefit from a palliative approach, dosing and timing of dialysis, optimizing symptom management, and establishing patient-centred goals of care. Nevertheless, given the magnitude of burdens associated with dialysis near the end of life, implementing a palliative approach to dialysis care based on expert opinion is reasonable. Codifying quality metrics for a palliative approach to dialysis care could alleviate concerns of substandard care that does not align with the current disease-focused metrics, thereby promoting patient goals and

improving utilization of appropriate services near the end of life (Renal Physicians Association & American Society of Nephrology, 2010; Germain, & Cohen, 2007).

Key domains for a palliative approach to dialysis care include elicitation of patient goals of care; physical, psychological, and spiritual symptom management; patient and caregiver satisfaction; and caregiver support (Germain, & Cohen, 2007).

A palliative approach to dialysis care by definition targets maintenance dialysis patients nearing the end of life who want to minimize the intensity of care in order to focus on living as comfortably as possible, rather than on meeting current standard-of-care metrics for maximal rehabilitation and survival (Brown et al., 2007). However, given the inflexibility of the in-centre haemodialysis environment, deviations from conventional thrice-weekly dialysis treatment schedules to variable once- or twice-weekly dialysis treatments would be both inefficient and expensive since utilization of and hence reimbursement for each potential treatment in each shift would not be maximized. This further underscores the value of incorporating the option of staff-assisted home dialysis, which could be a way to circumvent the issue of inflexible schedules for in-centre haemodialysis as well as be an option for patients for whom travel to a dialysis facility is burdensome. Existing models of delivering and funding staff-assisted home haemodialysis or PD should be explored for implementation in the United States (Brown et al., 2007).

Finally, facility-specific standardized mortality ratios and quality measures for dialysis patients should be distinct and reported separately for those undergoing a palliative approach to dialysis care versus those seeking



aggressive therapy and rehabilitation. Current practices of aggregating data for all dialysis patients regardless of their goals of care misrepresent the delivered quality of care as reported on public reporting sites, discourage a palliative approach and may have negative financial consequences for dialysis providers (Weiner, 2011; Renal Physicians Association & American Society of Nephrology, 2010). A failure to implement a separate reporting mechanism representing achievement of standards specific to patients choosing a palliative approach could lead to dialysis providers “cherry-picking” and, worse, subjecting patients nearing the end of life to unwanted and possibly detrimental treatment.

#### **Decision Making Regarding Conservative Care**

The number of patients with advanced chronic kidney disease opting for conservative management rather than dialysis is unknown but likely to be growing as increasingly frail patients with advanced renal disease present to renal services. Conservative kidney management includes on-going medical input and support from a multidisciplinary team.

Improving quality of death and access to palliative care is of international concern and in some countries strategies to provide a dignified death in those who are dying have been developed (Department of Health, Social Services and Public Safety (DHSSPS), 2010). In addition there is a need to ensure those with non-malignant disease have equitable access to appropriate and supportive care services towards the end-of-life (Small, Barnes, Gott, Payne, Parker, & Seamark, 2009). The number of people living with end-stage kidney disease (ESKD) has increased in part due to improved access of an aging population to ESKD care but also due to a higher

prevalence of risk factors for chronic kidney disease such as diabetes and hypertension (Levey, Schoolwerth, Burrows, Williams, Stith, & McClellan, 2009). Worldwide, over 1.4 million people receive renal replacement therapy and the incidence is growing annually by approximately 8 % (Schieppati, & Remuzzi, 2005).

Older people with advanced chronic kidney disease have increasing prevalence of co-morbidities (Steencamp, Castledine, Feest, & Fogarty, 2010) and high mortality with a median 2.5 life years remaining for those over 75 years. In addition treatment withdrawal accounts for ~20 % of overall deaths (United States Renal Data System, 2002). Evidence is emerging that dialysis may be of little value, in terms of survival benefit and quality of life, to some frailer patients with multiple co-morbid conditions and poor functional status (Gilg, Rao, & Fogarty, 2013; Murtagh, Addington-Hall, & Higginson, 2011). This has led to questioning of the suitability of renal replacement therapy for ESKD in this population and the impact on quality of life (Gilg, Rao, & Fogarty, 2013; Murtagh, Addington-Hall, & Higginson, 2011).

ESKD is a life-limiting condition associated with substantially increased risks of morbidity and mortality. The glomerular filtration may continue to fall in patients with ESKD until a point is reached where dialysis would normally be initiated to maintain life. In a number of renal units in the UK, patients with ESKD are offered an alternative treatment to dialysis or transplantation known as conservative kidney management where a palliative care approach is adopted and supportive care provided by the multidisciplinary team often in liaison with the community team and general practitioner (GP).

Deciding when to withhold dialysis in this population and provide conservative kidney management as an alternative requires thorough ethical deliberation and complex decision-making. Some patients may not benefit from dialysis but there is limited evidence to guide patients, carers and staff when making this important decision (Murtagh et al., 2011)

There are few service models designed to support this group and little known about how they can be best managed. Ideally, clinicians should be able to accurately distinguish between a patient who will do well on dialysis and a patient who will do poorly; however, any attempt to define such a population has been largely unsuccessful. Some studies have explored age (Murtagh et al., 2011), functional status (Jassal, & Watson, 2009), and comorbidity burden (Murtagh, Sheerin, Addington-Hall, & Higginson, 2011) as predictors of survival but the development of a criterion score to select people for dialysis has not been developed and individualized assessment is always necessary. Informing that assessment with good quality research centred on patient and carer experiences is still required. When these complex decisions are made, the ways in which conclusions are made are difficult to extract, teach and embed in practice.

A recent thematic synthesis of qualitative studies described patients with ESKD and their caregiver perspectives on conservative management and end-of-life care and found only five studies offering a limited insight into quality of life (QOL) and decision making in those managed without dialysis with no exploration of changes over time. A systematic review of conservative management identified literature in this field as widely distributed and difficult to uncover with database search strategies. Findings were limited and

preliminary in nature comparing small groups of patients. Results were not stratified by age or comorbidities and the authors suggest that in patients who opt for non-dialytic management of their kidney disease, guidelines are still required to determine the best clinical practice in this area.

As haemodialysis (HD) has become established as standard care for patients with end-stage renal disease (ESRD), physicians and patients alike may believe that they have little choice but to start HD or other forms of renal replacement therapy. Urgent decisions about starting HD are often made in the acute care setting in which an illness has resulted in acute renal failure or significant worsening of chronic renal failure (Marrón, Martínez Ocaña, & Salgueira, 2005). Patients report being rushed to make decisions at a time when they are too sick to process the information given (Morton, Tong, Howard, Snelling, & Webster, 2010). Studies have shown that patients with ESRD have limited knowledge of their prognosis and that few have been presented with alternative treatment options (Stringer & Baharani, 2011; Davison, 2010).

A Canadian study, two-thirds of patients with chronic kidney disease (CKD) indicated that they chose HD over supportive care because it was their physician's (52%) or family's (14%) wish, and 61% of these dialysis patients regretted having started HD (Davison, 2010). These findings are similar to those of a small qualitative study that showed that at 6 months after the start of HD, only 45% of patients found HD acceptable and that the symptom burden was higher at 6 months than at initiation of dialysis treatment (Stringer & Baharani, 2011). The prevalence of death attributable to withdrawal of dialysis has increased to 25% to 34% in patients 75 years and older (US Renal Data

System, 2008). Additionally, 37% of patients lack decision-making capacity when the decision to discontinue HD is made, which can add to the burden of surrogates. The high level of both regret for having started HD and subsequent withdrawal from HD suggests an approach for this age group that may be incongruent with the patients' wishes, and that treatment burdens may outweigh its benefits.

### **Facilitating Shared Decision Making**

Patients report being comfortable discussing end-of-life issues with both family and nephrology staff. Fifty percent of patients with ESRD reported that they would prefer to have these discussions with their nephrologist and 39% with their family doctor (Davison, 2010). Moreover, patients expect their physicians to initiate these conversations. An overwhelming majority (97%) also prefer detailed information about survival during their first visit to a nephrologist, before giving informed consent for HD. Shared decision-making tools have been developed to predict early or short-term mortality in patients undergoing HD (Couchoud, 2010). These tools classify patients' mortality risk and establish hospice eligibility for those in the highest risk percentiles.

Risk stratification can serve as a good basis for discussion with patients and families when reviewing treatment options. End-stage renal disease has a distinctive disease trajectory when managed conservatively, with a stable functional status maintained through most of the terminal year until a precipitous drop-off is observed in the last 1 to 2 months of life (Murtagh et al., 2011) This disease trajectory most closely resembles that of cancer and thus would be a good fit for a hospice and/or palliative care philosophy.

Palliative care should be offered to all patients who suffer with the burdens of their disease or its treatment. Palliative care does not preclude renal replacement therapy; indeed, it can and should be done concurrently with HD.

While the integration of the principles of palliative care into the HD population has grown in the past decade, barriers remain. Nearly half (48.8%) of graduating nephrology fellows do not feel competent providing end-of-life care (Berns, 2010). Hospice utilization for the dying HD patient remains low, even for those patients who choose to withdraw from HD (Murray, Arko, Chen, Gilbertson & Moss, 2006). Specific programs designed to overcome some of these barriers, such as the Renal Palliative Care Initiative at Baystate Medical Center, have shown promise. Their approach consists of systematic symptom assessment, evidence-based treatment guidelines, morbidity and mortality conferences, bereavement services, systematic advanced care planning, and facilitating hospice referral. This approach provides HD patients and their families with continuous palliative care throughout the disease and bereavement process. It is believed that the principles guiding these programs deserve more widespread consideration and implementation.

### **Theoretical Framework of the Study**

The comfort theory developed in the 1990s by Katharine Kolcaba was used for the study. Kolcaba described comfort as existing in 3 forms: relief, ease, and transcendence. Also, Kolcaba described 4 contexts in which patient comfort can occur: physical, psychospiritual, environmental, and sociocultural. If specific comfort needs of a patient are met, for example, the relief of postoperative pain by administering prescribed analgesia, the individual experiences comfort in the relief sense. If the patient is in a

comfortable state of contentment, the person experiences comfort in the ease sense, for example, how one might feel after having issues that are causing anxiety addressed. Lastly, transcendence is described as the state of comfort in which patients are able to rise above their challenges. (Kolcaba, & Kolcaba, 1991).

Kolcaba includes definitions of key elements of her nursing theory, as well. Health care needs are defined as those needs identified by the patient and/or family in a particular nursing practice setting. Intervening variables are factors that are not likely to change, and over which health care providers have little control. These variables include prognosis, financial situation, social support, and others. Health-seeking behaviors are the behaviors of a patient in an effort to find health. Institutional integrity is the value, financial stability, and wholeness of health care organizations at the local, regional, state, and national levels. Finally, best policies are protocols and procedures developed by an institution for overall use after the collection of evidence (March, & McCormack, 2009).

Comfort is an immediate desirable outcome of nursing care, according to Comfort Theory. Comfort as a product of holistic nursing art. (Kolcaba, 1995). A broader theory for comfort was introduced (Kolcaba, 1994). The theory has undergone refinement and tested for its applicability. The Theory of Comfort considers patients to be individuals, families, institutions, or communities in need of health care. The environment is any aspect of the patient, family, or institutional surroundings that can be manipulated by a nurse or loved one in order to enhance comfort. Health is considered to be

optimal functioning in the patient, as defined by the patient, group, family, or community (Kolcaba, 2010).

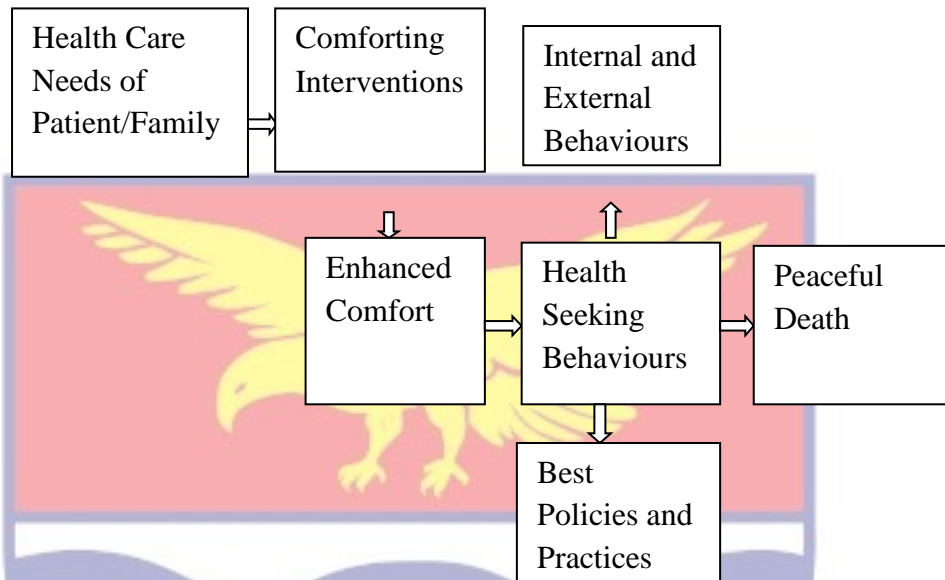


Figure 3: Comfort Theory. Adapted Conceptual Framework from Comfort Theory by Katherine Kolcaba (1991).

### Chapter Summary

A palliative approach to dialysis care could be an important aspect of treating selected patients on maintenance dialysis. As a patient-centered rather than disease-oriented approach to the delivery of dialysis care among patients with limited life expectancy, a palliative approach to dialysis care could alleviate the suffering of such patients. Much work is needed to facilitate incorporation of this approach into the existing dialysis delivery infrastructure globally in order to realize its most effective use.



## CHAPTER THREE

### RESEARCH METHODS

The purpose of this chapter is to describe the study methods. The qualitative descriptive methodology, methodological rationale, and theoretical underpinnings are outlined. The procedures for recruiting participants, data collection, data management, and data analysis are described. Human subject considerations and trustworthiness were also described in this chapter.

#### Research Design

Descriptive qualitative with phenomenological overtone research design was used for this study. Tappen (2011), stated that a qualitative study is an inquiry process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. This design seeks to discover how people make sense of everyday activities and interpret their social world in order to live in socially acceptable ways (Polit & Beck, 2007). This research design was used to gain adequate information from health care professional and patients/family. Moreover, in qualitative research the researcher plays an active role in order to evaluate, explore and assess the perceptions and beliefs of the participants on alternative treatment for ESKD. Also in qualitative studies, the researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting (Tappen, 2011).

A phenomenological study describes the meaning and experience of each participant because it is used to study areas where little is known about the subject (Nieswiadomy, 2008). Phenomenological studies are rigorous,

critical, and systematic (Nieswiadomy, 2008) but the disadvantage of this study is that it is thought provoking and strenuous (Nieswiadomy, 2008).

### **Research Setting**

Initially, the plan was to recruit study participants within the Kumasi Metropolis, where dialysis treatment is offered which are Komfo Anokye Teaching Hospital (KATH), Peace and Love Hospital and Naghe Clinic. Unfortunately, study recruitment at the Peace and Love Dialysis centre was not initiated due to that institutions' suspension of all research study in the hospital.

Therefore the study was done in Komfo Anokye Teaching Hospital (KATH), and Naghe Clinic only. This hospital and clinic are in Kumasi, Ashanti Region of Ghana and these settings were selected purposively because they are two larger centres', out of the three centres that perform dialysis for ESKD. The research was conducted only in the Medicine Department of KATH (Dialysis Centre) and dialysis centre of the other site.

### **Population**

The study population were healthcare practitioners at the dialysis centres and patient/family who had ESRD and were willing to participate in the study. The inclusive criteria is healthcare practitioners (professional nurses and doctors), who had worked in the dialysis centre for two years or more. This is because the professionals may have gathered long term experiences in managing patients with ESKD and are more likely to share in depth first hand experiences. The exclusive criteria included other nurses (enrolled, rotation, student, and community), healthcare assistants, house officers and medical students. These personnel's were excluded due to their short duration of stay

at the dialysis centres because of the rotational nature of their training and being non- members of the centres.

### **Sampling Procedure**

A purposive sampling technique was used to obtain 17 participants (8 healthcare practitioners and 6 patient and 3 family members) out of 30 healthcare practitioners and 32 patients in all the three centres in Kumasi Metropolis. Purposive sampling is done for qualitative studies because it is directed by the purpose of the study and not by statistical calculations (Tappen, 2011). The sample was recruited based on the inclusion criteria of the study, healthcare practitioners from the selected study areas and patients/family diagnosed with ESKD and are on dialysis for treatment. The sample size was determined by the number of participants needed to achieve data saturation (Polit & Beck, 2007). This occurred by the seventeenth interview when the themes were established and nothing new was forthcoming from the interviews.

The inclusion criteria were that the healthcare practitioners who are actively involved in the care of patients diagnosed with ESKD on dialysis or conservatively managed and their family who are willing to articulate their perception, beliefs, experiences and expectations on palliative care.

### **Ethical Considerations**

Participation was voluntary and only consented healthcare professionals, patients on dialysis or conservatively managed and family were included in the study. Authorities at the various hospitals and clinic were informed of the study, formal introductory letters and also permission was sought from the research division unit of KATH, as well as ethical clearance

from the Institutional Review Board, University of Cape Coast. To maintain confidentiality, names of all correspondents were withheld and remained anonymous. The need for the study was explained to all participants to get informed consent from them.

### **Data Collection Instruments**

The researcher used semi-structured interviews based on list of topics and questions that must be addressed in an interview. A written topic guide or interview guide was used to ensure that all question areas are covered. This is to encourage participants to talk freely about all the topics and questions on the guide. Three separate written interview guide were employed, for healthcare professionals', patients and family members of patients with ESKD on dialysis or managed conservatively. A face-to-face interview was used to get information from the respondents. The research instrument also made it possible to provide the respondents response in their own voice (Tappen, 2011). It made it easy to discuss sensitive issues that people might have felt uncomfortable discussing in a group (Evalued, 2006). Though this instrument (face-to-face) interview is time consuming and different interviewers might appreciate and transcribe interviews in different ways, the interview guide allowed detailed questions to be asked. Respondents own words were recorded and this could clarify ambiguities and incomplete answers (Evalued, 2006). The instrument was also used to get a detailed verbatim report of the events surrounding the decision making to opt for palliative care as alternative treatment to dialysis by the respondents.

## Data Collection Procedures

Qualitative data were collected through face-to-face semi-structured interviews. Demographic data were collected first followed by in-depth interviews (using an interview guide, Appendix A). The interviews lasted between 30 to 90 minutes at the offices of the Dialysis Centres. Demographic data included age at the time of the interview, self-reported ethnicity, gender, number of years as a health care professional, rank, number of years diagnosed with ESKD, occupation, educational background, religious affiliation, and duration on dialysis. An audio-recording device was employed to record all interviews. All audio-recordings were transcribed and translated for data analysis. In order to ensure quality control, all transcribed and translated data were double entered and internal consistency was maintained. Data entry and editing were done concurrently. A period of three months was used for administering and collecting all the data. Data were collected from patient/family who were diagnosed with ESKD and on dialysis or managed conservatively and healthcare professionals. Data were collected until saturation was reached.

The researcher evaluated the interview guide questions after the first interview to ensure their accuracy, understandability, and appropriateness for the purposes of this study. The researcher was open to emergent themes that occurred while conducting the interviews. The same interview guide questions were used for all interviews with revisions of the questions occurring. The questions were more specific concerning palliative care as alternate treatment for ESKD. The researcher simultaneously conducted interviews and analysed the transcripts for emerging themes. The participants were asked if they were

willing to be re-contacted, to respond to the researcher's interpretation of emerging themes. This was considered to be a member check and helped establish credibility.

Field notes were kept by the researcher to describe observations made, including body language and emotional reactions of the participant and the time and setting of the interview. In addition, the researcher reflected upon her own thoughts at the time of the interview, which included biases and personal reactions to the interview. Additional reflections were made on the effectiveness of methods and questions used in the interview. These notes were dictated into the tape recorder at the end of each interview and included in the transcriptions. The field notes provided a context for the interview when analyzing the data.

### **Data Processing and Analysis**

All interviews were audiotaped and transcribed verbatim. NVivo 10 software was used to manage and organize the qualitative data (QSR International, Doncaster, Victoria, Australia). The researcher proofread all transcripts by comparing them to the audio tapes.

Qualitative content analysis was used to examine the data for this study and it is the analysis of choice in qualitative descriptive studies (Tappe, 2011). Content analysis is an appropriate choice for a nursing study with sensitive information such as found in this study (Polit & Beck, 2007). With this type of analysis, the researcher looked at the text data and used codes, patterns, and themes to classify the data. The transcript audiotapes were listened to following the interview and then each transcript was read for overall content and compared to the audiotape. A summary of each transcript

was written. The researcher studied each experience separately and then across all the transcripts. Sequential qualitative analysis was conducted as each interview was completed. Excerpts from the transcripts were grouped within NVivo 10. These excerpts would be considered units of meaning and were sentences or paragraphs related by context or content (Graneheim & Lundman, 2004). These units of meaning were given a label or code (Graneheim & Lundman, 2004). An Excel spreadsheet (Microsoft, Inc., Redmond, WA, USA) was developed to examine similarities or differences with lived experiences by age, experiences with ESKD, views and attitude on palliative care.

### **Trustworthiness**

Trustworthiness was established through credibility, transferability, dependability, and confirmability. Credibility refers to confidence in the truth of the data and interpretations of the data (Polit & Beck, 2007, p. 196). To achieve credibility, all interviews were done by the researcher and sufficient time was allotted to each interview (Graneheim & Lundman, 2004). The researcher asked for peer debriefing from the staff (nurses and doctors), patients and relatives to ensure credibility. Discussions between the respondents and researcher were held following reading of each transcript to discuss categories (Graneheim & Lundman, 2004). Lastly, member checks allowed the researcher to have participants' correct errors and add information to ensure credibility (Lincoln & Guba, 1985). In this study, participants who were contacted did not find any errors or need for additional information.

“Transferability is the extent that the findings can be transferred to or have applicability in other settings or groups” (Polit & Beck, 2007, p. 202).

Transferability was enhanced by describing the population and context of the research in depth. Confirmability or objectivity is degree to which study results are derived from characteristics of participants and the study context, not from researcher bias (Polit & Beck, p. 196). Dependability and confirmability were achieved through an audit trail. An audit trail has three parts: the raw data prior to coding, the analysis of the data, and the findings.

### **Reflexivity**

In qualitative studies, the researcher becomes the instrument and is intimately involved in data collection and analysis. It was therefore important to reflect upon biases the researcher may have, a term called reflexivity (Polit & Beck, 2007). This researcher had 10 years' experience with haemodialysis management, hospital emergency experience, and chronic renal nursing experience. The researcher had personal experience with critical incidents in the care of patients. She has also been involved in dialysis and palliative treatment debriefings and attended dialysis and palliative treatment seminars. She is a member of palliative team, in the Family Medicine Directorate (KATH). While conducting the interviews and analysing the data the researcher remained cognizant of these potential biases.

### **Chapter Summary**

Qualitative data were collected through face-to-face semi-structured interviews. Also in qualitative studies, the researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting.



## CHAPTER FOUR

### RESULTS AND DISCUSSION

The previous chapter emphasized on methods used in undertaking this study. This chapter therefore focuses on the findings and discussions from the study carried out. The findings (data) have been captured under sessions which were used in the interviewing processes. Qualitative descriptive methodology was used to study the subjective perception on palliative care as alternate treatment to ESKD. Face to face semi-structured interviews with 17 participants were contacted. There were four (4) overarching themes that emerged from the interviews and they were discussed and analysed using the specific objectives of this thesis. A detailed description of the themes and objectives is summarized and includes illustrative quotes.

#### Results

The data were analysed using content analysis; editing analysis style, in this, the researcher read through the data and interpreted them using meaningful segment and the data were collected using in-depth interview guides. The purpose of data analysis was to organized, provide structure to and elicit meanings from the data collected (Pilot & Beck, 2007), generally searching for recurring regularities or themes. These themes were discussed based on the research objectives:

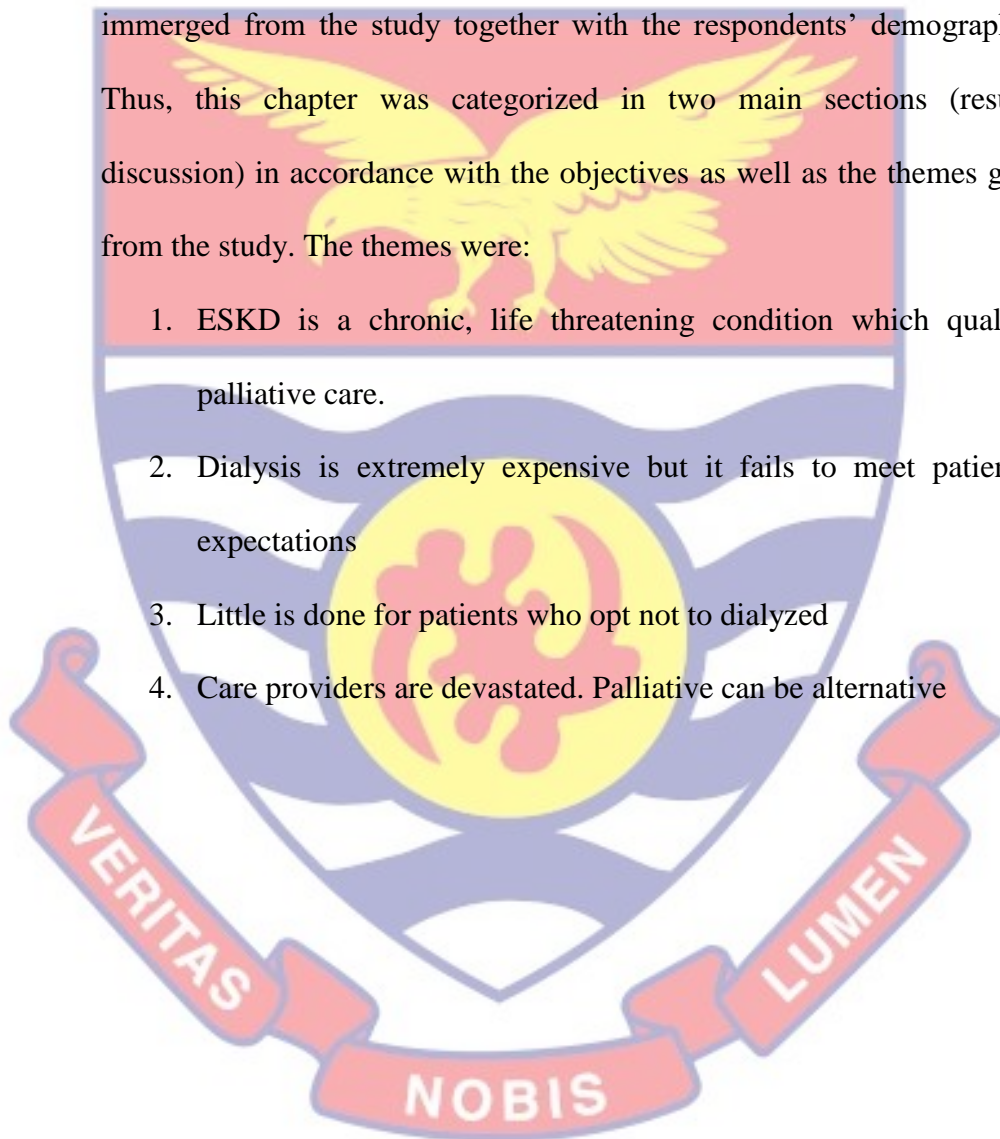
1. explore perceptions of healthcare practitioners on palliative care for ESKD,
2. investigate patients' views and beliefs on palliative care for ESKD,
3. investigate patient family's views and beliefs on palliative care for ESKD and

4. examine healthcare practitioners' attitudes towards patients on palliative care for ESKD.

The search did not only involve discovery of commonalities across the participants but also a search for natural variations. In discussing the results of this study, the researcher developed the practice of following themes that

emerged from the study together with the respondents' demographic data. Thus, this chapter was categorized in two main sections (results and discussion) in accordance with the objectives as well as the themes generated from the study. The themes were:

1. ESKD is a chronic, life threatening condition which qualifies for palliative care.
2. Dialysis is extremely expensive but it fails to meet patient/family expectations
3. Little is done for patients who opt not to dialyzed
4. Care providers are devastated. Palliative can be alternative



### Demographic Characteristics of the Respondents

Table 1- Demographic Characteristics of Health Care Practitioners (N=8)

Respondents	Frequency	Percentage (%)
<b>Profession</b>		
Registered Nurse	5	62.5
Medical Doctors	3	37.5
<b>Age (in years)</b>		
20-29	1	12.5
30-39	4	50.0
40-49	1	12.5
50-59	2	25.0
<b>Sex</b>		
Male	3	62.5
Female	5	37.5
<b>Religion</b>		
Christian	7	87.5
Islam	1	12.5
Traditional	0	0.0
<b>Ethnicity</b>		
Akan	6	75.0
Ewe	1	12.5
Others	1	12.5
<b>Marital Status</b>		
Married	7	87.5
Single	1	12.5
<b>Qualification</b>		
General Nurse	5	62.5
Medical Doctor	3	37.5
<b>Education</b>		
Certificate	0	0.0
Diploma	1	12.5
Bachelor	6	75.0
Masters	1	12.5
<b>No. of years served</b>		
1 – 5	2	25.0
6 – 10	2	25.0
11 – 15	1	12.5
15 – 20	2	25.0
21 and above	1	12.5

Source: Fieldwork, Walters (2016)

Table 2- Demographic Characteristics of Patient/Family (N=9)

Respondents	Frequency	Percentage (%)
<b>Identity</b>		
Patients	6	66.7
Relatives	3	33.3
<b>Age (in years)</b>		
20-29	1	11.1
30-39	4	44.5
40-49	2	22.2
50-59	2	22.2
<b>Sex</b>		
Male	6	66.7
Female	3	33.3
<b>Religion</b>		
Christian	7	77.8
Islam	2	22.2
Traditional	0	0.0
<b>Ethnicity</b>		
Akan	6	66.7
Ewe	1	11.1
Others	2	22.2
<b>Marital Status</b>		
Married	7	77.8
Single	2	22.2
<b>Occupation</b>		
Student	2	22.2
Civil Servants	2	22.2
Traders	3	33.4
Farmers	2	22.2
<b>Education</b>		
No Formal Education	3	33.3
Diploma	1	11.1
Bachelor	4	44.5
Masters	1	11.1

Source: Fieldwork, Walters (2016)

## Demographic Characteristics of the Respondents

The respondents were 17 and their details were captured in the two tables above (tables 1 and 2). The respondents were in two categories; eight (8) healthcare practitioners (five nurses and three medical doctors) from KATH and Naghe Clinic, nine (9) patient/family (six patients and three relatives) who are currently on dialysis. For the healthcare practitioners, five (5) were females and three (3) males while for the patient/family, six (6) were males and three (3) females. Regarding the age ranges of respondents, majority (eight) of them were in the age range of 30-39 years and minority (two) were in 20-29 years. In terms of religion, 14 of the respondents were Christians and three Muslims but none of them was traditional believer. Regarding marital status, 14 are married while three are singles and most of the respondents were Akans (12). Concerning education, ten (10) which is majority of the respondents had bachelor's degree and 3 of them had no formal education.

### **Objective One: Issues on the perceptions of healthcare practitioners on Palliative care as alternative treatment to dialysis treatment of ESKD**

Most respondents elaborated that, palliative care is the treatment given to patients whose disease is not responsive to curative treatment and includes control of pain, other symptoms, and psychological, social, and physical problems. The respondents perceived that patients' living with chronic diseases will die but to promote peaceful death, quality of life should be offered before the inevitable happens, which can be achieved through palliative care.

“Palliative care is a form of treatment given to patients with chronic

diseases to be precise, conditions that are not curable. It is given to patients in order to give them quality life so they can live a prolong life for long both psychological and physical. In short I think it's a form of symptom management so that the patient can have a quality life before he/she dies" (Nurse AAB, PNO).

"Ehm, Palliative care involves care of patients with terminal condition which usually, basically deals with pain relief and then nursing the patient to a peaceful death" (Nurse, NA, SSN).

"I understand it is a care that is provided to relieve pain, discomfort and counseling for patients who are near dying experience" (Doctor KP, PS).

On the issue of what category of patients qualify to be on palliative care, most respondents were of the view that ESKD qualifies for palliative care treatment. Many of the respondents also stated ESKD is in the same category as cancer, making the severity of the condition not less important as cancer which is popularly known for its palliative care treatment.

"All forms of incurable diseases, cancers, end organ failures including ESKD and all that" (Doctor TA, SMO).

"I think those on terminal conditions, like cancers when chemotherapy or radiation therapy will not heal the client completely. People in End Stage Kidney Disease who cannot afford dialysis nor transplant..." (Nurse YJ, SSN).

"Patients with chronic conditions such as cancer, chronic kidney failure, liver failure" (Nurse NA, SNN).

The quotes above make it clear that it is patients with life threatening

conditions that undergo palliative care, which includes cancers, end organ failures and AIDS. They were of the view that palliative care extends beyond cancer management and incorporates other life threatening conditions, which most respondents identified ESKD as inclusive.

Respondents identified that ESKD is a chronic disease and patients with this chronic disorder can become terminally ill requiring palliative care. However, other respondents also reported that, palliative care as a treatment can be offered for ESKD patients who do not opt for dialysis treatment. Many elucidating decisions why patients may opt out of this surviving therapy is solely financial.

There is therefore the need to consider palliative approach to dialysis if patients cannot afford to receive active treatment in the form of renal replacement therapy (RRT).

“...with end stage, the ultimate (treatment) is Renal Replacement which is either dialysis or a transplant so...” (Nurse ABY, NO).

“...if one does not opt for dialysis, then he should have the means for transplant. But in our system, very - very few people can afford that, conservative becomes a choice for many, who for reasons best known to us cannot...” (Doctor AA, SMO).

Many patients with ESKD, at the end stage of their renal disease may need to make informed decision pertaining to their treatment options during counseling before dialysis treatment may be initiated. Conservative management is a choice for many who choose none of the RRT. Regular reviews and management with drugs and diet are considered under the conservative pathway in most instances.

“When we counsel patient for dialysis initiation if they can’t afford (dialysis), doctors review them and put them on drugs. Depending on the cause of the Kidney Disease... and mostly they pop-of” (Nurse, YJ SSN).

It can also be noted that even though conservative management is available patients still face the chance of dying because this option of treatment is not considered as lifesaving. Therefore approach to care for patients with ESKD should not only be centered on the RRT but also palliative approach to dialysis care.

Hence many are of the view that palliative care can be incorporated in the conservative management or become alternative care for treatment of pathway. According to Noble, Meyer, Bridges, Kelly and Johnson (2008) a palliative approach to dialysis care could be an important aspect of treating selected patients on maintenance dialysis.

The above assertion explains the need to incorporate palliative approach to dialysis care in general treatment for ESKD patients and their families. Several respondents were of the view that conservative management which is an option of therapy for patients with ESKD should accommodate palliative aspect of care.

“A conservative approach to the management of ESKD may be more appropriate for patients with advanced, (CKD) who have opted not to have Renal Replacement Therapy (RRT) which dialysis is inclusive” (Doctor DA, R).

“...they can be managed conservatively and that goes for the palliative care as well. So with conservative management, you manage the



symptoms that come up, and then make sure they enjoy quality of life until they die” (Nurse AAB, PNO).

“...we can do conservative management with drugs, and then manage the various symptoms that come with the condition...” (Nurse ABY, NO).

The immediate quote above led the researcher to ask a follow up question which stated, “Do patients know conservative management as an option or you choose it because they did not opt for dialysis?” Respondents answered that, conservative management is done when patients are unable to provide for the cost treatment in both centers where the study was conducted.

“We do it (conservative management) when they actually can’t afford dialysis because for patients with end stage, the ultimate is Renal Replacement which is either dialysis or a transplant so it’s actually because they can’t afford the main treatment for the condition” (Nurse ABY, NO).

“In our case we have dialysis and conservative management, elsewhere transplant is also an option patients can consider during the decision making process, which is not yet available. Currently some are on dialysis and many others are managed conservatively... even when the patients are at the end stage and cannot pay for dialysis, he continues to come for regular reviews. I wouldn’t say that is palliative, he/she is managed conservatively until he dies” (Nurse AAB, PNO)

Palliative care as an approach of care has not yet been utilized by healthcare professionals, though conservative management is an option that patients should benefit from its palliative aspect of care. The researcher asked

further follow up questions to ascertain if services provided at the Dialysis Centers, consider palliative as a treatment service. The respondents stated:

“No – we do not... at the moment we do not have such resource”  
(Nurse TM, SNO).

“Well the moment I have not heard of such plan” (to include palliative care as a service) (Nurse, JY, SSN).

“No, but the nurses do their best with basic education on fluid restriction, advice on nutrition but that does not qualify for palliative care as we know. Pain and discomfort is not attended to. The patient and his family are expected to know ahead of time, what the signs of death are and can embrace that without fear” (Doctor AT, SMO).

Nurses take some initiative to provide some aspect of palliative care even though it does not qualify for the standard palliative care for people living with advanced ESKD where death is eminent;

“The next option is to nurse the patient to death (How do you do that? Asked the researcher) well – considering the definition given by Virginia Henderson and accepted by the WHO. Nursing also has to do with nursing a patient to a peaceful death. Now, with a patient having a terminal disease and then opting to stop dialysis. Now the next very thing to do will be to give palliative care. Palliative care deals with controlling pain, giving support ,managing symptoms so when the patient decided to stop dialysis at home what the family can do is to control some of these measures I have just mentioned” (Nurse TM, SNO).

“We manage with drugs, but medications cannot take care of all the

issues so we prepare the patient towards death” (Nurse NA, SNN).

Notwithstanding, a respondent is of the view that these nursing measures constitute palliative care, when asked, do you do palliative care? She responded:

“Yes, we counsel them on how to go about the patient’s diet, drugs management and others. This is done at the time of conservative management” (Nurse NA, SNN)

On the issue of what will be healthcare professionals’ expectation of patient who wants to choose palliative care to dialysis, respondents expected patients who choose to undergo the palliative pathway to eventually die, thus patients need to know the outcome of their decisions to choose conservative management:

“I expect the patient to know the outcome of such decision is death. Because if the patient is not on any plan like dialysis, complications will set in, soon they become breathless from pulmonary oedema and dialysis becomes indicative. If he still cannot opt for it, the worse will happen.” (Doctor KP, physician specialist).

“Outcome of withdrawal is death, so I expect the patient to understand and that he will be able to cope well with such decision” (Doctor AD, RD)

“So right from the beginning before even the persons starts (doctor’s reviews), when the patient reports and you are giving the education, you let them know the options available, what the patient will require during the disease process. So once you let them know, you prepare them from the very day that they come, and it becomes easier at the

last stage. Knowing really the outcome of not undergoing dialysis at all. You lay out the options. But then, because you see the patient understand the condition and the effect of not doing dialysis, because you are doing palliative care, the patient understands what he is going through and I think they accept that and die peacefully” (Nurse ABY NO).

Another issue revealed under this study is the support services available for patients who choose not to dialyze or withdraw from dialysis therapy because they run out of money but lack social interventions for support.

“In Ghana here, I have not heard of any support but we have patient association here, who meet once a month to discuss their problems and we the health workers provide them with health talks That is the only thing, but for financial support we don’t have any available in Ghana as of now. It is only when the need arises sometimes, that the patient as an individual solicit funds from philanthropies, the radio stations and so forth, but it is something which is not available in Ghana but in few occasions people support those who are going for transplant. Few philanthropists do that with the help of a radio stations. Some people do that ...” (Nurse AAB, PNO).

“As a unit, there are no such support systems presently. Here in Ghana... I actually thought there was kidney foundation supporting centers, but I hadn’t seen any support on their part since I have been here, 3 years now” (Nurse ABY, NO).

“Nothing... Virtually nothing” (Doctor AT, SMO).

## **Objective Two: Issues of the patient beliefs on Palliative Care as an alternative treatment to dialysis treatment of ESKD**

Under this session, patients were interviewed in order to get their candid account with regards to their beliefs on palliative care. On the issue of how patients got to know they have ESKD, most respondents stated that they were told at the hospital by the renal specialist at Teaching Hospitals even though they had visited several general practitioners:

“The doctor (general practitioner) asked me to do some labs. When I was referred here (KATH), and she (renal specialist) confirmed I had End Stage kidney Disease and I required dialysis. The doctor who asked me to undergo dialysis was the first to inform me about the condition after several visits to different hospitals, none of those doctors told me, I had a kidney problem. It was only recently this doctor told me” (KKF).

“...I was referred to KATH, (it was there that) the doctor said I have hypertension that is damaging my eyes and kidneys” (AKP).

“I was referred to a specialist (at KBTH) who... Suggested dialysis for me. I was pregnant 5 years ago when the nurses check my urine, they have protein in it (I was not told what that means). At the time I was due to deliver the blood pressure wasn't coming down, so I had a caesarean session. Later I was going for reviews at Korle-Bu renal clinic (Where I was later told of my diagnosis) and later I become severally ill and was put on dialysis” (NKE).

Most respondent believed that their disease condition is as a result of a spiritual cause.

“The cause... is spiritual so no wonder all these other problems are happening, but someone can also kill you spiritually” (AKP).

“Yes spiritually. Really because I know that very great men of God has fallen sick and are gone, so I take it as part of my full life at a point, we will one day pass on but if this is the course- fine!” (PNA).

“I believe that God allows such conditions to come over people” (SKF).

Others believe that people who have moral problems are the ones that are likely to be affected by Kidney Disease.

...I’m not a drunkard, even prior to that on and so forth; everybody knows I don’t go near them. Even with my feeding, my wife and children know that I will be the first to caution them, if it’s not healthy whenever they are preparing it” (PNA).

“I don’t understand why I could get a problem during pregnancy and it gets me to this extent. I don’t understand any of this...I have never involved myself in any situation that can predispose me to kidney disease. Such as... alcohol consumption, smoking, herbal use and illicit drug use. My religious believe doesn’t allow all these, so why can I have a kidney damage?” (EKN).

Many believe the primary cause is hypertension or Diabetes

“I had been a diabetic and on medications... It was the anti-diabetic drugs that aggravated the condition to end stage Kidney disease” (PNA).

“I believe that, the part of the body which filters the blood is the one that has been damaged. The doctors say that it is as a result of my diabetes and hypertension which I have had over 20 years” (SKF).

Even when the cause of the kidney disease is known to many of the respondents, very few understand what the treatment regimens were;

“She (the doctor) only said I had a kidney disease that requires dialysis. That was the only option she explained to me..... I do not know any alternative treatment to dialysis. Dialysis is the only treatment I know for this condition” (SKF).

The researcher further asked; any other you can remember?

“No... may be transplant” (AKP).

“Aside dialysis there is transplant, but in each case the money involved is not too easy to raise...” (PNA).

Understanding that dialysis treatment is continuous therapy and not affordable, some looked for alternative treatment.

“No, I was only told of dialysis and I did not understand that it had to be a long term treatment. (Long silence...) If I stop dialysis, then I am going to die. I don't know if anything can be done again. Then I will die... I did not know I had to do dialysis all the time so I was worried.

I thought it was only for few sessions and I will no longer require the treatment. It is difficult for me now, knowing that I will require it for a very long time. The financial component makes it difficult for me to do it continuously” (SKF).

“We are in a spiritual camp right now, where many pastors pray for me. I also believe in prayers. If the demon that is causing the illness is

rebuked out of my system, everything shall be well. So we are praying” (AKP).

A respondent described ESKD to be coupled with pain and associated with other symptoms’;

“I have swollen leg; you can’t know where it comes from, cardiac conditions and chest pain. You are almost always told you don’t have enough blood in you” (PNA).

Palliative measures can relieve pain to prevent patients from suffering unnecessarily if patients are not thriving on dialysis. Patients prefer not to unduly overstretch themselves if they are not benefiting from dialysis mostly due to financial restraint.

Patients do not only feel pain as a result of their disease but more so they believe it’s a life threatening condition;

“Yes I believe my condition is life threatening, because I am told that if I do not come for dialysis I will die. If I do not have money to come for treatment, I believe I will die. This is a burden for me” (SKF).

“Oh ...any medical condition can be life threatening, when I’m seriously ill, I feel it (death) can happen, especially if I need blood- I do not receive blood because of my religious faith, but if I die because I do not receive blood, my soul will be in the hands of God” (EKN).

Even though respondents believe ESKD is life threatening condition, they believe little or no attention is provided by their healthcare providers in managing their predicament.



“I vomit, I go to toilet, and these are abnormal things that will not happen to any normal human being. Even though I’m doing the dialysis this continues to come” (PNA).

This made the researcher to ask a follow-up question; “what do your doctors say about them”?

“They ask you have you been running. You answer them (yes, expressed by nodding the head) and they don’t say anything about it. Whether they expect kidney patients to run (have diarrhoea) or not I don’t know” (PNA).

“...but I thought I would be well after several reviews and referrals, but nothing has changed. I feel as bad as I was first told” (AKP).

Immediate quote indicate that dialysis in itself is not meeting the expectation of patients even though they pay so much for the treatment and is an on-going supportive care. Respondents were of the belief that, death is eminent but also a normal process which some expressed preparedness to face in their state:

“God created death as part of human life which is a normal process, every person will die” (SKF).

“Yes... Eh negative entropy – anything that has a beginning has an end. Powerful people like Jesus Christ died... spiritual people like Okomfo Anokye where are they? I have buried so many people, so I’m prepared to face it, except of course nobody likes it” (PNA).

“Life and death are in the hands of God. All of us will die one day” (EKN).

Respondents did not only feel neglected by their health care providers but also reported social neglect. Patients also feel psychological burden associated with social neglect.

“They are fared up with me, they come with me to dialysis but they complain all the time, you see they are tired of following me here end there” (AKP).

“Psychological, for instance some people will want to tell you that it’s because of bad things you have done that is causing you this problem, being paid in your own coin sort of, so that makes it painful to cope. Sometimes you feel socially neglected” (PNA).

“My family worries over my coming for dialysis every time. They think I am wasting money for a treatment which is not going to bring me cure. It is just waste of money” (SKF).

“My family is also very supportive with encouragement and moral support....They do not complain, but I see it to be draining. Every resource that comes to the home has to be channelled for the cost of my treatment. My parents have to stop farming and be with me to the hospital most of the time because my husband teaches” (EKN).

All respondents attributed death to be the doing of God; hence spirituality is highly expressed among people living with Kidney disease as a coping mechanism. Spirituality has a major role to play in palliative care.

“Only God understand... I believe in God, I have strong Christian faith with a supportive congregation who intercede on my behalf... that gives me the hope” (EKN).

“I am a Christian, so it’s my priest who has been encouraging me... The priest says it’s only God who is a healer and I should remain calm” (SKF).

Respondent reported palliative care would be their choice of treatment in order not to waste family’s resources and also prevent suffering before death.

“When dialysis is not helping? Yes if it comes to that I am not benefiting or thriving on dialysis I think I should not continue because the cost is huge. I have three little children who are still in school. The money can be used to support them and we see where God will take me. (Very emotional... tears flowing)” (EKN).

“I will choose the palliative care if I am not going to suffer before dying. I will gladly accept any treatment that takes care of me, other than dialysis which is not expensive and devoid of suffering. I will encourage (care providers) the doctors to include palliative care when people run out of money so that other problems that are associated with kidney failure are addressed. As I said after 4 months if I run out of money and there is no help coming from anywhere. I will opt for palliative care if that service is available for me so that I will not suffer but die peacefully (PNA).

From the above quotations patients desire palliative care towards dying, in order for them not to suffer unduly. Some advocates that palliative care should be implemented and needed awareness creation to improve decision making towards choosing palliative as alternative treatment to dialysis in managing ESRD.

“I will encourage (care providers) the doctors to include palliative care when people run out of money so that other problems that are associated with kidney failure are addressed. Education must also be given to us on other available options” (SKF).

“Yes in fact, please do (implement palliative care) that. Life continues even after death, that’s our belief. So if I’m not getting well via the dialysis and somebody has time to talk to me, discuss my problems and spiritual wellbeing, why not?” (PNA).

Knowing the condition is life threatening, have you made any advanced preparation towards dying? The researcher asked:

“Oh yes, I have discussed with my wife and children. This is not conclusive, knowing our cultures’ perception towards death and sharing of inheritance.... we have not concluded in all area we need to discuss, but gradually we will bet there...” (PNA).

Patients believe their condition is life threatening and they can die as a result but no advanced preparation is planned, especially one that involves healthcare practitioner. On the other hand, a respondent when asked same question as the above stated:

“What is it that is remaining, that I should plan how we can manage after death”? I have not spoken to the kids about it, but I presume they know it can happen because of the rampant hospitalization. My husband has used all his savings; there is nothing to plan about” (EK).

### **Objective Three: Issues of patients relatives on palliative care as an alternative treatment for ESKD**

Most of the respondents are aware of their relatives' diagnoses. Their understanding of the disease is that the kidneys are damaged or not working. They believe it has associated cause:

“He has kidney damage-both kidneys are damaged and that he cannot pass urine” (GNA).

“About 10 years ago when he was diagnosed with kidney disease... Before that, he is a known hypertensive for 20yrs and diabetic for about 3 to 4 years” (MKB).

“The hypertension might have being with him for a long time without us knowing. That may be the cause of the kidney failure, but he is too young for this” (EKH).

In contrast to the above, one respondent believe the cause of the condition is a curse:

“We were told her kidneys are not working, but the illness presented as a curse. This is because all her body was swollen up especially her feet” (AKA).

Family members attribute the cause of ESKD to either clinical cause or spiritual cause. This may explain the reason why some patients sort for clinical interventions and others combine prayers and other spiritual care.

“She believes someone might have cursed her with a certain river deity so we searched for cure from spiritualist and herbalist but to no avail” (AKA).

“We are currently at a prayer camp, the curse should be reversed

(EKH)

Family members have knowledge that ESKD is life threatening and they are devastated about the condition.

“Hmm... sometimes I feel she may not be alive the following day. Her breathing changes, she refuses to eat or drink anything or even speak with anyone. Her temperature becomes so high and she shivers. I think that can cause her death, can't that happen?” (MKM).

“He is always not well, cannot sleep at night- for two weeks all of us have not slept. He is said not to have blood (being anaemic) and cannot urinate, so that (death) can happen” (MKM).

“...the boy is so weak, he complaints of pains all over him. At times you see his breath changes. He goes to toilet often with a lot of blood. This can cause him to die; I am so scared that can easily happen” (EKH).

“Yes we think it can cause her death, many times she cannot breath at night. All the time she needs to be transfused. Looking at how emaciated and the suffering she is going through I do not doubt that this will be her cause of death ... I will not be surprised” (MKM).

The above signifies that relatives are of know, the outcome of the disease and will not be surprised if their relation should die. Dialysis as a treatment coupled with its cost is a great burden for most families.

On the issue of stress and challenges relatives go through in caring for their sick relatives, some respondents elaborated that it is not easy:

“When the symptoms are getting worse. It used to worry the children but now, they are beginning to understand. We have to live with that.

The challenge will be managing other complications that come with kidney disease, like vomiting, not eating, itching, anemia management. ...this is expensive, lack of sleep, loss of interest in everyone and everything. The first year was terrible, but as I said we are praying and believing God for miracle” (MKB).

“This is devastating news for us. It has brought a great silence in the house....We have not yet recovered from the shocking news of his diagnosis. The family is in deep crisis. Issues of travelling from Dorma to here, money for the machine every two days. This gives me sleepless nights” (GNA).

From the above, it can be noted that, aside cost which serve as the major challenge to relatives, the treatment is also time consuming:

“There are challenges, because dialysis is costly. Everything is cash and carry and you are expected to pay without the National Health Insurance (NHI). Not to talk of the cost of the injections Erythropoietin (EPO), transportation and long hours of spending on the machine, it is actually a worry” (GNA).

“Our concerns have to do with money, at times, the dialysis staff contributes and pay for her dialysis treatment. Apart from that, we do not receive any support whether financially or any other from anyone. The family has to find every means possible to pay for the treatment. The cost of dialysis alone is so burdensome. There seems to be no hope. No help is coming from anywhere” (AKA).

“No money is coming from anywhere. We are looking up to Allah, to provide. We do not receive any support whether financially or any other from anyone” (MKM).

On the other hand, a respondent rather has a burden travelling to and fro with other members of the family as a burden.

“...having to travel all the way here only for few hours and return back...” (GNA).

Even though dialysis is extremely expensive patients’ relatives believe that the treatment is not meeting their expectations:

“When he is not on the machine, nothing is done for him. Even at the district hospital, they do not do anything for him; all they ask is that we have to take him to Kumasi for dialysis” (GNA).

“He (her husband) was a bit discouraged hearing that the treatment is not curable” (AKA).

“when she started being sick, the doctor’s said that the machine will cause her kidneys to revive and it will begin to work on its own. But we have done dialysis for several months and no improvement is seen.

He doesn’t look well at all” (MKM).

“She has never been well. Not a single day, this woman will say I feel well. After six months of dialysis there are no signs of her getting well. It is very frustrating” (MKM).

“Even now she is not getting any better, if they know she will die, they should let us know, so that all these monies will not go waste” (AKA).

Respondents are of the view that dialysis is not meeting the expectation of their relation to have an improved health status as assured by



the health care providers. They are of the view that, if dialysis treatment will not enable their loved one to survive they will not decline to choose palliative care as alternate treatment to dialysis if the service is available;

“We will not decline this service if it is available; the cost of dialysis alone is so burdensome. There seems to be no hope. No help coming from anywhere. Now we know the machine cannot cure the illness. At first we thought it will wash off all the waste and he will have the kidneys working again. So an alternative will be a better option knowing that he will die anyway. (Long silence... it is not easy at all)” (GNA).

“Oh... that (palliative care) will be a good idea, because as I said she sometimes would not talk, even when she is in pain, she cries all the time. We don't know anything to do for her to feel ok. If a treatment will take care of these concerns it will benefit her” (MKM).

For me, because of the cost, if the person cannot survive on dialysis they should let her stop. Death is in the hand of Allah the Almighty (MKM).

For a respondent of a younger patient (20 years) she (mother) wanted to keep to conservative management but felt his son is too young to choose the pathway.

“Hmm, it can help but can you look at a young man like this only to die. What can we say if it is the will of God? Little can we do. But we wish we can support him to start the dialysis and come for regular review (conservative) in that case if anything happens you know it is the will of God” (EKH).

This is an indication that relatives are willing to opt palliative care as alternative treatment which is less costly comparable to dialysis. In order for them to have some funds to cater for other needs such as transportations and other health care needs.

**Objective Four: Attitudes of Healthcare practitioners towards patients on palliative care for ESKD**

One of the main issue revealed under this study was how easy or difficult will it be for healthcare practitioner to tell his/her patient that he or she has ESKD which is chronic and most respondents replied that it is a herculean task. Respondents have hard times dealing with end of life issues of people with ESKD. They expressed a burden to disclose patients' diagnosis and prognosis to them. Some described their reaction as mixed feelings which can arise emotion. Others described them as difficult, anxious moment which is disturbing and a terrible experience for a professional to encounter when no hope can be offered to the patient in an incurable condition.

“This comes with mixed feelings it depends on the patients' age. If the patient is very old and cannot afford dialysis... As old as 70-80 years and cannot afford dialysis. It is not that painful or emotion doesn't rise. It is only when the patient is middle aged, or as young as in the teenage upwards and the patient cannot afford” (Nurse AAB, PNO).

“It comes with its own anxiety levels... the difficulty comes in when the patient looks unto you for a kind of hope, knowing that coming to see the specialist can change her situation only to be told it's incurable. It's kind of disturbing” (Doctor KP, RS).

“Very difficult, extremely difficult” (Nurse JY, SSN).

“This is a very difficult thing to do knowing that the disease is incurable. To break the news to a patient, it is a very difficult thing to do, but as a professional, you just have to put yourself together and break the news. You just have to do your job. As much as it is difficult you also have to do your job as a professional” (Nurse TM, SNO).

Most health care professionals were devastated with a hopeless situation. Patients have chronic conditions that require an intervention but there seem little funds available to execute this life sustaining intervention. Dialysis treatment is costly and requires cash and carry payment procedures.

“We will talk about the cost involved, and it is not easy at all telling the patient that they have end stage and they will need dialysis or transplant to survive” (Nurse ABY, NO).

“Sometimes you feel like your hands are tied. This is what is going to help the person yet, there’s no money to execute your plan. The patients can’t be blamed, for the average Ghanaian the cost of dialysis is unbearable. You discuss with the entire family and no sign that situation will change. You feel the situation is helpless” (Doctor, RS).

“Hmm. This is a difficult thing too. I feel very sad, anyway but such is life, patient cannot afford, there is nothing else we can really do” (Nurse JY, SSN).

“I usually don’t want to talk about patients’ impact on my feelings. It is so unbearable, unacceptable so to say, when you tell a patient this is incurable, but I’m sorry I can’t help you”(Doctor TA, SMO)

Even in their devastation Health care professionals still have positive attitude towards patients who may choose the palliative pathway as alternative to dialysis.

“Well I just have to support the patient and do my best for the patient”

(Nurse JY, SSN).

The researcher further asked a follow up question; where your best will include? This is what the respondent answered:

“Rendering all the palliative care services I know I can” (nurse, YJ).

This shows that healthcare practitioners have a positive attitude towards ESKD patients who cannot afford dialysis or withdrawal from dialysis to consider conservative management or palliative care but they find it difficult disclosing the prognosis to them. However, situation may have been different if health workers had adequate training to address such dilemmas. In their difficult circumstance most health care professionals’ felt prepared to perform their professional roles in the absence of requisite skills and expertise they still felt the patients need their support and deserve their best performance of duty.

“...I don’t really have that skill, and I’m not in that capacity but I try my best. I learnt from my seniors and predecessors, I try my best. Yea – I psych myself and I’m prepared to do that. I’m prepared” (Nurse JY, SSN).

“It is a situation we’ve come to live with and so as health providers you should always be prepared to give out such information – I have no formal training to do so but ehm it’s on the job training and we’ve gained enough experience to speak to patients concerning End Stage

Renal Disease” (Nurse MT, SNO).

“Uncomfortable, because I have not been given further training aside medical education to deal with these situations. As a medical officer, I do what I can. But I strongly believe it should be a specialist consultation or clinic for such purposes. But here we are. We find ourselves here, so we do our job as required of us” (Doctor DA, RD).

It can be observed that healthcare professionals are willing to deliver palliative care service as alternative care to patients who cannot afford dialysis treatment or choose the conservative pathway if the needed infrastructure exist.

“...because it’s the only way, you are telling your patient; you need this or you are going to die... since we don’t do real palliative care, it’s very difficult – very (emphasized) (Nurse ABY, NO).”

Respondents reported that palliative care at the moment is not inclusive in their work protocols for managing patients with ESRD but they work together with patients relatives to meet the needs of the patient and their families.

“At the moment we do not have measures to support a patient who is about to die as in given, palliative care... If the patients and their families’ needs do not go anyway contrary to the protocols of the unit or the hospital at large then we can give such request by the patient and family. With palliative care it is not only about the patients, but also about the family so each and every member of the family is involved. The patient as well as his family is involved so we do not have to single out the patient but also his family” (Nurse MT, SNO).

“Well at the moment I have not heard of such plan (to include palliative care in our practice as a protocol (Nurse JY, SSN).

“No, there is no system at the moment in place for them... Any care you give will be very successful with the participation of the people directly involved, I mean cooperation helps in giving out the care you really have to give” (Nurse ABY, NO).

Healthcare professionals felt sad when patients could not pay for dialysis, they felt financial constraint of patients were beyond their obligations to help, many stated that in such situations there is nothing they can do to help the patient financially

“I don’t have an option. It has to do with finances and I cannot help” (Nurse NA, SSN).

“Definitely if the patient can afford for transplant or if his family is ready to do transplant, the patient would start with dialysis so that complications do not set in. So if the patient cannot start dialysis at all, then it is very sad. But as a health worker I don’t have much to do in terms of financial support so though it is sad there is nothing I can do about it” (Nurse AAB, PNO).

“This is a difficult thing too. I feel very sad, anyway but such is life, patient cannot afford, there is nothing else we can really do” (Nurse JY, SSN).

“It is just terrible... Patient then stops because he cannot come in without money” (Doctor TA, SMO).

“When they run out of money nothing can be done, the treatment is cash and carry; they need to pay as they come in. Without money, the

patient has little chance of survival. Besides the cost of dialysis, managing ESKD involves money. All these are to be paid for. With the exception of few of the drugs, even the most expensive ones are not covered by insurance, they need to buy. If they can't have the means to buy, it makes treatment difficult" (Doctor KP, SP).

This is an indication that dialysis is extremely expensive which most patients are unable to afford making some opt not to initiate this costly treatment or withdrew from it if funds run out. In some occasions some end up dying:

"When we counsel patient for dialysis initiation if they can't afford... eventually they relapse or the condition get worsen and they are sent to the A & E as emergency and mostly they pop-off" (Nurse JY, SSN).

"...the patient will definitely die" (Nurse NA, SSN).

Furthermore, respondents were asked on how they give care to ESKD patients. In order to know whether the care is based on their professional skills or the needs of the patient and their family's wishes, most respondents replied that it involves both:

"I give my care based on what the family and the patient wants but as a professional I also do my part. But you have to tell them about the treatment option, so that what they want is what you do for them. The focus of care is towards the patient basically but, with chronic conditions, you cannot focus on the patient only - (you consider) both (Nurse AAB, SSN).

"I combine both what the family wants and on my professional skills, if it goes contrary to the protocols I counsel them and educate them on

what will help them”( Nurse, NA, SSN).

While many focused on both the patient and the family to provide their care, very few were of the view that the family should be the focus of care, at the time the patient is terminally ill.

“At the terminal stage, the family is supported to care for the patient.

The focus should be for the family to provide care” (Doctor, KP, PS).

This respondent had a contrary view to the above:

“The focus is the patient but you don’t ignore the family. Their management is based on life changing modalities. So you will need the family on that” (Doctor TA, SMO).

Asides these, professionals also concentrated on their own skill while consenting to patients’ family wants:

“My profession skill is the pivot of my care, I include patients and their family wants if that will improve on the care we are providing, because some relatives will work together to suggest a decision which is detrimental or against the patients will” (Doctor AD, MO).

It can be inferred from the above quotes that, healthcare practitioners takes into account the needs of the patients themselves and their family. Health professionals do not impose their skills on them. Also health professionals do not ignore the needs and rights of the patient and their families.

It affirms the fact that palliative care is not only for patients with life limiting conditions alone, but also their families. Few of the respondents elaborated that, there is no support for ESKD patients.

“In Ghana here, I have not heard of any support but we have patient



association here, who meet once a month to discuss their problems and we the health workers provide them with health talks. That is the only thing, but for financial support we don't have any available in Ghana as of now. It is only when the need arises sometimes, that the patient as an individual solicit funds from philanthropies, the radio stations and so forth, but it is something which is not available in Ghana. But in few occasions people support those who are going for transplant. Few philanthropists do that with the help of a radio stations. Some people do that (Nurse AAB, PNO).

It was observed that even though the social support is not forthcoming, family support was most often available to the patients; psychologically and financially.

“...family support, they support them financially and psychologically”  
(Nurse NA. SSN).

This implies that poor people in the society who are affected by this terminal disease will end up dying without any comforting measures if they do not receive family support because there is no support services that will assist them to obtain the best of treatment.

Therefore, there is the need for non-governmental bodies, religious bodies, cooperate organizations and associations to come to the aid of these patients. This respondent confirms that:

“Sometimes, during our counseling, we try to let them know if they are Christians they should inform their church or pastors, church leaders. If they are Moslems too; same. We have patients who actually get help from churches and mosques or places that they worship. Some people are actually surviving

on those things. If they can also see their church members may be they can come in and help” (Nurse JY, SSN).

## Discussion

### **Objective One: Issues on the perceptions of healthcare practitioners on Palliative care as alternative treatment to dialysis treatment of ESKD**

From the quotes under this session, it is clear that patients with life threatening conditions are those that undergo palliative care, which includes cancers, end organ failures and AIDS. They were of the view that palliative care extends beyond cancer management and incorporates other life threatening conditions, which most respondents identified ESKD as inclusive. Respondents identified that ESKD is a chronic disease and patients with this chronic disorder can become terminally ill requiring palliative care.

However, other respondents also reported that, palliative care as a treatment can be offered for ESKD patients who do not opt for dialysis treatment. Many elucidating decisions for patients to opt out of this surviving therapy (dialysis) is solely financial. There is therefore the need to consider palliative approach to dialysis if patients cannot afford to receive active treatment in the form of renal replacement therapy (RRT).

The respondents’ response to palliative care as alternative of ESKD to dialysis is consistent with a study by Tamura and Meier (2013) which stated that, many dialysis patients may desire a palliative approach to dialysis care, which focuses on aligning patient treatment with patients’ informed preferences. Also Centres for Medicare & Medicaid Services in 2012 reported that Palliative approach to dialysis care is a transition from a conventional disease-oriented focus on dialysis as rehabilitative treatment to an approach

prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden for maintenance dialysis patients in their final year of life. Similarly, in a study of patients with advanced CKD in Canada, majority preferred their care to focus on decreasing pain and suffering, but quite a number 18% favored dialysis to extend their lives (Davison, 2010).

**Objective Two: Issues of the patient beliefs on Palliative Care as an alternative treatment to dialysis treatment of ESKD**

Patients' beliefs on palliative care as an alternative treatment to dialysis treatment of ESKD were mainly centered on most respondents stating that they were told at the hospital by the renal specialist at Teaching Hospitals even though they had visited several general practitioners. This gives clear indication that there was inadequate knowledge and understanding of palliative treatment that led to late referrals of chronic kidney disease. This finding does not support Kimmel (2000) and Kirchgessner et al. (2006) who stated that patient satisfaction with care correlates with perceived quality of life and disease burden, thus supporting its relevance to a palliative approach to dialysis care. Also this study is consistent to Wong et al. (2014) study which indicated that, patients are committing themselves to intensive patterns of health care utilization, in many instances without full understanding and adequate discussion of the implications

Most respondents believed that their disease condition is as a result of a spiritual cause as culturally symbolic with general body swelling. This is in conformity with study by Weissman et al. (2010) which stated that Potential key domains in palliative care as alternative treatment in ESKD to dialysis

include eliciting patient goals of care; physical, psychological, and spiritual symptom management; patient and caregiver satisfaction; and caregiver support. Others believe that people who have moral problems such as smoking and alcohol use are likely to be affected by kidney disease.

All respondents attributed death to be the doing of God; hence spirituality is highly expressed among people living with Kidney disease as a coping mechanism. Spirituality has a major role to play in palliative care

Many on the other hand believe the primary cause of ESKD is hypertension or Diabetes. Very few of patient respondents understand what the treatment regimens are, believing that dialysis as a therapy has the capacity to revamp end stage kidney Disease to function as normal, which is in line with a study done by Levey et al. (2009) that stated that higher prevalence of risk factors for chronic kidney disease such as diabetes and hypertension.

Patients suffering from ESKD believe they receive little or no attention from their healthcare providers in managing their predicament. Especially the time that they are not dialyzing.

Respondent were of the belief that, death is eminent but normal process which they expressed being prepared to face death in their state

Several respondents were of the view that conservative management which is an option of therapy for patients with ESKD should accommodate palliative aspect of care. This supports DHSSPS (2010) report that indicated that number of patients with advanced chronic kidney disease opting for conservative management rather than dialysis and that conservative kidney management includes on-going medical input and support from a multidisciplinary team.

### **Objective Three: Issues of patients relatives on palliative care as an alternative treatment for ESKD**

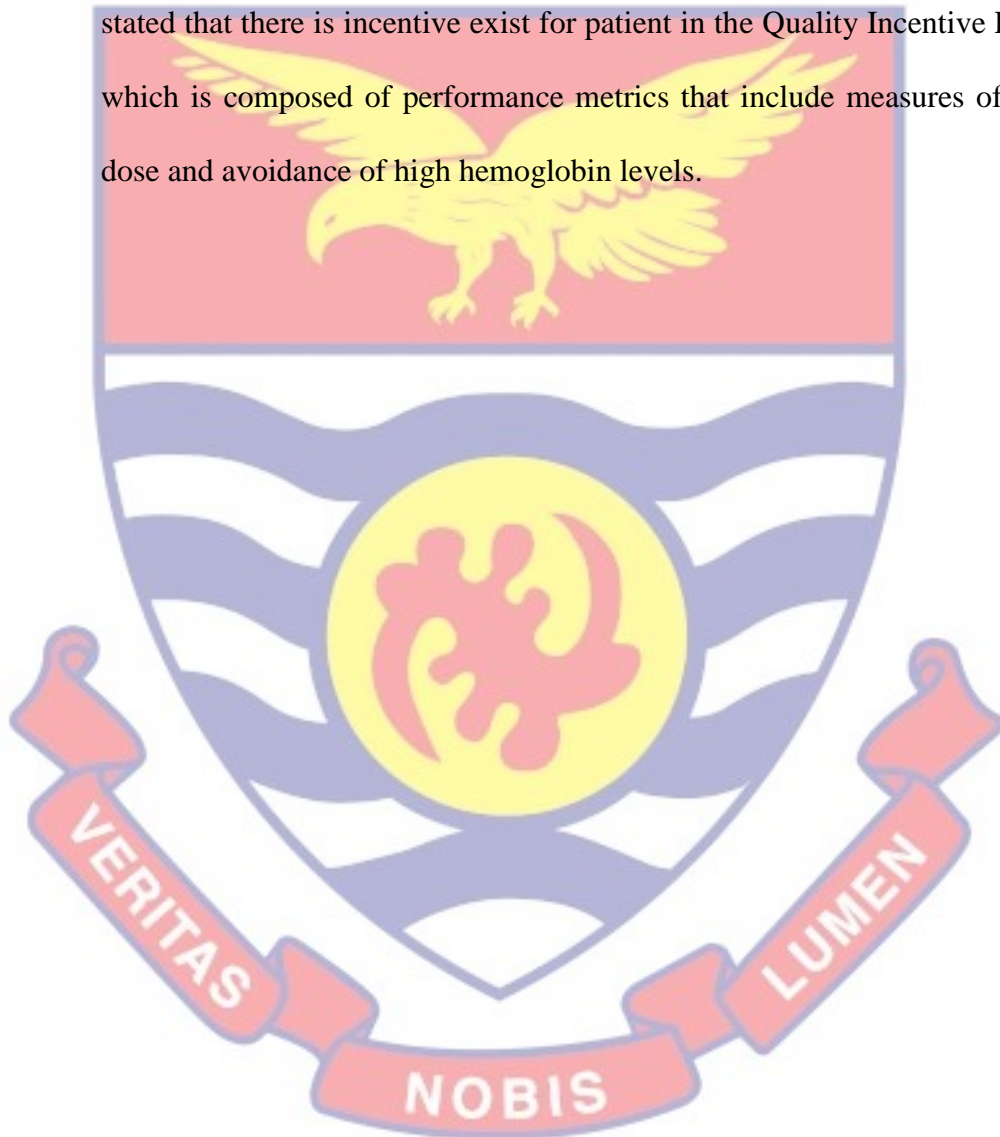
Most of the respondents were made aware of their relatives' diagnoses at the time of hospitalization and their understanding of the disease is that their kidneys are damaged or not working and needed initiation of dialysis treatment. This is in support of a study by Wong et al. (2014) which stated that dialysis patients initiate dialysis in the hospital, and many experience high rates of subsequent hospitalization.

### **Objective Four: Attitudes of Healthcare practitioners towards patients with ESKD**

Respondents have hard times dealing with end of life issues of people with End Stage Kidney Disease. They expressed a burden to disclose patients' diagnosis and prognosis to them. Some described their reactions as mixed feelings which can arise emotion. Others described it as difficult, anxious moment which is disturbing and a terrible experience for a professional to encounter when no hope can be offered to the patient in an incurable condition. Studies by Davison (2010), Wright (2008) and Fine (2005) are in line with the finding of this study when they stated that several factors pose barriers to a palliative approach to dialysis care for appropriate patients. For example, while patients with ESKD prefer to be given information about their prognosis by their physicians and those who participate in end-of-life discussions may tend to prefer less aggressive care, few dialysis patients report having had even limited discussions about their wishes.

Most health care professionals were devastated with a hopeless situation. Patients have chronic conditions that require an intervention but

there seem little funds available to execute this life sustaining intervention. Dialysis treatment is costly and requires cash and carry payment procedures. A report from U.S. Renal Data System (2013) stated that economic and regulatory factors also pose barriers. However Centres for Medicare & Medicaid Services (2013) report is not in consistent with this study when they stated that there is incentive exist for patient in the Quality Incentive Program, which is composed of performance metrics that include measures of dialysis dose and avoidance of high hemoglobin levels.



## CHAPTER FIVE

### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter gives an overview of the study and presents the summary of major findings, conclusions and recommendations. The primary objective of the study is to establish patient/family and healthcare practitioners' perception on palliative care as alternate to dialysis in the treatment of ESKD in Kumasi Metropolis. The study focused on the perceptions of patients, relatives and health care providers on palliative care as an alternate to dialysis in the treatment of ESKD.

#### **Summary**

In the background study, a brief explanation to palliative care and dialysis treatment was given. The purpose of the study was highlighted, and reason for undertaken this study was made. It expresses the definition of palliative care and dialysis treatment as well as people who qualify to undergo palliative and types of palliative care services for patients with CKD. Also highlight on some of the challenges faced in understanding the information from respondents. The aim of the study is to evaluate perception of patient/family and healthcare practitioners on palliative care as alternate to dialysis in the treatment of end-stage kidney diseases in Kumasi Metropolitan. The study was conducted in Kumasi Metropolis. The research setting is the Komfo Anokye Teaching Hospital and Nahge clinic where management of ESKD with Dialysis is provide.

#### **Major Findings**

1. As regards issues on the perceptions of healthcare practitioners on palliative care as alternative treatment to dialysis treatment of ESKD,

Most respondents elaborated that, palliative care is the treatment given to patients whose disease is not responsive to curative treatment and includes control of pain, other symptoms, and psychological, social, and physical problems. The respondents perceived that patients' living with chronic diseases will die but to promote peaceful death, quality of life should be offered before the inevitable happens, which can be achieved through palliative care. They were of the view that palliative care extends beyond cancer management and incorporates other life threatening conditions, which most respondents identified ESKD as inclusive.

2. Concerning issues of the patient beliefs on Palliative Care as an alternative treatment to dialysis treatment of ESKD. Patients' beliefs on palliative care as an alternative treatment to dialysis treatment of ESKD. All respondents attributed death to be the doing of God; hence spirituality is highly expressed among people living with Kidney disease as a coping mechanism. Spirituality has a major role to play in palliative care
3. With issues of patients' relatives on palliative care as an alternative treatment for ESKD, most of the respondents said they were made aware of their relatives' diagnoses at the time of hospitalization and their understanding of the disease was that their kidneys are damaged or not working and needed initiation of dialysis treatment. However no one mentioned palliative care as another form of treatment.
4. Attitudes of Healthcare practitioners towards patients with ESKD. Respondents have hard times dealing with end of life issues of people



with End Stage Kidney Disease. They expressed a burden to disclose patients' diagnosis and prognosis to them. Some described their reactions as mixed feelings which can raise emotion. Others as difficult, anxious moment which is disturbing and a terrible experience for a professional to encounter when no hope can be offered to the patient in an incurable condition.

### **Conclusions**

The study reveal that palliative care is the treatment given to patients whose disease is not responsive to curative treatment and includes control of pain, other symptoms, and psychological, social, and physical problems. The survey has made it evidently clear that most of the respondents perceived that patients' living with chronic diseases will die but to promote peaceful death, quality of life should be offered before the inevitable happens, which can be achieved through palliative care. The study also demonstrated that patient/family believe on palliative care as an alternative treatment to dialysis treatment in the care of ESKD. Healthcare practitioners found it difficult to accept that patient should go for palliative care. It is concluded that at the advanced stage of ESKD where dialysis will not improve quality of life, palliative nursing care is the alternative treatment to dialysis in the management of ESKD.

### **Recommendations**

#### **Recommendations for Practice**

The results of the study revealed that healthcare practitioners find it difficult to tell patients/family about the advanced nature of their condition (ESKD). Based on this finding, healthcare practitioners should always make

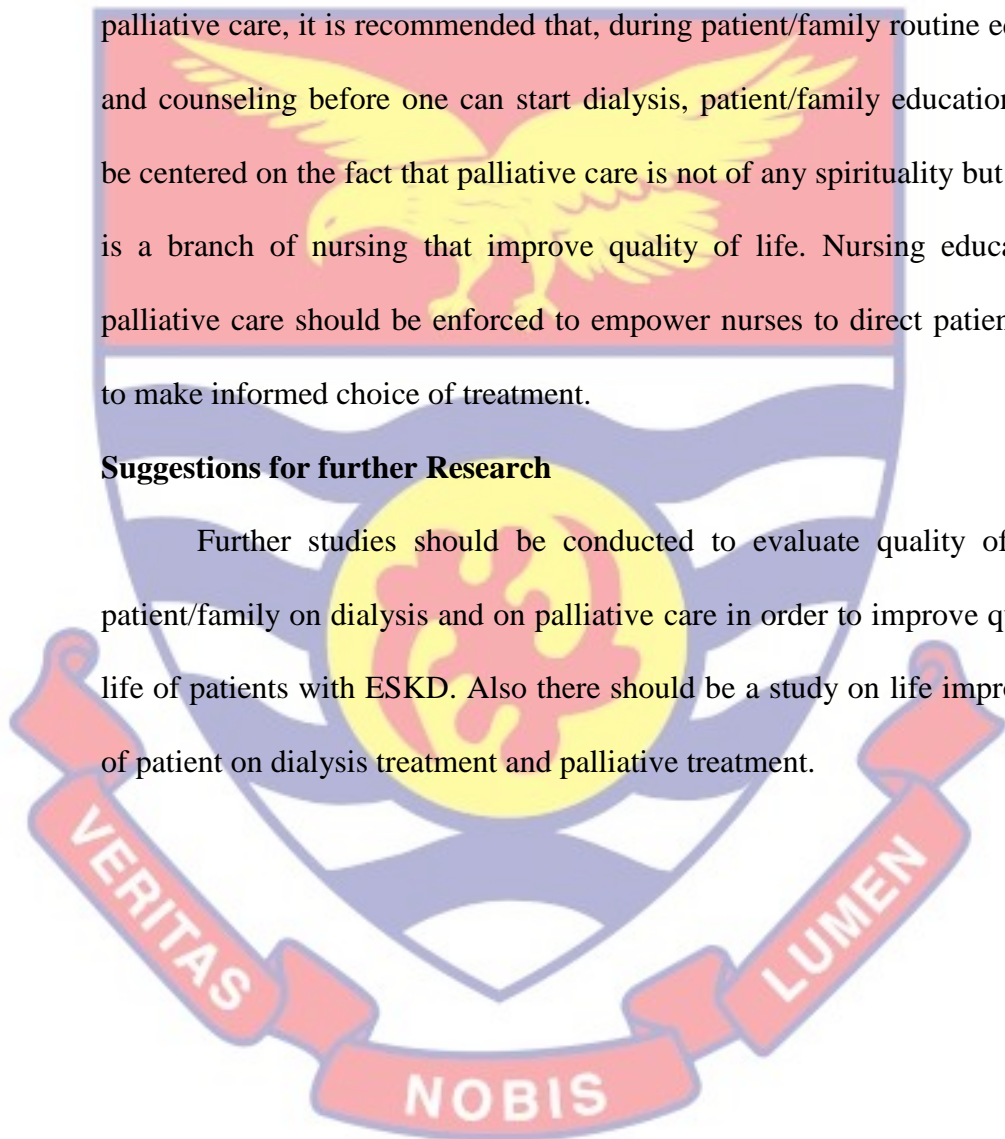
treatments options available for patient/family to make an informed choice. Palliative as an alternate management for ESKD should be part of treatment options in the management of all patient/family with ESKD.

### **Recommendations for Education**

Based on the finding that spirituality has a major role to play in palliative care, it is recommended that, during patient/family routine education and counseling before one can start dialysis, patient/family education should be centered on the fact that palliative care is not of any spirituality but rather it is a branch of nursing that improve quality of life. Nursing education on palliative care should be enforced to empower nurses to direct patient/family to make informed choice of treatment.

### **Suggestions for further Research**

Further studies should be conducted to evaluate quality of life of patient/family on dialysis and on palliative care in order to improve quality of life of patients with ESKD. Also there should be a study on life improvement of patient on dialysis treatment and palliative treatment.



## REFERENCES

- Achempim-Ansong, G., & Donkor, E. S. (2012). Psychosocial and physical experiences of haemodialysis patients in Ghana. *Africa Journal of Nursing and Midwifery*, *14*(1), 38-48.
- Al-Arabi. S. (2006). Quality of life: Subjective Descriptions of Challenges to patients with End Stage Renal Disease. *Nephrology Nursing Journal*, *33*(3), 285-293.
- Aldridge, M. D., Meier, D. E. (2013). It is possible: Quality measurement during serious illness. *Journal of American Medical Association of Internal Medicine*, *173*, 2080–2081.
- ANNA (2014). Letter to CMS Regarding IMPAQ Technical Expert Panel (TEP) Measure Development Process. Retrieved from [https://www.annanurse.org/download/reference/health/activities/3\\_7\\_14.pdf](https://www.annanurse.org/download/reference/health/activities/3_7_14.pdf) on 23/07/16.
- Bakwell, A., Hinggins, R., & Edmunds, M. (2002). Quality of life in peritoneal dialysis patients: Decline over time and association with clinical outcome. *Kidney International*, *61*, 239-248.
- Baumrucker, S. J., Carter, G. T., Stolick, M., Oertli, K. A., Sheldon, J. E., & Morris, G. M. (2009). The case for palliative dialysis. *American Journal of Hospice Palliative Care*, *26*, 303–307.
- Belasco, A., Barbosa, D., Bettencourt, A. R., Diccini, S., & Sesso, R. (2006). Quality of life of family caregivers of elderly patients on haemodialysis and peritoneal dialysis. *American Journal Kidney Diseases*, *48*, 955–963.

Berns, J. S. (2010). A survey-based evaluation of self-perceived competency after nephrology fellowship training. *Clinical Journal of American Society of Nephrology*, 5(3), 490–496.

Bowling, A., Banister, D., Sutton, S., Evans, O., & Windsor, J. (2002). A multidimensional model of the quality of life in older age. *Ageing & Mental Health*, 6, 355-371.

Brown, E. A, Dratwa, M., & Povlsen, J. V. (2007). Assisted peritoneal dialysis—an evolving dialysis modality. *Nephrology Dialysis and Transplant*, 22, 3091–3092.

Brown, E. A. (2009). Peritoneal dialysis in the elderly. *Contribution to Nephrology*, 163, 264–269.

Carson, R. C., Juszczak, M., Davenport, A., & Burns, A. (2009). Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clinical Journal for American Society of Nephrology*, 4(10), 1611–1619.

Castrale, C., Evans, D., Verger, C., Fabre, E., Aguilera, D., Ryckelynck, J. P., & Lobbedez, T. (2010). Peritoneal dialysis in elderly patients: Report from the French Peritoneal Dialysis Registry (RDPLF). *Nephrology Diaylysis and Transplant*, 25, 255–262.

Centers for Medicare & Medicaid Services (2013a). ESRD Quality Incentive Program. Retrieved from <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ESRDQIP/index.html> on 02/01/16

Centers for Medicare & Medicaid Services. (2013b). Final CY, End-Stage Renal Disease Prospective Payment System. 1352–F2012.

Centre to Advance Palliative Care (2013). Defining palliative care: Building a palliative care program. Retrieved from <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc> on 3/3/16.

Centres for Medicare & Medicaid Services (2012). Centre for Clinical Standards and Quality/Survey & Certification Group. Ref: S&C 12-48-NH. Retrieved from <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-48> on 7/03/16.

Chambers, J. D., Weiner, D. E., Bliss, S. K., & Neumann, P. J. (2013). What can we learn from the U.S. expanded end-stage renal disease bundle? *Health Policy, 110*, 164–171.

Chandna, S. M., Da Silva-Gane, M., & Marshall, C. (2011). Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrology Dialysis Transplantation, 26*(5), 1608–1614.

Cohen, L. M., Moss, A. H., Weisbord, S. D., & Germain, M. J. (2006). Renal palliative care. *Journal of Palliative Medicine, 9*, 977–992.

Cohen, L. M., Ruthazer, R., Moss, A. H., & Germain, M. J. (2010). Predicting six-month mortality for patients who are on maintenance hemodialysis. *Clinical Journal of American Society of Nephrology, 5*, 72–79.

Conway, P. H., Mostashari, F., & Clancy, C. (2013). The future of quality measurement for improvement and accountability. *Journal of American Medical Association, 309*, 2215–2216.

Couchoud, C. (2010). Dialysis: can we predict death in patients on dialysis? *National Review of Nephrology, 6*(7), 388–389.

Crockett, A., Craston, J., Moss, J., & Alpers, J. (2002). The impact of anxiety, depression and living alone in chronic obstructive pulmonary disease. *Quality of Life Research, 11*, 309-316.

Davison, S. N. (2006). Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clinical Journal of American Society of Nephrology, 1*, 1023–1028.

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*, 195–204.

Davison, S. N., & Torgunrud, C. (2007). The creation of an advance care planning process for patients with ESRD. *American Journal of Kidney Diseases, 49*(1), 27-36.

Davison, S. N., Jhangri, G. S., & Koffman, J. (2014). Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *British Medical Journal Support Palliative Care*. doi:10.1136/bmjspcare.

Davison, S. N., Jhangri, G. S., Holley, J. L., Moss, A. H. (2006). Nephrologists' reported preparedness for end-of-life decision-making. *Clinical Journal of American Society of Nephrology, 1*, 1256–1262.

Department of Health and Human Services (2002). Profile of older Americans. Retrieved from [http://www.aoa.gov/prss/fact/alph/fact\\_global\\_ageing.asp](http://www.aoa.gov/prss/fact/alph/fact_global_ageing.asp) on 12/005/16.

Department of Health, Social Services and Public Safety (DHSSPS). (2010). Living matters: dying matters. A palliative and end of life care strategy

for adults in Northern Ireland, 2010. Retrieved from [http://www.dhsspsni.gov.uk/8555\\_palliative\\_final.pdf](http://www.dhsspsni.gov.uk/8555_palliative_final.pdf) on 02/03/16.

Department of Statistics, Ministry of the Interior, ROC (1997). Report on the Old Status Survey of R.O.C. in 1996. Department of Statistics, Ministry of the Interior, ROC, Taipei.

Elsharif, M., & Elsharif, E. (2011). Causes of end-stage renal disease in Sudan: a single-center experience. *Saudi Journal of Kidney Diseases Transplant*, 22(2), 373.

Evaluated. G. (2006). *Advantages of interviews*. Retrieved from [www.evaluated.bcu.ac.uk/tutorial/4c.htm](http://www.evaluated.bcu.ac.uk/tutorial/4c.htm) on 17/11/15,

Fassett, R. G., Robertson, I. K., Mace, R., Youl, L., Challenor, S., & Bull, R. (2011). Palliative care in end-stage kidney disease. *Nephrology*, 16(1), 4-12.

Feldman, R., Berman, N., Reid, M. C., Roberts, J., Shengelia, R., Christianer, K., Eiss, B., & Adelman, R. D. (2013). Improving symptom management in haemodialysis patients: Identifying barriers and future directions. *Journal of Palliative Medicine*, 16, 1528–1533.

Fine, A., Fontaine, B., Kraushar, M. M., & Rich, B. R. (2005). Nephrologists should voluntarily divulge survival data to potential dialysis patients: A questionnaire study. *Peritoneal Dialysis International*, 25, 269–273.

Germain, M., & Cohen, L. M. (2007). Renal supportive care: View from across the pond: the United States perspective. *Journal of Palliative Medicine*, 10, 1241–1244.

Gilg, J., Rao, R., & Fogarty, D. (2013). UK Renal Registry 16th Annual Report: Chapter 1 UK Renal Replacement Therapy Incidence in 2012: National and Centre-specific Analyses. *Nephrology Clinical Practice*, 125, 1–28

Giri, M. (2004). Choice of renal replacement therapy in patients with diabetic end stage renal disease. *Edna Erca Journal*, 30 (3), 138–42.

Global Action on Ageing (2002). International Plan of Action on Ageing.

Retrieved from

[www.globalageing.org/waa2/documents/international\\_plan2002.doc](http://www.globalageing.org/waa2/documents/international_plan2002.doc) on 24/05/16.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.

Groothoff, J. W., Grootenhuis, M. A., Offringa, M., Stronks, K., Hutten, G. J., & Heymans, H. S. A. (2005). Social consequences in adult life of end-stage renal disease in childhood. *Journal of Paediatrics*, 146(4), 512-517.

Gunda, S., Thomas, M., & Smith, S. (2005), National survey of palliative care in end stage renal diseases in the UK. *Nephrology Dialysis Transplantation*, 20, 392-95

Hackett, A. S., & Watnick, S. G. (2007). Fellows' Forum: Withdrawal from dialysis in end-stage renal disease: medical, social, and psychological issues. *Seminars in Dialysis*, 20(1), 86- 90.



Heidenheim, A. P., Muirhead, N., Moist, L., & Lindsay, R. M. (2003). Patient quality of life on quotidian hemodialysis. *American Journal of Kidney Diseases*, 42 (1 Suppl), 36–41.

Hellstrom, Y., & Hallberg, R. (2001). Perspective of elderly people receiving home help on health care and quality of life. *Health and Social Care in the Community*, 9, 61-71.

Hines, S. C., Glover, J. J., & Babrow, A. S. (2001). Improving advance care planning by accommodating family preferences. *Journal for Palliative Medicine*, 4(4), 481–489.

Hines, S. C., Glover, J. J., Babrow, A. S., Holley, J. L., Badzek, L. A., & Moss, A. H. (2001). Improving advance care planning by accommodating family preferences. *Journal of Palliative Medicine*, 4, 481–489.

Holley, J. L. (2005). Palliative care in end-stage renal disease: Focus on advance care planning, hospice referral, and bereavement. *Seminal Dialysis*, 18, 154–156.

Institute of Medicine (2003). Improving palliative care for cancer: Summary and recommendations. Retrieved from [http://iom.edu/~media/Files/Report Files/2003/Improving-Palliative-Care-for-Cancer-Summary-and-Recommendations/PalliativeCare8pager.pdf](http://iom.edu/~media/Files/Report%20Files/2003/Improving-Palliative-Care-for-Cancer-Summary-and-Recommendations/PalliativeCare8pager.pdf) on 4/4/16.

Irish Kidney Association (2003). Chronic dialysis services. Support 10, Autum, 10-11 Jindal, K. K. & Goldstein, M. B. (1988), Urea kinetic modelling in chronic haemodialysis: benefits, problems and practical solutions. *Seminars in Dialysis*, 1, 82-85.

Jassal, S. V., & Watson, D. (2009). Dialysis in late life: benefit or burden.

*Clinical Journal of American Society of Nephrology*, 4(12), 2008–12.

Karger, S. (2009), End-Stage of Renal Diseases. Retrieved from

[www.karger.com](http://www.karger.com) on 27/04/16.

Kimmel, P. L. (2000). Psychosocial factors in adult end-stage renal disease

patients treated with haemodialysis: Correlates and outcomes. *American Journal of Kidney Diseases*, 35(Suppl 1), S132–S140.

Kimmel, P. L. (2013). The weather and quality of life in ESRD patients:

Everybody talks about it, but does anybody do anything about it? *Seminial Dial* 26, 260–262.

Kirchgessner, J., Perera-Chang, M., Klinkner, G., Soley, I., Marcelli, D.,

Arkossy, O., Stopper, A., & Kimmel, P. L. (2006). Satisfaction with care in peritoneal dialysis patients. *Kidney International*. 70, 1325–1331.

Kolcaba, K. (1995). Comfort as process and product, merged in holistic

nursing art. *Journal of Holistic Nursing*, 13(2), 117-131.

Kolcaba, K. (2010). An introduction to comfort theory. In *The comfort line*.

Retrieved from <http://www.thecomfortline.com/> on 23/10/16

Kolcaba, K. Y. (1994). A theory of holistic comfort for nursing. *Journal of*

*Advanced Nursing*, 19(6), 1178-1184.

Kolcaba, K. Y., & Kolcaba, R. J. (1991). An analysis of the concept of

comfort. *Journal of Advanced Nursing*, 16(11), 1301-1310.

Kurella Tamura, M., Covinsky, K. E., Chertow, G. M., Yaffe, K., Landefeld,

C. S., & McCulloch, C. E. (2009). Functional status of elderly adults

before and after initiation of dialysis. *New England Journal of Medicine*, 361, 1539–1547.

Kurella, M., Covinsky, K. E., Collins, A. J., & Chertow, G. M. (2007). Octogenarians and nonagenarians starting dialysis in the United States. *American Internal Medicine*, 146, 177–183.

Levey, A. S., Schoolwerth, A. C., Burrows, N. R., Williams, D. E., Stith, K. R., & McClellan, W. (2009). Comprehensive public health strategies for preventing the development, progression, and complications of CKD: report of an expert panel convened by the Centres for Disease Control and Prevention. *American Journal of Kidney Disease*, 53(3), 522–35.

Levin, A., Hemmelgarn, B., & Culeton, B. (2008). Guidelines for the management of chronic kidney disease. *Canadian Medical Association Journal*, 179(11), 1154-1162.

Lia, K., Tzeng, R., Wang, B., Lee, H., & Amidon, R. (2005). Health related quality of life and health utility for the institutional elderly in Taiwan. *Quality of Life Research*, 14, 1169-1180.

Low, J., Smith, G., & Burns, A. (2008). The impact of end-stage kidney disease (ESKD) on close persons: a literature review. *Nephrology Dialysis Transplantation*, 2, 67–79.

Marcello, T., Wiebe, N., Culeton, B., Lee, H., Klarenbach, S., Shrive, F., & Manns, B. (2007). Kidney Disease Network. Systematic review of the clinical efficacy and safety of sevelamer in dialysis patients. *Nephrology Dialysis Transplantation*, 22(10), 2856-2866.

March, A., McCormack, D. (2009). Nursing Theory-Directed Healthcare: Modifying Kolcaba's Comfort Theory as an Institution-Wide Approach. *Holistic Nursing Practice*, 23(2), 75-80.

Marrón, B., Martínez Ocaña, J. C., & Salgueira, M. (2005). Spanish Group for CKD Analysis of patient flow into dialysis: role of education in choice of dialysis modality. *Peritoneal Dialysis International*, 25 (suppl 3), S56–S59.

Morton, R. L., Tong, A., Howard, K., Snelling, P., & Webster, A. C. (2010). The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *British Medical Journal*, 340, c112.

Morton, R. L., Turner, R. M., & Howard, K. (2012). Patients who plan for conservative care rather than dialysis: a national observational study in Australia. *American Journal of Kidney Disease*, 59(3), 419–427.

Moss, A. H., Ganjoo, J., Sharma, S., Gansor, J., Senft, S., Weaner, B., Dalton, C., MacKay, K., Pellegrino, B., Anantharaman, P., & Schmidt, R. (2008). Utility of the surprise question to identify dialysis patients with high mortality. *Clinical Journal of American Society of Nephrology*, 3, 1379–1384.

Mowad, L. (2004) Correlates of quality of life in older adult veterans. *Western Journal Research*, 26, 293-306

Murray, A. M., Arko, C., Chen, S. C., Gilbertson, D. T., & Moss, A. H. 2006 Use of hospice in the United States dialysis population. *Clinical Journal of American Society of Nephrology*, 1(6), 1248–1255.

Murtagh, F. E. M., Sheerin, N. S., Addington-Hall, J., & Higginson, I. J. (2011). Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clinical Journal of American Society of Nephrology*, 6(7), 1580–90.

Murtagh, F. E., Addington-Hall, J. M., & Higginson, I. J. (2011). End-stage renal disease: a new trajectory of functional decline in the last year of life. *Journal of American Geriatric Society*, 59(2), 304–8.

Murtagh, F. E., Addington-Hall, J. M., Edmonds, P. M., Donohoe, P., Carey, I., Jenkins, K., & Higginson, I. J. (2007). Symptoms in advanced renal disease: A cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *Journal of Palliative Medicine*, 10, 1266–1276.

Murtagh, F. E., Marsh, J. E., & Donohoe, P. (2007). A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrology Dialysis Transplantation*, 22(7), 1955–1962.

National Kidney Foundation (2006). Detection of chronic kidney disease in patients with or at increased risk of cardiovascular disease. *American heart Association Journal*, 114, 1083-1087.

National Statistics (2005), People Migration. Retrieved from [www.statistics.gov.uk](http://www.statistics.gov.uk) on 13/06/16.

Naumann, V. J., & Byrne, G. J. A. (2004). WHOQOL-BREF as a measure of quality of life in older patients with depression. *International Psychogeriatrics* 16, 159-173.

NHS Kidney Care GMMKC, & Advanced Renal Care (ARC) Project. (2012).

*Getting it right: end of life care in advanced kidney disease* (ed. NHS).

NHS Kidney Care, UK.

Nieswiadomy, R. M. (2008). *Foundations of nursing research* (5<sup>th</sup> Ed.). New Jersey: Pearson Education, Incorporated.

Nissenson, A. R. (2014). Improving outcomes for ESRD patients: Shifting the quality paradigm. *Clinical Journal of American Society Nephrology*, 9, 430–434.

Noble, H., Meyer, J., Bridges, J., Kelly, D., & Johnson, B. (2008). Patient experience of dialysis refusal or withdrawal—a review of the literature. *Journal of Renal Care*, 34(2), 94-100.

O'Connor, N. R., Dougherty, M., Harris, P. S., & Casarett, D. J. (2013). Survival after dialysis discontinuation and hospice enrollment for ESRD. *Clinical Journal of American Society Nephrology*, 8, 2117–2122.

Oliver, M. J., Quinn, R. R., Richardson, E. P., Kiss, A. J., Lamping, D. L., & Manns, B. J. (2007). Home care assistance and the utilization of peritoneal dialysis. *Kidney International*, 71, 673–678.

Parker, T. 3rd., Hakim, R. Nissenson, A. R., Steinman, T., & Glassock, R. J. (2011). Dialysis at a crossroads: 50 years later. *Clinical Journal of American Society of Nephrology*, 6, 457–461.

Patel, S. S., Peterson, R. A., & Kimmel, P. L. (2005). The impact of social support on end-stage renal disease. *Seminal Dialysis*, 18, 98–102.

Perazella, M. A., & Khan, S. (2006). Increased mortality in chronic kidney disease: a call to action. *The American Journal of the Medical Sciences*, 331(3), 150-153.

Pierratos, A., McFarlane, P., & Chan, C. T. (2005). Quotidian dialysis – update 2005. *Current Opinion in Nephrology and Hypertension*, 14(2), 119-1224.

Polit, D. F., & Beck, C. T. (2007). *Nursing research generating and assessing evidence for nursing* (8<sup>th</sup> ed.). Philadelphia: Lippincot, Williams, & Wilkins

Quill, T. E., & Abernethy, A. P. (2013). Generalist plus specialist palliative care—creating a more sustainable model. *New England Journal of Medicine*, 368, 1173–1175.

Renal Association (2003). *Treatment of Patients with Renal Failure: Recommended Standard and Audit Measures*. London. Renal Association and Royal College of Physicians.

Renal Physicians Association & American Society of Nephrology (2010). *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. (2nd Ed.). Washington, DC. Renal Physicians Association and American Society of Nephrology.

Reuben, D. B., & Tinetti, M. E. (2012). Goal-oriented patient care—an alternative health outcomes paradigm. *New England Journal of Medicine*, 366, 777–779.

Sarnak, M. J., Levey, A. S., Schoolwerth, A. C., Coresh, J., Culleton, B., Hamm, L. L., & Parfrey, P. (2003). Kidney disease as a risk factor for development of cardiovascular disease a statement from the American

Heart Association Councils on kidney in cardiovascular disease, high blood pressure research, clinical cardiology, and epidemiology and prevention. *Circulation*, 108(17), 2154-2169.47

Scanlan, M. J., Gure, A. O., Jungbluth, A.A., Old, L. J., & Chen, Y. T. (2002).

Cancer/testis antigens: an expanding family of targets for cancer immunotherapy. *Immunological Reviews*, 188, 22-32.

Schell, J. O., Green, J. A., Tulsy, J. A., Arnold, R. M. (2013).

Communication skills training for dialysis decision-making and end-of-life care in nephrology. *Clinical Journal of American Society of Nephrology*, 8, 675–680.

Schieppati, A., & Remuzzi, G. (2005). Chronic renal disease as a public health problem: epidemiology, social, and economic implications. *Kidney International Supply*, 68, 7–10.

Singh, P., Germain, M. J., Cohen, L., & Unruh, M. (2014). *The elderly patient on dialysis: Geriatric considerations. Nephrology Dialysis and Transplantation*, 29, 990–996.

Small, N., Barnes, S., Gott, M., Payne, S., Parker, C., & Seamark, D. (2009). Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. *British Medical Council Palliative Care*, 8(1), 6.

Stencamp, R., Castledine, C., Feest, T., & Fogarty, D. (2010). The Renal Association UK Renal Registry. The Thirteenth Annual Report December 2010. Retrieved from [https://www.renalreg.org/wp-content/uploads/2014/09/Renal-Report-2011\\_press-bw.pdf](https://www.renalreg.org/wp-content/uploads/2014/09/Renal-Report-2011_press-bw.pdf) on 13/03/16.



Stringer, S., & Baharani, J. (2011). Why did I start dialysis? A qualitative study on views and expectations from an elderly cohort of patients with end-stage renal failure starting haemodialysis in the United Kingdom. *International Urology and Nephrology*, 44(1), 295–300.

Suet-Cging, W. L. (2001). The quality of life for Hong Kong dialysis patients. *Journal of Advanced nursing*, 35, 218-227.

Tamura, M. K., & Meier, D. E. (2013). Five policies to promote palliative care for patients with ESRD. *Clinical Journal of American Society of Nephrology*, 8, 1783–1790.

Tappen, R. M. (2011). *Advanced nursing research from theory to practice*. United States of America: Jones & Bartlett Learning, Limited Liability Company.

The National Quality Forum (2013). Measures, reports, and tools. Retrieved from [http://www.qualityforum.org/Measures\\_Reports\\_Tools.aspx](http://www.qualityforum.org/Measures_Reports_Tools.aspx) on 05/05/16.

Thompson K. F., Bhargava, J., Bachelder, R., Bova-Collis, R., & Moss, A. H. (2008). Hospice and ESRD: knowledge deficits and underutilization of program benefits. *Nephrology Nursing Journal*, 35: 461–466, 502, quiz 467–468.

Trivedi, D. D. (2011). Palliative dialysis in end-stage renal disease. *American Journal of Hospital Palliative Care*, 28, 539–542.

Tsai, S., Chi, L., & Chou, P. (2004). Health related quality of life among urban, rural and island community elderly in Taiwan. *Journal of the Formosan Medical Association*, 103, 196-204.

Tseng, S. Z., & Wang, R. H. (2001). Quality of life and related factors among elderly nursing home residents in Southern Taiwan. *Public Health Nursing, 18*, 304-311.

U.S. Renal Data System (2013). *USRDS 2013 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*. Bethesda, MD.

United States Renal Data System. (2002). *USRDS 2002 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Disease.

US Renal Data System (2008). National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; Bethesda, MD: 2008. *USRDS 2008 Annual Data Report, Volume 2: Atlas of End-Stage Renal Disease in the United States*.

Weiner, B. (2010). The Development of an Attribution-Based Theory of Motivation: A History of Ideas. *Educational Psychologist, 45*(1), 28-36.

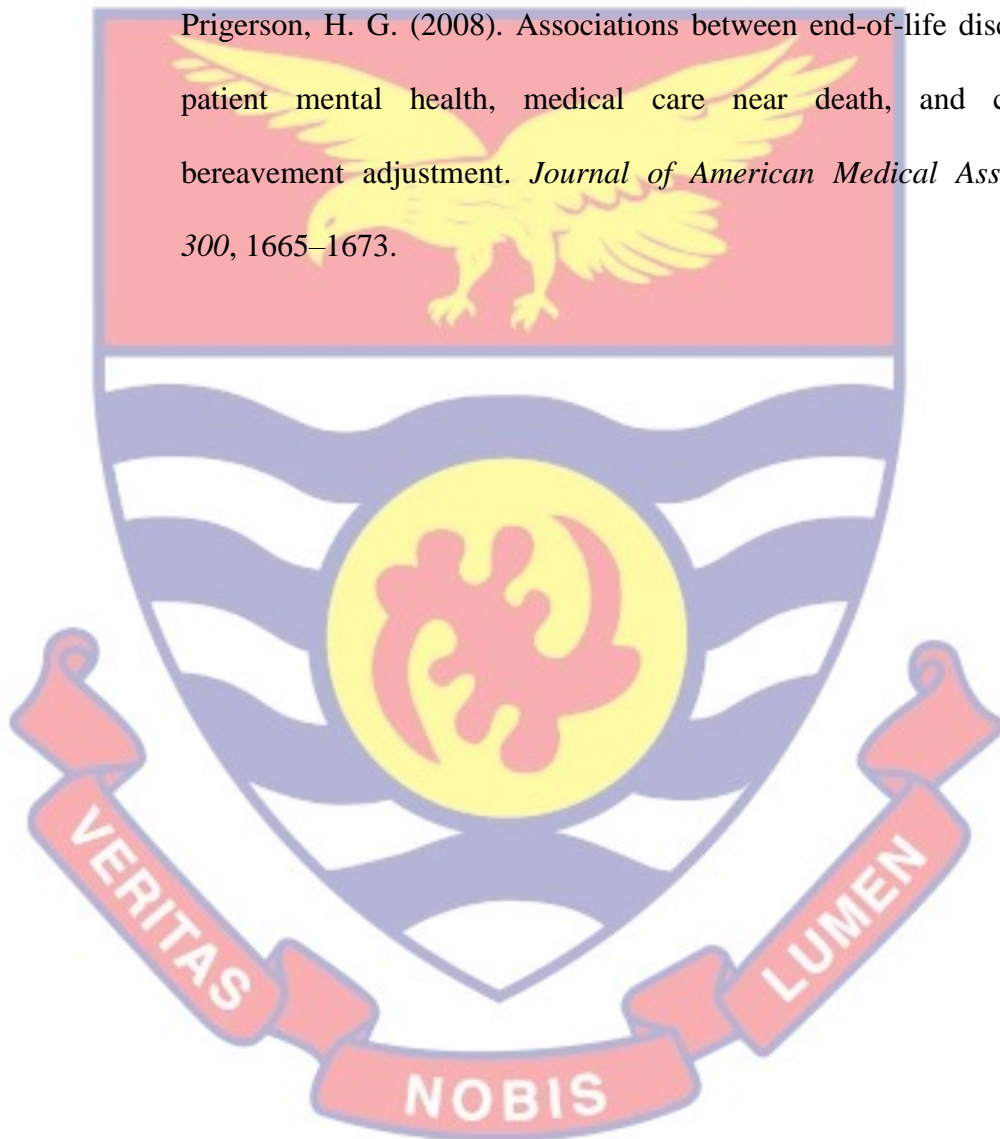
Weiner, D. E. (2011). The 2011 ESRD prospective payment system: Welcome to the bundle. *American Journal of Kidney Diseases, 57*, 539-541.

Weissman, D. E., Morrison, R. S, & Meier, D. E. (2010). Center to Advance Palliative Care palliative care clinical care and customer satisfaction metrics consensus recommendations. *Journal of Palliative Medicine, 13*, 179-184.

Wong, S. P., Kreuter, W., & O'Hare, A. M. (2012). Treatment intensity at the end of life in older adults receiving long-term dialysis. *Archives of Internal Medicine, 172*, 661-663

Wong, S. P., Kreuter, W., & O'Hare, A. M. (2014). Healthcare intensity at initiation of chronic dialysis among older adults. *Journal of American Society of Nephrology*, 25, 143–149.

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson, V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of American Medical Association*, 300, 1665–1673.



## APPENDIX A

### INTERVIEW GUIDE

What are healthcare practitioners' perceptions on palliative care as alternative treatment to dialysis for ESKD?

#### Questions

1. What is your understanding on palliative care?
2. What category patients qualify to be on palliative care?
3. What treatment is available for a patient if he/she does not opt for dialysis?
4. What can be done for patients who choose not to undergo dialysis or terminate care if financial resources run out?
5. What will be your expectation of patient who wants to choose palliative care to dialysis?

What are patients/family beliefs on palliative care as alternative treatment to dialysis for ESKD?

#### Questions

1. How did you know that you have ESKD?
2. What belief do you have on this illness?
3. What was your feeling and thought when you were first told you have ESKD?
4. Do you have any spiritual, social and psychological values that help you to cope with this condition?
5. Do you consider your disease condition as a live threatening illness?
6. What treatment options do you know about your illness?
7. Will you accept palliative care as an option when you realised that you are not thriving on dialysis?

8. What is your perception towards life and dying? Do you see them as normal process?
9. How do you see your family's reaction to the diagnosis?
10. Are there any support system to help you and your to cope with the condition?
11. Do wish there was something more than dialysis?
12. How would you accept a treatment option that does not only considers the medical aspect of your health but also physical, psychological, spiritual and social aspect of your health?


What are healthcare practitioners' attitudes towards patients' withdrawal from dialysis to palliative care for ESKD?

#### Questions

1. How easy or difficult is it for you to tell a patient that he/she has ESKD which is incurable?
2. Do you feel adequately prepared anytime you have to break the news to a patient that has ESKD?
3. What support systems are available to let a patient live a quality life until he/she dies?
4. How do you feel a patient cannot afford dialysis?
5. Do you give care to ESKD patients based on your professional skills or based on what the patient/family wants?
6. Do you focus on the patient or he/she family at terminal stage of the ESKD?

## APPENDIX B

### Ethical Clearance

**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](mailto:irb@ucc.edu.gh)  
OUR REF: UCC/IRB/3/42  
YOUR REF:  12<sup>TH</sup> FEBRAURY, 2016

---

Mrs. Catherine Sarfo-Walters  
School of Nursing and Midwifery  
University of Cape Coast

Dear Mrs. Sarfo-Walters,

**ETHICAL CLEARANCE –ID NO: (UCCIRB/CHAS/2015/105)**

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for implementation of your research protocol titled: **“Perception of Patients/Family and Healthcare Practitioners on Palliative care as Alternative to Dialysis in the Treatment of End Stage Kidney Diseases in Kumasi Metropolis.”**

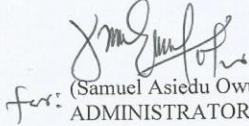
This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

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,

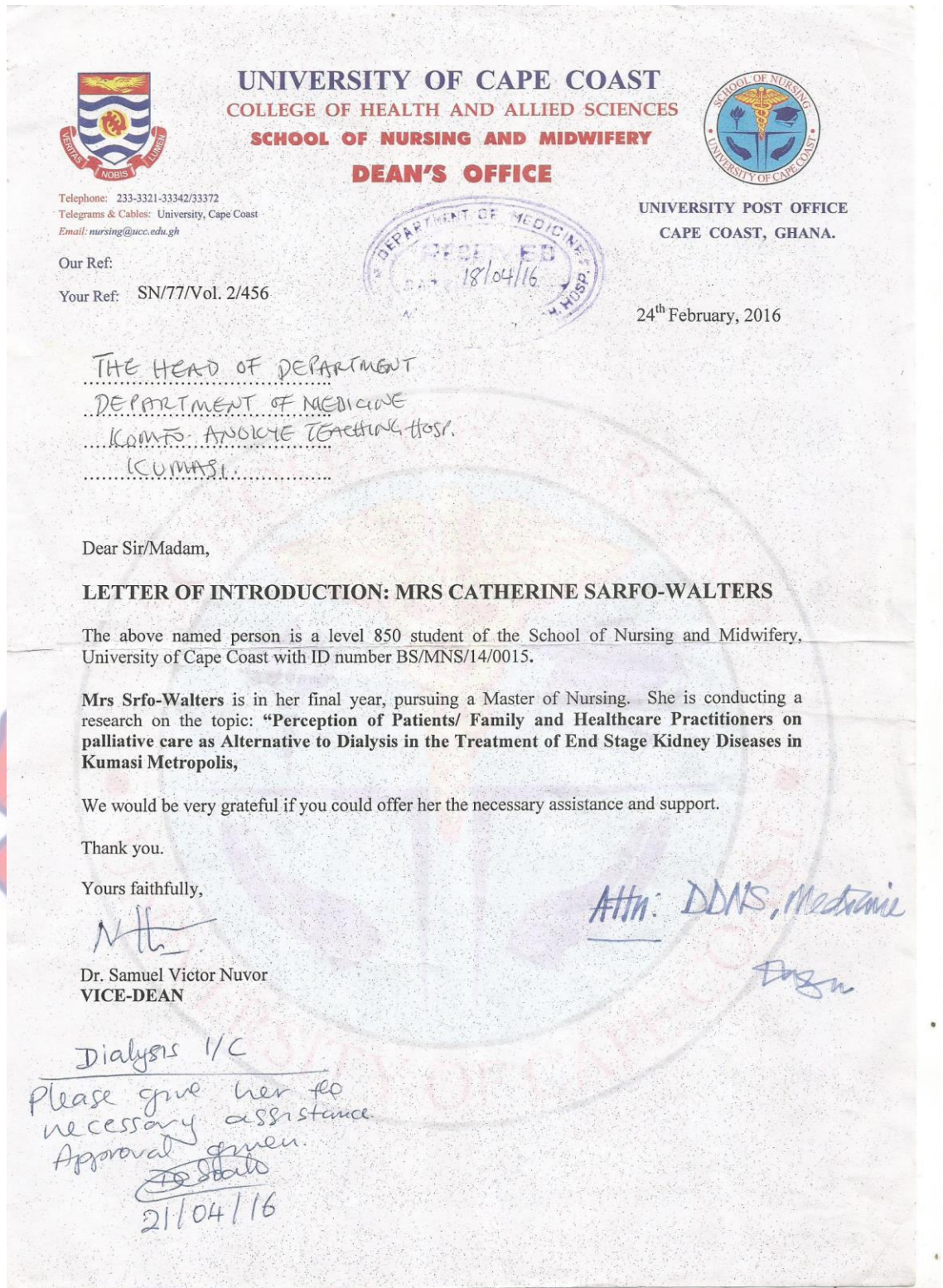
  
for: (Samuel Asiedu Owusu)  
ADMINISTRATOR

cc: The Chairman, UCCIRB

**ADMINISTRATOR**  
**INSTITUTIONAL REVIEW BOARD**  
**UNIVERSITY OF CAPE COAST**  
Date:.....

APPENDIX C

Introductory Letter



## APPENDIX D

### Approval from KATH

21<sup>st</sup> April, 2016

Mrs. Catherine Sarfo-Walters  
School of Nursing and Midwifery  
University of Cape Coast  
Cape Coast

Dear Madam,

**RE: STUDY ON "PERCEPTION PATIENTS/FAMILY AND HEALTHCARE PRACTITIONERS ON PALLIATIVE CARE AS ALTERNATIVE TO DIALYSIS IN THE TREATMENT OF ESKD"**

With reference to the above, we write to grant you permission to carry on with your research in the Renal Unit of the Directorate of Medicine, KATH.

However, we would like to advise that during this period of association with the Renal Unit, you shall maintain strict confidentiality as to the data collected and shall make no reference with patients' name or identity.

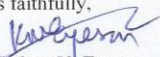
You shall not permit or allow any person to have access to any books, documents or papers in your possession for the purpose of this data. Any data gathered here should be considered confidential and should be treated as such.

Your confidentiality obligation shall continue even after the research is completed. Please conduct this research as professionally as possible.

We reserve the right to rescind this permission should we have any reason to suspect an abrogation of confidentiality.

We look forward to a mutually beneficial collaboration and are certain that the outcome of this research will be valuable. We hope that it will be shared with the Directorate of Medicine after completion.

Yours faithfully,

  
Dr. Kodwo N. Eyeson  
Head, Renal and Hypertensive Unit  
Directorate of Medicine  
Komfo Anokye Teaching Hospital  
Kumasi.

DR. K. N. EYESON  
DEPARTMENT OF MEDICINE  
KATH - KUMASI



APPENDIX E

Approval from Naghe Clinic



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



Telephone: 233-3321-33342/33372  
Telegrams & Cables: University, Cape Coast  
Email: [nursing@ucc.edu.gh](mailto:nursing@ucc.edu.gh)

UNIVERSITY POST OFFICE  
CAPE COAST, GHANA.

Our Ref:  
Your Ref: SN/77/Vol. 2/456

24<sup>th</sup> February, 2016

THE MEDICAL DIRECTOR  
NAGHE CLINIC  
KUMASI

Dear Sir/Madam,

**LETTER OF INTRODUCTION: MRS CATHERINE SARFO-WALTERS**

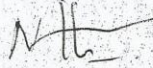
The above named person is a level 850 student of the School of Nursing and Midwifery, University of Cape Coast with ID number BS/MNS/14/0015.

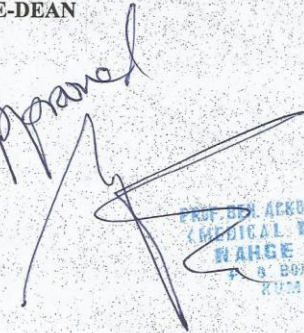
Mrs Sarfo-Walters is in her final year, pursuing a Master of Nursing. She is conducting a research on the topic: "Perception of Patients/ Family and Healthcare Practitioners on palliative care as Alternative to Dialysis in the Treatment of End Stage Kidney Diseases in Kumasi Metropolis,

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

Approved  


PROF. BEN AKKON EGHAN, JNR  
(MEDICAL DIRECTOR)  
NAGHE CLINIC  
P.O. BOX 14162  
KUMASI