DECISION MAKING IN END STAGE KIDNEY DISEASE (ESKD) IN GHANA: EXPLORING PATIENT AND CLINICIAN PERSPECTIVES

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Abstract

Introduction

This study was carried out in Ghana, where the incidence of end stage kidney disease (ESKD) is increasing in a context of limited treatment options. Understanding the issues patients with ESKD grapple with when diagnosed with this life-threatening condition is essential to improve healthcare policy and practice in such low- and middle-income settings. In the absence of evidence related to the African ESKD patient journey, this study aimed at exploring how decisions about ESKD management are being made, especially in under-resourced settings where specific treatment modalities are not always available. The study addresses an important gap in the literature concerning choice and decision making in an international context. The key research question for this study is, in terms of the context, does the problem of limited resources in low- and middle-income countries present different choices to the patient with ESKD facing decisions about their treatment?

Methodology and Methods

The study employed a qualitative research design, using grounded theory methodology. Twenty-seven participants in three renal centres, comprising twenty-two patients with ESKD and five clinicians, were selected using the theoretical sampling approach and interviewed for this study. Constant comparative analysis was employed in data analysis.

Results

A conceptual map depicting the ESKD patient journey and key phases of decision making was developed from this study. Ghanaian patients with ESKD are mostly unaware of the implications of their initial symptoms, and end up delaying seeking healthcare from a hospital. Some of those who seek care from hospitals are initially diagnosed with and treated for other conditions other than ESKD. Thus, many patients with ESKD in Ghana present late to a renal centre. Treatment for ESKD is initiated for various reasons, including, initially, the urgent need to avoid premature death. Many approach their condition in terms of hoping for a cure and do not always understand the chronic nature of their condition. Decisions on initiating haemodialysis (HD) are mostly shared between clinicians and patients and/or their families but the process is mainly driven by the need to ascertain patient and family's

ability to finance HD, rather than considering other aspects of treatment burden. The subject of death or conservative management is not openly discussed and, once this is brought up, patients usually do everything possible to opt for another form of treatment, including the simultaneous use of other non-RRT and traditional or faith-based healing approaches.

Clinicians play vital roles in the decision making of patients with ESKD although they have general feelings of helplessness while supporting these patients. Convergence between individuals' experiences of realities of living with and managing ESKD, and support from clinicians in the renal setting ultimately leads to a reconstruction of health expectations that commensurate management goals of ESKD. This sums up the substantive theory of 'reconstructing health expectations' that was generated from this study.

Conclusions

Financial and geographical inaccessibility of renal replacement therapy (RRT) as well as the relative lack of biomedical treatment choices make decision making daunting for the individual with ESKD in Ghana. Reluctance to discuss death as a potential outcome is a hindrance to the consideration of conservative management as a treatment option. Effective realignment of healthcare policies to address changing patterns of diseases is necessary to contribute to prevention, early detection and effective management of ESKD in the country. An improved approach to conservative management is urgently required, including training support for clinicians on shared decision making as well as sensitisation of patients on this modality.

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List of Abbreviations

CHRPE – Committee on Human Research, Publications and Ethics

CKD – Chronic Kidney Disease

EPRC – Ethical and Protocol Review Committee

ESKD – End Stage Kidney Disease

NCDs – Non-Communicable Diseases

NHIS – National Health Insurance Scheme

RRT – Renal Replacement Therapy

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CHAPTER 1. BACKGROUND

1.1 Introduction

The increasing burden of non-communicable diseases (NCDs) alongside high rates of communicable diseases in low- and middle-income countries presents unique challenges for citizens and healthcare systems of such countries (Engelaer et al., 2014). Chronic kidney disease (CKD) is ranked 19th among the top leading causes of death globally in the Global Burden of Disease 2013 (GBD 2013) study, up from the 36th position in 1990, although its impact varies in different geographical locations (Naghavi et al., 2015, Ogata et al., 2013, Stanifer et al., 2016). Yet, it has received far less attention globally, especially in low- and middle-income countries (Jha et al., 2013, Naghavi et al., 2015, Stanifer et al., 2016). Limited resources, both human and material, and non-existence of well-coordinated healthcare policies are some of the challenges that make the impact of CKD and other non-communicable diseases most felt in low- and middle-income countries, including Ghana, my home country. This study was borne out of a desire to explore experiences of living with and managing end stage kidney disease (ESKD) in Ghana in the face of limited resources, after being exposed to the almost unlimited access of patients with ESKD to various treatment forms in the United Kingdom.

The thesis is organised into eight chapters. Chapter 1, the background chapter, begins with a section on the theory of epidemiologic transition and the increasing global prevalence of CKD, describing its staging according to the Kidney Disease: Improving Global Outcomes (KDIGO) CKD work group. This is followed by two sections on management approaches of end stage kidney disease (ESKD), the last stage of CKD, mainly renal replacement therapy (RRT) and non-RRT approaches. The chapter then describes factors that are, generally, considered essential when individuals with ESKD are choosing a management approach. It then describes renal replacement therapy in low- and middle-income countries to compare and contrast services in these settings with those in high-income countries. The profile of Ghana, the country within which this research was undertaken, is then described to provide detailed information on key areas such as healthcare in the country, health-seeking behaviours of the citizenry and existing healthcare policies. Specific information on ESKD and its management in Ghana is also presented to serve as a basis

for justifying this study. The aim and objectives of this research are then presented, followed by an outline of the remaining chapters of the thesis.

1.2 Epidemiologic Transition and ESKD

It has been over four decades since Omran (1971) theorised that societies experience significant shifts in mortality and disease trends in his classical epidemiologic transition theory. Omran (1971) explained that a society gravitates from high mortality and fertility towards low mortality and fertility, and socioeconomic factors are primary drivers of this transition although other determinants such as medical technology may play significant roles in some parts of the world. However, many low- and middle-income countries experience contemporary (or delayed) epidemiologic transition which is characterised by substantial decline in mortality while fertility remains significantly high (Omran, 1971).

Many low- and middle-income countries are increasingly recording heart diseases, cancers and other NCDs, suggesting that these countries are in the 'age of degenerative and man-made diseases', as described in the epidemiologic transition theory (Dalal et al., 2011, Omran, 1971, Stanifer et al., 2014). Yet, communicable diseases remain the prominent cause of morbidity and mortality in most of these countries, especially among infants, children, and females in their reproductive years – a concept described as the double burden of communicable and non-communicable diseases (Atiim and Elliott, 2016, Byrne et al., 2015, Engelaer et al., 2014, Kapiga, 2011, Omran, 1971, Remais et al., 2012).

Chronic kidney disease (CKD), which describes abnormalities of kidney structure and/or function, has become an issue of worldwide public health concern as its global incidence and prevalence continue to escalate at unprecedented rates, with its associated life-threatening complications (Cepoi et al., 2012, Eknoyan et al., 2004, NICE, 2014, Sumaili et al., 2009, Zhang and Rothenbacher, 2008). CKD is characterised by steady deterioration of kidney function until there is a permanent complete loss, referred to as end stage kidney disease (ESKD) or kidney failure (Billington et al., 2008, Silvestri, 2002, Usherwood and Johnson, 2005). The National Institute for Health and Care Excellence (NICE, 2014) and the Kidney Disease: Improving Global Outcomes CKD work group (KDIGO, 2013) have classified CKD into various risk categories using estimated

glomerular filtration rate (eGFR) and serum albumin creatinine ratio (ACR) (Table 1).

Table 1: Classification of CKD using GFR and ACR Categories (KDIGO, 2013, NICE, 2014)

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				< 3mg/mmol	3– 30 mg/mmol	>30 mg/mmol
GFR categories (ml/min/1.73m^2)	G1	Normal or high	≥90			
	G2	Mildly decreased	60 – 89			
	G3a	Mildly to moderately decreased	45 – 59			
	G3b	Moderately to severely decreased	30 – 44			
	G4	Severely decreased	15 – 29			
	G5	Kidney failure	<15			

Increasing risk

Increasing risk

Low risk (if no other markers of kidney disease, no CKD)

Moderately increased risk

High risk

Very high risk

There are over 100 million people living with CKD worldwide although variations exist in its incidence and prevalence across different geographical regions and among different ethnic groups (Ogata et al., 2013, Vassalotti et al., 2006). For instance, genetic factors are believed to play vital roles in increasing the incidence of CKD and rate of progression to ESKD, especially among individuals of African descent (Evans and Taal, 2011, Jha et al., 2013, Martins et al., 2012). Progression to ESKD is also influenced by factors such as the underlying cause of CKD, and co-existence of other diseases or infections (Johnston and Noble, 2012). An increasing aging population and extended survival periods for people with ESKD living in European countries and North America are among factors that account for the higher global prevalence of ESKD (Ayodele and Alebiosu, 2010, Barsoum, 2006, Loos et al., 2003, Morsch et al., 2006). However, it is well-known in the renal community that the prevalence of ESKD is lowest in low- and middle-income countries although its incidence is highest in these countries (Alebiosu and Ayodele, 2005, Barsoum, 2006, Naicker, 2009). This has largely been attributed to a host of factors

including poorly developed renal services, little awareness of ESKD and higher mortality among persons with ESKD in many such countries (Ayodele and Alebiosu, 2010, Barsoum, 2006, Couser et al., 2011).

The role of other non-communicable diseases (NCDs) in increasing the global incidence and prevalence rates of ESKD cannot be overemphasised as diabetes mellitus and hypertension are two leading causes of CKD (Ayodele and Alebiosu, 2010, Caskey et al., 2011, Thomas et al., 2008, Ulrich, 2009). Higher prevalence of these NCDs suggests that more people will develop CKD which may then progress to ESKD without appropriate interventions (Ayodele and Alebiosu, 2010, Caskey et al., 2011, Thomas et al., 2008, Ulrich, 2009).

1.3 Renal Replacement Therapies for ESKD Management

Once at the end stage of chronic kidney disease, individuals require one of three categories of renal replacement therapies (RRTs) – kidney transplantation, haemodialysis (HD) or peritoneal dialysis (PD) – for survival (Evans and Taal, 2011, Murphy et al., 2008, Murray et al., 2009, Niu and Li, 2005).

In addition to the relatively better quality of life that patients enjoy after the procedure, kidney transplantation appears to be the cheapest modality in the long term so long as the transplanted kidney continues to function (Lee et al., 2005). The (NHS Blood and Transplant Special Health Authority (2009)) averages the cost benefit of kidney transplantation to be £241,000 over a ten-year period in the UK (the median transplant survival time) as long as the grafted kidney is still functioning. A similar study comparing costs of kidney transplantation and dialysis in Portugal revealed that kidney transplantation costs €61,658.14 (about £44,400) in the first year and €6,526.32 (about £4,700) annually after the first year. Dialysis, on the other hand, costs €28,033.71 (about £20,190) annually. The authors concluded that dialysis and kidney transplantation costs break even at 32 months, after which dialysis costs exceed kidney transplantation costs (Rocha et al., 2012). Despite these relative benefits of the therapy, only small fractions of the ESKD population are able to undergo kidney transplantation as donor kidneys are mostly unavailable (White et al., 2008, Wu et al., 2004). There have been some improvements, though, with the United States Renal Data System (2015) reporting that 29.2% of patients with ESKD in the USA had a functioning

kidney transplant on 31st December 2013. Unavailability of well-trained transplant clinicians and facilities contributes to lower usage of kidney transplantation, especially in low- and middle-income countries (Garcia-Garcia et al., 2012, Garcia-Garcia and Jha, 2015).

Patients with ESKD in the UK and similar high-income countries can access in-centre or home haemodialysis, continuous ambulatory peritoneal dialysis, automated peritoneal dialysis while on a register for kidney transplant, albeit many find the primary decision to be between haemodialysis or peritoneal dialysis (Tweed and Ceaser, 2005). Consequently, many patients with ESKD either have haemodialysis or peritoneal dialysis, with over 80% of the global dialysis population having haemodialysis (Jablonski, 2007, United States Renal Data System, 2015). Only a few countries such as Hong Kong, Jalisco region of Mexico, Iceland, New Zealand, and Colombia have 30% or more of their patients with ESKD receiving peritoneal dialysis, with Hong Kong being the highest with 72% (United States Renal Data System, 2015). About 1.4 million of the 1.8 million people who were receiving renal replacement therapy worldwide in year 2004 were having a type of dialysis (Grassmann et al., 2005).

Haemodialysis and peritoneal dialysis both serve to replace some functions of the diseased kidneys and offer improved prognosis to patients with ESKD by extending their lives and improving quality of life (Vilar and Farrington, 2011). Each has a different mechanism of action, though. In haemodialysis, waste products are removed by an artificial semi-permeable membrane (dialyser) through an extracorporeal circuit by the processes of diffusion and ultrafiltration (Challinor, 2008, Murphy et al., 2008). Access to the patient's blood is via two main routes – arterio-venous fistula (AVF) or arterio-venous graft, and percutaneous access such as femoral, subclavian or jugular lines, which can either be temporal or permanent (Challinor, 2008, Marchant, 2008). Peritoneal dialysis, on the other hand, does not require blood to be removed from the body. Instead, dialysate (a balanced solution of electrolytes) is instilled into the peritoneal cavity through a catheter that is surgically placed inside the peritoneum. Waste substances and water are then removed across the surface area of the peritoneum by the processes of diffusion and osmosis (Wild, 2008).

Renal replacement therapy (RRT) has gone through several phases of development and has become the mainstay of ESKD management, particularly in high-income countries (Blagg, 2007). Recent reports suggest that the lives of more than 2 million people are sustained by RRT worldwide. However, it is estimated that this represents only 10% of the number that need RRT as more than 1 million people die from untreated ESKD annually (Couser et al., 2011). Caskey et al. (2011) report that every one-year increase in life expectancy at 60 years old increases RRT incidence by 12%. Globally, the number of people that require some form of RRT is believed to increase by about 8% annually (Alebiosu and Ayodele, 2005, Bamgboye, 2003, Grassmann et al., 2005, White et al., 2008). On a more positive note, the incident rates have fairly slowed or stabilised in some high-income countries over recent years and this has partly been attributed to increased awareness of CKD (Couser et al., 2011, United States Renal Data System, 2015).

The cost of managing ESKD by renal replacement therapy is high. Generally, patients with ESKD represent around 0.03% of the total population in many high-income countries but their treatment alone takes about 2% to 3% of the annual healthcare budget (Couser et al., 2011). It accounts for about 1.12% and 2% of the total healthcare budget in the USA and Europe respectively (Hamer and Nahas, 2006, Su et al., 2010, Sumaili et al., 2009). An estimated amount of £1.45 billion was spent on the management of CKD in England between 2009 and 2010, accounting for approximately 1.3% of the total amount spent by the National Health Service (NHS) within that period. More than half of this estimated amount was spent on RRT for the 2% of the CKD population that progressed to ESKD (Kerr et al., 2012, NICE, 2014). These higher costs are largely as a result of the repetitive nature of dialysis that accumulates the cost over time (Noble, 2011). The higher costs of managing ESKD tend to serve as a huge impediment for initiation and sustenance of renal replacement therapy in low- and middle-income economies, as will be discussed in a later section.

1.4 Non-RRTs for ESKD Management

An alternate patient choice to renal replacement therapy is a supportive, non-dialytic care (also known as conservative management /palliative care). This approach focuses on symptom control such as fluid and electrolyte corrections and anaemia management to maximise quality of

life but usually results in death within months based on comorbidities and age of the patient (Chandna et al., 2011, Davison and Sheerin, 2014, Douglas, 2014, Morton et al., 2012, Murphy et al., 2008, Rosenberg et al., 2008). The term 'conservative management' is commonly used to describe palliative care in the renal setting. A systematic review by O'Connor and Kumar (2012) comprising 13 studies identified that the median survival on conservative management of ESKD ranged from 6.3 months to 23.4 months, and is different from withdrawal of dialysis where imminent death is the obvious corollary. Quality of life within this survival period can be markedly improved by appropriate management.

According to the World Health Organization (2015) "palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". The World Health Organization (2015) explain that, in addition to relieving pain and other distressing symptoms, palliative care aims to support the patient to live as actively as possible until death, but not to adjourn or hasten it. Strong arguments have been made to consider palliative care as an international human rights issue (Brennan, 2007, Connor and Bermedo, 2014). In line with this, the World Health Organization has developed a Public Health Model for palliative care, with four key components, that seeks to enhance integration of palliative care into health care systems of various countries. These four components are formulating appropriate policies; ensuring adequate drug availability; promoting education of policy makers, health care workers, and the public; and implementing palliative care services at all levels throughout the country (Connor and Bermedo, 2014, Ddungu, 2011, Stjernswärd et al., 2007, World Health Organization, 2014).

Notwithstanding, many countries have not included palliative care in their health agenda as they are yet to consider it as a public health problem or human rights issue following the series of recommendations by the World Health Organization (Sepúlveda et al., 2002). In addition, evidence suggests that inadequate information on the concept of palliative care and its benefits among individuals at the end of life and their family negatively influences acceptance and utilisation of palliative care services although this varies in different geographical settings (Bull et al., 2014, McIlfatrick

et al., 2013, McIlfatrick et al., 2014). McIlfatrick et al. (2013) conducted a survey in Northern Ireland to ascertain public awareness and attitudes towards palliative care. They noted that although 83% of the 600 respondents reported to have heard the term palliative care, more than half of them reported little or no knowledge of what it means. The study identified that unwillingness of the public to openly discuss death and dying, and a lack of discussion on palliative care at the time of diagnosis or treatment initiation serve as key barriers to palliative care. It is noteworthy that public awareness of palliative care may be lower than reported in the study by McIlfatrick et al. (2013) because the response rate was 17% and their participants were self-selected individuals with specific interest in cooperating with health care research.

Conservative management is an increasingly accepted choice among individuals with ESKD, especially among very elderly patients with ESKD and those with comorbidities (Davison and Sheerin, 2014, Johnston and Noble, 2012). Indeed, the World Health Organization (2015) identifies ESKD as one of the diseases that would require palliative care. However, there are divided opinions about conservative management as an approach to managing ESKD. On the one hand, it is perceived as the best approach for elderly people with ESKD and those with comorbidities as dialysis does not always offer survival benefits for them (Douglas, 2014, Johnston and Noble, 2012, Morton et al., 2012, Noble, 2011, O'Connor and Kumar, 2012, Obrador, 2016). Survival benefits from dialysis are hindered further when individuals present late for renal services and are required to start treatment within three months of presenting to the renal centre (Davison and Sheerin, 2014). On the other hand, family and friends who act as informal carers, sometimes, act to prevent individuals at the end of their life from accessing optimum palliative care services by discouraging clinicians from having open and honest discussions about end-of-life (Noble et al., 2014). Inadequate information about conservative management as well as delayed initiation of discussions on the approach has been identified as a key barrier to its use as a treatment approach for ESKD (Lazenby et al., 2016, McIlfatrick et al., 2013, McIlfatrick et al., 2014).

Lazenby et al. (2016) interviewed 20 clinicians, comprising 15 doctors and 5 senior nurses on their experiences and perceptions about involving haemodialysis patients on end-of-life decisions in Wales, UK. The study

identified that patients were mostly not told about their prognosis, with reasons that prognosis was hard to estimate, patients did not desire to know about their prognosis, or clinicians were uncomfortable initiating discussions on end-of-life issue. Another study by Song et al. (2013) explored perspectives of patients with ESKD on the kind of information that is provided to individuals with ESKD before initiating dialysis in the USA. They report that only one patient in their study was offered palliative care as an option but this was presented in a manner that made it objectionable to be considered. They explain that this could have been due to some clinicians emphasising survival as a key benefit of dialysis in order to persuade patients to start and extend their life at all cost. Others also believed that giving patients detailed information about their disease and its trajectory would not be helpful. This usually results in end-of-life care issues being discussed only after patients have generally, deteriorated, making disease and symptom management less than optimal. On the other hand, evidence suggests that individuals with ESKD are prepared to discuss end-of-life issues earlier in their illness trajectory, especially before treatment initiation, and look up to their clinicians to provide more information on the subject and to guide them on what the process entails (Davison et al., 2010, Davison and Simpson, 2006, Lazenby et al., 2016). It is believed that individuals with ESKD are likely to know more about conservative management as an option and choose it when they seek care in a renal setting where the approach is more established and discussed (Germain et al., 2011, Tonkin-Crine et al., 2015).

Palliative care could be described as limited, at best, and non-existent, at worst in many low- and middle-income countries (Ddungu, 2011). Murray et al. (2003) conducted two qualitative studies, one in Scotland and the other in Kenya, that compared experiences of individuals dying from cancer. The studies identified stark differences between experiences of patients from both countries – while those in Scotland mostly received active treatment and palliative care after diagnosis, those in Kenya mainly awaited death after diagnosis without any active treatment or palliative care. This is because of lack of specialist palliative care for patients in the Kenyan community. However, there were some positive experiences for patients in Kenya, including having a sense of spiritual comfort due to their belief in God, which was lacking among several patients in the Scotland study. In effect, although conservative management is increasingly being used in the management of ESKD in some high-income

countries albeit not at expected rates, its use in several low- and middle-income countries is yet to be fully explored.

Complementary and alternative medicine has been recognised as playing a supportive role to biomedicine in many countries in Europe and North America. A similar concept used in low- and middle-income countries is 'traditional medicine' (Jenkins et al., 2015, Oreagba et al., 2011, Salisu and Prinz, 2009, World Health Organization, 2003, Xu and Chen, 2012). Traditional medicine has been described as "the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness" (World Health Organization, 2013). Many perceive this approach to be a 'natural' form of treatment (Adibe, 2009, Brown et al., 2007). There is evidence that CAM and traditional medicine use has been increasing globally, especially among individuals with chronic conditions. However, there is limited data to clearly delineate clinical situations where such approaches are appropriate (Fischer et al., 2014, Frass et al., 2012).

Use of CAM approaches such as medicinal herbs has been reported among individuals with ESKD amidst concerns that some of them have potential toxic effects on the kidney. A survey conducted by Osman et al. (2015) among pre-dialysis, dialysis and transplant patients in Egypt revealed that 54% of the 1005 respondents reported using CAM, with herbal medicine being the commonest. Men, urban dwellers, individuals with high education, those with higher income, and those who were employed were more likely to utilise CAM in this survey. CAM was used for a host of reasons in the survey, including confidence in its efficacy, lower costs as well as dissatisfaction with biomedicine. Another survey conducted among patients with ESKD in the USA by Birdee et al. (2013) revealed that 36% of the 89 respondents of the survey had utilised CAM within a month prior to the survey. The commonest CAM used among these respondents was mind-body practices such as yoga, meditation and prayer, with only a few people using herbs. However, this study was based in a single renal centre in a single state in the USA and may not have provided an accurate estimation of CAM use in the entire country.

In summary, the use of non-RRT approaches in managing ESKD is increasing in some geographical locations and among specific groups. Conservative management, which is seen as the best approach for very elderly patients with ESKD as well as those with comorbidities, is increasing in high-income countries but less common in low- and middle-income settings. CAM, as well as traditional medicine use, also appears to be increasing although there is no evidence supporting their use in the ESKD patient population.

1.5 Choosing Treatment Modality

Factors such as availability of treatment modality, physician preferences as well as medical indication have traditionally accounted for the choice of treatment for a patient. The dialysis unit has been regarded as a specialised area with high technology and the focus of nephrology research has mostly been on therapeutic outcomes to the frequent neglect of patients' perspectives on care (Aasen et al., 2012). As a result, clinicians may not fully appreciate the deepest concerns of patients with ESKD regarding decision making on RRT (Bass et al., 1999, Tweed and Ceaser, 2005). In addition to the current discourse on increasing patient choice in healthcare, which will be explored in a later section, there are no reported significant differences between haemodialysis and peritoneal dialysis in terms of their medical effectiveness and impact on quality of life. Patient preference is, therefore, taking centre stage in decision making in the ESKD patient population and clinicians are being entreated to consider patient preferences in decisions regarding the choice of a dialysis modality (Boateng and East, 2011, Couchoud et al., 2015, Kelly-Powell, 1997, Morton et al., 2012, Wu et al., 2004). It, therefore, becomes imperative to explore how decisions about ESKD management are being made, especially in under-resourced settings where specific treatment modalities are not always available.

It is noteworthy that one study in the UK (Winterbottom et al., 2012) concludes that most patients with ESKD perceive their decision making to be between 'dialysis' and 'no dialysis'. In other words, the first critical decision is whether to choose survival or death, even before the type of RRT modality becomes an option if the former is chosen (Harwood and Clark, 2013). Nonmedical factors remain central to the choice of dialysis modality by patients with ESKD (Boateng and East, 2011, Couchoud et al.,

2015). It is under such circumstances that understanding patients' perspectives on various treatment approaches has become a necessity as that is anticipated to guide healthcare personnel in supporting them in their decision making process (Lin et al., 2005). Adequate knowledge of patients' perspectives on the various treatment modalities will aid in planning and ensuring efficient renal services and will also lead to the implementation of appropriate educational interventions for people newly diagnosed with ESKD and their relatives or significant others (Morton et al., 2010). Consequently, patient decision making in the management of ESKD has received increased attention (Harwood and Clark, 2013, Morton et al., 2010). There have been calls for this to be explored in different sociocultural and healthcare settings in light of the influence of culture and resources on treatment decision making (Charles et al., 2006, Pierce and Hicks, 2001).

1.6 RRT in Low- and Middle-Income Countries

There is limited data on CKD in low- and middle-income countries, defined by the World Bank as countries with gross national income (GNI) per capita less than $1,045 and between $1,045 and $12,736 respectively (Evans and Taal, 2011, The World Bank, 2016, White et al., 2008). The incidence of CKD in low- and middle-income countries is perceived to be higher than that of high income countries, occurring mostly in a relatively younger age group (between 20 and 50 years old), with many of the affected individuals being breadwinners of their families (Alebiosu and Ayodele, 2005, Alebiosu, 2002, Bamgboye, 2003, Barsoum, 2002, Naicker, 2009). In addition to hypertension and diabetes mellitus being leading causes of CKD, it is believed that glomerulonephritis and CKD from unknown causes account for a significant number of the CKD population in low- and middle-income countries (Couser et al., 2011). Suggestions have been made to consider widespread use of herbal or traditional medicine as a potential cause in cases of CKD from unknown causes (Jha et al., 2013, Stanifer et al., 2014)

It is estimated that that around 70% of the global incidence of ESKD will be within low- and middle-income countries by year 2030 (Barsoum, 2006, Stanifer et al., 2014). Meanwhile, the prevalence is less than 100 per million population (pmp) in most low- and middle-income countries, particularly in sub-Saharan Africa, as compared to other parts of the world (3138 pmp in Taiwan, 2411 pmp in Japan, 2043 pmp in the USA, and 800

pmp in Europe) (Barsoum, 2006, United States Renal Data System, 2015). More than 1 million deaths results from untreated ESKD and majority of this occurs in low- and middle-income countries (Couser et al., 2011). This is partly because efficient and well developed renal care services for persons with ESKD, including improved RRTs, extends their time of survival, but many low- and middle-income countries do not have well developed renal care services (Ayodele and Alebiosu, 2010). Even though about 1.8 million people were treated for ESKD worldwide in 2004, the total number that accessed treatment from sub-Saharan Africa was less than 5% (Grassmann et al., 2005, Naicker, 2009). The ESKD population receiving dialysis in most sub-Saharan African countries is less than 20 pmp (Naicker, 2009). Moreover, lack of CKD awareness is thought to serve as a barrier to many people accessing appropriate renal care even when it is available (Couser et al., 2011). Thus, although the incidence rates are high, higher mortality rates of patients with ESKD in sub-Saharan Africa cause the prevalence to be relatively low (Barsoum, 2006).

Unlike many high-income countries in Europe and the United States of America, costs of RRT in many sub-Saharan African countries are catered for privately by individuals or through donor support, making RRT financially inaccessible to many (Alebiosu and Ayodele, 2005, Ayodele and Alebiosu, 2010, Naicker, 2003). Non-existent or limited government subsidy, lack of health insurance policies to cover dialysis costs, fewer renal centres, inadequate human resource, and restriction of most of the available renal centres to urban areas all contribute to the lack of accessibility (Ayodele and Alebiosu, 2010). Only a few countries in sub-Saharan Africa (including Mali, Mauritius and South Africa) have their governments supporting RRT for a limited number of patients with ESKD (Naicker, 2009). Thus, it becomes a daunting task to sustain RRT programs for all patients with ESKD in such settings, especially as many patients can only afford dialysis costs for around three months (Alebiosu, 2002, Naicker, 2009). A report on a study that was conducted in Nigeria revealed that only 3 out of a cohort of 141 patients with ESKD (2.1%) could afford the cost of haemodialysis sessions beyond 12 months after initiation (Arije et al., 2000). An estimated 40% of patients with ESKD on dialysis in many low- and middle-income countries undergo dialysis for less than the average conventional 12 hours per week, having just one or two dialysis sessions every week (Barsoum, 2002, Rayment and Bonner, 2008). Moreover, persons who undergo regular dialysis are reported to be

only partially rehabilitated because of lack of expert human resources, technical inefficiencies and limited supply of other essential components (Barsoum, 2002, Barsoum, 2006). Thus, many patients die as a result of no or inadequate provision of RRT in such settings.

1.7 Profile of Ghana

This chapter will now turn towards Ghana in order to provide more detailed information on the context for this study. It will explore the healthcare structure within the country, health-seeking among the citizenry, healthcare policies in the country and how these are likely to influence care of individuals with ESKD.

Ghana is a tropical country situated on the west coast of Africa, with average temperatures between 21°C and 35°C and is bordered by Togo, Burkina Faso and Cote d'Ivoire (Amoah et al., 1998, WHO Country Office Ghana, 2005). Statistical report from the 2010 census published by the Ghana Statistical Service (2013) puts the total population of Ghana at 24,658,823 with 48.8% (12,024,845) being males and the remaining 51.2% (12,633,978) being females. This represents a 30.4% increase from the total population in 2000 (18,912,079). About 43% (10,617,930) of the total population are dependent (less than 15years and over 65years old) and life expectancy is 63.4 years at birth. There are ten administrative regions in the country, and these regions are further divided into districts – 212 districts in total (Ghana Statistical Service, 2012, Government of Ghana, 2012, WHO Country Office Ghana, 2005). About 35.7% of the population live within the Ashanti (19.4%) and Greater Accra (16.3%) regions, the two most densely populated regions.

The 2010 population and housing census report by the Ghana Statistical Service (2013) revealed that 74.1% of Ghanaians who are 11 years or older are literate in English, French or a Ghanaian language, with some variations based on gender (about 80% of men as compared to 68% of women) and locality (84% in urban areas compared to 63% in rural areas).

There are three major religions in the country – Christianity, Islam and Traditional. About 71.2% are Christians, 17.6% are Muslims (Islam),5.2%

belong to the traditional religion while 5.3% do not belong to any of these religions (Ghana Statistical Service, 2013)

Ghana is classified as a lower-middle-income country by the The World Bank (2016) and ranks 15th among 48 countries in sub-Saharan Africa with a GNI per capita of $1,590. The economy is driven mostly by agriculture, contributing about 42% of gross domestic product (GDP) which stands at US$38.62 billion (The World Bank, 2016, World Health Organization, 2009). Ghana, however, depends largely on international support in many ways, though it is has a lot of natural resources (Central Intelligence Agency, 2012).

1.7.1 Healthcare in Ghana

The healthcare system in Ghana has been organised into three major levels: primary (health centres and health posts), secondary (district and regional hospitals) and tertiary (four teaching hospitals) (Amoah, 2002, Amoah et al., 2000, World Health Organization, 2014). The Ministry of Health (MOH, Ghana) formulates, monitors and evaluates policies, mobilises resources, and regulates health service delivery in Ghana while the Ghana Health Service (GHS) delivers service and implements health policies and programmes designed by MOH (Ghana Health Service, 2009, World Health Organization, 2009).

Many African countries do not have a reimbursable National Health Service as there are in the UK and other high-income countries (Mbanya et al., 2006). This was the case in Ghana until the introduction of the National Health Insurance Scheme (NHIS) in 2003 to serve as a means to achieving universal health coverage in the country, and this has improved financial accessibility to healthcare for many citizenry (Mills et al., 2012, National Health Insurance Scheme, 2009, World Health Organization, 2009). For instance, out-patient department (OPD) attendance rose from about 8,000,000 in 2000 to 15,712,070 in 2007 (Ghana Health Service, 2007). Most of the general, as well as specialist in-patient and out-patient services, are catered for by the NHIS and, recently, free maternal care has also been added to the list of services catered for by the scheme as part of measures to reduce maternal mortality (National Health Insurance Scheme, 2009, World Health Organization, 2009). Membership and payment of premiums are dependent on whether the individual is in the formal or informal sector. While members in the formal sector contribute

about 2.5% of their salaries through the Social Security National Insurance Trust (SSNIT) contributions, those in the informal sector are expected to pay between Gh₵7.2 to Gh₵48 (approximately £2 – £10) as yearly premiums based on their income. However, various districts have set fixed premiums owing to the inaccurate measures of assessing incomes of those in the informal sector (Amporfu, 2013, Blanchet et al., 2012, Jehu-Appiah et al., 2011).

In spite of these positive developments, the number of healthcare personnel in Ghana remains low. There are about 2033 physicians and 24,974 nursing/midwifery personnel, with densities of 1.0 and 10.5 per 10,000 of the Ghanaian population respectively (World Health Organization, 2012, World Health Organization, 2014). Although this is a global problem, comparing this to UK densities of 27.9 and 88.3 per 10,000 for physicians and nursing/midwifery personnel respectively highlights the relative shortage in Ghana (World Health Organization, 2014). In addition to fewer healthcare training institutions in the country, migration of health personnel to high-income countries is likely to have contributed significantly to these observed shortages. Buchan and Sochalski (2004) identified that about 500 nurses left Ghana in year 2000 alone. Scarcity of doctors in remote areas of the country has, therefore, stimulated the training of medical assistants to lead in the medical management of common conditions within the rural areas (McPake and Mensah, 2008).

1.7.2 Healthcare-Seeking in Ghana

Healthcare delivery in Ghana has been described as pluralistic as it consists of both biomedicine and traditional medicine. Biomedical services are provided in hospitals, clinics, health centres or health posts, and maternity homes and are either publicly funded or privately funded (Tabi et al., 2006). Many Ghanaians approve of biomedicine and will seek it in the first instance because of the highly investigative and analytical processes that its personnel utilise in identifying the causes of diseases (De-Graft Aikins, 2003, De-Graft Aikins, 2005). However, factors such as high costs of care, geographical inaccessibility to health facilities, and inability of biomedicine to cure certain diseases also deters people from utilising such services (Kolling et al., 2010).

Consequently, many Ghanaians use traditional medicine, often concurrently with biomedicine. It is estimated that 80% of Africans use traditional medicine for primary health care while 60% of Ghanaian children with high fever as a result of malaria are treated with herbal medicines at home (World Health Organization, 2003). Traditional medicine remains popular among the citizenry and is only frowned upon when its use endangers life or leads an individual who clearly needs healing through a modality with proven efficacy (mostly biomedicine) not to take the expected steps (Price et al., 2011). Unspecified drug dosages, unclear information on the mechanism of action of drugs, as well as adverse reactions that are sometimes related to herbal medicines, are also significant issues that are raised to criticise use of traditional medicines in Ghana (De-Graft Aikins, 2003).

Choice of biomedicine or traditional medicine is believed to be partly dependent on an individual's knowledge on and beliefs about causes of diseases. De-Graft Aikins (2003) identifies four knowledge modalities of individuals about causes of diseases in Ghana – common sense, 'scientised', religious, and emotional knowledge. De-Graft Aikins (2004) explains that common sense knowledge refers to those meanings that individuals ascribe to their illness experience in relation to their social observations and interactions. 'Scientised' knowledge refers to aspects of common sense knowledge that are formulated from encounters with biomedical personnel, media, literature, or from other individuals diagnosed with the same condition. Religious knowledge is based on their religious beliefs while emotional knowledge is based on their personal experiences of the disease. Individuals are more likely to attribute a disease to sorcery when there is no clear association between their 'scientised' knowledge and the characteristics of the disease, and in these circumstances will mainly use traditional medicine.

Traditional healers mostly promise cure to their users, a claim that is not made in biomedical care in terms of management of chronic conditions (Kolling et al., 2010). Consequently, many people choose traditional medicine with the hope of being cured, especially of diseases that biomedicine does not have cure for. Accessibility and availability of traditional medicine, as compared to biomedicine, are also cited as other factors that influence many people to choose traditional medicine. The World Health Organization (2013) estimates that biomedical services are

limited in many African countries, with the ratio of medical doctors to population standing at 1:40,000 while that of traditional healers to population stands at 1:500.

'Healer shopping', a common practice in Ghana as well as many other African countries, is when a patient seeks care from a second or third healer without a referral from the first healer for an episode of illness (De-Graft Aikins, 2005, Kroeger, 1983). Many individuals who practice healer shopping use traditional medicine, if their first contact was with biomedicine (Awah, 2006). Several reasons have been given for simultaneous or sequential use of traditional medicine and biomedicine but poverty and the quest for cure seem to be the most common causes. A survey conducted in Nigeria revealed that 69.4% of the 278 respondents admitted to concurrent use of biomedicine and traditional medicine within a period of one month preceding the study (Adibe, 2009). Traditional medicine was used for both communicable and non-communicable diseases in the survey. Nxumalo et al. (2011) conducted a similar survey in South Africa where 1.2% of their 21,593 respondents, comprising 4762 households, reported using traditional medicine in the previous month. Reasons included perceptions that traditional medicine is effective, promotes continuity of care and is easier to access. The survey revealed that 64% of all households included in the survey spent at least 10% of their monthly expenditure on traditional medicine. Interestingly, utilisation of traditional medicine declined among households with higher socioeconomic status while those utilising traditional medicine were more likely to be poor, unemployed or living in rural areas. The authors attributed the observed lower traditional medicine utilisation rates to interventions from the South African government to dissuade the citizenry from using traditional medicine and biomedicine simultaneously. However, they add that social desirability bias and perceived stigma towards its use could have led to under-reporting of utilisation of traditional medicine. Anecdotal evidence suggests that prevalence of traditional medicine use is high in Ghana even though there is no specific data published on it in the country.

Concurrent or sequential use of traditional medicine with biomedicine is believed to have contributed to the occurrence of many avoidable complications and mortalities in many African countries, including Ghana (Adibe, 2009, Awah, 2006, De-Graft Aikins et al., 2010, Nxumalo et al.,

2011). De-Graft Aikins (2003) explains that individuals are likely to revert to biomedical care after utilising traditional medicine when their condition worsens. A similar finding was reported by Kroeger (1983) to depict that users of traditional medicine turn to biomedicine when faced with severe diseases or complications mainly because of better equipment and services provided by biomedicine. However, in offering a solution, De-Graft Aikins (2005) recommended an expansion and regulation of scientifically-approved herbal medicines in Ghana as they have proved effective in the management of certain ailments, including diabetes mellitus. Moreover, the World Health Organization (WHO) has collaborated with many countries, including Ghana, to authenticate herbal treatment of several conditions, including HIV/AIDS, diabetes mellitus, sickle cell anaemia and malaria through research (World Health Organization, 2003). The citizenry seems to be using more herbal medicine in the country, hence regulating it would enhance safety with its use.

1.7.3 Healthcare Policies on NCDs in Ghana

Healthcare policies in many African countries have prioritised the management of communicable diseases over that of non-communicable diseases (NCDs). There is a lack of clearly formulated policies for the prevention and management of NCDs (Cobden et al., 2010, Mbanya et al., 2006). This is partly because the focus of the international community has mainly been on communicable diseases including HIV/AIDS, although this focus has recently been challenged (De-Graft Aikins, 2007). Although the disease profile of Ghana has been characterised by high levels of communicable diseases such as malaria and HIV/AIDS, the country is believed to be experiencing an epidemiologic transition characterised by escalating prevalence of non-communicable diseases (World Health Organization, 2009). This implies that Ghana is experiencing a double burden of communicable and non-communicable diseases. The increasing prevalence of NCDs has been linked strongly to urbanisation and increasing prevalence of obesity and is more difficult to manage in terms of costs and facilities, particularly, for lower-middle-income countries like Ghana (Cobden et al., 2010, Mbanya et al., 2010, Tagoe and Dake, 2011). A study of epidemiologic transition among approximately 30,000 individuals in Northeast Ghana identified general reductions in mortality and fertility between years 2002 and 2011 (Engelaer et al., 2014). The authors identified that mortality resulting from infectious diseases reduced

during the period of study possibly due to increased awareness of infectious diseases and their management. Interestingly, the study area is among the least developed areas in the country and does not have most of the factors believed to be contributing to the increasing prevalence of NCDs in the country.

Some efforts have been made in response to the epidemiologic transition in Ghana as the Ministry of Health has now made attempts to shift from the curative approach to a more public health approach (Agyei-Mensah and De-Graft Aikins, 2010). The first response to the growing burden of NCDs in the country was the establishment of a Non-Communicable Diseases Control Programme (NCDCP) by the Ministry of Health in 1992 (Ministry of Health, 2012). This paved the way for the development and implementation of several other strategies aimed at addressing the increasing NCD burden. A Regenerative Health and Nutrition Programme (RHNP) was introduced in 2006 to aid in the prevention and management of NCDs (Tagoe and Dake, 2011). This programme highlights such behaviours as promoting healthy eating, regular exercise, drinking potable water, and rest and was integrated into the 5-year Programme of Work (5yPOW) of the Ministry of Health for 2007 – 2011 (Ministry of Health, 2007, Tagoe and Dake, 2011). However, there seems to have been no structured evaluation of this policy after it was incorporated into the 5yPOW of the Ministry of Health of Ghana. A major criticism of this programme has been that it is run parallel to other programmes targeting non-communicable diseases in the country, making the prevention and control of NCDs inefficient (Bosu, 2012, Bosu, 2013).

A national policy for the prevention and control of chronic non-communicable diseases was formulated by the Ministry of Health (2011). This had five key components comprising primary prevention, early detection and clinical care, health system strengthening, NCD financing options, and monitoring and evaluation. However, this policy document was short of well-defined targets and outcomes and would have been difficult to evaluate. A five-year strategy for the management, prevention and control of chronic non-communicable diseases was then developed, spanning the period between 2012 and 2016 (Ministry of Health, 2012). Two more components, rehabilitation and palliative care, and social support systems and partnerships, were added to the five in the national NCD policy. This document included well-defined targets but the strategy

has not yet been evaluated. The National Health Insurance Scheme that was introduced in 2003 has been covering a greater part of the cost of managing some chronic diseases such as hypertension and diabetes mellitus in Ghana (National Health Insurance Scheme, 2009, World Health Organization, 2009).

1.8 ESKD and its Management in Ghana

Unfortunately, there are no reliable data on the prevalence of CKD in Ghana. However, De-Graft Aikins (2004) and the World Health Organization (2009) report an increasing prevalence of chronic illnesses in the country, and CKD cannot be excluded. Reports suggest that the prevalence of NCDs such as diabetes mellitus and hypertension is increasing in Ghana but malaria and other communicable diseases remain leading causes of morbidity and mortality (De-Graft Aikins, 2007, De-Graft Aikins et al., 2010, De-Graft Aikins et al., 2014, World Health Organization, 2009). Increasing prevalence of diabetes mellitus and hypertension suggests a concomitant increase in prevalence of complications, including CKD over time (Ayodele and Alebiosu, 2010, Caskey et al., 2011, Thomas et al., 2008, Ulrich, 2009). However, information provision on communicable diseases tends to overshadow that of NCDs, making the citizenry more familiar with approaches to managing communicable diseases such as being on prescribed treatment for a relatively shorter period of time and being cured.

Other sources indicate that about 2687 cases of kidney diseases were recorded in 2011 at the outpatient department of the Korle Bu Teaching Hospital (KBTH), the largest teaching hospital in the country (a 31% increase as compared to that of 2010) (Okertchiri, 2012). Okertchiri (2012) adds that kidney diseases account for about 10% of hospital admissions at KBTH. The prevalence of CKD among persons with hypertension in Ghana is estimated to be 46.9%, and this increases to about 55% among those with pre-existing diabetes mellitus (Osafo et al., 2011). This is similar to figures in a study from a hospital in Cameroon where the prevalence of CKD among patients with hypertension was 49.7% using the modification of diet in renal disease (MDRD) equation (Kaze et al., 2016).

Ghana, like many other African countries, lacks the necessary facilities required for the effective management of ESKD. People with ESKD in

Ghana can undergo haemodialysis but there are inadequate resources to meet the increasing demand for it. For instance, Komfo Anokye Teaching Hospital (KATH), the second largest teaching hospital in Ghana, serves about 10 million people but had just 5 dialysis stations at the dialysis unit in the recent past (Adjei, 2010, Eghan et al., 2009). Even the leading teaching hospital, KBTH, had only 18 dialysis stations (Okertchiri, 2012). There is no national registry for chronic kidney disease in the country although efforts are being made to establish one, in association with other African countries (Davids et al., 2016). To get a sense of the current picture of renal care in the country, contacts were made with renal centres across the country for some characteristics of their patients and the centre during data collection for this study in April 2014. Details of this are provided in Table 2.

	Unit	Number of Dialysis Patients			Age Range	Average Number of Sessions	Cost per Session (GH¢)	Number of Haemodialysis Stations
		Males	Females	Total				
1	Komfo Anokye Teaching Hospital	5	2	7	26 – 78	2	150	5
2	NAHGE	12	2	14	19 – 76	2	110	8
3	Police Hospital	16	2	18	23 – 79	2	140	6
4	Ghana-Canada Medical Center	3	3	6	26 – 50	3	170	3
5	KBTH Renal	160	98	258	11- 82	2	140	17
6	KBTH Cardiothoracic Centre	21	17	38	27 – 85	3	200	10
7	Peace and Love Hospital	5	2	7	38 – 67	2	150	4
8	Cape Coast (Nov. 2014)	26	11	37	26 – 68	2	250	10
9	Accra Kidney	5	4	9	35 – 60	2	190	6
10	Benghazi Dialysis Unit	9	1	10	33 – 50	2	180	5
Total		**262**	**142**	**404**				**74**

Table 2: Details of Renal Centres in Ghana (April 2014)

Seventy-four haemodialysis stations nationwide for a population of about 25 million people, compared with a mean of about 90 haemodialysis stations per million population in European Union countries (Kaitelidou et al., 2005) highlight the inadequacy in Ghana. Moreover, the cost of dialysis sessions appears to be another setback to achieving effective outcomes; one dialysis session costs, on the average, about GH₵190 (about £35) while the average income in Ghana is about £260 per year.

The only study on survival patterns of patients with ESKD on haemodialysis in Ghana was published by Eghan et al. (2009). The researchers identified an early mortality of 37.5% in the incident haemodialysis population, with 27.5% mortality occurring within the first 90 days of initiating dialysis. This was attributed to financial constraints and late referral of patients to renal centres. The National Health Insurance Scheme currently does not cover the cost of dialysis for patients with ESKD (National Health Insurance Scheme, 2009). Patients, therefore, have to make out-of-pocket payments or rely on donor funds to undergo haemodialysis. A few are also supported by their employers. Consequently, many patients with ESKD do not survive for long due to the high cost of managing ESKD and the limited facilities (Eghan et al., 2009, GNA, 2010).

Peritoneal dialysis is currently not a renal replacement therapy option for adult patients with ESKD in Ghana, and kidney transplant surgery is in its nascent stages. For instance, kidney transplant surgeries were first performed in the country at the Korle Bu Teaching Hospital (Accra) in November 2008 (GNA, 2008). However, the surgery was made possible through the services of transplant surgeons visiting from overseas. Plans are underway to train Ghanaian specialists in kidney transplant surgery. The cost of one transplant surgery is up to GHS 40,000 (about £13,300) and this is not affordable for a majority of the ESKD population (Okertchiri, 2012).

In summary, the incidence of ESKD is considered to be increasing in Ghana although there are no accurate national records to confirm this. The lack of a renal registry also implies that there is limited information on the trajectory of the disease. Existing renal services are inadequate to meet the increasing demand, neither are there clear policies to address the increasing challenges posed by CKD and ESKD. An effort has been made

to provide a sense of renal services in the country in Table 2 but this has only highlighted the inadequacy of renal services in the country. The next section will present the aim and objectives of this study.

1.9 Aim and Objectives of the Research

In the light of the context described above, it is clear that individuals diagnosed with ESKD in Ghana will have different experiences as compared to those in high-income countries, especially in terms of making decisions about their treatment. The aim of this research, therefore, is to explore experiences of the Ghanaian patient with ESKD in relation to the global context and generate a substantive theory that explicates the process of patient decision making in ESKD management in Ghana.

The specific objectives were to:

1. Explore experiences and perceptions of patients with ESKD living in Ghana and how these influence patient decision making.
2. Examine the contextual factors (healthcare system, culture, resources) and their influence on patient decision making in Ghana.
3. Examine conservative management as an alternative approach for individuals with ESKD in Ghana
4. Generate evidence that will inform debate and policies on care of patients with ESKD in Ghana and also offer recommendations for future research, policy and practice.
5. Contribute to international evidence on patient decision making from a lower middle-income setting.

1.10 Structure of the Thesis

This background chapter has described epidemiologic transition and the double burden of communicable and non-communicable diseases in many low- and middle-income countries. Prevalence of CKD and ESKD was presented, after which RRT was presented as the mainstay approach to managing ESKD, albeit non-RRT approaches are increasingly becoming popular among certain ESKD populations. The chapter has highlighted the increasing incidence of ESKD and its impact in low- and middle-income countries, particularly in sub-Saharan Africa, and discussed some of the unique factors contributing to this. The situation in Ghana has also been

described to explain the context for this study, focusing on health-seeking behaviours of the citizenry as well as health policies that have been formulated to address the increasing NCD burden in the country. The chapter has emphasised that the healthcare context in Ghana and health-seeking behaviours of the people could influence patient decision making differently and established the need for patient decision making to be explored. The rest of the thesis has been structured as follows:

Chapter 2, the next chapter, will explore research on patient decision making and how it has become intrinsic in healthcare. It will then explore the concept of patient choice in healthcare delivery and examine research on decision making in the management of individuals with ESKD. The chapter will then provide further justification for this study after examining ethical issues in patient decision making.

Chapter 3 will describe the methodology for this study and explain the rationale for various decisions made in the course of this research, including the use of grounded theory and its major features as well as the processes involved in getting ethical approval for this study.

Findings of this research will be presented in three chapters – chapters 4, 5 and 6. Chapter 4 will present general characteristics of all participants of this study as well as their unique stories and experiences with ESKD. Chapter 5 will then present major findings from patient interviews while chapter 6 will present findings from clinician interviews.

Chapter 7 will discuss key findings from this study with respect to the global literature and objectives of this research while chapter 8 will present the substantive theory that has been generated from this grounded theory study. Major conclusions of this study will then be presented, followed by implications of the study.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction to the Chapter

This chapter reviews literature on patient decision making. It begins with an introduction to decision making theories, describing decision making as a cross-discipline concept and emphasising decision making patterns in healthcare. Exploring various decision making theories was deemed relevant to this study in order to identify and critique those that are being utilised within the healthcare setting. Three key theoretical models that are used within the healthcare setting are then discussed, concluding that shared decision making, one of three key theoretical models, has widely received increasing attention as the model that enhances patient choice and autonomy. However, the chapter argues further that this is not the case globally. The concept of patient choice is then explored and geographical variation in privileging patient choice in clinical decision making is emphasised. Various research studies on patient decision making are then explored, highlighting that patient involvement in decision making is a process that has evolved over time. Decision making among patients with ESKD is discussed, paying particular attention to four systematic reviews that have described experiences of patients with ESKD with decision making on their treatment. This is followed by a further justification for this research, after highlighting underlying assumptions and explaining that the context of renal care and renal replacement therapies is different in different parts of the world. A case is made for the need to explore decision making experiences of patients with ESKD in different geographical settings

2.2 Introduction to Decision Making Theories

Decision making research has received much attention across various academic disciplines including economics and psychology and has resulted in extensive theoretical and conceptual debates within and across these disciplines (Bekker, 2010, Beresford and Sloper, 2008). Decision making theories are generally classified as normative, descriptive or prescriptive (Bekker et al., 1999). Normative theories such as 'expected utility theory' focus on explaining how decisions should be made while descriptive theories such as 'information processing theory' describe how decisions are actually made in the real world (Beresford and Sloper, 2008, Chapman and Sonnenberg, 2000). The information processing approach is the

commonly used approach, even within the healthcare setting, as people generally make decisions by selectively paying attention to external cues or information to create a mental representation of the decision context and then evaluating this mental representation to arrive at a decision (Bekker, 2010, Shaban, 2012).

Zeleny (1982) adds that, traditionally, there are two main approaches to studying decision making – an outcome-oriented approach and a process-oriented approach. The outcome-oriented approach premises that correctly predicting the outcome of a decision process will lead to a good understanding of the process and comprises the normative theories while the process-oriented approach maintains that a good understanding of the decision process can lead to a correct prediction of the outcome. The latter is essentially descriptive although it has features of normative and prescriptive theories: knowledge of how decisions are made can highlight how they should be made whereas knowledge of how decisions should be made cannot provide any clue as to how decisions are being made.

Studying differences between normative and descriptive theories allows identification of biases or differences between how decisions should be made and how they are actually made leading to the development of prescriptive theories and models in an attempt to improve decision making (Baron, 2004, Shaban, 2012). In other words, knowing about decision biases gives clues on the cognitive processes that underlie decision making and lead to identification of areas where improvements are necessary (Chapman and Elstein, 2000). Thus the focus of prescriptive theories is to assist people and train them to make good decisions (Bekker et al., 1999, Shaban, 2012) and, especially in healthcare, this can translate into improved patient care and better health outcomes (Chapman and Elstein, 2000). It is widely believed that emphasis should be on understanding the process and not simply the outcome of making a decision (Bekker, 2010). Thus, decision making is generally described as effective when an individual facing choices understands the facts relating to each choice and its implications in relation to their values (Fischhoff, 2005). Consequently, recent initiatives aimed at improving decision making in the healthcare setting give precedence to enhancing sound understanding of various choices the patient faces. It is believed that the use of decision aids with key components such as accurate and explicit presentation of the decision problem, all options and their potential

consequences as well as approaches to encourage the decision maker to consider their values and risk perceptions in terms of the consequences of their decision will lead to a good decision (Bekker, 2010). (The use of decision aids in improving patient decision making has been explained further in Section 2.3.3.)

The focus of decision research in healthcare is on improving decision making so as to achieve better patient care and outcomes, and efforts are mostly directed at policy makers or individual patients (Chapman and Sonnenberg, 2000). Andermann (2013) identifies three levels of decision making – individual, population and global. All these levels are closely linked because global treaties and national policies greatly influence individual-level decisions while collective individual-level decisions significantly affect national and global health. The focus of this research is on individual-level decision making, specifically patient decision making. It is, therefore, noteworthy that different key theoretical models have been used to examine and describe patient decision making in the clinician-patient encounter (Charles et al., 2006). The subsequent sections will explore the various theoretical models used in the healthcare setting and the concept of patient choice, a key driver of the increasing focus on patient decision making in healthcare.

2.3 Theoretical Models of Patient Decision Making

There are three common theoretical models for patient decision making. These are usually described as paternalistic, informed and shared decision making models although there is no one generalised definition or scope for each of these models (Charles et al., 1997, Emanuel and Emanuel, 1992, Wirtz et al., 2006). These models appear to present a continuum of authority, with the clinician being the ultimate decision-maker in the paternalistic model and the patient being the ultimate decision-maker in the informed decision making model. Shared decision making involves exchange of information between two or more concerned parties (mostly the clinician and the patient) before a decision agreed upon by all concerned parties can be made (Charles et al., 1999). Thus, the differences between these models lie in the different roles that the clinician and the patient play and how much choice the patient has (Wirtz et al., 2006).

	Paternalistic	Shared	Informed
Information flow	One way (clinician to patient); clinician provides minimum information necessary to obtain informed consent from patient	Two way; clinician presents all clinical facts; patient presents information on their preferences	One way (clinician to patient); clinician presents all information needed by patient to make decisions
Deliberation	Clinician alone, or with other colleagues	Clinician and patient (possibly with significant others)	Patient alone, or with significant others
Ultimate decision-maker	Clinician	Both clinician and patient	Patient

Table 3 shows characteristics of each of these three models.

	Paternalistic	Shared	Informed
Information flow	One way (clinician to patient); clinician provides minimum information necessary to obtain informed consent from patient	Two way; clinician presents all clinical facts; patient presents information on their preferences	One way (clinician to patient); clinician presents all information needed by patient to make decisions
Deliberation	Clinician alone, or with other colleagues	Clinician and patient (possibly with significant others)	Patient alone, or with significant others
Ultimate decision-maker	Clinician	Both clinician and patient	Patient

Table 3: Theoretical models of decision making (Charles et al., 1999)

2.3.1 Paternalistic Decision Making Model

The paternalistic model is, arguably, the most familiar model in the clinical setting. Under this model, clinicians utilise their expertise to identify patients' diagnoses, the required diagnostic investigations as well as treatment. Selective information is then presented to patients to encourage them to give their consent to those approaches that are considered best from the clinician's perspective (Emanuel and Emanuel, 1992). However, there has been a general shift of focus of decision making from the clinician's perspectives of what works best to the patient's preferences in light of current evidence, especially with the advent of evidence-based practice (Butterworth et al., 2012, Caspi et al.,

2004, Fineout-Overholt et al., 2005). This is because the paternalistic model is deemed inappropriate in many instances in the current healthcare context, especially in Northern America and Western Europe where greater patient autonomy and choice have been advocated (Azétsop and Rennie, 2010). Counter to paternalistic decision-making, the patient has the fundamental right to understand reasonable explanations for all the available options, including the pros and cons of each option (Fowler, 2012, Johnstone, 2009). What is more, the patient stands to lose a lot, in terms of their health and survival and, thus, it is only appropriate for priority to be given to their preferences on clinical issues instead of that of others (Ho, 2008). The ultimate goal is to ensure that patients are actively involved in making health decisions that contribute to the achievement of their healthcare goals (Chewning et al., 2012). Patients, especially those with chronic conditions, are more likely to adhere to a treatment regimen when they recognise it as their own decision (Vermeire et al., 2001). Notwithstanding, the paternalistic approach is usually the default approach in emergency situations where time spent in deliberating between options might result in fatal outcomes (Charles et al., 1997, Emanuel and Emanuel, 1992, Moreau et al., 2012, Wirtz et al., 2006). It also appears to be the default approach in some clinical settings and among some cultural groups outside North America and Western Europe (Hamann et al., 2012, Searight and Gafford, 2005).

2.3.2 Informed Decision Making Model

The informed decision making model requires the clinician to provide the patient with all information needed to make a decision, and leaves deliberation and the ultimate decision making to the patient (Charles et al., 1999). It sees the individual as one who deserves to be respected as self-governing and has the capability to understand and to deliberate on critical choices (Elwyn and Edwards, 2009). What is more, well-informed patient decisions will lead to effective utilisation of healthcare services since they will, mostly, be maximally congruent with the patient's values (Deyo, 2000, Sheu et al., 2012). Informed decision-making has also been widely accepted as a good indicator of quality care (Entwistle and Watt, 2006). However, a major argument used to criticise this approach is that individuals from different cultural backgrounds would prefer their clinicians to make key decisions regarding their care and may feel abandoned when their clinicians adhere to the informed decision making model (Davies and

Elwyn, 2008, Hamann et al., 2012, Searight and Gafford, 2005). What is more, clinicians may not see the need to provide information on non-existent options in resource-constrained settings. In practice, both shared and informed decision making models are often used interchangeably as patients express satisfaction with the extent of their participation in either of them (Edwards and Elwyn, 2006).

2.3.3 Shared Decision Making Model

Shared decision making appears to have gained clinical relevance as it has been associated with positive patient outcomes such as satisfaction with care (Charles et al., 1997, Da Silva, 2012, Légaré et al., 2010). It has an advantage of combining the knowledge and expertise of the clinician with the values, preferences, opinions and goals of the patient to achieve a common acceptable ground for making an ultimate clinical decision (Edwards and Elwyn, 2006). It has other benefits such as increasing patient knowledge, reducing anxiety with regards to the care process, improving patient outcomes and aligning care with patient values (Oshima Lee and Emanuel, 2013). It is perceived as the best approach in situations where there is a lack of evidence to clearly support one clinical decision over others, as in the case of choosing a dialysis modality, and it encourages clinicians' support for the choice of the patient for as long as they want to exercise it (Boateng and East, 2011, Davies and Elwyn, 2008, Holm and Davies, 2009, Oshima Lee and Emanuel, 2013). The desire to ensure long-term patient satisfaction and to avoid costly medical claims have been adjudged as key driving forces towards shared decision making in many high-income countries, in addition to the ethical principles of safeguarding self-management and self-determination (Elwyn and Edwards, 2009).

Several initiatives have been made in an effort to promote shared decision making within the clinical context. These include passive approaches such as prompting health professionals, giving out printed or electronic information on various subjects to patients and active approaches such as formulating action plans and setting care goals for both patients and clinicians (Da Silva, 2012). Légaré and Witteman (2013) propose three requisites for shared decision making to take place: both clinician and patient must appreciate the need for a decision to be made; both should be aware and understand the best existing evidence regarding the benefits and risks of each option; and the decision making should incorporate the

clinician's guidance as well as values and preferences of the patient. Thus decision making processes where patients are unaware of or do not understand existing best evidence on all options cannot be described as shared decision making.

Implementation of shared decision making is enhanced in clinical settings when clinicians are motivated to do it and believe that it will improve healthcare processes and patient outcomes (Légaré et al., 2008). Elwyn et al. (2012) have proposed a three step model for implementing shared decision making in clinical practice – 'choice talk', 'option talk' and 'decision talk'. The choice talk step involves the clinician ensuring that the patient is aware of the availability of reasonable options; the option talk step requires the clinician to provide more precise information on the available options; the decision talk step requires the clinician to support the patient in considering their preference and deciding on what is best. Within this range of initiatives lies the utilisation of decision aids.

Decision aids, a form of decision support technology, are tools that are utilised in assisting individuals to know more about options that are available to them and to encourage them to actively participate in the decision making process in light of their personal values and preferences as well as current evidence (Durand et al., 2008, Elwyn et al., 2006). Thus, the use of decision aids allows clinicians to support individual patients and/or their families to assimilate complex concepts about their disease condition or clinical management, and to make informed decisions that reflect their unique values and preferences (Murray et al., 2004). They are mainly available in print, web based, video or audio forms (Harrison et al., 2009, Stiggelbout et al., 2012). Some decision aids include stories from other patients who might have gone through similar challenges with the aim of clarifying major issues to new patients facing the task of making a decision (Barry, 2002). It is believed that patients are able to relate well to salient information in personal stories but their impact is poorly understood and requires further exploration (Khangura et al., 2008). Some decision aids have been designed for patients' use in their homes in preparation for subsequent consultation sessions even though it is believed that the best approach will be for clinicians and patients to use them together during consultations (Harrison et al., 2009, O'Connor and Edwards, 2009).

The relevance of using decision aids have been well highlighted through systematic reviews. A systematic review by Stacey et al. (2011) that compared the use of decision aids to usual care concluded that decision aids improve knowledge of patients on available options, reduce decisional conflicts and motivate patients to actively participate in decision making with little or no anxiety. However, their impact on patients' satisfaction with and outcomes of decisions was not statistically significant. This was attributed to inadequate power of most of the included studies. All 86 RCTs came from only eight countries (Australia, Canada, China, Finland, Germany, Netherlands, United Kingdom, and United States of America), with none of them coming from any African country. This might infer that studies on decision aids within Africa may be non-existent or that the characteristics of such studies did not meet their inclusion criteria.

Although there is a plethora of evidence to support the use of decision aids and shared decision making in the academic research setting, they face numerous criticisms and challenges in their routine application in clinical settings due to a number of factors (Harrison et al., 2009). Time constraint appears to be the most cited impediment (Légaré et al., 2008, Stacey et al., 2011). Many patients feel that times allocated for consultation are too short to permit them to acquire more information and reflect on this information to make informed decisions while others feel guilty about taking up their clinicians' time in light of their high workload (Joseph-Williams et al., 2014). It is believed that time spent by health care practitioners in assisting patients to access and utilise decision aids means extra burden and cost to practitioners and health care financiers (Barry, 2002).

However, time constraint seems to be an impediment that is not only exclusive to shared decision making (with or without aids) but also to other routine clinical interventions (Légaré et al., 2008). A number of barriers to shared decision making were also identified in a systematic review by Joseph-Williams et al. (2014), including patients seeing themselves as inferior to clinicians in terms of expertise and clinicians using medical terminology exclusively in their interactions. It is also argued that research on shared decision making has largely been highly selective in terms of clinical settings as they are conducted in academic centres or leading health centres, and concepts may not generally be applicable to other clinical settings (Légaré and Witteman, 2013, O'Connor

and Edwards, 2009). Moreover, this model appears to be more applicable in settings where the patient has more than one choice and does not seem to offer solutions to guide patient decision making in resource-constrained settings or under circumstances where there is only one 'acceptable' choice for the patient.

This section has explored three commonly used theoretical models for patient decision making, including their pros and cons. It has described shared decision making as the widely accepted model of patient decision making in an era where patient choice and autonomy are being advocated to play central role in clinician-patient interactions. Yet, this advocacy does not appear to have been given the same attention in different geographical settings or among different cultural groups. The subsequent section will further examine the concept of patient choice and how this influences patient decision making in different healthcare settings.

2.4 Patient Choice in Decision Making

Choice is seen as an outcome of a process that requires evaluation of two or more alternatives of some positive value and a decision about which option(s) to select (Beresford and Sloper, 2008). Choices are usually described in terms of their options (potential actions or inactions of an individual), outcomes (possible consequences of these actions or inactions), values (the relative significance of these outcomes), uncertainties (with regards to the outcome that will be experienced) and decision rules (how these elements are integrated to make a choice) (Fischhoff, 2005).

The rise in consumerism in healthcare and increasing emphasis on patient autonomy and patient rights have led to a general shift from paternalism to shared decision making in healthcare (Azétsop and Rennie, 2010, Charles et al., 1999, Fotaki, 2009, Greener, 2007). Choice in healthcare is seen as necessary and desirable. It is necessary because of the ever increasing needs and demands for limited resources; it is desirable as it stimulates discourse on key aspects of healthcare efficiencies and cost-effectiveness of available options (Van de Ven, 1995). Choices include which healthcare facility to seek care from, and preference for clinicians, diagnostic and treatment procedures – increasing these is believed to promote provision of quality healthcare services for all (Barr et al., 2008, Greener, 2007, Greener and Mannion, 2009). Yet, the choice of healthcare

provider is seen as the easiest and most feasible one for patients as compared to the choice of what diagnostic and treatment procedures to have and when to have them (Greener, 2007). Even with the choice of healthcare provider, patients are believed to have preference for providers that are close to their homes and mostly remain loyal to their local hospital as their choice is informed by factors such as availability of car-parking spaces and waiting times but not by clinical excellence (Fotaki, 2009, Greener, 2007, Greener and Mannion, 2009). Consequently, policy documents have focussed on patients' choice of healthcare provider while little is known about patients' choice of treatment types (Greener, 2007).

Emphasis has increasingly been placed on involving patients in decision making regarding their treatment in recent years (Chewning et al., 2012). It is argued that more patient choice will improve healthcare providers' efficiency and responsiveness while empowering the patient (Vrangbaek et al., 2012). This is not to suggest that clinicians should cede decision making entirely to the patient because, although patients have access to more information now than ever through the internet and other sources, they may not be able to discern between reliable and unreliable information (Elwyn et al., 2012, Greener, 2007). Moreover, although it is claimed that individuals want greater choice in healthcare, the number of people who want more choice falls drastically among those who are experiencing some forms of illnesses (Greener and Mannion, 2009). Patients with acute conditions may not know much about the disease and would leave key decisions about their treatment to their clinicians, as compared to those suffering from long-term illnesses who develop their knowledge over time to become 'expert patients' (Greener, 2007). What is more, although giving more choice to patients is believed to ensure equitable access to essential healthcare services, it could create social inequalities in access to healthcare. In a survey to evaluate choice reform that was introduced in healthcare in Norway, Ringard (2012) noted that increasing levels of patients' formal education directly correlated with the likelihood of making a choice of healthcare facility. This has a potential to lead to reorganisation of the health system to suit the demands of stronger and more vocal patients, while vulnerable patients such as the aged with co-morbidities and those from deprived backgrounds may be neglected (Davies and Elwyn, 2008, Vrangbaek et al., 2012).

This begs another question – are the calls for increasing patient choice and autonomy ubiquitous? The discourse on increasing patient choice and autonomy has mainly been in North America and Western Europe and does not seem to be the case or apply easily to other geographical areas and among different ethnic groups (Charles et al., 2006, Searight and Gafford, 2005). Many patients of Eastern European descent, for instance, are comfortable with paternalism and would defer many key decisions to the clinician who is perceived as the expert (Hamann et al., 2012, Searight and Gafford, 2005). Many sub-Saharan African cultures also view the clinician as an authority and would not interfere in their work by seeking to be given more choice. Thus, although it is perceived as the norm for patients of North American or Western European descent to advocate for their inclusion in clinical decision making and to be given more choice, this is not always the case for patients from other backgrounds. What is more, increasing patient choice comes with increasing demand for more resources (Greener, 2007), and this would serve as a major setback to increasing patient choice in several low- and middle-income countries where significant resource constraints abound. There is evidence to show that patients' desire to be given more choice and included in decision making about their care has evolved over time. The next section reviews this evidence.

2.5 Patient Decision Making Patterns

Arora and McHorney (2000) analysed preferences for decision making among 2197 patients with various chronic conditions from the Medical Outcomes Study in USA. They identified that 69% of the respondents preferred a passive role in decision making although the percentages varied among different categories of respondents. Younger and highly educated patients, as well as women, were more likely to actively participate while those over 75 years of age were more likely to leave decision making entirely to their physicians. This seems to support the findings cited earlier from the Norwegian survey by Ringard (2012), where patients with higher formal education and women were more likely to desire more choice. However, preference was measured only once in this study by Arora and McHorney (2000). Patient preference may change with time among individuals with chronic diseases as confidence in self-management increases over time (Charles et al., 1999).

Levinson et al. (2005) also conducted a study in USA to explore the impact of health status and demographic variables on patients' preferred roles in decision making. Out of the 2765 respondents considered, just over half (52%) preferred their physicians to make the ultimate decision; this was more prominent among those aged 45 years and beyond. Most of the findings mirrored that of Arora and McHorney (2000) as more women, the highly educated, and the young mostly preferred to be actively involved in decision making. Women tend to act as health advocates for their families and, therefore, tend to seek more information from alternate sources so as to make appropriate decisions for themselves and their families though, sometimes, their opinions are more likely to be rejected by physicians (Elderkin-Thompson and Waitzkin, 1999, Levinson et al., 2005). Individuals with good health status also preferred to be actively involved in the decision making process while those with poor health status preferred their physicians to make ultimate decisions regarding their treatment (Levinson et al., 2005). This is expected as patients who have been diagnosed with a life-threatening condition such as ESKD or those who feel vulnerable tend to leave decision making to the clinician who is perceived as an expert (Chewning et al., 2012).

The concept of shared decision making started gaining more momentum after the publication by Charles et al. (1997) and has increased in popularity since then (Edwards and Elwyn, 2009). Thus, the concept might still be unfamiliar to the aged. It is, therefore, not surprising that both studies found that elderly patients, even those above 45 years in Levinson et al. (2005) study, tend to leave ultimate decision making to their physicians. A systematic review on patient decision role preferences between 1980 and 2007 by Chewning et al. (2012) identified that majority of patients preferred to share decision making with their physicians in about 63% of the 115 included studies. Analysis of the included papers based on their years of publication showed that active decision making by patients was common in just 43% of those published before 1990, 51% of those published between 1990 and 1999, and 71% after 1999, depicting an increasing trend in patient participation in decision making over time. This trend highlights the shift from the paternalistic model to the shared model of patient decision making. However, even though Chewning et al. (2012) conducted a comprehensive search on five major databases with no restrictions on countries, none of the 115 studies reviewed was conducted in an African country. This may imply that patient decision

making has not been adequately explored within the African continent or such studies have not been adequately disseminated.

2.6 Experiences of Decision Making in Patients with ESKD

When considering patient decision making, it is useful to narrow the focus. In this study, the patients of interest are those suffering from ESKD and it is to this condition that this chapter now turns.

Decision making has been studied extensively among patients with ESKD, mostly through qualitative approaches as subjective experiences are key to patient decision making. Qualitative approaches allow the diverse perspectives of patients with ESKD to be examined thoroughly (Lee et al., 2008, Morton et al., 2010, Tweed and Ceaser, 2005). Most of the earliest studies in relation to ESKD management focussed on the perspectives of healthcare providers, until the late 90s when the perspectives of patients gained prominence (Breckenridge, 1997).

2.6.1 Search Strategy

In order to identify studies on decision making in ESKD, a comprehensive search was carried out on four major databases (MEDLINE via Ovid, CINAHL Plus with Full Text [EBSCO], EMBASE via Ovid, and PsycINFO via Ovid). MEDLINE and CINAHL were searched initially to identify and analyse keywords and index terms used to describe the articles. Keywords and index terms identified through this exercise were then used to identify studies across the four databases. Details of these keywords and their combinations have been provided in Box 1 and the search was last updated in August 2016.

1. chronic kidney failure.mp. or Kidney Failure, Chronic/
2. chronic kidney disease.mp. or Renal Insufficiency, Chronic/
3. chronic renal disease.mp. or Renal Insufficiency, Chronic/
4. chronic renal failure.mp. or Kidney Failure, Chronic/
5. end stage renal disease.mp. or Kidney Failure, Chronic/
6. end stage renal failure.mp. or Kidney Failure, Chronic/
7. end stage kidney disease.mp. or Kidney Failure, Chronic/
8. end stage kidney failure.mp.
9. kidney failure.mp.
10. renal failure.mp.
11. ESRD.mp.
12. ESRF.mp.
13. CKD.mp.
14. ESKD.mp.
15. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14

16. Renal Dialysis/ or haemodialysis.mp.
17. HD.mp.
18. Peritoneal dialysis.mp. or Peritoneal Dialysis/

19. Continuous ambulatory peritoneal dialysis.mp. or Peritoneal Dialysis, Continuous Ambulatory/
20. CAPD.mp.
21. PD.mp.
22. Kidney Transplantation/ or Kidney transplant.mp.
23. renal transplant.mp.
24. Renal replacement therapy.mp. or Renal Replacement Therapy/
25. RRT.mp.
26. hemodialysis.mp.
27. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26

28. decision making.mp. or Decision Making/
29. patient decision making.mp.
30. decision.mp.
31. decide.mp.
32. choose.mp.
33. choice*.mp.
34. chosen.mp.
35. choosing.mp.
36. patient choice*.mp.
37. 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36

38. 15 and 27 and 37
39. limit 38 to English

Box 1: Keywords and combinations used in searching for literature

2.6.2 Inclusion and Exclusion Criteria

Studies were to be considered eligible for this literature review when they:

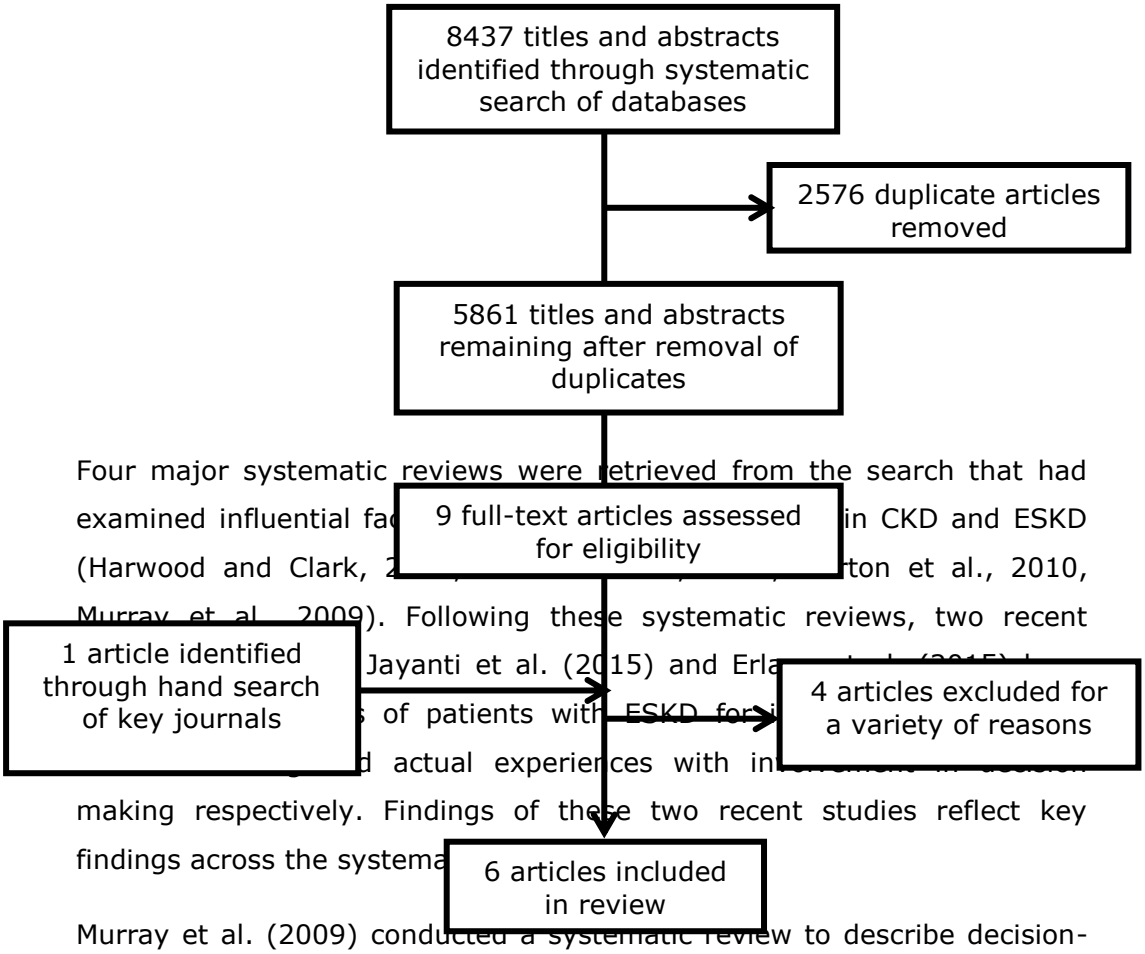
i. explored the process of decision making on the choice of treatment from the perspectives of adults with CKD or ESKD;
ii. explored perspectives of other persons other than the patient, but in addition to patient perspectives in the same study.

Articles were to be excluded if they solely explored perspectives of other persons other than the patient with ESKD or patient satisfaction with choice of treatment option.

2.6.3 Search Results and Study Selection

The search across the four included databases identified 8437 articles. These were reduced to 5861 following removal of duplicates. Titles and abstracts of these articles were screened to identify those that were relevant to this review. It was identified that there had been recent systematic reviews exploring patients' perspectives on choosing treatment modality for ESKD. A decision was, therefore, made to identify all systematic reviews that met the inclusion criteria for this review as well as empirical studies that have been published since the most recently published systematic review. Seven articles were identified that appeared eligible for this review. The seven full-text articles were retrieved and closely compared with the inclusion and exclusion criteria, after which one study (Robinski et al., 2016) was excluded because it focussed on

patients' satisfaction with their choice of treatment. The quality of the included articles was assessed using critical appraisal skills programme (CASP, 2013) tools for evaluating systematic reviews and qualitative studies. All included articles had good quality, meeting 6 out of the ten criteria.



Four major systematic reviews were retrieved from the search that had examined influential fac in CKD and ESKD (Harwood and Clark, 2 rton et al., 2010, Murray et al., 2009). Following these systematic reviews, two recent Jayanti et al. (2015) and Erla s of patients with ESKD for d actual experiences with in making respectively. Findings of these two recent studies reflect key findings across the systema

Murray et al. (2009) conducted a systematic review to describe decision-making needs of CKD patients, identify factors that influence patient decision making in CKD as well as interventions that support or hinder decision making. They identified that common decisions that have to be made by patients with ESKD include the type of RRT to choose, whether to withdraw or continue dialysis, and kidney transplantation options (living related donor or cadaveric). After reviewing 40 studies, mostly from the USA, Canada, and the UK, Murray et al. (2009) identified that opinions of family members and/or healthcare providers, knowledge of other patients' experiences, self-perceived burden to others, desire to maintain lifestyle and risk-benefit analysis are among the factors that inform decision making among patients with ESKD. However, these factors were not discussed in light of whether they support or hinder patient decision

making. No studies were identified that had assessed interventions that support or hinder patient decision making. It appears that cost as well as unavailability of a specific modality is not a major issue for consideration by patients in high-income countries when deciding on ESKD treatment. This is mainly because of the existence of health insurance policies that cater for the costs of managing ESKD. For instance, about 80% of the costs are covered by insurance in the USA (Singh and Bhandari, 2004) while the NHS covers the full costs of treatment in the United Kingdom (Baboolal et al., 2008). None of the included studies was conducted in a sub-Saharan African country or a low-income country where patients with ESKD have to make out-of-pocket payments to undergo dialysis.

Another systematic review by Morton et al. (2010) synthesised views of CKD patients and their carers' (excluding clinicians) decision making and the factors that influence those decisions. Unlike the systematic review by Murray et al. (2009), this review only included qualitative studies and excluded studies that explored decisions on withdrawal from dialysis. Eighteen qualitative studies met their inclusion criteria and, again, none of these studies was conducted in a sub-Saharan African country or a low-income country. The included studies utilised various methodologies including grounded theory (n=6), phenomenology (n=3), exploratory (n=1) while the remaining 8 did not specify their methodology. Key themes such as confronting mortality, lack of choice, gaining knowledge of options, and weighing alternatives were identified after synthesising findings from the included studies. Confronting mortality described feelings, attitudes and thoughts patients had towards ESKD as a life-threatening condition, with a number of patients being startled by the reality that their disease could lead to their death. Some patients, particularly the elderly, felt that receiving RRT could make them a burden for their families and, therefore, chose palliative management. Others also felt that it was not yet time for them to die and did not give much consideration to non-RRT options. These highlight how personal decisions about initiating RRT are for patients with ESKD. Lack of choice was considered in three ways: 1) patients not getting choices because of a physiological contraindication or physician preference; 2) patients not getting adequate information on all available choices, hence, being limited to one or a few options; and 3) renal centre not being adequately resourced to offer various RRT modalities. This 'constraints on resources' is a striking sub-theme, depicting that lack of resources may restrict

decision making even in high-income countries. For instance, the review identified that many patients chose home dialysis due to limited access to centre-based dialysis. In three of the included studies conducted in the USA, many patients stated the need to have a health insurance that covered the full costs of their dialysis sessions. The review also identified that many patients chose palliative care not because they could not afford the cost or had limited resources but because they wanted to avoid the daily stresses associated with dialysis and have supportive end-of-life care. For instance, an included qualitative study by Ashby et al. (2005) in Australia concluded that patients with ESKD may decline RRT when they feel that they may burden others, experience deteriorated quality of life, feel neglected by others, or are unsure of their prognosis. Gaining knowledge of options described how patients obtained information about treatment options and how these influenced their decisions. Experiences of other patients seemed to have a significant influence on patient decision making in this review, with the authors suggesting that patients with ESKD may find information from other patients with ESKD more persuasive and influential than that from clinicians when making decisions. The authors concluded that creation of vascular access for patients with ESKD around the time of decision making seems to predetermine haemodialysis while inhibiting choice of other treatment approaches, including palliative care. Moreover, the needs of many patients with ESKD and their carers are not being met. These findings have key issues that may be mirrored in low- or middle-income countries while others could highlight the striking differences between different healthcare settings in different countries.

Harwood and Clark (2013) also carried out a metasynthesis of qualitative studies to generate evidence on contextual factors that influence decision making among CKD patients. They included 16 studies, mainly from the United States of America and the United Kingdom and none from a sub-Saharan African country or a low-income country, with a total of 410 patients at different stages of CKD. All the patients drew on their personal values such as how their choices will intrude on their 'normal' life when making decisions about RRT.

The metasynthesis also revealed that although the ultimate decision to opt for RRT is the sole responsibility of the patient, other external factors including opinions of informal caregivers (family members or close friends) and other patients are vital. Morton et al. (2012) note that many informal

caregivers prefer their family members to be on some form of active dialysis treatment than to recommend conservative management. A Canadian study identified that about 61% of patients regretted initiating dialysis, and most of them explained that their decision to initiate dialysis was in a bid to fulfil the desires of either their physicians or family members although the author partly attributed this to depression (Davison, 2010, Harwood and Clark, 2013). This calls for a thorough examination of patients' perspectives and expectations when making decisions and the reasons for their ultimate choice.

A recent systematic review by Hussain et al. (2015) synthesised qualitative evidence on how and why different factors influence patients with ESKD and clinicians' decisions to start and/or withdraw dialysis. Twelve studies were included in this review, involving 206 patients and 64 clinicians. The review identified that the decision making process evolves as patients with ESKD progress along the trajectory of the disease. Aside from making personal judgements about the impact of treatment on their quality of life as well as a survival advantage, the review identified that individuals with ESKD made decisions about treatment on gut instinct. Patients with ESKD choose RRT regardless of the personal implications. Others choose dialysis to lessen symptoms experienced without any form of treatment or are 'forced' by the inevitability of death as their kidney function deteriorates. Other patients with ESKD choose death because of the burden associated with dialysis.

The review also identified that patients with ESKD cope with the process either by controlling the problem or controlling their emotions. Problem-controlling patients seek information, advice and opinions in an attempt to gain command of the situation while emotion-controllers focus on handling negative situations such as shock, anger, fear and torture which are associated with the situation. The latter group usually employ various methods, including nurturing false hopes, relying on others for decision making, avoidance, and accepting treatment passively to control emotions.

In terms of clinicians' decision making, Hussain et al. (2015) identified that they are mainly guided by biomedical criteria such as age, prognosis, comorbidities, physical function and results of blood tests to guide decisions and not patient preferences. Clinicians, however, face ethical

dilemmas occasionally, whether to offer life-prolonging treatment which may prolong suffering instead of enhancing patient's quality of life. The authors, however, added that clinicians continue to offer treatment even when that would not be beneficial because withholding treatment is seen as difficult. Clinicians also experience a sense of powerlessness in response to inevitable disease progression.

The review also identified that withdrawal from dialysis is usually considered when patients have commenced treatment for some time and feel that their condition is not improving any longer or that they are being restricted by the therapy. Clinicians mostly have concerns about discussing withdrawal from dialysis because of ethical and moral implications of such decisions and may avoid or query such discussions. However, only a few studies included in the review explored decision making among patients with ESKD who chose conservative management. These findings serve as a good evidence base to support increasing calls for shared decision making in ESKD which combines the expertise of clinicians with preferences and values of the patient with ESKD.

Jayanti et al. (2015) collected data from 535 patients with ESKD in five renal centres across the UK to assess their preference for information-seeking and decision-making using the Autonomy Preference Index (API) tool. The study identified that being of a younger age, female, having a lower comorbidity index score, and white ethnicity background positively correlates with a preference for inclusion in decision making.

Erlang et al. (2015) interviewed nine CKD patients who had just made a decision about their RRT and before starting treatment in Denmark. The study aimed at identifying how these patients perceived their involvement in decision making about their treatment. Uncertainty about the progression of the disease and the future due to the absence of symptoms of CKD caused participants to delay making a treatment choice while the presence of symptoms made participants appreciate the urgent need for a decision to be made. Participants felt involved in the decision making process when they felt that they were well-informed about the disease and had been able to express their concerns to clinicians through dialogue. Feeling involved gave participants a feeling of independence, irrespective of the degree of involvement.

In summary, patients' treatment choice of RRT is mostly in response to their perceptions about how that choice would affect their lives as well as their families and less on the effectiveness of those options. In one earlier study on patient decision making in ESKD, patients were more likely to reject a treatment option or express reservations about it when it did not correspond with their past experiences, values or beliefs. Decisions were made with different anticipation for their future, with hope as a key driver. Patients who felt that their treatment had been successful convinced themselves that they had made an appropriate choice while those who felt their condition was not improving were uncertain whether they made the right choices. Many respondents who chose to start treatment in this study felt that it was not their time to die (Kelly-Powell, 1997).

2.7 Underlying Assumptions of the Reviewed Literature

It appears that a basic assumption that underlies the evidence that has been discussed above is that issues and concerns about patient decision making are the same globally, and that approaches to addressing them will obtain the same support and yield similar outcomes in different cultural and healthcare settings (Charles et al., 2006). Shared decision making rests on the premise that giving more choice to the patient seems most applicable in settings where more than one acceptable medical choice exists (Charles et al., 1997, Whitney et al., 2008). However, such situations are not always guaranteed globally. There are instances where there is only one acceptable medical choice or there are two or more options but one is largely superior to the other(s). Decision making may be unilateral under such circumstances, with either the clinician or the patient controlling it and, where there are conflicts, negotiating a possible agreement (Whitney et al., 2008).

The existence of more than one acceptable medical choice may, however, be limited in some settings as is preponderant in low- and middle-income countries owing, primarily, to lack of resources (Greener, 2007, Kuruppuarachchi and Hapangama, 2008, Samele et al., 2007). Other times too, there may be one acceptable evidence-based medical choice and a patient preference for complementary or alternative therapy which may not have any evidence in its favour. Decision making under such circumstances has received little attention in the literature. Wye et al. (2009) explored such a decision making context and concluded that clinicians were more inclined to recommending the choice perceived to be

supported by research evidence while overlooking patient preferences and their sources of information. Yet, financial challenges on the part of patients and their families as well as their values and beliefs may make these evidence-based options objectionable to them, leading them to ignore the suggestion.

2.8 Ethical Issues in Patient Decision Making in ESKD

Patient decision making is seldom black-and-white and this may present challenging ethical dilemmas to patients and/or clinicians in the course of care. Dialysis and kidney transplantation are generally perceived to be significant contributors to the foundations of bioethics as the discipline arose in the 1960s when these therapies were being rationed or denied to sections of the population even in high-income countries (Maiorca, 1998). There were no treatment choices for people with uraemia in the past. The idea of using artificial kidneys to treat uraemia was introduced in 1913 but its effectiveness in humans was first demonstrated through independent works of Kolf and Murray in Holland and Canada respectively for the management of acute kidney injury in the 1940s (Darmady, 1948, MacLean et al., 1948, Vilar and Farrington, 2011). When dialysis was agreed as a mode of treatment for patients with chronic kidney failure in the 1960s in the USA, financial and space limitations led to the establishment of a committee that rationed the therapy by reviewing cases of patients to determine who could have the treatment (Blagg, 2007).

While dialysis is no longer rationed in many high-income countries, rationing is still used in the allocation of kidneys for transplantation because they are not always available (Moosa and Kidd, 2006). However, it is generally considered unacceptable for a clinical decision to be made based on financial limitations of the patient in many high-income countries (Maiorca, 1998, Schumann and Alfandre, 2008). In contrast, poverty and other sociocultural factors continue to restrict many individuals from accessing specific kinds of healthcare interventions in many low- and middle-income countries (Dirks and Levin, 2006, Maiorca, 1998, Moosa and Kidd, 2006). Clearly, resources and processes within high-income countries are different from those within many low- and middle-income countries, especially within the African continent. Rationing is used sometimes to ensure consistent supply of healthcare services such as dialysis in some parts of Africa, but these processes raise more ethical concerns in terms of selecting eligible patients as the young, employed or

urban dwellers are more likely to be favoured (Dirks and Levin, 2006, Moosa and Kidd, 2006). In Ghana, there is no form of rationing and patients receiving RRT for ESKD have to bear all the costs or be sponsored by their employers or private institutions. Thus, limited resources within many African countries may present unique conundrums for patients with ESKD in terms of decision making. The next section will provide further justification for this study.

2.9 Justification for this Research

It has been demonstrated that individuals with ESKD have to come to terms with a life-threatening condition, deal with inadequate information and select from limited choices, and carefully evaluate alternatives during decision making on their clinical management (Morton et al., 2010). The information needs of many patients with ESKD and their informal carers are not being met (Morton et al., 2010, Murray et al., 2009). Thus, further knowledge of patients' experiences and perspectives will be useful in providing quality care that addresses patients' unique needs. There are indicators that opinions of family members, friends and even other patients significantly influence patients' decision making (Gordon, 2001, Harwood and Clark, 2013, Morton et al., 2012). These findings raise pertinent issues that require further exploration, particularly in low- and middle-income countries where family or friends play a pivotal role in the long-term management of a patient's chronic illness (Azétsop and Rennie, 2010). Key questions are: do the choices patients make reflect the desires of these significant others or the individual patient? In terms of the context, does the problem of limited resources in low- and middle-income countries present different choices to the patient with ESKD facing decisions about their treatment? Do patients with ESKD get adequate support while making decisions about their treatment? How can health services in low- and middle-income settings provide optimal choices and information for individuals who are diagnosed with ESKD?

The burden of ESKD in Ghana is increasing in the face of limited treatment options (Eghan et al., 2009, Okertchiri, 2012, Osafo et al., 2011), and there are projections that 70% of the global incidence of CKD will be within low- and middle-income countries (Barsoum, 2006). Amidst these disturbing circumstances, CKD patients within these countries have to decide between initiating dialysis or not. Although the cost tends to deter many from initiating dialysis, other factors may also motivate some of

these patients to initiate haemodialysis, knowing well that their treatment may be for a short period. According to Okertchiri (2012), there are about 135 patients on dialysis at the Renal Unit of KBTH alone, and there are yet other dialysis patients in other renal centres across in Ghana. However, no study has been undertaken to explore the dynamics of patient decision making on treatment. To improve uptake of dialysis, or to improve care for individuals who cannot afford dialysis, a deeper understanding of the experiences and perspectives of Ghanaian patients with ESKD on their clinical management and decision making is a necessity. This calls for urgent approaches that explore decision making among patients with ESKD in the Ghanaian context.

It is easy to dismiss the relevance of this study by citing 'lack of choice' as predominant in this setting. However, the availability of dialysis therapy (albeit inadequate) implies that people will have to choose between that and other possible courses, including traditional medicine, spiritual healing or no treatment, hence the need for this study. In reality, many of the patients beginning dialysis in low- and middle-income countries die or discontinue within three months of initiation (Eghan et al., 2009, Sakhuja and Sud, 2003). However, understanding the issues that patients have to grapple with when diagnosed with ESKD and are required to decide on a treatment approach, is critical to promoting adherence to treatments of their choice or other appropriate therapies that can ameliorate their condition while addressing their deepest concerns.

The literature on patient decision making on treatment for life-threatening conditions has been dominated by studies from high-income countries, particularly in North America and Western Europe, with none from any sub-Saharan African country. Low- and middle-income countries, including several countries in sub-Saharan Africa, are facing a rapidly escalating disease burden from ESKD – and chronic diseases in general. Most of these diseases are life-threatening, especially in their advanced stages. There is, therefore, the need to extensively explore decision making among different socioeconomic and cultural groups to fill some of the gaps identified in relation to patient decision making (Morton et al., 2010, Pierce and Hicks, 2001). This is because sociocultural factors, ethnomedical beliefs and practices, and unique characteristics of individual patients affect their decision making on healthcare treatment options (Gordon, 2001). It is therefore anticipated that findings from this study

will offer a unique contribution to the global literature on patient decision making, especially for patients facing life-threatening conditions as a result of non-communicable diseases in countries experiencing epidemiological transition

2.10 Summary of Chapter

This chapter has reviewed the literature on decision making and its place in healthcare. Three key theoretical models that have been used within the healthcare context over the years have been described and critiqued. The chapter has also explored the concept of patient choice and emphasised that there have been increasing efforts to promote patient inclusion in decision making regarding their care, hence leading to a general shift from paternalism to shared decision making. Yet, evidence on this has only come from high-income countries, mainly in North America and West Europe. This led to a justification of the need for such a study to be undertaken in other settings where the healthcare context and health-seeking behaviours of the citizenry are different from those in North America and West Europe. The next chapter will describe the methodology that was employed for this study.

CHAPTER 3. METHODOLOGY

3.1 Introduction to the Chapter

The aim of this chapter is to explain the rationale for various decisions made in the course of this research, including the use of grounded theory and its major features. The chapter begins with an explanation for the rationale for choosing the methodological approach of grounded theory, followed by a description of its main features. Data collection and analysis methods for the research are then presented followed by a discussion of ethical considerations in the study design.

3.2 Rationale for Choice

Research methodology describes the processes a researcher utilises in studying any phenomenon of interest, and may be classified broadly (qualitative or quantitative) or narrowly (such as grounded theory, phenomenology) in social research (Silverman, 2009). Formulation of a research question and the choice of a methodology, to a greater extent, is a reflection of the beliefs of the researcher about the nature of reality, the relationship between what can be known (object of study) and the knower (researcher), and the best approach to discovering this reality (Annells, 1996, Krauss, 2005).

Positivism, which has its roots in empiricism, considers observation and measurement as central to the acquisition of knowledge (Benton and Craib, 2011, Krauss, 2005). Its ontological assumption is that there is a single reality that is guided by unchangeable natural laws and processes and this reality, in principle, is comprehendible through research. The epistemological basis of positivism is that the object of study is independent of the researcher, a concept termed dualism or objectivity. Thus, researchers are required to separate themselves from the phenomena of study, and to ensure that all forms of influence are avoided or controlled (Guba and Lincoln, 1994). However, the phenomena of interest in the social sciences involve humans and their real life experiences. Since humans can reflect on problems and act in response, especially when being observed, positivism is mostly an inappropriate paradigm of inquiry to use within the social sciences (Benton and Craib, 2011, Healy and Perry, 2000). Researchers can only better understand phenomena of interest within the social sciences by being involved to

some extent instead of being separate or independent, as is advocated for by positivism (Healy and Perry, 2000). The ontological and epistemological tenets of positivism were, therefore, deemed inappropriate for the aims of this study.

Constructivism, another paradigm of inquiry, maintains that knowledge is gained through interpretations that are attached to the phenomenon being studied, proposing an interaction between the researcher and the study subjects to obtain data. This is termed subjectivist epistemology. Moreover, reality is described as a specific belief system that is upheld in a particular context at a particular time and is constructed socially by and between individuals who experience it, hence, the existence of multiple realities (Darlaston-Jones, 2007, Denzin and Lincoln, 2011, Guba and Lincoln, 1994). The place of language in constructivism is very significant as reality becomes comprehendible through interviews, conversations or narratives (Darlaston-Jones, 2007). Qualitative researchers maintain that reality is a social construction and emphasises on the subjective nature of the relationship between the researcher and object of study (Denzin and Lincoln, 2011). Constructivism is, therefore, strongly linked to qualitative research, and includes aspects such as symbolic interactionism (Annells, 1996, Denzin and Lincoln, 1994, Guba and Lincoln, 1994). Constructions of ill people are reflections of how they comprehend their experiences and the diverse situations they go through (Charmaz, 1990), making constructivism and qualitative methods significant in exploring patients' perspectives and experiences.

Symbolic interactionism is considered as a theory of human behaviour and, also, as a method of investigating the relationship between individual behaviours and forms of social organisations (Annells, 1996, Denzin, 2005). It is traced to the works of George Herbert Mead (1863–1931) and Herbert Blumer (1900–1987) (Annells, 1996, McCall and Becker, 1990). Symbolic interactionists maintain that every activity that can be observed within a society originates from individuals, described as acting units, and these individuals act in a bid to respond appropriately to a prevailing situation after its interpretation (Blumer, 2005, McCall and Becker, 1990). They, thus, focus on the process of interpretation through which individuals construct an action, and not on conditions that precede the process of interpretation or the outcome of the process (Blumer, 2005).

Symbolic interactionism has been criticised because it is perceived to overlook the influence of institutions, class and moral structures, thereby, distorting social phenomena (Annells, 1996). However, it is argued that actions do not result directly from social forces acting on humans within a society. Instead, actions are believed to result from interpretations of prevailing situations by the individual (Blumer, 2005). Individuals in a particular society give similar interpretations to the situations they face, and through previous interactions, they tend to act alike; the social structures may only establish the situation but not determine how the individuals should act (Blumer, 2005). However, since the 'self' is primary to all forms of interaction and it comes with diverse interpretations, there comes about some nuances in the way a given society might respond to a prevailing situation over time (Denzin, 2005). Consequently, the best way to fully comprehend a social process is for the inquirer to appreciate the interpretations ascribed by individual members of that particular context (Jeon, 2004). This aspect of symbolic interactionism is very similar to hermeneutics as they both seek to understand phenomena from individuals' perspectives (Jeon, 2004). However, this research sought to generate a theory that will explain the process of decision making among the ESKD patient population in Ghana and this is beyond the scope of hermeneutics.

The ontological and epistemological stance of the author of this thesis is that of constructivism. In alliance with the constructivists' view of the existence of multiple realities that are context-dependent, methods of inquiry for this study sought to go beyond the 'what' questions posed by positivism to 'how' and 'why' questions to ensure a deeper exploration of experiences that could not just be quantified (Darlaston-Jones, 2007).

Choice of a methodology is based on the kind of questions the research seeks to answer (Corbin and Strauss, 2008, Silverman, 2010). Meanwhile, research questions on 'how' and 'why' of a phenomenon are best answered by qualitative research (Green and Thorogood, 2004). More particularly, qualitative approaches are highly useful in providing an in-depth understanding of the personal experiences and the processes that patients go through when making decisions (Harwood and Clark, 2013, Morton et al., 2010). As this research sought to bring the perspectives of Ghanaian patients with ESKD to light, having an independent relationship with the respondents was seen as inappropriate. Thus, while the positivistic

approach would have limited this research to 'what decisions were being made?' questions, the constructivist approach were expected to explore why and how those decisions were being made within the Ghanaian context as well as generating a theory.

Qualitative approaches such as phenomenology or ethnography are some approaches that could have been used for this study. Phenomenological studies focus on the meaning and importance attached to a phenomenon by those experiencing it, and is appropriate for studies that explore poorly defined concepts (Polit and Beck, 2012, Starks and Trinidad, 2007) while ethnographers seek to describe behaviour of participants from a cultural perspective (Aldiabat and Le Navenec, 2011). The aim of this study, however, transcended the description of participants' experience of ESKD or an effort to understand their behaviour in relation to their cultural background. Rather, it sought to comprehend the interpretations participants make out of their experience of ESKD and how that influences their decision making in their prevailing social context.

As little is known about decision making on treatment for ESKD in resource-poor contexts (Morton et al., 2010, Pierce and Hicks, 2001), the grounded theory method was deemed more appropriate as it utilises data that has been obtained meticulously to generate theory about a lesser known phenomenon of interest (Benton, 1996, Charmaz, 2008, Glaser and Strauss, 1967). Using grounded theory can offer alternative interpretations of patients' beliefs and actions to clinicians alongside those that are readily available to them in the clinical settings (Charmaz, 1990). The new information may enhance communication between clinicians and patients and to ensure care is directed towards the specific needs of clients (Charmaz, 1990). Symbolic interactionism informs the epistemological assumptions of grounded theory (Annells, 1996, Goulding, 1998, McCann and Clark, 2003).

3.3 Grounded Theory

Grounded theory methodology was developed from a research on 'awareness of dying' by Barney Glaser and Anselm L. Strauss in the 1960s, and was developed as an alternative to the then verification or hypothesis-testing research dominant in sociology (Glaser and Strauss, 1967, Jeon, 2004, Maijala et al., 2003, Noble and Mitchell, 2016, Wimpenny and Gass, 2000). Grounded theory has been utilised to generate theories in areas

with little information and to provide new perspectives on existing knowledge and formal theories (Goulding, 1998, McCann and Clark, 2003). It provides researchers with flexible analytic guidelines that ensure focussed data collection and generation of substantive or formal theories that explicate common patterns of social life although several researchers tend to treat the strategies as rigid rules. (Aldiabat and Le Navenec, 2011, Annells, 1996, Charmaz, 2008, Charmaz, 2011, Glaser and Strauss, 1967, McCann and Clark, 2003). Thus, its focus is on the influence of social structures and processes within a given social setting (Jeon, 2004, Starks and Trinidad, 2007). Substantive theories, the commonest type of theory generated from grounded theory studies, focus on specific social issues and deal with narrow areas of inquiry such as patient care, while formal theories are usually generalised and deal with a broader conceptual area of inquiry such as stigma, or socialisation (Glaser and Strauss, 1967, McCann and Clark, 2003).

Grounded theory differs from other approaches in certain respects. Instead of setting out to test a hypothesis or theory, grounded theory researchers start with broad research questions that may be modified after entering the field and allow emergence of relevant theory from data. Thus, there is no a priori conceptual framework or hypothesis (Charmaz, 1990, Corbin and Strauss, 2008, Wimpenny and Gass, 2000). Moreover, while researchers using other approaches collect their data before beginning its analysis, grounded theory researchers employ concurrent data collection and analysis, utilising emerging categories from initial data to direct and shape further data collection. This approach often leads researchers towards unanticipated directions (Charmaz, 1990, Charmaz, 2008, Noble and Mitchell, 2016). There are criticisms that grounded theorists may be methodologically incompetent in setting clear objectives and plan for their research (Bryant, 2002) but, as will be discussed in the subsequent subsections, these criticisms are misinterpretations of the processes involved in a grounded theory study. The major processes of grounded theory are theoretical sensitivity, theoretical sampling, constant comparative analysis, coding, memo writing, and integration of theory (McCann and Clark, 2003). These processes are mostly steps that are taken methodologically to ensure that a theory that is well grounded in data is generated at the end of a grounded theory study. These processes of grounded theory all occur simultaneously in the course of a research

study (Jeon, 2004). The processes and how they were applied to this study have been explained as part of the data collection and analysis methods in the section on data collection methods, instrument and data processing. Grounded theory also appears to be commonly misconstrued and misused as many researchers who purport to have used this approach end up not developing any substantive theory that is grounded in their data (Woods, 2003). Yet, it is argued that a deeper commitment to and application of the processes of grounded theory in a study would lead to generation of a theory that is well grounded in data. Coding, theoretical sampling, and theory construction are often misunderstood but getting these aspects right also ensures rigour of the study (Charmaz, 2011, Jeon, 2004).

3.3.1 Glaserian and Straussian Grounded Theory

Grounded theory, as compared to other methodologies, is relatively in its nascent stages and has been described as an emergent method but has been subjected to several debates, especially after the methodological split between the two co-originators (Charmaz, 2008, Walker and Myrick, 2006, Woods, 2003). This has led to grounded theory being described as either Glaserian grounded theory or Straussian grounded theory. The differences between Glaserian and Straussian grounded theory do not lie in the use of language and processes as these are similar. Instead, the differences lie in the way the processes are carried out, the role of the researcher as well as activity and the degree of intervention regarding the process of data analysis (Charmaz, 2008, Walker and Myrick, 2006). The differences do not suggest that one approach, either Glaserian or Straussian, is superior to the other. Glaser was trained in Columbia University, with a rich background in quantitative social research methods while Strauss trained in University of Chicago with a more qualitative research focus (Jeon, 2004, Strauss and Corbin, 1990). This accounts for some of the different stances taken by both originators when explaining processes involved in grounded theory studies.

One main area that is a subject for various debates is the timing of literature review. Indeed, the originators of grounded theory argued against reviewing existing literature in the area of substantive interest before data collection and analysis. This was to ensure that categories emerged naturally from empirical data analysis and avoid the possibility of

stifling the generation of a theory that is grounded in data (Dunne, 2011, Glaser and Strauss, 1967). However, both Glaser and Strauss now have different stance on this, following their methodological split.

On the one hand, Glaser (1998) argues that the researcher should enter the field with no preconceptions but should allow research problems to emerge after entering the field. Literature review of the substantive area should also be postponed until after categories have been developed as this reduces the tendency of the researcher using preconceived concepts and categories in analysing data (Charmaz, 1990, Glaser, 1998). This enhances the likelihood of generating a theory that is grounded in the data (McGhee et al., 2007). Moreover, if there is insufficient literature, the researcher may problematise those areas identified by the literature review rather than identifying those that emerge from data in the field (McGhee et al., 2007).

On the other hand, Straussian grounded theory proponents maintain that, in addition to emerging from the field, research problems for inquiry may be identified through personal experiences, suggestions by other researchers, or from gaps identified in the literature (Charmaz, 2008, McCann and Clark, 2003, Strauss and Corbin, 1990). Meanwhile, a decision to enter the field without a research question, as advocated for by Glaser (1998) may pose certain challenges to the researcher, including difficulties in gaining approval from many ethical committees or institutional review boards, applying for grants, and having a successful proposal for a doctoral study (Cutcliffe, 2005). An initial literature review provides justification for the study, especially, when making an application for ethical approval and, in areas where little is known, the paucity of data can only be established through an initial literature review (McGhee et al., 2007). Strauss and Corbin (1990), thus, encourage having a general idea about the area of inquiry through an initial literature review. Moreover, it is a daunting task for the researcher to completely separate themselves from their wealth of knowledge, experience and ideas before entering the field (Jones and Alony, 2011). The debate on the stage for literature review centres on ensuring that the researcher is open-minded when entering the field. McGhee et al. (2007) argue that by rigorously applying constant comparative analysis, researchers are more likely to avoid bias that may emanate from their misconceptions or preconceptions.

Following extensive discussions with both supervisors of this study and other researchers with rich experience in the conduct of grounded theory studies and qualitative research in general, a decision was made to combine both an initial literature review and a later literature review in this study. An initial review of the literature on decision making revealed that little is known about patient decision making in ESKD in the African context. This provided the conviction that the study would meet one criterion of a PhD thesis – generation of new knowledge. An initial literature review was also required to meet the requirements of the PhD confirmation review process as well as gaining ethical approval for the study to be carried out. McCann and Clark (2003) argue that the second literature review in grounded theory studies relates newly developed theory, its properties and concepts to extant theory and research. A second literature review for this study focussed on exploring relationships between concepts that emerged from this grounded theory study and existing concepts and theories. This second literature review will be presented in a later section.

3.4 Study Sites and Access

Comparison of data from two or more research sites or geographical locations aid in grounding theoretical statements (Baszanger, 1992). Therefore, three out of the ten renal centres in three administrative regions of Ghana were chosen for this research. These were a combination of public-funded and private-funded institutions. The centres were selected because they are quite established in terms of resources, as compared to the other units, and have been operational for a minimum of five years. Moreover, two of the renal centres belong to large teaching hospitals in their respective regions. A fourth centre that met these criteria could not be included as a site for this study because it was being refurbished at the time of planning this study and during the initial data collection period.

A contact person was identified in each of the renal centres selected for this study, while the proposal was being finalised, to discuss the prospects of conducting the study at their renal centre. These persons then introduced the me to research gatekeepers of their facilities.

The Wellcome Trust Society and Ethics Small Grant, recognising the potential significance of the findings of this research, funded a visit by my lead research supervisor and I to all included renal centres in March 2013

(Grant reference 101141/Z/13/Z). This visit facilitated entry into the renal centres, after which a copy of the proposal was submitted to research gatekeepers of each respective centre for administrative approval. Data collection began in each of the centres only after gaining ethical approval from respective ethics committees of the renal centres.

3.5 Data Collection Methods, Instrument, and Data Processing

Data collection was by semi-structured one-to-one interview. The use of interview in qualitative research has good justifications as it allows the researcher to pose a range of in-depth questions thereby ensuring that respondents fully describe their subjective experiences and attitudes (McCann and Clark, 2003, Peräkylä, 2005). Advocates of structured interview argue that its use ensures consistency in the type and way questions are asked in order to identify variations in responses (Mason, 2002). Semi-structured interviews, on the other hand, allow the interviewer to modify questions and approaches based on cues from ongoing or previous interview sessions (Mason, 2002). Although the researcher might begin with data collection on a wide range of issues, interviews become more specific as categories begin to emerge (Corbin and Strauss, 2008), making semi-structured interviews the preferred type of interview for this grounded theory study. Indeed, while it is essential to ensure variations are noted, grounded theory researchers are also encouraged to ensure a certain degree of flexibility so as to respond to situations that may arise from the data while on the field (Strauss and Corbin, 1990).

A semi-structured interview guide (Appendix I) was developed in collaboration with both supervisors of this study, after studying other interview guides used for studies on patient decision making in ESKD. The interview guide was developed in line with objectives of this study. The first interview was to serve as a pilot interview but was included in the data analysis since the guide did not require major changes after this interview session. Interviews were conducted in English language or Twi (a popular Ghanaian dialect and my first language) based on the preference of each participant. A translated version of the interview guide (Appendix II) was used for interviews conducted in Twi. Eligible patients were approached, first by a nurse working in the respective renal centre, then by me, to discuss goals of the research and their desire to participate. I

approached clinicians directly and invited them to participate in the study; those who agreed signed the consent form and were interviewed. An information sheet (Appendix III) that summarises the research was given for their perusal and those willing to participate were given the consent form (Appendix IV) for their signature or thumbprint.

Interviews were conducted within the various centres where participants either get their care or work. Each interview session lasted for 30 minutes or more, with the longest interview session lasting for 63 minutes. Those who were on haemodialysis preferred to be interviewed during their dialysis sessions while those who were not on haemodialysis preferred to be interviewed while waiting to see a doctor on their clinic days. I interviewed patients who were not on haemodialysis in offices provided for me at the respective renal centres in order to ensure and maintain privacy during interviews. Doors to these offices were shut and no other person was allowed to come in during an interview session. For those interviewed during dialysis sessions, spacing between dialysis machines ensured that other patients did not overhear whatever was being discussed. In addition, I sat close to participants to ensure that we did not have to raise our voices during the interview. On occasions where clinicians had to attend to participants in the course of an interview, the session was paused to allow them to finish attending to participants and leave before the interview was resumed. Indeed, this act assured participants that whatever was being discussed during the interview would be treated as confidential. Clinicians were interviewed in the offices provided for me at the respective renal centres or in a consulting room in the case of medical doctors. All interview sessions were audio-recorded and transcribed afterwards. I translated those in the Twi language to the English language, and two colleagues who are also researchers and are fluent in both Twi and English languages verified the accuracy of the translation. There were no back translations during this process. All participants preferred to be interviewed in their respective renal centres. The subsequent subsections will present the main processes involved in a grounded theory study and how they were applied to this study.

3.5.1 Theoretical Sensitivity

In grounded theory, the principle of theoretical sensitivity requires the researcher to enter the field with consciousness of the nuances of data. It

describes the researcher's ability to understand and interpret the data as well as separate relevant and irrelevant data (McCann and Clark, 2003, Noble and Mitchell, 2016). Theoretical sensitivity is enhanced through in-depth reading about the phenomena of interest, professional and personal experience, and close attention to the analytic process (Noble and Mitchell, 2016). Theoretical sensitivity is lost when the researcher is inclined to a preconceived theory (Glaser and Strauss, 1967). The ability of the researcher to remain open to new and 'unexpected' data, and to make efforts to analyse processes aids efforts in constructing a theory that is grounded in data (Charmaz, 2006). It is, therefore, crucial for the researcher to maintain theoretical sensitivity throughout the research process to aid the generation of a theory that is grounded in the data but not from his/her preconceptions or existing theories (Jeon, 2004, McGhee et al., 2007).

Initial review of literature on patient decision making aided development of my theoretical sensitivity during this study. Asking questions of the data, writing memos, and constantly comparing data with data were approaches used to maintain theoretical sensitivity while going about data collection and analysis. Remaining open-minded throughout the period of data collection and analysis was also instrumental to maintaining theoretical sensitivity. In addition to these, having interactions with clinicians who have been practising in the renal centres contributed to a deeper understanding of the context of patient decision making while enhancing interpretation of data that was collected.

3.5.2 Theoretical Sampling

'Theoretical sampling' describes the approach used by grounded theory researchers and is different from purposive sampling although the latter is usually used initially (Jeon, 2004). Theoretical sampling requires that, after an initial purposive sampling, further sampling decisions including characteristics of respondents, sample size, settings and data to be collected are made with reference to the emerging theory or categories (Corbin and Strauss, 2008, Glaser and Strauss, 1967, McCann and Clark, 2003). Thus, tentative categories should be developed from the data before starting theoretical sampling (Charmaz, 2011, Noble and Mitchell, 2016). In other words, theoretical sampling is more responsive to data instead of being established before initiation of the research, as in

traditional sampling methods (Corbin and Strauss, 2008). Theoretical sampling is also guided by the need to ensure that the substantive theory is grounded in the empirical data (Jeon, 2004).

Traditionally, people are sampled in research, while controlling variables. However, theoretical sampling is driven by concepts, instead of persons, leading researchers to then identify persons, places or situations that would give more information about these concepts in the course of data collection. The basic rationale is for the researcher to explore the data that has been gathered in order to identify how these concepts vary under different circumstances (Corbin and Strauss, 2008). In other words, participants with varying experiences or accounts of the phenomenon of interest are recruited to promote exploration of different dimensions of the social processes or issues being studied (Charmaz, 1990, Starks and Trinidad, 2007). Each interview or observation is coded and analysed before subsequent sessions, and categories identified are usually explored in the subsequent sessions (Starks and Trinidad, 2007). New data collected is compared with emerging categories in order to establish conceptual boundaries regarding the evolving theory. Interview questions may, therefore, be modified and decisions on follow-up interviews made as part of theoretical sampling (Jeon, 2004). Hence, structured interviews are out of place in theoretical sampling, and semi-structured or unstructured interviews are more welcome in theoretical sampling (Corbin and Strauss, 2008).

This study employed the principles of theoretical sampling and involved adult patients with end stage kidney disease (≥18 years old) at different stages in the trajectory of the disease seeking care from the three renal centres involved in this study. In the initial design, it was anticipated that participants would comprise patients who were yet to begin dialysis, those who had started dialysis, and those who had chosen 'no dialysis', or those who had withdrawn from dialysis

Five patients on dialysis were identified, recruited and interviewed initially through the use of purposive sampling. These initial interviews were transcribed and analysed for emerging concepts and categories. Memos were written on these initial categories and used to explore new ways to gather more data, and from which group of participants. Following this initial analysis, a decision was made to recruit and interview individuals

who had been on haemodialysis for at least 12 months based on emerging categories. Five individuals who met these criteria were identified with support from clinicians in the various renal centres and interviewed.

Another decision that was made after analysis of the initial data was to interview a sample of clinicians. This aimed at exploring some of the issues raised in the initial patient interviews and gaining a deeper understanding of issues confronting patients with ESKD as well as processes across the various renal centres. Four clinicians were interviewed as a result. These interviews were also transcribed and analysed in order to refine some of the categories that were emerging as well as to identify more gaps that needed further exploration in patient interviews.

Patients who had not started haemodialysis were then interviewed alongside those who had undergone or were about to undergo kidney transplant surgery. This was done to explore experiences of patients with ESKD who were at the stage of starting renal replacement therapy albeit not all of them were ready to start. More memos were written alongside the concurrent data collection and analysis. It became relevant to interview individuals who had made decisions not to be on dialysis or those who had withdrawn from dialysis. The aim was to explore their health expectations at a stage where having a renal replacement therapy was less likely. However, no person meeting these criteria was identified as both groups mainly terminated their visits to the renal centres. Two individuals who were considering quitting haemodialysis were identified and interviewed. Finally, one more clinician was interviewed to explore some of the key categories and findings from the initial data analysis.

Ideally, theoretical sampling should continue until saturation is achieved. This is when concepts and categories have been adequately well-defined such that collecting additional data cannot expand the properties of the category and variations and links between categories can be clearly explicated (Glaser and Strauss, 1967, McCann and Clark, 2003, Westbrook, 1994). However, in doctoral studies, a researcher has to acknowledge a point at which concepts have been adequately explored and well-defined for the purposes of that particular research and report on areas that have not been explored as part of the limitations of the study (Corbin and Strauss, 2008).Regular discussions were held with both

supervisors of this study on emerging categories and those that needed further exploration were agreed upon. This continued until an agreement was made that key concepts had been adequately defined. As explained earlier, a few concepts could not be explored adequately because of challenges in accessing the patient population that could provide more data to refine them. The reviewed literature showed that involving family members as well as informal care givers of individuals with ESKD provide different perspectives on the patient decision making process (Murray et al, 2009, Harwood and Clark, 2013). However, a decision was made not to include opinions of family members and informal caregivers in this study. This is the first study to explore patient decision making in persons with ESKD in a sub-Saharan African country. Thus the focus was on getting the subjective experiences and perceptions of those with the disease. Moreover, the time-bound nature of doctoral studies could not permit continuous exploration of all categories.

3.5.3 Constant Comparative Analysis

This key dimension of grounded theory methodology refers to the simultaneous collection and analysis of data. It comprises comparison of incidents that relate to each category, integration of categories and their properties, delimiting the theory, and writing the theory. This continues until a theory grounded in the data is generated (McCann and Clark, 2003). Constant comparative analysis enhances theoretical sensitivity by stimulating the researcher to reflect on incidents, concepts and categories as well as directing further sampling decisions (Jeon, 2004). The researcher continuously compares data and asks more questions about the data and, by so doing, sharpens his/her thinking and promotes a better understanding of the data. This allows the researcher to clarify emerging concepts and categories and to test emerging hypothesis in order to achieve accurate descriptions. Consequently, the theory that is generated will have high explanatory and predictive power (Glaser and Strauss, 1967, Jeon, 2004, Strauss and Corbin, 1990).

Constant comparison was central to analysis of data in this study. Data from different participants were compared with one another to identify similarities as well as differences under specific circumstances. For instance, comparisons were made of participants' experiences of noticing symptoms, being diagnosed with ESKD to identify similarities and

differences. Factors that influenced choices and treatment decisions of participants were also constantly compared. Categories were also compared with one another to identify conditions under which they were discovered and to delimit their definitions and properties.

3.5.4 Coding

Coding is a vital process in qualitative data analysis as it is the first step that allows the qualitative researcher to move beyond specific statements in the data to shaping an analytic frame by which analytic interpretations of the data are made (Charmaz, 2006). It requires the researcher to put aside their preconceived ideas while allowing the data and its interpretation guide analysis, and to search for the right word or words that best describes concepts in data (Corbin and Strauss, 2008). This is the stage at which data is conceptualised and categorised (open coding), patterns and relationships between categories are identified (axial coding), and an overarching category is identified and linked to other categories (selective coding) (Corbin and Strauss, 2008, Jeon, 2004, McCann and Clark, 2003, Noble and Mitchell, 2016). Glaser (1998), identifies only two steps in the coding stage; substantive coding and theoretical coding. The three stages of coding described by Corbin and Strauss (2008) were used for coding data for this study. Although the creativity of the researcher is central to the emergence of categories, codes and categories should be inductively generated from data collected from the field and not from the preconceptions of the researcher (McGhee et al., 2007).

Each interview transcript was read while listening to the audio version to verify its accuracy, after which open coding of each transcript was done. No software was used for the analysis of data from this study. This was to allow me to gain mastery of manual qualitative data analysis since data analysis software such as NVIVO is not always readily available for my use. However, Microsoft Word was used in processing the data. Open coding began with initial coding, using line-by-line coding of each transcript, followed by incident-to-incident coding. These ensured openness to all theoretical possibilities that could be discerned while keeping me close to the data (Charmaz, 2006). Data was coded for actions instead of topics as this promotes search for processes in the data, and was achieved by coding with gerunds (Charmaz, 1990, Charmaz, 2006). An excerpt of this coding process has been shown in Box 2.

In vivo codes were used as much as possible in order to preserve participants' special terms and meanings (Charmaz, 2006). Incident-to-incident coding also enhanced comparison of incidents in different interviews in order to identify similar or varying participant responses to similar processes and issues. Open coding of the data also involved sifting through the data using frequent and significant codes that had been generated during initial coding. For instance, after generating the 'noticing symptoms' code, which describes patient participants' descriptions of changes in their usual state of health, all other transcripts were searched to compare how each patient participant described this process. Codes generated from initial coding also guided areas to explore further in subsequent interviews.

Not knowing more about treatment before starting. Describing assurance of cure from doctor Talking to other dialysis patients Taking mind off (short-term cure) expectations. Praying for money to sustain treatment Persisting with choice of treatment. Becoming anaemic before treatment. Having haemotransfusion Family supporting via blood donation	I didn't know it was going to take a long time for the curement but talking to people who have this thing, this kidney disease, some of them have come here 2 years, and I said 'ah, I thought, I didn't know because it was only explained to me that only, the doctor said once I have started the treatment, I'll, by all means, be cured. So I didn't know it was going to take a long time like this, I thought about 6 months or I will be cured. But talking to people who have the disease, they, they said, some of them said they have come here 2 years, 3 years and what not so I've taken my mind off. Only I'm praying that I get the money every week, 3 million to come and pay and then take the treatment. I've taken my own mind off Yes, I will still [have started treatment], because I was not eating and I became anaemic and, even before they started the treatment, I had to take blood, people supported me. I had to call family members to come and donate blood. I took blood about 20 (units) so I knew if I had not taken this treatment, maybe I will have died a long time

Box 2: Example of Line-by-line Coding of Data, as used for this Study

Axial coding was carried out after some categories had emerged from the open coding process. Indeed, open coding and axial coding are done in close cooperation, with the distinction between the two being described as 'artificial' – it only emphasises that once data is broken apart to identify concepts, it is brought back together by clearly relating the identified concepts (Corbin and Strauss, 2008). Categories were compared with one another and related to subcategories at this stage while using diagrams and flow charts to demonstrate these relationships. Some of these diagrams are shown in Figure 2 and Figure 3. It must be emphasised, however, that the coding process was not as linear as has been described.

Earlier transcripts were revisited to search for new concepts that were generated from later interviews. Memo writing, which is described in detail in the next subsection, also aided the process of refining categories and establishing relationships between concepts, codes, and categories.

Selective coding was used to establish relationships between the four main categories identified in this study after identifying 'confronting mortality: adjusting to new life' as the core category. The core category is the category that has the greatest explanatory significance and can successfully link all the other categories together (Corbin and Strauss, 2008). Initially, 'believing that tomorrow will be better: the linchpin of initial patient decisions' category was considered as the core category. However, further examination of the properties of this latter category showed that decision making on treatment is not a one-off process in ESKD management – it is an ongoing process. Confronting the realities of living with and managing ESKD as well as taking steps to adjust to this new life is the pinnacle of the ongoing decisions that patients with ESKD have to review each time they are due for treatment. Further revisions of memos written during analysis of data for this study highlighted this 'truth' and eventual discovery. Hence, a final decision to establish that initiation of treatment leads individuals to confront realities and adjust to the new life, which then informs their ongoing decisions about their management.

3.5.5 Memo Writing

Memos are notes written by the grounded theory researcher in the course of a study to explain the development of a theory (McCann and Clark, 2003). Thus, memos serve as an audit trail of the emerging theory and demonstrate reliability and rigour in the research process (Hoare et al., 2012). Memo-writing is a key process in grounded theory research as it prompts the researcher to analyse ideas about data, codes and categories in several possible ways (Charmaz, 2006). This makes the researcher more analytic and reflective while coding. It also aids in retention of and elaboration on insights that aid in the development of theoretical codes (Jeon, 2004). Memo-writing should be done during the entire research process, and grounded theory researchers are encouraged to openly address how their prior knowledge or experience might influence their perspective, and memo writing helps them to do that (McGhee et al., 2007).

Memos were written on some of the key codes and categories in the course of data collection and analysis of this study. An example has been shown in Box 3. This memo was written after interviewing the first five dialysis patients who were selected through initial purposive sampling. Initial analysis of data showed that patient participants did not usually expect to have the disease or a change in their health status when they did. This led them to pursue various actions in order to identify what could be happening to them. This memo, therefore, analysed the process of searching for a cause after patient participants had noticed some changes in their usual state of health. It was through writing memos that concepts such as 'attributing a cause' and the role of disease causal belief in shaping people's search for a cause of their change in health status were identified and explored in subsequent interviews. Memo-writing also promotes reflexivity and theoretical sensitivity of the researcher. Indeed, memo-writing is a key step between the process of data collection and writing of drafts from research (Charmaz, 2006). Thus, segments of the memos have appeared in the findings presentation in Chapter 5. While some of the memos were developed, retained and presented as key categories or subcategories in the results chapters, others were modified and presented as part of other categories or subcategories.

Memo – Searching for a Cause (24th October 2013)

This describes the steps that patients take in identifying the underlying cause of their symptoms prior to their being diagnosed with chronic kidney disease (CKD) and the factors that they attribute the disease to. The dialysis respondents mostly start to experience non-specific symptoms and, not knowing what is happening to them, begin to take steps towards identifying the cause. For instance, one respondent was 'not feeling fine' and had prolonged vomiting. He reported to a clinic where he was diagnosed with and treated for typhoid. But the symptoms persisted after that treatment and that caused him to keep searching for the cause of his ailment until an accurate diagnosis of end stage kidney disease (ESKD) was made in a teaching hospital. Similarly, another respondent was not feeling well but deferred going to the hospital because of impending university examinations. He, however, reported to the hospital later when the symptoms persisted, and was diagnosed with ESKD.

While others believe that 'maybe somebody was doing it' after the diagnosis of ESKD was made, others also think of it as a complication of various medical conditions they have. There are still others who are yet to come to terms with what might have contributed to their developing ESKD even though they have been on dialysis for a year or more. They ponder over whether it is actually a complication of a previous medical condition or that it might have resulted from a curse. It seems that the Ghanaian patient is less likely to accept the diagnosis of a terminal illness without searching for a cure. Belief on cause is likely to influence the course of action/steps taken towards management. Thus, majority may seek traditional medicine which promises a cure for almost all ailments. Others go to prayer camps and/or other spiritualists while others stay on biomedicine while seeking other opinions on their condition. They are still others who hold on doggedly to biomedicine but may face stiffer opposition from their significant others.

Once an accurate diagnosis of ESKD has been made, what steps do patients take?

Box 3: An Example of a Memo Written during this Study

3.5.6 Integration of Theory

Integration of theory is the ultimate analytic step of grounded theory studies, and identification of a core category is vital to the success of this process. (Corbin and Strauss, 2008). How a decision was made on the core category of this study has been explained in the section on 'coding'. After comparative analysis, conceptual theories or their properties, as well

as hypotheses (general relationships between categories and their properties), are generated from the data. The researcher constantly interacts with the data in the course of the study, uses memos as well as his/her analytic skills to generate a theory that is grounded in data (McCann and Clark, 2003).

Key concepts were identified from the data during open coding. These concepts (codes) were raised to subcategories and then to categories by constantly comparing incident to incident and data to data. In fact, continuous reading of interview transcripts and analysis of the data, writing and revising the findings, and revisiting and writing memos during the study period led to an appreciation of the "analytic story behind the data" (Corbin and Strauss, 2008). Further processes were required in order to generate the theory and these included establishing links between the various categories that had been identified. Series of diagrams and flow charts were constructed and used to sort out and provide a visual representation of relationships between key concepts as well as categories (Charmaz, 2006, Corbin and Strauss, 2008). Once the core category was identified from analysis of the patient interviews, this was linked to the central theme arising out of the clinician interviews. It is in establishing the relationship between the core category from the patient data and the central theme in the clinician data that the substantive theory was 'discovered'.

3.6 Ethical Considerations

Administrative approval was obtained from the respective authorities in the various renal centres. Ethical approval was obtained from the Committee on Human Research, Publications and Ethics (CHRPE, KNUST; Appendix V) and the Ethical and Protocol Review Committee (EPRC, University of Ghana Medical School; Appendix VI), both in Ghana, and from the Medical School Research Ethics Committee, University of Nottingham, United Kingdom (Appendix VII). Theoretical sampling presents unique challenges to researchers seeking ethical approval as emerging categories influence data sources and not all these sources or approaches can be foreseen in the planning stage. Thus, the proposal was modified to reflect the probability of gathering data from other sources apart from patient interviews only, as planned originally. When the need to interview clinicians arose, both ethical committees were informed of the

developments and their approval was obtained (Appendix VIII). Major ethical issues that were considered in this research have been presented below.

Risks: Having participants to recount their experiences through the interviews was seen as emotionally laden for some of the participants, if not all. They were assured that they could choose not to respond to a question if they judged it uncomfortable or private. For instance, one participant started crying at about 5 minutes into the interview. She was given some time after which she was asked if she felt capable and willing to continue the interview to which she responded in the affirmative before the interview session was resumed.

Voluntariness: Eligible participants were made to understand that participation in the research was purely voluntary. Thus, they were not under any obligation to participate in the study after the aim and objectives had been explained to them. A few individuals, therefore, explained that they could not be part of the study for various reasons including feeling unwell, concerns about voice recording and the interview process among other factors. Such individuals were not recruited to participate in the study.

Informed Consent: Once an eligible participant agreed to participate in the study, an informed consent form was given to them for them to sign to buttress their verbal consent before being interviewed. For those who could not read the English language, the content of the informed consent form was read out and translated for them after which they were kindly asked for thumbprint. A copy of the signed or thumb-printed informed consent form was given to each participant and I kept another copy for my records.

Confidentiality: Participants were made to understand that all information that will be gathered through this research will be treated as highly confidential. They were made to understand that only the research team will have full access to the data and, even if this happens, anonymity will be well ensured. The recorded interviews and transcripts were kept securely on a password-protected computer. Names and other personal identifiers were replaced by pseudonyms in the transcripts.

Withdrawal from the Research: Participants were made to understand that they may choose to withdraw from the research at any time during the course of the interview without having to provide a detailed explanation. It was explained to patients that choosing to withdraw from the study would not affect the expected care delivery in any way. However, information that they might have provided before the withdrawal might be used in the analysis. None of the participants withdrew from the study after giving their consent.

Compensation: Key rings with the University of Nottingham's logo were given to each participant as souvenirs at the end of the interaction to compensate for their time. Those who had unique issues that came up in the course of the interviews were advised to seek support.

3.7 Reflexivity on the Research Process

Reflexivity describes a process whereby a qualitative researcher performs a critical self-reflection to ascertain how his or her personal values, emotions, decisions, and interpretations could influence the research (Charmaz, 2006, Corbin and Strauss, 2008, Noble and Smith, 2015, Polit and Beck, 2012). In other words, the qualitative researcher strives to clearly make their influence on the research process known to themselves and to their audience or readers through reflexivity (Gentles et al., 2014). Reflexivity is relevant in qualitative inquiries as it encourages the qualitative researcher to examine the context of knowledge and understandings within epistemological frames while strengthening rigour of the research process (Berger, 2015, Engward and Davis, 2015, Hall and Callery, 2001). Reflexivity increases transparency and trustworthiness of qualitative research process and its outcomes (Berger, 2015, Gentles et al., 2014). However, being too reflexive has the potential to stifle creativity in the researcher and eventually produce a theoretical account which may not be called a 'grounded theory' (McGhee et al., 2007).

Reflexivity can include an exploration of the researcher's influence on areas such as decisions about research design, data collection, analysis, write-up and, also, how the research process influences the researcher (Gentles et al., 2014). Decisions about the research topic, choice of grounded theory methodology and the use of semi-structured interview are some of the areas where I had direct influence. Even though the kinds of research questions to be answered in a study influence the choice of

methodology, this is also a reflection of the epistemological and ontological stance of the researcher (Annells, 1996, Corbin and Strauss, 2008, Krauss, 2005, Silverman, 2010). My choice of the research topic was a product of my previous encounters with ESKD patients both in Ghana and the United Kingdom as well as my interest in their management and experiences. My penchant for constructivism was also instrumental in my choice of methodology. Indeed, a reference to approaches that had been used by other researchers during the initial review of the literature also guided my decisions, alongside insightful comments from my supervisors and the team that moderated my confirmation review.

The rationale for other decisions on methods for generating data for this study has also been provided in the appropriate sections, including reasons for selecting the included renal centres, the use of semi-structured interviews instead of structured interviews, recruitment of participants, language for interviews and setting for interviews. For instance, language and setting for interviews were based on preferences of respective participants, serving as a means of establishing rapport and encouraging them to share their experiences freely. I ensured the interview sessions were free from distractions as much as possible by conducting some of the interviews, where possible, in offices with closed doors. To assure patient participants of confidentiality, I paused the interview session whenever anyone else came close to the setting of the interview and only resumed once these individuals left the room or site.

Personal characteristics of the researcher also have a degree of influence on the research in terms of gaining access to the research setting, establishing relationships with participants, and the use of language in generating data (Berger, 2015). Being a Ghanaian, there were some statements by participants that I initially took for granted during data collection because of my 'insider' perspective. This was evident after transcribing the first two interviews and discussing the transcript with both supervisors of this study. Steps were taken to explore participants' statements further, even when I felt that I understood what they implied, by probing further. Thus, sharing my data with my supervisors and frequent discussions on aspects of the research also aided in controlling how much influence my personal values and perspectives had on the research process. Being a clinician also enhanced effective interactions with clinician participants as that meant that I could relate to a lot of their

experiences. This encouraged their generosity in sharing their experiences which proved useful in corroborating some key information from patient participants.

I also had to put my non-verbal responses in check, especially during patient interviews. In fact, this was one of the many lessons I had learnt from an 'Individual and Group Interviews' module I attended. However, starting the actual patient interviews and hearing some of the patient stories made this challenging sometimes. My training is in biomedicine and I do not subscribe to the tenets of traditional medicine. Therefore, I could hardly understand why some participants would go to any other place aside a hospital with some of the initial changes they noticed in their health. But listening to patient stories and reading earlier transcripts gave me clues that helped me to consider their actions from their perspectives. Statements such as *"you are sick and you don't know whether you will get better there", and "[you] just follow because, at that moment, you are the one that is sick"* made me appreciate that individuals only wanted to feel better, irrespective of what form of treatment they received.

This research covered emotionally-intense subjects, as it entailed patient participants' descriptions of the realities of living with and managing ESKD. As will be described later in the results chapters, the majority of the participants felt that death is closer and that their aspirations could be cut short should they fail to continue treatment. Indeed, emotions are central to the conduct of qualitative research, and empathetic connections between qualitative researchers and participants enhance a deeper understanding of the experiences of participants (Fitzpatrick and Olson, 2015). Listening to participants stories of their daily efforts to adjust to the 'new' life on haemodialysis, or having them question their own chances of survival was very distressing for me. In fact, when a participant started crying in the course of one interview, I considered discontinuing that session, pausing for some time and gathering the courage to continue only after the participant expressed a willingness to continue the session. Fitzpatrick and Olson (2015) describe a process of becoming emotionally callused where the researcher develops a diminished emotional sensitivity to some of the distressing moments they encounter repeatedly in a study. Regular discussions with my supervisors about some of these challenges, and reminding myself of the objectives of the study are what spurred me on in such distressful moments. I had to keep reminding myself that

findings from this study could prove beneficial in addressing some of these challenges participants are facing and, hence, the need to brace myself up and generate quality and reliable data.

The use of grounded theory methods helped me to control the influence of my values and personal interpretations on the findings. For instance, using line-by-line coding kept me closer to the data but ensured that I was open to all theoretical possibilities (Charmaz, 2006). Constant comparative analysis, as well as memo-writing, was done throughout the period of data collection, analysis and thesis write-up. This also ensured that I remained open to all theoretical possibilities, reflected on and clarified emerging concepts, and further controlled how my perceptions could influence data analysis and the entire research process (Jeon, 2004, McGhee et al., 2007).

3.8 Validity and Reliability

Producing high-quality studies is of great concern to researchers across all disciplines, and there are various approaches that are utilised to ensure this in a study (Polit and Beck, 2012). This has been a contentious issue, especially in qualitative research, with the argument that terms such as 'rigour' which are used in quantitative research are not applicable for interpretative inquiries (Noble and Smith, 2015, Polit and Beck, 2012). For grounded theory studies, it is believed that rigorous application of the main features, including theoretical sampling, theoretical sensitivity, constant comparative analysis should be enough to make the findings and the theory credible (Glaser and Strauss, 1967, Hall and Callery, 2001). In addition to rigorously following the key processes involved in grounded theory studies during this study, other measures that are believed to enhance the credibility of findings of qualitative research were employed.

Reflexivity, which the qualitative researcher uses to account for personal biases and their potential influence on the study findings (Noble and Smith, 2015) was done, as has been described above. Collecting data from multiple research sites and from both patients and clinicians also contributed to having comprehensive accounts of issues of importance to this study. Regular discussions with my research supervisors, who are both experts in qualitative research and kidney failure helped me to identify taken-for-granted issues and pursue them further in subsequent interviews.

3.9 Conclusion of Chapter

This chapter has described and justified the use of grounded theory methodology for this study. It has provided an explanation for how the major features of grounded theory were applied to this study. It has also highlighted some key steps in the conduct of this study, including gaining access to institutions included in the study, gaining ethical approval, sampling decisions, the interview process, data processing and analysis, and substantive theory generation as well as challenges associated with these key processes. The next chapter will be the first of three chapters presenting findings from this study.

CHAPTER 4. CHARACTERISTICS OF STUDY PARTICIPANTS

4.1 Introduction to the Chapter

This chapter is the first of three findings chapters. Its purpose is to promote a deeper understanding of the context of this study by providing a synopsis of the unique stories and experiences of each participant. The chapter begins with a general description of characteristics of the patient participants, followed by a general description of the clinician participants. A brief profile of each of the participants is then presented, where their key experiences before being diagnosed with ESKD up until the day of the interview are presented. Their expectations and aspirations are also presented in some instances.

4.2 Characteristics of Patient Participants

The study involved a total of twenty-two patients with ESKD. Table 4 provides a summary of numbers of patient participants while Table 5 summarises their key characteristics. The ages of the patient participants ranged from 24 years to 73 years. Only three of the patient participants were above 60 years old, the age for retirement from public service in Ghana. As shown in Table 4, seventeen of the twenty-two patient participants were males while five of them were females. Fourteen of the patient participants were receiving renal replacement therapy (RRT); thirteen were on haemodialysis, with one scheduled for a kidney transplant surgery three days from the day of his interview, while the other participant had undergone kidney transplant surgery two years prior to the day of his interview. Nine of the thirteen participants on haemodialysis were males while the remaining four were females. This was a reflection of the total dialysis population in Ghana by April 2014, as shown in Table 2 (page 23).

Participants	Males	Females	Total
Dialysis Patients	9	4	**13**
Non-Dialysis Patients	7	1	**8**
Transplant	1	-	**1**
Total	**17**	**5**	**22**

Table 4: Numbers of Patient Participants

	Participant	*RRT Status	Age	Sex	Duration of Dialysis/Diagnosis	Weekly Sessions	Payment	Employment	Other known chronic condition(s)	Residence
1.	Agya	D	65	M	9 months	2	Out-of-pocket	Retired	None	Within region
2.	Obrempong	D	48	M	12 months	3	Out-of-pocket	Full time/ part-time Student	Hypertension	Within region
3.	Barima	D	26	M	1 month	2	Out-of-pocket	Student	None	Within region
4.	Kantinka	D	39	M	15 months	2	Out-of-pocket	Unemployed	Hypertension	Within region
5.	Nana	D	73	M	6 months	3	Sponsored	Part-time (teaching)	Hypertension, diabetes mellitus	Within region
6.	Kwasi	D	33	M	5 years	2	Out-of-pocket	Unemployed	None	Within region
7.	Onua	D	50	M	6 years	2	Sponsored	Full time (healthcare)	Hypertension	Within region
8.	Wofa	D	62	M	11 years	3	Sponsored	Retired	Hypertension	Within region
9.	Adwoa	D	43	F	19 months	2	Sponsored	Full time (teaching)	None	Within region
10.	Abena	D	28	F	2 months	3	Out-of-pocket	Full time (self-employed)	Diabetes	Within region
11.	Akua	D	55	F	4 years	2	Out-of-pocket (Support from Church and Rev Minister)	Full time (teaching)	Hypertension	Within region
12.	Eno	D	51	F	12 months	2	Out-of-pocket	Unemployed (quit trading)	None	Within region
13.	Owoahene	D	30	M	12 months (3 days away from transplant)	2	Out-of-pocket	Unemployed	None	Within region
14.	**Papa	T	50	M	16 months (2 years transplant)	3	Out-of-pocket	Full time (self-employed)	Hypertension	Within region
15.	Akonta	N	24	M	21 months	N/A	Out-of-pocket	Employed	Sickle cell disease	Outside region
16.	Kwadwo	N	58	M	3 years	N/A	Out-of-pocket	Unemployed	Hypertension	Within region
17.	Kwabena	N	39	M	1 year	N/A	Out-of-pocket	Unemployed	None	Within region
18.	Kwaku	N	41	M	4 months	N/A	Out-of-pocket	Unemployed (quit driving)	Hypertension	Within region
19.	Yaw	N	46	M	1 year	N/A	Out-of-pocket	Unemployed (quit driving)	None	Within region
20.	Kofi	N	50	M	3 months	N/A	Out-of-pocket	Employed	Hypertension	Within region
21.	Kwame	N	42	M	3 years	N/A	Out-of-pocket	Unemployed	None	Within region
22.	Piesie	N	30	F	2 years	N/A	Out-of-pocket	Self-employed (trader)	Hypertension	Outside region

Table 5: Characteristics of Participants *RRT Status – D: Dialysis; T: transplant; N: Non-dialysis **Participant started haemodialysis before having transplant

As shown in Table 5, the participants on haemodialysis had been on treatment for periods ranging from 1 month to 11 years although only four of them had been on haemodialysis for more than 2 years. Nine of the fourteen participants receiving RRT were making out-of-pocket payments for all aspects of their treatment while four were getting full financial support through various arrangements with their employers or, in one instance, the employers of her husband. The remaining participant was getting partial financial support from her church.

Six of the fourteen participants receiving RRT were in full-time employment while four were unemployed as a result of their disease. Two of the three participants who were above 60 years old had retired while one was still engaged in a part-time job. The remaining person was a full-time university student. All participants lived in the regions of the country where they were receiving RRT although two of them needed to relocate from one region to another. This is because there are only three of the ten administrative regions in Ghana with renal centres. Individuals who need RRT outside these three regions, therefore, have to travel across regions on a regular basis or relocate to a region with a renal centre. Six participants receiving RRT attributed their ESKD to hypertension while one participant attributed her ESKD to a history of diabetes mellitus. One person attributed his ESKD to both hypertension and diabetes mellitus. The remaining six participants receiving RRT had no known history of chronic diseases. Eight patient participants had not started any form of RRT at the time of their interviews (Table 4). Various reasons, including financial issues, were given for these delays in starting. Seven of them were males while only one was a female. As shown in Table 5, four of the participants who were not receiving RRT attributed their ESKD to hypertension while one attributed his ESKD to sickle cell disease. The remaining three had no known history of chronic diseases before being diagnosed with ESKD. Thus, ten out of the twenty-two patient participants attributed their ESKD to hypertension only while nine had no known chronic condition that was believed to have caused their ESKD. One of the remaining three people attributed her ESKD to diabetes mellitus only, another one to sickle cell disease while the other attributed his ESKD to both hypertension and diabetes mellitus. These have been summarised in Table 6 below.

Chronic Condition	Number of Participants (Percentage)
Hypertension only	10 (45.45)
No known chronic condition	9 (40.90)
Diabetes mellitus only	1 (4.55)
Sickle cell disease (SCD)	1 (4.55)
Hypertension and diabetes mellitus	1 (4.55)
Total	**22 (100)**

Table 6: Summary of Chronic Conditions Causing ESKD in Patient Participants

The youngest of the non-RRT participants was 24 years old, as compared to 26 years for those receiving RRT. The oldest participant among those who were not receiving RRT was 58 years old, as compared to 73 years for those receiving RRT. The non-RRT participants were relatively younger, with a mean age of 41.3 years, as compared to 46.6 years for the group receiving RRT. Although none of the eight participants who were not receiving RRT was above 60 years, only three were in full-time employment while five were unemployed as a result of their illness. The period within which the non-RRT participants had been diagnosed ranged from 1 month to 3 years. It must be emphasised, however, that five of them had been diagnosed with early stages of CKD and had been managed in their respective renal centres for some time before progressing to ESKD while three were diagnosed at the end stage. All eight participants were making out-of-pocket payments for their management although those who had subscribed to the NHIS had some aspects of their treatment being paid for by the authority. Two of the eight participants lived outside a region with a renal centre and had to travel for, at least, 3 hours to access treatment each time.

4.3 Characteristics of Clinician Participants

As explained in the previous chapter, a decision was made to interview a sample of clinicians in the course of concurrent data collection and analysis. This was in line with theoretical sampling which stipulates that sampling decisions, including characteristics of respondents and the kind of data to be collected, are made with reference to emerging categories after initial purposive sampling and data analysis (Corbin and Strauss,

2008, Glaser and Strauss, 1967, McCann and Clark, 2003). Clinicians were interviewed as a way understanding contextual factors that influence ESKD management in the country through the lens of the practitioner. Consequently, five clinicians, comprising two medical doctors and three nurses were interviewed, as shown in Table 7. Their years of experience in caring for patients with chronic kidney disease ranged from 2 to 24 years.

Respondent	Sex	Role	Years of Experience
Maame	F	Nurse	2 years
Awuraa	F	Nurse	3 years
Owura	M	Nurse	3 years
Ohemaa	F	Medical Doctor	3 years
Ohene	M	Medical Doctor	24 years

Table 7: Characteristics of Clinician Participants

A key difference that was noted between the two professional groups is that the medical doctors chose to specialise and work with patients with kidney diseases while all three nurses were assigned to the renal centres which might not necessarily have been their area of interest. While there is a structured programme and mentoring to train doctors in nephrology in one of the teaching hospitals in Ghana, there is no formal training for nurses working in dialysis settings but on-the-job training with periodic attendance of an Annual Renal Nurses' Conference that was introduced recently. The following were some of the responses on how they ended up working in renal centres;

> *"I was posted here by my nurse-in-charge, the director" (Awuraa, nurse).*

> *"It was a training programme for nurses on the ward that the nurses in the wards will come to the dialysis unit for a 3-month rotation and go back to the ward. But, when I came, they maintained me, I didn't go back to the ward" (Maame, nurse).*

> *"My main aim was to get somebody to mentor me and I found someone who had interest in nephrology so that drew me into nephrology" (Ohemaa, medical doctor)*

The next section presents a brief profile of each of the participants, including the clinicians.

4.4 Profile of Participants

4.4.1 RRT Participants

4.4.1.1 Agya

Agya is a 65-year old man who had been living alone and had not been *"feeling fine"*; he had been vomiting for over a month. He had moved to another city to take on a part-time job after his retirement but decided to return to his wife and family when he noticed that his condition was not improving. He felt helpless, he did not know what was happening to him neither did his wife. She thought that *"maybe somebody was doing it"*, implying that her husband might have been cursed or bewitched. Agya, however, thought it was *"another disease"*. Generally, many Ghanaians suspect they are suffering from malaria when they feel unwell and, usually, start some form of treatment before going to the hospital if symptoms persist – many antimalarial drugs are sold over-the-counter. After efforts to control his vomiting at home had failed, the family decided to take him to a district hospital where he was wrongly diagnosed with, and treated for, typhoid. The vomiting persisted after being discharged home from the hospital. Some friends visited him and, through their interaction, insisted that he should seek care from a teaching hospital. He agreed so they took him to the nearest teaching hospital where he was diagnosed with ESKD. His decision to seek further care from a teaching hospital was very much the result of the persistence of his symptoms and pressure and input from his family and friends.

He was advised by a doctor to use his money to take care of his children instead of having dialysis but he decided against that. His reason for starting treatment was that, at age 65years, he is too young to die as many people who have died in his family were 90years and over. He expected to be cured within six months after starting dialysis. However, he has been on dialysis for nine months and, upon realising that his cure expectations were not met, he now advocates for more information to be provided to patients before they initiate dialysis. He has two sessions each

week and has enjoyed immense financial and emotional support from his friends and family during his diagnosis and treatment.

4.4.1.2 Obrempong

Obrempong is a 48-year old man who attributes his ESKD to hypertension that he has had for about eight years. He explains that there was no mention of chronic kidney disease (CKD) as a possible complication of hypertension in the course of his management and no effort was made to monitor his kidney function. He relied on what he tags as *"rumours"* or what his doctor friends told him and these scared him as it appeared as though he had come to the end of his life, with a couple of weeks or months to live. He started haemodialysis and decided to educate himself on how to preserve his life. Although he found conflicting information over the internet, he was relieved to know that other people have survived on haemodialysis for several decades abroad and to notice improvement in his condition after starting dialysis. He feels rejected by his family and his girlfriend broke up with him because of his disease – they all think he will be dying soon. He believes that this could also be because many people associate ESKD with a curse and will do anything possible to be dissociated from that curse.

He sold some of his property in order to pay for kidney transplant surgery in India because he had heard that it was easy to get donors there. However, he learnt that a law had been passed to ban organ donations to foreign nationals when he got there. This is because people were either murdered for their organs or forced to sell them out of poverty and both are unethical. He had to return to Ghana to continue with haemodialysis and hope for a donor. He has been on haemodialysis for twelve months and has three sessions each week. He believes that treatment has been subsidised, even catered for completely, by some governments abroad and cannot understand why there is no support from the Government of Ghana.

4.4.1.3 Kantinka

Kantinka is a 39-year old man who had been living in the USA for eleven years and decided to move back to Ghana and pursue further education. He attributes his ESKD to a ten-year hypertension that he has had though he thinks he might have developed ESKD because he returned to Ghana. He also attributed it to the nature of his work environment in the USA but

was quick to question that because he is the only person to have developed ESKD among his colleagues.

He involved his family in his decision to start dialysis since he expected financial support from them because the cost involved is huge for one person to bear. He has two haemodialysis sessions each week and makes out-of-pocket payment for them. He explained that he is stable on haemodialysis and even doubts his diagnosis of ESKD as he looks quite healthy compared to most of the patients he sees in the renal centre. One of his concerns has been with the fact that his haemoglobin (Hb) level has been low, causing him to tire easily when he engages in mild activities. His major concern, however, has been with the age at which he has been diagnosed with ESKD, and he feels this is a greater burden. He gets immense support from the family in terms of paying for his treatment and has siblings who are willing to donate a kidney for him once they are able to raise money for kidney transplant surgery. He does not have expectations of a cure but very much looks forward to having a kidney transplant.

4.4.1.4 Adwoa

Adwoa is a 33-year old woman who attributes her ESKD to two miscarriages she had some time ago. She bled a lot after her first miscarriage and noticed that she had not passed urine after three days. She was referred to a renal centre and was treated for some time. Her condition became severe after she had a second miscarriage and was referred to a renal centre again.

She was diagnosed with CKD in 2009 and had an arteriovenous (AV) fistula created but did not start dialysis until in 2012. She was going for monthly reviews at the renal centre within that period. She delayed starting dialysis because she had learnt that she will be on it forever once started unless she had a kidney transplant. Moreover, she was not having any obvious symptoms within that period but only had her blood values showing high urea and creatinine levels. She also felt that dialysis was too expensive and did not have money to start. It was when her symptoms exacerbated that she visited a doctor friend who was kind enough to give her an amount being requested as initial deposit for dialysis to start. Her husband's company has been paying for her treatment since the initial deposit ran out. Her major source of information about ESKD and its

management has been her doctor friends. Though she gets some information from the renal centre occasionally, she feels that is inadequate. She hopes to have transplant someday and has been making arrangements to raise the needed amount since her husband's company has not shown interest in paying for that. She has two dialysis sessions each week and has scheduled her sessions such that she is able to continue working.

4.4.1.5 Abena

Abena is a 28-year old married woman with two children and manages her own business. She has been a known type 1 diabetic for seven years. She was only able to control her blood sugar levels after five years of her diagnosis. She realised in April 2013 that her feet and abdomen were getting bigger than usual and thought that she might be pregnant. She went for a scan which revealed that she had ascites and that fluid was accumulating around some of her vital organs including the liver and the kidneys. She was advised to see a renal specialist. She went to the nearest teaching hospital where she was diagnosed with ESKD. She knew that diabetes could result in problems with her kidneys but, as she put it, *"I knew a lot of the kidney having to do with diabetes but I didn't know it can generate on its own and become a whole new sickness for me"*.

She cried when she realised that she had to be on dialysis because she knew of the costs involved through the experience of a relative who was on dialysis. Her family did everything in their power to avoid her having to be on dialysis by providing her with various herbal drugs. But she put all those aside and opted to start dialysis because she believes in biomedicine instead of herbal medicine. She makes out-of-pocket payment for her dialysis, with support from her husband. She makes conscious efforts to know more about ESKD and its management by reading books on the condition. She has three dialysis sessions each week. She has been on dialysis for two months and hopes that her condition is acute and that dialysis is for a short term.

4.4.1.6 Akua

Akua is a 55-year old teacher who attributes her ESKD to hypertension and excessive weight gain. She was diagnosed with early stage CKD but progressed to ESKD within five years. She learnt that being on dialysis will be expensive for her and made efforts to avoid it by modifying her lifestyle

but that was not helpful. She tried to avoid dialysis even when her blood creatinine level was at 700µmol/L. She delayed starting dialysis for two more years but had to start within two days of reporting back at the renal centre because her blood creatinine level was above 2000µmol/L.

She had initial financial support from a family member in order to settle the amount required as an initial deposit. She then paid for subsequent sessions with the support of her husband but her husband died within one year. Her Reverend Minister and her church have been supporting her financially since her husband's demise, paying about 70% of her total monthly dialysis costs. She has been on dialysis for four years and being on dialysis has been challenging for her. She sees survival as paramount and knows that she will die within a short period without dialysis. She now seizes every opportunity she gets to advise others about the need for lifestyle modification in preventing chronic diseases.

4.4.1.7 Nana

Nana is a 73-year old man who has been on haemodialysis for about five months. He attributes his ESKD to having to live with hypertension for over two decades. However, developing this complication after living with hypertension for over two decades suggests that he might have controlled it well. His dialysis costs are catered for by his employers. He argues for the National Health Insurance Authority to cover haemodialysis costs for its subscribers. He described numerous times where he had to pay for dialysis costs for other patients with ESKD having challenges sustaining their treatment because of the cost. He believes that information provision to patients at his renal centre is inadequate. He has planned his work routines around his treatment schedule so that he is able to have all his thrice-a-week dialysis sessions and continue with his part-time work. He does not want to discuss kidney transplant because he thinks he is too old for that. Also, he feels that living on only one kidney will not be easy for the donor and such a person should, rather, enjoy their life to the fullest.

4.4.1.8 Kwasi

Kwasi is a 33-year old bachelor and a pastor. He noticed that he was feeling *"dull"* and could not do things the way he wanted to. He kept postponing a visit to the hospital for a check-up on several occasions until *"the day came for [him] to come".* As a man of God, he believes that everything that happens on this earth happens in the time that God has

appointed and that his continuous adjournment of a visit to the hospital was in accordance with the will of God. The doctor on duty did not let him go home on the day he went to the hospital. He was diagnosed with ESKD and was on admission for two and a half months. He started dialysis within this period.

He has been on haemodialysis for 5 years and his parents have been paying for his treatment in all this period. His motivation for continuing haemodialysis is that he believes he will be healed at a point in time and also believes that the disease may be to test his faith in God. He has been praying for a healing miracle to take place and says that he has set a date by which he expects such miracle to have happened. He knows that he will die if he does not have dialysis. He started with three sessions a week but had to reduce it to two sessions per week due to financial constraints. He testifies that he felt much better when he was having three sessions per week and would have preferred to continue with that. He wonders why ESKD is becoming common in Ghana, especially among the youth as he sees young people being diagnosed with ESKD day in and day out. He hopes to have a transplant but, in addition to trying to organise money for the surgery, he says he is waiting to know the will of God before he takes up any opportunity for a kidney transplant.

4.4.1.9 Onua

Onua is a 50-year old man who attributes his condition to a family history of hypertension. He believes he did not follow the prescribed treatment plan for his hypertension. He has been on haemodialysis for about 7 years. Starting haemodialysis, for him, was not without reluctance. He denied the diagnosis and then thought that his kidney function would be restored once he managed his hypertension effectively but that was not the case

He found it challenging to adjust to dialysis and, as a result, skipped some sessions as he felt he was much better before starting dialysis. However, he made a commitment to do whatever it takes to preserve life once he realised that it was at stake. The full cost of his treatment is being paid for by his employers. He has some reservations about having a kidney transplant. Apart from the difficulty in getting a donor, he also believes that a possible organ rejection makes it a tough decision to make, especially after meeting a patient who had done four different transplant surgeries and was back on dialysis. In spite of this, he wanted to travel to

India so he could have a transplant surgery but could not because he learnt that a law has been passed that bans Indians from donating kidneys to foreigners.

4.4.1.10 Wofa

Wofa is a 62-year old retired public servant who attributes his ESKD to hypertension. He has been on dialysis for eleven years. He feels information provision in the Ghanaian healthcare setting is inadequate as he was managed for some time when he developed CKD without being told about his diagnosis. He was only *"slapped with the information"* when he progressed to ESKD. His main concern was about how he would finance his treatment when the diagnosis was made. However, he got partial financial support for his treatment initially, and then full financial support through his interaction with some key people in government.

He used herbal medicines for about 6 months around the time he started dialysis because he had expectations of a cure and, also, thought it was not harmful. But he did not notice any changes and decided to stop it so he could concentrate solely on having dialysis. He has been to some prayer centres with the hope of experiencing a miracle from God. He said he does not want to have a kidney transplant because he believes that, at his age, it will be unfair to take a kidney donated by a younger person. He sees more people being diagnosed with ESKD every day and attributes this to lifestyle and general lack of education on some of these conditions. He advocates for some form of support from the government for all persons with ESKD.

4.4.1.11 Barima

Barima is a 26-year old university student who has been on dialysis for about a month. His condition came about suddenly and, as a result, he is unaware of what might have caused it. His major concern is that he was not fully informed about his condition for him to make an informed choice on dialysis. He thinks his doctors should have let him know from the very beginning that he had a chronic condition and that dialysis would not cure it. Yet, he does not have any regrets for starting dialysis as he believes it has sustained his life and helped relieve some of the symptoms he was experiencing.

He makes out-of-pocket payment for dialysis and paid the initial deposit through financial contributions from his neighbours. He has run out of

money after being on dialysis for a month and is uncertain how he will continue to raise money for his treatment. He is, therefore, thinking about withdrawing from dialysis and has suggested this to the nurses. He has been praying to God every day since he believes that ESKD is deadly without God's intervention.

4.4.1.12Eno

Eno is a 51-year old woman who was diagnosed with ESKD about a year ago. She had to quit her trading business because of the disease. She spent a week on admission in another hospital before being referred to the renal centre. She started dialysis within days of being diagnosed and has spent all her savings on dialysis. She did this with the hope that once she gets well she could work to make more money. Her treatment was discussed with her daughter and, as a result, she feels her daughter did not explain it to her adequately. Her sister has been supporting her financially since she ran out of money.

She attributes her ESKD to hypertension that she has had for about four years. Although she did not believe she had been cursed, she had to capitulate to the demands of her mother to see a fetish priest for the supposed curse to be reversed. She has, however, not noticed any changes in her condition after the curse was reversed. She has been to various prayer centres but that is yet to improve her condition. She does not want to withdraw from dialysis because she knows she will die as a result. However, she thinks she cannot continue dialysis because her sister who has been supporting her financially has also run out of money.

4.4.1.13Owoahene

Owoahene is a 30-year old man who was diagnosed with ESKD in January 2012 but has no known identifiable cause. He started dialysis with the hope that there may be a way out of his condition. He waited for about a month after his diagnosis before starting dialysis partly because he was concerned about how he would raise money to sustain it. He has been on dialysis since then though he skipped some sessions to pursue spiritual healing abroad. As at the time of the interview, he was three days away from having a kidney transplant surgery. Yet, he said he was looking forward to a spiritual healing more than the transplant because he believes biomedicine could not give him 100% treatment but God can. His brother is donating a kidney to him.

Several people have suggested that his condition could be as a result of a curse but he does not believe their explanations. He believes that God may be using this disease to teach him some things about life and describes the way by which he was able to raise money for his transplant as miraculous. He thinks information provision is inadequate and also has some reservations about how care is organised for patients with ESKD.

4.4.1.14Papa

Papa is a 50-year old man who attributes his ESKD of four years to hypertension that he has had for 25 years. He had not heard anything about ESKD before his diagnosis and said the disease came about suddenly. He did not entirely believe the diagnosis and the treatment approaches that were presented to him. Consequently, he sought herbal treatment for about two months since he wanted to be cured. He decided to start dialysis when he did not notice any improvement after trying alternative approaches.

Adjusting to dialysis was difficult for him so he was motivated him to have a transplant after being on dialysis for about 16 months. His niece donated a kidney to him. He was able to fund his dialysis and transplant costs with proceeds from his business. He feels the decision to have transplant was the best as he now has his life back although that has also taught him to modify his lifestyle in diverse ways. He interacts with other persons with ESKD and advises them often on the need for lifestyle modification. He advocates for more public education on kidney failure as he believes the lack of education is contributing to the high prevalence of the disease.

4.4.2 Non-RRT Participants

4.4.2.1 Akonta

Akonta is a 24-year old man who attributes his ESKD to sickle cell disease that he has had since infancy. He feels that his life has changed tremendously after his diagnosis. He believes that information provision has been inadequate even though he has been attending the renal clinic regularly. As at the time of the interview, he had been told about the various treatment options that are available to him and had developed a preference for transplant as compared to dialysis. However, he had little information on the processes he has to go through to get the transplant done and had scheduled to meet a doctor for more information on that.

4.4.2.2 Kwadwo

Kwadwo is a 58-year old commercial driver who had to quit working after he was diagnosed with CKD about three years ago. He has progressed to ESKD but has not started haemodialysis because his friend who has been paying for his treatment said he could afford the amount involved. Instead, he gets erythropoietin injection as and when his friend sends him money. He has been having the injection for about a year and only prays that his condition does not worsen. He lives with his wife and children in a town that is a three-hour journey by public transport to the renal centre.

Although he has had hypertension for 7 years, he did not attribute his ESKD to that but said he does not know what brought about his ESKD. He does not believe that his condition is due to a curse. He wonders why others pay money to fetish priests for a curse believed to have caused ESKD to be reversed. He knows that ESKD can kill him but he believes that people die even though they may not be sick so he is not afraid to die. However, his concern is about who will take care of his family when he dies. He, therefore, tries to do everything in his power to stay alive, even if it means spending his money on treatment instead of food. He only prays for God to guide the doctors to find a cure. But if he has to die, he prefers to die quickly instead of being bed-ridden before his death.

4.4.2.3 Kwabena

Kwabena is a 39 year old man who is unsure of what might have caused his condition as he cites an accident he was involved in at work in 1996 as a possible cause. He also thinks that he might have been exposed to some chemicals in the work place and that might have contributed to him developing ESKD. He has not started dialysis because he cannot pay the amount that is being requested as initial deposit. He is unable to raise money to cover his treatment costs because he is no longer working and, as a result, has had to rely on his brothers' financial support.

4.4.2.4 Kwaku

Kwaku is a 41-year old 'long-journey' driver with hypertension diagnosed about 5 years ago. He had to overstay for about two months in one of his usual journeys to a neighbouring country and ran out of his blood pressure control medications. His blood pressure rose to a point where it was difficult to control and he believes this might have accounted for his ESKD. He was diagnosed with ESKD about four months ago. He has been told

that he needs to start dialysis but says he cannot afford the amount being asked. He has stopped working because he does not want another situation where he will miss his hospital appointment because he is out of the country.

He does not know much about ESKD or its management but is afraid to ask doctors for some explanations because of an experience he had with a doctor. He will rather stay quiet and do what he is told rather than make his doctor angry by asking questions. He also seems not to know about the consequences of not having dialysis.

4.4.2.5 Yaw

Yaw noticed the first set of symptoms that led to his diagnosis of ESKD about a year ago. He is a 46-year old taxi driver but had to stop driving because of his symptoms. A doctor diagnosed him as having a kidney problem and promised to treat him. But his symptoms recurred after about three months of treatment and, although the doctor promised to continue treating him, he decided to go to another hospital that his friend introduced to him. He was referred from this other hospital to the renal centre where he has been managed since. He believes that he has been receiving better treatment in the renal centre and wishes he had come there earlier.

He has been to other places to see pastors and herbalists for treatment but none of them has been helpful. He does not believe that his condition is as a result of a curse. However, he feels pressured each time someone tells him to seek alternative treatment. He goes to these other places because he believes that get better from these other places.

4.4.2.6 Kofi

Kofi is a 50-year old man who has lived with hypertension for 10 years and was diagnosed with ESKD in January 2014. He attributes his ESKD to an accident he had ten years ago and to excessive use of pain killers. He has been told that he needs to start dialysis. He told his company about it and the company will be supporting him for three months – he is finalising arrangements for this. He, however, questions the need for dialysis when he would have to pay so much money for it and not be cured. He wishes he could have a transplant after being on dialysis for some time.

4.4.2.7 Kwame

Kwame is a 42-year old footballer who has been going in and out of the hospital for about 7 years because he had not been feeling well. But his diagnosis of CKD was confirmed to him by a family doctor three years ago. He was referred to the renal centre a year ago. He was advised that the best form of treatment is a kidney transplant although this is very expensive. He has started undergoing some tests with a friend who is willing to donate a kidney if they are compatible. But raising money for his treatment is a big challenge for him as he depends on his parents, to a greater extent, for money. He is, therefore, relying on his family's decision and financial support to be able to start dialysis or pay for the transplant. He expects to get better by having either transplant or dialysis. However, he believes that every type of disease has a cure which may not have been discovered yet. Consequently, if anyone can promise him a cure, whether traditional medicine or biomedicine, he will not hesitate to try that.

4.4.2.8 Piesie

Piesie is a 30-year old woman who attributes her kidney disease to the use of herbal preparations while trying to conceive. She developed hypertension two years before she was diagnosed to be having a kidney problem. She is aware that she might need to be on dialysis but she does not expect that to be any time soon. She is under a lot of pressure from family and friends to return to using herbal preparations to help her to conceive again since she had a miscarriage with an earlier pregnancy but she has decided against that and is waiting on God. She seems to know little about the treatment options that are available to her but believes that healing is from God so she will get better one day.

4.4.3 Clinician Participants

4.4.3.1 Ohene

Ohene has been practising as a medical doctor for thirty-three years and has been in nephrology for twenty-four years. He believes that the Ghanaian culture makes it easier for patients to follow doctors' or nurses' advice but the lack of infrastructure and support prevents the patient from doing so. He feels helpless around such patients and finds possible ways to help them.

4.4.3.2 Ohemaa

Ohemaa has been working as a resident doctor in the renal centre for three years. She sees the cost of treatment as a major challenge for most of the patients she cares for and has seen many of them die because they could not pay for dialysis. She attributes the increasing incidence to poor management of diabetes, hypertension and other kidney diseases. She also thinks that the role of herbal medicines in causing ESKD should not be downplayed. From her experience, many of the patients that present with ESKD report late. She, therefore, advocates for early detection and early management policies in order to delay the increasing need for renal replacement therapy in the country. She is of the opinion that the few renal centres available in the country are a hindrance to ESKD management. She says some persons refuse treatment because of the distance they have to travel to get to a renal centre for a dialysis session. She sees decision making on treatment as a collaboration between a doctor, patient and family and advocates for measures to ensure all parties are involved to ensure positive results.

4.4.3.3 Awuraa

Awuraa is a nurse who has been working in the renal setting for three years. She says that none of the patients who were diagnosed with stage 3 CKD has progressed to ESKD, portraying that if CKD is diagnosed and managed early, the incident dialysis population will reduce. She explains that telling patients they need dialysis to survive is very difficult to do, *"that's why, sometimes, other people will go through the counselling with the patient without even telling them it's for life. They will tell them you start with this amount and let's hope for what God will do."* She is of the opinion that, sometimes, the patients just fail to accept that they need dialysis to survive and might show this in their utterances or behaviour. She only hopes there will be some form of support from the government so that patients and their families would not have to bear the costs alone.

4.4.3.4 Maame

Maame has been practising as a nurse for four years but has been in the renal setting for two years. She feels that patients usually listen to advice from other patients more than that from clinicians. She believes that including ESKD in the conditions covered for by the National Health Insurance Authority is one approach to ensuring that patients get the best care possible. She also believes that clinicians, particularly nurses caring

for these patients, should get specialist training which will have a positive impact clinical outcomes.

4.4.3.5 Owura

Owura has been working as a nurse in the renal setting for three years and had on-the-job training. He believes that many of the patients he cares for are helpless and does everything in his power to support them. He believes that herbal drug use plays a key role in the development of ESKD in many patients though he also cites diabetes, hypertension and infections as common causes. He advocates for more public education on ESKD and its causes to aid in reducing the increasing prevalence.

4.5 Summary of Chapter

This chapter has described the general characteristics of participants of this study. It has also provided more details on the context of the study through life stories of the unique characteristics and experiences of patients with ESKD in Ghana. These life stories show that, indeed, there are commonalities in the unique experiences of all these individuals. A key finding is that participants were generally younger and mostly under the retirement age of 60 years in Ghana. This has been described as a general reflection of the ESKD population in the country. Participants were receiving only two forms of RRT, in-centre haemodialysis and kidney transplantation, with the former being in the majority. Live donor kidneys are only used in performing kidney transplant surgeries.

The next chapter will bring these stories and experiences together in order to describe the common ESKD patient journey identified in this study. A conceptual map that has been developed to depict this ESKD patient journey and key decisions at various stages of the patient journey will be described after explaining the main categories identified in this study.

CHAPTER 5. CONCEPTUAL MAP OF THE ESKD PATIENT JOURNEY AND DECISION MAKING STAGES

5.1 Introduction to the Chapter

A key finding of this study is that patients undergo a journey which, although specific to each individual, indicates that the patients share commonalities in the psychosocial processes that characterise their experiences. The patient journey comprises four major phases (categories) that were identified from the data. These are;

A. From symptoms to certainty: reaching a confirmed diagnosis of ESKD,
B. Deliberation or procrastination: ascertaining the likely trajectory of ESKD,
C. Believing that tomorrow will be better: the linchpin of initial patient decisions, and
D. Confronting reality: adjusting to new life.

The purpose of this chapter is to describe each of these categories and a conceptual map showing the ESKD patient journey and stages where key decisions are made. The relationship between these categories is depicted in Figure 1, which shows that an individual will progress from the first category of 'from symptoms to certainty: reaching a confirmed diagnosis of ESKD' to the second category of 'deliberation or procrastination: ascertaining the likely trajectory of ESKD' in a sequential manner. The individual then progresses to the third category of 'believing that tomorrow will be better: the linchpin of initial patient decisions', once in the second category. However, individuals may move back and forth between the second and third categories from time to time and this will be explained in subsequent sections. An individual will then progress to the fourth category of 'confronting reality: adjusting to new life' from the third category and may move back and forth between this category and the third category.

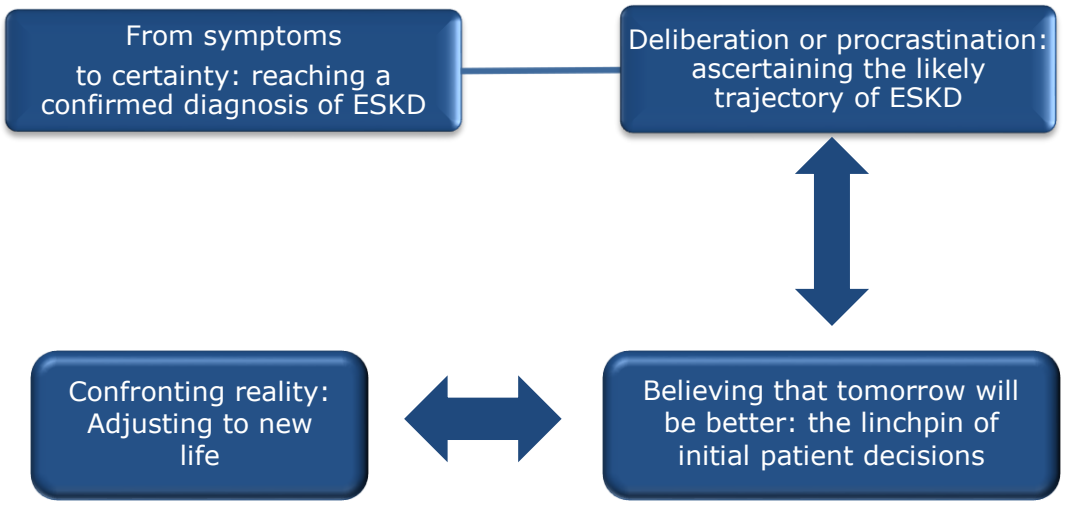


Figure 1: Relationship between Major Categories

The subsequent sections will now explain each of the four categories and their respective subcategories.

5.2 From Symptoms to Certainty: Reaching a Confirmed Diagnosis of ESKD

This category describes the process by which individuals become known patients with ESKD after noticing various changes in their usual health status. The four subcategories that make up this category are linear and sequential. Each of these phases is explained in the subsequent subsections.

5.2.1 Noticing Symptoms

Analysis of data from patient participants shows a common journey to becoming a known ESKD patient. Individuals first notice some changes in their health status while going about their usual activities. 'Noticing symptoms' describes patient participants' descriptions of these changes in their usual state of health. Sometimes, these changes are as obvious as noticing oedema of the feet, ascites or prolonged vomiting while others experience less obvious and non-specific changes such as feeling weak, tiring easily, having headaches and joint pains, feeling dizzy, 'feeling dull' among many others. The excerpts below are examples of how two participants described events that marked the beginning of their disease.

"About seven years ago, I saw that I [had] oedema of the feet" (Akua, dialysis patient).

"I was feeling weak and got tired easily. I also had recurring headaches and joint pains. Then I noticed that my feet were also swelling but this subsided in the morning...I also noticed that my face was getting puffy each morning" (Kwame, non-dialysis patient).

Once they start noticing symptoms, they begin to ponder over what could be happening to them and begin searching for a cause of these changes that they have noticed. The next subsection describes the processes involved in searching for a cause of the changes they notice.

5.2.2 Searching for a Cause

Searching for a cause involves actions that individuals perform in an attempt to identify the underlying cause of their symptoms prior to their formal diagnosis of ESKD. This subcategory includes actions that are performed or stopped with the hope of relieving or reducing symptoms that are being experienced. Four key processes were identified in the search for a cause of symptom(s) being experienced, as is shown in Figure 2.



Figure 2: Key Processes Involved in Searching for a Cause

Participants mostly start their search for a cause by attributing a cause and then attempting a remedy. Their beliefs about probable causes of the changes they have noticed greatly influence the steps or actions that are taken while searching for a cause. They start and/or stop performing certain activities with the hope of identifying which ones would be helpful in relieving their symptoms. The excerpts below describe attempts made by two participants to remedy their symptoms.

> *"So from that time I was not eating, because anytime I ate, I vomited so I thought it wasn't even necessary to eat at all" (Agya, dialysis patient).*

> *"...I elevated them [feet] with pillows while sleeping…I felt that if pregnant women who have swollen feet elevate their feet while sleeping and that helps, then it will help me also. I noticed the swelling reduced each time I did that but that has not been the case now" (Kwame, non-dialysis patient).*

Under the umbrella of 'attributing a cause', individuals attribute their symptoms to a host of factors including their lifestyle or an event in their life, another disease or to spiritual causes including curses. Some of those who develop ESKD as a complication of another chronic disease are usually aware that they can develop ESKD as a result of their pre-existing disease. Yet, when they notice changes in their usual health status they, mostly, do not suspect that they have developed a complication of their pre-existing chronic disease but attribute their symptoms to other events. For instance, one participant, Obrempong, who was a known hypertensive, after noticing swelling of his feet for the first time one morning, thought that he might have been bitten by an insect. He applied warm compresses for some time with the hope of relieving it and visited the hospital subsequently when he did not notice any improvement. Abena, as has been described in the profile of patient participants, thought she was pregnant until a pregnancy scan revealed that she had ascites and pedal oedema which implied she had kidney disease and not pregnancy as she had assumed. She was advised to see a renal specialist. Indeed, several participants reported inadequate knowledge about ESKD and largely attributed some of their initial actions to inadequate knowledge of signs and symptoms of ESKD as they had not heard anything about the disease in their lifetime. Some of them also attributed their initial actions to a lack of regular monitoring of kidney function while being treated for various

pre-existing chronic diseases thereby making them unaware of when their kidneys started failing and possible signs and symptoms to look out for.

There are also those who attribute the changes they notice in their health to another disease instead of ESKD. Such thoughts are usually founded on their previous experiences or on incorrect information given to them when they seek care from some hospitals.

> *"I started feeling stomach aches so I went to a district hospital and they told me I had to undergo surgery because they suspected an inguinal hernia" (Kwadwo, non-dialysis patient).*

> *"I went to the [district] hospital….when they diagnosed they saw it was typhoid so they admitted me to that hospital. They treated me for about a month or so….the doctor said the typhoid [was] gone but still, when I [ate], I vomited" (Agya, dialysis patient).*

It must be added, however, that others are accurately diagnosed with ESKD when they visit some hospitals for the first time and do not end up mistaking their signs and symptoms for another disease. This will be explained further in the next subsection on 'being diagnosed with ESKD'.

Others attribute a cause of these changes in health status based on their spiritual or religious beliefs. For instance, one participant was of the opinion that his symptoms had been brought about by Satan because he might have wronged God.

> *"Sickness comes from [the] Archenemy [Satan] and then, I, one way or the other, it's by your doing, whether you've done something wrong, you wronged God somewhere or you've done something that you are not supposed to do" (Kwasi, dialysis patient).*

The participant quoted above believed prayers to God would help resolve the symptoms he was experiencing.

Some individuals seek support in searching for a cause when their symptoms persist after their individual attempts for remedy are unsuccessful. The discomfort associated with having persistent symptoms usually motivate such participants to seek this kind of support. They discuss the symptoms as well as the remedies they have attempted with their family and/or friends some of whom may be healthcare

professionals. Such interactions usually come with further recommendations on actions that could be taken. Further recommendations from significant others to participants may include seeking spiritual guidance, herbal treatment or reporting to a hospital. For instance, Onua, a health professional, discussed his persistent symptoms and the steps he had taken to alleviate them with a physician friend who recommended further actions to be taken including strict adherence to his prescribed treatment for hypertension, including close monitoring of his blood pressure.

Suggestions made by friends or family of an individual, in some instances, influence what they end up attributing their symptoms to and their search for a cause. However, there are times when individuals may be reluctant to take these further recommendations into account, especially when they are asked to repeat some steps they have taken previously in an attempt to remedy the situation. As a result, relatives and/or friends, sometimes, have to insist for these further actions to be taken. For instance, friends of Agya had to insist before he sought care from a teaching hospital after being incorrectly diagnosed with and treated for typhoid in a district hospital. It is the eventual visit to a teaching hospital that led to an accurate diagnosis of ESKD.

Several others may be told by their family or friends or, in some instances, religious leaders that they are experiencing changes in their health status because of a curse that might have been placed on them. Curse causal suggestions are made as a result of their presenting symptoms and would require the individual to consult a spiritualist for guidance on how to reverse the curse. However, most people tend to ignore such suggestions. They reflect on their lives to ascertain whether they have memories of offending anybody or whether there are justifiable reasons for someone to be jealous of them as these are believed to be two common grounds for one to be cursed by somebody within the society. In some instances, individuals are ambivalent about what to believe when they feel that there are grounds for them to have been cursed. However, they argue against these suggestions of a curse being placed on them when they find no basis for them.

> *"Before somebody curses you, maybe you have done something…that thought only came when people started saying*

this and that...[I] take a step backwards to see if I have, possibly, offended somebody but I haven't seen any" (Owoahene, dialysis patient).

"….the pastor said that I have been cursed but I know within me that I have not offended anybody to warrant that so I never believed them" (Yaw, non-dialysis patient).

"You only get worried about some of these things [curses] when you have done wrong but I know myself, I don't engage in some immoral acts so I don't believe I can be cursed. If you don't believe in that then it will not happen to you – that is my belief" (Kwadwo, non-dialysis patient).

However, there are times when the persistence of these significant others in terms of ensuring that their recommended actions are followed lead these individuals to succumb to their demands even though they are not in support of these recommended actions. For instance, the family of Eno thought that she might have been cursed and insisted that she went to see a fetish priest with them. Although she did not believe that she had been cursed, she went with them after the family had insisted for a while.

"Initially, I was told that I might have been cursed but I argued that I haven't offended anybody in any way to be cursed. But my mother took me to a place [fetish priest]" (Eno, dialysis patient).

Individuals with these changes in their health status often succumb to the demands of their significant others when they feel that not yielding have the potential to bring about conflicts. They, therefore, yield to some of these requests in order to avoid confrontations with their significant others. Others agree to try out some of these recommendations hoping that solutions to their problems could come through various approaches other than hospital care alone while others feel that they are not in a position to make a fully informed decision about where to seek care from because of their illness.

"You listen to people when you are sick. Everybody tries to advise you, I mean, so you listen to people….and just follow because, at that moment, you are the one that is sick and your mind, actually you are not really focussed so you tend to listen to people, friends, family members, everybody wants to take you to a clinic or a

hospital or a prayer camp so I think nothing motivated myself to go [to a prayer camp] but it's what friends or people asked me to do" (Papa, transplant patient).

"When they [significant others] recommend taking you to a place and you refuse they will talk….it appears as though you are being disobedient or disrespectful. You are sick and someone recommends a place to you, probably you might get help from going to this place" (Yaw, non-dialysis patient).

However, an individual is likely to stop following these recommended actions of consulting spiritualists or using herbal medicines when their symptoms persist after visiting them. They, subsequently, decide to seek care from hospitals. Eno, for instance, stopped consulting a fetish priest when she did not notice any improvement in her condition.

"…I realised they were just extorting money from me so I stopped and decided to come to the hospital alone" (Eno, dialysis patient).

Searching for a cause continues in a 'cyclical' manner, as is shown in Figure 2, until an accurate diagnosis of ESKD is made in a hospital setting. The subsequent section explores the various processes by which a diagnosis of ESKD is confirmed.

5.2.3 Being Diagnosed with ESKD

This subcategory refers to the period within which an accurate diagnosis of ESKD is made and this always occurs within a hospital setting. Sixteen participants sought walk-in care in a private, district, regional or teaching hospital after their initial attempts to remedy the changes in their health status had failed. The kind of hospital facility depends on which type is closest to the individual, recommendations made to them by significant others or through a referral from one type of facility to another. Six participants, however, experienced sudden changes in their health status which resulted in them requiring emergency care. Circumstances leading to such emergency situations were different. Some had noticed changes in their health status and were searching for a cause but had dismissed or adjourned a decision to seek care from a hospital before a sudden worsening of their condition led to their emergency hospital care. the others were being managed routinely for a chronic condition such as diabetes mellitus, hypertension or, in one case, sickle cell disease before a

sudden change in their condition warranted emergency care and led to an eventual diagnosis of ESKD.

> *"I've been coming to sickle cell clinic since, almost every month but it seems they didn't realise it till...I had some hypertensive encephalopathy so they rushed me, I was convulsing and they brought me here. That was when they found out that I was having chronic kidney disease due to the sickle cell [disease]" (Akonta, non-dialysis patient).*

> *"I was attending a [hypertensive] clinic every month. Every month I will come, go and do a test and they will look at the test and ask me to come the following month, nothing was said until I collapsed again and I was told that I developed a chronic renal problem. That's how it happened" (Wofa, dialysis patient).*

Accurate diagnosis of ESKD may be made in a private, district or regional hospital where they first report at while others have to be referred to a teaching hospital before an accurate diagnosis of ESKD would be made. Others may also report first at a teaching hospital, without being referred from another hospital, where they would end up being diagnosed with ESKD. Accurate diagnosis of ESKD is, however, not always straightforward as a few may be wrongly diagnosed with and treated for other conditions such as malaria and typhoid before an eventual diagnosis of ESKD is made. Mostly, this may occur in hospital settings other than teaching hospitals. Having persistent symptoms after an initial treatment in these hospitals may often result in such individuals being referred to other hospitals for further care or the individual may make a personal decision to get a second opinion and further care from another hospital. Those who are accurately diagnosed with ESKD in a private, district or regional hospital may be referred to the nearest teaching hospital as renal centres in the public sector are all currently located within teaching hospitals. Many Ghanaians prefer to seek healthcare from public hospitals because it is less expensive as compared to receiving healthcare in private hospitals.

> *"I went to a district hospital….they did some laboratory investigations and told me that there are some things within me that are not working well so I was referred to this place [teaching hospital]" (Kwadwo, non-dialysis patient).*

"I was having a headache, I went to the hospital and my BP was up, it was about 185/120 so the doctor just referred me to this [teaching] hospital. So I came there and the doctor diagnosed me" (Barima, dialysis patient)

"A man in my church who is a doctor decided to take care of me. He did this for about three months giving me some injections. This relieved the swelling but I noticed the swelling again. This time, a friend of mine took me to another doctor in private practice. He made me take an X-ray….after the X-ray he referred me to this [teaching] hospital" (Yaw, non-dialysis patient).

The teaching hospitals have specialist staff and facilities for the purposes of training more healthcare personnel. They are, therefore, well-equipped, in terms of human and material resources, to accurately diagnose and treat many forms of diseases. Comparatively, some of the district or private hospitals may not have specialist or well-trained clinicians and may also lack the necessary material resources such as laboratory reagents to aid in accurate diagnosis and treatment of various forms of diseases. Three out of the four teaching hospitals in the country have renal centres where many patients with ESKD start treatment. The remaining renal centres are located within private hospitals. It is noteworthy that most of the patients with ESKD getting care from the private renal centre included in this study had been diagnosed in a teaching hospital and had started getting care from there before transferring to the private facility for various reasons, including proximity to their homes and nature of services required.

Accurate diagnosis of ESKD was made late for most of the patient participants and this was largely due to delays in seeking care in a hospital after noticing symptoms as well as being incorrectly diagnosed with and treated for another disease when care was sought from some hospitals. Kidney function of many of those who had precursor conditions of CKD such as diabetes mellitus and hypertension was, reportedly, not monitored regularly, also contributing to the delayed diagnosis of ESKD. Participants were mostly diagnosed with excessively high blood urea and creatinine levels as a result.

"When I came, she [the doctor] asked me to do creatinine test which I did….they just checked my creatinine level which was way beyond 2000 [µmol/L]" (Papa, transplant patient).

"So they told me to do the test. I was told that the normal creatinine levels range from 0-100 [µmol/L]….mine was about 2000 [µmol/L]….he [the second doctor] made me repeat the creatinine test and this time, it was about 2400 [µmol/L]" (Kantinka, dialysis patient).

"When I sent it [laboratory report] to him [the doctor], he said, he was a little alarmed and told me that it appears I have a kidney problem so he transferred me. In fact, my creatinine clearance at that time was about 2574 [µmol/L]" (Owoahene, dialysis patient).

However, nine participants were diagnosed at an early stage of CKD through prompt treatment-seeking from a hospital or rigorous monitoring of their laboratory results as part of the management of a precursor chronic condition.

So far, it has been revealed that many individuals who are diagnosed with ESKD in Ghana are unsure of what initial changes in their usual health status mean, and they usually try various approaches in an attempt to ascertain what is happening to them. Different processes lead to the majority of them presenting late at a renal centre and being diagnosed with ESKD – only a few participants of this study were diagnosed with early CKD. The next subsection explores how individuals react when a diagnosis of ESKD is made.

5.2.4 Reacting to Diagnosis

Reacting to diagnosis describes the phase in the individual's life when they realise that changes in their usual health status are associated with a life-threatening disease and how they respond to this news. Many participants did not know much about ESKD at the time of their diagnosis although some had heard about ESKD as a possible complication of a chronic disease they have. In a setting where patients feel that doctors and nurses have been trained to know more about their health than they can ever know, it is not uncommon for patients to accept the diagnosis without questioning. Thus, when a diagnosis of ESKD was made and related to their chronic condition, some of such participants had less difficulty

accepting the diagnosis. They usually admitted that poor management of the earlier chronic disease, mostly hypertension or, in one case, diabetes mellitus, had resulted in their developing ESKD.

> *"I mean the end result of all hypertension and diabetes is kidney failure so it's something that, once you've started this thing, hypertension, idiopathic hypertension and diabetes, then one should expect that it will occur" (Nana, dialysis patient).*

> *"In fact, I didn't take it [hypertension] serious, I didn't know how it is so I didn't take it serious in taking the medicine, so I stopped somewhere along the line and it [blood pressure] was up, up, up and then, before I realised, it has damaged the kidneys" (Akua, dialysis patient).*

But this was different for those who had no known previous chronic disease that could result in ESKD. Many of such participants found it hard coming to terms with the diagnosis as they were unable to identify any particular cause of their ESKD or factors that might have contributed to its development. One participant indicated that even his clinicians had doubts about his diagnosis while another could not identify any lifestyle of his that is believed to have contributed to the development of ESKD.

> *"After all the tests and the confirmations, even the doctors themselves doubted that that was what I was suffering from….they still didn't believe that even if it is kidney failure, it is chronic" (Owoahene, dialysis patient).*

> *"I have been thinking about it but can't seem to know what caused it. They say alcohol, smoking and consuming fatty foods can cause it but I don't do these things" (Barima, dialysis patient).*

One participant who had lived abroad for many years and was diagnosed with ESKD upon his return to Ghana even considered the possibility of having developed ESKD as a result of his relocation to Ghana.

> *"A lot of people have this problem, a lot of people, Ghana here, I don't know if there is something wrong. Sometimes, I feel like if I hadn't come [to Ghana] and I was there [abroad], I wouldn't have [had this disease]" (Kantinka, dialysis patient).*

Many participants reflected on the period within which they noticed symptoms for the first time and, after several attempts to identify and remedy the cause of their symptoms had proven futile, they anticipated that once an accurate diagnosis had been made in the hospital, the cure was imminent. The concept of living with a chronic disease for a lifetime is new to many Ghanaians mainly because of the high prevalence of communicable diseases which are mostly treatable. When these individuals were told in the hospital that ESKD has no cure and that it is a terminal disease, they then began to ponder over the severity of what was happening to them. There is a common belief that no disease is without a cure, especially among proponents of traditional medicine and spiritual healing. Such a belief made it difficult for the majority of the participants to accept that their disease is terminal. Generally, only a few Ghanaians will completely disregard traditional medicine or spiritual healing, especially when biomedicine offers no lasting solution. What is more, knowing about treatment options available to them and the costs involved became another hurdle that made accepting the diagnosis a daunting task. Words such as 'disheartening' and 'unpleasant' were used to describe their feelings when they were diagnosed with the disease and its likely trajectory and issues surrounding its management were explained to them. This mostly led to moments of reflection where they began to ask questions such as "why me?" The statements below are excerpts from two participants:

> *"It's a problem when you have it at a younger age, you think like 'why did I have this?' you know, everybody, unless you don't think" (Kantinka, dialysis patient).*

> *"If I have God, why me? I do ask those questions when the sickness came because I was praying with my friends, why not my friends but me?" (Kwasi, dialysis patient)*

Other individuals, however, seemingly denied facts about the disease after their diagnosis had been confirmed while aligning themselves with their beliefs about causes of disease and searching for a different opinion from other hospitals or outside the biomedical setting.

> *"They [second district hospital] also did all their investigations and they confirmed it was now kidney failure so I have to be*

transferred here [teaching hospital]….I was in denial" (Onua, dialysis patient).

"Well...I didn't believe it [the diagnosis] first that, I mean, I have never even heard the word kidney failure before in my life, my entire life so it was a surprise to me and, initially, maybe, there is a different means of maybe getting it repaired or something by herbal or prayers and all that. So I went through that for about, maybe, 2 months" (Papa, transplant patient).

This usually continued until their symptoms became life-threatening or they did not notice any improvements in their condition after using other approaches outside biomedicine and usually led them to accept the ESKD diagnosis. Family and/or friends, sometimes, had to intervene before individuals accepted the diagnosis of ESKD.

"For instance, for me, first I didn't want to accept that I was sick but they [parents] convinced me to accept that I'm sick so that I will take my time and then do what I'm supposed to do for me to get well" (Kwasi, dialysis patient).

It must be emphasised, at this point, that not all participants accepted their diagnosis before going through the next processes to be described. They still had doubts about their diagnosis and its severity. Such participants were more likely to try other approaches other than the prescribed biomedical approaches in order to confirm or disprove some of the information they had been given about their diagnosis.

In summary, patients with ESKD in Ghana are mostly unaware of the disease and its clinical manifestations before being diagnosed. Changes in their usual state of health start a series of processes or activities that eventually lead to a confirmed diagnosis of ESKD. Once a confirmed diagnosis of ESKD is made, individuals mostly react to news about their diagnosis in two ways, either accepting the news and trying to identify what their next steps would be or having doubts about the terminal nature of their illness and seeking different 'verdict' through other sources. This is the phase where individuals progress to the next category of 'deliberation or procrastination: ascertaining the likely trajectory of ESKD' albeit there could be back and forth movement between these two or the two may occur simultaneously.

5.3 Deliberation or Procrastination: Ascertaining the Likely Trajectory of ESKD

This category focusses on ways by which patients with ESKD ascertain the likely trajectory of the disease, available treatment options as well as prognosis after they have been told about their diagnosis. Thus, the category explores ways of acquiring information about ESKD and how participants interpret that information and utilise it to make decisions about subsequent courses of action. It has been explained above that individuals in this category may also be in the phase of reacting to the diagnosis of ESKD alongside seeking information about the disease and deciding how to utilise that information.

Figure 3 shows that participants in this category progress through three phases – from 'lacking information' to 'acquiring information' and then to 'managing information'. Efforts to utilise acquired information led some individuals to recognise the need to acquire more information regarding ESKD and its management, hence the cyclical relationship between the phases. Each of these phases has been explained in the subsequent subsections.

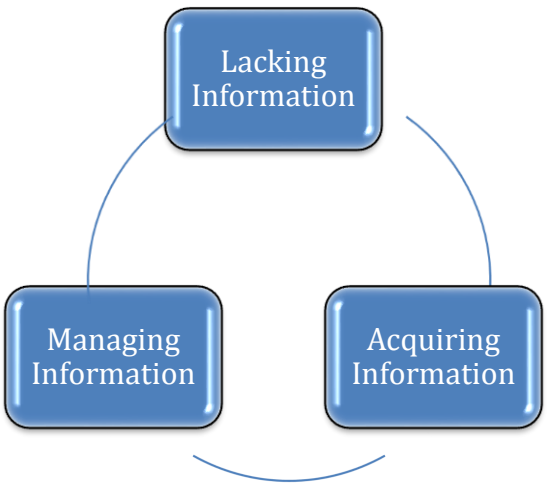


Figure 3: Subcategories of 'Deliberation or Procrastination: Ascertaining the Likely Trajectory of ESKD'

5.3.1 Lacking Information

Although there is an increasing prevalence of chronic diseases in the country, there have not been corresponding efforts at increasing public awareness of these kinds of diseases as there has been for communicable diseases such as HIV/AIDS. Only a few chronic conditions, including hypertension and diabetes mellitus, are well known among the Ghanaian populace. Thus, there is limited awareness of ESKD and its outcomes as compared to other diseases. While some participants had heard about it as a complication of a chronic disease they have, others heard about ESKD for the first time when they were diagnosed and did not know much about it in terms of its pathophysiology, clinical manifestations, and management.

> *"I didn't know what it [kidney failure] is, I didn't know" (Akua, dialysis patient).*

> *"I [had] never heard the word kidney failure before until I had it" (Papa, transplant patient).*

> *"I did not know anything about kidney failure before coming here [renal centre]" (Kwabena, non-dialysis patient).*

Many of the diseases in Ghana are acute and communicable in nature and are easily treated with drugs alone. Thus, the concept of having to modify their lifestyle in addition to taking drugs to achieve effective control of chronic conditions instead of curing them was new to many. It was, therefore, not surprising for some patients to expect that they would be taking only drugs to manage their chronic conditions and whatever complications that would result. Several participants of this study who developed ESKD as a complication of hypertension or diabetes mellitus were either not aware of it as a possible complication or were not expecting it to be severe and, as a result, did little to ensure effective control of their chronic condition. They expected prescribed drugs alone to control their chronic conditions effectively and reported limited or no awareness of the significance of lifestyle modification to achieving positive clinical outcomes. Others were also not taking their drugs as prescribed.

> *"I [would] come and they [would] give me medication, Lasix and other [anti] hypertensive drugs like nifedipine and so on. I was just going to work and living normal" (Wofa, dialysis patient).*

"At the weekends, I was partying and stuff like that….and my pills, because of the kind job I was doing, I wasn't taking my pills for a while because if I take it, I feel dizzy" (Kantinka, dialysis patient).

Some participants reported that they did not have adequate information about the possible complications of their chronic conditions and how to avoid developing them.

"You know, they give the broad, kidney failure, heart failure, [and] all the complications of hypertension. But they didn't hammer on [emphasise] the kidneys" (Onua, dialysis patient).

"They [clinicians at the hypertensive clinic] did not say anything [about hypertension and kidney failure]. It was later on that a doctor told me that hypertension has affected my kidney but I did not know that it was that serious" (Kofi, non-dialysis patient).

Others explained that their kidney function was not monitored closely while their chronic condition was being managed and, in some instances, had to insist for their kidney function to be monitored. They explained that if they had been well informed about the severity of ESKD as a complication of diabetes mellitus or hypertension, they would have lived differently in order to avoid ending up with the disease.

"I went to my doctor……in fact I forced him to let me go in for laboratory tests and after the tests I was informed that one kidney is almost off, the other one is also getting spoilt" (Akua, dialysis patient).

"In my case, if I had a doctor who had even investigated that the kind of pressure I was having, if he had investigated on my kidneys and what not, I could have, at least, stopped certain things that actually aggravate the cause, but I didn't know….because I wasn't dedicated, I didn't know the consequences of this [hypertension], I was just living my normal life until the whole thing got worse" (Obrempong, dialysis patient).

The above surmises that, from the patient's perspective, many clinicians manage ESKD precursor chronic conditions with little attention to preventing or monitoring them for their potential complications. But this lack of information needed not to persist once they had been diagnosed

with the disease. The subsequent subsection explores means by which participants gained more information about ESKD after their diagnosis.

5.3.2 Acquiring Information

This subcategory describes how individuals with ESKD obtain information about their disease, its management as well as prognosis. Individuals acquired information about ESKD from sources such as clinicians, relatives and friends, literature, media, the internet, and from other patients with ESKD, mostly after they had been diagnosed. Participants had opposing views on the adequacy of information provision in the renal centres, even after they have been diagnosed. Some participants felt that information provision in renal centres is inadequate.

> *"I didn't have any information about my management. I come [to the renal clinic], they just give me my BP drugs and ask me to go and come in a month's time. They actually didn't tell me anything about my management" (Akonta, non-dialysis patient).*

> *"The education is low….I was here [renal centre] for almost two years but I didn't have any idea about what is affecting me….and there is some secrecy surrounding the whole thing. Because of the enormity of the financial commitment, they tend not to shock you with the information as to the nature of the disease so before you become aware, you become traumatised" (Wofa, dialysis patient).*

Consequently, some participants had to rely on other clinicians outside the renal centres for more information about ESKD while others relied on the internet and books to educate themselves on ESKD.

> *"Most of the information I have, it's from people I know, not people who are here [renal centre] per se, who are working as nurses or doctors but because the person is a friend and so sit down with the person [and] talk" (Adwoa, dialysis patient).*

> *"My sister….she reads more of this dialysis thing so she communicates with me. If there is a problem I ask her and she goes on Google, the internet, and tells me stuff" (Kantinka, dialysis patient).*

> *"When I had the condition, I decided to read about it, so I had a series of books and then I had a lot of information on the net*

[internet]. As for the net, you can read a lot" (Obrempong, dialysis patient).

However, some participants felt that information from renal centres has been helpful in their management of the disease.

"They say that even if you take the drugs but don't eat well, you will not get better so they educate us on our diet and other things. I feel that it is good they educate us when we come here" (Yaw, non-dialysis patient).

In the end, all participants had some information about ESKD and its management albeit some reported that the information was inadequate, irrespective of their source of information. Yet, participants needed to rely on this newly acquired information, regardless of its adequacy or otherwise, to make subsequent decisions about their care. The next subsection, therefore, describes how individuals utilised information that was acquired on ESKD to make decisions.

5.3.3 Managing Information

Once information had been gathered through various means, the next step was to utilise this in making decisions to achieve desired goals and to direct their care. This is the focus of this subcategory and the crux of the category on 'deliberation or procrastination: ascertaining the likely trajectory of ESKD'. Information gathered includes the likely trajectory of ESKD, available treatment options and their financial implications, and prognosis. Some cried upon realising the new status that ESKD had conferred upon them and what its management entailed. Others were concerned about how the society perceived the disease and the kind of support available to patients.

"The first time I came here [renal centre] I cried. I, though I didn't know much about the disease, I was worried for myself because I knew the functions of the kidney and if mine is not working then that means waste will still be in my body and I was going to, I thought I was going to die"(Abena, dialysis patient).

"Honestly, the news was very devastating simply because, in this part of the world, they see kidney failure as, like death – once you get it, you die…after I had the disease, I discussed it with a lot of

doctors…some were my friends…and their perception…was very appalling. They say there is nothing, as for kidney [failure], you will be on dialysis for some time and the tail end, you will go [die] so their comments were very discouraging" (Obrempong, dialysis patient).

Many participants reported that information that was provided after their diagnosis did not empower them to make informed decisions, with some of them having a perception that key information was being deliberately kept from them. A few of them did not know about haemodialysis as a treatment option available to them and other treatment options that they could have aside haemodialysis. For instance, when some participants were asked about other treatment options for ESKD apart from haemodialysis, the following responses were noted:

"No, I'm not aware of any treatment. Nobody has told me there is any treatment apart from people saying prayers is also necessary so I should pray" (Agya, dialysis patient).

"I have only been told to keep on taking my drugs so I don't know of any other way to manage this problem. I am only praying that the drugs will bring this problem to an end" (Kwaku, non-dialysis patient).

There are limited treatment options for many patients with ESKD in Ghana. Kidney transplantation, the renal replacement therapy that is said to have a significant positive impact on patients' quality of life is not an option for many Ghanaian patients with ESKD due to costs and availability of kidney transplantation surgeons in the country. Currently, there is no trained personnel to carry perform the surgery independently in the country. A programme has been running for about five years which involves a kidney transplant team from the United Kingdom travelling to Ghana to perform the surgery for a few people who have been successful in getting suitable donors as well as raising money to pay the cost of about GHS 40,000 (about £13,300). However, some participants did not see kidney transplant surgery as a choice they would opt for. They questioned whether it was, financially, a prudent decision to opt for kidney transplant with its associated risks and possible outcomes including organ rejection and death during or after the surgery.

"What if……..you want to go ahead and do it [kidney transplant], at the moment they finish you die? What is the essence, what is the profit or the benefit? The money is wasted" (Kwasi, dialysis patient).

"It's [transplant] not like a one-off thing – you go for a loan, get it done and then that is it…there was this man, he died, I think two weeks or three weeks ago, he had the transplant twice or three times and still it didn't work, and he had to be on dialysis and then finally, he passed away" (Adwoa, dialysis patient).

Others were also concerned about how to raise the bulk sum required for a kidney transplant surgery as well as the probability of getting a suitable kidney donor. They had, therefore, resolved not to consider kidney transplant surgery as an option, emphasising that a decision to choose kidney transplantation should be taken studiously.

"Another decision should have been the transplant but can I get about 350 million (GHS 35,000 or about £10,000) to do the transplant, apart from even getting the donor? I don't have it so I don't think of going in for transplant" (Akua, dialysis patient).

"If we have money to do the dialysis, it's somehow better than the transplant because, for me, I've read a lot on transplant, to the extent that if the body can reject the organ….so, as a patient….you can make an informed decision yourself rather than just going straight and saying that I'm going to do transplant, it's something" (Obrempong, dialysis patient).

Peritoneal dialysis, another renal replacement therapy, is not an option for adult patients with ESKD although it is done for some paediatric patients with acute kidney injury in some hospitals in the country.

Another potential option is conservative management which focuses on symptomatic management to ensure a peaceful death. However, this was not seen or presented as a viable option for individuals with ESKD while some resisted suggestions to consider this option. Indeed, there are no structured systems to ensure that conservative management is done effectively in Ghana. It was noted that many patients stopped seeking care at the renal centre when the available treatment approaches seemed infeasible to them. In fact, no patient belonging to this group could be

identified and recruited from any of the three renal centres to be part of this study. These patients were reported to seek alternative forms of treatment such as using herbal medicine or going to spiritual centres – this will be explored further in the chapter on perspectives of clinicians. Moreover, conservative management has its own cultural and religious implications for many Ghanaians. The subject of death was not openly discussed and, once this was brought up, many patients and their families did everything possible to opt for another form of treatment so as to avoid death. Others also found it hard to believe that they have a terminal disease.

> *"But for me, I feel I will, everything is in God's hands so whatever, because some people are, they don't have this disease, they are strong but they still die. So if I, I have the disease that doesn't mean I will, I will die as they are saying. That's what I've been thinking" (Agya, dialysis patient).*

They ended up leaving the renal centre to other places where they would be promised a cure or opted for haemodialysis which appears to be the only realistic and 'affordable' option that has come to stay and is available to many patients with ESKD in the country. The reluctance to accept that death is imminent impedes the further advancement of conservative management in the country. It, therefore, seemed incongruous for the clinician to explain all other options when there is an assumption that the only viable and 'acceptable' approach is haemodialysis. The section on 'describing prevailing trends' in the next chapter explores this further.

A key issue that comes up when the subject of treatment is broached is the costs involved. The National Health Insurance Aut (NHIA) in the country does not provide coverage for its subscribers for the treatment of ESKD. Consequently, all patients with ESKD have to make out-of-pocket payment for dialysis, iron supplements, erythropoiesis stimulating agents (ESAs), and for kidney transplant once a suitable donor has been identified and the surgery is to take place. Statements such as *"we knew the cost was expensive", "it (treatment cost) kills people….financially",* and *"it (treatment) will cost you much money"* were common utterances of many of the patient participants. Treatment mostly starts only when an initial deposit has been paid, except in emergency cases. These are issues that individuals with ESKD in Ghana tend to deliberate on to decide whether to start treatment or not and on which treatment to choose. Participants

made choices based on the information they had acquired. Notwithstanding, key factors such as their health beliefs and practices, values, and existing support network were instrumental in the choices and decisions made. The subsequent section describes the kinds of choices made by participants and key factors that influence these choices as well as processes involved in the decision making. It emphasises that a belief that tomorrow will be better was the linchpin for initial patient decisions regarding treatment initiation for ESKD in Ghana.

5.4 Believing that Tomorrow will be Better: The Linchpin of Initial Patient Decisions

Critical among the decisions that individuals diagnosed with ESKD have to make are whether to initiate treatment or not and, if they choose to initiate treatment, what kind of treatment modality that should be. This category describes the phase where an individual diagnosed with ESKD actually makes decisions about their treatment with respect to information acquired through either of the sources described above. It focusses on reasons for which individuals with ESKD in Ghana initiate treatment, the type of treatment they choose, factors that reinforce that decision or lead to a modification of choices in the early stages of treatment initiation as well as whose decision it is for treatment to start in the first place. This category will be described under four key factors which have a significant influence on decisions that are made by individuals with ESKD in Ghana. The factors are personal attributes, finances, healthcare system as well as a support network. Figure 4 shows these factors and their key components.



Figure 4: Key Factors Influencing Patient Decision Making in ESKD in Ghana

5.4.1 Personal Attributes

Personal attributes refer to beliefs, values and experiences of individuals and how these influence the decisions they make regarding their treatment. It explores processes such as how an individual interprets and utilises acquired information to make decisions about their treatment at a personal level. The significance accorded to personal attributes in decision making in this study is based on the theory of symbolic interactionism which premises that actions of an individual do not directly result from social forces within a society, but a product of their interpretation of prevailing circumstances (Blumer, 2005, McCall and Becker, 1990).

The decision to initiate treatment after an accurate diagnosis of ESKD had been made had key personal influences for participants of this study. Indeed, patients with ESKD are likely to die within days or weeks without any form of renal replacement therapy. Key deliberations for an individual diagnosed with ESKD, therefore, are whether to choose survival by starting a renal replacement therapy or another approach that could ensure this or to choose conservative management which would focus on symptom management, or no therapy at all, until death occurs. Participants of this study had to draw on their values and beliefs to choose

whether to initiate treatment and to decide what kind of treatment that should be. Almost all participants maintained that their decision to start treatment was solely independent, knowing that their lives were at stake without dialysis, even when clinicians seemed to be suggesting otherwise.

> *"Then he [doctor] said 'oh, then when we are going to treat you it will cost you much money so it's better, the money that you will use for the treatment, it's better you go home and then use the money to look after your children.' So I was thinking 'ah, then does it mean I have to die because of money or what? So I told him no, I can look after myself so he should rather treat me" (Agya, dialysis patient).*

> *"I took the decision [to start haemodialysis]…. I convinced those closer to me to support me, like my cousin, I live with one of my cousins and my husband. I made them aware that this is my decision" (Abena, dialysis patient).*

Only one person explained that he has been making decisions about his treatment with his family but did not suggest that his views are not sought or that he is coerced into making some decisions against his values and beliefs.

> *"I have been taking decisions with my family" (Kantinka, dialysis patient).*

Clinicians alluded to this notion of decision making being very personal for patients with ESKD, although they explained that a decision to start haemodialysis always results from a dialogue between them, patients and, in many instances, their significant others. Once patient participants get to know the likely trajectory of ESKD, they mainly initiate treatment in order to preserve their lives. The ESKD population in Ghana comprises relatively younger people. The majority of the participants were below age 60 years and felt that they had not accomplished enough for their lives to be cut short. Thus, many participants chose to start treatment so as to avoid death at a younger age. How 'young' is defined was subjective. While others looked at their age in relation to the age range that people usually die in their families, others looked at it in terms of their lifetime accomplishments. The excerpts below are from some participants describing their views about their age and the need to avoid premature death:

"Initially, I knew there was no option, either I do it to survive or I die" (Obrempong, dialysis patient)

"I thought at age 65 [years], because in my family nobody had died at this young age, 65 [years], all people around 90 [years] going before they died. So I thought instead of going to sit in the house to die at 65, it's better I find money to do it. That's why I started it" (Agya, dialysis patient).

"All that I'm looking for is to get the money and go and do the transplant…..my age, I see it to be a burden, you know, if I was like 70, 60 [years], I don't care but 39 [years], this is the right time for me to enjoy life and this thing [ESKD] is disturbing me. It's a headache to me, you know. If you are 70 years, you know, you don't think like the way I will think, you know" (Kantinka, dialysis patient).

A key finding that is the crux of this category is that many participants initiated treatment with the belief that they were in for a short term therapy. Some participants attributed such expectations to inadequate information provision at the times when they were considering their treatment options. They claimed that their clinicians did not explain to them that haemodialysis is for a lifetime but gave them assurances that they would be better once they started the therapy.

"The doctor said once I have started the treatment, I'll, by all means, be cured. So I didn't know it was going to take a long time like this, I thought about 6 months I will be cured….yea, I felt within 6 months I have to be cured" (Agya, dialysis patient).

"I don't know the reason why he [the doctor] did not explain that to me. He said I should come and do the dialysis so that the swellings reduce. So I knew that when you come to dialysis for, let's say 10 times or 6 times, it will go. So I was coming here happy since I was going to be OK" (Barima, dialysis patient).

Another participant who was only having erythropoietin expressed his desire to get better so he would not have to continue spending money on treatment, suggesting a limited awareness of the likely trajectory of ESKD and the goals of treatment.

"If it [ESKD] goes away, then I can use my money for other things. But once I still have this disease, I will use all my money for treatment so I am only praying that the disease goes away so I can feel better" (Kwadwo, non-dialysis patient).

In effect, patient participants did not always understand the chronic nature of their disease as at the time of initiating treatment and had curative expectations. This seeming 'deception' by clinicians was explored further in the clinician interviews and their responses are noted in the next chapter.

However, this seeming deception did not exclusively lead individuals to believe that there will be a better tomorrow where their disease would be cured and the need for continuous treatment would be curtailed. It has been explained that many individuals with terminal diseases in Ghana are more likely to refuse conservative management or palliative care as a form of therapy. In fact, they usually have initial doubts about the terminal nature of their condition until their experiences show otherwise. Refusing suggestions of palliative care is partly due to a general belief that receiving biomedical care would preserve their lives and grant them an opportunity to experience supernatural healing or cure in due course. Patient participants mostly described initial ambivalence about the possibility of their lives being preserved without any form of treatment and started treatment with the hope that there could be positive prognosis for their disease in the future, including the possibility of having a therapy that could cure ESKD. Indeed, most of them were diagnosed at a stage where signs and symptoms of ESKD were prominent, making them to have experienced the life-threatening nature of the disease. They, thus, felt that starting treatment was a way of saving themselves for the moment while awaiting better potential outcomes in the future.

"What about if I decide to leave myself the way I was [without treatment] and then, possibly, something happens to me? I wouldn't know what nature or what God has for me, in store for me the following day or two. So I was just trying to save myself for the moment, believing that tomorrow will be better" (Owoahene, dialysis patient).

"I always say that there is a cure for it [ESKD] but we haven't discovered it yet because once this disease is there, there should be a cure" (Kwame, non-dialysis patient).

"I believe that for any illness that we have in this world, God has a way, God has created a way out of such situations and it is because of ignorance that we have not been able to get there. So I believe that there is some treatment outside dialysis which mankind may discover sooner or later, yea" (Wofa, dialysis patient).

Such expectations were also due to various disease causal beliefs – belief in faith healing or traditional medicine which promises a cure for almost all kinds of diseases. Proponents of traditional medicine believe that every human disease is curable, and the use of appropriate herbs aids in experiencing a cure. Moreover, it is believed that herbs are natural and are less likely to have any untoward effect on the consumer. Others believe that every disease has a spiritual origin and could only be cured when spiritual freedom is achieved. Such individuals were more likely to practice healer shopping by seeking spiritual healing through prayers and/or by consulting spiritualists.

"Some diseases are bought [spiritually] for you and the more you pray, although the disease would have been given to you already, the more you pray, the person can withdraw so that when you pray well God will help so that the sickness will go away" (Yaw, non-dialysis patient).

There were others who held on doggedly to biomedicine after being introduced to faith healing or traditional medicine and, as a result, faced opposition from their significant others in some instances regarding their choice. There appears to be a relationship between a person's educational background and their beliefs about causes and management of some diseases. It appears that people who have attained tertiary education tend to accept the tenets of biomedicine and tend to seek care from hospitals and other healthcare facilities even though they may have some beliefs in traditional medicine. It is thought that 'native' family members (those who have not attained formal education and mostly living in rural areas) are more likely to advocate for the use of traditional/herbal medicine. What is more, others felt that the society generally equates some of the key manifestations of ESKD without RRT, including ascites and pedal oedema, with being cursed or bewitched. This contributed to the suggestions of using non-biomedical approaches for the management of the disease.

"My native relatives, they are very native and they believe in herbs rather than modern medicine" (Abena, dialysis patient).

"Traditionally, our people also think that it [ESKD] is a curse, once you get it it's a curse….because I am elite, I have gone to school so even though they said it's a curse, I had read on the net (internet) a lot, when I had the condition, I decided to read about it, so I had a series of books and then I had a lot of information on the net" (Obrempong, dialysis patient).

However, this is not always the case as there seems to be several elite Ghanaians who advocate for the use of herbs. It was, therefore, not uncommon to come across patients who were utilising traditional medicine and/or seeking spiritual healing alongside biomedical care irrespective of their educational background or social status. For instance, 62-year old participant, Wofa, a civil servant who had been on dialysis for many years had this to say;

"Oh, I tried it [using herbal drugs] for some time, about 6 months. It wasn't too bad" (Wofa, dialysis patient).

And when he was asked whether he was still having haemodialysis within that period his response was:

"Yea, I was coming [for dialysis] and I was doing my test" (Wofa, dialysis patient).

Other participants also explained their reasons for using traditional medicine or seeking spiritual care concurrently with biomedical care.

"Well, we know our God, there is no disease or illness that He cannot cure and mine is not [an] exception….the medical situation that we have available cannot give me 100% treatment but God, I know God can, even transplant does not….solve all my problems, only some" (Owoahene, dialysis patient).

"Recently, a customer of mine insisted that I go to church with him….sometimes, you just want to try [going to pastors]. You are sick and you don't know whether you will get better there. Also, there are times when the doctors say that 'at this stage, all you can do is to pray'. So you get confused" (Yaw, non-dialysis patient).

Such beliefs kept many of them hopeful while raising money through various means for treatment as well as encouraging them to practice healer shopping by trying other approaches that aligned with their beliefs.

It is noteworthy, however, that not all the patient participants started treatment soon after being diagnosed with ESKD and being told about the available treatment options. There are those who, initially, did not believe facts about the disease as well as those who tried to avoid haemodialysis initially once they got to know what it involved, especially in terms of cost and duration of treatment, until they were 'forced' to start. In other words, such patients waited until their condition became more life-threatening before they started treatment. The excerpts below explain why some participants initially avoided haemodialysis:

> *"Because I was told that if you do it [haemodialysis] you will be on dialysis forever unless, maybe, you get a transplant….and even money too is a factor, I didn't have the money to do the dialysis" (Adwoa, dialysis patient).*

> *"You have to wait for a period of two months for the fistula to mature then you start [haemodialysis] but I added a few weeks. I thought that maybe when I come things will change. I came and did the labs…still, the condition was the same so I had to start [haemodialysis]" (Onua, dialysis patient).*

Clearly, patients with ESKD in Ghana choose one form of treatment or another based on their values and disease causal beliefs, their availability as well as their affordability. The ultimate decision to utilise biomedical or other forms of treatment mainly rested on the individual participant although a few explained that persistence from significant others made them yield to their desires on some occasions. The decision to start haemodialysis always resulted from a dialogue between clinicians, participants and/or their significant others. However, it is noteworthy that patients did not always seem to understand the chronic nature of the disease and some seemed to think dialysis would actually be a cure. One thing remained a constant bane to all individuals with ESKD that were on haemodialysis in Ghana – the costs involved. This has been presented in the next subsection.

5.4.2 Finances

It has been explained that individuals with ESKD in Ghana are required to make out-of-pocket payment for RRT. Thus, the financial stance of an individual or their significant others is instrumental in dialysis initiation and sustenance in Ghana. Evidently, participants of the study were content with their lives being preserved by haemodialysis and all its associated complications except for its costs, and this is a major factor that contributes to poor outcomes of ESKD and RRT in Ghana. The psychological trauma resulting from being diagnosed with a life-threatening condition is worsened by thoughts about how to raise money in order to settle accumulated debts as well as pay for treatment.

> *"The only problem I have now is the cost. I see many patients who, apart from the clinical issue, are tormented by finance, issues about finance. And I think the government will have to seriously look into that area" (Nana, dialysis patient).*

> *"It was basically about me financing it [dialysis]. Can you imagine, as a civil servant, how much do I earn? If I pay 450 Ghana Cedis (about £135) a week, not to talk about the other injections…how many patients can afford that? It's terrible and…sometimes you have the money, sometimes you don't" (Obrempong, dialysis patient).*

Thoughts about their lives being cut short should they run out of money to pay for their treatment is one of the most stressful experiences for individuals with ESKD in Ghana. At such moments, many of them are likely to criticise themselves for starting treatment in the first place. But thoughts about the inevitability of death, should they withdraw from haemodialysis, cause them to raise money somehow to continue their treatment.

> *"When it comes to a time when the money is very difficult to come by, then you hear some people saying 'I would have preferred death to this' but, even with that, they are still on the machine" (Akua, dialysis patient).*

Some patient participants of this study reported having to use their personal savings to start dialysis while others relied on donations from their significant others or loans to pay for their treatment. Some had to

sell off their property in order to continue having dialysis. This raises some issues of concern – will they sell off everything they have toiled for to finance their treatment? What happens once everything has been sold off? What is the stance of families towards such decisions? Individuals had to make personal decisions on how much of their property they could sell if they had any, how much of their savings they could use, or how much loan to acquire to fund their treatment when they had the means. Indeed, the financial stance of the individual with ESKD was influential in their role in decision making on treatment – being financially independent meant more power in the decision making while being financially dependent on others meant less power in decision making. A clinician also described the case of a patient who sold some of his property to start treatment in order to 'buy time' and prepare a will before dying. One participant explained that he would consider selling some of his properties and investing the money in a sinking fund to complement his monthly salary in order to pay for his treatment.

> *"What I will do is to sell some of them [property] and put it in a sinking fund that will run itself so monies will be generated from those investments to take care of it [treatment]…it's because I have those properties. What about an average person who is a mason, a farmer, sometimes when I look at some of these things, it's so hurting" (Obrempong, dialysis patient).*

As shown in Table 2, which provides details of renal care in Ghana, only a few patients with ESKD have the conventional three haemodialysis sessions in a week. This is because patients are mostly unable to afford the costs of three dialysis sessions each week. Moreover, if the primary goal of preserving their lives can be achieved with two sessions per week, then doing so will help save some money while enabling them to survive for a relatively longer period.

It would be anticipated that the cost of biomedical treatment for ESKD, haemodialysis being the commonest in the country, could drive some participants to seek alternative, relatively cheaper forms of treatment. Indeed, some participants made statements that seemed to confirm this.

> *"I couldn't afford (the cost of treatment) so I went to stay home and I tried that the creatinine level will come down" (Akua, dialysis patient).*

However, the cost of RRT did not exclusively drive people to seek other forms of treatment as individuals' values and beliefs about causes and management of some diseases had a key influence on their course of action, as has been explained above. For instance, family members of one respondent, Abena, introduced her to various herbal medicines with the belief that they will spend less, yet get a cure for her disease. She, however, did not follow their counsel because of her personal values and beliefs, and she had to do this tactfully to avoid conflict with her family members. Moreover, she could organise money by herself to fund her treatment without depending on her family members, and this gave her more power to make the final decision of using biomedicine.

> *"So I told them (family members), and I wish you were in my house to see the kind of herbal medicines that they brought,….they were all trying to save the situation because we knew the amount involved in coming for dialysis – it's really expensive….so we were trying to prevent me coming here to spend this amount of money" (Abena, dialysis patient).*

A decision to start haemodialysis or other biomedical treatment approaches, in light of all that have been described above, begs further questions. Does the healthcare system produce a congenial atmosphere to support patient decision making on treatment in ESKD? Do patients get any form of support when required? Do they always feel right about their decisions? Do they easily adapt to their treatment choice and its demands on their lives? These were explored and have been presented in subsequent sections.

5.4.3 Healthcare System

The healthcare system exerts its influence on patient decision making in ESKD through its structures such as availability of various modalities as well as accessibility to renal services. Existing healthcare policies and practices also has a bearing on decisions that the citizenry makes before and during treatment for ESKD. Although policies have been formulated and being implemented to address the increasing menace of chronic diseases in Ghana, these have not been directed at addressing ESKD such as promoting early detection of the disease and enhancing access to RRT. The subsection on 'being diagnosed with ESKD' highlighted some issues with the healthcare system in Ghana which resulted in patients being

diagnosed late. It has been explained that some participants felt that non-existence of regular monitoring meant they did not know much about ESKD as a potential complication of chronic conditions they were being managed for.

In addition, accessibility to renal services is low due to the lower numbers of renal centres as well as renal specialists in the country. It has been explained that all renal centres in the country are located within three out of the ten administrative regions of the country, leading to geographical inaccessibility for those outside these three administrative regions. In fact, the realistic options are either relocating to a region with a renal centre or travelling from a region without a renal centre to a region with a renal centre for renal services each time they are required. However, these are not always practical considering how many times dialysis patients, for instance, have to frequent a renal centre for sessions each month. Relocating to another region also comes with its own challenges, including losing employment for those who are not self-employed.

> *"Since I'm working I can't have that time coming every three times in a week, from [Eastern Region] to this place [Greater Accra Region]. It will be a bit hectic…I don't know which work they will give me that excuse duty to be coming for treatment three times in a week, three days off, no. It's not possible" (Akonta, non-dialysis patient).*

Financial accessibility is another issue. As has been explained earlier, the existing National Health Insurance Scheme does not cover costs of chronic haemodialysis or any other form of renal replacement therapy and its associated therapies such as erythropoietin stimulating agents. This implies that individuals have to make out-of-pocket payment at the point of service for dialysis, and this tends to have a degree of influence on their decision making, as has been explained in the previous subsection. Another key influence on the decision making of the Ghanaian patient with ESKD on treatment is in relation to the available modalities. Haemodialysis is the only modality that individuals with ESKD in Ghana can access almost at any time it is needed so long as they can pay for it. All other RRT modalities are either non-existent or are restricted, in terms of availability, to the average Ghanaian patient with ESKD. Some participants were in the position to pay for kidney transplant surgeries but could not go ahead with the procedure because of unavailability of trained kidney transplant

surgeons in the country or difficulties in getting suitable donors. Some had gone to the extent of travelling abroad with the hope of getting donors and surgeons to carry out this procedure. Some participants explained that they know some patients with ESKD who travelled abroad for successful kidney transplant surgeries. However, attempts by other patients with ESKD to have kidney transplant surgeries abroad proved futile. One participant, Obrempong, after hearing from other patients that it was easier to get donors and a transplant done in India so long as one could afford the costs, travelled there and had this to say:

> *"Even though I had the money I couldn't get any [donor] so I said, ah, so all the information I had was quite false....then I went to the Ministry of Health there....they told me that it used to be [but] people were killing other people just for the kidney and people were, it's like, out of poverty, were selling their kidneys for survival. But now they have passed a law, there is nothing of that sort anymore" (Obrempong, dialysis patient).*

The pluralistic nature of healthcare delivery in Ghana also implies that individuals with ESKD may choose to seek healthcare through avenues other than biomedicine. Some patient participants described how they had used complementary and alternative medicine in the course of their disease trajectory, even alongside renal replacement therapy. Meanwhile, there are no data supporting the effectiveness of these other approaches in managing ESKD. Thus, while the individual diagnosed with ESKD in Ghana believes that there is a better tomorrow while making decisions about their treatment, the healthcare system does not always present a congenial atmosphere that would lessen the stresses associated with the decision making process.

5.4.4 Support Network

This subcategory describes all forms of assistance rendered to an individual while having to live with a chronic condition. Support rendered to individuals with chronic diseases may be in terms of accessing healthcare, getting drugs and other forms of treatment, meeting financial demands, and adjusting to a new life.

Patients who are diagnosed with ESKD in Ghana face enormous challenges, especially within the initial period after diagnosis as some

participants reported not knowing anything about ESKD or its management before their diagnosis. Thus, as has been explained earlier, many participants started with significant information needs. Participants needed to be educated on possible causes of their condition so as to clear myths or misconceptions that could deter them from following an appropriate course of action. They also needed to be educated on the likely trajectory of their disease as well as the various forms of treatment available to them in order for them to fully comprehend what to expect. The role of clinicians as educators was, therefore, paramount in supporting patients to address their informational needs. Clinicians fulfilled this role either by being the direct source of information for these patients or by directing them to other reliable sources such as books or websites. One non-dialysis participant reported that they benefit from group teachings that are carried out before they are seen by a doctor each time they come to the renal centre.

> *"We come here every month....each time we come here they educate us about so many things including our diet…I feel that it is good they educate us when we come here" (Yaw, non-dialysis patient).*

Although clinicians supported participants in their decision making by providing them with information on issues regarding ESKD, some participants felt this kind of support was inadequate. For instance, one participant, Adwoa, explained that she had to acquire information about ESKD from her doctor friends from outside her renal centre. Another participant, Kantinka, explained that he read economics and law but not medicine and was ready to do whatever his clinicians told him. However, he felt that information provision was inadequate for patients at the renal centre and his efforts to get more information had negatively influenced his relationship with some clinicians.

> *"The way our system is, medical care, people don't know much, and when you ask too many questions they say you are too known [proud], but you are not. Sometimes you have to say something else you will die just like that" (Kantinka, dialysis patient).*

The timing of information provision is critical as there are times that giving information may not produce its desired goals owing to patients' psychological and physical state. Some participants explained that they

may have been too ill or confused to be educated on ESKD or had difficulty remembering the things they were told when they presented at the unit.

> *"I was crying a lot at that time so I would not have even listened to them" (Eno, dialysis patient).*

Participants described other forms of support they were getting from clinicians apart from looking up to them as health educators. The diagnosis of ESKD, details about its likely trajectory as well as management approaches caused emotional and psychological trauma for almost all participants. Participants reacted differently to this news; while some denied it initially, others cried and were uncertain about their future. Consequently, while patients were under their care, clinicians provided some form of emotional and psychological support for these patients and this was noted by some of the patient participants.

> *"I think the nurses here have been wonderful. They, sometimes, we the patients, we annoy them but they still care for us…they've played a big role. When I came here they also sat me down. I told you I broke down in this room, I cried. But they explained to me that 'it's not anything that you should be afraid of. It has come already so the best thing you can do is protect yourself, do the right thing, you'll live longer'. So they spoke to me and they calmed me down a little bit" (Abena, dialysis patient).*

Besides this, clinicians also provided some form of social support for these patients while, occasionally, some clinicians even had to provide financial support for some patients in paying for their treatment.

> *"They [clinicians] will talk to you, they will call you over the weekends, any complications, any this and, it's so nice, yea. Sometimes when they are having parties and other things they invite you to come to socialise and, it's so fun" (Obrempong, dialysis patient).*

> *"You know some of the nurses they use their money to pay for the patients, like it comes like emergency and the person doesn't have money, they do it for the person and they pay themselves, out of humanity" (Abena, dialysis patient).*

An additional form of support that participants needed is that from their family (both nuclear and extended) and friends. Having to live with a chronic condition implies that there may be the need to frequent a health facility, modify routine activities, and to depend partially or totally on others as a result of debilitation. Although several occasional visits to health facilities remain integral to the successful management of such conditions, most of the work will be done in the homes or work environments of these patients and, thus, a good support from family members and friends is essential. More particularly, patients with ESKD on conventional haemodialysis visit the dialysis unit twice or thrice each week and spend about four hours during each visit. These patients may need somebody to help them in their transportation to and from the dialysis unit and, usually, this will be a friend or a family member. One respondent had this to say:

> *"Oh, you don't want to be alone, when you have problems, and my family they are there" (Kantinka, dialysis patient).*

Family support was also in the form of money and other resources. Many participants had to make out-of-pocket payments for each haemodialysis session as well as other associated therapies such as iron supplements and erythropoiesis stimulating agents (ESAs). These costs were usually too much for just one person to bear without any external financial support.

> *"If anything, we [patient and family] sit down and plan because one person cannot take the financial burden so it's split and they all understand that this is the situation and I need help so they help because it's, that's how we go through day by day" (Kantinka, dialysis patient).*

> *"I, personally, can't afford that; I am counting on my cousin because she can help. I depend also on my parents…if I have to make any payments then I will have to rely on my family" (Kwame, non-dialysis patient).*

Thus, family and friends, in some cases, made financial contributions towards the cost of treatment. They demonstrated commitment towards ensuring that their relative or friend got the best treatment available to them. Others donated blood or organ to support treatment.

"Even before they started the treatment, I had to take blood, people supported me, I had to call family members to come and donate blood, I took blood about 20 [units] so I knew if I had not taken this treatment, maybe I'll, I will have died a long time" (Agya, dialysis patient).

"And luckily, my donor was a very young person, my niece, who was physically fit, in her late 20s and she didn't have any other medical problem so it was quite OK" (Papa, transplant patient).

"Well, it was not so difficult [getting a donor] because it is my brother that is giving me" (Owoahene, dialysis patient).

But not all respondents got this kind of support from their families as one elaborates in the excerpt below:

"And can you imagine the painful aspect it is, somebody you've been caring [for], you've loved, you've taken care of, when you get to the hard times like this [being diagnosed with ESKD], they just left and, therefore, you are seen as, it's really a thorn on you, I tell you, when your immediate family rejects you and somebody that you think is so closer, was enjoying everything when you were OK, within a short time that you are [ill], they find excuses here and there and, finally, they just leave. So then you become alone, that is the position and the challenges that go with it" (Obrempong, dialysis patient).

Support, sometimes, came from the community or society within which the participant lives or from their employers to complement that of the family in meeting the financial needs of the patient.

"So it became very difficult [after the demise of husband] but by God's grace, I informed my church and they started paying 5million (GHS 500 or about £150) every month, then the Reverend Minister also decided to help me with 5million (GHS 500 or about £150). So I have to add the rest" (Akua, dialysis patient).

"My husband went to see his bosses at the office and talked to them that this is the problem that he has so they said if I make any payment I should bring the receipt and they will reimburse me, so that's how come I've been paying" (Adwoa, dialysis patient).

"The doctor told me that dialysis is expensive…so my brother informed people within the neighbourhood and they have been giving me some money to show their support. Also, parents of the kids I teach as part-time give me some money from time to time. That helped us to raise money" (Barima, dialysis patient).

Participants also described a support network that exists within the renal centres among patients with ESKD. This support ranged from sharing information and ideas to, sometimes, having to support other patients in paying for the cost of their treatment.

"I talk to them [other patients with ESKD], sit with them, I explain things to them. In fact, I even support a few of them if they are acutely financially distressed, I don't mind supporting them for one or two dialysis sessions" (Nana, dialysis patient).

Yet, there seems to be one form of support that almost all participants were looking out for – support from the government or the National Health Insurance Authority (NHIA). Almost all respondents were advocating for the NHIA to provide coverage for its subscribers with ESKD and that any degree of support would be greatly appreciated. What is more, some participants suggested that if coverage implies the payment of a relatively higher NHIS premium, they will be more than willing to pay while others suggested the creation of a special tax system to support treatment of patients with ESKD in the country. They believed these would address the cost barrier that deters many patients with ESKD from accessing renal replacement therapy for the management of their disease.

"When you [NHIA] can go and take a third or a half or two-thirds of the cost I'm sure they [patients with ESKD] will be grateful for whatever help they are given" (Nana, dialysis patient).

"The government should also see it as a problem, this is a social menace that needs to be resolved, or that needs to be rectified. So, if there could be some tax, some form of tax such that those taxes could be used to supplement the cost, then a lot more people will access the treatment" (Obrempong, dialysis patient).

Participants explained that the various forms of support described in this subsection, if present at all times, would enhance effective management of

ESKD. The next section presents the final category in the ESKD patient journey and decision making stages in the Ghanaian setting.

5.5 Confronting Reality: Adjusting to New Life

Individuals diagnosed with ESKD go through different phases, as has been elaborated above, and have to make several adjustments in their life to accommodate the changes that come with their illness. This section on 'confronting reality: adjusting to new life' explores various challenges that the diagnosis of ESKD and its treatment pose to patients and the approaches that are usually used to adapt to this new life. It also explores how the individual's experiences with the realities of living with and managing ESKD inform a gradual shift of their health expectations over time.

ESKD eventually debilitates the patient if treatment is not started promptly, thereby making them less productive. The first reality that many individuals that have been diagnosed with ESKD have to face is that their condition may prevent them from actively engaging in many forms of activities including those associated with their work life and daily living.

> *"It [ESKD] has actually affected me, it got to a time I couldn't go to work because of the oedema. Actually, it's not a good disease to have and be working with it. It's horrible and I wouldn't wish anybody should go through such thing" (Akonta, non-dialysis patient).*

This was especially common as many of the participants were diagnosed when their disease had advanced and symptoms were quite bad. Almost all participants of this study described diverse symptoms that reduced their functional abilities before they were diagnosed. Others had noticed improvements in their functional abilities after initiating treatment while others were still experiencing these symptoms at the time of data collection.

> *"If you had seen me before [starting haemodialysis], I couldn't even walk here [renal centre] without standing on the way like 10 times. I easily got tired, you feel like the whole world is on you….it was really difficult for me at that time" (Abena, dialysis patient).*

"I get tired easily, even from walking, so I can't work as I used to" (Kofi, non-dialysis patient).

"I was unable to do anything. I was tired when I was walking, even, everything" (Barima, dialysis patient)

What is more, those who had started conventional, in-centre haemodialysis had to frequent the renal centre twice or thrice weekly, based on their financial capabilities, having to spend an average of 4 hours on the haemodialysis machine per each visit. This put many of them at risk of losing their jobs and some ended up losing them or quitting unless they were self-employed.

"Actually, I don't work for the moment sake of this sickness but I have been doing this, selling something to keep me going" (Kwasi, dialysis patient).

"Because I have to come [to renal centre] every month I don't want to [work] because I, mostly, have to travel abroad. I am afraid I might not be able to return within a month so I have decided to stay home and take care of myself before I resume work" (Kwaku, non-dialysis patient).

"This country what kind of job, unless you have your own private store, you know, there's no job that is going to hire somebody who has to go the hospital, twice, two, three times a week. So here it's the way the system is and having the chronic ailment like this one is not a joke" (Kantinka, dialysis patient).

Others were fortunate to have their work schedules made more flexible for them by their superiors and/or employers so they could have time for their treatment sessions. Others also worked around their schedules with the respective renal centres in order to have their sessions before or after their regular working hours.

I have two [dialysis sessions each week]. Because I don't want to miss [work], I come on Sundays…I come here [renal centre] on Wednesdays…he [supervisor] allows me" (Adwoa, dialysis patient).

"I used to come here [renal centre] around 3:30 in the morning and the nurses were so kind to us, they will hook us on the

machine around 3:30 so by 8:00 you finish. I even got to work earlier" (Wofa, dialysis patient).

Nana, a part-time worker chose to work on days that he did not have a dialysis session so as to balance the two.

"I've arranged it in such a way that I have my [dialysis] sessions on Mondays, Wednesdays and Fridays and I [work on] Tuesdays and Thursdays so I have a full week and I have the weekend to rest" (Nana, dialysis patient).

The social life of many participants was affected somehow as some of them had to avoid some social gatherings because they had to spend more time in the renal centres.

"Sometimes I don't go to church because I have to come [for haemodialysis] on Sundays….and then, sometimes, you have to go to other social gatherings, a family member is dead, you should be there. But because I'm not too strong like I used to be, sometimes, I don't go" (Adwoa, dialysis patient).

"I go back home [after haemodialysis on Fridays], I'm very tired. I don't even get to see my kids because, by the time I get home, they are all asleep. Saturday, they want to go out with me but I'm tired, I can't go. I have to sleep so it's, sort of, it's preventing me from living my normal life" (Abena, dialysis patient).

The challenges do not end there as individuals, especially those who had started haemodialysis, had to modify their lifestyle, including food and fluid intake. Many found these food and fluid restrictions very difficult initially but made commitments to adhere to them in order to achieve goals of their clinical management.

"Me, I don't drink no more, all the things I was doing I don't do it no more, I know how to control the things because this is management. When you have this problem, you have to manage yourself. If you don't do it, you are gonna end up dying, yea. I try to manage, so many things…no drinking, no smoking, so many things I like, I have to put a stop" (Kantinka, dialysis patient).

"But when you come, you start dialysis, they will tell you, you are supposed to drink [water] the medium size [750mls], one a

day…..so, the water, it's good to sip, you are not supposed to drink but to sip. How can you sip water? It's not a mineral [soft drink], it's not anything, it's just water to drink but, as time goes on, you learn how to do all these things. That is all. I tell you, it's not easy" (Kwasi, dialysis patient).

There are still other challenges that are experienced exclusively by individuals who are on haemodialysis albeit in different forms and intensities. Apart from having to virtually remain in one position for about four hours, others experienced pain and cramps during or after their haemodialysis sessions. Others also had issues with their access types and blood pressure.

"Sometimes you will be on the machine and cramps, cramps will catch you. You can't do anything. You are on the machine, when you try to get up, the needles will come out and your blood will just flow out and you can die. If the cramps come, you have to put your legs down. Sometimes, your BP can fall. So many things and, if you are lucky, you will survive if you are OK" (Kwasi, dialysis patient).

"Things like having cramps when you are on the machine and, er, I have a fistula done and, at night, I can't stand it. The pain….it feels like my hand is, there's a major blood pump which causes your hand to, it freezes, your hand freezes. You can't do anything with it, it will just be pumping like that….sometimes too when you finish, you itch all over your body, I wonder what causes that. But I think it's individual because some people finish and they are in perfect shape, they can go home" (Abena, dialysis patient).

In handling some of these inherent challenges, some participants reported that they had to monitor their bodily responses to some of the changes that they noticed and identify ways to adapt to them. The ways of adapting varied and, at times, some patients discussed what worked best for them with other patients in the renal centre in order to help them employ similar approaches in managing themselves.

"Once I got to know that [BP fluctuation], if the BP is down, I will be off so, nowadays, what I do is, when I'm on the machine, I don't remove the cuff. I press the BP and then check if it is up, then I go down. If it is down, it has fallen down, I have to raise my

head. If it is up, I have to low my bed. So you can see that" (Akua, dialysis patient).

Decision making about ESKD treatment is not a one-off event as individuals had to review their choice of continuing treatment or withdrawing from it, and adhering to lifestyle modification guidelines on a daily basis and between sessions.

"You see other colleagues who are normal [do not have ESKD], they drink a whole lot of water. Sometimes you become so thirsty you'll have to drink but you have to, then your mind will just prick you, 'hey my friend, what are you trying to do to yourself? Just take a little'" (Obrempong, dialysis patient)

In the face of some of these changes resulting from the disease and the challenges, participants usually motivated themselves by reconsidering factors that made them opt for treatment in the first place. A striking finding among participants despite these challenges, however, was how they had changed their initial perspectives and expectations regarding chronic disease and its management. They had moved from overt expectations of cure to managing their condition in the long term. Increased awareness of the terminal nature of ESKD resulted in participants now managing their disease for survival instead of expecting a cure. In fact, most of them had fully accepted the diagnosis and were ready to adhere to guidelines given to them in the renal centre for their survival and to prevent worsening their circumstances by not using other forms of treatment.

"I think I have come to accept the disease and I'm just managing it to survive; that is it" (Obrempong, dialysis patient).

"I don't want to go for any other alternative medicine and, later, develop a problem that's even worse than what I am in already so we decided to go for the dialysis" (Abena, dialysis patient).

Thus, changing perspectives and attitudes in the course of their treatment was commonplace among patient participants. Although they mostly did not comprehend the life-threatening nature of ESKD and RRT as a lifelong therapy around the time of initiating treatment, most patient participants learnt to reorient their expectations about the trajectory of the disease as

well as its management with time. They had learnt to love what they did for survival even though that included handling a lot of challenges.

> *"Then anytime having to come and waste a lot of time here [renal centre] is also another thing [challenge] but you have to love it otherwise, you have to love what you do to survive you. You should just psyche yourself up and you need to do it. So I don't allow the time constraints and those things to, as it were, discourage me" (Obrempong, dialysis patient)*

It has been explained that most of the participants initiated treatment with the goal of preserving their lives while believing that there will be a better tomorrow if they are sustained by haemodialysis. Thus, it was not unusual to find that many patients were content with the outcomes of care irrespective of the challenges they had to face on a daily basis. They were still on course to achieving their primary goal of preserving their lives. Some believed that God had allowed them to survive for a reason and that when the time for them to die is due, no intervention in any form would save them. They thus attributed their survival to the grace of God and hoped that they could continue treatment for as long as possible.

> *"Once I'm alive, in fact, even though sometimes you will be prompted to think of what has happened to you but, because of the grace of God, and as I'm alive, I think I appreciate it because, sometimes, you come and then you are informed [that someone] is dead, a lot of people are dying on the machine…but once I'm alive, I appreciate the work of God" (Akua, dialysis patient).*

Others also derived their motivation to continue treatment from comparing their current state of health to how they felt before starting treatment or to other patients. The improvements that they noticed served to spur them to continue treatment and to believe that whatever approaches they had been implementing so far was working for them.

> *"Oh, at least, it's [haemodialysis] made me go and come because initially, I couldn't do anything, I couldn't eat, when you put food in your mouth you vomit, you don't feel fine. But now, if I don't tell you I'm on dialysis, I'm sure you wouldn't know so I just want to thank God for that, that I'm able to, I still go to work" (Adwoa, dialysis patient).*

"But you just have to encourage yourself and then move on. There are people who are amputated, who have diabetes and their legs are amputated, they are moving on. And if there is a means of you surviving on the machine, then it is not a problem" (Obrempong, dialysis patient).

In conclusion, having to live with and manage ESKD is full of challenges, including those that are peculiar to patients in the Ghanaian context, and requires several forms of sacrifices and commitments. Many of the participants seemed to have accepted many of their daily challenges as 'normal'. This is mainly because of their ultimate goal of preserving their lives. This motivated several of the patient participants to utilise diverse approaches to adapt to this new life.

5.6 The ESKD Patient Journey

This section will now explain the ESKD patient journey, which is shown in Figure 5. The patient journey begins when an individual starts noticing symptoms which, eventually, lead to a confirmed diagnosis of ESKD. The first category of 'from symptoms to certainty: reaching a confirmed diagnosis of ESKD' details the processes involved in the patient journey where individuals move from noticing signs and symptoms and not knowing what these mean to the point where a confirmed diagnosis of ESKD is made. Many individuals, at this stage, may not know much about non-communicable diseases or ESKD as a complication of other chronic diseases like diabetes mellitus and hypertension. A few individuals may have heard about ESKD may not be aware of the burden associated with the disease. Decisions at this phase centre on actions that are taken and/or avoided in order to ascertain possible causes of changes that individuals notice in their usual state of health.

Individuals then progress to the second category of 'deliberation or procrastination: ascertaining the likely trajectory of ESKD'. The three subcategories of this category are not shown in the conceptual map in Figure 5. Instead, the conceptual map shows that an individual procrastinates or deliberates on their next course of action. Individuals, now aware of their limited information about ESKD, obtain information about the disease through a variety of sources. However, information that is obtained during this time is mostly inadequate to inform patient decision making even though decisions about treatment are still made. One thing

that is evident at this stage is ESKD patients' uncertainty about the likely trajectory of the disease, including its potentially life-threatening nature. Many patients with ESKD carry this ambivalence to the next category of 'believing that tomorrow will be better: the linchpin of initial patient decisions'. They, therefore, move back and forth between these two categories. 'Believing that tomorrow will be better: the linchpin of initial patient decisions' category describes the rationale for which individuals with ESKD initiate treatment in Ghana and what forms of treatment these may be. They may follow one of two courses – haemodialysis or other treatment – which may lead them to a common point in the journey, the 'confronting reality: adjusting to new life' category. The course taken by each individual at this stage is influenced by four key factors comprising personal attributes, support network, healthcare system, and finances. Individuals mostly make initial decisions about treatment guided mainly by the belief that things could be better and not giving up hope. This belief motivates the Ghanaian patient with ESKD to try out various options until they identify an option that would enhance their health status or accept that not much can be done about their disease. Thus, at this stage, they may end up using their lifetime savings or selling some personal property, in some instances, and/or getting financial support from others in order to initiate and sustain treatment.

However, these expectations are modified with time because of their experiences of realities of managing ESKD with haemodialysis, moving to the fourth category of 'confronting realities: adjusting to new life'. Individuals at this stage would have come to appreciate the terminal nature of ESKD and would just be managing it to survive although occasional movement to the previous category of believing that tomorrow will be better and hoping for a more positive outcome may be observed.

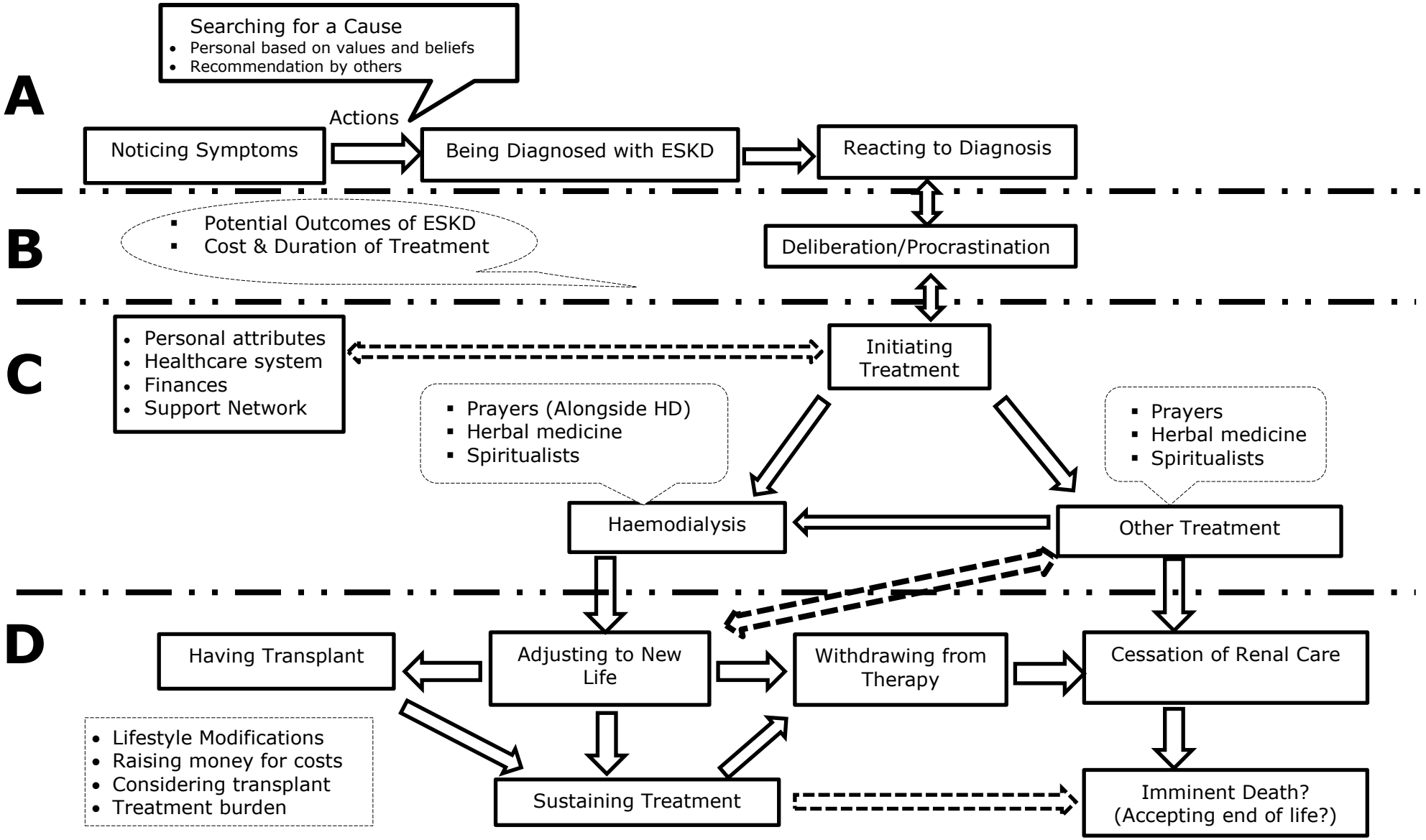


Figure 5: Conceptual Map Showing ESKD Patient Journey and Decision Making Stages: **A** – From Symptoms to Certainty: Reaching a Confirmed Diagnosis of ESKD; **B** – Deliberation or procrastination: ascertaining the likely trajectory of ESKD; **C** – Believing that tomorrow will be better: the linchpin of initial patient decisions; **D** – Confronting reality: adjusting to new life.

5.7 Summary of Chapter

A key finding from the patient interviews that has been presented in this chapter is that they undergo a journey which starts when they first notice changes in their usual state of health that lead to a confirmed diagnosis of ESKD. The journey is represented in a conceptual map (Figure 5 page 144) and this chapter has explained that map, detailing the key phases (categories) in this patient journey. The key processes involved in this patient journey comprise reaching a confirmed diagnosis of ESKD after experiencing a range of symptoms, acquiring and managing information about ESKD and its management, making various choices with a primary objective of preserving their lives and a belief that 'tomorrow' will be better, and confronting the realities of living with a potentially life-threatening condition and making several sacrifices to adjust to this new life. Various factors which are influential to this patient journey and decision making have also been described. Although a belief that tomorrow will be better mostly motivated individuals to start treatment, evidence from this chapter also shows that some patients did not understand the nature of ESKD and RRT when making decisions about their treatment.

The next chapter will present findings from clinician interviews.

CHAPTER 6. FEELING HELPLESS: PERSPECTIVES OF THE ESKD CLINICIAN

6.1 Introduction to the Chapter

In line with the principles of theoretical sampling in grounded theory, a sample of clinicians were interviewed to explore their perspectives on emerging categories identified from analysis of the patient interviews and to gain a deeper understanding of issues that confront patients with ESKD as well as the context of managing the disease. The purpose of this chapter is to present data from the clinician interviews and show how these corroborated patients' perspectives in many ways.

'Feeling helpless' describes clinicians' general feelings and dispositions towards the care of and experiences with individuals with ESKD in Ghana, and is the overarching category that was identified from the clinicians' interviews. The category has two key subcategories, which are 'describing prevailing trends' and 'rendering support'. A general feeling of helplessness was easily identifiable in clinicians' descriptions of the prevailing trends of ESKD and its management in Ghana as well as in the kinds of support they rendered to patients. The 'describing prevailing trends' subcategory presents clinicians' views on vital issues pertaining to ESKD management in Ghana while the 'rendering support' category expounds the 'getting support' subcategory from the patient participants' data and the kinds of support clinicians give to patients with ESKD in their respective renal centres. The two subcategories from the clinician interviews are described below, with a summary of how each of these contributes to the overarching category provided at the end of each subcategory.

6.2 Describing Prevailing Trends

This subcategory centres on clinicians' descriptions of various facets of ESKD care in Ghana and comprises three key components – *'describing causes', 'describing barriers' and 'describing routine care and outcomes'.* The subsequent subsections describe each of these components respectively.

6.2.1 Describing Causes

Some trends such as increasing prevalence of ESKD, delays in diagnosing ESKD as well as non-adherence to therapy were revealed through the interviews with patient participants. This component describes clinicians' perspectives on various factors that account for these trends as reported by the numerous patients they have interacted with in their years of practice and through their own unique experiences.

Ten patient participants attributed their ESKD to hypertension only while one attributed it to diabetes mellitus only. Another patient participant mentioned both diabetes mellitus and hypertension as probable causes of his ESKD. Two clinicians had these to say when asked about leading causes of increasing prevalence of ESKD in Ghana from their perspective;

> *"Most of the patients that come have a history of hypertension or diabetes" (Maame, nurse).*

> *"I think, in Ghana, recently some studies have been done, and it looks like hypertension and diabetes and then glomerulonephritis [are the leading causes of ESKD], the pattern has not really changed" (Ohemaa, medical doctor).*

Many persons with these precursor chronic conditions do not report to an appropriate clinic for effective management. Others register and attend hypertension or diabetes clinics for the management of these precursor conditions but do not adhere to prescribed regimen, making them more at risk of developing ESKD as a complication. These were inferred from comments from one of the clinicians.

> *"Some [patients] too don't attend the BP [hypertension] or diabetes clinic....we had a patient who said he was a diabetic for a long time, he was attending diabetes clinic [but] when he came in he told us 'I never restricted my diet, I ate everything I was told [not to], and that's how come I landed here, I caused it, I was advised by the nurses but I never listened', he has been saying this most often. He has been saying…that's how he became a CKD patient. So it's mostly they don't want to take their drugs or they default in taking their drugs" (Awuraa, nurse).*

The increasing prevalence of ESKD was also partly attributed to the widespread use of non-biomedical approaches to managing hypertension and diabetes as well as many other diseases that Ghanaians suffer from, thereby possibly exacerbating pre-existing minor kidney problems.

> *"Some [patients] too, as I said, they use herbal concoctions [medicines] at home. If they have the BPs [hypertension]….they use herbal concoctions [medicines] at home so when they come they get worse" (Awuraa, nurse).*

> *"Some [individuals] may resort to other herbal medicines, OK. I'm not saying herbal medicine is bad but then, for us, most of the drugs are excreted by the kidney. So….when the kidney is not working well and you put in other toxic things, you will not be able to remove it then they will build up in the system and cause more damage" (Ohemaa, medical doctor).*

The second part of this subcategory describes causes of observed delays in diagnosing patients with ESKD. The patient interviews revealed that many of the participants were diagnosed in later stages, in very critical states. This was corroborated by comments from clinicians.

> *"I can say more than, about 90% of the patients we see. Most of our patients come in just end stage" (Ohemaa, medical doctor)*

> *"Most of the time, they come in a bad [critical] state….they come with pulmonary oedema, they come with hyperkalaemia, they come with, some of them, they are in uraemic state, their urea is high, their creatinine is high, their potassium levels are way higher" (Maame, nurse).*

In addition, analysis of the patient interviews showed a common trend for many of the patients with ESKD – they were going about their usual life routines when they started noticing some symptoms. They started searching for a cause of these symptoms and this search was greatly influenced by their values, beliefs and/or recommendation by others, mainly family and friends. The search for a cause took some of them to nearby hospitals while others sought non-biomedical care. Not all health facilities are well equipped with human and material resources in Ghana. Thus, individuals getting care from some of these poorly resourced health facilities were not always accurately diagnosed. This contributed

significantly to the delays in being accurately diagnosed with ESKD. One medical doctor expressed her opinion on what contributes to patients being diagnosed in the late stages of the disease which summed up the above trend.

> *"One thing is the disease….it will be with you for a long while and all you'll be feeling, it's like, you are not sick but you are not feeling well kind of, maybe just some bad appetite, you will treat yourself as malaria on and off or, if you don't go to proper hospital, they will just be giving you antimalarial and typhoid, that kind of diagnosis. So, sometimes people will treat themselves for malaria and typhoid and then, one day they will just collapse or one day somebody will take the trouble to measure their BP or one day somebody will just check their blood level and know that the blood level is very low, then another person may also take the trouble to check for the kidneys so that's how come" (Ohemaa, medical doctor).*

While searching for a cause, many a Ghanaian patient tends to attribute their symptoms or disease to witchcraft or curse. Clinicians made comments about such observations and some of them have been presented below:

> *"….about 90% of them [patients with ESKD], even educated ones think they've been bewitched or they've been cursed….they think it's not ordinary to have the condition. Even if you try to explain to them that you've had diabetes for a long time, you've had hypertension for a long time and that's what has led you to this [ESKD], they don't want to believe you...Most of them, they think either it's from their workplace that somebody has, I mean I don't know, cursed them or their relatives have bewitched them" (Awuraa, nurse).*

> *"There was one client too who also said, actually, he stayed in Germany, and then came down to Ghana. Then when his kidney shut down, according to him, he told me personally and told most of the staff in the unit that the family thought it was the wife who had then cursed him" (Owura, nurse).*

These beliefs about causality were largely attributed to lack of awareness of ESKD, its causes, manifestations as well as management. Ascites, pedal oedema and generalised oedema, which are all late presentations of ESKD without RRT, are among the signs that, when an individual exhibits in Ghana, are more likely to be interpreted as signs that they have been cursed or bewitched. Many individuals with such signs were, therefore, more likely to consider the possibility of being cursed or bewitched than having ESKD. When asked about why many people tend to attribute ESKD to curses, one nurse had this to say:

> *"I think it is lack of awareness because most of their beliefs [are] not scientific based….so, if they don't have the scientific basis and idea and understanding, what the forefathers or what they used to believe is still persisting because they saw all those signs and symptoms when they referred to these people as being cursed. So it's there and, you know, the society, people easily pick grudges, people become angry and they just say all sorts of things, like curses here and there, and if the kidney fails, the people don't look up to anywhere than to say that he's been cursed" (Owura, nurse).*

Such beliefs about disease causality greatly influence patients and/or their family on further actions to take in order to remedy the situation. They, mostly, resort to non-biomedical approaches such as going to prayer camps or other spiritualists in order to get relief from the symptoms they are experiencing. This is independent of whether they have been accurately diagnosed with ESKD in a hospital or they have noticed symptoms and are taking steps to remedy the situation and can have dire consequences. Many of these spiritualists also perform certain incantations and rituals to give the individual and their family a belief that, indeed, they have been cursed or bewitched. Some will be told that the effects of the curse have been neutralised or the curse has been reversed, as was in the case of Eno, and have to allow time for symptoms to disappear. All these contribute to the delays in getting to the hospital until they realise that their signs and symptoms are persisting and, in some instances, are becoming life-threatening.

> *"…..so they took him [a patient] to so many places to perform rituals for him. There was one mallam, one ritualist who then fixed*

the teeth to his feet because there was oedema, so he just put the teeth to the legs and started removing pins from the throat [these are believed to be some approaches used by some of these spiritualists], and told him that it was his youngest aunt who had then cursed him. So he planned on going to kill the aunt until it was so bad that he couldn't even raise the head and they brought him to the hospital" (Owura, nurse).

"There are times when they have the disease they are encouraged by family members to go and seek spiritual help in prayer camps. Others go to see fetish priests and they are kept for quite a long time…..Ghanaians mostly believe in spiritual and fetish priests and, sometimes, they go there first before seeking care at the hospital. So when they go there first they usually come late and when they come late, the end is not too good, it's disastrous because they would have wasted precious time" (Ohene, medical doctor).

It has been explained in the subsection on 'being diagnosed with ESKD' that patients ended up in renal centres via two main routes. The first is a referral to the centre from other hospitals or health facilities that do not have renal centres. These patients may have been accurately diagnosed with ESKD before referral or they may get to the hospital with a renal centre before they are accurately diagnosed and referred to the renal centre. Such patients, sometimes, have to travel a long distance, sometimes out of their region to another region with a renal centre for care. The second route is when patients are referred to the renal centre from other units or departments within the hospital – these are internal referrals. This was also confirmed by one clinician;

"Because this centre is a teaching hospital, so patients are sometimes referred from other regional or district hospitals to this place. Sometimes too we can have an internal referral from the wards" (Awuraa, nurse).

However, the process of being referred was seen to contribute to delayed presentations at renal centres in some instances. This is because some doctors feel reluctant to refer these patients to renal centres with an excuse that they will die eventually, whether they are referred or not.

"So that [reluctance] also adds to the late referrals because some of them [doctors] don't want to refer the patients. So there are times the patients' family walk to us and tell us this is the case and then we go to the ward and take the patient and start doing the dialysis" (Ohene, medical doctor).

Clinicians also shared their perspectives on factors that contribute to patients' non-adherence to biomedical therapy or reasons for which they used other non-biomedical approaches alongside haemodialysis. This is the third aspect of this subcategory. Clinicians were of the opinion that patients who believed that their disease resulted from a curse or witchcraft had the tendency to abandon biomedical care for non-biomedical care. These patients then visit pastors or spiritualists with the hope of getting the curse reversed. They explained that some patients also seek biomedical care and non-biomedical care concurrently, as was attested to by Wofa and Papa.

"I don't really see them going to the prayer camps but they tell us they've been seeing other pastors so it's common" (Awuraa, nurse).

"The few ones that have been told that, like, you are scheduled for dialysis, they won't come, they will leave for some time, you won't see them. When they come they will tell you, maybe they went to a man of God and then, those people when they come back, they don't really stay longer and they die" (Ohemaa, medical doctor).

"Even though those who can afford dialysis are still coming for treatment, they are also going for prayers, visiting places in the name that if it's a curse they will be cured." (Owura, nurse)

However, patients' views about disease causality and their search for liberation from perceived curses are not the exclusive drives for non-adherence as numerous challenges they encounter also play a significant role in defining their health-seeking behaviour. The next sub section describes clinicians' perspectives on some of these barriers that patients with ESKD face in Ghana.

6.2.2 Describing Barriers

This component centres on common challenges that are faced by individuals with ESKD in Ghana on a daily basis in relation to their disease and its management from the perspectives of clinicians. Most of these challenges were also raised in the patient interviews. All clinicians were unanimous on the threat posed by the costs involved in managing ESKD for patients and their families. The NHIS covers some of the drugs prescribed for the non-dialytic population as well as partial support for those with acute kidney injury requiring dialysis. However, there is no support for those with ESKD and patients have to bear the full cost of treatment, which is a major burden for almost all of them. Some patients get financial support from their employers while others get financial support from their family and/or close friends. However, a greater number of these patients get no financial support and have to pay for their treatment themselves.

> *"It's like you get someone, if you are able to tell the person 'this is your problem', 'these are the options you have' but then there is no money for the person to, maybe [do] this dialysis…. some relatives, it's not that they don't want to help, they are willing to help but they look back and they can't hold on to anything" (Ohemaa, medical doctor).*

They are, therefore, unable to have the conventional treatment of three 4-hour dialysis sessions each week. A majority of the participants on dialysis have two dialysis sessions each week and is a reflection of the general trend across all renal centres within the country, as has been shown in Table 2. The frequency of dialysis sessions reflects the financial capabilities of the patient and the financial support network available to them, implying that wealthy patients are able to afford better care while the poor ones deteriorate.

> *"Money is another big factor in most of the cases. I have another patient who comes in once every two weeks because there is no money to pay for dialysis" (Ohene, medical doctor).*

> *"….some [patients with ESKD] are coming [for dialysis] once [each week]. Some too can even go to the extent of [one dialysis session every] two weeks, some people will not come at all. You will be*

there, once a while in a month, the person will tell you I've got money for one treatment so I'm coming for treatment and the person will come" (Owura, nurse).

Patients with ESKD also have other concerns that are related to their social responsibilities – they may have children, spouses and family members to think about when faced with the challenge of raising money for their treatment. Some patient participants sold their property to pay for their treatment. Indeed not all of them had property they could sell to pay for their treatment but such patients organised money through diverse ways, including using up their savings and getting donations from others, to give dialysis a try. This was because many of them, somehow, nurtured expectations of a cure, expected that their condition would improve over time, or were not fully informed about the prognosis of their condition. They blamed the clinicians for not being open to them about their prognosis and for not telling them that dialysis is for a lifetime – these came up in the patient interviews. However, clinicians did not agree. They were of the opinion that these patients are made aware that ESKD has no cure and require lifelong dialysis for survival. They, however, find it hard accepting this reality and live in denial or try other avenues in order to seek a cure or buy time while they brace themselves up for the worse.

"Oh, basically they do know. It's just that they refuse to accept the fact that they have to be on the machine [dialysis] for the rest of their lives" (Ohene, medical doctor).

"From what I know, they accept to start [dialysis] but, after some time, they get fed up because, normally, they don't want to hear it's for a lifetime, they think you are saying it's for a lifetime, it's your own problem but once they start, once they are put on the machine, they will be healed" (Awuraa, nurse).

There come times in the course of their treatment where they have to decide whether to continue dialysis using all their resources or to bequeath them to their significant others and this, in many instances, serves as a barrier to continuing on dialysis for many patients.

"It gets to a time they feel they should stop doing dialysis because all that they've toiled for, if they are not careful, they are going to sell all to care for themselves. When it comes to that, they also

have children. I quite remember we finished dialysis for somebody, one client, and all that he just said was 'thank you for helping me to make my will'. So if a client passes such a comment, then you wouldn't be surprised, one day, to hear from the client that 'I'm not coming for dialysis anymore'" (Owura, nurse).

"I know one patient who was on dialysis for some time and then he had sold two or three houses and then he said 'enough' and stopped dialysis and died because he felt by selling all those assets, there will be none left for the children and he didn't see how he could die and leave nothing for the children so he stopped" (Ohene, medical doctor).

The organisation of renal services was described as a barrier to effective management of ESKD in the country. It was a commonplace in patient interviews as well as clinicians' interviews for participants to compare renal services in Ghana to those abroad. The popular observation was that many of the things that Ghanaian patients with ESKD have to pay for are catered for by health insurance or governments abroad. This makes ESKD management financially inaccessible to many patients and, consequently, more challenging to live with the disease in Ghana.

"If you go abroad…they have insurance so they don't have to pay for the dialysis [at the point of care]….they get free medications like erythropoietin which we have to buy in Ghana, they have Venofer which is free, which we have to buy in Ghana, and all those amenities. And they have the doctors in the mornings and evenings to look after them…so they have advantages than we have. And they have very good healthcare [system] also than we have" (Ohene, medical doctor).

"Let's say the states [the USA]. It's [RRT cost] covered by insurance so no matter what, if I was going to have 5 dialyses in a week, I'm having my 5 dialyses in a week. All my medications are catered for by insurance. But over here, the patients buy everything, from their iron medications, anything that has to do with the condition, they buy it, it's not covered by insurance. And these medications are very expensive" (Maame, nurse).

Geographical inaccessibility was also seen as another factor which compounds the challenges of managing ESKD in Ghana as renal centres are only available in three out of the ten administrative regions of Ghana.

> *"So far, in the whole nation, there are two major dialysis [renal] centres so you can imagine, if you are in the Northern Region and you develop end stage kidney disease and you need dialysis….you are somebody who is working, how can you do that?....sometimes we get patients, because of that thing, they just say they don't even want the treatment, they just want to go home and they will go" (Ohemaa, medical doctor).*

The high workload in renal centres was identified as another deterrent to the organisation of effective renal services in the country. Clinicians believed that increasing ESKD patient population should have called for increasing numbers of staff as well as more training programmes to ensure they are well equipped to render effective care. However, this has not been the case. Thus, they end up not being able to provide essential services that patients need, including patient education.

> *"All we need is to get more human resource because the patients, now I don't know whether we are in [an] epidemic of CKD…in terms of the job, it's like, overwhelming. You want to do your best but you get tired" (Ohemaa, medical doctor).*

> *"Counselling is supposed to be done like every day…but when you look at the ratio of nurses to patients….I'm not giving excuses but we don't have the time to be doing that on a daily basis" (Maame, nurse).*

How, then, is care organised for patients with ESKD on a day-to-day basis and what are the usual outcomes in light of the above? The next subsection provides a picture of how care is organised routinely across renal centres in Ghana.

6.2.3 Describing Routine Care and Outcomes

This component describes general daily practices in a typical renal centre in Ghana. Patients who are referred to renal centres are directed to do laboratory investigations for a confirmation of their diagnosis and staging. Patients who report early to the renal centre or are diagnosed in early

stages of CKD are managed with the goal of slowing the rate of deterioration of kidney function and delaying the need for dialysis and this goal is mostly achieved. This is done by closely controlling blood pressure and blood sugar while preventing other injuries to the kidneys. Most of the drugs needed to achieve this goal are provided for by the NHIA for its subscribers. Clinics are organised for such patients where they visit biweekly, monthly or quarterly based on their needs. Other specialists, including dieticians, are invited to these clinics occasionally to give their expert advice to patients. Health talks on specific aspects of CKD and its management are given while patients prepare to see a medical doctor.

> *"Our main aim is to prevent them from reaching the last stage that will need [renal] replacement therapy. So we try to control their BPs, their diabetes, infections or drugs that they are on, we try to see whether the drug is not toxic to the kidney and advise them on what diet they should take so that we try to let them stay at one stage for a longer time." (Ohemaa, medical doctor)*

However, as has been explained earlier, many of the people getting care in the renal centres presented in later stages of the disease, leaving little to no room for interventions that could have delayed the need for dialysis.

Other conditions, including anaemia, are also managed in these clinics. However, erythropoietin and other agents used for managing anaemia in CKD are not covered for by the health insurance and these are expensive. It, however, does not cost much to have haemotransfusion. Consequently, blood transfusion, in the face of all the risks associated with it, is used to manage anaemia in many of these patients since they only have to pay a small fee for processing blood products.

> *"The only thing it [health insurance] covers is their drugs, the anti hypertensives. Come to Hb, the basic labs, it doesn't cover. Even if you are to do a blood transfusion, you have to pay a processing fee of GHS 35 [about GBP 7]. So the anaemia, the drugs to manage anaemia is expensive for them" (Owura, nurse).*

Clinicians explained that they usually educate patients on the likely trajectory of ESKD after their diagnosis even though some participants felt this was inaccurate or inadequate. They are then taken through counselling process to educate them on what is entailed in starting

dialysis. This is usually done in the company of a family member or significant others to ensure that patients get as much support as they would need. Getting the news about their diagnosis and its implications is a stage that patients react to quite differently. ESKD is incurable, costly in terms of its management and terminal without any form of renal replacement therapy, making the news more devastating for patients and difficult for them to accept the diagnosis and the proposed biomedical management approaches. Reactions to this news varied among patient participants, with some crying while others denied the potential impact of the disease on their life. Sometimes, such reactions were directed towards the clinician giving the news and were quite unpleasant

> *"Some [patients] don't take it lightly and, at the counselling stage, if you [clinician] don't take care, because, personally, I have had an experience, the patient told me 'you are not God, I rebuke it in Jesus name, you are not God, you can't tell me I'm supposed to be put on a machine for my lifetime unless transplant, no way. I know God will take care of me'….some patients will hold you, attack you because you are telling them they are going to do it for life unless they get a transplant or other stuff. Once you say it's for life, they don't want to hear that" (Awuraa, nurse).*

Such reactions made some clinicians avoid the role of disclosing news to patients about their diagnosis or concealing part of the information, especially, regarding ESKD being a terminal disease. Some clinicians, however, reported that time constraints did not permit them to take patients and their families through the counselling process. This might have contributed to the seeming deception reported in the patient participant interviews.

> *"Sometimes you will be forced to keep certain things to yourself but you have to tell them too…..oh, for the counselling, I don't want to go there…..it's something I don't even want to do" (Awuraa, nurse).*

The decision to start dialysis was described, characteristically, as shared as clinicians provided information needed by patients and both agreed on what should be done. But such interactions tend to focus on exploring patients or their families' ability to finance HD rather than on treatment burden and potential outcomes.

"So the patient alone cannot decide that I have money, I want to start and the doctor alone cannot say well, you have the disease so come and start, no. We have to discuss among family members so it's a team work, like I said, patient, family members and the doctors" (Ohemaa, medical doctor).

Patient participants felt that information given to them was not comprehensive enough to ensure they were fully aware of what treatment entailed.

The cost element implies that individuals who start dialysis may have to abandon it at a point once they run out of money. As a result, many individuals with ESKD in Ghana start dialysis but are unable to sustain treatment for a long time unless they are getting financial support from their employers or philanthropists. Two of the three renal centres in this study had three years as the longest survival period among their dialysis patients as at the time of data collection, with several others dying within months of starting haemodialysis. This is because many patients in these two units make out-of-pocket payments for dialysis with no external financial support, either from their employers or other sponsoring bodies, and could not continue raising money for their treatment. Yet, the third renal centre had some patients surviving on dialysis for up to twelve years because they have been receiving regular financial support for payment of their dialysis costs.

Some patients start dialysis while pursuing other forms of treatment that, in their view, can cure their disease. Consequently, clinicians were of the opinion that some patients seek other forms of treatment while on dialysis but they do not tell them about this since they do not support any non-biomedical approach to managing ESKD. Clinicians got to know about these practices only after the demise of such patients or through their interactions with other patients.

"I think some of them go to see other, they seek other means of curing the condition. Some of them go to the herbalist, some of them go to the spiritualist. Most of the time, it's these two, either they go in for traditional medications or they go in to see a spiritual figure that they feel has supernatural means, the condition can be healed or something" (Maame, nurse).

Conservative management is not a choice patients with ESKD in Ghana voluntarily opt for. When asked about encountering patients with ESKD who voluntarily opted for conservative management, only one of the clinicians explained that she once encountered one of such patients in her three years of practice in the renal centre and this patient eventually opted to be on dialysis.

> *"So far it's just one patient I came across like that. He had money alright but I didn't know why he wanted to opt for that [conservative management]. But I think it was ignorance. Upon education, he changed his mind and is now on dialysis" (Ohemaa, medical doctor).*

However, conservative management is not an obvious option for those who do not have the means to start dialysis as there are no means to follow up on them once they withdraw from or are unable to start haemodialysis. Moreover, there are no structured policies to provide conservative management or end of life care for such patients.

> *"We don't follow the people or be checking on them all the time because we are understaffed, work is also overwhelming us. So one day, you will be here and they will call you, the person is dead or you will be there and they will call, this person can't breathe, the person is dying so we say take the person to the emergency unit" (Owura, nurse).*

So far, the subcategory of 'describing prevailing trends' and its components have been explained. Many of the statements that confirmed or explained some findings from the patient interviews have been highlighted. Descriptions by clinicians regarding causes of increasing prevalence of ESKD in the country, delayed presentation of patients with kidney diseases to renal centres, the numerous challenges faced by patients with chronic kidney disease, and the routine care and outcomes present situations that clinicians have tremendous challenges modifying to improve patient outcomes. Thus, feelings of helplessness were common undertones while clinicians described prevailing trends of various aspects of ESKD and its management in Ghana. The next section will describe the various roles that clinicians play in providing renal care and supporting patient decisions as well as what they wish they could offer.

6.3 Rendering Support

This subcategory describes the central roles that clinicians play in the lives of patients getting care from the various renal centres. The subcategory focusses on information provision and emotional support. It also refers to the culture of support that is created within the renal centre through interactions between clinicians and patients, and other types of support that clinicians desire for individuals with ESKD in the country.

Many patient participants did not know much about the disease or its treatment at the time of their diagnosis. The clinicians, therefore, had a responsibility to educate patients on what might have brought about their disease and what its management entails. This was especially vital at the stage when patients were deliberating on what to do after being diagnosed. However, findings from the patient interviews suggested that information provision was inadequate at this stage and this was explored in the interviews with clinicians. Although some of them did say that information provision may not be adequate due to understaffing, clinicians were also of the opinion that patients had the tendency to see other sources of information as more reliable than that from clinicians.

> *"When they sit outside and they are waiting for their turn, you see, they discuss whatever they are going through and, instead of them coming to seek information from the nurses or the doctors, they seek information from themselves. 'So I come and I tell you that when I do this and that, I'm OK, so far as another patient is telling me that when I do this and that, then it means when I also do it I will be fine because the patient is in the same predicament that I am'. So I think they believe what others tell them than what the health professionals tell them" (Maame, nurse).*

Another role played by clinicians in the care of patients with ESKD is the provision of emotional support and this was mainly provided through interactions with patients as well as creating a friendly environment in the renal centres.

> *"Sometimes, some people will call you and say "you people are so superb. When I come here and I see people, I feel like my problems are half way down" (Owura, nurse).*

"And over here [renal centre]….we live like a family….so, that alone, somebody goes home and the person will not have that freedom to talk or freedom to do whatever he wants to do….but when they come here they have a lot of people here they can talk to…." (Maame, nurse)

Clinicians, however, described feeling helpless under circumstances where they painfully have to watch a greater number of patients they could have saved through dialysis die because they could not raise enough money to pay for the cost of dialysis.

"….so you just look at the patient dying just because of money" (Ohemaa, medical doctor).

"Majority of the patients can't afford haemodialysis so they, unfortunately, die. It's hard for us to see the patient, who you could have saved, die because they can't afford the treatment" (Ohene, medical doctor).

Consequently, some clinicians had to pay for some patients to have a haemodialysis session in some instances.

"The money is too much for [some of] them [patients] so, I remember a patient once came, you see the treatment is GHS 150, the patient came with I think GHS 80 or so; he asked specifically for one of the nurses. I called this nurse and the patient told him that he has only GHS 80 and he should add up to it for him to have the dialysis and he did" (Awuraa, nurse).

The clinicians also shared their opinions on how the care of patients with ESKD in Ghana could be improved and these centred around three major areas – reducing the incidence of ESKD through preventive approaches, reducing costs of treatment to the patient at the point of care, and equipping the clinician with adequate training in the management of ESKD. These areas were mostly beyond what clinicians could do, either individually or collectively, to ensure sustained series of actions that will improve outcomes of ESKD and its management in Ghana.

In terms of reducing the incidence of ESKD, they made suggestions such as increasing public awareness of ESKD, creating and sustaining early

detection of CKD programmes, and controlling CKD effectively to delay or prevent progression to ESKD.

> *"I think the first thing is for people to be aware of the disease, that there is this disease in the community and be aware of certain signs and symptoms like facial puffiness, swollen legs, oliguria or nocturia and a few other symptoms and that when they have those things they should be brought to the hospital and then the doctors will take care of it" (Ohene, medical doctor).*

> *"When we are able to identify them earlier, the treatment is effective, so they stay for a very long time. I know one client who has remained at stage 3 [CKD]…for more than 5 years" (Owura, nurse).*

In relation to reducing the cost of treatment to the patient, clinicians' recommendations focused on the government devising policies to lower the cost or the NHIA catering for some of the costs for the patient with ESKD.

> *"There was a time I and my colleagues were deliberating that how about the government forming some policy, like he will be deducting from we those who are working, maybe, some small percentage of our salaries to support the kidney centres so that they can have the treatment free" (Awuraa, nurse).*

> *"I feel that our health insurance should be for cases like kidney failure and other things. Other conditions like malaria that the health insurance covers, most Ghanaians can afford to treat those things….common cold, common headache" (Maame, nurse).*

The last but not the least, they believed that having adequate numbers of well-trained clinicians to manage the renal centres will improve management of ESKD in the country.

> *"I think we are doing our best. All we need is to get more human resource….if we can get more hands to help, that will solve some of our problems" (Ohemaa, medical doctor).*

> *"I think if the government is able to put up a school or something that will train the nurses for dialysis, I think it will be a good initiative" (Maame, nurse).*

6.4 Summary of Chapter

This chapter has presented findings from interviews with clinicians and has shown how views of clinicians corroborated with perspectives of patients with ESKD in diverse ways. The chapter has shown that, generally, clinicians feel helpless about issues regarding management of ESKD in the country. Clinicians appreciate the increasing incidence of ESKD in the country and the challenges the disease poses for patients and their families. They also witness a lot of deaths from the disease because of challenges associated with its management in the country. Yet, clinicians do not feel adequately prepared to initiate discussions on conservative management with patients with ESKD because of a lack of training and facilities as well as the potential reaction of patients and/or their families. Even in the midst of feeling helpless, clinicians are providing as much support as they can for patients with ESKD receiving care in their respective renal centres. Their main aim is to support patients with ESKD and guide them through the management of the condition for as long as possible. Although the subjective experiences and perspectives of the patient with ESKD are key to understanding experiences of patients with ESKD with decision making, analysis of interviews with clinicians has expounded the process of patient decision making and the context within which patient decisions are being made in Ghana. Clinicians play a central role in this process of patient decision making in ESKD in Ghana, guiding patients to manage the disease as much as they can.

CHAPTER 7. DISCUSSION

7.1 Introduction to the Chapter

This is the first study to explore patient decision making in ESKD in a sub-Saharan African country after calls were made for patient decision making to be explored in other settings apart from North America and Western Europe (Morton et al., 2010, Pierce and Hicks, 2001). It is also the only study in sub-Saharan Africa to have explored patients with ESKD' experiences of symptoms and health-seeking behaviour even before a diagnosis of ESKD was confirmed. The key objectives of this research were to:

1. Explore experiences and perceptions of patients with ESKD living in Ghana and how these influence patient decision making.
2. Examine the contextual factors (healthcare system, culture, resources) and their influence on patient decision making in Ghana.
3. Examine conservative management as an alternative approach for individuals with ESKD in Ghana
4. Generate evidence that will inform debate and policies on the care of patients with ESKD in Ghana and also offer recommendations for future research, policy and practice.
5. Contribute to international evidence on patient decision making from a lower middle-income setting.

The study confirms that patients with ESKD in Ghana are far from having unrestricted access to RRT, as is the case in most high-income countries, neither is there any form of access rationing to the therapy according to age, employment status, and race as is practised elsewhere (Etheredge and Paget, 2015, Moosa and Kidd, 2006). It has examined how patient characteristics, experiences and the healthcare system influence patients' decisions around health-seeking and treatment of ESKD. ESKD may now be described as a long term condition in many high-income countries owing to higher survival rates on RRT, thus patients in such countries do not perceive themselves as having a terminal illness (Davison and Simpson, 2006, Lazenby et al., 2016). However, ESKD is still very much a terminal disease in Ghana since the survival period among patients with ESKD, even those receiving haemodialysis, is relatively shorter.

This chapter will now focus on discussing the study findings in respect of patient decision making in ESKD in Ghana. The chapter will begin by exploring the place of shared decision making in ESKD in Ghana. It will then discuss the various choices available to the patient with ESKD in Ghana, after which the place of conservative management will be examined. Factors that actually influence decision making of patients with ESKD in Ghana, as have been identified in this study, will then be discussed in the light of global evidence.

7.2 Shared Decision Making in ESKD in Ghana: Same Concept, Different Objectives

Shared decision making has received increasing attention in some parts of the world, with objectives such as improving patient outcomes and aligning ultimate decisions with patient values in order to enhance patient satisfaction with care (Da Silva, 2012, Légaré et al., 2010, Oshima Lee and Emanuel, 2013). It mainly combines the clinician's expertise with the patient's values in order to arrive at an optimal decision (Edwards and Elwyn, 2006). Indeed, shared decision making has largely been practised in healthcare settings where patient choices are perceived to have similar outcomes, with none of these choices being considered superior to the others (Oshima Lee and Emanuel, 2013). Yet, shared decision making may not have received wide global recognition as a term to describe the process of patient decision making (Searight and Gafford, 2005). Some of its tenets seem to be guiding patient decision making in Ghana albeit implicitly while objectives of the decision-making process may be different in different healthcare settings.

Decisions on initiating HD among patients with ESKD in Ghana, as identified in this study, could be described as mostly shared between clinicians and patients and/or their families even though the term 'shared decision making' is not used. It could be argued that several aspects of patient decision making in Ghana are characteristically paternalistic since clinicians are more likely to decide on what is 'best' for the patient without necessarily having a discussion with them about their options. However, since patient participants of this study perceived that the ultimate decision to start HD was theirs, the process was not entirely paternalistic. In fact, traces of paternalistic decision making was inferred from some expressions of one patient participant. Agya, a dialysis patient, explained that a doctor told him to go home and use the money he would be spending on dialysis

to take care of his children. Yet, it was his preference that was taken as he maintained that he would be on dialysis and, eventually, started receiving the therapy

In addition, clinician participants also explained that discussions are held with patients with ESKD and/or their families before treatment initiation. Although these discussions are aimed at providing information on the likely trajectory of ESKD as well as treatment options, the process is mainly driven by the need to ascertain patient and family's ability to finance HD, rather than considering other aspects of treatment burden. Moreover, 'choice talk' and 'option talk' as proposed for implementing shared decision making (Elwyn et al., 2012) tend to centre on haemodialysis only in the Ghanaian setting. This is because other available options are perceived as infeasible by the clinician or the patient and/or their families. In conclusion, some aspects of shared decision making such as discussing a possible course of actions with patients with ESKD take place in the Ghanaian setting, implying that the process could be described as shared decision making. However, because discussions are focused on only one main option which may not necessarily be in line with values, beliefs, or preferences of the patient, the concept of shared decision making cannot be entirely applied to the practice in ESKD in Ghana. The next section will describe choices the Ghanaian patient with ESKD has and how these differ from choices that exist for patients with ESKD elsewhere.

7.3 Choices of the Ghanaian Patient with ESKD

Efforts are being made to increase patient autonomy and to ensure patients have a menu of choices during decision making globally (Chewning et al., 2012, Fowler, 2012). Key among choices being offered to healthcare users are facilities to seek care from as well as available treatment options (Greener, 2007, Greener and Mannion, 2009). It is generally believed that the first critical decision for individuals confronted with potentially life-threatening illnesses is whether to opt for active curative or long-term treatment or palliative treatment (i.e. whether to choose possible survival or death) and the choice they make further directs subsequent choices. For individuals with ESKD, this concerns whether to choose survival by receiving RRT or death without RRT but conservative management (Harwood and Clark, 2013, Winterbottom et al., 2012).

Haemodialysis, the first RRT to be developed, was rationed in the early stages of its development in many high-income countries and persons with ESKD had to meet certain strict criteria including being of a younger age and in employment before receiving the therapy (Blagg, 2007, Crowther et al., 2009). However, there is, now, almost unrestricted access to haemodialysis and peritoneal dialysis for all patients with ESKD in many high-income countries, irrespective of the person's age, gender, occupation or comorbidities (White et al., 2008). Some form of rationing still persists for kidney transplantation globally due to limited availability of donor kidneys (White et al., 2008).

A key difference between patient participants of this study and patients with ESKD in many high-income countries lies in what treatment choices require more deliberation. On the one hand, this critical decision of choosing survival or death appears to be one without much deliberation for patients with ESKD in high-income countries, including elderly patients, because accessibility to RRT is generally not a major source of concern. Choosing survival seems to be the obvious choice, and there are mechanisms and health policies in place to enhance this choice, including having unrestricted access to RRT. Instead, the decision about the RRT modality to choose, mainly haemodialysis or peritoneal dialysis in their various forms, requires more deliberation in these countries, as identified in systematic reviews of Murray et al. (2009) and Harwood and Clark (2013). On the other hand, the Ghanaian patient with ESKD who chooses survival does not need more deliberation on which treatment modality to choose as haemodialysis is the only obvious biomedical choice in the country. Instead, choosing survival or death demands more deliberation from the Ghanaian patient with ESKD – they have to consider whether they can access haemodialysis, how to pay for their treatment, how long they can finance haemodialysis, and the frequency of haemodialysis sessions based on their finances, if they choose survival on dialysis.

The prevailing circumstances in the country seem to present death as the imminent outcome of ESKD and the option that would ultimately befall all patients with ESKD, whether sooner or later. Yet, there appears to be some 'secrecy' surrounding this as death is not discussed explicitly as a potential outcome of the disease for various reasons. In effect, although death and end of life care could be an option for the Ghanaian patient with ESKD, they were less likely to consider it deeply or, at least, talk about it.

Patient participants in this study either alleged that clinicians did not openly inform them about such an outcome or expected RRT or other forms of treatment to cure the disease as soon as possible and were, therefore, reluctant to discuss the subject of death. Indeed, treatment decisions by persons with ESKD are mainly influenced by the need to preserve life at all cost when 'good' death is not seen or presented as a viable option (Song et al., 2013). This study reveals that the need to preserve life is central to treatment decisions made by the Ghanaian patient with ESKD. Age and personal aspirations were identified as key reasons for which individuals felt the need to initiate treatment for ESKD and preserve their lives. The fact that age and personal aspirations are important reasons for initiating treatment for ESKD in order to avoid death at all cost is understandable. Participants felt that they were either too young to die or had families and other responsibilities to take care of so death could not be an option. This is in light of data that shows that the ESKD patient population in Ghana is relatively younger and mostly comprises persons in their productive years – 86% of the patient participants of this study were between 20 and 60 years. Only 14% of the respondents were above the retirement age of 60 years in Ghana, compared to the UK and the USA where 36.2% and 38.6% of individuals receiving RRT are above the retirement age of 65 years respectively (UK Renal Registry, 2014, United States Renal Data System, 2014). In fact, if retirement age in Ghana was to be 65 years, then this percentage would have been much lower. Hence, it cannot be overemphasised that decisions about initiating treatment for ESKD in Ghana are a matter of life and death for individuals with the disease, what Morton et al. (2010) conceptualise as 'confronting mortality'.

The ESKD patient population usually have a primary preferred choice of kidney transplantation but the lack of donor kidneys restricts this choice to only a few individuals (White et al., 2008, Wu et al., 2004). The problem of unavailability of donor kidneys for transplantation in the country, as it is in other parts of the world, is further complicated by the Ghanaian patient with ESKD having to bear the full cost of kidney transplantation surgery. Moreover, there is a lack of trained Ghanaian kidney transplantation surgeons to perform the surgery as and when donor kidneys are available for patients with ESKD in the country. Some participants of this study expressed their desire to have a transplant, with one of them travelling abroad with the hope of getting this choice because there were no trained

kidney transplantation surgeons in the country to perform the surgery at the time he had money. The implication is that while a few patients can deliberate on how to get a suitable donor for a kidney transplant surgery, the procedure is not an option for a majority of the ESKD patient population in Ghana because of its associated high costs.

Patient choice is more practical for patients with ESKD in terms of having either haemodialysis or peritoneal dialysis as both are mostly available in several countries and neither is generally deemed superior to the other (Boateng and East, 2011, Couchoud et al., 2015, Morton et al., 2010). Even in that, it cannot be said that choices are unreservedly available to all patients with ESKD. The systematic review by Morton et al. (2010) identified 'lack of choice' as a common experience of patients with ESKD making decisions about their treatment in some high-income countries, particularly the USA. This lack of choice usually results from physician preference, inadequate information on available options, resource constraints, or contraindication of an option owing to medical or physiological reasons. Thus, although there is a range of options available to patients with ESKD in some countries by principle, this is not always practical and some patients end up being eligible for only one option.

The situation is more prominent in Ghana where there are no peritoneal dialysis services for adult patients with ESKD and kidney transplant surgery is rarely done. This means that while patients with ESKD in other settings have various forms of haemodialysis and peritoneal dialysis to suit their unique needs and lifestyle, lack of choice is hugely felt by the Ghanaian patient with ESKD who only has the option of in-centre haemodialysis (albeit a few persons have home haemodialysis). Ghanaian patients with ESKD can choose how often to have haemodialysis sessions but this is largely dictated by their finances. Indeed, some participants of this study articulated that they had no choice when it came to management of their disease – they were only having haemodialysis because they would die without it. A critical examination of the conceptual pathway depicting the ESKD patient journey in Ghana shows that patients face inevitable death as prevailing circumstances make it difficult for their sustenance on haemodialysis over a prolonged period. Only four of the fourteen participants on RRT in this study had been on treatment for more than two years at the time of data collection, with reports that most patients with ESKD are sustained on haemodialysis for only a couple of

weeks. The clinicians interviewed in this study explained that they, many a time, watch helplessly as their patients with ESKD die because they do not have the means to initiate or continue haemodialysis treatment. This strongly suggests that there is an urgent need for a care pathway that would provide support for patients who cannot afford dialysis and who will die. This could include the option of having dialysis for a limited time to get their affairs in order or to give them time to pursue other treatment choices that are in line with their values and beliefs.

Choice of a renal centre is also limited for the Ghanaian patient with ESKD. All renal centres in Ghana are located within three of the ten administrative regions in the country. As a result, some of the participants interviewed in this study had to travel across administrative regions in order to access renal care. This, in addition to limited RRT types in the country, implies that the Ghanaian patient with ESKD has only one biomedical option and not a menu of biomedical choices as patients with ESKD in several high-income countries appear to have.

The above factors, coupled with financial factors as well as individuals' values and beliefs, lead them to practice healer shopping by seeking other options that may not necessarily be in line with the tenets of biomedicine. Other options such as going for prayers or consulting spiritualists, and using herbal medicine were chosen by some participants alongside their haemodialysis treatment. Others were reported to choose these other options over haemodialysis entirely even though no individual with such characteristics was identified and interviewed in this study. It must be reiterated that De-Graft Aikins (2005) recommended regulation and expansion of research on scientifically-approved herbal medicines in Ghana as they are used by many for their primary health care needs and have proven their efficacy (World Health Organization, 2003). Patient participants who reported using any of these other options alongside haemodialysis decided to use them purely as complementary therapies to aid their objective of preserving their lives while hoping for a better future. However, there is insufficient evidence to support the use of herbal medicine as a treatment approach for chronic kidney disease. In fact, it is believed to contribute to increasing prevalence of CKD in areas where its use is widespread (Jha et al., 2013, Stanifer et al., 2014). While clinicians rely on anecdotal evidence and their personal experiences to decry utilisation of some of these options, they are unable to deter patients with

ESKD from pursuing these options. Clinicians interviewed in this study reported not following up on all those who discarded biomedicine for these other options although they usually got news on the demise of some of them. Moreover, use of these other approaches is not discussed first with the clinician before being started, leaving little or no room for clinicians to identify and support individuals who may be using the two approaches concurrently.

It has been explained that some Ghanaian patients with ESKD utilise traditional medicine or seek spiritual healing in a bid to avoid conflicts with their significant others while others see that as pursuing cheaper forms of treatment. The latter rationale suggests that financial status of an individual with ESKD or their significant others is instrumental in decisions to opt for biomedical treatment or otherwise. The implication would have been that only the wealthy would utilise biomedicine while the poor utilise traditional medicine. However, that is not the sole factor for health-seeking and treatment decisions. De-Graft Aikins (2005) identified that many Ghanaians privilege biomedicine over other treatment approaches because of its proven effectiveness in diagnostics and pharmacology. Moreover, the society generally accepts biomedical explanation and solutions for chronic diseases, including diabetes mellitus. Hence, many Ghanaians are likely to seek biomedical care once initial actions to remedy observed changes in their health status do not restore their health. The case is different for ESKD though. Ascites and generalised oedema which are cardinal signs of ESKD without treatment are generally associated with being cursed within many Ghanaian societies. This is complicated by the lack of a cure for ESKD in biomedicine, leading many to strongly believe that their disease is indeed the result of a curse. The lack of a cure for ESKD in the biomedical setting also provides an opportunity for proponents of traditional medicine or spiritual healing to present their approach as superior to biomedicine. Some participants who accepted the biomedical explanation of their disease found it difficult to accept its terminal nature without RRT, refuting the 'verdict' of death by clinicians and inclining themselves towards their religious knowledge and beliefs with the hope of getting better.

What is more, while biomedical prognosis of ESKD is death without RRT, religious knowledge gives hope of a possible cure or healing from all forms of diseases. Thus, although conservative management is an acceptable

approach to managing ESKD and, indeed, some patients have expressed preference for, or utilise this approach in some high-income countries, including Australia and Canada (Davison, 2010, Morton et al., 2012, Morton et al., 2010), the situation is quite different in Ghana. While the aged person will consider conservative management and palliative care as a treatment option in many high-income countries, the relatively younger Ghanaian patient with ESKD, full of aspirations and responsibilities, may not see this is an option and will seek other approaches that would give them the slightest chance of survival. Participants mostly demonstrated aversion towards the idea of withdrawing from dialysis whenever it was broached. Clinicians' responses also demonstrated that patients, mostly, did not want to accept the terminal nature of their disease. In fact, clinicians are not in the position to introduce and discuss end-of-life care or conservative management issues effectively unless they have undergone adequate training on the subject.

Instead, participants described events that suggest an active search for interventions that could improve their health over time. This called for active information seeking from various sources and pursuit of other options alongside haemodialysis. This iterative movement between 'deliberation or procrastination: ascertaining the likely trajectory of ESKD' through active information seeking and 'believing that tomorrow will be better: a linchpin for initial patient decisions' is, therefore, a characteristic feature of ESKD patient experiences and decision making in Ghana. Consequently, some individuals take what biomedicine has to offer in terms of preserving their life while they seek a 'permanent' solution. In other words, they start haemodialysis while looking for a cure from elsewhere through healer shopping. This is the key reason why some patients with ESKD in Ghana reported pursuing other approaches to treatment alongside the biomedical option, or were reported to have abandoned biomedicine for alternative treatment. While it cannot be denied that utilisation of complementary and alternative medicine is closely associated with costs of biomedical treatment and financial stance of the patient (Kolling et al., 2010, Nxumalo et al., 2011), participants of this study expressed that they would utilise traditional medicine if that gave them a slightest chance of survival and improvement in their health

In concluding, yes, Ghanaian patients with ESKD have a menu of choices when deciding on their treatment even though these choices are, to a

greater extent, different from the choices available to patients with ESKD in high-income countries. These choices are mostly in line with values and beliefs of many of the ESKD patient population but are seen as contraindicated when receiving biomedical care or insignificant in the management of ESKD. Haemodialysis is the only option in the country with adequate evidence from around the world supporting its ability to preserve life for many years (UK Renal Registry, 2014, United States Renal Data System, 2014). Kidney transplantation is in its nascent stages and has been associated with a host of issues that may limit the number of people that can undergo the surgery in the country, including the costs as well as availability of donor kidneys or trained surgeons. Consequently, clinicians do not have explicit discussions about the menu of choices individuals with ESKD in Ghana have as most of them are seen not to fit the tenets of biomedicine and only haemodialysis is seen as the obvious choice. What is more, evidence from this study suggests that patients with ESKD in the country do not get adequate information about haemodialysis which is the only viable RRT approach in the country.

Notwithstanding, it appears that none of the available options can aid many a Ghanaian patient with ESKD to preserve their life in the long term, whether haemodialysis or non-RRT options – whatever is available seems to be for the short term. Difficulties associated with being sustained by haemodialysis for a long period makes it a short term approach for many. They, thus, resolve to hold on to biomedicine for as long as they possibly can and hope for a better future while looking for or pursuing other options that can preserve their lives. Individuals could spend their lifetime savings on haemodialysis and may still not live beyond three months after initiation of haemodialysis once their money runs out. Death as an outcome in such circumstances remains same for those who utilise traditional medicine alongside haemodialysis or those who rely solely on traditional medicine even though there is no data on how long the latter group can survive. This seeming equipoise between haemodialysis and traditional medicine in terms of sustaining life, coupled with perceived benefits and challenges associated with each, make either of the two a viable option for several Ghanaian patients with ESKD. This is a strong indication that conservative management should be presented as a viable option for all patients with ESKD in Ghana despite comprising a relatively younger population, and a bespoke presentation of the choice is strongly advocated for. The next section would explore conservative management

as a treatment option for individuals with ESKD and its place in the Ghanaian setting.

7.4 Conservative Management and the Ghanaian Patient with ESKD

The World Health Organization (2014) explains that adults with a number of chronic conditions can benefit from early palliative care interventions. In fact, palliative care services are likely to provide the greatest benefits for patients who are most likely to die early or those who are suffering the most (Davison, 2012). This characteristically describes elderly patients with ESKD as well as those with various comorbidities who are, mostly, in many high-income countries, and existing evidence supports this (Douglas, 2014, Johnston and Noble, 2012, Morton et al., 2012, Noble, 2011, O'Connor and Kumar, 2012, Obrador, 2016). It is widely advocated that palliative care services should be offered on the basis of need as a continuum of care, starting when an incurable disease is diagnosed and increasing as the person approaches end of life (World Health Organization, 2005, World Health Organization, 2014) The situation in Ghana is different in certain respects, as has been shown in this study. Patients with ESKD in the country are relatively younger but a host of factors, including comorbidities, functional status and late presentation at renal centres makes the relatively younger Ghanaian ESKD patient more likely to die and, consequently, more likely to benefit from conservative management (Davison and Sheerin, 2014). Indeed, evidence suggests that only a few patients with ESKD who start RRT in Ghana live beyond 2 years (Eghan et al., 2009).

Yet, it is evident from findings of this study that many a Ghanaian patient with ESKD would avoid discussing conservative management as a treatment option, at least, in the initial days after being diagnosed. Consequently, conservative management is not presented or seen as a viable option when discussing treatment choices with patients with ESKD in the country. What is more, the subject of death is not openly discussed with patients with ESKD and their families in Ghana because of their general inclination towards supernatural healing or clinicians' fear of negative and, possibly, violent reactions from some patients. Some clinicians in this study actually described their experience of negative reactions of some patients and their significant others on some occasions where the subject of death from ESKD without dialysis was broached. As a

result, some of them deliberately avoided discussing treatment options for ESKD or withheld information about death as an imminent outcome without RRT. Values, fears and wishes of individual patients influence their preference for palliative and end of life care while values, beliefs, and knowledge of clinicians influence integration of palliative care in predialysis education and discussions on treatment options (Bull et al., 2014, Davison, 2006). The implication is that when clinicians include conservative management in their discussion of treatment options, patients with ESKD and their families are more likely to consider it as a potential choice. However, when conservative management is not presented as a viable option to patients with ESKD, then they are less likely to consider it or even ask about it.

A lack of training on palliative care among clinicians in renal settings in Ghana is also a potential contributor to this as clinicians in the renal setting are not familiar with palliative care services. Indeed, similar studies elsewhere have shown that clinicians either felt that patients with ESKD did not want to know more about poor prognosis of their disease or the clinicians were uncomfortable holding discussions about end-of-life care and conservative management because of their lack of experience on the subject (Lazenby et al., 2016, Song et al., 2013). Davison and Sheerin (2014) suggest that, in situations where RRT has no survival advantage or improvement in the quality of life, palliative care will ensure quality care as patients near the end of life. In relation to the above, the Ghanaian patient with ESKD who has a 32.4% chance of dying within the first 90 days of starting haemodialysis or the majority that will die within 24 months of starting treatment (Eghan et al., 2009) could have quality care as they near the end of life. However, findings of this study indicate that patients with ESKD in Ghana initiate and maintain dialysis until all hope for cure or improvement in health is lost after trying out several avenues, or the stage where continuing dialysis is practically impossible. Moreover, lack of formal training of clinicians on palliative care makes them unprepared to initiate conversation on the subject. These leave little or no room for consideration of palliative care.

Ghana is classified as one of 74 countries that have patchy palliative care services that are heavily donor-dependent for funding and not well supported (World Health Organization, 2014). Palliative care services have not been publicised as they ought to be in the country, contributing to

reduced awareness among the citizenry. The non-existence of a clear pathway leading to conservative management as well as the lack of healthcare policies to promote conservative management of ESKD serves as hindrances to promoting conservative management in the country. These call for urgent efforts to explore ways by which conservative management can be expressed as a viable option for some of the ESKD population, especially those with severe co-morbidities or impaired functional status and are less likely to derive greater benefits from dialysis. An approach is to consider palliative care as an individual's human right which would then contribute to coming up with measures that would not infringe upon these rights. The Public health model for palliative care seeks to achieve that, advocating for policy support in countries where palliative care is not fully developed (Stjernswärd et al., 2007, World Health Organization, 2014). Having clear-cut policies would ensure that there is a clear pathway that will be of utmost significance to the individual who needs palliative care. For instance, conservative management could be presented as a follow-up approach for haemodialysis in Ghana, considering the fact that some patients with ESKD initiated treatment in an attempt to buy time while they braced themselves up for imminent death. What is more, this treatment pathway could be substantiated by statistics on low survival pattern of patients with ESKD on haemodialysis in Ghana, as was reported in the study by Eghan et al. (2009). Conservative management can also succeed in Ghana when patients accept the biomedical explanation of ESKD as a terminal disease without RRT and clinicians undergo rigorous training on palliative care and how to initiate and sustain discussions on the subject with patients and families who may benefit from it the most.

The next section will discuss factors that actually influenced decisions of the Ghanaian patient with ESKD from the point of noticing symptoms to initiating treatment after an accurate diagnosis has been established and beyond. This will be discussed in light of global literature.

7.5 Factors Influencing Patient Choices and Decision Making in ESKD

This study has shown that individuals with ESKD undergo a journey, and a conceptual map depicting this ESKD patient journey in Ghana has been presented in Chapter 5 (page 144). Key phases where individuals face decisions of greater significance to their lives were emphasised in the

pathway. Several factors were identified to influence decisions that are made and these were organised into four main categories – personal attributes, finances, healthcare system, and support network (Figure 4). This section will discuss these factors while exploring similarities and differences between these in the Ghanaian setting and globally. It will argue that the impact of these factors on patients' decisions varies based on their geographical location.

7.5.1 Personal Attributes

It is undeniably clear that an individual's values and beliefs play a central role in their responses to changes in their usual states of health as well as life-threatening diseases. In fact, patient participants of this study described initial experiences and perspectives that were typical of two knowledge modalities of health and illnesses among Ghanaians, as identified by De-Graft Aikins (2004) – common sense knowledge and religious knowledge. Common sense knowledge, which refers to meanings that individuals ascribe to their health and illness experiences based on social observations and interactions, was mostly dominant. This was particularly common among participants who had mild or non-specific initial symptoms. They started by trying to ascertain the cause of the changes they were noticing and interpreting what they could mean. Such participants either performed actions that they believed would have a positive influence on their health or stopped certain actions that they believed to have contributed to their symptoms. Seeking biomedical care was a commonplace albeit that did not always lead to an immediate accurate diagnosis of ESKD.

Patient participants described perspectives that reflected religious knowledge when faced with cardinal manifestations of ESKD without RRT such as ascites and pedal oedema. This was especially common among individuals with no known CKD precursor condition such as diabetes mellitus or hypertension. One would have expected those experiencing such cardinal symptoms to seek biomedical care as a first option. However, as these signs are generally associated with being cursed in many Ghanaian communities, suggestions of seeking spiritual care made some of them unsure of what to do. In fact, the influence of an individual's religious beliefs on understanding the disease process has been reported among patients with ESKD in Taiwan (Lin et al., 2005), implying that a person's religious beliefs shape their health-related values and practices.

However, patient participants of this study did not always take full responsibility for actions that reflected their religious beliefs except for personal prayers. Instead, they generally attributed such actions as seeing a spiritualist or a fetish priest to explicit or tacit coercion by their families or significant others and emphasised how they argued against or resisted such suggestions, presenting themselves as main actors of the decision making. Only two participants openly admitted that their religious knowledge informed, and was still informing their health-seeking decisions, making seeking prayers in a church an integral part of their health-seeking. Indeed, it seems generally acceptable to perform religious practices such as prayers in a church, but not going to a fetish priest because of the dominance of Christianity in Ghana. What is more, participants had gained an understanding of ESKD from frequenting their respective renal centres and, knowing that clinicians do not encourage alternative treatment forms for ESKD, were less likely to openly admit performing such actions. Lin et al. (2005) also reported a similar finding in their study that patients with ESKD in Taiwan are less likely to talk about using alternative approaches in a typical biomedical setting. In this respect, it would have been appropriate to explore perspectives of patients with ESKD who are solely using alternative therapy for the disease. However, it was not possible to identify patients with ESKD outside a typical biomedical setting and interview them because of the terminal nature of the disease without RRT.

Perceptions about how the disease, as well as its treatment, would affect an individual's life guide decision making on the treatment of ESKD. Indeed, the systematic reviews of Murray et al. (2009), Morton et al. (2010), Harwood and Clark (2013) and Hussain et al. (2015) identified that patients with ESKD considered personal factors such as how treatment would affect their lifestyle and quality of life, risk-benefit analysis, and their perceived burden to other people when making treatment decisions. But this personalised decision is mostly made with reference to other key social factors, including opinions of families, friends and other patients with ESKD (Harwood and Clark, 2013). Little consideration is usually given to the effectiveness of the various dialysis modalities and this may be due to clinical equipoise between outcomes of these options. Similarly, patient participants of this study were influenced by their values and beliefs while making decisions about their care once a diagnosis of ESKD was confirmed. They chose to start treatment with the

main aim of preserving their lives because they did not want to die prematurely. Yet, some participants were nurturing expectations of a cure of the disease.

As has been explained earlier, choices of the Ghanaian patient with ESKD, in terms of treatment, are different from those in many high-income countries. Disease causal beliefs are significant predictors of whether an individual would choose biomedicine alone, in the form of haemodialysis, or use both biomedicine and alternative medicine concurrently, or even use traditional medicine alone for managing their disease. This study has revealed that there is a higher tendency for the Ghanaian patient with ESKD to practice healer shopping while on treatment. While this may be because some cannot afford to pay the higher costs of treatment by haemodialysis, others do this because they find it hard accepting ESKD as a disease without a cure and potentially life-threatening.

7.5.2 Finances

This sub-section will emphasise the financial stance of an individual as a linchpin to initiating RRT in Ghana and in other African countries. It will examine other contexts where the individuals' or their families' finances do not play key roles in receiving RRT. This will lead on to a discussion of different outcomes that finances can bring to the prognosis of ESKD in different geographical settings with different healthcare financing policies.

A recent prospective UK study of patients with ESKD commencing RRT identified a mortality rate of 41% and 60% after 5 years and 10 years respectively. Cardiovascular events accounted for 39% and 30% of the deaths at 5 years and 10 years respectively (Browne et al., 2014). This confirms that, indeed, patients in the UK and other high-income countries are maintained on RRT for as long as their health condition permits, or when a personal decision is made to withdraw from RRT. Yet, Eghan et al. (2009) partly attributed early mortality observed among incident haemodialysis patients in a renal centre in Ghana to financial constraints. Moreover, only 3 out of 141 incident haemodialysis population could finance their treatment beyond 12 months in a study in Nigeria (Arije et al., 2000). Seventy-seven percent of participants of this study were making full out-of-pocket payments for their treatment. Unsurprisingly, only four of the twelve participants receiving haemodialysis had been receiving this RRT for more than 2 years, with only one of these four

participants making full out-of-pocket payment for treatment. In other words, consistent financial support is a prerequisite for patients with ESKD to survive on haemodialysis for up to a year and beyond in Ghana and several other low- and middle-income countries. This underscores the influence of adequate finances on treatment outcomes in Ghana and in other similar settings where there is no health insurance coverage for ESKD management.

Those who had to rely on others for a majority of the amount needed for treatment did not have much power to choose treatment and when to start it. It is commonplace for people living with chronic diseases in Ghana to have to depend on their families for financial support and this dependence can result in family tensions and abandonment (De-Graft Aikins, 2007).

Availability of haemodialysis and other renal services for ESKD management, irrespective of how few they are, does not address the issue of financial inaccessibility. Many patients with ESKD survive on haemodialysis for only a few months as they cannot finance it for longer periods. This could have catalysed the development of palliative care services for individuals with ESKD in the country or implementation of universal health coverage. However, this is not the case as deaths mostly occur in patients' homes or at various emergency centres with no structured palliative or end of life care. Moreover, the increasing of NCDs prevalence in low- and middle-income countries serves as a huge impediment to achieving unrestricted access to healthcare mainly because of the double burden of communicable and non-communicable diseases (De-Graft Aikins et al., 2014).

Ghana has two main policies to promote universal health coverage: community-based health planning and services (CHPS) programme which focuses on training community health workers to provide preventive and curative healthcare services in remote and underserved areas of the country, and the NHIS which has been described earlier (De-Graft Aikins et al., 2014, National Health Insurance Scheme, 2009). The NHIS is being applauded internationally (Jehu-Appiah et al., 2011, Knaul et al., 2012, Latko et al., 2011). However, the higher costs of haemodialysis have led to it being left out of treatment catered for by the NHIS, even for the management of acute kidney injury. In fact, the huge costs associated

with ESKD and RRT can collapse an individual's finances as well as health insurance systems and plans for universal health coverage in economies like Ghana. However, interventions that are aimed at reducing the increasing incidence of CKD and slowing its progression to ESKD, subsidies on treatment costs, and multiple stakeholder support can contribute to reducing the huge financial burden associated with RRT for individuals and their families in Ghana (Teerawattananon et al., 2016). Expanding the NHIS to cover aspects of treatment costs for ESKD would be a key step to relieving the financial burden on patients in the country.

7.5.3 Healthcare System

There have been concerted efforts to diagnose CKD in its early stages in many high-income countries and to institute measures to delay progression to ESKD. Other strategies also seek to reduce late presentation for renal services. In the UK, for instance, persons who present to a renal centre less than 90 days before starting RRT are said to have presented late (Farrington et al., 2009). The percentage of patients presenting late has been decreasing steadily over the years, decreasing from 23.9% in 2006 to 18.4% in 2013 (Gilg et al., 2015). However, several participants of this study presented in the later stages of the disease, with clinicians estimating that about 90% of patients getting care in the various renal centres present late. The results chapter elaborated the processes by which these late presentations occur, detailing the patient journey from 'noticing symptoms' to 'being diagnosed with ESKD' as significant to these late presentations. However, two key issues in relation to the Ghanaian healthcare system are vital to patients presenting late and their choice of treatment modality – accessibility to renal services and availability of RRT modality.

All ten renal centres in Ghana are located within only three of the ten administrative regions of the country. The implication is that many persons with ESKD may never be diagnosed in regions without renal centres because of the potential lack of expertise. Those who are diagnosed with ESKD would have difficulties accessing treatment in a renal centre. Piesie and Akonta, two participants of this study, lived outside regions with renal centres and had to travel overnight in order to access care the next day. This was possible for them because they were yet to start haemodialysis and visited the renal centre only once every month. Once they start haemodialysis, they would be required to travel to the

renal centre, at least, twice each week which would be very stressful. They would then have one of two realistic choices – either relocate to a region with a renal centre or quit seeking renal care. The lack of renal centres could also indicate that awareness of renal diseases and their management as a clinical specialty is low within the country. This could have had a significant influence on the wrongful diagnosis of some of the participants when they sought care from some health facilities. Access to a nephrologist is also another challenge even when an accurate diagnosis of ESKD has been made. There were also assertions that some clinicians do not refer persons with ESKD to renal centres because they believe death is inevitable. Such factors have a tremendous influence on patients presenting late at renal centres.

The second factor, which is also vital to patient decision making on the choice of RRT modality lies in their availability. It is clear that patient choices are influenced by available options. This signifies that patient decision making is greatly influenced by options presented by the healthcare system. Haemodialysis is the commonest RRT modality globally (Martchev, 2008, Zhang et al., 2007) and is the only established modality in the country in its conventional form. Kidney transplantation is in its nascent stages. As a result, patients' choice is limited to haemodialysis, and kidney transplantation in some instances, when biomedicine is preferred. There are no peritoneal dialysis or conservative management services in the country, hence, these treatment modalities are not utilised by Ghanaian patients with ESKD in the management of their disease.

Informational needs of patients, especially those with chronic diseases, are mostly difficult to meet, even in high-income countries, and those with ESKD are not exempted (Murray et al., 2009). Addressing informational needs of such patients is a prerequisite to involving them in decision making albeit some may not show active desire for information (Chewning et al., 2012, Légaré and Witteman, 2013). Various decision supports, including patient decision aids, have been used to enhance patients' knowledge in order to empower them for decision making (Murray et al., 2004, Stacey et al., 2011). This study also identified significant informational needs among Ghanaian patients with ESKD regarding causes of the disease, renal replacement therapy and its outcomes as well as conservative management as a management approach. Indeed, disease causal beliefs as well as sources of information other than clinicians might

have contributed to these information needs. However, there are currently no decision aids or informational leaflets to meet informational needs of patients and to support their decision making.

7.5.4 Support Network

This sub-section will examine support that is available to patients with ESKD in Ghana while making their decisions and compare it to other countries. It will argue that while individuals with ESKD in Ghana get massive support from their families and communities in some instances there is a perceived deficit in information provision when making decisions.

Individuals with chronic diseases require support from family members and significant others to achieve effective self-management goals (Novak et al., 2013). Thus, although decisions are personal, individuals are most confident about their choices when they are convinced that they can rely on their families or significant others for support when the need arises. Studies included in the systematic reviews of Murray et al. (2009) and Harwood and Clark (2013) were conducted mainly in North America and Western Europe, where there has been increasing emphasis on promoting patient choice and autonomy in health care decisions (Chewning et al., 2012, Fotaki, 2009, Harwood and Clark, 2013, Murray et al., 2009). Yet, patients in these studies considered how burdensome they could be to others when deciding whether to initiate RRT and which modality they should opt for. Increasing emphasis on patient autonomy implies that views of the patient are paramount to those of their family or significant others when these conflict. One would, therefore, anticipate perspectives or wishes of family members and significant others to be influential in decisions that are made about care. It is in this light that support from families and other sources are considered a key influence on decision making among the ESKD patient population.

Azétsop and Rennie (2010) argue that patient autonomy should not be an absolute ethical principle that guides patient decision making in resource-limited countries as an effort to correct the predominant paternalism that exists in such settings. They express reservations about ethical principles that are not rooted in family and social relationships in such settings and suggest combining community- and tradition-oriented views with trust, partnership and solidarity in addition to autonomy as an alternative to

paternalism. Personal factors alone cannot account for decisions that the Ghanaian patient with ESKD makes even though they play a central role. These factors intertwine with a host of other factors to inform patient decisions. For example, patient participants of this study needed financial support from their families in several instances, implying that they needed assurance of this financial support before biomedical treatment could start. Indeed, many participants of this study elaborated on the significance of their families in their general management. Seeming conflicts only arose in situations where participants resisted suggestions by their significant others to use alternative treatment approaches in place of, or alongside haemodialysis where this was against their personal values and beliefs.

As with all other chronic diseases, support from family and significant others cannot be overlooked when achievement of treatment outcomes is a priority. Patients' decisions around treatment initiation have been described mostly as personal. However, the support that patients with ESKD get, or its lack thereof, tends to reinforce their choices or make them consider other alternatives respectively. Participants described support from key sources including clinicians, family, significant others, other patients with ESKD, and, in some cases, from their communities. Various forms of support were described based on what stage of the conceptual pathway the participant was at. For instance, when searching for a cause of their symptoms, some participants elaborated on persistence from their friends as instrumental in making them decide to seek care in some health facilities. Others described how family and their communities contributed to paying for their treatment when the need arose. Clinicians provide information to participants, and emotional, psychological, social, and even financial support in some instances. Patients with ESKD share their experiences with one another in the various renal centres. The two participants who had kidney transplantation as RRT had family members donating organs for the surgery. Indeed, the support network is highly instrumental in promoting well-being of the individual right from the initial stages when they do not fully appreciate the significance of the changes in their health status up until the very 'end'. The existence of such emotional, psychological and practical support have been found to provide a context that allows individuals with ESKD to 'be themselves' while integrating their illness experience into their day-to-day lives (Davison and Simpson, 2006). Some of the participants of this study had expressed a desire to be on RRT but a lack of financial support

prevented them from initiating treatment. Participants receiving RRT but without consistent support expressed fears about sustaining it. But, per the objectives of this thesis, how do these forms of support compare with support available to patients with ESKD in other geographical locations?

Wilson et al. (2015) explored perspectives of 30 patients and clinicians in three haemodialysis units in the UK on self-management using focus group interviews. They identified a major category of the haemodialysis unit as a cultural field, a family with clinicians and patients providing emotional, social, and informational support to aid in management of ESKD. However, clinicians in the Wilson et al. (2015) study had concerns about the possibility of misinformation when some patients adopt specific information for other patients while exchanging information. This study identified the existence of a similar network of support across all the renal centres and similar concerns among clinicians in Ghana. A clinician in this study explained that some patients believe that information from other patients is more authentic and practical since they might be experiencing similar challenges.

Although clinicians provide information to patients in the Ghanaian renal centres, evidence from this study implies that patients perceive information provided by clinicians alone as inadequate to support an informed decision at the start of treatment. Clinicians cited lack of time and their workload as factors contributing to their inability to provide adequate information. However, some clinicians argued that patients might have forgotten some of the information that was provided over the period. Indeed, inadequate information provision has also been reported by patients with ESKD in some high-income countries. In a recent study, Song et al. (2013) identified that majority of the patients interviewed from fifteen different renal centres reported that information provided did not prepare them adequately for their decision to start dialysis. Participants of this study, as in the study by Song et al. (2013), were mostly aware of the certainty of death without dialysis and dialysis as a life-long treatment but not complications and mortality after initiating dialysis as at the time of making their decisions. This is because their decisions were driven by the need to preserve life at all cost, with other significant details of what dialysis entails, such as the impact of dialysis on their day-to-day lives, being overshadowed. Hence, it is unsurprising that many patients report

inadequate information provision at the outset of treatment after they have become familiar with what treatment entails.

Professional organisations such as the American Society of Nephrology, Renal Physician's Association, and the American Board of Internal Medicine have endorsed shared decision making approach for decisions on dialysis initiation in cognisance of the fact that there is no best option and each encompasses factors that different individuals may ascribe different significance to (Tamura and Periyakoil, 2013). Yet, Song et al. (2013) reported that only 13% of their participants perceived decision making on their dialysis initiation to have been collaboratively made between them and their clinicians. Only 39% were content with the processes by which decisions were made about their dialysis initiation. Although participants of this study mostly made the decision to initiate treatment, almost all of them believed that they were not adequately informed, or were given false assurances and were unhappy with the process. On the contrary, clinicians maintained that they provide the necessary information needed to make decisions on dialysis. They, however, suggested that some patients ignore information provided by clinicians and are inclined to adhere to information provided by other patients or significant others when making decisions.

Clinicians in this study reported that family and significant others were mostly present during discussions, where they were told about the need for dialysis and this was corroborated by some participants. Clinicians encouraged this practice, knowing that treatment for ESKD in the Ghanaian setting is complex and patients would require greater support, especially financial, for treatment goals to be achieved. However, Song et al. (2013) report that over half of their participants (53.5%) were alone when they were asked to make decisions about dialysis initiation. This could be attributed to an overemphasis on patient autonomy to the detriment of family support in many high-income countries. It could also be that clinicians perceive that once patients do not have any cost issues to ponder over, they would not be relying on others for support during their treatment. The potential benefits of having family and significant others around for discussions about treatment include being made aware of the care needs of the patients and feeling actively involved in the management. Indeed, such is the practice recommended by Azétsop and Rennie (2010) in settings like Ghana.

Schell and Arnold (2014) explain that an initial discussion with newly diagnosed patients with ESKD is always difficult for a host of reasons. Firstly, words alone are not enough to explain to patients and prepare them for life on dialysis. Secondly, it is impossible to ascertain how any individual will fare on dialysis, especially for the elderly. Lastly, but more commonly, all possible complications from starting dialysis cannot be compared with the certainty of dying without dialysis, leading many individuals to try out dialysis as a 'default' decision. They suggest that dialysis patients are, mostly, inadequately prepared for the end of life. They, therefore, recommend having a second discussion with patients three months after starting dialysis, hoping that they would have had a first-hand experience of dialysis and to include that in their subsequent decisions. A second conversation, they believe, would also allow some of the challenges associated with life on dialysis to be addressed, and to make appropriate referrals when palliative care becomes necessary. They add that a second discussion could also reduce forgetfulness among patients with ESKD on what key information they need for their treatment decisions, as was suggested by clinicians in this study. Participants of this study reported being educated more about their condition each time they visited. However, they did not get the opportunity to formally discuss their treatment decisions again. Many of them explained that they would still have chosen to start dialysis if they had to make a decision again, implying that they are content with dialysis and all its associated demands on their life.

This section has explored four key factors that influence decision making among patients with ESKD in Ghana, and the similarities and differences between these factors in different geographical locations. Decision making was seen as very personal by most of the participants of this study. Personal factors in this study were similar to those identified in studies on patient decision making in ESKD in several instances. Patient values and beliefs were instrumental. An individual's interpretation of the disease process influenced their response and decision making. Varying disease causal beliefs resulted in some patients with ESKD choosing CAM alongside biomedicine, which is clearly different from what has been reported in studies from several high-income countries. A support network is seen as essential in achieving management goals of chronic diseases and its presence or absence influences choices of the patient with ESKD. Support network identified in this study was described as similar to what exists for

other patients with ESKD elsewhere. The remaining two factors, health system and finances, were seen to be different in the Ghanaian setting. The health system in Ghana presents options that are different from those presented to patients with ESKD in several high-income countries, causing the Ghanaian patient with ESKD to greatly experience restrained options and resulting in differences in choices made. 'Finances' is the only factor that is entirely different in the Ghanaian setting as compared to many other high-income settings owing to the lack of health insurance policies to take care of costs of treatment. This impacts the length of time by which patients with ESKD are sustained by the only viable RRT option in the country and the concomitant use of other options.

7.6 Summary of Chapter

This chapter has discussed key findings of this study in relation to existing literature. The chapter has explained that the decision to start haemodialysis is mostly shared between clinicians and patients and/or their families although the lack of choice and the different healthcare context make the objectives of this process different from that which is known in many high-income countries. Conservative management as an alternative to RRT in the country has also been discussed. It has also explained that personal factors and support network inform decisions of patients with ESKD in Ghana significantly and this is similar to the global literature. However, differences in healthcare systems and financing make decisions more stressful for the Ghanaian patient with ESKD. The chapter has also explained that epidemiologic transition and the double burden of communicable and non-communicable diseases have contributed to creating a stressful context where the Ghanaian patient with ESKD is unaware of the long-term management goals of NCDs at the onset of treatment. It argued that although there is, seemingly, a lack of choice for the patient with ESKD in Ghana, this lack of choice also exists for patients in some high-income countries under certain circumstances. While patients with ESKD in Ghana are aware of this lack of choice, they anticipate clear policies that will enhance their decision to choose life through receiving RRT as happens in many high-income countries. Some patients with ESKD in Ghana pursue other non-biomedical options that are in line with their values and beliefs albeit there is no clear evidence supporting these options.

The next chapter will present the substantive theory that has been generated from this study and as well as explain how that is applicable in the Ghanaian setting.

CHAPTER 8. RECONSTRUCTING HEALTH EXPECTATIONS – THE SUBSTANTIVE THEORY

8.1 Introduction to the Chapter

This chapter brings together the findings and discussion to show how the substantive theory has emerged through constant comparative analysis of the data. The substantive theory of 'reconstructing health expectations' will be presented and explained to highlight how the process of making decisions on ESKD management is different in Ghana and other similar settings as compared to other high-income countries. The implication of this theory will be described and ways of utilising this theory to support the care of patients with ESKD in Ghana will be recommended.

8.2 The Substantive Theory

Through constant comparative analysis, writing memos and theoretical sensitivity, 'confronting reality: adjusting to a new life' was identified as the core category. This section will explain the substantive theory of 'reconstructing health expectations' that was generated from analysis of data for this study. Each of the four categories and their subcategories identified in this study has been explained in detail in the results chapter. The relationship between the core category and the remaining categories, as shown in the conceptual map (Figure 5, page 144) has also been explained in the section on the ESKD Patient Journey. In fact, the conceptual map shows the entire ESKD patient journey in Ghana, showing various routes and their potential outcomes. This conceptual map also subsumes the substantive theory that has been generated from this study, which will now be explained.

This study found that many patients with ESKD in Ghana, at the time of making a decision about their treatment, are unsure of what the goals of management of the disease are. Their initial decisions about treatment are mainly guided by expectations of a cure and a belief that things could be better. They try out various approaches and may end up raising money through various avenues in order to finance their treatment. Individuals begin the process of changing their perspectives and expectations about ESKD and its management once they come to a full realisation that the disease is terminal without any form of RRT. This usually happens after they have been on treatment for some time. Their subsequent decision

making, therefore, reflects their new understanding of the disease and its management goals, as has been explained in the 'confronting reality: adjusting to new life' category. Thus, they move from expecting cure while on treatment to managing the disease to survive.

Data from interviews with clinicians confirmed this key finding in the patient data that many individuals diagnosed with ESKD start treatment with expectations of a cure. Clinicians added that such individuals perceive any different opinion as antagonistic and untrue, and explained feeling helpless because of such trends. However, continuous informational and other forms of support from clinicians help individuals with ESKD to modify their perspectives and health expectations while confronting realities of the disease and its management.

Certainly, individuals diagnosed with ESKD confront mortality when making decisions about their treatment (Morton et al., 2010). Preserving lives and improving the quality of these lives are central to the management of ESKD globally (Boateng and East, 2011, Kelly-Powell, 1997). However, the conditions under which the Ghanaian patient with ESKD make the decision to preserve their lives, including the lack of biomedical options, make this a unique process to the patient in Ghana and, probably, in similar settings. Indeed, various studies on decision making in ESKD conclude that personal values and beliefs are central to patients' choices (Harwood and Clark, 2013, Kelly-Powell, 1997, Morton et al., 2010). Thus, individuals' beliefs that there could be a better tomorrow in terms of improvement in their health status serve to spur them on to do anything within their means to preserve their lives 'for the moment'. However, these beliefs and expectations of a future without ESKD give way to accepting the terminal nature of the disease and managing it as a long-term condition on dialysis for survival. Convergence between individuals' experiences of realities of living with and managing ESKD, and support from clinicians in the renal setting ultimately leads to a reconstruction of health expectations that commensurate management goals of ESKD (Figure 6).

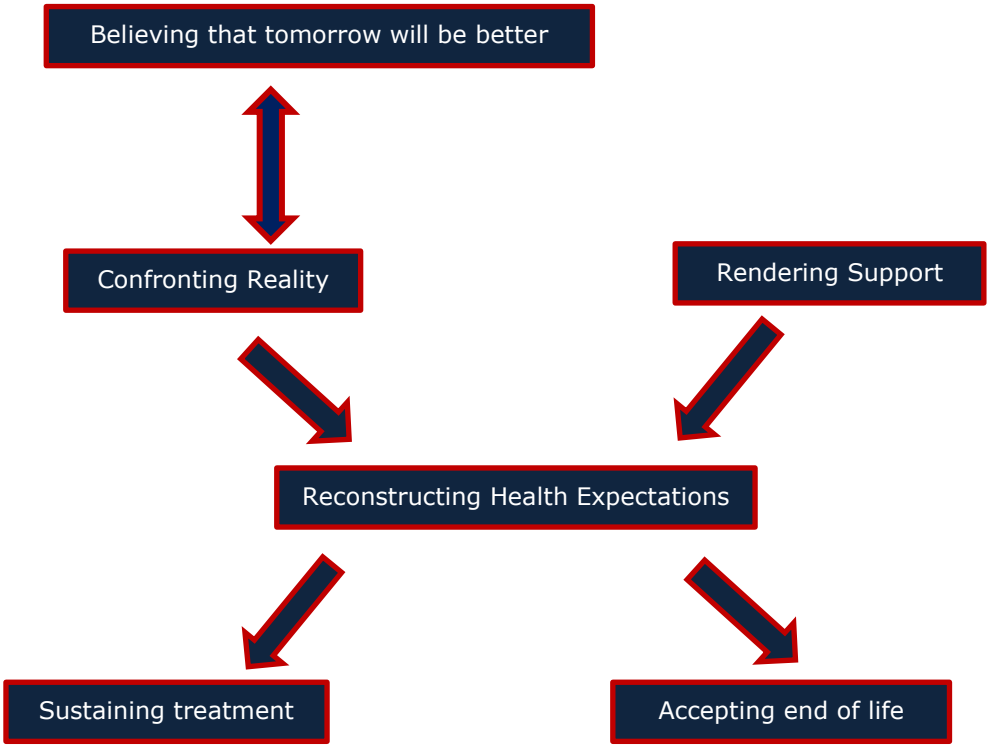


Figure 6: The Theory of Reconstructing Health Expectations

The substantive theory of reconstructing health expectations, therefore, stipulates that an individual, once diagnosed with ESKD in Ghana, would go through various processes before reconstructing their health expectations from that of a cure to that which is commensurate with management goals of ESKD. The key concepts and processes are as follows:

a. Many persons who are diagnosed with ESKD will have limited or no information about ESKD as a terminal disease without RRT
b. Once a diagnosis of ESKD is confirmed, affected individuals obtain information about the disease from various sources to influence their decision about treatment
c. Many persons initiate treatment with the hope that they would be cured of the disease, irrespective of being aware that the disease could be terminal
d. Treatment is in various forms, including haemodialysis, kidney transplant, and utilising traditional medicine or faith-healing; healer shopping is a common practice

e. Being sustained on dialysis for some time exposes the individual to the realities of being diagnosed and living with ESKD, its treatment and associated complications
f. Individuals appreciate the terminal nature of the disease and modify their health expectations of a cure to that of managing a long-term, potentially terminal disease, and do all they can to achieve goals of managing the disease with the help of clinicians.

The next section will now discuss epidemiologic transition and the essence of reconstructing health expectations in response to changing disease trends.

8.3 Epidemiologic Transition: Reconstructing Health Expectations of the Ghanaian Patient with ESKD

This section will consider the epidemiologic transition. Firstly, changing trends of diseases globally and the double burden of communicable and non-communicable diseases in Ghana will be discussed. Secondly, challenges this poses for patients with ESKD and how they cope with the disease will be explored. The challenges this poses for clinicians and how they contribute to achieving goals of managing the disease will also be discussed. Thirdly, practical approaches that could be employed by healthcare institutions and governments in their bid to reduce the impact of the new trends of diseases will be discussed. Finally, existing policies on addressing NCDs in Ghana will be critiqued.

It is now general knowledge that patterns of diseases are changing globally, following Omran's (1971) theory of epidemiology of population change. While many low- and middle-income countries are experiencing contemporary or delayed epidemiologic transition, the continued presence of communicable diseases makes such countries experience a double burden of these diseases. Interestingly, the citizenry of most of these countries are more familiar with principles and policies used in managing communicable diseases such as having curative therapy that usually lasts for a short period. They, thus, tend to have similar expectations of receiving a curative treatment with a shorter duration when being managed for non-communicable diseases. Lifestyle modification approach to self-management and lifelong treatment seem new and challenging to implement. For instance, many participants of this study had expectations that dialysis would cure their disease within a short period, implying

limited awareness of management approaches and goals associated with NCDs. However, such expectations are also partly attributable to the individual's health, religious or cultural beliefs.

Participants' beliefs about causes of ESKD informed their expectations of a cure through other approaches other than biomedicine. Those who utilised traditional medicine alongside dialysis had hopes that it could cure their disease. The pursuit of healing through prayers and other faith-related actions is popular, especially among individuals with long-term illness (Tomkins et al., 2015). In fact, individuals who are diagnosed with terminal diseases are more likely to try approaches within and outside biomedicine in a bid to reverse the situation. Ghanaians are generally religious and many believe that cure for any kind of disease is possible through divine means, making the pursuit of faith-based healing increasingly popular in the country (De-Graft Aikins et al., 2014). All participants believed that prayers, alongside haemodialysis, were integral in achieving their care objectives while others pursued faith-based healing or traditional medicine at a point in their journey. Indeed, familiarity with goals of managing communicable diseases which are mostly curable results in many Ghanaians expecting that all forms of diseases could be cured. But these expectations are mainly attributable to lack of awareness of the changing pattern of diseases globally.

In the face of such shifts in disease patterns and health beliefs, one would expect formulation and implementation of policies that seek to emphasise attitudes that could prevent dire consequences of these new trends of diseases in the country. Suggestions have been made to formulate sustained health-systems response that will detect NCDs and provide comprehensive treatment plans using duly trained healthcare professionals and innovative technology (Dalal et al., 2011, Kapiga, 2011). Another proposal concerns development and sustenance of health information systems that would track these changing disease trends effectively for utilisation by national health planners and policy makers (Byass et al., 2014, Echouffo-Tcheugui and Kengne, 2011). Task-shifting management of key NCDs to nurses is also reported to have contributed to achievement of effective control of chronic diseases (Echouffo-Tcheugui and Kengne, 2011). However, many sub-Saharan African countries have not adapted processes or policies within their healthcare systems to address the changing trends of diseases (Byass et al., 2014, Cobden et al., 2010,

Mbanya et al., 2006). What is more, there seems to be inadequate measures to track changing trends of disease in an effective way (Byass et al., 2014). For instance, there is currently no renal registry in Ghana although processes to establish one have begun. A general assumption that chronic diseases are rare or do not present substantial public health challenges undermine formulation and implementation of policies targeted at addressing the increasing prevalence in many low- and middle-income countries. (De-Graft Aikins, 2007) Hence, users of such healthcare systems may not be well equipped with information on what kinds of diseases are increasingly becoming prevalent, how to manage them and how to avoid them.

Ghana has made efforts at formulating policies to address and adapt to the epidemiologic transition in the country, with Regenerative Health and Nutrition Policy a key one (Agyei-Mensah and De-Graft Aikins, 2010, Ministry of Health, 2007, Ministry of Health, 2012, Tagoe and Dake, 2011). Indeed, primary prevention is instrumental in addressing epidemiologic transition and the increasing prevalence of NCDs, more especially in settings with limited healthcare expenditure. Yet, knowledge of risk factors of these NCDs is poor among the citizenry (De-Graft Aikins et al., 2010). Findings from this study suggest that many individuals who developed ESKD as a complication of diabetes mellitus or hypertension had scanty information on ESKD as a possible complication of their disease. Some participants only heard about ESKD for the first time when they were diagnosed. Some of those who had heard about ESKD as a complication of a chronic disease they have did not feel empowered with information on how to prevent it. Some also believed that their disease could be cured with time if they adhered to prescribed treatment. Indeed, low numbers of clinicians, inadequate healthcare infrastructure, and limited patient knowledge on self-management has been associated with many complications and deaths in Ghana, Cameroon and other low- and middle-income countries (De-Graft Aikins et al., 2010). This implies that primary and secondary prevention strategies may not be achieving their expected outcomes in the country. What is more, there is no existing national renal registry to track the trends of ESKD in the country and to institute appropriate healthcare responses to the changing trends. Certainly, there is urgent need for coordinated healthcare policies, more research and appropriate technology in response to these changing trends, and well-

trained healthcare professionals to implement these policies in the country (Kapiga, 2011).

Evidence from this study suggests that existing health policies in Ghana are not targeted at ESKD. Regular monitoring of individuals with precursor chronic diseases of CKD in order to ensure early detection and adoption of strategies to slow progression of CKD is lacking. With acute health conditions, playing passive sick role may promote adherence to treatment as the patient has certain obligations to fulfil, including increased tendency to rely on family and clinicians for care and receiving treatment (Griva et al., 2013). The situation is, however, different with chronic conditions where the individual is encouraged to actively self-manage the condition, and playing the sick role may deter them from active self-management. When people are used to acute health conditions, they are more inclined towards playing the passive role and leaving all decisions to clinicians. It is when people embrace the concept of epidemiologic transition and how disease trends are that they make efforts to change their thinking about management of diseases. It, therefore, comes as no surprise when many participants of this study were looking forward to being cured when they were discussing treatment options for their disease – many Ghanaians are not aware of the changing pattern of diseases in the country. As has been stated earlier, expectations of cure also suggest a limited awareness of management goals of NCDs although this can partly be attributed to the individual's health, religious or cultural beliefs. Yet, many of the participants who had started treatment had gained more information about ESKD and its management over time. Consequently, such participants had reoriented their health expectations to that of managing their condition to survive without having expectations of a short-term treatment or a cure. Thus, reinforcement of decision to continue receiving dialysis was made in line with management goals of ESKD.

8.4 Review of Extant Literature: Relationship between the Substantive Theory and Existing Theories on Chronic Illness Experiences

It has been explained that a second literature review in grounded theory studies allows newly emerging concepts and theory from a new study to be compared with concepts and theories from existing literature (McCann and Clark, 2003, McGhee et al., 2007). This section will discuss various components and concepts of the theory of 'reconstructing health

expectations' in relation to existing concepts and theories on the experiences of living with and managing chronic diseases.

There has been a longstanding interest in exploring how individuals respond to and manage various diseases. Initially, this focused on acute disease conditions, with Parsons' sick role theory a commonly cited one, especially within medical sociology (Williams, 2000, Williams, 2005). Parsons' work described illness as a form of social deviance, interfering an individual's normal role capacity at work and in the family and the individual, assuming the sick role, is exempted from some normal obligations while seeking competent care in order to get well (Griva et al., 2013, Parsons, 1951, Varul, 2010, Williams, 2005). With changing trends of diseases from acute and infectious conditions to chronic and non-communicable conditions came criticisms of Parsons' sick-role concept and the need to appreciate how individuals transition in their responses to various long-term disease states (Bury, 1982, Reeve et al., 2010, Varul, 2010, Williams, 2005). For instance, Varul (2010) argues that an individual may not be able to return to their normal role capacity because of the presence of a chronic disease while it is rarely the same for acute diseases.

Many chronic diseases or NCDs, by their nature, start insidiously, 'creeping up' instead of 'breaking out', and may not be seen as incapacitating for the individual until in their advanced stages (Bury, 1982, Bury, 1991). However, the individual mostly experiences several changes in their bodies or roles and are required to accommodate these changes while seeking to keep their lives as near normal as possible. Bury (1982) describes these initial experiences that are associated with the onset of chronic diseases as a 'biographical disruption', emphasising that the meanings attributed to a chronic disease process and the context within which the disease occurs are rarely separable (Bury, 1991). Meanings are made in relation to the consequences of these experiences as well as their symbolic significance for the individual, beginning with marked uncertainties and progressing through a search for information while giving consideration to social responses to their experiences (Bury, 1991, Williams, 2000). Thus, the biographical disruption theory focusses on disruption of the life trajectory, biography and taken-for-granted experiences of individuals with chronic diseases and how they make sense of this illness experience (Bury, 1982, Cayless et al., 2009).

Criticisms of Bury's (1982) work on biographical disruption have been in relation to age and stage in the life of an individual when a chronic disease creeps up. Respondents in the work of Bury (1982) were relatively younger and the argument has been that the diagnosis of rheumatoid arthritis was interpreted as premature aging and a significant disruption to the 'normal' aging trajectory whereas this is not characteristically extraordinary in elderly patients who are diagnosed with chronic diseases (Llewellyn et al., 2014). This would be a seemingly legitimate criticism of the biographical disruption theory if individuals had a choice of when to develop a chronic and potentially life-threatening disease. But this is not the case. The incidence and prevalence of chronic diseases are highest in relatively younger people in low- and middle-income countries (Alebiosu and Ayodele, 2005, Barsoum, 2002, Naicker, 2009). Hence, many individuals with chronic diseases in such settings will find their chronic disease as biographically disrupting. Indeed, Llewellyn et al. (2014) found that framing their illness as old age, the existence of other serious illnesses in their lives, and the probable relative stability of their disease at the time of the interviews led their elderly participants to describe experiences of continuity and less biographical disruption following their diagnosis of CKD.

Reeve et al. (2010) argue that focussing on disruptive processes alone in the lives of individuals living with chronic diseases may not be an adequate reflection of actual events in their lives while the emphasis on their narratives alone may neglect their emotional experiences. In other words, individuals do not spend their entire life trying to ascertain the meaning of their illness experience. Instead, Reeve et al. (2010) described two categories from their study – biographical flow where individuals' lives continued with only transient moments of difficult disruptive events, and biographical fracture where an individual experiences a significant disruption to continuity of their everyday lives to the point of requiring external support to restore continuity. Indeed, deliberate efforts were made to recruit individuals with rheumatoid arthritis at the earliest possible point of the disease trajectory in the Bury (1982) study. One would expect that many individuals diagnosed with terminal cancer and within the final six months of life, solely based on clinical grounds, would have had time to think through their diagnosis, come to terms with their prognosis and made several adjustments in their lives, hence the contrasting findings in the Reeve et al. (2010) study. Moreover, individuals

may employ 'normalisation' as a form of coping, bracketing off the illness to lessen its impact on their self-identity or as a way of incorporating the illness experience fully into their identity and public self (Williams, 2000).

Participants of this study were relatively younger as compared to the ESKD population in many high-income countries, and the diagnosis of ESKD was perceived as a life-changing experience for many. Participants' descriptions of their initial experiences showed a lot of disruptions in their lives. The 'noticing symptoms' subcategory has described how the disease crept up into the lives of participants, with most of them describing the initial symptoms as changes in their usual health. Participants' search for a cause of the changes in their health was marked with a higher degree of uncertainty, and following an accurate diagnosis of ESKD, participants focused on ascertaining the consequences and significance of the disease on their lives. In reacting to the diagnosis, participants asked questions such as 'why me?' and 'why did I have this?' as they tried to assess the impact of their illness experiences on their lives. Many felt that the disease was a major threat to their lives and aspirations.

The earlier phases and concepts of the 'reconstructing health expectations' theory, therefore, are in conformity with many of the tenets of the theory of biographical disruption by Bury (1982, 1991). However, this theory goes beyond the biographical disruption theory. Indeed, Bury's (1982) work comprised individuals at the earliest possible point in the trajectory of their chronic illness experience and did not explore later aspects of living with a chronic disease. Nonetheless, other works have explored later responses to chronic diseases. It is, therefore, not surprising that Reeve et al. (2010) and Llewellyn et al. (2014), respectively, identified 'biographical flow' and 'continuity', with little or no biographical disruption in several participants of their studies. This biographical flow or continuity seems achievable only after individuals have lived with a chronic disease for a while and, possibly, started treatment, including conservative or palliative forms of treatment. Thus, participants' descriptions of their experiences reflected continuity or biographical flow after confronting realities of living with ESKD and adjusting to their 'new' life.

Yet, the transition from biographical disruption to biographical flow or continuity involves an interplay between personal and contextual factors while the meanings ascribed to these illness experiences and an

individual's responses to these changes are reflections of the healthcare system. Kleinman (1978) identifies three interrelated sectors within many health care systems and these are the popular sector, the folk sector and the professional sector. The popular or lay sector comprises identification and definition of an illness experience and initiation of activities to manage this illness experience within the family, societal or community context (Helman, 2007, Hughner and Kleine, 2004, Kleinman, 1978, Nandasena and Senarath, 2015). About 70 to 90 percent of illnesses is managed within this sector globally, and decisions to seek care from any or both of the other two sectors is made here, influenced by factors such as beliefs and socioeconomic factors (Atwine et al., 2015, Helman, 2007, Kleinman, 1978). The folk sector is made up of non-professional healing specialists who, sometimes, play intermediary roles between the popular sector and the professional sector, the latter comprising mainly of biomedicine (Helman, 2007, Hughner and Kleine, 2004, Kleinman, 1978).

The central role played by the popular sector in health-seeking has been highlighted in this study. In fact, De-Graft Aikins (2003, 2004) has described four knowledge modalities that inform the popular sector or lay perspectives within the Ghanaian setting and these have been duly applied to the development of the theory of 'reconstructing health expectations'. Participants tried to manage their illness experiences within the popular sector but, faced by the persistence of their symptoms, made decisions to seek further care from the professional sector and, sometimes, in the folk sector. It could be argued, therefore, that the concepts that have been identified in the theory of 'reconstructing health expectations' have already been described in patients living with chronic diseases. Is this theory, therefore, relevant? Does this theory add anything to existing theories on living with chronic diseases other than using new terms to describe what has already been described? Certainly, the answer is YES in both instances.

This theory emphasises the shift of expectations from curative to long-term with potential end-of-life outcomes among individuals who, initially, demonstrate little awareness of management goals of chronic conditions, and the central role clinicians play in enhancing this shift. It has been explained that many low- and middle-income countries are experiencing the double burden of NCDs and communicable diseases (Atiim and Elliott, 2016, Byrne et al., 2015, Engelaer et al., 2014, Kapiga, 2011, Omran,

1971, Remais et al., 2012). This is a theory that is, therefore, anticipated to guide management of NCDs in such settings by making clinicians aware of the probable ways patients will respond to their chronic illness experiences. Moreover, this theory also highlights how various theories on responses to chronic diseases differ.

In conclusion, while a study of the initial experiences of chronic illness led to the development of the biographical disruption theory (Bury, 1982), others of the later experiences emphasise biographical flow (Reeve et al., 2010) or continuity (Llewellyn et al., 2014). This theory, however, proposes that biographical disruption and biographical flow are concepts that are applicable to different phases of a chronic illness experience.

8.5 Strengths and Limitations of this Study

This was a multicentre study, collecting data from three of the leading renal centres in the country. The views and experiences expressed here, therefore, are more likely to mirror views and experiences of clinicians and patients with ESKD across Ghana. What is more, collecting and comparing data from two or more research centres lead to grounding theoretical statement (Baszanger, 1992). The substantive theory that has been generated from this study is, therefore, anticipated to be applicable nationwide and even in other sub-Saharan African countries as it is well grounded in the data.

A limitation of this study is that views are solely from patients with ESKD who had started dialysis, those who had undergone kidney transplant surgery, and those who were yet to start treatment as well as a sample of clinicians. Views from patients with ESKD who had decided not to be on dialysis, those who had withdrawn from dialysis, or those who were using traditional medicine or pursuing faith-healing alone would have provided a different perspective on decision making in Ghana. However, it was practically impossible to identify a patient who met these criteria in a typical renal centre. Patients with ESKD who withdrew from dialysis and those who chose not to start dialysis were either not followed up by the renal centre or were reported to have passed away. Although clinicians and patient participants provided snippets of experiences of such patients, getting a subjective experience could have enriched the data and analysis in diverse ways.

Some of the interviews were conducted in Twi (a popular Ghanaian dialect and my first language) and, although efforts were made to ensure no meaning was lost in translation, this could still be a limitation for this research.

8.6 Implications for Research

A literature search for this study identified four published systematic reviews that have looked at various aspects of patient decision making in ESKD. A common finding among all four systematic reviews is that the patient is central to all decisions that are made about their treatment. Utilisation of shared decision making model implies that information is provided to patients in different forms, including the use of decision aids, to ensure that they are well informed when making decisions about their treatment (Harwood and Clark, 2013, Hussain et al., 2015, Morton et al., 2010, Murray et al., 2009). There is a menu of choices for patients with ESKD in high-income countries when making decisions about their treatment, with little or no restrictions in terms of accessibility, affordability or duration. Conservative management is also increasingly becoming popular. However, none of the included studies in any of the systematic reviews was conducted in a sub-Saharan African country.

This is the first study to look at experiences of patients with ESKD in relation to decision making in a sub-Saharan African country and is expected to contribute to the global literature. A recommendation of this study, in relation to the substantive theory of 'reconstructing health expectations', is to develop decision-making aids appropriate to the Ghanaian context, utilising the conceptual map. Such aids could be researched and evaluated and may be relevant to other low- and middle-income countries.

Patients with ESKD who had decided not to be on dialysis, those who had withdrawn from dialysis, or those who were solely using traditional medicine or pursuing faith-healing alone could not be recruited to be part of this study. Although data has been collected rigorously and snippets of their experiences have been captured in the study, adding their subjective experiences could have broadened or validated some of the key findings of this study. Such patients could provide useful information on experiences of living with ESKD without RRT in Ghana. A further study exploring views

of these groups of patients with ESKD would be a step in the right direction.

This study could have considered perspectives of families of patients with ESKD receiving care in the respective renal centres. However, the objective of the study was to explore the subjective experiences of patients with ESKD and how that influence their decision making. A study exploring perceptions of family members could lead to greater appreciation of the impact of decisions of individual on their families.

8.7 Implication for Policy

This study has identified some key trends and issues in the management of ESKD in Ghana. A greater number of people diagnosed with ESKD presented late at the respective renal centres. The majority of those with precursor conditions, including diabetes mellitus and hypertension were unaware of CKD as a potential complication. Many patient participants were not aware of the need to modify their lifestyle as part of managing their precursor condition. Considering the high costs associated with managing ESKD for the patient and economy, stringent measures are required to identify CKD in its earlier stages and to slow down its progression. Primary and secondary prevention of CKD saves lives while reducing financial burden associated management of ESKD (Francis et al., 2016). Clear policies on management of such precursor conditions, including routine kidney function tests, at least, once a year will contribute to early detection of a decline in kidney function. The NHIS has stopped providing coverage for haemodialysis for acute kidney injury and it is no more listed as part of the treatments the scheme covers (National Health Insurance Scheme, 2009). Indeed, the high costs must be too much for a burgeoning health insurance scheme. Yet, providing coverage for such services as routine kidney function tests among patients with conditions like diabetes mellitus and hypertension can contribute to reducing the higher incidence of CKD among these groups of patients. To slow down the progression, those identified to have early stages of CKD could then be referred to a nearby renal centre for further evaluation and management of the kidney disorder.

Anecdotal evidence suggests that the Regenerative Health and Nutrition Policy has increased awareness of the need for regular exercise among Ghanaians. Integrating this policy with other programmes that are

targeted at NCDs could contribute to reducing the increasing incidence of NCDs.

In Ghana, conservative management is not seen as a viable option for managing ESKD. Yet, mortalities resulting from the disease remains high. There is an urgent need for policies that will guide implementation of conservative management as an alternative for patients with ESKD in Ghana. Indeed, the Public Health Model for palliative care advocates for policy support in countries where palliative care is not fully developed while promoting the education of clinicians and the general public (Stjernswärd et al., 2007, World Health Organization, 2014). Specialist training for clinicians on conservative management for ESKD and palliative care, in general, would enhance their confidence in initiating discussions about the modality when discussing treatment options with patients.

8.8 Implications for Practice

This study identified stark differences in the Ghanaian setting. Patients with ESKD have limited biomedical treatment modalities and are further restricted by costs of treatment as well as geographical accessibility. A key finding is that Ghanaian patients with ESKD are mostly unaware of the implications of their treatment decisions, having expectations that do not mirror goals for ESKD management. They mostly have doubts about the potentially terminal nature of ESKD, initially making treatment decisions with expectations of a cure. They then reconstruct their health expectations after appreciating the terminal nature of the disease, a stipulation of the substantive theory. This theory has implications at three levels – the individual with ESKD, clinicians at the renal centre, and the healthcare system.

A good understanding of the ESKD patient journey and the substantive theory implies that active information seeking prior to decisions will ensure individuals are fully aware of the implications of their treatment decisions. Adoption and utilisation of this conceptual map in teaching newly diagnosed CKD, or even patients with ESKD, would contribute to an appreciation of the ESKD trajectory. This could contribute to an early appreciation of potential outcomes of the disease and key decisions that need to be made to avoid or control them. It could, potentially, lead patients to discard expectations of a cure while taking central stage in

their management, including active self-management through lifestyle modification.

This substantive theory is expected to enhance interactions between clinicians at renal centres in Ghana and individuals diagnosed with ESKD. An understanding of the ESKD patient journey, as shown in the conceptual map, and the eventual process of reconstructing their health expectations to meet goals of ESKD management would assure clinicians that they have key roles to play in this transformational process. It would guide clinicians on what kind of support may be required by patients with ESKD at different stages of the patient journey. Many patient participants of this study reported that clinicians do not explain the non-curative management of the disease to them while clinician participants rebutted by explaining that patients tend not to believe their explanations. This strongly suggests that clinicians also need a reorientation about how they communicate about, and manage NCDs. Although patients with ESKD usually prefer to defer making a treatment decision when they are not experiencing symptoms, feeling well informed about their options make them feel involved in decision making about their treatment (Erlang et al., 2015). Information provision through different approaches, including the use of patient information leaflet and patient decisions aids, could be explored. In this era where patterns of diseases are changing in Ghana, a reorientation of clinicians' expectations of patients' responsibilities in managing NCDs is a necessity. A shift of focus from how clinicians manage NCDs to how patients can self-manage will contribute to patients appreciating the need to reorient their health expectations. A concerted effort by clinicians managing patients with diabetes mellitus and hypertension to incorporate lifestyle modification in their teaching sessions with patients will go a long way to reducing the incidence of CKD and ESKD.

Healthcare system approaches would require policy support to implement strategies such as instituting ESKD preventive measures and introducing conservative management as has been discussed above. In addition, there is urgent need of a renal registry which would provide up-to-date information on the trends and dynamics of CKD and ESKD in the country.

'Discovering' the Substantive Theory: a Reflection on the PhD Journey

This journey began with one of the most difficult steps of the research process – deciding upon a research topic. My interest in the management of CKD and patients' quality of life, coupled with exposure to the vast resources available to CKD and patients with ESKD in the UK, led me to ask myself one key question – how are patients with ESKD in Ghana coping with the challenges associated with accessing treatment in the face of limited resources. As I tried to find an answer to this question in the literature, I kept coming across articles that had explored decision making in ESKD in high-income countries but not in Ghana or any other sub-Saharan African country. Eventually, a decision was made to explore experiences of patients with ESKD and how that influence their decision making on treatment. My supervisors were happy with this idea and offered guidance in diverse ways on how to develop the idea. An initial review of the literature pointed me to grounded theory methodology as its purposes resonated with my desire to identify an 'explanation' for how decisions are being made about ESKD management in Ghana. I took some courses on qualitative research, interviewing to prepare me for the study.

A characteristic feature of grounded theory methodology is that it comprises flexible analytic processes which allow a relevant theory to emerge from data (Charmaz, 2011, Corbin and Strauss, 2008, Glaser and Strauss, 1967). These processes, comprising theoretical sensitivity, theoretical sampling, constant comparative analysis, coding, memo writing, and integration of theory, when followed studiously in the course of research, would facilitate generation of a theory that is grounded in the data (Jeon, 2004, McCann and Clark, 2003). Working on this research as a novice qualitative researcher was fraught with uncertainties at various points along the doctoral study period – do I have the requisite skill to carry out this research? Am I doing the analysis the way it should be done? Have I omitted an essential element of the research process? Have I identified the core category? Indeed, Corbin and Strauss (2008) have identified some of these concerns for the novice qualitative researcher and have addressed them extensively. Charmaz (2006) also sets out practical steps that direct the novice grounded theory researcher on how to systematically go about generating a theory that is relevant to their area of interest.

Constant comparative analysis requires data analysis to be done alongside data collection and this proved useful in building my confidence in the research process. This continued throughout the period of writing drafts of this thesis. Having an opportunity to discuss key findings and concepts with other people encourage novice grounded theory researchers to make a conceptual leap, gain more perspective and confidence (Corbin and Strauss, 2008). Frequent discussions with my supervisors about my initial interviews, analyses and memos helped me to identify my areas of strength as well as those that needed improvements. Supervision meetings offered me the opportunity to get critical feedback on my analysis and writing and highlighted more issues that needed to be explored.

I had the opportunity to present some of my findings to a group of nurses in Ghana, PhD colleagues and some MSc students in Nottingham, United Kingdom, and at a World Congress of Nephrology (WCN, 2015) in Cape Town, South Africa. I had series of discussions with many people about my findings during these sessions which also gave me different perspectives on my study. The end product of all these is the substantive theory that has been presented above and the entire thesis.

Conclusions

The pattern of diseases has changed over time globally, predominantly shifting from communicable diseases to non-communicable diseases (NCDs), and each of these paradigms has different underlying principles in terms of approaches and goals of management. While communicable diseases have curative goals after diagnosis, and playing the sick role may enhance patient adherence to treatment, non-communicable diseases have self-management, control of the disease as well as prevention of complications as goals over a lifetime, with no curative goals. This has required a reorientation of healthcare systems and policies to guide management of these diseases, including increasing patient choice and sharing decisions with patients. There have been several advancements in embracing this shift in high-income countries, and mechanisms and policies have been put in place to improve patient outcomes.

The cost of managing ESKD is remarkably high, putting a greater financial strain on healthcare systems and impeding initiation and sustenance of RRT interventions in several low- and middle-income countries. Consequently, the incidence of ESKD is highest in low- and middle-income countries but the prevalence is lowest in these settings. The clinical equipoise between HD and PD outcomes makes it imperative to include patients in decisions as non-medical factors remain paramount in making a choice. Moreover, there is increasing emphasis on promoting patient choice and autonomy in clinical decision making. The first decision facing the patient with ESKD is whether to initiate treatment or not and, if they choose treatment, what kind of modality that should be. However, the literature on patient decision making on treatment for life-threatening conditions had been clearly dominated by studies from high-income countries, particularly in North America and Western Europe, with none from any sub-Saharan African country.

There was, therefore, the need to extensively explore decision making among different socioeconomic and cultural groups to fill some of the gaps identified in the literature in light of the influence of culture and resources on treatment decision making, hence this study. Low- and middle-income countries, including several countries in sub-Saharan Africa, are facing rapidly escalating disease burden from ESKD – and chronic diseases in general.

This thesis reports on a study that employed grounded theory methodology to interview twenty-seven participants in three renal centres in Ghana, comprising twenty-two patients with ESKD and five clinicians. Participants were selected using theoretical sampling approach and interviewed for this study. Constant comparative analysis was employed in data analysis.

It is evident that the prevalence of NCDs is increasing in Ghana alongside communicable diseases. Previous evidence and those gathered in this study suggest that the prevalence of ESKD is on the ascendancy. Some policies have been developed to address this challenge but these do not seem to be achieving their desired objectives as many individuals are not aware of the changing trends of diseases and treatment goals of NCDs. There are no clear policies to promote early detection of CKD or slow down its progression. Evidence from this study suggests that patients with precursor conditions of CKD are not actively engaged in self-management practices that can contribute to delaying or preventing the onset of CKD. The Ghanaian healthcare system lacks adequate resources to promote easy geographical and financial accessibility to quality renal services, and higher costs of treating ESKD serve to hamper efforts to promote unrestricted access of patients with ESKD to healthcare through the NHIS. The majority of the staff working in renal settings have only had on-the-job training and are unfamiliar with other aspects of renal care, including conservative management and kidney transplantation, as a result. The implications are that the ESKD patient population would continue to escalate at unprecedented rates without appropriate primary and secondary prevention interventions directed at the disease, especially among patients with precursor CKD conditions. The Ghanaian patient with ESKD would have difficulties accessing treatment and experience restrained choices within the biomedical setting.

A theory of 'reconstructing health expectations' was generated from this study. This theory stipulates that individuals with ESKD facing treatment decisions in Ghana shift their health expectations from curative to long-term management goals when confronted with the reality of living with the disease albeit this may follow complex processes. This is against the backdrop that there is, generally, limited awareness of the long-term management goals for non-communicable diseases among the citizenry. A conceptual map depicting the ESKD patient journey and key stages of

decision making was developed from analysis of the study data to show the processes patients with ESKD go through before reorienting their health expectations to commensurate goals of ESKD management.

The study has shown that Ghanaian patients with ESKD initiate treatment for various reasons, including, initially, the urgent need to avoid premature death. Many approach their condition in terms of hoping for a cure and do not always understand the chronic nature of their condition. Expectations of treatment outcome are influenced by indigenous beliefs in traditional medicine, spiritual healing and the promise of a 'cure'. HD is limited to a few centres, and patients must make extremely high out-of-pocket payments for treatment as it is not covered by the National Health Insurance Scheme. Decisions on initiating HD are mostly shared between clinicians and patients and/or their families and the process is mainly driven by the need to ascertain patient and family's ability to finance HD, rather than considering other aspects of treatment burden. Despite the limited access to HD, there are currently no structured systems for conservative management. The subject of death or conservative management is not openly discussed and, once this is brought up, patients usually do everything possible to opt for another form of treatment, culminating in the simultaneous use of other non-RRT approaches.

Treatment decisions of the individual with ESKD in Ghana are influenced by an array of factors including disease causal beliefs, expectations of treatment outcome and costs of treatment. While the healthcare setting in several high-income countries ensures that individuals living with ESKD are more aware of the likely trajectory of the disease and all possible outcomes, this is not the case in the Ghanaian setting. Financial and geographical inaccessibility of RRT, as well as the relative lack of biomedical choices, make decision making more daunting for the individual with ESKD in Ghana. Reluctance to discuss death as a potential outcome is a hindrance to initiation and sustenance of conservative management.

The global evidence clearly supports haemodialysis as the predominant option in the country that can help patients to achieve this goal as there is no data that supports other non-biomedical options utilised by the Ghanaian patient with ESKD. However, patients with ESKD would continue to think otherwise when mortality of those on dialysis remain as high as 32.4% within 90 days of treatment initiation in the country (Eghan et al.,

2009). Adequate information tailored to the unique needs of the Ghanaian patient with ESKD would go a long way to reducing the concurrent use of biomedicine and traditional medicine in the management of ESKD and boost their confidence in using haemodialysis for managing their disease.

Effective realignment of healthcare policies to address changing patterns of diseases will contribute to prevention, early detection and effective management of NCDs in the country. Finding innovative ways to reduce high costs associated with RRT will contribute to making RRT financially accessible to people that need it in low- and middle-income countries. Programmes such as 'the affordable dialysis prize' which was announced at the World Congress of Nephrology in Cape Town in March 2015 and awarded in March 2016 can bring ideas to lowering costs of RRT to the fore (Knight and Perkovic, 2016). Providing adequate information on the disease to promote self-management may be effective in addressing unique challenges faced by individuals with ESKD in Ghana while guiding decisions about their care. Empowering clinicians through further training would contribute to improving patient outcomes. An improved approach to conservative management is also urgently required, including training support for clinicians as well as sensitisation of the citizenry on this modality.

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Appendices

Appendix I. Interview Guide (English Language)

1. *Please describe the history of your kidney disease to me*

Cues: when did you first find out that you were ill? What symptoms did you experience? What did you think was happening to you? What actions did you take to get well? When were you first told that you had kidney disease? How did you feel when you found out that you had kidney disease? What did you think might have caused your kidney disease? What made you think those factors might have caused your kidney disease?

2. *Please tell me what you knew about kidney diseases before your diagnosis?*

Cues: Had you heard anything about kidney disease? How did you get to know that? Did you know anybody with kidney disease?

3. *Can you tell me how you feel about your kidney disease?*

Cues: Do you feel it has affected your life in any way? Do you feel it is still affecting your life in any way?

4. *Please tell me any thoughts you have had about the treatment you are having?*

Cues: Can you tell what you know about the treatment? How did you get to know this? Do you know of any other treatments you could have had? How did you know about these? Would you rather you had any of the other treatment options?

5. *How did you decide to be on this treatment?*

Cues: Were you told about all possible treatments for you? Who told you about the treatment? Were you told about the treatment options alone or in the company of others (i.e. your spouse, children, other family members, other patients, employers)? Did you have much time to deliberate on what to do? Would you prefer to have received the information earlier or later? Why? Did these other people suggest what you should do to you? Did you talk to others with your diagnoses before deciding on the treatment? Were you made to choose the treatment you are on now? Do you think your interaction with all these people influenced

your decision? What else do you think influenced your decision? What made you choose this treatment?

6. *How did you feel about deciding on a treatment?*

Cues: Did you feel valued? Did you feel the decision should have been taken by someone else other than you? Who should this person have been? Do you feel you were involved in the decision making to a greater extent?

7. *How do you feel about this treatment?*

Cues: What do you think are the good things about this treatment? What do you think are not so good about this treatment? How do you feel about the cost of the treatment? Do you feel this treatment is as helpful as you were told about it before you started? Is there something about the treatment that you feel you should have known before starting? Will this have made you refuse the treatment if you had known earlier? Do you intend to continue this treatment for long? Do you have any particular challenges with this treatment? Will you have chosen this same treatment if you knew all the things you now know about it when making the decision?

8. *Please tell me about your expectations while on this treatment?*

Cues: Do you expect a cure? Do you expect your health to deteriorate over time? Do you have any plans for how you should be cared for if your health deteriorates? Have you been told of what can be done for you should your health deteriorate?

9. *Do you have any ideas on how care for others with kidney disease can be improved?*

Cues: What do you think they should be told when they are diagnosed with kidney disease? How will you expect them to be treated? Who should make decisions for them on their treatment (the individual, the doctor, the spouse or family)? What could be done to help decision making? Is there anything else that might be helpful to others who have to make a similar decision as yours? How involved should they be in the decision making?

10. *Can you comment on the care that you have received in this unit?*

    Cues: Have staff in the unit been supportive? How have they been doing this? Has the unit been running efficiently since you started coming here? Do you think care can be organised any differently to support others who have to make a decision?

11. *Do you have any general comments on what we have discussed so far?*

Appendix II. Interview Guide (Twi)

1. *Me pa wo kyɛw ka wo yareɛ yi ho asɛm kakra kyerɛ me*

Cues: ɛberɛ bɛn na wo dii kan hunuu sɛ wo yare? Nsakraeɛ bɛn na wo hunuuie wɔ wo nipadua mu? ɛdeɛn na na wo dwene sɛ ɛreyɛ wo? ɛdeɛn na wo yɛ faa ho sɛ ɛbɛyɛ na wo ho bɛtɔ wo? ɛberɛ bɛn na wo dii kan hunuu sɛ wo sââ na ɛho aka? Wo dii kan hunuu sɛ wo sââ na ɛho aka no, ɛyɛɛ wo sɛn? ɛdeɛn na na wo dwene sɛ ɛde sââ yareɛ no baeɛ? ɛdeɛn na ɛmaa wo dwenee sɛ saa nnoɔma yi na ɛde sââ yareɛ no baeɛ?

2. *Me pa wo kyɛw ka deɛ na wo nim fa sââ yareɛ ho kyerɛ me*

Cues: Na w'ate sââ yareɛ yi ho asɛm pɛn? ɛkwan bɛn so na wo tee ho asɛm? Na wo nim obi a ɔwɔ sââ yareɛ yi bi?

3. *W'adwene yɛ wo sɛn wɔ wo sââ yareɛ yi ho?*

Cues: Wo dwene sɛ ɛde ɔhaw bi aberɛ wo anaa? Wo dwene sɛ ɛgu so reha wo wɔ ɔkwan bi so anaa?

4. *Kyerɛ w'adwene wɔ ɔkwan a yɛrehwɛ wo yi ho?*

Cues: ɛdeɛn na wonim fa ho? ɛkwan bɛn so na wo tee ho asɛm? Wonim ɔkwan foforɔ bi a anka yɛbetumi afa so ahwɛ wo? ɛkwan bɛn so na wo tee ho asɛm? Wobɛnya a anka saa akwan ahodoɔ yi bi so na yɛ fa hwɛ wo anaa?

5. *ɛyɛɛ dɛn na w'adwene sii pi sɛ yɛnhwɛ wo wɔ ɔkwan a yɛrehwɛ wo seisei yi so?*

Cues: Yɛkaa akwan ahodoɔ a yɛbetumi ahwɛ wo kyerɛɛ wo? Hwan na ɔne wo dii saa nkɔmmɔ yi? Wo nkoaa na yɛne wo dii nkɔmmɔ anaa sɛ na obi ka wo ho (wo kunu/yere, wo mma, w'abusua ni anaa w'adwuma wura)? Wo nyaa mmerɛ bebree ansa na woresi w'adwene pi wɔ deɛ wopɛ sɛ woyɛ ho? Wobɛnya a anka yɛne wo dii nkɔmmɔ no ntɛm anaa sɛ anka yɛtwɛnn kakra kaa ho? Adɛn ntira? Obi foforɔ kyerɛɛ n'adwene wɔ deɛ ɔpɛ sɛ woyɛ ho? Wo ne wɔn a ɔwɔ sââ yareɛ yi bi dii nkɔmmɔ ansa na woresi w'adwene pi? Obi 'hyɛɛ' wo ansa na worefa saa kwan yi anaa? Wo dwene sɛ nkɔmmɔ a wo ne afoforo diie no boa maa wo sii w'adwene pi anaa? ɛdeɛn biem na ɛboa maa wo sii w'adwene pi? ɛdeɛn nti na wo faa saa kwan a yɛde hwɛ wo yi?

6. *Woredwene kwan a yɛmfa so nhwɛ wo no, ɛyɛɛ wo sɛn?*

Cues: Yɛde obuo maa wo? Na ɛyɛ wo sɛ obi nka deɛ ɛwɔ sɛ wo yɛ nkyerɛ wo? Hwan na anka wopɛ sɛ okyerɛ wo deɛ wobɛyɛ? Wo dwene sɛ wo dii akotene wɔ mmerɛ a yɛresusu kwan a yɛbɛfa so ahwɛ wo no sedeɛ na wopɛ no?

7. W'adwene wɔ ɔkwan a yɛrefa so hwɛ wo yi ho ne sɛn?

Cues: Nnoɔma papa bɛn na ɛwɔ ho? Nnoɔma bɛn na ɛnnyɛ wɔ ho? Ne boɔ no te sɛn ma wo? Wo dwene sɛ aboa wo sɛdeɛ yɛ ka kyerɛɛ wo mfitiasee no anaa? Biribi wɔ hɔ a wofiri sɛ anka ɛwɔ sɛ yɛka kyerɛ wo mfitiasee no a yɛanka ansa na worehyɛ aseɛ? Anka saa ade yi bɛma w'apo saa ɔkwan yi anaa? W'adwene sɛ wobetoa saa ɔkwan yi so? Wo wɔ biribi a w'ani nnye ho wɔ ɔkwan a yɛrehwɛ wo yi ho? Sɛ na wonim nnoɔma a wonim seisei ara yi wɔ mmerɛ a na woredwene ho mfitiasee no a, anka wobɛfa saa ɔkwan yi so ama yɛahwɛ wo anaa?

8. ɛdeɛn na worehwɛ anim wɔ mmerɛ a yɛrehwɛ wo yi?

Cues: Worehwɛ sɛ wo ho bɛtɔ wo? Worehwɛ sɛ wo yareɛ no mu bɛyɛ den? Sɛ ɛyɛ den a, wonim ɔkwan bi a wopɛ sɛ yɛfa so hwɛ wo? Sɛ wo yareɛ no mu yɛ den a, yɛaka deɛ yɛbetumi ayɛ ama wo akyerɛ wo?

9. Wonim ɔkwan bi a yɛbetumi ahwɛ wɔn a wɔn sââ ho aka yie?

Cues: ɛdeɛn na wo dwene sɛ sɛ obi sââ ho ka a, yɛnka nkyerɛ no? Kwan bɛn so na wobɛpɛ sɛ yɛnhwɛ wɔn? Hwan na ɛwɔ sɛ ɔkyerɛ ɔkwan a yɛmfa so nhwɛ wɔn (nnipa no ara, ne Dr, ne hokafoɔ anaa abusuafoo)? ɛdeɛn na yɛbetumi ayɛ aboa ama wɔafa adwene wɔ ɔkwan a yɛbɛfa so ahwɛ wɔn? Biribi foforo bi wɔ hɔ a wonim sɛ ɛbɛboa afoforɔ a wɔredwene kwan a yɛbɛhwɛ wɔn sââ yareɛ anaa? Kwan bɛn so na yɛbetumi ama wɔadi akotene wɔ mmerɛ a yɛredwene kwan a yɛbɛfa so ahwɛ wɔn mu?

10. W'adwene yɛ wo sɛn wɔ sedeɛ yɛrehwɛ wo wɔ ayaresabea ha?

Cues: Adwumayɛfoɔ a ɛwɔ ha no kɔ wo mmoa? Kwan bɛn so na wɔaboa wo? Ayaresabea no yɛ adwuma yie ɛfiri mmerɛ a wofiti aseɛ baa ha? Yɛbetumi ayɛ biribi foforɔ de aboa wɔn a wɔredwene kwan a yɛbɛfa so ahwɛ wɔn?

11. Wo wɔ biribi foforɔ ka wɔ nkɔmmɔ a yɛadi yi nyinaa ho?

Appendix III. Participant Information Leaflet

University of Nottingham
School of Nursing, Midwifery and Physiotherapy
Division of Nursing

Title of Project: Decision Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring Patient Perspectives

Name of Investigators*:* Linda East, Catrin Evans, John Appiah-Poku, Edward Appiah Boateng

Healthy Volunteer's Information Sheet

Invitation paragraph

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet and you will be given a consent form for your signature or thumbprint. Thank you for reading this.

Background

Patient decision making is very important in healthcare as individuals and/or their family members usually have to choose one of several diagnostic investigations or treatment options. However, uncertainty of prognosis, symptoms, anxiety about adverse outcomes, support systems, and inadequate information are among many factors that make the process of decision making a difficult one, both for the clinician and the patient. Patients with end stage kidney disease (ESKD) also face similar challenges when deciding on their management.

The burden of end stage kidney disease (ESKD), also known as kidney failure, is increasing in Ghana although there are few treatment options in the country. However, no study has been done to explore how patients make decisions on their management. To improve the numbers of patients

that have dialysis, or to improve care for those who do not choose dialysis, a deeper understanding of the experiences and perspectives of Ghanaian patients with ESKD on their clinical management is necessary. This calls for urgent approaches that explore decision making in patients with ESKD in the Ghanaian context on 'dialysis' or 'no dialysis'. The purpose of this research is to explore the experiences and perceptions of patients with ESKD in Ghana on decision making and to recommend ways to support them in the process.

What does the study involve?

Data collection will be by one-to-one interview. It is anticipated that respondents will comprise of patients who are yet to begin dialysis, those who have started dialysis, and those who chose 'no dialysis', or those who have withdrawn from dialysis. A maximum of five (5) patients already on dialysis will be interviewed initially. More participants will then be interviewed, and the interview guide will be modified as needed, based on issues that arise from the first five interviews. This will continue until no new major issue comes up again. For practical reasons such as time constraints, the total number of participants for this study will not be more than 50.

Each interview will have duration of between 45minutes to 90minutes. The interviews will be conducted within the various centres where respondents get their care or in their homes based on their preference. Each interview session will be recorded and detailed notes will also be taken by the researcher before, during and after the session. Interview will be conducted in English language or in Twi (a popular Ghanaian dialect) based on the preference of each participant.

Why have you been chosen?

You are being asked to be part of this research because you have been diagnosed with kidney failure

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What do I have to do?

You will have to tell us what time you may be available for the interview and whether you want that to be in your house or in the hospital. You will also have to tell us whether you prefer to be interviewed in English or Twi.

What are the possible disadvantages and risks of taking part?

Having to recount your experiences through the interviews may be emotionally challenging for you. You can be rest assured that you may choose not to respond to a question if you judge it uncomfortable or private.

What if something goes wrong?/Who can I complain to.

"In case you have a complaint on your treatment by a member of staff or anything to do with the study, you can initially approach the researcher on the field (Edward Appiah Boateng on 0242350891). If this achieves no satisfactory outcome, you should then contact the local supervisor, Rev. Prof. John Appiah-Poku on 0322063253 or by e-mail, jappiahpoku1@gmail.com."

"In the unlikely event that you suffer injury to yourself or damage to your property as a result in taking part in this research, the University does have an insurance policy to cover harm arising as a result of the defect in the design of the study. In addition, all medical practitioners taking part in the research have personal medical negligence cover."

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept on a password protected database and is strictly confidential. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study?

A comprehensive report on this research, in the form of a PhD thesis, will be submitted to the University of Nottingham. Aspects of the research will also be published in a professional nursing journal. A summary of key findings and recommendations based on these findings will also be submitted to the various renal centres and to the National Kidney

Foundation in Ghana. Abstracts and posters may also be presented at conferences during and after the PhD programme. Stringent measures will be taken to ensure anonymity of respondents and research sites in any publication that will arise out of this research.

Who is organising and funding the research?

This is a PhD research and the studentship is from the University of Nottingham International office (UK) and the Kwame Nkrumah University of Science and Technology (KNUST, Ghana). There will be no personal payments made to any of the researchers for including you in this study.

Who has reviewed the study?

The study has been reviewed and approved by the Ethical and Protocol Review Committee (EPRC) of the University of Ghana Medical School, the Committee on Human Research, Publications and Ethics (CHRPE) of the Kwame Nkrumah University of Science and Technology School of Medical Sciences (KNUST-SMS), and the University of Nottingham Faculty of Medical and Health Sciences Ethics Committee.

Contact for Further Information

Thank you very much for taking time to read this leaflet. If you have further questions concerning this study, please do not hesitate to contact Mr Edward Appiah Boateng on 0242350891 or send an e-mail to ntxebap@nottingham.ac.uk

Appendix IV. Consent Form

University of Nottingham
School of Nursing, Midwifery and Physiotherapy
Division of Nursing

Title of Project: Decision Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring Patient Perspectives

Names of Investigators: Linda East, Catrin Evans, John Appiah-Poku, Edward Appiah Boateng

Healthy Volunteer's Consent Form

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result.
- I agree to the above investigators contacting my general practitioner [and teaching or university authority if appropriate] to make known my participation in the study where relevant.
- I agree to comply with the reasonable instructions of the supervising investigator and will notify him immediately of any unexpected unusual symptoms or deterioration of health.
- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be

made anonymous. Data will be kept for 7 years after the results of this study have been published.

- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.
- I confirm that I have disclosed relevant medical information before the study.

Name: ……

Address: ……..

Telephone number: …….

Signature/Thumbprint: ……**Date:** ……

I confirm that I have fully explained the purpose of the study and what is involved to:……I have given the above named a copy of this form together with the information sheet.

Investigator's Signature: ……...**Date**: ……

Investigator's Name: ……

Statement of person witnessing consent (Process for Non-Literate Participants):

I certify that information given to the participant in the Twi language is a true reflection of what I have read from the study Participant Information Leaflet attached.

Name: ……..……

Signature: ……..…… **Date:** …….

Study Volunteer Number: ……..

Appendix V. Ethical Approval Letter, CHRPE

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

Our Ref: CHRPE/AP/152/13 5th July, 2013.

Mr. Edward Appiah Boateng
Department of Nursing
Faculty of Allied Health Sciences
KNUST-KUMASI.

Dear Sir,

LETTER OF APPROVAL

Protocol Title *"Decision-Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring the Quandaries."*

Proposed Sites: *Komfo Anokye Teaching Hospital (Dialysis Centre),*
Peace & Love Hospital (Dialysis Unit), Korle Bu Teaching Hospital, (renal Centre).

Sponsor: *Principal Investigator.*

Your submission to the Committee on Human Research, Publications and Ethics on the above named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 2nd April, 2013 from the Komfo Anokye Teaching Hospital (study site) indicating approval for the conduct of the study in the Hospital.
- A notification letter of 26th March, 2013 from the Peace & Love Hospital (study site) indicating approval for the conduct of the study in the Hospital.
- A completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Proposal.
- Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, renewable annually thereafter. The Committee may however, suspend or withdraw ethical approval at anytime if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you Sir, for your application.

Yours faithfully,

Osomfuor Prof. Sir J. W. Acheampong MD, FWACP
Chairman

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: chrpe.knust.kath@gmail.com / chrpe@knust.edu.gh

Appendix VI. Ethical Approval Letter , EPRC

UNIVERSITY OF GHANA MEDICAL SCHOOL
COLLEGE OF HEALTH SCIENCES
ACADEMIC AFFAIRS OFFICE

Phone: +233-0302-666987-8
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My Ref. No: MS-AA/C.2/Vol.16[A]

Your Ref. No.

P O Box 4236
Accra
Ghana

25th June, 2013

Edward Appiah Boateng
University of Nottingham
UK

ETHICAL CLEARANCE

Protocol Identification Number: MS-Et/M.10 – P 3.62/2012-13

The Ethical and Protocol Review Committee of the University of Ghana Medical School on 25th June, 2013 unanimously approved your research proposal.

TITLE OF PROTOCOL: "Decision-Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring the Quandaries"

PRINCIPAL INVESTIGATOR: Edward Appiah Boateng

This approval requires that you submit six-monthly review reports of the protocol to the Committee and a final full review to the Ethical and Protocol Review Committee at the completion of the study. The Committee may observe, or cause to be observed, procedures and records of the study during and after implementation.

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

You are required to report all serious adverse events related to this study to the Ethical and Protocol Review Committee within seven (7) days verbally and fourteen (14) days in writing.

This ethical clearance is valid October 2014.

As part of the review process, it is the Committee's duty to review the ethical aspects of any manuscript that may be produced from this study. You will therefore be required to furnish the Committee with any manuscript for publication.

Please always quote the protocol identification number in all future correspondence in relation to this protocol.

Signed:.....
PROFESSOR JENNIFER WELBECK
(CHAIRPERSON, ETHICAL AND PROTOCOL REVIEW COMMITTEE)

cc: Dean
Head of Department
Research Office

Appendix VII. Ethical Approval, UoN

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

The University of Nottingham

Faculty of Medicine and Health Sciences

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

Tel: +44 (0) 115 8231063
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18th July 2013

Edward Appiah Boateng
PhD Student
c/o Dr Linda East
Director of Postgraduate Studies
School of Nursing Midwifery and Physiotherapy
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

Dear Mr Boateng

Ethics Reference No: OVS E11072013 SNMP
Study Title: Decision Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring Patient Perspectives.
Chief Investigator/Supervisors: Dr Linda East, Director of Postgraduate Studies, Dr Catrin Evans, Lecturer, School of Nursing, Midwifery and Physiotherapy.
Lead Investigator/Student: Mr Edward Appiah Boateng, PhD Student, School of Nursing, Midwifery and Physiotherapy.
Duration of Study: September 2013-April 2014 8mths **No of Subjects:** 50

Thank you for your recent application to conduct a study for your PhD in Ghana which was considered by the Committee at and the following documents were received:

Edward Appiah Boateng, Decision Making in ESKD in Ghana: Exploring Patient Perspectives, Ethics Application, Appendices, Version 1, June 2013:

1. UoN Medical School Research Ethics Application Form
2. Appendix I: Interview Guide
3. Appendix II: Consent Form
4. Appendix III: Participant Information Leaflet
5. Appendix IV: Research proposal
6. Letter of conditional approval from the University of Ghana Medical School Ethical and Protocol Review Committee dated 14th May 2013.
7. Letter of peer review from Dr D A Antwi, Head of Department of Physiology, College of Health Sciences, University of Ghana, 20th June 2013.
8. Letter of Conditional approval from the School of Medical Sciences/Komfo Anokye Teaching Hospital, Kwame Nkrmah University of Science and Technology College of Health Sciences Committee on Human Research, Publication and Ethics dated 31st May 2013

These have been reviewed and are satisfactory and the study proposal has been given a favourable opinion.

Conditions of Approval:

1. A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are sought for each overseas project in accordance with all local laws, and that the host organisation involved also gives their

permission where applicable. Please submit Letters of permission and approval when these are available for our records.

2. You must follow the protocol agreed and inform the Committee of any changes.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely



Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

Appendix VIII. Ethical Approval for Amended Protocol, CHRPE

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH PUBLICATION AND ETHICS

Our Ref: CHRPE/AP/431/13

29th November, 2013.

Mr. Edward Appiah Boateng
Department of Nursing
Faculty of Allied Health Sciences
KNUST-KUMASI.

Dear Sir,

LETTER OF APPROVAL

Protocol Amendment: ***"Decision-Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring the Quandaries."***

Your submission to the Committee on Human Research Publication and Ethics on amendment to protocol number CHRPE/AP/152/13 which was approved on 5th July, 2013 refers.

The Committee has considered the ethical merit of your proposed amendment to interview some healthcare professionals and family members which was not part of the original protocol and approved it.

Thank you Sir, for your application.

Yours faithfully,

Osomfuor Prof. Sir J. W. Acheampong MD, FWACP
Chairman

Room 8 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: chrpe.knust.kath@gmail.com / chrpe@knust.edu.gh

Appendix IX. Ethical Approval for Amended Protocol, EPRC

UNIVERSITY OF GHANA MEDICAL SCHOOL
COLLEGE OF HEALTH SCIENCES
ACADEMIC AFFAIRS

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My Ref. No. MS-AA/C.2/Vol 17[A]
Your Ref. No.

P O Box 4236
Accra
Ghana

10th February, 2014

Edward Appiah Boateng
The University of Nottingham
School of Nursing, Midwifery & Physiotherapy
Room B33 – Medical School
Queen's Medical Centre – Nottingham NG7 2HA
United Kingdom

Dear Mr. Appiah Boateng,

Re: Decision-Making in End Stage Kidney Disease (ESKD) in Ghana: Exploring the Quandaries –No. MS-AA/C.2/Vol.16[A]

Your request for permission to amend the above study has been approved.

It is noted that the amendment is to allow the Principal Investigator to interview some healthcare professionals and family members which was not part of the original protocol.

I wish you successful continuation of the study, whose validity is still till October, 2014.

Yours sincerely,

Prof. Jennifer Welbeck
Chairperson (Ethical and Protocol Review Committee)