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# Walden University

College of Health Sciences

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### Patience Eze

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Walden University 2017

### Abstract

Chronic Kidney Disease Awareness and Quality of Care in Abuja Nigeria

by

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MLS, North Carolina Central University, 2007MIS, North Carolina Central University, 2004MPA, University of Lagos, Nigeria, 1991

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health

Walden University

August 2017

#### Abstract

Chronic kidney disease (CKD) is a non-communicable progressive disease that can lead to kidney failure or end-stage renal disease. In Nigeria, many people do not have access to health care due to extreme poverty, which means that those suffering from diabetes or high blood pressure or kidney disease, that have been identified as the two main risk factors, may not know their health status. The purpose of this phenomenological study was to explore the level of CKD awareness among Nigerians and if cultural beliefs affect individuals' health seeking behaviors because of the diverse nature of the Nigerian population. The protection motivation theory provided the framework for the study. Data were collected through semi-structured interviews with 14 participants, and data analysis included traditional coding. Findings indicated that CKD awareness in Nigeria is low. The social change implication is that the findings may be used to increase awareness of the CKD mortality and morbidity rate in Nigeria to facilitate the development and implementation of health policies that could lower the morbidity and mortality rate of CKD.

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#### Dedication

This is for every girl or lady who is depressed or demoralized because she has been told that she is not intelligent or good enough, academically or otherwise. You **must not** allow anybody to mold your destiny because you can be whatever you want to be in life. I did it by turning the psychological abuse by a man I loved and married into a new strength by not allowing his psychological abuse to define me or who I could be. Rather, I remained focused even in the midst of difficulties to achieve all that I wanted to academically. And today by the special grace of God, I have three master's degrees and a doctoral degree.

It was not easy or funny, but I did it and you can too. YES YOU CAN!!!

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#### Chapter 1: Introduction to the Study

Chronic kidney disease (CKD) is a progressive disease that cannot be reversed and can lead to kidney failure or end-stage renal disease (ESRD) if it is not detected and treated early (Centers for Disease Control and Prevention [CDC], 2012). Because of its chronic nature and potentially serious complications, individuals suffering from CKD experience poor quality of life, financial burden, and significant life changes that also affect their families (Nagelkerk, Reick, & Meengs, 2006; Naicker, 2003). In Nigeria, CKD is devastating due to extreme poverty, poor accessibility to health care, and a diverse population that makes standardized health education difficult if not impossible because of differences in culture, values, and beliefs. In this study, I explored the effect of cultural beliefs and lack of awareness among individuals with family history of diabetes, hypertension, or kidney disease and individuals who have gone through renal This assisted in determining whether cultural beliefs and the lack of replacement. awareness about CKD and its preventive measures were barriers to screening for diabetes, hypertension, and kidney disease for prevention, and whether cultural beliefs affect individuals' health care seeking behaviors. According to the National Institutes of Diabetes and Digestive and Kidney Diseases ([NIDDK], 2014) and CDC (2014), it is only through screening that individuals will know whether they have kidney disease because it has no signs or symptoms. Screening and treatment of diabetes and hypertension are cheaper than treating kidney disease (Kidney Consultants International [KCI], 2012). Understanding the patient's cultural beliefs and effective patient-provider

communication could enable the provider to counsel patients on the need to control the risk factors of CKD and to screen for renal damage (Murphree & Thelen, 2010).

Kidneys are not only part of the urinary tract system that filters and removes waste products, including excess fluid from the blood through urine, but also play the important role of controlling blood pressure, bone maintenance, and production of red blood cells to provide oxygen for the entire body (CDC, 2012). Individuals suffer from CKD when their kidneys can no longer filter blood properly due to damage to the kidney, which leads to a buildup of wastes in the body that can lead to other health problems, such as cardiovascular disease (CVD), bone disease, and anemia (CDC, 2010). Diabetes, which happens because of high blood sugar level, and high blood pressure or hypertension have been identified as the two main causes (about two-thirds) of CKD cases worldwide (National Kidney Foundation, 2013). Other causes of CKD identified by the CDC include disorders that are inherited, like malformations, autoimmune disorders, obstructions, polycystic kidney disease, and recurring urinary tract infections. HIV/AIDS has been identified as one of the factors that are fast becoming a major cause of kidney disease in Nigeria (KCI, 2012).

At an interactive forum/awareness creation event by medical experts to mark the 2013 World Kidney Day in Nigeria, Bamgboye (2013a), the head of dialysis and transplant unit of St. Nicholas Hospital Lagos attributed the increase in CKD prevalence in Nigeria to environmental chronic infections and various unhealthy life choices.

According to Bamgboye, these include malaria, hepatitis B or C if not found early and treated, indiscriminate use of herbal concoctions, bleaching creams and soaps, alcohol,

hard drugs and smoking, exposure to hydrocarbon solvents, and low socioeconomic status, among others. The complication in using herbal concoctions is that they may contain metals and substances that can damage the kidneys and most of the time people do not know the contents of the concoction they take. In addition, bleaching creams and soaps may contain a level of mercury that may injure the kidneys (KCI, 2012). Exposure to lead found in paint and the use of unsterilized sharp instruments could result in the transmission of HIV and hepatitis, which will ultimately affect the kidney (Osinfade, 2008). Bamgboye stressed that urgent steps must be taken so that more Nigerians will not come down with CKD and ESRD.

Cultural appropriate prevention is critical because most people who cannot afford dialysis or kidney replacement are either sent home to die or take the no-treatment option until they die. In addition to the health consequences resulting from CKD, Bamgboye (2003; 2013b) pointed out that it has an adverse economic effect on individuals and their families. Apart from the high cost of renal replacement that makes it unaffordable to many, late presentation, inadequate renal replacement therapy and poor literacy level are factors that contribute to high morbidity and mortality from CKD in Nigeria (Arogundade & Barsoum, 2008). Prevention seemed to be the only feasible long-term option.

In this chapter, I cover the background of CKD as a global problem and examine how it affects Nigeria. The problem statement section addresses the present situation of CKD in Nigeria and why the problem is a significant issue that needs to be addressed. I explained the purpose of this study and the meaning of CKD from participants' perspectives, and list the research questions that guided the study. I also describe the

theoretical framework, significance, and the social implications of the study. Finally, I present the definitions of operational terms, assumptions, scope, and delimitations of the study.

#### **Background of the Problem**

CKD has been identified as a global non-communicable health problem that has continued to kill many people worldwide silently (Chen et al., 2010; Couser & Riella, 2011). People die from diseases such as CKD that can be prevented or properly treated or managed if they are caught early. For instance, over 20 million U.S. adults may be suffering from CKD without being aware of it (Burton, 2012). According to the CDC (2012), kidney disease is the ninth leading cause of death in the United States with diabetes and CVD accounting for 72% cases of kidney disease. The CDC stressed that the trend will continue if there are no effective and aggressive health interventions. Across Central America, CKD has been identified as the cause of death of about 20,000 over the past decade and a leading cause of deaths among men in hospitals in El Salvador, with Chichigalpa, Nicaragua identified as one of the hardest hit places in the world (Murphy, 2014).

In United Kingdom (UK) in 2008/2009 1,739,443 people were identified through the renal registry as patients with Stages 3-5 CKD by the National Health Service (NHS) (2010), and the actual prevalence could be higher. Total expenditure in England on renal problems between 2008 and 2009 was 1.3bn UK pounds. Data from the 2009 Australian Bureau of Statistics ([ABS], 2011) showed that the rate of premature death from CKD is very high in Australia. Statistics showed that CKD was the ninth leading cause of death

in Australia, with about 50 people dying from kidney failure daily (ABS, 2011). About 1.7 million adults suffer from mild kidney disease in Australia who could end up with kidney failure or CVD, and morbidity rate and cost of CVD disease and diabetes are said to be multiplied as a result of CKD (Kidney Health Australia, 2009). According to the CDC (2014), people who suffer from CKD are 16 to 40 times more likely to die before getting to ESRD. Women of child-bearing age who have been through renal transplant were always not encouraged to plan a family because of the possible adverse effects on renal grafts and potential offspring (Willis et al., 2000).

In 2011, the United Nations (UN) High Level Meeting on Non-Communicable
Diseases (NCDs) designated renal disease as an important NCD that is a burden and a
threat to economic and social developments globally. A report by Chronic Kidney
Disease EpiCast (2013) indicated that there will be an increase of 69.5 million cases of
CKD in 2012 to 81 million in 2022 across the United States and 5EU because of the
increase in hypertension, diabetes, and obesity conditions. Because of its asymptomatic
nature at an early stage, CKD is under-diagnosed, and as a result, many people suffering
from it are not aware (NKKD, 2012), which compounds the problem. It is only when the
function of the kidney becomes significantly impaired that the signs and symptoms may
become apparent (Mayo Clinic, 2012), and treatment may be ineffective.

The situation in North African countries like Morocco, Algeria, Tunisia, Libya, and Egypt, is not good. Investigators reported that the annual incidence of ESRD in this region is between 34 and 200 per million people, with respective prevalence of 30 to 430 patients per million populations (Rayane & Haddoum, 1998; Kamoun et al., 1997).

Remuzzi (2001) revealed that there is a higher prevalence of acute CKD in developing countries like Nigeria than in the developed world, and 5-7% of the world populations suffer from CKD (Couser, Remuzzi, Mendis, & Tonelli, 2011).

In Nigeria, there are 36 states with a federal capital territory in Abuja. The health system in Nigeria has three levels, primary, secondary, and tertiary that corresponds with the level of supervisory government, federal, state, and local. Nigeria is the most populous country in Africa with an estimated 170,123,740 people according to the CIA FactBook (2012). About 60% of the population lives below the poverty line, and life expectancy of women and men is 55/49 years respectively (CIA FactBook, 2012). Even though Nigeria is an oil producing country, which generates huge revenue, many people live in poverty because of unequal distribution of wealth. There is a relationship between poverty and ill health (Townsend, Phillimore, & Beattie, 1988) since individuals who live in very poor areas have less access to health care because they are less likely to have health insurance.

Addressing a health problem such as CKD in Nigeria is challenging because there are 250 ethnic groups and 380 languages, and the cultural and religious beliefs are very diverse (CDC, 2012). The Federal Ministry of Health in Nigeria does not provide financial allocation that could enable the chronic disease department to create awareness through community health education on the importance of checking kidney health (A. Daniel, personal communication, February 14, 2014). The 2016 federal budget indicated that only one million naira (N1, 000,000.00), which was about \$3,174 at the official rate

of (N315 to \$1 as of October 2016) was budgeted for non-communicable diseases department by the Federal Ministry of Health.

There are 15,000 new cases of ESRD annually that require dialysis in Nigeria, which also has its own complications (Nathan Kidney Foundation, 2013). According to Onifade (2008), in a Nigeria tertiary health center the mortality rate from CKD within three months of diagnosis is 90%, which represents about 11.4% of all medical admissions. Onifade further stated that less than 1% of the patients can afford renal transplant.

The financial burden for treatment and renal replacement in Nigeria is so great that some CKD patients have resorted to using social media to appeal for donations from the general public to enable them to go through dialysis or to afford kidney replacement (Adebanjo, 2014; Aluma, 2013; Umukoro, 2013). Out of 50,000 CKD patients who should be on dialysis only 1,000 are on dialysis because of the cost (Bamgboye, 2013c). Table1 shows the breakdown of annual cost of kidney management, continuous ambulatory peritoneal dialysis (CAPD), and renal transplant and immunosuppressant in Nigeria (KCI, 2012) where the per capita income is \$2,600 (CIA FactBook, 2012).

Table 1
Annual Cost of Kidney Management and Renal Transplant in Nigeria

Average Annual Costs of Kidney Management	Naira ( <del>N)</del>
For two times per week (hemodialysis).	2,388,168
For three times per week (hemodialysis)	3,255,368
For Continuous Ambulatory Peritoneal Dialysis (CAPD)	3,699,925
Cost of Renal Transplant and Immunosuppressant	Naira ( <del>N)</del>
Cost per year	2,401,340
Cost for two years	4,802,680

*Note*: Naira is the Nigerian currency and the average exchange rate for \$1 to the Nigerian Currency in 2012 when KCI provided these figures was \$\frac{N}{164}\$. In 2017, the average bank exchange rate for Naira to \$1 was \$350, while the parallel (black) market rate was between N400 and N500. The 'back market' rate is what most Nigerians have access to because of the cumbersome process involved in accessing it through the banks. This means that the figures above would be more than triple what is listed above because of inflation and Naira devaluation. Source: KCI (2012).

In an economy that is 'technically' in recession, according to the Nigeria Finance Minister, Kemi Adeosun (2016), the average Nigerian cannot afford the average weekly cost of dialysis sessions and immunosuppressant drugs. These drugs are not readily available at local pharmacies and have to be imported for patients (KCI, 2012). The current depreciation of the Nigerian currency weakens it against other major currencies, and as a result, access to these drugs is almost impossible for most post-transplant patients in Nigeria. Because these imported drugs are required to be taken for life in combination with other drugs, the cost of renal transplant is compounded according to

KCI (2012). The Nigerian government does not subsidize such drugs for survivors of renal transplant, which could contribute to the death of many average Nigerians who end up dying from the disease because of lack of treatment.

In a study that considered the prevalence of CKD in Nigeria, Odubanjo,
Oluwasola, and Kadiri (2011) noted that previous investigators under-estimated CKD
prevalence because only individuals listed on admission or treatment registration records
were considered. Therefore, the number of individuals without access to hospital care
was omitted in these studies. The gross under-estimation was compounded because
Nigeria does not have regional or National CKD or renal registries. Odubanjo et al.
pointed out that when patients without access to tertiary care were included in their study,
the burden of CKD in Nigeria was significantly higher than had been reported (between
1.6% and 12.4%).

In the current study, I examined the level of CKD awareness in Nigeria, and also explored the cultural beliefs of the participants to determine whether they affect the healthcare seeking behaviors of individuals in Nigeria and how. If individuals do not know about CKD and its risk factors, or do not know their kidney condition, they will not know what they can do to make life changes that can prevent CKD. Therefore, it was important to find out whether the population, especially individuals with a history of diabetes or hypertension in their families, is aware of CKD, its risk factors and outcomes, and preventive measures. Diabetes is responsible for about 20-40% of CKD cases, and national hypertension prevalence was put at over 11% (Kidney Transplant Doctors

[KTD], 2012), about 85% of ESRD patients have hypertension, which causes the acceleration of renal disease (Alebiosu, 2003).

Bamgboye (2013d) pointed out that one out of every five Nigerians has hypertension, although many people suffering from hypertension are not aware of their condition. This means that they are not receiving any treatment, which could lead to complications like CKD.

#### **Problem Statement**

The estimated number of CKD cases in Nigeria is between 50,000 (Bamgboye, 2013d) and 60,000 annually with only 27 dialysis units for an estimated population of 120,000,000, and fewer than 50 hemodialysis are done locally (KCI, 2012). Failure to detect CKD early can lead to CVD, which complicates CKD (Couser et al., 2011). Currently in Nigeria, about 36.8 million people are CKD patients who need either the expensive dialysis or kidney transplant process according to Bamgboye (2013e). Many people in Nigeria cannot afford this due to the economic crisis. This situation has led to the death of many CKD patients (Gunber, 2013).

Nigeria is a multi-ethnic country with two main religious groups and diverse cultures. Cultural practices, such as religious beliefs and traditional beliefs affect the health choices individuals make, depending on how their beliefs influence their perception, attitude, and management of CKD disease or other health related problems (Onyeabochukwu, 2007; WHO, 2007). Nigerians' upbringing and environmental orientation play a vital role in health choices, such as, seeking health information or basic primary care that could assist in early detection of diseases.

Although many Nigerians are coming down with kidney failures and there is an increase in the mortality rate from CKD (Bamgboye, 2013f), very little is known about CKD in Nigeria. This situation was confirmed by a study at the Ogun State University Teaching hospital that addressed the level of awareness of the people about CKD. Out of 130 people who participated in the study, 68% were not aware of CKD and its risk factors, and CKD was the third reason people were medically admitted at the teaching hospital (Alebiosu, 2002). There is currently no literature on cultural or religious beliefs Nigerians hold about CKD, and it is not known whether Nigerians can access accurate and culturally appropriate information for CKD knowledge and awareness. Therefore, there was a need for study in this area to explore these factors because appropriate CKD education with thorough understanding of cultural beliefs of the target population could lead to increased screening and prevention.

## **Purpose of the Study**

The purpose of this study was to examine the level of CKD awareness among individuals with family history of diabetes, hypertension, or kidney disease, and to explore the effect of cultural beliefs on awareness and knowledge of CKD in Nigeria. Targeting at-risk individuals was necessary because diabetes and hypertension are two prominent risk factors, with 9.1% to 29.9% of ESRD cases in a developing country like Nigeria being caused by diabetes and 13% to 21% by hypertension (Barsoum, 2006). According to Barsoum (2006), the prevalence of diabetes will double by 2030 in the developing world, and about 70% individuals suffering from ESRD will come from this part of the world. A recent blood alcohol content screening conducted by the Lagos State

Ministry of Health (Obinna & Ojomoyela, 2016) among 600 commercial drivers in Ikeja area of the state revealed that most of them suffered from hypertension and diabetes.

The objective of this study was to explore the meaning of CKD by individuals who have successfully been through kidney transplant, including their family members based on their personal and family experience.

#### **Research Questions**

The study was guided by the following research questions:

- 1. What level of awareness and knowledge do individuals at risk have about CKD in Nigeria?
- 2. What is the perception of CKD of individuals who have gone through renal replacement?
- 3. How would culture and personal healthcare seeking behaviors affect CKD awareness in Nigeria?
- 4. What educational programs about CKD, if any, are in place in Nigeria to inform healthcare providers and the general population about CKD and its complications or consequences?

#### Theoretical Framework

According to Crosby (2006), theories provide an understanding of verifiable phenomena by organizing relationships into a clear picture, provide a starting point for making future predictions, and also guide research question. Some theories of behavior include the theory of reasoned action (TRA), which is a behavioral theory that postulates that all behaviors are based on intentions, and provides a link between behavioral intent

and attitudes and subjective norms; the health believe model (HBM) was developed in the 1950s by a group of researchers who were trying to understand why many people did not participate in disease prevention and detective programs (Sharma & Romas, 2012). The HBM is one of the most commonly used theories in health promotion and health education (Glanz, Rimer & Lewis, 2002, National Cancer Institute, 2003); and the protection motivation theory (PMT) of Rogers (1983), which is the theoretical framework for this study.

PMT posits that adaptive and maladaptive coping with a health threat is possible after the health threat (perceived vulnerability or susceptibility and perceived severity) and coping skills (response efficacy and self-efficacy) have been appraised. The threat appraisal of the PMT could enable individuals with a history of CKD, diabetes or hypertension to evaluate the possibility of being vulnerable for CKD and the level of severity if the individuals suffer from CKD. The coping appraisal includes response efficacy that allows individuals to evaluate the effectiveness of screening in preventing CKD if the individual proactively screens for diabetes or hypertension as recommended by his or her healthcare providers.

Self-efficacy makes the individuals believe that they can adequately execute recommended course of actions or responses. PMT can be used in enhancing healthy lifestyles, enhancing diagnostic health behaviors, and preventing disease (Boer, 1996).

#### **Nature of the Study**

The nature of the study was qualitative because of its discovery-oriented approach (see Rudestam & Newton, 2007). I explored the reality of phenomenon of the interest to

enhance understanding of the situation and the meanings and values attributed to it by individuals (see Hewitt-Taylor, 2001). According to Creswell (2009), the qualitative approach makes it possible for the investigator to have a better understanding of people's attitudes, behaviors, value systems, concerns, motivations, aspirations, culture, and lifestyles. I employed a phenomenological design to focus on understanding a phenomenon from participants' lived the experiences through in-depth interviews and conversations. This included a detailed description of the feelings, experiences, knowledge, and beliefs of individuals with a history of diabetes and/or hypertension. The study participants were adults who were residents of Abuja, the Federal Capital Territory (FCT) of Nigeria with family history of hypertension, diabetes, or CKD. Data were collected through interviews and field notes to describe their lived experiences, socioeconomic status, feelings, and views of participants.

### **Operational Definitions**

Asymptomatic: The lack of signs and symptoms showing an individual is suffering from a disease.

Cardiovascular disease: Conditions that affect the proper functioning of the heart and the blood vessels, caused by high blood pressure against the walls of the arteries when the heart is pumping blood, and high cholesterol (CDC, 2013) when blood vessels have been blocked by fatty deposits making it difficult for the arteries to receive enough blood flow (Mayo Clinic, 2013).

Concoction: A mixture of ingredients, such as, herbs, powdery substances, and others that are dissolved into liquid form for ingestion.

Culture: The way of living of a group of people that distinguishes that group from another (Hofstede, 1984).

Diabetes: The condition when the blood glucose levels are excessively high (KCI, 2012). End-stage renal disease: The final stage of kidney disease when the kidneys of an individual no longer able function well enough to remove waste and excess water from the body (National Institutes of Health, 2013).

Filter blood: Millions of tiny filters in the kidneys that are called glomeruli that clean the blood by separating the blood from the wastes and excess.

Healthcare seeking behavior: Any action undertaken by individuals who perceive they have a health problem for finding an appropriate remedy Tipping and Segall (1995).

Hypertension: Alternative name for high blood pressure, which refers to a situation in which the blood pressure is higher than normal amount (KCI, 2012).

Morbidity rate: The frequency at which a particular disease occurs in a population.

Prevalence: The number of existing cases of a health condition in a population.

*Risk factors*: Attributes or characteristics that increase the chances of an individual developing the disease (World Health Organization, 2013).

Socioeconomic status: The social class of an individual or group that is measured by a combination of education, income and occupation (American Psychological Association, 2013).

### Assumptions

The study was based on two assumptions. One was that using open-ended questions would enable participants to respond truthfully regarding their personal perspectives and experiences. Participants had the freedom to respond to questions in a way they felt was appropriate based on the questions' scope given and the participants' perspective. Secondly, I assumed that individuals with family history of diabetes or hypertension or CKD would be willing to participate because they had witnessed the effect of these diseases on their family members and families.

# **Scope and Delimitations**

The scope of this study involved exploring the level of CKD awareness among the population of Abuja, Nigeria, and the effect of cultural beliefs on healthcare seeking behaviors. I did not cover the patient-provider communication while exploring the level of CKD awareness and the effect of cultural beliefs on awareness and knowledge of CKD in Nigeria because of the difficulty in determining whether there was effective communication. The nature of the study did not allow me to explore the level of communication to determine whether the provider was communicating with his or her patients in a culturally appropriate manner during counseling about risk factors or screening. Also, with over 250 ethnic groups, it was not realistic for me to recruit from all groups in Nigeria.

#### Limitations

The first limitation was that in a qualitative study, the researcher is the primary data collection instrument and analyst, which can sometimes make it difficult for the

researcher to understand the phenomenon from the participants' perspective because of possible bias. I kept an open mind about participants' perceptions and views and ensured that participants' values and behaviors were respected as they contributed their knowledge and experience to the study. Also, I made a conscientious effort to inform each participant about my personal experience with CKD because I lost my father to CKD. It is important for investigators to report any personal and professional information that may affect the data collection, analysis, and interpretation (Patton, 2002). The study was further limited by the fact that Nigeria constantly had power outages and network failures that affected data collection and management. I was able to overcome this limitation by having paper copies of the computer screen-shots in the same order as they appeared on the computer, which enabled me to continue with my work even when there was a power failure or connectivity problem.

## Significance of the Study

This qualitative study provided a better understanding of the association between awareness and CKD in Nigeria and how cultural or religious values influence how individuals respond to health issues like CKD. The study added to the current literature on the global burden of CKD, especially in developing countries like Nigeria. Also, there was need to identify what prevents the target population from seeking health care or screening for diabetes and hypertension, and from taking proactive measures for CKD prevention.

The knowledge gained from this study may help the target population and healthcare providers in understanding how early prevention and detection measures could

reduce CKD prevalence and the financial and economic burden in Nigeria. The results of this study may also serve as a catalyst for the development of culturally appropriate standard healthcare education programs by the Ministry of Health that could help in increasing CKD awareness and prevention in Nigeria. The financial and health-related burden caused by CKD in Nigeria could be reduced if people are aware of the risk factors of CKD, complications, and other consequences because they may be more likely to take proactive measures to prevent it from happening. Results also provided insight into the critical need for a centralized renal registry for appropriate planning, CKD management, and treatment for improved quality of life and health outcomes of people suffering from CKD and ESRD in Nigeria.

## **Summary**

In this chapter, I looked at CKD as a global problem and the situation in Nigeria where many people have died from CKD because they could not afford the expensive treatment or kidney transplant due to poverty. Very little is known about CKD in Nigeria, yet the prevalence is high. I also explained why CKD is a significant problem that requires urgent attention in Nigeria.

Chapter 2 provides a literature review on CKD and presents the research strategies.

### **Chapter 2: Literature Review**

Chronic kidney disease (CKD), also known as chronic renal disease, is a condition that is characterized by a gradual loss of kidney function over time, and when it progresses can lead to kidney failure (National Kidney Foundation [NKF], 2013). In Nigeria, deaths from kidney-related diseases are more than those from malaria and HIV/AIDS (Bamgboye, 2013g). CKD is a quiet disease because it does not have noticeable signs and symptoms that are apparent to the patient at the early stage of the disease. Studies in some parts of Nigeria indicated that 10 people out of every 100 will have CKD, and in some parts, one out of every five people will have CKD at some point in life according to Bamgboye (2013h). The rate of CKD prevalence in Nigeria is between 8% and 45%, depending on the region and population that was studied (Abioye, Akinsola, & Ezeoma, 1995; Alebiosu & Ayodele, 2005; Nwankwo, Bello, & El Nahas, 2005).

The financial cost for treating CKD and renal replacement in Nigeria is very high, which makes it difficult for many people to have access to care because of poverty (Couser et al., 2011). Lack of access to health care and proper management can adversely affect the quality of life of individuals suffering from CKD because of its possible complications and chronicity. Even the few who can afford CKD care in Nigeria may not have access to it due to unavailability of care, poor management, frequent labor action, and Islamic terrorist attacks (Ahmad, 2014; Alebiosu, 2006;

Bamgboye, 2013h; & Nossieter, 2014), which makes the situation in Nigeria very complex.

Many researchers have studied the prevalence of CKD in Nigeria and the risk factors (Alebiosu, Ayodele, Abbas, & Olutoyin 2006; Bamgboye, 2003; Barsoum, 2006; Odubanjo et al., 2011; Okoye, Oviasu, & Ojogu, 2011; Ulasi & Ijoma, 2010), but none have looked at the effect of culture on health to better understand how cultural beliefs can affect CKD prevalence and awareness. The intention in this study was to examine the level of CKD awareness among individuals with family history of diabetes, hypertension, or kidney disease, including individuals that have gone through renal transplant. Also, I explored the effect of cultural beliefs on the health seeking behaviors of individuals in Nigeria. Nigeria has different ethnic groups, and each group has its own cultural practices that influence individuals' attitudes about health, illness, medical care, consequences of medical treatment, and decision-making processes (McLaughlin & Braun, 1998). Chapter 2 provides a literature review of current studies about CKD. It also provides a detailed review and discussion of promotion motivation theory (PMT), and how it has been applied in previous studies.

#### **Literature Search Strategy**

To conduct a thorough review of current articles for reference, I used different sources, including Walden online library and a general Internet search. The databases I accessed included, MEDLINE, Academic Search complete, CINAHL plus, and ABI/INFORM complete. Key words include kidney disease; renal disease; chronic kidney disease; renal transplant; dialysis; ESRD; developing countries; Nigeria; cultural

beliefs; and *awareness* to find English studies published up till August 2016 that addressed kidney disease worldwide, African regions, and particularly Nigeria. I gathered more information from general Internet search, symposia, newspaper publications, different books, kidney foundations websites, and direct communications.

#### **Theoretical Foundation**

Researchers use theories in qualitative studies to give a broad explanation of attitudes and behaviors (Creswell, 2009). Most theories used in health promotion research are phenomenological theories that specify which variables are involved in health-related behaviors and how the variables interact to determine the behavior (Crosby, 2006). Such theories include the TRA that predicts behavioral intention which is a compromise between stopping at attitude predictions and predicting behavior by separating behavioral intention from behavior (Plotnikoff, Lippke, Courneya, Birkett, & Sigal 2008). TRA could also be used to understand the relationship between attitudes, intentions, and behaviors. The HBM is another theory that is based on the premise that individual's health behavior depends on their personal beliefs about a disease (Graham, 2002). I used the PMT, which is also a behavior theory, developed by Rogers (1983) as a guide for this study.

In a multi-ethnic and multi-cultural country like Nigeria, health behaviors and attitudes that are acceptable in one culture may not be acceptable in another because of different cultural and religious beliefs. In addition, individual cultural practices affect individual health's decisions, which may assist in disease prevention or increase its prevalence (Onyeabochukwu, 2007). Roger's (1975) PMT originally provided a lens for

understanding fear appeals with the assumption that when individuals' well-being is threatened, they will be motivated to take action to prevent or reduce the threat. It is the fear of a health threat that could give an individual the impetus to assess the severity of the threat and the possibility of being vulnerable. Also, an individual must perceive himself or herself as being capable of addressing the threat in recommended way or ways (Eckart, 2011; Jones, 2010; Lennon & Rentfro, 2010). In a multi-cultural country like Nigeria, it is the individual's cultural meaning of health, illness, and disability; and the individual's perception of being able to address the health threat that could encourage him or her to take recommended action (Ravindran & Myers, 2012).

In 1983, Rogers included the persuasive communication component that emphasized on cognitive processes, with each process appraising communication information about noxiousness of health threat, vulnerability, or efficacy. According to Rogers (1983), the cognitive appraisal for each communication variable could either facilitate or not facilitate attitude change. Figure 1 shows a schema of Rogers (1983) protection motivation theory. It is the result of the cognitive evaluation that could either lead to an adaptive response, which is protection motivation, such as screening for CKD risk factors, or a maladaptive response, such as not screening for risk factors. Not screening for CKD risk factors could mean that the chance for early detection of CKD and treatment has been missed. The protection motivation, which is the individual's willingness to perform the recommended coping response based on his or her response efficacy and self-efficacy, is what arouses, sustains, and directs protective health behavior by individuals (Rogers, 1975). An individual's self-efficacy is influenced by actual

experience, vicarious experience, and culturally appropriate verbal persuasion (Bandura, 1977).

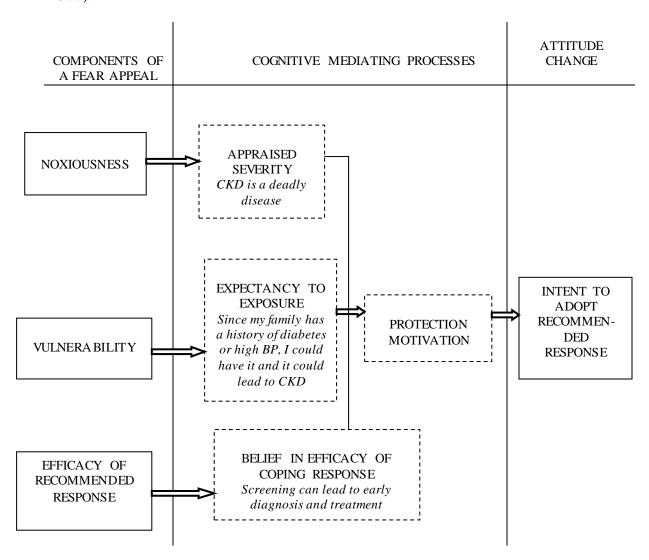


FIGURE 1. Schema of the protection motivation theory Components of fear appeal, its cognitive mediating processes, and attitude change. Source: Rogers (1983).

PMT also communicates the boomerang effect where persuasions and intentions to act could be very low because individuals do not have any effective way to protect themselves when there is health threat (Keller, 1999). This means that protection motivation may not be aroused if CKD is not appraised by individuals as severe, a health threat, or that no action can be taken to prevent it. In such situations, individuals could resort to denial, avoidance, and wishful thinking (Roser & Thompson, 1995).

Some of the major advantages of PMT include providing a more analytical conception of the constituent components of a fear appeal, and emphasizing cognitive rather than emotional, mediational processes (Rogers, 1975). When compared to other theories of health behavior, PMT suits the context of health behavior because when protection motivation is stimulated, it can generate a change in intentions or behaviors, such as screening for CKD risk factors (Grindley, Zizzi, & Nasypany, 2008). In addition, PMT is a comprehensive health communication theory that can be broadly applied to any situation that involves threat (Rogers & Prentice-Dunn, 1997). PMT can be used as a tool to predict that individuals' cultural beliefs about CKD can be changed if they perceive CKD to be severe, that they are vulnerable, can effectively screen for risk factors, and that screening can help to prevent CKD and its complications. Focusing on the PMT threat variables and the consequences of not screening for the risk factors and CKD could stimulate protection motivation, which in turn could increase awareness of CKD, including its risk factors, complications, and preventive measures.

PMT has been applied in studies targeting reducing alcohol use during pregnancy, enhancing healthy lifestyles, and preventing disease. For example, Courneya and Hellsten (2001) used PMT to determine that persuasive communications could arouse protection motivation when individuals perceive a health threat. Colon cancer prevention was shown to be a motivation for individuals who participated in their study and perceived that colon cancer disease was severe, that they were vulnerable, and that exercise was an effective way to reduce or prevent them from having colon cancer. Conversely, participants who perceived colon cancer disease as not severe were not motivated to exercise as a means for colon cancer prevention. Courneya and Hellsten concluded that when individuals perceive a threat, they are more willing and motivated to change their behavior if they perceive the recommended coping strategy is effective in reducing the threat (Rogers & Prentice-Dunn, 1997).

In a qualitative review of health communication campaigns for alcohol prevention targeting pregnant women or women attempting to become pregnant, Cismaru, Deshpande, Thurmeier, Lavack, and Agrey (2010) determined that PMT was used as a theoretical framework to create effective communications. The campaigns focused on the PMT threat variables of severity and vulnerability in emphasizing the negative consequences of taking alcohol during pregnancy to create increased perceived severity and vulnerability. Self-efficacy cognition gives the target audience the confidence that they can stop alcohol consumption during pregnancy. The outcome of most of the campaigns was increased awareness and an increase in the number of women who stopped alcohol consumption during pregnancy. A pretest-posttest and a three-month

follow-up survey showed that 56% of participants were abstaining from alcohol or drinking less after 18 months (Masis & May, 1991). This shows the effect PMT principles have when they are entrenched in health communication efforts.

Bennett, Rowe, and Katz (1998) also studied PMT to see whether individuals would adhere to preventive medication after considering vulnerability to asthma, its severity, and costs and benefits of doing so. The study revealed that individuals who perceived asthma as a chronic health threat that could be severe, and the probability of an episode that could interrupt their lifestyles; strongly adhered to recommended preventive measure. There were significant associations between levels of reported adherence and measures of severity, and vulnerability according to Bennett et al.

Grindley (2008) explored the use of PMT as a screening tool in a sample of individuals with orthopedic conditions to predict patient adherence behavior. According to Grindley et al., fear could be aroused in orthopedic rehabilitations from the noxious experiences of pain that could persist or worsen, loss of mobility, prescription for rehabilitation or that the situation could lead to other health complications. The coping appraisal depends on the individual's confidence that he, or she can complete the prescribed sessions and exercises, and that the prescribed treatment will provide assistance. Perceived severity of injury, perceived vulnerability, perceived treatment efficacy, and perceived self-efficacy were measured. It was shown that participants with high adherence to recommended behaviors had greater self-efficacy than those with low adherence. Also, there was a strong relationship between higher self-efficacy and higher treatment efficacy, and lower self-efficacy was related to a great number of barriers. The

finding confirmed the assumption of PMT that behavior and attitudes can be changed through a cognitive mediating process (Rogers & Prentice-Dunn, 1986; Sturges & Rogers, 1996), when fear is aroused by stimuli (Rogers, 1975). Change in health behaviors and attitudes for healthy lifestyles by individuals could produce the following health benefits in Nigeria:

- increasing the number of people with CKD who can live longer and improving quality of life in Nigeria,
- increasing the number of people in Nigeria with CKD who are aware that they
  have the disease,
- increasing the number of individuals in Nigeria with diabetes and hypertension
  who are aware that they are at risk for CKD and therefore should take proactive
  actions, such as screening for CKD for early identification and intervention,
- reducing the morbidity rate in Nigeria as a result of CKD, and
- reducing the number of new cases of kidney failures in Nigeria.

## **Review of Literature**

This review addresses current literature on CKD as it affects developed and developing countries, particularly Nigeria. I cover risk factors that are directly associated with increasing rates of CKD in Nigeria where 5% of the adult population, according to Bamgboye (2013i), is suffering from some kind of kidney problem and associated consequences. I also cover traditional cultural beliefs and health behaviors; the global

effect of CKD on economies, health care systems and individuals; current CKD care and management in Nigeria, and CKD awareness in Nigeria and preventive measures.

### Global Effect of CKD

Kidney disease is identified by the World Health Organization ([WHO], 2006) as a leading cause of increased premature cardiovascular disease, which is the primary cause of global morbidity and mortality. According to the WHO, 2006 Global Report on preventing chronic diseases, CKD is the 12<sup>th</sup> leading cause of death and 17<sup>th</sup> leading cause of disability worldwide. There is a significant association between CKD, increased hospitalization, morbidity, and death (National Health Service [NHS], 2010). Eggers (2011) on his contribution on the incidence of ESRD noted that over 2 million people worldwide need renal replacement to live near normal life even though it is likely this number could be 10% lower than those who need it. Eggers pointed out that unfortunately, this number will continue to increase because of the increase in diabetes and hypertension prevalence. CKD, according to the National Institute of Diabetes and Digestive and Kidney Diseases ([NIDDK], 2014) is one of the primary causes of premature death and high economic cost on both the public and private sectors. In 2012, Lozano et al. studied the global and regional mortality of 235 causes of death for 20 age groups in 1990 and 2010. Their systematic analysis revealed that deaths from diabetes and CKD were almost doubled worldwide in 2010 when compared with deaths from previous years.

The burden of CKD is greater in developing countries than in developed countries because of diabetics, hypertension, and CVD disease epidemics in developing countries

like Nigeria (Couser, Remuzzi, Mendis, & Tonelli, 2011). According to Barsoum (2006), over 70% of ESRD patients may be inhabitants of developing countries by 2030. Many people suffering from CKD in developing countries do not have access to renal replacement therapy (RRT) because of its cost and financial hardship (Zang, 2008). Many people see health care as unnecessary due to poverty, and some turn to their religion with the belief that their faith will heal them without seeking medical attention, which some think is delusional (Griffith & Griffith, 2002).

Arogundade et al. (2008) identified CKD as a public health threat that takes up large portions of health care finances in developed countries and significantly contributes to morbidity, mortality, and life expectancy decrease in the developing world. The common cause of morbidity and mortality in Nigeria for example is CKD based on information from outpatient, admission and discharge, and dialysis unit registers, although the exact prevalence rate is not known due to lack of renal registry (Alebiosu, Ayodele, Abbas, & Olutoyin, 2006). Hsu et al. (2009) showed that about 2% of Iranian adults develop CKD annually. But mortality from CVD and CKD-related complications and the economic burden of RRT has significantly increased both in the developed and developing countries (Imai, Yasuda, & Makina, 2011; Hippisley-Cox & Coupland, 2010; Imai et al., 2008).

Ulasi and Ijeoma (2010) said CKD problem in developing countries was highlighted through a review of medical records of all ESRD patients seen at University Teaching Hospital (UNTH) Enugu in South-East Nigeria for 13 years, between May 1990 and December 2003. The study revealed that medical deaths caused by renal-

related disease were 22.03% of all deaths at UNTH. Ulasi et al. also noted that because of the high cost of renal-replacement, only few patients were able to go through the process since many people cannot afford renal-replacement. The investigators suggested that there is need for increased awareness and effective preventive measures that will help to reduce the CKD impact in Nigeria.

High financial cost and loss of productivity were identified by Couser et al. (2011) as the main CKD associated societal effects. There has been a steady increase in the cost of CKD treatment and management over the years worldwide, which has been attributed to the high prevalence of complications with individuals with CKD (North Carolina Institute of Medicine, 2006). The public health and financial burden of CKD worldwide has reached epidemic levels and it is expected that it will continue to rise mainly due to low awareness, under-diagnosis, and under-treatment of CKD (Vupputuri, 2008).

CKD does not only increase the burden of overall health care resources globally, but also has a great economic impact on individuals that suffer from CKD and their families. Even in a developed country like the United States, almost 25% of Medicare budget is used for treating CKD and ESRD patients (Friedman & Friedman, 2006). And according to the 2016 USRDS Annual Data Report, the United States overall amount spent on caring for patients on Medicare in 2015 was \$50.4 billion, accounting for 20.1% of the total Medicare expenditure. In developing countries like Nigeria, the burden caused by high cost of CKD and its related comorbidities treatments is staggering

because there is no renal data system coupled with the fact that the Nigerian government does not supplement the cost of CKD treatments.

Banerjee, Powis, Shevlin, Barnes, Soo, and Sutcliffe (2010), conducted a population-based case-control study in London to find out the health outcomes of children born to mothers with CKD. They studied and assessed the individual well-being of each child in terms of physical health, neurodevelopment and psychological health of 24 children from mothers with CKD and compared them with 39 matched control children from mothers without CKD. Out of the mothers with kidney related problems, 8 had renal transplant, 3 with CKD, and 11 had mild renal disease. The study determined that children born to women with renal disease had greater externalizing behavioral problems, such as rule breaking and aggressive behavior than children born to mothers without any form of renal disease. The finding reconfirmed the fact that when an individual is suffering from CKD that members of his or her family also bear the burden caused by CKD, which also could extend to the community and the country as a whole.

Apart from financial burden, most CKD patients also suffer from other long-term complications, such as anemia, malnutrition, mineral and bone disorders, among others (Chen et al., 2010; United Kingdom Renal Association Guidelines, 2007; Boulware et al., 2006; Drayer et al., 2006). This could lead to poor quality of life and extended loss of working lives of individuals suffering from CKD because they are unable to work.

Different researchers have determined that CKD and ESRD patients suffer from a lot of physical and emotional problems, with high prevalence of depression, and go through significant disruptions in quality of life (Davidson et al., 2005; Kimmel, 2002; Lopes et

al., 2002; Evens et al., 1985; Johnson et al., 1982). Patients receiving dialysis suffer sexual dysfunction (Palmar, 2003; Rosas et al., 2001), which contributes to the high burden of CKD.

Since CKD is a chronic disease that requires dialysis, individuals suffering from CKD may often take time off from work for dialysis and other treatment-related issues that could lead to excessive absence from work. Excessive absence from work could in turn be a threat to Nigeria's future economy because according to KCI(2012), CKD prevalence is common among the working population between the age of 20 and 50 years. The people in this age group are expected to be economically productive (Arogundade & Barsoum, 2008). Unfortunately, inadequate diagnostic facilities and limited treatment options lead to very poor diagnosis in Nigeria (NIDDK, 2012), coupled with the fact that the early stages of CKD is asymptomatic, which compounds the problem.

## Risk Factors and Health-Related Consequences of CKD

According to Kidney Consultants International of Nigeria (2012), CKD is an irreversible progressive condition, which develops from the complex complication of diabetes and hypertension that can lead to disability and death. About 5-7% of world population, made up of developing countries, disadvantaged and minority population suffer from kidney disease as a result of poor health outcomes of diabetes and hypertension (Couser, Remuzzi, Mendis, & Tonelli, 2011; Peters, 2014).

Siegel and Lontenberg (2007, p.9) noted that factors that increase chronic disease existence, such as CKD include unhealthy lifestyles and behaviors, deteriorating

socioeconomic status, and inadequate access to quality health care. This was confirmed in a study by Okoye, Obiasu, and Ojogu (2011) in a rural community in Edo state, Nigeria where the prevalence of CKD was 27.2%. The study explained that the prevalence, incidence, and treatment of CKD are partly as a result of co-existing medical conditions and modifiable risk factors, which includes lifestyle, socioeconomic status, and culture. It was identified that there was a significant association between age, use of nephrotoxic agents (herbal, NSAIDS, skin lightener), hypertension, diabetes, obesity and CKD.

Infectious diseases have been identified as one of the risk factors of ESRD in developing or low-income countries, next to poor sanitation, poor clean and safe water supply, and high concentrations of disease vectors that are common in countries where poverty rate is high (García-García, 2014). According to Garcia-Garcia, in Nicaragua it was found that the increased CKD prevalence among male farmers less than 60 years old was associated with exposure to pesticide, dehydration, alcohol consumption, and exposure to heavy metals. Also, a high prevalence of CKD in El Salvador was found among male farmers exposed to toxic pollutants, while in Sri Lanka it was identified that there was an association between exposures to pesticide and pollutants, and recurring episodes of acute renal failure and CKD respectively (García-Garcia).

This reconfirms that there is a relationship between poverty and disease, including CKD. Nigeria, where 60% to70% of the population barely survives below poverty level (Ogun, Adewolo, Familoni, Jaiyesimi, & Fakoya, 2000), is one of such countries where there is extreme poverty because of unequal distribution of wealth. Poverty level in Nigeria explains why the burden of CKD is high in Nigeria. Because it is most likely that

people who live in low income areas will not have access to good sanitation, standard good healthcare, and information about preventive health behaviors, therefore more vulnerable to diseases, as it is the case in Nigeria. Garcia-Garcia (2014) also noted that life exposure to poverty and exposure to heavy metals due to poor living environments increases the risk of CKD of this population.

The NKF (2002) identified additional risk factors for CKD as poor education level, autoimmune diseases, neoplasia, family history of kidney disease, reduction in kidney mass, and low birth weight. In addition to hypertension and diabetes, it was established in Iran that smoking is a significantly risk factor for CKDs3-5 (Toshidi, Hasheminia, Mohebi, Khalili, Hosseinpanah, Babak & et al., 2012), and chronic glomerulonephritis in Nigeria (Erikpo, Udo, Ikpeme, & Effa, 2011).

Suckling and Gallagher (2012) looked at the risks and commonalities of CKD, diabetes, and CVD and the burden of disease they caused across developed and developing worlds and insisted that prevention and early detection when combined with a holistic approach to vascular care improve outcomes can reduce costs. According to CDC (2012), there is a strong correlation between diabetes and kidney failure, with diabetes accounting for 44% of all new kidney failure cases in 2008. As noted by CDC, out of this population, 48,374 people started end-stage kidney disease treatment, while 202,290 people suffered from end-stage kidney disease as a result of diabetes and live on chronic dialysis or kidney transplant.

Individuals of black African heritage, as in Nigeria are at increased risk of developing CKD four times than individuals of other races (Odubanjo et al., 2011;

Bamgboye, 2013j). This is attributed to the fact that hypertension, which plays a role in the etiology and progression of ESRD, is also highly prevalent among individuals of black African heritage (Naicker, 2003; 2009). For example, African Americans are said to have higher kidney failures than any other group in the US (NIDDK, 2012). They are likely to progress to ESRD 18 times more than whites once CKD is established. In 2007, 90% of ESRD was attributed to African Americans with HIV/AIDS infection (Naicker & Fabian, 2011). This is because Africans have the same frequency and severity of hypertension and have the tendency to have renal failure just like Nigerians according to Ojogwu (1990).

In a 10-year retrospective study carried out at the Olabisi Onabanjo University Teaching Hospital (OOTH), Sagamu, Nigeria to determine the pattern of chronic renal failures, Alebiosu, Ayodele, Abbas, and Olutoyin (2006) noted that CKD is a common cause of morbidity and mortality in Nigeria. Clinical data retrieved from the medical outpatient, admission and discharges, and dialysis unit register include age and sex of patients, symptoms presented, complications and the etiology of the CKD, number of patients who received dialysis, frequency and the duration of dialysis.

Out of the 153 participants who were at the peak age of between 20-49 years, 90 were males and 63 females participated in the study. Most of the patients were referred and presented late, and the main causes were mainly glomerulonephritis 41.2%, hypertension 26.1% and diabetes 13.1% according to Alebiosu et al. And only 34 patients could afford hemodialysis while the 21% afforded only three sessions of hemodialysis and 5.9% of the patients had about 7 dialysis sessions at the OOTH Sagamu, Nigeria as

noted by the investigators. The findings reconfirmed that only few people in Nigeria could afford the enormous cost of treating CKD due to poverty and lack of access to healthcare, which leads to the late presentation of the disease for timely and appropriate intervention. And late presentation contributes to the high morbidity from CKD in Nigeria (Erikpo et al., 2011).

In addition to other risk factors, Akinsola, Odesanmi, Ogunniyi, and Ladipo (1989), observed in their study on likely diseases that cause CKD that proteinuria, significant analgesic intake and arthritis contributed significantly to CKD in Nigerians.

Some of the associated health-related consequences of CKD identified by the CDC (2014) include:

- The body of individual suffering from CKD can hold too much fluid that could lead to swelling in the person's arms and legs, or fluid in his or her lungs. The individual can also develop and inflammation of the sac-like membrane (known as pericardium) around his or her heart.
- There could be a sudden increase in the potassium levels of a kidney
  patient's blood (called hyperkalemia) that could keep the patient's heart
  from working properly, and could also lead to death.
- The immune system of a CKD patient could become weakened that make the person to become vulnerable to infection.

## **Cultural Beliefs and CKD**

According to the World Health Organization (WHO), every society or community has its certain way of doing things, which highly influences the people's perception,

attitudes and behavior on how diseases and health related problems are managed (2007). For example, it is the cultural values of a community that could determine the type of measures individuals will take to ensure that they have good health, and one's responses to CKD or its risk factors. It is important that health care professionals should appreciate community and individual differences in health care values based on the recognition that cross-cultural differences exist world-wide in terms of health matters (Surbone, 2007). Different studies suggested that there could be an improved health outcome if there is a culturally competent health care system that considers social, racial, and cultural factors (Vega, 2005; Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; & Langer, 1999).

In Nigeria where there are different ethnic groups with different cultural practices, the way of lives of each ethnic group determines the development of total health and social development ramifications when compared to global health and societal development (Ojua, Ishor & Ndom, 2013). The different ethnic groups in Nigeria have healthcare beliefs and practices that differ from one another because of each group's perspectives and values about health and illness as CKD (McLaughlin & Braun, 1998).

Some culture in Nigeria believe that serious illness is as a result of supernatural power invoked by ancestral spirit out of anger to punish an individual who has upset his or her ancestors (Ojua & Omono, 2012). The general belief is that people normally do not suffer from serious diseases by chance but from a supernatural cause. Therefore, incurable diseases or chronic diseases, such as CKD that defile scientific and orthodox treatments, which some call "extreme spiritual disease" are attributed to spiritual forces

directed by witches, wizards, sorcerers, evil spirits or angered ancestors (Ojua & Omono; Obot, 2012).

Traditional African medicine has been with Nigerian rural dwellers for generations, and in terms of ill-health has been their first consideration for treatment because it is easily accessible, coupled with the fact that orthodox medicine is always expensive, fake, and/or inaccessible (Ojua, Ishor & Ndom, 2013). Even though the use of traditional medicine has been frequently associated with CKD among the poor, and that nephrotoxicity from its use has led to about 37.5% cases of acute tubular necrosis in Nigeria (Garcia-Garcia, 2014), many people still use it. Traditional medicine has also been attributed to about 11% of acute renal failure in East Africa and in South Africa where infections in addition to traditional were identified as among the main causes of acute renal failure according to Garcia-Garcia.

The general misconception of majority of average Nigerian is that treatment of chronic diseases, such as diabetes, hypertension, and CKD, among others cannot be treated by orthodox medicine due to ignorance (Obot, 2012). As a result, they prefer to use the traditional African medicine. The hospital becomes their last resort when the traditional medicine fails (Katung, 2001; Ulasi et al., 1998). Even some people that reside in urban areas who have access to healthcare most of the time leave the hospital to seek traditional medicine attention (Omotosho, 2010). Because they probably think that the treatment outcome of chronic diseases with orthodox medicine may be unsuccessful.

Unfortunately, most Nigerians do not practice the culture of routine check-up or screening for risk factors of diseases that they could be vulnerable to because of the

family history of such diseases (Okoye et al., 2011). Instead, they depend and believe in traditional medicine like spiritual healing and urine therapy CKD treatment (Okaka & Ojogwu, 2012). The general misconception of majority of average Nigerian is that treatment of chronic diseases, such as diabetes, hypertension, and CKD, among others cannot be treated by orthodox medicine due to ignorance (Obot, 2012). As a result, they prefer to use the traditional African medicine. The hospital becomes their last resort when the traditional medicine fails (Katung, 2001; Ulasi et al., 1998).

Figure 2 shows the link between people's cultural practices, health, life expectancy and scientific development, which shows that individual's cultural practices could affect their health in a negative or positive way and their scientific and economic development (Ojua, Ishor & Ndom, 2013). The reverse could also be the case as further noted by Ojua and colleagues.

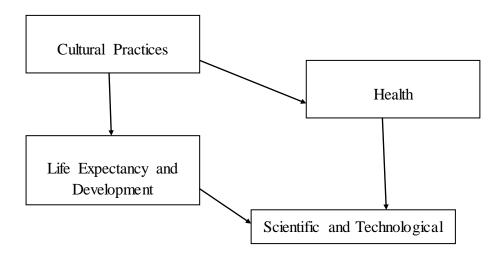


Figure 2: The link between people's cultural practices, health, life expectancy and scientific development. SOURCE: Ojua, Ishor & Ndom (2013).

# Current CKD Care and Management in Nigeria

In developed countries like U.S., the government bears most of the costs of dialysis, making it accessible to about 93% of CKD patients (Alebiosu et al., 2006) and in Japan the government pays US\$40,000 annually to dialysis provider per patient (Kurokawa, Nangaku, Saito, Inagi, & Miyata, 2002). But in Nigeria, CKD patients bear the total cost of treatment without any form of government support (Alebiosu et al., 2006), which creates serious financial burden on patients and family members. And as a result, only very few people can afford long time dialysis treatment and/or renal replacement, while many of them die from the silent disease because of lack of funds. That is why most CKD patients will first seek help with spiritual and alternative medicine providers before a Nephrologist as their last resort when others fail, which leads to late presentation, and probably death from the disease because of late presentation (Erikpo et al., 2011).

Another study in Nigeria also showed that only 1.9% of CKD patients were able to remain on dialysis for over 12 months, while 5.1% did 7 and 12 months, 12.7% between 3 and 6 months, and 70.8% could afford to remain on dialysis for less than 1 month (Arije, Kadiri, & Akinkugbe, 2000). Unfortunately, lack of proper treatment facilitates the disease progression and increases complications (CDC, 2014).

In 2006, Bosa carried out an evaluative study in Kaduna State Nigeria in order to determine the current practice of Medical officers in the state both in the private and public sector, with the exception of specialists and how it could help in early detection of CKD. Out of the 96 participants, 65% of the doctors only tested 10% of their patients for

proteinuria while 85% of the doctors tested less than 10% of their patients for haematuria, and 30% tested for proteinuria in 39% of diabetes mellitus patients they treated. 35% of the doctors tested 29% of individuals suffering from hypertension for proteinuria. The result clearly showed that CKD screening was hardly considered by the primary and secondary care officers in their routine practice considering the fact that being the first contact with patients provides them the opportunity to screen for CKD for early detection, evaluation, and prevention of ESRD.

Alasia, Emem-Chioma, and Wokoma (2012) used a teaching hospital in Nigeria to conduct a clinical study to show the current ESRD care in Nigeria and most Sub-Saharan Africa (SSA) countries. 320 patients receiving hemodialysis treatment were followed for a period of 7 years, and received weekly dialysis. Data was retrospectively analyzed and the result showed that more than 80% of patients funded their dialysis treatments, with 128 patients dead within 90 days because of their inability to pay the prohibitive cost of care, and that there was low opportunity for kidney transplant. The literature clearly demonstrated that poverty and lack of government support for ESRD care lead to poor outcomes.

Other problems as identified by Ayo (2001) include frequent power supply disruptions and unstable water supply in Nigeria. Additionally, Nigeria has experienced serious terrorist attacks, abductions, and kidnapping, which have affected the quality of life in Nigeria. People were scared of going about their normal business and services. The healthcare delivery services were also disrupted either due to terrorist attacks non-payment of healthcare providers' salaries, allowances, or entitlements. For example,

the last terrorist attack at a bus station in Abuja killed about 70 people who were preparing to board buses, which seriously disrupted almost every activity in Abuja (Ross, 2014). And in 2011, at least 21 people died at the United Nations (UN) building that was attacked by a suicide bomber (Nossieter). In Southern part of Kaduna State, 40 people were killed by terrorists (Ahmad, 2004), while over 400 suspected terrorists were arrested near Abia State in the Eastern part of Nigeria. Because of these problems, among others, most people suffering from renal failure who could not afford the cost of dialysis and renal transplantation eventually died from it in Nigeria because of unavailability of treatment (Bamgboye, 2003). Bamgboye identified prevention as the only solution that is available to all in Nigeria.

Lack of renal registries in Nigeria also compounds the situation because it makes monitoring the trends in incidence, prevalence and outcomes in both children and adults with CKD and ESRD difficult (ESPN/ERA-EDTA Registry, 2010; McTaggart et al., 2009). Because lack of centralized valuable data makes planning, management, and delivering of health almost impossible, it leads to poor quality of life and outcomes of people with CKD and ESRD in Nigeria (Asinobi, Ademola, Ogunkunle, & Mott, 2014).

Another barrier is that the few available dialysis units are located in the urban areas, and as a result, many patients travel long distance for dialysis (Bamgboye, 2003), which increases their financial burden. Some states in Nigeria, like Yobe, Benue, and Kogi states do not have even one dialysis center, most states like Enugu, Akwa Ibom, Kebbi, and Oyo have just one dialysis center (Erikpo et al., 2011). As a result, patients receiving dialysis travel long distances from their locations for dialysis according to

Bamgboye. Figure 3 is the map of Nigeria that shows the distribution of dialysis centers in Nigeria. Each black circle identifies a location of a dialysis center in a state where there is any dialysis center or centers. The low number of dialysis centers as shown in the map confirms limited access to dialysis, which could lead to poor care management of CKD patients and increase in morbidity and mortality from CKD in Nigeria. Not only that there are few dialysis centers in Nigeria, there is no regulation that guides the dialysis center activities in Nigeria in order to avoid preventable deaths in the renal clinics (Bamgboye & Ajai, 2014). As a result, some of the clinics are not manned by trained nephrology and dialysis staff as further noted by Bamgboye and colleague.

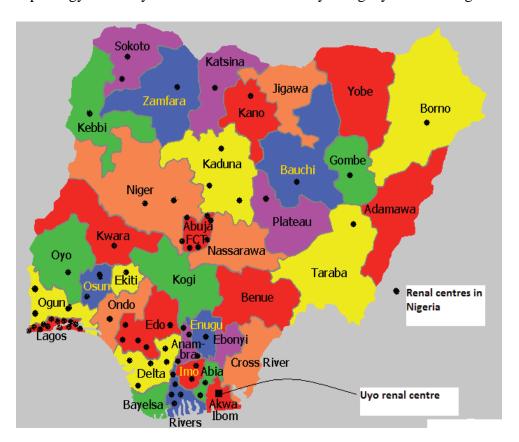


Figure 3. Map of Nigeria showing the distribution of dialysis centers. Source: Erikpo et al. (2011).

### **Awareness and Prevention of CKD**

Diseases can only be prevented if there is knowledge of the disease and the risk factors. Lack of awareness makes it difficult for individuals with access to health care to check their kidneys health. Knowing ones kidney function status through awareness and screening could be enabling factors for lifestyle and dietary changes early enough to prevent the kidneys from complete deterioration (Jain, 2014).

There is very low awareness about CKD even though many people have been "sentenced to death" by CKD in Nigeria, with a high mortality rate of between 40% and 50% (Odubanjo et al., 2011). Also, Okaka and Ojogwu (2012) in their study determined that the knowledge of CKD and its causes is low in Nigeria when they examined the awareness level of kidney disease among non-medical students in Benin City, Nigeria. The general knowledge of CKD and possible causes among the participants was found to be poor. Out of the 295 participants that were studied, 94 % did not know that CKD could be an inherited disease; only 25% knew that hypertension is a CKD risk factor, while 24% and 7% believed that CKD was caused by native concoctions and skin lightening soaps and creams respectively. In another study by Ulasi, Ijeoma, & Kalu (2005), skin lightening soaps and creams have been associated with CKD as a risk factor in Nigeria. This also signifies the need for increased awareness of CKD and its risk factors for improved knowledge of CKD to assist in reducing the prevalence of CKD in Nigeria.

The low level of awareness is also attributed to lack of government participation in putting together enlightenment programs like mass media education in different major

languages to inform and educate people about risk factors of chronic diseases, such as CKD. For instance, no form of activities was carried out by the Federal Ministry of Health to commemorate World Kidney Day (WKD) in March 2013 and in 2014 in Nigeria (B. Bene, personal communication, March 13, 2014). Activities to commemorate WKD could assist in creating awareness of CKD and its risk factors, and inform Nigerians about the importance of kidney to their health and recommend preventive measures, and encourage healthy living behaviors.

The need for awareness of CKD cannot be over emphasized since the implementation of appropriate therapies depends on the physician's awareness, and adherence to recommended therapies is primarily determined by patient awareness (Tout et al., 2011). Lack of knowledge could lead to late presentation, which increases the morbidity and mortality of CKD in Nigeria (Okaka et al., 2012). In a study to examine the correlation between awareness and the recognition of CKD among healthcare providers and patients, Tout and colleagues used patients with clinical markers. It was identified that "90% of patients with two to four markers of CKD and 84% of patients with 5 markers of CKD" did not know that they had CKD even though clinical markers were expected to trigger CKD recognition by healthcare providers according to Tout et al. But the reverse was the case because provider awareness of CKD was low. Thereby proving the importance of finding effective ways to create awareness about CKD, its risk factors and complications so that early detection of CKD will be facilitated for effective implementation of therapy that could minimize CKD associated complications.

CDC (2016) identified prevention and treatment of CKD's risk factors as the most efficient way to reduce personal suffering and financial costs of CKD. Prevention program as the primary key to reducing CKD prevalence was demonstrated by Chen, Hsu, Yamagata, and Langham in their 2009 study. They looked at prevalence, awareness, associated risk factors of CKD, and the effectiveness of preventive programs in Shangai, Japan, Taiwan, and Australia. The study in Shanghai revealed that despite the fact that CKD prevalence was very high that awareness was low. In Japan, it was found that the number of ESRD cases was decreased due to urinalysis screening program implemented and supported by the local governments and the Ministry of Health, Labor and Welfare. This was evidence that a preventive program that is supported by the government is very important attribute in the fight against kidney disease.

Another effectiveness of preventive program(s) was also evidence in Taiwan after the implementation of CKD care program and diabetic share care program. An evaluation of CKD care program showed that individuals on CKD care program had a lower cost of hemodialysis initiation and total health care when compared with individuals that were receiving usual care with lower hospitalization rate. The Taiwan study confirmed people with advanced CKD stages could benefit from an integrated pre-ESRD care as a preventive measure.

Early detection through screening of high-risk individuals through Kidney Evaluation for You program was proved to be cost effective in CKD prevention in Australia according to Chen et al. (2009). Education and primary care initiatives in Australia through Kidney Check Australia Taskforce preventive program resulted in

reducing the number of deaths from CVD, ESRD, and also reduced the number of people on dialysis or those that needed transplantation. Murphree and Thelen (2010) insist that the progression of CKD can be slowed through strict blood pressure control, proteinuria reduction, hyperlipidemia control of identified high risk population, and early treatment of CKD complications by primary care physicians. Primary care physicians are therefore urged to equip themselves with good knowledge about CKD to enable them provide quality care to CKD patients since their familiarity with CKD is suboptimal Coresh et al., 2007)

Early checkups for blood pressure, sugar and urine, and diagnosis prevent hypertension and diabetes, which are the two primary CKD risk factors from moving to kidney disease or failure if they are treated and put under control (Peters, 2014).

Preventing CKD through early treatment of the risk factors will save costs since it is cheaper to treat hypertension and diabetes than to treat CKD according to Peters and prevent kidney damage. According to reports by Kadiri and Arije (1999) after studying 45 patients with acute renal failure who had taken traditional herbal concoctions before doing through dialysis, death from CKD could be prevented if proper education and awareness are provided. Three people died after taking concoction and receiving dialysis, which Kadiri et al., believed would have been avoided if there was proper education and awareness to inform patients of the implications of taking herbal concoction.

# **Summary and Conclusions**

In conclusion, there is need for increased awareness for CKD preventive measures through effective government participation in order to reduce the high rate of morbidity and mortality from CKD in Nigeria.

Many studies have focused on the morbidity and mortality rate of CKD and awareness. However, what was not known was how cultural beliefs could affect the healthcare behaviors of Nigerians in responding to preventive measures that could prevent CKD, such as, screening for diabetes, CVD, or CKD. This study described how low level of awareness and the traditional cultural beliefs of Nigerians could affect the way people respond to CKD-related health education and recommendations for preventive measures.

Chapter three provides detailed discussions of the research design and methodology, including how the participants were identified, ethical protection, the role of the investigator, and how the collected data was managed and analyzed.

# **Chapter 3: Research Method**

The literature review in Chapter 2 highlighted the prevalence of CKD, and the increased rate of morbidity and mortality from CKD in Nigeria because of the high financial cost involved in CKD treatment, which many Nigerians cannot afford due to poverty. Lack of access to primary care physicians, lack of proper counseling, and lack of healthcare education on preventive measures make the situation in Nigeria very complicated. The purpose of this study was to explore the level of CKD awareness among individuals with family history of diabetes, hypertension, or CKD, including those who have gone through renal replacement, and how cultural beliefs affect the health seeking behaviors of individuals in Nigeria. This chapter provides the details of the research methodology, design, study context, participants, role of the researcher, and the measures taken to protect the participants. I also described the data collection plan and data analysis process.

# Research Methodology

Qualitative research methodology was used to explore and understand the research phenomenon. A qualitative approach enables researchers to improve their understanding of the issues that affect people (Dickson-Swift, James, Kippen, & Liamputtong Rice, 2006). These include, people's attitude, behavior, value systems, concerns, motivations, aspirations, culture, and lifestyles (Creswell, 2009). Qualitative researchers are able to gain a better understanding of these issues because they are placed very close to the raw words and the real life of the participants (Brodsky & Faryal, 2006). In addition, qualitative methodology provides the researcher with both answers to

questions posed and the opportunity to observe participants during interviews according to Creswell.

# **Research Design**

To explore the awareness and the morbidity and mortality rate of CKD in Nigeria, and how cultural beliefs affect health seeking behaviors of individuals, I used a phenomenological design. Phenomenology is "the study of phenomena as they present themselves in direct experiences" (O'Leary, 2004, p. 122). The phenomenological design is descriptive and explorative in nature, which assists in capturing the essences of the lived experiences of the participants. A focus on CKD or renal failure from the participants' point of view revealed their perspectives on CKD and its risk factors, and provided a better understanding of their health-seeking behavior.

According to Moustakas (1994), experience and behavior are integrated and in an inseparable relationship of a phenomenon with the person experiencing the phenomenon. The phenomenological design also provided me with an in-depth understanding of CKD as it affects the Nigerian population, including knowledge and awareness of CKD. The following research questions were used for this study:

- 1. What level of awareness and knowledge do individuals at risk have about CKD in Nigeria?
- 2. What is the perception of CKD of individuals who have gone through renal replacement?
- 3. How would culture and personal healthcare seeking behaviors affect CKD awareness in Nigeria?

4. What educational programs about CKD, if any, are in place in Nigeria to inform healthcare providers and the general population about CKD and its complications or consequences?

### Role of the Researcher

I functioned as an observer and participant with no personal or professional relationship with the participants. To clarify my position as the researcher and my potential bias (Creswell, 1998), I lost my father to kidney a stone, I lost a close relative to renal failure, and recently my half-brother had a kidney transplant. Conducting this research was challenging and I was drained emotionally and psychologically because listening to participants' experiences brought back painful memories. According to Sampson, Bloor, and Fincham (2008),

"one of the dangers of undertaking research which is fuelled by a desire to achieve answers to personal issues, anxieties and frustrations is that once undertaken you are exposed on a day to day basis to situations which trigger painful memories (p. 926)."

However, I believe that there was need to study the level of CKD awareness in Nigeria, and see whether and how cultural beliefs in a multi-ethnic country like Nigeria affect health behaviors of individuals, such as screening for CKD or its risk factor.

I shared my personal and family experiences with participants, which enabled me to improve my understanding of the world of my participants who had either been through CKD-related problems or had a family member with family history of CKD because I could see the participants' personal experiences and consequences through their eyes. Sharing my experiences assisted me in developing effective rapport and trust with the participants and made most of them relaxed and willing to open up without fear,

thereby closing the gap between the investigator and the participant. Some researchers have argued that investigators' self-disclosure allows participants to know that they understand what they are talking about, probably have been there too, and are respect, be open, honest, and empathetic (Dickson-Sweft et al., 2007; Rager, 2005). This made participants comfortable and willing to discuss their experiences and disclose detailed information because they felt that the investigator was familiar with their world (Darra, 2008; Goodrum & Keys, 2007; Perry, Thurston & Green, 2004). It is not fair for an investigator to expect a participant to be open and honest to discuss his or her personal experiences if the investigator is not prepared to do same (Dowling, 2006).

# **Participants of the Study**

Participants were male and female adults between ages of 21 and 51 years of different ethnicities with a history of hypertension, diabetes, or CKD in their families and were willing to participate. Individuals who already went through renal replacement and family members were part of this population. Fourteen participants were residents of Abuja, Nigeria and were purposefully selected from different cultural and religious backgrounds to get insights and in-depth understanding of CKD in Nigeria. Sampling from Abuja, the capital of Nigeria, made it easier for me to access individuals from different ethnic and religious backgrounds, and socioeconomic status than using individual states. Part of the inclusion criteria was that the participants should also be able to answer questions clearly. Individuals who were unable to understand and respond to questions clearly, or had physical or mental inability to participate were excluded.

# **Study Setting and Sampling Strategy**

The study setting was Abuja, the federal capital of Nigeria, in West Africa. Polkinghorne (2005) defined *sampling* in a qualitative study as the selection of participants and existing study-relevant documents, used as the basis for making inferences about the population. According to Patton (2002), there are no specific rules for sample size in qualitative research. Sampling size could be an individual, a university, a city, or a nation (Frankfort-Nechmias & Nachmias, 2002). For this study, I used the concept of saturation, which was the point when responses from participants to the same questions did not provide new information about CKD in Nigeria. I stopped collecting data as soon I had enough data from a sample size of 14 that gave me enough data for understanding the participants' values and beliefs about CKD from their frame of reference (Grbich, 1999).

## **Procedures**

The following procedures provide the chronological guide for identifying, contacting, and recruiting the participants and for collecting and analyzing data:

- I obtained study approvals from institutional research board (IRB) and the National Health Research Ethic Committee (NHREC) in Nigeria (Appendix E).
- 2. I contacted three healthcare providers in the prospective participating hospitals and the dialysis center in Abuja via phone to inform them about the study.
- 3. I sent the information letter (Appendix A) about the study to healthcare providers requesting their assistance for recruitment of participants, and I followed up with several visits.

- 4. I obtained approved consent from the hospitals and the dialysis center that participated in sample selection.
- 5. I accessed participants through community partners from a cross section of two governmental hospitals, and a dialysis center in Abuja that were randomly picked; representatives sent invitation letters to prospective participants on my behalf, and through posters.
- 6. I used a snowball sampling to reach hidden or hard-to-reach potential participants who did not have access to healthcare.
- I scheduled information sections with prospective participants based on locations convenient to them.
- 8. I provided detailed information about the purpose of the study, procedures, duration, anticipated benefits, confidentiality, right to decline or withdraw, and contact information about their rights (American Psychological Association [APA], 2010) at the first meeting. The detailed information was both in English and broken English. Participants were given the option to choose the version they were most convenient with.
- I provided contact information and asked interested prospective participants to contact me for clarifications and to schedule interview.
- 10. I followed up with a call or text message after a week if not contacted by the participant.
- 11. Before each scheduled interview, I ensured that the tape recorder and other electronic devices at the location of interview were in good working condition.

- 12. At the initial interview, I provided a copy of the letter (English or broken English) that described the study to the participant and a consent form, either in English or broken English to read and sign. This interview covered questions that were listed in the first interview. (Interview protocol for interview one is located in Appendix C).
- 13. I informed participants of their right not to answer any question they were uncomfortable with, or not to continue with the interview if they desired.
- 14. I scheduled an appointment for the second interview about one or two weeks later.
- 15. Questions for the second interview included those listed in Interview 2 that covered research questions were covered during the discussion. Interview protocol for the second interview can be found in Appendix C.
- 16. After each interview, I transcribed the data.
- 17. I scheduled a third interview after transcribing data collected from the first and second interviews for further clarification and/or transcript review.
- 18. I coded and analyzed data.

## **Data Collection and Storage**

Data for this study were collected through two sections of personal semistructured in-depth interviews with 14 participants and field notes. Participants were given the opportunity to choose a private location in Abuja that was free from any distractions and convenient to them. Interviews were tape-recorded with the consent of the participant and transcribed. Although personal interviews were time consuming and expensive, they provided a good opportunity for both the participant and me to clarify misunderstandings or probe responses for more details. During the interviews, I was able to get involved by following leads and asking the participants further questions for more explanation. In addition, the participant's body language during the interviews provided me with non-verbal cues for more information (Simon & Goes, 2013).

The first interview did not cover any particular research questions, but mainly involved general information gathering about the participant's background for good understanding of the individual's life experience. Participants were asked to describe early life experiences with friends in the neighborhoods, work-places, schools and families, which enabled them to provide clear perspectives of their current situation (Seidman, 1998). This revealed the type of family the participant come from and his or her family orientation, and the meaning of health or healthcare behaviors. The nature of the study was discussed at this interview with a clear explanation of the purpose of the study and how it could benefit the participant and Nigeria as a whole. The first interview also provided an opportunity for me to share my personal CKD experiences for the purpose of building rapport with the participants. The consent form was also signed at this meeting. Participants were reminded that there would be a second interview, and as a precaution against losing participants after the first interview. I made follow-up calls and sometimes sent text messages.

Most of the second interview meetings took place two to three weeks after the first interview meeting at the convenience of the participant. The interview focused on questions designed to give the participant the opportunity to provide detailed responses

about his or her experiences and personal perspectives about CKD, its risk factors, and complications.

In order to address the first research question, I asked the participants if they know about CKD, what they know about it, how they got to know about it, and if they know what could cause it and how to prevent it. For the second research question, the participants were asked the meaning of CKD, and specifically, post-transplant participants were asked how they feel about going through renal replacement, how it has affected him or her directly and the effect on their family. And to address the third research question, I used questions that focused on the participant's culture, if his or her culture encourages orthodox medicine or traditional medicine, and what the participant's first preference would be if he or she falls sick. The research question on educational program about CKD in Nigeria was addressed by asking the participant if he or she knows about any health education on CKD and its risk factors that is available in his or community and the location. How he or she gets information about chronic diseases like CKD? The exact questions for the first and second interviews are listed in Appendix C. The matrix in Appendix D shows the connection between the research questions and the questions I asked the participants.

A third interview was scheduled for clarifications and/or transcript review purposes where participants were provided with the original transcripts for verification.

The data collected from the discussion interviews, notes, and the transcripts were organized in a file and securely saved both in soft copy in a database and email

attachments on my private computer, and hard copies in a locked safe in my home and outside my home.

## **Data Analysis**

I used the traditional method of coding for this study instead of the qualitative analysis software, which helped me in "highlighting the thinking and mechanics involved" (Patton, 2002) in my data analysis. Data collected during the interviews and field notes were organized in files that I created for the transcripts because according to Creswell (1998), "creating and organizing files" is the first step in the analysis process. Bogdan and Biklen (1982, p.145) described qualitative data analysis as "working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others."

After organizing the data in files, I systematically read through all of the transcripts several times to familiarize myself with responses and to synthesize the emerging preliminary categories from the participants' responses to my interview questions. This enabled me to have a general sense of the information participants provided (Patton, 2002). It also assisted me in identifying the information contained in my collected data and to begin to understand the meaning of CKD from the participants' perspectives. In addition, it enabled me to compare responses to interview questions to see their relevance to research questions as the themes emerged from the raw data, and placed them into meaningful general categories for analysis. According to Ryan and

Bernard (2003), investigators must have thematic categories, which can be broad and link different many expressions or more focused and link very specific type of expressions.

In the next step of my analysis, I reexamined the identified general categories to see how they could be merged into new themes for good understanding of CKD awareness and the effect of cultural beliefs on health care seeking behaviors in Nigeria. Through merging of categories, I began to have a clearer and bigger picture of the study of interest because coding not only describes the phenomenon of interest, but it also creates a better understanding of it (Simon, 2011). Therefore, manually highlighting the meaning of CKD risk factors, complications, and the burden of CKD according as expressed by the participants in the form of feelings, emotions, or actions was necessary. Then, I eliminated categories that did not relate to understanding the personal experience or meaning of CKD or renal failure and connected descriptions or expressions were grouped and labeled

Finally, I translated the data into a story line or a research report to give a good account that "closely approximates the reality it represents" (Strauss & Corbin, 1990, p.57).

### **Data Verification**

In qualitative studies, trustworthiness is used instead of validity, and dependability instead of reliability (Davies & Dodd, 2002; Stenbacka, 2001; & Seale, 1999). Trustworthiness support the investigator's argument that his or her findings are "worth paying attention to" (Lincoln & Cuba, 1985, p.290). Also, study findings must be from experiences and ideas and not the researcher's preferences (Shenton, 2003). I used

member checking for this study to ensure that the participants' views and expressions were not misrepresented so that the phenomenon were described from participants' perceptions, and a way to eliminate bias (Trochim, 2006). Member checking is a process of quality control that provides a study participant the opportunity to give a feedback through the data participants provided during discussion interviews for accuracy, credibility, and to enhance participants' involvement. It is also known as participant verification (Rager, 2005), which helps in reducing the incidence of incorrect data and the incorrect interpretation of data, with the overall goal of providing findings that are authentic and original (Creswell, 2007; Moustaches, 1994). I scheduled meeting with individual participants and gave them original copies of the transcripts that have their structural descriptions of CKD and their personal views and/or experiences to review because trustworthiness support the investigator's argument that his or her findings are "worth paying attention to" (Lincoln & Cuba, 1985). Some participants made corrections and/or provided additional information before approving their data while others just reconfirmed the data after review.

To clarify my potential bias as it relates to the topic of study (Creswell, 1998), I conscientiously informed participants during the interview discussions that I lost my father to kidney stone, a close relative to renal failure, and that my half-brother had a kidney transplant. During the in-depth discussion interviews, I found similar experiences in terms of lack of awareness, wrong diagnosis, and late presentation, pain as a result of lack of funds to take care of the sick and from an untimely death of a loved one. And also the sufferings that family members go through both during the care period and after the

loss of a family member to CKD. And I could relate to the emotional, psychological, and financial challenges that most of the participants experienced or were experiencing. I also informed participants that my main role as the researcher was to carefully listen to their personal experiences and perceptions and not to ask leading questions that could make them to respond in a way that could be consistent with my experience. I also used the same approach for the data analysis process.

## **Ethical Issues and Protection of Participants**

Study participants were adults who were capable of determining whether to participate or decline. Since human subjects were participants of this study, I obtained study approval from the Institutional Research Board (IRB) and the National Health Research Ethic Committee (NHREC) in Nigeria that ensured that very high ethical standard was followed and maintained. Each participant was given a copy of approved detailed informed consent that provided information about the purpose of the study, duration, procedures, right to decline or withdraw, any associated consequences, reasonably foreseeable factors as it could affect their participation prospective benefits, confidentiality limits, and contact information about their rights (American Psychological Association, 2010). The intention was to enable the participant make informed decision. I reminded participants of their right not to answer any question they were uncomfortable with, and that they were free to withdraw from the study at any point in time if they wanted.

I did not include the participant's personal information or anything that would identify the participants in the study reports so that the participants will not be identified

or their personal information compromised. Only code names known by me were used to identify each participant. Consent forms signed by participants were placed in a secured cabinet only accessible to me. Approval to tape-record the interview and Statement of Confidentiality were included in the signed consent form.

None of the participants encountered or experienced any stress or anxiety during the study.

## Chapter 4: Results

In chapter 3, I described the research methodology, design, participants, role of the researcher, and measures taken to protect the participants. I also described the data collection plan and analysis, and the verification process. In a developing country like Nigeria where many people resort to either traditional medicine, or self-medication, or live in denial because of the cost or lack of access to healthcare, the morbidity and mortality rate of CKD is very high. Even the few who had access to healthcare did not attach much importance to regular healthcare checkup that could help to diagnose the risk factors of chronic diseases like CKD early enough for proper management due to absence of health education programs that target prevention. Lack of appropriate information, counseling, and suitable healthcare management mostly contributed to incorrect diagnosis and late presentation. In this study, I looked at levels of CKD awareness in Nigeria, and explored whether cultural beliefs affected individuals' health-seeking behaviors, and the meaning of CKD from the perspectives of post-kidney transplant individuals, and those with family history of diabetes or hypertension, or CKD. I interviewed 14 people who provided detailed information about their personal perspectives and experiences with CKD. This chapter provides detailed information on participants' recruitment, participant profiles, data collection and management, reliability, and themes. In addition, I present findings relevant to the research questions and protection motivation theory. The study was guided by the following research questions:

1. What level of awareness and knowledge do individuals at risk have about CKD in Nigeria?

- 2. What is the perception of CKD of individuals who have gone through renal replacement?
- 3. How would culture and personal healthcare seeking behaviors affect CKD awareness in Nigeria?
- 4. What educational programs about CKD, if any, are in place in Nigeria to inform healthcare providers and the general population about CKD and its complications or consequences?

#### Recruitment

Participants were recruited through two government hospitals and a dialysis center in Abuja that were randomly chosen. The community partners sent invitation letters to prospective participants on my behalf. Also, big posters with notes in both English and broken English were strategically posted at locations approved by community partners' representatives. To reach hidden or hard-to-reach participants who did not have access to healthcare, I used a chain referral through participants. These participants were given flyers with information about the study to give to individuals they know who might be suffering from diabetes or hypertension, but did not have access to healthcare.

I encountered several barriers during the recruitment process. For example, some participants did not keep appointments and did not respond to follow-up calls and text messages. Because of the poor economic situation in Nigeria, many people were interested in participating only if they were paid more money than what was approved by the IRB. Some people responded and kept their appointments only to find out during the

initial interview that they did not know why they were participating or what they were participating in. The attraction was the \$30 thank-you gift that was stated in the posters and flyers. Some of them disappeared after the first interview. At the end, 14 out of the identified individuals between the ages of 21 and 51 fully participated in the study; 38% were female and 62% were male.

Initially, the proposed sample size was 10 to 20; however, at the saturation point after interviews with 14 participants, I stopped collecting data. Four out of the 14 participants were post kidney transplant patients. The rest were either from families with history of hypertension or diabetes, or CKD, or both. The names of participants and their state of origin were not used in order to protect their identity.

# **Participants Demographics**

Participant1, Adams is a 51-year-old man from the Middle Belt part of Nigeria, a Christian, and a business man. He has a family history of diabetes; both parents suffered from diabetes for many years and died from its complications. He is diabetic and hypertensive. He was recruited via poster pasted at one of the government hospitals. He has access to healthcare through his wife's health insurance from work, which covers him and their children. He believes in medical treatment as opposed to traditional medicine. Although he is diabetic and hypertensive, which are the two main risk factors of CKD, he knows very little about CKD. He only knows about the functions of kidney that he learned through his secondary school biology class. His healthcare provider has not informed or counseled him about the link between diabetes and hypertension, and CKD. He gets his health information online.

Participant 2, Kelvin, is a 41-year-old man from the Niger Delta part of Nigeria, a Christian who works for the federal government. He has a family history of hypertension; both parents were hypertensive. His father died at age 44 from hypertension, and mother at 57. He was brought up primarily by his mother. He is suffering from high blood pressure, and was recruited via poster. His culture affects his healthcare activities and living style. He knows about the function of the kidneys through biology class in secondary school, but has not really received any form of counseling from his doctor, and has not received any health education on CKD. He gets health information from the Internet.

Participant 3, Femi, is a 51-year-old Christian man from the South Western part of Nigeria, and a business man. He is from a family with history of hypertension and heart attack. His father died from complications of a heart attack at the age of 65; his mother is alive but had a heart attack that left her in a wheel chair. He was a heavy smoker as a young man and diabetic. He believes in traditional medicine because that is what he was brought up with based on his culture and family beliefs. He was forced to go the hospital for the first time in 2012 when he was sick for a long time and the sickness did not respond to the traditional medicine he was taking. He was eventually diagnosed with diabetes and kidney disease. His cultural belief affects his healthcare decisions because he grew up with the knowledge that traditional medicine is better than hospital care and inexpensive. He gets information about diseases or infections from beer parlors where he goes for drinks with his friends. He did not know about CKD until February this year when his doctor told him that he had kidney problems.

Participant 4, Gladys, is a 42-year-old woman; a Christian from the Northern part of Nigeria who works in the education sector. She is from a family with history of diabetes, and her family combines its medical treatment with prayers. Her mother and younger brother died from complications of diabetes at the age of 60 and 40 respectively, and her younger sister is also suffering from diabetes. She was recently diagnosed with diabetes too. She has been experiencing chest pain in the early morning. She sees a doctor about symptoms that she is not familiar with and prays about them. For the symptoms she is familiar with she does self-medication. Her religion and culture initially affected her choice of healthcare until she lost her brother to diabetes. Her preference of using the hospital started after she lost her younger brother to diabetes because her brother was using a concoction given to him by a traditional medicine man. Her brother's health deteriorated and he died barely two hours after he arrived at the hospital. She got to know about CKD in 2011 when she lost her cousin to CKD, which was not diagnosed early and the family did not have the required amount of money to send her to India for kidney transplant. She does not know what causes kidney disease. She gets general health information in the hospital or from watching television programs if they are giving general information about a particular disease or infection. She was recruited through invitation letter.

Participant 5, Habiba, is a 27-year-old woman from the Northern part of Nigeria, a Muslim, who works for the federal government. She is from a family with history of hypertension; her mother and father are hypertensive. She is diabetic and hypertensive. She is a post kidney transplant participant. Before she was informed she had kidney

disease, she would go for a whole year or years without going for medical checkup even though she has access to healthcare. Her mother took care of the family health problems at home because she is a nurse until she was diagnosed of CKD. She had been hearing about CKD through general information but did not really know much about it or took it seriously. When she fell ill she was being treated for malaria and diabetes without knowing she had something serious. She woke up sometime in 2015 and saw that her legs from her feet to the thighs and her face were swollen and she was not urinating very well. She could not eat much and vomited whatever she ate. The first doctor she saw kept her under observation and travelled outside the country while she was waiting. She had to see another doctor when her health was deteriorating. The second doctor informed her that she could either be on dialysis for the rest of her life or do a kidney transplant, and that both of them expensive. Her culture believes in traditional medicine, but her parents do not. She was recruited through invitation letter.

Participant 6, Aisha, is a 38-year-old woman from the North Eastern part of Nigeria, a Muslim, and a full time house wife. Her husband had diabetes and did not know until he became very sick. She is from a family that believes in traditional medicine and also married into a family that believes in same, therefore, her culture affects the way she takes care of her health. Her husband was constantly sick and the family thought it was his "usual" malaria sickness and he was taking the "normal" concoction they take for malaria, which did not help him. He was taken to the hospital only after his sickness deteriorated with swollen legs, and he was informed he had kidney disease. Because the family could not afford kidney transplant, her husband was on

dialysis for almost two years and died at home when they could no longer afford it. She was recruited through invitation letter.

Participant 7, Banji, is a 32-year-old man from the Northern part of Nigeria, a Christian, and a healthcare provider. He is from a family with history of hypertension, hepatitis, and kidney disease. His father has hepatitis C, while mother has hypertension and hepatitis B. One of his uncles died from kidney disease and his maternal cousin is presently on dialysis. His parents mostly use traditional herbs and only go to hospital when they are forced. According to him, most people in his culture do not go to hospitals because of poverty, which makes it difficult for them to pay hospital bills, and as a result they see traditional medicine as their best choice. Banji goes to hospital because he works in the hospital and has access to healthcare. He has friends and neighbors who do not seek medical care and believe in God's intervention when they are sick. For instance, he has a neighbor who is HIV positive, but has refused to get treatment from the hospital. Banji knows that he has a family history of kidney disease and hepatitis and sees the difficulties kidney patients on dialysis go through. He does an annual blood work to check for hepatitis, HIV, and blood pressure to avoid kidney disease. To him, CKD means death. His religion and culture have little effect on his health care choice. He gets his health information through television programs and bill boards if a group is trying to create awareness and also goes to the national library to research diseases that he is hearing about for the first time. He was recruited through the poster.

Participant 8, Sherriff, is a 25-year-old man from the Middle Belt part of Nigeria, a Christian, and a teacher by profession. He is from a family with history of kidney

disease; his father died in 2012 just 3 weeks after a kidney transplant in India; he took ill and their mother, who is a nurse, was treating him at home for pneumonia not knowing that he had kidney problems. It was when he was not responding to treatment at home, stopped talking and could not urinate that he was taken to the hospital, and was diagnosed with kidney disease. His father was a victim of late presentation. His death affected the family so badly that his sisters now live reckless lives because there is nobody to fall back on and a strong voice to caution them. Sherriff is presently suffering from a kidney stone; his mother advised him to pray instead of going for surgery, which he has been doing but his health is deteriorating. At first, his doctor was treating him for sexual transmitted disease because he was not urinating well. When he did not respond to the treatment, they started running other tests that led to the diagnosis of kidney stone, and his doctor has not given him any form of counseling on CKD. In addition, he is also experiencing heart pains and has not been to the hospital to tell his doctor because he does not have money. The last time he had a regular medical checkup was in 2013. He now does self-medication most of the time because of lack of funds to go to the hospital as most of his income is spent on tests because of his health condition. Any time he feels ill he prays and only goes to the hospital if he does not get better. However, he would like to go to the hospital more often instead of self-medication so that he will not die young and leave his children to go through what he is going through with his siblings. He has friends who believe in traditional medicine and self-medication. He was doing same until he realized that such habits were not good for his health. He gets his health information from radio programs.

Participant 9, Charity, is a 21-year-old woman from the South Eastern part of Nigeria, a Christian, and a food stuff trader. She is from a family with history of kidney disease; her mother collapsed in the market in March, 2016 and died from CKD complications 2 days after she was rushed to the hospital, apparently she did not know she had CKD. Charity dropped out of school to become her younger brother's mother because they lost their father at a tender age. Her family does a lot of herbal medicine and self-medication because of poverty. She described her life style as "barely surviving" from day to day. Up to the time her mother was rushed to the hospital they had not been to any hospital for care or checkup. She does not know much about her culture because she has lived in Abuja all her life. Church is like her second home because that is where she finds "peace" since after her mother's death. Her church believes in miracle healings through prayer and that is what she believes in too, so her religion affects the way she takes care of her health. She will go to Church first for prayers if she falls sick because she cannot even afford to go to any hospital, and she finds traditional medicine readily available and cheap while prayer is a free medicine. She believes that if her mother was taken to the Church that she would have not have died. She felt "helpless, confused, and empty" when she lost her mother to CKD. She does not know anything about CKD. She intends to ensure that she and her brother go to the hospital in the future at least for medical checkup as recommended by a doctor who is her church member so that they will not suffer their mother's fate. She has not received any form of counseling about CKD. To her, CKD means "pain, misery, and suffering," and it was like her life was turned "up-side-down" without knowing who or where to turn to. She and her siblings

lost their accommodation. They moved in with an aunt who started using them as house maids and they had leave and moved into an abandoned bus by the market where they sell. After one month, somebody helped them to get accommodation in a church where they stayed until they got a one-room accommodation. She gets her health information by chance, especially in the market through traditional medicine hawkers who talk about illnesses their medicine can cure. She was recruited through chain referral.

Participant 10. Andrew, is a 36-year-old man from the South Western part of Nigeria, a Christian, who works for a financial institution, and from a family of four. Their parents always preached against self-medication; always took them to the hospital for malaria treatment, which was their common ill health as young kids and adults. He is a post-transplant participant and from a family with history of diabetes and high BP; his maternal grandfather had diabetes and died from diabetes complications. His mother is hypertensive, and his twin brother also has high BP. The environmental culture abroad that requires people to get appointments before they see their doctors, which mostly takes long to get, discouraged him as a student abroad and he started doing self-medication. He continued with self-medication even after he came back and got a job that provides basic healthcare insurance in Nigeria and was not going for healthcare checkups. He believes that regular health checkup would have helped to diagnose his CKD early enough and treated because according to him, things really got worse before he was referred to a specialist. Most of his friends (young adults) don't attach any importance to living healthy life, and he did same until he had CKD. He got to know about CKD through people that were soliciting for financial assistance to enable them do kidney

transplant, but he did not understand how serious it was because nothing was said about the causes or how to prevent it. At some point in 2012, his legs were swollen and a doctor asked him to drink a lot of water to flush his system, which he did and everything seemed normal. But in May/June 2015, he started feeling dizzy and was unable to sleep, and his urine was foamy with his taste butts not feeling normal. He saw a doctor who referred him to a kidney specialist who diagnosed his condition as CKD through test results and gave him the options of kidney transplant or dialysis, and also informed him that both are capital intensive. The doctor recommended transplant if he could afford it because of his age. He almost lost his life doing dialysis a couple of time because his BP was always dropping and he reacted to blood transfusion. He now knows that not being obese and constantly going for regular checkup could help early diagnosis and treatment that could prevent CKD. He has an alarm set for each time he needs to take a particular medicine and when to exercise. He gets his health information online and from doctors when he visits hospitals. He was recruited through invitation letter sent by a community partner.

Participant 11, Michael, is a 26-year-old male from the Northern part of Nigeria, a Christian, who works in a pharmacy store. His father had CKD and hepatitis C, and died while still going through dialysis because they could not afford kidney transplant. He does self-medication for familiar symptoms, but goes to the hospital for medical attention and prays if it persists. He has not had any health crisis, and has health conscious friends that do not smoke or take traditional medicine. He first heard about CKD through general information about people soliciting for money for transplant through the newspapers, but he did not understand its seriousness until early 2015 when his father was diagnosed with

CKD and they were told what was involved care-wise and financially. He was sad when he was told about his father's health condition because he knew they did not have the type of money involved in managing CKD and transplant. It was through the financial support of their church members and other caring individuals that their father went through dialysis. He knows that high BP or diabetes can cause CKD through the discussion his father had with his doctor. Since his father passed on, he is taking a second look at his health and lifestyle because he does not want to through what his father went through. He has decided that he will go to the hospital at least once annually for health checkup, and he checks his BP at home with domestic BP kit. To him, CKD is a disease that people should not play with because it is very expensive and causes serious all-round discomfort upon the patient and his/her family, and most of the time leads to death. His family does not do traditional medicine because his father did not like anything traditional and his religion does not affect how he takes care of his health. He gets his health information through his work place at a pharmacy store, and because he wants to be a healthcare provider, he is curious in knowing about diseases so he makes enquiries with nurses and doctors during his hospital visits with his father for dialysis, but most of the information is not CKD related. His father's sickness affected their family a lot, financially and psychologically. He wants the federal government to create serious awareness about CKD to let people know how serious it is and how they can prevent it. According to him, he used to hear about CKD, but now he knows what it means. He was recruited through poster.

Participant 12, Lanre, is 42-year-old male from the Niger Delta area of Nigeria, a Christian, and a business man. He is from a family with history of CKD, hypertension, and diabetes. His mother died from CKD complications while waiting to get dialysis which she never got because there was only one dialysis center in a neighboring state and people had to queue and wait for a long while to get dialysis treatment. His father is hypertensive and diabetic. His maternal uncle also died from CKD. Lanre was diabetic and hypertensive before his CKD diagnosis. He died in May 2016 after the interview discussions, 3 months after is kidney transplant surgery. He smoked a lot during his university education years because the university cultural environment encouraged young adults to smoke due to peer pressure, and only stopped smoking in 2010. His parents did not practice self-medication and traditional medicine. According to him, up till the time he was diagnosed of CKD, the only sickness he had was always malaria. Three years before he was diagnosed of CKD, he noticed he always had swollen legs, especially when he travelled, but he did not take it seriously until he noticed blood in his semen. He saw a doctor who recommended him to a specialist who diagnosed him of CKD through his test results. He did dialysis first for two years because he did not have the money for transplant. He described his dialysis experience as stressful, painful, and expensive because his family sacrificed a lot to ensure he went for his sessions and he always had cramps and crisis. He also lived a very restrictive life, not having the freedom to travel far away from his residential location because of poor access to or lack of dialysis centers in locations that he could be traveling to. To him, kidney disease is like a time-bomb waiting to explode. He had agreed with his wife and determined to ensure that his only

son would not live a carefree life like he did, which he felt was what primarily contributed to his health problem. Money was the most challenging part of his experience all through. He was passionate about participating with any non-profit organization to create awareness about CKD and kidney donation. He got his health information from online and through cell phone health tips subscription. He was recruited through invitation letter by a community partner.

Participant 13, Blessing, is a 42-year-old woman from the South Eastern part of Nigeria, a Christian, who she works with one of the federal government departments. She is from a family with history of hypertension; her mother had hypertension before she died, her brother is hypertensive, and she is also suffering from high BP. The only sickness she and her sibling had growing up was malaria and their father always took them to the hospital or would buy drugs from pharmaceutical stores. Presently, she uses her employer's clinic at work or goes to the hospital if she is sick. She has health conscious friends both at work and home. She was not specifically informed about kidney disease by anybody; she got to know about kidney disease through a television program where a doctor was talking about kidney disease and people soliciting for money for kidney transplant. She realized it was a deadly disease and that it is cheaper and better for her to live a healthy life since she is hypertensive. She made a self-commitment to stick to doctor's recommendation and be consistent with taking her drugs. She goes for medical checkup every two months and checks her BP at home daily before she leaves home for work. Her religion and culture do not affect her choice of healthcare, and she will go to the hospital first if she is sick or feels sick because in the hospital you will be

tested first before you are giving a prescription unlike the traditional medicine, and she thinks that the concoctions could be poisonous. Blessing has not received any formal counseling about CKD. She gets her health information from the social media and health tips on her phones, which she subscribed to, and sometimes through friends.

Participant14, Tosin, is a 38 year-old man from the South Western part of Nigeria, a Christian, and a business man. He is the first person in his family to be diagnosed with high BP and eventually CKD. He did self-medication for typhoid for months without any relief before he followed the advice of his medical doctor friend to go to the hospital for a test. The first doctor he saw diagnosed him with high BP and prescribed drugs for him without running any tests. When the pains and unknown symptoms continued, he had to see another doctor who diagnosed him with CKD after running series of tests, and that was the first time he was heard of CKD. Tosin is another case of misdiagnosis and late presentation.

"Before then, I was just going through pain and agony because the doctor who treated me earlier discovered that I had high blood pressure and just gave me some medications without running any tests to know what actually caused it."

He went through dialysis for a year and six months, and three sessions per week. By the time he was preparing for transplant he had used up all his savings and exhausted every source of financial help from church and family members, and friends. His wife who was pursuing a postgraduate degree had to abandon it because of lack of funds. He had to use the media for public financial appeal, which helped him to raise enough fund for his transplant. He still depends on friends and the public appeal fund for his post-transplant

drugs. He was scared that the new kidney may relapse because of the high cost of drugs that are not readily available in Nigeria, and he was running out of funds.

He gets his health information from the Internet, and his culture and religion do not affect his choice of healthcare. Because of experience, he has reached a decision with his wife that they would not engage in self-medication again, and must seek a second opinion on health-related issues from a medical doctor. Also, his wife and son have gone for a health checkup which the family took for granted. He was recruited through poster.

# **Data Analysis**

After the transcribed data was printed in large size fonts for better view with three-lined space and organized in data files, the responses were thoroughly reviewed and analyzed through a four-step process. In the first step, I systematically read through the transcribed data several times and carried out a critical reflection of the information from each participant's perspective and experiences without doubt for general understanding. In the process, I made some reflective notes in the margins, which I later listed in my dissertation memo, which assisted in the development of the initial codes. In the second step, I transferred all the responses into a spreadsheet that I created to enable me compare responses from individual participants, which enabled me to get a better understanding and make sense of the information provided as a whole. It also assisted me in identifying the detailed information contained in my collected data. The third stage involved highlighting participants' statements, comments, or words that cut across the majority of the responses and are directly relevant to the phenomenon being studied. I used the

constant comparative method of analysis in the coding process whereby the initial codes are revisited several times until I was sure that no new themes could emerge.

As preliminary themes emerged from the raw data, I placed them into meaningful general categories because investigations must have thematic expressions that can be broad and link different many expressions or more focused and link very specific type of expressions (Ryan & Bernard, 2003, pp. 85-109). In the fourth step, I reexamined the identified preliminary major and minor categories to see how they could be synthesized into new themes for good understanding of CKD awareness and the effect of cultural beliefs on healthcare seeking behaviors in Nigeria. Every category that did not relate to the understanding of CKD awareness, perceptions and personal experiences, and cultural effect was eliminated as the connected categories were merged. It was only at this point that the participants' responses were changed into third person expressions without changing the meaning content of the participant's responses. Every day language about individual awareness of CKD, perceptions or experiences of CKD, and cultural effect was used for the reframed and new merged descriptive themes (Giorgi & Giorgi, 2003) based on the relationship between the interview questions and participants' responses. The descriptions of the identified themes are provided below.

### Themes Identified

The purpose of this study was to discover the level of CKD awareness in Nigeria, whether cultural beliefs affect individuals' health seeking behaviors, and also the meaning of CKD from the personal perspectives and experiences of individuals who have gone through renal replacement and those with family history of diabetes, or

hypertension, or CKD. It also revealed whether individuals could be aroused or motivated to respond to recommended adaptive measures that they could positively implement if they perceived they were vulnerable to CKD, and that the severity could be high when compared with the low cost of recommended adaptive response. Because individuals' willingness to perform the recommended coping response based on individual's response efficacy and self-efficacy, is what arouses, sustains, and directs protective health behavior by individuals (Rogers, 1975).

I noticed that during the interviews most of the participants found a voice and used the opportunity to vent suppressed emotions, while some gained self-awareness as they recounted their stories and experiences (Colbourne, 2005). I presented below are the findings and the codes that represents each theme and the part of the data that it is associated with, and what the findings mean to the study participants. I also discussed the analysis of protection motivation theory as it relates to the research questions.

### **Lack of Awareness**

Participants mostly described what they know about CKD as 'nothing' and few had limited knowledge of the functions of kidney through a biology course they took in school. The first time some of them heard about CKD was from general information in the newspapers or television when individuals were soliciting for financial assistance for kidney transplant or dialysis without taking any "special interest" or "understand" what it means because not much was said about it. They did not know the risk factors and how it could be prevented, and some did not think about it again "until they were diagnosed with CKD" or a relation was diagnosed with CKD. Only the participants who have either lost

a family member to CKD or already had kidney transplant could tell the risk factors, although some family members had general knowledge of what could cause CKD.

In responding to what do they know about CKD and what can cause it, five participants stated

"I got to know about it after my cousin's death when we were told what killed her...I do not really know much about it;" "I got to know about it through the news and newspapers when they talk about celebrities or other people that are soliciting for financial...but I really did not understand how serious it is because it was not happening to anybody around me;" "I did not really know much about chronic kidney disease;" I know very little about kidney disease. I only know the functions of the kidney through my secondary school biology class. But I do not know what causes kidney disease;" "I do not know anything about CKD... I first heard about CKD when the doctor ... told us what killed our mother in March, 2015;" "We were taught in secondary school that the kidney cleans the blood ....And if the kidney is not functioning well that it could lead to other diseases;" "I heard about kidney disease ...through general information when people talk about those that have gone for kidney transplant, though I did not understand what it is or means....I did not know what could cause it until early January 2015 when my father was diagnosed of kidney disease;" "I do not know anything about kidney disease. The first time I heard about kidney disease was in February of this year when my doctor told me that I have a kidney disease after a test."

Because of the low level of CKD awareness in Nigeria, majority of this group also did not know the risk factors and how it could be prevented. Even individuals from families with either history of diabetes or high BP or both, and in some cases also hepatices or HIV did not know that they were at high risk and could develop CKD. And most of the participants suffering from hypertension or high BP or diabetes were not counseled by their primary healthcare providers about the link between their illness and CKD, which could enable them to take the necessary care to prevent CKD. Lack of healthcare education or public enlightenment programs contributed to very poor attitude to healthcare screening, and as a result many people at risk of developing CKD did not know their health status.

### **Source of Health Education**

For the question on how the participants get general health information and information about diseases like CKD, the responses revealed that the majority of them got their information mostly from unauthenticated sources, such as the Internet, general television programs, especially if there was an outbreak, or subscribed to telephone health tips, or through local traditional drug hawkers, or just by chance. This is evidence that there are no standard health educational programs in Nigeria that could inform healthcare providers and the general population about disease such as CKD and its complications or consequences.

#### **Preventive Medicine**

In describing how often they go for medical checkup, post kidney transplant participants, Andrew, Lanre, and Habiba indicated that they "rarely" went for medical

checkups or would go for a whole year or years without going for "it" before they were diagnosed with CKD. Femi, a diabetic patient had not been to any hospital or health center "all his life" up to the point he was forced to do so because of his health condition. The general poor healthcare culture in Nigeria attributed much to the reason why the few people who had access to healthcare would only go to the hospital "once in while" or "hardly" went to the hospital for medical checkup, and instead preferred to do more of "self-medication."

### **Cost of Care**

The group described the increasing economic hardship and high cost of access to healthcare as why they indulged in self-medication and concoction for "familiar" symptoms to cut costs. Those who preferred to go to the hospital found that the long distance to most hospitals and the cost of tests increased the general cost of care, which they could not afford. Lanre lost his mother to CKD because there was only one dialysis center that was four hours' drive from their home with limited care, and people had to queue for weeks while waiting for their turn for dialysis. His mother died without getting the care she needed. Aisha's family preferred kidney transplant to dialysis for her husband, but it was "beyond" their reach. Her husband was on dialysis for almost two years, and when they "could not afford it any longer, his health degenerated and he eventually died at home." Gladys said that her cousin died from CKD disease because they "did not have money to fly her abroad for kidney transplant." And Michael's father preferred to do kidney transplant, but they did not have the required money, and even for

the dialysis, it was only through the "financial support" they got from their church members and other caring individuals that sustained them until his father died.

Some of the diabetes and high BP patients diagnosed with CKD after they had spent so much money on tests, and realized how much it would cost to be on dialysis or do kidney transplant would just go home and wait for death because of their inability to go for the recommended treatment. Femi responded that he was "shocked and devastated" about his CKD diagnosis because he could not "financially manage another health problem" after he had already spent all his money on "all sorts of tests and diabetes" treatment. Majority of this group indicated that money was the most challenging aspect of their experience. In her response, Aisha stated "we were just begging for money from even people we did not know." In a country where 64% of her population is living below poverty level (UN, 2016), the fact is that psychologically, most people would get disorganized because of the cost of treatment; just give up and eventually die without getting any care or proper care.

## **Advanced CKG Stage**

Lack of healthcare screening, awareness of CKD and its risk factors, self-medication, wrong diagnosis, and poor healthcare management mostly attributed to late stage presentation of CKD for proper treatment for this group. Poor health management and unprofessional attitude of some healthcare professionals worsened the situation. Habiba, in responding to how and when she heard about CKD noted that the first doctor she saw "just kept me under observation and …travelled to the US" while she was waiting even after telling her that she could be suffering from CKD. This doctor did not bother to

refer her to a specialist who could take proper care of her. She had to see another doctor when her health was deteriorating who then referred her to a specialist. Also, initially she was being treated for malaria instead of diabetes. Andrew had swollen legs and was asked by his doctor to drink a lot of water to "flush his system" without the doctor conducting any test. Then he started experiencing foamy urine, unusual taste butts and dizziness. According to him, "things really got worse" before he was referred to a kidney specialist because of the initial wrong diagnosis. Femi indicated that at the initial stage of his sickness that he was taking a traditional medicine, which was what he "grew up taking" but his sickness was not responding. It was only when his sickness became "worse" that he was forced to go to the hospital and was diagnosed of diabetes and CKD.

Sheriff was brought up by a mother who was a nurse and a father who insisted on medical care, but had resorted to "self-medication most of the time" because of "lack of fund." His mother was treating his father for pneumonia at home and was only taken to the hospital "when he was not responding to treatment at home." That was when he was diagnosed with CKD, but they lost him to CKD because of self-medication and wrong diagnosis that led to late presentation and his death.

### CKD Burden

Each participant in this study who has either been through kidney transplant or has a family member who has, or family members of individuals going through dialysis, or individuals suffering from kidney stone or diabetes or high BP experienced individual and/or family burden in different ways. Some relief came in the form of support they had either from family or organizations or individuals. Only 5 of the 14 participants had

health insurance through their employment or spouse's employment. Other participants took care of their healthcare expenses themselves. In responding to what kidney disease mean to them, their experience and how it has affected them in order to understand their perception of CKD, some of the individual reactions were as follows:

Femi: "It means more financial burden for me and my family, and I do not know

how we are going to manage because I have really exhausted financial

support from family...it's just painful."

Aisha: "It means widowhood and suffering...It is very painful and killing....We

sold practically everything my husband had as a property, and now at

young age I have to take care of four young children...it is painful and

expensive"

Michael: "It is not a disease that people can play with because it is very

expensive....You will not have rest of mind because you are thinking

about how to get money for dialysis and what will happen to your family

if you die...It has really affected our family a lot because every money we

have is spent on dialysis."

Adams: "...my diabetes and high BP have affected my erection; I no longer have

full erection."

Habiba: "It is horrible; ...not something you can wish even your enemy. It is

draining psychologically, emotionally, mentally, and financially."

Sheriff: "It means something that destroys, dangerous, and it hurts...a deadly

disease. It has affected me and my younger ones, especially since after

my father's death..."

Kelvin: "Death sentence. Because over time, family members I know who had

kidney disease never made it through."

During dialysis and/or kidney transplant, participants revealed that sometimes family members would take their "frustrations" out on them because of the agony they were going through, which made it look as if "the whole family was sick." Some of them had to travel "long distance" to get to the dialysis center, and sometimes all the machines would have been occupied by the time they got there, so they had to wait for 2 to 3 hours, which created additional "burden." Being on the machine for four hours each time and having to wait for a while to recover made it very "stressful." Dialysis also "restricted" their movement, making it almost impossible for patients to travel outside their location because of "poor access" to dialysis centers at locations they could be traveling to. Lanre said that it was a very "tormenting" period for him because it was very difficult to live a "restrictive" life.

Andrew described his dialysis experience before transplant as "terrible and stressful;" he almost lost his life twice because his blood pressure was always dropping and he reacted to blood transfusion. And because he was not counseled about the effects and what to expect after transplant, "it was difficult for me to adjust to the restrictions after the surgery," and not being able to see his family members affected him emotionally and psychologically. Lanre on his part had crisis during dialysis period and even slumped

once because her BP was high and he had cramps. Habiba described it as a very "rough" period for her and her family, and "physically and mentally" draining because she felt so "lonely".

Most of the participants expressed that they experienced spirit of hopelessness because of their condition. Abraham in describing how he felt when he was informed that he had CKD stated that he was "worried and thought it was the end of life." Aisha said she realized that her family was in a "big hole" while Femi felt like "committing suicide" because he did not want his children have memory of him as a father who was always sick and could not provide for his family. And Andrew stated that he was really shocked and it was like his "world was crashing" on him.

# **Cultural and Religious Effect**

In addressing the third research question, how culture and personal healthcare seeking behaviors affect CKD awareness in Nigeria, I looked at work environment, academic environment, living environment, and any other thing that identifies a way of living for a group of people. Majority of the participants were influenced at some individual levels by their culture or religion on how to manage their health problems and their health-seeking behavior in one way or the other. This shows that there is link between individual's cultural practices and their healthcare practices or preferences in Nigeria, which could affect them negatively or positively. Culture influences how and where individuals experience and manage health problems, including CKD, and how to evaluate recommended strategies for prevention and treatments (Mendell & Novak, 2005; Narayan, 2002; Furnham et al., 1999).

Andrew's living environment affected his healthcare seeking behaviors. He lived in an environment where it took a while to get an appointment to see a doctor, which was not what he was used to, that "discouraged" him and he never bothered to see a doctor again for the years he was abroad. He started doing self-medication, which continued even after he got back to Nigeria and got a job that provided basic health insurance. Femi grew up in a culture that believed in traditional medicine, which influenced his choice of healthcare.

"Our people believe in traditional medicine, so that is what my parents used and ministered to us any time we fell sick. Also, when I was young, my mother gave us 'agbo', a traditional medicine made up of herbs every month for prevention of malaria or other diseases I do not know about."

His first preference for healthcare was a traditional medicine doctor any time he had unknown health signs, but readily took 'agbo', a standard traditional medicine that was readily available to him for known symptoms according to him. Although alcohol drinking affected Kelvin's health, but he would still drink to please his friends because in his culture, drinking alcohol was a symbol that you were a 'real' man. Sheriff would pray first each time he felt sick and would only go to the hospital if he did not get better. When he told his mother who happened to be a nurse that his doctor said he needed surgical operation because of kidney stone, she discouraged him about the surgery and asked him to 'just pray.' Banji grew up with parents that only did herbal medicine and would only go to the hospital if they were forced, but that his current religion, which is Christianity, encouraged him to see a medical doctor for healthcare. Aisha's parents

generally used local herbs and consulted medicine men for difficult health problems. She also married into a family that did same and as a result, traditional medicine had been her way of life in terms of healthcare. Lanre grew up with parents, who were strict and preferred hospital care to traditional care, but the University environment influenced him negatively and he started smoking heavily even at home, which drastically affected his health. And Habiba said that her culture believes in traditional medicine, which was always very accessible and inexpensive.

# **Inconsistent Finding**

Malaria is a common disease in developing countries, and according to the National Malaria Control Program (NMCP), (2016) in Nigeria, 26% of 627,000 people who die from malaria each year are from Nigeria. As a result, most Nigerians readily assume every sign of fever as malaria and start self-medication either by taking preferred drugs bought from local drug stores or traditional medicine like 'agbo' that is readily available in the local markets and from hawkers. The same was the case with this group, notwithstanding their individual religious or cultural background and their socioeconomic status, and it contributed much to the late presentation of CKD and/or misdiagnosis. I called it *malaria culture* because every member of this group claimed he/she knew the symptoms of malaria and did self-medication for it without going to the hospital or a healthcare center for proper tests and diagnosis.

When Aisha's husband was sick on and off, they thought he was having his "usual malaria sickness" and were treating him for malaria with the "normal herbal concoction" they took for malaria in their family. He was taken to the hospital only when

he became very sick and was diagnosed of CKD and he eventually died. Femi said that the only sickness he knew he had always was malaria and he always took herbal medicine for it, not knowing that he was suffering from diabetes that led to his CKD, which was diagnosed late. Blessing stated that she was "prone to malaria", and always treated herself for malaria with drugs he bought from pharmaceutical stores. She only found late that she had high BP too. Habiba indicated that she would not go for two months without having malaria. She did not know that she was suffering from CKD and was being treated at home for malaria and diabetes for almost three months even though she had access to healthcare. She had to go to the hospital when she started having complicated symptoms and was diagnosed of CKD. According to Lanre, the only sickness he suffered from was malaria up to the point he was diagnosed of diabetes and high BP. Andrew in describing his health experiences said "nothing much except the regular malaria" until 2013 when he was diagnosed of high BP. And Kelvin said he had "malaria crisis" always as a child.

# **PMT** and Its Effect on Participants

The major assumptions of Rogers (1975, 1983) PMT are (1) that individuals are likely to respond to adaptive measures if they believe that they are vulnerable to CKD; (2) that the severity is high, like CKD complications; (3) the adaptive response associated costs are small, and (4) that they can confidently implement the recommended response (Boer, 1996). Individuals weigh their perceptions against perceived benefits for the overall influence on a recommended behavior (Becker, 1974).

The threat appraisal of the PMT made Aisha to consider the high severity of CKD and how much her family had lost to CKD in terms of life and material things, as a result has been to the hospital for a medical checkup for the first time in her life. She also took her mates and mother in-law along for screening in order to avoid going through the same experience again.

"I have been to the hospital once for a basic health checkup as advised by his doctor so that I will be alive to take care of my young children since my husband is no more. He believes that if we had found on time that my husband had diabetes and started treating and managing it properly that it would not have affected his kidney. I also took my mother in-law and the other wives to the hospital for screening."

This shows how PMT can effectively change individuals' cultural beliefs about diseases like CKD if they recognize that it is severe and that they are vulnerable, can efficiently screen for risk factors that could help to prevent the disease and its complications.

Banji is a healthcare provider who sometimes works with CKD patients on dialysis and has the knowledge of the difficulties they encounter. Because he is from a family with history of kidney disease, hypertension and hepatices and therefore could be vulnerable to CKD he regularly checks his blood pressure and sugar level. He also does annual blood work to check for hepatitis and HIV, because he could confidently implement the recommended response.

"I work in the hospital and have *access* to healthcare .... Since I know that I have kidney disease, diabetes, and hepatices in my family I now do an annual Blood work to check for HIV, hepatices C, blood pressure check and blood sugar for diabetes."

Sheriff who lost his father to CKD primarily because he was doing self-medication for the wrong disease, and had been suffering from kidney stone preferred hospital care to self-medication because of his perceived susceptibility and severity even though he could barely afford it. His father's death to CKD has also motivated him to advocate to parents who suffer from CKD to tell their children and encourage them to go for screening for early identification and proper management or prevention. In responding to the question on how he felt when he was informed about CKD he admitted that he was scared and affected emotionally mainly because of his children.

"I feel bad and scared because I lost my father to it, and when I was told that I had kidney stone I also became very worried because I think I could die like my father from kidney disease. It affects me emotionally, especially when I think about my children because I want to be there for them.... When I wake up at night and look at my children and feel scared that the disease might kill me like it did to my father and I will not be there for them. Most of my savings and the money I make are now spent on tests because of my health problem. Also, parents suffering from kidney disease should tell their family members and also encourage them to go for a test."

Andrew's twin brother has been motivated to start taking good care of his health medically and to live a healthy living life because of what Andrew went through as a dialysis patient and during his kidney transplant, including the effect it had on their family. When discussing how the experience has affected him and his family he indicated that he has gained more knowledge about his health and that his family now eats healthier than before.

"We are more prayerful now and eat healthier than we used to do. My twin brother is now taking good care of himself – medically, and living a healthy life so that he will not go through what I have been through. I would say that every member of my family is now more health conscious than we were. We try to see expert opinion in practically everything, just to make sure we are doing the right thing."

Since Michael's father passed on, he has taken a second look at his health and lifestyle by evaluating the possibility of him being vulnerable to CKD. Because of the fear appeal, he just would not want to go through what his father went through. He has decided that he will go to the hospital at least once annually for health checkup, in addition to checking his BP at home with domestic BP kit.

Because Charity abruptly lost her mother to CKD's complication because of self-medication and traditional herb medicine intake, she has a new perspective on taking care of her health. She has decided to heed to a doctor's advice by ensuring that she and her sibling would at least go for medical checkup as soon as they can afford it. The doctor

informed her that if her mother had been going for an annual checkup, her condition would probably have been diagnosed early enough for proper care or management.

Like I said before, my religion believes in healing miracles through prayers and that is what I believe in. However, one of our church members, a doctor, has advised me to try as much as possible to go to the hospital with my brother, at least once every year to check ourselves.

According to her, we may not know if we have diabetes or hypertension that causes kidney diseases. Although we do not have money now, but I will ensure my brother and I do that as soon as possible.

Persuasive component of the PMT was what aroused protection motivation in Charity, which made her to take the doctor's recommendation for health screening. CKD prevention became the motivation for this participant, considering its severity and that she and her sibling were vulnerable, and that screening was an effective way to prevent them from having CKD.

Blessing who is hypertensive and from a family with history of hypertension and stroke indicated that when she realized that it is cheaper and better for her to live a healthy life, she made a self-commitment to stick to doctor's recommendation and be consistent with taking her drugs. She goes for medical checkup every 2 months and checks her BP at home daily before she leaves home for work. Her reaction when she was informed about CKD as a high BP patient is as follows:

I feel that it is a deadly disease; it's like a time bomb, and I do not want to die. And since I am also on drugs ... and was told I had enlarged heart.

So I made a self-commitment that I will stick to doctor's recommendation and be consistent with taking my drugs.

### **Summary**

This chapter provided information about the barriers or challenges encountered in recruiting study participants in developing countries like Nigeria because of the poor economic situation and the misleading effect of malaria culture in Nigeria. My findings revealed that lack of standardized public health education, counseling, and CKD awareness; high cost of health, and poor healthcare access could lead to self-medication, late presentation, misdiagnosis, and death from CKD. Based on the data I collected, there is evidence that fear appeal or health threat of the PMT could motivate individuals with history of CKD, diabetes or hypertension to evaluate the possibility of being vulnerable for CKD and the cost or pains of its severity and take action to prevent it. In chapter 5, I will provide the interpretation of the study findings, implications for social change, recommendations, and the conclusions of the study.

## Chapter 5: Discussion, Conclusions, and Recommendations

The negative impact of CKD globally and in Nigeria has been well documented. There is a very high prevalence of CKD in Nigeria, but what is not clear is whether awareness of CKD and its risk factors, and cultural beliefs have contributed to increased morbidity and mortality from CKD in Nigeria. This study was carried out to examine the level of CKD awareness among individuals with family history of diabetes, hypertension, or kidney disease, and the effect of cultural beliefs on awareness of CKD in Nigeria.

Also, I explored the meaning of CKD according to individuals who went through kidney transplant successfully. Before this study, there was no documentation on whether and how cultural or religious beliefs affect health-seeking behaviors in Nigeria. I conducted a phenomenological study to understand the personal views of participants based on indepth interviews (see Morse, 1994).

The study revealed very low levels of understanding and poor knowledge of CKD in Nigeria, even among at-risk individuals who were suffering from diabetes or hypertension or CKD, or a combination of the risk factors. There was no standard healthcare education program and there was limited or no access to healthcare because of its cost, making the situation in Nigeria worse. The government has not provided any form of health care intervention for CKD patients and their families. I also found that most participants were experiencing so much difficulty that having one meal a day was a big problem due to the economic recession. Therefore, it has become practically impossible for most people to afford screening costs. The economic crisis in Nigeria and the extreme poverty have led to a growing number of individuals resorting to self-

medication, late presentation of diseases, and soliciting for financial assistance for healthcare treatments for dialysis and kidney transplant that many Nigerians cannot afford. Based on the interview data, people would go to the hospital only when they cannot treat their illness with concoction from traditional medicine men or through self-medication, and if their health situation has become unbearable. The study findings also revealed the link between a person's cultural practices and healthcare preferences in Nigeria, and that individuals' belief about diseases like CKD can be changed if they recognize that the disease is severe, that they are vulnerable, and that the can prevent it.

## **Interpretation of the Findings**

#### Lack of awareness

Study data strongly suggested that lack of CKD awareness in Nigeria led to late presentation among this group of interests as most of them signified that they first heard about CKD when they or their family members were diagnosed with CKD. This is consistent with Alebiosu's (2002) findings of lack of awareness about CKD and its risk factors even when CKD was the third reason people were medically admitted at the teaching hospital where the study was conducted. Because this study group was not aware of CKD, they also did not know about its risk factors and how to prevent it. For instance, a participant's mother collapsed and died of CKD complications without knowing that she had it. Even those who had access to health care did not know the importance of screening periodically. Lack of education and counseling of individuals suffering from hypertension or diabetes by primary health care providers contributes to the high prevalence of CKD in Nigeria.

### **Source of Health Education**

In responding to the interview question on how participants get their health information, I discovered that there was no standard health education for the masses. Participants indicated that they got their health information from the Internet or general television programs or subscribed telephone health tips, or through local drug hawkers or by chance. Interview findings showed that lack of health care education and public education programs contributed to an apathetic attitude toward health care screening, and as a result many people at risk of developing CKD did not know their health status.

## **Cost of Care**

Most participants identified money as the most challenging aspect of their experience. Aisha stated "we were just begging for money from even people we did not know." Some of the few who had access to healthcare through employment or their spouses' employment also complained of the cost of care because they only had limited healthcare access, which means they had to bear the cost of primary care. As a result, they did not bother to go for a health screening or periodic medical checkup because most of the time any diagnosed problems would be covered at their own expense. In a country where most people are living below poverty level, the fact is that psychologically, most people would get disheartened because of the cost of treatment and give up, and eventually die without getting any attention.

The number of people soliciting for financial assistance for dialysis or kidney transplant has continued to grow in Nigeria. For instance, a daily newspaper (TheGuardian) of January 7, 2016, had a publication of a mother of five soliciting for

N6, 000,000 (\$18,462) for a kidney transplant. In July 15, 2016, a young man through another national daily newspaper (The SUN) was seeking for public assistance for N10, 000.000 (\$30,769) needed for him to go for a kidney transplant in India, according to Ezeh. In his the publication of July 29, 2016 of the same newspaper, Bobby reported that an actor was soliciting for N11, 000,000 (\$33,846) for kidney transplant. On August 11, 2016, a 20-year-old young man was soliciting for N7, 500,000 (\$23,077) to enable him to go for a kidney transplant through the THIS DAY Newspaper as reported by Umechiedo. Although it could be considered deadly, most patients have resorted to herbalists who they deem as the cheaper alternative for their health care needs.

## **Advanced CKD Stage**

The prevalence of advanced CKD was found to be very high because of self-medication, under diagnosis, poor health management and unprofessional attitudes of some healthcare professionals. A participant did not understand how a doctor would abandon her and travel outside the country without a word of advice or medical recommendation after telling her that she could be suffering from kidney disease.

Another participant was asked to drink water to flush his system, and the doctor did not carry out any test to find out what he was suffering from. Some participants lost their family members who were already at advanced CKD because of self-medication that led to late presentation of their condition.

#### CKD Burden

Every participant experienced individual and family CKD burden because only very few people have minimum access to health care. Participants went through serious

emotional, psychological, and financial crisis because of their health condition. The CKD burden was so much that one person considered committing suicide. Another participant after he was informed how much it would cost to do a kidney transplant, decided not to spend what he had for it and wrote his 'will' so that his wife could use the money to take care of their children after he had passed on. He only agreed to go on with the kidney transplant when his wife threatened to kill herself so that she would die before him.

Unfortunately, he died after his kidney transplant and my second interview with him. His young wife is now left alone to take care of their children with almost no financial assistance from anybody, and every member of his immediate family and extended family depended on him. Those who survived their kidney transplant also experience stress because of restrictions from adjusting to a new health status and the funds needed to purchase the required imported drugs that would enable them to live a close normal life.

### **Cultural and Religious Effect**

Most participants expressed that they were influenced by their personal beliefs based on their living or upbringing environment or family orientation concerning their health. Participants who grew up in families that believed in traditional medicine chose the same when they were suffering from CKD risk factors and CKD, and those who believed in their religion prayed first for healing, and only went to the hospital when they did not get well. Those whose family orientation encouraged orthodox medicine and had access to healthcare preferred hospital care. Also, a participant whose culture sees alcohol drinking as a sign of being a 'real man' would drink alcohol with friends even when he

knew it would have a negative effect on his health condition. Upbringing and environment play a vital role in lifestyles and the choices concerning health care.

### **Inconsistent Finding**

Malaria was a common health concern among participants. All participants claimed malaria as the only known sickness they suffered from and most did self-medication to treat it. It turned out that they were also suffering from CKD risk factors, which led to late presentation and sometimes death. Some participants self-diagnosed and treated themselves for malaria only to be diagnosed with CKD at late stage. One participant was treating herself for malaria only to find out that she had high blood pressure. Another participant who had access to health care was also self-treating for malaria and was eventually diagnosed with diabetes.

## **Reflection of PMT Principles**

The major assumptions of Roger's (1975, 1983) PMT are (a) individuals are likely to respond to adaptive measures if they believe that they are vulnerable to CKD; (b) the severity is high, like CKD complications; and (c) the adaptive response associated costs are small. The effect of PMT principles in this study conforms to the findings of other studies, such as, the study by Grindley et al. (2008) where PMT was successfully used as a screening tool in a sample of individuals with orthopedic conditions to predict patient adherence behavior.

The threat appraisal of the PMT made Aisha consider the high severity of CKD and how much her family had lost to CKD in terms of life and material things; as a result she has been to the hospital for a medical checkup for the first time in her life. She also

took her mates and mother in-law along for screening to avoid going through the same experience again. She reported:

I have been to the hospital once for a basic health checkup as advised by his doctor so that I will be alive to take care of my young children as my husband is no more. He believes that if we had found on time that my husband had diabetes and started treating and managing it properly that it would not have affected his kidney. I also took my mother in-law and the other wives to the hospital for screening.

This shows that PMT can be used as a tool to effectively change individuals' cultural beliefs about diseases like CKD if they recognize that it is severe, that they are vulnerable, and that they can efficiently screen for risk factors that could help to prevent the disease and its complications.

Banji is a healthcare provider who sometimes works with CKD patients on dialysis and has the knowledge of the difficulties they encounter. Because he is from a family with history of kidney disease, hypertension and hepatitis, and therefore he could be vulnerable to CKD, prevention of CKD motivated him to do a regularly blood pressure and sugar level check. He also included annual blood work to check for hepatitis and HIV, because he could confidently implement the recommended response. Banji reported:

I work in the hospital and have *access* to healthcare .... I know that I have kidney disease, diabetes, and hepatitis in my family, so I now do an annual

Blood work to check for HIV, hepatitis C, blood pressure check and blood sugar for diabetes.

Sheriff lost his father to CKD primarily because of self-medication for the wrong disease, and had been suffering from kidney stone. He preferred hospital care to self-medication because of his perceived susceptibility and severity even though he could barely afford it. His father's death from CKD also motivated him to encourage parents who suffer from CKD to tell their children and encourage them to go for screening for early identification and proper management or prevention. In responding to the question on how he felt when he was informed about CKD, he admitted that he was scared and affected emotionally mainly because of his children.

I feel bad and scared because I lost my father to it, and when I was told that I had kidney stone I also became very worried because I think I could die like my father from kidney disease. It affects me emotionally, especially when I think about my children because I want to be there for them... When I wake up at night and look at my children and feel scared that the disease might kill me like it did to my father and I will not be there for them. Most of my savings and the money I make are now spent on tests because of my health problem. Also, parents suffering from kidney disease should tell their family members and also encourage them to go for a test.

Andrew's twin brother has been motivated to start taking good care of his health and to live a healthy lifestyle because of what Andrew went through as a dialysis patient

and during his kidney transplant, including the effect it had on their family. When discussing how the experience affected him and his family he indicated that he has gained more knowledge about his health and that his family now eats healthier than before.

We are more prayerful now and eat healthier than we used to do. My twin brother is now taking good care of himself – medically, and living a healthy life so that he will not go through what I have been through. I would say that every member of my family is now more health conscious than we were. We try to see expert opinion in practically everything, just to make sure we are doing the right thing.

Since Michael's father passed away, he has taken a second look at his health and lifestyle by evaluating the possibility of him being vulnerable to CKD. Because of the fear appeal, he just would not want to go through what his father went through. He has decided that he would go to the hospital at least once annually for health checkup, in addition to checking his blood pressure at home with domestic BP kit.

Because Charity abruptly lost her mother to CKD's complication due to self-medication and traditional herb medicine intake, she has a new perspective about taking care of her health. She has decided to heed to a doctor's advice by ensuring that she and her sibling would at least go for a medical checkup as soon as they can afford it. The doctor informed her that if her mother had been going for an annual checkup, her condition would probably have been diagnosed early enough for proper care or management. She stated:

Like I said before, my religion believes in healing miracles through prayers and that is what I believe in. However, one of our church members, a doctor, has advised me to try as much as possible to go to the hospital with my brother, at least once every year to check ourselves.

Although we do not have money now, but I will ensure my brother and I do that as soon as possible.

The persuasive component of the PMT was what aroused protection motivation in Charity and made her to take the doctor's recommendation for health screening. CKD prevention became the motivation for this participant, considering its severity and that she and her sibling were vulnerable, and that screening was an effective way to prevent them from having CKD.

Blessing is from a family with health history of hypertension and stroke. She indicated that when she realized that it is cheaper and better for her to live a healthy lifestyle since she is hypertensive that she made a self-commitment to stick to doctor's recommendation and be consistent with taking her drugs. She goes for a medical checkup every two months and checks her blood pressure at home daily before she leaves home for work. Her reaction when she was informed about CKD as a high BP patient is as follows:

I feel that it is a deadly disease; it's like a time bomb, and I do not want to die. And since I am also on drugs ... and was told I had enlarged heart.

So I made a self-commitment that I will stick to doctor's recommendation and be consistent with taking my drugs.

Based on the data I collected, there is evidence that fear appeal or health threat of the PMT could motivate individuals with a history of CKD, diabetes or hypertension to evaluate the possibility of being vulnerable for CKD and the cost or pains of its severity and take action to prevent it.

# Limitations of the Study

The main religious groups in Nigeria are Christians and Muslims. The primary limitation was that some members of the Muslim community approached were not willing to participate because they thought that the since I am a Christian that I was investigating their religion. There has been a great suspicion between Christians and Muslims in Nigeria since the Boko Haram Islamic terrorist group started killing Christians even in the churches. As a result, the study data contained minor information on the perceptions of members of the Muslim community on CKD. This could affect study transferability and the generalizability of the result because each religious group has its own social values and beliefs affect the way their members respond to good health care interventions (Kline & Huff, 2007).

Another limitation is that this study was done in Abuja, the federal capital territory of Nigeria in collaboration with community partners that includes two hospitals and a dialysis center. The representatives of the community partners sent out invitational letters and provided strategic positions for posters to be pasted. This means that most of the participants were those who already had access to the hospitals and dialysis center with the exception of the few who were recruited through flyers given to participants.

Not much of the personal views and perceptions of the rural dwellers about CKD were included in this study, and also could affect transferability of the result.

### Recommendations

I recommend that a similar study should be carried out in rural areas and local markets so that those who do not have access to health care or with very limited access to community health centers can participate and also benefit from the awareness created through participation. It can also help to have a better understanding of the personal perception of these rural dwellers about health and how their culture affects their health care choices, which will help in knowing how best to create awareness of health-related issues as CKD. I also recommend a study that will cover the patient-provider communication that will enable the researcher to know whether healthcare providers communicate with their patients, especially at-risk patients, in cultural appropriate manner during counseling about risk factors or screening.

# **Implications for Social Change**

Individuals who participated in this study have demonstrated the urgent need to create awareness for CKD, its risk factors, and complications as CKD epidemic levels and burden continues to increase in Nigeria due to lack of knowledge, under-diagnosis, late presentation, and the cost of health care. The social change implication is that if individuals are armed with good information about CKD, the risk factors and consequences, and its preventive measures, they could make better and informed healthy life choices. Also, family physicians would be equipped with the information that could enable them to provide adequate care for individuals suffering from CKD, which is a

growing health concern in Nigeria (Murphree & Thelen, 2010). Because when the provider has good knowledge and awareness of CKD, it would likely enable improved patient awareness of CKD risk factors and preventive measures, prevalence, available treatments, and its consequences, such as, high morbidity and mortality rate from CKD. Improved awareness could make individuals take proactive actions for better health outcome and healthy lifestyle. Taking proactive measures for prevention could help in reducing CKD prevalence, burden, and the mortality from CKD in Nigeria. Also, it could serve as a catalyst for the development of cultural appropriate standard health care education programs that could increase CKD awareness and its preventive measures in Nigeria and enable people and healthcare providers understand the importance of preventive measures and early detection of CKD. Because if CKD is identified early through screening, there is the possibility that CKD progression could be slowed, and also prevent the complications and late presentation that may lead to poor outcomes or ESRD or possibly death, and increased health care and economic burden in Nigeria.

The theoretical implication of this study is that although the social and economic background of a person may influence the individuals' health behaviors or choices, however, the PMT threat variables can stimulate protection motivation because of the fear of having CKD. This stimulation can increase awareness of CKD, risk factors, complications, and the preventive measures as they respond to the CKD threat. If people perceive that CKD is severe, that they are vulnerable, and that they can effectively screen for the risk factors, which can help to prevent CKD and its complications, they would most likely be inspired to be proactive and take preventive measures.

### **Conclusions**

The level of CKD awareness in Nigeria is too low. And as the number of people soliciting for financial assistance for dialysis and kidney transplant continues to grow in Nigeria, there is an urgent need for CKD intervention by the federal government of Nigeria. There is no doubt that CKD is a grave burden to individuals suffering from it, and could be a serious burden and threat to the economics of Nigeria if there is no urgent intervention by providing free preventive health care for the low income and rural dwellers, and also subsidize the cost of dialysis and post-transplant drugs.

Since individuals' cultural values could determine how they perceive illness, there is a need for cultural appropriate health education programs by both government and non-governmental health organizations. Considering the fact that Nigeria is a multi-ethnic country, thorough knowledge of the community, family, and individuals is very important for effective communication of CKD risk factors and complications with them through the language, medium and level that will be acceptable to each ethnic or religious group. Health behaviors and attitudes that are acceptable in one culture may not be acceptable in another because of different cultural and religious beliefs. The urgent need for increased CKD awareness cannot be over emphasized because it is only when the physician has good knowledge of a health problem that he can recommend appropriate treatments and management, and the proper implementation of the recommended care primarily depend on the patient's awareness. "Knowledge, they say, is powerful" and "A Healthy Country is a Wealthy Country."

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#### Appendix A: Letter to Healthcare Providers

Date:

Name of Healthcare Provider Organization Address

Dear (Name),

My name is Patience Eze and I am a doctoral candidate at Walden University. I am conducting dissertation research on chronic kidney disease and quality of Care in Abuja, Nigeria to see if cultural beliefs affect what people know about the disease and their main source of knowledge. There is currently no literature on how cultural or religious beliefs affect individual health seeking behaviors, considering the diverse nature of the Nigerian population. Therefore, there is need for information in this area to provide understanding of the personal experiences of those who have gone through chronic kidney disease or renal transfer, which could lead to increased awareness of the risk factors and complications, and improved health lifestyle for prevention.

Your assistance in conducting this important research will be very significant in achieving the purpose of the study. If you are willing in participating, please identify adults who have been treated or are receiving treatment for chronic kidney disease in your hospital and/or dialysis center, or have successfully gone through renal transfer under your care. Identifying these individuals will provide the opportunity to identify their family members who may be at high risk of having chronic disease or diabetes or hypertension because of their family history of the disease. I would like to meet with the identified potential participants to discuss the nature of the study.

Participation is purely voluntary, therefore, participants are free to decide whether they want to participate or not and can withdraw from the study at any time. Any information provided by the participants will be kept absolutely confidential.

I will highly appreciate it if you would call me at (0703) 247-8201 to discuss any questions or concerns you may have about this study and your role in the identification of potential participants. I can also be reached via email at <a href="mailto:name@waldenu.edu">name@waldenu.edu</a>.

Sincerely,

Patience Eze Doctoral Candidate Walden University

### Appendix B: Letter to Participant

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Name of Participant Address

Dear (Name),

My name is Patience Eze and I am a doctoral candidate at Walden University. I am conducting dissertation research on chronic kidney disease and quality of Care in Abuja, Nigeria to see if cultural beliefs affect what people know about the disease and their main source of knowledge. There is currently no literature on how cultural or religious beliefs affect individual health seeking behaviors, considering the diverse nature of the Nigerian population. Therefore, there is need for information in this area to provide understanding of the personal experiences of those who have gone through chronic kidney disease or renal transfer, which could lead to increased awareness of the risk factors and complications, and improved health lifestyle for prevention.

I understand that your time is of essence to you and will appreciate it if you would consider participating in this study. I will be meeting with you on two to three different occasions for about two hours each meeting to enable me to fully understand your experience. Meetings can be held at your preferred private location and you are not required to do anything you feel uncomfortable doing. The purpose of these meetings is to get to know you, and to learn your perceptions about chronic kidney disease and your personal experiences. All information you provided during our meetings will be kept absolutely confidential.

Please contact me at (0703) 247-8201 to schedule a date and time that is convenient for you that we can meet. You can also reach me at <a href="mailto:name@waldenu.edu">name@waldenu.edu</a>. I look forward to hearing from you and discussing this needed study with you.

Patience Eze Doctoral Candidate Walden University

### Appendix C: Interview Protocol

Interview Protocol for Interview Number One						
Name of Interviewer:						
Name	Name of Interviewee:					
Location	on:					
Date:						
1.	Please how would you describe your family background?					
2.	What type of value did your parents attach to health in your family?					
3.	What do you normally do any time you are physically challenged or you feel physically unable to do things you normally do without any problem?					
4.	How does your cultural or religious belief affect the way you take care of your health?					
5.	What have been your health experiences up till this point?					
6.	How would you describe your friends in your neighborhood and work place?					
7.	Is there any other thing you would like to add to the information you provided					

Interview Protocol for Interview Number Two

Name of Interviewer:					
Name	Name of Interviewee:				
Locati	on:				
Date:					
1.	Please describe how and when you first heard about chronic kidney disease?				
2.	Who informed you about it and what were you told you about chronic kidney disease?				
	<ul><li>a. How did you feel when you were informed about chronic kidney disease, that is, how did you received it?</li><li>b. What did he or she tell you could be the next line of action?</li></ul>				
3.	What do you know about chronic kidney disease?				
	<ul><li>a. How often do you go for medical check-up?</li><li>b. What type of screening do you do each time you go for medical check-up?</li></ul>				

	measures that can prevent you from having chronic diseases like kidney
	disease?
4.	What do you know that can cause it?
5.	How do you think that it can be prevented?
6.	What does chronic kidney disease mean to you?
7.	How do you describe your experience going through dialysis/renal replacement?
	a. Please explain what you would have done differently if you had a second chance?
8.	What was the most challenging aspect of your experience?
9.	How has the experience affected you directly and your family?

c. What type of counseling do your medical provider give for preventive

- 10. Please describe how your cultural and/or religious beliefs affect your choice of healthcare.
- 11. Would you prefer to go to the hospital first or for the traditional medicine, and why?
  - a. Please explain why you will choose to go to the hospital/traditional medicine first.
  - b. How does your belief/culture affect your choice of health care?
- 12. How do you normally get general health information and information about diseases like chronic kidney disease?
- 13. What type of health education have you received so far?
- 14. Please describe how the health information you receive has helped your knowledge about chronic kidney disease and/or how it has not?
- 15. Is there any other information about CKD and/or your experience you want to add to the information you have already provided.

Appendix D: Matrix of the Relationship between Research Questions and Participants' Questions

Research Questions	Participant's Questions	
What level of awareness and knowledge do individuals at risk have about CKD in Nigeria?	<ul> <li>Please describe how and when you first heard about chronic kidney disease?</li> <li>What do you know about chronic kidney disease?</li> <li>What do you know that can cause?</li> <li>How do you think that it can be prevented?</li> </ul>	
2. What is the perception of CKD by individuals who have gone through renal replacement?	<ul> <li>What does chronic kidney disease mean to you?</li> <li>How do you describe your experience going through dialysis/renal replacement?</li> <li>What was the most challenging of your experience?</li> <li>How has the experience affected you directly or your family?</li> </ul>	
3. How would culture and personal healthcare seeking behaviors affect CKD awareness in Nigeria?	<ul> <li>Please describe how your cultural and/or religious beliefs affect your choice of healthcare?</li> <li>Would you prefer to go to the hospital first or for the traditional medicine, and why?</li> </ul>	
4. What educational programs about CKD, if any, are in place in Nigeria to inform healthcare providers and the general population about CKD and its complications or consequences?	<ul> <li>How do you normally get general health information and information about diseases like chronic kidney disease?</li> <li>What type of health education have you received so far?</li> <li>Please describe how the health information you receive has helped your knowledge about chronic kidney disease and/or how it has not?</li> </ul>	



## FEDERAL CAPITAL TERRITORY HEALTH RESEARCH ETHICS COMMITTEE

Research unit, Room 10, Block A Annex, HHSS FCT Secretariat No. 1 Kapital Street Area II, Garki, Abuja - Nigeria

Name of Principal Investigator:

Patience Eze

Address of Principal Investigator:

No 50 Usuma Street, Maitama - Abuja, Nigeria.

Date of receipt of valid application:

06/01/2015

### NOTICE OF RESEARCH EXEMPTION

# Study Title: Chronic Kidney Disease Awareness and Quality of Care in Abuja, Nigeria.

The activities described in the submitted application, research protocol and documents have been reviewed by the FCT Health Research Ethics Committee (FCT HREC).

Further to the review, the FCT HREC has determined that in line with the National Code for Health Research Ethics, Section B: - Exemption (research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior) the activities described in the above research protocol meets the criteria for exemption.

Consequently, the FCT HREC has approved the activities as exempt from her oversight.

This exemption dates from 27/01/2015 to 26/01/2016. Please note the National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the code. The FCT HREC reserves the right to conduct compliance visit to your study site without previous notification.

Thank you.

Desmond Emereonyeokwe For: Secretary, FCT HREC

January 27, 2015