



**No Money, No Treatment, No Life: The Lived
Experiences of Haemodialysis Patients in Nigeria**

By

Chidiebere Valentine Ekuma

School of Health and Society

University of Salford, UK

**A Thesis Submitted in Partial Fulfilment of the
Requirements of the Degree of Doctor of Philosophy**

October 2018

Table of Contents

List of Tables.....	vii
List of Boxes.....	viii
List of Figures.....	ix
Acknowledgements	x
Abbreviations	xi
Abstract.....	xii
Chapter 1: Chronic Kidney Disease and the Nigerian context.....	1
1.1 Introduction.....	1
1.2 Chronic Kidney Disease	3
1.2.1 Global Incidence of CKD.....	4
1.2.2 Aetiology and Risk Factors for Developing CKD	7
1.2.3 Best Practice Management of CKD.....	8
1.2.4 Complications of dialysis	14
1.2.5 Mortality in end-stage kidney disease patients on dialysis therapy.....	15
1.2.6 Impact of CKD and treatments.....	16
1.3 Health care services in Nigeria	18
1.3.1 Structure of the Healthcare Systems/Services in Nigeria.....	18
1.3.2 Healthcare financing in Nigeria.....	21
1.3.3 Health Care Finance Policies in Nigeria and Health Care Coverage	22
1.4 Perspectives on death and dying in Nigeria.....	24
1.5 The anticipated contributions of the study to knowledge	26
1.6 Summary	27
Chapter 2: Current understanding of CKD patient experience	28
2.1 Introduction.....	28
2.2 Search Strategy	29

2.2.1	Initial search	29
2.2.2	Updated search	30
2.3	Results of the literature search.....	32
2.3.1	Overview	32
2.3.2	Study Aims	32
2.3.3	Patient Modality	33
2.3.4	Sample and Sampling Method.....	34
2.3.5	Ethical Issues	34
2.3.6	Methods/ Data Collection.....	35
2.3.7	Researcher Bias	36
2.3.8	Quality of Evidence	36
2.3.9	Analysis and Synthesis	38
2.4	Main Themes and Review Findings	39
2.4.1	Uncertainty	40
2.4.2	Meaning of illness	41
2.4.3	Body Image	43
2.4.4	Physical effects.....	44
2.4.5	Dependence on dialysis and dialysis machine.....	45
2.4.6	Normality and lifestyle	46
2.4.7	Relationships: Families and healthcare professionals	47
2.4.8	Suffering	48
2.4.9	Spirituality/Religion	49
2.5	Summary of the review	49
2.6	Gaps in literature.....	51
2.7	Research aims, objectives and questions	51
2.7.1	Research aim.....	51
2.7.2	Research objectives	51

2.7.3	Research questions	52
2.8	Summary of the review	52
Chapter 3:	Conceptual Framework.....	54
3.1	Introduction.....	54
3.2	Illness representation	54
3.3	Spirituality	62
3.4	Culture/cultural beliefs	63
3.5	Health care access and health service utilisation	65
3.5.1	Barriers to the utilisation of health care services.....	66
3.6	Conceptual Framework Model	67
3.7	Summary.....	68
Chapter 4:	Methodology of the Research.....	70
4.1	Introduction.....	70
4.1.1	Research aim.....	71
4.1.2	Research objectives	71
4.1.3	Research questions	71
4.2	The research paradigm.....	72
4.2.1	Qualitative research	73
4.3	The research design	76
4.3.1	Time.....	77
4.3.2	Change	78
4.3.3	Iterative nature.....	79
4.4	Sampling, size and procedure	82
4.5	Study setting	83
4.6	Gaining access	84
4.7	Data collection methods.....	84
4.7.1	Data collection schedule.....	85

4.7.2	The interview process	86
4.7.3	The Role of the Researcher in the interview process	88
4.8	Ethical considerations and research governance.....	90
4.9	Data analysis	92
4.9.1	Analysis of participants` hospital records/documents.....	93
4.9.2	Analysis of interview data	93
4.9.3	Ensuring quality in the research process	98
4.9.4	Reflexivity and my role in the research process.....	101
4.9.5	Summary.....	105
Chapter 5:	ESKD in Nigeria – challenging experiences	106
5.1	Introduction.....	106
5.2	Recruitment and study participants.....	107
5.2.1	The recruitment.....	107
5.2.2	Study Participants	107
5.3	Thematic Analysis	121
5.3.1	Understanding ESKD and treatment	123
5.3.2	Meaning of living as ESKD patients on dialysis.....	140
5.4	Summary of the chapter	147
Chapter 6:	Dialysis decision and Impact of ESKD and Treatment.....	149
6.1	Introduction.....	149
6.2	Dialysis decision	149
6.2.1	Cost as a barrier	150
6.2.2	Societal norms /cultural beliefs	152
6.2.3	Religious influences	154
6.2.4	Geographical issues	156
6.2.5	Physical symptoms	159
6.2.6	Dialysis as secondary to other needs	161

6.2.7	Dialysis services	164
6.2.8	Summary of key findings: dialysis decision.....	170
6.3	Impact of CKD and dialysis.....	170
6.3.1	Changing body/bodily impact	171
6.3.2	Employment challenges.....	173
6.3.3	Finances and sources of income	177
6.3.4	Religious practices.....	180
6.3.5	Changing social relationships.....	181
6.3.6	Psychological and emotional impact	183
6.3.7	Summary of key findings: Impact of CKD and dialysis treatment	185
6.4	Summary of the chapter	186
Chapter 7:	No Money, No Treatment, No Life- “CKD is a death sentence”	188
7.1	Introduction.....	188
7.2	What was known before this study	188
7.3	What this study adds	189
7.4	Discussion of the findings.....	190
7.4.1	Introduction	190
7.4.2	Illness identity	190
7.4.3	Causes.....	191
7.4.4	Time line/Control	191
7.4.5	Consequences	192
7.4.6	“A death sentence”-inequality and lack of service provision.....	192
7.4.7	Accessing irregular dialysis-misinformed and wasting scarce resources....	199
7.4.8	Being healed by faith and herbal remedies.....	205
7.5	Key contributions to knowledge	209
7.6	Strengths and limitations of the study.....	209
7.6.1	Strengths	209

7.6.2	Limitations of the study	211
7.7	Recommendations	212
7.7.1	Implications for practice	212
7.7.2	Implications for health care policy	214
7.7.3	Implications for research	215
7.8	Conclusions.....	216
	References	217
	Appendices	286
	Appendix 1: Critical Appraisal Checklist for Literature Review	286
	Appendix 2: Studies included in the literature review.....	289
	Appendix 3: Critical Appraisal Summary.....	302
	Appendix 4: Example of Literature search strategy in CINAHL	307
	Appendix 5: Participants` information sheet	308
	Appendix 6 : Participants` Invitation Letter	313
	Appendix 7: Informed consent form.....	314
	Appendix 8: University of Salford Ethical Approval	315
	Appendix 9: UNTH Ethical Approval	316
	Appendix 10: Draft interview guide	317
	Appendix 11: Extracts of framework analysis matrix	317

List of Tables

Table 1: Stages of Chronic Kidney Disease	3
Table 2: Funding of kidney transplant management in Nigeria	14
Table 3: Indicators of health expenditures in Nigeria (WHO, 2017)	22
Table 4: Search strategy, keywords and results.....	31
Table 5: Demographic characteristics of participants	109
Table 6: Frequency of dialysis sessions throughout the period of the study.....	111
Table 7: Summary of themes.....	122

List of Boxes

Box 1: Participant`s inclusion criteria	82
Box 2: Data corpus	92
Box 3: Stages of framework analysis	95
Box 4: Analytical framework	96
Box 5: Criteria for the assessment of the quality of naturalistic inquiry.....	99
Box 6: Audit trail of essential information.....	100

List of Figures

Figure 1: International comparison of RRT incidence rates in 2014 as reported in UKRR (2017, pg 39)	6
Figure 2: Illustration of the location of PD catheter	11
Figure 3: Location of dialysis facilities in Nigeria	18
Figure 4: Common-Sense Model of Illness Representations	58
Figure 5: Conceptual Framework	68

Acknowledgements

My sincere gratitude and appreciation go to my supervisors **Prof Paula Ormandy** and **Dr Lesley Lappin** for their immense support, guidance, patience, understanding and commitment throughout this journey. I am eternally grateful.

My appreciation also goes to my family most especially my wife **Amarachi** and my son **Chidiebere** for their patience, support, love, care, sacrifices and prayers. I am most grateful.

I am immensely grateful to **Dr Julius Okoye** of UNTH for his guidance and support, all the nurses and staff of Renal Ward, UNTH and the research participants for their patience despite their circumstances.

My gratitude also goes to the members of staff of the University of Salford Library especially **Maggie Costello** for her help in formatting this thesis.

To my friends and colleagues most especially **Dr and Mrs Charles Arewa**, I am eternally grateful for your advice, love, support and sacrifices.

Abbreviations

AVG	Arteriovenous Graft
APD	Automated Peritoneal Dialysis
AF	Atrial Fibrillation
ACS	Acute Coronary Syndrome
ATR	African Traditional Religion
CKD	Chronic Kidney Disease
CAPD	Continuous Ambulatory Peritoneal Dialysis
CFRN	Constitution of the Federal Republic of Nigeria
CASP	Critical Appraisal Skills Programme
CSM	Common-Sense Model of Illness Representation
DH	Department of Health
ESKD	End-Stage Kidney Disease
ESRF	End-Stage Renal Failure
EPS	Encapsulated Peritoneal Sclerosis
FMOH	Federal Ministry of Health
GFR	Glomerular Filtration Rate
GBD	Global Burden of Disease
HD	Haemodialysis
HIV	Human Immunodeficiency Virus
HFP	Health Financing Policy
HCP	Health Care Practitioners
UKKR	UK Kidney Registry
USRDS	US Renal Data System
RRT	Renal Replacement Therapy
QLR	Qualitative Longitudinal Research

Abstract

Background: Chronic kidney disease is one of the major health challenges across the world, and a silent killer of Nigerian people because they can't pay for life saving treatment which has been available for over 30 years. People pay for their own haemodialysis (HD) treatment without any government or healthcare insurance-based support system. Studies have explored the lived experiences of dialysis patients in other parts of the world, where governments support the patients with the cost of care, there is no evidence that reports the lived experiences of what it means to be a dialysis patient in Nigeria. It is important to expose the experiences of HD patients living in a healthcare system where there is unequal access to treatment; where factors such as culture, cost, family and dependents needs influence and affect compliance to treatment. The aim of the study was to explore the experiences of CKD patients receiving HD in Nigeria.

Methods: Seventeen eligible HD patients were recruited (5 females and 12 males). A qualitative longitudinal research approach was used in the conduct of the study over a period of seven months. Semi-structured interviews were conducted in three waves (1, 4 and 7 month) while a reflexive journal was kept through the period of the study and was used in the data analysis. All the interview data were analysed using framework analysis approach. Following the first interview, summary of the interview transcripts was sent to the participants for confirmation before the second and the third interviews. The transcripts of the three interviews were analysed and presented as the themes.

Findings: This study exposed the unique experiences of people living with ESKD in Nigeria, reported as 'death sentence'. Those who the money to access dialysis services had survived longer while those who had no money died early. However, that survival came at a price, often the family, friends and even whole villages would sell assets to fund short term dialysis treatment. This was unsustainable and resulted in increased poverty for the families and the dialysis patient, who ultimately died due to irregular and sub-optimum treatment. Decisions to attend dialysis sessions or adhere to treatment regimen was influenced by cultural practices/societal norms, costs issues, geographical barrier, family needs and religion. Lack of accurate information on conservative management (where there would be no financial gain for the health care facility) forced patients to make decisions to commence dialysis, resulting in early death due to inability to sustain the cost of treatment.

Conclusion: Healthcare practitioners need to provide accurate information on conservative management to enable patients to make informed choices over their lives. They should be discouraged from selling all they have to pay for treatment, stripping themselves and their

families of meagre resources, for very little gain, and health policy should support funded HD programmes.

Chapter 1: Chronic Kidney Disease and the Nigerian context

1.1 Introduction

Patients suffering from long-term conditions such as end-stage kidney disease (ESKD) experience various psychological, physical and socio-economic challenges which can reduce their quality of life and in some instances, result in social exclusion (Department of Health [DH], 2001); these experiences influence an individual's needs and priorities (DH, 2012). Dialysis patients in Nigeria experience similar challenges but with the added pressure of having to pay for their treatment costs and sustain employment while undertaking treatment. There is limited evidence to explore the impact this financial stress has on the lived experiences of people managing chronic kidney disease (CKD) undertaking dialysis in Nigeria. Although many patients fail to sustain and/or attend for treatment (Arogundade et al., 2011; Okafor, 2012; Arogundade, 2013). This thesis is one of the first studies to gain a deeper understanding of the economic, cultural, family and societal challenges ESKD patients face when accessing haemodialysis (HD) treatment in Nigeria. The study generates an evidence base to inform government policy and enhance service delivery.

The Thesis is divided into seven chapters. This chapter introduces the structure and topic of the Thesis and focus of the research. My motivations and passion for this study are captured and the health context of Nigeria described. The global incidence, aetiology and risk factors for developing CKD, alongside international best practice management of CKD are compared to the choices and treatment options available for people living in Nigeria. The structure of Nigerian healthcare systems and renal care services are examined alongside generating a clear understanding of the 'Pay for Health Treatment' policy in Nigeria and the impact this has for many people living on low incomes.

Chapter Two provides a critical analysis of current literature examining the lived experiences of people with CKD; searching for existing evidence of what we currently know about the experiences of HD patients in Nigeria. The key concepts were exposed which informed the development of this study regarding what to examine and explore within the Nigerian HD patient population to compare patient experience across various parts of the globe.

Chapter three discusses the key theoretical concepts arising from the literature reviewed. The key concepts were discussed in relation to healthcare services in Nigeria and the relevant

theories guiding the study while possible relationships existing among these concepts were highlighted. The concepts from the literature reviewed which were explored in the current study included illness representation, spirituality, cultural belief and healthcare utilisation. These concepts amongst other key issues were explored in detail in this study to understand how they impact on the experiences of dialysis patients in Nigeria.

Chapter four brought together the gaps identified from the literature, the methodology lessons learnt, and theoretical concepts important to the study and the Nigerian context to develop a PhD study to generate high quality research. The theoretical concepts uncovered in Chapter Three informed the framework for the study, used to draw out the meaning of illness, access to treatment, religious/spiritual, cultural and economic influences that impact on patients` experiences and their lives living with a long-term condition. The chapter also discussed the research approach used in this study and the method of data analysis was clarified.

Chapter five presents the study participants` biographies to gain an understanding of the type and range of people recruited and involved in the study. It highlights the clinical blood results of the participants over time and the frequency of their dialysis throughout the period of the study. The chapter also presents a critical analysis of the themes of understanding CKD and the treatment and meaning of living as CKD patients on haemodialysis.

Chapter six presents a critical analysis of the themes of the impact of CKD and dialysis, and the challenges of accessing treatment. It highlighted the issues that affect the ability of dialysis patients in low-resource settings to access regular treatment.

Chapter seven discusses the findings of the study and critically appraised the findings in the context of current literature and Nigerian health policy. It also examined the limitations of the research. It highlighted the new knowledge contributed by this study and made the appropriate recommendations for practice, research and policy and the conclusions of the study.

1.2 Chronic Kidney Disease

The kidneys are essential excretory organs which regulate body fluid, electrolyte and acid-base balance of the human body. Injury or damage to any of the kidneys in an individual can have far-reaching consequences for the growth, systemic functions and existence of the person. When appropriate measures are taken in the control of both the diet and the blood pressure, an individual diagnosed with an ongoing or progressive kidney disease could lead a healthy life for the rest of his/her life (Ormandy, 2008). However, when the injury or damage to the kidneys is irreversible, compromising normal bodily functions of the kidneys, normal growth of the individual and life, it is known as chronic kidney disease (CKD) (Barnett, Li Yong, Pinikahana and Si-Yen, 2008). The National Kidney Foundation Kidney Disease Quality Outcome Initiative (NKFQOI, 2002) defined CKD as the condition of the kidney where the glomerular filtration rate (GFR); the rate at which the kidneys filter waste products from the blood (Levey et al., 1999), falls below 60ml/min per 1.73m² for at least 3 months irrespective of the cause. Individuals whose kidneys are not damaged but have a GFR of 60ml/min/1.73m² are also included in this definition because clinically this indicates that they have lost over half of their normal kidney function and are at risk of additional complications (NKF, 2002). The GFR is an estimated figure which corresponds to the percentage of the kidney which is still normal and functional in an individual; in CKD, the critical level is when an individual's GFR becomes less than 15ml/min/1.73m². This indicates only 15% of the kidneys functioning (Levey et al., 2011) and at this point renal failure is said to be established, with an individual requiring a more dynamic treatment regimen to survive. CKD was classified in 2002 into five stages shown in Table 1 (Levey et al., 2003, p.139).

Table 1: Stages of Chronic Kidney Disease

Stages of CKD	Description of stages	Estimated GFR (ml/min/1.73m ²)
Stage 1	The GFR is normal but the structural abnormalities indicate kidney disease	90 or more
Stage 2	The kidney function is mildly reduced and already known to have some kidney disease or damaged	60-89

Stage 3	There is moderately reduced kidney function	30-59
Stage 4	Kidney function is severely reduced	15-29
Stage 5	Very severely reduced kidney function	Less than 15

A patient at stage 5, end-stage renal failure (ESRF) or end-stage kidney disease (ESKD) presents with a chronic, irreversible condition in which the kidney function is severely reduced, and the only means of survival is through renal replacement therapy (RRT) (NKF, 2002). The RRT is a therapy that replaces the normal blood-filtering function of the kidneys. It includes dialysis (haemodialysis and peritoneal dialysis) and renal transplantation. The aim of the RRT is to prolong the life of the individual and to enhance the quality of life through an independent living with minimal support (Kimmel and Patel, 2006; Barnett et al., 2008).

1.2.1 Global Incidence of CKD

According to the Global Burden of Disease (GBD) study in 2010 (Lozano et al., 2010), CKD ranked 27th in the comprehensive list of causes of death worldwide in 1990 (depicting an age-standardised death rate of 15.7 per 100,000 annually), and this rose to 18th in 2010 (depicting an annual death rate of 16.3 per 100,000). This escalation of CKD up the list was reported as second only to that of HIV and AIDS globally (Lozano et al., 2010).

There is no national data on the incidence and prevalence of CKD in Nigeria. This is due to lack of any established renal registry in the country, thereby making it difficult to give any accurate statistics on the true CKD situation in the country (Okafor and Kankam, 2012). Most of the statistics on the prevalence and incidence of CKD in Nigeria are therefore based on institutional studies. Ulas and Ijoma (2010) highlighted the enormity of the CKD problem in Nigeria using a Federal Teaching Hospital in the South-Eastern State in Nigeria as case study. It was reported that ESKD accounted for 8% of all the medical admissions in the hospital and 42% of all renal admissions. Similarly, in the South-Western part of Nigeria, the frequency of CKD in the overall admissions of a different University Teaching Hospital was captured over a ten year (1992-2002). Over the 10 years 3.6% of admissions (182 out of 5,107 cases) were recorded as related to ESKD (Alebiosu, Ayodele, Abbas and Olutoyin, 2006). Although there is no existing renal registry in Nigeria, studies have shown that the

incidence of CKD in Nigeria range of 1.6% to 12.4% (Alebiosu, Ayodele, Abbas, and Olutoyin, 2006; Afolabi, Abioye-Kuteyi, Arogundade and Bello, 2009; Odubanjo, Oluwasola and Kadiri, 2011). However, these figures represent only findings from a few hospital-based studies; therefore, they do not include many patients who do not have access to hospital care who could not have been represented. Nigeria ranks third in the list of African countries with the largest number of patients on haemodialysis (HD) (6.3 per million populations) after South Africa and Kenya (Pozo et al., 2012). These figures indicate ESKD is a growing and expanding problem for Nigerian people and health services.

In the wider African context, there is also no national registry for renal disease in any of the African countries (Naicker, 2013). This therefore makes statistics on the prevalence of CKD in most African countries unreliable. However, in a recent review of the prevalence, causes and treatment regimen for ESKD in Sub-Saharan Africa (SSA) based on published literature and relevant data obtained from renal experts in Africa by Naicker (2013), CKD was reported to affect mainly young adults in the age of 20 and 50 years in SSA mainly due to hypertension and glomerular diseases. It has been estimated that the incidence of CKD is at least three or four times higher in African countries than in the developed countries of the world (Naicker, 2003). It has also been predicted that by the end of 2020 the prevalence of CKD and ESKD will have increased substantially because of a concomitant increase in the cases of diabetes mellitus and cardiovascular diseases by 130% in Africa (Schenna, 2000).

In contrast however, the United States of America (USA) Renal Data System (USRDS), the United Kingdom (UK) Renal Registry (UKRR) and the national renal registries of many other nations especially the developed countries of the world have been recording data on the incidence of CKD in their various countries. For instance, the USRDS has been keeping annual data on RRT in the USA since 1980 to the current date, to facilitate the comparison of the incidence, prevalence and RRT services globally. The UKRR which shares data with the USRDS collates individual patient data of all CKD patients in the 71 adult renal centres across the UK (52 renal centres in England, five in Northern Island, five in Wales and nine in Scotland) and has since 1998 to 2015 published 19 annual reports to evaluate RRT services within the country (Caskey, Steenkamp and Thomas, 2017; USDRS, 2017). It is therefore pertinent to draw basic comparative information from these two data sources.

There has been a steady rise in the incidence of ESKD globally. For instance, according to the 19th UK Annual Renal Report (Gilg, Methven, Casula and Castledine, 2017), the total

number of CKD patients initiating RRT in the UK in 2015 was 7,814 representing an incidence rate of 120 per million population (pmp) in contrast to 115 pmp in 2014, although the incidence rate from 2006 to 2013 was reported to have been stable for England (Gilg, Pruthi and Fogarty, 2014). This overall increase represents increases in the incidence rate from each of the four countries making up the UK. A similar pattern increase was observed across various countries in 2014 according to the latest yearly reports available in those countries. The incidence rate in the UK was reported to be like those in various other countries in Northern Europe, New Zealand and Australia (Figure 1). However, the incidence rate has remained considerably lower than in some other countries such as the USA, Japan and Greece (Gilg et al., 2017).

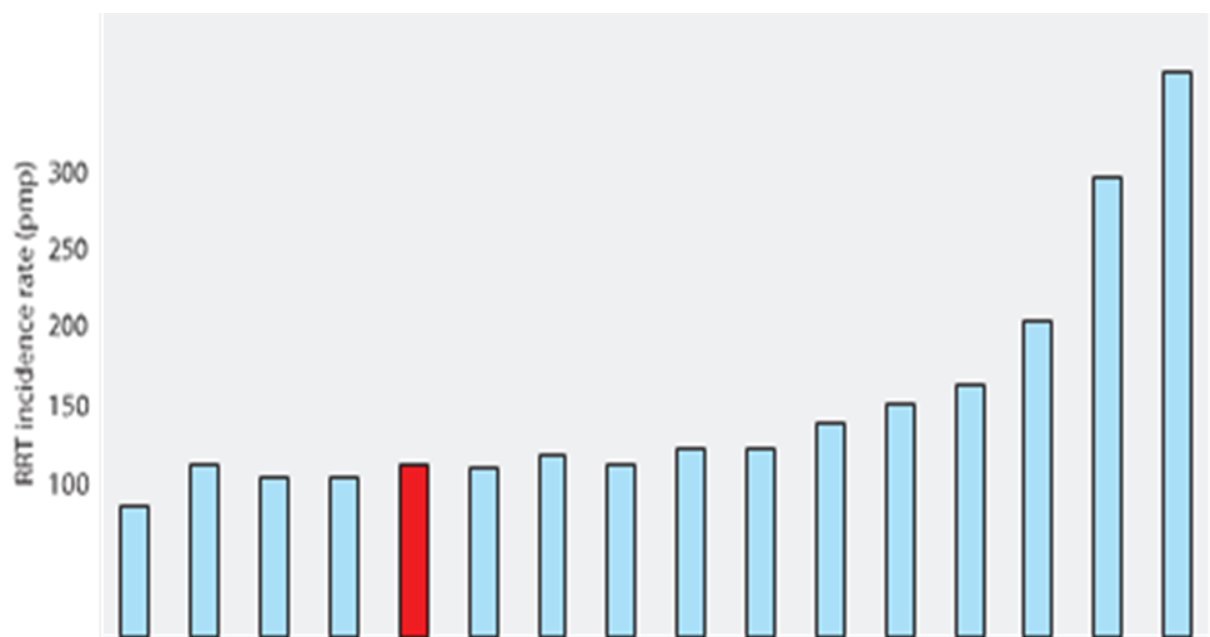


Figure 1: International comparison of RRT incidence rates in 2014 as reported in UKRR (2017, pg 39)

A B C D E F G H I J K L M N O P

KEY

A-Iceland; B-Finland; C-Norway; D-Australia; E-Netherlands; F-United Kingdom; G-Sweden; H-Austria; I-New Zealand; J-Denmark; K-Spain; L-France; M-Canada; N-Greece; O-Japan; P-United States of America.

1.2.2 Aetiology and Risk Factors for Developing CKD

There is a variation in the causes or predisposing factors to CKD worldwide. Generally, the major causes of CKD in developed countries like the UK, the USA, are diabetes mellitus and hypertension while infectious diseases, environment and industrial pollution, and herbal medicines are other causes which have been linked with the development of the condition in Asian and Sub-Sahara African countries (Jha et al., 2013; USRDS, 2017). Other factors that have been associated with the development of CKD in developed nations are old age, obesity and smoking (Levey and Coresh, 2012; Jablonski and Chonchol, 2014).

In Nigeria, chronic glomerulonephritis, hypertension and diabetes mellitus have been reported as the three major causes of CKD (Alebiosu and Ayodele, 2005; Arogundade, 2011; Bamgboye, 2011; Bello et al., 2013). Age, obesity, consumption of herbal medications, protracted use of non-steroidal anti-inflammatory drugs, and a family history of diabetes mellitus have also been reported as risk factors for the development of CKD in Nigeria (Akinsola, Odesanmi, Ogunniyi and Ladipo, 1989; Okpere, Anochie, Eke, Bell-Gam and Jaja, 2012; Wachukwu, Emem-Chioma, Wokoma and Oko-Jaja, 2015). Studies have shown that CKD and ESKD patients in Nigeria present at a very relatively young age of 20 to 50 years, compared with similar patients in the developed world (Arogundade and Barsoum, 2008; Arogundade et al., 2011; Arogundade, 2013). This finding according to Arogundade (2013) could be due to high prevalence of infection-related glomerulonephritis and the genetic susceptibility of people of black descent to hypertensive renal damage. Similarly, glomerulonephritis is a common cause of CKD in Asian countries (Jha et al., 2013). Across the Sub-Saharan African (SSA) countries, hypertension is the leading cause of CKD with statistics ranging from 25% in Senegal, 29.8% in Nigeria, 45.6% in South Africa to 48.75% in Ghana (Naicker, 2013). A significantly male prevalence of CKD has been reported in various parts of SSA (Diouf et al., 2000; Arogundade and Barsoum, 2008; Naicker, 2010; Arogundade et al., 2011). The increase in the prevalence of infectious diseases because of poor sanitary conditions, large concentrations of disease-transmitting vectors, inadequate supply of safe water, consumption of uncontrolled food additives, pesticides, environmental pollution, abuse of analgesics, and excessive consumption of herbal medications have continued to heighten the burden of CKD in low-income and developing countries (Jha, 2004; Ayodele and Alebiosu, 2010). Variations in genetic factors have been linked with the

development of non-diabetic CKD in people of African heritage (Kao et al., 2008; Kanji et al., 2011).

1.2.3 Best Practice Management of CKD

The functions of the kidneys are vital to life. Prior to the 1960's in the UK and in many countries the diagnosis of CKD would have resulted in an individual's certain death (Department of Health [DH], 2004). Since this time, there has been remarkable improvement in the understanding and treatment of the condition, resulting in patients living much longer. The advances over the years in the management of CKD include: accelerated growth and improved availability of dialysis facilities, the development of kidney transplantation option in combination with the introduction of more effective anti-rejection drugs, and the ability to treat older CKD patients with co-morbid conditions (DH, 2004; Gill et al., 2005; Carson, Juszcak, Davenport and Burns, 2009). All these have led to reduction in the mortality rate and improved quality of life in CKD patients. Another crucial advance in the management of CKD over the years is indeed, the successful treatment of young infants and children through dialysis and kidney transplantation, resulting in good long-term outcomes (DH, 2004; Gill et al., 2005; Gill et al., 2013; Kaur and Davenport, 2014). The introduction of RRT has helped to improve the lives of CKD patients, with some surviving the rigours of treatment for more than 30 years, particularly if they receive a kidney transplant, although this is rare in cases of renal transplantation (DH, 2004; Smyth, 2012; Methven, Steenkamp and Fraser, 2017).

Generally, haemodialysis (HD) and peritoneal dialysis (PD) are the common forms of dialysis. HD involves the circulation of the patient's blood through a dialysis machine, which filters the waste products and excess water, and these are passed into a special liquid known as the dialysate. Normally, ESKD patients on HD require three sessions of it, with each of these sessions lasting for hours in a renal dialysis centre, the patient's home or in a satellite unit. When patients choose to dialyse at home, they are given the appropriate trainings for them to be able to do this. The National Institute for Health and Care Excellence (NICE) had recommended that all patients who have been assessed and considered to be suitable for HD treatment should be availed the opportunity of choosing to have HD at home or in renal centre (NICE, 2002). Despite this guidance, home HD has been poorly-used in the UK as a

choice treatment in ESKD patients (NICE, 2002). In Nigeria, home HD is not an option; dialysis treatment is available only to those with sufficient resources to pay for the high cost of treatment. There is no access to any form of government support for healthcare and specifically for renal patients and in addition to the high cost of dialysis treatment. Patients also are expected to procure ancillary ESKD treatment medication for the management of anaemia and mineral bone disease associated with the disease, which places access to such treatment out of the reach of the patients with low incomes (Okafor, Ekwem and Wakoma, 2012; Oluyombo, Obajolowo, Ayorinde, Olanrewaju and Okunola, 2014).

Internationally, the use of daily HD and nocturnal HD have received increased attention. In daily HD treatment, the patients receive daily short sessions of HD while patients on nocturnal HD are given longer slower HD treatments overnight, perceived to be more effective as a replacement of kidney function (Lebner, Nesrallah and Mendelssohn, 2007; Raymont and Bonner, 2008). Predominantly in ESKD patients with undamaged arteries and veins, the vascular access of choice for HD is an arteriovenous (AV) fistula. This vascular access has the least complications but takes more than two months to develop fully after its formation (NKF, 2006; Santoro et al., 2014). The AV fistula is a surgically-modified blood vessel created through the connection of an artery to a vein, and this is usually created in the upper or wrist of the patient. The creation of a fistula through the connection of the artery to the vein increases the size and the strength of the blood vessel, thereby enhancing the transfer of blood from the patient to the dialysis machine and back to the patient's blood vessel. The AV fistula is often created 6 weeks before the commencement of HD, to allow time for the skin and the tissues surrounding the fistula to heal. However, where the blood vessels of the patient are too narrow to enable the creation of an AV fistula, an alternative procedure called an AV graft (AVG) which involves the use of synthetic tubing known as graft in connecting an artery to a vein may be recommended. Once established, two thin needles are inserted into the AV fistula or the AVG and secured into place during each session of dialysis. Each of the needles slowly draws blood from the patient's AV fistula or graft and transfers this to the dialysis machine (dialyser) which contains a special liquid known as dialysate and series of membranes that act as filters.

As a temporary measure in emergency situations or where permanent access cannot be achieved, venous catheters are often inserted into a vein in the patient's neck (jugular vein), chest or the groin. These catheters split into two tubes with two caps outside the body of the patient and is designed to be connected to the line which conveys blood to the dialysis

machine and another line which carries blood from the machine back to patient`s body). In Nigeria, most ESKD patients on dialysis treatments use a temporary form of vascular access because of late presentation or referral to the nephrologists, limited number of vascular surgeons who are skilled in the creation of AVF in the country, and the high cost of treatment (Chukwuonye and Oviasu, 2012).

Peritoneal Dialysis (PD) involves the introduction of dialysis fluid into the peritoneal cavity located in the patient`s abdomen. Like the HD, access is necessary for PD, although this is not created into the circulatory system of the patient. A tube or catheter through a surgical procedure and under the influence of a local anaesthesia is inserted into the peritoneal cavity through the abdominal wall of the patient. The peritoneal cavity is lined by a thin peritoneal membrane which acts as a filter for excess water and waste products from the blood. There are basically two types of PD. Continuous Ambulatory Peritoneal Dialysis (CAPD) in which case the fluid is exchanged (drained out of the peritoneum and then manually replaced) four to five times a day or Automated Peritoneal Dialysis (APD) in which there is more frequent fluid exchange and the patient is connected to a machine which filters the blood throughout the night while the patients are asleep. The evolution of the different types of PD was to enhance the efficiency of PD treatment and promote the convenience of the treatment for patients (Pike, Hamidi, Ringerike, Wisloff and Klemp, 2017).

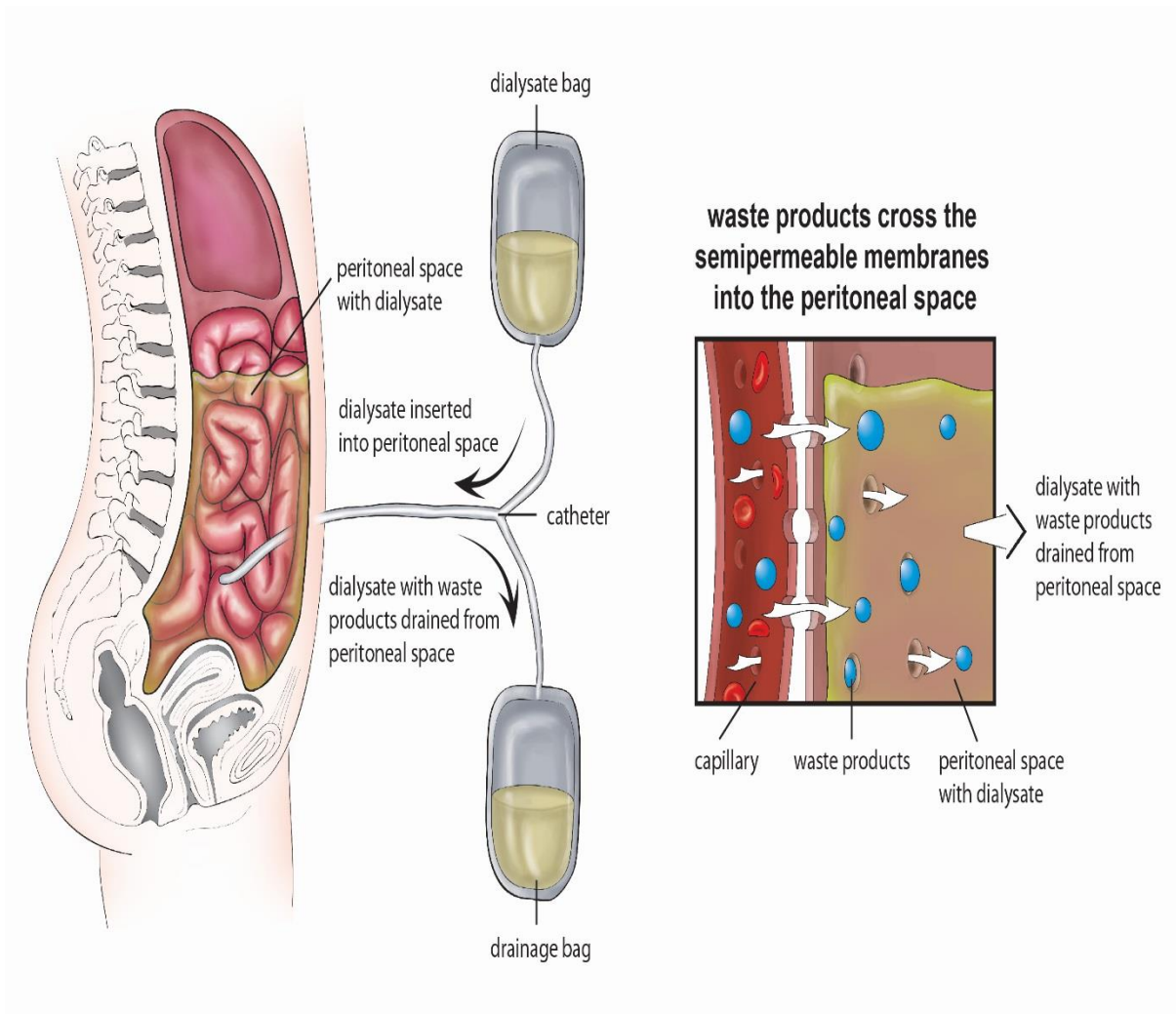


Figure 2: Illustration of the location of PD catheter

Compared to HD and PD, kidney transplantation has been demonstrated to be the best form of RRT, for almost 40% of ESKD patients who are clinically stable, as it corrects the already lost endocrine function in ESKD (DH, 2008; Chukwuonye and Oviasu, 2012). In this procedure, kidney organs can be donated from a deceased or living donor. Nowadays, living donations occur between family members, close friends or through altruistic donors who have the same blood group and closest tissue type as the patient, to reduce the chance of organ rejection. In recent times, there has been a consideration for paired donation, in which a family member is willing to donate their kidney to an unknown patient in exchange for the benefit of their own relative who needs a kidney given by another paired donor (DH, 2008); this practice is not yet available in Nigeria.

RRT services have been offered in Nigeria since 1981 with Obafemi Awolowo University Teaching Hospital (OAUTH), Ile-Ife and the University College Hospital (UCH), Ibadan

were the pioneering centres (Bamgboye, 2003; Agbaji and Abene, 2012). The predominant form of RRT available in Nigeria is the HD (Bamgboye, 2003; Alebiosu et al., 2006; Arogundade and Barsoum, 2008; Naicker, 2009). PD is still to this date largely due to a lack of availability of PD fluid, not manufactured in the country, thus requiring importation and increasing the cost of PD treatment to more than HD, placing access to such treatment beyond the reach of many low and middle-income patients (Arogundade, Sanusi, Hassan and Akinsola, 2011; Agbaji, 2011; Agbaji and Abene, 2012). A review of RRT modality in OAUTH (Nigeria) over a period of 19 years revealed that CAPD represented only 1.2% of RRT in the centre (Arogundade et al., 2011). The low utilisation of PD services within this major centre suggests that uptake within wider Nigeria could be even less. The increased risk of infection (peritonitis) discourages wider use of PD in Nigeria (Arije, Akinlade, Kadiri and Akinkugbe, 1995; Arogundade et al., 2004). Currently, there is minimal training and experience of PD among renal staff in the various renal centres in Nigeria reflecting the low use of the therapy, which also acts as a barrier to increasing use. There are currently more than 30 government-owned health facilities and several privately-owned healthcare facilities providing HD services across the various states in Nigeria (Agbaji and Abene, 2012). Although, these centres are inadequate to effectively manage the rise in ESKD within the Nigerian population. Most of these centres are situated in the urban areas, with limited access to services by patients living in rural areas (Bamgboye, 2003). The locations of the various dialysis centres in Nigeria are as shown in Figure 3.

There are variations in the cost of HD services across the country between the government-owned and privately-owned health facilities; with the cost of each HD session ranging from 25,000 to 40,000 naira (£88 to £140) (Agbaji and Abene, 2012; Chukwuonye and Oviasu, 2012). This is a very expensive to patients as in other parts of the world and the patients bear these costs as government subsidy is almost non-existent and the national health insurance scheme does not include renal care (Agbaji and Abene, 2012; Arogundade, 2013). To put this into perspective, the Nigeria's National Minimum Wage (NMW) is only 18,000 naira (£70) per month and a new graduate earns less than a 100,000 naira (£350) per month (Chukwuonye and Oviasu, 2012; Nwude, 2013). It is therefore an economic challenge for ESKD patients to sustain dialysis treatment, and this is clearly demonstrated through an unacceptable mortality rate of 80% for ESKD patients, many dying within some weeks after diagnosis (Arije, Kadiri and Akinkugbe, 2000; Bamgboye, 2003; Arogundade et al., 2011). One of the centres which provides HD to 70 % of its ESKD patients found that only 5% of

these patients could maintain their treatment for more than 12 weeks, largely due to financial constraints (Akinsola, Adekun and Arogundade, 2000; Grassmann, Gioberge, Muller and Brown, 2006; Arogundade et al., 2011; Arogundade, 2013). Similarly, a recent evaluation of HD services across the country revealed that most ESKD patients in Nigeria cannot maintain the normal three sessions of HD per week and most them (over 90%) stopped treatment by the end of a period of three months (Agaba et al., 2003; Alasia, Emem-Chioma and Wakoma, 2012).

Kidney transplantation has been recognised worldwide as the gold standard treatment option for ESKD because it is relatively cost-effective, improves the quality of life of the patients and reduces the frequency of hospitalisation in the ESKD population (Arogundade, Abd-Essamie and Barsoum, 2005; Arogundade and Barsoum, 2008; Dominguez, Harrison and Atal, 2011; Haller et al., 2011; Garcia, Harden and Chapman, 2012). However, its choice or utilisation globally has been constrained by the huge financial implications involved, difficulty in obtaining donor organs, issues of immunosuppression, and more recently organ trafficking (Badmus et al., 2005; Unuigbe, 2006; Arogundade and Barsoum, 2008; Sanusi, Arogundade and Badmus, 2008; Bamgboye, 2009; Howard et al., 2009; Glazier and Delmonico, 2012; Gondos et al., 2012). In the Nigerian context, funding has remained the major challenge to establishing renal transplantation because the majority of the ESKD patients cannot pay the cost of the procedure; thus, access to transplantation is reduced and often not even a choice for patients (Bamgboye, 2009; Howard et al., 2009). In almost half of the ESKD population funding of renal transplantation preparation and surgery in the country is often borne by the patient or their relatives, while the other half of the population source funds from their employers, philanthropists, and government donations (Arogundade, 2013, p.242: Table 2).

Table 2: Funding of kidney transplant management in Nigeria

Sources	Transplant surgery	Maintenance therapy
<i>Private /personal</i>	48 (33.6%)	107 (74.8%)
<i>Employer</i>	34 (23.8%)	34 (23.8%)
<i>Philanthropists</i>	13 (9.1%)	Nil (0%)
<i>Other donations</i>	31 (21.7%)	Nil (0%)
<i>NGO</i>	2 (1.4%)	2 (1.4%)
<i>Governmental support</i>	15 (10.5%)	Nil (0%)
<i>Health insurance</i>	Nil (0%)	Nil (0%)

***NGO- Non-governmental organisations**

There is no cadaveric transplantation in Nigeria, only living donation is practised. Most of the donors are genetically-related, the rest of the cases emotionally-related (Arogundade, 2013). The independent ethical committee in the various transplant centres usually ensure that the altruism of the emotional donors is maintained and where necessary seeks legal authorisations; this is to prevent commercialism and adhere strictly to the Declaration of Istanbul (International Summit on Transplant Tourism and Organ Trafficking [ISTTOT], 2008; Glazier and Delmonico, 2012). The evidence indicates that greater than 50% of ESKD patients in South Africa do not have access to dialysis or transplantation (Moosa and Kidd, 2006; Katz, Gernholtz and Naicker, 2011).

1.2.4 Complications of dialysis

Despite the benefits of dialysis for ESKD patients, it is associated with some complications. Venous catheters are associated with increased risk of serious sepsis, morbidity and mortality (Hokimoto et al., 2015; Landry and Braden, 2015; Wang, Wang, Liang, Lu and Liu, 2015; Rivara et al., 2016). A lack of good vascular access (VA) is a major cause of morbidity in HD patients, and is responsible for 25% of hospital admissions in dialysis patients (Levy, Morgan and Brown, 2001; Tzanakaki et al., 2014; Tong et al., 2016). Similarly, a significantly high risk of thrombosis, and other complications which affect prognosis have been reported to be associated with the use of CVC (Lok and Foley, 2013).

PD has also been linked with the development of encapsulating peritoneal sclerosis (EPS) - a rare but serious clinical condition which occurs because of long-term PD therapy. The exact incidence of EPS worldwide is not known but it's reported that the incidence increases as time spent on PD increases (Hurst et al., 2014; Alatab et al., 2017).

1.2.5 Mortality in end-stage kidney disease patients on dialysis therapy

Although maintenance dialysis therapy has successfully prolonged the lives of ESKD patients, mortality remains high within the population especially within the early period of transition to ESKD when the patients are most vulnerable (Pozzoni et al., 2004; Sim et al., 2018). High mortality rates of up to 30 percent has been reported within the first year of patients' transition from CKD to ESKD (Chan et al., 2011; Foley et al., 2014; Saran et al., 2017). Although the evidence is not exclusively consistent, studies have shown spikes in mortality rates within the first few weeks to months transition to ESKD (Chan et al., 2011; Lukowsky et al., 2012; Wick et al., 2017). This alarming rate of mortality has therefore been the drive behind the Healthy People 2020 goals to reduce ESKD mortality rate to 333 per 1000 patient years at risk within the first three months of transition from CKD to ESKD (Healthy People2020, 2018). Cardiovascular complications are the major causes of morbidity and mortality among dialysis patients (Mavrakanas and Charytan, 2016). The common cardiovascular complications include acute coronary syndrome (ACS), sudden cardiac death (SCD), heart failure, atrial fibrillation (AF) and stroke.

In Nigeria just like in many African countries, there is no national data on the mortality rates in ESKD patients. This is due to the lack of any established renal registry in the country, thereby making it difficult to give any accurate national statistics on the true situation of CKD in the country (Okafor and Kankam, 2012). However, some authors have reported mortality rate of 80 percent for ESKD patients, with many dying within some weeks after diagnosis (Arije, Kadiri and Akinkugbe, 2000; Bamgboye, 2003; Arogundade et al., 2011).

1.2.6 Impact of CKD and treatments

In addition to the function of removing waste products from the blood, the kidney regulates the acidity level of the body, blood pressure, water level, production of haemoglobin and bone formation. Thus, when the kidney's fail it results in the need to follow fluid and dietary restrictions, alongside complex drug regimens, HD or PD treatments to promote the survival and the quality of life of the patients (Baines and Jindal, 2000; Pang, Ip and Chang, 2001; Barnett et al., 2008). Ineffective treatment regimen and imbalance in ESKD patients predispose them to numerous complications such as cardiovascular disease, fluid overload, hyperkalaemia, acidosis, malnutrition, anaemia, renal osteodystrophy and fluid depletion (Levy et al., 2001; Stevens et al., 2004). Sexual dysfunction is also a complication associated with CKD and these usually occurs earlier before ESKD is established, but in most cases, it is irreversible even after commencing RRT (Palmer, 1999; Finkelstein and Finkelstein, 2002). In male patients, the sexual dysfunction includes decreased libido, premature ejaculation, erectile dysfunction and difficulty in reaching orgasm; while in female patients it includes lack of vaginal lubrication, dyspareunia, decreased libido, infertility and difficulty in achieving orgasm (Finkelstein and Finkelstein, 2002). There are also menstrual irregularities in the ESKD patients (Rathi and Ramachandran, 2012) and a reduced chance of conception and successful pregnancy, although this can improve after a successful renal transplantation (DH, 2004). Even with renal transplantation, the long term complex drug regimens which follow the surgical procedure create numerous side effects. It is therefore not surprising there are poor rates of survival for ESKD patients on dialysis given the complexity of the cause of the disease, co-morbidity and the requisite treatment modality.

The management of ESKD also has both financial and social implications including changes in lifestyle for the patient. The time taken off from work to keep to dialysis schedules for HD can be over 20 hours per week if the patient attends the prescribed three times a week schedule, including time travelling to and from the renal centre. The treatment time have a significant effect on an individuals' ability to sustain work. In most developed worlds, large numbers of ESKD patients give up their work or reduce their working hours just before or after the initiation of dialysis treatment (Curtin, Oberley, Sacksteder and Friedman, 1996; USRDS, 2017). For instance, ESKD patients on chronic RRT in the USA are regarded as "disabled" and are therefore enlisted for Medicare benefits, and following a successful renal transplantation, the patient may be expected to return to work to enhance the rehabilitation (Eng et al., 2012). However, in some other developed countries, the patients are expected to

have worked for up to a certain number of years or to have been gainfully employed (Julian-Mauro, Molonuevo-Tobalina and Sanchez-Gonzalez, 2012). Employment issue has been reported as one of the major concerns for dialysis patients (Morton et al., 2017). Dialysis patients who are of working age are more likely to be unemployed than their age-mates who are healthy (Kutner, Bowles, Zhang, Huang and Pastan, 2008; Muehrer et al., 2011; Helantera et al., 2012; Essue, Wong, Chapman and Li, 2013). The factors that have been identified to be associated with job loss after the initiation of dialysis in ESKD patients include: gender (female), older age (over 49 years), dialysis mode (HD rather than PD as first treatment modality), concurrent chronic diseases, poor or no Erythropoietin usage before ESKD and poor health insurance coverage (Helantera et al., 2011; Muehrer et al., 2011). Similarly, family caregivers are also at a high risk of losing their jobs because of the time demands for an individual who is on dialysis (Morton, Tong, Webster, Snelling and Howard, 2011).

Even ESKD patients who choose to do PD also experience similar difficulties associated with maintaining dialysis treatment while on employment in the long-term. This disruption in the normal working hours of the patients will obviously place financial burden on the patients and this can affect the entire families including the affordability of the cost of treatment (in the case of Nigeria, South Africa and the rest of the African continent). There is also the difficulty of planning and being able to afford embarking on holidays for patients on HD as they would need to be close to renal centres where they can maintain their treatment, while PD patients would need to plan for the delivery of the dialysis fluid to their holiday destinations (for patients in developed world). However, for HD and PD patients in developing world like Nigeria, South Africa and the rest of the countries in SSA, embarking on holidays is a luxury which is hardly within the reach of the ESKD patients as most of them bear the expensive cost of their RRT services. Therefore, patients suffering from long-term conditions such as ESKD experience various psychological, physical and socio-economic challenges which can reduce their quality of life and in some instances, result in social exclusion (DH, 2001) and these experiences also influence their choice of needs and priorities (DH, 2012; Morton et al., 2017).

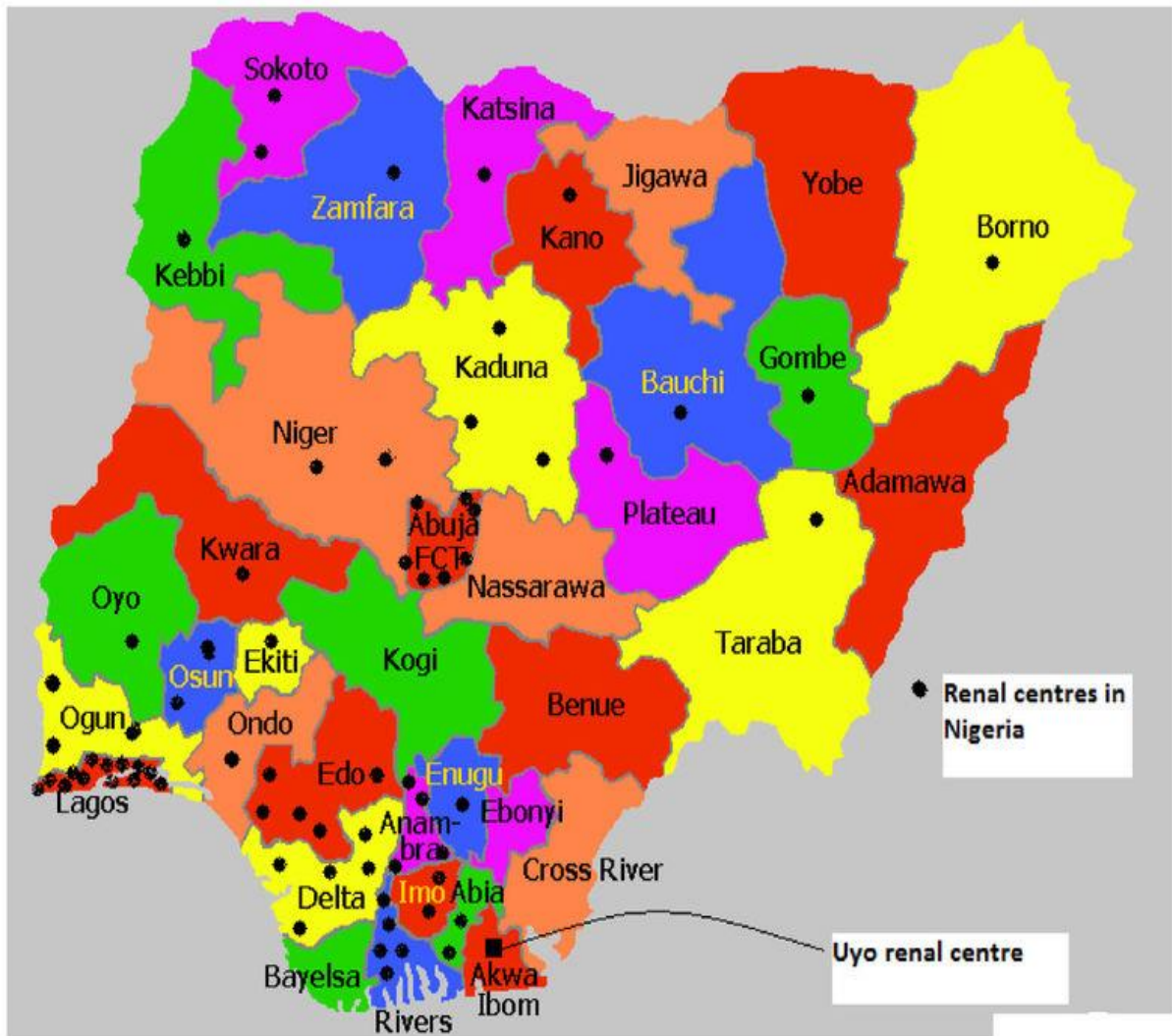


Figure 3: Location of dialysis facilities in Nigeria

1.3 Health care services in Nigeria

This section will discuss the structure of the health care system in Nigeria, health care financing, the healthcare financing policy and health coverage in the country.

1.3.1 Structure of the Healthcare Systems/Services in Nigeria

The organisation of healthcare services in Nigeria is complex, comprising of both private and public-sector providers. The private providers include non-governmental and religious organisations, private-for-profit providers, community-based organisations and traditional

care providers (World Health Organisation [WHO], 2015). The Nigerian public sector, in principle, operates a decentralised three-tier healthcare system with responsibilities entrusted to the three tiers of government agencies: The Federal Ministry of Health (FMOH), the State Ministry of Health (SMOH) and the Local Government Health Department (LGHD). The governance system in the country is categorised into one Federal Government, thirty-six State Governments including the Federal Capital Territory Abuja, and 774 Local Government Areas (Lukpata, 2013; Okebukola and Brieger, 2016). All the three tiers are involved in major health system functions including planning, financing and service provision. The public-sector financing of health care in Nigeria is therefore tied to the national funds which are allocated to the three tiers of government. The sharing formula of the funds confers undue financial advantage on the Federal Government as almost half of the funds are allocated to the Federal Government while the thirty-six States in Nigeria are allocated a quarter of the fund and the remaining quarter goes to the 774 local governments (Lukpata, 2013). However, the allocation of funds to the local governments is through the state governments in deference to the 1999 constitution of Nigeria (Constitution of the Federal Republic of Nigeria [CFRN], 1999). The devolution of the responsibility of managing PHC to the Local Governments without any guaranteed financial matching has resulted in varying patterns of health outcomes across the local governments depending on the ability of the community to influence the demand and supply of the PHC services (Babalola and Fatusi, 2009; Ononokpono and Odimegwu, 2014). The channelling of funds meant for the Local Governments through the States has created a lot of loopholes for corruption, whereby the various State Governments allocate to the Local Governments whatever amount they consider appropriate and this has further weakened the functional capacity of this tier of government.

The FMOH is responsible for the formulation of national health policy for the country and provides technical and financial support to the overall health system, coordinating and supervising services in the two other levels (Omosho, 2017). It is responsible for international relations on health matters regarding the country and provides tertiary health services/facilities through the Federal Medical Centres, Federal Teaching Hospitals and National Laboratories. The FMOH also carries out disease surveillance, training of health professionals and regulation of drugs (Okebukola and Brieger, 2016). The SMOHs provide secondary care services through comprehensive health centres and state hospitals. It also regulates and provides technical support to primary health care (PHC) services provided by

the LGHD, through primary healthcare centres (PHCs). The State Governments are mostly responsible for the funding and management of the secondary healthcare facilities which include the general hospitals, and some of the primary healthcare facilities. The State authorities are also responsible for the training of nurses, midwives, health care technicians and provision of technical assistance to the health programmes and facilities of the LGHD (National Primary Health Care Development Agency [NPHCDA], 2013; Okebukola and Brieger, 2016).

The 774 Local Governments in conjunction with the State Governments are responsible for the management of the LGHD. They provide the necessary human resources and other logistics for the provision of PHC. Every community is an integral part of a local government area which is administered by the local government authority. Although the State Governments and the Local Governments are jointly responsible for the LGHD, the decision on what sub-national government takes primary responsibility for the provision of PHC is dependent on the internal arrangement within each state (CFRN, 1999; FMOH, 2004; Abimbola et al., 2015). Generally, the States oversee the recruitment of healthcare personnel to work in the PHCs which are operated by the Local Governments. However, the States retain this responsibility only for the senior healthcare workers such as doctors, nurses, midwives and senior community health workers while they delegate the function of hiring junior health personnel such as junior community health workers to the Local authorities (Bonilla-Chacin, Okigbo, Malife, Sherburne-Benz and Ruhl, 2010).

Although the local governments have the main responsibility for managing the PHC, all the three tiers of government and various agencies participate in PHC as the constitution of Nigeria is silent on the roles of each of the various governments in healthcare provision (Omosho, 2017). This at times results in duplication, overlap, and confusion of roles and responsibilities. In addition, the PHC which constitute the mainstay of the national health system has continuously remained in shackles largely due to lack of political will, gross underfunding, and a lack of capacity at the Local Government levels which are supposed to implement PHC at the grassroots to the communities (Omosho, 2017).

1.3.2 Healthcare financing in Nigeria

Health care in Nigeria is financed by a combination of tax revenue, out-of-pocket payments, donor funding, and health insurance (social and community) (WHO, 2009; Olakunde, 2012). Nigeria's health expenditure is relatively low, even when compared with other African countries. The total health expenditure (THE) as a percentage of the gross domestic product (GDP) from 1998 to 2000 was less than 5%, falling behind THE/GDP ratio in other developing countries such as Kenya (5.3%), Zambia (6.2%), Tanzania (6.8%), Malawi (7.2%), and South Africa (7.5%) (Soyinbo, 2005). Recent publications show that there has been a steady rise and fluctuations in the THE since 2009 to 2014. For instance, the THE was 23.97% in 1997, it rose to 31.4% in 2001 and fell to 29.2% in 2005. In 2009, the figure rose again to 36.3% but fell drastically again in 2013 to 15.6% (WHO, 2017) as shown in Table 2. These figures clearly show a lack of government commitment or will towards funding the health care systems in Nigeria. Olaniyan, Oburota and Obafemi (2013) reported that government financing of healthcare in Nigeria for many years contributed less than 20% of the total health care financing in the country while out-of-pocket financing of healthcare by the citizens has consistently risen higher than 67% of the total healthcare financing. This situation has therefore resulted in unequal access to healthcare for the poor citizens who struggle to meet basic daily needs and as such find it difficult to afford cost of medical care (Ichoku and Fonta, 2009). Achieving a successful health care financing system continues to be a challenge in Nigeria. Limited institutional capacity, corruption, unstable economic, and political context have been identified as factors why some mechanisms of financing health care have not worked effectively (Adinma and Adinma, 2010). The capacities of facilities installed many years ago are now overstretched and the building infrastructure in various states of disrepair. Evidence suggests the Nigerian public seems to be reverting to the traditional care providers, because of problems of access and affordability (Emuakpor, 2010; Abdulraheem, Olapipo and Amodu, 2012; Jaro and Ibrahim, 2012). Moreover, the demography of Nigeria shows that about 55% of the total population live in the rural areas compared to 45% in urban cities (Omoruan, Bamidele and Phillips, 2009) and most of the rural dwellers are poor and predominantly peasant farmers. Figures from 15 years ago indicated that Primary health care were catering for less than 20% of the potential patient population (Gupta, Gauri and Khemani, 2003). The goal of the National Health Policy (1987) revised in 2004 (Federal Ministry of Health, 2004) was to introduce a comprehensive healthcare system based on primary health care that is preventive, protective, restorative and

rehabilitative to all Nigerian citizens. In addition, within the available resources it was envisaged that health would be promoted to assure and increase productivity, social well-being and the quality of life of individuals and communities (Adeyemo, 2005). This ambitious goal has not been realised.

Table 3: Indicators of health expenditures in Nigeria (WHO, 2017)

	1997	2001	2005	2009	2013
Total expenditure on health as % of GDP	4.6	5.2	6.6	5.8	3.9
General expenditure on health as % of THE	23.5	31.4	29.2	36.3	15.6
Private expenditure on health as % of THE	76.5	68.5	70.8	67.3	66.8
Out-of-pocket expenditures as % of THE	94.6	91.4	95.8	95.6	95.8

1.3.3 Health Care Finance Policies in Nigeria and Health Care Coverage

Over the years, successive governments in Nigeria have made varying efforts aimed at addressing the healthcare financing issues. Uzochukwu et al. (2015) highlighted that has led to the development of several policies and plans with a view to achieving universal health coverage (UHC). Some of the policies and plans include: The National Health Policy (NHP), Health Financing Policy (HFP), National Health Act (NHA) and National Strategic Health Development Plan (NSHDP).

The major thrusts of the National Health Policy with respect to healthcare financing is to expand the sources of financing healthcare and strengthen private sectors' contribution towards this. It also seeks to engage households and communities through community-based schemes in financing PHC services in Nigeria. It explores the public-private partnership approaches for the expansion of health financing options at all levels of care.

The NHFP was enunciated in 2006 by the FMOH to promote equity and access of Nigerians to quality and affordable healthcare, and to promote accountability and efficiency through

the development of a fair and sustainable health financing system (FMOH, 2006). The overall goal of the policy is to ensure the availability of adequate and sustainable resources to all levels of care through an efficient allocation mechanism to PHC services.

The NSHDP (2010-2015) represents a shared desire to strengthen the national health care systems and to substantially improve the health status of Nigerians. It was developed as the reference health care development document for all stakeholders in the healthcare sector and to promote accountability in the realisation of the national health goals and targets. The overall goal of NSHDP is to ensure the availability and provision of adequate funds and other resources for the provision of accessible, efficient, affordable, and equitable healthcare services at the Federal, State and Local levels.

The National Health Act (2014) provides the legal framework for the regulation, management and funding of PHC services in Nigeria. The NHA includes a provision for the basic health care provision fund (WHO, 2014). The Act created the National Primary Health Care Development Fund (NPHCDF) which is responsible for the disbursement of the funds meant for essential drugs for PHC, maintenance of PHC facilities and development of human resources through the State Primary Health Care Boards for onward distribution to the Local Government Health Authorities. The act stipulates that:

- 50% of the funds shall be used for the provision of basic health services to all the citizens in eligible PHC facilities via the NHIS.
- 25% of the funds shall be used to supply essential drugs to the PHC facilities
- 15% of the fund shall be used for the provision and maintenance of PHC facilities, equipment and transport for PHC.
- 5% of the funds shall be used for the development of human resources for eligible PHC facilities; and
- 5% of the funds shall be used for National Health Emergency and Epidemic Response by the Federal Ministry of Health.

Although the NHA Act and other policies and plans as highlighted clearly defined the roles of the various tiers of government in Nigeria and provided roadmaps for the nation`s health care systems, the realisation of the objectives has largely remained a wishful thinking as poor funding, systemic corruption and lack of political will on the part of the government in investing heavily on the health care systems.

1.4 Perspectives on death and dying in Nigeria

Death is an inevitable end to human life, however, just as people have different perception of life, so do they have of death. The differences in the perception of death by individuals or groups is like the understanding of life itself from a religious, cultural or scientific perspective (Neimeyer, Wittkowski and Moser, 2004). While the interpretation of life from a scientific perspective may result in an individual's preparation for death based on medical report and other scientific evidences, those who see death from the religious perspective are to a large extent concerned with religious injunctions regarding death, and those who have cultural perspective of death consider other factors which are responsible for a person's death. These factors may include the assumption or belief that one's enemies could use spiritual powers to cause misfortune, and deities can strike people to death or end people's lives if they offend the gods and other spiritual forces (Okechi, 2017). Although most religions provide frameworks for answering the existential questions regarding death and dying, however, individual's attitude and belief towards death and dying beyond any cultural and socio-economic factors, may affect one's conception or perception of the phenomenon of death and dying (Wulffs, 1991).

Among various societies in the world, how, when, where and what can cause death has become a source of concern to not only individuals and groups but also specialists such as sociologists, psychologists, social workers, etc. globally (Okechi, 2017). Evidence has also shown that the divergence in culture, civilisation and life experiences can significantly affect the perspectives of individuals and groups on death and dying (Weafer, 2009). In most developed nations, individuals perceive death as a stage in life, which everyone will come to irrespective of time or context. For instance, a survey by the Irish Hospice Foundation showed that among the Irish people, about 14 percent of Irish adults had written up living will or advanced directives, which is an order to terminate their lives whenever they are faced with terminal illnesses (Weafer, 2009). Similarly, most Europeans and Americans have the understanding that death is a necessary end that needs preparation by every individual based on their values and beliefs; for example, some European nations have legally-approved assisted suicide and individual approval for life termination when should one be faced with severe health complications (Wright, Zozula and Wilcox, 2012). The

perception of death in Africa generally and in Nigeria particularly, however, is unique when compared to other parts of the world (Umoh, 2012). In the African perspective, only elderly persons are perceived to have completed their assignments on earth and are assumed to have gone home to be with their ancestors when they die; the death of a young person is therefore naturally seen as unacceptable and is attributed to the handwork of an enemy (Okechi, 2017). This perception is becoming increasingly worse in contemporary times when many socio-economic factors are fuelling the low life expectancy and health indicators in many African nations. In most African societies especially in Nigeria's rural communities, there is a lot of overt or covert bitterness shown after the burial of a dead relative. In most cases, some individuals or even some family members must avoid the burial scene due to various reasons ranging from the fear of being accused to being bewitched at the burial arena. In addition, out of fear, some individuals may choose to leave the community during the burial to avoid being caught up in any form of troubles. However, most cases of such deliberate avoidance are perceived as an implicit sign of guilt; this can lead to the destruction of the houses and other personal belongings of such people.

In most African communities including Nigeria, rejecting the possibility of individuals dying of natural cause as inevitable is fast becoming the ideal way of coping psychologically in moments of grief. Typically, Nigerian communities find it difficult to accept the inevitability of death. Consequently, due to the difficulty in establishing any reliable scientific explanation, which can convince the bereaved especially with a poor health care system, the only alternative argument therefore lies in the realm of spiritual enemies and witchcraft as the cause of death. For instance, among the Anang people of Southern Nigeria, presumably incurable disease conditions are portrayed as unnatural and occur as a handwork of the enemy or the gods (Okpechi, 2017). Due to the poor health care system and a lack of adequate health awareness among the poor masses, several health conditions such as epilepsy, elephantiasis, paralysis, etc., according to popular beliefs among the people do not just strike the victims naturally. Such diseases are therefore believed to be inflicted upon one, or as they are described locally, "given to the victims by enemies".

The knowledge of life expectancy and the factors affecting it is lacking among traditional Nigerian communities even in modern times. For instance, culturally it is abominable for one to say that somebody may die even from chronic illnesses in typical Nigerian communities especially if the person suffering from the condition is still young. Should one say such a thing, one either is deemed mentally unfit or is wishing people death as a

messenger of doom. Therefore, the only message or comment that is widely acceptable among the people is that everyone irrespective of his or her health condition will live a long life. Hence, any preacher preaching about death will likely lose members, any researcher researching on death and dying and any government agency working on death-related information may not receive proper attention from potential participants.

1.5 The anticipated contributions of the study to knowledge

Many research evidences exist in literature on the experiences of ESKD patients who are receiving HD or PD. These studies reported the experiences of dialysis patients to include emotional or psychological issues, disruptions in family relationships, dependence on dialysis machine, body image issues, suffering, spirituality, and uncertainty. However, all these studies were conducted in health care systems with equal access to dialysis services or those in which the government offered subsidies to ESKD patients. While we know what the experiences are for these group of dialysis patients, we do not know what the experiences of dialysis patients in Nigeria or any African context where the healthcare systems are characterised by unequal access to treatment and the patients pay out of pocket. Therefore, this study is the first to explore the experiences of dialysis patients in any health care systems with unequal access to health services. Also, while previous other studies collected data either one off or in two successions, none of them utilised a QLRs approach in exploring the experiences of ESKD patients on dialysis. Collecting a one-off data does not give a true picture of what life is like for dialysis patients as no two days are ever the same like in every chronic condition.

The findings of this research have the potential to:

- (1) Add new knowledge to what is already known on the experiences of dialysis patients globally.
- (2) Enhance the delivery of renal care services in Nigeria.
- (3) Make methodological contributions in understanding the experience of patients living with long term conditions.

1.6 Summary

Patients suffering from long-term conditions such as ESKD experience various psychological, physical and socio-economic challenges which can reduce their quality of life and in some instances, result in social exclusion. Diabetes mellitus, hypertension, infectious diseases, environment and industrial pollution, and herbal medicines are other causes which have been linked with the development of the condition in Asian and Sub-Saharan African countries. There is no national data on the incidence and prevalence of CKD in Nigeria; this is due to lack of any established renal registry in the country. ESKD accounts for 8% of all the medical admissions in the hospital and 42% of all renal admissions in a hospital-based record in Nigeria. Studies have shown that the incidence of CKD in Nigeria is in the range of 1.6% to 12.4%. Nigeria ranks third in the list of African countries with the largest number of patients on haemodialysis (HD) (6.3 per million populations) after South Africa and Kenya. Most ESKD patients in Nigeria cannot maintain the normal three sessions of HD per week and many of those (over 90%) stopped treatment by the end of a period of three months. This study will therefore explore the experiences of haemodialysis patients in such a healthcare where people pay out of pocket for the cost of their treatment.

The next chapter will highlight and discuss the findings of a systematic review of previous studies which examined the experiences of ESKD patients who are receiving dialysis treatment with a view to establishing the gap in literature.

Chapter 2: Current understanding of CKD patient experience

2.1 Introduction

The introductory chapter provided an overview of CKD, highlighting the global incidence, aetiology and risk factors for developing CKD, the impact of CKD on the physical body and the side effects, alongside identifying best practice management, but more importantly the limited options for people in Nigeria. The structure of healthcare systems/services in Nigeria, renal services and policy in Nigeria and highlighted potential real-life issues Nigerian people face in accessing regular life-saving treatment. This chapter seeks to understand and highlight research evidence that exists which reports ESKD dialysis patient experience and the impact it has on their daily lives. By doing this the gaps in literature and knowledge will be exposed and will situate the current study (Jesson, Matheson and Lacey, 2011; Fink, 2014). The chapter presents the findings of a systematic review of previous studies which examined the experiences of ESKD patients who are receiving dialysis (haemodialysis or peritoneal dialysis).

The purpose of this systematic review was two-fold:

- (1) To identify and present a detailed synthesis of the best available evidence exploring the experiences of ESKD patients who are receiving dialysis, and
- (2) To identify the gaps in literature of what is currently known on the topic to contextualise the current study.

The review process followed the qualitative systematic review protocol developed by Butler, Hall and Copnell (2016). The review question was:

What are the experiences of ESKD patients who are receiving dialysis?
--

The literature search process is clearly described alongside the critical appraisal methods employed in determining the quality of the studies included in the review. The findings provide a synthesis of both common themes and divergent views gleaned from the qualitative studies reviewed. The limited evidence base provides a rationale to support a deeper in-depth which seeks to expand the understanding of the experiences of ESKD patients who are on dialysis (Ring, Ritchie, Mandava and Jepson, 2013).

2.2 Search Strategy

2.2.1 Initial search

The search strategy forms a major component of the literature review in any research study. To ensure literature relevant to the study was retrieved, a comprehensive approach of searching the bibliographic databases, citation tracking and a search for grey literature (such as dissertations, conference papers, unpublished reports), to avoid review bias, was adopted (Cooper, 1998; Conn et al., 2003). The search strategy is defined, with a focus on seeking the patient perspective; the voices of the patients living with the condition. The initial literature search was completed between January and November 2015.

Five databases were considered appropriate to search because they contained core electronic journals of health care research, and these databases included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature On-Line (MEDLINE Ovid), Web of Science, Psych Info and Google Scholar. Initially broad search terms were used and then the key words were refined to have a more focused search and to retrieve an output of relevant literature (Table 4).

To facilitate the recall of related terms and ensure that all relevant studies were retrieved, the keywords and their related terms were combined during the search using the Boolean operators “AND” and “OR”, the MeSH headings, and databases` thesauri (Brettell and Grant, 2004). The search was limited by language (only studies published in English) and date; no earlier than 1993 (to present day) as different forms of dialysis were more readily available from this time (Ormandy 2008). The combined search of the five electronic databases (CINAHL, MEDLINE, Web of Science, Psych Info and Google Scholar) using the refined specific search terms yielded a total of 805 studies. The review of the abstracts indicated 50 papers were related to the topic of study. On further scrutiny of the full article, 32 papers met the inclusion/exclusion criteria and were included in the review (Table 4).

A manual search of grey literature was performed to expose any articles not listed in the databases, but no further papers were located (Brettell and Grant, 2004; Pope, Mays and Popay, 2007).

2.2.2 Updated search

The updated search was completed in November 2017 to retrieve any published evidence relevant to the review and which might have been omitted during the initial search and ensure that no existing relevant evidence was omitted. Therefore, the initial literature search strategy was repeated in November 2017 and this yielded 312 references from the five databases and these were saved into the Endnote and screened for any possible duplicates. This further reduced the number of abstracts relevant to the review to 40. The titles and abstracts of the 40 were screened using the same inclusion and exclusion criteria. Only six primary studies (Al Nazly, Ahmad, Musil and Nabolsi, 2013; Guerra-Guerrero, Camargo Plazas, Camero, Santos Salas and Cofre Gonzalez, 2014; Shaw, 2015; Gullick, Monaro and Stewart, 2016; Burns, Tranter and Raghunath, 2017; Nagpal et al., 2017) and a systematic review (Reid et al., 2016) were identified as relevant and the full texts were identified. However, Reid et al. (2016) was later excluded because almost all the studies it reviewed had already being included in the current review. Four studies (Asti et al., 2006; Davison and Simpson, 2006; Polaschek, 2007; Wu et al., 2016) were excluded because they did not meet the criteria listed in Table 4, and a literature review (Polaschek, 2003b) was excluded because it did not clarify the review strategy. Similarly, another study by Pugh-Clarke, Read and Sim (2017) was excluded because it explored the symptom experiences of non-dialysis dependent ESKD patients. The 38 primary studies provided the evidence base for the final review (Table 4; Appendix 2).

Table 4: Search strategy, keywords and results

Stage	Keywords/Search terms	Total papers
Broad topic search (all databases)	Dialysis, renal failure, end-stage renal failure, CKD, renal replacement therapies, experiences of ESKD, experiences of RRT.	10,020
Refined search (all databases)	End-stage kidney disease; Chronic kidney disease; Renal failure ; End-stage renal disease; End-stage renal failure; Kidney failure; Kidney disease; Renal replacement therapy (RRT); Dialysis patients; Haemodialysis; Peritoneal dialysis; Lived experiences; Perceptions of dialysis; Coping with chronic kidney disease; Perceptions of chronic kidney disease; Meaning of illness; Illness representation; Meaning of dialysis; Experience of chronic kidney disease; Perspectives of chronic kidney disease patients; Living with chronic kidney disease.	805 (312)
Abstract review	Title and abstract relevant to topic	50 + (40)
Inclusion/Exclusion	<p>Inclusion:</p> <ul style="list-style-type: none"> • published between 1993 and 2017 • English language only • studies and reviews on ESKD patient experiences on dialysis; patient meaning of ESKD and dialysis • studies on dialysis patients` perspectives of their condition and treatments • studies related to adult ESKD patients (>18 years) <p>Exclusion:</p> <ul style="list-style-type: none"> • healthcare professional`s perspectives of patient experiences • abstracts only/ conference/opinion papers 	<p>32+ (6)</p> <p>18 (34)</p>

	<i>Total papers reviewed</i>	38
--	------------------------------	-----------

2.3 Results of the literature search

2.3.1 Overview

The thirty-eight primary studies published between 1993 and 2017 were selected for the review. Thirty-seven of the studies employed qualitative approaches, and only one study (Caress et al., 2001) employed both qualitative and quantitative approaches. The most popular qualitative study design was interpretative or descriptive phenomenology, this is often the method of choice for in-depth exploration of people’s feelings and experiences (Speziale and Carpenter, 2007). Although, the range of qualitative approaches suggested phenomenology was one of many different methodologies that could appropriately be used to explore the topic of patients` lived experiences. In eight studies (Hagren et al., 2005; Hardwood et al., 2005; Tong et al., 2009; Clarkson and Robinson, 2010; Ekelund and Andersson, 2010; Tong et al., 2013; Shaw, 2015; Burns, Tranter and Raghunath, 2017) the research designs employed were unclear although, the methods used to elicit data were adequately described. A summary of the studies included in this review is shown in Appendix 2. Three of the studies were conducted in the United Kingdom (UK), seven Australia; six Sweden; five Canada; four United States of America (USA); two in both New Zealand and Iran; one each in Singapore, Greece, Philippines, Brazil, Spain, Republic of Ireland, Chile, and Jordan. None of the studies explored the lived experiences of CKD patients within an African country or healthcare systems with such an inequitable access to dialysis treatment for CKD patients.

2.3.2 Study Aims

Whilst some studies combined different aims to investigate research questions, there was clear overlap of study aims across all the studies reviewed. The studies generally sought to explore a deeper understanding of the meaning of living with CKD, perceptions, attitudes, views, and experiences of CKD patients undergoing dialysis. Most of the studies clearly

explored the life experiences of CKD patients on dialysis, meaning of renal illness and dialysis treatment, meaning of life to dialysis patients, and the views, thoughts, feelings and perceptions of dialysis patients about their treatment. One study examined the experiences of social interactions in the daily lives of CKD patients on HD (Kazemi et al., 2011) while only one of the studies investigated the experiences of dialysis and its impact on CKD patients and their partners (White and Grenyer, 1999), while one other study (Mitchell et al., 2009) explored HD patients' views on what helps them while transiting onto dialysis therapy. One study (Tanyi and Werner, 2008) specifically examined the experiences of spirituality among CKD stage-5 women and those on HD.

2.3.3 Patient Modality

All studies included within the review involved CKD patients receiving various forms of RRT; HD patients were the most prevalent participants as twenty-seven studies exclusively recruited only patients receiving HD; five studies combined patients receiving HD or PD, and one (White and Grenyer, 1999) recruited PD patients and their partners only (Appendix 2). Three studies recruited a cross-section of patients at CKD stages 1-5: patients not currently receiving dialysis treatment (pre-dialysis), alongside those on HD, PD and renal transplant (Caress et al., 2001; Tong et al., 2009; Tong et al., 2013), while only one of the studies (Sadala et al., 2012) involved only PD patients. The mode of dialysis was unclear in two of the studies (Molzahn et al., 2008; Nagpal et al., 2017) the different patient dialysis modalities of the participants; however, only one of the studies (Shaw, 2015) involved patients who combined both modes of dialysis. It recruited patients who were on only PD (7), patients who were on HD (10) and patients who combined both PD and HD (3). Most of the HD studies involved participants receiving in-centre treatment compared with home dialysis therapy, highlighting that in-centre HD is the commonest delivery method of HD treatment in most parts of the world. In addition, only one of the studies (Burns, Tranter and Raghunath, 2017) involved patients who were on in-centre night haemodialysis (INHD).

2.3.4 Sample and Sampling Method

The number of participants recruited in each of the 37 qualitative studies varied from three (Giles, 2005) to 63 (Tong et al., 2009) while the only mixed method study (Caress et al., 2001) had 405 participants. Twenty-five studies recruited samples less than 21 participants (range 3-20) while twelve other qualitative studies had samples ranging from 23 to 63 (Appendix 2). Twenty-six studies recruited participants from one centre or study site, while nineteen studies selected participants across different centres. There was variance in the gender representations across the various studies; most of the studies recruited more males than females; two studies (Polaschek, 2003; Giles, 2005) recruited only men while one recruited only women (Tanyi and Werner, 2008). The age ranges varied in accordance with the renal modalities, with more elderly patients receiving HD treatment. One study targeted younger people on dialysis with participant's ages ranging between 12 and 24 years (Tong et al., 2013); another recruited younger aged adult ranging from 30-45 years (Herlin and Wann-Hansson, 2010), whereas Axelsson et al. (2012) targeted older patients aged between 66-87 years. The demographic details of patient ethnicity were not explicit across the studies; although some identified participants as either Caucasians, Asians or Black Americans.

The clarity of reporting the sampling methods, participant selection and recruitment were mixed across the 38 primary studies. Most of the studies (28) reported using a non-probability sampling design. Four used a convenience sampling approach (Hagren et al., 2005; Velez and Ramasco, 2006; Polaschek, 2007; Clarkson and Robinson, 2010). Twenty-two studies used purposive sampling approach: more specifically one study used purposive convenience sampling (Tanyi and Werner, 2008); two used theoretical sampling (Harwood et al., 2005; Kaba et al., 2007) while another described using a purposive theoretical approach (Faber et al., 2003). In nine studies, the sampling approach was unclear (White and Grenyer, 1999; Caress et al., 2001; Hagren et al., 2001; Molzahn et al., 2008; Herlin and Wann-Hansson, 2010; Lai et al., 2012; Guerra-Guerrerro et al., 2014; Lindsay et al., 2014; Vestman et al., 2014).

2.3.5 Ethical Issues

Thirty-three studies reported gaining ethical approval from the appropriate ethical authorities (Hospital, University, or Local Research Ethics Committee) and described the processes

used to gain informed consent from the participants prior to recruitment, which included providing information to participants. Three gained permission to undertake the study from the Directors of the hospital sites where the study was to take place (Davison and Simpson, 2006; de Guzman et al., 2009; Vestman et al., 2014), while another five studies (Faber et al., 2003; Hagren et al., 2005; Velez and Ramasco, 2006; Ekelund and Andersson, 2009; Sabet et al., 2011) provided no clear indication whether ethical approval was obtained from the appropriate authority. All studies except two described the participant data protection, confidentiality, and anonymity measures adopted within the studies (Faber et al., 2003; Vestman et al., 2014).

2.3.6 Methods/ Data Collection

Thirty-seven studies used exclusively qualitative methods in the collection of data. Almost all the studies used interviews as the means of data collection, although with some variations in the details of the interview process except two studies (Molzahn et al., 2008; Vestman et al., 2014) which collected data through written narratives of the patients. Most of the qualitative studies (24) adopted open-ended interviews while ten used semi-structured interviews. The majority were individual interviews except Tong et al. (2009) which used focused group interviews. Sadala et al. (2012) conducted narrative interviews, Lai et al., (2012) performed an open-ended conversational type of interview whereas Vestment et al. (2014) collected data through written narratives. Most of the studies (26) conducted one interview at one point in time, whereas others (7 studies) performed multiple interviews over time. The interview schedule, examples of the questions asked, or the topics discussed was clearly presented in five studies (Herlin and Wann-Hannsson, 2010; Axelsson et al., 2012; Lai et al., 2012; Al Nazly et al., 2013; Nagpal et al., 2017). The length of time of interviews ranged from 26 minutes (Monaro et al., 2014) up to three hours (Velez and Ramasco, 2006). In addition, six studies combined interviews with data collection methods such as participant diaries, observations and the reflective accounts by the researchers.

There were variations in the underpinning philosophy and description of the studies. Thirteen of the qualitative studies described clearly and followed an analytical process such as Colaizzi's methodology and content/thematic analytical methods, showing clarity and depicting trustworthiness of the data (Gregory et al., 1998; White and Grenyer, 1999;

Polascheck, 2003; Giles, 2005; Ravenscroft, 2005; Velez and Ramasco, 2006; Molzahn et al., 2008; Tanyi and Werner, 2008; Moran et al., 2010; Sabet et al., 2011; Al Nazly et al., 2013; Guerra-Guerrerro et al., 2014; Gullick, Monaro and Stewart, 2016). As stated earlier, seventeen studies used phenomenology, of which eleven used interpretive phenomenology (hermeneutics) and six descriptive phenomenology with bracketing (Appendix 2), but only two of these (Tanyi and Werner, 2008; Sabet et al., 2011) reported details of the bracketing processes or measures and reflexivity within the study. Many of the studies simply provided a broad description of the data analysis by coding and thematic analysis. Clearly, some of the studies may have been pressured by the policy of the journal and the limited space allocated, as there were differences in the details and depth of the various studies reported in the journals.

2.3.7 Researcher Bias

Most of the researchers were external to the field of renal care while across the various studies the researchers were a mix of academic nurses, doctoral students in nursing, renal specialists, nurse practitioners, renal social workers and medical practitioners in renal medicine. In two studies, members of the research team were also Directors of the Renal Unit where the studies were conducted (Harwood et al., 2005; Herlin and Wann-Hansson, 2010). This could possibly have increased the chance of introducing bias in the study both in their selection of patients and in what patients may say about their experience to people who care for them. Ten studies did not provide any information on the professional background of the researchers making it difficult to assess potential bias (Gregory et al., 1998; Curtin et al., 2002; Faber et al., 2003; Davison and Simpson, 2006; Tanyi and Werner, 2008; de Guzman et al., 2009; Al Nazly et al., 2013; Lindsay et al., 2014; Vestman et al., 2014; Shaw, 2015).

2.3.8 Quality of Evidence

Different assessment criteria have been developed to evaluate the quality of qualitative research studies and enhance evidence-based healthcare practice. This has resulted in an increased volume of systematic reviews and the hierarchy of research evidences, essential

for evidence-based practice (Ross et al., 2009; Gopalakrishnan and Ganeshkumar, 2013). Since almost all the papers in this review (37) were qualitative except for one (Caress et al., 2001) which is mixed methods, it was therefore important to consider the potential methods of quality appraisal. While the critical appraisal of quantitative studies is well established, the appraisal of qualitative research studies is generally prone to poor acceptance and there exists little consensus on what makes a good qualitative study and whether the critical appraisal of qualitative studies should be undertaken at all or what should be done with the findings of such studies (Dixon-Woods et al., 2006; Downe, 2008; Thomas and Harden, 2008; Porritt, Gomersall and Lockwood, 2014; Toye et al., 2014; Butler, Hall and Copnell, 2016). This is because the appraisal seems not only more subjective and less deductive but also more of an art than a scientific endeavour (Booth and O'Rourke, 2001). In addition, the instruments of data collection in qualitative research studies such as focus groups or interviews appear to be more susceptible to the influence and bias of the researcher (Rees et al., 2010). Debates suggest that such research studies do not seek replicable findings and generalisation but seek to provide concrete and clear observation of the phenomenon being studied (Rolfe, 2006; Porter, 2007). More recently, there are growing agreements that qualitative research studies will not only increase the knowledge base but will broaden the scope of evidence-based health care practice (Hurst, 2011; Reid et al., 2016). Three distinct factors to assess quality include, the need to use criteria like those used in appraising quantitative research studies, develop new sets of criteria for qualitative studies and to have no pre-planned set of criteria (Rolfe, 2006).

Several qualitative research appraisal tools with similar assessment criteria have been published, with an ongoing debate over which of the tools is most appropriate for the appraisal of qualitative studies in systematic reviews (Spencer et al., 2003; Dixon-Woods et al., 2006; Briggs, 2008; Downe, 2008; Toye et al., 2014). Although research on the use of checklists in the appraisal of qualitative research suggests that it is not desirable nor practicable to choose only a single appraisal tool (Barbour, 2001), the Critical Appraisal Skills Programme (CASP, 2015) was selected for reviewing the studies included in this review (Appendix 1a); the systematic review was critically appraised using the critical appraisal checklist for systematic review (Appendix 1b). The rationale for choosing the framework is due to the diversity of the methodology used in the various studies and the simplicity of the checklist in providing a framework for assessing the qualities of all types of qualitative studies, also it has been used effectively in other systematic reviews of

qualitative studies (Kane, Wood and Barlow, 2007; Hannes, 2015). The tool or framework used in appraising the quality of qualitative research studies should demonstrate (i) a clear aim of the research study, (ii) an appropriate methodology and (iii) a justification for the sampling strategy used (Rees, 2010); the CASP tool utilised clearly fulfils these criteria. The CASP tool contains ten questions which facilitate rapid evaluation of each of the studies, however, it does not provide a scoring system for the studies reviewed. The quality of each of the studies was assessed using the tool, 25 studies satisfied all the 10 items on the CASP checklist while thirteen studies did not satisfy one or two items on the checklist (Appendix 3). The researcher and another doctoral researcher (B.N.) independently appraised the studies using the CASP tool. Some of the studies did not fulfil all the items on the checklist, but clearly reported the results of the studies using well-illustrated participant narratives, quotes and comments. Only a few of the studies did not include details of the quotes or narratives of the participants (Harwood et al., 2005; Noble et al., 2010; Herlin and Wann-Hansson, 2010). The majority reported a thorough, clear and rigorous approach to the data analysis. Since there are currently no accepted methods for the exclusion of studies based on their appraisal score, all the studies were included in the data synthesis and analysis (Thomas and Harden, 2008; Hannes, 2011).

2.3.9 Analysis and Synthesis

The synthesis of qualitative research studies has generated many discussions in the literature (Finfgeld, 2003; Thorne et al., 2004; Flemming, 2007). The debate aimed at increasing the knowledge base of healthcare in consonance with the principles of evidence-based practice, which require a change from the use of individual primary studies to an integration of these individual studies in the construction and formulation of theories (Sandelowski, 1993; Rolfe, 2006; Porter, 2007). This expectedly should influence healthcare professionals and enhance the translation of theory into practice. Some of the arguments put forward by these authors have questioned the possibility or the acceptability of conducting syntheses of qualitative evidence and whether it is acceptable to carry out a synthesis of qualitative studies conducted using different approaches (Sandelowski, Doherty and Emden, 1997).

There are numerous methods of synthesising qualitative research studies, and these include meta-ethnography, meta-synthesis, thematic analysis, meta-summary, meta-narrative

mapping, meta-study, case survey, content analysis and qualitative comparative analysis method (Dixon-Woods et al., 2005; Pope and Mays, 2006). However, meta-ethnography and meta-synthesis are two common methods used in synthesising qualitative research studies, although they require higher skills or expertise, time and many reviewers and are therefore not usually recommended for inexperienced researchers (Finfgeld, 2003; Thorne et al., 2004). The synthesis of qualitative studies with a similar methodology is advocated, but even though similar themes can be identified across various studies the mixing of methods could lead to difficulties in the development of theory because of the differences in the epistemological foundations of the various studies (Estabrooks, Field and Morse, 1994; Jensen and Allen, 1996). Others adopted a more pragmatic approach (Paterson et al., 2001).

The diversity of the groups of participants and the methods in the various studies elicits some pertinent questions as to how the findings should be presented. One way could be initially to examine the experiences of the HD patients, then the experiences of HD and PD patients combined, and finally those of the PD patients alone (Hurst, 2011; Polit and Beck, 2014). However, following a careful analysis of all the studies included in this review, it was obvious that several common concepts and themes had emerged. This therefore informed the decision of the researcher to present the narratives in terms of the common themes and concepts derived from all the qualitative studies included in this review (Hurst, 2011).

2.4 Main Themes and Review Findings

Polit and Beck (2014) stated that the analysis of qualitative evidence generally starts with the search for common categories and themes, so the findings from each study were examined separately and then tabulated together allowing cross cutting common themes to emerge. DeSantis and Ugarriza (2000, p.362) offered a useful definition of a theme as:

‘An entity that brings meaning and identity to a current experience and its variant manifestations. As such a theme captures and unifies the nature or basis of the experience into a meaningful whole.’

A variety of concepts emanating from the studies were also helpful to the evaluation process, with themes emerging at the levels of concepts of categories, domains or taxonomies

(Parahoo, 2014). Nine core themes representing the key findings identified from the analysis of the combined studies in the review, these included:

- Uncertainty
- Meaning of illness
- Body image
- Physical effects
- Dependence on dialysis and dialysis machine
- Normality and lifestyle
- Relationships: Families and healthcare professionals
- Suffering
- Spirituality/religion

2.4.1 Uncertainty

The theme of uncertainty was associated with possible prognosis of the disease condition and the treatment outcomes and this was prominent across 13 of the qualitative studies in the review (Appendix 2). The patients expressed uncertainty concerning the debilitating impact of their health due to constant interruptions in their life activities occasioned by serious illness episodes (White and Grenyer, 1999; Kaba et al., 2007). Uncertainty was often ameliorated when the patients visit the hospital and see other patients who were worse off. The constant feeling of uncertainty by CKD patients who were on dialysis was reinforced not only by their health condition but also by the sense of insecurity and anxiety about the impact of CKD on their future (Tong et al., 2013). For some of the patients, this feeling of uncertainty and frustration usually grew whenever they were informed that their creatinine level had gone high during clinic visits (Tong et al., 2013). Young adult patients were more anxious and uncertain about the possibility of ever finding a life partner, being able to raise their own families, and pursuing their career ambitions. Younger women were uncertain about the possibility of having a baby in future due to their dialysis treatment (Tong et al., 2013).

One of the studies (Molzahn et al., 2008, p.14) described the experience of “liminality” as “ambiguous or in-between spaces” which are associated in the literature with uncertainty. The study involved a narrative review of the stories written by the dialysis patients in books,

which involved secondary analysis, weakening constructs and inferences since the researchers did not have a direct access to the patients. However, the themes which emerged from the study were centred on the experience of living in “liminal space” by dialysis patients while awaiting transplantation. This is like the study of Monaro et al. (2010) in which case the theme of uncertainty was associated with waiting for a transplant, while the experience of living in hope waned and in turn created uncertainty. Living in a liminal space and experience of uncertainty as described the studies were defined around the alterations and the in-between situation felt by the dialysis patients; this however provided a contrast between “independence” and “dependence” and being “normal” and “not normal”. Although the theme of uncertainty was associated with waiting for transplantation Herlin and Wann-Hansson (2010), identified patients were more anxious and uncertain about the possibility of getting a matching donor and the prognosis of the surgery.

The concept of uncertainty was referred to as a situation of the “unknown” by the patients; while others described it as temporal which changes over a period (Curtin et al., 2002; Polaschek, 2003; Kaba et al., 2007). The fear of death was a major cause of uncertainty among dialysis patients regarding the prognosis of their disease condition and the treatment regimen (Curtin et al., 2002; King et al., 2002; Velez and Ramasco, 2006; Ekelund and Andersson, 2010). However, some of the dialysis patients expressed positive disposition and readiness to accept death whenever it came (Curtin et al., 2002; Ekelund and Andersson, 2010; Velez and Ramasco, 2006). This awareness of death enhances patients` sense of self-awareness and reflection (Moch, 1989; Carpenter et al., 1999).

2.4.2 Meaning of illness

The course of illness in CKD is distinctive to individual patients and families (Jablonski, 2004). As these patients continue to live with the health condition and the stress associated with it, they begin to question the meaning of their illness and the life they are living, and this usually helps them substantially in adjusting to the management of their conditions (Gregory, Way, Hutchinson, Barrett and Parfrey, 1998). The meaning of relates to the “meaning” based on the individual experiences of the patients. There has been increased recognition of the concept of meaning of illness across disciplines and this has led to the description of the concept from different perspectives; from the discipline of psychology

(Leventhal et al., 1998) and from the theories on stress and coping (Lazarus and Folk, 1984) (discussed further in the next chapter). However, it is arguable that every model of health crisis has a common feature, that pre-existing belief structures influence patients' representations of illness (Sharpe and Curran, 2006).

The representation of the meaning of illness varied across the studies. Meaning of illness was represented as living in pain, stress and other social and psychological inconveniences associated with dialysis treatment and learning to deal with the negative changes in one's life (Faber et al., 2003; Axelsson et al., 2012); this therefore led the patients to constantly question the essence or meaning of life (Axelsson et al., 2012). In other studies, meaning of the illness was described in terms of a loss of "normality" which has extensive and long-lasting impact on the patients' lives and identity (Caress et al., 2001; Velez and Ramasco, 2006). The specific meanings of illness among dialysis patients were influenced by situational factors such as experience of their condition, knowledge, sociocultural forces and includes a cognitive appraisal of the patients' illness episodes and lifestyle changes (Gregory, 1998), these factors shape the reaction of patients to illness (Velez and Ramasco, 2006). This could be described as "knowing" and "doing", and it includes knowing the diagnosis, understanding the treatment regimens, knowing how to control the negative feelings associated with the condition and the limitations associated with the treatment regimen. On the other hand, the "doing" involves the translation of the knowledge into action. However, the knowledge of the patients clearly did not translate into consistent health behaviours.

Only one of the studies in the review explored how meaning of illness is represented by dialysis patients using a quantitative approach (Caress et al., 2001). Caress et al. specifically explored the subjective meaning of illness in a cross-section of pre-dialysis, dialysis and transplant patients using the Meaning of Illness Schema based on the work of Lipowski (1983) in which patients were offered eight choices of possible meanings of illness. The schema was based on the belief that individuals have different perspectives to illness; while some may view illness positively as a sort of challenge, others view it negatively as a form of loss or punishment. Again, this is consistent with the assertions of Lipowski (1983) and the findings of other studies included in this review (Curtin et al., 2002; Faber et al., 2003; Giles, 2005; Polaschek, 2007; de Guzman et al., 2009; Ekelund and Andersson, 2010; Axelsson et al., 2012); however, this has been reported elsewhere to be somewhat at variance with the current trends of promoting patient empowerment (Gibson, 1991; Richards, 1999).

The information on the prognosis of their condition was more of a concern to the pre-dialysis and the transplant patients than it was for the dialysis patients (Caress et al., 2001). Although the study of Caress et al provided interesting perspectives on the meaning of illness, the finding is weakened by the fact that the quantitative measurement employed in the study cannot be a good approach to elicit information on a subjective construct like the “meaning of illness”. Therefore, the qualitative approach adopted in the other studies discussed earlier in this review does provide a more objective, personal, sensitive, and unbiased understanding which can hardly be ignored in the search for meaning.

2.4.3 Body Image

Patients reported that the commencement of HD treatment had both positive and negative changes in their bodies. Although there was initial fear of disability or possible death before commencing dialysis, some of the participants reported improvement in their well-being and better daily functions since commencing dialysis (Monaro et al., 2014). Some of them reported feelings of physical depletion, headache and fatigue due to dialysis. In Tong et al. (2013), some of the participants who had smaller or shorter body stature than their colleagues felt they were much weaker; particularly, some of the male participants perceived themselves as less masculine than their peers. Patients were self-conscious about the body scars and protrusion from their bodies.

The bodily changes in dialysis patients were generally reported as uncomfortable, impacting negatively on not only their self-images and functions but also on how other people perceived their bodies. The bodily changes reported were related to scarring resulting from arteriovenous (AV) fistula for HD and physical changes on their bodies, medication use resulting in hair loss, weight gain and increased body hair, skin changes and loss of freedom to carry out activities of daily living independently (Kazemi et al., 2011; Lindsay et al., 2014). These changes were reported to have resulted in changed sexuality, which negatively impacted on their inter-personal relationships. However, some participants expressed a lack of concern about the scars and body image. Younger dialysis patients were more upset about changes in their self-images due to the bumps of AV fistula and living with the dialysis catheter in their necks (Kazemi et al., 2011). Both the older and the younger patients reported that the self-image negatively affected their degree of social interaction with others.

Giles (2005) explored the existential concept of the body, due to the continuous dependence of the body on the dialysis machine for survival. Giles utilised the van Manen's (1997) work to understand the concept of the lived body in home haemodialysis patients and their subjective experiences of the treatment. The concept specifically relates to the human body as a physical entity within the realm of dialysis. Giles (2005) discussed the patients' relationship to the HD machine; patients described the relationship as that of a struggle between their bodies and the dialysis machines. Older HD patients nearing end of life interpreted their deteriorating bodies differently (Axelsson et al. 2012). While some of the patients likened their deteriorating bodies to "deteriorating machine", others interpreted it because of old age or not sure if it's due to their disease condition.

2.4.4 Physical effects

The physical impact of CKD and dialysis reported across the studies focused on how they affect daily activities of the patients. The side effects of both PD and HD and the medications were regarded as negative. The physical effects manifested as various symptoms and the patients described them in terms of enduring, suffering or loss of autonomy. The physical effects are often associated with reduction in the physical activities of the patients and this made them more reliant on support persons in the performance of daily tasks (Polaschek, 2003; Noble et al., 2010; Al Nazly et al., 2013; Lindsay et al., 2014; Monaro et al., 2014). The commonest excessively distressing symptom reported was increasing fatigue (Polaschek, 2003; Axelsson et al., 2012; Al Nazly et al., 2013; Monaro et al., 2014). Patients reported that their symptoms were often not considered important by their healthcare providers. This is related to the common medical doctrine which presupposes that patients are considered "well" in as much as their clinical and biomedical indicators are normal. For instance, symptoms such as pruritus and restless leg which are capable of imposing significant problems in the daily lives of dialysis patients may sometimes be ignored as minor. These physical symptoms according to Curtin (2004) can significantly impact on self-management by the patients. Most patients on nocturnal HD (Burns, Tranter and Raghunath, 2017) reported they experienced feeling less tired or having more energy since they commenced dialysis and improved ability to manage their fluid and dietary regimen when compared to their pre-dialysis period while only a few experienced physical symptoms such

as cramps and allergy to paper tape. These physical symptoms were related to the longer hours the patients spent on the machine.

2.4.5 Dependence on dialysis and dialysis machine

Patients receiving HD generally referred to the impact of the dialysis machine on their lives and this seemed to dominate their entire experience of treatment discourse (Curtin et al., 2002; Polaschek, 2003; Kaba et al., 2007; Sabet et al., 2011; Axelsson et al., 2012; Gullick, Monaro and Stewart, 2016). The dialysis machine was perceived to be in total control of the body by the patients, while the body was being separated from self, and the patient feeling to have lost control over self (Giles, 2005; Velez and Ramasco, 2006; Ekelund and Andersson, 2010; Kazemi et al., 2011; Shaw, 2015; Gullick, Monaro and Stewart, 2016). In many cases paradoxically, the machine was an essential tool for sustaining life and which the patient cannot do without (Hagren et al., 2001; Curtin et al., 2002; Faber et al., 2003; Hagren et al., 2005; Sabet et al., 2011; Guerra-Guerrerro et al., 2014; Vestman et al., 2014; Shaw, 2015). Therefore, patients regard dialysis and the machine as essential components of their lives (Sabet et al., 2011; Shaw, 2015; Gullick, Monaro and Stewart, 2016). This acceptance of the dialysis machine's life-saving facet has been described by Curtin (2002) as self-adaptation and reframing experience which confers on the patient some degree of control over the treatment. Similarly, Polaschek (2003) described this as a relationship between autonomy and dependence. The depiction of the dependence engendered by the machine was reflected in the patients' view of the entire illness process as a struggle between dependence and independence (Kaba et al., 2007; Molzahn et al., 2008).

The amount of time spent on dialysis has also been variously described across the studies (Hagren et al., 2001; Ravenscroft, 2005; Ekelund and Andersson, 2010; Herlin and Wann-Hansson, 2010; Kazemi et al., 2011; Al Nazly et al., 2013; Shaw, 2015; Gullick, Monaro and Stewart, 2016). One study (Burns, Tranter and Raghunath, 2017) which involved patients on nocturnal HD (performed overnight whilst the person was asleep) reported that patients had improved quality of life because the treatment allowed the patients a lot more time to engage in other non-dialysis activities. How patients adapt to the machine and cope with it is somewhat variable, some studies expressing dialysis in terms of "work" or a "career" (Faber et al., 2003; Gullick, Monaro and Stewart, 2016). The study by Faber (2003)

has adopted work as the main theme, as patients attempt to cope with the limitations imposed by dialysis. In Moran's study time was described as 'killing time' and 'waiting time', both related to individuals' perceptions of how much time is taken waiting to go on the machine and time whilst on the machine causing boredom (Moran et al., 2009b). Similarly, in Gullick, Monaro and Stewart (2016) time according to the dialysis patients were grouped into "lost time", "clock time" and "lived time" and these times described the compartmentalising of the life of a patient on dialysis into dialysis and non-dialysis days. This leads to another dominant theme of all the studies regarding the ways in which the experience of dialysis disrupts normality.

2.4.6 Normality and lifestyle

Most of the studies included in this review have focused on the investigation of the experiences of patients on dialysis, and these experiences are largely related to the way dialysis affects and disrupts normal life. This therefore includes the social, psychological, emotional and physical impact on the patients. While some studies reported the negative view of a struggle for normality (Hagren et al., 2001; Dekkers et al., 2005; Molzahn et al., 2008), others reported one of optimism and success in achieving some level of normality (Curtin et al., 2002; Velez and Ramasco, 2006). Molzahn et al. (2008) and Tong et al. (2009) described this as having to put one's life on the hold or losing normality and control over one's life. Many other studies described the struggle of negotiating and dealing with the unwanted side effects of dialysis to adopt a new way of life (Gregory et al., 1998; Hagren et al., 2001; Curtin et al. 2002; Faber et al., 2003; Dekkers et al., 2005, Hagren et al., 2005; Velez and Ramasco 2006; Guerra-Guerrero et al., 2014; Gullick, Monaro and Stewart, 2016; Nagpal et al., 2017). To achieve some level of control over their lives, some patients undertook some adaptive measures which involved fitting the treatment plan into their lives (Curtin et al., 2002; Polaschek, 2003b; Curtin et al., 2004; Ravenscroft, 2005; Polaschek, 2007; Gullick, Monaro and Stewart, 2016). Curtin et al. (2002) also identified that although it may take a lot of efforts, participants often endeavoured to have some level of normality or even to the "new normal" situation. This struggle for normality could be achieved through hobbies, socialisation or the patient engaging in meaningful employment (Walton, 2002); however, this depend on how well the individuals have adapted to the regime of dialysis therapy. Gregory (1998) describes this process of adaptaion as a move from the old self to a

new self. Curtin et al. explored the experiences of long-term dialysis survivors-those who had been on dialysis for at least four years. Words such as “enduring” have been used by patients when describing what it means to remain positive as dialysis patients (Gregory et al., 1998). Patients who were regarded as successful in achieving this appeared to have certain common attributes such as stoicism, optimism, fighting spirit, motivation, autonomy and self-assurance (Caress et al., 2001; Hagren et al., 2001; Curtin et al., 2002; Hagren et al., 2005; Polaschek, 2007). These attributes in some cases may be linked to spirituality (Tanyi and Werner, 2008). It can be argued that similar factors may have influenced other interviews (Caress et al., 2001; Polaschek, 2007).

2.4.7 Relationships: Families and healthcare professionals

All the studies of experiences of CKD patients receiving dialysis referred to families and the healthcare providers, as the major social support structures around the patients. Families were usually described in a very positive sense as the most important source of support, financially and emotionally. However, the impact of the disease on the family may also be profound as patients become increasingly more dependent on them (Gregory et al 1998, Hagren et al 2001; Polaschek, 2003; Hagren et al., 2005; Nagpal et al., 2017). Some studies have highlighted that the illness often strengthen family relationships, and this could be a source of motivation for the patient (Polaschek, 2003; Molzahn et al., 2008). The role of the healthcare providers in their illness experience was also described in the studies in both a positive and a negative sense. Patients who were dependent on in-centre dialysis also referred to the impact of staff within their respective units. Participants were conscious that they were dependent on the renal staff, and that their lives were in their hands (Faber et al., 2003). The level of support the participants required was linked to the expertise of the staff, the level of trust existing between the staff and the patient (Gregory et al., 1998; Ravenscroft, 2005; Kaba et al., 2007). These positive views according to the participants reflect the appreciation of the caring attitude of the medical and nursing staff. Nursing staff were found to play a more dominant caring role than the medical staff, while the medical staff were often mentioned as not being present enough. Some participants however, experienced loneliness and social isolation (Kaba et al., 2007; Molzahn et al., 2008), which resulted in some of them “putting on appearances”, and giving full information to the healthcare professionals (Caress et al., 2001; Hagren et al., 2001; Polaschek, 2003). While some of the patients chose to

become an integral part of the dialysis community, others preferred to separate themselves from it (Faber et al., 2003). The participants also described the dominant attitude of some medical and nursing staff. The asymmetry of the relationship between the medical and nursing staff and the patients, and the medicalisation of symptoms were also highlighted frequently in some of the studies (Faber et al., 2003; Velez and Ramasco, 2006; Polaschek, 2007). The paternalistic approach to how healthcare practitioners deal with patient problems seems to create negative feelings with some patients on dialysis and this was reflected as some of the patients requested that dialysis nurses should be friendlier with them and carry out more effective communication while giving them nutritional and dietary information (Al Nazly et al., 2013). In studies of self-care patients, learning the medical language is seen to be an important feature of the process (Curtin et al., 2004; Polaschek, 2007).

2.4.8 Suffering

Suffering is a word used in many studies to describe the physical and emotional turmoil of the participants (Faber et al. 2003, Polaschek, 2003; Ravenscroft, 2005). Hagren et al. (2001) uses suffering as a focus to discuss the losses the participants felt because of HD, discussing it as loss of freedom, and strain on the family. The authors further described the suffering as taking place on three levels: suffering as related to sickness and treatment, suffering related to the care being provided, and suffering related to each person's unique life and existence (Hagren et al., 2001). The authors also described the ultimate suffering as the fear of death, which is always present as dialysis patients. Hagren (2001) described the existential optimism participants used as a way of reducing suffering. A combination of the fear of possible machine breakdown or what could happen should the machine fail to work and a reflection on their illness, expectations and hope all add to the sufferings of the participants. The major limitation of Hagren's study is the nature of the interviews. The interviews were very brief because of the frailty of the participants. This may have limited the richness and depth of the participants' responses in contrast to a major feature of qualitative studies (Parahoo, 2014). Participants described ways of reducing suffering and coping with words such as hope, endurance and perseverance. Hagren et al. (2001) also found that waiting for a transplant was described as an example of suffering by the participants.

2.4.9 Spirituality/Religion

Spirituality was used as the focus of experiences, using spirituality to gain acceptance of their illness and to help them to come to terms with the possibility of death, which offered a slightly different perspective (Tanyi and Werner, 2008). It described how participants used spirituality as a powerful coping strategy. However, the participants in this study were only women, so did not include the perception of male dialysis patients of their religion as a coping tool. The authors described other themes such as fortification (an inner strength which gives individuals the will to remain alive and to help others). This however involves the patients learning about their illness and the self-care required. Tanyi and Werner (2008) also described the theme of emotional modulation or fostered coping which helps patients to reduce anger and depression and promote happiness in them. Another study described participants expressing their faith in God as helping them cope with their condition, they perceived their diagnosis of CKD and being on dialysis as a test of their faith in God (Al Nazly et al., 2013). They also expressed their diagnosis of CKD and being on dialysis has strengthened their faith in God; however, they reported that their dialysis routines sometimes made it very difficult for them to keep to their religious commitments especially during the religious fasting periods. Similar findings identified patients expressed tenacity and resilience rooted in spirituality (Nagpal et al., 2017).

Other studies have occasionally referred to spirituality, but often in a negative sense when participants have searched for meaning, blaming their illness on spiritual factors or on divine intervention (Caress et al., 2001; Velez and Ramasco, 2006). This could be explained by the way these studies were conducted and the questions used. Interestingly, many of the coping behaviours arising through spirituality were found in the other studies and could therefore be regarded as illustrations of an inherent human quality.

2.5 Summary of the review

The purpose of this review was to identify existing evidences on the experiences of CKD patients receiving dialysis treatment, as expressed through the voices of the patients and their perspectives on living with the condition. Thirty-eight studies, which met the inclusion criteria, were therefore chosen and reviewed. Thirty-seven of those studies used qualitative

approaches while only one used both a qualitative and quantitative approaches (Caress et al., 2001). All the studies were assessed on their quality using the CASP tool. Almost all the studies reviewed were conducted in developed countries of the world and only a few from developing countries, with none from any developing country or any African nation where there is unequal access to healthcare treatment. The themes identified from the studies include the themes of uncertainty, meaning of illness, body image, physical effects, dependence on dialysis and dialysis machine, normality and lifestyle, relationships, families and healthcare professionals, suffering and spirituality/religion.

The themes and concepts described from the findings of these studies can help to provide understanding of the multidimensional and complex experiences of individuals living with CKD. While most of the studies focused on in-centre HD, there are common elements across all modes of RRT. There is however, an over-representation of participants on HD compared to PD as only five of the studies involved only PD patients. Unlike the other studies, the HD experience relates to the machine, time spent on the machine, the environment and the side effects. It is difficult to determine whether the medical discourse was more predominant in the HD patients than those on PD. There were also studies that only included either men or women, often from white backgrounds. Different ethnic minorities and gender are not truly represented in these studies, cultural differences were rarely referred to in fact, and only one study used culture as its focus (Kaba et al., 2007).

The studies included in this review provide useful insights into the sociological considerations and psychosocial issues for individuals living with CKD. The coping and adaptation perceived in these studies relate to their journey from diagnosis up to starting dialysis and their continued lifetime on dialysis. From the studies in this review the meaning of illness, unless explicitly described, was often viewed differently; some studies concentrate on the negative aspects of CKD and others the value and positive features of the adaptive process. These conflicting views can be assigned to the different theoretical and methodological approaches adopted in the various studies, and experience of long-term condition was a common element (Thorne et al. 2002).

2.6 Gaps in literature

Following a comprehensive search of existing literature on the topic (January 1993-2017), several studies have explored the experiences of CKD patients receiving different forms of dialysis in various settings. The evidence has identified many core themes related to the experiences of CKD patients receiving dialysis in well-structured healthcare systems in which the patients have access to regular dialysis and did not have to pay for their care. However, we do not know what the experiences are for dialysis patients in healthcare systems with unequal access to healthcare such as Nigeria or any other African country where the patients must pay from their pockets for the full cost of dialysis without any health insurance or government support. None of the studies reported any major issues associated with access and sustainability of dialysis by the patients. Therefore, we do not know how issues such as the culture of the people, economic circumstances, and familial and societal issues affect people with long-term conditions such as ESKD, and how these issues affect their ability to access and sustain dialysis. It is therefore pertinent to explore and highlight the experiences of these patients and create awareness on their plights. While some of the studies reviewed collected data at more than one point, none used a longitudinal approach in gathering data as patient`s experience of their illness changes or otherwise over time. No two days are same for patients suffering from long-term conditions such as CKD. There are clear gaps in evidence which have been used to form the basis of this PhD study and informed the research aims and study objectives.

2.7 Research aims, objectives and questions

2.7.1 Research aim

The overarching aim of this study is to explore the experiences of CKD patients receiving haemodialysis in healthcare systems with unequal access to treatment.

2.7.2 Research objectives

The specific objectives of this study are therefore to:

- Gain a deeper understanding of the meaning of living with CKD and receiving dialysis and how this influences treatment.
- Explore and describe experiences of dialysis patients in healthcare systems with unequal access to healthcare and highlight any change in the experiences or otherwise over time.
- Explore the impact of economic, social, cultural, societal and familial issues on access and sustainability of dialysis treatment
- Explore the views of the patients regarding ways to improve their access and sustainability of treatment

2.7.3 Research questions

The research questions guiding this research are:

- What does living with CKD and receiving dialysis mean to dialysis patients in healthcare systems with unequal access to treatment?
- What are the experiences of dialysis patients in Nigeria?
- What socio-economic, cultural, familial or societal issues influence patient's decision to access and sustain dialysis?

The next chapter will discuss the theoretical issues arising from the literature reviewed in this chapter and discuss the theory informing the current study.

2.8 Summary of the review

The purpose of this review was to identify existing evidences on the experiences of CKD patients receiving dialysis treatment, as expressed through the voices of the patients and their perspectives on living with the condition. Thirty-eight studies, which met the inclusion criteria, were therefore chosen and reviewed. Thirty-seven of those studies used qualitative approaches while only one used both a qualitative and quantitative approaches (Caress et al., 2001). All the studies were assessed on their quality using the CASP tool. Almost all the studies reviewed were conducted in developed countries of the world and only a few from

developing countries, with none from any developing country or any African nation where there is unequal access to healthcare treatment. The themes identified from the studies include the themes of uncertainty, meaning of illness, body image, physical effects, dependence on dialysis and dialysis machine, normality and lifestyle, relationships, families and healthcare professionals, suffering and spirituality/religion.

The themes and concepts described from the findings of these studies can help to provide understanding of the multidimensional and complex experiences of individuals living with CKD. While most of the studies focused on in-centre HD, there are common elements across all modes of RRT. There is however, an over-representation of participants on HD compared to PD as only five of the studies involved only PD patients. Unlike the other studies, the HD experience relates to the machine, time spent on the machine, the environment and the side effects. It is difficult to determine whether the medical discourse was more predominant in the HD patients than those on PD. There were also studies that only included either men or women, often from white backgrounds. Different ethnic minorities and gender are not truly represented in these studies, cultural differences were rarely referred to in fact, and only one study used culture as its focus (Kaba et al., 2007).

The studies included in this review provide useful insights into the sociological considerations and psychosocial issues for individuals living with CKD. The coping and adaptation perceived in these studies relate to their journey from diagnosis up to starting dialysis and their continued lifetime on dialysis. From the studies in this review the meaning of illness, unless explicitly described, was often viewed differently; some studies concentrate on the negative aspects of CKD and others the value and positive features of the adaptive process. These conflicting views can be assigned to the different theoretical and methodological approaches adopted in the various studies, and experience of long-term condition was a common element (Thorne et al. 2002).

Chapter 3: Conceptual Framework

3.1 Introduction

Following the literature reviewed in chapter 2, all the previous studies exploring the experiences of ESKD patients receiving dialysis were conducted in regions of the world where the participants had equal regular access to treatment or received healthcare support from the government. However, all the available evidence shows that there have been no previous similar studies conducted in regions of the world like African societies and particularly Nigeria where dialysis patients must pay out of pocket for their treatment. This therefore underscores the need for this study to explore what it means to be a CKD patient receiving haemodialysis services in such a system. To guide this study therefore, it is crucial to discuss in this chapter the key theoretical concepts arising from the literature reviewed and these will be explored in the current study. The key concepts will be discussed in relation to healthcare services in Nigeria and the relevant theories guiding the study while possible relationships existing among these concepts will be highlighted. The concepts to be explored include illness representation, spirituality, cultural belief and healthcare utilisation. These concepts amongst other key issues will be explored in detail to understand how they impact on the experiences of dialysis patients in Nigeria.

3.2 Illness representation

Illness representations or meaning of illness refers to the ways in which individuals define and adjust to various perceived interruptions to their health (Scambler, 2007). It is conventional in the field of medical sociology to distinguish between illness and disease; while illness refers to the subjective definitions of health problems, disease refers to the “professional” or objective definitions of health problems which is based on signs and symptoms. The diagnosis of a chronic disease such as ESKD and its subsequent management brings about uncommon experiences and meanings to not only the patient but also the family. In the biomedical world, there is less emphasis on illness and its meaning while more attention is focused on diseases (Larsen, 2009). Disease can be measured and quantified and fits well into the medical model framework. Illness and its varied meaning does not fit into

this model; it is not a black and white concept as it consists of many shades of grey and as such could not be easily measured or quantified (Larsen, 2009).

Kleinmann writing extensively on illness behaviour and its meaning, highlighted the concern that researchers have “reduced sickness to something divorced from meaning to avoid the hard and still unanswered technical questions concerning how to go about measuring meaning and objectivising and quantitating its effect on health status and illness behaviour” (Kleinmann, 1985, p.149). Drawing on the importance of this scientific work, Kleinmann views it as “detrimental to the understanding of illness as human experience, since they redefine the problem to subtract that, which is mostly innately human, beliefs, feelings...” (p. 149). According to the common sense self-regulation model (Leventhal et al., 2001) individual illness perception influences the coping responses to an illness. The Leventhal perspective seeks to explain that individual clients construct their own illness representations to help them make sense of their illness experience. These representations form the basis of appropriate or inappropriate coping responses exhibited by clients suffering from chronic illnesses as could be seen in CKD patients who are receiving dialysis treatment (Leventhal et al., 2001). Charmaz (1984) in her research in which she interviewed individuals with chronic illnesses through a symbolic interactionist perspective described this concept with the phrase “loss of self”. The influences on the loss of self develops from managing a chronic condition and the illness experience associated with it. Charmaz (1994) described the illness experiences of the clients as living a restricted life, experiencing social isolation, being discredited and burdening others. She further highlighted that the individual with chronic illness slowly feels a disappearance of their self-image: a loss of self without the development of an equally valued new one (Charmaz, 1994, p. 168). Meaning of illness in CKD patients has been represented as living in pain, stress and other social and psychological inconveniences associated with dialysis treatment and learning to deal with the negative changes in one`s life (Faber et al., 2003; Axelsson et al., 2012); this led the patients to constantly question the essence or meaning of life (Axelsson et al., 2012). Meaning of illness has also been described in terms of a loss of “normality” which has extensive and long-lasting impact on the patients` lives and identity (Caress et al., 2001; Velez and Ramasco, 2006). One of the studies in the literature reviewed (Caress et al., 2001) explored how meaning of illness is represented by dialysis patients using a quantitative approach (Caress et al., 2001). Caress et al. specifically explored the subjective meaning of illness in a cross-section of pre-dialysis, dialysis and transplant patients using the Meaning

of Illness Schema based on the work of Lipowski (1983) in which patients were offered eight choices of possible meanings of illness. The schema was based on the belief that individuals have different perspectives to illness; while some may view illness positively as a sort of challenge, others view it negatively as a form of loss or punishment. The meaning of illness is influenced by situational factors such as experience of their condition, knowledge, sociocultural forces and includes a cognitive appraisal of the patients' illness episodes and lifestyle changes (Gregory, 1998) and these factors shape the reaction of patients to illness (Velez and Ramasco, 2006). Thorne (1993, 1999) asserted that the meaning ascribed to long-term conditions as seen in ESKD by individuals is shaped and heavily influenced by the social and the political contexts in the society and the healthcare system. The review indicated various roles played by the patients in the management of their conditions, use of technology, the healthcare systems involved, and the impact treatment and disease management had on their social life (Faber et al., 2003; Tong et al., 2009; Kazemi et al., 2011).

In understanding how Nigerian CKD patients' interpretation or representation of illness influence their coping actions, I will utilise the Leventhal's self-regulatory model of illness behaviour. This will help me to frame the interview questions to explore how the meanings of living with CKD and receiving dialysis treatment could shape the coping strategies of dialysis patients in dealing with the emotional and cognitive distress associated with their condition. The Common-Sense Model of Illness Representations otherwise known as the Self-Regulation Theory was initially defined in the late 1960s and early 1970s by Leventhal as the model which provides the framework for understanding how the symptoms and emotions individuals experience during a health threat or diagnosis influence their perception of the illness and how the individuals' personal beliefs determine their responses and how they cope with the threat to their health (Browning et al., 2009). Leventhal and his colleagues in their research explored how fear messages related to acute situations could lead people giving up smoking or taking health-promotion actions, such as wearing seat belts while driving (Leventhal, Brissette and Leventhal, 2003). In their research, Leventhal et al. found that various types of information were needed to influence not only the actions but also attitudes to any perceived threat, and these lasted for short period of times. In the extension of their model, Leventhal et al. wanted to find out those adaptive and coping efforts that are necessary in individuals suffering from chronic illnesses such as chronic kidney disease and others. This therefore led to the proposition of a hierarchically organised model

of adaptation featuring the three major constructs of: (i) “representation” of the illness experience which might guide (ii) action planning or “coping” responses and performance of these, followed by (iii) “appraisal”, or monitoring of the coping efforts (Nerenz and Leventhal, 1983) (to be discussed later in this chapter). The model is like many other theories of problem-solving behaviour such as the Transactional Model of Stress and Coping (Lazarus and Folkman, 1984), wherein chronic kidney disease and the associated treatment regimen are considered as stressful experience. A unique feature of the Leventhal’s proposition is the delineation of the active parallel cognitive processing of how individuals regulate their responses to “illness danger”. The model proposes that individuals develop their understandings of their illnesses or diagnoses through a formulation of their own ideas about what the illness is, its causes, impact on their lives, how long it will last, and whether it can be cured, managed or controlled. For instance, CKD patients in Nigeria might develop a better understanding of the illness through self-questioning by asking relevant questions such as: what is chronic kidney disease? What are the treatment options available for me? What can I objectively do about it? Should I commence dialysis treatment or local herb consumption? How long can I sustain the treatment? This understanding is usually not medically validated but based on individual experience of the patients with physical and emotional impacts, social influences and interactions with the healthcare practitioners. It creates an individual’s illness representations which influence the actions or coping strategies adopted to mitigate individual health risk or health changes (Browning et al., 2009). The two central phenomena of the Common-Sense Model (CSM) of Illness Representations are based on the notion that individuals are problem-solvers and can deal with the perceived reality of their health threats and the emotional reactions to these threats. In relation to ESKD patients, the CSM posits that they can initiate and maintain their treatment (dialysis or transplantation) based on the meaning they ascribe to their illness and the coping strategy they adopt in dealing with it. There are three major constructs of this model: illness representation, coping and appraisal (Fig 4).

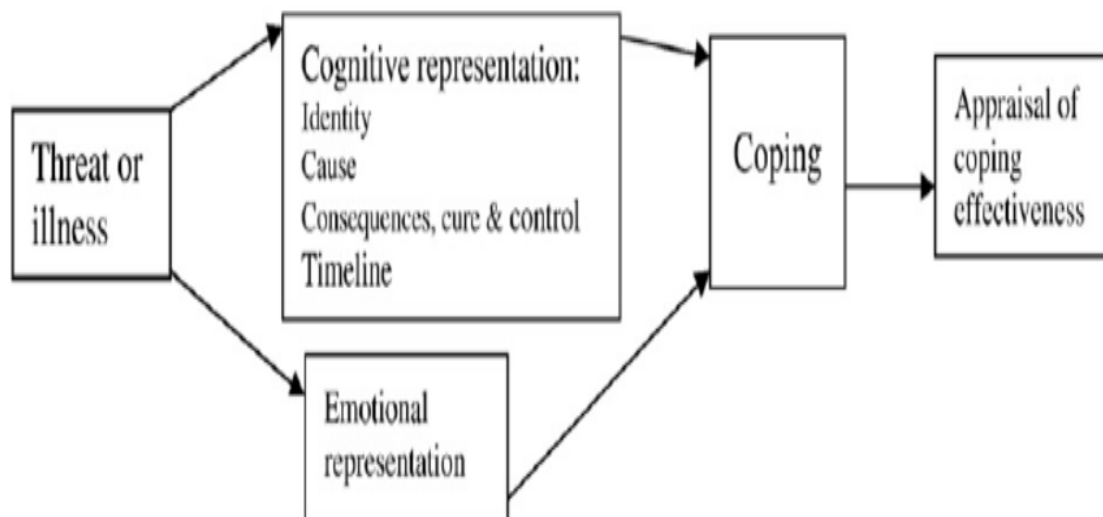


Figure 4: Common-Sense Model of Illness Representations

Illness representations guide individuals in interpreting new illness threats and allows for both cognitive and emotional reactions along with potential coping strategies to assist in dealing with the health threat. The cognitive and emotional representations are two separate but related components of illness representations. Emotional representations were overlooked in the initial instrument development to measure illness representations and were not clearly defined (Moss-Morris et al., 2002). Emotional representations are responses to the illness that engulfs the attention of one's consciousness and elicits an unwanted reaction. Emotional representations in chronic illness such as chronic kidney disease consist of feelings of upset, anxiousness, depression, anger, worry and fear (Moss-Morris et al., 2002). The emotional reactions expressed by the patients such as fear and/or anger to symptoms and other extraneous events have been found to be separate motivators for seeking healthcare (Moss-Morris et al., 2002). These motivators were found to be unrelated to the perceived seriousness of the disease and are an alternative way to regulate one's emotional reactions to an illness situation (Moss-Morris et al., 2002). It is therefore necessary to explore in this study if ESKD patients on dialysis in Nigeria would be willing and motivated to carry on with dialysis treatment if they perceive that withdrawal from or non-sustenance of dialysis could lead to adverse health consequences for them. On the other hand, the emotional representations of anger, depression, upset because of the possible consequences of living with CKD and receiving dialysis, paying for the dialysis treatment out of pocket, in a health care system with unequal access to dialysis care, and lack of adequate family or social support in managing the condition might impact negatively on patients' ability to maintain

dialysis treatment. It also worthy to explore how these shapes the meaning of being CKD patients in such a society. Also, different cultural or ethnic groups may collectively have feelings or beliefs about certain health issues, this could also influence the illness representation and the subsequent actions taken to deal with the health condition. This is necessary as the meaning of illness is socially and culturally-constructed (Conrad and Barker, 2010).

Coping strategies are based on the individual's illness representation and a response plan or procedure that is developed (Diefenbach and Leventhal, 1996). For patients on dialysis, coping could mean accepting and confronting mortality and reframing one's life by adopting a positive outlook, a technique used for restructuring and reorganising one's thoughts and beliefs (Tanyi and Werner, 2008). For ESKD patients in Nigeria, it could mean resorting to spiritual means or adoption of unscientific measures for dealing with the illness. It is therefore necessary explore this further in this study. Patients on dialysis could therefore resort to various coping strategies such as spirituality, family members and friends or possibly denial of the health condition as has been reported in literature (Spinale et al., 2008; Tanyi and Warner, 2008). Lastly, an appraisal is done to evaluate the progress of the coping actions and is compared to expected outcomes. The progression of each of these stages (representation, coping, and appraisal) is not unidirectional, the process can occur from the bottom-up or top-down, and for example appraisal outcomes can lead to differences in representation which might lead to new and different coping actions (Diefenbach and Leventhal, 1996). Leventhal et al. (1997) and Leventhal and Diefenbach (1991) propose that patients' illness representations are based on five distinct components. These components comprise; identity, cause, time-line, consequences of an illness and curability /controllability of the illness. Leventhal et al. (1997) described five components of the illness representations construct thus:

(i) Identity: The identity component consists of the "label" or name individuals give to the condition or health threat and the symptoms associated with. It includes the beliefs individuals hold for the health condition and the symptoms they experience. Dialysis patients may label their health condition based on the impact it has on their ability to maintain their jobs, care for their families and lead a normal life.

(ii)Cause: This refers to the patient's beliefs regarding the major cause of the condition or health threat. Generally, before the advent of orthodox medicine, ancestral spirits constituted

a major part of the ordered structure of the African Traditional Religion (ATR). It was widely believed among Africans that upsetting the ancestors results in the disruption of this order and hence illness and disharmony occurs (Ojua, Ishor and Ndom, 2013). This belief persists in some African societies as all living things including man is believed to be in a harmonious relationship with the gods and the spirits; such relationship is based on the vital forces which these entities generate. A state of health is therefore believed to exist only when there is a healthy relationship between man and his ancestors (White, 2015). This belief is not only common among those who practise the African Traditional Religion, but it also found among some Christians and Muslims at one point or the other (Omotosho, 2010). In Nigeria for instance, Sickle Cell Disease (SCD) in children (called *Ogbanje* in local dialect) is believed to be due to reincarnation within the family of a child who died due to an illness (Nzewi, 2001). This belief often leads to discrimination of SCD patients in Nigeria and it influences the health-seeking behaviour of the parents of SCD children in the country. It is therefore necessary to explore in the current study, the interpretation of CKD patients in Nigeria regarding the causes of their illness and the impact such interpretation has on the compliance with their treatment regimen. The representations patients have regarding the cause of the condition may be based on the pieces of information they gathered from their personal experiences as well as the opinions of the health care practitioners, significant others and possibly media sources, reflecting previous lifestyles, stress, environment factors and pathogens. The causes attributed to their health condition has implications for patients' health seeking behaviour as patients who are spiritually or culturally-inclined may not want to seek appropriate health care.

(iii)Time-line: This indicates the perceived duration and course of an illness. It is the predictive belief a patient holds about how long the condition might last, i.e. is it acute or is it going to be chronic? These beliefs can always be re-evaluated as time progresses, and it has been suggested that 'Inside every chronic patient is an acute patient wondering what happened?' (Brown, pg.1443). The expectations of patients regarding time line of their health condition or threat has been categorised into three: acute (symptomatic and curable), cyclic (symptomatic, removable but recurrent) and chronic (a stable part of the self regardless of symptoms) (Leventhal and Nerenz, 1983). In Nigeria for instance, this perceived duration of the illness by CKD patients could have some implications on whether they bother at all to initiate or maintain treatment. It is necessary to explore this because since the patients pay out of pocket without any support from the government, they may

choose not to commence treatment at all. They may choose not to start the treatment at all if they understand that CKD is a long-term condition which they must live with and still die of as they may never sustain the treatment. However, such decision may depend on patients' knowledge or understanding of the prognostic information given by the HCPs.

(iv)Consequences: The consequences component highlights the perceived physical, economic and psychosocial consequences of illness. Being diagnosed of ESKD and having to be on dialysis is a very dramatic situation with lots of consequences for many patients. This could affect family income and priorities, social relationships, perceived or actual stigma and discrimination in some cultural settings, loss or possible change of occupation for the patient, changes in body image and dealing with the management of the symptoms associated with the condition and possibly death. This study will therefore explore the impact (if any) of the understanding of CKD patients' in Nigeria regarding the economic consequences on their sustainability of treatment. These representations may develop into more realistic beliefs over time. It is pertinent in this study therefore to know if patients are motivated to go for dialysis because of their belief that they will be well in the end; do they not maintain dialysis because they place more priority on meeting the financial needs of their families? Or because they feel there is no need to continue dialysis as they perceive they will die of the condition, or because they fear that not maintaining dialysis could lead to their death.

(v)Curability/controllability: This component is about the beliefs individuals have about whether the condition can be cured or kept under control and the extent to which the individual plays a role in achieving this.

Illness representations are fluid and therefore change as individual patients assimilate new information into the representations (Anagnostopulous and Spanea, 2005). As people with chronic illness like ESKD acquire new information about their health condition and their treatment (dialysis) and then evaluate their attempts to moderate or cope with its effects and consequences, new representations are formed and developed based on these experiences. This then allows the individuals to utilise different coping strategies and develop new representations when illness threats are re-encountered (Leventhal et al., 1984; Anagnostopulous and Spanea, 2005).

3.3 Spirituality

The meaning of the concept of spirituality has developed and changed with time, and various meanings can be found alongside each other. Its definition has long been a debatable issue and therefore it has no singular or widely-accepted definition (Dyson, Cobb and Forman, 1997; Vachon, Fillion and Achille, 2009). However, for the current study, spirituality according to Tanyi and Werner (2003) is defined as an instinctive human component which can facilitate meaning in illness, optimism, solace and provide a strong coping mechanism necessary in dealing with chronic illnesses. According to Waaijman (2003, p.2), the traditional meaning of spirituality is a process of reformation which "aims to recover the original shape of man, the image of God". In modern times, spirituality has shifted from the early Christianity connotation of a life that is oriented towards the Holy Spirit (Wong, 2009) to a more encompassing concept that does not necessarily connote only religion. It has therefore, included an emphasis on the deepest meanings and values which guide peoples' lives and the subjective experiences of a sacred dimension (Saucier, 2006). Although religion and spirituality are often used interchangeably, the two mean different things. Tanyi (2002, p.502) highlighted that "spirituality is more of an individual, encompassing relational component with others, God or a higher power, and the self and one's search for life's meaning and purpose".

From the literature reviewed (Chapter 2), it was identified that spirituality was used as the focus of experiences by female patients on HD, to gain acceptance of their illness and to help them to come to terms with the possibility of death (Tanyi and Werner, 2008). Religion also was also found to help dialysis patients cope in with their illness (Al Nalzy et al., 2013). Similarly, the diagnosis of CKD and patients being on dialysis has been found to strengthen their faith in God (Nagpal et al., 2017). In the examples cited here, spirituality/religion was expressed in the positive sense. However, religion or spirituality was also expressed in a negative sense in the study of Caress et al. (2001) where it was reported that in the search for the meaning of their illness, CKD patients blamed their illness on spiritual factors or divine intervention. Studies have shown that spiritual and religious beliefs enhance coping in cancer patients by enabling them to accept their illness and deal with it in a more positive way (Weaver and Flannelly, 2009). It is necessary to explore in the current study, the possible impact of spirituality/religion on CKD patients who are depended on dialysis in

Nigeria. This is very important as most Nigerians identify as being religious or spiritual (Dowd, 2014; Angerbrandt, 2015).

Studies in Nigeria have shown contrasting influence of religion on the utilisation of health services or compliance with medical treatments. Spirituality and religious beliefs have been found to promote adherence to Highly-Active Anti-Retro-viral Therapy (HAART) among HIV/AIDS patients in Nigeria (Ayuk, Udonwa and Gyuse, 2017). Similarly, another study exploring the influence of religion on the utilisation of maternal health services in Northern-Central Nigeria (Al-Mujtaba et al., 2016), found minimal influence of religious belief on the compliance with the utilisation of the healthcare services. However, Umar (2017) found that ethnicity and religious beliefs influenced patients' use of maternal and child health services in the six geo-political regions of Nigeria. Nothing is known in literature about the influence of religious beliefs or spirituality in the compliance of ESKD patients with dialysis therapy in Nigeria. The current study will therefore explore any impact of religious beliefs on the compliance to treatment of HD patients in Nigeria. Questions relating to participants' perception of dialysis treatment and its efficacy will be elicited. It will also seek to find out if the religious beliefs of the study participants have any impact on their illness representations.

3.4 Culture/cultural beliefs

“Culture is the core, fundamental, dynamic, responsive, adaptive, and relatively coherent organizing system of life designed to ensure the survival and wellbeing of its members and is shared always to find meaning and purpose throughout life and to communicate caring” (Kagawa-Singer et al., 2010, p.17). It is the social behaviour and norms found in every human society. Culture comprises the values, beliefs and lifestyles which enable the people of a society to adapt to their environment using the available resources and technology (Kagawa-Singer, 2001). Culture through its perspective or construction of reality, provides the means to understand life events, especially during difficult times such as when an individual develops a chronic illness like cancer or CKD (Kagawa-Singer et al., 2010). Therefore, through the specific values, beliefs and rituals of a people, this perspective or worldview helps in making sickness and death more understandable and easier to deal with.

It shapes the behavioural and the emotional reactions of individuals to a disease condition and how one`s social network provides comfort, support, care and safety.

The cultural practices of a people affect both the health and all aspects of one`s life including their interpersonal relationships, contribution to the society and disease condition (Ojua, Ishor and Ndom, 2013). This is particularly so because individuals are affected by what happens in the environment within which they interact. All people irrespective of their race or creed, have certain beliefs and practices regarding health and illness. These beliefs and practices therefore influence the perception of individuals, their attitude and behaviour in the management of illnesses they encounter (Ojua et al., 2013). Therefore, the cultural belief system of a society provides the lens through which people can make sense of, interpret, label and explain their illness experiences (Goins, Spencer and Williams, 2011). This study will therefore explore issues of cultural practices that could be a barrier towards compliance with treatment by the study participants.

The culture of a society also frames the attitude towards gender roles in any society (Kagawa-Singer et al., 2010). This is particularly necessary to be explored in this study in which the research participants live in a multi-ethnic society with diverse cultural practices (Adedini et al., 2014). Different ethnic factors play a role in influencing healthcare behaviour among the people. For instance, amongst women, delays in getting permission from their husband to seek medical care have been found to be a major barrier to the timely utilisation of healthcare services in some parts of the country (Adedini et al., 2014). Wall (1998) found that Hausa women in the Northern region of Nigeria are hardly seen in the public because due to the adoption of a strict form of wife seclusion practice known as *purdah*. Because of this practice of spatial constraint, most Hausa women have little or no autonomy and freedom to move around; hence, they are subject to male control, social exclusion and isolation. More recently, Hugo (2012) found that women in *purdah* are expected to always remain indoors but can go out with the permission of their husbands only in extreme circumstances where they need medical treatment. This harmful cultural practice has negative implications for the society as even in extreme circumstances such as child labour, a woman in *purdah* is not allowed to seek medical help until the husband gives her the permission or takes her to the medical facility. It is therefore worthy to explore similar issue of cultural practices and how it affects married women who are on dialysis in Nigeria.

Due to the huge cultural differences existing within the Nigerian society, there are massive variations in the utilisation of healthcare services among various ethnic groups in the country. For instance, Babalola and Fatusi (2009) found that the utilisation of antenatal and postnatal services was lower among women of Hausa ethnic group in comparison to the women of Yoruba and Igbo ethnic groups. More recently, Ononokpono et al. (2013) found lower antenatal care visits among Hausa/ Fulani/Kanuri women in comparison with women of other ethnic groups. These evidences are true reflections of the ethnic differences existing within the healthcare system in Nigeria and how it affects access to healthcare utilisation. Patients suffering from ESKD in Nigeria do not exist in isolation as they are part of the healthcare system where one is excluded on the account of personal characteristics such as gender and economic status. It is therefore worthy to explore in this study how societal norms or cultural practices impact on the health care behaviour of dialysis patients in Nigeria with a view to eliciting cultural barriers to regular medical treatment.

3.5 Health care access and health service utilisation

Health care access is a complex term to define. According to the Institute of Medicine (IOM) (1993), access to healthcare means utilising appropriate healthcare services to achieve the best health outcomes. In this study, access to healthcare would mean ESKD patients in Nigeria who have opted to depend on HD for their treatment having regular access to dialysis services as prescribed by the HCPs. Access to healthcare is based on the following four measurable dimensions: availability, accessibility, accommodation and affordability (Gulliford et al., 2002).

Availability- this refers to the adequacy of the supply of health care resources such as nurses, doctors, and other health care professionals; of facilities such as hospitals and clinics and of specialised health care programmes such as emergency care, mental health services, peritoneal dialysis or haemodialysis facilities and facilities for renal transplantation. Patients in need of health care services may have access to them but often encounter different challenges in utilising the services, and thus the potential access may not be achieved. Thus, Donabedian (1972) noted that the true proof of access to health care is simply not the presence of a health care service or facility but the utilisation of it. Pechansky and Thomas

(1981) identified three major barriers to the efficient utilisation of health care services as personal, organisational and financial barriers.

Accessibility- this refers to the relationship between the location of the health care resources and the location of the health care clients or patients, regarding the patients` travel time and transportation resources, distance and cost of travelling. If the location of renal facilities in Nigeria is geographically distant to the residents of the patients, the costs of accessing dialysis services will be generally higher and this may affect the ability of the patients to access the services as they must pay out of pocket.

Accommodation- the relationship between the way in which the health care resources are organised to attend to patients (including hours of operation, telephone services, appointment systems, walk-in-facilities) and the ability of the patients to accommodate these factors and the patients` perception of their appropriateness.

Affordability- this refers to the relationship of prices of health care services and patients` ability to pay, healthcare providers insurance or existing health insurance. Patients` perception of the worth of the health care services relative to the total cost is important, as is the patients` knowledge of the prices, total cost and potential credit facilities.

3.5.1 Barriers to the utilisation of health care services

Personal barriers- Patients` recognition of their needs for health care services and their subsequent decisions to seek these services forms the major step in accessing healthcare services. The prospect of utilising health care services by patients depends on the balance between patients` perception of their health care needs and their beliefs, attitudes and previous experiences with the health care services (Mechanic, 2015). Therefore, access to health care services implies that the individual health care service user recognises and accepts the need for the services, consents to assume the role of a service user and acknowledge the resources they are ready to utilise. These processes of gaining access to the healthcare services are dependent on not only the social and cultural influences but also on the environmental constraints (Gulliford et al., 2002). This study will therefore explore possible personal barriers the participants face in accessing regular dialysis services.

Financial barriers- Financial barriers can impact patients` utilisation of health services even in some developed nations where the healthcare services are generally free, some specific services such as eye tests, dental check-ups and dispensing of prescribed medications are paid for by the patients out-of-pocket. Patients could also incur costs due to the time lost from work in travelling to and from the healthcare facility. This is also important to explore in this study as most dialysis patients in Nigeria pay out of pocket. The impact of the user charges and other extraneous costs incurred by ESKD patients as they access dialysis in healthcare systems with unequal access to dialysis services could affect them in different ways depending on their socio-economic status. For some of the patients, access to dialysis services may not be compromised by financial issues, whereas for others the cost could mean a major deterrent to seeking dialysis services (Lundberg et al., 1998). The impact of the financial barriers therefore depends on both the magnitude of the costs and the patients` ability and willingness to pay.

Organisational barriers-The inefficient use of existing capacity or the failure to design health care services around the needs of patients could result in long waiting hours and waiting lists and constitute organisational barriers to the utilisation of health care services. Also, systematic variations in the referral practises especially from the primary health care level to the secondary health care level may act as barriers to the effective utilisation of health care services (Gulliford et al., 2002).

3.6 Conceptual Framework Model

Fig.5 shows the relationship between the various concepts discussed above. It demonstrates that the culture (cultural beliefs) and spirituality (religion) respectively can influence both illness representations and health behaviour (utilisation of health services or compliance with treatment) by CKD patients. This will be further explored in this study to understand how they influence compliance of the participants to deal with their illness. These concepts will therefore guide the formulation of the interview questions as will be highlighted in the methodology chapter (chapter 4).

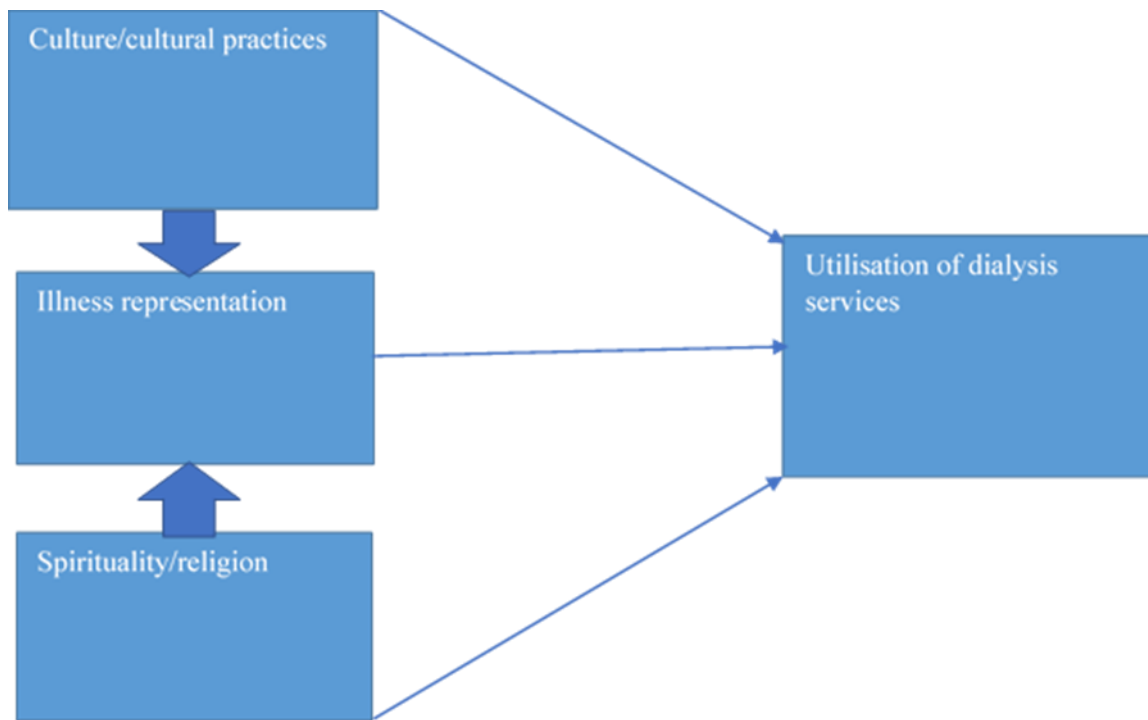


Figure 5: Conceptual Framework

3.7 Summary

This chapter discussed the key theoretical concepts arising from the literature reviewed in the previous chapter, and which will be explored in the current study. The concepts to be explored include illness representation, spirituality, cultural belief and utilisation of dialysis services. These concepts amongst other key issues will be explored in detail to understand how they impact on the experiences of dialysis patients in Nigeria and sustainability of dialysis treatment. The key concepts were discussed in relation to healthcare services in Nigeria and the relevant the Common-Sense Model of Illness Representation which will guide the study while possible relationships existing among these concepts were explored.

The next chapter will bring together the gaps in knowledge identified from the literature reviewed, the methodology lessons learnt, and theoretical concepts important to the study

and the Nigerian context to develop a PhD study to generate high quality research. The study aims, and objectives clarify the focus and the sample, recruitment and approach provide a comprehensive plan that guided the chosen study.

Chapter 4: Methodology of the Research

4.1 Introduction

When the literature on the experiences of CKD patients receiving dialysis was critiqued (Chapter Two) there was no evidence base found exposing the experiences of people in Nigeria. Indeed, there was no patient experience evidence gathered within African countries like Nigeria, where people have no access to health insurance or government support for dialysis treatment. The difference for these people compared to those in developed countries is they are required to pay from their own pockets for dialysis; so only those with the funds to pay for treatment can access it. Throughout the literature there was a dearth of studies identified that exposed and described the economic, cultural, familial and societal issues facing patients suffering from long term conditions such as CKD, within other African contexts. This lack of evidence and gaps in the understanding of Nigerian (or African) patient experience living with an inequitable health service, informed the need and focus of the PhD.

The critical review did however, provide a valuable insight into the methods that had been used to explore the experiences of patients and the impact of dialysis on their quality of life. For the plethora of studies from developed countries the research methodology predominantly examined data snapshots collected at a single point in time. Whilst this approach uncovered valuable patient experiences, it relied on what could be recalled and discussed within the time frame on maybe a single data collection event, which potentially limited the richness of data. Other methods will be discussed in this chapter that follow and measure the impact of living with dialysis, over time, to gain a deeper understanding of how experiences and priorities may change. The theoretical concepts uncovered in Chapter Three inform the analytical framework for the study, used to draw out the meaning of illness, access to treatment, religious/spiritual, cultural and economic influences that impact on patient experience and their lives living with a long-term condition.

This chapter brings together the gaps identified from the literature, the methodology lessons learnt, and theoretical concepts important to the study and the Nigerian context to develop a PhD study to generate high quality research. The study aims, and objectives clarify the focus and the sample, recruitment and approach provide a comprehensive plan that guided this study.

4.1.1 Research aim

The overarching aim of this study is to explore the experiences of CKD patients receiving haemodialysis in healthcare systems with unequal access to treatment.

4.1.2 Research objectives

The specific objectives of this study are therefore to:

- Gain a deeper understanding of the meaning of living with CKD and receiving dialysis and how this influences treatment.
- Explore and describe experiences of dialysis patients in healthcare systems with unequal access to healthcare and highlight any change in the experiences or otherwise over time.
- Examine the impact of economic, social, cultural, societal and familial issues on access and sustainability of dialysis treatment

4.1.3 Research questions

The research questions guiding this study are:

- What does living with CKD and receiving dialysis mean to dialysis patients in healthcare systems with unequal access to treatment?
- What are the experiences of dialysis patients in Nigeria?
- What socio-economic, cultural, familial or societal issues influence patient's decision to access and sustain dialysis?

4.2 The research paradigm

Every researcher is guided by beliefs, perspectives or worldviews and pattern of interaction with their environment; this therefore influences the ways or choices of methods used by researchers in answering the research questions. These set of beliefs or worldview which guide the choice of methods used by a researcher are known as *paradigms* (Mertens, 1998; Lincoln and Guba, 2000) or *epistemologies and ontologies* (Crotty, 1998). Research paradigms serve as a guide for a disciplined enquiry and are identified by ontological, epistemological and methodological issues, and by the theoretical perspectives underlying the chosen research methodology (Guba, 1990; Crotty, 1998). A research paradigm has been described as:

“patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished” (Weaver and Olson, 2006, p.460)

Indeed, a research paradigm signals an individual’s perceived worldview and guides the research process (Kikuchi, 2003). Epistemology is the scientific study of knowledge, its nature and validity (Pope and Mays, 2006) seeking to answer the question of what the relationship between the researcher and the phenomenon is. Commonly used paradigms in nursing research are the positivist, post positivist, interpretive and critical social theory paradigms (Weaver and Olsson, 2006), although the positivist paradigm has dominated nursing research in the last decades (Polit and Beck, 2004).

As a Nigerian I have experienced the health care culture, and whilst I have been fortunate to be born within a family with the finances to pay for health care we have not experienced the drain on resources a long-term condition may create. I find the whole system inequitable and have watched friends die early because of their inability to pay for much needed health care, which has driven me to undertake this research to expose the real-life issues for people, on low incomes. For this study of patient experiences in Nigeria the ontology or nature of reality (Crotty, 1998; Pope and Mays, 2006) is sought through exposing and valuing the individual meaning and understanding of their illness, in the context of their lives, culture and economic world (Addo and Eboh, 2014; Parahoo 2014). There is no single truth when exploring a person’s experience, but truth is what a person says it is, related realities of people which are difficult to quantify. To expose the related realities of people living within the Nigeria context qualitative approaches are considered the best approach, reinforced by the

domination and success use of qualitative approaches in the literature (Reid, Flowers and Larkin, 2005; Hurst, Summers and Caress, 2014; Parahoo, 2014). This type of exploration is more suited to gain rich meaningful data to create collective reality of the context being studied.

Qualitative studies are defined more by key characteristics rather than by any explicitly bounded definition (Denzin and Lincoln, 2011). These characteristics include: the researcher as the primary tool of data collection, face-to-face data collection in naturalistic settings, focus on the in-depth description and understanding of the participants` opinion, views and meanings, flexible and creative strategies into the private world of the research participants, inductive or deductive methods of data analysis, use of purposeful samples in data collection, interactive and reflexive process and adopting a holistic approach in understanding the meanings of the phenomena being studied by collecting and analysing data from multiple sources and approach (Stake, 2010; Creswell, 2012; Parahoo, 2014; Corbin and Strauss, 2015; Merriam and Tisdell, 2015). In contrast, quantitative research methodology is based on the foundation of an objectivist approach to social sciences and it generally adopts experimental methods as measures of reducing or eliminating bias to establish facts, causes of behaviour and relationships in an objective manner (Denscombe, 2014; Parahoo, 2014). Researchers need to choose what methodology is best for answering the research questions; therefore, qualitative, quantitative and mixed methods can be appropriate for different research (Parahoo 2014). For this study a qualitative approach best reflects the interest and paradigm of the researcher to give a voice and platform to people managing a long-term condition in a context of inequitable health care. Listening to, hearing and reporting these subjective experiences is the focus of this study.

4.2.1 Qualitative research

Qualitative research has been defined as an approach to the scientific enquiry which allows researchers to explore human experiences in social and personal contexts to gain a deeper understanding of the various factors influencing those experiences (Addo and Eboh, 2014). Parahoo (2014) defined qualitative research as an umbrella term that describes diverse research approaches which seek to understand human experiences, perceptions, beliefs, intentions, opinions, motivation, and behaviours by means of exploration. Qualitative researchers are premised on the belief that interpretation is crucial to the exploration and the

understanding of all social phenomena (Parahoo, 2014). It suits the focus of this study which seeks to gain a deeper understanding of human experiences as it is lived by carefully collecting and analysing usually subjective, qualitative data was more aligned to the research questions raised from the literature and would generate new knowledge (Polit and Beck, 2009; Borbasi and Jackson, 2015).

A qualitative research methodology is appropriate when researching complex human or social phenomenon which cannot be reduced to numbers or are not amenable to measurement (Denzin and Lincoln, 2011; Parahoo, 2014; Robson and McCartan, 2015). The holistic approach which is associated with qualitative methodology is crucial in gaining deeper understanding of the people being studied or the events in their social settings or lives (Denzin and Lincoln, 2011). The individual experiences of each research participant are fully embraced by the characteristics and philosophy of qualitative research methodology as it offers the participants the opportunity to talk about the totality of their experience of the phenomenon being studied in their own words and the meaning they ascribe to events in their lives and not through the lens of the researcher (Denzin and Lincoln, 2011; Parahoo, 2014). It enables researchers to put participants' responses into context as the participants' experiences of the phenomenon being studied can be socially, culturally and historically constructed (Parahoo, 2014). Also, it enables the researcher to appreciate the participants' constructions of their worlds, to empower them to share their narratives and to generate theories where little or none exists (Creswell, 2012). Therefore, qualitative researchers generally aim to gather rich and in-depth data to understand human behaviour and to offer explanations of possible influences on the behaviour and meaning through the interaction of the researcher and the participants within their natural settings (Denzin and Lincoln, 2011). Because of the characteristics of qualitative research methodology stated earlier, it is pertinent that qualitative researchers demonstrate commitment to remain open-minded, be flexible, to take risks and be able to view things from multiple perspectives (Merriam and Tisdell, 2015). Qualitative research approaches tend to answer research questions which focus on the *why* and *how* and not only *what*, *where* and *when*. The qualitative approach will explore why ESKD patients do not sustain regular dialysis in Nigeria and whether or how familial, societal, cultural, economic and religious factors influence the decisions of the participants to access dialysis. A qualitative research methodology was therefore chosen for this study because of the congruence of the underpinning philosophy of qualitative inquiry with the aims and objectives of this research project. Usually, a holistic approach is used in

qualitative research to refer to the relationship or connections existing between the philosophical framework and the research method chosen (Hesse-Biber and Leavy, 2017). The researcher viewed the various aspects of the phenomenon being studied such as the meaning of living with ESKD and receiving dialysis, poor access to dialysis, the impact of the socioeconomic issues, geographical, religious and familial issues as closely interconnected, and these parts can only be interpreted within context.

There are a plethora of different methods or strategies for conducting qualitative research, some of the common approaches include: ethnography, grounded theory, phenomenology, narrative research, and case studies (Creswell, 2009). Other qualitative methods include discourse analysis (Parahoo, 2014; Silverman, 2016), historical research and community-based participatory research (Liehr and Lobiondo-Wood, 2006); ethnomethodology, action research, biographical studies and qualitative longitudinal research (QLR) (Neale and Flowerdew, 2003; Draper, 2007; Denzin and Lincoln, 2013). Although these qualitative strategies or methods share similar characteristics described previously in this section, each of them has its specific characteristics in terms of not only the methodological and theoretical assumptions but also in terms of aims and methods.

The underpinning assumptions were examined for the different qualitative methods and strategies and the pros and cons considered before a best method identified. An ethnographic study would have been useful if I could have spent a long time in the HD facility, but patients may have viewed me more as a HCP than a researcher and not fully independent. Viewing patient experience as a phenomenon was a possibility using Phenomenology focusing on the individuals' interpretation of their experiences based on the ways the experiences are expressed by the individuals (Parahoo, 2014). Whilst the method has been used to interpret the complex nature of human experience, more importantly the need for the experience to be studied in the true way it is lived (Polit and Beck, 2003), it felt a complex method which impinged the free flow of the research. Biographical and narrative approaches would provide a way of capturing people's experiences using time and events to help organise data. However, reflecting on the observation from the literature and the lack of patient experience follow up over time the method that seemed to fit well with the research focus was a possible QLR approach. This qualitative method utilised humanistic enquiry, was flexible and enabled themes to be followed up with individuals, thus fostering confirmation of and clarification of analytical interpretations.

4.3 The research design

A QLR approach has been described as an emerging methodology used to investigate social phenomena, although its theoretical orientation and paradigm are yet to be fully understood (Neale and Flowerdew, 2003; Holland, Thomson and Henderson, 2006). Longitudinal research designs are characterised by the collection of data about a phenomenon over a period of two or more distinct times (Menard 2002). QLR is hinged on the investigation and detailed interpretation of changes in the phenomena being studied over a period (Saldana, 2003; Thomson and Holland, 2003; Carduff, Murray and Kendall, 2015) and it's also based on the foundational principles of time, duration and change within a social context (Saldana, 2003; Carduff, Murray and Kendall, 2015; McCoy, 2017). The passage of time and change are two inextricable constructs in the context of understanding human experiences (Holland, Thomson and Henderson, 2006). Since time is an inherent component of QLR, this orientation provides a unique way of understanding possible relationships among experiences, time and change in a social context (Calman, Brunton and Molassiotis, 2013). There is an opportunity to collect individual experiences of people managing ESKD over a period compared with a one-off interview which may not fully capture the whole experience of patients, particularly when experiences of living with a long-term condition changes over time.

Every longitudinal study is context-specific and is influenced by the research goals, research questions, methodology and conceptual framework (Saldana, 2003). There is no consensus on when to generate research data throughout the period of a longitudinal study; it depends on the context of what is being studied and other factors considered relevant to the study (Saldana, 2003). Traditionally, longitudinal research designs have always been used in quantitative studies with only a relatively few qualitative studies adopting the approach (Hermanowicz, 2013; McCoy, 2017). However, over the last decade QLR designs have become increasingly prominent in social science disciplines such as criminology, anthropology, social policy, sociology, education and psychology (Hermanowicz, 2013; Carduff, Murray and Kendall, 2015; Thomson and McLeod, 2015). To understand complex worlds and conceptualisations of time, there is an increasing number of studies that utilise qualitative techniques to collect and analysing data from participants followed over a distinct

period (Calman, Brunton and Mollasiotis, 2013; Miller, 2015). This has led to the recognition of the QLR approach as not only a distinct and an acceptable manner of conducting research but also as one that comprises a range of prospective methodologies (Snelgrove, 2014; Thomson and McLeod, 2015). Some critics argue that QLR cannot be regarded as a methodology because it does not have a clear theoretical and philosophical foundation (Hermanowicz, 2013; Miller, 2015). McCoy (2017) suggested that while QLR highlighted time and change to be pertinent in understanding experiences, it provided no clear procedure which the data collection and analysis could be hinged upon. Because of this, QLR has become known as a research orientation which is often combined with other research designs and methods (Hermanowicz, 2013; Thomson and McLeod, 2015). In a practical sense, the analytical and empirical potentials of QLR occurs when fused with other qualitative research methodologies that have distinct data collection and analysis approach (Calman et al. 2013), to enhance qualitative research rigor (McCoy, 2017). While the QLR orientation is a means through which data could be collected across time, it becomes the specific qualitative methodology that answers such questions as what changes occurred, how such changes occurred and why the changes occurred in the context of sociocultural environment and time (Carduff et al., 2015). Therefore, the approach through which the findings are conceptualised can vary greatly depending on the how the QLR has been combined with other qualitative methodologies (McCoy, 2017). To maintain both theoretical and methodological congruence, QLR should combined with only qualitative methodologies which share its focus on the key characteristics such as time, change and the inherent iterative nature (Saldana, 2003; Calman et al., 2013; Miller, 2015), which require further discussion.

4.3.1 Time

The synchronised biographical time of both the researcher and the participants serve as the medium of movement between the past and the present in QLR, thereby allowing for the opportunity to capture the HD patient's prospective and retrospective accounts of their experiences (Carduff et al., 2015; Thomson and McLeod, 2015). While prospective QLR studies use multiple interviews to track research participants' outcomes, retrospective studies require the participants to recount their past experiences currently (Holland, Thomson and Henderson, 2006). This process of traversing between the present and past emphasises the temporal dimensions of experience and complicates the linear constructions

of time (Miller, 2015). It is particularly useful when talking to patients to keep going back and forward in different time to better understand and identify changes in the meaning of their illness. The traditional notion of time as a linear construction shifts during the back and forth movement in time during the data collection and analysis phases of QLR (Calman et al., 2013). Saldana (2003) identified that different periods of time and different points in time are qualitatively idiosyncratic reflecting different experiences, influenced also by cultural conditions surrounding an individual's geographic location, which can impact on the speed and duration of the individual's perceived change across time. Therefore, the individual's construction of time (for example how long they have had an illness or felt ill) has been recognised as a major contextual factor influencing the individual's subjective experiences and is a distinct feature of data sets in studies which employed the QLR orientation (Saldana, 2003; Miller, 2015; McCoy, 2017).

4.3.2 Change

Just like time is a contextual construct, so also is change and change can only be interpreted through an individual's perspective of the back and forth movement between the past and the present (Carduff et al., 2015; Thomson and McLeod, 2015). Every researcher and every QLR study must choose a flexible approach in the classification of change (Saldana 2003). This distinctive definition of change can be influenced and can continue to emerge and be constructed just as the study progresses and the data collected analysed. Whilst change is defined in a study by the pre-determined aims and outcomes it is important that QLR researchers clarify the various contextual factors that subjectively and inevitably influence change within the phenomena being studied (Saldana 2003).

Additionally, apart from the need for a continuous revision of the definition of change in for every QLR study, Lewis (2007) highlighted that QLR researchers must be aware of the four kinds of change that can be observed or exposed through the analysis of qualitative research data in QLR studies:

- (I) Narrative change which reflects the constantly unfolding individual stories of the participants across time with the reactions, hopes and feelings associated with these stories.

- (II) Change within the context of time and occurs as participants reinterpret and retell their stories or re-describe events in their lives during later interviews. As Calman et al. (2013) noted, certain issues that appears very important to the participants at one point in time may change with additional experiences and their perspectives of time. Therefore, in this way, Lewis (2007) highlighted that QLR provides more opportunity for engaging the research participants in the analysis of change, observing any possible features of change in the participants` narratives and interpretations, and thus reflecting inconsistencies to enhance a collaborative interpretation of the research participants` account of their stories.
- (III) Change arising as the researcher continues to see the research participants more clearly across the period of the study (Lewis, 2007; Carduff et al., 2015). As the participants continue to reinterpret and subsequently change their stories or narratives over time, so also is the QLR researcher learning more about the participants over time and this evokes reinterpretations of the research participants` experiences, stances and behaviours (Lewis, 2007).
- (IV) The last type of change that can be observed in QLR studies is no change. The absence of change and the subsequent presence of continuity in the phenomenon being studied could be positive as it may depict consistency, stability or maturity and it could also be negative in that it may reflect a failure in progress or dearth of development (Lewis, 2007).

In the understanding of change as a major tenet of QLR, Lewis (2007) urges qualitative longitudinal researchers to be acquainted with the different kinds of change and the potential meanings they reflect regarding research participants` lived experiences. Similarly, qualitative longitudinal researchers are challenged to confront their preconceptions about change and allow the definition of change in QLR studies (if any) emerge without imposition (Pettigrew, 1990; Saldana, 2003; Lewis, 2007).

4.3.3 Iterative nature

Another key tenet of QLR data generation is the iterative nature as it draws on what was learnt previously to understand what has changed to tell the participants` stories over time (McLeod and Thomson, 2009; Carduff et al., 2015). QLR is therefore characterised by the practice of going back and forth to research participants` archived data or any form of

recorded personal narratives or histories (Miller, 2015). This process of going back to previously collected data according to Miller (2015) raises some philosophical concerns founded in positivism about whether the process of going back to previous interpretations of participants' narratives and data is possible. Mertens (2015) noted that from the ontological perspective of subjective realities, truly returning to previous data collected from participants would be impossible, as the passage of time leads to further interactions of the participants with their environments and this subsequently evokes changes in the perception of truth, being and knowledge of not only the research participants but also the QLR researcher. However, Miller (2015) highlighted that this inability of the researcher to truly go back to the previous research data sets provides an opportunity for the emergence of new reflections and interpretations among the research participants and for the researcher to edit, add or alter the earlier interpretations or understandings of the of the phenomenon being studied. The secondary analysis of earlier data collected alongside the primary analysis of newly collected data elicits the blurring of distinct data sets and data analysis phases which are beneficial for richer understanding of the participants' experiences (Miller, 2015). The QLR orientation and its associated iterative analysis of cumulative data sets therefore provides an opportunity for gaining fresh analytic insights for extending, revisiting and retheorising periods of significant transition (Calman et al., 2013; Miller, 2015).

The QLR approach was chosen in this study based on the belief that the experiences of the individual dialysis patient being studied is unique and these experiences constantly change over time. The choice of QLR approach was inspired by not only the desire to explore any possible changes but also to understand why and how the changes occurred within the social and cultural context (Holland, Thomson and Henderson, 2006). It also expresses the interaction between time and the cultural aspects of social life, thereby representing time as a non-linear factor (Neale and Flowerdew, 2003). This study will therefore seek to understand over time the cultural, familial and societal issues facing patients managing a LTC such as CKD who must pay from their pockets for dialysis without any health insurance; how these issues affect their access to dialysis treatment and how their experiences of dialysis treatment changes or otherwise over time. The researcher was inspired by the desire to gather rich, in-depth data over the course of the research as opposed to a snap shot in time adopted by most other studies (Chapter two). Carduff, Murray and Kendall (2015) noted that one of the crucial benefits of QLR is the nuanced understanding of the phenomenon being studied which evolves over a period, particularly crucial in

understanding the experiences of illness in individuals. The prospective benefits of understanding the needs of people with chronic illnesses in response to the temporal and complex changes they experience have been highlighted in other studies using the QLR approach (Murray and Sheik, 2006; Murray et al., 2009; Cavers et al., 2012). Although, no previous other study has used the QLR approach in exploring the lived experiences of CKD patients receiving dialysis in any country or setting.

The research adopts a QLR approach, capturing the experiences of a cohort of CKD (stage-5) patients over time (seven months) to better understand the obstacles and challenges they face when accessing HD treatment. Seven months was the time frame selected to because the anecdotal evidence suggested the long-term survival for many patients in Nigeria accessing HD was not much longer than six months. It was hoped that over a shorter time the researcher may be able to sustain three waves of data collection during the QLR approach (discussed later). QLR enabled the researcher to develop a relationship with the research participant over time and generate a rich textured in-depth account of everyone's lived experience of accessing HD (Holland, Thomson and Henderson, 2006; Henwood and Coltart, 2012; Neale, 2012). Indeed, the aim was to gain a deeper understanding of the wider economic, cultural, family and societal challenges faced by people with CKD accessing HD in Nigeria and identify why some people do not attend for treatment. Exploring these concepts and lived experience over a longer period provides an opportunity for the participant to have a stronger voice, limiting the often-power imbalance inherent in the researcher-participant dyad (Carrick et al., 2001), and avoiding a biased perspective gained sometimes from one interview at one moment in time. It allows the researcher to map repeated challenges faced by people with CKD in Nigeria over time and identify and share strategies that some people adopt to overcome issues. This deeper understanding of the real-life experiences in the community mapped to the impact of health policy is particularly pertinent for a researcher working within the government, to ensure health policy is meeting the needs of the population.

The research was underpinned by theoretical assumptions of symbolic interactionist that self is dynamic and always in process (Mead, 1934; Blumer, 1969), drawing on the work of Charmaz (2002) that human experiences constantly change especially during periods of chronic illness such as CKD, which also reinforced the need for a study longitudinal in nature. The research fostered a collaborative approach wherein the participants were experts on their own lives and working together through the participant describing and the researcher

listening, probing and clarifying it was possible to gather in-depth information or knowledge specific to their individual experiences. The use of one-to-one interviews was an effective means of gaining insights into the experiences of research participants (Holloway, 2005; Creswell, 2009).

4.4 Sampling, size and procedure

A purposive sampling technique was used in the selection of participants for the study. This method of sampling is often but not exclusively used in qualitative research; where the researcher deliberately chooses ‘*who to include in the study on the basis that those selected can provide the necessary data*’ (Parahoo 2006, p.232). All patients who met the inclusion criteria and were willing to participate in the research were recruited, while those who did not meet the selection criteria, excluded (Box 1).

Box 1: Participant's inclusion criteria

- Adult ESKD patients aged at least 18 years
- Patients who have been receiving haemodialysis for at least 3 months
- Ability to speak English or Igbo language
- No mental or cognitive impairment
- Ability to give informed consent

Whatever sampling technique employed in choosing participants in a research must ensure that the population being studied is adequately represented (Parahoo, 2006; Ingleton, 2007). In this study this was somewhat unrealistic given there was no accurate Hospital record detailing the number of HD patients in the facility, those still alive at the time of this study, thus the scope or characteristics of a target population were unknown. A review conducted in the facility (Ulasi and Ijoma, 2010) indicated that the facility served about 908 CKD patients (593 males /315 females). I contacted the authors to gain more information, but they highlighted that the Hospital didn't have the facility for proper record keeping, they could estimate that the Renal Unit had close to one hundred patients on HD. Therefore, I initially set out to recruit up to 15 participants, then decided to increase the number of participants to

20 to minimise the impact of high attrition rate which is usually associated with longitudinal research (Soloff et al., 2003). Recruiting participants was a major challenge not least because when I embarked on data collection the Hospital was still on strike for about five months during (July- November 2015). Even when the strike was called off the turmoil of catching up in the healthcare facility, water quality delaying treatment, the anger and unrest within the patient population made the research at the bottom of people's priorities. As a result, and to allow issues to settle, I delayed the recruitment of the participants for the study until about the first week of January 2016. Overall, a total of 17 participants (5 females/12 males) were recruited for the study. To capture a wide range of lived experiences, the sample was drawn from across different age groups (over 18 years), cultures and economic status as appropriate, although it was just not possible to recruit an equal number of male and female participants. Although the sample was small it did not pose a problem for the study, particularly as there is no documented consensus on what an acceptable sample size in qualitative research is (Parahoo, 2006; Holloway, Wheeler and Holloway, 2010). Having too many participants when using purposive or theoretical sampling could lead to the generation of too many complexes which may cloud the issues being investigated and complicate the process of data analysis (Schwandt, 2007).

4.5 Study setting

The centre for the study is the University of Nigeria Teaching Hospital (UNTH), Enugu, Nigeria. The Nephrology Clinic of UNTH is the only public healthcare facility providing services to patients from the catchment area predominantly from the South-Eastern region of Nigeria which has an estimated population of 16 million people (National Population Commission [NPC], 2006). The only data available, as mentioned earlier, reports that the dialysis unit provides HD services to approximately 908 CKD patients (593 male/315 female) with mean age of 42.55 ± 15.43 years, with end stage renal disease being the cause of 22.03% of all medical deaths in the facility (Ulasi and Ijoma, 2010).

4.6 Gaining access

Potential participants were identified through the assistance of the Head of the Renal Unit. Written information sheets and invitation letter were provided to potential participants attending the unit for dialysis by the researcher with the help of the matron. Participants were then contacted a week later by the researcher to answer any questions regarding the study and enquire if they would like to be involved (Appendices 5 and 6). However, tracking people referred to dialysis who do not attend (because they may not be able to attend for any reason) was more difficult and it required a direct contact of the Head of the Renal Unit and then the provision of written information or direct explanations of the study over the phone if the distance to the unit is too far for them to travel. All interviews where at all possible were planned to take place face to face either in the participants` home or hospital, but all chose to be interviewed within the hospital setting.

4.7 Data collection methods

For this research, lived experience data were better gathered through narrative interviews provided by the research participants (Lindseth and Norberg, 2004). These narratives were then converted into texts and interpreted to elicit meanings the participants ascribed to the experiences. The primary data for the research were collected using semi-structured qualitative interviews within three waves of data collection (months 1, 4, and 7) and this allowed a three-month interval between each interview to analyse individual experiences and identify themes to clarify and discuss in the follow up interviews as part of a tailored longitudinal interview approach. Each interview lasted between 30 minutes to 1 hour, was digitally recorded (with the participants` consent) and took place in a room in the dialysis unit, where it was possible to talk privately without being disturbed. Individual interview was considered appropriate to achieve the research objectives;

“As with any qualitative research data collection tool, is to explore the `insider perspective`. To capture, in the participants` own words, their thoughts, perceptions, feelings and experiences. (Taylor, 2005, p.39)

Semi-structured interviews provided a flexible approach to phrasing and ordering of interview questions, enabling the elaboration of information or exploration of ideas of

interest, which the researcher may not have previously thought about as important (Britten, 2006; Gill et al., 2008). In semi-structured interviews, the researcher has a degree of control in the interview process, using predetermined interview questions to guide the interview process, but the ability to allow the free emergence of topics to expose the participants' perspective (Parahoo, 2006). This means at the outset the researcher does not have a full knowledge of all the questions to ask the participants but using QLR the responses of participants and areas of interest can be built into subsequent interviews across the whole sample, allowing deeper clarification and confirmation of data. Secondary data collected during each wave of data collection included the monthly haematology and biochemistry test results of the participants which were obtained from their respective Hospital Records (such as haemoglobin levels, serum Urea and Electrolytes, and albumin levels).

4.7.1 Data collection schedule

Data collection occurred in three waves over a seven-month period.

4.7.1.1 First wave

The first wave of data for the research was collected between January 7 and January 22, 2016. A total of 17 participants (5 females/ 12 males) who were recruited for the study were interviewed after giving an informed consent to participate in the study. The data collection commenced with the introduction of the researcher and the purpose of the study, and then asking the initial question.

4.7.1.2 Second wave

The second wave of data was collected between April 14 and April 25, 2016. The total number of participants remaining on the study was 12 (4 females and 8 males) and these were interviewed. 4 male participants were reported dead by the hospital management and 1 female participant was critically ill at the time of the second interviews and therefore could not have participated. Informed consent was obtained again, and participants did sign the consent forms provided.

4.7.1.3 Third wave

The third wave of data was collected between July 25 and August 2, 2016. A total of 6 participants (2 females and 4 males) who were still alive and consented to continue with the study were interviewed, while the other 6 had passed on before the period of this interviews.

4.7.2 The interview process

A good qualitative research interview question must be open-ended, clear, neutral and sensitive (Patton and Patton 2002; Britten 2006), the researcher opened each interview with the question: *Tell me your experiences with respect to haemodialysis treatment?*

Underlying the research was the philosophy that every individual's illness experience is unique and no two individuals' experience is the same (Jablonski, 2004). As such I went to the field with an open mind, set to explore the experiences of the dialysis patients by posing the initial question and allowing the participants to express freely their views, perceptions and concerns without introducing personal prejudice. Before asking the question, demographic details were gathered alongside biographical information about their family, dependents, their disease progression, and lifestyle. Once a participant had answered the initial question posed, specific questions were used to elicit richer, clearer and more in-depth descriptions of their experiences. The interview process guided by a list of simple questions (see below) and the use of scheduled and unscheduled probes to obtain detailed narratives from the participants (Qu and Dumay, 2011).

- What does living with CKD mean to you and your life, what impact does living with CKD have on the quality of your life?
- What symptoms do you experience? How does this make you feel?
- What are your experiences with respect to HD treatment, what influences whether you attend or not, what challenges do you face when accessing treatment?
- What are your experiences of the care that you receive at the unit or from the doctor? How often are you reviewed and followed up?

- What influences whether you attend dialysis or not? (physical symptoms, cost of treatment, whether you work or not, your culture, beliefs, needs of your family, where you live)
- Are there any government interventions that could make a difference to your experience of treatment and CKD?

Scheduled probes enabled me to elaborate on the emerging responses from the participants, using phrases such as “please tell me more about this”, each time a participant disclosed information of interest to the research. I asked the initial broad question and followed the threads of the conversation to probe and explore the physical, psychological and social experiences of living with CKD, to understand if access to the healthcare system was unequal, for who and how. Silences were allowed, not all cultures are expressive and talkative some are taciturn and could use silences as a part of their language (Qu and Dumay 2011). Indeed, silences allowed participants time to reflect and think, add more depth, regain energy and concentration, although it was not easy they were “tolerated” (Doyle 2004, p. 11). Having a good knowledge of the subject area being researched, observing gestures, facial expressions and body language, being sensitive to the use of specific language and the vocalisations used by the research participants was important in this setting full of different cultures and customs (Taylor, 2005; Kvale and Brinkham, 2009).

Care was taken to manage the researcher-participant relationship, ensuring that participants did not perceive the relationship to be intrusive or neglectful throughout the research period. This was achieved by ensuring that data collection was continuous, not too frequent and sensitive to possible changes in the participants without constituting a nuisance to them. Certain lines of inquiry were initiated during the first interview and any new emerging issues were followed through subsequent interviews. To ensure over time participants were well enough to be involved in the research, I established a mechanism of constant communication with the head of the renal unit, to avoid contacting the individual’s family and causing any distress, this turned out to be the most vital link. A reflective diary was also maintained throughout the study to enhance the collection of rich data and promote the credibility of the study and assist the researcher in the data analysis process (Pope, Ziebland and Mays, 2000; Saldana, 2003). Interviews were audio-recorded and lasted between 30 minutes to 1 hour because most of the participants were too tired to withstand long periods of talking.

During the second wave of data collection, the interviews from the first wave had been transcribed and emerging themes and categories noted. Going back to the research participants during the second interview with the summary of the transcripts from the first interview helped in clarifying meanings and interpretations (preventing over interpretation) to ensure that it is their voices and not my assumptions and interpretations that were transcribed (Taylor, 2005). The summary from the first interviews served as a prompt to guide the second interview and new ideas were followed through in the second and third waves of data collection.

4.7.3 The Role of the Researcher in the interview process

I continually reflected on my role in the entire interview, important for qualitative interviewers to reflect on being part of the research process and articulate possible assumptions which might influence the study design and implementation (Taylor, 2005). At the outset I had to consider carefully how the participants might view my “intrusion” into their experience of their health condition, what their perspectives of themselves could be and how much information they could be willing to disclose during the interviews. It was pertinent for me to undertake adequate interview preparation, to understand and recognise an interviewee’s response to questions were influenced by factors such as age, gender, social class and professional status (Silverman, 2013). Understanding it may be difficult to uncover the true feelings and emotions of the participants during one interview session, so the benefit of interview waves allowed the narrative to move further than a public account.

Two participants knew me as a nurse from my previous practice setting while others identified me as a research student but had no idea of my professional background. I carefully considered my approach towards all participants (those that knew me before and those that didn’t have a prior knowledge of who I am) because I wanted them to view me from the perspective of a researcher even though that couldn’t possibly erase their mental picture of me as a nurse. It has been shown that participants in qualitative interviews may respond differently to questions posed to them by persons they perceive as being of higher status when compared with their responses to a student researcher or a novice researcher (Richards and Emslie, 2000; Taylor, 2005). After gaining informed consent, I fully introduced myself and encouraged general conversation to elicit any concerns the participants might have regarding the research. This helped in establishing a rapport and develop a level of trust that

encouraged participants to feel relaxed before the interview commenced. This process was repeated at each wave of the data collection and participants were informed of their right to withdraw from the study whenever they wished which not affect their treatment in any way.

It was important for me to decide in advance on what information to reveal during the interviews. I tried to be mindful of the issues as a nurse researcher, but at times it was impossible to keep one`s role as a clinician out of the interview process (Carolan, 2003; Clarke, 2006). To resolve tension, I used reciprocity, *‘the practice of exchanging things with others for mutual benefit’* (Carolan, 2003, p.12) this enabled participants to see me as a human being, a Nigerian, not just as a researcher. I also considered other issues such as the use of a digital recorder where it should be placed or positioned during the interviews, what I should wear to the interview sites, how to deal with emotional or difficult issues which might arise during the interview and the need to be careful of my body gestures during the interviews. I needed to consider where the interview took place at private place/room at the unit that was conducive for participants to feel comfortable to stay and agree to participate in the interviews. The frailty of participants was considered which influenced the time frame for the interviews to suit individual preferences. It was very difficult to interview participants who came from very far distances to the Hospital who did not want to be interviewed in their homes but did not present for dialysis during the day hours. This led to me needing to stay in a hotel overnight to interview such participant(s) the next day before they travelled back to their rural homes.

4.7.3.1 The Reflexive Journal

Keeping a journal helps researchers carrying out qualitative interviews to be reflexive and examine experiences to enhance their understanding of the research topic and the entire research process (Taylor, 2005). The choice of the term reflexive not reflective was deliberate since the two words have different meanings. Reflection defined as *“internally examining and exploring an issue of concern, triggered by an experience, which creates and clarifies meaning in terms of self, and which results in a changed conceptual perspective”* (Boyd and Fales, 1983, p.100) is not necessarily specific to research (Dasgupta and Charon, 2004) Reflexivity specifically acknowledges the role of the researcher in the entire research process (Jasper, 2005); where researchers carry out critical self-reflection, analyse and take

note of personal values and biases which could affect the data collection processes and the interpretation (Polit and Beck, 2008).

In this study, reflexivity formed a crucial aspect of data collection, exploring issues of personal bias, decisions along the life course of the research, reflexive thoughts and to record these in my personal memos and diaries (Carolan, 2003; Taylor, 2005; Polit and Beck, 2008). The diary provided the opportunity to explore emerging themes from the data, to make a comparison with my previous assumptions about the topic being researched (Taylor, 2005). This certainly helped to ensure the final analysis of the data reflected the participants' meaning, beliefs and views and was not just an exercise aimed at placing the data into preconceived categories. Indeed, it provided depth of understanding to context when the spoken words were not enough to convey true meanings or when someone had difficulty expressing themselves (Van Manen, 2016). The process of reflexivity was continuous, and it served as a vital resource for audit trails to elicit the trustworthiness of the entire research process (Jasper, 2005; Taylor, 2005). Extracts from the reflexive journal have been used in the presentation of the findings, to reinforce meaning and capture context, research decisions, conflict, challenges and experiences.

4.8 Ethical considerations and research governance

Full ethical approvals were obtained from both the Research Ethics Panel of the University of Salford and the University of Nigeria Teaching Hospital Health Research Ethics Committee (Appendices 8 and 9). Before the commencement of the data collection, the potential participants were given copies of the participants' information sheet (Appendix 5) to read and those who could not read the sheets were given full explanation of the content of the sheets and the research process. All questions were fully answered, and clarifications adequately made. Patients who agreed to participate were given the consent forms (Appendix 7) to sign and were informed of their right to withdraw at any stage of the research and that would not affect their treatment. Confirming consent was a continuous process rather than a one-off practice but took place at the start of each interview wave, recommended particularly in longitudinal research of this kind (Crow et al., 2006; Holland et al., 2006). This was important in this study since the researcher needed to spend a considerable time in the field

collecting the data. Doing this enabled the researcher to reconfirm the agreement by the participants to continue to participate in the study.

The nature of qualitative research can appear harmless but is associated with certain risks to research participants; such as distress and anxiety, misrepresentation, exploitation and identification of the participants in published research work (Richards and Schwartz, 2002). Indeed “*people have rights over their lives and beliefs and actions, and the use that is made of information about them*” Alderson (2001, pg. 17). In this study the process of carrying out in-depth qualitative interviews could initiate or uncover emotional issues or cause offence. This was a major concern where getting the participants to talk about their experiences of their condition, could be very distressing. The researcher informed the psychological support services at the unit of the research to secure follow up support for people should the need arise. In addition, the researcher showed empathy, avoided probes which caused distress, and opted to stop an interview as necessary (Clarke, 2006).

To ensure the confidentiality and privacy of the research participants, all the information provided were used solely for this study. The responses (transcripts), contact details and email addresses were safely stored on password-protected private computer accessed only by the researcher. Participants` responses were coded and anonymised using pseudonyms to ensure the confidentiality of identities. All interview recordings were transcribed by the researcher, so no other persons had access to the details of the transcripts, although anonymised transcripts were independently analysed by the research supervisor.

The role of the researcher was also considered very important from the ethical standpoint. The researcher ensured professionalism and integrity throughout the period of data collection and this helped to maintain existing trust between him and the research participants. The participants were made to feel relaxed and able to talk freely in line with the philosophy of the methodology chosen for this study. They were also allowed to choose wherever they wanted to be interviewed without any pressure from the researcher as discussed previously in this section; this was necessary to limit the often-power imbalance inherent in the researcher-participant dyad (Carrick et al., 2001).

4.9 Data analysis

A large amount of data was collected, which then formed the corpus, which was analysed to answer the research questions. The process of analysis of the data started with the data transcription and the details of the processes are described in the following sections. The interviews data collected were transcribed by listening carefully to the recordings as the first step towards the data analysis. The transcription was carried out by the researcher, which was time-consuming due to the large data set, but necessary because some participants were interviewed in the local dialect. Personal transcription helped in the familiarisation with the data and the understanding of the emerging ideas during the data analysis. I didn't want any part of the participants' response being distorted due to poor interpretation or translation of their responses from Igbo language to English, which could have led to misrepresentation of the patients' voices, views and opinions.

During the first phase of the data collection, all the interview transcripts were manually coded, and emerging concepts, themes, and issues noted. Prior to the second stage these themes were confirmed with the participants to ensure that their voices were appropriately represented. The emerging issues, themes and opinions were further explored in more details in the subsequent phases while new questions were also asked. Similar steps as described in phase one were also followed in analysing the data collected during the second phase. Detailed analysis of all the transcripts including the data collected in the third phase was carried out manually, this was preferred to stay true and in contact with the data throughout. This was then combined with other data sets (Box 2).

Box 2: Data corpus

- 35 interviews with the participants-recordings and transcripts
- 17 patients' folders: health history, treatments regimen, results of blood chemistry
- Researcher's reflexive journal and field notes

4.9.1 Analysis of participants` hospital records/documents

Document analysis involves the location, evaluation, and interpretation of documents and drawing conclusions about the evidence to generate meaning, gain understanding and provide empirical knowledge (Corbin and Strauss, 2008; Fitzgerald, 2012). The analysis of the participants` hospital records added depth and context to the interview data and the field notes taken throughout the period of the study through a process of triangulation (Patton, 2002; Carter et al., 2014; Yin, 2014). Carter et al. (2014) asserts that collecting information from multiple perspectives in research enhances the validation of the data. The hospital records that were reviewed included the medical history of the participants, the results of the participants` blood chemistry- Serum creatinine, Glomerular filtration rates (GFR), and Blood Urea Nitrogen (BUN) at each stage of the data collection process. The hospital records were analysed prior to each interview session, during the coding process and throughout the period of data analysis through an iterative process of meticulous reading, re-reading and using annotations to ensure that any conclusions made was sound and relevant to the aims of the study. For instance, reviewing each participant`s hospital record/document helped me in familiarising myself with their present health history, attendance to hospital appointments, attendance to dialysis prior to the date of the interviews, the frequency of their review by the consultants, the results of their kidney function tests and other pieces of information necessary in achieving the aims of this research. All the key points were noted in my research diary and these were used during the analysis of the data. Doing this helped me a lot in understanding the narratives made by the participants during the interviews even though I still had to seek some clarifications on certain points or issues from the participants individually after each interview sessions.

4.9.2 Analysis of interview data

Inductive or deductive approaches are used in analysing qualitative data in research (Spencer, Ritchie and O`Connor; 2004; Lathlean, 2006). The inductive approach involves analysing qualitative data without any predetermined theory, framework or structure by using the actual data generated during the study to attain the structure for the analysis (Lathlean, 2006; Burnard et al., 2008), most commonly used approach to analyse qualitative data. Conversely, the deductive approach involves the use of predetermined structure,

theories or framework in analysing research data (Burnard et al., 2008). Fundamentally, researchers using deductive approach impose their own structure or framework or theories on the data and then use these in analysing the interview transcripts (Williams, Bower and Newton, 2004). Although the deductive approach is relatively quicker and easier in analysing qualitative data, the inflexibility of the approach could potentially bias the entire data analysis process since the coding framework has been predetermined which limits the chances of theme and theory development (Burnard et al., 2008).

The framework analysis (FA) approach was applied in the analysis of the data generated in this study. The choice of this approach was guided by the research aims and the research questions, which the study sought to answer. The analysis aimed to organise, explore and explain the data collected with a view to understanding: the meaning of living with ESKD to the participants and how this influenced their treatment, describing the experiences of the dialysis patients over time, and how societal, financial, cultural, geographical, familial and capture other wider contextual issues influencing their ability to access and sustain dialysis treatment. FA was selected because it is a flexible approach that can be adapted for use in many qualitative approaches, not aligned with any theoretical, philosophical or epistemological approach (Gale et al., 2013). It provides a clear track of how decisions were made in arriving at the themes, enhances transparency in the data analysis process and encourages teamwork (Ritchie and Lewis, 2003; Dixon-Woods, 2011; Swallow, Lambert, Santacrose and Macfadyen, 2011; Ward et al., 2013). The FA is a method of data analysis rather than a research paradigm and its ontological position adheres closely to subtle relativism (Snape and Spencer, 2003), which argues that the social world researchers seek to study exists independently of individual subjective understanding, however is only accessible in qualitative research through participants' interpretations which are further interpreted by the researcher (Hammersley and Atkinson, 2007). Using this approach in the analysis of the research data enabled me to remain true to the data and remain open-minded in ensuring that my preconceptions did not influence the interpretations given to the interview extracts. The analysis process of the data occurred throughout the entire period of data collection and beyond until the final research report was produced.

The FA approach involved five distinct stages which were interlinked, methodical and rigorous (Ritchie and Spencer, 1994) (Box 3). The process of the analysis started during the phase of data collection and it involved actively looking for issues that relate to the research questions in the data, thinking about the patterns of meaning and reflecting on the entire

experience of the data collection (interviews, documents and field notes/research diary). The final stage was the reporting of the final themes from the data.

Box 3: Stages of framework analysis (Ritchie and Spencer, 1994; p.173)

- Familiarisation with the data
- Developing and testing an analytical or theoretical framework
- Indexing
- Charting
- Synthesising data by mapping and interpreting

4.9.2.1 Familiarisation with the data

Having conducted all the interviews at every stage of the data collection myself, it was easier and less time-consuming for me to familiarise myself with the depth of the data from the beginning of the data collection process (Spencer, Ritchie, Ormston, O'Connor and Barnard, 2013). The interviews were transcribed verbatim shortly after the completion of each stage of the data collection before the commencement of the next wave of interviews. Familiarisation involved listening to each interview recordings, reading the transcripts, and making any analytical notes of preliminary impressions and thoughts in the margins of each transcript. Despite the large volume of the data gathered in each stage, it was necessary to review each of the transcripts in detail at each phase. All the key phrases were highlighted using pen highlighters and labelled as the initial codes as a means of staying true to the data instead of using the Nvivo (Spencer et al., 2013). Reviewing the entire transcripts ordinarily is not required when using FA in data analysis as this normally occurs in the later stages of the data analysis process (Srivastava and Thomson, 2009). However, to familiarise myself with all the key issues, ideas, and themes during each wave of data collection, to inform the subsequent interview questions continuous immersion in the data was necessary. All the field notes and reflexive journal excerpts documented through each data collection wave were read alongside the transcripts and referred to during analysis.

4.9.2.2 Developing and testing an analytical or thematic framework

The development of the framework started with the comparison of all the codes that were applied to each transcript to ensure uniformity. Ritchie and Spencer (1994) highlight that the process of developing framework categories is informed by both a priori concerns and the emergent issues arising from the earlier familiarisation stage. However, the degree to which this is used involved a process of trial and error to identify the categories that provide the best fit for the research data and the research questions. Accommodating both a priori and emergent issues in the development of framework categories ensured that the framework not only focused on the research questions but also incorporated the research interests of the researcher and the issues most pertinent to the participants (Parkinson et al., 2016). Initially, the framework was used as a data management system rather than interpreting the data. This led to the formation of framework categories and the generation of initial codes, reflecting the concepts uncovered by the guiding conceptual framework (discussed in the previous Chapter), and incorporating key issues followed up through the data collection waves. The framework categories had to be flexible and remain open to participant-oriented issues arising from the research data, so the framework was tested through a pilot analysis of the first wave interviews. There were codes which did not fit into the framework, which resulted in the inclusion of “other” code under each category to capture relevant data that did not fit but could not be ignored.

Box 4: Analytical framework

- Meaning of living with ESKD
- Impact of ESKD on quality of life
- What influences attendance to dialysis
- Challenges to accessing dialysis treatment
- Experiences of symptoms and its impact
- Experiences of care by doctors and nurses
- Interaction between the interviewee and the interviewer
- Others

There was also overlap across categories which led to the adjustment and refining of categories and clarity of key emerging sub-categories. This refinement helped ensure data fit and reduced repetition (Ward et al., 2013), as shown in Box 4.

4.9.2.3 Indexing and Charting

The refined analytical framework (Box 4) was applied to each of the subsequent interview transcripts. Working through each of the transcript texts using the Microsoft Word document, chunks of the text were highlighted, indexed and categorised (Spencer et al., 2013). Data which did not fit into any of the categories were placed under the “Other” category.

After the completion of the indexing processes as described, data was organised into a more manageable format, to enhance data analysis for the next stage of the FA approach (Parkinson et al., 2016). Summaries of data were extracted from each transcript and charted using a spreadsheet to generate a framework matrix. Efforts to maintain a balance between the reductions of the data and retain original meaning, views, and opinions of the participants were made. To ensure this, quotes of the participants` responses to the interview questions and references to illustrative or interesting quotes were copied word-for-word and included in the charts (Gale et al., 2013). Alongside a summary of thoughts regarding the quotes for each participant was noted on the margin of the Microsoft Word spreadsheet (Furber, 2010) as shown in Appendix 11. Considering the frailty of many of the participants in this study, there was no need for me to paraphrase their words as they were taciturn in the interviews, so the words of the participants were used, as verbalised by them without altering the meanings underpinning and upholding the philosophical positions of the study. Appendix 11 shows extracts from the framework matrix used in the study. The rows show the categories from the framework while the participants are shown in the columns in a case-based chart. This enabled the summaries to be read across for either within-case analyses, or downwards for between between-case analyses or for the analysis of any specific theme (Ward et al., 2013).

4.9.2.4 Synthesising data by mapping and interpreting

The aim of this stage was to move beyond data management towards understanding what the data means, to pull together the data maps/charts and interpret the entire data set (Ritchie and Spencer, 1994). Patterns in the data were explored and sets of themes developed to capture the participants' experiences of living with ESKD, dialysing within systems with unequal access to healthcare. Charts were reviewed, checking all the extracts or quotes in the charts against the original interview transcripts, the field notes and the audio recordings and compared the various themes and sub-themes with each other to identify their relationships and identify if any changes or merging was required (Ward et al., 2013; Parahoo, 2014). This led to the merging of some themes where there was insufficient data to support. This was necessary to avoid what Bryman (2016) refers to as "anecdotalism"- a term which describes situations where few instances of a phenomenon are erroneously considered as a theme or a pattern when they are truly idiosyncratic and could therefore not represent a theme. Other themes were expanded, separated or even renamed to appropriately reflect the data and the relationships existing between them (Parahoo, 2014). The entire process of the data analysis and theme development was reflective and iterative, independently checked by the supervisory team for accuracy, truth and credibility. Each theme (discussed in the next two findings chapter) were constructed to reflect the contents and the hierarchy of meaning within the data, while the labels given to each theme and sub-theme were deliberately concise to express the core meaning of the themes and the sub-themes.

4.9.3 Ensuring quality in the research process

For any research project to be valuable, it is crucial to demonstrate the quality and the integrity of the entire research process. Qualitative researches are often criticised as lacking scientific rigour and justification of the methods; mostly they are considered to produce anecdotal evidence, are biased by the researcher's predispositions and it generally lacks generalisability (Sandelowski, 1993; Rolfe, 2006; Pope and Mays, 2013). What constitutes rigour or quality in qualitative research has been a subject of debate amongst scholars and as such, there is no consensus regarding the standards by which the quality of qualitative researches is judged (Cutcliffe and McKenna, 2004; Rolfe, 2006; Parahoo, 2014). Silverman and Marvasti (2008) argue that the quality of any research should be assessed using criteria

which are considered appropriate and that the perception of the credibility of a research comes from those judgements that are made using such criteria. The criteria will vary according to the different approaches such as phenomenology, critical theory, ethnography, grounded theory, and feminist inquiry (Silverman, 2017).

The term “rigour” which denotes quality in research process was replaced by the term “trustworthiness” for judging naturalistic inquiry (Lincoln and Guba, 1985). Although no definitive criteria exist for the evaluation of quality in qualitative research, the use of clear evaluative criteria enhances the transparency of the entire research process, the critical thoughts undertaken in the research and the personal values of the researcher (Patton, 2014). This research established trustworthiness through the concepts of credibility (internal validity), dependability (reliability), confirmability (objectivity or reliability), and transferability (external validity or generalisability) (Box 5).

Box 5: Criteria for the assessment of the quality of naturalistic inquiry (Lincoln and Guba, 1985)

Credibility	Refers to the truth or believability of the research findings
Dependability	Demonstrating that the findings of the study are consistent and could be repeated
Confirmability	Refers to the extent to which the findings of the research are shaped by the participants` and not the researcher`s interest or motivation
Transferability	Demonstrating that the findings can be applied in other settings similar to those of the study

In this study *credibility* was achieved through rigorous in-depth field work, the truth of the participants responses gathered overtime using repeated measures allowing confirmation and changes in opinions and experiences to be captured. Primary interview data was supported by collating patient clinical indicators as a measure of adequate dialysis. The researcher ‘self’ within the research was acknowledged at the outset through a critical self-reflection and reflexivity which continued throughout the period of data collection (Patton, 2014), having a Nigerian background facilitated a deeper understanding of the embedded culture. *Dependability* describes the constancy of the research data over a similar condition (Tobin and Begley, 2004; Polit and Beck, 2012), addressed through a robust audit trail using Halpern`s (1983) categories for reporting information (Box 6). All the methodological and analytical decisions made during the entire research process were clearly documented giving

a transparent account of the research steps taken and the rationale for taking the steps; from the commencement of the research project to the development and reporting of the research findings. The accuracy of the interview transcriptions was considered essential and checked by reading the transcripts whilst listening to the interviews.

Box 6: Audit trail of essential information

Category	Audit trail
Raw data	All audio recordings, interview transcripts, field notes, journal excerpts, and copies of documented information from the participants` hospital files were stored securely and available for external scrutiny. All the interview data were anonymised before the storage.
Data reduction and analysis products	The steps taken in coding each interview transcripts and the synthesised findings are stored in a secure computer whereas the hard copies of word documents are available for examination and some are attached at the appropriate appendix section of the research report.
Data reconstruction and synthesis products	The process of theme development, the relationships between the themes and the existing literature, the findings of the research, the conclusions, the final report and its connection to exiting literature are all stored securely electronically as Word documents readily available for examination.
Process notes	All the decisions made were recorded in the form of field notes, in a reflexive journal used as part of the data set, alongside research supervision forms and the research report.
Materials relating to intentions and dispositions	Copies of ethical approvals for the research, participant information sheets which contain details of the proposed research are included in the appendices. The research proposal is available on request, and a copy held by the Ethics and Research Committee of the University.
Instrument development information	All the forms and guides used in the conduct if this research is included in the appendices section of the research report.

Confirmability refers to the extent to which the findings of the research were shaped by participants` and not the researcher`s interest or motivation. To enhance the confirmability of the research I maintained a reflective diary throughout the period of the study, had constant critical discussions with my supervisory team, and most importantly validated the research findings using QLR with the participants themselves, where possible. The interpretations of the findings and the conclusions will be discussed in Chapter 6; rich quotes of the participants` responses to the interview questions and the extracts from my reflexive journal will be included to demonstrate how each theme was derived (Cope, 2014). These confirm the authenticity of the research and the relevance of the new knowledge generated in enhancing clinical practice. No previous other study has explored the experiences of ESKD patients receiving dialysis services in healthcare systems with unequal access to healthcare. Therefore, the findings of this study are unique and invaluable to ESKD patients, the healthcare providers and the government in shaping the healthcare policy in the country.

Transferability refers to findings that can be applied in other settings or groups like those of the study (Polit and Beck, 2012; Houghton, Casey, Shaw and Murphy, 2013). It replaces the concept of generalisability or external validity which is associated with the positivist paradigm. This is perhaps more difficult to achieve in qualitative research as the focus is not on generalising findings. However, the similar themes across individual accounts (discussed in the following chapters) reinforces the transferability and applicability of the findings to other ESKD patients, the healthcare setting and the wider Nigerian context.

4.9.4 Reflexivity and my role in the research process

In qualitative research, both the researcher and the subjects being studied are interconnected in the social process of research (Kvale and Brinkmann, 2015). The researcher could be a veritable tool for generating new insights into the phenomenon being studied. However, even though the researcher is the instrument of data collection in qualitative research (Parahoo, 2014), it is pertinent that whatever influence the researcher has on the data generation and analysis process is made explicit to ensure the trustworthiness of the research findings (Baillie, 2015; Morse, 2015). Therefore, my role as the researcher and whatever influence I may have had on this research project is discussed here.

Reflexivity involves self-awareness (Lambert, Jomee and McSherry, 2010) and that means the researcher being actively involved in the research process. It is the recognition as researchers that we are a part of the social world we seek to study (Ackerly and True, 2010; Morse, 2015). The process of reflexivity requires that a researcher should be critically aware of the ways his or her personal values, assumptions and prejudices may have affected the methodological design, conduct, analysis of the data and the conclusions drawn in the research project (Patton, 2014). Reflexivity was used in this research to enhance the quality of the findings in terms of its credibility, dependability and transferability (Lincoln and Guba, 1985).

Reflexivity involves a continuous process of my reflecting on my values as a researcher and recognising, examining and understanding how my assumptions, social background and locations affected the entire research processes (Hesser-Biber, 2012). Patton (2014) states that the process of reflexivity can be enhanced by using multiple researchers in discussing the beliefs, assumptions, values, and perspectives of the researchers during the research process. Although there have not been multiple researchers involved in the full conduct of this research project, I regularly engaged with my research supervision team, fellow doctoral researchers and other experienced researchers who have carried out and published extensive qualitative research studies to openly share my research work with them and to seek their views, comments and opinions regarding any aspect of the research work including my role, views and values as it relates to the research project. Koch and Harrington (1998, pg. 888) refer to this process as “critical gaze turned towards the self”, examining my personal position, self and identity within the research process. To ensure a transparent audit trail of all the decisions I made throughout the research project, I kept a reflexive journal throughout the three phases of the data collection and this was used as part of the data corpus during the data analysis phase. The reflexive journal contains information such as the field notes I took during the research, any participants` comments or observations of interest to the research project, private participant`s comments, thoughts, questions or concerns which they did not express during the interview processes; my thoughts about the patients` responses and observations were documented in the journal and rationales for taking any action were also recorded.

My roles in this research process included: researcher, nurse lecturer and a nurse as I had cared for two of the participants in my previous role as nurse in the similar clinical context must be acknowledged in this research. In this context I was aware of my “insider/outsider”

role as a researcher on one hand and a former healthcare practitioner who had cared for some of the participants on the other. My influence on every aspect of the research process are discussed in the appropriate sections throughout the thesis.

I qualified as a Registered General Nurse (RGN) in 2010 having completed a five-year degree nursing programme in Ebonyi State University, Abakaliki, Nigeria. I worked initially in the adult surgical and medical wards, but I spent most of my clinical practice hours in the dialysis unit in two different hospitals in the Eastern and the Western part of Nigeria. Since 2012, I have maintained my skills in clinical nursing practice, but I have worked mainly as a nurse lecturer teaching and supporting undergraduate nursing students while I also practised part-time in a private hospital. The motivation to embark on this study arose from my professional experience as a nurse in the renal unit. I observed Nigerian HD patients suffering from CKD unable to access regular treatment, many patients dropping out and/or not attending treatment at all. In some cases, when these patients are given the information that they are suffering from CKD at the renal clinic, they are hardly seen to come back to the hospital for any follow up care and there is no mechanism for tracking any diagnosed patient to know what treatment options they are embarking on. Some of the patients when referred for RRT didn't turn up for any session because they were aware that they could not afford the treatment costs long term, others attended once or twice a month depending upon their financial circumstances and other needs. Medical professionals, doctors and nurses felt helpless, I felt helpless but began to accept there was nothing I could do to rectify the situation. The whole health system was inequitable, this we knew in Nigeria, but I had not experienced it as starkly as inequitable treatment of CKD patients from lower socioeconomic backgrounds. There is no CKD register unlike the UK and no one follows people diagnosed with CKD, monitors their treatment choices and how their treatment progresses; those referred for HD treatment if they don't attend appear to be forgotten. As I started my PhD I knew from the outset that I wanted to explore the plight of Nigerian people with CKD referred for HD, to find out what it means for them to live with their condition and receive dialysis services in a healthcare system with unequal access to healthcare. This is necessary to bring the plights of the renal patients to the attention of policy makers and to seek ways of improving access to dialysis care in the country.

Researcher motivation is crucial in carrying out a successful research project (Alvesson and Stoldberg, 2018). Although I was a relatively inexperienced researcher at the commencement of this study, I have been highly motivated to undertake this research and I

brought certain knowledge and skills acquired during my professional life which has continued to strengthen me. I view myself this research as a “conveyor” of the voices or messages of the frail participants in this research who by their social and economic backgrounds ordinarily may not be heard. I do recognise that undertaking this research is an arduous project especially using a qualitative longitudinal research approach which would mean that I will spend a considerable period on the field collecting the relevant data. However, I am a very resilient person and my ability to manage large tasks without giving up will be a great asset during the research, to stay through and collect all the necessary data including the interviews, observations, and collecting useful information from the participants` hospital files to enhance the credibility and the transferability of the research findings.

Having conducted a primary research in the past, I had some knowledge and skills of conducting a research, but I was careful and deliberately conscious not to allow my previous knowledge or values interfere with or influence my decisions in the entire research process in a negative manner. Therefore, before the commencement of the data collection phase, I carefully considered my opinions regarding the plights of the patients and what my thoughts were regarding their experience of their condition and recorded this in my reflexive journal for reflection throughout the period of the data collection and analysis. I was also aware of the possibility of my tilting the direction of the interview towards my personal interests. To avoid this, I had to stick to the question items written in the interview guide while I am asking only probing questions following each of the questions to obtain rich and in-depth account of the phenomenon being studied.

4.9.5 Summary

This research adopted a QLR approach, in capturing the experiences of a cohort of CKD (stage-5) patients over time (seven months) to better understand the obstacles and challenges they face when accessing HD treatment. The QLR approach was chosen in this study based on the belief that the experiences of the individual dialysis patient being studied is unique and these experiences constantly change over time. The choice of QLR approach was inspired by not only the desire to explore any possible changes but also to understand why and how the changes occurred within the social and cultural context.

A total of 17 participants (5 females/12 males) were recruited for the study. To capture a wide range of lived experiences, the sample was drawn from across different age groups (over 18 years), cultures and economic status as appropriate, although it was just not possible to recruit an equal number of male and female participants.

The primary data collected was through semi-structured interviews while the secondary data included blood chemistry results of the participants within the period of the study. The data was collected in three phases over a period of seven months. The interview transcripts were analysed using framework analysis.

The findings chapters are split into with chapter five presenting the first two themes and chapter six presenting the next two themes of the study. Chapter five will present the analysis of the data generating relating to the two themes.

Chapter 5: ESKD in Nigeria – challenging experiences

5.1 Introduction

The overarching aim of this study was to explore the experiences of CKD patients receiving HD in healthcare systems with unequal access to treatment. The qualitative longitudinal exploratory research approach captured the experiences of a cohort of participants over a period of seven months to better understand the obstacles and challenges they face when accessing treatment in Nigeria. The people managing CKD in this study experienced a “life world” dominated by poor access to dialysis treatment, this included trying to maintain normality and to adjust to the impact of the CKD and dialysis on every aspect of their lives. In a world where dialysis has extended the life of people with ESKD (for some in the UK up to 20-30 years), the findings of this study expose the plight of people who just don't have the resources to pay for regular HD treatment and the impact on their family. These people predominantly die within the first 3-6 months of being diagnosed with kidney failure.

The chapter first presents the study participants biographies to gain an understanding of the type and range of people recruited and involved in the study. From the analysis of the interview transcripts four key themes were generated, two will be discussed in detail within this chapter, focusing on the experiences of people:

- Understanding ESKD and treatment
- Meaning of living as ESKD patient in dialysis

Two further themes will be presented in chapter six, focusing on the impact and challenge of accessing treatment:

- Dialysis decision
- Impact of CKD and dialysis

5.2 Recruitment and study participants

5.2.1 The recruitment

Seventeen participants (five females/ twelve males) were recruited for the study. The seventeen were interviewed in the first wave of data gathering, twelve in the second wave (four females and eight males) and six (two females and four males) participants in the third wave of data gathering. Sadly, ten participants, 59% of the study sample died during the three waves of the study spanning a seven-month period, with one person critically ill, who was also excluded from the study. The problem of sustained participation across the three waves of the study reflects the key finding that people who couldn't pay for regular treatment were dying.

Participants were recruited from the health facility through information sheets and informal discussion. Participants had time to ask questions and completed a written consent form, agreeing to be interviewed three times for the study and share their experiences. At each wave of interview's consent to be involved and their participants understanding of the study was confirmed. All the interviews took place within the health care facility at the request and preference of the participants.

5.2.2 Study Participants

The geographical spread of the participants ranged from Ogoja in Cross River State, Ebonyi State, Rivers State, Ebonyi State and Enugu State, Nigeria. The mean age of the participants was 52 and the age ranged from 19-83 years. There was no existing renal registry in Nigeria to demonstrate the average age of people commencing HD in the country and to compare the average age of the participants in this study (Alasia, Emem-Chioma and Wokoma, 2012). All the names presented throughout the thesis are pseudonyms to ensure the anonymity of the participants in accordance with ethical principles. All the participants were receiving HD in the same hospital facility.

The demographic details of the participants are summarised in Table 5. The five women worked in roles ranging from civil servant, teachers, nurse and two farmers. Most of the men

recruited were also working some in professional roles such as teacher, graphic designer, civil servant or businessmen, alongside traders, and physical professions such as mechanic and carpenter. One male was a student and the other an unemployed graduate.

Table 5: Demographic characteristics of participants

Participant	Age (years)	Gender	Occupation	Family	Aetiology of CKD
A	32	Female	Teacher	Husband; parents; no children	Poorly-managed spontaneous abortion
B	66	Male	Trader	7 children; 1 Wife	Hypertension
C	45	Female	Auxiliary nurse	6 children; (husband died)	Diabetes mellitus
D	50	Male	Business	4 children; 1 Wife	Chronic gouty arthritis
E	65	Male	Mechanic	4 children; 1 Wife	Diabetes mellitus
F	34	Male	Unemployed (Graduate)	Mum, Dad and 5 siblings	Chronic glomerulonephritis (CGN)
G	20	Male	Student	Mum, 6 siblings (dad died)	Hypertensive nephrosclerosis
H	53	Male	Business	1 Wife; 5 children	Hypertension and diabetes mellitus
I	83	Male	Trader	2 Wives; 16 children	Hypertension
J	41	Male	Graphic designer	1 Wife; a child	Cause unknown
K	38	Male	Carpenter	1 Wife; 2 children	Obstructive nephropathy
L	50	Male	Civil servant	1 Wife; a child	Chronic glomerulonephritis (CGN)
M	45	Male	Lecturer	1 Wife; 2 children	Polycystic kidney disease (PKD)
N	69	Male	Trader	10 children; 1 Wife	Hypertension
O	50	Female	Farmer	4 children; (Husband died)	Diabetes mellitus
P	71	Female	Farmer	3 children; Husband	Diabetes mellitus
Q	66	Female	Retired civil servant	2 children; Husband (sick)	Hypertension

The most common cause of ESKD was hypertension (6 people) followed by poorly controlled diabetes mellitus (4 people). Other causes included Chronic Glomerulonephritis (CGN) and Polycystic kidney disease (PKD). Younger people lived with their parents, older men and women lived with their husband or wives and dependent children (ranging from 1-16).

Table 6 presents the frequency of dialysis in between the interview waves, frequency measured by the number of sessions accessed in the month prior to the interview. For example, participant A had two dialysis sessions in the month before the first interview (T1), one in the couple of months before the second interview (T2) and one again in the two to three months before the third interview (T3). Compared to someone in the UK who over a seven-month period would have received three sessions a week (approximately 84 sessions). Most of the participants received the standard 4 hours of dialysis in each session and in some instances, were prescribed 6-8hours. The commonest vascular access was venous catheter because of the late presentations of most of the patients to the renal clinic while some of them had AV graft. All the seventeen participants were interviewed during the first wave (T1). Five people were unable to take part in interviews at the second wave (T2) as four had died and one was critically ill. Similarly, ten people had died by wave three and one person remained critically ill. Only six of the participants who were still alive and physically strong enough were interviewed during the third wave (T3). As indicated in the appropriate section in Chapter 4, T1 was between January 7 and January 22, 2016; T2 was between April 14, 2016 and April 25, 2016 while T3 was between July 25 and August 2, 2016.

Table 6: Frequency of dialysis sessions throughout the period of the study

Participants	Frequency of dialysis*			Participation in interviews		
	T1	T2	T3	T1	T2	T3
A	2	1	1	Yes	Yes	Yes
B	2	-	-	Yes	RIP	RIP
C	1	2	1	Yes	Yes	Yes
D	2	2	1	Yes	Yes	Yes
E	1	1	-	Yes	Yes	RIP
F	1	2	-	Yes	Yes	RIP
G	1	1	-	Yes	Yes	RIP
H	2	2	1	Yes	Yes	Yes
I	1	-	-	Yes	RIP	RIP
J	7	-	-	Yes	RIP	RIP
K	2	2	-	Yes	Yes	RIP
L	5	5	4	Yes	Yes	Yes
M	12	12	10	Yes	Yes	Yes
N	0	-	-	Yes	RIP	RIP
O	1	1	-	Yes	Yes	RIP
P	0	1	-	Yes	Yes	RIP
Q	1	-	-	Yes	Critically ill	Critically ill

*Frequency = number of dialysis session in the previous month

5.2.2.1 Presenting the participants and their biographies

The summary of each participant`s background, their personal circumstances and brief overview of their experiences are presented with pseudonyms ranging from A-Q. It was important to me as a researcher to generate a participant biography, so the reader could get to know about the people who took the time to be involved, and to provide authenticity and reality to the study findings.

Mrs A

Mrs A was a 32-year-old teacher married without children, originally based in Abuja but had to relocate to her village in Enugu State, when she and her husband could not cope with the cost of dialysis care in the capital city. She had been on HD since January 2015 (12 months prior to first interview). She was diagnosed of ESKD secondary to poorly managed repeated spontaneous abortion. At the time of recruitment into the study, she was living with her parents in the village because of a lack of funds to take care of her medical bills and the inability of the husband to pay the rent on their house. According to her, the husband who was a petty trader had sold all his goods and some properties to sustain her treatment in Abuja but she had to return home to accept support from her parents regarding her treatment. Mrs A was interviewed during all three waves of data collection.

Mr B

Mr B was a 66-year-old petty trader who lived in Rivers State-an adjoining State to Enugu. He was married and had seven children who lived with him and were all still in school. He had been on HD since January 2015 (26 months prior to first interview). He had dialysed only twice in the last month prior to the first interview. According to him, he would have loved to access dialysis in his locality but there was no dialysis facility available and so he was forced to travel far on public transport from Omoku to Enugu for dialysis (204 kilometres). Sometimes he doesn`t access dialysis on the exact day he arrives in Enugu for his treatment due to long waiting hours as there were usually too many other dialysis patients waiting. Mr B`s wife is a peasant farmer and supports her husband in paying for their children`s education and looking after her husband. Sadly, I could not meet him for the second and third interviews as he was reported to have died.

Mrs C

Mrs C was a 65-year-old widow who lost her husband in 2012. She had been on HD since May 2015 (8 months prior to first interview) and managed to dialyse once a month depending on her circumstances. Mrs C's late husband had a second wife with two children who at the time of the interviews had no job and was fully dependent on Mrs C for survival. Mrs C had six children although two had died. She was an auxiliary nurse in one of the private medical centres in Abakaliki where she had worked for almost 30 years, helping to fund the training of one of her daughters who was a medical doctor. She currently has two of her children in University studying Law and they are still dependent on her meagre income. Mrs C reported that she had to stop her job temporarily to be able to take care of her health before she resumes. She travels very far from Abakaliki (70.1 kilometres) sometimes most times on public transport and sometimes in the family car when her son is available to take her to access dialysis care. On the day of the first interview, Mrs C reported she had had dialysis only once in the past month as she could not afford attending her routine hospital appointments. She was on hospital admission in the facility during the period of industrial action but was discharged to dialyse in a private renal dialysis facility before I met her for the first interview. Mrs C participated in the three interview sessions.

Mr D

Mr D was a 50-year-old businessman who had been dialysing for about eight months before the date of the first interviews. According to him, he had been having dialysis twice every week since April 2015 (9 months prior to first interview). He was married and had four children who currently lived with him and were undergraduates. He was diagnosed with chronic gouty arthritis over six years ago which resulted in ESKD and HD treatment. Mr D's wife was a nurse and according to him she has been very supportive helping him in maintaining his treatment and offering useful advice; he had abandoned his business in faraway Niger State in the northern part of Nigeria where he was based and returned to Enugu as there was not a single dialysis centre there. Before presentation to the facility, he had been on Uloric medication, sent to him by one of his family friends who was a physician based in the United States. However, his Uric acid level did not come down despite his adherence to his medication regimen, even when he tried a different brand of anti-gout for better results. He could not see any difference in the treatment with this and then he was referred to the UNTH where the diagnosis of ESKD was confirmed, and he was advised to

go on dialysis. He was not a known diabetic or had any history of hypertension. He was dialysing in a hospital-owned dialysis facility, which he described as a ‘death centre’ due to the inefficiency of the management. He was interviewed in all three waves of data collection.

Mr E

Mr E was a 65-year-old HD dialysis patient who had been on dialysis since March 2015 (11 months prior to first interview). He was married and had four children who still lived with him; all his children had graduated from the University but none had yet gained any meaningful employment at the time of the first interview. He was a known diabetic (Type-2) and had constantly failed to keep to his management regimen. Mr E used to be a mechanic, a job he described as extremely energy demanding which he had to quit when he was diagnosed of ESKD and instead took up a local security job, which he described as “less demanding” but with meagre pay. Mr E’s wife was a peasant farmer who supported him in the cost of his treatment. According to him, he had dialysed only once in the last month prior to the first interview. He was interviewed in the first and second interview sessions but sadly could not be interviewed in the last phase as he was reported to have died.

Mr F

Mr F was a 34-year-old graduate who had been on HD since May 2015 (8 months prior to first interview). He was the first child in a family of five. According to him, he used to smoke in the past prior to this condition but he does not drink alcohol or take any form of illicit drug. Mr F had completed his University education and was yet to secure meaningful employment, hindered by his ailing health. He had only one session of HD in the previous one month before the first interview session. His parents and five younger siblings were supporting him. Mr F was interviewed in both the first and second wave but was sadly reported to have died, when I returned for the third interview.

Mr G

Mr G was a 20-year-old student who had been on HD since February 2015 (11 months prior to first interview). He was the first child in a family of six children. Mr G had completed his secondary education but was unable at the time to continue to University because of his poor health and medical condition. He was living with his uncle who offered to assist him set up a business in South Africa where both of them (he and his uncle) were living before he was diagnosed of ESKD. Mr G was a deeply religious man (he was a Christian). He

consistently reported how the condition had affected his Christian life in the interview excerpts. He was being supported by his parents who were peasant farmers and partly by his uncle. Mr G was restless and unsettled intermittently during the second interview. His Father, who appeared deeply religious asked me if I wished his son would continue to be on dialysis; he insisted that God would heal his son and he would certainly not continue to be on dialysis, which I echoed Amen. He was interviewed twice but was sadly reported to have died when I returned to complete the third interview.

Mr H

Mr H was a 53-year-old businessman who had been on HD since March 2015 (10 months prior to first interview). He had been diagnosed with hypertension and diabetes mellitus some years ago in a hospital in Lagos and had been on the treatment since then. Mr H was married and has five children who lived with him. He had lost his sight because of poorly-managed diabetes mellitus and hypertension. According to him, he was doing very well in his business in Ikom Cross River State before the onset of this condition which had since drained his financial account. Mr H was being supported by his lovely wife who now managed the business. He was diagnosed of ESKD in late 2014. Mr H lived about 213 kilometres away from the dialysis facility and he commuted via public transport for his dialysis treatment as there was no dialysis facility close to his town. He alleged biased treatment by the dialysis nurses in the only dialysis facility (State-owned) where he used to dialyse which prompted him to register for his treatment in another State. Mr H was interviewed during all three waves of data collection.

Mr I

Mr I is an 83-year-old trader who was on dialysis for about eight months before his recruitment into this study. He was married with two wives and had sixteen children from both wives who lived with him during the period of this interview. He had been on HD for about 10 months prior to the first interview. He looked smart and very much younger than his age. He lived in a village about 30 kilometres from the dialysis facility and was normally accompanied to the facility by one of his daughters. He was initially receiving his dialysis at the Park Lane Teaching Hospital but was referred to the UNTH to continue his treatment because of certain managerial issues at the centre. Mr I had only one session of HD in the last month prior to the first interview. He was interviewed in the first interview but sadly was reported to have died by the family before the second interview.

Mr J

Mr J was 46 years old and lived with his wife and their only child in Abakaliki which is about 60 kilometres from the nearest dialysis facility. He had been on HD since June 2015 (7 months prior to first interview). Mr J had had seven sessions of HD in the last month prior to the first interview due to his recurrent high serum urea level. He was on admission in another private Hospital in Abakaliki where he was diagnosed of ESKD and then referred to UNTH because of a lack of any dialysis facility in Abakaliki. Mr J was had no history of diabetes or hypertension and no history of any other medical condition. He was diagnosed of chronic renal failure due to an unknown cause. He indicated he was good at drinking excessive amounts of alcohol when he was “still in the world” referring to when he was living a “carefree” life, but expressed deep regret over his past lifestyle as he felt his condition was a result of his abuse of alcohol.

Mr J did not look well, he appeared pale and ascitic, on the first day I met him at the facility but he insisted on being recruited to the study. He was interviewed in the first wave but unfortunately, was reported to have died before the second wave of data collection.

Mr K

Mr K was a 38-year-old carpenter, married and had two children who lived with him. He couldn't afford a session of HD in the last month prior to the first interview session. According to him, his condition started sometime in 2014 when he felt sick and had to take some self-prescribed anti-malarial medication for almost a month without any improvement before presenting to the hospital in Markurdi Benue State where he lived with his family. He was diagnosed of ESKD in November 2014 and commenced dialysis treatment in February 2015 (11 months prior to first interview).

He appeared to be unwell and in mild distress when I was interviewing him for the first time but he vehemently rebuffed my observation and insisted he was fine. His face was puffy and the legs appeared heavily swollen. I asked if he wished to stop the interview until he felt better but he insisted he was fine and wanted to continue, he would not accept he was experiencing symptoms of fluid overload. He was interviewed in the first and second waves of data collection but he was reported to have died when I returned to conduct the third interview.

Mr L

Mr L was a 50-year-old civil servant who had been undergoing HD since December 2014 (24 months prior to first interview). He lived with his wife and their only child (still in school) in Abakaliki. Mr L was diagnosed with ESKD in a Federal Teaching Hospital in Abakaliki and referred to the UNTH for HD as the Hospital did not offer dialysis services. According to him, he had had five sessions of HD one month prior to the date of the first interview.

Mr L was quite irritable at the onset of the first interview. I paused the interview to elicit what was wrong with him, to see if I could be of help in any way possible. I asked if he preferred that I stop the interview but he insisted that I continue. Despite insisting I continue with the interview, he was very reluctant to talk through his experience, he appeared to be bothered by something, but wouldn't say. I proceeded but kept the interview short as at the time it felt a difficult ethical decision. During the second and third wave interviews he appeared a lot livelier, settled and happy to discuss his experiences.

Mr M

Mr M was a 45-year-old lecturer who was diagnosed of ESKD secondary to Polycystic Kidney Disease (PKD). He was married and had two children who he lived with. Mr M had been on HD since October 2014 (15 months prior to first interview) and had about 12 dialysis sessions within a month period prior to the first interview. He lived within 20 kilometres from the dialysis facility and he has consistently accessed two dialysis sessions a week since the diagnosis.

He recalled how difficult it was for him to commence antihypertensive medications due to lack of funds as he was still undertaking a Master degree study when the diagnosis of PKD was made. According to him, he had spent almost all his life earnings on his treatment and the government didn't offer any form of assistance, despite having served the State as a Commissioner in the past. He had to sell most of his property, including houses, to pay for his treatment. At the time of the first interview, he told me he was planning to undergo a renal transplant in the UK and he had been in contact with the proposed Hospital but was finding it hard get a donor. Mr M appeared healthy in stark contrast to every other participant recruited in this study, more than likely related to the regular dialysis he received twice weekly. He was interviewed in all three waves of the study, and at the last interview he was

yet to undergo the transplant due to challenges relating to finance and identifying a suitable donor.

Mr N

Mr N was a 69-year-old petty trader who had been on HD since April 2015 (9 months prior to first interview). He was married and had ten children of which three were still in school and dependent on him. Mr N was on admission a few days prior to the first interview in a private medical centre due to the industrial action in UNTH and he was referred to dialyse in a private dialysis facility where I met him for the first interview. He lived about 15 kilometres away from the dialysis facility. According to him, he did not attend any dialysis session in the last month prior to the first interview and he recounted he had had only three sessions of HD since he was diagnosed with the condition and advised to commence treatment. He appeared well and asymptomatic despite not accessing treatment. Sadly, he was reported to have died before the second and third interviews.

Mrs O

Mrs O was a 50-year-old widow who has diagnosed of ESKD in 2015. She was on HD for 8 months prior to the first interview. She lived in her village about 80 kilometres from the nearest dialysis centre, with her four children. Mrs O was a peasant farmer who struggled with the management of her condition, because of poorly managed diabetes mellitus. According to her she had not had any dialysis in the last month prior to the first interview. She recounted using a herbal concoction to manage her condition as she could not afford the cost of dialysis care. According to her, the herbal remedy offered her some momentary respite, but her condition deteriorated after prolonged ingestion of the concoction. Mrs O believed despite her condition, she could be cured by the herbal remedy. She consistently complained how it was difficult for her to cope with the care of her children as she had no support from her family or her late husband's brothers. She managed the meagre proceeds from the sale of her agricultural produce to pay for her care and the upkeep of her children who were still dependent on her. Whilst she appeared well during the first interview, she was pale, symptomatic with her face swollen at the second interview. Sadly, she died before the third wave interview.

Mrs P

Mrs P was a 71-year-old farmer who lived with her husband and their three children in a village about 50 kilometres away from the dialysis facility. She was diagnosed with diabetes mellitus and chronic hypertension in 2014 but she dismissed it initially insisting that God would heal her. Mrs P had been on irregular HD for 13 months prior to the first interview. According to her, she never believed the diagnosis was true and so she could not adhere to the treatment regimen. Mrs P's religious beliefs were strong and whether she had dialysis or not God would heal her, as a result she saw dialysis as just something she had to do because the doctors prescribed it, she did not believe it would offer her any lasting relief. Mrs P downplayed the importance of dialysis to her health, maintaining it was time-consuming and she could not afford to be waiting so long at the hospital when she was supposed to come back home and prepare a meal for her husband and children. She reported she had not received any dialysis in the previous month prior to the first interview. Mrs P was interviewed in the first and second waves of data collection but was reported to have died before the third interview.

Mrs Q

Mrs Q was a 66-year-old retired civil servant who lived with her ailing husband and their two daughters within the suburb of Enugu, about 30 kilometres to the dialysis facility. She retired from her job about two years ago and has been accessing dialysis for only about 8 months prior to the recruitment into this study. Mrs Q had only one session of HD in the last month prior to the first interview. She recounted that despite her health condition she was always finding it difficult to seek permission from her work place and colleagues to go for dialysis, even when she had managed to raise the money. She also recounted her ordeal in caring for her husband who was chronically ill (she didn't want to disclose the ailment and her decision was respected) and looking after her own health. Mrs Q was interviewed once and she had been critically ill throughout the time frame of the study unable to be interviewed in the second and third waves of data collection.

The interviews provided some interesting ethical challenges, not least the decision to continue an interview when a person appeared unwell and irritable, suffering different ESKD symptoms not least fluid overload. When this occurred I continually reassessed the interviewee and reaffirmed consent to continue. For one interview despite consent I drew the interview to a close early as I felt the participant was not well enough at that time to

continue (Mr L). The benefit of the qualitative longitudinal approach however, enabled me to follow up any gaps in the interview process for some of those people. For others it exposed the stark reality of irregular dialysis access over time, resulting in early death for ten out of 17 participants unable to sustain participation in all three waves of the study, over a seven-month time frame.

5.3 Thematic Analysis

The overarching aim of this study was to explore the experiences of CKD patients receiving haemodialysis in healthcare systems with unequal access to treatment. Specifically, the study sought to:

- (i) Gain a deeper understanding of the meaning of living with CKD and receiving dialysis and how this influences treatment.
- (ii) Explore and describe experiences of dialysis patients in healthcare systems with unequal access to healthcare and highlight any change in the experiences or otherwise over time.
- (iii) Explore the impact of economic, social, cultural, societal and familial issues on access and sustainability of dialysis treatment
- (iv) Expose the views of the patients regarding ways to improve their access and sustainability of treatment.

Following the methods described in chapter four, four themes were identified from the data collected, each of these themes will be presented in detail alongside the extracts from the interview transcripts and the researcher's reflexive journal. The reflexive journal excerpts provide context and meaning to the data and capture thoughts, feelings, and participant behaviour real time. In keeping with the methodological and philosophical approach adopted in this study, all the extracts are taken verbatim from the recordings made during each interview session. The four themes and their respective sub-themes are as follows:

Table 7: Summary of themes

Main Theme	Sub-Themes
(1) Understanding CKD and treatment	<ul style="list-style-type: none"> • Knowledge and information gaps • Superstition and self-interpretation
(2) Meaning of living with CKD and depending on dialysis	<ul style="list-style-type: none"> • CKD and dialysis as stressors • Death • Disruptions • Losses
(3) Dialysis decision	<ul style="list-style-type: none"> • Cost as a barrier • Societal norms • Religious influences • Dialysis as secondary to other needs • Geographical issues • Dialysis services • Physical symptoms
(4) Impact of CKD and dialysis	<ul style="list-style-type: none"> • Changing body/bodily impact • Employment challenges • Finances and sources of income • Changing social relationships • Religious practices • Psychological and emotional impact

The process of developing the themes based on the interview transcripts had been discussed in the relevant section of Chapter 4 (copies shown in Appendix 11). The experiences of the participants are illustrated in Figure 5.

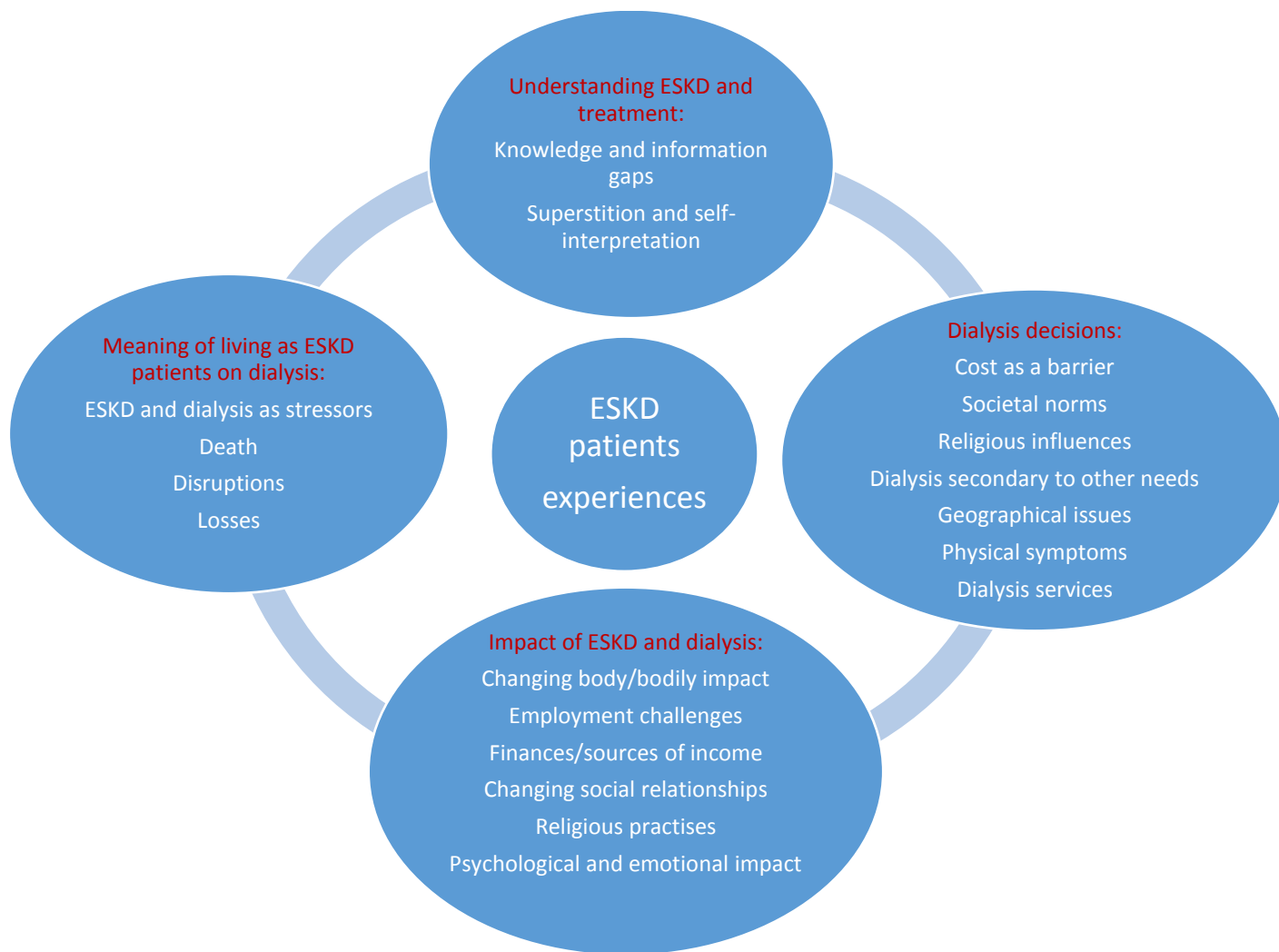


Figure 6: Thematic representation of the findings

5.3.1 Understanding ESKD and treatment

The first theme-understanding ESKD and treatment focuses on two key sub-themes: knowledge and information gaps and superstition and self-interpretation. These two themes highlight the experiences of Nigerian HD patients, exposing poor information provision, lack of knowledge and gaps in both disease and treatment education, which reinforced superstitions and caused self-interpretation which was often inaccurate.

5.3.1.1 Knowledge and information gaps

Many participants demonstrated a lack of adequate information regarding the cause, treatment and possible outcomes of their condition. This resulted for most patients in raised levels of uncertainty and the need for self-interpretation to try to make sense of their condition and HD. The uncertainty associated with this condition arose from being given contradictory information, not knowing what to eat or drink and what foods to avoid, not knowing the local sources of the foods that were recommended by the healthcare practitioners (HCPs). This uncertainty, particularly surrounding a lack of adequate information, was demonstrated by some participants during the interviews when they had to pause many times to ask me the local sources of protein which they had been advised to avoid and to ascertain the possible local sources of the foods they had been advised to eat and the amount of fluid to take each day. The responses of the participants regarding knowledge of their treatment confirmed the inadequate and inappropriate information provision to ESKD patients in the context of this study was a major issue.

For one participant, the nurses rarely have the time to give adequate information on the prescribed food and drink choices. Participants felt nurses were much more interested in the patients making the necessary payments for the dialysis than having time to give them any reasonable information regarding their treatment, when information was provided it was usually at the first session, before the commencement of dialysis:

Dr Bob wrote a list of the foods and drinks I should avoid. He said they are mostly foods containing protein. They included foods like beans, milk, and many others. For the nurses immediately, you come they find out if you have paid and have the necessary materials. So, they don't bother or have time to talk about the foods and lifestyle you should maintain especially if they had told you during the previous

dialysis sessions. It's like they only tell the patients before patients start dialysis (the first dialysis session /pre-dialysis). Well, if you ask them they can answer you. If you don't ask them, they may not have the time to tell everyone (Mr J, Int. 1).

The perception of the HCPs not giving the participants details of the prescribed food and drink choices was maintained throughout the period of the study. Although some of the participants described being given information, they insisted simply telling them to avoid foods that contain protein was not enough. They often made suggestions on the need for the HCPs to provide them with printed materials on the list of the food and drink choices as demonstrated thus:

The nurses informed me to avoid any food that contains protein. They told me that that will include beans, egg, red meat, etc. They encouraged me to eat fish, and white meat. I was told to avoid any food that contains protein as it is dangerous for my health. They also highlighted the importance of me avoiding medications that are not prescribed by the doctor and the need for me to be taking the pills the doctor prescribed for me. The nurses should do more in explaining to the patients at every session of dialysis or during any contact the foods they should be eating and those they should avoid. For instance, if you are telling me to avoid foods that contain proteins, how can I know all of them? So, I think it will be better if these things can be highlighted on leaflets and explained to us in our local dialect. It will make a lot of difference for us. Simply saying avoid any food that contains protein is not really clear especially to patients who are not educated (Mr G, Int. 1).

In India my doctor referred me to the nutritionists, again I was even given a chart of the things I should eat or avoid. I wasn't given such here but the only thing is that there is no organised way of doing this here and just may be when you ask they will tell you don't eat this, don't eat that unlike in India where there was already a plan and you are given a copy of the plan; in fact, I still have the note from my doctors in India. Down here I believe the nurses should be able to educate dialysis patients on their nutrition and lifestyle especially when they don't seem to be compliant with the dietary regimen. To tell you the truth, the nurse is the first contact (the main contact) between a patient and the hospital. So, they should be able to tell the patient the things to avoid helping the patient (Mr M, Int. 1).

The need for a continuous reinforcement of information by the HCPs reflected participants experienced throughout the study. The assumption that patients already knew what to eat or drink and what to avoid was not helpful to the participants as summarised by the comment from Mr F thus:

Apart from the initial time when I commenced dialysis, the nurses have never given me any further information on what I should eat or avoid. Maybe they assumed that I already know and didn't see any reason to waste their scarce time talking about that again with me. I would like the nurses to take time to explain to me the things I

should not eat and those that I can eat especially those that are available locally and are relatively affordable (Mr F, Int. 1).

When patients have limited understanding of health information or what the HCPs are communicating to them they feel disempowered to make rational health decisions on simple actions such as deciding what food or drinks they should take. This was expressed by one of the participants that despite being informed of the prescribed food and drink choices, she could not decide how to choose foods that do not contain protein from the local food sources available to her:

The nurses and the doctors told me the kind of food I should be eating the first day I went for dialysis. They always remind me again whenever I ask them any question regarding that and the amount of fluid I should be taking but most of the time I find it difficult to know what food contains protein especially when I eat the local food I harvested from my farm (Mrs O, Int. 1).

For some other patients, there seemed to be a discrepancy in the way the HCPs provide them with information. This depends on the healthcare setting (Private or public). The public dialysis settings were reportedly more likely to give health information to the patients than the private settings, which they accuse of being only interested in money while not paying much attention to their well-being:

I was at the Park Lane Teaching Hospital and now at the UNTH and the nurses did give such information to me; meanwhile this is not done in most private establishments (private renal facilities) as they are too busy for that and are a lot more money-conscious. The private of facilities are business-oriented and they want you to keep coming (patronising them) but when you come to the UNTH, you will be educated on your nutrition and lifestyle by the dieticians. They explain this to us each time we attend the renal clinic. It is only in private settings that they do not do this. Therefore, I would want the private renal facilities to improve on (Mrs E, Int. 1).

Another participant had an opposite experience and identified that the private dialysis facilities provided him detailed information regarding his food and drink choices as prescribed by the doctors while this was not available in the public dialysis facility. He attributed this lack of information to excessive workload of the dialysis nurses in the facility, which made it difficult for them to have adequate time for patient education:

There is no further information that I was given here. When I was admitted in the other private clinic where the diagnosis was first made the nurses explained everything to me regarding the kind of food I should be eating, types of drink and the quantity and other lifestyles I have to avoid or maintain. In fact, there are leaflets containing this information in that clinic and some were pasted on the walls of the

clinic. So here, it is only what the doctor told me that I maintain. The nurses have not been telling me anything regarding what to eat and what to avoid. I think they are too busy. You can see the number of people who are waiting here today to be put on the machine. That is how it is every time you come here (Mr N, Int. 1).

Surprisingly, some of the participants reported not being given information regarding their food and drink choices. Because of this lack of information on diet and lifestyle modifications required in this condition, Mrs C during the first interview session was more focused on adhering to the medications that were prescribed for her by the doctors. The interview highlighted that despite her daughter was a medical doctor and has been supporting her financially in her treatment cost but had not been addressing her information needs. She worried about the HCPs in the dialysis facility not giving her information even though she has been undergoing dialysis in the facility for over a year. She was overwhelmed by sense of uncertainty not knowing what the appropriate food and drink choices for her condition could be. Her voice during the conversation echoed the frustration she felt with a lack of information by the HCPs:

I have never been told or given information on the things I should avoid eating or lifestyle it was only in Abakaliki that I was educated on nutrition and lifestyle. They hardly tell me anything on all that. All I do is to keep to the medications prescribed by the doctor (Mrs C, Int. 1).

Another participant, MR I during the first interview expressed worries over the delay and lack of adequate information by the HCPs. He had consistently eaten foods that he was supposed to avoid because of lack of information regarding. Mr I demonstrated willingness and readiness to self-care if given the right information on time despite his lack of belief in dialysis as a treatment for his condition. He also suggested that the HCPs should make a list of the foods they should eat and give to the patients at every point of contact:

I strongly believe that lack of proper or adequate information regarding my diet and lifestyle is the main cause of my body always swelling and this makes me to come here for dialysis. If I am avoiding the things, I should avoid my kidneys will start getting better but I don't always know those things. For instance, it was just yesterday that I heard that people who are receiving dialysis are not supposed to eat Okro soup. Okro soup incidentally is my favourite soup and I have been having it without being told that I shouldn't eat it now. I was told that I should not eat Semolina and that's also one of my favourite foods. It was only yesterday that I started eating bitter leaf soup. So, ignorance of the specific food I should eat or avoid is a major source of worry for me. I just want to know whatever I can do in my capacity to help myself even though doing dialysis is not a solution to my problem. They should write

out the list of the foods and drinks to be taken and those to be avoided, make photocopies of it and give to the patients each time they come here for dialysis. It will go a long way in helping us (Mr I, Int. 1).

For Mr K, it was only the doctors who gave him information, the nurses did not. He rationalised the reason for this lack of information from the nurses to be either due to the amount of work they must do, since there were always too many patients waiting on the queue to be dialysed. Whereas the doctors had more time to give patients information during consultation at the renal clinic:

I was not told anything. They did not inform me about the kind of food I should be eating or those I should not eat. It was only the doctor who told me on the first day before I started dialysis. Since then, I can't recall hearing anything of such from the nurses. Maybe they are too busy or they felt the doctor must have told me and felt the doctor must have told me and so couldn't bother to talk about it (Mr K, Int. 1).

Another participant described a similar experience and expressed disgust at the way some nurses communicated with them, although he pointed out that other nurses treated them well with respect and dignity:

Erm....like I said the other time, the doctors are generally nice to me and they give me the details of my care and try to encourage me to comply with my treatment regimen. However, most of the nurses here show some signs of stress and aggression. I don't like the way they talk to the patients. To be fair to them ...erm there are some of them who are very good and they show you kindness and compassion and provide answers to your questions as a patient (Mr F, Int. 2).

*When I interviewed some of the participants during the first interview session, their responses showed that they were not given adequate information regarding their treatment, food and lifestyle while they continued dialysis treatment. I was struck that the HCPs did not continue to reinforce the health information continuously at every dialysis session. However, during the second interview session, some revealed that nurses did provide them with the necessary information although continued to point to the doctors who were more readily disposed to do this. This reinforced the importance of using a qualitative longitudinal approach in this study, it offered me an opportunity to understand the changes or otherwise which could occur in the experiences of care of the patients. **Reflexive journal field notes: January 7, 9 and 20, 2016; April 17, 2016.***

During the second interview, Mr G not only complained about the nurses not giving him enough information regarding his treatment regimen, he alleged that the nurses treated him

and other patients in the facility in a paternalistic manner as though they have no right to know anything about their treatment. He felt “ignored”, “neglected”, “not being heard” and powerless because of his health condition. There was a clear resentment of the loss of control over his life because of the condition and being on dialysis. I did not see this as the issue with him since he had been on dialysis for just fifteen months as at the time of this second interview:

Erm,the doctors are a lot better than the nurses here. I'm not saying that all the nurses here are bad, no. All I'm saying is that many of them appear too stressed up and when you ask them questions, they hardly take time to explain things to you. Maybe.....maybe...erm they are too busy because of the number of people who come here for dialysis. There are those of them who still take time to give you details of the answers to any question you ask them. What I mean is that when you ask them questions, they will claim they are busy and will not answer you. Some of them still explain to me later on anyway but I would expect them to have more time to give us more information regarding our treatment. They should treat us like people who have rights. It's not our fault that we are sick and we come here for treatment (Mr G, Int. 2).

*During this second interview with Mr G, my instinct was that the nurses were too busy with their work that they did not have enough time to provide answers to his questions. From my observation, there were too many ESKD patients on the waiting list and I could hardly find a conducive room in the facility where I could conduct the second interview due to the number of patients who were present. It was possible that he was not actually ignored as he felt but I was careful not to influence what he thought or said about his experience of care by the nurses. It may therefore well be that the nurses did not realise that he felt ignored and neglected at the postponement of when to provide him with the information he required. **Reflexive journal field notes: April 15, 18 and 24, 2016.***

Some of the participants in this study also reported conflicting health information by the HCPs. Giving of conflicting information to the participants could be because of poor knowledge of renal diets by the HCPs and in most cases, could result in uncertainties among the patients in the facility. It can also lead the patients to the consumption of foods and drinks that are not recommended for ESKD patients and deny them the opportunity to make effective diet decisions. For some of the participants like MR G, he recalled being given conflicting information regarding his diet by the HCPs, and how he had inadvertently depended on local foods, which he was supposed to avoid:

Even when they tell you to avoid taking certain fruits, usually they are not clear or specific about it; orange is a fruit, water melon is a fruit and to my mind banana is a fruit. So, there should be clearer explanations. The other day I came here I asked one of the doctors on duty and he said to me “you can eat anything”. I was not satisfied with the response and I insisted on getting clearer answers from the nurse who later told me to avoid proteins (Mr G, Int. 1).

Many participants in the study demonstrated a lack of adequate knowledge of the treatment options and outcomes of ESKD. Those who were informed of the treatment options and the importance of dialysis to their health had higher levels of education and or their partners/spouses are HCPs.

For Mr M who was a university Professor and had been on a regular dialysis three times weekly for nearly two years as at the time of this study, he acknowledged the importance of dialysis and the danger of herbal consumption for ESKD patients during the second interview:

Obviously no, because you don't know the chemical content of the herbs and you will end up further damaging the kidneys. So, it's never an option although it's the lot in the rural areas in this clime (Mr M, Int. 2).

Mr D, educated up to university level, was married to a registered nurse, and had been on regular dialysis three times weekly for eight months prior to the first interview. He had this to say regarding herbal remedy during the second interview:

Herbal remedy is not a good option for my treatment even though it's a common treatment when someone is sick in our society (Mr D, Int. 2).

During the third interview session, I wanted to find out if he had ever taken herbal remedy for the management of his condition despite his level of education. His response suggested that apart from his level of education, the wife who is a registered nurse obviously had some influence on his treatment decisions:

I have never taken herbal remedy in this condition. In fact, even if I think about it my wife will never allow that, remember she's a nurse and would never condone that. I don't think it's a better option definitely (Mr D, Int. 3).

Whilst the educational level of some of the participants and occupation of either the participants or their spouses seemingly influenced their responses to the knowledge of the

treatment of their condition, this was different for some participants. Mrs C had been an auxiliary nurse in one of the private medical centres in her town for 30 years and one of her daughters who has been supporting her in the payment of her medical treatment is a medical doctor. Arguably, she would be expected to have a good knowledge of the treatment options for her condition and to comply strictly with the prescribed treatment regimen. However, her narrative during the first interview session surprisingly suggested that she did not believe the dialysis she was receiving from the facility would make her well, but continued to access treatment to please her daughter:

I have defaulted consistently in managing my condition until about one year ago when I was placed on oral antidiabetics. I have consistently declined insulin injections when the condition became worse. Even though I am an auxiliary nurse, I didn't believe that orthodox medicine was the best means for my treatment and so, I was taking our herbal concoction all the time for my condition. I was later placed on monthly observation until when my blood sugar level dropped to a reasonably lower level. During this period, I constantly defaulted in keeping my hospital appointment until in 2014 when I had very severe headache, which led her to taking Tramadol tablet (Mrs C, Int. 1).

During the second interview session, Mrs C declined to comment on her view or use of herbal remedy for her condition and her wish was respected. However, during the third interview, she maintained that even though she was not sure of the impact of the herbal remedy on her health, she still consumed it and would never disclose that to the HCPs. She felt “isolated in her own world” from the tone of her voice and questioned why she would disclose her use herbal remedy to the HCPs. Even though she recognised that her consumption of herbal remedy was “*certainly not better than doing dialysis*” she could not give up the habit, especially if she failed to attend dialysis:

It's my use of herbal remedies...yes, I still use herbal remedies and even though I come here for dialysis, I still try to use it because of my belief that it's helping me. I try to hide this from my doctor anyway and I'm very sure you are not going to tell them. Erm... I don't know really. I don't think it is better than dialysis but it's just a cultural thing and I think it's good for my health but it's certainly not better than doing dialysis. I try to use it most of the times I fail to come here for dialysis due to certain reasons (Mrs C, Int. 3).

Similarly, another participant educated to university level and a civil servant was also adamant that the consumption of herbal remedy had no adverse impact on his health. His belief on the effectiveness of herbal remedies on his illness was based on the cultural norm

of the society and not based on any evidence. This perception of herbal remedy as a sort of “alternative” to dialysis for ESKD patients certainly influenced whether he could be bothered to attend dialysis sessions or consultations. He believed the herbal remedy offered almost the same relief as dialysis:

Herbal remedies are okay because if you think about it before the white man brought orthodox medicine to Africa, our great grandparents were using herbs for healing and it worked (Mr L, Int. 2).

During the third interview session with Mr L, I realised that his perception of herbal remedies as an “alternative solution” to his health condition was influenced by his inability to afford the cost of maintaining his dialysis. This reinforced the value of a longitudinal research approach in this study as his response during the first and second interviews did not reveal this. He was aware of the importance of attending dialysis sessions but was clearly constrained in his choice of treatment by lack of funds:

I did say that and yes to be honest with you I have been forced by the situation to take some despite the fact that you can say that I'm educated and should know that it may not be entirely good, but then what can you do when you don't have money to continue to seek orthodox treatment as you would like? (Mr L, Int. 3).

His response, like other participants in the study, showed that even though the HCPs did give information regarding his treatment, he chose to do what he liked and still wanted to “be seen” by them as adhering to his treatment plans, thus often hiding this information from the renal doctors and nurses. Perhaps reporting this information to the HCPs earlier could have helped in their management and could well have produced better clinical outcomes. He did not think about the impact of herbal consumption on his kidneys but was more concerned about “appearing to be a good patient” who complies with his treatment regimen as demonstrated by this comment:

No, no, no....you don't say that to your doctor. The doctors you know would always speak against patients taking herbal remedies, so telling them that would be wasting your time and you are making them see you as not taking any advice they give you especially regarding what you should eat and what you should avoid (Mr L, Int. 3).

Another participant provided similar comments thus:

I didn't tell them about the treatment because they are not going to support it. They like people coming here for dialysis so that they can make more money. If you tell them about another treatment, they will try to discourage you from the treatment and since I'm being better from the treatment, I don't think anyone should discourage me

from doing that. So,.....erm... that is why I don`'t want to tell them here (Mr H, Int. 3).

*I was struck by responses of some of the participants who chose to indulge in herbal consumption and had to hide the information from their HCPs practitioners. I was more surprised that they cared less about the possible implications of their actions but were more interested in maintaining the label of "good patient", so HCPs assumed they were compliant with the health information and advice provided. However, I realised that this was a major feature of lack of education. Not necessarily lack of education by the HCPs but a failure of the patients to understand the consequences of their pretences because they knew that their use of herbal remedies would not be supported by their HCPs. They saw the doctors as "Lords" and could not challenge their authority or advice because doing so would mean invoking their "anger" in their treatment. This view was maintained throughout the period of the study to the detriment of these patients. **Reflexive journal field notes: April 18 and 24, 2016; July 26, 2016.***

More concerning was his perception of the herbal remedy as still very helpful despite his acknowledgement that it is not a good option for him as an ESKD patient. To him, a good day was the day he felt relieved from the symptoms of his condition after the consumption of herbal remedy and a bad day was any day he did not feel relieved. The lack of symptom relief appeared to be a major factor influencing his choice to do whatever he can to attend dialysis despite the cost concerns:

Well sometimes, I do and at some other times, I do not. It depends on the present condition I find myself. Sometimes I take it and feel well so in that case I could say it is helpful but at some points, it is not (Mr L, Int. 3).

Some other participants held similar views on the effectiveness of herbal remedy thus:

Sometimes I tend to feel so but I think the dialysis is still very good but may be combining the two is better than just the dialysis. You see when I was going on only the machine I wasn`'t feeling this better and I was always tired but I think I have improved greatly since I started the combination of the treatment (Mr H, Int. 3).

Erm,well...I do believe that herbal remedy is an alternative to dialysis treatment for poor people like us who cannot afford the high cost of dialysis in this part of the world (Mr E, Int. 2).

Mrs O also revealed that her perception of the herbal remedy as helpful sometimes makes her to forgo attending dialysis:

I would say yes because erm.....sometimes instead of coming for dialysis I would resort to using herbal remedies. You know it`s part of our culture for a very long time now. So,there are times that I would feel like not going for dialysis but choose to use local herbs since they are also good for my health even though the doctors said it`s not good (Mrs O, Int. 2).

Overall, the major factor, which influenced the participants in this study to resort to herbal consumption, was economic. A lack of adequate funds to sustain their dialysis treatment prompted them to imbibe the age-long African culture of treating illnesses with herbs without any knowledge of the possible consequences on their health. This will be analysed in details under the next theme. The following comments support how money influenced some of the participants to use herbal remedies:

I have been using herbal remedies in managing my condition as I don`t have money (Mrs O, Int. 1).

I know that dialysis is very good because any time I go there for dialysis.....I feel a lot better and stronger and I can breathe well, but.....in the absence of money I had to seek alternative (Mr E, Int. 2).

I am considering going for an alternative medicine, as I can no longer cope with the cost of this dialysis. There is a place I was told that they can cure this condition without dialysis or the so-called transplant. It`s lack of money to cope with this dialysis thing that is driving me back to alternative medicine again. I strongly believe that I will be healed, and my kidneys will be okay when I start that (Mr H, Int. 2).

*As I listened to the participants during the interviews, I began to imagine the impact of lack of money to sustain treatment on patients in healthcare systems with unequal access to healthcare. I initially felt that their perception of herbal remedies as effective in their health condition was based on ignorance and lack of information but I later realised their inability to sustain the cost of dialysis was actually the major factor which influenced their use of the herbs. The issue of herbal consumption was general practice among the people especially when they could not afford the cost of seeking medical care and so, it was not a practice just isolated to ESKD patients as seen in this study. **Reflexive journal field notes: January 8, 2016; April 16, 2016; July 25, 2016.***

Another participant resorted to the use of herbal remedy because of long waiting periods at the dialysis facility:

Well, erm...erm.... the thing is that I was taking local medicine; you know what I mean? I was taking our local herbal concoction. When I started taking the concoction, I was feeling quite better but after some time, I discovered that my health started going worse. Also, most times when you come here, you have to wait for so

long to be attended to and the appointments they were giving me was too lengthy. So, so, that was why it was like I stopped using the medications and the management the way the doctor said to me (Mr E, Int. 1).

Most of the participants seemed to lack adequate knowledge of the fact that ESKD was a long-term condition. This lack of adequate information appeared to have stemmed from the period of diagnosis and commencement of dialysis wherein it seemed they did not make an informed decision on what option would be better for them. Information of a realistic prognosis, particularly the implications of irregular dialysis, on symptoms and well-being were lacking which disabled people from making an informed decision. Even with this information, finances (or lack of) and a belief they would be healed (discussed in later themes) were influential in how people managed their illness. This is demonstrated by this example:

Erm.....generally I don`'t know how long this condition will last. I don`'t know when I will be healed but then I trust in God for my healing (Mrs P, Int. 2).

5.3.1.2 Superstition and self-interpretation

From the interpretation of the interview transcripts, there was a general superstition expressed regarding the causes of ESKD by some of the participants as they attempted to understand how their illness originated. Some attributed the cause to some unknown “supernatural forces” which they believed had inflicted the condition on them because of some sort of “human invocation” to deal with them. There was a general notion that “people do not suffer any major illness by chance” in the study. They saw the biomedical causes of ESKD as secondary and believed that any health condition that defies orthodox treatment was underpinned by supernatural forces directed by wizards, witchcrafts, angered ancestors and evil spirits. This belief was a major feature of misinformation and impacted on how the participants perceived attending dialysis sessions.

For some participants, the cause of their health condition was attributed to supernatural or spiritual attack by their “enemies” or those who do not wish them well represented by this example:

When I woke up from the sleep, I started having pain in my neck and this has lasted for almost 2 months now. I therefore rushed to my doctor and complained about it and he downplayed it while I also called my brother (the medical doctor based in the US) to tell him that “they have come for my neck o”. I was having the impression

that my enemies in the village were using diabolical means to attack my health but he (the doctor) told me that it's not a serious issue (Mr D, Int. 1).

Another participant related the cause to poisoning:

Although the doctors made the diagnosis, I have a strong feeling I was poisoned. I believe I was "poisoned" through diabolical means and I have removed the poison from my body through unorthodox means. The poisoning is the cause of my condition (Mr H, Int. 1).

When I tried to find out the details of how he supposedly "removed" the "poison" from his body, he declined further comments and requested that we move on with other questions on the interview guide. However, he maintained the view that he was poisoned by his detractors to destabilise his business within subsequent interview sessions:

I still have the feeling that.....that I was poisoned and that is the cause of this condition. Look.....the target is just my business and my family. My enemies are after me but ...they will all fail in in Jesus name, Amen (Mr H, Int. 2).

I still believe so that my condition was caused by poisoning by the people in my village, but I will be over it in Jesus name (Mr H, Int. 3).

His embedded and real belief that his enemies were after his business and that he would do everything within his capacity to defeat them clouded his understanding of the disease progression and treatment; even with the finances his decision making was underpinned and influenced by a misconception.

During the second interview session, he was considering going for what he described as an "alternative or complementary treatment" which involved the use of fruits and some herbs in managing his condition. I could not understand why he wanted to go for the "alternative treatment" as he could still afford the cost of dialysis; the cost of this "treatment" could offer him at least six months of regular dialysis. I had an informal conversation with him to elicit the details of why he was having such thought. He disclosed to me that he did not feel reassured that dialysis alone would offer him any solution to his health problem. So, he felt that a combination of dialysis and the "alternative treatment" would offer him the "cure" he longed for. I was in a dilemma regarding what to do as I did not feel comfortable with his plans, knowing the implication that would have on his already diseased kidneys. I thought of informing the renal doctors and the nurses to explain the implications of him doing that and possibly that could dissuade him from proceeding on his plan. However, I had to keep to the information he disclosed to me confidential. Therefore, I counselled him on the implication of the planned treatment on his kidneys and I sought to know if there was any way I could help to ensure he maintained his regular dialysis. I also suggested the option of renal transplant to him, but he declined consistently. When I met him during the third interview

session, he stated that he was getting well based on the result of his clinical tests. On observation, he seemed better than he was when I interviewed him during the previous sessions. Sadly, he passed away a few months after the completion of the data collection. Reflexive journal field notes: January 22, 2016; April 14 and 20, 2016; August 2, 2016.

For Mrs O, a 50-year old widow who was diagnosed of ESKD secondary to poorly-managed type-1 diabetes mellitus, she demonstrated lack of knowledge of the cause of her condition. According to her, her brothers-in-law accused her of killing her husband and attributed the cause of her health condition to the “wrath of the gods” on her for the alleged killing as she expressed in this statement:

They claimed that I'm suffering from this condition because I killed my husband. They, they said that this condition is a consequence of the wrath of the gods against me for allegedly killing my husband. I don't know why anyone would ever think that I killed my husband. They even went as far as asking me to drink the water they used in washing my late husband's body before his burial. It's, it's very devastating for me I wish he was alive to support me in this difficult period of my illness (Mrs O, Int. 1).

The interpretation of the cause of her health condition because of the “wrath of the gods” affected her ability to receive any form of support from her late husband's family. She was left alone to “suffer” what they felt was the consequence of “her action”. She felt alone in her life, living with ESKD and depending on dialysis without any support from her close family members:

I have nobody supporting me and my children. My husband has died and his brothers don't come close to me and my children as they are insisting that I killed him and that is why I'm suffering from this condition. I didn't kill my husband and why would I do that? (Mrs O, Int. 2).

As I interviewed Mrs O during the first and second interviews, I felt very emotional, sad and wished I could do something to change her situation. I felt sad for her as a woman who was a victim of an outdated culture of her people whereby if a woman is suspected of killing her husband, she is given the bath water from the corpse of the late husband to drink to prove her innocence. She did not use the word “loneliness” during the interviews with her but the tone of her voice and my observation suggested so. I asked her if she felt loneliness as an ESKD patient who is on dialysis without any support but accusation by those who should have supported her in her condition. She confirmed she felt so. Reflexive journal field notes: January 22, 2016; April 17, 2016.

There were also self-interpretations of the causes of ESKD and “who should suffer from the condition.” Some of the participants expressed a clear lack of knowledge of the cause of

ESKD. For Mr F, he expressed regret for his past lifestyle which he described as full of “booze” and “smoking”. He attributed his past which he described as “reckless” to his present condition. Although, he was unsure of what was the cause for his condition:

I have never taken any illicit drug or indulged in alcohol consumption; yes, I used to smoke cigarette occasionally and that was a long time ago. So, I keep wondering and asking myself everyday what could possibly have caused this? I regret ever smoking in my life, but the doctor said the cause is queried. So, it means smoking cigarette couldn't possibly have been the cause (Mr F, Int. 1).

Others believed that ESKD was not supposed to affect them because of their poor social status. For them, ESKD is a disease condition of the rich and those who can afford the cost of treatment:

This condition is not supposed to affect a poor person like me who doesn't have the means to treat myself (Mrs O, Int. 2).

This condition is not supposed to affect a commoner like me (Mrs P, Int. 2).

Mrs O had no idea of the cause of her condition even though she was told by the doctor that it was possibly due to her poorly-managed type-1 diabetes mellitus. She felt “torn” and confused even though she believed the doctor. It was evident that her life world was dominated by not just her living with ESKD and going through the burden of her treatment alone but living with the attribution of her condition to her husband's death. She had to ask me I knew the cause of her condition:

I want to ask what really caused my condition. Do you know?.....even the doctors could not tell me the cause of my condition and they only said the cause is queried (Mrs O, Int. 2).

She paused severally during the interviews to ask me if I believed her story that she was not responsible for the death of her husband.

Superstition and self-interpretation were also reported in this study in relation to kidney donation. ESKD patients who can afford the cost of renal transplantation faced the great challenge of finding the suitable kidneys due to grievous superstitious beliefs held by suitable potential donors. In addition to facing the challenge of paying for the huge cost of renal transplantation, this issue of finding suitable donors who were willing to donate was “burdensome” for participants. There were expressions of superstition among potential donors as they held the views that donating one of their kidneys would result in the shortening of their lifespan. Others reportedly expressed that donating their kidneys to

someone else would mean “not being whole” when they die as they would have lost a vital component of their bodies. These expressions were not related to any religion or faith but were based on issues surrounding death and dying. The following excerpts were from one of the participants who described his experiences of living with ESKD and waiting for a suitable kidney donor:

Erm... the people are generally afraid of dying after the donation. They usually think that when you donate an organ like the kidney, then your lifespan will be shortened. Some others also expressed the fear that when they donate an organ like the kidney to a recipient, then a certain vital part of their whole being is lost and when they die, they may not have their whole remains interred (Mr M, Int. 2).

Mr M described the anxiety and uncertainty he faced while waiting to find a suitable donor. Although he could afford the cost of regular dialysis three times every week, his experience of living with ESKD and being on dialysis without being able to proceed on the planned renal transplantation made him feel powerless and uncertain about his future and possible outcomes of living with ESKD. This feeling of powerlessness arose from the not being able to influence his close family members who were suitable potential donors but refused to donate to him for various reasons which he saw as based on no evidence. He made the following comments during the third interview with him:

Waiting to find the right donor has been like hell for me. It has been full of uncertainties and anxiety as I don't know when and how to go about it anymore. I just wish there's anything else I can do but erm.....I don't know and I'm confused (Mr M, Int. 3).

Curiously, the superstitious beliefs reported by some of the participants as expressed by potential donors, was also expressed by one of the female participants in this study as illustrated by this comment:

Such a practice has its consequences and can lead to the death of the person to whom the body part was given. So, even if I have the money for that I wouldn't even contemplate going for it (Mrs O, Int. 2).

5.3.1.3 Summary of key findings: Understanding ESKD and treatment

- Lack of adequate information was common among the participants in the study.
- Poor health literacy, superstition and faith hindered the understanding of information even when it was provided.
- Excessive workload and poor attitude towards patients were the common reasons attributed to the lack of information by the participants.
- The information provided by the HCPs on patients` diet, lifestyle modifications and treatment regimen were inadequate and often contradictory which created a sense of dilemma and uncertainty for the patients.
- Lack of adequate knowledge of the treatment options and the outcomes of ESKD was common among the participants.
- Participants believed that herbal remedies could help them, some to relieve symptoms others as cheaper alternative treatment to dialysis (which they couldn't not afford).
- Participants purposely failed to disclose the use of herbal remedies to HCPs to be 'a good patient'.
- Whilst higher education levels (and relatives with health care training) for some provided increased knowledge of treatment options and the importance of dialysis the misunderstanding of this knowledge for some translated into poor management of their disease and access to treatment
- There were expressions of superstitious beliefs regarding the causes of ESKD, such as being poisoned, an attack by their enemies, and the wrath of the Gods.
- Some believed no matter what treatment their faith in God would heal them.
- Finances influenced access to treatment even though some understood they needed to access dialysis three times a week, it was financially impossible.
- Long waits at the dialysis facility put some people off attending for dialysis.

The next theme highlights the meanings the participants ascribed to their health condition and being on dialysis and how this impacted their treatment.

5.3.2 Meaning of living as ESKD patients on dialysis

The second largest theme resulting from the data was the meaning given to the condition participants were suffering from, their treatment and how this influenced their health care decisions. The sub-themes were inextricably linked and dominated by a sense of anxiety, guilt and the unknown. This theme is very crucial in understanding why dialysis patients in this healthcare setting do not follow through their dialysis regimen and in helping the healthcare practitioners modify the information they give to the patients regarding their diagnosis, treatment options and the prognosis of their condition.

The meanings given to living with ESKD and being on dialysis by the participants were largely based on their individual experiences of living with the condition, feeling of abandonment due to lack of adequate support systems to ensure sustainability of treatment, the uncertainty of the possible prognosis and the impact of the condition on every aspect of their lives as corroborated by the following sub-themes:

- ESKD and dialysis as stressors
- Death
- Disruptions
- Losses

5.3.2.1 ESKD and dialysis as stressors

Living with ESKD and being dependent on HD was seen by most of the participants as a stressor on their individual lives in terms of time spent on dialysis, financial strain on their lives and their respective families and restrictions on their social lives. The construction of living with ESKD and depending on HD as stressors in terms of the time spent waiting on the queue for dialysis in the facility was ambivalent in the study. While most participants viewed waiting in the queue as time-consuming and tiresome, they still believed that it's the

only option of treatment available to them, which they could not do without. This perception of ESKD and dialysis did not seem to deter them from attending dialysis whenever they had the means to. They felt that it was a big challenge to their lives but would do anything possible to “fight” to live.

The first excerpt is from Mr H who was in addition to living with ESKD and being on dialysis was suffering from poorly-managed diabetes mellitus which had dominated his life and “taken” him away from his once “lucrative” business which he loved doing. His depiction of living with his condition and being on dialysis as stressors was related to the abandonment of his business and having to focus on his treatment:

Going on dialysis for me means abandoning everything I have laboured for and focusing on taking care of my health, attending dialysis three times per week according to the doctor and giving up my financial role towards my family as I will not be able to concentrate on doing my business as before (Mr H, Int. 1).

Others related it to the impact on their career/job and their family as illustrated by this example:

Living with this condition means a stop to my usual way of life of going to the farm regularly and taking care of my children as I have nobody else to do this for me (Mrs O, Int.1).

During the first interview session with Mr M, not only did he describe what living with ESKD and depending on dialysis means for him in terms of his job and family, he also described it in terms of the strain on his finances and cost of treatment thus:

When you talk about the meaning of this condition, to me, it is....it is.... terrible! It is a big strain on my life, my finances, my family and my job. So, that`s the problem and I`m still borrowing to complete the cost of my care and also my family is there to be taken care of (Mr M, Int. 1).

For MR L, the construction of living with ESKD and depending on dialysis was related to the length of time it takes him to travel from where he lives in Abakaliki to the dialysis facility located in a different State, waiting in the long queue and not being certain of getting dialysed same day.

Dialysis is a big stressor. I called it a stressor because of the amount of time it takes me to travel to Enugu for my dialysis, as I told you earlier on that I live and work in Abakaliki and you can imagine what it means for me to travel from such a very far

distance to this place for dialysis and then I must wait for a very long time because of the large number of people who are waiting to be dialysed in this facility (Mr L, Int. 1).

While many of the participants described living with the condition and depending on dialysis explicitly as a stressor, Mrs C during the second interview session metaphorically likened it to “being perpetually confined to hell. This description was related to her life world of living with the physical symptoms of ESKD and the frustration of “knowing what to do” but not having the means to embark on this which in this situation was her inability to afford the cost of sustaining her dialysis:

I describe every day as a living hell because I have not been feeling well, I cannot say that I'm feeling better or well at all and the symptoms keep increasing every day. It's true that I have been able to manage to have dialysis once every month since then but if I had the means-that is money, I would have been attending four times every month since then and.....and.....you know that I would be feeling much better than I am now. So, when you know how to make yourself feel better, but you don't have the money to achieve that then it is very frustrating and then that is the living in hell and then I'm dying gradually each day without any help (Mrs C, Int. 2).

*During the second interview session with Mrs C, she appeared pale and distressed. I tried to elicit if she had any issues troubling her, but she insisted that all was well with her. I also offered to stop the interview, but she persisted that she was fine. I was struck by her appearance as she recounted how lack of money to sustain her dialysis made her feel like living in perpetual hell. In my observation, she felt powerless as she could not afford the cost of regular treatment. Her situation made me to understand and appreciate the experience of many other dialysis patients in the facility who couldn't even pay for a session of HD in a month. **Reflexive journal field notes: January 18, 2016; April 20, 2016; July 27, 2016.***

The participants` construction of living with ESKD and depending on dialysis as stressors did not affect or influence their attitude towards going for dialysis.

5.3.2.2 Death

Not being able to pay for the cost of dialysis or sustain the HD treatment was also linked to the meaning some of the participants ascribed to living with ESKD and depending on dialysis. The initial diagnosis of CKD was always greeted by shock, denial and subsequent acceptance of the situation and having to depend on dialysis as expressed by most of the

participants. Living with the condition and not being able to access or continue with the prescribed treatment constructed as a “death sentence” by some participants.

For some participants, not being able to afford the cost of dialysis and sustaining treatment means living with the symptoms and possibly death. Some examples of the excerpts depicting this are:

Things are really getting worse for me. Maybe by the next time you come here I would have been dead as my family have sold all they have to support me in this condition all to no avail. If I don't have the money to come here and go on the machine, it would mean that I will live with this condition and the symptoms and then die of it (Mrs A, Int. 3).

Living with this condition to me is a death sentence of which I cannot be free until the day I die. Since I graduated from the University, I have not been able to gain any meaningful employment to be able to support my mother and my other siblings only to be told that I'm suffering from kidney failure. So, living with this condition and not having the money to go for treatment means that I'm already dead (Mr F, Int. 1).

For Mrs A, living without the chance of bearing children was related to her description of living with ESKD and being on dialysis as a death sentence. She was visibly sad while she narrated how she had series of spontaneous abortions which were poorly-managed by the doctors in a private clinic. She recounted how her life had been dominated by her “horrible” experience of the health condition and dialysis issues and the sadness of not having any child due to the condition and her treatment:

Living with this condition is death for me. It's like.....umm, umm... How could I lose my health and my future through pregnancy? Children mean a lot to me and all my effort to have one has resulted in having to live with this condition. For me, living with this condition and not having any child and no hope of ever having any means this life is not worth living and I'm as good as dead (Mr A, Int. 1).

Although she perceived living with ESKD as death, she showed resilience and the willingness to live and never to give in to her condition. The choice of the word “death” by the participants to describe the experience of living with ESKD and being on dialysis reflects the severity of the condition to them.

5.3.2.3 Disruptions

Participants described living with the condition and being on dialysis as a huge disruption in their lives. Some who described living with ESKD and being on dialysis as a disruption in their lives felt their condition was temporary and with time they will be fine. Whilst they demonstrated resilience, optimism and courage in the face of adversity and suffering, those who thought it was temporary were unperturbed as they misunderstood the fact that ESKD was a long-term condition. This further highlights the knowledge gap in the understanding of ESKD and treatment.

For a male young participant aged 38 years who had been on dialysis about a year before the first interview, being on dialysis for him meant “suffering”, a sudden change in his life ambitions and “loss of hope”. He described how his condition had affected his job, family and his sources of finance:

To me living with this condition is a setback in my life. I am only 38-year-old with two kids who mean so much to me. You can imagine living with this condition at this age when I'm supposed to be strong and work hard to look after my family. This is the stage of my life when I'm supposed to work extremely hard to train my children to the level of education I want them to attain as I had no such opportunity in my life but, but, erm, erm.... this condition is trying to cut short my dream. So, to me life as a dialysis patient is a life of suffering, end of my dream and hopelessness as I don't know if I would be alive to fulfil my life dreams (Mr K, Int. 1).

Other participants expressed with similar thoughts:

Living with kidney failure to me means living with an enemy which tends to stop every dream you have in life. It means an abrupt disruption of my life plans andIt's awful and it's going to end all my life plans and ambitions (Mr B, Int. 2).

Erm...living with CKD means a disruption in my life. Look at me now, at my age I'm supposed to be enjoying my retirement with my grandchildren but I have been on medications and requiring dialysis every week (Mrs Q, Int. 1).

Mr K was in mild discomfort during the first interview session, but he vehemently rebuffed my observation and my suggestion to stop and allow him to get some rest. His face was puffy, and the legs appeared heavily swollen. He could not accept that his legs were swollen. I was caught in the dilemma regarding what to do as he consistently insisted that he was fine, but my observation was that he was very symptomatic and at times a little confused. I persuaded him, and he finally accepted, to have the interview rescheduled to a later date, although this did not take place as he was unwell. Initially I did not really understand why he wanted to carry on

with the interview even when it was obvious that he was labouring to make coherent speeches. However, I concluded that even though his physical body was weak, he was determined to get the story of his experience of living with the condition out there. He wanted to talk to me about what life, the missed opportunities and how he had lots to offer as a young man, which was cut short because he couldn't access regular dialysis. With equitable treatment this young man could have continued to make a valuable contribution to the community and local economy. Reflexive journal field notes: January 10, 2016; April 20, 2016.

5.3.2.4 Losses

The representation of living with ESKD and depending on dialysis as a “loss” by some participants related to the impact of the condition on their body image, finances or sources of income, privacy and inter-personal relationships. The functional and physical effect of ESKD and dialysis sometimes caused participants to worry how their bodies had “failed them”, and although the loss of independence was difficult to accept, they showed resilience and the eagerness to return to their “normal” way of life. This made them feel powerless and “useless” but they were prepared to overcome it and carry out their daily activities unaided.

Mr I expressed his loss of his social life and the desire to regain his “previous self”, this loss of independence meant his role had changed:

Erm, when you talk of the meaning of this condition, I can't do most of the things I used to do in the past. It's true that I'm no longer working due to my age but I miss most of the things I used to do such as drinking wine, going out with my friends and doing things for myself instead of being dependent on others (Mr 1, Int. 1).

Loss was also related to the feeling of “isolation”, “loneliness” and “abandonment” the participants experienced in their life world as ESKD patients in a healthcare system with unequal access to treatment. The participants expressed being “let down” and “deserted” by their friends who they had always been in regular social contact with but were left to deal with their health condition alone. The following excerpt represent how participants described their loss of social relationships:

And.....and.... you can see why I said that living with this condition is hell as nobody else can help you and you are basically on your own. You are deserted by your friends, relations and those you have always enjoyed their companies. So, you are practically left alone in the cold (Mrs A, Int. 2).

Participants also described living with ESKD and being on dialysis as a loss in relation to the impact on their sources of income or finances. They expressed how being on dialysis had rendered them “dependent” on family members and friends. For one male participant, it made him feel “sad” and “redundant” as he felt a sense of “loss of control” over issues in his family as most of his financial responsibilities had been shifted to the wife. Another man Mr H expressed similar thoughts:

As a man, I would prefer being able to pay for my treatment and supporting my family and doing many things for myself as against my current situation where I must practically depend on my family for everything even though I dialyse at least twice every week. It makes me feel like a burden to my fellow man. I feel like I’m tied to someone and quite inseparable and have lost my financial freedom (Mrs D, Int. 3).

It has been like hell because things have been very terrible for me. It has been very tough coping with the stress occasioned by this condition. I have lost my independence and financial freedom in life and now I must depend on the efforts made by my wife in dealing with this situation and I have no other support (Mr H, Int. 3).

*I was quite emotional listening during these interviews and while I listened to the recordings. I could recall Mr D weeping as he expressed his sadness and perceived lack of control over his condition and the impact it had on him. I fought hard to hold back my tears. Culturally, it takes extreme emotions for an Igbo man of his age to shed tears. So, coming from the same ethnic origin with Mr D gave me an insight into the level of worry and anxiety that pervaded him. **Reflexive journals field notes: January 20, 2016; April 18, 2016; August 1, 2016.***

5.3.2.5 Summary of key findings: Meaning of living as ESKD patients

- The meanings given to living with ESKD and being on dialysis were largely based on individual experiences of living with the condition, feelings of abandonment due inadequate support systems to ensure sustainability of treatment, the uncertainty of the possible prognosis and the impact of the condition on every aspect of their lives.
- Unequal access to healthcare services were described by the participants as stressors, death, disruptions and losses on their lives.
- The construction of living with ESKD and being on dialysis as a stressor by the participants was related to the time spent on dialysis, the financial strain on their lives and their families, and the restrictions on their social lives.
- Participants described living with the condition and being on dialysis as a huge disruption in their lives in terms of daily life structures and future ambitions.
- The representation of living with ESKD and depending on dialysis as a loss was related to the impact of the condition on their body image, finances or sources of income, privacy and inter-personal relationships.
- Although there was general feeling of uncertainty among the participants, they demonstrated resilience, optimism and courage in the face of adversity and suffering.
- The notion that the condition was temporary signalled a misunderstanding of the meaning of a long-term condition.

5.4 Summary of the chapter

This chapter brought together the key findings from the two largest themes of the study although there was considerable overlap within the themes (certainly financial issues) to be discussed in the next chapter. There was a considerable lack of information provided by HCPs which resulted in misunderstandings and deficits in knowledge. This lack of knowledge then impacted directly on the individual being able to make informed decisions. There was evidence of actions of missing dialysis, taking herbal remedies and making decisions whether to wait a long time and pay for treatment, where decisions were being made daily, some informed by experience of feeling better some because finances were

strained. The evidence does suggest that decisions to continue treatment, even irregular one off spurious sessions once a month, spending all the money they had saved (and their families) were not fully informed. No individual mentioned the option of conservative management, whether this had been discussed or that they had been told if they didn't keep up regular treatment they would certainly die. A finding supported by the ever-reducing sample during the interview waves. Indeed, some people perceived ESKD to be temporary and curable by herbal remedies and their faith, sadly these people died.

The collation of Nigerian peoples lived experiences is powerful and enlightening uncovering the real issues people face and their resilience, but also highlighting the stark reality of mortality in this under resourced and poor country, where people who made a valuable contribution to the society are left to die from ill-health unless they are wealthy culminating in a: "No money, No treatment" culture.

The next chapter will focus on the impact of CKD and dialysis, and the challenges of accessing treatment. It will highlight issues that affect the ability of dialysis patients in low-resource settings to access regular treatment.

Chapter 6: Dialysis decision and Impact of ESKD and Treatment

6.1 Introduction

The previous chapter presented two themes- understanding CKD and its treatment and the meaning of illness in CKD. It exposed the knowledge gaps among the participants and the need for provision of adequate information by the HCPs. This lack of knowledge impacted greatly on the individuals being able to make informed decisions regarding their treatment choices. The current chapter will focus on the impact of CKD and dialysis, and the challenges of accessing treatment. It will highlight issues that affect the ability of dialysis patients in low-resource settings as found in this study to access regular treatment.

6.2 Dialysis decision

Making the decision to attend dialysis sessions was one of the prominent themes found in this study. It is a very important theme as one of the objectives of this study is to understand why most of the HD patients in the Nigeria do not sustain their dialysis treatment and there is no means of accounting for the reasons. Generally, the participants demonstrated the willingness and readiness to attend regular HD sessions as recommended by the HCPs. However, several factors enabled or impaired this important decision. The theme has the following sub-themes:

- Cost as a barrier
- Societal norms
- Religious influences
- Dialysis as secondary to other needs
- Geographical issues
- Dialysis services
- Physical symptoms

Based on the experiences of the participants, the only similarity existing among the sub-themes is that most of them affected adversely the decisions of the participants to attend regular dialysis sessions.

6.2.1 Cost as a barrier

Almost all the participants expressed cost as the major barrier to their accessing regular dialysis. Participants expressed several instances where, they were willing to attend dialysis sessions but were constrained by lack of money. All the participants paid for the cost of accessing their ESKD treatments out-of-pocket. Only one of the participants reported that the full cost of his treatment was borne by a close relative. Participants described how they felt “left out”, “abandoned” and “excluded” from the “normal” people in the society. The inability to afford the cost of dialysis treatment often led participants to resort to the use of herbal remedies which some of them perceived as an “alternative” to dialysis. Generally, participants perceived the cost of dialysis as excessively high but were determined to access it whenever they can afford the cost. Some participants associated the cost of treatment with the cause of ESKD and sometimes questioned why they should suffer from the condition. They perceived ESKD as a disease condition which should affect “only the rich” and never the “poor” or the “less privileged” in the society who can hardly afford the cost of regular treatment. Although this can be perceived as a major feature of lack of information, it may not necessarily be but could be their construction of ESKD as a disease condition. The cost of treatment for most of the participants includes not just the money they have to pay for each dialysis session, it includes costs of laboratory and radiological investigations, consultation fees for every session of HD, the cost of hospitalisation if they need to be admitted after dialysis (in some cases), cost of feeding, and cost of medications. These costs vary among facilities, with the cost being more expensive in private facilities as expected than in public facilities. This situation is far worse for HD patients residing in rural areas who must go through the horrible experience of travelling to the city via unsafe and irregular public transport system to get to the dialysis facility. Similarly, those who are resident in other States where there are no dialysis facilities had to commute via private or public transport systems to the facility and this adds to their total cost of dialysis treatment.

Participants who lived in distant States or in the rural areas also highlighted the challenges they faced in accessing dialysis as the cost of transportation sometimes delved into the money they had for dialysis thus:

The cost of travelling to the hospital is too much and it adds to the total cost of my dialysis any time I'm coming here. So...so...you can imagine what that means (Mr G, Int. 2).

For instance, we spend about #15,000 on transportation to come for a session on dialysis. We come all the way from Ikom in Cross River State and you can imagine the risks involved (Mr H, Int. 1).

Throughout the period of the study, it was evident that the major barrier to accessing and sustaining dialysis among most of the participants is affordability of the cost of dialysis.

This was illustrated by the following comments:

I have not been able to go for dialysis, as I would love due to different reasons mainly due to lack of money and the distance issue. It has made me feel much worse throughout this period but I hope that I will be able to get money soon and go (Mrs C, Int. 2).

The cost of the treatment like I have said before clearly discourages me from coming here and so it is to many other dialysis patients who come here for treatment. It is excessively high and frankly unaffordable for common people like me (Mrs A, Int. 3).

Overall, although the cost of treatment was a major barrier to sustaining dialysis among the participants, they demonstrated “hope” to live. This therefore affected their ability to sustain treatment. While the cost of treatment was not a major barrier to those who can afford the cost of treatment, it was evidently an obstacle for the less privileged and this further highlights the experience of dialysis patients within the healthcare system.

*The impact of the cost of dialysis on the patients in this facility was horrendous as presentation to the dialysis facility without the requisite amount to pay before being dialysed amounted to death. On some occasions during the interview sessions, I witnessed the death of some patients whose conditions were critical at the point of presentation but could not pay for the cost of treatment on time. The situation was worse for patients whose families could not afford initial financial deposits to the hospital. The sight of patients passing away while their family members rallied round to sort out financial issues regarding their treatment was a “normal” occurrence in the facility. Patients who had the means to pay for their treatment did not have to go through the hassles but always attended their dialysis sessions on schedule. These experiences provided more insight into my understanding of the experiences of dialysis patients in Nigeria and in deed the general healthcare system of the country where its “money first before service” irrespective of patients` health condition. **Reflexive journal field notes: January 15, 2016; April 18 and 24, 2016; July 26, 2016.***

6.2.2 Societal norms /cultural beliefs

The cultural inclinations of the participants were a dominant issue in this study which affected dialysis decisions. Cultural issues played a major role in the compliance of some participants with attending dialysis sessions, treatment regimen and health check-ups. The cultural norms of the society observed among the participants relate to the use of herbal remedies for treatment, attitude towards seeking healthcare services, and cultural expectations of the people.

The use of herbal remedies as described by some of the participants was due to their cultural beliefs that herbal consumption is an effective treatment in any illness. The following comments illustrate how some of the participants described the impact of culture on their decision to use herbal remedies for their illness:

You know that we like using our local herbs to treat any health condition that we have here, and it has always worked for us. Even as I`m taking the medicines given to me by the doctors, sometimes I still complement it with the local herbs especially when I don`t have money to go for dialysis (Mr K, Int. 2).

My son, you cannot take away the drinking of local herbs away from our people. It is part of our lives and even religious belief doesn`t affect that. I don`t want to tell him because he would try to discourage me from doing that. He treats me well I don`t want to be seen as disobeying himso the best thing for me is to not tell him about it (Mrs P, Int. 2).

Although some of the participants used herbal remedies, they often hid this behaviour from the HCPs who they perceived would discourage them from such behaviour:

It's private although I will tell you the truth, yes, I do take herbal remedies sometimes although I don't tell my doctor anyway because they will always try to discourage you from doing it (Mr L, Int. 2).

Erm,normally I don't tell the doctor that I still use the herbal remedy. Yes, I still use the herbal remedy sometimes....not as much as I used to drink it before (Mrs P, Int. 2).

Some others attributed the use of herbal remedies as a treatment for ESKD to their inability to afford the “high cost” of dialysis (as discussed under the cost sub-theme). The cultural inclination of herbal consumption affected negatively the decision to attend dialysis treatment by these participants. The cultural expectations of the society also had influence on the participants` dialysis decisions. The dominant cultural expectations of the society which had serious impact on the treatment decisions of the participants included looking after one`s siblings, the first wife in a polygamous family looking after the rest of the husband`s wives if the husband is late and the societal expectations as a woman. These cultural expectations had negative impact on the participants` ability to access dialysis as they should have. These were illustrated by the following comments:

You know that in our culture you have to take care of your siblings, your father and your mother and every other member of your extended family as much as you can, so all of these people depend on my meagre salary and now I have been dealing with the issue of attending dialysis. That is why I have not been able to cope with the recommended amount of dialysis in a week because sometimes even when I want to come for dialysis and my siblings have financial issues I try to assist them first and then defer my dialysis for a later time. You see that It's not quite easy for me (Mr L, Int. 1).

Waiting in the queue is time-consuming and I cannot afford waiting so long at the hospital when I'm supposed to go back home and prepare meal for my husband. You know in our culture, no matter what could be happening to you, as a wife you are supposed to cook for your husband. So, I don't always stay on the queue any day the queue is so much; so, for me it's a big issue as I cannot afford to wait that long (Mrs P, Int. 1).

*As I interviewed some of the participants, I was struck by their strong inclination to the cultural belief of the society, which obviously influenced their decision of treatment for their illness, as they should have. More surprising for me was their attitude towards these cultural practices, which they did not see as wrong but were perceived to be an integral part of their lives. There were instances where I was moved by my emotions to discourage them from continuing with their adherence to those cultural beliefs, but I realised I needed to respect their choices and their belief system and keep to my role as a researcher and not a clinician in that context. **Reflexive journal field notes: January 15, 2016; April 18, 2016; August 2, 2016.***

Although some of the participants had some cultural inclinations which affected their dialysis decisions, most of the participants in the study expressed that their cultural belief did not influence their dialysis decisions. The following comments demonstrate this:

I don't have any cultural inclination that could have affected my decision to come here for dialysis treatment (Mrs A, Int. 3).

No, like I told you the other day, I have no cultural inclination and even if I do, it couldn't affect or influence my decision to come here for dialysis. I do know the importance of dialysis for my condition and skipping dialysis is very detrimental to my health and that's why I do all I can to come here three times every week as per the prescription and that's why you can see that I don't look like a dialysis patient in this part of the world (Mr M, Int. 3).

The major cultural issues which affected dialysis decisions among the participants were therefore culture of herbal consumption and cultural expectations from the society.

6.2.3 Religious influences

The religious beliefs of some of the participants also influenced their decisions or views on RRT. While some participants held strong views regarding their religious belief as a source of healing, some others did not. For some participants in the study, their faith in God was the true source of “healing”, “comfort” and “restoration” of their health while dialysis was often discountenanced and seen as secondary to “divine healing”. Religious belief often made some of the participants to accept their living with ESKD as the “will of God” in their lives and this helped to reinforce their belief in divine intervention to “save” them. The

following comments of some of the participants illustrate how religious belief influenced their perception of dialysis as not being a “major” solution to their condition:

Someone`s faith saves him; you know? It is my belief that if I trust God for healing, he will heal me of this condition. Prayer can save me. They said my kidneys are bad; what is kidney failure in the sight of God? God takes care of bigger situations and heals more dangerous conditions, so in the sight of God my condition is nothing. I believe this condition is his will in my life as it`s only what he approves of that can happen in a man`s life. So, dialysis or no dialysis, once it`s God`s will for me to be healed I will be healed (Mr G, Int. 1).

Someone can still do dialysis and die the same day; so, it`s only God who gives life. If God proclaims that I am going to live, even without this dialysis I can still live. God can still do it (Mr I, Int. 1).

I have no cultural inclination but my belief as a Christian is that no matter what I face in life, my God will always see me through. In fact, this dialysis thing in my view is not necessarily the ultimate cure for my condition. So, dialysis or no dialysis God must heal me. My healing will come from God not from dialysis (Mrs P, Int. 1).

Some of the participants perceived attending dialysis sessions as simply trying to “please” the doctors because of the way they were cared for by them and not necessarily as a major source of treatment for their condition. In other words, dialysis was secondary to the “supernatural healing” in their condition. This is illustrated by the following comment:

Erm,to be honest with you my son, I had to do it not because I felt the need to do it but because the doctor who has been very nice to me in the way he treats me actually insisted that I needed to do it (Mrs P, Int. 2).

Although the religious beliefs of some of the participants influenced their perception of dialysis and subsequently the decision on dialysis attendance, it had no influence on dialysis decision among some of them as can be seen in the following comments:

My religious belief doesn`t stop me from receiving dialysis if I have the means to go about it (Mrs C, Int. 3).

For my religious belief...erm....it has never stopped me from coming for dialysis. Dialysis is necessary for my health and it`s not prohibited by the bible so, my religion is not a problem; although I cannot receive blood or human tissue or organ into my body and it`s the only major reason why I have not been serious with the proposal for a transplant which my cousin has been talking about (Mr D, Int. 2).

The religious beliefs of participants in this study not only shaped their dialysis decision, it also had influence on their acceptance of the idea of renal transplantation as they were counselled by the HCPs. Although the thought of renal transplant for most of the participants in the study was “a luxury” due to their horrible experience of affording the cost of regular dialysis, some of them perceived receiving the kidney of others via renal transplantation as “abhorrent”, and “unacceptable” and against the tenets of their religion:

The doctor talked about the option of transplant. He said it's the best form of treatment for the condition but my religious belief does not permit me to accept any body part from another human being. Every human part is sacred and unique to the person; so.... erm the option of transplant is out of it for me (Mr L, Int. 2).

My religious belief doesn't allow me to accept blood, or any organ from anyone. I am of the Jehovah Witness Christian denomination. It's a part of my religious belief that cannot be negotiated with anyone because if you respect any human life you do not try to prolong it by taking other person's organ. So, doing that would mean going against my religious faith (Mrs P, Int. 2).

Apart from the fear I have regarding the possible outcome of the operation, it is against my belief as a Christian to receive the kidney of another human being. Every human part is very unique and God gave everybody their own, so I don't think I can possibly go for the operation (Mr D, Int. 2).

*During the first interview session, I witnessed the death of a young female dialysis patient in the facility who refused to be given blood transfusion due to her religious belief. She was brought into the facility from one of the rural areas in the State for dialysis. Blood investigations revealed that her haematocrit was 12 percent and she needed to be infused with blood. She declined all advice by the HCPs to be transfused because her religious faith as a Jehovah Witness forbids her from accepting any human tissue or organ into her system. She passed away after a couple of hours of waiting as the nurses informed her that it was against the policy of the facility to dialyse patients with such a PCV value without blood transfusion. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.***

6.2.4 Geographical issues

The distance of where participants lived to the location of the dialysis facility was also an issue in the study. Most of the participants either travelled from distant villages or different States to the dialysis facility. This often presented difficulties for them in arriving the facility on time for their dialysis appointments. It also adds to the cost of treatment for these set of

patients and often “discouraged” them from attending dialysis sessions or other medical appointments. The concentration of most of the dialysis facilities in the country within the cities posed serious threat to the effective management of ESKD in the country. In some instances, patients who had consistently failed to attend dialysis for various reasons were brought into the facility from very far villages at the points when their blood urea and creatinine levels were extremely high that they were almost dying.

On multiple occasions during the study, patients were brought in dead from the rural areas because of complications of symptoms of ESKD occasioned by non-dialysis. Some of these patients could have possibly survived the complications had they lived close to the dialysis facility or if they had any dialysis facility closer to them.

Going for dialysis for most of the participants meant they had to give up other activities for the day such as going to work, caring for their children, keeping other appointments and sometimes returning home on the same day. Some of them described instances where they had to put up in the hotel for some days as they missed their dialysis appointment on the scheduled time due to transport challenges from their respective states to the dialysis facility. Missing dialysis appointment time was compounded by the issue of high number of patients on the dialysis waiting list; this meant that patients who missed their appointed time irrespective of the cause would most likely either go back home and be rescheduled or sleep over in the hospital to be rescheduled for the next day. Sleeping over in the hospital was not cost-free as patients who elected to are expected to pay for the cost of “staying in bed” as that amounted to being on admission until the scheduled period of dialysis. This therefore added to the high cost of dialysis treatment and often affected participants’ ability to travel back to their homes after dialysis sessions.

Some participants described their experience of being dialysis patients and living very far away from the dialysis facility thus:

I have spent all my life savings on this condition. We spend about #2,500 and #3,000 (£5-£6) on fuel each time we are coming here for dialysis from Abakaliki. Sometimes we hire cabs from Abakaliki when our family car breaks down to the dialysis centre here in Enugu as it’s not always convenient for me to come here by public transport for instance there was a day my condition deteriorated and we needed to rush down here for dialysis so we had to search almost endlessly for where to hire a vehicle and so we had to come by public transport and before we could arrive here I was almost dead (Mrs C, Int. 1).

We spend about #15,000 (30) on transportation to come for a session of dialysis. We come all the way from Ikom in Cross River State and you can imagine the risks

involved. For instance, the number of accident scenes on the Abakaliki-Enugu highway is frightening enough for one to undertake such a risk travelling down here. I was always coming with my wife before but at some point, I stopped her because instead of the two of us taking the risk, it is better that one of us should be taking the risk. Like today I prepared to be here alone, but my younger sister spoke extensively to me last night on why we should come together. This encouraged me to come here today with her especially because of my sight problems (Mr H, Int. 1).

The cost of travelling to the hospital is too much and it adds to the total cost of my dialysis any time I'm coming here. So...so...you can imagine what that means. Meanwhile we manage to come not minding the cost and the inconveniences (Mr G, Int. 2).

The distance issue was understandably more “worrisome” and “distressing” for the older participants than it was for the younger ones. For Mrs Q who was 66 years old and lived with her ailing husband and her 2 kids, travelling from her village to dialyse in Enugu via public transport system was problematic as she expressed thus:

Distance to the dialysis facility is a very big issue for me. You can imagine me at my age now...erm...erm...it's not easy for me to walk to the dialysis centre. Even when I try to get on the public transport, it's not always easy as you know how our public transport system is in this country. If my husband was ok he would have been the one taking me there but unfortunately, like I told you he is very sick and I'm the one caring for him. You can imagine a sick person caring for another sick person! (Mrs Q, Int. 1).

Although the issue of distance between the location of the dialysis facility and patients' residence affected the decision of some of the participants in attending dialysis sessions, this was not the case in for some participants in the study. While they admitted that the cost of travelling substantially increased their overall cost of treatment, they remained “resilient” and felt “indomitable” by this experience in their illness journey. The participants whose dialysis decisions were not affected by geographical issues provided the following comments:

Well the place where I live ordinarily is supposed to be a factor affecting my decision to come for dialysis as I don't live in this state and I have to travel from a very far distance to here but honestly once I have the money to come for dialysis, I wouldn't mind travelling to here for the dialysis (Mr B, Int. 1).

You know that I'm a civil servant as I told you the other time we met? It is not easy for me to be taking permission all the time to travel to Enugu here for my treatment three times every week assuming I have the money to follow the doctor's recommended sessions of dialysis for my treatment (Mr L, Int. 2).

Although the dialysis facility is located on the outskirts of the city, it is very far for some of the participants who had to travel from other States for their treatment. There is high risk of travelling on the roads ranging from bad road, high chances of accidents on the roads and having to pay high fare to the facility. During the data collection, I had a first-hand experience of some of the complaints made by the participants regarding travelling to the facility as I went to the facility via public transport system on several occasions. Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.

6.2.5 Physical symptoms

The participants' decision to go for dialysis sessions was also largely influenced by their experience of the physical symptoms associated with ESKD. Most of the participants spoke about how they would have avoided going for dialysis but were "forced" to attend by the distressing symptoms they experienced. Although the ability to afford the cost of dialysis was identified by almost all the participants as the major factor which affected their decision to go for dialysis as highlighted earlier, the physical symptoms was the second major factor which influenced their decisions to "go to any length" irrespective of the cost issue to attend dialysis sessions. Participants described a feeling of "normality" they feel after each dialysis session and compared it to a feeling of "having normal kidneys":

You know when I don't go for dialysis, my legs swell up, even my face and my hands but...when I go on the machine, I feel better and the swelling comes down. I didn't want to go for dialysis the other time.... after the last time you interviewed me but my whole body was very swollen, and I almost died....so that was why I had to go on the machine. Erm.....we live in a village and it's not easy for us to get here (Mr G, Int. 2).

When participants perceived the physical symptoms, they experienced as "minor", they chose to "ignore" them and carry on with their daily activities without a thought of going for dialysis. However, when the symptoms became "severe" or "serious" because of build-up of waste products in their blood, participants expressed this often left them with no other option than to seek dialysis. Some of the participants were often confused in recognising whether the symptoms they experienced were due to the accumulation of

waste products in their blood because of failure to attend dialysis or arising from other health conditions they are suffering.

For most of the participants who usually waited to come down with the physical symptoms before making the decision to go for dialysis, dialysis was a “necessity” only when the symptoms are “difficult to bear” and not a decision that should be made based on recommendations by their HCPs as illustrated by the following comments:

I cannot just come here if not for the symptoms that is very difficult for me to bear. You can see how my body looks now. My whole body has risen and my face full of my body fluid.....so, it makes me feel distressed and I am not able to breathe well at all. This is the kind of situation that makes me come here to go on the machine and my family try to borrow money to make sure I come here if there is no money (Mr K, Int. 2).

I always try to come here and go on the machine only when the symptoms become so much that I can no longer cope with it. If the symptoms like the pain in my belly, the swelling of my belly and the hiccups which make me uncomfortable are less, then I don't need to come here as I would rather use the money to look after my children's needs than giving it to the hospital people, do you understand? (Mrs O, Int. 2).

If not for the fact that I was really down, vomiting, my legs were swollen and I couldn't do anything, I wouldn't have been here today to go on the machine like today, my family would have used the money to sort out other family matters (Mrs A, Int. 3).

The perception of attendance to dialysis as a necessity only when the physical symptoms are worse or unbearable can be a major feature of lack of adequate information as these participants would have known that living with their condition without conservative management was unhealthful. For some other participants, the decision to go for dialysis was motivated by the fear of the possible effect of the physical symptoms on their overall health. The physical look of other patients who were brought into the dialysis facility at a terminal stage due to failure to adhere to dialysis therapy often motivated some of the participants as demonstrated by the following excerpts:

I have been seen a lot of people who come here for dialysis only when the symptoms are so high, their whole body is swollen, their urea levels are high and they are almost dying; that's what I see here anytime I come for dialysis and sometimes I see people die while they are still waiting to go on the machine because their conditions are so bad before they are brought here usually because they don't have the money to come here or because of the distance of where they live to this place. So,.....after seeing such thing I don't think any sane person would want to wait to come down with the symptoms before coming here for the dialysis

when you have the money or funding support to come here for treatment. The physical symptoms have never really made me to go for dialysis but somehow you can say it has made me because I have always attended the dialysis not because I came down with any of the major symptoms but because I don't want to suffer from any of them. The symptoms are very horrible and I don't think I want to go through all that any time (Mr D, Int. 3).

For Mr M who was diagnosed of ESKD secondary to PKD, going for dialysis is a necessity irrespective of the presence or absence of any physical symptoms gave similar thus:

Usually, I don't come down with the symptoms except at the initial stage after the diagnosis but since then I have always tried to go on dialysis as recommended you know my case is particularly exceptional because of the cause of my kidney failure which like you know is PKD. I can't afford to come down with the symptoms if my urea and creatinine levels accumulate so high. It will weaken me and that would mean I won't be able to do anything and I can't just afford that right now or anytime. I need to be fit to be able to move around and source all that I need to go for the transplant (Mr M, Int. 3).

*Generally, the health seeking behaviour of Nigerians is poor as documented in literature and confirmed by the responses of the participants. Most of the participants involved in the study were quite frail and appeared almost lifeless. They reflect the general presentation of the dialysis population in the facility. Their look corroborates the responses provided during the interviews that the physical symptoms mainly influence their decision to attend dialysis. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.***

6.2.6 Dialysis as secondary to other needs

Most of the participants prioritised family needs above going for dialysis therapy. Though they expressed having the knowledge of the importance of regular dialysis and expressed the willingness to embark on it, they were constantly constrained by the high cost of dialysis sessions. Therefore, the perception of dialysis as secondary to family needs was related to the inability to afford the cost of dialysis concurrently with meeting crucial family needs. Choosing between going for dialysis therapy and meeting other family needs was a difficult decision for most of the participants. However, family needs always took precedence over

the decision to go for dialysis especially for the male participants than it was for the female participants. This was understandably so as it is customary in African context for the males to take full responsibility of the family needs while the females are considered “weaker sex” and “dependent” on the males. This therefore makes it more difficult for them to access regular dialysis treatments since they must pay out-of-pocket amid competing family needs to be seen as “responsible” head of their respective families. The following comments corroborate these assertions:

The needs of my family normally come first before this dialysis as I must support my kids and the entire family. My daughter has been an immense source of help though. I would have come here to go on the machine more times than I did in the last two months if not for the needs of my family sometimes (Mrs C, Int. 3).

Basically, it's the needs of my family that have interfered with my plan to come for dialysis as I would have wished in the last two months but what can I do? My family is much more important than me you know? I needed to sort out a few financial issues that my family had and so ...I couldn't raise the money to come here for my treatment. It limits my chances of receiving dialysis the way I would love to butwhat can you do? You have to support your family first before anything else (Mr L, Int. 2).

Although Mr D is being supported in his cost of treatment by his cousin, making the decision to receive regular dialysis treatment was also constrained by the needs of his family. During the first interview session, he received adequate fund from his cousin for his treatment cost and did not complain about the family needs affecting his ability to go on regular dialysis. However, during the second interview session, he revealed he no longer received regular funding for his treatment. This made him to skip some sessions of dialysis he would have loved to do to save some money and take care of the family needs as he stated thus:

Erm....., somehow, I can say that the need of my family is an issue. If you can remember I told you that my children are still in the University studying so it's a lot of cost for me and my family. I would have been coming for the dialysis three times every week since my cousin gives me money for that but....erm....I reduced the frequency of my coming here so that I can use part of the money for the payment of my children's school fees and support them in their studies. So,erm....I would say it has affected it but not really so much as I still come here for my treatment every week (Mr D, Int. 2).

Meeting basic family needs such as food and paying school fees for their children were the major family issues that impaired participants' ability to go for treatment. This was particularly more difficult for the older patients who were not in active employment but depended on their irregular pension payments from the government to pay for their health

care. Mr E is a 65-year old mechanic who later turned a security guard due to his health condition. He made this comment regarding the impact of other family needs on his dialysis decision during the second interview before he passed away:

Erm.....the needs of my family is also a big issue for me and to a great extent it affected my ability to go for dialysis in the last 2 months. In fact, I wanted to go for dialysis last week but there was no food for my children to eat and they also needed to pay their school fees.....so...I had to use the only money I had to sort these out. If I was still employed maybe, I would have asked my employer for some upfront payment to enable me solve these problems and then still be able to go for my dialysis but.....that is it my brother (Mr E, Int. 2).

Similarly, Mrs Q who is a retired civil servant expressed similar constraint during the first interview thus:

Many times the needs of my family do affect my ability to come for dialysis. When we don't have much money, I have to make do with the little we have to take care of the family need first before talking about going for dialysis, you know I'm no longer in active service and it's not easy with us pensioners as the government doesn't pay us on time (Mrs Q, Int. 1).

Although the family needs of most of the participants in this study affected their dialysis decision making, only three of them reported that it had no impact on their dialysis decision. While these participants admitted they faced difficulty in accessing regular dialysis without any support and at the same supporting their families financially, they had to remain resilient and creative in ensuring sustaining their dialysis treatment as illustrated by the following excerpt:

Erm, ...the needs of my family is there but it has never affected my going to dialysis as my wife is working, although I must admit it has not been easy as we also have to train our kids you know?, ...so, erm but it has never been an issue anyway. The needs of my family are there but they also need me to be alive,so we try as much as we can to forgo unnecessary expenses and save for my dialysis (Mr M, Int. 2).

*The impact of family needs on their dialysis decision created many emotions for me. Being a son of someone with a long-term condition and being a parent myself, I could understand the concerns of many of the participants in trying to take care of their family needs first before attending to their treatment. The participants were often in dilemma as to whether to go for dialysis or to take care of family needs first. However, the latter often took precedence, and this affected their ability to sustain their treatment. **Reflexive journal field notes: April 22, 2016; August 2, 2016.***

6.2.7 Dialysis services

Another major sub-theme under the theme of dialysis decision is the issue of dialysis services the participants received. The dialysis services were characterised by various challenges which impaired participants` ability to access dialysis services regularly. Participants described their experience of the challenges as “horrible” and “unacceptable”. Their life world as ESKD patients receiving dialysis services in the facility was also dominated by a sense of uncertainty. The uncertainty was related to incessant strike action by the HCPs in the facility because of poor remuneration by the government. This strike action not only affected the participants` dialysis services, it also delayed the recruitment of participants for this study as it lasted several months.

Dominant among the major challenges the participants faced in the facility was the issue of long waiting hours because of too many ESKD patients receiving dialysis services in the facility. The facility serves as the only Federal Government-owned dialysis centre in the State and it serves patients from neighbouring States where some of the participants in the study came from. This meant that most of the patients had to wait for too long number of hours and some had to cancel other daily engagements in order not to miss their dialysis schedule. The experience of long waiting hours therefore created what some participants described as “uncertainty in the schedule” of dialysis. The following are some of the participants` comments on their experiences of long waiting hours for dialysis:

You can see the kind of queue that is here now? See the number of patients who are here waiting for dialysis, it`s not an easy condition, sometimes we come here and we end up spending two days because of the number of people who are waiting to be dialysed (Mrs O, Int. 2).

My experience of dialysis treatment has not been a nice one. There are always long queues here just like you have seen for yourself. For you to be attended to, you have to leave your house very early in the morning to come here and you have to abandon every other plan you have for the day as the number of people who come here to dialyse every day is too much (Mrs P, Int. 1).

Another participant described the experience of waiting for too long and almost the entire day to go on the dialysis machine as a “normal” part of their life world as dialysis patients in the facility. He also described how some of the patients who were waiting passed away even before being placed on the dialysis machine as a “common occurrence”:

It`s a common thing here and you can see that for yourself. All you need to do if you want to see for you to be here until the end of the day and you will understand

what I have been talking about. The worst is that while we are waiting here somebody might drop dead due to the long waiting hours (Mr H, Int. 3).

*There were always too many patients waiting to be dialysed in the facility. This could be because the cost of a session of HD is cheaper there than in the private facilities in the city. Some of the patients who waited laid on the floor while they waited for their turn to go on the HD machine. Issues such as establishing more dialysis facilities especially in the rural areas, travelling and accommodation within the dialysis facility were raised by most of the patients I interacted with during the study (including the participants). These will be highlighted in the recommendation section of the thesis. **Reflexive journal field notes: April 22, 2016; August 2, 2016.***

The long waiting hours associated with going for dialysis in this study sometimes affected participants' decision to go for dialysis. The thought of spending an entire day waiting and not being sure of going on the machine also forced one of the participants to resort to the use of herbal remedies as he described thus:

Most times when you come here, you have to wait for so long to be attended to and the appointments they were giving me was too lengthy. So, so, that was why it was like I stopped using the medications and the management the way the doctor said to me (Mr E, Int. 1).

For Mr F, the long waiting hours created some form of “uncertainty” in his dialysis experience and this often made him to postpone going for his treatment:

Sometimes when I remember that going for dialysis would mean having to spend the whole day in the hospital and sometimes it may not be your turn to be dialysed on the same day you are booked for it because they might have some emergency dialysis going on and so that disrupts the schedules, I... kind of say ok let me be sure before I go. Meanwhile, you can't always be too sure though (Mr F, Int. 2).

Other major challenges participants in this study experienced was incessant break down of the dialysis machines and strike actions by the HCPs which often forced them to either wait until the machines are repaired or seek dialysis services elsewhere mainly in the private facilities which are extremely expensive and beyond the reach of most of the patients. The breakdown of dialysis machines often caused abrupt shutdown of machines while dialysis sessions are ongoing. The experience of strike actions which resulted in the

death of some of the dialysis patients was described as “horrible” and “avoidable”. This is summed in the following comment of Mr E during the first interview:

My experience at the UNTH is that their machines are always breaking down. There was a day I was on the dialysis machine and dialysis session had commenced; and I had to spend more than extra four hours (more than 8 hours). The engineers had to start working on the machine unit by God's grace. It was the fault of the management of the hospital and lack of attention by the government because that kind of situation can hardly occur in private renal facilities. To be honest with you, UNTH is not worth existing at all. We were there on admission before the workers went on strike and the time this happened, I had spent 4 days on the admission in the medical ward. All of us patient was discharged. It wasn't supposed to be so because the hospital treats numerous health conditions and many of the patients whose health conditions were critical died. Uuhmm! It wasn't a good experience for me (Mr E, Int. 1).

*The issue of machine breakdown and strike action by the HCPs dealt with most of the patients in the facility including me as a researcher as the recruitment of participants for this study was put on hold for several months until the strike action was called off. Even when the strike action was called off, the facility faced the challenge of not having water for dialysis and some of their HD machines broke down. The experience was very frustrating for me as an “outsider” who was there for a limited period to complete this study; I could only imagine the experience of the poor patients who had to depend solely on this facility because of their inability to afford the cost of dialysing in private renal facility. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.***

Inherent within the dialysis services is the participants` experience of the attitude of some of the HCPs towards them which they described as “awkward” and “unprofessional”. Most of the participants praised the professional attitude of most of the nurses and the doctors who they described as “empathetic”, “compassionate” and “kind” in their services to them:

The nurses and the doctors are kind and very humane in their approach to my care. They have been wonderful. They always told me to avoid foods that contain protein and to not take any medication apart from the ones that the doctors asked me to buy and take (Mrs C, Int. 3).

For Mrs O, the attitude of the HCPs towards her care and the psychological care they provided helped in her adjustment to the condition and attendance at dialysis:

The doctors and the nurses are doing well. They always treat me nicely, they are quite polite and when you are even feeling down they try to encourage you. The doctors always remind me that I shouldn't eat any food that contains protein, but I

don't know all of them. They also try to give me information regarding my treatment and condition from time to time (Mrs O, Int. 2).

During the second interview session, Mr M described a similar experience and how it encouraged him to continue seeking dialysis care in the facility:

My experience of care from the nurses has always encouraged me to go for dialysis. You recall that I told you about a dialysis centre where I used to dialyse whenever I go to Abuja? The service there is really poor, and the hygienic practice of that facility is nothing to write home about. If the service you receive from a service provider is satisfactory, then you have no reason not to continue the patronage, so that explains why I come here for my dialysis (Mr M, Int. 2).

However, one of the participants described his experience of the treatment he received from some of the HCPs as “horrible” but was left with “no alternative” choice to make. The experience created an atmosphere of “fright” and “uneasiness” for him and constantly made him to “keep to himself” and often avoided asking the HCPs relevant questions regarding his care. This experience made him feel “intimidated” and “powerless”. He narrated his experience thus:

The doctor is not friendly because the only question I asked her was greeted by a very rude and shocking response and so even when I had other questions to ask regarding my care, I couldn't muster the courage to ask because I don't know what her reaction could be. In that private facility, for the nurses, it depends on the environment in which they found themselves working. If your boss is full of harassing people (patients), then the atom of that harassment will be there so like I told you, I was always afraid and mine was to sit down on the machine bed for 4 hours and then get out and look for where I can get cure for myself (Mr H, Int. 1).

When I interviewed him during the second phase of this study, he mentioned that he had another “ugly” experience from another doctor in the facility. He was strong in his choice of words for the doctor he described during the first interview as he called him a “nasty doctor”. However, he declined to discuss his experience with the second doctor in this interview as he mentioned he wouldn't want to talk about it:

You know last time I told you about a nasty doctor? Well, I have had another ugly experience from another doctor, but I don't really like to talk about it. Erm...many of the doctors are doing well now as they take more time to explain things to us. The nurses are also very okay in doing this too (Mr H, Int. 2).

His choice of name for the doctor during the second interview was a reflection of his provoked emotions. This could also be the reason why he declined to speak about his experience with the second doctor. This revelation further highlights the usefulness of a QLRs approach in this study as it provided the opportunity to explore any changes in the patients' experiences of their treatment.

*Throughout the interview sessions with Mr H, I wasn't really surprised about his experience with the doctors. As a nurse who had worked in a similar environment, I recalled seeing some of my colleagues speak to patients in manners that made them feel powerless. From my perspective, the HCPs appeared to arrogate so much power and influence to themselves while the patients perceive them to "hold the key to their well-being". The attitude of the doctors towards him made him feel alienated and he had found it difficult to ask relevant health questions which he needed as a LTC patient. **Reflexive journal field notes: January 10, 2016; April 22, 2016.***

Although Mr H had these "ugly" experiences in his interactions with some of the doctors, he still maintained his dialysis attendance. This was because of his feeling of "powerlessness" in a healthcare system which he perceived as paternalistic and does not offer him any choice. Therefore, the experience of care did not affect his dialysis decision:

Erm.....what can we do my son? We have no choice.....if you are treated shabbily by the seller of a product, which is abundant in a market place where you have, you will have a choice to buy elsewhere but when the product is scarce in the market, you may endure all the treatment and go for the product because you need it. Do you understand what I'm trying to say? We have no choice so....I simply ignore the ill-treatment from any of the workers, go on the machine, and leave this place. My experience doesn't determine whether I come for dialysis or not (Mr H, Int. 1).

Similarly, although most other participants in the study maintained positive views regarding their experiences of care they received, a "lack of choice" in seeking dialysis services from the private facilities meant the experience of care had no impact on their dialysis decision. Curiously, the responses given by most of the participants in respect of their care experiences reflects a general attitude of patients in Nigeria where "patients are not expected to criticise the actions or expressions of your HCPs". Most of the participants tended to ignore any negative attitude they observed from their HCPs and were more concerned about their health

condition. This is illustrated by the following responses to the question whether the attitude of the HCPs towards their care affect their decisions to continue to attend the facility for their dialysis:

*Erm.....no it has never stopped me from going for dialysis. Although if I have a choice I would choose to go to the private dialysis centre where the doctors and the nurses are more compassionate and kind to the patients. Do you understand what I mean? No one likes where he or she is treated like s**t. So.....I.... simply try to ignore some of the bad attitude of some of the nurses and do my dialysis (Mr G, Int. 2).*

As a dialysis patient, I don` t think you have another option regarding your treatment whether you are treated well or not by the nurses in this centre. This is the only government-owned dialysis facility around here, so you can` t but come here to save cost of the treatment (Mr L, Int. 2).

*While I was interviewing the participants, I thought the “positive views” regarding the experience of care by the HCPs motivated the participants to continue attending dialysis in the facility. However, it was during the analysis of the data that I realised that it was, because the participants had no other choices, as dialysing in the private facility was very costly and quite unaffordable for most of them. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.***

6.2.8 Summary of key findings: dialysis decision

This section discussed the theme of dialysis decision by the research participants. The cost of treatment was a major barrier to accessing regular dialysis services among the participants and often caused them to resort to herbal consumption, which they described as an “alternative” to dialysis. Those who could afford the cost of treatment accessed regular dialysis services throughout the period of the study. The physical symptoms experienced by the participants was a major force, which drives them to seek dialysis services. Participants cared less about going for dialysis when they felt minimal symptoms but paid attention to seeking dialysis services mainly when they faced major physical symptoms. Adherence to societal/cultural norms of the society also affected participants’ ability to receive regular treatment. The cultural norms of the society influenced negatively on their ability to seek dialysis services. The cultural/societal norms include the use of herbal remedies for treatment, attitude towards seeking healthcare services, cultural expectations of the society as a married woman, and the first wife in a polygamous family looking after the rest of the husband`s wives if the husband is late. The religious beliefs of some of the participants had negative influence on their health-seeking behaviour as some of them held the belief that God will heal them and therefore did not believe in the dialysis treatment. This therefore affected their compliance with treatment regimen. Geographical issues and family needs also served as barriers to regular dialysis access among the study participants. The dialysis services were also characterised by too long waiting hours, poor supply of dialysis supplies including water for dialysis and disrespectful treatment by some of the HCPs.

6.3 Impact of CKD and dialysis

The last theme in the study was the theme of the impact of living with ESKD and depending on dialysis. It has the following sub-themes:

- Changing body/bodily impact
- Employment challenges

- Finances and sources of income
- Changing social relationships
- Religious practises
- Psychological and emotional impact

6.3.1 Changing body/bodily impact

The participants described the bodily impact of ESKD and being on dialysis on their activities of daily living, job or carrier, body image, and interpersonal relationships. Most of the participants in the study were observed to be frail and lethargic but resilient in their attitude towards their health condition and management. The participants described their experience of the physical symptoms as a “debilitating component” of their life world as dialysis patients. They described the impact of the physical symptoms they experienced as causing their bodies to “fail them” in their desire to carry out those activities they would normally do. The experience of the bodily impact of living with ESKD and depending on dialysis was expressed mainly by the female participants in the study understandably because of the way they perceive the society “views” them as dialysis patients. The generalised body swelling seen in most of the participants was metaphorically described as “being falsely-pregnant”. This term was used to describe the perception of the swelling in their abdomen by the society as a sign of pregnancy. This was very “worrisome”, “upsetting” and “undignifying” as the patients felt they were “perpetually pregnant” without any “product of conception”.

The impact of ESKD on the body was very much worrying for the youngest female participant in the study (Mrs A, aged 32). The physical symptoms made her constantly “weak” and unable to do things for herself without assistance from family members, which made her, feel like a “burden on others”:

My whole body is now swollen because of this condition and I now look like I'm pregnant again when I'm not. Every day I experience excruciating pain especially down my abdominal region and this makes me feel paralysed. It makes me very much uncomfortable and unable to do anything (Mrs A, Int. 1).

She was visibly worried during the second interview about “loosing” her body as a woman and the knowledge that she will never conceive again. According to her, the “loss of her body” was because of the disfigurement from the fistula scars on her body and the impact of her health condition on her chances of having a child (this had been described fully earlier under the meaning of illness theme):

Living with this condition means that I'm always feeling so ashamed of myself looking at how the fistula has disfigured my body, my hand...I can no longer wear anything that is transparent, and the scars will be seen. It makes me feel awful, disfigured and disgusted about how I have lost my body. I know that how I look like is not supposed to be my priority now but I'm also concerned about how I look or my body image as a woman (Mrs A, Int. 2).

The impact of ESKD and dialysis treatment affected her perception of her “look” and this often made her to skip some dialysis sessions, as she was not confident of her look:

I still do feel very much sad and ashamed of how my body has been disfigured by the fistula and the effect of the dialysis on my body. However, it has not in any way affected my coming here for dialysis (Mrs A, Int. 3).

Mr P described similar experience thus:

I also have the swelling, which you can see, on my face, my legs and my belly. It makes me look like I'm pregnant at 71 years of my life. It's not good my son as it makes me feel very bad and unease to go to attend church services and stay where people are (Mr P, Int. 1).

*I observed during the interviews that Mrs A constantly mentioned being sure, she would never have children. It shows me how much children mean to her and the constant thought always made her sad and distraught. The second interview with her was very distressing for me as she wept in between the interview questions and despite my pleas to discontinue, she insisted that she was fine. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 2, 2016.***

6.3.2 Employment challenges

Living as an ESKD patient who is dependent on HD meant “living with the burden” of finding any reasonable job and “being dependent” financially on your family or loved ones due to lack of sustainable employment opportunities as found in this study. Although most of the participants who expressed their experiences with employment issues demonstrated the willingness and fortitude to deny their pains and get jobs to be able to afford the cost of their treatments, but they were discriminated against and in some cases stigmatised. Participants were always judged based on their physical appearances, which in most instances were clearly “frail”. This affected their chances of employment and created a sense of stigmatisation:

I was invited for interviews by the three schools I applied to, but I was told clearly by the Heads of two of the schools that I'm fully qualified for the job but my physical look did not inspire confidence for them to proceed with my employment. They were very clear, and I really understood them. For the head of the third school, she did not get back to me even after all efforts I made to have a feedback from her. I do think she has the same impression but really found it difficult to tell me (Mrs A, Int. 3).

Erm...there was a restaurant I went to last week to seek employment, but I was told clearly that looking at the way I look they can't offer me any job since the job entails that I should be strong and smart. I tried to convince the owner of the business that I am just a dialysis patient and it wouldn't affect my performance on the job but.... that worsened my chances. He simply asked me to take time to look after my health as the work demands much energy (Mr F, Int. 2).

I....applied to some places to work but when they see me and my physical look they asked me if I was okay, so I told them truly that I'm a dialysis patient and they told me “no we cannot employ you”. So, it has not been easy with me (Mr K, Int. 2).

Some of them who were still on their employment did not receive any form of financial support from their employers towards their treatment and their treatments often interfered with their work schedules. They felt “abandoned” and were left to “bear their burden” alone as illustrated by the following excerpt:

No, I am not receiving any form of support from my former employer. You know how private employers behave. The medical centre where I was working is privately owned and the owner doesn't really care. In fact, I told you before that even when I went back to see if they can reinstate me to enable me work and support my family and my treatment I was told that I'm no longer fit to work with them. I believe he made his judgement based on my physical look, as I looked quite frail. So.....erm I think it wasn't his fault because this condition has made me look very different from

every normal human being and it's hard to see any employer who can employ me for any job here (Mrs C, Int. 2).

The disruptions in the work schedule of some of the participants due to travelling to the facility for dialysis sessions often created “feelings of loss of privacy” as they always had to reveal to their work colleagues why they were always away from work to attend their hospital appointments. There were also feelings of “uncertainty” among these participants, as they feared their continuous absence could lead to the loss of their jobs. This experience was worse among those employed in the private sectors than for those in the public sector.

The physical symptoms the participants experienced often affected their chances of sustaining their jobs and led to the sale of personal belongings to pay for the cost of their treatments. It also made some of the participants to feel a sense of “self-doubt” and “incapacitation” that even if they got employment opportunities, they might not be able to cope with the job demands. This can be seen in the case of Mrs A who was a schoolteacher but lost her job as she could not cope with the symptoms of her condition and had to relocate to live close to her family for their support:

I can no longer get back on my teaching job or any other job in life. Who can ever employ me again? Even if I'm employed, where do I find the strength to perform my job? So, this condition has rendered me useless and incapacitated. This condition has led me to be unemployed and not only that, my husband has become poor due to this condition. He has sold all the goods in his shop and other property to pay for my medical bills and this has got to the point that we are no longer able to pay our rent (Mrs A, Int. 1).

Mrs C had a similar experience, and this forced her to quit her job and had to depend solely on her daughter for her treatment:

Since the commencement of dialysis, I have always experienced constant fatigue which affected my performance on my job and so I had to quit my job in November 2015 because I find it very difficult to walk unaided and so can't be tolerated to carry on in my workplace. I'm no longer able to work again (Mrs C, Int. 1).

For Mr E, his health condition and the dialysis treatment he was receiving constituted a “nuisance” to his life. He could not sleep properly in the night but could only sleep in the daytime. This affected his ability to cope with his new security guard job as he had to deal

with not only the sleeplessness at night but also the fatigue associated with his illness and was always falling asleep on duty:

I do not sleep well in the night time. I'm thinking it could be a side effect of the medications I'm taking although the doctors said it's because I need to undergo dialysis. It's really disturbing me so much; you can imagine when other people are asleep in the night and you are awake doing nothing. I sleep in the daytime. It affects my job as I had to leave my previous job and now it makes me sleep at work where I'm doing security work (Mr E, Int. 1).

When I interviewed him during the second phase of the data collection, he was already sacked because of the impact of the physical symptoms and sleeplessness at night, which he could not cope with:

I.... still don't sleep well in the night time and ...when I go to work I sleep on duty. You asked me about work.....I have lost my job now. I was sleeping on duty one day and.....my boss caught me, and he said he could no longer keep a security man who sleeps when he is supposed to be awake. So...so.....that was how I was fired from my security job and since then I have not been able to get another one. It's not his fault. If you look at the nature of my job, I...shouldn't be sleeping on duty anyway but....it's not my fault. Maybe it's because of the effect of my condition which makes me feel very tired and I don't sleep in the night time (Mr E, Int. 2).

The loss of his job affected his ability to cope with the cost of treatment as he had no form of support from any source and his family members were still dependent on him. Mr E metaphorically described himself as a “walking corpse”. This expression was used by some other participants in the study to describe what life means for them as dialysis patients who could not afford the cost of treatment and had to live everyday with the knowledge that they are going to die from their illness:

Erm.....it has made me not to have any money to talk of going to the hospital for dialysis. You know that if you don't have money to pay, nobody is going to listen to you when you go to the hospital for your treatment not to talk of going for any hospital appointment. So....erm.....It's hard my brother. Here if you don't have money, then you are a walking corpse. That is the major reason why I have not gone for dialysis since the last two months now. It has made my life worse, ...my condition has turned worse as you can see (Mr E, Int. 2).

Mr E's likening of himself to a "walking corpse" just like some other participants in the study in my reflection suggests a feeling of incapacitation as a result of knowing what to do as a dialysis patient but was restricted by financial constraints. It also demonstrates an awareness of the likely prognosis of his illness. Reflexive journal field notes: January 10, 2016; April 22, 2016.

The impact of the illness on employment or job issues was not peculiar to the participants who were employed in the private or public sectors. Others who were running private businesses also expressed how their business ventures were "paralysed" because of the physical symptoms they experienced which affected their ability to cope with the demands of their businesses. This was illustrated by the following comments:

When I go back to my business I experience so much pains in my joints and I'm so fatigued that I hardly do anything since my job involves lifting or carrying goods out from the stores manually but if it's only to bring out goods for a customer I wouldn't have much reason to worry (Mr D, Int. 1).

It has been a very tough time for me my brother. I....I....have been trying to see if I can get a job here as I can no longer continue with my carpentry job due to the constant tiredness that I always have but I have not been able to get one. Erm,....I have been living my life from hand to mouth and now....I am a big problem for my family. You know if not for them I wouldn't have been able to go for dialysis more than once since and my health condition would have been much better (Mr K, Int. 2).

For Mr J, his frailty and not having anybody who he could entrust his business to meant he had to shut down his business just to take care of his health. This meant he could not afford to sustain his treatment and take of other family needs:

I am no longer able to go to work regularly and so I spend most part of my time staying at home. I don't have apprentices or any subordinate who supports or assists me in my business. How can I get money to sustain my dialysis and other treatment if I don't carry on with my business? So, erm...but I need to be strong to do anything. I can't concentrate on doing anything meaningful when you think about the impact of the symptoms of this condition, the needs of your family, going for dialysis in such an extremely far distance so that you can live (Mr J, Int. 1).

The employment issues some of the participants faced persisted throughout the period of the study and this possibly caused some of them to drop from accessing dialysis, as they could not cope with the high cost of their treatment. Those of them who were still alive in the second and third phases of this study made the following comments:

No, I have not been able to secure any other job. You can imagine how wasted I look now, so it has been very difficult to get a job. Which employer will give a job to a potential employee like me my brother? This condition makes me feel so tired that I hardly can do anything for myself let alone working for anyone. So, so, I have been bearing my burden all alone and with the support from my family (Mrs A, Int. 2).

Erm, basically I have had financial challenge, which made it difficult for me to go for dialysis. You know I told you last time that I have not gotten any job to do since I graduated from the university. So, so..... the cost of my treatment has been borne by my aged parents and my younger brothers who are really struggling to make ends meet. In addition, one of my brothers who has been supporting me has just lost his job and now he cannot even afford to look after himself not to talk of having any money to give me for my care. So...his loss of job has now added to my issues and pressures as he cannot support me financially as he used to do in the past (Mr F, Int. 2).

*Although I was quite emotional and empathetic while the participants recounted their ordeal in securing job opportunities, at the back of my mind I felt their fragile look could have contributed to that. However, I was stunned by the manner with which some of the potential employers spoke to some of the participants. **Reflexive journal field notes: January 10, 2016; April 22, 2016; July 27, 2016.***

6.3.3 Finances and sources of income

Participants expressed how their illness and dependence on dialysis had affected their sources of income and rendered them financially independent. The financial impact of living with ESKD and depending on dialysis for them included giving up their work or businesses (as already discussed above), spending all their life savings on their treatment and dependence on family members or friends for their treatment costs in certain cases. This often-created uncertainty in their lifeworld as dialysis patients as other family needs could take precedence over their treatment and this makes them feel “unsure” about when they could go for their treatment. For the family members, the economic implications of caring for relatives who are dependent on dialysis included giving up work or other daily schedules, holidays and the costs of travelling from their locations to the dialysis facility. The study did not set out to include the family members but two of the family members were eager to highlight the impact the illness and the treatment had on them and I had to oblige them.

Mr D described the impact of the illness and his treatment on his source of income thus:

Currently, I have no grown up male child or any helper at the shop. I used to have a sales boy but since I became ill and travelled back home for treatment, my business has crumbled, and the boy has stolen all my money. I had to shut down my motorcycle parts shop and asked him to move over to the other shop where I sell mobile phones until I return (Mr D, Int. 1).

Generally, for the participants, their experiences of their illness were worsened by a lack of any form of financial assistance or dialysis subsidy from the government, which could have made life easier for them. During the interview sessions, many of them asked me if I was going to assist them with the cost of treatment or “speak for them” as they felt the appropriate health authorities should be able to assist them. Struggling to cope with the experience of symptoms and working to afford the cost of dialysis and other family needs meant the thought of any sort of recreation or holiday is a luxury for them unlike ESKD patients in developed societies.

The experience of financial independence was worse for the male participants than for the female participants. This could be because of the societal norm of “the man being the head of the family” and “should be able to provide for the family”. This often made the male participants in the study feel “powerless”, “worried” and experienced some form of role conflict in their quest to fulfil this “essential” role in the family. This is captured by the following comments from two of the male participants:

So, my business has suffered, and my income has depleted as I have to pay for my dialysis and look after my family. It's not been easy with me coping with the financial pressure I have faced since this condition started (Mr B, Int. 1).

It has....it has.... done a lot of damage to my business and that has made me to be reductant and I cannot support my family financially the way I used to do before. I...I.... have given up this important role of every man to his family to my wife. It makes me sad terribly. My children are still in the University studying and they need financial support from me but now I cannot do all that as I used to do and all the money I was using for my business is almost gone in taking care of their cost of studying. I cannot leave everything for my wife to do you know? (Mr D, Int. 2).

The experience of loss of financial independence was not limited to only the male participants, two female participants also expressed loss of financial freedom due their illness and treatment thus:

We both now depend on my family for our upkeep. This is not the kind of life I wished for myself and my husband but it`s now the reality (Mrs A, Int. 1).

Assuming I am still working and earning salaries it will help me in the payment of my medical bills but now I don`t work, and I have become a burden to my daughter who is a medical doctor as now takes care of my bills (Mrs C, Int. 1).

For Mrs O, the cost of her treatment led her to selling her properties, as she could no longer cope with the high cost of treatment:

My son,...it has not been easy with me and my children. I have sold virtually everything I have to be able to keep to my treatment, but it has not been enough (Mrs O, Int. 2).

Though Mr D`s cousin supported him financially in his treatment, giving up his business because of ESKD and dependence on dialysis was very frustrating for him and wished he could change the situation. He wished he could retune to his “previous self” which described as “normal”. He made this comment during the third interview:

As a man, I would prefer being able to pay for my treatment and supporting my family and doing many things for myself as against my current situation where I must practically depend on my family for everything even though I dialyse at least twice every week. It makes me feel like a burden to my fellow man. I feel like I`m tied to someone and really quite inseparable and have lost my financial freedom.I have had to shut down my business over there and look after myself and it`s really been telling on me and my ability to cope with my financial obligations (Mr D, Int. 3).

*The impact of the illness and the treatment on the participants` finances and their sources of income worsened due to a lack of support from the government, which they described as abandoning them to their fate. They repeatedly asked me if the government could come to their aid throughout the period of the study. Some of them also severally encouraged me to utilise the findings of this study to highlight the challenges they faced to the appropriate authority. **Reflexive journal field notes: January 10, 2016; April 22, 2016.***

6.3.4 Religious practices

Some of the participants in this study appeared religious and they utilised their religion as a source of coping with the stress of living with their illness. All the participants identified themselves as Christians belonging to the various denominations of Christianity. Not being able to perform religious rituals such as doing “midnight prayers”, praying early in the morning before embarking on their daily schedules and attending religious events were perceived by some of the participants as the worst impact of the physical symptoms associated with their life world as dialysis patients. The most common symptoms that participants reported as barriers to their religious practices were fatigue and joint pain, which they described as “excruciating” and “debilitating”. They often referred to God as the source of their healing as discussed in the previous theme.

The inability to cope with their religious obligations as Christians due to the impact of the symptoms resulted in the perception by some of the participants that ESKD and the treatments are “intrusions” into their “normal lives”. To them, there is a distinction between their “normal lives” as faithful Christians who prayed every day and at the right hours, attended church programmes and events and their current “lives” on dialysis where all these values, which they cherish, had been “lost”. Therefore, living with ESKD and depending on dialysis is a barrier to the expression of their Christian values.

One of the male participants expressed the impact on his Christian life thus:

It has affected negatively on my Christian life. I don't have the energy to pray as much as I used to in the past because of fatigue which I experience every day (Mr G, Int. 1).

During the second interview, he expressed the impact of the symptom on his religious life thus:

Erm.....the weakness has worsened, and I can no longer attend fellowships in the church or even pray the way I used to do before. I still try hard to pray but the weakness is usually worse in the day times, so praying in the daytime is now very difficult for me (Mr G, Int. 2).

For Mrs P, her religious life is an “essential” aspect of her life, which she cherished and will never relinquish because of her illness. She described the impact of her illness on her religious life thus:

Even these days I am not able to pray in the middle of the night the way I used to. My spiritual life is very important to me but to be honest with you, this condition has imparted it negatively, but I will never give up (Mrs P, Int. 1).

She went further describing the impact on her thus:

So,...erm,...you can imagine what it means for my family and me. I always like to go to church and attend all the church activities but that has not been possible due to this illness (Mrs P, Int. 1)

The religion of the participants meant so much to them. It was their source of comfort, hope and coping with the stress associated with their illness. I admired their perseverance and sense of optimism in the face of adversity. Reflexive journal field notes: January 15, 2016; April 20, 2016.

6.3.5 Changing social relationships

The families of the participants played crucial roles in their experience of living with the illness and affording the cost of treatment. They constantly mentioned the roles of their families as their major source of support. Some often highlighted being “over dependent” on their families for help in carrying out activities of daily living, transportation to the dialysis facility and payment of their treatment costs. This often created a sense of guilt, loss and anxiety and participants described how they should have been the ones assisting their family members financially but were constrained by their illness and the treatment. To them, their illness was a unifying factor, which brought every member of the family together, and they were not seen as “burden” on their families. Clearly, from the interview data, some of the participants were the ones who perceived themselves as “burden” on their respective families.

There were many instances in the interviews where participants described how their families had been “the force pulling them through” in their illness experience by providing every

necessary support, encouragement and the determination to carry on and never to surrender to the illness. Mrs A described how her poor parents struggled to pay for the cost of her treatment thus:

The cost of this dialysis is very high and poor people like us can hardly afford it and it's only through the grace of God that I'm alive today as my poor parents struggle to raise money for my dialysis (Mrs A, Int. 1).

Mrs C also perceived herself as a “burden” to her daughter who takes care of her treatment costs:

Assuming I am still working and earning salaries it will help me in the payment of my medical bills but now I don't work, and I have become a burden to my daughter who is a medical doctor as she now takes care of my bills (Mrs C, Int. 1).

However, only one of the participants described experience of negative treatment from members of her extended family (late husband's brothers) who accused her of being responsible for the death of her husband. She described her experience thus:

I have nobody supporting my children and me. My husband has died and his brothers don't come close to my children and me as they are insisting that I killed him and that is why I'm suffering from this condition. I didn't kill my husband and why would I do that? (Mrs O, Int. 2).

Participants described the impact of their illness and the associated symptoms on their relationships with their friends and associates. The illness confined some of them as they struggle to cope with the symptoms, which they described as “agonising” and “restrictive”. It often alienates them from their peers, as they feel ashamed of their present look in their illness. The following are some of the comments they made in their description of the impact on their relationships:

How can my belly be so swollen? It makes me stay indoors and I find it difficult to go out and associate with my friend. Erm... I cannot recall any day the physical symptoms affected my coming for dialysis. It only affects my social relationships with my friends as I don't go out with them again (Mrs B, Int. 1).

You can see me now; you can see how my body is like I'm pregnant with all my whole body swollen..... I can no longer go out as much I could, and it has affected my ability to go out with my friends for social events (Mrs O, Int. 1).

Two other participants felt abandoned by their friends and expressed reduction in their social circle as result of their illness. They described the impact on their relationships with friends thus:

I am feeling abandoned by my friends and my brothers and sisters who are supposed to help me get the right treatment but then they are not doing anything (Mr H, Int. 3).

I am particularly confined by this condition; I can't go out as I used to do in the past when I was okay. You know when things were good I used to have many friends flocking around me. But since this condition started, it has reduced the number of friends that I have. Sometimes some of my friends don't even pick up my calls or even call me back probably they feel I will ask them for help. So, it's just a few of my close friends who still call and check on me (Mr J, Int. 1).

*In all the interviews conducted, participants were full of praises for their families who have always been their "pillar of support". Surprisingly, there was little or no mention of the support of the HCPs in their illness experience. **Reflexive journal field notes: January 10, 2016; April 22, 2016; August 1, 2016.***

There was no mention of the impact of the illness on participants' relationship with their work colleagues.

6.3.6 Psychological and emotional impact

The physical symptoms some of the participants experienced often resulted in psychological and emotional impacts on them. The commonest symptoms participants reported as "troubling" and "very uncomfortable" were swelling in the ankles, feet and abdomen, and generalised body pain especially in the joints and the chest, which often made them unable to breathe properly. The swelling in the abdomen was more worrying for the participants as they perceived themselves to be "pregnant". This feeling was found to be more common among the female participants especially the older ones who could not reconcile their "new look" with their previous "self". This resulted in the perception of negative body image among the participants and affected their interpersonal relationships, as they had to "keep to themselves". Some of the participants described the impact of their illness and the associated symptoms on them thus:

The swelling is quite discomforting to me. It makes me feel very heavy and it doesn't permit me to breathe well; even now, I can't breathe well, and it disturbs my sleeping pattern. I only manage to sleep a few hours in a day; I'm only managing my life (Mrs C, Int. 1).

Others described the impact of the illness on their body image thus:

I don't sleep well in the night. Erm, it makes me feel like vomiting especially when my face and my legs swell, and I don't go for dialysis. Sometimes, my legs will be doing me like I'm walking even when I'm sitting down in a place without doing anything. All these make me feel awful and unease (Mrs Q, Int. 1).

Sometimes, when my belly is swollen I am not able to go out due to severe weakness that I feel and because I feel sad and shamed to go out to church because of the swelling, which makes me, feel like someone who is pregnant (Mrs P, Int. 2).

This condition makes me stay in-doors all the time as my whole body is usually swollen and I find it stressful to walk about as I used to do in the past. You can see that my whole body is swollen now; how can I go out like this and everybody will start looking at me and some others will start asking me if I'm okay (Mr G, Int. 1).

The distress caused by the physical symptoms and the swelling which affected Mr H often led him to have suicidal ideation as he expressed during the third interview session thus:

I still feel same way of putting an end to this situation, but I hope everything will be fine someday. I have been having the same thought especially whenever my body keep swelling up and its affecting the way I breathe, you know it could be very distressing and it makes me very anxious (Mr H, Int. 3).

*During the analysis of this data, I read severally the lines of the second interview transcripts, which suggests Mr H had suicidal ideation. I took notice of the comment- "I still feel the same way of putting an end to this situation". It suggests to me that perhaps this ideation had existed even before the first interview but he either deliberately masked it or he felt he expressed it during the first interview. This further highlighted to me the importance of the QLRS approach which I used in this study as this important issue could possibly not have been uncovered if I had used any other approach. However, I was in a dilemma regarding what to do in that circumstance without compromising the principle of confidentiality of participant's information. I encouraged him to talk openly about any issues he might have which could be bothering him and I listened to him carefully without being judgemental. He was also encouraged to speak more openly about any worries he might have to either his family members or members of the healthcare team. **Reflexive journal field notes: January 10, 2016; April 22, 2016; July 25, 2016.***

Another participant also discussed the impact of the illness and the symptoms on him thus:

Whenever I undergo HD sessions I feel free, I feel better and normal but after some time my body will start experiencing pain, with fine tremors on my upper and lower extremities and feeling unwell. It also affects my appetite, as I wouldn't be able to feed as normal. I don't feel hungry most of the time, and a lot of abnormal feelings occur on my mind in fact don't feel happy at all. I'm always sad because of this condition and the associated symptoms (Mr E, Int. 1).

The debilitating impact of the illness was also found to lead to diminished self-worth in some participants. Not being able to concentrate on working and providing for the family made some of the male participants to feel a sense of “worthlessness” as they could no longer cope with their traditional roles as “the head of the family”. Mr D discussed how he felt at not being able to play this role thus:

It has not been quite easy especially watching my wife deal with all the financial matters in the family and now everyone of us have been dependent on her. It makes me feel less worthy as a man. You can imagine what it means for a woman to be the person catering for a family in our society. It kind of makes me feel that I'm no longer a man, in fact as though I'm no longer alive because I should be the one providing for my family and my wife's role would be supportive and not being the one in charge of everything (Mr D, Int. 3).

6.3.7 Summary of key findings: Impact of CKD and dialysis treatment

The bodily impact of the illness was more worrying for the female participants than the males because of the effect on their reproductive lives. In addition, the disfigurement from the fistula scars on the body created a sense of negative body image in the female participants. The participants experienced employment challenges due to the physical symptoms of their illness and the inability to cope with the pressure of job and treatment of their illness. ESKD patients faced discrimination in employment issues and were often stigmatised. For those who were fortunate enough to keep hold of their jobs, they faced the pressure of travelling very far distances from their residents to the dialysis facility. They also lacked financial support from their employers and work colleagues due to incessant absence from work due to the debilitating impact of their illness. Living with ESKD and being on dialysis created financial challenges for the participants, as they had to quit their job, businesses and still provide for their families without any assistance from the government. This experience was particularly worse for

the male participants than the females as most of them were the breadwinners of their respective families. Families were the major source of support for the participants and participants felt abandoned and deserted by their friends. The illness therefore had negative impact on their wider interpersonal relationships and deprived them of more support. The cost of treatment placed huge financial burden on the family members who had to pay for the cost of dialysis. It also affected the employment of some family members who cared for them.

6.4 Summary of the chapter

This chapter has exposed the various challenges faced by dialysis patients in a healthcare system with unequal access to healthcare where the poor patients must pay out of their pockets for the huge cost of treatment. The cost of treatment was found to be the major barrier to accessing regular dialysis services. Lack of money to access regular dialysis often caused them to resort to herbal consumption, which they described as an “alternative” to dialysis. Those who could afford the cost of treatment accessed regular dialysis services throughout the period of the study. The physical symptoms experienced by the participants was a major force, which drives them to seek dialysis services. Some cultural/societal norms also influenced negatively on the ability of the patients to seek dialysis services. The cultural/societal norms include the use of herbal remedies for treatment, attitude towards seeking healthcare services, cultural expectations of the society as a married woman, and the first wife in a polygamous family looking after the rest of the husband`s wives if the husband is late. The concentration of the government-owned renal facilities within the cities also served as barrier to accessing regular dialysis services by the participants as it increased the cost of their treatment, which they could hardly afford. Religious beliefs also had negative influence on the compliance to treatment by some of the participants because they believed in God for their healing. The dialysis services were characterised by too long waiting hours, poor supply of dialysis supplies including water for dialysis and disrespectful treatment of patients by some of the HCPs.

This chapter also highlights the employment challenges and discrimination in workplace faced by dialysis patients in Nigeria. In addition, the impact of CKD and dialysis on interpersonal relationships, patients' finances, the family and the body image of patients were also highlighted.

The next chapter will discuss the findings of this study in within the context of other related studies.

Chapter 7: No Money, No Treatment, No Life- “CKD is a death sentence”

7.1 Introduction

This chapter highlights what was already known about experiences of dialysis patients in regions of the world with equal access to treatment, the new knowledge resulting from the current study and a discussion of the key findings presented in Chapters 5 and 6 of this thesis.

7.2 What was known before this study

From the literature reviewed in Chapter 2 and wider literature on dialysis patients, we know the following about the experiences of ESKD receiving dialysis:

- Living with ESKD is associated with uncertainty regarding waiting for dialysis and renal transplantation, and possible prognosis of their disease condition.
- Meaning of illness in ESKD is represented by living in pain, stress and other social and psychological discomforts associated with the treatment. The meaning of illness shapes how individuals deal with the management of their illness.
- Haemodialysis impacts negatively on the body image and social relationships of ESKD patients.
- Dialysis disrupts the normal life of ESKD patients and has social, psychological, emotional and physical effects on them.
- Dialysis patients use various coping mechanisms such as hoping for normality, faith and spirituality, socialisation, hobbies and engaging in meaningful employment in dealing with their illness. Religious beliefs have no impact on decision to seek dialysis services.
- Family is a major source of support in ESKD providing financial and emotional support. However, family needs have no impact on decision to seek dialysis services.
- No previous explored the experiences of dialysis patients in health care systems with unequal access to healthcare to treatment.

- We did not know the impact of culture, cost, religious beliefs and institutional challenges on access to treatment in ESKD patients.

7.3 What this study adds

- It exposes the challenges faced by ESKD patients receiving haemodialysis in healthcare systems with unequal access to dialysis to treatment. It reveals that cost is a huge barrier to regular access to treatment for dialysis patients. It also exposes the negative impact of religious beliefs, societal norms/cultural practices, geographical issues, poor health care policy and family needs on the ability of ESKD patients to seek renal services.
- This study also exposes that physical symptoms and the fear of the possible consequences is a major factor that influences decisions of ESKD patients to seek dialysis services in such context. This contrasts with what is known in literature.
- Meaning of illness has no impact on the health seeking behaviour of dialysis patients in health care systems with unequal access to treatment.
- Lack of adequate communication regarding treatment choices (especially with respect to conservative management), nutritional and prognostic information are challenges to effective management of ESKD in low-resource settings.
- Lack of awareness of the causes of chronic kidney disease and the effective management. People`s perception of the causes of chronic kidney disease and treatment was inaccurate and misinformed.
- Religious and superstitious beliefs in addition to cost of treatment are the major barriers to renal transplantation in Nigeria.
- Qualitative longitudinal research approach is a valuable approach for gaining deeper understanding of the lived experiences of patients suffering from chronic illnesses.

7.4 Discussion of the findings

7.4.1 Introduction

Leventhal's Common-Sense Model (CSM) of Illness Representations (Leventhal, 1997) posits that individuals' illness perception influences the coping responses to an illness. The Leventhal perspective seeks to explain that individuals construct their own illness representations to help them make sense of their illness experience. These representations form the basis of appropriate or inappropriate coping responses exhibited by clients suffering from chronic illnesses (Leventhal et al., 2001). The themes deduced from the interviews did not reflect Leventhal's common-sense model of illness representation. The meaning of illness did not change as the illness progressed, participants continued with their maintenance dialysis and received more information. Therefore, the meaning of illness had no impact on the sustainability of treatment by the participants. The key findings are therefore discussed below:

7.4.2 Illness identity

Participants in this study were patients with stage 5 CKD who perceived no specific symptoms at the onset as shown by their hospital records and corroborated by the participants during the interviews. Many of them sought medical attention because they felt uncomfortable or presented with various signs and symptoms (fatigue, generalised body weakness, foamy urine, oedema, and vomiting) which they could not cope with. This finding is therefore consistent with Leventhal's self-regulation model which states that the identity or label a patient gives to an illness depends on the presence of physical symptoms and the information from various channels such as healthcare practitioners, the illness experiences of other people and the health information they receive via the mass media (Leventhal et al., 1984; Diefenbach and Leventhal, 1996). Early identification of symptoms and treatment are crucial in preventing the progression of CKD to ESKD (Locatelli, Vecchio and Pozzoni, 2002; Feehally et al., 2008).

As indicated in chapter one, Nigeria ranks third in the list of African countries with the largest number of patients on haemodialysis (HD) (6.3 per million populations) after South Africa and Kenya (Pozo et al., 2012). This figure indicates that ESKD is a growing and

expanding problem for Nigerian people and the health services. This may be due to multiple causes. Studies have shown that most people in Nigeria (less than 35 percent) especially those in the rural communities have no knowledge of CKD (Ayokunle et al., 2015; Okwuonu et al., 2015; Oluyombo et al., 2016). To achieve early diagnosis and treatment, individuals must be able to self-identify abnormal symptoms. Otherwise, they might misinterpret abnormal symptoms and care less about seeking medical help as reported by some of the participants. This is consistent with the generally poor health-seeking behaviour among Nigerians as reported in other literatures (Abdulraheem, 2007; Omotosho, 2010; Chukwunke et al., 2012). By the time some of the participants felt uncomfortable and noticed obvious symptoms which prompted them to seek medical care, their CKD had progressed to ESKD which is irreversible.

7.4.3 Causes

Some participants believed the cause of their illness was supernatural or spiritual attack by their “enemies” or those who do not wish them well. They saw the biomedical causes of ESKD as secondary and believed that any health condition that defies orthodox treatment was underpinned by supernatural forces directed by wizards, witchcrafts, angered ancestors and evil spirits. One of the participants believed his illness was caused by his past inappropriate lifestyle believed it is a punishment for her sins by God. However, a few of the participants believed their illness was due to some other primary chronic diseases such as diabetes mellitus, hypertension and PKD based on the medical. The causes described by the participants were consistent with those reported in previous other studies (Haroun et al., 2003; Stengel, Tarver-Carr, Powe, Eberhardt and Brancati, 2003; Shankar, Klein, and Klein, 2006). The beliefs of most of the participants regarding the cause of their illness demonstrate low level of knowledge of CKD among the people.

7.4.4 Time line/Control

Some of the participants knew that their illness cannot be cured but could be controlled. However, a few of them demonstrated a lack of knowledge of the course of their illness as shown in the interviews. Based on cognition and beliefs, most of the participants believed that following their doctors` recommendation to maintain dialysis appropriate sessions of weekly dialysis was the best way to manage their illness, however, they were constrained by

lack of money for the treatment. Therefore, the duration of the illness and possibility of being cured or otherwise had no impact on them sustaining their dialysis treatment.

7.4.5 Consequences

During the interviews, when participants talked about illness consequence perceptions, most of them did not want to talk about the possible consequences like death. Only a few of them talked about the possible consequences. This finding is consistent with the typical Nigerian culture of not talking about death or dying (Okpechi, 2017). Most of the participants also described the negative consequences of their illness on their finances, social relationships, religious practices and employment.

7.4.6 “A death sentence”-inequality and lack of service provision

Based on the literature reviewed in Chapter 2, this is the first study to explore the lived experiences of ESKD patients receiving dialysis services in low-resource settings with unequal access to treatment like Nigeria. The study identified several barriers that impaired the patients` ability to sustain access to regular dialysis services. These barriers included cost of treatment, location of dialysis services, societal norms and family needs. The findings show that the cost of treatment is the major barrier to regular access to dialysis services by ESKD patients in Nigeria. As discussed in the introduction of this thesis (Chapter 1), health care in Nigeria is financed by a combination of tax revenue, out-of-pocket payments, donor funding, and health insurance (social and community) (WHO, 2009; Olakunde, 2012). Majority of ESKD patients in Nigeria therefore pay out-of-pocket (OOP) for their RRT without any healthcare insurance and the non-availability of PD services further compounds their problems (Okafor and Kankam, 2012; Arogundade, 2013). This was found to be the case in this study as almost all the participants paid OOP and only one of them was supported by his cousin. This therefore creates massive inequality gap in the access to dialysis services among dialysis patients as was found in this study as only those who have money can access regular treatment while those who cannot afford the cost of treatment are left to die. It also shows that living with ESKD in Nigeria is a death sentence to the patients just as they often described in the interviews. The finding of the current study is like that of another, which investigated the impact of out-of-pocket payments for healthcare services on the utilisation of primary health care in the South-Eastern region of Nigeria (Onah and Govender, 2014).

The finding of this study therefore supports the view that OOP payments put patients into medical poverty trap, as they often had to borrow to be able to access the services without any government support or health insurance services available to them. The cost of treatment for the participants included direct costs such as: dialysis session fees, cost of consumables, outpatient consultation fees, drugs, costs of laboratory and radiological investigations, and the cost of hospitalisation if they need to be admitted in the facility after dialysis. The indirect costs include cost of feeding, transportation and the monthly cost of loss of productivity for the patients and their caretakers for each session of dialysis and other clinical consultations. For those of them who live in rural areas far away from the city, the cost of transportation often prevented them from attending dialysis sessions. This therefore consistently impaired the ability of some of the participants to maintain their treatment while those who could afford the cost of treatment received treatments as prescribed as evidenced by the dialysis frequency throughout the period of this study (Table 7). It also caused some of the participants to resort to herbal consumption.

The cost of treatment of renal diseases has been documented as a leading threat to health care resources globally even in the most advanced nations of the world (Mushi, Marschall and Fleßa, 2015). The major factor found to have influenced dialysis decisions and the coping strategies of almost all the participants regarding their illness was the cost of treatment. This finding contrasts with the CSM as cost is not one of the five constructs of the model. Therefore, this study adds a new dimension of cost to the Leventhal's CSM as the cost of treatment influenced the illness perception of the participants and their coping responses. In Nigeria, the cost of a session of dialysis varies among facilities, with the cost being excessively higher in private facilities than in the public facilities. This is further worsened by the lack of regulatory framework for the provision of dialysis services in the country to ensure quality and patient safety (Bello, 2014). There has been an increase in the number of dialysis facilities in the country in recent years. Most of the new facilities are owned and run by private individuals. Although this is a commendable development, it has however generated many disturbing questions regarding the quality of the services rendered to ESKD patients in those facilities. The concerns stemmed from the fact that most of the owners of these new facilities are business moguls who see these facilities as business investments for making profits. This concern in addition to the issue of shortage of qualified nephrology personnel in the country as discussed in Chapter 1, has led the Nephrology Association of Nigeria (NAN) and several leading nephrologists in Nigeria to raise concerns

regarding the quality and safety of the services they offer to patients (Braithwaite, Mabayoje, Amira and Coker, 2012; Bello, 2014). In addition, the lack of local regulatory oversight has created an opportunity for arbitrary charges for the cost of a session of dialysis in private facilities as observed in this study. This further adds to the challenges of the poor dialysis patients in the country who can hardly afford to sustain their treatment. Therefore, it is necessary for the government to increase the financial commitment to healthcare, include RRT in the NHIS and where possible subsidise the cost of dialysis for the patients. It is also necessary for the government to put in place a regulatory framework for the provision of renal services in the country to ensure the safety of ESKD patients. While many other studies have evaluated and compared the costs of RRT in various regions of the world, none has considered the impact of cost on access to treatment and sustainability of dialysis among ESKD patients in healthcare systems with unequal access to treatment. The finding of this study therefore, exposes the major barrier faced by ESKD in accessing dialysis services in low-resource settings.

Another major finding of the study is the issue of long waiting hours to be dialysed. The participants faced in the facility was the issue of long waiting hours because of too many ESKD patients receiving dialysis services in the facility. Some of the participants described having to wait for too long number of hours to be dialysed, and some had to cancel other daily engagements in order not to miss their dialysis schedule. The amount of time spent on dialysis has been variously described across the studies reviewed in chapter 2 (Hagren et al., 2001; Ravenscroft, 2005; Ekelund and Andersson, 2010; Herlin and Wann-Hansson, 2010; Monaro et al., 2009b; Kazemi et al., 2011; Al Nazly et al., 2013; Shaw, 2015; Gullick, Monaro and Stewart, 2016). The finding of this study is consistent with that of a previous study (Monaro et al., 2009) where time spent by dialysis patients was described as “lost time” and this was further categorised into “killing time” and “waiting time”, and both relate to patients’ perceptions of how much time is taken waiting to go on the dialysis machine and time while on the machine causing boredom. Similarly, in Gullick et al. (2016) time according to the dialysis patients were grouped into “lost time”, “clock time” and “lived time” and these times described the compartmentalising of the life of a patient on dialysis into dialysis and non-dialysis days. In contrast however, Burns, Tranter and Raghunath (2017) found that patients on in-centre night HD (INHD) had improved quality of life because the treatment allowed the patients a lot more time to engage in other non-dialysis activities as INHD is done at night times and is accompanied with sleeping during the

process. The experience of long waiting hours therefore created feelings of uncertainty among the participants. This finding supports those of previous studies associating the concept of uncertainty with haemodialysis patients (Tong et al., 2013; Kim et al., 2017; Sahaf et al., 2017). Long waiting hours to receive medical care has been associated with poor health outcomes including death (Prentice and Pizer, 2007; Pomerantz et al., 2008). Similarly, previous studies on cancer and heart disease patients have found prolonged waiting hours for care to be associated with an increased risk of mortality and morbidity in the patients (Starfield et al., 2005; Fahmy et al., 2009). The long waiting hours often discouraged some of the participants from attending dialysis sessions and forced them to resort to the use of herbal remedies which are readily available and cheaper than dialysis. Long waiting hours was found to have affected negatively the ability of some female participants to access regular dialysis. They cited societal norm/cultural expectations of married women not staying late away from home and being expected to do house chores like cooking for their husband as challenges they faced in dealing with the issue of long waiting hours. Waiting for too long late into the nights was therefore a taboo for them, and this caused them to skip some dialysis sessions. For most of the participants in this study who are frail, long waiting hours could therefore lead to the deterioration of their health condition and possibly death as was observed on a few occasions in the facility during the period of the study. This situation could have been better if more dialysis facilities were established in the rural areas to reduce the pressure on the only facility existing in the city.

The distance between where participants lived to the location of the dialysis facility was also found to be a barrier to regular dialysis services. This often-presented difficulties for them in arriving the facility on time for their dialysis and sometimes resulted in missing hospital appointments. The concentration of most of the dialysis facilities in the country within the cities posed serious threat to the effective management of ESKD in the country. It also adds to the cost of treatment for the participants and often “discouraged” them from attending dialysis sessions or other medical appointments. This finding is consistent with those of other studies where travel times to dialysis facilities served as geographic barrier to travelling to dialysis facilities in Wales (White et al., 2006), England (Maheswaran et al., 2003; Judge et al., 2011) and Japan (Kashima, Matsumoto, Ogawa, Eboshida and Takeuchi, 2012). It therefore suggests that the issue of geographic barrier to the effective utilisation of renal services is also observed internationally. Previous other studies have demonstrated an association between patients living closer to healthcare facility and having better health

outcomes when compared to those living further away (Jackson et al., 2013; Albornoz et al., 2016). This supports the observation in this study where in some instances, patients who had consistently failed to attend dialysis for various reasons were brought into the facility from very far villages at the points when their blood urea and creatinine levels were extremely high that they were almost dying. Some of these patients could have possibly survived the complications had they lived close to the dialysis facility or if they had any dialysis facility closer to them. Geographic challenges for commuting seemed to decrease participants' access to dialysis services as observed throughout the period of the study from the interviews. Some of them described instances where they had to put up in the hotel for some days as they missed their dialysis appointment on the scheduled time due to transport challenges from their respective States to the dialysis facility. Missing dialysis appointment time was compounded by the issue of high number of patients on the dialysis waiting list; this meant that patients who missed their appointed time irrespective of the cause would most likely either go back home and be rescheduled or sleep over in the hospital to be rescheduled for the next day. Sleeping over in the hospital was not cost-free as patients who elected to are expected to pay for the cost of "staying in bed" as that amounted to being on admission until the scheduled period of dialysis. This therefore added to the high cost of dialysis treatment and often affected participants' ability to travel back to their homes after dialysis sessions. The remote areas have serious challenge of public transportation infrastructure. Although I could not obtain any data on the actual availability of transportation means of the participants, most of them however use public transport system which they described as "erratic" and others use their private cars to commute to the facility. The latter means of transportation would be almost impossible from my observation as most of the participants in this study appeared quite frail. The distance issue was understandably more "worrisome" and "distressing" for the older participants than it was for the younger ones as they had difficulty in driving their car by themselves or travelling to the dialysis facility unaided by their family members. The extra cost of transportation often discouraged participants from attending dialysis and resulted in the postponement of the decision to attend dialysis. Establishing and maintaining dialysis facilities in the rural and remote areas would be vital in reducing the widening accessibility gap among ESKD patients on dialysis therapy. Providing public transport system or any other support system such as ambulance pickups for the patients could be a very important resource for the patients especially the elderly ones and those resident in rural areas where there are no facilities yet.

The cultural belief system of a society provides the lens through which people can make sense of, interpret, label and explain their illness experiences (Goins, Spencer and Williams, 2011). Cultural belief played a major role in the compliance of some of the participants with their treatment regimen and health check-ups. The cultural norms of the society observed among the participants relates to the attitude towards seeking healthcare services, and cultural expectations of the people. From the literature reviewed in chapter 2, ESKD patients on dialysis referred to family members, friends and HCPs as their source of social support. Generally, families were described in the positive sense as an important source of financial and emotional support. (Gregory et al 1998, Hagren et al 2001 ; Polaschek, 2003 ; Hagren et al. 2005 ; Nagpal et al. 2017). This is supported by a similar finding in the current study. In addition, the impact on the family may be profound as patients become increasingly dependent on them (Hagren et al., 2005; Nagpal et al., 2017); this was observed in the case of two younger participants in this study who depended fully on their respective families for their care. As they described during the interviews, their parents had to sell family properties to support them financially in their cost of treatment. This finding is synonymous with the finding of Gulics et al. (2013) which reported that chronic illness places huge financial burden on the family of the patient. Meeting basic family needs such as food and paying school fees for their children often affected participants` ability to go for dialysis. This was particularly more difficult for the older patients who are not in active employment but depended on their irregular pension payments from the government to pay for their health care. Though they had adequate knowledge of the importance of regular dialysis and expressed the willingness to embark on it, they were constantly constrained by the high cost of dialysis sessions and the competing needs of their families. Therefore, in most cases, going for dialysis sessions or other hospital appointments was perceived as secondary to family needs and participants often skipped dialysis sessions to meet them. The inability to sustain the cost of treatment was observed to be worsened by some societal norms/cultural expectations of the society. The cultural expectations/practices include older adults being responsible for the financial needs of their younger siblings, the first wife in a polygamous family looking after the rest of the husband`s wives if the husband is late and the societal expectation of a married woman cooking for her husband and doing house chores irrespective of her health condition. These were found to impact negatively on the ability of female ESKD patients to access regular dialysis services in this study and thus widens the inequality gap in the access to treatment between male and female ESKD patients. Some of the women reported skipping some hospital appointments because of obeying their cultural

norms of cooking for their husband. Cultural beliefs and practices have been found to be associated with adverse outcomes in pregnancy, labour and postpartum period in SSA (Sumankuuro, Crockett and Wang, 2018). This suggests the need for mass education of the people to dissuade them from conforming to harmful cultural practices at the expense of their health.

The construction of living with ESKD and being on haemodialysis by the participants in this study as death was not surprising because of their lack of agency to deal with the demands of their illness. This is consistent with the work of Gregory et al. (1998) which identified that situational factors such as the knowledge, experience of an illness, socio-cultural forces and a cognitive appraisal of the illness episodes and lifestyle changes influence the meaning given to an illness by patients, and these factors shape patients' reaction to the illness (Velez and Ramasco, 2006). The depiction of living with ESKD as death was as a clear expression of frustration of "knowing"- having the knowledge of the nature of their illness, the management regimen and the possible prognosis and being constrained by lack of necessary financial resources to sustain their treatment. The representation of meaning of life as ESKD and dialysis as death as expressed by the participants in this study has not been reported elsewhere in literature. This is particularly so in part because almost all previous similar studies on the experiences of ESKD were conducted in regions of the world where the participants have regular access to healthcare including RRT, received healthcare support from the government and did not have to worry about the cost of treatment like those in this study. However, previous other study (Caress et al., 2001) based on the Meaning of Illness Schema (Lipowski, 1983) had reported that dialysis patients described living with ESKD as a challenge which was consistent with "fighting spirit". The authors reported that participants demonstrated a sense of fatalism by accepting to put up with their illness without letting it affect their daily lives; such demonstration of "fighting spirit has been shown to improve health outcomes in cancer patients (Luker et al., 1996; Pintado, 2018). The meaning of illness as ESKD patients by the participants was clearly shaped by their understanding of the fact that they will die of their illness due to the lack of money to maintain treatment. This finding supports the assertion of Leventhal's SRM (Leventhal, 1980) that time line and cure/control dimensions of an illness shape patients' meaning of their illness. However, the meaning the participants ascribed to their illness in contrast to the posits of SRM had no impact on their coping and health behaviour as these were heavily shaped by the cost of treatment as found from the interview transcripts over time.

The lack of equal healthcare access to ESKD patients and by extension the general Nigerian populace has serious cost implications for the government and the society. This is because patients suffering from chronic illnesses as observed in this study are lost to death due to lack of health insurance and affordable care. As can be seen from the findings of this study, most of the participants were quite frail and passed on before the completion of the study. This therefore deprives the society of their valuable contributions. It shows by extension, the negative impact of ESKD and poor healthcare policy on the Nigerian society and the need for urgent action by the government.

7.4.7 Accessing irregular dialysis-misinformed and wasting scarce resources

The effectiveness of the care given to patients with long-term conditions is strongly affected by the quality of the communication, the rapport and the therapeutic relationship between the HCPs and the patient, including others who are involved in the care and support of the patient (Checton et al., 2012). One major finding of this study is the clear lack of adequate information on the treatment options for the management of ESKD. Although most of the participants demonstrated awareness of renal transplantation as a treatment option, they clearly lacked any knowledge of conservative management as a better choice than dialysis in the management of ESKD. This lack of information therefore affected the ability of the participants to make informed decisions about using their money wisely for the appropriate treatment. This finding is consistent with those of previous other studies which found that lack of information on the available treatment options constrained decision making on RRT by ESKD patients and thereby limited their options (Trisolini et al., 2004; Harwood et al., 2005; Landreneau and Ward-Smith, 2006). This finding may not be entirely surprising because, most Nigerians have poor health-seeking behaviour and do not bother going for health checks until they are severely-ill (Onwujekwe et al., 2010; Audu et al., 2014; Ajaegbu and Ubochi, 2016). Therefore, this finding could mean that the participants presented to the renal clinic when they were already in advanced stage of the disease and the only option left would usually be to commence dialysis before patients develop severe symptoms leading to hospitalisation as discussed in the introduction (chapter 1). The management options usually communicated to the participants as found in this study are haemodialysis and renal transplantation since peritoneal dialysis was not practised in Nigeria as at the time of this

study. However, considering the poor economic situations of the participants, renal transplantation seemed out of reach and affording the cost of regular dialysis almost untenable. This therefore, left them with no other option than to initiate HD as the only orthodox treatment they can afford. In addition, the lack of provision of information on conservative management despite its advantages over dialysis to the participants could be due to the non-familiarity with the option or a lack of information to counsel the patients and their families. This therefore suggests that educational programs targeting renal patients, primary care physicians, renal nurses and the entire renal community should be designed to raise the awareness of the importance of conservative management as a viable and acceptable alternative treatment. Whatever the circumstances of the patients are, it is pertinent to give adequate information on all the treatment options available to ESKD patients and allow them to make informed choice based on their resources, cognition and life goals. Perhaps the participants could have opted to undergo conservative management of their illness as opposed to spending their meagre resources to commence haemodialysis knowing fully well that they could not sustain their treatment. They could also have chosen to die and use their little resources to plan for their funeral or made different treatment choice based on the full information given to them. This is necessary as Seah et al. (2013) found that the financial implications of maintenance dialysis largely influence ESKD patients' decision to opt out of dialysis and depend on conservative non-dialytic management. More so, conservative non-dialytic management of ESKD has been reported to offer better survival advantage over dialysis and improves quality of life in the patients (Fasset et al., 2011; O'Connor and Kumar, 2012). HCPs involved in renal services should therefore discuss conservative non-dialytic management as an alternative while counselling patients and their families about dialysis especially the elderly patients or those with increased comorbidity. Since most of the patients cannot afford the cost of maintaining their dialysis without any support from the appropriate authority as found in this study, HCPs should do well to inform them of the consequences of not maintaining dialysis after initiation as was common among the participants. This is very important as patients who decline to initiate dialysis have been reported to live for months to years with the appropriate supportive care unlike withdrawal from dialysis which ultimately leads to death (O'Connor and Kumar, 2012).

The need for ESKD patients to have access to information that enables them to make informed choices and achieve the best possible quality of life has been emphasised by the UK National Services Framework for renal services (DOH, 2004). In addition, provision of

information to ESKD patients at the commencement of dialysis has been discussed in literature and the need for this have been highlighted. Most of the studies on information provision in CKD have focused on examining the roles of ESKD patients in decision making for the choice of dialysis modality, and their information needs (Szabo et al., 1997; Orsino et al., 2003; Lin, Lee and Hicks, 2005; Tweed and Ceaser, 2005; Lee, Gudex, Povlsen, Bonnevie and Nielsen, 2008; Murray et al., 2009; Chanouzas, Ng, Fallouh and Baharani, 2012; Harwood and Clark, 2013). These studies highlight the enormous challenges ESKD patients face in making a choice between the dialysis modalities available to them.

Studies examining the impact of education on the choice of dialysis modalities have demonstrated that pre-dialysis education programme promotes the choice of home-based therapies by ESKD patients (Rasgon et al., 1996; Gomez et al., 1999; Wilson and Clarke, 2004; Goovaerts et al., 2005; Ribitsch et al., 2013). Similarly, an incomplete presentation of treatment options to dialysis patients has been reported as the major reason for the poor utilisation of home-based dialysis therapies and possible delayed access to renal transplantation (Mehrotra et al., 2005). This supports the view that pre-dialysis patient education should focus on not only patients' lifestyles but also on their beliefs and facts about dialysis. Curiously, in all the studies mentioned above, little emphasis was placed on the complications, risk factors and prognostic information on ESKD treatments. Some authors have argued that the provision of prognostic information has been neglected by HCPs for various reasons including ethical dilemma and the conventional paternalistic approach of the medical profession (Fine et al., 2005; Miller, 2005; Holley, 2007). However, the paradigm shifts to a more autonomous approach and acceptance of the need for patients to be fully informed has further advanced the debate for the provision of prognostic information to patients. In the current study, some of the participants demonstrated clear lack of knowledge regarding the possible prognosis of their illness as evidenced by some of the questions they posed to me during the interviews sessions and their assertions regarding their treatment as highlighted in Chapter 5. While some of the participants perceived ESKD as an illness that can be cured through few sessions of haemodialysis, others had the perception that they can be cured by divine intervention. It is therefore inconclusive whether this was a manifestation of lack of provision of prognostic information by the HCPs or because of the African cultural practice of not discussing unwanted outcomes such as death when one is suffering from an illness (Ekore and Lanre-Abass, 2016) as discussed in chapter 1. This also reflected in this study as only two of the participants talked about death. In the context

of this study, providing the patients with adequate prognostic information is pertinent; because being aware of the possible prognosis may offer them the opportunity to make decisions whether to commence dialysis and still die from the symptoms due to inability to sustain the cost of dialysis, or to channel their meagre resources towards planning for the end of their lives. A systematic review of patients' information need (Ormandy, 2008), identified thirteen information topics that are of importance to CKD patients. Some of the topics include information on RRT, lifestyle regimen and physical symptoms of the illness (Ormandy, 2008). However, it is still not yet clear when is the best time during the progression of CKD to provide the respective information or in deed which of the topics is of higher priority at any point in time (Ormandy, 2008)? This study is limited in the extent to which answers to the questions of what, when and how much risk information should be provided to ESKD patients. For patients who have been diagnosed to be in advanced stages of CKD as the participants in this study, this finding suggests that every necessary information should be given to them right from the point of diagnosis to enable them make decisions regarding their healthcare and their end-of-life decisions.

Within the UK renal services, enhancing patient participation in the management of their health through the provision of patient information is a priority (DOH, 2004). This further demonstrates the importance of information in ensuring better patients outcomes. However, there are no formal guidelines on the development of patient information resources or to evaluate the quality, source and the amount of information on renal services that the patients are given (Winterbottom, Conner, Mooney and Bekker, 2007). The health information patients need is quite diverse and vary according to their age, sex, preferences, beliefs, general literacy level, first language, coping strategies, skills and abilities (Coulter, Parsons and Askham, 2008). The information needs of patients often change during an illness and this is prevalent in patients with long-term conditions such as ESKD (Coulter, Parsons and Askham, 2008). It is therefore pertinent for HCPs to recognise that at the initial point of diagnosis, patients often need viable information to support their health care decisions including reassurances to reduce anxiety. However, this information needs change later to more specific and detailed information when they focus on the long-term self-care and prognosis of the illness.

Communication and interpersonal skills have been emphasised as one of the four key areas of professional nursing practice (Nursing and Midwifery Council [NMC], 2014). Effective communication among healthcare practitioners, patients and their families are an essential

aspect of quality healthcare practice, and it plays a major role in improving patient outcomes (Holman and Lorig, 2000; Pomey et al., 2015). There was a clear lack of adequate and effective communication of nutritional and prognostic information to the participants. Various reasons were ascribed by the participants as to why the HCPs did not give them adequate information regarding their treatment. The reasons included lack of time for proper explanation of necessary information and assumption that participants already had the necessary knowledge. Similar finding has been reported in a previous study assessing CKD management in the UK (Ahmad, 2006) where lack of time due to excessive workload on HCPs was found to be a barrier to effective counselling of patients. However, this study did not set out to include the HCPs and so, there was no concrete information on why the HCPs did not communicate effectively with the participants in respect of their treatment regimen, and the possible outcomes of their illness. It is well recognised that the successful management of chronic illness depends on active patient involvement and enhances self-management. Self-management of long term conditions therefore involves both the adoption of new health behaviours by the patients and changes in existing behaviours. However, evidence has shown that achieving behaviour change is dependent on many other factors including effective communication with HCPs (Michie, Miles and Weinman, 2003). Similarly, health literacy is fundamental to promoting self-care among patients with long-term conditions (Coulter and Ellins, 2007; Edwards, Davies and Edwards, 2009). If patients with long-term conditions cannot obtain, process, understand and utilise basic health information, they will not be able to make appropriate decisions regarding their health or treatment. Health literacy does not only involve patient's ability to read and understand health information but it also includes empowering patients to make health decisions. Patients with low health literacy have poorer health status and are less likely to comply with prescribed treatments and self-care plans (Coulter and Ellins, 2007).

Another major finding of the study was the clear lack of adequate nutritional education of the participants. Participants reported being given conflicting nutritional information by the HCPs. Due to the educational levels of most of the participants it was not clear whether the conflicting nutritional information was provided by the renal dieticians or other HCPs. However, one of the participants was categorical that he was given conflicting nutritional information by a doctor. This affected their ability to make simple nutritional decisions and created a sense of confusion to the participants. Poor patient communication by healthcare practitioners has been associated with decreased patient confidence and satisfaction (Epstein,

1995; Preston, Cheater, Baker and Hearnshaw, 1999). This finding is consistent with that of another study which explored patients' experiences of dietary change in type-2 diabetes mellitus (Ball et al., 2016) where conflicting nutritional information from HCPs and other sources created confusion in the ability of patients to maintain healthy diet. This is very worrisome and raises questions about the healthcare practitioners' knowledge of the nutritional management of HD patients. Studies have shown that ESKD patients prefer receiving dietary education from experts like renal dietitians who can provide them with the requisite practical and constructive advice (de Brito-Ashurst et al., 2010; Meuleman et al., 2014). However, this may not be feasible in low-resource settings such as Nigeria as was observed in this study. This finding therefore suggests that it is necessary that all HCPs involved in renal care should be trained on the nutritional management of renal conditions especially in low-resource settings such as the context of this study where inadequate number of renal dieticians or entirely lack of any would mean the renal nurses and doctors must carry out this role. This is necessary to ensure that all clinicians involved in renal care have the relevant knowledge and skills to provide flexible, personally and culturally-relevant nutritional counselling to ESKD patients. In addition, some of the participants reported difficulty in identifying the local food sources based on the recommendation to avoid foods that contain protein. This means that it is necessary for the HCPs to design nutritional leaflets detailing the local sources of food that contains protein and those foods that are necessary in the management of their illness. This will help to reinforce the initial information provided at the commencement of their dialysis session. The leaflets should be designed in a clear, concise and readable format; it should be made readily accessible and comprehensible in both English and the local language of the of the patients' community to enable shared decision-making.

Although most of the study participants appeared frail and fatigued as result of their inability to sustain their management regimen and cope with the symptoms of their illness, they were optimistic, resilient and defiant of the possible prognosis of their condition. Despite their frailty, they were willing to engage in meaningful employment to be able to pay for their treatment but could not secure any. This finding supports that of a previous study (Huang et al., 2017) which reported low level of employment as a challenge among persons of working age who were on maintenance haemodialysis. The physical symptoms (as can be inferred from the clinical parameters- Tables 8, 9 and 10) experienced by some of the participants who were on employment were found to affect their ability to cope with their jobs due. This

resulted in their loss of their job and worsened their ability to cope with the cost of maintaining their treatment, and most of them had to skip many sessions of HD as evident on the dialysis frequency table (Table 7). Another surprising finding in this study is that discriminatory tendencies by potential employers due to physical appearance and stigmatisation from work colleagues were reported to be barriers to successful employment by the study participants. This finding corroborates those of previous other studies (Huang et al., 2017; Tsutsui et al., 2017) which found lack of acceptance by employers and superiors and misunderstanding by work colleagues due to frequent hospital visits and physical symptoms as the main challenges that affect employment in haemodialysis patients. This finding therefore suggests that dialysis patients, the public and employers should be educated on the treatment choices and the therapeutic goals for ESKD. The importance of employment in the rehabilitation of haemodialysis patients, enhancement of their socioeconomic status as well as in the promotion of their quality of life should be stressed (Muehrer et al., 2011; Julian et al., 2012). These should also be taken into serious consideration when formulating healthcare policy or quality control programs for ESKD population to help working age patients keep their jobs. In addition, the provision of social support, vocational rehabilitation or employment counselling could help lower some of the barriers to employment in dialysis patients who have the capacity and the capability to engage in meaningful employment. It may also be pertinent to adapt haemodialysis shifts to the lifestyle of individual patients to improve the chances of employment continuation in dialysis patients.

7.4.8 Being healed by faith and herbal remedies

The spiritual and religious beliefs of patients help in their experience of coping with a chronic illness by providing them with hope, confidence and support or they can interfere with the successful management of their condition (Harvey and Silverman, 2007). This is because patients may neglect self-care activities and prescribed treatment by relying on prayers or medications in the management of their illness (Quinn, Cook, Nash and Chin, 2001). The religious beliefs of the participants in this study influenced their decisions and views on RRT. While some participants held strong views regarding their religious belief as a source of healing, some others did not. For some, their faith in God was the true source of “healing”, “comfort” and “restoration” of their health while dialysis was often discountenanced and seen as secondary to “divine healing”. This finding sharply contrasts

that in the literature reviewed (Tanyi and Werner, 2008) in which spirituality/religion was found to be crucial in the acceptance of diagnosis, adjustment and adherence to treatment by ESKD women on HD. Religion/ spirituality helped the participants in this study accept to accept their living with ESKD as the “will of God” in their lives and this helped to reinforce their belief in divine intervention to “save” them. However, religiosity/ spirituality has been associated with non-compliance with immunosuppressive medications in renal transplant patients (Silva et al., 2016).

In the context of wider literature, religion/spirituality have been reported to facilitate patients` adherence to medical treatment (Singleton, 2002; Caspi, Koithan, and Criddle, 2004). However, it has been associated with poor compliance with Anti-Retroviral Therapy (ART) in HIV/AIDS patients (Kremer, Ironson and Porr, 2009; Martinez, Lemos and Hosek, 2012; Nozaki et al., 2013). Therefore, the religious beliefs of some of the participants in this study had a negative influence on their health behaviour. This made them to perceive attending dialysis sessions as simply trying to “please” the doctors because of the way they were cared for by them and not necessarily as a major source of treatment for their condition. This finding suggests a massive gap in knowledge of the participants which needs adequate attention to help save the ESKD population. Religious leaders should be involved in creating awareness of the causes and treatment regimen of CKD in Nigeria especially in the rural areas.

The religious beliefs of participants in this study not only shaped their dialysis decision, it also had influence on their acceptance of the idea of renal transplantation as they were counselled by the HCPs. Although the thought of renal transplant for most of the participants in the study was “a luxury” due to their horrible experience of inability to afford the cost of regular dialysis, some of them perceived receiving the kidney of others via renal transplantation as “abhorrent”, “unacceptable” and against the tenets of their religion. During the third interview, one of the participants surprisingly remained adamant that he was prepared to “die” than to ever contemplate renal transplantation. While many studies have considered factors influencing kidney donation or the donation of other organs, none has evaluated the willingness of ESKD patients to accept kidneys. However, uncertainty about risk to personal health has been reported as the main cause of reluctance to accept xenotransplantation by a majority of ESKD patients in the Netherlands (Kranenburg et al., 2005); while only a small percentage cited religious or spiritual reasons for non-acceptance. The finding of the current study therefore provides a unique perspective to understanding

issues surrounding renal transplantation among ESKD patients in African context. It suggests that while renal transplantation is the gold standard treatment for ESKD, its acceptance may be limited by cultural or religious beliefs as found in this study. Therefore, it is pertinent to create awareness on the importance of transplantation among ESKD patients especially those resident in rural areas to quash such beliefs and promote RRT for ESKD patients.

Although religious beliefs influenced the dialysis and transplant decisions of some participants in this study, it generally served as a source of “hope”, “comfort” and “strength” in coping with the experience of living with ESKD and receiving dialysis in a health care system with unequal access to treatment.

Another finding of the study is that herbal remedies were believed to be effective in the management of ESKD by some of the participants, and they consistently held this view throughout the period of the study. This belief is culturally constructed as surprisingly, some of the participants who stated they often consumed herbal remedy as a treatment are educated and stated such practice has been an essential part of the culture of the society when one is ill. This finding supports that of a previous study (Lee, Charna, Chewa and Ng, 2004) in which the use of complementary and alternative medicine (CAM) by patients suffering from chronic illnesses such as arthritis, musculoskeletal disorders and stroke were significantly associated with cultural beliefs of the patients than satisfaction with the quality of the health care services they received. Similarly, herbal use has been found to be common among patients diagnosed with long-term conditions such as diabetes mellitus, hypertension and hyperlipidaemia (Tulunay, Aypak, Yikilkan and Gorpelioglu, 2015). In contrast to the findings of other studies (Barnes, Bloom, Nahin, 2008; İpek et al., 2013; Soner, Şahin and Şahin, 2013), this study did not observe any relationship between the use of herbal remedies by the participants and their educational level, as some of them are educated individuals. Those studies found that people who had high levels of education were more likely to use herbal remedies in the management of their chronic illnesses. In addition, while women have been found to be more prone to use herbal remedies (Barne et al., 2008; Ipek et al., 2013; Soner, Sahin and Sahin, 2013), this study in contrast had almost equal number of men and women who reported use of herbal remedies. However, the study did not include equal number of men and women as participant and so; it could be difficult to make a non-biased conclusion regarding this. In contrast to the finding of Tulunay et al. (2015) in which herbal remedies were often recommended by the HCPs for the management of chronic diseases,

this study did not find such. In fact, all the participants who reported their use of herbal remedies during the interviews stated that they hid such information from the HCPs to be compliant with the recommendations given to them. Withholding a major clinical information by patients is a sort of intentional deception in the healthcare practitioner-patient relationship, which can hinder effective clinical care (Palmieri and Stern, 2009). This practice was evident throughout the period of this study. The concealment of the practice of herbal consumption by some of the participants who indulged in the act suggests a fear of reprimand by the HCPs or possibly because of feeling of loneliness or social isolation which could result in patients` hiding of information as reported in previous other studies included in the literature reviewed (Kaba et al., 2007; Molzahn et al., 2008). One of the participants who later reported his use of herbal remedies did not reveal this during the first interviews but was considering opting for it during the second interview. While I probed further during the interview, he revealed why he was opting for the herbal treatment. This finding highlights the importance of using a QLRS approach in this study as it shows the changes in the treatment decisions, views, options and reasons among dialysis patients in low-resource settings which I could not have uncovered in a snapshot of interview. The concealment of useful lifestyle information by patients could lead to poorer health outcomes for them as the combination of orthodox treatment and the herbal remedies could worsen their biochemical test results. This practice suggests knowledge gap and complete lack of education as these participants did not seem to understand the impact of herbal remedies on their already-diseased kidneys. The use of herbal remedies by the participants was also found to be related to their inability to sustain the cost of dialysis, which they perceived as exorbitant and beyond their reach as discussed above. The inability to sustain the cost of treatment was observed to be worsened by some cultural expectations of the society.

The use of herbs in the treatment of illness is an ancient societal/cultural norm in most African societies which persists today due to ignorance and strongly-held beliefs in its efficacy to heal all diseases (Abdullahi, 2001; Boadu and Asase, 2017). This was observed in this study as participants consistently maintained their position in its efficacy to heal their illness. In some cases, as noted in the interviews, some of the participants reported combining their medical management (dialysis) with the herbal consumption in the hope that it will cure their disease. This further demonstrates lack of awareness, information and knowledge about the causes, treatment and prognosis of ESKD among Nigerians with little or no formal education and those resident in the rural communities. This practice therefore

conflicts with the orthodox management of ESKD and is a clear barrier to the effective management of ESKD in low-resource settings where the patients are severely poor and can hardly afford healthcare.

7.5 Key contributions to knowledge

This study exposed the various challenges faced by ESKD who are dependent on haemodialysis treatment for their survival in a healthcare system where only those who have the money to access dialysis services survive longer while those who do not have die early. It highlights the level of mortality associated with CKD in regions of the world where patients and their families bear the burden of the illness and the cost of treatment without any form of support from the government. It also exposes the negative impact of some religious beliefs, societal norms and cultural practices on compliance with treatment in dialysis patients. In addition, it highlights the need for the provision of detailed information to dialysis necessary for the management of renal patients to enable them to make informed choice regarding their treatment. It also demonstrates that qualitative longitudinal research approach is valuable approach for gaining deeper understanding of the lived experiences of patients suffering from chronic illnesses.

7.6 Strengths and limitations of the study

7.6.1 Strengths

The key strengths of the study include:

- The use of a QLRs approach in its conduct. Adopting a QLRs approach enabled me to explore in detail, what it means to be a renal patient receiving dialysis services in a low-resource setting like Nigeria. Several other studies had been conducted in regions of the world where ESKD patients on dialysis treatments either have equal access to healthcare or where the cost of renal services is being subsidised by the government. The experiences of such patients as can be seen from the literature reviewed (Chapter 2) clearly contrast those of the participants in this study. Patients

in such climates lived longer and had better quality of lives in contrast to those in the setting of this study whose lives were dominated by the impact of the illness and lack of resources to seek the necessary treatment. Therefore, collecting a snapshot of data from the participants in the study reviewed could be a good representative of the illness experiences of the patients studied. However, such would have been a contrast in this study, as a snapshot of interviews could not have given a detailed picture of the experiences of the patients in such setting. Therefore, QLRS approach offered the unique opportunity to engage with the participants over time and gain a deeper understanding of their lives as dialysis patients in a low-resource country where they had to struggle to pay out pocket for their treatments despite their frailty and disability. It also enables me to dig deeper into the cultural and societal norms which act as barriers to effective compliance with treatments as can be found from the interview transcripts where some of the participants were not willing to talk about certain issues in the first interview session but were more relaxed and comfortable to share their experiences of the illness. This unique importance of QLRS approach in giving researchers the opportunity to establish a mutual trust with the research participants to elicit information on the phenomena being studied is an excellent strength of this study. This is because most of the participants as can be seen in their difficult stories would not have revealed a lot about their experiences. In addition, in a society where HCPs are “Lords” and patients obviously have no much say in their care, most of the research participants would not have been courageous enough to speak out on their true experience of the care they were being given by the HCPs. This supports the finding of other researches, which found that QLRS has therapeutic potentials for research participants (Holland et al., 2006; Murray et al., 2009; Taylor, 2009) because a trusting relationship between the researcher and the participants enables the participants to share their stories.

- Using a QLRS approach in this study was also apt as it offered the opportunity to follow the participants through over the period of the study and gain a real understanding of the mortality issue among ESKD population in Nigeria as was found in this study. Using a snapshot approach in the data collection could not have revealed the danger of the patients face as can be seen in the number of participants left on the study during the third phase of the data collection.

- The combination and application of other data such as the reflexive journal inserts in the formulation of the respective themes and an acknowledgement of ‘self’ within the research at the outset through a critical self-reflection and reflexivity which continued throughout the period of data collection enhances the credibility of this study. In addition, the truth of the participants’ responses gathered overtime using the QLRS approach allowing confirmation and changes in opinions and experiences to be captured adds to the credibility and the dependability of the research findings.
- Another major strength of this study is that it is the first to examine the experiences of ESKD patients receiving dialysis treatment in healthcare systems with unequal access to healthcare. It is also the first study to expose the impact of contextual issues such as cultural/societal norms, cost of treatment, family and religious beliefs on sustainability of dialysis treatment. It therefore adds a new perspective into what was known on the lived experiences of dialysis patients globally.

7.6.2 Limitations of the study

Although the findings of this study have contributed new knowledge to the understanding of the lived experiences of ESKD patients who are receiving dialysis services, the findings may not be transferable (generalizable) to other contexts due to the limitations in the study design. The limitations therefore include:

- **Lack of transferability-** Qualitative studies exploring patients’ experiences by their nature are not transferable. This is due to the characteristics small sample size, which cannot represent a whole population. However, the usefulness and transferability of the study should not be judged based on positivist criteria but by the criteria, which are consistent with the philosophical values underpinning qualitative studies. Therefore, the aim of the research, which was to explore the experiences of CKD patients receiving haemodialysis in healthcare systems with unequal access to treatment, was achieved through in-depth interviews of the participants and did not intend to generate any statistically generalisable finding.

- **Nature of the study sample-** The study included higher number of men than women, so to some extent may represent more of the experiences of male dialysis patients than those of female patients. Perhaps recruiting equal number of male and female patients could have given a different mix of the experiences of the patients. It is pertinent to do this as studies have shown higher prevalence of CKD in females than in males in Nigeria (Oluyombo et al., 2013; Nalado et al., 2016; Abene et al., 2017). In addition, most of the study participants were quite frail because of the impact of their illness and so could not respond to some of the questions or speak for too long during the interviews sessions. This could possibly have denied me the opportunity to capture further details of their stories, which could have further enriched the depth of study the findings.
- **Possible researcher influence-**In a qualitative study like, my role as researcher may have influenced the interviews and the interpretation of the findings even though I was conscious of that and I tried to be detached from having any influence of any form on the whole process. As I had acknowledged in the reflexivity section (Chapter 4), bringing my professional experience as a nurse who had cared for two of the research participants into the research process could have influenced the ways I framed the interview questions and my perception of the healthcare system. Therefore, my personal biases and preconceptions could have influenced the way the interviews progressed.

7.7 Recommendations

This section presents a summary of the implications of the research findings for practice, policy and research.

7.7.1 Implications for practice

The following recommendations are made for clinical practice based on the research findings:

- There is a need to improve information provision to dialysis patients and their families. The specific recommendations in this area:

- (a) There needs to be a discussion regarding the option of conservative non-dialytic management while counselling patients and their families about dialysis especially the elderly patients or those with increased comorbidity. This is necessary to provide them with the information to make choices regarding their condition and consider fully end-of-life issues given the financial pressures of treatment.
- (b) There needs to be information provided on the consequences of initiating dialysis options and not sustaining treatment. It is also pertinent for the HCPs to improve on the provision of prognostic information to the patients.
- (c) Nutritional information provided to CKD and ESKD patients needs to be improved. This can be achieved by designing nutritional leaflets detailing the local sources of food that contains protein and those foods that are necessary in the management of their illness. This will help to reinforce the initial information provided at the commencement of their dialysis treatment. The leaflets should be designed in a clear, concise and readable format; it should be made readily accessible and comprehensible in both English and the local language of the of the patients` community to enable shared decision-making.
- Mass education and creation of awareness on the causes, prevention and treatment of CKD in Nigeria is required. This is particularly important within rural communities where many people reside and are less likely to have the knowledge of the condition. There is a need to involve religious and community leaders in carrying out this mass awareness programme to ensure its effectiveness. This will help reduce the prevalence of CKD in the country, promote health-seeking behaviour among the people, break the cultural and barriers to dialysis access, quash superstitious beliefs surrounding kidney/organ donation and transplantation,
 - HCPs involved in renal services require training on appropriate information provision and nutritional management of renal conditions in low-resource settings. This is necessary to ensure that all clinicians involved in renal care have the relevant knowledge and skills to provide flexible, personally and culturally relevant nutritional counselling to ESKD patients. It will also help eliminate the cases of

HCPs providing patients with contrasting nutritional information and enhance the confidence of patients in their healthcare providers.

- There is a need to develop and promote patient empowerment through adequate patient-centred information provision that reflects and respects their opinions and choices.

7.7.2 Implications for health care policy

Based on the research findings, the following recommendations are made to improve the health care policy in Nigeria:

- The Nigerian government needs to change the current health policy and include renal services on the NHIS programme to enable those people without the funds to pay for treatment to have equitable access to health care. This should be made available for all citizens as a right without exclusion based on personal circumstances. This means that the service should not exclude individuals who are not working in the government sector as the cost of renal treatment is a huge burden for families to bear and the government should be taking the lead in tackling this problem.
- More government funded renal facilities are required, particularly within rural and remote areas, which to reduce the widening accessibility gap among ESKD patients on dialysis in Nigeria. The establishment of these services in the rural areas would help alleviate the hardship dialysis patients' resident in the rural areas face in accessing the services from the available centres in the city. Siting of dialysis facilities in the rural areas will also help in reduce the increasing pressure on the few facilities located in the cities, characterised by long waiting hours.
- The government should consider the provision of a public transport system or support system such as ambulance pickups for those unwell or elderly patients, and those resident in rural areas where there is no local access to renal facilities.

- There is a need for the government to develop a regulatory framework to monitor the cost and quality provision of renal services in the country to ensure safety of ESKD patient treatment and prevent corrupt pricing and extortion. This will curtail the arbitrary charges for a cost of dialysis session seen in the private dialysis facilities.
- In the formulation of healthcare policy, the government should consider the inclusion of the provision of social support, vocational rehabilitation or employment counselling to the ESKD population. This will help lower some of the barriers to employment in dialysis patients who have the capacity and the capability to engage in meaningful employment. It will also help to enhance the socioeconomic status as well as promote the quality of life of ESKD patients.

7.7.3 Implications for research

This study has raised a few issues that are relevant for future research. Therefore, the following suggestions are made as possible research topics:

- Exploration of the knowledge and perception of conservative non-dialytic management of ESKD among healthcare providers.
- Assessment of the knowledge of nutritional management of ESKD among doctors and nurses involved in renal services.
- Exploration of the lived experiences of HCPs working in the renal services.
- Exploration of the lived experiences of elderly dialysis patients in low-resource settings.
- Exploration of the burden of care among the families of dialysis patients in low-resource settings.
- Exploration of the lived experiences of ESKD patients who were diagnosed but could not go on to initiate dialysis therapy.

7.8 Conclusions

Money was a major issue which threaded throughout the study and affected patients` ability to access regular dialysis services. It impacted negatively on not only the meanings participants ascribed to living with ESKD and depending on haemodialysis but also on the decisions they made with respect to sustaining their treatment regimen. Lack of money often made some of the participants to resort to the use of herbal remedies, skip dialysis sessions and resort to religion as a source of healing. Dialysis patients should be discouraged from selling all they have to pay for treatment thereby stripping themselves of the meagre resources of their families for very little gain. Healthcare practitioners should provide accurate information on the treatment options for ESKD to patients to enable them to make informed choices over their lives.

Therefore, within the limitations expressed, this study was successful in providing an invaluable insight into how ESKD patients who are dependent on haemodialysis live and manage their condition in a healthcare system with unequal access to treatment. It has also added to the global understanding of the topic and provided evidence to advise change in practice in both renal services and healthcare policy in Nigeria.

References

2017 USRDS Annual Data Report: Executive Summary. (2017) (pp. 1-246). United States of America. Retrieved from

https://www.usrds.org/2017/download/2017_Volume_1_CKD_in_the_US.pdf

Abdullahi, A. (2011). Trends and Challenges of Traditional Medicine in Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 8(5S). doi: 10.4314/ajtcam.v8i5s.5

Abene, E., Gimba, Z., Agaba, P., Uchendu, D., Olaniru, O., Ocheke, I., & Agaba, E. (2017). Chronic kidney disease screening: results of the 2013 world kidney day activities conducted at the Jos University Teaching Hospital. *Highland Medical Research Journal*, 17(1), 1-5.

Abimbola, S., Olanipekun, T., Igbokwe, U., Negin, J., Jan, S., & Martiniuk, A. et al. (2015). How decentralisation influences the retention of primary health care workers in rural Nigeria. *Global Health Action*, 8(1), 26616. doi: 10.3402/gha.v8.26616

Ackerly, B., & True, J. (2010). *Doing feminist research in political and social science*. Basingstoke, Hampshire: Palgrave Macmillan.

Ackers, L., Webster, H., Mugahi, R., & Namiiro, R. (2018). What price a welcome? Understanding structure agency in the delivery of respectful midwifery care in Uganda. *International Journal of Health Governance*, 23(1), 46-59. doi: 10.1108/ijhg-11-2017-0061

Addo, M., & Eboh, W. (2014). Qualitative and quantitative approaches. In R. Taylor, *The Essentials of Nursing and Healthcare Research* (pp. 137-154). London: Sage Publications.

Adedini, S., Odimegwu, C., Imasiku, E., & Ononokpono, D. (2014). Ethnic differentials in under-five mortality in Nigeria. *Ethnicity & Health*, 20(2), 145-162. doi: 10.1080/13557858.2014.890599

Agaba, E., Lopez, A., Ma, I., Martinez, R., Tzamaloukas, R., Vanderjagt, D., & Tzamaloukas, A. (2003). Chronic haemodialysis in a Nigerian Teaching Hospital: practice and costs. *The International Journal of Artificial Organs*, 26(11), 991-995.

Agbaji, O., & Abene, E. (2012). Care of patients with end-stage renal disease in Nigeria: a call for a change in paradigm. *Jos Journal of Medicine*, 6(3), 28-31.

Ahmad, A. (2006). Current chronic kidney disease practice patterns in the UK: a national survey. *QJM*, 99(4), 245-251. doi: 10.1093/qjmed/hcl029

Ahrari, S., Moshki, M., & Bahrami, M. (2014). The Relationship between Social Support and Adherence of Dietary and Fluids Restrictions among Hemodialysis Patients in Iran. *Journal of Caring Sciences*, 3(1), 11-19.

Ajaegbu, O., & Ubochi, I. (2016). Health Seeking Behaviour among Undergraduates in the Faculty of Health Sciences and Technology, University of Nigeria Enugu Campus. *International Journal of Evaluation and Research in Education (IJERE)*, 5(3), 181. doi: 10.11591/ijere.v5i3.4537

Akinsola, A., Adelekun, A., & Arogundade, F. (2000). Continuous Ambulatory Peritoneal Dialysis (CAPD) practice in OAUTH Ile-Ife, Nigeria: a preliminary experience. *Nephrology Dialysis Transplant*, 29, 774-782.

Akinsola, W., Odesanmi, W., Ogunniyi, J., & Ladipo, G. (1989). Diseases causing chronic renal failure in Nigerians- a prospective study of 100 cases. *African Journal of Medical Sciences*, 18(2), 131-137.

Akpan, E., & Ekrikpo, U. (2015). Chronic Kidney Failure: Knowledge of Kidney Disease, Perception of Causes and Symptomatology in Uyo, Nigeria. *Open Journal of Nephrology*, 05(03), 91-97. doi: 10.4236/ojneph.2015.53014

Al Nazly, E., Ahmad, M., Musil, C., & Nabolsi, M. (2013). Hemodialysis Stressors and Coping Strategies among Jordanian Patients on Hemodialysis: A Qualitative Study. *Nephrology Nursing Journal*, 40(4), 321-327.

Al-Arabi, S. (2006). Quality of life: subjective descriptions of challenges to patients with end stage renal disease. *Nephrology Nursing Journal*, 33, 285–292.

Alasia, D., Emem-Chioma, P., & Wokoma, F. (2012). A Single-Center 7-Year Experience with End-Stage Renal Disease Care in Nigeria—A Surrogate for the Poor State of ESRD Care in Nigeria and Other Sub-Saharan African Countries: Advocacy for a Global Fund for ESRD Care Program in Sub-Saharan African Countries. *International Journal of Nephrology*, 2012, 1-7. doi: 10.1155/2012/639653

Alasia, D., Emem-Chioma, P., & Wokoma, F. (2012). A Single-Center 7-Year Experience with End-Stage Renal Disease Care in Nigeria—A Surrogate for the Poor State of ESRD Care in Nigeria and Other Sub-Saharan African Countries: Advocacy for a Global Fund for ESRD Care Program in Sub-Saharan African Countries. *International Journal of Nephrology*, 2012, 1-7. doi: 10.1155/2012/639653

Alatab, S., Najafi, I., Pourmand, G., Hosseini, M., & Shekarchian, S. (2017). Risk factors of severe peritoneal sclerosis in chronic peritoneal dialysis patients. *Renal Failure*, 39(1), 32-39. doi: 10.1080/0886022x.2016.1244075

Albornoz, C., Cohen, W., Razdan, S., Mehrara, B., McCarthy, C., & Disa, J. et al. (2016). The Impact of Travel Distance on Breast Reconstruction in the United States. *Plastic and Reconstructive Surgery*, 137(1), 12-18. doi: 10.1097/prs.0000000000001847

Alderson, P. (2001). *On doing qualitative research linked to ethical health care*. London: Wellcome Trust.

Alebiosu, C., Ayodele, O., Abbas, A., & Olutoyin, I. (2006). Chronic renal failure at the Olabisi Onabanjo University Teaching Hospital, Sagamu, Nigeria. *African Health Sciences*, 6(3), 132-138.

Alebiosu, C., Ayodele, O., Abbas, A., & Olutoyin, A. (2006). Chronic renal failure at the Olabisi Onabanjo University Teaching Hospital, Sagamu, Nigeria. *African Health Sciences*, 6, 132–138.

Al-Mujtaba, M., Cornelius, L., Galadanci, H., Ereka, S., Okundaye, J., Adeyemi, O., & Sam-Agudu, N. (2016). Evaluating Religious Influences on the Utilization of Maternal Health Services among Muslim and Christian Women in North-Central Nigeria. *Biomed Research International*, 2016, 1-8. doi: 10.1155/2016/3645415

Alvesson, M., & Sköldbäck, K. (2018). *Reflexive methodology: new vistas for qualitative research* (3rd ed.). London: Sage.

Anaf, J., Baum, F., Newman, L., Ziersch, A., & Jolley, G. (2013). The interplay between structure and agency in shaping the mental health consequences of job loss. *BMC Public Health*, 13(1). doi: 10.1186/1471-2458-13-110

Anderson, R., & Bury, M. (1988). *Living with chronic illness*. London: Unwin Hyman.

Angerbrandt, H. (2015). Religion, ethnicity and citizenship: demands for territorial self-determination in southern Kaduna, Nigeria. *Journal of Contemporary African Studies*, 33(2), 232-250. doi: 10.1080/02589001.2015.1066081

Annells, M. (2007). What's common with qualitative nursing research these days? *Journal of Clinical Nursing*, 16(2), 223-224. doi: 10.1111/j.1365-2702.2006.01666.x

Ansell, D., Feest, T., Raman, R., Williams, A., & Winearls, C. (2005). *UK Renal Registry Report: The Eight Annual Report*. Bristol: UK Renal Registry.

Archer, M. (1995). *Realist social theory* (1st ed.). Cambridge: Cambridge University Press.

Archer, M. (2003). *Structure, agency, and the internal conversation* (1st ed.). Cambridge, UK: Cambridge University Press.

Arije, A., Akinlade, K., Kadiri, S., & Akinkugbe, O. (1995). The problems of peritoneal dialysis in the management of chronic uraemia in Nigeria. *Tropical & Geographical Medicine*, 47(2), 74-77.

Arije, A., Kadiri, S., & Akinkugbe, O. (2000). The viability of haemodialysis as a treatment option for renal failure in a developing economy. *African Journal of Medicine & Medical Sciences*, 29, 311-314.

Arogundade, F. (2013). Kidney transplantation in a low-resource setting: Nigeria experience. *Kidney International Supplements*, 3(2), 241-245. doi: 10.1038/kisup.2013.23

Arogundade, F. (2013). Kidney transplantation in a low-resource setting: Nigeria experience. *Kidney International Supplements*, 3(2), 241-245. doi: 10.1038/kisup.2013.23

Arogundade, F., & Barsoum, R. (2008). CKD Prevention in Sub-Saharan Africa: A Call for Governmental, Nongovernmental, and Community Support. *American Journal of Kidney Diseases*, 51(3), 515-523. doi: 10.1053/j.ajkd.2007.12.006

Arogundade, F., Abd-Essamie, M., & Barsoum, R. (2005). Health-related quality of life in emotionally related kidney transplantation: deductions from a comparative study. *Journal of Kidney Diseases & Transplant*, 16, 311-320.

Arogundade, F., Olatunde, L., Ishola, A., Bappa, A., Sanusi, A., & Akinsola, A. (2004). Peritoneal dialysis peritonitis: still a major limiting factor in peritoneal dialysis management today? *African Journal of Nephrology*, 8, 52-56.

Arogundade, F., Sanusi, A., Hassan, M., & Akinsola, A. (2011). The pattern, clinical characteristics and outcome of ESRD in Ile-Ife, Nigeria: Is there a change in trend? *African Health Science*, 11(4), 594-601.

Asti, T., Kara, M., Ipek, G., & Erci, B. (2006). The experiences of loneliness, depression, and social support of Turkish patients with continuous ambulatory peritoneal dialysis and their caregivers. *Journal of Clinical Nursing*, 15(4), 490-497. doi: 10.1111/j.1365-2702.2006.01330.x

Atkin, K., & Ahmad, W. (2001). Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 53(5), 615-626. doi: 10.1016/s0277-9536(00)00364-6

Audu, O., Bako Ara, I., Abdullahi Umar, A., Nanben Omole, V., & Avidime, S. (2014). Sociodemographic Correlates of Choice of Health Care Services in Six Rural Communities in North Central Nigeria. *Advances in Public Health*, 2014, 1-7. doi: 10.1155/2014/651086

Aujoulat, I., Luminet, O., & Deccache, A. (2007). The Perspective of Patients on Their Experience of Powerlessness. *Qualitative Health Research*, 17(6), 772-785. doi: 10.1177/1049732307302665

Avis, M. (2005). Is there an epistemology for qualitative research? In I. Holloway, *Qualitative research in health care* (1st ed., pp. 3-16). London: Open University Press.

Axelsson, L., Randers, I., Jacobson, S., & Klang, B. (2012). Living with haemodialysis when nearing end of life. *Scandinavian Journal of Caring Sciences*, 26(1), 45-52. doi: 10.1111/j.1471-6712.2011.00902.x

Ayodele, O., & Alebiosu, C. (2010). Burden of Chronic Kidney Disease: An International Perspective. *Advances in Chronic Kidney Disease*, 17(3), 215-224. doi: 10.1053/j.ackd.2010.02.001

Ayuk, A., Udonwa, N., & Gyuse, A. (2017). Influence of Spirituality and Religion on Adherence to Highly Active Antiretroviral Therapy in Adult HIV/AIDS Patients in Calabar, Nigeria. *Recent Advances in Biology and Medicine*, 03, 48. doi: 10.18639/rabm.2017.03.456895

Babalola, S., & Fatusi, A. (2009). Determinants of use of maternal health services in Nigeria - looking beyond individual and household factors. *BMC Pregnancy and Childbirth*, 9(1). doi: 10.1186/1471-2393-9-43

Babalola, S., & Fatusi, A. (2009). Determinants of use of maternal health services in Nigeria - looking beyond individual and household factors. *BMC Pregnancy and Childbirth*, 9(1). doi: 10.1186/1471-2393-9-43

Badmus, T., Arogundade, F., Sanusi, A., Akinsola, W., Adesunkanmi, A., Agbakwuru, A., & Fatoye, F. (2005). Kidney transplantation in a developing economy: challenges and initial report of three cases in a Nigerian Teaching Hospital. *Central Africa Journal of Medicine*, 51(9-10), 102-106.

Baillie, L. (1996). A phenomenological study of the nature of empathy. *Journal of Advanced Nursing*, 24(6), 1300-1308. doi: 10.1111/j.1365-2648.1996.tb01038.x

- Baillie, L. (2015). Promoting and evaluating scientific rigour in qualitative research. *Nursing Standard*, 29(46), 36-42. doi: 10.7748/ns.29.46.36.e8830
- Baines, L., & Jindal, R. (2000). Non-Compliance in Patients Receiving Haemodialysis: An In-Depth Review. *Nephron*, 85(1), 1-7. doi: 10.1159/000045622
- Bakari, A., Abbo Jimeta, U., Abubakar, M., Alhassan, S., & Nwankwo, E. (2012). Organ transplantation: Legal, ethical and Islamic perspective in Nigeria. *Nigerian Journal of Surgery*, 18(2), 253-260. doi: 10.4103/1117-6806.103103
- Ball, L., Davmor, R., Leveritt, M., Desbrow, B., Ehrlich, C., & Chaboyer, W. (2016). Understanding the nutrition care needs of patients newly diagnosed with type 2 diabetes: a need for open communication and patient-focussed consultations. *Australian Journal of Primary Health*, 22(5), 416. doi: 10.1071/py15063
- Balls, P. (2009). Phenomenology in nursing research: methodology, interviewing and transcribing. *Nursing Times*, 105(32), 30-33.
- Bamgboye, E. (2003). Hemodialysis: Management problems in developing countries, with Nigeria as a surrogate. *Kidney International*, 63(s83), 93-95. doi: 10.1046/j.1523-1755.63.s83.19.x
- Bamgboye, E. (2006). End-stage renal disease in sub-Saharan Africa. *Ethnicity & Disease*, 16(2 Suppl 2), S2-5-9.
- Bamgboye, E. (2009). Barriers to a functional renal transplant program in developing countries. *Ethnicity & Disease*, 19(1 Suppl 1), 56-59.
- Bamgboye, E. (2011). Retrieved from <http://endstagekidneydisease.org> kidney disease in Nigeria: the magnitude of the problem
- Barker, C. (2003). *Cultural studies* (1st ed.). London: SAGE.
- Barkwell, D. (1991). Ascribed meaning: a critical factor in coping and pain attenuation in patients with cancer-related pain. *Journal of Palliative Care*, 7(3), 5-14.

Barkwell, D. (1991). Ascribed meaning: a critical factor in coping and pain attenuation in patients with cancer-related pain. *Journal of Palliative Care*, 7(3), 5-14.

Barnes, P., Bloom, B., & Nahin, R. (2008). Complementary and alternative medicine use among adults and children: United States, 2007. *National Health Statistics Reports*, (12), 1-23.

Barnett, T., Li Yoong, T., Pinikahana, J., & Si-Yen, T. (2008). Fluid compliance among patients having haemodialysis: can an educational programme make a difference? *Journal of Advanced Nursing*, 61(3), 300-306. doi: 10.1111/j.1365-2648.2007.04528.x

Becker, B., Burrows-Hudson, S., Callahan, M., Fuller, J., Hoffart, N., & Johansen, K. et al. (2003). *Employment for People with Kidney Disease A Review of the Benefits for Patients, Providers, and Payers* (pp. S1-S8). Retrieved from <http://www.lifeoptions.org>

Bello, B. (2014). Identifying the Barriers to Achieving Sustainable Dialysis Programs in Sub-Saharan Africa: Nigeria as a Reference Point. *Journal of Nephrology & Therapeutics*, 04(05). doi: 10.4172/2161-0959.1000186

Bello, B., & Raji, Y. (2016). Knowledge, attitudes and beliefs of first-degree relatives of patients with chronic kidney disease toward kidney donation in Nigeria. *Saudi Journal of Kidney Diseases and Transplantation*, 27(1), 118. doi: 10.4103/1319-2442.174141

Bello, B., Raji, Y., Sanusi, I., Braimoh, R., Amira, O., & Mabayoje, O. (2013). Challenges of providing maintenance hemodialysis in a resource poor country: Experience from a single teaching hospital in Lagos, Southwest Nigeria. *Hemodialysis International*, 17(3), 427-433. doi: 10.1111/hdi.12024

Boadu, A., & Asase, A. (2017). Documentation of Herbal Medicines Used for the Treatment and Management of Human Diseases by Some Communities in Southern Ghana. *Evidence-Based Complementary and Alternative Medicine*, 2017, 1-12. doi: 10.1155/2017/3043061

Bonilla-Chacin, M., Okigbo, A., Malife, N., Sherburne-Benz, L., & Ruhl, O. (2010). *Improving primary health care delivery in Nigeria*. Washington, D.C.: World Bank Group.

- Borbasi, S., & Jackson, D. (2015). *Navigating the maze of nursing research* (4th ed.). Chatswood, N.S.W.: Elsevier Australia.
- Boyd, E., & Fales, A. (1983). Reflective Learning: Key to Learning from Experience. *Journal of Humanistic Psychology*, 23(2), 99-117. doi: 10.1177/0022167883232011
- Braimoh, R., Mabayoje, M., Amira, C., & Coker, H. (2012). Quality of hemodialysis water in a resource-poor country: The Nigerian example. *Hemodialysis International*, 16(4), 532-538. doi: 10.1111/j.1542-4758.2012.00682.x
- Bramley, L., & Matiti, M. (2014). How does it really feel to be in my shoes? Patients' experiences of compassion within nursing care and their perceptions of developing compassionate nurses. *Journal of Clinical Nursing*, 23(19-20), 2790-2799. doi: 10.1111/jocn.12537
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Brettell, A., & Grant, M. (2004). *Finding the evidence for practice: a workbook for health professionals*. Edinburgh: Churchill Livingstone.
- Brinkmann, S., & Kvale, S. (2015). *Interviews: Learning the Craft of Qualitative Research Interviewing* (3rd ed.). Los Angeles: Sage Publications.
- Britten, N. (2006). Qualitative interviews in healthcare. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (pp. 11-19). London: Blackwell Publishing.
- Brown, F. (2002). Inside every chronic patient is an acute patient wondering what happened. *Journal of Clinical Psychology*, 58(11), 1443-1449. doi: 10.1002/jclp.10091
- Browning, K., Wewers, M., Ferketich, A., Otterson, G., & Reynolds, N. (2009). The Self-regulation Model of Illness Applied to Smoking Behavior in Lung Cancer. *Cancer Nursing*, 32(4), E15-E25. doi: 10.1097/ncc.0b013e3181a0238f
- Brunori, G., Viola, B., Parrinello, G., De Biase, V., Como, G., & Franco, V. et al. (2007). Efficacy and Safety of a Very-Low-Protein Diet When Postponing Dialysis in the Elderly:

A Prospective Randomized Multicenter Controlled Study. *American Journal of Kidney Diseases*, 49(5), 569-580. doi: 10.1053/j.ajkd.2007.02.278

Bryman, A. (2016). *Social research methods* (5th ed.). Oxford: Oxford University Press.

Burns, T., Tranter, S., & Raghunath, V. (2016). In-centre night dialysis program: a single centre experience. *Renal Society of Australasia Journal*, 13(2), 58-64.

Burton, C. (2000). Living with stroke: a phenomenological study. *Journal of Advanced Nursing*, 32(2), 301-309. doi: 10.1046/j.1365-2648.2000.01477.x

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociol Health & Illness*, 13(4), 451-468. doi: 10.1111/j.1467-9566.1991.tb00522.x

Butler, A., Hall, H., & Copnell, B. (2016). A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. *Worldviews on Evidence-Based Nursing*, 13(3), 241-249. doi: 10.1111/wvn.12134

Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, 13(1). doi: 10.1186/1471-2288-13-14

Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, 13(1). doi: 10.1186/1471-2288-13-14

Carduff, E., Murray, S., & Kendall, M. (2015). Methodological developments in qualitative longitudinal research: the advantages and challenges of regular telephone contact with participants in a qualitative longitudinal interview study. *BMC Research Notes*, 8(1). doi: 10.1186/s13104-015-1107-y

Caress A., Luker, K., & Owens, R. (2001). A descriptive study of meaning of illness in chronic renal disease. *J Adv Nurs*, 33(6), 716-727. doi: 10.1046/j.1365-2648.2001.01713.x

Carolan, M. (2003). Reflexivity: a personal journey during data collection. *Nurse Researcher*, 10(3), 7-14. doi: 10.7748/nr2003.04.10.3.7.c5892

Carpenter, J., Brockopp, D., & Andrykowski, M. (1999). Self-transformation as a factor in the self-esteem and well-being of breast cancer survivors. *Journal of Advanced Nursing*, 29(6), 1402-1411. doi: 10.1046/j.1365-2648.1999.01027.x

Carson, R., Juszczak, M., Davenport, A., & Burns, A. (2009). Is Maximum Conservative Management an Equivalent Treatment Option to Dialysis for Elderly Patients with Significant Comorbid Disease? *Clinical Journal of the American Society of Nephrology*, 4(10), 1611-1619. doi: 10.2215/cjn.00510109

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. (2014). The Use of Triangulation in Qualitative Research. *Oncology Nursing Forum*, 41(5), 545-547. doi: 10.1188/14.onf.545-547

Caskey, F., Steenkamp, R., & Thomas, K. (2017). *UK Renal Registry 19th Annual Report of the Renal Association* (pp. 1-422). Bristol, United Kingdom. Retrieved from https://www.renalreg.org/wp-content/uploads/2017/09/19th-Annual-Report_web_book.pdf

Caspi, O., Koithan, M., & Criddle, M. (2004). Alternative Medicine or “Alternative” Patients: A Qualitative Study of Patient-Oriented Decision-Making Processes with Respect to Complementary and Alternative Medicine. *Medical Decision Making*, 24(1), 64-79. doi: 10.1177/0272989x03261567

Catz, S., Kelly, J., Bogart, L., Benotsch, E., & McAuliffe, T. (2000). Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology*, 19(2), 124-133. doi: 10.1037//0278-6133.19.2.124

Cavers, D., Hacking, B., Erridge, S., Kendall, M., Morris, P., & Murray, S. (2012). Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *Canadian Medical Association Journal*, 184(7), E373-E382. doi: 10.1503/cmaj.111622

Central Intelligence Agency. (2014). *the CIA World Fact Book*. Washington, D.C.: Skyhorse Publishing Inc.

Chan, K., Maddux, F., Tolhoff-Rubin, N., Karumanchi, S., Thadhani, R., & Hakim, R. (2011). Early Outcomes among Those Initiating Chronic Dialysis in the United States. *Clinical Journal of the American Society of Nephrology*, 6(11), 2642-2649. doi: 10.2215/cjn.03680411

Chanouzas, D., Ng, K., Fallouh, B., & Baharani, J. (2011). What influences patient choice of treatment modality at the pre-dialysis stage? *Nephrology Dialysis Transplantation*, 27(4), 1542-1547. doi: 10.1093/ndt/gfr452

Charmaz, K. (2000). Experiencing chronic illness. In G. Albrecht, R. Fitzpatrick & S. Scrimshaw, *The Handbook of Social Studies in Health and Medicine* (1st ed., pp. 277–292). London: Sage Publications.

Checton, M., Greene, K., Magsamen-Conrad, K., & Venetis, M. (2012). Patients' and Partners' Perspectives of Chronic Illness and Its Management. *Families, Systems and Health*, 30(2), 114-129.

Chilcot, J., Wellsted, D., Da Silva-Gane, M., & Farrington, K. (2008). Depression on dialysis. *Nephron Clinical Practice*, 108, 256–264.

Chiu, L. (2000). Lived Experience of Spirituality in Taiwanese Women With Breast Cancer. *Western Journal of Nursing Research*, 22(1), 29-53. doi: 10.1177/01939450022044250

Chong, M. (2009). Is Reflective Practice a Useful Task for Student Nurses? *Asian Nursing Research*, 3(3), 111-120. doi: 10.1016/s1976-1317(09)60022-0

Chukwuonye, I., & Oviasu, E. (2012). The Plight of Chronic Kidney Disease Patients in Nigeria. *Journal of Dental and Medical Sciences*, 2(2), 52-55. doi: 10.9790/0853-0225255

Clarke, A. (2006). Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher*, 13(4), 19-29. doi: 10.7748/nr2006.07.13.4.19.c5987

Coelho, A., Parola, V., Escobar-Bravo, M., & Apóstolo, J. (2016). Comfort experience in palliative care: a phenomenological study. *BMC Palliative Care*, *15*(1). doi: 10.1186/s12904-016-0145-0

Conn, V., Valentine, J., Cooper, H., & Rantz, M. (2003). Grey Literature in Meta-Analyses. *Nursing Research*, *52*(4), 256-261. doi: 10.1097/00006199-200307000-00008

Conrad, P. (1987). The experience of illness: recent and new directions. In J. Roth & P. Conrad, *Research in the Sociology of Health Care: the Experience and Management of Chronic Illness* (1st ed., pp. 1–32). Greenwich, CT: JAI Press.

Conrad, P., & Barker, K. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, *51*(1_suppl), S67-S79. doi: 10.1177/0022146510383495

Cooper, A., Lloyd, G., Weinman, J., & Jackson, G. (1999). Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs. *Heart*, *82*(2), 234-236. doi: 10.1136/hrt.82.2.234

Cooper, H. (1998). *Synthesising research* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Cooper, L., & Roter, D. (2003). Patient-provider communication: the effect of race and ethnicity on process and outcomes of healthcare. In B. Smedley, A. Stith & A. Nelson, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (pp. 199-214). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK220358/pdf/Bookshelf_NBK220358.pdf

Cooper-Wiele, J. (1989). *The Totalizing Act: Key to Husserl's Early Philosophy*. Dordrecht: Springer Netherlands.

Cope, D. (2014). Methods and Meanings: Credibility and Trustworthiness of Qualitative Research. *Oncology Nursing Forum*, *41*(1), 89-91. doi: 10.1188/14.onf.89-91

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: techniques and procedures for developing Grounded theory* (3rd ed.). Thousand Oaks: Sage Publications.

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research*. Los Angeles: SAGE.

Cormier-Daigle, M., & Stewart, M. (1997). Support and coping of male hemodialysis-dependent patients. *International Journal of Nursing Studies*, 34(6), 420-430. doi: 10.1016/s0020-7489(97)00035-7

Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, 335(7609), 24-27. doi: 10.1136/bmj.39246.581169.80

Coulter, A., Parsons, S., & Askham, J. (2008). *Policy brief: Where are the patients in decision-making about their own care? WHO 2008 and WHO on behalf of the European Observatory on Health Systems and Policies 2008*. Denmark: World Health Organisation.

Creswell, J. (2013). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4th ed.). Thousand Oaks, California: Sage Publications Inc.

Creswell, J. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (3rd ed.). London: SAGE Publications.

Crist, J., & Tanner, C. (2003). Interpretation/Analysis Methods in Hermeneutic Interpretive Phenomenology. *Nursing Research*, 52(3), 202-205. doi: 10.1097/00006199-200305000-00011

Crotty, M. (1997). Tradition and culture in Heidegger's Being and Time. *Nursing Inquiry*, 4(2), 88-98. doi: 10.1111/j.1440-1800.1997.tb00082.x

Crotty, M. (1998). *The foundations of social research: Meanings and perspective in the research process*. Thousand Oaks, California: Sage.

Crow, G., Wiles, R., Heath, S., & Charles, V. (2006). Research Ethics and Data Quality: The Implications of Informed Consent. *International Journal of Social Research Methodology*, 9(2), 83-95. doi: 10.1080/13645570600595231

- Cukor, D., Coplan, J., Brown, C., Friedman, S., Cromwell-Smith, A., Peterson, R., & Kimmel, P. (2007). Depression and Anxiety in Urban Hemodialysis Patients. *Clinical Journal of The American Society Of Nephrology*, 2(3), 484-490. doi: 10.2215/cjn.00040107
- Cukor, D., Coplan, J., Brown, C., Friedman, S., Newville, H., & Safier, M. et al. (2008). Anxiety Disorders in Adults Treated by Hemodialysis: A Single-Center Study. *American Journal of Kidney Diseases*, 52(1), 128-136. doi: 10.1053/j.ajkd.2008.02.300
- Curtin, R., Mapes, D., Petillo, M., & Oberley, E. (2002). Long-Term Dialysis Survivors: A Transformational Experience. *Qualitative Health Research*, 12(5), 609-624. doi: 10.1177/104973202129120133
- Curtin, R., Oberley, E., Sacksteder, P., & Friedman, A. (1996). Differences between employed and nonemployed dialysis patients. *American Journal of Kidney Diseases*, 27(4), 533-540. doi: 10.1016/s0272-6386(96)90164-x
- Cutcliffe, J., & McKenna, H. (1999). Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing*, 30(2), 374-380. doi: 10.1046/j.1365-2648.1999.01090.x
- Cutcliffe, J., & McKenna, H. (2002). When do we know that we know? Considering the truth of research findings and the craft of qualitative research. *International Journal of Nursing Studies*, 39(6), 611-618. doi: 10.1016/s0020-7489(01)00063-3
- DasGupta, S., & Charon, R. (2004). Personal Illness Narratives: Using Reflective Writing to Teach Empathy. *Academic Medicine*, 79(4), 351-356. doi: 10.1097/00001888-200404000-00013
- Davison, S., & Simpson, C. (2006). Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ*, 333(7574), 886. doi: 10.1136/bmj.38965.626250.55
- de Brito-Ashurst, I., Perry, L., Sanders, T., Thomas, J., Yaqoob, M., & Dobbie, H. (2010). Barriers and facilitators of dietary sodium restriction amongst Bangladeshi chronic kidney

disease patients. *Journal of Human Nutrition and Dietetics*, 24(1), 86-95. doi: 10.1111/j.1365-277x.2010.01129.x

de Guzman, A., Chy, M., Concepcion, A., Conferido, A., & Coretico, K. (2009). The Language of Coping: Understanding Filipino Geriatric Patients' Hemodialysis Lived Experiences. *Educational Gerontology*, 35(9), 769-783. doi: 10.1080/03601270802708384

Denscombe, M. (2014). *The Good research guide* (5th ed.). Maidenhead, England: McGraw-Hill/Open University Press.

Denzin, N., & Lincoln, Y. (2011). *The Sage handbook of qualitative research* (4th ed.). Los Angeles: Sage.

Denzin, N., & Lincoln, Y. (2013). *Strategies of qualitative inquiry* (4th ed.). Thousand Oaks, CA: SAGE.

Department of Health. (2001). *The expert patient: a new approach to chronic disease management for the 21st century*. London: Department of Health.

Department of Health. (2004). National service framework: kidney disease. Retrieved from <https://www.gov.uk/government/publications/national-service-framework-kidney-disease>

Department of Health. (2004). *The National Service Framework for Renal Services: Part One: Dialysis and Transplantation*. London: Department of Health.

Department of Health. (2005). *Creating a patient-led NHS- delivering the NHS improvement plan*. London: Department of Health.

Department of Health. (2008). *Organs for transplant: a report from the organ donation taskforce*. London: Department of Health.

Department of Health. (2012). *Living with long-term conditions: a policy framework*. London: Department of Health.

- DeSantis, L., & Ugarriza, D. (2000). The Concept of Theme as Used in Qualitative Nursing Research. *Western Journal of Nursing Research*, 22(3), 351-372. doi: 10.1177/019394590002200308
- Diefenbach, M., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5(1), 11-38. doi: 10.1007/bf02090456
- DiMatteo, M. (2004). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology*, 23(2), 207-218. doi: 10.1037/0278-6133.23.2.207
- Diouf, B., Ka, E., Niang, A., Diouf, M., Mbengue, M., & Diop, T. (2000). Aetiologies of chronic renal insufficiency in adult internal medicine service in Dakar. *Dakar Medical*, 45(1), 62-65.
- Dixon-Woods, M. (2011). Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine*, 9(1). doi: 10.1186/1741-7015-9-39
- Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy*, 10(1), 45-53. doi: 10.1258/1355819052801804
- Dixon-Woods, M., Bonas, S., Booth, A., Jones, D., Miller, T., & Sutton, A. et al. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, 6(1), 27-44. doi: 10.1177/1468794106058867
- Domínguez, J., Harrison, R., & Atal, R. (2011). Cost–Benefit Estimation of Cadaveric Kidney Transplantation: The Case of a Developing Country. *Transplantation Proceedings*, 43(6), 2300-2304. doi: 10.1016/j.transproceed.2011.06.006
- Donabedian, A. (1972). Models for Organizing the Delivery of Personal Health Services and Criteria for Evaluating Them. *The Milbank Memorial Fund Quarterly*, 50(4), 103. doi: 10.2307/3349436

- Dowd, R. (2014). Religious Diversity and Religious Tolerance. *Journal of Conflict Resolution*, 60(4), 617-644. doi: 10.1177/0022002714550085
- Dowling, M. (2004). Hermeneutics: an exploration. *Nurse Researcher*, 11(4), 30-41.
- Downe, S. (2008). Metasynthesis: A guide to knitting smoke. *Evidence-Based Midwifery*, 6, 4-8.
- Doyle, J. (2004). Introduction to interviewing techniques. In D. Wood, *Handbook for IQP Advisors and Students* (1st ed., pp. 11-14). Worcester, MA: Worcester Polytechnic Institute.
- Draper, J. (2007). The relationship between research question and research design. In A. Crookes & S. Davies, *Research into practice: essential skills for reading and applying research in Nursing and health care* (1st ed.). London: Elsevier Publications.
- Draper, J. (2007). The relationship between research question and research design. In P. Crookes & S. Davies, *Essential skills for reading and applying research in nursing and health care* (2nd ed., pp. 69-84). China: Elsevier Ltd.
- Drew, N. (2001). Meaningfulness as an Epistemologic Concept for Explicating the Researcher's Constitutive Part in Phenomenologic Research. *Advances in Nursing Science*, 23(4), 16-31. doi: 10.1097/00012272-200106000-00003
- Duffy, F., Gordon, G., Whelan, G., Cole-Kelly, K., & Frankel, R. (2004). Assessing Competence in Communication and Interpersonal Skills: The Kalamazoo II Report. *Academic Medicine*, 79(6), 495-507. doi: 10.1097/00001888-200406000-00002
- Dyson, J., Cobb, M., & Forman, D. (1997). The meaning of spirituality: a literature review. *Journal of Advanced Nursing*, 26(6), 1183-1188. doi: 10.1046/j.1365-2648.1997.00446.x
- Edwards, M., Davies, M., & Edwards, A. (2009). What are the external influences on information exchange and shared decision-making in healthcare consultations: A meta-synthesis of the literature. *Patient Education and Counseling*, 75(1), 37-52. doi: 10.1016/j.pec.2008.09.025

- Ekelund, M., & Andersson, S. (2010). "I need to lead my own life in any case"—A study of patients in dialysis with or without a partner. *Patient Education and Counseling*, 81(1), 30-36. doi: 10.1016/j.pec.2009.10.025
- Ekore, R., & Lanre-Abass, B. (2016). African cultural concept of death and the idea of advance care directives. *Indian Journal of Palliative Care*, 22(4), 369. doi: 10.4103/0973-1075.191741
- Ellis, L., & Crookes, P. (2007). Philosophical and theoretical underpinnings of research. In P. Crookes & S. Davies, *Research into practice: essential skills for reading and applying research in Nursing and Healthcare* (2nd ed., pp. 51-68). New York: Elsevier Limited.
- Eng, M., Zhang, J., Cambon, A., Marvin, M., & Gleason, J. (2011). Employment outcomes following successful renal transplantation. *Clinical Transplantation*, 26(2), 242-246. doi: 10.1111/j.1399-0012.2011.01441.x
- Engemann, J., Friedman, J., Reed, S., Griffiths, R., Szczech, L., & Kaye, K. et al. (2005). Clinical Outcomes and Costs Due to Staphylococcus aureus Bacteremia among Patients Receiving Long- Term Hemodialysis •. *Infect Control Hosp Epidemiol*, 26(6), 534-539. doi: 10.1086/502580
- Epstein, R. (1995). Communication between primary care physicians and consultants. *Archives of Family Medicine*, 4(5), 403-409. doi: 10.1001/archfami.4.5.403
- Essue, B., Wong, G., Chapman, J., Li, Q., & Jan, S. (2013). How are patients managing with the costs of care for chronic kidney disease in Australia? A cross-sectional study. *BMC Nephrology*, 14(1). doi: 10.1186/1471-2369-14-5
- Estabrooks, C., Field, P., & Morse, J. (1994). Aggregating Qualitative Findings: An Approach to Theory Development. *Qualitative Health Research*, 4(4), 503-511. doi: 10.1177/104973239400400410
- Ethier, J., Lindsay, R., Barre, P., Kappel, J., & Common, A. (1999). A clinical practice guideline for vascular access. *Journal of American Society of Nephrology*, 10(Suppl 13), S297-S305.

- Faber, S., de Castell, S., & Bryson, M. (2003). Renal Failure: Toward a Sociocultural Investigation of an Illness. *Mind, Culture, And Activity*, 10(2), 143-167. doi: 10.1207/s1532-7884mca1002_4
- Facet methodology: the case for an inventive research orientation. (2011). *Methodological Innovations Online*, 6(3), 75-92.
- Fadare, J., & Salako, B. (2010). Ethical issues in kidney transplantation – reflections from Nigeria. *Transplant Research and Risk Management, Volume 2*, 87-91. doi: 10.2147/trm.s14371
- Fahmy, N., Aprikian, A., Al-Otaibi, M., Tanguay, S., Steinberg, J., & Jeyaganth, S. et al. (2009). Impact of treatment delay in patients with bladder cancer managed with partial cystectomy in Quebec: a population-based study. *Canadian Urological Association Journal*, 3(2), 131. doi: 10.5489/cuaj.1045
- Fasset, R., Robertson, I., Mace, R., Youl, L., Challenor, S., & Bull, R. (2011). Palliative care in end-stage kidney disease. *Nephrology*, 16(1), 4-12. doi: 10.1111/j.1440-1797.2010.01409.x
- Fassett, R., Robertson, I., Mace, R., Youl, L., Challenor, S., & Bull, R. (2010). Palliative care in end-stage kidney disease. *Nephrology*, 16(1), 4-12. doi: 10.1111/j.1440-1797.2010.01409.x
- Federal Ministry of Health. (2006). *National Health Financing Policy*. Abuja, Nigeria: The Federal Ministry of Health.
- Federal Republic of Nigeria. (1999). *Constitution of the Federal Republic of Nigeria*. Abuja: Federal Ministry of Health of Nigeria.
- Fine, A., Fontaine, B., Kraushar, M., & Rich, B. (2005). Nephrologists Should Voluntarily Divulge Survival Data to Potential Dialysis Patients: A Questionnaire Study. *Peritoneal Dialysis International*, 25, 269-273.

Fink, A. (2014). *Conducting research literature reviews: From the internet to paper* (4th ed.). Los Angeles, California: Sage.

Finkelstein, S., & Finkelstein, F. (2002). Evaluation of sexual dysfunction in dialysis patients. In A. Nissenson & R. Fine, *Dialysis Therapy* (1st ed., pp. 368-373). Philadelphia: Hanley and Belfus.

Fitzgerald, T. (2012). Documents and documentary analysis: reading between the lines. In A. Briggs, M. Coleman & M. Morrison (Eds.), *Research Methods in Educational Leadership and Management* (3rd ed., pp. 296-297). London: Sage Publications Ltd.

Foley, R., Chen, S., Solid, C., Gilbertson, D., & Collins, A. (2014). Early mortality in patients starting dialysis appears to go unregistered. *Kidney International*, 86(2), 392-398. doi: 10.1038/ki.2014.15

Furber, C. (2010). Framework analysis: a method for analysing qualitative data. *African Journal of Midwifery And Women's Health*, 4(2), 97-100. doi: 10.12968/ajmw.2010.4.2.47612

Gadamer, H. (2004). *Truth and method* (4th ed.). Wiltshire: Antony Rowe.

Gale, N., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1). doi: 10.1186/1471-2288-13-117

Gallant, M. (2003). The Influence of Social Support on Chronic Illness Self-Management: A Review and Directions for Research. *Health Education & Behavior*, 30(2), 170-195. doi: 10.1177/1090198102251030

Garcia, G., Harden, P., & Chapman, J. (2012). The Global Role of Kidney Transplantation. *Transplantation*, 93(4), 337-341. doi: 10.1097/tp.0b013e318245f186

Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story. *Social Science & Medicine*, 30(11), 1149-1159. doi: 10.1016/0277-9536(90)90255-q

- Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story. *Social Science & Medicine*, 30(11), 1149-1159. doi: 10.1016/0277-9536(90)90255-q
- Gibson, C. (1991). A concept analysis of empowerment. *J Adv Nurs*, 16(3), 354-361. doi: 10.1111/j.1365-2648.1991.tb01660.x
- Giles, S. (2005). Struggles between the Body and Machine. *Social Work in Health Care*, 41(2), 19-35. doi: 10.1300/j010v41n02_02
- Gilg, J., Methven, S., Casula, A., & Castledine, C. (2017). *UK Renal Registry 19th Annual Report of the Renal Association* (pp. 1-422). Bristol, United Kingdom. Retrieved from https://www.renalreg.org/wp-content/uploads/2017/09/19th-Annual-Report_web_book.pdf
- Gilg, J., Pruthi, R., & Fogarty, D. (2014). *UK Renal Registry 17th Annual Report: Chapter 1 UK Renal Replacement Therapy Incidence in 2013: National and Centre-Specific Analyses*. Bristol: UK Renal Registry.
- Gill, J., Schaeffner, E., Chadban, S., Dong, J., Rose, C., Johnston, O., & Gill, J. (2012). Quantification of the Early Risk of Death in Elderly Kidney Transplant Recipients. *American Journal of Transplantation*, 13(2), 427-432. doi: 10.1111/j.1600-6143.2012.04323.x
- Gill, J., Tonelli, M., Johnson, N., Kiberd, B., Landsberg, D., & Pereira, B. (2005). The impact of waiting time and comorbid conditions on the survival benefit of kidney transplantation. *Kidney International*, 68(5), 2345-2351. doi: 10.1111/j.1523-1755.2005.00696.x
- Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *BDJ*, 204(6), 291-295. doi: 10.1038/bdj.2008.192
- Gillanders, S., Wild, M., Deighan, C., & Gillanders, D. (2008). Emotion Regulation, Affect, Psychosocial Functioning, and Well-being in Hemodialysis Patients. *American Journal of Kidney Diseases*, 51(4), 651-662. doi: 10.1053/j.ajkd.2007.12.023

Gillis, A., & Jackson, W. (2002). Introduction to nursing research. In A. Gillis & W. Jackson, *Research for Nurses: Method and Interpretation* (1st ed., pp. 3-36). Philadelphia: F.A. Davis.

Glanz, K., & Bishop, D. (2010). The Role of Behavioral Science Theory in Development and Implementation of Public Health Interventions. *Annual Review of Public Health*, 31(1), 399-418. doi: 10.1146/annurev.publhealth.012809.103604

Glanz, K., Rimer, B., & Lewis, F. (2002). *Health behaviour and health education* (3rd ed.). San Francisco: Jossey-Bass.

Glanz, K., Rimer, B., & Viswanath, K. (2008). *Health behavior and health education: theory, research, and practice* (4th ed.). San Francisco, CA: Jossey-Bass.

Glazier, A., & Delmonico, F. (2011). The Declaration of Istanbul Is Moving Forward by Combating Transplant Commercialism and Trafficking and by Promoting Organ Donation. *American Journal of Transplantation*, 12(3), 515-516. doi: 10.1111/j.1600-6143.2011.03862.x

Goins, R., Spencer, S., & Williams, K. (2011). Lay Meanings of Health Among Rural Older Adults in Appalachia. *The Journal of Rural Health*, 27(1), 13-20. doi: 10.1111/j.1748-0361.2010.00315.x

Golics, C., Basra, M., Salek, M., & Finlay, A. (2013). The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *International Journal of General Medicine*, 6, 787-798.

Golics, C., Khurdish, M., Basra, A., Salek, M., & Finlay, A. (2013). The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *International Journal of General Medicine*, 6, 787-798.

Gómez, C., Valido, P., Celadilla, O., Bernaldo, d., & Mojón, M. (1999). Validity of a standard information protocol provided to end-stage renal disease patients and its effect on treatment selection. *Peritoneal Dialysis International*, 19(5), 471-477.

Gondos, A., Döhler, B., Brenner, H., & Opelz, G. (2013). Kidney Graft Survival in Europe and the United States. *Transplantation Journal*, *95*(2), 267-274. doi: 10.1097/tp.0b013e3182708ea8

Goodwin, P., Leszcz, M., Ennis, M., Koopmans, J., Vincent, L., Guther, H., & Hunter, J. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine*, *345*, 1719–1726.

Goovaerts, T., Jadoul, M., & Goffin, E. (2005). Influence of a Pre-Dialysis Education Programme (PDEP) on the mode of renal replacement therapy. *Nephrology Dialysis Transplantation*, *20*(9), 1842-1847. doi: 10.1093/ndt/gfh905

Grassmann, A., Gioberge, S., Moeller, S., & Brown, G. (2006). End-stage Renal Disease-Global Demographics in 2005 and Observed Trends. *Artificial Organs*, *30*(12), 895-897. doi: 10.1111/j.1525-1594.1979.00999.pp.x-ii

Greater Manchester Renal Strategy Group. (2008). *Kidney patient care: the future for services in Greater Manchester 2005-2008*. Manchester: Greater Manchester Renal Strategy Group.

Gregory, D., Way, C., Hutchinson, T., Barrett, B., & Parfrey, P. (1998). Patients' Perceptions of their Experiences with ESRD and Hemodialysis Treatment. *Qualitative Health Research*, *8*(6), 764-783. doi: 10.1177/104973239800800604

Groopman, J. (2004). *The anatomy of hope*. New York: Random House.

Guba, E. (1990). The alternative paradigm dialogue. In E. Guba, *The Paradigm Dialogue* (1st ed., pp. 17–30). Newbury Park, CA: Sage.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In E. Denzin & Y. Lincoln, *Handbook of qualitative research* (1st ed.). Thousand Oaks, CA: Sage.

Guerra-Guerrerro, V., Camargo Plazas, M., Cameron, B., Santos Salas, A., & Cofre Gonzalez, C. (2014). Understanding the life experience of people on hemodialysis:

Adherence to treatment and quality of life. *Nephrology Nursing Journal*, 41(3), 289-297, 316.

Guest, G., MacQueen, K., & Namey, E. (2012). *Applied thematic analysis*. Los Angeles: Sage Publications.

Gullick, J., Monaro, S., & Stewart, G. (2016). Compartmentalising time and space: a phenomenological interpretation of the temporal experience of commencing haemodialysis. *Journal of Clinical Nursing*, 26(21-22), 3382-3395. doi: 10.1111/jocn.13697

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., & Hudson, M. (2002). What does 'access to health care' mean? *Journal of Health Services Research & Policy*, 7(3), 186–188.

Gyasi, R., Asante, F., Abass, K., Yeboah, J., Adu-Gyamfi, S., & Amoah, P. (2016). Do health beliefs explain traditional medical therapies utilisation? Evidence from Ghana. *Cogent Social Sciences*, 2(1). doi: 10.1080/23311886.2016.1209995

Ha, J., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. *The Ochsner Journal*, 10(1), 38-43.

Hagren, B., Pettersen, I., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, 34(2), 196-202. doi: 10.1046/j.1365-2648.2001.01745.x

Hagren, B., Pettersen, I., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, 34(2), 196-202. doi: 10.1046/j.1365-2648.2001.01745.x

Hagren, B., Pettersen, I., Severinsson, E., Lützn, K., & Clyne, N. (2005). Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing*, 14(3), 294-300. doi: 10.1111/j.1365-2702.2004.01036.x

Haller, M., Gutjahr, G., Kramar, R., Harnoncourt, F., & Oberbauer, R. (2011). Cost-effectiveness analysis of renal replacement therapy in Austria. *Nephrology Dialysis Transplantation*, 26(9), 2988-2995. doi: 10.1093/ndt/gfq780

Halpern, E. (1983). *Auditing Naturalistic Inquiries: The Development and Application of a Model*. (PhD thesis), Indiana University, Bloomington. Retrieved from <https://elibrary.ru/item.asp?id=7390072>.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in Practice* (3rd ed.). New York: Taylor & Francis Group.

Hannes, K. (2011). Critical appraisal of qualitative research: supplementary guidance for inclusion of qualitative research in Cochrane Systematic Reviews of Interventions. Retrieved from <http://cqrng.cochrane.org/supplemental-handbook-guidance>

Harvey, I., & Silverman, M. (2007). The Role of Spirituality in the Self-management of Chronic Illness among Older African and Whites. *Journal of Cross-Cultural Gerontology*, 22(2), 205-220. doi: 10.1007/s10823-007-9038-2

Harwood, L., & Clark, A. (2013). Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies. *International Journal of Nursing Studies*, 50(1), 109-120. doi: 10.1016/j.ijnurstu.2012.04.003

Harwood, L., Locking-Cusolito, H., & Spittal, J. (2005). Preparing For Hemodialysis: Patient Stressors and Responses. *Nephrology Nursing Journal*, 32(3), 295-303.

Harwood, L., Locking-Cusolito, H., Spittal, J., Wilson, B., & White, S. (2005). Preparing For Hemodialysis: Patient Stressors and Responses. *Nephrology Nursing Journal*, 32(3), 295-302.

Haslam, S., Jetten, J., Postmes, T., & Haslam, C. (2009). Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology. *Applied Psychology*, 58(1), 1-23. doi: 10.1111/j.1464-0597.2008.00379.x

Hassankhani, H., Taleghani, F., Mills, J., Birks, M., Francis, K., & Ahmadi, F. (2010). The challenges experienced by Iranian war veterans living with chemical warfare poisoning: a descriptive, exploratory study. *Scandinavian Journal of Caring Sciences*, 24(2), 290-298. doi: 10.1111/j.1471-6712.2009.00719.x

Hawkey, L., Thisted, R., Masi, C., & Cacioppo, J. (2010). Loneliness predicts increased blood pressure: 5-year cross-lagged analyses in middle-aged and older adults. *Psychology and Aging*, 25(1), 132-141. doi: 10.1037/a0017805

Healthy People2020. (2018). Chronic Kidney Disease | Healthy People 2020. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/chronic-kidney-disease>

Heiwe, S., Clyne, N., & Dahlgren, M. (2003). Living with chronic renal failure: patients' experiences of their physical and functional capacity. *Physiother. Res. Int.*, 8(4), 167-177. doi: 10.1002/pri.287

Helanterä, I., Haapio, M., Koskinen, P., Grönhagen-Riska, C., & Finne, P. (2012). Employment of Patients Receiving Maintenance Dialysis and After Kidney Transplant: A Cross-sectional Study from Finland. *American Journal of Kidney Diseases*, 59(5), 700-706. doi: 10.1053/j.ajkd.2011.08.025

Herlin, C., & Wann-Hansson, C. (2010). The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. *Scandinavian Journal of Caring Sciences*, 24(4), 693-699. doi: 10.1111/j.1471-6712.2009.00764.x

Hermanowicz, J. (2013). The Longitudinal Qualitative Interview. *Qualitative Sociology*, 36(2), 189-208. doi: 10.1007/s11133-013-9247-7

Hesse-Biber, S. (2012). *The handbook of feminist research* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.

Hesse-Biber, S. (2017). *The practice of qualitative research: Engaging Students in the Research Process* (3rd ed.). Thousand Oaks: California: Sage Publications.

- Higginbottom, G. (2004). Sampling issues in qualitative research. *Nurse Researcher*, 12(1), 7-19. doi: 10.7748/nr2004.07.12.1.7.c5927
- Hokimoto, S., Sakamoto, K., Akasaka, T., Kaikita, K., Honda, O., Naruse, M., & Ogawa, H. (2015). High Mortality Rate in Hemodialysis Patients Who Undergo Invasive Cardiovascular Procedures Related to Peripheral Artery Disease – Community-Based Observational Study in Kumamoto Prefecture –. *Circulation Journal*, 79(6), 1269-1276. doi: 10.1253/circj.cj-14-1308
- Hokkanen, H., Eriksson, E., Ahonen, O., & Salanterä, S. (2004). Adolescents With Cancer: experience of life and how it could be made easier. *Cancer Nursing*, 27(4), 325-335. doi: 10.1097/00002820-200407000-00010
- Holland, J., Thomson, R., & Henderson, S. (2006). *Qualitative Longitudinal Research: A Discussion Paper*. London South Bank University: Families and Social Capital ESRC Research Group Working Paper No 21.
- Holley, J. (2007). Palliative Care in End-Stage Renal Disease: Illness Trajectories, Communication, and Hospice Use. *Advances in Chronic Kidney Disease*, 14(4), 402-408. doi: 10.1053/j.ackd.2007.07.002
- Holloway, I., Wheeler, S., & Holloway, I. (2010). *Qualitative research in nursing and healthcare*. Chichester, West Sussex, U.K.: Wiley-Blackwell.
- Holman, H., & Lorig, K. (2000). Patients as partners in managing chronic disease. *BMJ*, 320(7234), 526-527. doi: 10.1136/bmj.320.7234.526
- Houghton, C., Hunter, A., & Meskell, P. (2012). Linking aims, paradigm and method in nursing research. *Nurse Researcher*, 20(2), 34-39. doi: 10.7748/nr2012.11.20.2.34.c9439
- House, J., Landis, K., & Umberson, D. (1998). Social relationships and health. *Science*, 241, 540-544.

- Howard, K., Salkeld, G., White, S., McDonald, S., Chadban, S., Craig, J., & Cass, A. (2009). The cost-effectiveness of increasing kidney transplantation and home-based dialysis. *Nephrology*, *14*(1), 123-132. doi: 10.1111/j.1440-1797.2008.01073.x
- Huang, B., Lai, B., Xu, L., Wang, Y., Cao, Y., Yan, P., & Chen, J. (2017). Low employment and low willingness of being reemployed in Chinese working-age maintained hemodialysis patients. *Renal Failure*, *39*(1), 607-612. doi: 10.1080/0886022x.2017.1361834
- Hugo, N. (2012). Purdah: Separation of Sexes in Northern Nigeria. Consultancy Africa Intelligence [Blog]. Retrieved from <https://arcanaintellego.wordpress.com/2012/06/13/purdah-separation-of-the-sexes-in-northern-nigeria/>
- Hummel, F. (2017). Powerlessness. In P. Larsen, *Lubkin`s Chronic Illness: Impact and Intervention* (10th ed., pp. 243-263). Massachusetts: Jones & Bartlett Learning.
- Hurst, H. (2011). *A Qualitative Study to Explore the Experiences of Patients with Encapsulating Peritoneal Sclerosis*. (PhD Thesis): University of Manchester, Manchester. Retrieved from https://www.research.manchester.ac.uk/portal/files/54513941/FULL_TEXT.PDF.
- Hurst, H., Summers, A., Beaver, K., & Caress, A. (2014). Living with Encapsulating Peritoneal Sclerosis (EPS): The Patient's Perspective. *Peritoneal Dialysis International*, *34*(7), 758-765. doi: 10.3747/pdi.2013.00053
- Husserl, E. (1970). *The idea of phenomenology*. The Hague, The Netherlands: Nijhof.
- Huus, K., & Enskar, K. (2007). Adolescents' experience of living with diabetes. *Paediatric Nursing*, *19*, 29-31.
- Ichoku, H., & Fonta, W. (2009). Catastrophic healthcare expenditure financing and poverty: empirical evidence from Nigeria. *Journal of Social And Economic Development*, *11*(2), 1-16.

Ingham-Broomfeld, R. (2015). A nurses' guide to Qualitative Research. *Australian Journal of Advanced Nursing*, 32(3), 34.

Ingleton, C. (2007). Populations and samples: identifying the boundaries of research. In P. Crookes & S. Davies, *Research into practice: essential skills for reading and applying research in Nursing and Health care* (2nd ed., pp. 113-128). London: Elsevier.

Institute of Medicine. (1993). *Committee on monitoring access to personal health care services: access to health care in America*. Washington, DC: National Academy Press.

International Summit on Transplant Tourism and Organ Trafficking. (2008). The Declaration of Istanbul on organ trafficking and transplant tourism. *Kidney International*, 74, 854-859.

Ipek, G., Guray, Y., Demirkan, B., Guray, U., Kafes, H., & Bayigit, F. (2013). The prevalence of alternative herbal medicine and nutritional complementary product intake in patients admitted to out-patient cardiology departments. *Turk Kardiyoloji Dernegi Arsivi-Archives Of The Turkish Society Of Cardiology*, 41(3), 218-224. doi: 10.5543/tkda.2013.15146

Irving, M., Tong, A., Jan, S., Cass, A., Rose, J., & Chadban, S. et al. (2011). Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation*, 27(6), 2526-2533. doi: 10.1093/ndt/gfr683

Jablonski, A. (2004). The Illness Trajectory of End-Stage Renal Disease Dialysis Patients. *Research and Theory for Nursing Practice*, 18(1), 51-72. doi: 10.1891/088971804780956028

Jablonski, K., & Chonchol, M. (2014). Recent advances in the management of hemodialysis patients: a focus on cardiovascular disease. *F1000prime Reports*, 6. doi: 10.12703/p6-72

Jackson, K., Glasgow, R., Hill, B., Mone, M., Sklow, B., & Scaife, C. et al. (2013). Does Travel Distance Influence Length of Stay in Elective Colorectal Surgery? *Diseases of the Colon & Rectum*, 56(3), 367-373. doi: 10.1097/dcr.0b013e31827e939e

- Jackson, M. (2002). *The politics of storytelling: Violence, transgression, and intersubjectivity*. Copenhagen [Denmark]: Museum Tusulanum Press, University of Copenhagen.
- Jacobson, D. (1986). Types and Timing of Social Support. *Journal of Health and Social Behavior*, 27(3), 250. doi: 10.2307/2136745
- Jadhav, S., & Lee, P. (2014). Understanding the Experience of stress on initiation of Haemodialysis: A Phenomenological Study. *International Journal of Nursing*, 3(1), 11-19.
- JAN Forum: Saving the discipline – Top 10 unfinished issues to inform the nursing debate in the new millennium. (2001). *J Adv Nurs*, 35(1), 138. doi: 10.1046/j.1365-2648.2001.01830.x
- Janz, N., & Becker, M. (1984). The Health Belief Model: A Decade Later. *Health Education & Behavior*, 11(1), 1-47. doi: 10.1177/109019818401100101
- Jasper, M. (2005). Using reflective writing within research. *Journal of Research in Nursing*, 10(3), 247-260. doi: 10.1177/174498710501000303
- Jensen, L., & Allen, M. (1996). Meta-Synthesis of Qualitative Findings. *Qualitative Health Research*, 6(4), 553-560. doi: 10.1177/104973239600600407
- Jesson, J., Matheson, L., & Lacey, F. (2011). *Doing your literature review: Traditional and Systematic Techniques*. Los Angeles: Sage Publishers.
- Jesson, J., Matheson, L., & Lacey, F. (2011). *Doing your literature review: Traditional and Systematic Techniques*. Los Angeles: Sage.
- Jetten, J., Haslam, A., & Haslam, C. (2012). *The Social Cure: Identity, Health and Well-Being* (1st ed.). New York: Psychology Press.
- Jha, V. (2004). End- Stage Renal Care in Developing Countries: The India Experience. *Ren Fail*, 26(3), 201-208. doi: 10.1081/jdi-120039516

- Jha, V., Garcia-Garcia, G., Iseki, K., Li, Z., Naicker, S., & Plattner, B. et al. (2013). Chronic kidney disease: global dimension and perspectives. *The Lancet*, 382(9888), 260-272. doi: 10.1016/s0140-6736(13)60687-x
- Jin, J., Sklar, G., Oh, V., & Li, S. (2008). Factors affecting therapeutic compliance: A review from the patient's perspective. *Therapeutics and Clinical Risk Management*, Volume 4(1), 269-286. doi: 10.2147/tcrm.s1458
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *J Adv Nurs*, 32(1), 243-248. doi: 10.1046/j.1365-2648.2000.01466.x
- Judge, A., Caskey, F., Welton, N., Ansell, D., Tomson, C., Roderick, P., & Ben-Shlomo, Y. (2011). Inequalities in rates of renal replacement therapy in England: does it matter who you are or where you live? *Nephrology Dialysis Transplantation*, 27(4), 1598-1607. doi: 10.1093/ndt/gfr466
- Julian, M., Molinuevo, T., & Sanchez, G. (2012). Employment in the patient with chronic kidney disease related to renal replacement therapy. *Nefrologia*, 32(4), 439-445.
- Julian-Mauro, J., Molinuevo-Tobalina, J., & Sanchez-Gonzalez, J. (2012). Employment in the patient with chronic kidney disease related to renal replacement therapy. *Revista Nefrologia*, 32(4), 439-445.
- Kaba, E., Bellou, P., Iordanou, P., Andrea, S., Kyritsi, E., & Gerogianni, G. et al. (2007). Problems experienced by haemodialysis patients in Greece. *Br J Nursing*, 16(14), 868-872. doi: 10.12968/bjon.2007.16.14.24325
- Kagawa-Singer, M. (2001). From genes to social science. *Cancer*, 91(S1), 226-232. doi: 10.1002/1097-0142(20010101)91:1+<226::aid-cncr9>3.0.co;2-1
- Kagawa-Singer, M., Valdez Dadia, A., Yu, M., & Surbone, A. (2010). Cancer, Culture, and Health Disparities: Time to Chart a New Course? *CA: A Cancer Journal for Clinicians*, 60(1), 12-39. doi: 10.3322/caac.20051

Kanji, Z., Powe, C., Wenger, J., Huang, C., Ankers, E., & Sullivan, D. et al. (2011). Genetic Variation in APOL1 Associates with Younger Age at Hemodialysis Initiation. *Journal of The American Society Of Nephrology*, 22(11), 2091-2097. doi: 10.1681/asn.2010121234

Kao, W., Klag, M., Meoni, L., Reich, D., Berthier-Schaad, Y., & Li, M. et al. (2008). MYH9 is associated with nondiabetic end-stage renal disease in African Americans. *Nat Genet*, 40(10), 1185-1192. doi: 10.1038/ng.232

Kashima, S., Matsumoto, M., Ogawa, T., Eboshida, A., & Takeuchi, K. (2012). The Impact of Travel Time on Geographic Distribution of Dialysis Patients. *Plos ONE*, 7(10), e47753. doi: 10.1371/journal.pone.0047753

Katz, I., Gerntholtz, T., & Naicker, S. (2011). Africa and Nephrology: The Forgotten Continent. *Nephron Clinical Practice*, 117(4), c320-c327. doi: 10.1159/000321524

Kaur, A., & Davenport, A. (2014). Hemodialysis for infants, children, and adolescents. *Hemodialysis International*, 18(3), 573-582. doi: 10.1111/hdi.12163

Kaveh, K., & Kimmel, P. (2001). Compliance in Hemodialysis Patients: Multidimensional Measures in Search of a Gold Standard. *American Journal of Kidney Diseases*, 37(2), 244-266. doi: 10.1053/ajkd.2001.21286

Kazemi, M., Nasrabadi, A., Hasanpour, M., Hassankhani, H., & Mills, J. (2011). Experience of Iranian persons receiving hemodialysis: A descriptive, exploratory study. *Nursing & Health Sciences*, 13(1), 88-93. doi: 10.1111/j.1442-2018.2011.00586.x

Keeney, S., & McKenna, H. (2014). An exploration of the choices of patients with chronic kidney disease. *Patient Preference and Adherence*, 1465. doi: 10.2147/ppa.s60766

Keeping, L., English, L., & Fleming-Courts, N. (2001). Informal and Incidental Learning with Patients Who Use Continuous Ambulatory Peritoneal Dialysis. *Nephrology Nursing Journal*, 28(3), 313-314, 319-322.

Keskin, G., & Engin, E. (2011). The evaluation of depression, suicidal ideation and coping strategies in haemodialysis patients with renal failure. *Journal of Clinical Nursing*, 20(19-20), 2721-2732. doi: 10.1111/j.1365-2702.2010.03669.x

Kikuchi, J. (2003). Nursing Knowledge and the Problem of Worldviews. *Res Theory Nurs Prac*, 17(1), 7-17. doi: 10.1891/rtnp.17.1.7.53167

Kim, Y., Kim, M., Bhandari, P., & Choi, S. (2017). Experience of the waiting area as perceived by haemodialysis patients and family carers. *Journal of Advanced Nursing*, 74(2), 364-372. doi: 10.1111/jan.13448

Kimmel, P. (2000). Psychosocial factors in adult end-stage renal disease patients treated with hemodialysis: Correlates and outcomes. *American Journal of Kidney Diseases*, 35(4), S132-S140. doi: 10.1016/s0272-6386(00)70240-x

Kimmel, P., & Peterson, R. (2005). Psychosocial Factors In Patients With Chronic Kidney Disease: Depression in End-Stage Renal Disease Patients Treated With Hemodialysis: Tools, Correlates, Outcomes, and Needs. *Seminars in Dialysis*, 18(2), 91-97. doi: 10.1111/j.1525-139x.2005.18209.x

King, N., Carroll, C., Newton, P., & Dornan, T. (2002). "You can't cure it so you have to endure it": the experience of adaptation to diabetic renal disease. *Qualitative Health Research*, 12(3), 329-346.

Knowlton, A., Arnsten, J., Eldred, L., Wilkinson, J., Gourevitch, M., & Shade, S. et al. (2006). Individual, Interpersonal, and Structural Correlates of Effective HAART Use Among Urban Active Injection Drug Users. *Journal of Acquired Immune Deficiency Syndromes*, 41(4), 486-492. doi: 10.1097/01.qai.0000186392.26334.e3

Kocaman, N., Kutlu, Y., Özkan, M., & Özkan, S. (2007). Predictors of psychosocial adjustment in people with physical disease. *J Clin Nurs*, 16(3a), 6-16. doi: 10.1111/j.1365-2702.2006.01809.x

- Koch, T. (1999). An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, 6(3), 20-34. doi: 10.7748/nr1999.04.6.3.20.c6085
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890. doi: 10.1046/j.1365-2648.1998.00725.x
- Kogon, M., Biswas, A., Pearl, D., Carlson, R., & Spiegel, D. (1997). Effects of medical and psychotherapeutic treatment on the survival of women with metastatic breast carcinoma. *Cancer*, 80(2), 225-230. doi: 10.1002/(sici)1097-0142(19970715)80:2<225:aid-cnrc9>3.3.co;2-a
- Kourakos, M., Fradelos, E., Papathanasiou, I., Saridi, M., & Kafkia, T. (2018). Communication as the Basis of Care for Patients with Chronic Diseases. *Nursing Education and Research*, 7(3-1), 7-12.
- Kranenburg, L., Kerssens, C., Ijzermans, J., Zuidema, W., Weimar, W., & Busschbach, J. (2005). Reluctant acceptance of xenotransplantation in kidney patients on the waiting list for transplantation. *Social Science & Medicine*, 61(8), 1828-1834. doi: 10.1016/j.socscimed.2005.03.035
- Kremer, H., Ironson, G., & Porr, M. (2009). Spiritual and Mind–Body Beliefs as Barriers and Motivators to HIV-Treatment Decision-Making and Medication Adherence? A Qualitative Study. *AIDS Patient Care and Stds*, 23(2), 127-134. doi: 10.1089/apc.2008.0131
- Kuchler, T., Henne-Bruns, D., Rappat, S., Graul, J., Holst, K., Williams, J., & Wood-Dauphinee, S. (1999). Impact of psychotherapeutic support on gastrointestinal cancer patients undergoing surgery: survival results of a trial. *Hepatogastroenterology*, 46, 322-335.
- Kutner, N. (1987). Social Worlds and Identity in End Stage Renal Disease. In J. Roth & P. Conrad, *Research in The Sociology of Health Care* (1st ed., pp. 249-291). Greenwich, London: JAI Press Inc.

Kutner, N., Bowles, T., Zhang, R., Huang, Y., & Pastan, S. (2008). Dialysis Facility Characteristics and Variation in Employment Rates: A National Study. *Clinical Journal of the American Society of Nephrology*, 3(1), 111-116. doi: 10.2215/cjn.02990707

Kvale, S. (2007). *Doing interviews*. Los Angeles: Sage Publications.

Kvale, S., & Brinkmann, S. (2009). *Interviews*. Thousand Oaks, CA: Sage.

Kyngas, H., & Rissanen, M. (2001). Support as a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing*, 10(6), 767-774. doi: 10.1046/j.1365-2702.2001.00538.x

Lai, A., Loh, A., Mooppil, N., Krishnan, D., & Griva, K. (2012). Starting on haemodialysis: A qualitative study to explore the experience and needs of incident patients. *Psychology, Health & Medicine*, 17(6), 674-684. doi: 10.1080/13548506.2012.658819

Lahey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. Underwood & B. Gottlieb, *Social support measurement and intervention: a guide for health and social scientists* (2nd ed., pp. 29-52). Oxford: Oxford University Press.

Lambert, C., Jomeen, J., & McSherry, W. (2010). Reflexivity: a review of the literature in the context of midwifery research. *British Journal of Midwifery*, 18(5), 321-326. doi: 10.12968/bjom.2010.18.5.47872

Landreneau, K., & Ward-Smith, P. (2006). Patients' Perceptions Concerning Choice among Renal Replacement Therapies: A Pilot Study. *Nephrology Nursing Journal*, 33(4), 397-402.

Landry, D., & Braden, G. (2014). Reducing Catheter-Related Infections in Hemodialysis Patients. *Clinical Journal of the American Society of Nephrology*, 9(7), 1156-1159. doi: 10.2215/cjn.04700514.

Lathlean, J. (2006). Qualitative analysis. In K. Gerrish & A. Lacy, *The research process in nursing* (1st ed., pp. 417-433). Oxford: Blackwell Science.

Laudan, L. (1977). From theories to research traditions. In L. Laudan, *Progress and its Problems: Toward a Theory of Scientific Growth* (1st ed., pp. 70–120). Berkeley: University of California Press.

Laventhal, H., Nerenz, D., & Steele, D. (1984). Illness representations and coping with health threats. In A. Baum, S. Taylor & J. Singer, *Handbook of psychology and health: Social psychological aspects of health* (1st ed., pp. 180-181). Hillsdale, N.J.: Lawrence Erlbaum Publishers.

Laverack, G. (2009). *Public Health: Power, Empowerment and Professional Practice* (2nd ed.). New York: Palgrave Macmillan.

Laverty, S. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*, 2(3), 21-35. doi: 10.1177/160940690300200303

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Pub. Co.

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping* (1st ed.). New York: Springer Pub. Co.

Lea Gaydos, H. (2005). Understanding personal narratives: an approach to practice. *J Adv Nurs*, 49(3), 254-259. doi: 10.1111/j.1365-2648.2004.03284.x

Lebner, A., Nesrallah, G., & Mendelsohn, D. (2007). Experience and evidence: is there enough support funding daily in-centre dialysis? *Nephrology News & Issues*, 21(12), 44-47.

Lee, A., Gudex, C., Povlsen, J., Bonnevie, B., & Nielsen, C. (2008). Patients' views regarding choice of dialysis modality. *Nephrology Dialysis Transplantation*, 23(12), 3953-3959. doi: 10.1093/ndt/gfn365

Lee, G., Charn, T., Chew, Z., & Ng, T. (2004). Complementary and alternative medicine use in patients with chronic diseases in primary care is associated with perceived quality of care and cultural beliefs. *Family Practice, 21*(6), 654-660. doi: 10.1093/fampra/cmh613

Leininger, M. (1985). *Qualitative research methods in nursing*. Orlando, Fla.: Grune & Stratton.

Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common-sense model of self-regulation of health and illness. In L. Cameron & H. Leventhal, *The Self-Regulation of Health and Illness Behaviour* (1st ed., pp. 42–65). London: Routledge.

Leventhal, H., Leventhal, E., & Contrada, R. (1998). Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology & Health, 13*(4), 717-733. doi: 10.1080/08870449808407425

Levey, A. (1999). A More Accurate Method to Estimate Glomerular Filtration Rate from Serum Creatinine: A New Prediction Equation. *Annals of Internal Medicine, 130*(6), 461. doi: 10.7326/0003-4819-130-6-199903160-00002

Levey, A., & Coresh, J. (2012). Chronic kidney disease. *Lancet, 379*, 165–80.

Levey, A., Bosch, J., Lewis, J., Greene, T., Rogers, N., & Roth, D. (1999). A More Accurate Method to Estimate Glomerular Filtration Rate from Serum Creatinine: A New Prediction Equation. *Annals of Internal Medicine, 130*(6), 461. doi: 10.7326/0003-4819-130-6-199903160-00002

Levey, A., Coresh, J., Balk, E., Kausz, A., Levin, A., & Steffes, M. et al. (2003). National Kidney Foundation practice guidelines for chronic kidney disease: evaluation, classification and stratification. *Annals of Internal Medicine, 139*(2), 137-147.

Levey, A., de Jong, P., Coresh, J., El Nahas, M., Astor, B., Matsushita, K., & Eckardt, K. (2011). The definition, classification, and prognosis of chronic kidney disease: a KDIGO Controversies Conference report. *Kidney International, 80*(9), 1000-1000. doi: 10.1038/ki.2011.310

Levy, J., Morgan, J., & Brown, E. (2001). *Oxford handbook of dialysis*. Oxford: Oxford University Press.

Lewis, J. (2007). Analysing Qualitative Longitudinal Research in Evaluations. *Social Policy and Society*, 6(04). doi: 10.1017/s1474746407003880

Library of Congress. (2008). "Country Profile." Retrieved from <http://www.loc.gov/findingaids>

Lin, C., Lee, B., & Hicks, F. (2005). The Phenomenology of Deciding About Hemodialysis among Taiwanese. *Western Journal of Nursing Research*, 27(7), 915-929. doi: 10.1177/0193945905278390

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry* (1st ed.). Beverly Hills, California: Sage Publications.

Lincoln, Y., & Guba, E. (2000). Paradigmatic controversies, contradictions and emerging confluences. In Y. Lincoln & E. Guba, *Handbook of qualitative research* (1st ed., pp. 163-188). Thousand Oaks, California: Sage.

Lindqvist, R., Carlsson, M., & Sjöden, P. (2000). Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal*, 27(3), 298.

Lindsay, H., MacGregor, C., & Fry, M. (2014). The experience of living with chronic illness for the haemodialysis patient: An interpretative phenomenological analysis. *Health Sociology Review*, 23(3), 232-241. doi: 10.1080/14461242.2014.11081976

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145-153. doi: 10.1111/j.1471-6712.2004.00258.x

Lipowski Z.J, Z. (1983). Psychosocial reactions to illness. *Canadian Medical Association Journal*, 128, 1069-1073.

Littlejohn, S., & Foss, K. (2009). Agency. In S. Littlejohn & K. Foss, *Encyclopedia of communication theory* (1st ed., pp. 28-32). Thousand Oaks, CA: SAGE Publications, Inc.

Lobiondo-Wood, G., & Haber, J. (2006). Qualitative approaches to research. In P. Liehr & G. Lobiondo-Wood, *Nursing Research: Methods and critical appraisal for evidence-based practice* (6th ed., pp. 148-175). St. Louis, Missouri: Mosby Elsevier.

Loghman-Adham, M. (2003). Medication noncompliance in patients with chronic disease: issues in dialysis and renal transplantation. *The American Journal of Managed Care*, 9(2), 155-171.

Lok, C., & Foley, R. (2013). Vascular Access Morbidity and Mortality: Trends of the Last Decade. *Clinical Journal of the American Society of Nephrology*, 8(7), 1213-1219. doi: 10.2215/cjn.01690213

Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4(1), 30-37. doi: 10.1054/cein.2000.0106

Lopez, K., & Willis, D. (2004). Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research*, 14(5), 726-735. doi: 10.1177/1049732304263638

Lozano, R., Naghavi, M., Foreman, K., Lim, S., Shibuya, K., & Aboyans, V. et al. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, 380(9859), 2095-2128. doi: 10.1016/s0140-6736(12)61728-0

Luker, K., Beaver, K., Leinster, S., & Owens, R. (1996). Meaning of illness for women with breast cancer. *Journal of Advanced Nursing*, 23, 1194-1201.

Lukowsky, L., Kheifets, L., Arah, O., Nissenson, A., & Kalantar-Zadeh, K. (2012). Patterns and Predictors of Early Mortality in Incident Hemodialysis Patients: New Insights. *American Journal of Nephrology*, 35(6), 548-558. doi: 10.1159/000338673

Lukpata, V. (2013). Revenue allocation formulae in Nigeria: a continuous search. *International Journal of Public Administration and Management Research*, 2, 32-38.

- Lundberg, L., Johannesson, M., Isacson, D., & Borgquist, L. (1998). Effects of user charges on the use of prescription medicines in different socio-economic groups. *Health Policy*, *44*(2), 123-134. doi: 10.1016/s0168-8510(98)00009-8
- Maheswaran, R., Payne, N., Meechan, D., Burden, R., Fryers, P., Wight, J., & Hutchinson, A. (2003). Socioeconomic deprivation, travel distance, and renal replacement therapy in the Trent Region, United Kingdom 2000: an ecological study. *Journal of Epidemiology & Community Health*, *57*(7), 523-524. doi: 10.1136/jech.57.7.523
- Mahler, H., & Kulik, J. (1998). Effects of preparatory videotapes on self-efficacy beliefs and recovery from coronary bypass surgery. *Annals of Behavioral Medicine*, *20*(1), 39-46. doi: 10.1007/bf02893808
- Mahomoodally, M. (2013). Traditional Medicines in Africa: An Appraisal of Ten Potent African Medicinal Plants. *Evidence-Based Complementary and Alternative Medicine*, *2013*, 1-14. doi: 10.1155/2013/617459
- Makaroff, K. (2012). Experiences of Kidney Failure: A Qualitative Meta-Synthesis. *Nephrology Nursing Journal*, *39*(1), 21-29, 80.
- Margaretha Strandmark, K. (2004). Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scandinavian Journal of Caring Sciences*, *18*(2), 135-144. doi: 10.1111/j.1471-6712.2004.00275.x
- Martinez, J., Lemos, D., & Hosek, and the Adolescent Medicine, S. (2012). Stressors and Sources of Support: The Perceptions and Experiences of Newly Diagnosed Latino Youth Living with HIV. *AIDS Patient Care and STDs*, *26*(5), 281-290. doi: 10.1089/apc.2011.0317
- Mathers, N., & Huang, Y. (2007). Evaluating qualitative research. In P. Crookes & S. Davies, *Research into practice: essential skills for reading and applying research in Nursing and health care* (2nd ed., pp. 85-93). London: Elsevier Limited.

Mavrakanas, T., & Charytan, D. (2016). Cardiovascular complications in chronic dialysis patients. *Current Opinion in Nephrology and Hypertension*, 25(6), 536-544. doi: 10.1097/mnh.0000000000000280

Mazzi, M., Rimondini, M., Deveugele, M., Zimmermann, C., Deledda, G., & Bensing, J. (2015). Does gender matter in doctor–patient communication during standard gynaecological consultations? An analysis using mixed methods. *Communication & Medicine*, 11(3), 285-298. doi: 10.1558/cam.v11i3.24806

McCormick-Brown, K. (1999). Health Belief Model. Retrieved from <http://www.jblearning.com/samples/0763743836/chapter%204.pdf>

Mcewan, M., Espie, C., Metcalfe, J., Brodie, M., & Wilson, M. (2004). Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods. *Seizure*, 13(1), 15-31. doi: 10.1016/s1059-1311(03)00080-3

McLeod, J., & Thomson, R. (2009). *Researching social change*. Los Angeles [Calif.]: Sage.

Mechanic, D. (2015). *Medical Sociology* (13th Ed.). New York: Routledge.

Mehrotra, R., Marsh, D., Vonesh, E., Peters, V., & Nissenson, A. (2005). Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. *Kidney International*, 68(1), 378-390. doi: 10.1111/j.1523-1755.2005.00453.x

Menard, S. (2002). *Longitudinal research* (2nd Ed.). Thousand Oaks [u.a.]: Sage.

Merriam, S., & Tisdell, E. (2015). *Qualitative research: A Guide to Design and Implementation* (4th Ed.). San Francisco, CA: Jossey-Bass.

Mertens, D. (1998). *Research methods in education and psychology: Integrating diversity with quantitative and qualitative approaches*. Thousand Oaks, California: Sage.

Mertens, D. (2015). *Research and evaluation in education and psychology*. Thousand Oaks, California: Sage.

- Methven, S., Steenkamp, R., & Fraser, S. (2017). *UK Renal Registry 19th Annual Report of the Renal Association* (pp. 1-422). Bristol, United Kingdom. Retrieved from <https://www.renalreg.org/reports/2016-nineteenth-annual-report/>
- Meuleman, Y., ten Brinke, L., Kwakernaak, A., Vogt, L., Rotmans, J., & Bos, W. et al. (2014). Perceived Barriers and Support Strategies for Reducing Sodium Intake in Patients with Chronic Kidney Disease: a Qualitative Study. *International Journal of Behavioral Medicine*, 22(4), 530-539. doi: 10.1007/s12529-014-9447-x
- Michie, S., Miles, J., & Weinman, J. (2003). Patient-centredness in chronic illness: what is it and does it matter? *Patient Education and Counseling*, 51(3), 197-206. doi: 10.1016/s0738-3991(02)00194-5
- Miller, R. (2005). Morbidity and mortality data associated with ESRD and dialysis: should patients be informed? The "truth," the whole truth, and nothing but the truth... informing ESRD patients of their prognoses. *Nephrology Nursing Journal*, 32(4), 441-442.
- Miller, T. (2015). Going back: 'Stalking', talking and researcher responsibilities in qualitative longitudinal research. *International Journal of Social Research Methodology*, 18(3), 293-305. doi: 10.1080/13645579.2015.1017902
- Miller, T., & DiMatteo, R. (2013). Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy*, 421. doi: 10.2147/dms0.s36368
- Milne, H., & McWilliam, C. (1996). Considering nursing resource as 'caring time'. *Journal of Advanced Nursing*, 23(4), 810-819. doi: 10.1111/j.1365-2648.1996.tb00055.x
- Mitchell, A., Farrand, P., James, H., Luke, R., Purtell, R., & Wyatt, K. (2009). Patients' Experience of Transition onto Haemodialysis: A Qualitative Study. *Journal of Renal Care*, 35(2), 99-107. doi: 10.1111/j.1755-6686.2009.00094.x
- Moch, S. (1989). Health within illness. *Advances in Nursing Science*, 11(4), 23-31. doi: 10.1097/00012272-198907000-00006

- Molzahn, A., Bruce, A., & Shields, L. (2008). Learning from Stories of People with Chronic Kidney Disease. *Nephrology Nursing Journal*, 35(1), 13-21.
- Monaro, S., Stewart, G., & Gullick, J. (2014). A 'lost life': coming to terms with haemodialysis. *J Clin Nurs*, 23(21-22), 3262-3273. doi: 10.1111/jocn.12577
- Moosa, M., & Kidd, M. (2006). The dangers of rationing dialysis treatment: The dilemma facing a developing country. *Kidney International*, 70(6), 1107-1114. doi: 10.1038/sj.ki.5001750
- Morse, J. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research*, 25(9), 1212-1222. doi: 10.1177/1049732315588501
- Morse, J., & Field, P. (2006). *Nursing research: The Application of Qualitative Approaches* (2nd ed.). Cheltenham, U.K.: Nelson Thornes.
- Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, 1(2), 13-22. doi: 10.1177/160940690200100202
- Morse, J., Bottorff, J., & Hutchinson, S. (1994). The phenomenology of comfort. *Journal of Advanced Nursing*, 20(1), 189-195. doi: 10.1046/j.1365-2648.1994.20010189.x
- Morse, J., Bottorff, J., & Hutchinson, S. (1994). The phenomenology of comfort. *Journal of Advanced Nursing*, 20(1), 189-195. doi: 10.1046/j.1365-2648.1994.20010189.x
- Morton, R., Da Silva-Gane, M., Cass, A., Patterson, K., Yip, A., Handke, W., & Webster, A. (2017). Interventions to aid employment for people on dialysis and their families. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.cd012702
- Morton, R., Tong, A., Howard, K., Snelling, P., & Webster, A. (2010). The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ*, 340(jan19 2), c112-c112. doi: 10.1136/bmj.c112

- Morton, R., Tong, A., Webster, A., Snelling, P., & Howard, K. (2011). Characteristics of dialysis important to patients and family caregivers: a mixed methods approach. *Nephrology Dialysis Transplantation*, 26(12), 4038-4046. doi: 10.1093/ndt/gfr177
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health*, 17(1), 1-16. doi: 10.1080/08870440290001494
- Muehrer, R., Schatell, D., Witten, B., Gangnon, R., Becker, B., & Hofmann, R. (2011). Factors Affecting Employment at Initiation of Dialysis. *Clinical Journal of the American Society of Nephrology*, 6(3), 489-496. doi: 10.2215/cjn.02550310
- Muehrer, R., Schatell, D., Witten, B., Gangnon, R., Becker, B., & Hofmann, R. (2011). Factors Affecting Employment at Initiation of Dialysis. *Clinical Journal of the American Society of Nephrology*, 6(3), 489-496. doi: 10.2215/cjn.02550310
- Muñoz-Laboy, M., Severson, N., Perry, A., & Guilamo-Ramos, V. (2014). Differential Impact of Types of Social Support in the Mental Health of Formerly Incarcerated Latino Men. *American Journal of Men's Health*, 8(3), 226-239. doi: 10.1177/1557988313508303
- Murray, S., & Sheikh, A. (2006). Serial interviews for patients with progressive diseases. *The Lancet*, 368(9539), 901-902. doi: 10.1016/s0140-6736(06)69350-1
- Murray, S., Kendall, M., Carduff, E., Worth, A., Harris, F., & Lloyd, A. et al. (2009). Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ*, 339(sep28 1), b3702-b3702. doi: 10.1136/bmj.b3702
- Murtagh, F., & Sheerin, N. (2010). Conservative management of end stage renal disease. In J. Chambers, E. Brown & M. Germain, *Supportive care for the renal patient*. Oxford: Oxford University Press.
- Mushi, L., Marschall, P., & Fleßa, S. (2015). The cost of dialysis in low and middle-income countries: a systematic review. *BMC Health Services Research*, 15(1). doi: 10.1186/s12913-015-1166-8

Nagpal, N., Boutin-Foster, C., Melendez, J., Kubiszewski, P., Uehara, K., & Offidani, E. et al. (2016). Experiences of patients undergoing dialysis who are from ethnic and racial minorities. *Journal of Renal Care*, 43(1), 29-36. doi: 10.1111/jorc.12185

Naicker, S. (2003). End-stage renal disease in sub-Saharan and South Africa. *Kidney International*, 63(s83), 119-122. doi: 10.1046/j.1523-1755.63.s83.25.x

Naicker, S. (2009). End-stage renal disease in Sub-Saharan Africa. *Ethnicity & Disease*, 19(S1-13), S1-S15.

Naicker, S. (2013). End-stage renal disease in Sub-Saharan Africa. *Kidney International Supplements*, 3(2), 161-163. doi: 10.1038/kisup.2013.4

Nakahara, R., Yoshiuchi, K., Kumano, H., Hara, Y., Suematsu, H., & Kuboki, T. (2006). Prospective Study on Influence of Psychosocial Factors on Glycemic Control in Japanese Patients with Type 2 Diabetes. *Psychosomatics*, 47(3), 240-246. doi: 10.1176/appi.psy.47.3.240

Nalado, A., Abdu, A., Adamu, B., Aliyu, M., Arogundade, F., & Sanusi, A. et al. (2016). Prevalence of chronic kidney disease markers in Kumbotso rural Northern Nigeria. *African Journal of Medicine and Medical Sciences*, 45(1), 61-65.

National Health Policy. (2016). *Promoting the Health of Nigerians to Accelerate Socio-economic Development*. Abuja: Federal Ministry of Health.

National Institute for Health and Care Excellence. (2002). *Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure*. London: National Institute for Health and Care Excellence.

National Primary Health Care Development Agency. (2013). *Integrating primary health care governance -primary health care under one roof implementation manual*. Abuja, Nigeria: NPHCDA.

National, K. (2006). KDOQI Clinical Practice Guidelines and Clinical Practice Recommendations for 2006 Updates: Haemodialysis Adequacy, Peritoneal Adequacy and

Vascular Access. *American Journal of Kidney Diseases*, 48, S91-S97. doi: 10.1053/j.ajkd.2006.05.016

Neale, B., & Flowerdew, J. (2003). Time, texture and childhood: The contours of longitudinal qualitative research. *International Journal of Social Research Methodology*, 6(3), 189-199. doi: 10.1080/1364557032000091798

Neimeyer, R., Wittkowski, J., & Moser, R. (2004). Psychological Research on Death Attitudes: An Overview and Evaluation. *Death Studies*, 28(4), 309-340. doi: 10.1080/07481180490432324

Nerenz, D., & Leventhal, H. (1983). Self-regulation theory in chronic illness. In T. Burish & L. Bradley, *Coping with Chronic Disease Research and Applications* (1st ed., pp. 13-37). New York: Academic Press.

Norlyk, A., & Harder, I. (2010). What Makes a Phenomenological Study Phenomenological? An Analysis of Peer-Reviewed Empirical Nursing Studies. *Qualitative Health Research*, 20(3), 420-431. doi: 10.1177/1049732309357435

Nozaki, I., Kuriyama, M., Manyepa, P., Zyambo, M., Kakimoto, K., & Bärnighausen, T. (2013). False Beliefs about ART Effectiveness, Side Effects and the Consequences of Non-retention and Non-adherence Among ART Patients in Livingstone, Zambia. *AIDS and Behavior*, 17(1), 122-126. doi: 10.1007/s10461-012-0221-2

Nursing and Midwifery Council. (2014). Standards for competence for registered nurses. Retrieved from <https://www.nmc.org.uk/standards/standards-for-nurses/pre-2018-standards/standards-for-competence-for-registered-nurses/>

Nwude, E. (2013). The politics of minimum wage in Nigeria: the unresolved issues. *Asian Journal of Empirical Research*, 3(4), 477-492.

Nzewi, E. (2001). Malevolent Ogbanje: recurrent reincarnation or sickle cell disease? *Social Science & Medicine*, 52(9), 1403-1416. doi: 10.1016/s0277-9536(00)00245-8

Obrador, G., Arora, P., Kausz, A., Ruthazer, R., Pereira, B., & Levey, A. (1999). Level of renal function at the initiation of dialysis in the U.S. end-stage renal disease population. *Kidney International*, 56(6), 2227-2235. doi: 10.1038/sj.ki.4491163

O'Connor, N., & Kumar, P. (2012). Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review. *Journal of Palliative Medicine*, 15(2), 228-235. doi: 10.1089/jpm.2011.0207

O'Connor, N., & Kumar, P. (2012). Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review. *Journal of Palliative Medicine*, 15(2), 228-235. doi: 10.1089/jpm.2011.0207

O'Connor, N., & Kumar, P. (2012). Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review. *Journal of Palliative Medicine*, 15(2), 228-235. doi: 10.1089/jpm.2011.0207

Odubanjo, M., Oluwasola, A., & Kadiri, S. (2011). The epidemiology of end-stage renal disease in Nigeria: the way forward. *International Urology and Nephrology*, 43(3), 785-792. doi: 10.1007/s11255-011-9903-3

O'Hare, A. (2009). The Management of Older Adults with a Low eGFR: Moving toward an Individualized Approach. *American Journal of Kidney Diseases*, 53(6), 925-927. doi: 10.1053/j.ajkd.2009.02.013

Ojua, T., Ishor, D., & Ndom, P. (2013). African Cultural Practices and Health Implications for Nigeria Rural Development. *International Review of Management and Business Research*, 2(1), 176-183.

Okafor, C., & Kankam, C. (2012). Future Options for the Management of Chronic Kidney Disease in Nigeria. *Gender Medicine*, 9(1), S86-S93. doi: 10.1016/j.genm.2011.10.002

Okafor, U. (2017). Transplant tourism among kidney transplant patients in Eastern Nigeria. *BMC Nephrology*, 18(1). doi: 10.1186/s12882-017-0635-1

Okafor, U., Wokoma, F., & Ekwem, I. (2012). Challenges of kidney care in a resource poor nation: A study of private kidney care centre in Nigeria. *Nigerian Medical Journal*, 53(1), 47. doi: 10.4103/0300-1652.99833

Okebukola, P., & Brieger, W. (2016). Providing Universal Health Insurance Coverage in Nigeria. *International Quarterly of Community Health Education*, 36(4), 241-246. doi: 10.1177/0272684x16657451

Okechi, O. (2017). Culture, Perception/Belief about Death and their Implication to the Awareness and Control of the Socio-Economic, Environmental and Health Factors Surrounding Lower Life Expectancy in Nigeria. *Acta Psychopathologica*, 03(05). doi: 10.4172/2469-6676.100128

Okpere, A., Anochie, I., Eke, F., Bell-Gam, H., & Jaja, T. (2012). Risk factors of chronic kidney disease in secondary school girls in Port Harcourt: a world kidney day activity. *Portharcourt Medical Journal*, 6(4), 22-25.

Olakunde, B. (2012). Public health care financing in Nigeria: Which way forward? *Annals of Nigerian Medicine*, 6(1), 4. doi: 10.4103/0331-3131.100199

Olaniyan, O., Oburota, J., & Obafemi, N. (2013). Equity in health care expenditure in Nigeria. *International Journal of Finance and Banking Studies*, 2(3), 76-88.

Oluyombo, R., Ayodele, O., Akinwusi, P., Okunola, O., Akinsola, A., & Arogundade, F. et al. (2013). A community study of the prevalence, risk factors and pattern of chronic kidney disease in Osun State, South West Nigeria. *West African Journal of Medicine*, 32(2), 85-92.

Oluyombo, R., Obajolowo, O., Soje, M., Ayorinde, M., Olanrewaju, T., & Okunola. (2014). Challenges of hemodialysis in a new renal care center: call for sustainability and improved outcome. *IJNRD*, 347. doi: 10.2147/ijnrd.s65835

Omosho, O. (2017). Socioeconomic and Policy Context of the Nigerian Health Care Financing System: A Literature Review. *International Affairs and Global Strategy*, 53, 8-16.

- Omotoso, D. (2010). Health Seeking Behaviour among the Rural Dwellers in Ekiti State, Nigeria. *African Research Review*, 4(2). doi: 10.4314/afrev.v4i2.58296
- Onah, M., & Govender, V. (2014). Out-of-Pocket Payments, Health Care Access and Utilisation in South-Eastern Nigeria: A Gender Perspective. *Plos ONE*, 9(4), e93887. doi: 10.1371/journal.pone.0093887
- Ong, L., Visser, M., Lammes, F., & de Haes, J. (2000). Doctor–Patient communication and cancer patients’ quality of life and satisfaction. *Patient Education and Counseling*, 41(2), 145-156. doi: 10.1016/s0738-3991(99)00108-1
- Ononokpono, D., & Odimegwu, C. (2014). Determinants of Maternal Health Care Utilization in Nigeria: a multilevel approach. *Pan African Medical Journal*, 17. doi: 10.11604/pamjs.supp.2014.17.1.3596
- Ononokpono, D., Odimegwu, C., Imasiku, E., & Adedini, S. (2013). Contextual Determinants of Maternal Health Care Service Utilization in Nigeria. *Women & Health*, 53(7), 647-668. doi: 10.1080/03630242.2013.826319
- Onwujekwe, O., Chukwuogo, O., Ezeoke, U., Uzochukwu, B., & Eze, S. (2010). Asking people directly about preferred health-seeking behaviour yields invalid response: an experiment in south-east Nigeria. *Journal of Public Health*, 33(1), 93-100. doi: 10.1093/pubmed/fdq065.
- Oreagba, I., Oshikoya, K., & Amachree, M. (2011). Herbal medicine use among urban residents in Lagos, Nigeria. *BMC Complementary and Alternative Medicine*, 11(1). doi: 10.1186/1472-6882-11-117.
- Ormandy, P. (2008). Information Topics Important To Chronic Kidney Disease Patients: A Systematic Review. *Journal of Renal Care*, 34(1), 19-27. doi: 10.1111/j.1755-6686.2008.00006.x
- Orsino, A., Cameron, J., Seidl, M., Mendelssohn, D., & Stewart, D. (2003). Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry*, 25(5), 324-331. doi: 10.1016/s0163-8343(03)00069-0

- Palmer, B. (1999). Sexual dysfunction in uraemia. *Journal of American Society of Nephrology*, *10*, 1381-1388.
- Palmieri, J., & Stern, T. (2009). Lies in the Doctor-Patient Relationship. *The Primary Care Companion to the Journal of Clinical Psychiatry*, *11*(4), 163-168. doi: 10.4088/pcc.09r00780.
- Pang, S., Ip, W., & Chang, A. (2001). Psychosocial correlates of fluid compliance among Chinese haemodialysis patients. *J Adv Nurs*, *35*(5), 691-698. doi: 10.1046/j.1365-2648.2001.01901.x
- Parahoo, K. (2006). *Nursing research*. Basingstoke: Palgrave Macmillan.
- Parahoo, K. (2014). *Nursing Research*. Basingstoke: Palgrave Macmillan.
- Parkinson, S., Eatough, V., Holmes, J., Stapley, E., & Midgley, N. (2016). Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*, *13*(2), 109-129. doi: 10.1080/14780887.2015.1119228
- Parnis, D., Du Mont, J., & Gombay, B. (2005). Cooperation or Co-Optation? Assessing the Methodological Benefits and Barriers Involved in Conducting Qualitative Research Through Medical Institutional Settings. *Qualitative Health Research*, *15*(5), 686-697. doi: 10.1177/1049732304271832
- Patel, S., Peterson, R., & Kimmel, P. (2008). Psychosocial Factors in Patients with Chronic Kidney Disease: The Impact of Social Support on End-Stage Renal Disease. *Seminars in Dialysis*, *18*(2), 98-102. doi: 10.1111/j.1525-139x.2005.18203.x
- Paternotte, E., van Dulmen, S., van der Lee, N., Scherpbier, A., & Scheele, F. (2015). Factors influencing intercultural doctor-patient communication: A realist review. *Patient Education and Counseling*, *98*(4), 420-445. doi: 10.1016/j.pec.2014.11.018
- Paterson, B. (2001). *Meta-study of qualitative health research*. Thousand Oaks, Calif.: Sage publications.

- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). London: Sage Publications Ltd.
- Patton, M. (2014). *Qualitative Research & Evaluation Methods: Integrating Theory and Practice* (4th ed.). London: SAGE Publications.
- Patton, M., & Patton, M. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, Calif.: Sage Publications.
- Pechansky, R., & Thomas, W. (1981). The concept of access. *Medical Care*, *19*, 127-140.
- Perloff, R., Bonder, B., Ray, G., Ray, E., & Siminoff, L. (2006). Doctor-Patient Communication, Cultural Competence, and Minority Health. *American Behavioral Scientist*, *49*(6), 835-852. doi: 10.1177/0002764205283804
- Pettigrew, A. (1990). Longitudinal Field Research on Change: Theory and Practice. *Organization Science*, *1*(3), 267-292. doi: 10.1287/orsc.1.3.267
- Phillips, J., Cohen, M., & Tarzian, A. (2001). African American Women's Experiences with Breast Cancer Screening. *Journal of Nursing Scholarship*, *33*(2), 135-140. doi: 10.1111/j.1547-5069.2001.00135.x
- Pierret, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health & Illness*, *25*(3), 4-22. doi: 10.1111/1467-9566.t01-1-00337
- Pike, E., Hamidi, V., Ringerike, T., Wisloff, T., & Klemp, M. (2017). More Use of Peritoneal Dialysis Gives Significant Savings: A Systematic Review and Health Economic Decision Model. *Journal of Clinical Medicine Research*, *9*(2), 104-116. doi: 10.14740/jocmr2817w
- Pintado, S. (2018). Breast cancer patients' search for meaning. *Health Care for Women International*, 1-13. doi: 10.1080/07399332.2018.1465427
- Polaschek, N. (2003). Living on dialysis: concerns of clients in a renal setting. *J Adv Nurs*, *41*(1), 44-52. doi: 10.1046/j.1365-2648.2003.02504.x

Polaschek, N. (2003). The experience of living on dialysis: a literature review. *Nephrology Nursing Journal*, 30(3), 303-309, 313.

Polaschek, N. (2007). Doing dialysis at home?: client attitudes towards renal therapy. *J Clin Nurs*, 16(3a), 51-58. doi: 10.1111/j.1365-2702.2006.01622.x

Polit, D., & Beck, C. (2003). *Nursing Research: Principles and Methods* (7th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Polit, D., & Beck, C. (2012). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia, PA: Lippincott Williams and Wilkins.

Polit, D., & Beck, C. (2014). *Essentials of nursing research: Appraising evidence for nursing practice* (8th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Polit, D., & Hungler, B. (1999). *Nursing Research: Principle and Method* (6th ed.). Philadelphia: Lippincott Company.

Polit, D., Beck, C., & Polit, D. (2008). *Resource manual to accompany Nursing research: generating and assessing evidence for nursing practice, 8th edition*. Philadelphia: Wolters Kluwer Health/lippincott Williams & Wilkins.

Pomerantz, A., Cole, B., Watts, B., & Weeks, W. (2008). Improving efficiency and access to mental health care: combining integrated care and advanced access. *General Hospital Psychiatry*, 30(6), 546-551. doi: 10.1016/j.genhosppsy.2008.09.004

Pomey, M., Ghadiri, D., Karazivan, P., Fernandez, N., & Clavel, N. (2015). Patients as Partners: A Qualitative Study of Patients' Engagement in Their Health Care. *PLOS ONE*, 10(4), e0122499. doi: 10.1371/journal.pone.0122499

Pope, C., & Mays, N. (2006). Synthesising qualitative research. In C. Pope & N. Mays, *Qualitative research in health care* (1st ed., pp. 142-152). Oxford: Blackwell Publishers Ltd.

Pope, C., & Mays, N. (2013). *Qualitative Research in Health Care*. New York, NY: John Wiley & Sons.

Pope, C., Mays, N., & Popay, J. (2007). *Synthesizing qualitative and quantitative health evidence: a guide to methods*. Berkshire: Open University Press.

Pope, C., Ziebland, S., & Mays, N. (2006). Qualitative research in health care. In C. Pope & N. Mays, *Qualitative Research in Health Care Third Edition* (3rd ed., pp. 75-88). London: BMJ Books.

Porrit, K., Gomersall, J., & Lockwood, C. (2014). Study selection and critical appraisal: the steps following the literature search in a systematic review. *American Journal of Nursing*, *114*(6), 47-52.

Porter, S. (2007). Validity, trustworthiness and rigour: reasserting realism in qualitative research. *Journal of Advanced Nursing*, *60*(1), 79-86. doi: 10.1111/j.1365-2648.2007.04360.x

Pozo, M., Leow, J., Groen, R., Kamara, T., Hardy, M., & Kushner, A. (2012). An overview of renal replacement therapy and health care personnel deficiencies in sub-Saharan Africa. *Transplant International*, *25*(6), 652-657. doi: 10.1111/j.1432-2277.2012.01468.x

Prentice, J., & Pizer, S. (2007). Delayed Access to Health Care and Mortality. *Health Services Research*, *42*(2), 644-662. doi: 10.1111/j.1475-6773.2006.00626.x

Preston, C., Cheater, F., Baker, R., & Hearnshaw, H. (1999). Left in limbo: patients' views on care across the primary/secondary interface. *Quality and Safety in Health Care*, *8*(1), 16-21. doi: 10.1136/qshc.8.1.16

Pugh-Clarke, K., Read, S., & Sim, J. (2017). Symptom experience in non-dialysis-dependent chronic kidney disease: A qualitative descriptive study. *Journal of Renal Care*, *43*(4), 197-208. doi: 10.1111/jorc.12208

- Qu, S., & Dumay, J. (2011). The qualitative research interview. *Qualitative Research in Accounting & Management*, 8(3), 238-264. doi: 10.1108/11766091111162070
- Quinn, M., Cook, S., Nash, K., & Chin, M. (2001). Addressing Religion and Spirituality in African Americans with Diabetes. *The Diabetes Educator*, 27(5), 643-655. doi: 10.1177/014572170102700505
- Rao, A., Casula, A., & Castledine, C. (2014). *UK Renal Registry 17th Annual Report: Chapter 2 UK Renal Replacement Therapy Prevalence in 2013: National and Centre-Specific Analyses*. Bristol: UK Renal Registry.
- Rasgon, S., Chemleski, B., Ho, S., Widrow, L., Yeoh, H., & Schwankovsky, L. et al. (1996). Benefits of a multidisciplinary predialysis program in maintaining employment among patients on home dialysis. *Advances in Peritoneal Dialysis*, 12, 132–135.
- Rathi, M., & Ramachandran, R. (2012). Sexual and gonadal dysfunction in chronic kidney disease: Pathophysiology. *Indian Journal of Endocrinology and Metabolism*, 16(2), 214. doi: 10.4103/2230-8210.93738
- Ravenscroft, E. (2005). Diabetes and Kidney Failure: How Individuals with Diabetes Experience Kidney Failure. *Nephrology Nursing Journal*, 32, 502-509.
- Rayment, G., & Bonner, A. (2008). Daily dialysis: Exploring the impact for patients and nurses. *International Journal of Nursing Practice*, 14(3), 221-227. doi: 10.1111/j.1440-172x.2008.00690.x
- Reid, C., Seymour, J., & Jones, C. (2016). A Thematic Synthesis of the Experiences of Adults Living with Hemodialysis. *Clinical Journal of the American Society of Nephrology*, 11(7), 1206-1218. doi: 10.2215/cjn.10561015
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.
- Ribitsch, W., Haditsch, B., Otto, R., Schilcher, G., Quehenberger, F., Roob, J., & Rosenkranz, A. (2013). Effects of a Pre-dialysis Patient Education Program on the Relative

Frequencies of Dialysis Modalities. *Peritoneal Dialysis International*, 33(4), 367-371. doi: 10.3747/pdi.2011.00255

Richard, C., & Engebretson, J. (2010). Negotiating living with an arteriovenous fistula for hemodialysis. *Nephrology Nursing Journal*, 37, 363–374.

Richards, H., & Emslie, C. (2000). The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing. *Family Practice*, 17(1), 71-75. doi: 10.1093/fampra/17.1.71

Richards, H., & Schwartz, L. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice*, 19(2), 135-139. doi: 10.1093/fampra/19.2.135

Richards, T. (1999). Patients' priorities. *British Medical Journal*, 318, 277.

Riedl, D., & Schüßler, G. (2017). The Influence of Doctor-Patient Communication on Health Outcomes: A Systematic Review. *Zeitschrift Für Psychosomatische Medizin Und Psychotherapie*, 63(2), 131-150. doi: 10.13109/zptm.2017.63.2.131

Ring, N., Ritchie, K., Mandava, L., & Jepson, R. (2013). A Guide to Synthesising Qualitative Research for Researchers Undertaking Health Technology Assessments and Systematic Reviews. Retrieved from [http://www.healthcareimprovementscotland.org/programmes/medicines and technologies/programme resources/synthesising_research.aspx](http://www.healthcareimprovementscotland.org/programmes/medicines_and_technologies/programme_resources/synthesising_research.aspx)

Ríos, A., López-Navas, A., Ayala-García, M., Sebastián, M., Abdo-Cuza, A., & Martínez-Alarcón, L. et al. (2010). Attitudes toward Living Kidney Donation in Transplant Hospitals: A Spanish, Mexican, and Cuban Multicenter Study. *Transplantation Proceedings*, 42(1), 228-232. doi: 10.1016/j.transproceed.2009.11.006

Ríos, A., Martínez-Alarcón, L., Sánchez, J., Jarvis, N., Guzmán, D., Parrilla, P., & Ramírez, P. (2009). Factors that influence the attitude of East European residents in Spain towards living kidney donation. *Transplant International*, 22(7), 707-716. doi: 10.1111/j.1432-2277.2009.00862.x

Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice*. London: Sage Publications.

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.), *Analysing Qualitative Data* (pp. 172-194). London: Routledge.

Rivara, M., Soohoo, M., Streja, E., Molnar, M., Rhee, C., & Cheung, A. et al. (2016). Association of Vascular Access Type with Mortality, Hospitalization, and Transfer to In-Center Hemodialysis in Patients Undergoing Home Hemodialysis. *Clinical Journal of the American Society of Nephrology*, *11*(2), 298-307. doi: 10.2215/cjn.06570615

Robson, C., & McCartan, K. (2015). *Real world research* (4th ed.). Malden, MA: Blackwell.

Rocco, M., & Burkart, J. (1993). Prevalence of missed treatments and early sign-offs in hemodialysis patients. *Journal of the American Society of Nephrology*, *4*(5), 1178-1183.

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, *53*(3), 304-310. doi: 10.1111/j.1365-2648.2006.03727.x

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, *53*(3), 304-310. doi: 10.1111/j.1365-2648.2006.03727.x

Rosland, A., Heisler, M., & Piette, J. (2011). The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. *Journal of Behavioral Medicine*, *35*(2), 221-239. doi: 10.1007/s10865-011-9354-4

Rosland, A., Kieffer, E., Israel, B., Cofield, M., Palmisano, G., & Sinco, B. et al. (2008). When Is Social Support Important? The Association of Family Support and Professional Support with Specific Diabetes Self-management Behaviors. *Journal of General Internal Medicine*, *23*(12), 1992-1999. doi: 10.1007/s11606-008-0814-7

Roth, J., & Conrad, P. (1987). The experience and management of chronic illness. In J. Roth & P. Conrad, *Research in the Sociology of Health Care: the Experience and Management of Chronic Illness* (1st ed., pp. 1-2). Greenwich, CT: JAI Press.

Sadiq Umar, A. (2017). The Use of Maternal Health Services in Nigeria: Does Ethnicity and Religious Beliefs Matter? *MOJ Public Health*, 6(6). doi: 10.15406/mojph.2017.06.00190

SAGE Publications Ltd. (2013). *Doing Qualitative Research: A Practical Handbook* (4th ed.). London.

Sahaf, R., Ilali, E., Peyrovi, H., Kamrani, A., & Spahbodi, F. (2017). Uncertainty, the Overbearing Lived Experience of the Elderly People Undergoing Hemodialysis: A Qualitative Study. *International Journal of Community Based Nursing and Midwifery*, 5(1), 13-21.

Sakalys, J. (2003). Restoring the Patient's Voice: The Therapeutics of Illness Narratives. *Journal of Holistic Nursing*, 21(3), 228-241. doi: 10.1177/0898010103256204

Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8. doi: 10.1097/00012272-199312000-00002

Sandelowski, M., & Barroso, J. (2002). Reading Qualitative Studies. *International Journal of Qualitative Methods*, 1(1), 74-108. doi: 10.1177/160940690200100107

Sandelowski, M., Doherty, S., & Emden, C. (1997). Focus on qualitative methods. Qualitative meta-synthesis: issues and techniques. *Research in Nursing And Health*, 20, 365-371.

Santoro, D., Benedetto, F., Modello, P., Pipito, N., Barilla, D., Spinelli, F., & Buemi, M. (2014). Vascular access for hemodialysis: current perspectives. *International Journal of Nephrology and Renovascular Disease*, 7, 281-294.

Sanusi, A., Arogundade, F., & Badmus, T. (2008). Renal transplantation: its evolution, problems, prospects and challenges. *Nigerian Journal of Health Sciences*, 8, 12-15.

Saran, R., Robinson, B., Abbott, K., Agodoa, L., Ayanian, J., ..., & Shahinian, V. (2017). US Renal Data System 2015 Annual Data Report: Epidemiology of Kidney Disease in the United States. *American Journal of Kidney Diseases*, 67(3), A4. doi: 10.1053/j.ajkd.2015.12.015

Saunders, M., Lewis, P., & Thornhill, A. (2009). Understanding research philosophies and approaches. *Research Methods for Business Students*, 4, 106-135.

Savage, S., & Clarke, V. (1998). Older women's illness representations of cancer: a qualitative study. *Health Education Research*, 13(4), 529-544. doi: 10.1093/her/13.4.529

Savage, S., & Clarke, V. (1998). Older women's illness representations of cancer: a qualitative study. *Health Education Research*, 13(4), 529-544. doi: 10.1093/her/13.4.529

Scambler, G. (2011). Health inequalities. *Sociology of Health & Illness*, 34(1), 130-146. doi: 10.1111/j.1467-9566.2011.01387.x

Schena, F. (2000). Epidemiology of end-stage renal disease: International comparisons of renal replacement therapy. *Kidney International*, 57(s74), 39-45. doi: 10.1046/j.1523-1755.2000.07407.x

Schwandt, T. (2007). *The SAGE dictionary of qualitative inquiry*. Los Angeles, Calif.: Sage Publications.

Seah, A., Tan, F., Srinivas, S., Wu, H., & Griva, K. (2013). Opting out of dialysis - Exploring patients' decisions to forego dialysis in favour of conservative non-dialytic management for end-stage renal disease. *Health Expectations*, 18(5), 1018-1029. doi: 10.1111/hex.12075

Seah, A., Tan, F., Srinivas, S., Wu, H., & Griva, K. (2013). Opting out of dialysis - Exploring patients' decisions to forego dialysis in favour of conservative non-dialytic

management for end-stage renal disease. *Health Expectations*, 18(5), 1018-1029. doi: 10.1111/hex.12075

Seligman, M. (1991). *Learned optimism*. New York: A.A. Knopf.

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), 1153-1166. doi: 10.1016/j.socscimed.2005.07.010

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), 1153-1166. doi: 10.1016/j.socscimed.2005.07.010

Shaw, R. (2015). Being-in-dialysis: The experience of the machine–body for home dialysis users. *Health: An Interdisciplinary Journal For The Social Study Of Health, Illness And Medicine*, 19(3), 229-244. doi: 10.1177/1363459314539775

Silva, A., Moratelli, L., Tavares, P., Marsicano, E., Pinhati, R., & Colugnati, F. et al. (2016). Self-efficacy beliefs, locus of control, religiosity and non-adherence to immunosuppressive medications in kidney transplant patients. *Nephrology*, 21(11), 938-943. doi: 10.1111/nep.12695

Silverman, D. (2016). *Qualitative research* (4th ed.). London: Sage Publications.

Silverman, D. (2017). *Doing qualitative research* (5th ed.). London: Sage Publications.

Silverman, D., & Marvasti, A. (2008). *Doing qualitative research: A Comprehensive Guide* (1st ed.). Los Angeles: SAGE Publications.

Sim, J., Zhou, H., Shi, J., Shaw, S., Henry, S., ..., & Jacobsen, S. (2018). Disparities in early mortality among chronic kidney disease patients who transition to peritoneal dialysis and hemodialysis with and without catheters. *International Urology and Nephrology*, 50, 963–971. doi: <https://doi.org/10.1007/s11255-018-1837-6>

Simon, B., Budó, M., Garcia, R., Gomes, T., Oliveira, S., & da Silva, M. (2013). Social support network to the caregiving family of an individual with a chronic disease: integrative review. *Journal of Nursing UFPE Online*, 7(5), 4243-4250.

Singleton, J. (2002). Caring For Themselves: Facilitators And Barriers To Women Home Care Workers Who Are Chronically Ill Following Their Care Plan. *Health Care for Women International*, 23(6-7), 692-702. doi: 10.1080/07399330290107430

Smith, B. (1999). Ethical and Methodologic Benefits of Using a Reflexive Journal in Hermeneutic-Phenomenologic Research. *Image: The Journal of Nursing Scholarship*, 31(4), 359-363. doi: 10.1111/j.1547-5069.1999.tb00520.x

Smyth, A. (2012). End-Stage Renal Disease and Renal Replacement Therapy in older Patients. *Nephro-Urology Monthly*, 4(2), 425-430. doi: 10.5812/numonthly.1825

Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis, *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (pp. 1-23). London: Sage Publications.

Snelgrove, S. (2014). Conducting qualitative longitudinal research using interpretative phenomenological analysis. *Nurse Researcher*, 22(1), 20-25. doi: 10.7748/nr.22.1.20.e1277

Sokolowski, R. (2006). *Introduction to Phenomenology*. New York: Cambridge University Press.

Soner, B., Sahin, A., & Sahin, T. (2013). A survey of Turkish hospital patients' use of herbal medicine. *European Journal of Integrative Medicine*, 5(6), 547-552. doi: 10.1016/j.eujim.2013.08.004

Spencer, L., Ritchie, J., & O'Connor, W. (2004). Analysis: practices, principles and processes. In J. Ritchie & J. Lewis, *Qualitative research practice* (1st ed., pp. 199-218). London: Sage Publications.

Spencer, L., Ritchie, J., Ormston, R., O'Connor, W., & Barnard, M. (2013). Analysis: Principles and Processes. In J. Ritchie, J. Lewis, C. Nicholls & R. Ormston (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (2nd ed., pp. 269-294). London: Sage Publications.

Speziale, H., & Carpenter, D. (2007). *Qualitative research in nursing*. Philadelphia: Lippincott Williams & Wilkins.

Srivastava, A., & Thomson, S. (2009). Framework analysis: a qualitative methodology for applied policy research. *Journal of Administration & Governance*, 4(2), 72-79.

Stake, R. (2010). *Qualitative Research*. New York: Guilford Press.

Stanford Encyclopaedia of Philosophy. (2013). Phenomenology. Retrieved from <http://plato.stanford.edu/entries/phenomenology/>

Starfield, B., Shi, L., Grover, A., & Macinko, J. (2005). The Effects of Specialist Supply on Populations' Health: Assessing the Evidence. *Health Affairs*, 24(Suppl1), W5-97-W5-107. doi: 10.1377/hlthaff.w5.97

Stevens, L., Djurdjev, O., Cardew, S., Cameron, E., & Levin, A. (2004). Calcium, Phosphate, and Parathyroid Hormone Levels in Combination and as a Function of Dialysis Duration Predict Mortality: Evidence for the Complexity of the Association between Mineral Metabolism and Outcomes. *Journal of the American Society of Nephrology*, 15(3), 770-779. doi: 10.1097/01.asn.0000113243.24155.2f

Stewart, A., Noakes, T., Eales, C., Shepard, K., Becker, P., & Veriawa, Y. (2018). Adherence to cardiovascular risk factor modification in patients with hypertension. *Cardiovascular Journal of South Africa*, 16(2), 102-107.

Strauss, A. (1975). *Chronic illness and the quality of life*. Saint Louis: Mosby.

Stretcher, V., & Rosenstock, I. (1997). The health belief model. In A. Baum, *Cambridge handbook of psychology, health and medicine* (1st ed., pp. 113-117). Cambridge, UK: Cambridge University Press.

Sumankuuro, J., Crockett, J., & Wang, S. (2018). Sociocultural barriers to maternity services delivery: a qualitative meta-synthesis of the literature. *Public Health*, 157, 77-85. doi: 10.1016/j.puhe.2018.01.014

Swallow, V., Lambert, H., Santacroce, S., & Macfadyen, A. (2011). Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: Care, Health and Development*, 37(4), 512-523. doi: 10.1111/j.1365-2214.2011.01219.x

Szabo, E., Moody, H., Hamilton, T., Ang, C., Kovithavongs, C., & Kjellstrand, C. (1997). Choice of treatment improves quality of life. A study on patients undergoing dialysis. *Archives of Internal Medicine*, 157(12), 1352-1356. doi: 10.1001/archinte.157.12.1352

Tanyi, R., & Werner, J. (2003). Adjustment, Spirituality, and Health in Women on Hemodialysis. *Clinical Nursing Research*, 12(3), 229-245. doi: 10.1177/1054773803253163

Tanyi, R., & Werner, J. (2008). Women's Experience of Spirituality within End-Stage Renal Disease and Hemodialysis. *Clinical Nursing Research*, 17(1), 32-49. doi: 10.1177/1054773807311691

Taskapan, H., Ates, F., Kaya, B., Emul, M., Kaya, M., Taskapan, C., & Sahin, I. (2005). Psychiatric disorders and large interdialytic weight gain in patients on chronic haemodialysis. *Nephrology*, 10(1), 15-20. doi: 10.1111/j.1440-1797.2005.00321.x

Taylor, S. (2009). Engaging and Retaining Vulnerable Youth in a Short-term Longitudinal Qualitative Study. *Qualitative Social Work: Research and Practice*, 8(3), 391-408. doi: 10.1177/1473325009337848

Taylor, S., & Sherman, D. (2004). Positive psychology and health psychology: a fruitful liaison. In P. Linley & S. Joseph, *In Positive Psychology in Practice* (1st ed., pp. 305-319). Hoboken, NJ: Wiley Publishers.

The National Bureau of Statistics. (2017). *Unemployment/Under-employment report* (p. 5). Abuja: NBS Nigeria.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1). doi: 10.1186/1471-2288-8-45

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1). doi: 10.1186/1471-2288-8-45
- Thomson, R., & Holland, J. (2003). Hindsight, foresight and insight: The challenges of longitudinal qualitative research. *International Journal of Social Research Methodology*, 6(3), 233-244. doi: 10.1080/1364557032000091833
- Thorne, S. (1993). *Negotiating health care* (1st ed.). Newbury Park, Calif.: Sage Publications.
- Thorne, S. (1999). The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36(5), 397-404. doi: 10.1016/s0020-7489(99)00031-0
- Tobin, G., & Begley, C. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48(4), 388-396. doi: 10.1111/j.1365-2648.2004.03207.x
- Tong, A., Henning, P., Wong, G., McTaggart, S., Mackie, F., Carroll, R., & Craig, J. (2013). Experiences and Perspectives of Adolescents and Young Adults with Advanced CKD. *American Journal of Kidney Diseases*, 61(3), 375-384. doi: 10.1053/j.ajkd.2012.09.024
- Tong, A., Sainsbury, P., Chadban, S., Walker, R., Harris, D., & Carter, S. et al. (2009). Patients' Experiences and Perspectives of Living with CKD. *American Journal of Kidney Diseases*, 53(4), 689-700. doi: 10.1053/j.ajkd.2008.10.050
- Tong, J., Liu, M., Li, H., Luo, Z., Zhong, X., & Huang, J. et al. (2016). Mortality and Associated Risk Factors in Dialysis Patients with Cardiovascular Disease. *Kidney Blood Pressure Research*, 41, 479-487.
- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC Medical Research Methodology*, 14(1). doi: 10.1186/1471-2288-14-80

- Trisolini, M., Roussel, A., Zerhusen, E., Schatell, D., Harris, S., & Bandel, K. et al. (2004). Activating chronic kidney disease patients and family members through the Internet to promote integration of care. *International Journal of Integrated Care*, 4(4). doi: 10.5334/ijic.114
- Tsutsui, H., Nomura, K., Ishiguro, A., Tsuruta, Y., Kato, S., & Yasuda, Y. et al. (2017). Factors associated with employment in patients undergoing hemodialysis: a mixed methods study. *Renal Replacement Therapy*, 3(1). doi: 10.1186/s41100-017-0105-z
- Tulunay, M., Aypak, C., Yikilkan, H., & Gorpelioglu, S. (2015). Herbal medicine use among Turkish patients with chronic diseases. *Journal of Intercultural Ethnopharmacology*, 4(3), 217. doi: 10.5455/jice.20150623090040
- Tweed, A., & Ceaser, K. (2005). Renal replacement therapy choices for pre-dialysis renal patients. *British Journal of Nursing*, 14(12), 659-664. doi: 10.12968/bjon.2005.14.12.18287
- Tzanakaki, E., Boudouri, V., Stavropoulou, A., Stylianou, K., Rovithis, M., & Zidianakis, Z. (2014). Causes and complications of chronic kidney disease in patients on dialysis. *Health Science Journal*, 8(3), 343-349.
- Uchino, B. (2004). *Social support and physical health*. New Haven: Yale University Press.
- Ulasi, I., & Ijoma, C. (2010). The Enormity of Chronic Kidney Disease in Nigeria: The Situation in a Teaching Hospital in South-East Nigeria. *Journal of Tropical Medicine*, 2010, 1-6. doi: 10.1155/2010/501957
- Umoh, D. (2012). Death is not natural: The African Story. *Journal of Religion and Spirituality*, 14(2012), 1-13.
- United Kingdom Renal Association. (2002). *Treatment of adults and children with renal failure: standards and audit measures (3rd ed.)*. London: The Lavenham Press Ltd.
- Unuigbo, E. (2006). Funding of renal care in Nigeria: a critical appraisal. *Tropical Journal of Nephrology*, 1, 33-38.

- Uzochukwu, B., Ughasoro, M., Okwuosa, C., Onwujekwe, O., Envuladu, E., & Etiaba, E. (2015). Health care financing in Nigeria: Implications for achieving universal health coverage. *Nigerian Journal of Clinical Practice*, *18*(4), 437. doi: 10.4103/1119-3077.154196
- Vachon, M., Fillion, L., & Achille, M. (2009). A Conceptual Analysis of Spirituality at the End of Life. *Journal of Palliative Medicine*, *12*(1), 53-59. doi: 10.1089/jpm.2008.0189
- Van der Zalm, J., & Bergum, V. (2000). Hermeneutic-phenomenology: providing living knowledge for nursing practice. *Journal of Advanced Nursing*, *31*(1), 211-218. doi: 10.1046/j.1365-2648.2000.01244.x
- van Manen, J., Korevaar, J., Dekker, F., Reuselaars, M., Boeschoten, E., Krediet, R., & NECOSAD Study Group. (2001). Changes in employment status in end-stage renal disease patients during their first year of dialysis. *Peritoneal Dialysis International*, *21*(6), 595-601.
- van Manen, M. (1996). Phenomenological pedagogy and the question of meaning. In D. Vadenberg, *Phenomenology and educational discourse*. Durban: Heinemann.
- van Manen, M. (2016). *Researching Lived Experience* (2nd ed.). Walnut Creek: Taylor and Francis.
- Van Manen, M. (1990). *Researching Lived Experience* (p. New York, United States of America). State University of New York Press.
- Vélez, E., & Ramasco, M. (2006). Meaning Of Illness and Illness Representations, Crucial Factors to Integral Care. *EDTNA-ERCA Journal*, *32*(2), 81-85. doi: 10.1111/j.1755-6686.2006.tb00456.x
- Waaajmann, C. (2003). *Spirituality: Forms, Foundations, Methods*. Leuven: Peeters.
- Wachukwu, C., Emem-Chioma, P., Wokoma, F., & Oko-Jaja, R. (2015). Prevalence of risk factors for chronic kidney disease among adults in a university community in southern Nigeria. *Pan African Medical Journal*, *21*. doi: 10.11604/pamj.2015.21.120.7079

- Waitzkin, H. (1984). Doctor-Patient Communication. *JAMA*, 252(17), 2441. doi: 10.1001/jama.1984.03350170043017
- Wall, L. (1998). Dead Mothers and Injured Wives: The Social Context of Maternal Morbidity and Mortality among the Hausa of Northern Nigeria. *Studies in Family Planning*, 29(4), 341. doi: 10.2307/172248
- Walton, J. (2002). Finding a Balance: A Grounded Theory Study of Spirituality in Haemodialysis Patients. *Nephrology Nursing Journal*, 29(5), 447-456.
- Wang, K., Wang, P., Liang, X., Lu, X., & Liu, Z. (2015). Epidemiology of haemodialysis catheter complications: a survey of 865 dialysis patients from 14 haemodialysis centres in Henan province in China. *BMJ Open*, 5(11), e007136. doi: 10.1136/bmjopen-2014-007136
- Ward, D., Furber, C., Tierney, S., & Swallow, V. (2013). Using Framework Analysis in nursing research: a worked example. *Journal of Advanced Nursing*, n/a-n/a. doi: 10.1111/jan.12127
- Weafer, J. (2009). *A Qualitative study of public perceptions of end of life care*. Dublin: The Irish Hospice Foundation.
- Weaver, A., & Flannelly, K. (2004). The Role of Religion/Spirituality for Cancer Patients and Their Caregivers. *Southern Medical Journal*, 97(12), 1210-1214. doi: 10.1097/01.smj.0000146492.27650.1c
- Weaver, K., & Olson, J. (2006). Understanding paradigms used for nursing research. *J Adv Nurs*, 53(4), 459-469. doi: 10.1111/j.1365-2648.2006.03740.x
- White, P. (2015). The concept of diseases and health care in African traditional religion in Ghana. *HTS Teologiese Studies / Theological Studies*, 71(3). doi: 10.4102/hts.v71i3.2762
- White, P., James, V., Ansell, D., Lodhi, V., & Donovan, K. (2006). Equity of access to dialysis facilities in Wales. *QJM*, 99(7), 445-452. doi: 10.1093/qjmed/hcl054

White, Y., & Grenyer, B. (1999). The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners. *J Adv Nurs*, 30(6), 1312-1320. doi: 10.1046/j.1365-2648.1999.01236.x

Wick, J., Turin, T., Faris, P., MacRae, J., Weaver, R., & Tonelli, M. et al. (2017). A Clinical Risk Prediction Tool for 6-Month Mortality after Dialysis Initiation among Older Adults. *American Journal of Kidney Diseases*, 69(5), 568-575. doi: 10.1053/j.ajkd.2016.08.035

Williams, A., Bower, E., & Newton, J. (2004). Research in primary dental care Part 6: Data analysis. *British Dental Journal*, 197(2), 67-73. doi: 10.1038/sj.bdj.4811467

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociol Health & Illness*, 22(1), 40-67. doi: 10.1111/1467-9566.00191

Wilson, V., & Clarke, M. (2004). *Pre-Dialysis Education and Care – An Important Factor in ESRD Management* [Ebook]. Fresenius Medical Care North America. Retrieved from <http://www.advancedrenaleducation.com/Literature/PDServeConnectionPastArticles/PreESRDANecessity/tabid/347/Default.aspx>

Winterbottom, A., Conner, M., Mooney, A., & Bekker, H. (2007). Evaluating the quality of patient leaflets about renal replacement therapy across UK renal units. *Nephrology Dialysis Transplantation*, 22(8), 2291-2296. doi: 10.1093/ndt/gfm095

World Health Organisation. (2005). *Country Cooperation Strategy*. Brazzaville: World Health Organization Regional Office for Africa.

World Health Organisation. (2011). *Rio Political Declaration on Social Determinants of Health*. Geneva: World Health Organisation.

World Health Organisation. (2014). *World Health Organisation Country Cooperation Strategy*.

World Health Organisation. (2017). *Global Health Expenditure Database*. Retrieved from <http://apps.who.int/nha/database>

Wright, B., Zozula, C., & Wilcox, B. (2012). Bad News about the Good News: The Construction of the Christian-Failure Narrative. *Journal of Religion & Society*, *14*(2012), 1-19.

Wu, C., Lin, C., Hsieh, H., & Chang, S. (2016). Lived experiences and illness representation of Taiwanese patients with late-stage chronic kidney disease. *Journal of Health Psychology*, *21*(12), 2788-2798. doi: 10.1177/1359105315587134

Wulffs, D. (1991). Understanding religion and life. *Journal of Religion, Spirituality & Aging*, *18*, 93-110.

Yin, R. (2014). *Case study research*. London: Sage Publication.

Young, A., Taylor, S., & Renpenning, K. (2001). *Connections*. St. Louis, Mo.: Mosby.

Young, B., Von Korff, M., Heckbert, S., Ludman, E., Rutter, C., & Lin, E. et al. (2010). Association of major depression and mortality in Stage 5 diabetic chronic kidney disease. *General Hospital Psychiatry*, *32*(2), 119-124. doi: 10.1016/j.genhosppsy.2009.11.018

Zachariae, R., Pedersen, C., Jensen, A., Ehrnrooth, E., Rossen, P., & von der Maase, H. (2003). Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy and perceived control over the disease. *British Journal of Cancer*, *88*(5), 658-665. doi: 10.1038/sj.bjc.6600798

Appendices

Appendix 1: Critical Appraisal Checklist for Literature Review

Yes/no or unclear are answers to the following questions

1. There is congruity between the stated philosophical perspective and the research methodology
2. There is congruity between the research methodology and the research question or objectives
3. There is congruity between the research methodology and the methods used to collect data
4. There is congruity between the research methodology and the representation and analysis of data
5. There is congruity between the research methodology and the interpretation of results
6. There is a statement locating the researcher culturally and theoretically
7. The influence of the researcher on the research, and vice-versa, is addressed
8. Participants, and their voices, are adequately represented
9. The research is ethical according to current criteria or, for recent studies; there is evidence of ethical approval by an appropriate body
10. Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data

(Briggs, 2008)

Appendix 2: Studies included in the literature review

Author (year)	Country	Aims	Methodology	Participants	Analysis	Finding	Quality
(1) White and Grenyer (1999)	Australia	To explore the impact of dialysis on patients and their partners	Qualitative interviews	Dialysis patients (HD HD) + their partners N=44	Husserlian phenomenological approach	<ul style="list-style-type: none"> Anxiety about uncertainty of health changes in lifestyles following initiation of dialysis Negative emotional respond to dialysis 	
(2) Mitchell et al. (2009)	United Kingdom	To identify factors identified by patients as helpful in the transition onto HD.	Semi-structured interviews	HD patients N=10	Interpretive content analysis	<ul style="list-style-type: none"> Preparation Cognitive style Social support 	
(3) Tong et al (2009)	Australia	To describe the experience of patients different stages of CKD about the meaning of CKD and its treatment influence lifestyles and relationships.	Focus group interviews	Patients at various stages of CKD (stage 1-3) HD + PD patients + to transplant N=63	Inductive and deductive process to develop themes	5 main themes <ul style="list-style-type: none"> Personal meaning of CKD managing & monitoring health lifestyle consequences Family impact informal support structures 	
(4) Tong et al. (2013)	Australia	To elicit the experiences and perspectives young	Qualitative interviews	Non-dialysis dependent CKD	Thematic analysis	5 mean the can <ul style="list-style-type: none"> Inferiority 	

		people waiting for kidney transplant		patients + HD + PD patients N = 27		<ul style="list-style-type: none"> • Insecurity • Injustice • Resilience • Adjustment mentality 	
(5) Polaschek (2003)	New Zealand	To gain an understanding of the experiences of Caucasian ESKD patients who are receiving home HD	Semi-structured interviews.	HD patients N=6	Themes were identified in relation to discuss analysis	<p>4 main themes:</p> <ul style="list-style-type: none"> • Limitations as a result of negotiating HD. • -Ongoingness and uncertainty of life on dialysis • Suffering due to continued symptoms. • Altered relationship between autonomy and dependence inherent in living on dialysis 	Aims were poorly stated and unclear
(6) Noble et al (2010)	United Kingdom	Not stated.	Qualitative interviews & observations.	CKD patients managed without dialysis N= 30	Unclear	Main findings related to physical and mental symptoms	
(7) Monaro et al (2014)	Australia	To describe the essence of the lived experience of patients and families in the early phase of long-term HD therapy	Phenomenological hermeneutic interviews	HD patients + family caregivers	Interpretive phenomenological analysis	<p>7 main themes</p> <ul style="list-style-type: none"> • Shock and grief • loss of sense of self • changed body feelings • loss of spontaneity and personal freedom 	

						<ul style="list-style-type: none"> • changed body feelings • refraining family role • loss of social connectedness 	
(8) Molzahn et al (2008).	Canada	To explore how people with CKD describe story experiences of liminality associated with CKD and its treatment	Secondary analysis of the participants, written narratives.	All RRTS	constructive approach	<p>4 contrasting themes</p> <ul style="list-style-type: none"> • restrictions/freedom • Not normal/normal • worse off/better off • Alone/connected 	
(9) Lindsay et al (2014)	Australia	To examine the life experiences of living with chronic illness for the HD patient	Existential phenomenological interview	HD patient (N = 7)	Thematic analysis	<p>3 main themes</p> <ul style="list-style-type: none"> • challenges of living with CKD <ul style="list-style-type: none"> • Body changes and embodiment • Illness experience and social relationships 	
(10) Lai et al (2012)	Singapore	To explore the lived experience of incident HD patient in Singapore	Semi-structured interview	HD patients N=13	Interpretive phenomenological analysis	<p>3 main theme</p> <ul style="list-style-type: none"> • Emotional distress • Treatment related concerns • Social support 	
(11) Kazemi et al (2011)	Iran	To investigate the experiences in the social interactions in the daily life of Iranian persons who are on HD	Qualitative semi-structured interviews	21 HD patients (9 females and 12 males)	Thematic analysis	<p>4 main themes</p> <ul style="list-style-type: none"> • living with fatigue • Change in self-image • Hiding the disease • Dependency on the device, place and time of HD 	

(12) Kaba et al (2007)	Greece	To explore how Greek patients receiving long-term HD perceive their problems and describe the impact on these patients' lives	Grounded theory interviews	HD patients N=23	Inductive theory development into major categories	5 major categories <ul style="list-style-type: none"> • Problem related to the symptoms • Limitations in life • Uncertainty • Dependence • Changes on personality 	
(13) Herlin and Wann-Hansson (2010)	Sweden	To describe how HD patients between 30 and 45 years of age experienced their dependence on HD treatment	Qualitative interview	HD patients N=9	Inductive and deductive progress to develop themes	Major theme was a total lack of freedom. 5 sub-theme were. A sense of fear	
(14) Harwood et al (2005)	United kingdom	To explore the specific stressors patients with CKD who are on HD recall experiencing as they approach dialysis.	Semi-structured interviews	HD patients N=11	Content analysis	4 major themes <ul style="list-style-type: none"> • Stressors • Emotional responses • Learning preparation and acceptance • Regret and dissatisfaction 	
(15) Hagren et al (2005)	Sweden	To examine how patients on maintenance HD express their life situation	Semi-structured interviews	41HD patients (15 females and 26 males)	Content analysis	3 main themes <ul style="list-style-type: none"> • Not finding space for living • Feeling evoked in the care situation • Attempting to manage restricted life. 	

(16) Giles (2005)	Canada	To investigate, explore and describe the embodied life-world experiences of people who lived with a HHD machine	Phenomenological interviews	HHD patients (3 males)	Interpretive phenomenological analysis	Major theme was that of a content struggle between the body and the dialysis machine	No justification was given on the poor sample size
(17) Ekelund and Andersson (2010)	Sweden	To elicit the psychological and psychosocial problem existing in dialysis patients and their partners.	Questionnaire-based interviews + telephone interviews	HD + PD+ their partners N=60	Inductive and deductive approach to derive themes	5 major themes <ul style="list-style-type: none"> • Importance of individual losing treatments • Dependence on an apparatus • Consequences of the disease and the treatment. • Hopes for the future. • Thoughts concerning life and death 	
(18) de Guzman et al (2009)	Philippines	To explore the essences or languages of coping according to a select of Filipino elderly patients with lived HD experience	Phenomenological interviews	HD patients N=13	Thematic analysis	3 major themes <ul style="list-style-type: none"> • Coping as scaffolding: the power to hold on. • Coping as sailing the power to see the difference 	
(19) Curtin et al (2002)	USA	To explore factors that enhance the survival of dialysis patients and enjoy good QOL	Exploratory description Semi-structured interviews	Long-term survivors of HD/PD/Renal transplant. A total of 18 patients (8	Content analysis	<ul style="list-style-type: none"> • Adaptation to changed situations • Life constraints/uncertainty/setbacks/dialysis treatment 	

				females and 10 males) were recruited for the study		<ul style="list-style-type: none"> Transformation active self-management 	
(20) Sadala et al (2012)	Brazil	To highlight the meaning of PD as experienced by patients with chronic renal	Hermeneutic interview	PD patient N=19	Qualitative structural analysis	3 major themes <ul style="list-style-type: none"> Facing the world of CKD and dialysis Living changes in one's own body Sources of support 	
(21) Velez and Ramasco (2006)	Spain	To describe and characterise the attributed meanings of ESRD and HD from patients' perspective as a first approach to the representational world of this event.	Narrative qualitative methodology involving interviews	12 HD patients (6 women and 6 men)	Content analysis	4 major categories: <ul style="list-style-type: none"> Illness experience Treatment and compliance Coping strategies Uncertain future 	
22)Tanyi and Werner (2008)	United States of America	To describe women's lived experiences of spirituality within ESRD and HD	Descriptive phenomenological method involving qualitative interviews	16 female HD patients recruited from 2 dialysis centres	Content analysis	Four major themes: <ul style="list-style-type: none"> Understanding Acceptance Fortification Emotion modulation 	

23)Ravenscroft (2005)	Canada	To explore the experience of kidney failure from the perspective of individuals with diabetes mellitus	Qualitative interviews using interpretive description approach	7 HD patients (5 females and 2 males) recruited from 2 HD centres	Inductive analysis	2 major themes and their sub-themes: <ul style="list-style-type: none"> • Global experience -diagnosis -illness intrusion -interactions with healthcare providers <ul style="list-style-type: none"> • Adjusting to living with kidney failure -personal control and -hope	
24) Monaro et al. (2010)	Republic of Ireland	To explore the experiences of ESKD patients receiving HD	Hermeneutical phenomenology approach	16 HD patients	Qualitative interpretive analysis	3 main themes: <ul style="list-style-type: none"> • Living in hope • Uncertainty • Being on hold 	
25) Sabet et al. (2011)	Iran	To describe the life experiences of ESKD patients within the HD unit	Descriptive phenomenological approach	10 HD patients (7 females and 3 males)	Colaizzi's method of analysis	4 main themes: <ul style="list-style-type: none"> • Haemodialysis as an irrefutable component of life • Tensions of dialysis life • Need to support • Effective adaptation 	

26) Hagren et al. (2001)	Sweden	To describe patients` experiences of suffering from ESKD	Interpretive qualitative design	15 HD patients (8 women and 7 men in a dialysis facility)	Qualitative interpretive content analysis	<p>2 main themes with their respective subthemes:</p> <ul style="list-style-type: none"> • Haemodialysis machine as a lifeline <p>-dependence -disrupted daily life -loss of freedom</p> <ul style="list-style-type: none"> • Alleviation of suffering <p>-gaining a sense of existential optimism -achieving a sense of personal autonomy</p>	
27) Vestman et al. (2014)	Sweden	To describe patients` experience of having home HD	Qualitative approach involving written narratives	Home haemodialysis patients, n=11	Qualitative analysis of the narratives	<p>5 main themes:</p> <ul style="list-style-type: none"> • Freedom to be at home and have self-control of the treatment • Feeling of being alone with the responsibility • Changes in the home environment • Well-being with HHD • Needs of aids and safety 	

28)Faber et al. (2003)	Canada	To understand the life experiences of people living with kidney failure	Multiple case study design using semi-structured interviews	4 dialysis patients (3 on HD but the mode of dialysis of one was not stated)	Strauss and Corbin (1988) analysis framework	Central theme: <ul style="list-style-type: none"> • “Work” involved in living with kidney disease 3 subthemes: <ul style="list-style-type: none"> -work in the biomedical community -work outside the hospital or dialysis setting -work entailed in living with the consequences of kidney disease 	The samples size used in the study was quite small and the modality of dialysis of one of the participants was not stated.
29)Caress et al. (2001)	United Kingdom	To explore the subjective meaning of illness in renal patients	Cross-sectional survey design	405 CKD patients (predialysis, n=155, dialysis=103, transplant=147)	Chi-square test and content analysis of the qualitative data	3 major themes: <ul style="list-style-type: none"> • Overcoming illness • Being “normal” • All adverse life events as a challenge 	
30)Gregory et al. (1998)	Canada	To explore patients` experiences and perceptions of ESKD and HD treatment	Grounded theory methodology	HD patients, n=36	Constant comparative method of data	3 main themes: <ul style="list-style-type: none"> • Redefinition of self • Quality of supports and 	

					analysis to identify themes	<ul style="list-style-type: none"> • Meanings of illness/treatment 	
31)Clarkson and Robinson (2010)	USA	To explore the lived experiences of ESKD patients	Qualitative interviews	10 dialysis patients (HD=6, PD=4)	Thematic analysis	<p>3 main categories emerged with sub-themes:</p> <ul style="list-style-type: none"> • Life changing on dialysis <ul style="list-style-type: none"> -restricted life -limitations and - hard on body • Coping and • Areas lacking <ul style="list-style-type: none"> -health management -education and -preparing the next generation 	
32) Axelsson et al. (2012)	Sweden	To describe and to elucidate the meanings of the lived experience of being severely ill living with haemodialysis when nearing end of life	Phenomenological hermeneutic method	8 aged HD patients (aged 66-87years) recruited from 4 different facilities	Qualitative structural analysis of data	<p>3 main themes and eleven sub-themes:</p> <ul style="list-style-type: none"> • Being subordinate to the deteriorating body <ul style="list-style-type: none"> -feeling that fatigue is taking over life -interpreting the deteriorating body -being increasingly dependent on others -feeling trapped -having a changing social life • Changing outlook on life 	

						<ul style="list-style-type: none"> -living with the sorrow of having to give up plans -having to accept a changed life -hovering between living the present and worrying about the future -reflecting on the meaning of a life with haemodialysis 	
33) Burns et al (2017)	Australia	To investigate and describe the experiences of INHD from a patient's perspective during the first 12 months of the in-house service	Descriptive qualitative methodology	8 male and 6 female INHD patients	Thematic analysis	<ul style="list-style-type: none"> • INHD had positive effects on physical health • Patients felt isolated from the rest of the dialysis patients • Patients experienced new symptoms related to poor sleep 	
34) Gullick et al. (2016)	Australia	To interpret the spatial-temporal experience of people with End-stage kidney disease and their families in the first months of haemodialysis.	Phenomenological approach	11 HD patients and 7 family members	Heideggerian hermeneutic framework	<ul style="list-style-type: none"> • Theme of Being-in-the-world as a new haemodialysis patient • Compartmentalising life into dialysis and non-dialysis days • Compartmentalising space 	

35) Nagpal et al. (2017)	USA	To understand the psychosocial context of living with ESKD among black and Latino adults who reside in a medically underserved community	Descriptive phenomenology	36 HD patients	Thematic analysis	<p>Five themes of:</p> <ul style="list-style-type: none"> • The transition to dialysis is abrupt and unexpected; • denial is often an initial response; • dialysis is the new normal and in order to survive one must forget the past and press forward; • dialysis changes everything and impacts the entire family; • strength was often found in faith and family 	
36) Shaw (2015)	New Zealand	To investigate the experience of being-in-dialysis as an intercorporeal relation between self and other,	Qualitative interviews; no clear design	7 PD and 13 HD patients	Thematic analysis	<ul style="list-style-type: none"> • Positive experience of home dialysis is relative to socio-economic positioning and the lived relation of patients to others 	

		technology and world					
37) Al Nazly et al. (2013)	Jordan	To examine the lived experiences of Jordanian patients with chronic kidney disease who received haemodialysis	Descriptive phenomenology using interviews	9 HD patients	Thematic analysis	Seven common themes: <ul style="list-style-type: none"> • lifestyle change, • time wasted, • symptom-related suffering, • marital and family role disruption, • religious commitment disruption • motivators to alleviate stressors, • and experience of healthcare providers' support 	
38) Guerra-Guerrero et al. (2014)	Chile	To explore the lived experiences of patients on Haemodialysis concerning the adherence to treatment and quality of life.	Hermeneutic Phenomenological approach Qualitative interviews	15 HD patients	Thematic analysis	Two main themes derived from the analysis: <ul style="list-style-type: none"> • Embracing the disease and dialysis, and • Preventing progression of the disease through treatment management. 	

Appendix 3: Critical Appraisal Summary

Studies	Clear statement of aim	Appropriate methodology	Appropriate design	Appropriate recruitment strategy	Appropriate data collection strategy	Relationship between researcher and participants	Ethical issues considered.	Rigorous data analysis	Clear statement of findings	Value of research
White and Grenyer (1999)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes
Mitchel et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tong et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tong et al.(2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Polaschek (2003)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Noble et al(2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Monaro et al.(2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Molzahn et al.(2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lindsay et al.(2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lai et al.(2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kazemi et al.(2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kaba et al. (2007)	Yes	Yes	Yes	No	Unsure	Yes	Yes	Yes	Yes	Yes
Herlin and Wann-Hanson (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Harwood et al. (2005)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes
Hagren et al. (2005)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes
Giles (2005)	Yes	Yes	Yes	Yes	Unsure	Unsure	Yes	Yes	Yes	Yes
Ekelund and Anderson (2010)	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	Unsure	Yes	Yes
De Guzman et al.(2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Curtin et al. (2002)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Sadala et al.(2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Velez and Ramasco (2006)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tanyi and Werner (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ravenscroft (2005)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Monaro et al.(2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sabet et al.(2011)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Hagren et al.(2001)	Yes	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes
Vestman et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Faber et al.(2003)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Caress et al.(2001)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes
Gregory (1998)	Yes	Yes	Yes	Unsure	Yes	Yes	No	Yes	Yes	Yes
Clarkson and Robinson (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure

Axelsson et al.(2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Burns et al.(2017)	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes
Gullick et al. (2016)	Yes	Yes	Yes	Yes	Yes	Unsure	No	Yes	Yes	Yes
Nagpal et al.(2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shaw (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes
Al Nazly et al.(2013)	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Unsure	Yes
Guerra-Guerrero et al.(2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix 4: Example of Literature search strategy in CINAHL

1. *End-stage kidney disease
2. *Chronic kidney disease
3. *Renal failure
4. *End-stage renal disease
5. *End-stage renal failure
6. *Kidney failure
7. *Kidney disease
- 8.*Renal replacement therapy (RRT)
9. *Dialysis patients
- 10*Haemodialysis patients
11. *Peritoneal dialysis patients
12. *1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13. *Lived experiences
14. *Perceptions of dialysis
15. *Coping with chronic kidney disease
16. *Perceptions of chronic kidney disease
17. *Meaning of illness
18. *Illness representations
19. *Meaning of dialysis
20. *Experience of chronic kidney disease
21. *Perspectives of chronic kidney disease patients
22. *Living with chronic kidney disease

23. *13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22

24. *12 and 23

Appendix 5: Participants` information sheet

Study Title: The lived experiences of haemodialysis patients in Nigeria and sustainability of treatment: a qualitative longitudinal study

For participants who can read English

I would like to invite you to participate in a research study on the lived experience of people who are referred to and/or accessing haemodialysis treatment. However, before you decide on whether to be involved you need to understand why this research is being done and what may be expected of you throughout the time of the study. Please take time to read the following piece of information carefully and ask any questions if anything is not clear to you or if you require further information. Feel free to decide whether you wish to take part or not.

The purpose of the study is to gain an insight of the experiences of haemodialysis patients in Nigeria and explore the factors affecting their access and sustainability of dialysis treatment in order to improve service delivery.

Why have I been invited?

You have been selected to participate in this study because you have chronic kidney disease and are receiving or have been referred for haemodialysis treatment in the Renal Unit of the University of Nigeria Teaching Hospital (UNTH), Enugu. Your name was randomly selected from all the possible patients that could be asked to be involved in the study.

Do I have to take part?

Participation in the research study is entirely voluntary. You are completely free to decide. This information sheet will describe the process of the research study and you are free to ask any further questions to enable you make an informed decision on whether to participate or not. You will then be asked to sign a consent form if you agree to participate in the study. If

you prefer a telephone interview then you will be asked to digitally record your verbal consent to be involved in the study, prior to the telephone interview. You are free to withdraw at any time, without giving a reason and this this will not affect the standard of care or treatment you receive in the facility.

What will happen to me if I take part?

If you agree to participate in the research study, you will agree to take part in 3 separate interview sessions over a period of 7 months. There will be three sessions of interview with each interview lasting between 1 to 2 hours at month 1 then repeated at 4 months and 7 months (3 to 6 hours of interview contact in total). The interview will take place at a time and place which is convenient for you and it will be tape recorded and securely saved in a data file which will be placed on a password-protected computer to which only the researcher will have access. The interview recordings will be transcribed and important issues from the conversation reflected to you in interview 2 and 3 to confirm that the analysis of your experience is accurate. The type of questions you may be asked during the interview could include:

- What does living with CKD mean to you and your life, what impact does living with CKD have on the quality of your life?
- What symptoms do you experience? How does this make you feel?
- What are your experiences with respect to HD treatment, what influences whether you attend or not, what challenges do you face when accessing treatment?
- What are your experiences of the care that you receive at the unit or from the doctor? How often are you reviewed and followed up?
- What influences whether you attend dialysis or not? (physical symptoms, cost of treatment, whether you work or not, your culture, beliefs, needs of your family, where you live)
- Are there any government interventions that could make a difference to your experience of treatment and CKD?

Secondary data will be collected from your hospital records in the Renal Unit. The data will include your monthly haematology and biochemistry tests such as the haemoglobin levels, serum Urea and Electrolytes, and albumin levels. These data will be collected at each wave of data collection.

Will I receive any payment or expenses?

For the time spent during each interview session, a travel cost of #2,000 will be paid by the researcher (ABC) as a reimbursement for your time and travel costs to attend the interview.

What will I have to do?

If you agree to be involved you just need to let me know and I will contact you and organise a date, time and place that will be convenient for you during the scheduled months for the interviews to take place as outlined earlier in this information sheet and you are free to let me know if there is any change in plan.

What are the possible disadvantages and risks of taking part?

This study should pose no known risks, discomfort or inconvenience to you. However, should you find any aspect of the study inconvenient, please feel free to let me know and this will not in any way affect the quality of your care or treatment. Also, should you feel upset about any aspect of the question or experience of your health condition, kindly let me know and support services can be made readily available for you from the renal unit as appropriate.

What are the possible benefits of taking part?

Participating in the research may not be of any benefit to you but the findings from this study will help in generating evidence which will be used in providing better access and sustainability of dialysis treatment to chronic kidney disease patients and in enabling the healthcare practitioners in improving the care they render to the patients.

Will my taking part in the study be kept confidential?

All the information you provide during the interviews will be used for this study only. Your responses, contact details and email address will be stored safely and confidentially on a password-protected computer, which will be accessed only by the researcher. Your responses to the questions will be transcribed and analysed to understand and describe your experiences and to elicit those issues affecting the sustainability of dialysis treatment. After the completion of the study, all your information will be stored anonymously and your email erased. In addition, your responses will be coded anonymised using pseudonyms instead of using your real names to ensure the confidentiality of your identity. No one will know that you have taken part in this study unless you choose to tell them.

What will happen if I don't carry on with the study?

If you withdraw from the study we will destroy all your identifiable samples/ tape recorded interviews, but we will need to use the data collected up to your withdrawal.

What will happen to the results of the research study?

The study findings will be published in a PhD Thesis and publications in academic journals. Any quotes from your interview that are used in any report/publication will not identify you unless you give specific consent. You can indicate after the third interview if you would like to be provided with a summary of the study findings and recommendations and these will be sent to you. Or if you decide later you want to see the results you can contact me direct at any time to ask for a copy of the findings.

Who is organising or sponsoring the research?

My research study is funded by the Tertiary Education Trust Fund of Nigeria in partnership with the Management of Ebonyi State University, Abakaliki, Nigeria. However, I am not under any obligation to make available any information you provide to me during the study.

What if there is a problem and I want to complain about how the research is being conducted?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do his best to answer your questions.

Researcher and Project Co-ordinator:

ABC PhD Student, University of Salford, Manchester, UK

Email: abc@edu.salford.ac.uk

Mobile: 080XXXXXXXX

If you remain unhappy and wish to complain formally you can do this either through the Matron in Charge of the Renal Dialysis Unit or the researcher's academic supervisor details below.

Matron, Renal Unit:

Mrs KLM

Phone: 080XXXXXXXX

Or Supervisor:

Professor XYZ, University of Salford, Manchester, UK

Phone: ++44 161 295 XXXX

Email: XYZ@salford.ac.uk

or

Mr AAA

Research and Innovation Manager

College of Health and Social Care

University of Salford

Phone+44(0)161 295 XXXX

E-mail: aaa@salford.ac.uk

Any further questions about the research or you want more information please

contact: ABC on 080XXXXXXXX

Thank you for taking the time to read this information

Appendix 6 : Participants` Invitation Letter

Dear.....

The lived experiences of haemodialysis patients in Nigeria and sustainability of treatment: a qualitative longitudinal study

You are respectfully invited to participate in a research study on the lived experiences of people who are referred to and/or accessing haemodialysis treatment in the dialysis unit of the University of Nigeria Teaching Hospital (UNTH), Enugu. The purpose of the study is to gain an insight of the experiences of haemodialysis patients in Nigeria and explore the factors affecting their access and sustainability of dialysis treatment to improve service delivery.

However, before you decide on whether to be involved you need to understand why this research is being done and what may be expected of you throughout the time of the study. Please take time to read the following piece of information on the participant information sheet carefully and ask any questions if anything is not clear to you. Feel free to decide whether you wish to take part or not. Should you have need further information on the study, kindly contact me on 080XXXXXXXX and I will be happy to discuss with you any questions you may have.

Kindly fill the enclosed consent form if you choose to participate in this study and send back to me in the pre-paid envelope provided.

Thank you very much for taking time to read this letter.

Yours sincerely,

ABC

PhD Student, University of Salford, Manchester

Appendix 7: Informed consent form

Study Title: The lived experiences of haemodialysis patients in Nigeria and sustainability of treatment: a qualitative longitudinal study

Participant Identification Number _____

Name of Researcher: ABC

Please sign and date each box

I confirm that I have read and understand the information sheet (28.7.15 v1.) for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	
I understand that my name and involvement in the study will remain confidential.	
I understand that any personal information about me such as my email contact address will not be shared outside of the study team and will only be used for this research (unless I have given instructions to be placed on a separate mailing list).	
I understand that the information I provide could be used as part of the final study report or journal publications but any comments used will not be identifiable to me.	
In understand that the interviews will be digitally recorded and transcribed	
I agree that you can collect my monthly blood results routinely collected on the dialysis data	
I agree to take part in the above study	

Name of Participant

Date

Signature

ABC

Name of Researcher

Date

Signature

Appendix 8: University of Salford Ethical Approval

**Research, Innovation and Academic
Engagement Ethical Approval Panel
Research Centres Support Team
G0.3 Joule House
University of Salford
M5 4WT
T +44(0)161 295 2280
www.salford.ac.uk/**

29 September 2015

Dear Chidiebere,

RE: ETHICS APPLICATION HSCR 15-93 – The lived experiences of haemodialysis patients in Nigeria and sustainability of treatment: a qualitative longitudinal study

Based on the information you provided, I am pleased to inform you that application HSCR15-93 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Sue McAndrew

Chair of the Research Ethics Panel

Appendix 9: UNTH Ethical Approval

Chief Sir Dr. C. J. UDEOGU,

UNIVERSITY OF NIGERIA TEACHING HOSPITAL

ITUKU - OZALLA, P. M. B. 01129, ENUGU

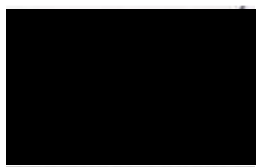
TEC: 024 - 252022. 252573. 252172, 2552134, FAX: 252665

**NHREC/05/01/2008B-FWA 00002458- IRB00002323
ETHICAL CLEARANCE CERTIFICATE**

TOPIC: THE LIVED EXPERIENCES OF HAEMODIALYSIS PATIENTS IN
NIGERIA AND SUSTAINABILITY OF TREATMENT: A QUALITATIVE
LONGITUDINAL STUDY
BY: CHIDIEBERE VALENTINE EKUMA

FOR A DOCTORAL DISSERTATION OF THE MULTI. PROFESSIONAL POST
GRADUATE STUDIES, SCHOOL OF NURSING MIDWIFERY, SOCIAL
WORK AND SOCIAL SCIENCES, UNIVERSITY OF SALFORD:
MANCHESTER.

This research project on the above topic was reviewed and approved by the
University of Nigeria Teaching Hospital Health Research Ethics Committee, This
certificate is valid for one year from date of issue. Please note that the Committee
Reserves the Right to monitor the Conduct of the study at any time for strict
Compliance to the Protocol.



Date:

Research Ethics Committee

Appendix 10: Draft interview guide

Draft Interview Guide Wave 1:

- Introduction of the researcher and purpose of the study
- Written (or recorded verbal) consent obtained

- Demographic details of the participant: age, gender, start of dialysis, frequency of treatment accessed over the last month, employment,

- Family, dependents, role and current social situation

- Biographical understanding of disease progression and start of treatment, referral to the service

General open conversation prompt questions:

- What does living with CKD mean to you and your life, what impact does living with CKD have on the quality of your life?
- What symptoms do you experience? How does this make you feel?
- What are your experiences with respect to HD treatment, what influences whether you attend or not, what challenges do you face when accessing treatment?
- What are your experiences of the care that you receive at the unit or from the doctor? How often are you reviewed and followed up?
- What influences whether you attend dialysis or not? (physical symptoms, cost of treatment, whether you work or not, your culture, beliefs, needs of your family, where you live)
- Are there any government interventions that could make a difference to your experience of treatment and CKD?

Draft interview Guide - Wave 2 & 3

- Introduction of the researcher and purpose of the study
- Written (or recorded verbal) consent obtained

- Review status and characteristic changes such as frequency of access to dialysis

- Review and confirm key themes from previous interview

- Tell me about your experiences since we last met and what it has been like for you over the last two months.

Use prompts to follow up interview themes and conversations, challenges positive and negative experiences, influences.

Appendix 11: Extracts of framework analysis matrix

<i>Partici pants</i>												
A	<i>Living with this condition is death for me. It`s like.....umm... How could I lose my health and my future through pregnancy?</i>	<i>I can no longer get back on my teaching job or any other job in life. Who can ever employ me again? Even if I`m employed, where do I find</i>	<i>We both now depend on my family for our upkeep. This is not the kind of life I wished for myself and my husband but it`s now the reality</i>	<i>My whole body is now swollen because of this condition and I now look like I`m pregnant again when I`m not</i> (Concerns about body)	<i>The cost of this dialysis is very high and poor people like us can hardly afford it and it`s only through the grace of God that I`m alive today as</i>	<i>Every day I experience excruciating pain especially down my abdominal region and this makes me feel paralysed. It makes me very</i>	<i>The care I receive from the nurses and the doctors here are okay. They always treated me well although when it comes to the issue of payment, they are not friendly on that. If</i>	<i>The nurses and the doctors have always taught me about what food and drinks to take and they also stressed the need for me to avoid buying drugs indiscriminately</i> (Information from				

	<p>(Description of living with CKD)</p>	<p>the strength to perform my job? So, this condition has rendered me useless and incapacitated. This condition has led me to be unemployed and not only that, my husband has become poor due to this</p>	<p>(Dependence on family)</p>		<p>my poor parents struggle to raise money for my dialysis (Concerns about cost of dialysis)</p>	<p>much uncomfortable and unable to do anything (Description of symptoms)</p>	<p>you don't pay, you are not going to be dialysed. In fairness to them, they are doing their best within the available resources they have at their disposal. They are compassionate, kind and empathic (Description of care received)</p>	<p>healthcare workers)</p>				
--	--	---	--------------------------------------	--	---	--	--	-----------------------------------	--	--	--	--

		<i>condition. He has sold all the goods in his shop and other property to pay for my medical bills and this has got to the point that we are no longer able to pay our rent</i> (Impact of condition on											
--	--	---	--	--	--	--	--	--	--	--	--	--	--

		employ ment)										
B	<i>I was managing this condition with the recommended medications but I couldn't comply with the treatment and other lifestyle adjustments. I kept on using herbal remedies which I bought from my</i>	<i>Living with kidney failure to me means living with an enemy which tends to stop every dream you have in life. It means an abrupt disruption of my life plans andIt's</i>	<i>I couldn't have imagined that I will have a condition whereby my whole body will swell and I will look like a pregnant woman (Descripti on of body image)</i>	<i>I have not been able to focus on my business due to the constant tiredness I always have and the swelling of my body (Impact of symptoms)</i>	<i>So, my business has suffered and my income has depleted as I have to pay for my dialysis and look after my family. It's not been easy with me coping with the financial pressure I have faced since this</i>	<i>How can my belly be so swollen? It makes me stay indoors and I find it difficult to go out and associate with my friends (Impact on social relations)</i>	<i>I normally experience constant pain in my abdomen. My face and my leg are swollen like you can see. Erm...erm ... I also vomit especially whenever I eat certain kinds of food. The swelling makes me feel sad and ashamed of myself as I look like a</i>	<i>So, I can say that the main thing that influence my decision to come for dialysis is money. If I have the money required for the dialysis, buying the materials that are needed and paying for my transportation on all the way from Port Harcourt and back</i>	<i>Also, erm... I cannot recall any day the physical symptoms affected my coming for dialysis. It only affects my social relations with my friends as I don't go out with them again (Impact</i>	<i>Well the place where I live ordinarily is supposed to be a factor affecting my decision to come for dialysis as I don't live in this state and I have to travel from a very far distance to here but honestly once I have the money</i>		

	<p>area and I was using this for almost 2 years. I tried keeping to my hospital appointments sometimes but failed to attend most of them (Culture of use of herbal remedies)</p>	<p>awful (Meaning of living with condition)</p>			<p>condition started (Impact of condition on finances)</p>		<p>pregnant woman (Impact of symptoms)</p>	<p>home then I have no option than to come for my dialysis. So, erm...erm... basically money is the major challenge I face (Impact of money on dialysis decision)</p>	<p>of symptom on social relations hips)</p>	<p>to come for dialysis, I wouldn't mind travelling to here for the dialysis (Distance as a non-issue)</p>		
C	<p>Since the commencement of dialysis,</p>	<p>The swelling is quite discomfort</p>	<p>I have spent all my life savings</p>	<p>Assuming I am still working and earn salaries it will help me in the</p>	<p>The people I'm paying</p>	<p>I have never been told or</p>	<p>Also, many of our people do not know</p>	<p>I have defaulted consistently in managing</p>				

<p><i>I have always experienced constant fatigue which affected my performance on my job and so I had to quit my job in November 2015 because I find it very difficult to walk unaided and so can't be tolerated</i></p>	<p><i>ring to me. It makes me feel very heavy and it doesn't permit me to breathe well; even now I can't breathe well and it disturbs my sleeping pattern. I only manage to sleep a few hours in</i></p>	<p><i>on this condition. We spend between #2,500 and #3,000 on fuel each time we are coming here for dialysis from Abakaliki. Sometimes we hire cabs from Abakaliki when our family car breaks down to the dialysis centre here in</i></p>	<p><i>payment of my medical bills but now I don't work and I have become a burden to my daughter who is a medical doctor as now takes care of my bills (Dependence on others for support)</i></p>	<p><i>school fees for are numerous because my late husband had 3 wives and I am the first so now that he is late I try to take care of the other 2 wives and their children. I pay the tuition fees for both my children and theirs;</i></p>	<p><i>given information on the things I should avoid eating or lifestyle it was only in Abakaliki that I was educated on nutrition and lifestyle. They hardly tell me anything on all that. All I do is to</i></p>	<p><i>what is called CKD or dialysis and so die out of ignorance for instance in Mount Carmel yesterday a restless dialysis patient was brought in from Abakaliki and he was gasping for breath; so even though he wasn't dead but you can imagine the difference having a</i></p>	<p><i>my condition until about one year ago when I was placed on oral antidiabetics. I have consistently declined insulin injections when the condition became worse. Even though I am an auxiliary nurse, I didn't believe that orthodox medicine was the best means for my treatment</i></p>				
--	--	--	--	--	--	--	--	--	--	--	--

<p>to carry on in my workplace. I'm no longer able to work again (Challenges with maintaining employment)</p>	<p>a day, I'm only managing my life (Impact of symptom on sleeping pattern)</p>	<p>Enugu as it's not always convenient for me to come here by public transport for instance there was a day my condition deteriorated and we needed to rush down here for dialysis so we had to search almost endlessly for where to hire a</p>		<p>for instance, this my daughter who is looking after me now is a third-year law student in EBSU and one of my sons is in second year studying microbiology and the other one is in first year studying Mass communication.</p>	<p>keep to the medications prescribed by the doctor (Non-information management regimen)</p>	<p>dialysis facility close to him would have had on his experience. So, it will be very good if the government can establish renal centres (even if it's just one or two) in Abakaliki. You can imagine the frustrations we are going through in getting money for</p>	<p>and so, I was taking our herbal concoction all the time for my condition. I was later placed on monthly observation until when my blood sugar level dropped to a reasonably lower level. During this period, I constantly defaulted in keeping my hospital appointment until in 2014 when I had very severe</p>				
---	---	---	--	--	--	--	--	--	--	--	--

			<p>vehicle and so we had to come by public transport and before we could arrive here I was almost dead (Experience of travelling for dialysis)</p>		<p>My step-children are 6 and I pay their tuition fees; although the eldest of them all has graduated and is now married but I paid her tuition fees although her study period. I am taking on this responsibility</p>		<p>dialysis and then money for transportation to Enugu (Distance as a barrier)</p>	<p>headache which led her to taking Tramadol tablet (Cultural belief)</p>				
--	--	--	---	--	--	--	---	--	--	--	--	--

					<i>because neither of them has a job and according to our culture, the first wife becomes the bread winner of the family if the husband dies (Cultural expectations)</i>							
D	<i>Before he brought me the medication, I had taken</i>	<i>When I go back to my business I experience so</i>	<i>You know I have to help myself by not carrying heavy</i>	<i>Currently, I have no grown up male child or any helper at the shop. I used to have a sales boy but since I became ill</i>	<i>This disturbance in my sleep pattern started immediately</i>	<i>You know if you miss dialysis in the morning hours,</i>	<i>From the day I commenced my dialysis, I have never spent my money</i>	<i>Life has not been so easy with me as I feel so worthless and I cannot provide for</i>	<i>My cousin wanted me to go to India for renal transplan</i>			

<p>several medications which I bought from the chemist shop to solve this problem. I have taken this medication on.... erm, erm, what is the name again? I can't even remember again, it was prescribed for me</p>	<p>much pains in my joints and I'm so fatigued that I hardly do anything since my job involves lifting or carrying goods out from the stores manually but if it's only to bring out goods for a customer</p>	<p>items out from the shop to avoid killing myself. I do this just to help myself because if I should try doing the things I used to do when I was fine and fit then I would die early and you know it's not good to disturb the kidneys. I</p>	<p>and travelled back home for treatment, my business has crumbled and the boy has stolen all my money. I had to shut down my motorcycle parts shop and asked him to move over to the other shop where I sell mobile phones until I return (Impact of condition on livelihood)</p>	<p>ely I and my family returned from the village. It doesn't happen to only me though, that same Sunday evening when we returned from the village, I had a restless night and couldn't sleep so I had to lie on a bench to rest my head and</p>	<p>then you have to join the long queue and you are not sure of being attended to on that day. Also, dialysis is here in the afternoon is not advisable because of the discomfort you may experience as a</p>	<p>on treatment. The total cost of my treatment is being paid by my cousin-the medical doctor based in the US. He sends me \$2,000 every month. He usually sends it before the 25th day of every month. So, the cost of my treatment has not really been</p>	<p>my family as I would love to and all major responsibilities have been abandoned to my wife (Feeling of worthlessness)</p>	<p>t but we are not ready yet. If not for my fear, any time I call him and tell him that I want to go for the transplantation, he is ever ready. Even in the last 3 days that I spoke to him on the phone, he mentioned it but I'm still afraid</p>			
--	--	---	---	---	---	---	---	---	--	--	--

<p>by one of the doctors in a peripheral clinic I visited earlier and it included several pain killers too. My thought then was that the medications had done their work and I had no clue that it was depositing some</p>	<p>I wouldn't have much reason to worry (Impact of symptom on job)</p>	<p>have to do whatever I can to remain alive and see what the future holds for me and my family (Positive spirit)</p>		<p>I slept off. When I woke up from the sleep, I started having pain in my neck and this has lasted for almost 2 months now. I therefore rushed to my doctor and complained about it and he downplayed it while I also</p>	<p>result of the prevalent hot weather (Long waiting hours)</p>	<p>an issue for me (Source of support for dialysis)</p>		<p>because I have never had an operation /surgery in the past; so, that instils fear in me. Ordinarily I am always healthy and I don't go to the hospital for anything, so this condition is strange and it's like an</p>			
--	---	--	--	--	--	--	--	---	--	--	--

	<p><i>harmful things on my kidneys and later my blood pressure got excessively high (Culture of self-medication)</i></p>				<p><i>called my brother (the medical doctor based in the US) to tell him that "they have come for my neck o". I was having the impression that my enemies in the village were using diabolical means to attack my health</i></p>				<p><i>accident to me (Uncertainty of transplant)</i></p>			
--	--	--	--	--	--	--	--	--	--	--	--	--

					<i>but he (the doctor) told me that it's not a serious issue (Superstitious belief)</i>							
<i>E</i>	<i>Well, erm...erm.... the thing is that I was taking local medicine ; you know what I mean? I was taking our local</i>	<i>Yes, whenever I undergo HD sessions I feel free, I feel better and normal but after sometime my body</i>	<i>I don't sleep well in the night time. I'm thinking it could be a side effect of the medications I'm taking although the doctors</i>	<i>My experience at the UNTH is that their machines are always breaking down. There was a day I was on the dialysis machine and dialysis session had commenced; and I had to spend more than extra four hours (more than 8 hours). The engineers had to start working on</i>	<i>They care more in the private dialysis facilities more than in the government facilities such as the UNTH in</i>	<i>The nurses are trying in their care because whenever difficult situations arise they adopt multi-professi</i>	<i>Imagine here in Leo Hospital is much more expensive than another private facility (Mount Carmel)- it's about #20,000 in Mount Carmel but it's#15,000</i>	<i>Yes, the need of my family does affect my coming for dialysis. However, there's nothing greater than life. Life comes first and so I can always put aside the need of my</i>	<i>Yes, I was at the Park Lane Teaching Hospital and now at the UNTH and the nurses did give such information to me; meanwhile</i>			

<p>herbal concoction. When I started taking the concoction, I was feeling quite better but after sometime, I discovered that my health started going worse. Also, most times when you come</p>	<p>will start experiencing pain, with fine tremors on my upper and lower extremities and feeling unwell. It also affects my appetite as I wouldn't be able to feed as normal. I don't feel hungry</p>	<p>said it's because I need to undergo dialysis. It's really disturbing me so much; you can imagine when other people are asleep in the night and you are awake doing nothing. I sleep in the day time. It affects my job as I</p>	<p>the machine unit by God's grace. It was the fault of the management of the hospital and lack of attention by the government because that kind of situation can hardly occur in private renal facilities. To be honest with you, UNTH is not worth existing at all. We were there on admission before the workers went on strike and the time this happened, I had spent 4 days on the admission in the medical ward. All of us patient was discharged. It's wasn't</p>	<p>fact they are taking good care of me in the private facilities but they charge more than the UNTH (Differences in care between private and government facilities)</p>	<p>onal approach in resolving it. The doctors are highly qualified and they take good care of me. I am reviewed once in a month although this depends on my health status (Care by health care</p>	<p>at the UNTH. You can see that so many people who are coming here for dialysis were referred from the UNTH because of the breakdown of their machine (Discrepancy in the cost of dialysis)</p>	<p>family to take care of my health and then attend to the need afterwards. No, the symptoms have never been a barrier towards my coming for HD (Impact of family need on dialysis decision)</p>	<p>e this is not done in most private establishments (private renal facilities) as they are too busy for that and are a lot more money-conscious. The private of facilities are business-oriented and they went you to keep coming</p>			
--	---	--	---	---	---	---	---	--	--	--	--

<p>here, you have to wait for so long to be attended to and the appointments they were giving me was too lengthy. So, so, that was why it was like I stopped using the medications and the management the way the</p>	<p>most of the time, and a lot of abnormal feelings occur on my mind in fact don't feel happy at all. I'm always sad because of this condition and the associated symptoms. However, I feel better,</p>	<p>had to leave my previous job and now it makes me sleep at work where I'm doing security work (Impact of symptom on employment)</p>	<p>supposed to be so because the hospital treats numerous health condition and many of the patient whose health conditions were critical died. Uuhmm! It wasn't a good experience for me (Poor maintenance of facility)</p>	<p>workers)</p>	<p>(patronising them) but when you come to the UNTH, you will be educated on your nutrition and lifestyle by the dieticians. They explain this to us each time we attend the renal clinic. It's only in private settings that they don't do</p>
---	---	--	--	------------------	---

	<i>doctor said to me (Culture of herbal ingestion)</i>	<i>agile and able to do the things I normally do in the past (Experience of symptoms and impact)</i>							<i>this. So, I would want the private renal facilities to improve on this (Patient education on management regimen)</i>			
F	<i>I have never been to the hospital to check my blood sugar level or my blood pressure and I</i>	<i>Living with this condition to me is like serving a life sentence of which I cannot be free until the</i>	<i>I have never taken any illicit drug or indulged in alcohol consumption; yes, I used to smoke cigarette</i>	<i>The doctors here are very nice as they talk to me politely and they take time to provide explanations on any questions I have regarding my condition. The nurses here are</i>	<i>Apart from the initial time when I commenced dialysis, the nurses have never</i>	<i>Apart from the issue of cost of dialysis one major factor that is discouraging me from</i>	<i>In fact, in the case of the University College Hospital Ibadan where I used to dialyse before returning</i>	<i>So, you are kept waiting for longer than necessary while some other patients can jump the queue and when you try to challenge</i>				

<p>have never been diagnosed of any medical condition in the past. I came to the hospital because of the swellings on my legs, arms and face. The doctor carried out examination on me and confirmed that I</p>	<p>day I die. Since I graduated from the University, I have not been able to gain any meaningful employment to be able to support my mother and my other siblings only to be told that I'm suffering</p>	<p>occasionally and that was a long time ago. So, I keep wondering and asking myself everyday what could possibly have caused this? I regret ever smoking in my life, but the doctor said the cause is queried. So, it</p>	<p>all the same. They don't take the patients seriously and sometimes when you want to ask them some questions, they pretend they don't know you are referring to them. I don't know if it's the nature of their job that is making them behave that way (Experience of care with nurses)</p>	<p>given me any further information on what I should eat or avoid. Maybe they assumed that I already know and didn't see any reason to waste their scarce time talking about that again with me.</p>	<p>accessing dialysis whenever I come here for dialysis is too much queue and you must spend the whole day being outside (waiting in the hospital) because of the number of patients who are</p>	<p>home, people are based on their tribe. The nurses attend to their Yoruba people first as they all speak same language and you are treated differently because you are not of their tribe; so, you are kept waiting for longer than necessary while some other</p>	<p>that you are made to wait longer. So, those of us who are of other tribes appear powerless unless we know anybody working there and when we complain it will worsen the treatment (Power imbalance)</p>				
---	--	--	--	--	--	--	---	--	--	--	--

<p>am suffering from CKD stage-5 and I was therefore advised to commence haemodialysis (Culture of not seeking healthcare)</p>	<p>from kidney failure (Meaning of living with CKD)</p>	<p>means smoking cigarette couldn't possibly have been the cause (Rationalisation of cause)</p>		<p>I would like the nurses to take time to explain to me the things I should not eat and those that I can eat especially those that are available locally and are relatively affordable (Information on management regimen)</p>	<p>waiting to be dialysed (Issue of waiting times)</p>	<p>patients can jump the queue and when you try to challenge that you are made to wait longer. So, those of us who are of other tribes appear powerless unless we know anybody working there (Biased treatment by nurses)</p>						
--	---	---	--	---	--	---	--	--	--	--	--	--

G	<i>When I commenced dialysis, the members of staff at the UNTH were about going on strike and the management also complained about breakdown of their machines; so, I had to continue dialysing</i>	<i>It has impacted negatively on my Christian life. I don't have the energy to pray as much as I used to in the past because of fatigue which I experience every day</i> (Impact on spiritual life)	<i>This condition makes me stay in-doors all the time as my whole body is usually swollen and I find it stressful to walk about as I used to do in the past. You can see that my whole body is swollen now; how can I go out like</i>	<i>The fatigue I experience everyday has made it very difficult for me to be able to do anything for myself. I have had to depend practically on my family for support financially and in doing anything. I feel very worthless as a human being right now</i> (Dependence for support)	<i>Since I commenced dialysis, I hardly sleep in the night but I sleep well in the day time, you see if I continue to sleep in the day time when I'm supposed to be working, it makes my condition worse as all the cost of</i>	<i>There at the Mount Carmel (that is the private centre) the nurses and the doctors were very good. They talked to me politely and treated me with dignity but here at the UNTH, the</i>	<i>At the UNTH, the nurses talk to you whichever way they want, you know we are powerless and as such we can't even challenge some of their attitude as we depend on them for our care. In fact, they make you feel worthless and even add to the pain of</i>	<i>To be fair to them, not all the nurses and doctors here are harsh but most of them are. There is one doctor here-Dr Onwe who is very good. He was the one who made us feel settled by talking us through my condition, the treatments I have to undertake, how to take my medicines and the</i>	<i>Yes, the nurses informed me to avoid any food that contains protein. They told me that that will include beans, egg, red meat, etc. They encouraged me to eat fish, and white meat. I was told to avoid any food that contains protein</i>	<i>Even when they tell you avoid taking certain fruits, usually they are not clear or specific about it; orange is a fruit, water melon is a fruit and to my mind banana is a fruit. So, there should be clearer explanations. The other day I came here I asked one of the</i>	<i>Someone e's faith saves him, you know? It is my belief that if I trust God for healing, he will heal me of this condition. Prayer can save me. They said my kidneys are bad;</i>
----------	---	---	---	---	---	---	---	--	---	---	---

<p>at the Mount Carmel dialysis facility in Emene, Enugu (Issues with machine breakdown)</p>		<p>this and everybody will start looking at me and some others will start asking me if I'm okay (Impact of condition on body image)</p>		<p>my treatment would be borne by only my parents and I have turned out to be a burden to their lives (Concerns about impact of symptom on employment)</p>	<p>nurses are completely different. Here when you ask anybody (the healthcare workers including nurses) any question about anything they will tell you angrily to go there and find out. In</p>	<p>your condition. They are easily irritated and I don't even know why. Sometimes, I feel it's because of the amount of work they have to do or may be due to the challenges of their job. Whatever the reason is, such attitude makes me feel it's my fault that I have this</p>	<p>things I should expect in the course of my condition. We were just lucky to have met him and incidentally I and Dr Onwe are from the same town but we didn't know each other in the past. Up till today, he still attends to us very well and whenever we call him he is ever ready to help us in</p>	<p>as it is dangerous for my health. They also highlighted the importance of me avoiding medications that are not prescribed by the doctor and the need for me to be taking the pills the doctor prescribed for me. The nurses</p>	<p>doctors on duty and he said to me "you can eat anything". I was not satisfied with the response and I insisted on getting clearer answers from the nurse who later told me to avoid proteins (Discrepancy in information)</p>	<p>what is kidney failure in the sight of God? God takes care of bigger situations and heals more dangerous conditions, so in the sight of God my condition is nothing. I believe this</p>	
--	--	---	--	--	---	---	--	--	--	--	--

						<p>that private centre, the nurses will come to me and tell me that I will be fine; they ask me about my worries and try to provide any explanation to my questions. I could</p>	<p>condition and this I'm sure could be the way other patients feel. I prefer the care I received at the private centre to that I'm receiving here but I can't continue there because it's more expensive than here (Power imbalance)</p>	<p>any way he can. You can see that when we came he immediately assessed me and suggested that I have to do another test today (Experience of care by doctors)</p>	<p>should do more in explaining to the patients at every session of dialysis or during any contact the foods they should be eating and those they should avoid. For instance, if you are telling me to avoid foods that</p>	<p>condition is his will in my life as it's only what he approves of that can happen in a man's life. So, dialysis or no dialysis, once it's God's will for me to be healed I will</p>	
--	--	--	--	--	--	--	--	---	---	--	--

						<p>recall the last time we went to the private centre, and I needed to be transfus ed with blood. The nurse without wasting time went and got the blood from the blood bank and commen</p>			<p>contain proteins, how can I know all of them? So, I think it will be better if these things can be highlight ed on leaflets and explained to us in our local dialect. It will make a lot of differenc e for us. Simply saying</p>		<p>be healed (Impact of religiou s belief on dialysis decisio n)</p>	
--	--	--	--	--	--	--	--	--	--	--	---	--

						<p><i>ced the transfusion without any bureaucracy as you would see at the UNTH. Not only did she start the transfusion but she was there by my bedside monitoring me and giving me some comfort</i></p>			<p><i>avoid any food that contains protein is not really clear especially to patients who are not educated</i> (Information to patients)</p>			
--	--	--	--	--	--	---	--	--	--	--	--	--

						by talking to me and reassuring me (Experience of care from the nurses)						
H	Although the doctors made the diagnosis, I have a strong feeling I was poisoned. I believe I was “poisoned” through	Going on dialysis for me means abandoning everything I have laboured for and focusing on taking care of	I am now being assisted to do things like a little child. I would love to have my bath, wash my clothes, go to the toilet and	Uumh, they are taking good care of their patients and that is why you can see people come for dialysis here. As we stay in the ward, they are very nice; I have dialysed in other facilities and I can tell you the difference between here and those, do you	When I asked the doctor in the former facility (a private facility) where I used to dialyse on how I can get that catheter that they	The doctor is not friendly because the only question I asked her was greeted by a very rude and shocking response and so even when I had other	Physical symptoms really do influence my coming for dialysis. Sometimes I don’t have money to embark on coming here as a result of other family needs and the far	Yes, distance is a serious issue for me. For instance, we spend about #15,000 transport to come for a session on	Uuhhmm, the need of the family will always be there from time to time and as far as you are an Ibo man, you have a responsibility towards your entire family. You have to	The job is theirs and they are doing their best and I must commend them for that (the nurses). Uummh	There is no dialysis centre in Ikom where I live with my family and in Calabar (UCTH) which is government-owned, if you don’t	

<p><i>diabolica</i> I means and I have removed the poison from my body through unorthod ox means. The poisonin g is the cause of my condition (Percepti on of cause of the conditio n)</p>	<p>my health, attandin g dialysis three times per week accordin g to the doctor and giving up my financial role towards my family as I will not be able to concentr ate on doing my business</p>	<p>go to the market on my own without any assistanc e but now I cannot do those things again. Of what use am I again? (Loss of independ ence)</p>	<p>understand? In terms of the care being rendered, the nurses here are so dedicated and so they do take care of the patients very well (Experience of care by nurses)</p>	<p>will fix in my eyes because of my eye problem, she said to me “go and meet your villagers, I don’t have time to do all those kinds of thing. She arrogantl y retorted, “When you are done with your urination you can</p>	<p>couch if you wish, so I manage d to do as she comman ded as I have no choice after all I can’t treat myself and since that day I decided never to dialyse there again (Power imbalan ce)</p>	<p>questions to ask regarding my care, I couldn’t muster the courage to ask because I don’t know what her reaction could be. In that private facility, for the nurses, it depends on the environmen t in which they found themselves working. If your boss is full of harassing people</p>	<p>distance but I have no choice when the symptoms become too much for me to bear (Physical symptoms as a factor influencing dialysis decision)</p>	<p>dialysis. We come your immediate family and also your extended family, do you understand ? So, the hazard will be there. At times, it prevents me from coming for dialysis (Family needs as an influencin g factor)</p>	<p>h I don’t see any other thing we are lacking ! Most times when you come here you see dialysis patients waiting all day up until 12 midnig ht waiting to go on dialysis due to</p>	<p>“know somebod y” just like in any other governme nt establish ments in this country, then you are in trouble because you will end up spending your entire day waiting and nobody will attend to you. So,</p>
---	--	--	---	--	--	--	--	---	--	---

		<p>as before (Meaning of life on dialysis)</p>			<p>come and lie on this couch if you wish, so I managed to do as she commanded as I have no choice after all I can't treat myself and since that day I decided never to dialyse there again. That was why I switched</p>	<p>between patients and doctors)</p>	<p>(patients), then the atom of that harassment will be there so like I told you, I was always afraid and mine was to sit down on the machine bed for 4 hours and then get out and look for where I can get cure for myself (Fear of the unknown)</p>		<p>for one to undertake such a risk travelling down here. I was always coming with my wife before but at some point, I stopped her because instead of the two of us taking the risk, it is better that one</p>		<p>the few number of functional machines available here (Long waiting hours for dialysis)</p>	<p>the government should provide more facilities especially in the rural settings (Biased treatment of patients)</p>
--	--	--	--	--	--	---	--	--	--	--	---	---

					<p><i>to this facility (Expe rience of care by doctors)</i></p>				<p><i>of us should be taking the risk. Like today I prepared to be here alone but my younger sister spoke extensive ly to me last night on why we should come together. This encourag ed me to come here</i></p>			
--	--	--	--	--	---	--	--	--	--	--	--	--

									today with her especiall y because of my sight problems (Distanc e as an influenci ng factor)			
<i>I</i>	<i>I have never felt sick all my life and never bothered to see any doctor for any treatment at all; even when I</i>	<i>Erm, when you talk of the impact of this condition, I can't do most of the things I used to do in the past. It's true that</i>	<i>You can imagine paying almost #30,000 for a session of dialysis and you are expected to do it three times every</i>	<i>The nurses did tell me to avoid taking much drinks and certain foods that contain proteins but I would still want them to give more information that are specific on the quantity or amount of fluid I can take daily when I'm not on admission in the hospital and</i>	<i>There are so many things I expect them to inform me because I'm paying so much for this dialysis; it's not #5, so I</i>	<i>Someone can still do dialysis and die the same day; so, it's only God who gives life. If God proclai ms that I</i>						

<p>feel my health is not okay, I simply take some herbal remedy and I get well and carry on with my business; so, that`s why if not that it looks like dialysis it`s necessary in this my condition, I wouldn`t even</p>	<p>I`m no longer working due to my age but I miss most of the things I used to do such as drinking wine, going out with my friends and doing things for myself instead of being depende</p>	<p>week. That means you must spend millions in a year in order to live. That means living with this condition without you being rich is living in fear of the unknown as you don`t know what next could happen to</p>	<p>possibly give me a full list of the food I can eat or avoid. I would want them to tell me the things I can do in order to live longer and reduce the frequency of my coming here for dialysis (Patient education)</p>	<p>should be well informed about my condition and treatment by the nurses and doctors. They should make a list of all these things (I mean the foods and drinks) and not for me to continue eating the same kind of food and</p>	<p>am going to live, even without this dialysis I can still live. God can still do it (Dialysis as secondary to religious belief)</p>							
--	---	---	---	--	--	--	--	--	--	--	--	--

	<p><i>bother myself being here (Poor health seeking behaviour)</i></p>	<p><i>nt on others (Loss of independence)</i></p>	<p><i>you if you don't have money to go for dialysis not to talk of going for transplant (Dialysis as uncertainty)</i></p>		<p><i>come here for dialysis all the time. I strongly believe that lack of proper or adequate information regarding my diet and lifestyle is the main cause of my body always swelling and this makes me to come here for</i></p>						
--	--	---	--	--	---	--	--	--	--	--	--

					<p><i>dialysis. If I am avoiding the things I should avoid my kidneys will start getting better but I don't always know those things. For instance, it was just yesterday that I heard that people who are receiving dialysis</i></p>								
--	--	--	--	--	---	--	--	--	--	--	--	--	--

					<p><i>are not supposed to eat Okro soup. Okro soup incidentally is my favourite soup and I have been having it without being told that I shouldn't eat it now. I was told that I should not eat Semolina and</i></p>							
--	--	--	--	--	--	--	--	--	--	--	--	--

				<p><i>that`s also one of my favourite foods. It was only yesterday that I started eating bitter leaf soup. So, ignoranc e of the specific food I should eat or avoid is a major source of worry for me. I just want to know whatever I can do</i></p>								
--	--	--	--	---	--	--	--	--	--	--	--	--

					<p><i>in my capacity to help myself even though doing dialysis is not a solution to my problem. They should write out the list of the foods and drinks to be taken and those to be avoided, make photocopies of it and give</i></p>							
--	--	--	--	--	---	--	--	--	--	--	--	--

					<p>to the patients each time they come here for dialysis. It will go a long way in helping us</p> <p>(Expectations on patient information)</p>							
J	<p>Living with this condition and dialysing every week is a very big lesson to me. It</p>	<p>I am no longer able to go to work regularly and so I spend most part of</p>	<p>I'm always very heavy and so fatigued that I hardly do those things I</p>	<p>They are doing their best but they need to show more compassion when it comes to the cost of dialysis. They shouldn't emphasise more on us paying the</p>	<p>Dr Onodugo wrote a list of the foods and drinks I should avoid. He said they are</p>							

<p><i>means that nothing is constant in life- someone who has everything going well for him or her today could be worse off tomorrow. If anybody had told me that I was going to have this kind of problem I</i></p>	<p><i>my time staying at home. I don't have apprentices or any subordinate who supports or assists me in my business. How can I get money to sustain my dialysis and other treatments if I don't carry on</i></p>	<p><i>used to do in the past. This affects my ability to do my business, do things for myself and associate with my friends. I am particularly confined by this condition ; I can't go out as I used to do in the past when I was okay. You know</i></p>	<p><i>money first but to save life first before money. I know they are doing their job and you have to show receipts before you go on dialysis but in some cases where they are seeing that someone is dying I think they should dialyze first and then the family of the patient can pay later. Life is precious and any little lapse in maintaining it could lead to death. Imagine the other day a dialysis patient was brought in here and he was</i></p>	<p><i>mostly foods containing protein. They included foods like beans, milk, and many others. For the nurses immediately you come they find out if you have paid and have the necessary materials. So they don't bother or</i></p>								
--	---	--	---	--	--	--	--	--	--	--	--	--

<p>wouldn't have believed it. It shows how temporal and uncertain life could be. Erm, erm...erm...my life on dialysis is erm...full of uncertainties because I don't know what the future holds for me as</p>	<p>with my business? So, erm...but I need to be strong to do anything. I can't concentrate on doing anything meaningful when you think about the impact of the symptoms of this condition, the needs of</p>	<p>when things were good I used to have lots of friends around me. But since this condition started, it has reduced the number of friends that I have. Sometime some of my friends don't even pick up my</p>	<p>in a critical condition because he couldn't dialyse for almost 3 months may be because he didn't have the money or for any other reason, but he died because the nurses insisted he must pay and present the receipts to them before he can be dialysed. You see? Where is the humanity? Where is the compassion? (No compassion)</p>	<p>have time to talk about the foods and lifestyle you should maintain especially if they had told you during the previous dialysis sessions. It's like they only tell the patients before patients start dialysis (the first dialysis</p>							
---	---	--	---	--	--	--	--	--	--	--	--

	<p>failure to come dialysis may be due to lack of money could mean preparin g for death (Meanin g of life on dialysis)</p>	<p>your family, going for dialysis in such an extremel y far distance so that you can live. You see, it`s difficult for me and my family My wife had gone to visit her family in Enugu for some time now and she</p>	<p>calls or even call me back probably they feel I will ask them for help. So, it`s just a few of my close friends who still call and check on me. My siblings are trying greatly in supportin g me beyond my expectati on (Impact of</p>		<p>session /pre-dialysis). Well, if you ask them they can answer you. If you don`t ask them, they may not have the time to tell everyone (Informa tion on nutrition and fluid intake by doctors)</p>							
--	--	---	---	--	--	--	--	--	--	--	--	--

		<p>hasn't returned . So, you can imagine what this condition means for my business -the only source of my income</p> <p>(Impact of symptoms on job)</p>	<p>physical symptoms on social relations hips)</p>										
K	<p>To me living with this condition is a setback in my life. I am only 38-</p>	<p>I am not sure where this whole condition will lead into because</p>	<p>It therefore makes me feel worthless as I can't even afford the cost of my</p>	<p>I was not told anything. They did not inform me about the kind of food I should be eating or those I should not eat. It was only the doctor who told</p>									

<p><i>year-old with two kids who mean so much to me. You can imagine living with this condition at this age when I'm supposed to be strong and work hard to look after my family. This is the stage of my life when I'm supposed</i></p>	<p><i>although after dialysis, I always feel a lot better but even being on that machine for 4 hours is not quite easy for me. I am not sure of living long enough to train my kids and look after my family especiall y as I don't</i></p>	<p><i>treatment and now have to depend on my wife and my parents for my survival. How can I still depend on my parents at this stage in my life? This is going back and not moving forward in my life as I should be supportin</i></p>	<p><i>me on the first day before I started dialysis. Since then, I can't recall hearing anything of such from the nurses. Maybe they are too busy or they felt the doctor must have told me and felt the doctor must have told me and so couldn't bother to talk about it</i></p> <p>(No information)</p>									
--	---	--	--	--	--	--	--	--	--	--	--	--

<p>to work extremely hard to train my children to the level of education I want them to attain as I had no such opportunity in my life but, but, erm, erm.... this condition is trying to cut short my dream. So, to me life as a dialysis</p>	<p>have the means to sustain my dialysis treatment I let alone talking about going for a transplant (Uncertainty)</p>	<p>g my family now and not them paying my bills. I'm always feeling exhausted all the time (Worthlessness)</p>									
--	---	--	--	--	--	--	--	--	--	--	--

	<p>patient is a life of suffering , end of my dream and hopelessness as I don't know if I would be alive to fulfil my life dreams (Meaning of condition)</p>											
L	<p>Dialysis is a big stressor. I called it a stressor because</p>	<p>Most times that I come here for dialysis I would</p>	<p>It is also a big stressor for me financially as coming</p>	<p>You know that in our culture you have to take care of your siblings, your father and your mother and every other</p>	<p>As a civil servant, it's also very difficult for me to be taking</p>	<p>For now, I'm still going to work and have not</p>	<p>Yes, the doctors and the nurses explained to me the foods to eat and those</p>					

<p>of the amount of time it takes me to travel to Enugu for my dialysis, as I told you earlier on that I live and work in Abakaliki and you can imagine what it means for me to travel from such a very far distance to this</p>	<p>not be able to go back to work and you can imagine what that means for a civil servant to be constantly taking permission on all the time to attend dialysis. It's not an easy one and that means you have</p>	<p>for dialysis is a big strain on my monthly income. The cost of dialysis is so huge that an average civil servant like can hardly afford to afford it more than once in a week and even doing it once a week doesn't come very</p>	<p>member of your extended family as much as you can, so all of these people depend on my meagre salary and now I have been dealing with the issue of attending dialysis. That is why I have not been able to cope with the recommended amount of dialysis in a week because sometimes even when I want to come for dialysis and my siblings have financial issues I try to assist them first and then defer my dialysis for a later time. You see that</p>	<p>permission three times every week in order to come for dialysis. You see there is no dialysis facility in Abakaliki and even after dialysis, I am always tired and find it difficult getting back to work after undergoing</p>	<p>requested for exemption from work. Erm, to be honest with you most of the time I am scared of the likely outcome of this condition. I don't want to die and leave my family behind as there will be</p>	<p>to avoid. Maybe they would need to do more to make it clearer especially to those patients who are not literate enough to identify classes of food. I don't think it's enough to simply tell patients that they should avoid foods that contain protein when they don't know</p>					
--	---	--	---	---	--	---	--	--	--	--	--

<p>place for dialysis and then I must wait for a very long time because of the large number of people who are waiting to be dialysed in this facility (Meaning of dialysis)</p>	<p>to let your colleagues know about your health condition and that means you don't have any privacy again (Loss of privacy)</p>	<p>easy. So, so, it's affecting me in every way and my family doesn't get enough money from my monthly salary for their upkeep (Cost issue)</p>	<p>It's not quite easy for me (Culture)</p>	<p>ng dialysis. So, it's very difficult for me. If I continue like this I risk losing my job as my boss and colleagues may not understand what it means to be suffering from this condition. Civil service has its rules and there's a</p>	<p>no one else to cater for them. My wife is not working now and every member of my family depend on me. I'm scared about the future and what it holds for me regarding this condition</p>	<p>what they are (Information)</p>					
--	---	--	--	--	--	---	--	--	--	--	--

					<i>minimum level of health you should have to be able to perform your duties (Fear)</i>	<i>(Uncertainty)</i>						
<i>M</i>	<i>I have spent about £85,000 already (that is about twenty-three million naira) so it's a whole lot of money. It</i>	<i>Like you came in when I was typing something. I was sending email to the UNDP office in Abuja trying to see if</i>	<i>To be sincere in this place, that is why I come here. They are very good; they attend to you with courtesy</i>	<i>The thing is, ordinarily cost and distance could influence it but for me I decided that no matter what because, because one I want to remain alive until... you know? I want to stay alive and look after my family. In fact, there is a</i>	<i>I could say for example, I'm very worried here because I know I have people who do dialysis in other centres sometime</i>	<i>I thank God I have been able to sustain my treatment; I have a very stable mind but I have been here and</i>	<i>So, these are the issues but if there's a good association that is receiving funding and doing advocacy... another thing I want to do is to do</i>	<i>Yes, because in India my doctor referred me to the nutritionists, again I was even given a chart of the things I should eat or avoid. No, I wasn't given such</i>	<i>I am very sorry to say that the point is this, the nurses at the UNTH, the way they behave and attend to patients</i>	<i>Also, the experience I have had with the doctors abroad is different from here because a doctor abroad will be able to tell you the problem,</i>		

<i>includes the cost of the transplant, medications and other materials needed for the surgery. I will still pay more, do you understand? It's because of this condition that I have sold all the properties I</i>	<i>there is any support I can receive from them. If it's just for the work I do I can't pay for my treatments, it's not possible because how much is my salary that I could contemplate maintain</i>	<i>and treat you like a human being and not just as a patient. That is why I come here (the private dialysis facility). I wouldn't want to, even when I go to Abuja I don't do dialysis there. I make sure I fly back to do my dialysis here</i>	<i>decision I took that I cannot succumb to this kidney issue. This condition will never defeat me and I will come out stronger. So, because of that decision I took I'm doing all I can by God's grace to be able to maintain this. I come from Nsukka, so I come every morning from Nsukka. So, I told myself that no matter what I'm going to make sure that I deal with it; I won't succumb to it, that's the decision I took and that decision is simply</i>	<i>s you go there is no light or that the machines broke down and sometime s you go they will tell a story for as whole month and nothing will happen. I don't know what they expect the patients to do. So, I believe</i>	<i>seen patients who cannot afford to do dialysis and sometime s I help them and some other times I encourage them; I know so many things. I remember many of them I started dialysis with are all dead</i>	<i>advocacy and encourage people to donate kidneys to patients because in developed countries abroad people come in willingly and sign that they want to donate their kidney. Our people here need to understand ; when you tell somebody here can</i>	<i>here but the only thing is that there is no organised way of doing this here and just may be when you ask they will tell you don't eat this, don't eat that unlike in India where there was already a plan and you are given a copy of the plan; in fact, I still have the note from my doctors in India.</i>	<i>is not done anywhere else in the world. In this place (the private centre) the nurses treat you like a human being and better may be because it's a private place but in UNTH, it's a different</i>	<i>how he will approach it and discuss with you before even treatment. To tell you the truth, I have a copy of my treatment file from India with me; so, whatever is in my medical file in the hospital in India is also in my file which I have with me. So,</i>		
--	--	--	---	--	---	--	--	--	---	--	--

acquired and I am left with nothing. When you talk about the meaning of this condition, to me, it is....it is.... terrible. It is a big strain on my life, my finances, my family and my job. So, that's the problem and I'm	ing my dialysis weekly not to talk of planning to go for renal transpl ant. There is no support for kidney patients in this country and just like in almost every other condition except in the case of HIV/AIDS	because I don't want to catch infection; I don't want any story. So, because of it, even if I'm travelling for a project in Abuja, I will make sure I fly out to Enugu to do dialysis. So, they are very good in the way they attend to	mean. That is why you may not notice that I'm a dialysis patient. I have a stable mind and I don't feel worried; I'm okay (Perseverance/determination)	the govern ment should find a way to subsidise the cost of dialysis and establish more dialysis centres especially within the rural settings	and I feel bad and pained about it; somehow I blame myself and wish I could do more than to assist them to live. I know that if we were able to form a dialysis association, they would have been	you donate your kidney? He or she feels you want him or her to die but somebody has 2 kidneys; he needs one and you will even live a better life than someone who has 2 kidneys. In fact, some naturally have only one kidney. It's not been so easy for me to get a	Down here I believe the nurses should be able to educate dialysis patients on their nutrition and lifestyle especially when they don't seem to be compliant with the dietary regimen. To tell you the truth, the nurse is the first contact (the main contact) between a patient and	ball game. In fact, I don't want to talk about my experience there as it's horrible (Care in government hospitals)	you are given a copy, tests, recommendations, everything, the way the doctor filled it. They will give you a copy and you take along. The same thing in the UK; I have the same record. In fact, in the UK after a session with the doctor, I will be sent an email on		
--	--	---	--	--	---	--	--	--	--	--	--

	<p>still borrowin g to complete the cost of my care and also my family is there to be taken care of (Meanin g of living with CKD)</p>	<p>S where the governm ent helps with the provisio n of HAART. It`s only God that is helping me because I still have the strength to do my work. Even the person I`m sending this email to doesn`t know</p>	<p>patients; the hygiene is what I also like. They are very..., they always make sure that their patients are kept away from infection. In fact, if you stay here you will notice it. So, it`s very....in fact, I have seen people, I remember</p>			<p>alive; even myself I cannot sustain it for them for too long (Guilt)</p>	<p>donor and getting one is really difficult now but we are exploring various options at the moment (Kidney donors)</p>	<p>the hospital. So, they should be able to tell the things to avoid to help the patient. The nurses here do it (referring to the private dialysis centre)(Inad equate information)</p>	<p>all the discussion, what was agreed, diagnosis, everything. I have it, I have all the email of the details of my interaction s with the doctors, everything is in my email; if you doubt it I can give you a copy from my email. I have the email for each visit. So, that is</p>		
--	--	---	--	--	--	--	--	---	--	--	--

		<p><i>I'm doing dialysis; he doesn't know I'm a kidney patient. There are diseases that the government should assist sufferers, the number one is this kidney issue and another one is</i></p>	<p><i>in Abuja, a friend they destroyed her fistula. Even when she had to put a neckline, they infected the neckline. So, you can imagine that; so, I don't..., that's why I'm always afraid of going elsewhere to do</i></p>						<p><i>how...but in this place (referring to Nigerian context) the way doctors treat patients is amazing and that is why it's difficult toit's like a boss-servant relationship here and that goes a long way to affect the recovery of the</i></p>		
--	--	--	---	--	--	--	--	--	--	--	--

		<i>cancer (No support)</i>	<i>dialysis (Care in private facility)</i>							<i>patient (Care by doctors)</i>		
N	<i>Living with this condition has done a great damage to my life. It has impacted adversely on my sexual life. My manhood no longer erects as its used to and this has affected my</i>	<i>So this condition means that I will not be able to work the way I used to in the past and be able to have the money to train my children who are still in the schools. How can someone</i>	<i>Many times I prepare to come here for my treatment but the issue of lack of money hindered me. I only come for treatment when I have saved enough for my treatment because I have to</i>	<i>So, basically no other factor determines that for me except money, the ability to pay is the issue for me. There are also many times that when I plan to come here for treatment and my family cannot afford to buy food or take care of any other need, I will have to cancel going for my dialysis. What can I do my son? It's family first. Sometimes, I can save some money to come but if my</i>	<i>There is no further information that I was given here. When I was admitted in the other private clinic where the diagnosis was first made the nurses explained everything to me</i>	<i>Sometimes, you even come here and they tell you there is no water or the machine has broken down. In fact, there was a time when the nurses and the doctors were on</i>						

<p>sexual ability. My manhood no longer rise again as it used to be. I used to be sexually active to be honest, I know I shouldn't be telling you this but I'm just being honest, there is nothing to hide</p>	<p>who is so weak like me go to work and raise some money? That is why it's difficult for me to come here for the dialysis the way my doctor asked me to do (Meaning of life on dialysis)</p>	<p>have money to pay for the hospital card and the dialysis and also for the medications. In terms of family support, it's only my first daughter who has been supporting me as much as she can because my first son is</p>	<p>children need to pay their school fees or any other fee in the school, I will have to attend to them first so that I won't continue to disturb my daughter for money (Family need)</p>	<p>regarding the kind of food I should be eating, types of drink and the quantity and other lifestyles I have to avoid or maintain. In fact, there are leaflets containing this information in that clinic and some were pasted on the walls</p>	<p>strike for several months and those of us who were on admission were hurriedly discharged before the closure of the hospital (Institutional issues)</p>							
--	---	---	--	--	---	--	--	--	--	--	--	--

	<p>as you are a man like me and I find it comfortable sharing this concern with you (Impact on sexual life)</p>		<p>married and now pays more attention to his own family and same with my second son. So this my daughter is the only source of financial help I have in this condition (Family support)</p>		<p>of the clinic. So here it is only what the doctor told me that I maintain. The nurses have not been telling me anything regarding what to eat and what to avoid. I think they are too busy. You can see the number</p>							
--	---	--	--	--	---	--	--	--	--	--	--	--

					<p><i>of people who are waiting here today to be put on the machine. That is how it is every time you come here</i></p> <p>(Information)</p>							
O	<p><i>It has led me into trying different methods to see if I can get healing. That is why I have</i></p>	<p><i>It has affected my quality of life negatively as I cannot carry on with my farming</i></p>	<p><i>I am not able to sleep most of the time; even when I sleep sometimes I don't sleep for</i></p>	<p><i>If you can remember I told you that my husband's people are not supporting me in any way. The care of my children and myself is my sole responsibility and most time it takes</i></p>	<p><i>Not really. Although sometimes the pain is so much that it affects my ability to</i></p>	<p><i>My husband's family accused me of killing my husband and that is why they</i></p>	<p><i>They claimed that I'm suffering from this condition because I killed my husband. They, they said that</i></p>	<p><i>Yes, the nurses and the doctors told me the kind of food I should be eating the first day I went for dialysis. They always</i></p>	<p><i>You can see me now; you can see how my body is like I'm pregnant with all my whole body</i></p>			

<i>been using herbal remedies in managing my condition as I don't have money. Sometimes I feel better by using the herbal remedies and some other times I don't feel better. I like using the</i>	<i>as I used to do. So, living with this condition means a stop to my usual way of life of going to the farm regularly and taking care of my children as I have nobody else to do this for me. You can see that if I don't</i>	<i>long and I sleep mostly in the day and this affects my ability to go to the farm most of the time. It does make me feel sad, worthless because I can no longer stand for my children the way I have been over the years since the</i>	<i>precedence over every other thing and that includes my very own health and life and my dialysis. Like every mother, most times that I might want to come here for dialysis if my children don't have money to feed or pay their school fees, I have to sort their own problem first before thinking about dialysis. I understand that if I come for dialysis I will be able to live longer for them but you know, most times it's very difficult</i>	<i>walk or do anything, it has never been a reason for not going for my treatment . Like I said before it's mainly money that is my problem (Physical symptoms as non-issue)</i>	<i>have abandon ed me and my children to suffer and I have no other form of support from anywhere or anybody (No support)</i>	<i>this condition is a consequence of the wrath of the gods against me for allegedly killing my husband. I don't know why anyone would ever think that I killed my husband. They even went as far as asking me to drink the water they used in washing my late husband's</i>	<i>remind me again whenever I ask them any question regarding that and the amount of fluid I should be taking but most of the time I find it difficult to know what food contains protein especially when I eat the local food I harvested from my farm (Patient</i>	<i>swollen. It makes me feel so much ashamed of myself but what can I do? It's not my fault that this condition befell me. I can no longer go out as much I could and it has affected my ability to go out with my friends for social</i>			
---	--	--	---	--	---	--	--	---	--	--	--

	<p>herbs and I believe it will heal me some day(Her bal remedies)</p>	<p>go to farm my family will suffer as we don't receive any support from my late husband 's family and my children are still depende nt on me for their survival and educatio n (Meanin g of conditio n)</p>	<p>death of my husband (Feeling worthless)</p>	<p>to make some of these choices (Family needs)</p>			<p>body before his burial. It`s, it`s very devastating for me I wish he was alive to support me in this difficult period of my life (Cause of condition)</p>	<p>information)</p>	<p>events (Body image)</p>			
--	---	---	--	--	--	--	---	---------------------------------	---	--	--	--

P	<p>Maybe it's my fault anyway, maybe I have offended God but I pray to him for his forgiveness. My God is compassionate and full of kindness; he is ever ready to forgive. I have always believed in God to</p>	<p>Living with kidney failure to me appears like I have been abandoned by God; it is a big blow on my Christian life. I can't believe that I have this condition. I don't just want to believe it</p>	<p>I can't believe that I have this condition. I don't just want to believe it</p> <p>(Denial)</p>	<p>Even these days I am not able to pray in the middle of the night the way I used to. My spiritual life is very important to me but to be honest with you, this condition has imparted it negatively but I will never give up</p> <p>(Spiritual impact)</p>	<p>I will never surrender to the devil; I will never surrender to this condition. My God is greater than any condition I have and I believe he will heal me at the appointed time. So, so...it will never make me stop</p>	<p>I always have pain in my joints. I, I..erm,..I always have pains within my abdomen too. The pain is like my body is being pierced by a sharp needle. I always have general weaknesses of my</p>	<p>My God is greater than any condition I have and I believe he will heal me at the appointed time</p> <p>(Religious belief)</p>	<p>I also have the swelling which you can see on my face, my legs and my belly. It makes me look like I'm pregnant at 71 years of my life. It's not good my son as it makes feel very bad and unease to go to attend church services and stay where people are</p> <p>(Body image/social isolation)</p>	<p>My experience of dialysis treatment has not been a nice one. There are always long queues here just like you have seen for yourself. For you to be attended to, you have to leave your house very early in</p>	<p>Waiting in the queue is time-consuming and I cannot afford waiting so long at the hospital when I'm supposed to go back home and prepare meal for my husband. You know in our culture, no matter what could be happening to you, as a wife you</p>	<p>I have no cultural inclination but my belief as a Christian is that no matter what I face in life, my God will always see me through. In fact, this dialysis thing in my view is</p>	<p>The doctors and the nurses are doing their best but they are not God. They are doing the best they can, but, but...erm. .. the ultimate healer is my God</p> <p>(Care experience)</p>
----------	---	---	---	---	--	--	---	--	---	---	---	---

	<i>heal me (Guilt)</i>	(Meaning of condition)			<i>worshiping God (Perseverance)</i>	<i>body that I won't be able to do a lot of things. It is always better any time I have dialysis anyway but you know I don't have the money to always go for dialysis. I also have the swelling which</i>			<i>the morning to come here and you have to abandon every other plan you have for the day as the number of people who come here to dialyse every day is too much (Waiting times)</i>	<i>are supposed to cook for your husband. So, I don't always stay on the queue any day the queue is so much; so, for me it's a big issue as I cannot afford to wait that long (Culture)</i>	<i>not necessarily the ultimate cure for my condition. I am doing the dialysis just because the doctor asked me to do it that it is beneficial for my health and not necessarily</i>	
--	----------------------------	-------------------------------	--	--	--	---	--	--	--	---	--	--

						<p><i>you can see on my face, my legs and my belly</i></p> <p>(Description of symptoms)</p>					<p><i>rily that I believe it will offer any lasting relief to my situation. So, dialysis or no dialysis God must heal me. My healing will come from God not from dialysis (dialysi</i></p>
--	--	--	--	--	--	--	--	--	--	--	--

											<i>s second ary to religiou s belief)</i>	
<i>Q</i>	<i>Erm...living with CKD means a disruption in my life. Look at me now, at my age I'm supposed to be enjoying my retirement with my grandchildren but I have</i>	<i>Not only that I'm dealing with my own condition, I am also taking care of my husband who has been critically ill over the years. So, you can imagine</i>	<i>I don't sleep well in the night. Erm, it makes me feel like vomiting especially when my face and my legs swell and I don't go for dialysis. Sometime s, my legs will be doing me</i>	<i>Distance to the dialysis facility is a very big issue for me. You can imagine me at my age now...erm...erm... it's not easy for me to walk to the dialysis centre. Even when I try to get on the public transport, it's not always easy as you know how our public transport system is in this country. If my husband was ok he would have been the one</i>	<i>So, that is the situation of things. Most importantly, the issue of money is a big challenge. If I had the money to be coming here even if it's just once in a week, I believe</i>	<i>My experience has not been a good one as the challenges I'm facing are too numerous for me. When I was still in active service and this diagnosis was made, it</i>	<i>My two daughters have graduated from the university but sadly they have been able to secure any meaningful employment and they still depend on me for their survival; they have both</i>	<i>Yes, many times the needs of my family do affect my ability to come for dialysis. When we don't have much money, I have to make do with the little we have to take care of the family need first before talking</i>	<i>I think the doctors and the nurses are doing their best in caring for us but the major challenge we have is money to pay for dialysis (Care experience)</i>	<i>I am reviewed normally every two weeks but sadly I don't have the money to be coming here like that so I can't even remember the last time I was reviewed (Reviews)</i>	<i>Yes, the nurses gave the information regarding the kind of food and drink to be taking. I think, they said it should be protein</i>	<i>Definitely yes, the government has abandoned me for example. How can I spend all my youthful years and energies working for the government only to be abandoned at this stage?</i>

<p>been on medications and requiring dialysis every week</p> <p>(Meaning of condition)</p>	<p>the impact this has on me and my life at this stage. It has taken away my freedom and liberty to enjoy my retirement and I wish I still have all the energy to cope with this level of stress in my life at this</p>	<p>like I'm walking even when I'm sitting down in a place without doing anything. All these make me feel awful and unease</p> <p>(Physical symptoms)</p>	<p>taking me there but unfortunately, like I told you he is very sick and I'm the one caring for him. You can imagine a sick person caring for another sick person! (Distance issue)</p>	<p>that my health condition will be better than it is now</p> <p>(Financial issue)</p>	<p>was hell for me because you can imagine a civil servant always taking permission to go to the hospital for treatment. Although the people you are working with in the office might understand but</p>	<p>travelled to Lagos recently to look for work and it's only me and my husband who is seriously ill that are at home with no other person to support us</p> <p>(No support)</p>	<p>about going for dialysis, you know I'm no longer in active service and it's not easy with us pensioners as the government doesn't pay us on time</p> <p>(Family needs)</p>			<p>free but it's not too clear even though I'm educated but I think it's difficult to know all the foods that contain protein. Maybe they should type these foods and make a few</p>	<p>Now they cannot even pay me my pension on time even though my monthly entitlement is not enough to go for dialysis twice in a month, it can go a long way in supporting my survival</p> <p>(Abandonment)</p>
---	---	---	---	---	--	---	--	--	--	--	--

		<p>age (Loss of freedom)</p>				<p>the thing is that you will now have to let them know exactly why you are always taking permissi on and that now means losing your privacy because they cannot just continue to take your excuses</p>				<p>pictures of them so that all the patients especia lly those who are not so educate d will be able to identify them (Pati ent inform ation)</p>	
--	--	---	--	--	--	---	--	--	--	---	--

						<i>all the time (Loss of privacy)</i>						
--	--	--	--	--	--	---	--	--	--	--	--	--

T2 CODES

Participa nts								
A	<p><i>I have not been able to secure any other job. You can imagine how wasted I look now, so it has been very difficult to get a job. Which employer will give a job to a potential employee like me my brother? This condition makes me feel so tired that I hardly can do anything for myself let alone working for anyone. So, so, I have been bearing my burden all alone and with the support from my family (Impact of</i></p>	<p><i>I have not been able to secure any other job. You can imagine how wasted I look now, so it has been very difficult to get a job. Which employer will give a job to a potential employee like me my brother? (Rationalisation of reason for job issues)</i></p>	<p><i>It makes me feel so ashamed of myself looking at how the fistula has disfigured my body, my hand...I can no longer wear anything that is transparent and the scars will be seen. It makes me feel awful, disfigured and disgusted about my body. I know that how I look like is not supposed to be my priority now but I'm also concerned about how I look or my body image as a woman (Bodily</i></p>	<p><i>I was.....I was..... really sad because of my dependence on my family who I should have been supporting financially and now my aged parents are the ones supporting me financially with their resources. They have done so much for me in life andan</i></p>	<p><i>Erm, like I said before the major challenge I have is actually that of money. It's really hard to get the money to pay for the treatment and when you don't have it, nobody is going to talk to you when you go to the hospital (Financial challenges to dialysis)</i></p>	<p><i>And.....and.... you can see why I said that living with this condition is hell as nobody else can help you and you are basically on your own (Meaning of living with CKD)</i></p>	<p><i>It's not easy for people like me who are living with this condition. The government can help us by reducing the cost of this treatment. It's too much for us. The government I believe can also set up more centres close to the rural areas for the many people who are living with this condition and</i></p>	<p><i>Erm.....the experience of care I received from the doctors and the nurses have been positive. They have not changed from their usual caring, kind and compassionate approach towards me. Honestly, they have been very supportive in terms of encouraging me to comply with my treatment plan and</i></p>

	<i>symptoms on job issues)</i>		<i>awareness/ Body image)</i>	<i>d now...this condition has made me toThis condition is really a setback in my life (Loss of financial freedom)</i>			<i>they are not even aware of it let alone coming for treatment (Participant's opinion)</i>	<i>explaining things that I don't know concerning my treatment (Experience of care)</i>
C	<i>I describe every day as a living hell because I have not been feeling well, I cannot say that I'm feeling better or well at all and the symptoms keep increasing every day. It's true that I have been able to manage to have dialysis once every month since then but if I had the means-that is money, I would have been attending four times every month since then and.....and.....you know that I would be feeling much better than I am now. So, when you know how to make yourself feel better</i>	<i>Erm.....there is no particular way or means of coping with the fatigue that I know. I only try to rest properly every day and it has affected the way I do the things I do every day. For instance, even to get up from the bed and brush my teeth sometimes is very difficult and you can imagine what would have happened if I don't have my children in the house, it means that I cannot even manage to eat (Information</i>	<i>It is only God who has been my consolation in this condition. I draw my daily strength from the scripture as a Christian, knowing and believing in God as my only source of strength and comfort (Religion as a coping strategy)</i>	<i>I have applied for three different jobs and..... up till now none has been successful. I even went back to the hospital where I was working as an auxiliary nurse to appeal to them to reinstate me but I was told that I am no longer fit to continue with the job. So.....erm...it has been very difficult for me especially</i>	<i>I believe he made his judgement based on my physical look as I looked quite frail. So.....erm I think it wasn't his fault because this condition has made me look very different from every normal human being and it's hard to see any employer who can employ me for any job here (Rationalisation of reason for job issues)</i>	<i>I am not receiving any form of support from my former employer. You know how private employers behave? The medical centre where I was working is privately-owned and the owner doesn't really care. In fact, I told you before that even when I went back to see if they can reinstate me to enable me</i>	<i>Well, nothing has changed really. The only change is that the doctor spent more time in explaining some things I should be eating and the medications I should avoid but the nurses are always too busy to give you details of that (Contrast in information giving by health workers)</i>	<i>I have not been able to go for dialysis as I would love due to different reasons mainly due to lack of money and the distance issue. It has made me feel much worse throughout this period but I hope that I will be able to get money soon and go (Financial challenges to dialysis)</i>

	but you don't have the money to achieve that then it is very frustrating and then that is the living in hell and then I'm dying gradually each day without any help (Meaning of living with CKD)	and knowledge gap)		without a job and with a couple of dependants on me too (Impact of CKD on job issues)		work and support my family and my treatment I was told that I'm no longer fit to work with them (Lack of support from employers)		
D	Erm.....I have not been able to find someone yet. It is not that easy my brother. Ihave tried many times but erm...it has been difficult. There was this boy my friend helped me to find to take care of the business for me. He started well at the beginning but after spending just three weeks, the whole story changed again. He started going out with bad peoplewho....who...taught him how to steal my money. So...erm I have decided to shut	To be honest with you....it's true that the doctor said my condition is due to the poorly-managed chronic rheumatoid arthritis that I have for so many years now. I still believe that my village peopleattacked me when we went home but I	Hahahaha.....erm.... .Yes I am still very much afraid to go for the operation my brother. My brother is ready to start the process of the operation but.....apart from the fear I have regarding the possible outcome of the operation, it is against my belief as a Christian to receive the kidney of another human being. Every human part is very unique and God gave everybody their own, so I don't think I can possibly go for the operation (Concerns	Erm.... yes the doctor talked about it with me and he mentioned to me that ...it's the best option of treatment for this condition butI'm still trying to make up my mind because of my	My brother.....you would think that because I have financial support for my dialysis.... then everything is fine for me. No, no.....living with this condition is a big disruption to my plans. It has....it has.... done a lot of damage to my business and that has made me to be reductant and I cannot support my family financially the way I used to do before. I...I.... have given up this important role of every man to his family to my wife	No ermthe cost of paying for dialysis did not affect my going to the hospital for my treatment. You know I told you that my cousin pays for that. So, for now that is not really an issue for me (Cost as a non-issue)	Distance is still an issue for me. If you can remember, the last time we met I told you that distance is a big issue for me, trying to get here especially when I have to dialyse early in the morning due to the long queues here and I don't drive at the moment. It makes me come here late sometimes and before I can come some	Erm, the nurses and the doctors are doing their best. They are giving their best in looking after me here . Erm.....they try to tell you what to eat and what not to eat. When you come here, they take their time to look for your file, take your blood sample for the tests that are needed to be done and also tell you about results . Although I have heard some

	<p>down the shop until God willing I'm fine and strong enough to go back to Minna to focus on the business. Even the other boy I told you that...was in charge of selling the motor cycle parts for me who I asked to move to the mobile phone shophas not been doing well; so, nothing is working my brother(Impact of CKD on source of income)</p>	<p>know that God will grant me victory (Superstition)</p>	<p>r e g a r d i n g t r a n s p l a n t)</p>	<p>religious belief. My religious belief is against accepting human organ or tissue into my body (Religion and transplant)</p>	<p>(Meaning of living with CKD)</p>		<p>other people are already on the machine and I have to wait until afternoon which I don't like. So, sometimes I can wait and some other times I have to go and schedule again. So.....erm....it affects my ability to come here as planned for my treatment and appointments (Impact of distance on dialysis access)</p>	<p>p e o p l e complain that they don't tell them what to eat and the things they should avoid. I believe maybe they were too busy to tell those patients anyway. You know they are always busy because of the number of people who come here every day for dialysis (Experience of care)</p>
E	<p>I have not been able to go for dialysis since the last time we met as I don't have the money to go. Ifif.....I had the money to go, I would have gone as you can see how my condition is right now .I know I shouldn't be telling you that I'm not</p>	<p>Erm,....well...I do believe that herbal remedy is an alternative to dialysis treatment for poor people like us who cannot afford the high cost of dialysis in this part of the world. I know that dialysis is very</p>	<p>The sleep issue I complained about the last time we met is still there. I.... still don't sleep well in the night time andwhen I go to work I sleep on duty. You asked me about work.....I have lost my job now. I was sleeping on duty on day and.....my boss</p>	<p>erm.....the needs of my family is also a big issue for me and to a great extent it affected my ability to go for dialysis in the last 2 months. In fact, I wanted to go for</p>	<p>The physical symptoms I experienced in the last two months have not in any way determined my going for dialysis. If I have the money.....erm.... even if I can't walk to go there I would crawl just to go for my dialysis</p>	<p>Hmm!.....living with this condition has been a nightmare for me. It has impacted my life in a very bad way and now I can't afford to cater for my family</p>	<p>It's not his fault. If you look at the nature of my job, I...shouldn't be sleeping on duty anyway but....it's not my fault. Maybe it's because of the effect of my</p>	<p>: I feel frustrated with the way things are in this country.....if you don't have money then it's like you are not worth living. The government doesn't care about us but people who are</p>

	<p>keeping to the recommendations for my treatment that the doctors said but what can I do again? I have been taking the herbal remedy even though I know it's not the best option for me but.....what do you want me to do since I don't have the money to go for my treatment in the hospital? (Impact of financial challenge to dialysis access)</p>	<p>good because any time I go there for dialysis.....I feel a lot better and stronger and I can breathe well, but.....in the absence of money I had to seek alternative (Information and knowledge gap)</p>	<p>caught me and he said he can no longer keep a security man who sleeps when he is supposed to be awake. So.....so.....that was how I was fired from my security job and since then I have not been able to get another one (Impact of physical symptoms on job)</p>	<p>dialysis last week but there was no food for my children to eat and they also needed to pay their school fees.....so...I had to use the only money I had to sort these out. If I was still employed maybe I would have asked my employer for some upfront payment to enable me solve these problems and then still be able to go for my dialysis but.....that is it my brother (Impact of family needs on dialysis decision)</p>	<p>(Physical symptoms as a non –issue)</p>	<p>(Impact of living with CKD)</p>	<p>condition which makes me feel very tired and I don't sleep in the night time (Rationalisation of reason for job issues)</p>	<p>suffering from HIV or AIDS receive more attention. May be health care workers are not bringing this issue of kidney disease and high cost of treatment of dialysis to the attention of the government. The government should assist us with the cost of treatment and make the dialysis more available to the rural areas (Participant's opinion)</p>
--	--	--	--	--	---	---	---	---

<p>F</p>	<p><i>Erm, basically I have had financial challenge which made it difficult for me to go for dialysis. You know I told you last time that I have not gotten any job to do since I graduated from the university. So, so..... the cost of my treatment has been borne by my aged parents and my younger brothers who are really struggling to make ends meet. Also, one of my brothers who has been supporting me has just lost his job and now he cannot even afford to look after himself not to talk of having any money to give me for my care. So...his loss of job has now added to my issues and pressures as he cannot support me financially as he used to do in the past (Impact of CKD on job issues)</i></p>	<p><i>Erm...there was a restaurant I went to last week to seek employment but I was told clearly that looking at the way I look they can't offer me any job since the job entails that I should be strong and smart. I tried to convince the owner of the business that I am just a dialysis patient and it wouldn't affect my performance on the job but.... that worsened my chances. He simply asked me to take time to look after my</i></p>	<p><i>Yes, I still feel the same way. In fact, I feel worse than I felt that day. I described living with this condition as a life sentence because of the impact it has had on my life expectations, hopes and aspirations. It has scuttled my lofty dreams. How else can I.....can I... describe a life condition where I cannot afford to pay for my treatment and I'm here dying without any help from the government? (Meaning of living with CKD)</i></p>	<p><i>I live each day as it comes with anxiety and not knowing what could happen to my life in this condition because I don't know the likely outcome when you have this condition (Uncertainty/ Poor knowledge of condition)</i></p>	<p><i>Erm....like I said the other time, the doctors are generally nice to me and they give me the details of my care and try to encourage me to comply with my treatment regimen. However, most of the nurses here show some signs of stress and aggression. I don't like the way they talk to the patients. To be fair to them ...erm there are some of them who are very good and they show you kindness and compassion and provide answers to your questions as a patient (Contrast in information giving by health workers)</i></p>	<p><i>Yes, it still influences my decision to go for dialysis. Sometimes when I remember that going for dialysis would mean having to spend the whole day in the hospital and sometimes it may not be your turn to be dialysed on the same day you are booked for it because they might have some emergency dialysis going on and so that disrupts the schedules, I.... kind of say ok let me be sure before I go. Meanwhile, you can't always be too sure</i></p>	<p><i>, the distance from my home to this place is very far. I had to get on three buses to be able to get here. You know how the public transport system is here in Enugu. So, most of the time I have to leave the house as early as 6am in order to get here before 8am. If I don't do that erm....it would mean that my dialysis for the day may not be possible. I can remember the other day I came here, I couldn't dialyse and I had to spend sleep over in the hospital in order to be dialysed the following day due to the distance issue (Impact of distance on</i></p>	<p><i>Erm,...to be honest I haven't seen any change yet. Nothing has changed. They only tell you to avoid foods that contain protein but they don't give you any further details (Information by nurses)</i></p>
-----------------	--	--	--	--	---	--	--	---

		health as the work demands much energy (Impact of CKD on job issues)				though (Impact of waiting hours on dialysis decision)	dialysis decision)	
G	<i>Erm,the doctors are a lot better than the nurses here. I'm not saying that all the nurses here are bad, no. All I'm saying is that many of them appear too stressed up and when you ask them questions, they hardly take time to explain things to you. Maybe.....maybe...erm they are too busy because of the number of people who come here for dialysis. There are those of them who still take time to give you details of the answers to any question you ask them. What I mean is that when you ask them questions, they will claim they are busy and will</i>	<i>Erm.....no it has never stopped me from going for dialysis. Although if I have a choice I would choose to go to the private dialysis centre where the doctors and the nurses are more compassionate and kind to the patients. Do you understand what I mean? No one likes where he or she is treated like s**t. So.....I.... simply try to ignore some of the bad attitude of some of the nurses and do my dialysis (Impact of experience of care on dialysis decision)</i>	<i>I don't believe in culture, so...I have no cultural belief. The needs of my family affect the decision for me to attend my hospital appointments and go for dialysis. You know, it's my poor parents who are paying for my dialysis and it's not easy. You know I have six younger siblings who are still in the schools and are dependent on our poor parents too like me? So,.....so...it's when they have the money that I come here (Impact of family needs on dialysis decision)</i>	<i>Hmm!.....living as a dialysis patient in this country means hell on earth for me. It is a mix of frustration and hope for me. It is frustration for me because..... I don't know what could happen to me in the end. I.....don't know what could be the outcome of this condition. Well, the Lord is my strength and my comfort. I draw my daily strength from my</i>	<i>Healing comes from God and only He can heal me. Dialysis is just a man-made thing and it can fail but only God can save me and heal me from this situation. Don't get me wrong.....dialysis is good in its own right but it doesn't cure or heal but God heals. Erm...my religious belief has never influenced my decision to come here for dialysis (Impact of religious belief on dialysis decision)</i>	<i>The cost of travelling to the hospital is too much and it adds to the total cost of my dialysis any time I'm coming here. So....so...you can imagine what that means. Meanwhile we manage to come not minding the cost and the inconveniences (Impact of distance on dialysis access)</i>	<i>The physical symptoms I experience have never stopped me from coming for dialysis but it is usually the main reason why I go for dialysis. You know when I don't go for dialysis, my legs swell up, even my face and my hands but...when I go on the machine, I feel better and the swelling comes down. I didn't want to go for dialysis the other time.... after the last time you interviewed me but my whole body was very</i>	<i>I experience a lot of pain in my joints especially in my arms and legs. This occurs mostly when I have stayed for too long without going for dialysis. It's an everyday experience for me, and.....and..... it's difficult for me to work. That is why I have been dependent on my family for practically everything including the cost of my dialysis treatment and doing basic things like bathing and washing my</i>

	<p>not answer you. Some of them still explain to me later on anyway but I would expect them to have more time to give us more information regarding our treatment. They should treat us like people who have rights. It's not our fault that we are sick and we come here for treatment (Contrast in information giving by health workers)</p>			<p>Christian faith and that is the hope I have (Meaning of living with CKD)</p>			<p>swollen, and I almost died....so that was why I had to go on the machine. Erm....we live in a village and it's not easy for us to get here (Impact of physical symptoms on dialysis decision)</p>	<p>clothes (Loss of independence)</p>
H	<p>It means a loss of my life. Not living with my full body, mind and soul as constantly thinking about this condition. It means loss of my freedom to perform my daily activities on my own (Meaning of living with CKD)</p>	<p>Yes, I still have the feeling that.....that I was poisoned and that is the cause of this condition. Look.....the target is just my business and my family. My enemies are after me but ...they will all fail in in Jesus name, Amen (Superstition)</p>	<p>I still have the feeling that.....that I was poisoned and that is the cause of this condition. Look.....the target is just my business and my family. My enemies are after me but ...they will all fail in in Jesus name, Amen (Information and knowledge gap)</p> <p>The doctor was not sure as he said ...erm...it might</p>	<p>You know last time I told you about a nasty doctor? Well, I have had another ugly experience from another doctor but I don't really like to talk about it. Erm...many of the doctors are doing well now as they take</p>	<p>The needs of my family are there too. If my family has no money to eat or solve any other problem.....it's not possible for me to be coming here for dialysis, although my wife usually insists but ...yeah (Impact of family needs on dialysis decision)</p>	<p>Yes, erm.....the issue of distance is a big problem for me. If you can remember I told you that I live in Ogoja and that is where I come from to do this dialysis. Sometimes I can have the money to</p>	<p>Well.....ordinarily it should but we are talking about life and death here but.....what can I do? I still try to come....I don't have any other place that is okay or closer for me to go. So...despite the very very long hours of waiting, I still</p>	<p>I am considering going for an alternative medicine as I can no longer cope with the cost of this dialysis. There is a place I was told that they can cure this condition without dialysis or the so called transplant (Culture of</p>

			<p>be due to poorly-managed hypertension and diabetes mellitus. So, you can see why I have been saying the cause is the poison, but I will defeat all my enemies (Information and knowledge gap)</p> <p>Yes, but it's lack of money to cope with this dialysis thing that is driving me back to alternative medicine again. I strongly believe that I will be healed, and my kidneys will be okay when I start that (Information and knowledge gap)</p> <p>Even if I have the money, I am worried about the possibility of getting the right kidneys and the possibility of rejection. I don't also know what could be the outcome of the</p>	<p>more time to explain things to us. The nurses are also very okay in doing this too (Experience of care)</p> <p>Erm.....what can we do my son? We have no choice.....if you are treated shabbily by the seller of a product which is abundant in a market place where you have, you will have a choice to buy elsewhere but when the product is scarce in the market, you may endure all the treatment and go for the product because you need it. Do</p>		<p>come here for my dialysis but it may not be enough to pay for the cost of transportation to come as you know it's a very far journey (Impact of distance on dialysis decision)</p>	<p>try to come (Impact of long waiting time on dialysis decision)</p>	<p>herbal ingestion)</p> <p>Yes, the doctor said it but....it is too expensive. I cannot be thinking about that now because I don't have the millions to even think about it. Also, even if I have the money, I am worried about the possibility of getting the right kidneys and the possibility of rejection. I don't also know what could be the outcome of</p>
--	--	--	---	--	--	--	--	---

			<p>surgery. So.....erm it's a very difficult choice my son. Even if I have such money I would leave it for my family to take care of themselves because I'm not sure that I won't die after the surgery (Uncertainty)</p>	<p>you understand what I'm trying to say? We have no choice so....I simply ignore the ill-treatment from any of the workers and go on the machine and leave this place. My experience doesn't determine whether I come for dialysis or not (Impact of experience of care on dialysis decision)</p>				<p>the surgery. So.....erm it's a very difficult choice my son (Concerns regarding transplant)</p>
K	<p>Life has been very difficult. Coping with a condition that you have no money to treat is like hoping against hope.....living under the illusion that you will be</p>	<p>It has been a very tough time for me my brother. I.....I....have been trying to see if I can get a job here as I can no longer continue with my</p>	<p>I cannot just come here if not for the symptoms that is very difficult for me to bear. You can see how my body looks now. My whole body has risen and my face full of my body</p>	<p>Erm.....yes the distance of my village to the dialysis centre influenced my ability or decision to come here for</p>	<p>You know that we like using our local herbs to treat any health condition that we have here and it has always worked for us. Even as I'm taking the medicines given to</p>	<p>The reason is that it is against my belief as a person. My religious belief forbids me from receiving any</p>	<p>I don't believe so but that doesn't mean that herbal remedies are inferior treatments but dialysis is better because</p>	<p>You know there is just only the centre that is owned by the government in this state and the private centres are very very expensive</p>

	<p>well when you are not doing anything about it (Description of living with CKD)</p>	<p>carpentry job due to the constant tiredness that I always have but I have not been able to get one. Erm,.....I have been living my life from hand to mouth and now....I am a big problem for my family. You know if not for them I wouldn't have been able to go for dialysis more than once since and my health condition would have been much better (Impact of physical symptoms on job issues)</p> <p>I....applied to some places to work but when they see me and my physical look they asked me if I was okay, so I told them truly that I'm a dialysis patient and they told me no we cannot employ you. So, it has not been easy with me</p>	<p>fluid.....so, it makes me feel distressed and I am not able to breathe well at all. This is the kind of situation that makes me come here to go on the machine and my family try to borrow money to make sure I come here if there is no money (Impact of physical symptoms on dialysis decision)</p>	<p>dialysis in the last two months. In fact, there was a day I was lucky to get the money for the dialysis but I couldn't get the money for transportation, so it delayed my coming here as I had to wait to raise the transport fare and before you know what was happening, I had used part of the money to buy some medications. Therefore, it really affected my ability to go within the period I wanted to go before the symptoms became worse and my whole body became</p>	<p>me by the doctors, sometimes I still complement it with the local herbs especially when I don't have money to go for dialysis (Culture of herbal ingestion)</p> <p>Even though I believe in our local herbs as good for treatment of any condition, I still believe that dialysis is better because any time I go for dialysis I always feel much better (Information and knowledge gap)</p> <p>I live each day thinking about what could be the result of this condition. I don't know if I'm going to die or be well in the end. I do want to live and take care of my family butI'm not sure as my health continue to get worse daily especially as I don't</p>	<p>body organ from another human being. Every person is special in his or her way and receiving another human organ into my body is abominable based on my religious belief (Impact of religion on transplant decision)</p> <p>Any day you are coming here for dialysis, it means that you have to cancel any other thing you need to do for the day, as you may not come back that same day due to the large number of people who come to go</p>	<p>I always feel better when I come here for dialysis than when I take herbal remedies to relieved the symptoms. As I said before, I only go for herbal option because I don't have money to go for dialysis (Impact of financial challenges to dialysis)</p> <p>If you don't have money nobody is going to admit you here for dialysis even if you are dying. So, lack of any form of support financially is stopping me from coming here for not only my dialysis but also for other hospital appointments I</p>	<p>and out of the reach of common people like me (Inadequate dialysis facility)</p> <p>The doctors are doing their best. They have been doing well in telling me the things I should be doing and the food I should avoid. They are also friendly in their approach to care. I think the nurses are also nice too. They take their time to explain things to you and show you that they do care about you (Experience of care)</p> <p>Well it is a place where you are treated well that you will always go. Isn't it? Meanwhile, whether I'm treated well or</p>
--	--	--	---	---	---	--	---	---

		<i>(Discrimination against dialysis patients regarding work)</i>		<i>swollen (Impact of distance on dialysis decision)</i>	<i>have money to maintain my treatment as recommended (Uncertainty)</i>	<i>on the machine (Impact of long waiting hours on dialysis access)</i>	<i>should be coming (Greatest challenge to dialysis)</i>	<i>not, it's my health that we are talking about and so, it wouldn't stop me from coming if I can afford to pay. You know that the cost of going to the private centre is much more, so you have no choice unless you are a rich person (Impact of experience of care on dialysis decision)</i>
L	<i>Basically, it's the needs of my family that have interfered with my plan to come for dialysis as I would have wished in the last two months but what can I do? My family is much more important than me you know? I needed to sort out a few financial</i>	<i>You know that I'm a civil servant as I told you the other time we met? It is not easy for me to be taking permission all the time to travel</i>	<i>It is very very difficult my brother. You know if you continue to take permission like that, your colleagues in the office may not understand and they might think you are going out for something else (Working and being on dialysis)</i>	<i>You know it's our culture and I cannot abandon them so long as I'm alive. I always try as much as I can to give them money from my little salary to support them and then my</i>	<i>It is usually a major reason why I come here for dialysis. If the symptoms are less, I don't think I need to be here as I would use the money to take care of other family needs. So....the symptoms mainly make me to come because when it's too much for me to</i>	<i>Herbal remedies are okay because if you think about it before the white man brought orthodox medicine to Africa, our great grandparents were using</i>	<i>The doctor talked about the option of transplant. He said it's the best form of treatment for the condition but my religious belief does not permit me to accept any body part from</i>	<i>The doctors and the nurses are doing well. They always teach me the things I should be eating and those I should avoid. I would like them to break down what they are teaching further</i>

	<p>issues that my family had and so...I couldn't raise the money to come here for my treatment (Impact of family needs on dialysis decision)</p> <p>Erm...the greatest I would say is the issue of being able to get the money to sustain my treatment and also being able to have the time from work to come here. So, distance to this centre is a big issue. If it was in Abakaliki, I could always try to schedule my dialysis for evening periods after work but here there are too many people waiting on the queue (Greatest challenge to dialysis)</p>	<p>to Enugu here for my treatment</p> <p>three times every week assuming I have the money to follow the doctor's recommended sessions of dialysis for my treatment</p> <p>(Distance issue)</p>		<p>family and I manage the remaining money. It has not been easy....it affected my ability to come here for dialysis sometimes</p> <p>(Culture of supporting extended families)</p> <p>It limits my chances of receiving dialysis the way I would love to butwhat can you do? You have to support your family first before anything else</p> <p>(Impact of family needs on dialysis decision)</p>	<p>bear, there is nothing else I can do but to try and come for dialysis even if it means I have to borrow money from someone (Impact of physical symptoms on dialysis decision)</p>	<p>herbs for healing and it worked</p> <p>(Information and knowledge gap)</p> <p>Well, it's private although I will tell you the truth, yes, I do take herbal remedies sometimes although I don't tell my doctor anyway because they will always try to discourage you from doing it</p> <p>(Culture of herbal ingestion)</p> <p>Before the white man brought orthodox medicine to Africa, our great grandparents</p>	<p>another human being. Every human part is sacred and unique to the person; so....erm the option of transplant is out of it for me</p> <p>(Impact of religion on transplant decision)</p>	<p>(Experience of care)</p> <p>Well, erm.....I can't really say that the experience of care from the nurses has influenced my coming here for dialysis. As a dialysis patient, I don't think you have another option regarding your treatment whether you are treated well or not by the nurses in this centre. This is the only government-owned dialysis facility around here, so you can't but come here in order to save cost of the treatment</p> <p>(Impact of experience of care on dialysis decision)</p>
--	--	---	--	---	---	---	---	---

						<p>were using herbs for healing and it worked but for this my condition, I don't think it's the best option for treating kidney conditions anyway (Unsure of impact of herbal remedy)</p> <p>Erm.....I am worried about the likely outcome of my condition. I don't want to die and abandon my family. I do hope I make it in the end. The possible outcome of this condition is a big source of worry for me and my family</p>		
--	--	--	--	--	--	--	--	--

						(Uncertainty)		
M	<p><i>Erm, living with my condition is a big struggle for my life. It is a big strain on my career, my family and everything I have worked for all my life (Meaning of life as a dialysis patient)</i></p>	<p><i>The major issue delaying the transplant is getting a donor. It has not been easy getting a donor yet either here or in the UK and my doctors and I are currently considering other options (Donor as a challenge to transplantation)</i></p>	<p><i>You know that in this clime people are not aware of the importance of organ donation. Some are afraid of the possible outcome of donating an organ to someone else and for some others, they are not able to donate due to religious reasons as their religion abhors such a practice (Information and knowledge gap)</i></p> <p><i>Erm... the people are generally afraid of dying after the donation. They usually think that when you donate an organ like the kidney, then your lifespan will be shortened. Some others also expressed the fear that when they donate an organ like the kidney to a recipient, then a certain vital part of</i></p>	<p><i>Erm, ...the needs of my family is there but it has never affected my going to dialysis as my wife is working, although I must admit it has not been easy as we also have to train our kids you know?, ...so, erm but it has never been an issue anyway (Family needs as a non-issue)</i></p> <p><i>Erm, ...like I said the other time, the symptoms are not really always there as I have always come</i></p>	<p><i>Obviously no, because you don` t know the chemical content of the herbs and you will end up further damaging the kidneys. So, it`s never an option although it`s the lot in the rural areas in this clime (Knowledge of effect of herbal remedies)</i></p>	<p><i>I would think that it has been quite easier for me going to dialysis than getting a donor. I do hope I will be able to overcome this hurdle in the shortest time possible. It has not been easy doing dialysis as prescribed by the doctor as it has taken a great toll on my finances, my life plans and family. The financial commitment to receiving dialysis is the greatest challenge. In all, I am grateful to</i></p>	<p><i>The nurses and the doctors have been wonderful. They are doing their best and whenever I come here the experience I have of their services remain the same. Erm,they always advise me on what to eat and those to avoid. They also take time to reassure me and tell me that all will be well in the end (Experience of care)</i></p> <p><i>Definitely my experience of care from the nurses has always encouraged me to go for dialysis. You</i></p>	

			<p><i>their whole being is lost and when they die, they may not have their whole remains interred</i> (Superstition)</p>	<p><i>for dialysis to keep fit health wise</i> (Physical symptoms as a non-issue)</p> <p><i>The distance is quite an issue for me, but it has never determined or influenced my decision to come here for dialysis</i> (Impact of distance on dialysis decision)</p>		<p>God (Greatest challenge to dialysis)</p>	<p><i>recall that I told you about a dialysis centre where I used to dialyse whenever I go to Abuja? The service there is really poor and the hygienic practice of that facility is nothing to write home about. If the service you receive from a service provider is satisfactory, then you have no reason not to continue the patronage, so that explains why I come here for my dialysis</i> (Impact of experience of care on dialysis decision)</p>	
--	--	--	--	--	--	--	--	--

<p>O</p>	<p><i>I always try to come here and go on the machine only when the symptoms become so much that I can no longer cope with it. If the symptoms like the pain in my belly, the swelling of my belly and the hiccups which make me uncomfortable are less, then I don't need to come here as I would rather use the money to look after my children's needs than giving it to the hospital people, do you understand?</i> (Impact of physical symptoms on dialysis decision)</p>	<p><i>I can remember the other day I managed to get the money for the dialysis but I didn't have the money for the transportation, I couldn't come and that made me to stay back until when I was brought here unconscious and the doctors told me when I became well that my blood urea level was too high. You see, if I had the means to come or if there was any dialysis centre close to my village I wouldn't mind trekking down to go on the machine</i> (Impact of distance on dialysis decision)</p> <p><i>So, if we don't have enough money to take care of our family needs and my dialysis at the same time, I have to first of all attend to my</i></p>	<p><i>This condition is not supposed to affect a poor person like me who doesn't have the means to treat myself</i> (Information and knowledge gap)</p> <p><i>He said it but how can you mention transplant to a poor person like me who cannot even afford the cost of regular dialysis?</i> (Transplant as meant for the wealthy)</p> <p><i>I learnt it involves taking the kidney of another person into my body, God forbid ...tufiakwa!</i> <i>That is against my cultural belief. In my culture a human being shouldn't receive the body part of another person,</i></p>	<p><i>The doctors and the nurses are doing well. They always treat me nicely, they are quite polite and when you are even feeling down they try to encourage you. The doctors always remind me that I shouldn't eat any food that contains protein but I don't know all of them. They also try to give me information regarding my treatment and condition from time to time</i> (Experience of care)</p> <p><i>I would say that it has affected it positively although money is the</i></p>	<p><i>You can see the kind of queue that is here now? See the number of patients who are here waiting for dialysis, it's not an easy condition, sometimes we come here and we end up spending two days because of the number of people who are waiting to be dialysed</i> (Issue of long waiting hours)</p>	<p><i>Even sometimes you come here and you are told that they don't have water or the machines are bad, so you have to wait until it is fixed before you can be dialysed. It's not the fault of the nurses or the doctors</i> (Other challenges)</p>	<p><i>I want to ask what really caused my condition. Do you know?.....even the doctors could not tell me the cause of my condition and they only said the cause is queried</i> (Information and knowledge gap)</p> <p><i>How can my life end like this and my brothers in law all accused me of being responsible for the death of my husband and that is the cause?</i> (Superstition)</p>	<p><i>Look at me, look at my whole body, my whole body looks like I'm pregnant when I'm not at my age</i> (Bodily awareness/ Body image)</p>
-----------------	--	--	---	--	---	--	---	--

		<p>children`s need and when I have the money I will come here (Impact of family needs on dialysis decision)</p> <p>The doctor warned me anyway that I should stop taking it that it can further worsen my condition but that is the doctor`s recommendation; if I don`t have money to come for dialysis, what can I do? So, it`s not really my making (Impact of financial issues on dialysis decision)</p>	<p>it`s an abomination and the gods frown at that (Impact of cultural belief on transplant)</p> <p>Such a practice has its consequences and can lead to the death of the person to whom the body part was given. So, even if I have the money for that I wouldn`t even contemplate going for it (Superstition)</p> <p>If you look at my condition now you would see that I`m almost dying, so I`m much more worried about the future of my children. I`m more worried about them because I don`t know what the future holds for them if I die. They would have nobody to</p>	<p>major determinant because if I don`t have the money to pay certainly none of them can ever attend to me even if I`m dying. Meanwhile, it doesn`t really matter in this condition if you are treated well or not as someone like me have no other choice even if they don`t treat me well because my major concern is to get well. You know in our society you don`t castigate someone who is looking after you even if he or she is wrong unless you don`t want them to</p>				
--	--	---	--	--	--	--	--	--

			<p>support them as I have sold almost all my property to look after myself in this condition</p> <p>(Uncertainty)</p>	<p>attend to you</p> <p>(Impact of experience of care on dialysis decision)</p>				
P	<p>The Lord has been my strength. He has given me victory over this condition. I have been coping well by the grace of God. I mean the Lord has been giving me the strength to cope with the situation caused by this condition ion my life. He alone is the source of my succour in dealing with this condition</p> <p>(Religion as a coping strategy)</p>	<p>Erm,.....to be honest with you my son, I had to do it not because I felt the need to do it but because the doctor who has been very nice to me in the way he treats me actually insisted that I needed to do it (Dialysis as secondary to religious belief)</p> <p>So, ...erm, ...you can imagine what it means for me and my family. I always like to go to church and attend all the church activities but that has not been possible due to this illness</p> <p>(Impact of CKD on participant's</p>	<p>The worst for me is when I'm feeling so much pain....very sharp pain in my knee and it always make me very week and I can't even walk. So, ...when this happens, I'm not able to go out to the farm and you know it's the only source of my income as my husband is no longer able to work and I have my three children to support</p> <p>(Impact of physical symptoms on job issues)</p>	<p>Sometimes, when my belly is swollen I am not able to go out due to severe weakness that I feel and also because I feel sad and shamed to go out to church because of the swelling which makes me feel like someone who is pregnant</p> <p>(Bodily awareness/ Body image)</p>	<p>Well, may be making sure that my husband is properly looked after could be described as a cultural inclination as that always make me not to wait for too long on the queue each time I come here for dialysis. It is the culture of our people that nothing should stop a woman from preparing food for her husband</p> <p>(Culture of specific gender role)</p>	<p>So, yes, there was a day I came hereI think that was about 2 weeks ago and if you see the kind of crowd that was here waiting to go on the machine, hmmm! It was too much that I had to go back after waiting for</p>	<p>The physical symptoms for me to be honest has never made me to come here although the doctor said it's the reason why my belly get swollen because I don't come here constantly for dialysis as he prescribed</p> <p>(Impact of physical symptoms on dialysis decision)</p> <p>Erm...I live far away from here but honestly the distance has never been a major factor for me in the last 2 months.</p>	<p>Erm,.....normally I don't tell the doctor that I still use the herbal remedy. Yes, I still use the herbal remedy sometimes....not as much as I used to drink it before (Culture of herbal ingestion)</p> <p>My son, you cannot take away the drinking of local herbs away from our people. It is part of our lives and even religious belief doesn't affect that. I don't want to tell him because he</p>

		<p>spirituality/religious practice)</p> <p><i>I am a strong Christian and I always believe in God for his healing. My faith in God for his healing is unshaken and he will heal me. Yes, that is the major reason why I have not bothered myself so much about going for dialysis except when the doctor insisted that I needed to go for it. My Christian faith dictates what I do in life and that includes even in this condition</i> (Impact of religion on dialysis decision)</p> <p><i>Maybe if I had the money to come here regularly I would have been doing that even though I don't believe in</i></p>				<p><i>like 3 hours and almost late into the night. I needed to go home and look after my husband as my children were not at home</i> (Issue of long waiting hours)</p> <p><i>I have many challenges in accessing dialysis even though I don't see it as the source of my healing. Part of the challenges is the issue of the long waiting hours here. Sometimes,</i></p>	<p><i>It would be better though if the facilities are brought closer to those of us who live in the rural areas</i> (Impact of distance on dialysis decision)</p> <p><i>The doctors have been treating me well. They are doing their best in looking after me. The nurses are amazing. They do their jobs very well</i> (Experience of care)</p> <p><i>They teach me what to eat and the things to avoid. They always talk to me nicely and treat me with respect maybe it's because of my age anyway, but generally they treat me well.</i></p>	<p><i>would try to discourage me from doing that. He treats me well I don't want to be seen as disobeying himso the best thing for me is to not tell him about it</i> (Attitude towards herbal ingestion)</p> <p><i>It is just our way of life and it's really hard for me to stop it. Somehow, I think it complements the dialysis treatment</i> (Information and knowledge gap)</p> <p><i>This condition is not supposed to affect a commoner like me</i> (Information and knowledge gap)</p> <p><i>Erm.....generally I don't know how long this condition will</i></p>
--	--	---	--	--	--	--	--	---

		<p>dialysis as a source of my healing from this condition (View on dialysis)</p> <p>My religious belief doesn't allow me to accept blood, or any organ from anyone. I am of the Jehovah Witness Christian denomination. It a part of my religious belief that cannot be negotiated with anyone because if you respect any human life you do not try to prolong it by taking other person's organ. So, doing that would mean going against my religious faith (Impact of religion on transplant decision)</p>				<p>like the last two weeks the queue is so much that I don't have the patience and time to stay here. You know I live in a very far village, so it's hard for me. Another issue is money ...money to be able to pay for the treatment because if you don't have money you can't go on the machine (Greatest challenge to dialysis)</p>	<p>Hey also explain to me how to take my drugs and tell me to always come here for my treatment (Experience of care)</p> <p>Erm ...no I don't think so. The nurses are nice but then if you don't have the money to pay for the treatment nobody is going to allow you go on the machine. So,yes it hasn't affected my decision to go for dialysis (Impact of experience of care on dialysis decision)</p>	<p>last. I don't know when I will be healed but then I trust in God for my healing (Information and knowledge gap)</p>
--	--	--	--	--	--	---	---	---

Q								

T3 CODES

Participants	Codes								
A	<p>God has been my strength. He alone has been my source of strength because this condition is really far above me and is really taking away all my energy every day (Religion as a coping strategy)</p>	<p>I was invited for interviews by the 3 schools I applied to but I was told clearly by the Heads of 2 of the schools that I'm fully qualified for the job but my physical look did not inspire confidence for them to proceed with my employment. They were very clear and I really understood them. For the head of the third school, she did not get back to me even after all efforts I made to have a</p>	<p>I still do feel very much sad and ashamed of how my body has been disfigured by the fistula and the effect of the dialysis on my body. However, it has not in any way affected here for dialysis (Bodily awareness/ Body image)</p>	<p>I would have come here more than just twice like I mentioned to you before but I couldn't because I had no money. I can remember in one of the days, my whole body was swollen and I couldn't walk, I was vomiting and couldn't eat because my creatinine level was very high and I didn't have money to come here for dialysis. My parents had to go and borrow some money with interest from the association they belong to before I could come here (Financial</p>	<p>The distance of the dialysis centre to my village is also a big issue as I am struggling with getting money for both dialysis and cost of transportation (Impact of distance on dialysis access)</p>	<p>It's a setback for me and my life ambitions and all I have planned for myself in the future. You can imagine now that I will never have children again in my life,.....I will never be fine to go back to the university to gain degree as I had planned all because of this condition (Meaning of living with CKD)</p>	<p>Erm,....the nurses have been nice, treating me respectfully and giving me every necessary information regarding my treatment plans but that doesn't mean they can do the dialysis when I don't have the money to pay (Experience of care)</p>	<p>If not for the fact that I was really down, vomiting, my legs were swollen and I couldn't do anything, I wouldn't have been here today to go on the machine like today, my family would have used the money to sort out other family matters (Impact of physical symptoms on dialysis decision)</p>	<p>I don't have any cultural inclination that could have affected my decision to come here for dialysis treatment (Impact of culture on dialysis decision)</p> <p>We don't have the money for me to come here regularly and most of the time I depend on my family...I mean my father and my mum because my husband has lost everything he has in the</p>

		<p>feedback from her. I do think she has the same impression but really found it difficult to tell me (Impact of CKD on job issues)</p> <p>I'm sure that my look is a big factor that has been stopping potential employers from offering me a job (Rationalisation of reason for job issues)</p> <p>I did apply for another job as a secretary in company. You know I can't do any job that demands so much energy because of my condition. The weakness wouldn't let me do any</p>		<p>challenges to dialysis)</p> <p>The cost of the treatment like I have said before clearly discourages me from coming here and so it is to many other dialysis patients who come here for treatment. It is excessively high and frankly unaffordable for common people like me (Impact of cost on dialysis decision)</p>					<p>course of this condition of mine.</p> <p>So,sometim es when there are other pressing needs of the family, it would mean that I won't be able to come here as I have to pay for going on the machine and for transportation to this place (Impact of family needs on dialysis decision)</p> <p>Sometimes we have the money for me to come here but then we don't have the means to come and that increases the cost of my treatment. You know I can't walk down from my village which is very far to this place andsometi mes it discourages me from coming until we are able</p>
--	--	--	--	---	--	--	--	--	--

		work that requires much strength, I went for the interview too but the feedback I got was that I wasn't successful this time (Impact of physical symptoms on job issues)							to get more money to come. It has happened many times in the course of this my treatment (Impact of distance on dialysis decision)
C	I was invited by 2 of them, one is a private hospital which required the services of an auxiliary nurse and another one is a private clinic which required the services of a cleaner. I didn't really mind what job it is as I just want a job in order to bethat is true and I still do that now, although it's not easy for me and I have also been trying to see if they can get something doing to ease the pressure on me. I am planning now to see if they can go back to the village to continue with farming as it's about rainy	Erm..... I don't know really. I don't think it is better than dialysis but it's just a cultural thing and I think it's good for my health but it's certainly not better than doing dialysis. I try to use it most of the times I fail to come here for dialysis due to certainthe doctor said so and even my daughter who is also a doctor has been talking about it but the issue is money. My daughter has just started practising as a doctor and has barely settled down and now I shouldn't be bothering her with the cost of treatment for transplant even when it's notthe distance is too far from Abakaliki where I live with my children and the cost of travelling to here for dialysis adds to the problem of my being able to come here and go on the machine. Sometimes it stops me from coming until my daughter is away from work	The nurses and the doctors are kind and very humane in their approach to my care. They have been wonderful. They always told me to avoid foods that contain protein and to not take any medication apart from	Erm, to be honest the greatest challenge I face is the issue of money to be able to come here regularly and the transportation issue that stops me from coming even when I have the money to come. Even when I have		

	<p>able to earn some money and support my treatment and my family. To be honest, up till now I cannot even tell you the outcome of the interviews as I haven't heard from any one of them. None of them has contacted me and I have made efforts to get a feedback from them all to no avail. When I managed to go to the hospitals, the secretary told me the vacancies have been filled with other employees and I had to go back home (Employment issues in CKD)</p> <p>.....it was clear to me</p>	<p>season at least we can have food to eat while we deal with our situation (Cultural practice of looking after hubby's other wives)</p> <p>.....I cannot say clearly yes or clearly no. Having them around me has been a form of support somehow and in other cases it has affected me negatively financially as I have to pay for certain things for them and that adds to my financial pressure and my ability to come here for my dialysis as prescribed by the doctors (Impact of the cultural practice on</p>	<p>reasons (Information and knowledge gap)</p>	<p>been easy for her supporting me with the cost of dialysis treatment. So..... you can see that it's not what I should be talking about now (Impact of cost on transplant decision)</p> <p>No, my religious belief doesn't stop me from receiving dialysis if I have the means to go about it (Impact of religion on transplant decision)</p>	<p>and then she can help me by brining me here with her car and you know what that means. She will have to take time off from her new job and that's not good especially foe someone who has just started a job (Impact of distance on dialysis decision)</p> <p>The needs of my family normally come first before this dialysis as I have to support my kids and the entire family. My daughter has been an immense source of help though. I would have come here to go on the machine more times than I did in the last two months if not for the needs of my family sometimes</p>	<p>the ones that the doctors asked me to buy and take (Experience of care)</p>	<p>the money to come here, the cost of transportation and the stress of having to wait in the scorching sun for hours waiting for public transport to come here is a big worry for me and many other patients like me (Greatest challenge)</p>		
--	---	---	---	--	---	---	---	--	--

	<p>that I might not get the job even during the interviews. I was only trying my luck to see how it goes. My look is horrible like you can see but somehow, I think I could still carry on with any of those jobs if I was offered because I have no choice but to muster some inner strength and carry on as I have no other source of support except my daughter (Rationalisation of reason for job issues)</p> <p>I seriously regret quitting my job before, maybe I should have managed to carry on but it was really difficult for</p>	<p>dialysis access)</p> <p>.....It's my use of herbal remedies...yes, I still use herbal remedies and even though I come here for dialysis, I still try to use it because of my belief that it's helping me. I try to hide this from my doctor anyway and I'm very sure you are not going to tell them (Culture of herbal ingestion)</p> <p>Erm,the culture issue has not been a factor influencing my decision to attend dialysis. Well, you might say it has because</p>			<p>(Impact of family needs on dialysis decision)</p> <p>.....if the symptoms become unbearable like when the vomiting, itching and my body swelling becomes so much that I cannot bear it any more, yes it makes me to want to come here for dialysis as coming here and going on the machine makes everything fine and I'm much better and feel like a human being again. So,.....erm..... yes mainly the symptoms I experience everyday influence my decision to come here and go on the machine (Impact of physical</p>				
--	--	--	--	--	--	--	--	--	--

	<p><i>me because I was always very tired and couldn't cope with the pressure of going to do dialysis, coping with the symptoms and having to go to work too. It was really hard but I can't blame myself. If I had the strength, I would have carried on but I couldn't as I was too feeble to carry on and I was constantly going late to work because of the impact of the symptoms on me (Impact of physical symptoms on job issues)</i></p>	<p><i>of me sticking with the culture of my people in looking after my husband's other wives and which has affected the money available for me to live on and look after my treatment. I just have to assist them to survive too as our husband is no longer there to cater for them (Impact of culture on dialysis decision)</i></p>			<p><i>symptoms on dialysis decision)</i></p>				
--	--	--	--	--	--	--	--	--	--

D	<p>I have been doing my best to cope with the situation. My family has been very supportive in helping me cope with the situation by helping me in carrying out many things that I should have been doing on my own (Source of support)</p>	<p>I have not been able to get someone yet. I have made series of efforts all to no avail and so,....I have had to shut down my business over there and look after myself and it's really been telling on me and my ability to cope with my financial obligations (Impact of condition on source of income)</p> <p>It has not been quite easy especially watching my wife deal with all the financial matters in the family and now everyone</p>	<p>How much are they going to pay me in the job I'm going to get besides looking at me now which employer do you think can think of offering me any job even though I don't look like I'm a dialysis patient, I still feel it inside me and its very tiring (Rationalisati on of job issues)</p>	<p>.....he has been assisting me but you know he's just an individual with his own family issues to sort out too. So, he's doing his best but the money has not been coming so frequently as it used to in the last few months and its not been easy at all. Don't get me wrong, he is really trying so hard in supporting me but if the cost of this treatment was lesser, you know it would have been much easier for me and my family and for him too even though he keeps reassuring me that money wouldn't be an issue for my treatment</p>	<p>I still believe so even though I don't have any proof yet. You can imagine how the whole thing started and all of a sudden I was diagnosed of kidney failure.....is that how human kidney fails so easily just from the treatment of gout that many people live with and nothing significant happens to them? So,....I still believe that I was attacked diabolically but I will be fine in the end; my detractors are just wasting their times (Superstition)</p>	<p>I had told you before that my religious belief forbids me from accepting another human organ into my body. It is against my religious belief and would rather die than do that. My wife and my cousin have been trying so hard to persuade me to accept the option but after life here there is another life and I shouldn't go against my religious belief. I know it's very difficult for everyone</p>	<p>Nothing has changed, the nurses and the doctors have been very kind, treating me respectfully and showing some genuine concerns towards me. They have been excellent in their care (Experience of care)</p>	<p>The physical symptoms have never really made me to go for dialysis but somehow you can say it has made me because I have always attended the dialysis not because I came down with any of the major symptoms but because I don't actually want to suffer from any of them. The symptoms are very horrible and I don't think I want to go through all that any time (Impact of physical symptoms on dialysis decision)</p>	<p>As the head of the family sometimes I try to save some money from my dialysis money to support the family and sometimes I try to skip one or more sessions in a month in order to save some money and support my family financially and so that's why I don't come here to go on the machine three times every week as the doctor prescribed even though my cousin gives the money for the three sessions per week (Impact of family needs on dialysis decision)</p> <p>I do have religious beliefs</p>

		<p>of us have been dependent on her. It makes me feel less worthy as a man. You can imagine what it means for a woman to be the person catering for a family in our society? It kind of makes me feel that I'm no longer a man, in fact as though I'm no longer alive because I should be the one providing for my family and my wife's role would be supportive and not being the one in charge of everything (Worthlessness)</p>		<p>(Financial support issues)</p> <p>As a man, I would prefer being able to pay for my treatment and supporting my family and doing many things for myself as against my current situation where I have to practically depend on my family for everything even though I dialyse at least twice every week. It makes me feel like a burden to my fellow man. I feel like I'm tied to someone and really quite inseparable and have lost my financial freedom (Loss of financial freedom)</p>		<p>in my family but then think about my religion too (Impact of religion on transplant decision)</p>		<p>I have been seen a lot of people who come here for dialysis only when the symptoms are so high, their whole body is swollen, their urea levels are high and they are almost dying; that's what I see here anytime I come for dialysis and sometimes I see people die while they are still waiting to go on the machine because their conditions are so bad before they are brought here usually because they don't have the money to come here or because of the distance of where they live to this</p>	<p>but it hasn't influenced my coming here for dialysis (Impact of religion on dialysis decision)</p> <p>I have never taken herbal remedy in this condition. In fact, even if I think about it my wife will never allow that, remember she's a nurse and would never condone that. I don't think it's a better option definitely (View on herbal ingestion)</p> <p>D3: so far, the greatest challenge I have is my inability to provide for my family and also finding somebody who is trustworthy to look after my business in the north (Greatest)</p>
--	--	---	--	---	--	---	--	---	--

								<p>place. So,after seeing such thing I don't think any sane person would want to wait to come down with the symptoms before coming here for the dialysis when you have the money or funding support to come here for treatment (Physical symptoms of others as a factor)</p>	<p>challenge to dialysis)</p> <p><i>I don't think I have had any positive experience to be honest with you. I can't talk about any positive experience when I am still suffering from this condition but I will be fine by the grace of God (Positive experiences)</i></p> <p><i>This condition is a negative experience for anyone who is suffering from it because it destabilises every plan you have as a man. I can't talk of my experience of watching people die here just because they can't afford to pay. It's really hard and it's not what I would love to talk about please</i></p>
--	--	--	--	--	--	--	--	---	--

									<p>(Negative experiences)</p> <p><i>Erm,.....I don't really have anything else to say but to ask you if there is anything these questions you are asking us can help us achieve especially with respect to reducing the price of the treatment. I know you are a nurse too, is there any way you can help us talk to your colleagues to bring down the cost of this treatment especially for very poor people who can't afford the huge cost of treatment?</i></p> <p>(Interaction between interviewee and interviewer)</p>
--	--	--	--	--	--	--	--	--	---

H	<p><i>It has been like hell because things have been very terrible for me. It has been very tough coping with the stress occasioned by this condition. I have lost my independence and financial freedom in life and now I have to depend on the efforts made by my wife in dealing with this situation and I have no other support</i> (Loss of financial freedom)</p> <p><i>The only support I have had been my wife and no one else, so.....it's been a very</i></p>	<p><i>The treatment has been going on well. I feel a lot better now and although sometimes it feels like there is no improvement. I feel so although I feel a lot better when I also go for dialysis after taking the medicine the pharmacist has been giving me</i> (Perception of alternative medicine to dialysis)</p> <p><i>I didn't tell them about the treatment because they are not going to support it. They like people coming</i></p>	<p><i>He only told me it's made of fruits and vegetables. You know he's a pharmacist and he knows better than us patients. So..... I didn't really bother to find out the details of the content as I have seen many people testifying of being healed by the treatment they received from the same pharmacist</i> (Patients` perception of healthcare workers)</p>	<p><i>sometimes I tend to feel so but I think the dialysis is still very good but may be combining the two is better than just the dialysis</i> (Information and knowledge gap)</p> <p><i>Yes I still believe so that my condition was caused by poisoning by the people in my village but I will be over it in Jesus name</i> (Information and knowledge gap)</p>	<p><i>The last time I came here for dialysis, the doctor was not around so I couldn't be reviewed and we had to go back because you know we always come from Cross River State which is very very far from here</i> (Issue with doctor`s review)</p> <p><i>Nothing has changed my son. I don't like to talk about it. I simply come here and do my dialysis and then go home. The private centres are better though don't get me wrong because you pay so much and they don't want to lose you so they do everything to</i></p>	<p><i>The issue of the distance is still very much there. In fact, it's very much worse now that we have to come here for the alternative medicine treatment and the consultation and review by the pharmacist once every two weeks. It's not quite easy as it has increased my burden of cost of treatment in this condition</i> (Impact of distance on dialysis decision)</p> <p><i>The needs of my family</i></p>	<p><i>Erm,.....I don't really have any cultural belief that can influence my decision to come here</i> (Impact of cultural belief on dialysis decision)</p> <p><i>It's a common thing here and you can see that for yourself. All you need to do if you want to see for you to be here until the end of the day and you will understand what I have been talking about. The worst is that while we are waiting here somebody</i></p>	<p><i>The greatest challenge actually is getting the means to get the treatment for this condition. It's the greatest issue in my life now and it has affected everything in my life</i> (Greatest challenge to dialysis)</p> <p><i>I have been fortunate to meet some of the nicest people in my life who have supported me on some occasions showing me compassion and even giving me money to pay for some treatments whenever I come here</i></p>	<p><i>The major problem I face now is being able to get the money to pay for the money required for this treatment by the pharmacist. It's really huge although we have paid some amount and the pharmacist is insisting that we must complete the payment before my next appointment with him. I need to do everything possible to realise the money because that can affect the treatment I'm receiving from him</i> (Concerns regarding alternative medicine treatment)</p>

	<p>distressing experience for me and my family (Source of support)</p> <p>I still feel same way of putting an end to this situation but I hope everything will be fine someday. I have been having the same thought especially whenever my body keep swelling up and its affecting the way I breath, you know it could be very distressing and it makes me very anxious (Negative emotions)</p>	<p>here for dialysis so that they can make more money. If you tell them about another treatment, they will try to discourage you from the treatment and since I'm being better from the treatment, I don't think anyone should discourage me from doing that. So,erm... that is why I don't want to tell them here (Perception about use of alternative medicine)</p> <p>You see when I was going on only the machine I wasn't feeling this better and I was always tired but I think I have improved greatly since I</p>			<p>be nice to you but here, it's all complaints about this or that not being available if you can understand what I mean (Experience of care)</p>	<p>will always be there but we have been trying hard to manage it even in the face of almost abject penury that we have faced recently (Impact of family needs on dialysis decision)</p> <p>I would say the major influence has been the symptoms which you know it's difficult to bear and so when it comes so hard like that, you have no choice but to come here and go on the machine (Impact of physical symptoms)</p>	<p>might drop dead due to the long waiting hours (Issue of long waiting hours)</p> <p>No,n ot at all because you just have to do whatever you can to be fine you know? (Impact of long waiting hours on dialysis decision)</p>	<p>and the money we have for treatment is not enough. There was an instant when we came here and the money we had was like #20,000 short of the required amount and the nurses wouldn't accept for me to be treated even though I have been coming here for a long time and can actually be regarded as a regular customer but you know how the system is, no one cares about relationships but the cash and until you pay nobody is going to attend to you</p>	
--	---	---	--	--	--	---	--	---	--

		<p><i>started the combination of the treatment (Perception about use of alternative medicine)</i></p>				<p><i>on dialysis decision)</i></p>		<p><i>(Positive experiences)</i></p> <p><i>I have also been attended to by a couple of doctors and nurses who are very nice and would take time to give me every necessary information regarding my treatment and what to do and those not to do.</i></p> <p><i>So,.....it's not been entirely bad</i></p> <p><i>(Positive experiences)</i></p> <p><i>I have so much negative experiences but the most distressing among them all is coming here and not having enough money to be able to pay for my treatment and</i></p>	
--	--	---	--	--	--	-------------------------------------	--	---	--

								<p><i>having to wait until a good Samaritan came my way to assist me in this condition. I have also been troubled a lot by the distance I have been traveling to come here and do dialysis. It has not been easy with us at all</i> (Negative experiences)</p>	
L	<p><i>In the last two months there was a day I came here and both the nurses and the doctors said they didn't have water so they couldn't dialyse any patient that day and I had to go back to</i></p>	<p><i>It's a big stressor on my life and those especially my wife who have to cope with the pressure of looking after me and our child and then her new job. It has been a big</i></p>	<p><i>Erm,.....the symptoms are always excruciating especially the pain (the abdominal pain) when the swelling starts and every part of my body is swollen so that is enough</i></p>	<p><i>It's always there even though I have not been earning enough to continue to maintain them financially as I used to but what can I do? I still have to do that as the only person in the family who at least can boast</i></p>	<p><i>Well sometimes, I do and at some other times, I do not. It depends on the present condition I find myself. Sometimes I take it and feel well so in that case I could say it is helpful but at some points,</i></p>	<p><i>You know here doctors and nurses are seeing as people who know it all regarding healthcare and so you</i></p>	<p><i>The doctors did mention to me the possible causes and the risk factors but you know it's not like the definite cause but just a risk. So, that I drank herbal</i></p>	<p><i>Well, ...erm... ..I would say the greatest challenge I have encountered in the last two months is actually the issue of distance because like I said before if the location</i></p>	<p><i>The only positive experience I have had in the course of this condition is that it has drawn me closer to my God. I have been much closer to my creator in the course of this condition and</i></p>

	<p>Abakaliki. You know I don't live here and so I couldn't wait until the following day because I had taken only one day off from work to go for dialysis (Issues with dialysis services)</p>	<p>stressor and yes I still see it as that because it has affected my life negatively and disrupted my plans (Meaning of living with CKD)</p>	<p>to make me come here for dialysis and in the last two months it really did (Impact of physical symptoms on dialysis decision)</p> <p>The distance issue is there and it has affected me because if you can remember the other day I came and the nurses and the doctors said there was no water if the centre was in Abakaliki I would have gone the following the day but because of the distance I couldn't go back as that would mean taking another day off from my job and that wouldn't be acceptable (Impact of</p>	<p>of any meaningful job. It's the culture of our people and I have to keep it. So,erm,that's the way it's been for some time now (Culture of looking after others)</p> <p>I did say that and yes to be honest with you I have been forced by the situation to take some despite the fact that you can say that I'm educated and should know that it may not be entirely good, but then what can you do when you don't have money to continue to seek orthodox treatment as you would like? (Culture of herbal ingestion)</p> <p>No, no, no.....you don't say that to your</p>	<p>it is not (Perception of herbal remedy)</p>	<p>telling them something like that is like going against the rules (Patients perception of healthcare workers)</p> <p>The doctors are the nurses have been doing well and they have been treating me with respect, care and compassion. They teach you what to do and the things not to do, and things you should avoid eating or drinking. So, I would say they have been trying</p>	<p>remedies I think....erm may not be enough to cause more troubles for me or do you think otherwise? (Information and knowledge gap)</p>	<p>of this dialysis centre was in the Abakaliki I would have been able to go on the machine at least twice in the last two month; so....distance is actually an issue here (Greatest challenge)</p> <p>Another issue is being able to take permission all the time from my employer for my treatment. Sometimes, I wake up some days extremely tired and feel like not doing anything because of the weakness in my body but I have no choice as I have to be serious with my job if I must keep</p>	<p>for me that is the only positive experience (Positive experience)</p> <p>The other experience I have had is the experience of the level of care my wife and other family members have offered me in the course of this condition, being there to offer words of encouragement and helping me in doing things I would normally have done on my own has been positive for me (Positive experience)</p> <p>I don't like talking about my negative experiences in this condition. They are too horrible and distressing for me to talk about (Negative experience)</p>
--	--	--	---	---	---	---	--	---	--

			<p>distance on dialysis decision)</p>	<p>doctor. The doctors you know would always speak against patients taking herbal remedies, so telling them that would be wasting your time and you are making them see you as not taking any advice they give you especially regarding what you should eat and what you should avoid (Attitude towards herbal ingestion)</p>		<p>very well (Experience of care)</p> <p>Look, it's the only centre around here in the South Eastern part of this country and if you say because of the treatment you are not going to come here then you must be prepared to pay a lot at the private centres. Do not get me wrong, you will definitely get better treatment there but then the money is not there for me to embark on such. So, ...what do you do? Just get on with what you can</p>		<p>earning some wages and maintain my treatment and support to my family members (Other challenge)</p>	<p>I would like to ask you if there is any government aid for people who are suffering from this condition especially with respect to the interviews you have been having with us since the last couple of months now. After this your research what way can you use this research to help us because a lot of people are dying from this condition every day and it goes unreported because the government or the society generally doesn't care? (Interaction between interviewee and interviewer relationship)</p>
--	--	--	--	---	--	--	--	--	---

						afford for now (Impact of experience of care on dialysis decision)			
M	<p>No, not yet. It has been a nightmare for me to get a matching kidney yet. I have been through a lot in a bid to get the kidney that will match mine (Donor challenges)</p> <p>They are not ready because they think donating one of their kidneys is against their religious beliefs and also for fear of possibly dying even after series of explanations were given to</p>	<p>I did mean the option of buying a kidney from India possibly but that option has not been feasible as I would have had the surgery done if it was so easy to come by. There was one of the middle men who usually help people in buying kidneys who almost duped me of my money because he knows I'm desperately in need of the kidneys and he wanted to</p>	<p>I have been coming but not as much because of my efforts and the movements involved in my sourcing for a kidney donor. I have been able to attend dialysis only about eleven sessions since the last time we met. I would have attended up to say twelve or thirteen times but the last time I came here sometimes two weeks ago, there was no water for dialysis and by the next day, there was</p>	<p>Well,.....erm.....I have not completed the payment yet but its remaining just a little left for me to pay. It has not been easy though as I have had to sell off almost all I have in terms of property and even had to borrow from some of my friends in order for the procedure (Cost as challenge to transplantation)</p> <p>It has been a nightmare but I'm only struggling to survive and live as I don't want to die and leave my young family behind. The cost</p>	<p>My brother, it's difficult to believe when I tell you that I have been on this battle all alone in my life. I have never received a dime from anybody since I started this treatment. It's been a personal struggle without any financial support from any source. The issue of healthcare in this part of the world is very personal and since the government doesn't care about providing free and accessible healthcare to</p>	<p>No, like I told you the other day, I have no cultural inclination and even if I do, it couldn't affect or influence my decision to come here for dialysis. I do know the importance of dialysis for my condition and skipping dialysis is very detrimental to my health and that's why I do all I can to come here three times every week as per</p>	<p>To be honest with you the nurses and the doctors are wonderful and very nice. They treated me with respect and dignity and they always show empathy in their care (Experience of care)</p> <p>Certainly yes, but then without the money only the care you receive cannot guarantee your being dialysed. They are absolutely wonderful and above all</p>	<p>Certainly, the use of herbal remedy or concoction like you know is as old as our culture. In fact, it's part of the way of life of our people despite the advent of orthodox medicine. It is not good to take herbal remedies because you don't know the content and it doesn't have dosage. Taking herbal remedies when one has renal condition obviously is going to further cause</p>	<p>Definitely not being able to find the right donor for close to six or seven months now is a sad experience for me and my family. If only I have been able to find the right donor who is willing to donate I would have been a lot more hopeful in this condition.</p> <p>Coming here and seeing people who are at the point of death in their lives is also a negative experience for me and it's a common occurrence here and you are not able to help</p>

<p>them. In fact, one of them clearly said that donating one of his kidneys to me would mean that I would automatically change to him and he would be “two persons living apart in the same world”, just to use his exact word. That’s one of the issues with organ donation in this part of the world and it seems not much is being done actually to educate would-be donors on the importance of organ donation. So,.....it’s the issue of superstitious belief here and I have made series of efforts and even made</p>	<p>exploit my desperation to his financial advantage but God for my Indian doctor who helped to ensure he was arrested and handed over to the police over there (Donor challenges)</p>	<p>so much queue here that I couldn’t and I was to travel the following day, so I had to defer it until I returned back to Enugu (Dialysis service issues)</p>	<p>of the treatment has really taken a toll on my family as I have had to withdraw my two children from private school to join public schools and you know what that means but that’s not my major concern now (Resilience)</p>	<p>the people, everyone who is sick is actually on their own. I know you might argue that I was in government and as such should be given free money to go abroad for medical care, no I didn’t receive any financial assistance from anyone apart from the money I recently borrowed from my friends to enable me complete the payment for the transplant in the UK. Not even my current employer has offered any financial assistance towards my treatment. So,.....that’s our society and I’m not just talking about me but I feel generally that people with long term conditions such</p>	<p>the prescription and that’s why you can see that I don’t look like a dialysis patient in this part of the world (Culture as a non-issue)</p> <p>The needs of my family are there but they also need me to be alive, so we try as much as we can to forgo unnecessary expenses and save for my dialysis (Family need as non-issue)</p> <p>Usually, I don’t come down with the symptoms except at the initial stage after the diagnosis</p>	<p>the hygienic level of this place makes me to come here to avoid infection elsewhere (Experience of care)</p> <p>I don’t think I have had any positive experience in the last two months really because it has been a nightmare for me in securing or getting the right donor despite all the efforts I have put in. I still do hope I can</p>	<p>damage to already damaged kidneys and thereby worsening the condition. But you know its poverty and ignorance that lead some of our people to carry on with this even when they may have been educated on the dangers of doing that (View on herbal remedy)</p>	<p>because I don’t have the resources and I just wish I could help. I was here the other day and a lady was brought in dead because she couldn’t afford to come here for almost two months and her urea and creatinine level was extremely high. So,.....its distressing for everyone who come here regularly for dialysis. I just wish the government or philanthropists can do more to assist this kind of patients (Negative experience)</p>
---	---	---	--	--	--	---	---	--

	<p>monetary promises to encourage him to donate to me but he wouldn't. He turned down every offer that I have made insisted that he cannot give one of his kidneys. The second one cited religious belief as his main reason and that he wouldn't live with just one of his body organs ...he insisted that only God created him and any of his body organs and only him can ever take any part of it away and he would rather die than part with any of his body organs. He also felt that donating would limit his life span and he doesn't</p>				<p>as this shouldn't be left to deal with the situation on their own. It's not an easy situation just like cancer. I would wish the government and charity organisations can do a lot more to assist people living with this condition (Lack of support)</p>	<p>but since then I have always tried to go on dialysis as recommended you know my case is particularly exceptional because of the cause of my kidney failure which like you know is PKD. I can't afford to come down with the symptoms if my urea and creatinine levels accumulate so high. It will weaken me and that would mean I won't be able to do anything and I can't just afford that right now or anytime. I need to be fit to be able to move around and source</p>	<p>find soon (Positive experience)</p>	
--	---	--	--	--	---	--	---	--

	<p>want to die early and leave his family behind to suffer despite all promises or offers made to him (Issues with donor)</p> <p>Waiting to find the right donor has been like hell for me. It has been full of uncertainties and anxiety as I don't know when and how to go about it anymore. I just wish there's anything else I can do but erm..... I don't know and I'm confused.</p>					<p>all that I need to go for the transplant (Fear of symptoms as a factor)</p> <p>The distance issue is there but it has never deterred me or affected my coming here because I'm very determined to live and never to cave in to the stress orchestrated by this condition in my life (Distance as non-issue)</p>			
--	--	--	--	--	--	--	--	--	--