

**DEVELOPING AN INTERVENTION MODEL TO MANAGE  
CAREGIVER BURDEN EXPERIENCED BY FAMILY  
CAREGIVERS OF PATIENTS LIVING WITH END-STAGE  
RENAL DISEASE IN NIGERIA**

A thesis submitted to: The Discipline of Nursing, School of Nursing and Public Health College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa in fulfillment of the requirement for the degree of Doctor of Philosophy in Nursing at the School of Nursing and Public Health, University of KwaZulu-Natal

By

**OYEGBILE, Yemisi Okikiade**

Student Number: 212516461

Supervisor

Professor Petra Brysiewicz

February 14<sup>th</sup> 2017

## DECLARATION

I, Yemisi Okikiade Oyegbile, declare as follows:

- (i) That the work described in this thesis has not been submitted to UKZN or other tertiary institutions for the purposes of obtaining an academic qualification, whether by myself or any other party.
- (ii) That my contribution to the project was as follows:  
As the principal researcher of the project, I conceived and designed the study. I conducted both qualitative and quantitative data analysis, interpreted the findings and wrote the manuscripts, and I am the first and corresponding author of the manuscripts considered in the thesis and submitted to different journals. This thesis was structured and written by me.
- (iii) That the contribution of others to the project was as follows:  
Prof. Petra Brysiewicz was the experienced study supervisor and intellectual contributor. She advised during the conception and design of the research project and supervised and assisted in the data analysis and interpretation of the findings. Prof. Petra Brysiewicz reviewed the draft manuscripts, approved them for submission to journals and is a co-author of the manuscripts considered in the thesis.

Yemisi Okikiade Oyegbile

Signed \_\_\_\_\_ Date: 25<sup>th</sup> August 2017

Prof. Petra Brysiewicz

Signed \_\_\_\_\_ Date: 25<sup>th</sup> August, 2017

## **FIRST AUTHOR CONTRIBUTIONS**

### **Manuscript 1**

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## **DEDICATION**

I dedicate this thesis to God Almighty who enabled me to complete this study in good health and with peace of mind.

I also dedicate this to my daughter Oluwatooyin Oluwaseyiwumi Oyegbile whose support and presence made the journey very exciting.

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## **LIST OF ACRONYMS**

AR	Action Research
EoL	End of Life
ESRD	End-Stage Renal Disease
FGD	Focus group discussion
HICs	High Income Countries
LAUTECH	Ladoke Akintola University of Technology Teaching Hospital
LMICs	Low Income Countries
MSWs	Medical Social Workers
OOPS	Out-of-Pocket Spending
RN	Registered Nurse
SNH	St. Nicholas Hospital
SPM	Stress Process Model (CSPM)
THE	Total Health Expenditure
UCH	University College Hospital
UN	United Nations
WHO	World Health Organization
ZBI	Zarit Burden Interview

## **ABSTRACT**

### **Purpose**

The purpose of the study was to develop and implement an intervention model to manage caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease in South-West Nigeria. The model that was developed may be used by nurses to assist these family caregivers.

### **Methodology**

Using an action research process, a complementary mixed-method data collection strategy explored and described the extent of caregiver burden, and described family caregivers' experiences of caregiving. With assistance from the research team, 96 participants were selected for the quantitative aspect of the study, and 15 for the qualitative aspect. Through the cyclical nature of the action research, establishing and exploring the experiences of family caregivers later resulted in the emergence of the crucial concepts and the development of the model. The knowledge process development of Chinn and Kramer (2011) guided the development of an intervention model, and the model implementation process was facilitated by the use of an implementation checklist.

### **Findings**

On measuring the caregiver burden, the family caregivers experienced moderate to severe burden in all domains of care. Family caregivers' descriptions of their experience of family caregiving led to the identification of five categories, namely: disconnectedness with others and self; never-ending burden; "feeling like "a fool being tossed around"; obligation to care and promoting a closer relationship. The diagrammatical model to manage caregiver burden resulted from the collaboration of the research team members, and the crucial concepts emerged from the integration of the findings from the study and the interrogation of the existing literature. Model implementation was not evaluated and feedback from nurses and family caregivers indicated that they were excited that the process helped them to manage their burden as caregivers.

## **Conclusion and recommendations**

Family caregivers' need for support should be addressed when they begin caregiving, and then subsequently as they continue to provide care, so that their health is not compromised. There is a need for the implementation and evaluation of this model to assist family caregivers cope with the challenges of prolonged caregiving.

Key words: *Caregiver burden, family caregivers, intervention model, action research, Nigeria*



# CHAPTER ONE: INTRODUCTION TO THE STUDY

## 1.1. Background

Family caregivers providing intense, substantial and prolonged care to their sick relatives with End-Stage Renal Disease (ESRD) may experience caregiver burden as a consequence of caregiving (Galvin, Corr, Madden, Mays, McQuillan, Timonen et al., 2016; Janssen, Spruit, Wouters and Schols, 2012). Caregiver burden might occur when the caregiving exceeds the family caregiver's resources and ability to cope with the demands of the caregiving, having consequences on every aspect of life for the family caregivers (Blum and Sherman, 2010; Northouse, Katapodi, Schafenacker and Weiss, 2012; Singh, 2016). More often, a family caregiver's appraisal of their caregiving situation may inform changes in their world-views, and reappraisal of their caregiving responsibilities might have deleterious consequences for the patient. Although there have been a lot of studies exploring the caregiver burden experienced by family caregivers of patients with ESRD in high-resource countries, not much has been done in exploring, describing and managing the caregiver burden experienced by family caregivers of patients with ESRD in low/middle income countries like Nigeria. There appears to be no intervention model to manage the caregiver burden experienced by family caregivers of patients with ESRD in Nigeria.

Family is the basic unit for providing care to the sick and injured; it also provides an identity for individuals, as well as social standing and support during difficult times, (McCleary and Blain, 2013). In recent times, family has been defined as 'who they say they are', and the relationships that exist between family members and the willingness to provide care to a sick relative might be informed by their conceptualisation of who a family member is (Erlingsson and Brysiewicz, 2015; Okoye, 2012). Family members in need of prolonged, extensive care usually seek such care through the family network for familial or cultural reasons (Yusuf, Adamu and Nuhu, 2011). Doss and Meizen-Dick (2015), however, argue that this practice can be detrimental to family caregivers in an environment where decisions are made, not only in self-interest but also in the interests of others. Although providing care could be beneficial for family caregivers, there are several consequences to doing so.

Family caregivers are volunteers providing care services to a sick relative, according to Hansen and Slagsvold (2013). They may be spouses, adult children, friends and volunteers who provide care without receiving remuneration (Namadi, 2016). Two criteria identified in literature for defining family caregivers are: the type of assistance provided and the extent of the assistance provided in terms of the number of hours of care and the number of times a week that care is provided (Namadi, 2016). Generally, for all chronically sick persons activities of care are comprehensive, including the mobility of patients at home or from one hospital to another for referral; managing domestic issues at home; symptom management; coordination of treatment protocols; scheduling appointments; providing psychological support and companionship, performing treatment procedures, keeping tabs on all expenditures and making sure bills are paid; managing the patient's contacts; dietary planning; and dealing with incontinence (Girgis, Lambert, Johnson, Waller and Currow, 2012). In low and middle income countries (LMICs), family caregivers might be required to provide all the above care and more to their loved ones for several reasons, including inadequate health care personnel and resources (Dondorp, Iyer and Schultz, 2016).

Cantekin, Kavurmacı and Tan (2016); Erlingsson, Magnusson and Hanson (2011) assert that caregiving is an ever changing experience, with each phase having its own peculiar history and unpredictable future. The experience usually evokes numerous emotions, often inflicting deleterious consequences on family caregivers, according to Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995); Bastawrous (2013). Caregiving for patients with End-Stage Renal Disease (ESRD) is distinctive, requiring the indefinite commitment of a family caregiver to caring for a loved one from diagnosis till death (Noble, Kelly and Hudson, 2013; Parham, Jacyna, Hothi, Marks, Holttum and Camic, 2016; Walker, Howard, Tong, Palmer, Marshall and Morton, 2016). As the patients' health deteriorates significantly at the end of life stage, the demand for caregiving increases and that family caregivers are more likely to experience caregiver burden (Cantekin et al., 2016; Caputo, Pavalko and Hardy, 2016; Mashayekhi, Pilevarzadeh and Rafati, 2015; Noble et al., 2013).

ESRD is a chronic, progressive and irreversible disease of the kidneys, resulting in an increasing dependency on family caregivers to provide care from the time of diagnosis until

the time of death, according to Odubanjo, Oluwasola and Kadiri (2011b). The unique course of ESRD initiates severe forms of caregiver burden (Axelsson, Klang, Lundh Hagelin, Jacobson and Andreassen Gleissman, 2015) manifesting as burnout, exhaustion and deterioration of the caregiver's physical and psychological health; leading to the increased morbidity of pre-existing illness or increased susceptibility to new stress related ill health and mortality (Noble et al., 2013). Caregiving for patients with ESRD in LMICs is substantial, intensive and expensive; more so as poor or inadequate healthcare funding and a lack of government support places the huge demand for care solely on family caregivers, attest Streid, Harding, Agupio, Dinat, Downing, Gwyther et al. (2014).

For most parts of sub-Saharan Africa and Nigeria, the diagnosis of ESRD can be equated to a death sentence in terms of the prohibitive costs of medication, dialysis and renal replacement therapy which are borne solely by family caregivers (Odubanjo, Okolo, Oluwasola and Arije, 2011a; Okafor and Kankam, 2012). It is common for family caregivers in these countries to dispose of valuable properties and spend a life time's savings to offset medical bills, assert (Kruk, Goldmann and Galea, 2009; Odubanjo et al., 2011a). In Nigeria, health insurance designed to absorb the risk of endless substantial spending only covers workers in the formal sector, leaving the citizens in the informal sector to bear the huge financial burden of caregiving for those without health insurance (Mohammed, Sambo and Dong, 2011). These factors appear to reduce the family caregivers' capacity to continue caregiving for their sick relatives.

As a result, family caregivers may experience changes in their worldview. They may be overwhelmed with feelings of uncertainties, increased vulnerability to several severe health challenges, financial problems and emotional tensions and conflicts during the prolonged trajectory of illness and treatment (Northouse et al., 2012; Singh, 2016). Family and spousal relationships that have been established pre-illness could be changed by the state of health of the person and the caring that is needed for the person with ESRD. The daily routine of the entire family might be disrupted by the illness of just one family member and changes might occur, both in the family's everyday activities and in human relations according to Given, Given and Sherwood (2012); (Manguba, 2011); Martiny, de Oliveira e Silva, Neto

and Nardi (2012). In the course of providing care to a sick relative, spousal family caregivers reported significant levels of anxiety and clinical depression compared to non-spousal caregivers, in studies by Ågård, Egerod, Tønnesen and Lomborg (2015); Caputo et al. (2016).

Over the years, literature has been inconsistent in the conceptualisation and measurement of caregiver burden; hence there is no uniform definition and tools to measure caregiver burden and this presents a challenge to researchers (Adelman, Tmanova, Delgado, Dion and Lachs, 2014; Bastawrous, 2013). Singh (2016) describes caregiver burden as an extensive, multidimensional construct that illustrates the consequences of caregiving on the physical, social, emotional, and financial aspects of life for family caregivers. More frequently, the quality of life (QoL) of a family caregiver is affected, depending on the availability of resources to cushion the effect of caregiving (Blum and Sherman, 2010; Northouse et al., 2012; Sercekus, Besen, Gunusen and Edeer, 2014). Different terms, such as, caregiver strain and caregiver stress have been used in literature to describe caregiver burden (Garlo, O'Leary, Van Ness and Fried, 2010; Given et al., 2012).

Nigeria is a country of contrasts between the rich and the poor. Despite the strong economic record of the country and abundant natural resources, corruption, poor health care funding and an inadequate health care delivery system might be responsible for the lack of government support for family caregivers and their chronically sick patients (National Bureau of Statistics, 2014). The United Nations (1948) (UN) universal declaration on human rights proposes that every human being has the right for autonomy and social security. Unfortunately, family caregivers lost their personal freedom to caregiving without any form of social security from the government. Family caregivers who take up the caregiving role without government support have been denied of their human rights, and might experience caregiver burden because of the lack of freedom and choice imposed on them by prolonged caregiving (Brinda, Rajkumar, Enemark, Attermann and Jacob, 2014; Noble et al., 2013).

As family caregivers provide prolonged, intensive and extensive care to their sick relatives and witness the deterioration in their relative's health status, they may experience serious

physical, social and emotional disruptions, assert Mystakidou, Parpa, Panagiotou, Tsilika, Galanos and Gouliamos (2013); Nakken, Spruit, Wouters, Schols and Janssen (2015). The situation may become aggravated due to the intensity of the care required, the amount of time spent on caregiving and the severity of the caregiver burden, according to Siegler, Brummett, Williams, Haney and Dilworth-Anderson (2010). Brinda et al. (2014) predicts that lacking or insufficient social, familial and government support are factors predisposing family caregivers to caregiver burden.

The disconnection experienced by family caregivers with others and with self and the need to provide prolonged care for the sick relatives might prevent family caregivers from achieving their life goals and result in them neglecting their personal health needs, suggest Bauer and Sousa-Poza (2015); Combs and Davison (2015). Chindaprasirt, Limpawattana, Pakkaratho, Wirasorn, Sookprasert, Kongbunkiat et al. (2014); Northouse et al. (2012) agree that as the social isolation increases as a result of the increased caring demand, that family caregivers might neglect self-care, adding that the caregivers could develop physical and psychological consequences as a result. Girgis et al. (2012) assert that conflicts arising from intense caregiving and the resulting failure to achieve various life goals often increase the caregiver burden for family caregivers.

Family caregivers who provide care to patients with ESRD experience a loss of identity and personal recognition as a direct effect of prolonged and intense caregiving, state Moore and Gillespie (2014). A family caregiver's over-commitment to caregiving, often required as an obligation when providing care, and their inability to take time off predispose them to a 'never ending burden' (Ugalde, Krishnasamy and Schofield, 2012). Consequently, family caregivers usually take on an identity created by the end-of-life stage of their patient, and this assumed identity is apparent for as long as the patient exists. Lack of recognition of the caregiver's roles might worsen the situation, and family caregivers might experience dejection, feel invisible and think their caregiving efforts are unappreciated by the patient and other family members (Erlingsson et al., 2011). The consequences of this can change the family caregiver's frame of reference, often giving rise to self-reflection and depression,

and may even compromise their caregiving (Axelsson et al., 2015; Noble et al., 2013; Pereira and Botelho, 2011).

A caregiver's feelings of abandonment may produce uncertainties, helplessness and hopelessness, which might intrude into the private space of this family caregiver, leading to a reduction in their quality of life (Noble et al., 2013; Sajjadi, Rassouli, Abbaszadeh, Brant and Majd, 2015). Consequently, family caregivers may experience a loss of power and control over the caregiving situation and their personal lives, and may develop emotional problems such as depression, agree Brémault-Phillips, Parmar, Johnson, Huhn, Mann, Tian et al. (2016). As a result, family caregivers may have to make a conscious effort to reflect, make significant life changes, and adapt to differing situations, in order to provide adequate care for the sick person, attest Hansen and Slagsvold (2013).

Exploring the role of space and place in caregiving is imperative in order to guide the understanding of their influence on caregiving and how family caregivers are impacted by them, argues Wiles (2005). The current trend of shifting care from institutional care to home-based care is a factor shaping the experience of caregiving. Places of care are constantly in negotiation with several players during caregiving and competing needs for space among different age groups in the home can create conflict between sick relatives and children especially, adds Wiles (2005). Each of the players perpetually negotiate and change the places of care, and manipulate caregiving roles with domestic responsibilities (Årestedt, Persson and Benzein, 2014).

Furthermore, certain characteristics in the physical, social and organisational environment can facilitate or inhibit good care. Studies have revealed that caregiver burden is also influenced by the characteristics of the patient, the caregivers, and the care environment, state Grant, Sun, Fujinami, Sidhu, Otis-Green, Juarez et al. (2013). The place where care occurs usually equates the quality of care received and the difficulties experienced, therefore attention should be placed on the nature of the place (Dondorp et al., 2016). Providing care in a restrictive environment also increases the risk of experiencing caregiver burden, add (Grant et al., 2013; Thrush and Hyder, 2014).

The cultural environment and expectations across cultures of family caregivers may also predicts the way in which caregiver burden is understood and evaluated (Hannon, Zimmermann, Knaul, Powell, Mwangi-Powell and Rodin, 2016). Culture expects family caregivers to always be around the sick person all the time otherwise they are perceived as deviants. It is common for family caregivers to experience frustration at every opportunity to attend to their physical care (Khosravan, Mazlom, Abdollahzade, Jamali and Mansoorian, 2014). To demonstrate empathy and commitment to caregiving, family caregivers are at the risk of neglecting their health, may develop symptoms of anxiety, depression and physical distress (Payne and Grande, 2013). Within the family, attention must be placed on the importance of providing respite through constant support for the family caregiver in order to avoid disruption of caregiving (Årestedt et al., 2014).

The values and culture of a people set the expectations about who to provide care (McCleary and Blain, 2013). Gender and relationship, employment status, marital status and degree of frailty of patient tend to dictates which family member provide care, and women are likely to provide care, more hours of care and more personal care (Caputo et al., 2016; Wiles, 2005). Like in other cultures, women are the caregivers in Nigeria, they could be spouse or the daughter of the sick person (Blum and Sherman, 2010; Yusuf, Nuhu and Akinbiyi, 2009). It is customary for either the eldest daughter or the eldest son's wife to take care of the aged, sick parent or relative (Namadi, 2016; Okoye and Asa, 2011). This cultural practice might impose significant amount of caregiver burden on female family caregivers who is also required to take responsibility in her immediate family (Caputo et al., 2016; Eggenberger, Meiers, Krumwiede, Bliesmer and Earle, 2011). Also, women can find fulfillment in providing care to a sick relative in times of need and derive satisfaction in being culturally compliant. Nurses and significant others can be encouraged to support family caregivers so that caregiving for sick relatives might continue unabated.

## **1.2. Statement of the problem**

The consequences of caregiver burden on family caregivers in Nigeria and the apparent lack of a support system needs to be explored. Family caregivers who provide prolonged, intense

and extensive caregiving to their sick relatives, often imposed on them by culture, have few resources left to continue caregiving without compromising their own health (Oyegbile and Brysiewicz, 2017) Post independence Nigeria has many challenges in terms of providing basic health services to its citizens with a population that stands at over 177 million people (The World Bank, 2016). Nigeria's per capita health expenditure of \$22 in 2010 is grossly inadequate when compared to the World Health Organization's (WHO) recommended amount of \$34 for a basic package of essential health services (Oxford Business Group, 2013). According to the African Development Bank Group (2013), in Nigeria, about 63 percent of the population lives below the poverty line of US \$1.00 per day. These socio-economic reasons might be responsible for the lack of support for family caregivers of patients with ESRD in Nigeria.

In Nigeria, the health care system is fragmented and complex, with a significant decline in the available health care resources (Asakitikpi, 2016; Uzochukwu, 2013) and Mokomane (2013); Northouse et al. (2012) suggest that inadequate health care funding might be responsible for the lack of a government policy on support for family caregivers in most parts of Africa. Government support for family caregivers is imperative for the continuity of care for ESRD patients without compromising the family caregiver's health. In addition to adequate funding, Hall (1990) and Wiles (2005) argue that the environment of care should be physically safe, and facilitate and enable adaptive and new behaviour for the caregivers.

For reasons of inadequacy of resources in Nigeria (Federal Ministry of Health, 2010), health care professionals rely on family caregivers to provide technologically-driven, formal and informal care for patients with ESRD. Although the family caregivers of patients with ESRD play this significant role, they appear to be 'hidden patients' whose needs are often neglected by health care professionals but they themselves need support during the caregiving process Blum and Sherman (2010); Yasuko, Ayumi, Takashi, Yasuko and Noriko (2015) because they become burdened by the task over time. Developing an intervention model might serve as a means of providing support during critical moments of caregiving and therefore prevent them from becoming patients themselves in the immediate future, suggest Aneshensel et al. (1995); Hoffman, Mofolo, Salima, Hoffman, Zadronzny, Martinson et al. (2012).



The environment of care in Nigeria, as for those in other resource-limited countries, is particularly difficult for family caregivers providing care to chronically sick relatives (Asakitikpi, 2016). Most often, family caregivers and their sick relatives are relocated to a completely new environment in order to access the level of care required, since tertiary institutions where renal care can be obtained are located in cities. Okafor (2009); Riviello, Letchford, Achieng and Newton (2011) argue that this causes a disruption in the family dynamics and indeed in all aspects of the lives of the family caregivers.

Whereas developed nations such as the United States, Australia and Japan, among others, have intervention models targeted at family caregivers for ESRD patients, that are either in-hospital or community based (Epiphaniou, Hamilton, Bridger, Robinson, Rob, Beynon et al., 2012), however such may not be adaptable in Nigeria as it is a multi-cultural, multi-ethnic, multi-religious, resource limited country (National Population Commission, 2014). For these reasons, I have to start from the scratch since the intervention model must be resource appropriate and culturally-relevant for family caregivers of patients with ESRD in the Nigerian context.

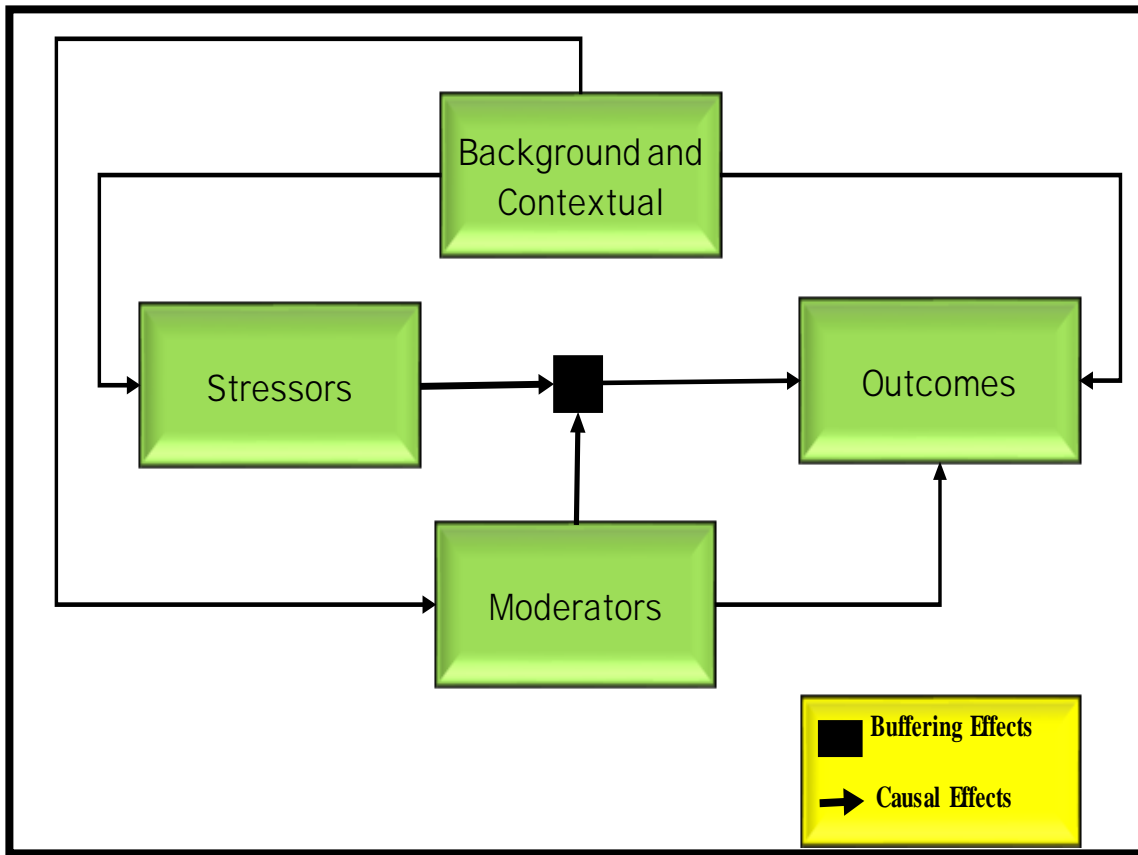
There appears to be lack of literature on intervention models to manage the caregiver burden for the family caregivers of patients with ESRD, not only in Nigeria but in Africa as a whole. Most of the intervention models for family caregivers in Nigeria are targeted at the family caregivers of patients with mental health issues, and are developed by medical practitioners, state Adeosun (2013); Oshodi, Adeyemi, Aina, Suleiman, Erinfolami and Umeh (2012). The acute care needed at times for ESRD patients and the complexity of chronic care goes from being highly specialised (dialysis) to basic activities of daily living, as well as physical and psychological involvement of family caregivers with great deal of uncertainties and high probability of death. Due to these reasons the intervention models developed for the family caregivers of patients with psychiatric illnesses therefore appear inappropriate for the family caregivers of patients with ESRD (Hudson and Aranda, 2013).

Although several factors have placed this huge responsibility of care on the family caregivers of the patients with ESRD in Nigeria, an exploration into the family caregivers' experiences

revealed that little has been done to manage the caregiver burden experienced by these caregivers of patients with ESRD in Nigeria (Chapters Two and Three). The current study therefore intends to provide nurses with an intervention model which highlights the crucial concepts and its relationship in managing the caregiver burden experienced by family caregivers. As nurses are very involved in providing care to ESRD patients as well as their family caregivers, having this model might be useful for nurses to use in managing caregiver burden experienced by these family caregivers.

### **1.3. Conceptual framework**

Several theoretical models were reviewed in an attempt to understand the process that leads to caregiver burden and the tools that could possibly be used to mitigate its consequences for family caregivers. The conceptual frameworks considered for the study were: (1). The Multidimensional Model, (2) the Stress-Theoretical Model, and (3) the Stress Process Model (SPM). The Stress Process Model provides frameworks within which to understand the course of stress and actions to mitigate its consequences for family caregivers and was thus chosen for this study.



**Figure 1. 1 Stress Process Model by Aneshensel et al. (1995)**

The model diagram in Figure 1:1 seeks to illustrate the relationship between background and contextual factors, stressors, outcome and moderators, which is essential in the management of caregiver burden. Four components are identified in the model, namely background and contextual factors, stressors, outcomes and moderators and describes their interrelatedness in the development of stress in family caregivers (Aneshensel et al., 1995). The first box on the left contains the stressors identified by family caregivers and which are defined as the variety of difficulties associated with caregiving that produced caregiver burden for family caregivers (Pearlin, Mullan, Semple and Skaff, 1990). Burden in family caregivers is the term used to describe the physical, emotional, and financial toll of providing care, and is measured by the Zarit Burden Interview questionnaire and categories from the qualitative data (Ghashghaei, Tran, Silva, Greenberg, Barnard and Adler, 2016; Zarit, Reever and Bach-

Peterson, 1980). These findings are integrated to identify the type of burden, as well as the relationship that exists between the crucial concepts in the model.

The SPM is particularly useful in capturing the dynamic features of problematic life experiences, caregiving being an excellent case in point (Pearlin et al., 1990). The model describes how disturbing, unexpected life events produce significant alterations in the life processes of family caregivers supporting relatives that are chronically sick (Payne and Grande, 2013; Pearlin et al., 1990).

### **1.3.1. Background and contextual factors:**

In the SPM, the background and contextual factors are social, economic, cultural, and political factors within which the stress process unfolds, explain Aneshensel et al. (1995); Pearlin et al. (1990). The model notes that the stress process unfolds within the context of social, economic, cultural and political factors and its understanding might assist the reader's perception of caregiver burden, since individuals confront stressors together with other facets of their lives (Caputo et al., 2016). According to the model, the status of people in terms of rewards, privileges, cultural values, opportunities, responsibilities and the availability of personal and social resources can determine the extent to which care-related stress might be experienced or contained Aneshensel et al. (1995); del-Pino-Casado, Frias-Osuna and Palomino-Moral (2012); Gysels, Evans, Menaca, Andrew, Bausewein, Gastmans et al. (2012). Caregiving, like any other experience in life, interacts with the socio-demographic characteristics of the patients and caregivers to produce an outcome in family caregivers (Park, Sung, Kim, Kim and Lee, 2015).

### **1.3.2. Stressors**

In the SPM, stressors are difficulties experienced in the course of providing care to sick relatives that could be directly related to caregiving called primary stressors or indirectly related to caregiving and known as secondary stressors (Pearlin et al., 1990). While some family caregivers might experience satisfaction and fulfillment during caregiving, others

may experience caregiver burden as an outcome (Hodge and Sun, 2012; Imaiso, 2015; Lou, Lau and Cheung, 2015).

Caregiving related stressors are usually multifaceted and proliferating, as one type of stress tends to produce more stressors for family caregivers providing care to an impaired relative (Aneshensel et al., 1995). The model describes sources of stressors from two perspectives: primary and secondary stressors. Primary stressors are difficulties directly related to caregiving situations, such as when family caregivers provide intense caregiving (Pearlin, 1989). Aneshensel et al. (1995); Hall (1990) attest that stress experienced by caregivers can be explained in terms of the combination of background and contextual factors, and factors inherent in the patient and their caregivers. Factors such as the quality of the pre-disease relationship between the care-recipient and the caregiver, the meaning of caregiving, cultural nuances, and expectations about the future of the relationship all interact to produce stress in family caregivers (Henriksson, Carlander and Årestedt, 2015; Nakken et al., 2015; Sánchez-Izquierdo, Prieto-Ursúa and Caperos, 2015; Streid et al., 2014).

Secondary stressors refer to the strains found in roles outside of caregiving, and two types are identified: role strains and intra-psychoic strains. According to the model, the inconsequential effect of stress can have its foundation in the changes brought about by the persistent nature of the disease, which generally alters the way of life of people over a prolonged period of time (Aneshensel et al., 1995). This can stimulate the negative evaluation of self-concepts, which may stimulate the aetiology of stress, assert Pearlin, Menaghan, Lieberman and Mullan (1981). As the lives of family caregivers tend to revolve almost exclusively around the routine of providing intense care, family caregivers may experience confusion about balancing their caregiving role with other adult social roles (Aneshensel et al. (1995); Glavin and Peters (2015), resulting in feelings of inadequacy, hopelessness and psycho-social burden (Gordon, Pruchno, Wilson-Genderson, Murphy and Rose, 2012). As the stressors proliferate, the family caregiver's capability to continue caregiving might be compromised, thus having serious consequences for the sick relative.

In this study, stress is any situation that impacts negatively on the ability of the family caregivers to provide care. Unfortunately, the context of this study does not permit asking direct questions about stressors, because that seems to be very private information. To accomplish the aim of determining the type of stress that family caregivers experienced, the researcher asked participants indirectly about the difficult aspects of caregiving in one of the interview questions. In this way, the family caregivers participating in the study was able to identify the stressors associated with caregiving when narrating their difficulties experienced. The findings from the interview, when integrated with the results of the quantitative study, facilitated the identification of the stresses experienced by the family caregivers.

### **1.3.3. Moderators**

Moderators are the personal and social resources available to family caregivers that help to modify the causal relationship between the stressors and the outcomes (Pearlin, 2010). Moderators can address the social, psychological, physical, financial and spiritual aspects of life and the model notes that moderators function either by reducing the magnitude of the relationship between the stressors and the outcomes or by breaking the link altogether, adds Pearlin (2010). According to Gladsam, Timm and Vittrup (2010), maintaining an equilibrium between the caregiving situation and the use of the available resources can alter the development of stress-related ill-health in family caregivers. Scholars Aneshensel et al. (1995); Pearlin et al. (1990); Raina, O'Donnell, Schweltnus, Rosenbaum, King, Brehaut et al. (2004); Zegwaard, Aartsen, Cuijpers and Grypdonck (2011) argue that moderators include coping, social support and concepts of mastery or self-efficacy, which determine how people are impacted differently in caregiving situations.

In this study, integration of findings from the qualitative and quantitative data revealed what the family caregivers said helped them to manage caregiver burden. Literature was interrogated to find similarities and differences in the concepts before a decision was made. In the model to manage caregiver burden, nurses may use the model to manage caregiver burden by increasing social connection and engagement, increasing participation in support

groups, increasing knowledge through education and increasing caregiver's identity and recognition.

#### **1.3.4. Outcome**

According to Zegwaard et al. (2011) the model notes that the outcomes are the consequences of caregiving stressors upon the individual's health, and may manifest as physiological, psychological, behavioural, social and financial consequences, which may increase the morbidity of pre-existing illnesses or result in mortality in extreme cases. In particular, the intensive and prolonged caregiving needed by patients with ESRD usually impose significant degree of caregiver burden on all aspects of life of the family caregivers.

In this study, the findings revealed that family caregivers experienced moderate to severe caregiver burden and that all aspects of their lives were affected by prolonged caregiving to a sick relative with ESRD. The utilization of the Stress Process Model as the theoretical framework helps to visualize the relationship between the background and contextual factors, stressors and the moderators, and how it leads to the required outcome, which is the potential reduction of the caregiver burden experienced by family caregivers of patients with ESRD.

The SPM helped the researcher to focus on various factors contributing to the experiences of caregiver burden and to focus on better outcomes for family caregivers, although the model was not evaluated within the scope of this study. The SPM helped to present a holistic account of caregiving experiences and guided the research team to find a holistic picture of caregiving that assisted in addressing the problems.

#### **1.4. Purpose of the study**

The purpose of the study was to develop and implement an intervention model to manage caregiver burden experienced by family caregivers of patients living with ESRD in Nigeria.

## **1.5. Objectives of the study**

The objectives of this study are to:

- Explore the extent of the caregiver burden experienced by the family caregivers of patients with ESRD in Nigeria;
- Describe the caregiving experiences of the family caregivers of patients living with ESRD in Nigeria;
- Develop an intervention model to manage caregiver burden; and
- Implement the model in one site in Nigeria.

## **1.6. Research questions**

The research questions are as follows:

- What is the extent of the caregiver burden experienced by family caregiver's of patients with ESRD?
- Which aspects of caregiving contribute to the development of caregiver burden?
- Which aspects of caregiving make the experience better?
- What support systems are available for family caregivers in Nigeria?
- What are the crucial concepts of an appropriate intervention to manage caregiver burden of the family caregivers of ESRD patients?
- What are the relationships that exist between the stressors, outcomes and moderators in the model?
- How do family caregivers perceive the implementation of the model?

## **1.7. Significance of the study**

It is the hope of the researcher that the outcome of this study will contribute significantly to the following:



### **1.7.1. Research**

This study may contribute to an increase in the limited body of knowledge regarding family caregivers of patients with ESRD in Nigeria and Africa. The findings could facilitate the starting point for further research in order to develop strategies to managing caregiver burden.

### **1.7.2. Practice**

This study highlights the experiences of caregiver burden for family caregivers of patients with ESRD especially as it guides the research team members to find holistic way of addressing the problem. The study also provides solution to real life / world problems and informs health care professionals (nurses) on how to start managing caregiver burden.

### **1.7.3. Education**

The study highlights the burden of care experienced by family caregivers of patients with ESRD and the complexities of managing the disease. This study has drawn the attention of nurses to the need to provide support for family caregivers. The study may create avenues for inclusion of the model to manage caregiver burden in the curriculum of training for nurses in Africa and in Nigeria. As this study involves registered nurses at the tertiary level of care, their knowledge and skills to facilitate the utilisation of intervention models for the family caregivers of clients with ESRD might be enhanced.

### **1.7.4. Administration**

This study may assist nurses to provide holistic care to family caregivers of patients with ESRD. Doing this might improve the quality of life for family caregivers and provide them with the support to continue caregiving.

## **1.8. Operational definitions of terms**

### **1.8.1. Family caregivers**

Family caregivers are those individuals who provide the majority of the patient's physical, emotional, financial, and social care needs throughout the continuum of care, from being hospitalised to providing care at home (Collins and Swartz, 2011). In this study, family caregivers could be the spouse, the children of the sick person, volunteers or adult family members providing care to patients with ESRD without receiving any remuneration for doing so.

### **1.8.2. Caregiving**

This refers to "helping behaviour that provides, or is intended to provide, aid or assistance to individuals in need" (Brown and Brown, 2014:75). In this study, caregiving is defined as providing all forms of care required by a patient with ESRD, including but not limited to: performing activities of daily living, the extensive coordination of dialysis care, the management of symptoms, disability, mobility issues and dressing, holding, talking to and providing comfort to their loved ones without receiving any financial benefit for doing so.

### **1.8.3. Caregiver's burden**

Caregiver burden is "the physical, financial, and psycho-social hardships of caring for a loved one, usually a family member, struggling with a medical condition" (Garlo et al., 2010, p. 2315). In this study caregiver burden is defined as the physical, emotional, and psychosocial pressure exerted on caregivers as a consequence of providing care to the sick person with ESRD.

### **1.8.4. End-Stage Renal Disease**

This is said to be present when the glomerular filtration rate (GFR) has fallen below 15ml / minute or if a patient requires renal replacement therapy at higher GFR levels, according to Odubanjo et al. (2011a).

### **1.8.5. Patient**

This is a person who is suffering from disease, injury, an abnormal state, or a mental disorder and is engaged in the related treatment (Medical Dictionary for the Health Professions and Nursing, 2012). In this study, a patient is someone receiving care from a family caregiver for a diagnosis of End-Stage Renal Disease.

### **1.8.6. Model**

A model is a pattern, plan, representation or description designed to show the main object or workings of an object, system or concept (Chinn and Kramer, 2011). In this study, the term model will be the plan to manage caregiver burden experienced by family caregivers of patients with ESRD in Nigeria.

## **1.9. Research setting**

The study was carried out in the South-Western region of Nigeria. Nigeria is in the West African sub-region of Sub-Saharan Africa, lying between latitudes 4°16' and 13°53' North and longitudes 2°40' and 14°41' East. With a total land area of 923,768 square kilometres, Nigeria is the fourteenth largest and the most populous country in Africa, with a population of about 177,475,986.0 (The World Bank, 2016). Nigeria is divided into six geo-political regions with different ethnic and cultural identities namely: the South-West, South-East, South-South, Middle belt, North-East and North-West. The South-Western region is comprised of the Oyo, Ogun, Osun, Ekiti, Ondo, and Lagos states.

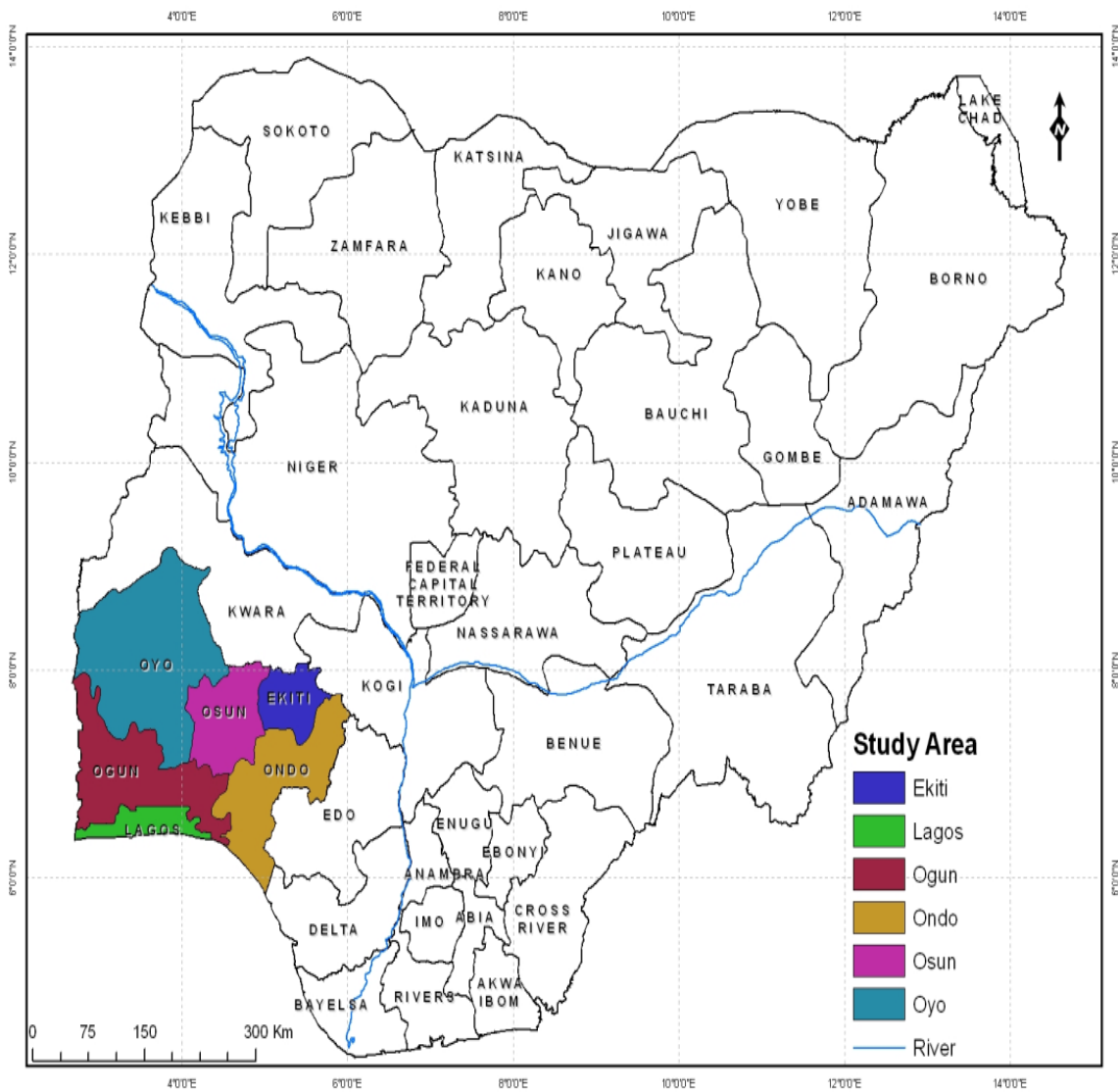
Nigeria is a country of contrast between the rich and the poor (National Population Commission, 2014) where about 63 percent of the population lives below the poverty line of less than \$1 per day limiting the citizens' affordability of the high cost of health care, according to The World Bank (2016). The national health system is, in principle, decentralised into a three-tier structure with responsibilities at the federal, state and local government levels. The state ministries of health are responsible for providing support for the secondary hospitals and the primary health care service. The research settings have been

purposively selected based on the renal care they provide to patients with ESRD (Creswell, 2012).

St. Nicolas hospital (SNH) was the first hospital to perform renal transplant in Nigeria and has the record of being the hospital to have performed the most kidney transplants in Nigeria. SNH is a tertiary centre receiving referrals from around the country for all kinds of disease, but more importantly for renal diseases (St. Nicholas Hospital, 2016).

The University College hospital (UCH) has a functioning renal unit equipped with haemodialysis and peritoneal dialysing machines. The hospital serves as a referral centre to several hospitals around the South-Western part of Nigeria. Patients diagnosed with kidney problems are admitted into wards designated for that purpose (University College Hospital, 2015).

The Ladoke Akintola University of Technology Teaching hospital (LAUTECH) is a tertiary institution that was established in 2004. The hospital is located in the capital city of Osun state, Nigeria. The bed component of the renal ward could not be determined as patients were admitted with other patients into the Female Medical and Male Medical wards of the hospital. The hospital has six beds in the dialysis unit with four functioning dialysis machines for haemodialysis and peritoneal dialysis. Currently, the unit is managed by four renal nurses and two nephrologists (Olaitan, unpublished).



**Figure 1. 2: Map of Nigeria showing the South-Western region by (Scientific & Academic Publishing, 2012).**

## **1.10. Overview of methods**

This section provides an overview of the methods used in the study.

### **1.10.1. Study orientation and design**

According to Morgan (2014); Tashakkori and Teddlie (2010) pragmatism is a research paradigm that can be used to find solutions to real-world problems. It emphasises that all aspects of research involve decisions about which goals are most meaningful and which methods are most appropriate. Pragmatism offers the researcher the opportunity of employing mixed-methods research to obtain data in order to reach an understanding of the topic, especially when either the quantitative or qualitative approach by itself is inadequate to best understand the research problem (Johnson, Onwuegbuzie and Turner, 2007; Plano-Clark and Creswell, 2008). The quantitative and qualitative data obtained provides detailed information about the experiences of the family caregiver's as documented in Chapters Two and Three.

Action research (AR) using a mixed method approach assisted with the development of an intervention model to manage caregiver burden. Research team members comprising of four family caregivers, two registered nurses in each of the research settings and the researcher were engaged from Cycle One to Cycle Four of the study. In Cycle One, research team members assisted in establishing if there was a need for the study, and being involved also served to make them start thinking about this aspect of the care they provide. Research team members engaged in the action research 'spirals' of planning, acting, observing, reflecting and re-planning in each cycle of the study, before transiting to the next cycle. Research team members met regularly and engaged in the three elements of action research, which are the systematic inquiry, professional practice intervention, and participation and change as per Herr and Anderson (2015); Reason and Bradbury (2008).

Creswell (2009) identifies three types of action research: technical collaborative, mutual collaborative and the enhancement approach. This study adopted the mutual collaborative approach in order to develop an intervention model to manage caregiver burden. This

approach involves a democratic process, engaging in mutual understanding as the process evolves. The researcher acted as the facilitator and collaborated with the research team members to develop the intervention model to manage caregiver burden, as per Holloway and Wheeler (2010).

Based on pragmatism and the study objectives of exploring the extent of the caregiver burden and describing the family caregiver's experiences of caregiving, a complementary mixed method data collection strategy was adopted. A complementary mixed method strategy involves the integration of data during collection, or analysis, or collection and analysis of the quantitative and qualitative data (Pluye and Hong, 2014). In this study, quantitative and qualitative data collection and analysis was done separately, but synthesised at the interpretation of findings stage (Heyvaert, Maes and Onghena, 2013; Pluye and Hong, 2014). The integration of the findings helped to identify the relationship between the crucial concepts that are necessary for developing a model to manage the caregiver burden experienced by the family caregivers of patients living with ESRD (Ulrika, Kidd, Wengstrom and Rowa-Dewar, 2011).

### **1.10.2. Study population, participants and sampling**

The family caregivers of patients with ESRD in Nigeria form the target population for this study. This includes all spouses, adult children (over 18 years of age), family members, as well as friends who met the inclusion criteria in all of the research settings. The participants for the study were selected purposively due to the important information they can provide that cannot be obtained from other sources (Polit and Beck, 2012).

Inclusion criteria include:

- a) Adult males or females, 18 years of age and above;
- b) Has been a family caregiver for patients with a confirmed diagnosis of ESRD for at least six months; and

- c) Does not receive any salary or remuneration from the government or family members for providing care.

### **1.10.3. Measurements**

These are the tools used in obtaining the data to measure the extent of the caregiver burden and to describe the family caregivers' experiences of caregiving.

### **1.10.4. Questionnaire**

The Zarit Burden Interview (ZBI) is a self-reported instrument developed by (Zarit et al., 1980). The questionnaire is used to assess caregiver burden in five domains of caregiving, namely burden in the relationship, emotional well-being, social and family life, finances and loss of control over one's life. The ZBI contained 22 question items on a Likert scale ranging from 0 (rarely) to 4 (nearly always). The possible outcome of the scores range from 0 – 88; the higher the score, the more severe the caregiver burden. The questionnaire was translated into the Yoruba language and checked for appropriateness by a certified Yoruba language teacher. The English and Yoruba translated versions of the questionnaire are shown in Annexure 7 & 8. The questionnaire contains two sections: demographic characteristics and question items. Permission to use the questionnaire was granted by the copyright owner.

### **1.10.5 Interviews**

Interviews were conducted to describe the family caregiver's experiences of care for patients with ESRD. This part of the study was carried out in two of the research settings. Participants were interviewed until data saturation was achieved, and no new information was uncovered (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles et al., 2009). Family caregivers described their caregiving experiences, identified the problems associated with prolonged caregiving, described the difficult and beneficial aspects of caregiving and identified the support systems available to alleviate their caregiver burden. The researcher conducted the interview using the open-ended questions to elicit responses from family caregivers. Interviews were conducted in a private space at the end of the ward since there were no private rooms to use for that purpose. Interviews lasted about 30 – 45 minutes for each participant and were audio-taped and transcribed at the close of each day.



#### **1.10.6. Field notes**

These resources were used to document the researcher's observation and experiences during the field work. Field notes were kept in order to detail the occurrences in the field and to develop a better understanding of the data that was valuable during the data analysis process (Polit and Beck, 2012). The notes allowed the researcher to document personal emotional feelings and challenges encountered during the field study, thus aiding reflection (Herr and Anderson, 2015).

#### **1.11. Data collection process**

Data collection is a required strategy for collecting information to address a research problem in a study, assert Polit and Beck (2012). In this study, an action research approach was adopted throughout the whole process. Data was collected in a way that provided responses to the research questions of the study. In Cycle One, the questionnaire was administered to elicit responses regarding the extent of the caregiver burden experienced by the family caregivers in three research settings in South-West Nigeria. In Cycle Two, an unstructured individual interview was conducted with 15 family caregivers selected from two research settings. The third cycle focused on the review of the related literature to interrogate the findings before a decision was made on the development of the model. Field notes, a research journal and a workshop were utilised to obtain data at every cycle of the research and also to reflect on the model implementation process.

For a pragmatic researcher using a complementary mixed method data collection approach, utilising different methods of data collection is required so that validation of the findings can be achieved through multiple perspectives (Creswell, 2009; McNiff and Whitehead, 2010; Plano-Clark and Creswell, 2008; Ulrika et al., 2011). In this study, mixing data from two sources permits an understanding of the deep emotional responses associated with the caregivers' experiences of caregiving and the burden associated with it. In order to achieve the study objectives and validate the findings, the study traversed four cycles in total, in accordance with McNiff and Whitehead (2010).

### **1.11.1. Cycle One: Extent of the caregiver burden and developing a research team**

Cycle One of the study explored the extent of the caregiver burden experienced by the family caregivers of patients with ESRD in Nigeria. This part of the study was conducted in three research settings in South-West Nigeria. A quantitative approach was used to collect the data and the participants in the three research settings who met the inclusion criteria were included in the cycle. Registered nurses in the wards and in the outpatient departments assisted the researcher to identify patients diagnosed with ESRD. The researcher requested the patients to identify a family caregiver who met the inclusion criteria. The researcher introduced themselves to the family caregivers and provided information on the study. The family caregivers who were willing and met the inclusion criteria were enlisted to participate in the study. The researcher administered the questionnaire individually to the family caregivers that same day if they were ready; otherwise it was administered on other days at the convenience of the family caregivers. For family caregivers providing care for patients in the wards, their completed questionnaires were retrieved that same day or on the following day, depending on the family caregiver's ability to complete the process. Family caregivers in the Outpatient departments completed the questionnaire and returned it to the researcher on the same day.

#### ***1.11.1.1. Establishment of the research team***

The researcher asked from nurses and family caregivers who might be interested in participating as research team members. The study engaged seven people as members of the research team during the first cycle of the study. The team comprised of the following: two registered nurses, four caregivers and the researcher. According to Laing (2003) and McNiff and Whitehead (2010), a research team consists of a few people who have a shared interest in the topic and can bring some form of expertise to the study. The research team verified the study design and then guided the study through collaboration in all cycles of the research process. The researcher facilitated the thoughts, identified the commonalities that reflect on the process (Creswell, 2009) and encouraged team members to participate in all phases of the research cycle. The researcher emphasised that all members of the team are equal and the ownership of data was negotiated and all agreed that it belong to the researcher.

### **1.11.2. Cycle Two: Exploring and analysing the experiences of the family caregivers**

This cycle explored and analysed the caregiving experiences of the family caregivers of the patients with ESRD in Nigeria. Qualitative data was collected using 15 individual in-depth interviews. This part of the study was carried out in two of the research settings. The unstructured interview process was adopted to obtain information from the participants and manifest content analysis was adopted for the qualitative data analysis. Participants completed an informed consent form and an appointment was scheduled for an interview at their convenience. The researcher explained the purpose of the study, their rights to privacy and confidentiality and that they could withdraw from the study any time without them or their patient suffering any form of recrimination. They were also informed that their voices would be audio-recorded.

There were no private rooms available for the interviews due to the resource limited research settings. The researcher used a curtain to screen the participants and attempted to provide some privacy at the end of the wards and conducted the interviews behind the curtain. The interviews lasted about 30 – 45 minutes for each participant.

### **1.11.3. Cycle Three: Model development process**

In the third cycle, only one research setting was involved. The team decided that there is the need for additional member since the death of patients made two of the family caregivers dropped out of the team. However, the researcher met with the bereaved family caregivers individually in their homes, shared the emerging concepts of the study with them and they offered suggestions accordingly Two family caregivers, two registered nurses and the researcher who had been research members were joined by a family physician who was added to the research team The family physician was invited because he was directly involved in providing care to patients with ESRD, as a professional.

The outcome of the study, presented in two journal articles was presented to the research team members at a research meeting. This meeting was held by the research team to identify those concepts emerging from the data from the qualitative and quantitative studies. The

researcher reviewed literature and presented it to the research team during the meeting before a decision was made on the emerging concepts to form the basis of the model. A sketch of an idea that was previously developed by the researcher and the research supervisor was presented to the research team members to use as a starting point for discussion. Research team members considered the model, made a few changes in terms of inclusion of more items in the stressors component and decided to adopt it for use. Following this, the research team members attended a workshop to set up a clear understanding of the concepts and clarify the relationships that existed between them (McNiff and Whitehead, 2010).

Authors Chinn and Kramer (2011) argue that the values of the researcher are an important component that must be integrated into the critical reflection process of model development. This was done twice at the meeting and at the workshop. The authors further explained that critical reflection is useful in gaining insight into how the theory / model relates to practice, research or educational activities. While trying to accomplish critical reflection, the researcher and research team members attended to the following concepts:

#### ***1.11.3.1. Clarity of the model***

In this study, the research team members attempts to see that the model appears clear enough to achieve its objective (Chinn and Kramer, 2011). Brain-storming sessions by the research team and the research supervisor was done by interrogating the relationship between the concepts and having discussions regarding what the meaning of the concepts were and what the model was trying to convey, and also by paying attention to the cultural interpretations of the words (Chinn and Kramer, 2011). The research team members and nurses who implemented the model understood the concepts identified in the model (Chinn and Kramer, 2011). Clarity of the model was achieved by drawing out the relationships that existed between the concepts, in a fashion that the participants could understand, and time was taken to describe the logical connections between the crucial concepts and other elements in the model, as instructed by Chinn and Kramer (2011).

#### ***1.11.3.2. Simplicity of the model***

In accordance with Chinn and Kramer (2011), the researcher ensured that the model was simple, that the elements within the concepts were few and that the relationship that existed between them was well defined. The model was simple for use since the concepts and elements included in the model were consistent with what the family caregivers described as the things that helped them to manage caregiver burden.

#### ***1.11.3.3. Generality of the model***

The research team members ensured that the model could facilitate generality to other clinical situations, especially for the family caregivers of chronically sick relatives. This was done by including broad concepts and elements that were useful for managing caregiver burden among other family caregivers providing care to their sick relatives at the end of life stage of their disease (Chinn and Kramer, 2011).

#### ***1.11.3.4. Accessibility of the model***

In this study, the researcher ensured that the concepts, sub-concepts, and purpose of the study were well defined for easy comprehension. Accessibility of the model was achieved through the facilitation of communication among the research team members. These health care professionals were able to communicate their findings, build knowledge and collaborate together to attempt to facilitate a change in practice in terms of managing the caregiver burden experienced by the family caregivers (Chinn and Kramer, 2011).

#### ***1.11.3.5. Importance of the model***

The model highlights the problems that these family caregivers were experiencing and it highlights simple solutions that can be put in place to make life better for them.

## **1.12. Model implementation**

The model was implemented in one of the research settings, based on the interest of the hospital management to implement the model. The hospital in question was thus adopted by the research team members as the facility of choice for this purpose. The family caregivers of patients with ESRD using this facility were invited to participate in this cycle, and these participants subsequently provided feedback in the form of suggestions and comments which further refine the model. Similarities and differences were identified and addressed by the research team members. Figure 1:3 presents the cyclical representation of the action research process and a summary of the research plan is presented in Table 1:1.

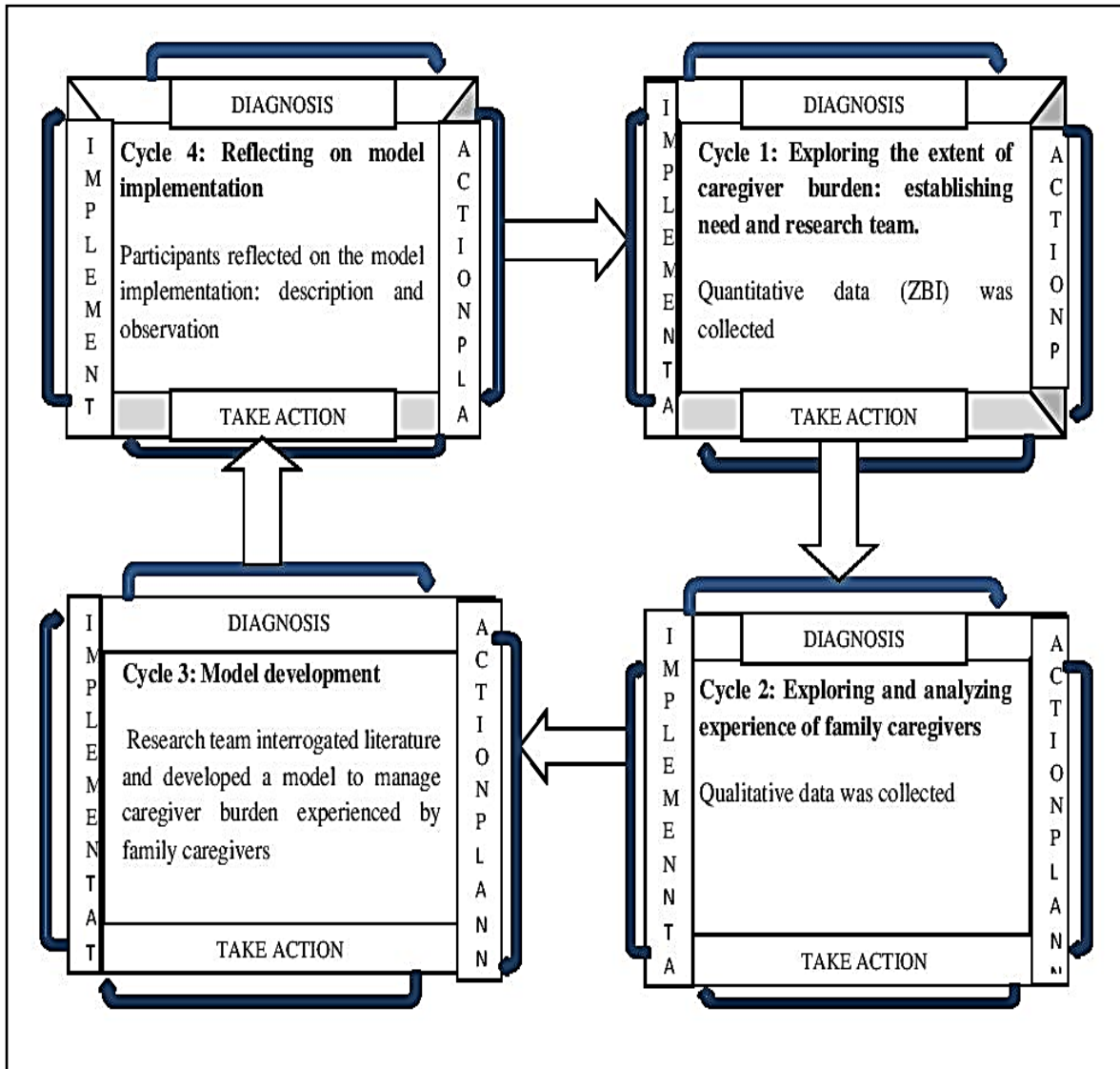


Figure 1. 3: Action research plan adapted from Ahmed (2009).

**Table 1.1: Research Plan**

	<b>Cycle 1</b>	<b>Cycle 2</b>	<b>Cycle 3</b>	<b>Cycle 4</b>
<b>Broad Objective</b>	Explore the extent of the caregiver burden experienced by family caregivers of patients with ESRD in Nigeria	Describe caregiving experiences of the family caregiver's of patients living with ESRD	Model development	Reflection on model implementation
<b>Research Approach</b>	Quantitative and Qualitative	Qualitative	Qualitative and Quantitative	Qualitative
<b>Research Participants</b>	Family caregivers and research team members	Family caregivers and research team members	Research team members	Research team members
<b>Research setting</b>	3 settings	2 settings	1 setting	1 setting
<b>Data collection tool</b>	Zarit Burden Interview	Semi-structured interview	Meeting	Workshop

### 1.13. Data analysis

Quantitative data was scored by adding the numbered responses of the individual items. The ZBI was analysed with the use of Statistical Package for Social Sciences (SPSS), version 21 with the assistance of a Statistician. Descriptive (mean, standard deviation, frequency, percentages) and inferential statistics (chi-square, correlation coefficient, analysis of variance (ANOVA) were analysed. The qualitative data was analysed using the Manifest Content Analysis to identify categories and sub-categories (Graneheim and Lundman, 2004). Details are provided in Chapters Two – Four and a sample transcript is shown in Annexure12. Although the quantitative and qualitative data were analysed separately, they



were integrated as per complementary mixed methods, when interpreting the findings, to present the detailed experiences of family caregivers in order to develop the intervention model. The qualitative data was used to complement the quantitative data in Chapter Two, in order to derive a network of categories that was used to identify the moderators. Action research allowed collaboration to occur between family caregivers, nurses and the researcher, in order to develop the intervention model and to bring about buy-in from family caregivers in an attempt to bring about a change in clinical practice.

## **1.14. Rigor**

This was established by ensuring credibility, transferability, dependability and confirmability, in accordance with Lincoln and Guba (1985).

### **1.14.1. Credibility**

Credibility was obtained through prolonged engagement with the participants, as the researcher spent seventeen weeks in face to face interaction and a year in total interacting with the participants in order to develop a rapport so that the participants felt comfortable and that the 'truth' was captured (Shenton, 2004). The participants were encouraged to re-tell their stories 'as they were' and were continually reassured that there were no right or wrong answers (Ritchie, Lewis, Nicholls and Ormston, 2013). Regular debriefing sessions were held with the research supervisor to review the activities of the study, to suggest new plans of action, to make appropriate changes and to discuss the categories emerging from the data. The participants were individually presented with feedback from their interview, and were asked if they agreed with the interpretation of the data, and whether the data accurately reflected their experiences of caregiving. Most of the participants agreed that the interpretations were a true reflection of the reality, while some small changes were made to some of the interview data. Most of the participants interviewed using the Yoruba language was not able to read and write, and that informed the follow-up interview with all participants irrespective of their literacy level. A follow-up interview was the only option as many participants were not willing to read transcripts in such emotionally laden circumstances.

#### **1.14.2. Transferability**

To ensure transferability, the researcher provided thick descriptions of all aspects of the study, so that the reader could make an informed decision as to whether the findings were transferable to other settings (Shenton, 2004) (See Chapters Three, Four and Five). Action research also allowed discussion to happen between the family caregivers and the researcher, however, the peculiarity of action research tends to limit the extent to which study findings can be transferred to other settings or generalised.

#### **1.14.3. Dependability**

This is necessary to ensure consistency and stability of the data over time and under different conditions (Lincoln and Guba, 1985). An audit trail was embarked upon by the researcher and a thorough detailing of the reflections of events observed during the data collection period was undertaken, including the decisions taken.

#### **1.14.4. Confirmability**

To ensure confirmability, the relevant participant ‘voices’ were selected and integrated into the findings, in an attempt to accurately describe the findings (Lincoln and Guba, 1985).

The researcher ensured that a complementary mixed method data collection strategy was followed by mixing qualitative and quantitative data together at the interpretation of findings stage, so as to identify the relationship that existed between the crucial concepts that were apparent in the study (Creswell, 2009). In-depth methodological description was done to allow integrity of the research results and to allow scrutiny of the study results. In addition to this, research team members and the research supervisor, who is an experienced researcher, guided the study. The study participants also agreed that the interpretations of the findings were a true reflection of the reality of caregiving experiences (Malterud, 2001; Shenton, 2004).

Approval for conducting this study is important in order to protect participants from the risks associated with research (World Medical Association, 2001). This approval was obtained

from the Bio-Medical Research Ethics Committee of the University of KwaZulu-Natal (UKZN) with the identification number BREC 226/14. Gatekeeper’s permission was obtained from all participating institutions in Nigeria before the commencement of the field study (LTH/EC/2014/11/0188 and UI/EC/14/0316); however the third institution did not provide a study approval number. As these were vulnerable participants, the researcher made provision for their protection. This was done by referring them to the Medical Social Workers in the research settings when the researcher picked up verbal and non-verbal cues indicating their psychological discomfort or distress. Five participants were referred and counselled by social workers in the research settings. At other times, the interview sessions were suspended until the participants were comfortable enough to continue.

### **1.15. Data quality storage and management**

Interviews were audio-recorded after obtaining consent from the participants. The quantitative data was coded and entered into a Microsoft Excel spreadsheet by the researcher. The researcher stored data in a password-protected personal computer and external hard drive. Papers used to take notes and audio tapes were secured. All data will be kept secured with the research supervisor for five years after the research has been concluded, before being destroyed according to the university’s policy.

### **1.16. Structure of the thesis**

**Table 1. 2: Summary of the structure and organisation of the thesis**

<b>Chapter</b>	<b>Objective</b>	<b>Manuscript</b>	<b>Research Approach</b>
1.	Introduction, background of the study and literature review and research methodology.	Relevant literature was reviewed to provide insight into caregiver burden	
2.	Literature review	Review of relevant literature was done to form the basis for the model development	Relevant books, journal article, books and other documents published in English only were reviewed
3.	Objective 1 – Explore the extent of the caregiver burden experienced by	Manuscript One: Measure and explore caregiver burden	The Zarit Burden Interview (ZBI) questionnaire was used to obtain quantitative data from 96

<b>Chapter</b>	<b>Objective</b>	<b>Manuscript</b>	<b>Research Approach</b>
	the family caregivers of patient with ESRD in Nigeria.	experienced by family caregivers of patients with ESRD	participants that were purposively selected for the study, while 15 family caregivers were interviewed for the qualitative data. Content analysis was used to integrate the quantitative and qualitative data and the emerging categories were utilised in developing the moderators in the model.
4.	Objective 2 – Describe caregiving experiences in family caregivers of patients living with ESRD in Nigeria	Manuscript Two. Family caregiver’s experiences of providing care to patients with ESRD in Nigeria.	Qualitative data was obtained from 15 participants. Manifest content analysis was used to identify categories. Categories identified formed the basis for the identification of the crucial concept’s contained in the model.
5.	Objective 3 - Develop and implement an intervention model to manage caregiver burden in one site in Nigeria	Manuscript Three: Developing an intervention model to manage caregiver burden experienced by family caregivers of patients with ESRD in Nigeria.	The process of developing the model was detailed, its description was presented, and the model implementation process was presented. The mutual collaborative approach of the Action Research method was utilised in the process that led to the collection of crucial concepts and elements in the model. The moderators were those things that family caregivers indicated helped them manage caregiver burden. A meeting was organised to develop the model and the model was implemented in a selected hospital in Nigeria.
6.	Chapter: Synthesis, Conclusions and Recommendations Summary and limitations		All the chapters were synthesised together

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## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1. Introduction**

The literature review was conducted to provide an overview of what authors have found elsewhere with respect to the study objectives. The intention is to provide an overview of what is already known about the subject with respect to local and international findings, and to contribute to the argument for need for this study (Holloway and Wheeler, 2010; Polit and Beck, 2012). This chapter reviews the caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease and related concepts. Relevant material was sourced using PubMed, Ebscohost, JSTOR, BioMedCentral, ScienceDirect, Sabinet, Springlink, Medline, Google Scholar, Scirus, Cumulative Index of Nursing and Allied Health Literature (CINAHL).

### **2.2. Search strategy**

Database was searched from 2005 to 2016 with search terms including relevant words and terms. Terms that were combined or used singly through the Boolean functions include: *End Stage Renal Disease, ESRD and family caregivers, epidemiology, description of family and significant others, caregiving, differences between formal and informal caregiver, caregiver's burden/strain, intervention models for family caregivers and patients with chronic illness, caregiver burden and theoretical frameworks, theories used in nursing*. These terms were used to obtain geographically specific data: *developed countries, low-middle income countries, developing countries, Africa, sub-Saharan Africa, and Nigeria*. Abstracts of relevant publications were also reviewed and information was obtained from chapters of recent books and web resources. Government documents, conference proceedings and position papers were also reviewed, with searches being restricted to journal article and books published in English only.

### **2.3. Cultural aspects of caregiving in the Nigerian context**

Culturally, most Nigerian ethnic groups practice patri-lineal descent, have patriarchal (father) authority and rule of residence (Imouokhome, 1995). A family unit in Nigeria

does not just refer to father, mother, sister and brother, but to the entire network of relatives, from cousins to nephews, uncles, daughters-in-law, brothers-in-law and grandchildren (Imouokhome Obayan, 1995). Not only does family provide identity for individuals, it also provides social standing and support in times of need (Mokomane, 2013). As most family members live in multi-generational settings, the family unit becomes a source of support and recovery for the sick and family caregivers (Mokomane, 2013).

The cultural environment and expectations of family caregivers may also predicts the way in which caregiver burden is understood and evaluated (Hannon, Zimmermann, Knaul, Powell, Mwangi-Powell and Rodin, 2015). Culture expects family caregivers to always be around the sick person at all the time, otherwise they are perceived as deviants. It is common for family caregivers to often experience frustration when attending to all their physical care needs (Khosravan, Mazlom, Abdollahzade, Jamali and Mansoorian, 2014). To demonstrate empathy and commitment to caregiving, family caregivers are at the risk of neglecting their health, developing symptoms of anxiety, depression and physical distress (Payne and Grande, 2013). Within the family, attention must be placed on the importance of providing respite through constant support for the family caregiver in order to avoid disruption of caregiving (Årestedt, Persson and Benzein, 2014).

#### **2.4. Support for family caregivers**

Support should be provided for family caregivers who experience a burden associated with caregiving, as might negatively affect the outcome for both family caregiver and the patient (Hannon et al., 2015; Streid, Harding, Agupio, Dinat, Downing, Gwyther et al., 2014). A number of authors have documented several forms of social support, including: emotional, informational, spiritual and instrumental (Epiphaniou, Hamilton, Bridger, Robinson, Rob, Beynon et al., 2012; Hudson and Aranda, 2013; Sandy, Kgole and Mavundla, 2013; Wong, Ki, Maharaj, Brown, Davis and Apolinsky, 2014).

In developed countries such as the United States of America, Australia and the United Kingdom, support for patients can take the form of Medicare, Medicaid / medical insurance and insurance policies covering pension, disability and death (Cruz, 2016).

Family caregivers might receive support in form of carer's allowance, emotional, information and psychological support (Australian Government, 2010; Family Caregiver Alliance, 2011). In the USA, Medicare also provides home health care to patients requiring dialysis services (Cruz, 2016). This policy provides substantial relief to family caregivers who will then not have to pay for hospital bills and home health care.

In contrast, few countries in sub-Saharan Africa provide government funding for renal care including RRT (Naicker, 2013). This does not occur in Nigeria, where family caregivers bear all the costs associated with caregiving for ESRD patients without any form of assistance from the government (Arogundade, 2013). Inadequate resources (financial, emotional, social etc.) is linked to psychological distress, with family caregivers with adequate support being more likely to cope with the burden associated with caregiving better than those without support (Epiphaniou et al., 2012; Girgis, Lambert, Johnson, Waller and Currow, 2012).

An essential form of support is provision of information, its absence causing confusion, uncertainties and frustration in family caregivers (Eslami, Rabiei, Abedi, Shirani and Masoudi, 2016; Sandy et al., 2013). Technology driven, computer based information support have been found to be relevant and acceptable in high income countries, such as the United States of America (Chi and Demiriz, 2015; Godwin, Mills, Anderson and Kunik, 2013) as family caregivers benefited from online education, internet support groups, computer-mediated interactive voice-response systems and online skill building (Godwin et al., 2013). Although the use of technology reduced cost of transport and waiting time for family caregivers who must accompany their sick relatives to the hospital, the resources needed for setting it and sustaining its use can place extra financial burden on family caregivers.

Furthermore, family caregivers are sometimes overwhelmed with irrelevant disease-related information from the media and web-based resources, and can become confused and uncertain about what to believe (Rabiei, Eslami, Abedi, Masoudi and Sharifirad, 2015). Family caregivers may also experience confusion when nurses do not provide them with relevant information that meets their needs. For this reason, nurses can provide coherence and evidence based information to family caregivers to avoid uncertainties



and psychological burden associated with spurious information (Gaeeni, Farahani, Seyedfatemi and Mohammadi, 2015; Rabiei et al., 2015).

Access to information through various sources is increasing worldwide, from which family caregivers in LMICs, including Nigeria, could also benefit. However, the level of literacy needed to use technology to the extent that it can meet urgent needs for information may be lacking. Most of the LMICs access to internet is limited, power supply is erratic and funding for its sustained use could be lacking. Information could be provided by health care professionals to family caregivers by sending Short Message Service (SMS).

Modelling is another type of support for family caregivers and entails a family caregiver who had achieved a good level of adaptation in caregiving may support others facing similar challenges to enable them function efficiently and manage challenges of caregiving (Eslami et al., 2016). Modelling could provide opportunities for family caregivers to share ideas about similar challenges and model the exemplary family caregivers who have gone through similar experiences. Eslami et al. (2016), argue that modelling is an important support needed by family caregivers to maintain their identity, persevere and function maximally in the prolonged time associated with chronic caregiving. Such groups can meet in the hospital when patients are keeping appointment with their physician thereby reducing the cost of transport. However, family caregivers differences in values and inability to discern those ideas that are worth imitating might cause confusion from information overload leading to psychological distress (Benbassat, 2014). Nurses can provide leadership in guiding discussion during such meetings to avoid distortion and ambiguity of information and increase knowledge of family caregivers.

Family caregivers might use faith and religion to find meaning in caregiving (Sánchez-Izquierdo, Prieto-Ursúa and Caperos, 2015). Spiritual activities could be done through praying, believing, transcendental meditation, relaxing etc. (Sánchez-Izquierdo et al., 2015; Sequeira, 2012). However, the adoption of spirituality alone might not necessarily mitigate the burden associated with caregiving, family caregiver's perception of receiving help from the Supreme Being might promote coping, resilience and adaptation

needed for the process. Spirituality has been a source of motivation and means of health promotion and wellness among caregivers globally (Delgado-Guay, 2014; Sercekus, Besen, Gunusen and Edeer, 2014). In studies conducted in the US among Latino's family caregivers and African American breast cancer survivor and their caregivers, religion and spirituality provided guidance, acceptance and optimism (Hodge and Sun, 2012; Sterba, Burris, Heiney, Ruppel, Ford and Zapka, 2014).

Members of religious groups have prayed on behalf of the sick and the family caregivers, and knowing that someone is praying seems to give hope and courage for family caregivers (Sterba et al., 2014). Globally, religion and spirituality are two sources of support that family caregivers can utilize to manage caregiver burden. Religion can provide the platform for family caregivers to connect with God, receive comfort, cope with and accept difficult caregiving situations. Nurses must recognize this need and permit religious leaders to visit family caregivers regularly while their sick relative is hospitalized. Family caregivers could be permitted to engage in spiritual activities as allowed for by policies guiding the hospital.

Support interventions are expected to add value to caregiver's level of satisfaction and ability to cope with various issues and improve outcomes for the person receiving care. However, sharing of the caregiving space with those providing support made family caregivers experienced loss of privacy and resulted in caregiver burden (Wittenberg-Lyles, Washington, Demiris, Oliver and Shaunfield, 2014).

## **2.5. Available support for family caregivers in Africa**

A study by (Streid et al., 2014) found that family caregivers in sub-Saharan Africa utilized support resources similar to those of Europe and North America, these being subsidized treatment for dialysis and renal replacement therapy for their citizens (Naicker, 2013). Africans utilize various ways of providing financial support to family caregivers, with adult children often contributing financially to settle medical bills of their sick parents, while extended family members may also contribute. A study by (Amoateng, Kalule-Sabiti and Oladipo, 2015) in North-West province of South Africa revealed that children may discontinue their education prematurely and enter the labour

market to assist the family caregiver financially. In extreme cases, female family caregivers may engage in prostitution to meet the financial needs of caregiving leading to higher risks of contracting sexually related infections, further compounding the already difficult situation (Amoateng et al., 2015). Government could provide financial support in form of carer's allowance to alleviate financial burden.

In the spirit of collective responsibility among Africans, family caregivers may receive support from family members, neighbour's, friends and members of religious organizations through visitation and offering of help (Amoateng et al., 2015). As most Africans live in multigenerational family setting, with many having large family with young children, they may replace the caregivers to provide respite for the family caregiver when the need arises, (Yusuf, Adamu and Nuhu, 2011). Support provided by adult children could be desirable and welcomed by sick parents, but could be problematic among adult siblings who share caregiving for parents leading to intra-family stressors (Ngangana, Davis, Burns, Mcgee and Montgomery, 2016).

The belief system of most Africans encourage communion with the Supreme Being during difficult moments of life, such as caregiving of chronically sick relatives (Amoateng et al., 2015). Africans often also wish to connect with their ancestors during difficult moments of life to assist with healing their loved one's illness and help them cope with challenges of caregiving (Delgado-Guay, 2014). Family caregivers seeking help may offer sacrifices for the atonement of the sins of their sick relatives, offer prayers, and engage in rituals on behalf of themselves and their sick relatives (Amoateng et al., 2015). Delgado-Guay (2014), argue that attention to spiritual needs improves the quality of life for family caregivers. However, caregivers experiencing spiritual pain had higher levels of anxiety, depression, denial, more behavioural disengagement, dysfunctional coping strategies, and worse quality of life. It is important for nurses to assess potential spiritual issues and institute spiritual intervention to decrease spiritual pain by referring family caregivers to chaplains or spiritual leader of their choice (Delgado-Guay, 2014; Hodge and Sun, 2012; Rabiei et al., 2015).

Family caregivers in LMICs are likely to use modelling in seeking information regarding the needs of their sick loved ones (Eslami et al., 2016). This is usually done on an

informal basis, as family caregivers interact together in the wards, with information being shared based on the experiences of those who had been there before (Eslami et al., 2016). While modelling can be a good source of information dissemination among peers, it is advisable that nurses should moderate such meetings to prevent misinformation. They may also receive professional help from psychologists, although the payment of professional or consultation fees might worsen the already difficult financial burden. Nurses can also produce newsletter addressing frequently asked questions regarding the particular conditions.

## **2.6. Space and place of care**

Exploring the role of space and place in caregiving is important in order to guide an understanding of their influence on how family caregivers are impacted by them (Wiles, 2005). The current trend of shifting from institutional to home care is a factor shaping the experience of caregiving. Technological innovations, financial pressure to reduce medical costs, social concepts of a place that meets need for autonomy and privacy, as well as care and safety tend to inform patients choice of home care (Khosravan et al., 2014; Wiles, 2005). Family caregivers sharing residence with chronically sick relatives, similar to older adult needing care, tend to provide more hours of care than those who live in separate residences thus impacting on their quality of life (Funk, Stajduhar, Toye, Aoun, Grande and Todd, 2010). The authors contend that nurses can educate family caregivers to request for help from other family members who can provide care when the need arise.

The locations of places are affected by several players. For instance, patients in need of care may decide on where to live based on close proximity to those who could provide care and support (Wiles, 2005). Chronically sick individuals may relocate to their country of origin or place of birth in order to stay closer to home when they are nearing death (Okoye, 2012). Family caregivers and sick relatives constantly negotiate and re-negotiate about place of care to meet current medical needs. In some instances, family caregivers have to relocate to a completely new environment to provide care and often experience conflicts as they negotiate and move to meet these needs, balancing caregiving roles with domestic responsibilities (Årestedt et al., 2014).

Competing needs for space among different age groups could also create conflict between sick relatives and children (Wiles, 2005). While sick relatives need a quiet place children need a place for leisure and play, resulting in ongoing negotiations among different age groups. Family caregivers assisting patients with ESRD to perform home dialysis experienced difficulty in terms of unsuitable home environment due to lack of space to store dialysis consumables, as well as the absence of an hygienic room for the procedure (Walker, Howard, Tong, Palmer, Marshall and Morton, 2016). In some cases, family caregivers negotiate with home-owners for structural modifications to accommodate dialysis and plumbing. Some family caregivers experienced rent increases and evictions in the course of providing intense caregiving in rented home environment. All these experiences seem to increase family caregiver's experience of caregiver burden.

## **2.7. Burden in the relationship**

Studies (Noble, Kelly and Hudson, 2013; Sajjadi, Rassouli, Abbaszadeh, Brant and Majd, 2015) found that family caregivers experienced burden in relationship, especially as care dependency increased, when patients approach the end of life. The number of hours spent for caregiving increased as patients near the end of their live, being able to do increasingly less for themselves (Byrd, Spencer and Goins, 2011). Family caregivers were overwhelmed by continuous provision of substantial care and increased vigilance, resulting to caregiver burden (Noble et al., 2013). Grieving the imminent loss of their loved ones also increased burden for some family caregivers. Noble et al. (2013) argue that family caregivers residing with their sick relatives developed burden in the relationship as caregiving activities continued unabated (Byrd et al., 2011).

Family caregivers who provided care to their spouses also derived fulfillment during caregiving as they saw it as a commitment to their marital vows. In the field of family nursing, studies (Girgis et al., 2012; Hodge and Sun, 2012) revealed that experiences associated with caregiving could be positive or negative. These factors included the type of pre-disease relationship between the caregiver and the patient, and availability of resources to provide care (Henriksson, Carlander and Årestedt, 2015; Nakken, Spruit, Wouters, Schols and Janssen, 2015). Experienced caregivers can provide support through

modelling and peer encouragement to those who are struggling with caregiving to enable them adopt measures to manage caregiver burden (Sandy et al., 2013).

## **2.8. Emotional well-being**

While caregiving to sick relatives usually recalls emotions in family caregivers, however, studies revealed that family caregivers were not emotionally disturbed by the behaviour of their sick relatives. The seeming contradiction in the emotional well-being may not be unconnected to the belief that family caregivers are expected to conceal their emotions irrespective of their feelings. It might not be strange for family caregivers to be ambivalent in such circumstances, as they are tied with powerful and ambivalent feelings of commitment, warmth, love, guilt, anxiety, frustration, and sometimes anger, as they provide care to their loved ones (Khosravan et al., 2014; Qi, 2015). In a study, family caregivers experienced fulfillment for doing something good and providing care to someone in need (Henriksson et al., 2015). Nurses and health care services can make the experience of caregiving less stressful as they provide educational and emotional support that might assist family caregivers gain control of the caregiving situation (Kemppainen, Tossavainen and Turunen, 2013).

Participation of family caregivers in support groups decreases stress as family caregivers shared challenges associated with caregiving situations with other caregivers and work together to support and help each other (Northouse, Katapodi, Schafenacker and Weiss, 2012; Sharif, Shaygan and Mani, 2012). It is important for nurses to provide leadership by organizing support group meetings where family caregivers can relate to each other. At the hospital level, support could be provided through pairing of family caregivers to engage in peer to peer telephonic conversation and provide a platform for open discussion of issues relating to caregiving. Support group in the context of managing caregiver burden is intended to provide space for open discussion of commonly experienced difficulties and a place where family caregivers can feel supported and encouraged (Kelly, 2010; Rodakowski, Skidmore, Rogers and Schulz, 2012). Support groups also facilitates relationships in which family caregivers discuss issues of caregiving openly, express fears and concerns surrounding caregiving and listen to other caregivers relate their experiences (Yu, Hu, Efird and McCoy, 2013).

## **2.9. Social and family life**

Caregiving to patients with ESRD imposed restrictions and affected all aspects of life of family caregivers in a study by (Bauer and Sousa-Poza, 2015). The family caregivers deferred achieving significant milestones and abandoned hopes in order to provide care to their sick relatives. The study noted that family caregivers experienced social isolation related to prolonged and intense caregiving. As family caregivers were engrossed with caregiving, they were disconnected from others and self, as the activities prevented them from participating in spiritual, social and family activities that could provide recreation. Family caregivers deferred seeking care for medical problems, thereby increasing their vulnerability to caregiver burden. Fear of negative consequences for their patients if they take time off or leave them to the care of others were cited as reasons for diminished connection to others and self (Rabiei et al., 2015; Sajjadi et al., 2015).

At the conceptual level, SPM explains that reduction in self-concepts; self-esteem and mastery usually increase family caregiver's vulnerability to various symptoms of stress (Pearlin, 2010). As lives of caregivers tend to revolve almost exclusively around the routine of providing care, they might experience confusion about balancing their caregiving role with other adult social roles thereby disconnecting from others and self, triggering the development of caregiver burden (Aneshensel, Pearlin, Mullan, Zarit and Whitlatch, 1995; Pearlin, 2010).

In order to manage caregiver burden, family caregivers must create time to participate in social, family, and spiritual activities in order to derive joy, hope and renewed relationships with others in the community (Eslami et al., 2016). Family caregivers can find time to connect socially in the society and engage with resources in the community to ensure adequate self-care. To achieve this objective, nurses need to encourage family caregivers to make arrangement to allow for someone else to assume the role for a period of time on a regular basis to enable them to rest and enjoy some leisure time, which will help to manage caregiver burden (Alnazly, 2016; Deek, Nouredine, Newton, Inglis, MacDonald and Davidson, 2016).

## **2.10. Finances**

Considerable financial costs are often associated with caregiving for ESRD patients, affecting family caregiver's resources and resulting in caregiver burden. Family caregivers can become bankrupt and embarrassed, with some soliciting fund publicly in newspapers to settle medical bills (Kruk, Goldmann and Galea, 2009). In a study (Oyegbile and Brysiewicz, 2017) in Nigeria, family caregivers settled huge medical costs by obtaining bank loans and also bought medical equipment and materials needed to provide care for their sick relatives as a result of poor health care funding. Medical services were sometimes disrupted for a considerable period of time due to non-payment of salaries and the breakdown of equipment affecting patient's outcomes and increasing the caregiving burden. National Health Insurance Scheme (NHIS) in Nigeria, which is at infancy stage, can only be accessed by those in the formal sector compelling those in the informal sector to make direct payment for medical expenses (Asakitikpi, 2016). All these placed huge burden of care on family caregivers in a country where support for family caregivers is non-existent (National Bureau of Statistics, 2014; Olakunde, 2012).

With respect to the SPM model in chapter one, background and contextual factors unfolds within the context of social, economic, cultural and political factors (Pearlin, 2010). Family caregivers with limited resources are likely to experience a burden since they might not be able to cope with resource intensive care required by patients with ESRD. Family caregivers with limited resources will need support to mitigate burden associated with caregiving. Solving financial challenges may not be accommodated by health care professionals, who might advocate for government policy on subsidizing renal care and providing financial support for family caregivers.

## **2.11. Loss of control over one's life**

Family caregivers can experience confusion as they provide pluralistic caregiving activities to their sick relatives (Girgis et al., 2012). More often, family caregivers provided layered care to sick relatives suffering from several co-morbidities without mistakes. Most family caregivers performed multiple roles including domestic, career-



related activities together with intense caregiving to chronically sick relatives all interplay to produce caregiver burden.

Another way that caregiver burden affects family caregiver's is to leave them with a feeling of being treated as fools because of their apparent lack of knowledge regarding ESRD, its treatment, and role expectation. Lack of knowledge about disease process, treatment, and outcome made family caregivers felt like fools and this has been cited as reasons for their feelings of fear, uncertainties, helplessness and hopelessness.

Nurses need to acknowledge that ignorance of the disease process and expectations exists and this creates fear and uncertainties for family caregivers (Eslami et al., 2016; Sajjadi et al., 2015; Sandy et al., 2013). Nurses should educate family caregivers on the disease process; detailing expectations at different stages of the disease, available referral services and resources, and teaching various coping skills to manage caregiver burden and increase family caregiver's competency (Hudson, Trauer, Kelly, O'Connor, Thomas, Summers et al., 2013). Such information could be disseminated through newsletter or brochure to inform family caregivers about pertinent information as it pertains to their sick relatives in order to improve patients outcome and respite for family caregivers (Grant, Sun, Fujinami, Sidhu, Otis-Green, Juarez et al., 2013).

The SPM explained that doubts about competency, loss of self-concept or erosion of personal identity due to ignorance about disease process can lead to psychosocial burden. Caregivers who are overwhelmed by lack of knowledge related to caregiving for their loved ones might doubt their ability to provide care, resulting in feelings of inadequacy and psychosocial burden (Rabiei et al., 2015).

A review of the literature found that various factors affect the family caregivers' ability to perform their duties and carry their burden. Their ability to perform to the best of their ability was informed by several factors including cultural expectations, availability of support, family caregiver's level of knowledge and availability of resources for caregiving. Concluding the literature, this information was very instrumental in forming the basis for the model development.

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## CHAPTER THREE MANUSCRIPT ONE

**Yemisi Okikiade Oyegbile & Petra Brysiewicz. Exploring Caregiver Burden experienced by Family Caregivers of Patients with End-Stage Renal Disease in Nigeria. Under review by *International Journal of African Nursing Sciences*.**

### **Abstract**

**Background** Family caregivers in many African countries bear the burden of caregiving alone, with the paucity of research, especially for caregivers of End-Stage Renal Disease patients, having concealed their needs.

**Aim** To explore the caregiver burden of family caregivers of End-Stage Renal Disease (ESRD) patients in South-West Nigeria.

**Design** Following a complementary mixed method data collection strategy, the quantitative data was collected using the Zarit Burden Interview questionnaire to measure the burden of caregiving. Qualitative data was thereafter obtained through in-depth, individual interviews and was analysed using content analysis.

**Settings** The three research settings consisted of two state hospitals and one private hospital that provide renal care in South-West Nigeria.

**Result** The mean burden of caregiving for the sample was 50.18 thus indicating that family caregivers experienced moderate to severe burden, which is high compared to the other studies. The participants' experiences of caregiving revealed the following categories: total dependence, acceptance of caregiving role, competing responsibilities, financial sacrifice and "not making mistakes".

**Conclusion** Understanding the extent of caregiver burden, what constitutes burden to family caregivers in low / middle-income countries, and the difficulties associated with caregiving for care-recipients with ESRD, allows appropriate strategies and interventions to be developed.

**Key words:** *End Stage Renal Disease, family caregivers, caregiver burden, complementary mixed methods, Nigeria.*

### **BACKGROUND**

Caregiving is defined as help, which may be in the form of aid and assistance provided to persons in need (Brown and Brown, 2014). Extensive activities of care provided by

family members exerts a considerable burden on them, especially in terms of demands and duration of care-provision (Northouse, Katapodi, Schafenacker and Weiss, 2012). Family caregivers are those individuals who provide the majority of the patient's physical, emotional, financial, and social care needs throughout the continuum of care, from being hospitalised to providing care at home, without receiving any remuneration (Collins and Swartz, 2011).

Caregiver burden is “the physical, financial, and psycho-social hardships of caring for a loved one, usually a family member, struggling with a medical condition” (Garlo, O'Leary, Van Ness and Fried, 2010, p. 2315). Family caregivers may develop caregiver burden, when the stress of care exceeds the resources available to cope with the demands of care (Northouse et al., 2012). As caring demands increase, family caregivers are usually isolated from social activities (Bauer and Sousa-Poza, 2015; Crespo, Santos, Canavarro, Kielpikowski, Pryor and Feres-Carneiro, 2013), which can make family caregivers vulnerable to varied health problems, both physical and psychological (Tong, Lowe, Sainsbury and Craig, 2010).

End Stage Renal Disease (ESRD) is a severe stage of chronic kidney disease that occurs when the glomerular filtration rate of the kidney is less than 15ml/minute, thus requiring dialysis and or renal transplantation (Levey and Coresh, 2012). ESRD prevalence is high among young people, usually between 20 to 50 years, in sub-Saharan African countries, and being diagnosed with a terminal illness at such an age carries a considerable demand for prolonged and substantial caregiving on the part of the family caregivers (Arogundade, 2013).

The substantial amount of caregiving required by patients with ESRD may increase family caregiver's vulnerability to emotional, physical and psychological consequences, which are typically high in resource limited countries (Ajuwon and Brown, 2012; Ekelund and Andersson, 2010). This vulnerability is due to the shortage of health care professionals, and in some instances institutions, making it necessary for the family caregiver to provide formal and informal care for patients with ESRD, at home and in the hospitals (Khosravan, Mazlom, Abdollahzade, Jamali and Mansoorian, 2014).



The caregiving environment in resource-limited countries presents with unique limitations and burdens (Dondorp, Iyer and Schultz, 2016). Tertiary care required by patients with ESRD is usually located in urban areas in low-resource countries, meaning that for many family caregivers and their sick relatives they are forced to relocate to a completely new environment, thereby disrupting the dynamics of the entire households, as well as its social and financial relationships (Walker, Howard, Tong, Palmer, Marshall and Morton, 2016; Tong et al., 2010). Re-adjustments regarding family responsibilities and other aspects of life become essential to cope with the changed circumstances. In Nigeria, as in other low-income countries, the unavailability of basic resources, and the limited healthcare infrastructure and personnel often delays treatment and increases the burden for the caregivers (Okafor and Kankam, 2012).

Although Nigeria is the largest economy in Africa (National Bureau of Statistics, 2014), it has challenges in terms of providing basic health services to its inhabitants, with a population of over 177.5 million people (The World Bank, 2014). Approximately, 63% of the population lives below the poverty line of US\$1.00 per day (African Development Bank Group, 2013), making access to private health care and external assistance difficult. The country's inability to utilize its vast resources for health development programmes may be responsible for the lack of support for family caregivers, resulting in them having to bear the considerable burden of care alone (Okafor and Kankam, 2012). A health insurance scheme, still in its infancy, covers only the formal sector, while most Nigerians in the informal sector settle medical bills through the out-of-pocket payment system (Adeosun, 2013). Similar to the experiences of ESRD patients in other low-income countries, dialysis and ESRD treatments are not covered by the scheme (Nugent, Fathima, Feigl and Chyung, 2011).

As family caregivers often bear the burden of caregiving alone, their physical, social, emotional, and financial life are negatively impacted, leading to caregiver burden (Given, Given and Sherwood, 2012). A paucity of research regarding caregiver burden among family caregivers of ESRD patients has meant that there appears to be a lack of support for these family members (Oyegbile and Brysiewicz, Unpublished).

This study therefore aimed to explore the caregiver burden of family caregivers of patients with ESRD patients in South-West Nigeria. This was part of a larger action research study to develop a model to manage caregiver burden among family caregivers of patients living with ESRD in Nigeria.

## **METHODS**

The use of quantitative measures alone to explore the extent of caregiver burden is insufficient to uncover deeper their experiences (Bastawrous, 2013). The Zarit Burden Interview (ZBI) (Zarit, Reever and Bach-Peterson, 1980) questionnaire was chosen for this study, as it has been widely used to measure the extent of caregiver burden. This predominantly quantitative study included qualitative data to further elaborate the domains of caregiving, with the former providing the foundation and context to integrate the latter results.

### **Research setting**

The study settings was two tertiary state hospitals and one privately owned hospital in South-West Nigeria. The initial quantitative data was collected from all three settings while only two settings participated in the qualitative data component. The hospitals were strategically located in the capital cities of their respective states, positioning them for referrals from the surrounding primary and secondary health care centres. The hospitals were purposively selected as they provide renal care and are attended by an average of 15 (current and new) renal patients weekly, with approximately 5-8 of these patients attending with their family caregivers.

### **Sample and sampling**

Participants were purposively selected from among family caregivers accompanying the ESRD patients to the wards and outpatient clinics of the three facilities. Inclusion criteria for both the quantitative and the qualitative data collection components included the following: (i) adult male or females, 18 years or older (ii) been a family caregiver to a patient with ESRD for at least six months and (iii) not receiving remuneration from the government or family members for providing the care. The sample size was calculated with the help of a statistician using the formula,  $n = Z^2_{(1-\alpha/2)}pq/d^2$  (where  $Z_{(1-\alpha/2)} = 1.96$  at 95% confidence;  $p$  = proportion of caregivers with moderate-severe burden,  $q = 1-p$ ; and

$d$  = absolute allowable error (precision). For this study, we assume no prior knowledge with regards to the proportion of who were moderately-severely burdened, we assume maximum possible variability i.e.  $p = 0.5$ ;  $q = 0.5$  and a precision ( $d$ )  $\pm 10\%$ . This yielded a final required sample size of 96 for the quantitative component.

### **Research tool**

The Zarit Burden Interview (ZBI) (Zarit et al., 1980) was used to explore the extent of caregiver burden. It contains 22 items investigating the five domains of caregiver burden namely: burden in the relationship, emotional wellbeing, social and family life, finances, and loss of control over life. The questionnaire items were rated using a five-point Likert scale, with 0 (rarely) being the lowest and 4 (nearly always) being the highest. Zarit et al. (1980) recommend that the total score of all responses should be summed up to reveal the level of caregiver burden. A score of 0-20 indicated little or no burden; 21-40 means a mild to moderate burden; 41-60 moderate to severe burden; while 61-88 means a severe burden is present (Zarit et al., 1980).

The qualitative interview question asked; *“How has it been looking after your loved one, can you tell me your experience?”* Follow-up questions were asked to elicit further responses from participants regarding caregiver burden. Permission to use and translate the questionnaire was granted by the copyright owner and the questionnaire, interview guide and informed consent form were translated into Yoruba language, which is the predominant language spoken by people in South-Western Nigeria. A certified Yoruba language teacher checked all documents for correctness and ease of comprehension, and the questionnaire was back translated into English (Chen and Boore, 2010).

### **Data collection**

Data were collected between February and May 2015, with patients diagnosed with ESRD being identified by registered nurses on the wards and in the outpatient clinics, who then informed the researcher. The patients were individually approached by the researcher who explained the study to them. They were required to identify the person(s) who they had been providing care for during the last six months before their participation was confirmed and informed consent obtained.

The researcher built rapport with family caregivers through the regular sharing of relevant, study-related information, as she was in the settings daily and the participants got to know her. For the convenience of the caregivers, the questionnaires were handed out to the participants while they were waiting at the patient's bedside (either in the wards or at the outpatient department), and were asked to return the completed document to the researcher once completed, either the same day or the following day.

After collecting the quantitative data, the researcher then returned to two of the research settings two weeks later to collect the qualitative data. Interviews were conducted in Yoruba and English, depending on the preference of participants, in a private space away from the other patients, lasting approximately 35-45 minutes. Of the 96 who participated in the initial questionnaire survey, six were interviewed. Participants were interviewed until no new data was uncovered, with a resultant sample size of 15. Interviews were audio-recorded to obtain accuracy, and were reviewed and transcribed verbatim by the first author (YOO) at the close of each day. All translation were then checked and confirmed by the certified language teacher. Throughout the data collection process the researcher was very aware of monitoring the participants for any signs of emotional distress.

### **Data analysis**

Quantitative data were coded and analysed using the Statistical Package for Social Sciences (SPSS) version 22 with the help of a statistician. The total score of the questionnaire was calculated to reveal the overall caregiver burden. The significance was set at 0.05, and an independent sample t-test compared the differences in the mean score of the burden of caregiving, according to gender and living status of the participants.

The qualitative data analysis was done using content analysis, the domains of the ZBI used to assist with coding (Ward, Furber, Tierney and Swallow, 2013). Regular debriefing sessions were held with the second author (PB) (an experienced qualitative researcher) to review the data analysis (identification of the meaning units, condensation, coding and development of categories) and to discuss the emerging categories. Thereafter the research team met to discuss the emerging categories and sub-categories of the qualitative data.

## **Rigor**

The ZBI has demonstrated validity and reliability in previous studies on family caregivers of patients with dementia, where the overall reliability for its items was 0.93 and the intra-class correlation coefficient for the test-re-test reliability of ZBI score was 0.89 (n=149) (Seng, Luo, Ng, Lim, Chionh and Yap, 2010). The ZBI has also been used in studies around caregiver burden amongst family caregivers of patients with dementia and schizophrenia. In this study, the test-retest reliability was done on the ZBI, and the Cronbach's alpha value was reported as good at 0.995.

The procedures to achieve trustworthiness of the qualitative findings included: credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). To achieve credibility, the researcher spent seventeen weeks interacting with participants to ensure that they felt comfortable while re-telling their stories truthfully. Feedback from the interview was presented to participants who were asked if they agreed with the interpretation of the data, and whether the data accurately reflected their experiences of caregiving. Small changes, in terms of the appropriate wording, were made where needed to ensure that their experiences were accurately reflected. Transferability was achieved through thick description of all aspects of the study, to ensure that readers could decide whether they could transfer the findings to other settings (Shenton, 2004). To achieve dependability, an audit trail, expert review, and field notes were used to detail the reflections of the events and decisions taken. To achieve confirmability, important and recurring voices of participants were included in the findings so as to describe them accurately (Lincoln and Guba, 1985).

## **Ethical considerations**

Approval for this study was provided by Biomedical Research Ethics Committee of the University of KwaZulu-Natal, South Africa where the researcher is a student (REF: BE226/14) and by all the ethics committees of the three hospitals in Nigeria. Privacy and confidentiality was maintained as data (both quantitative and qualitative) could not be traced back to the individuals. Participants were informed of their right to discontinue participation at any point without them or their loved ones with ESRD suffering any recrimination. The quantitative data entered into SPSS were de-identified and secured,

and only accessible to the researchers. As these were vulnerable participants, the researcher made provision for their protection by referring them to the Medical Social Workers in the research settings when verbal and non-verbal cues indicated psychological discomfort or distress. Five participants were referred and counselled by such social workers in the research settings.

## QUANTITATIVE RESULT

A total of 110 questionnaires were administered, with a response rate of 87% (n=96) with 14 questionnaires being either spoilt or not returned. The demographic data of the quantitative sample (Table 1) indicated that the family caregivers were predominantly female, married and were adult children of the patients. The average duration of caregiving was 14.2 months.

**Table.1: Demographic characteristics of participants - quantitative (n=96)**

Characteristics		N (%)
Gender		
	Male	40(41.7)
	Female	56(58.3)
Ages (M = 40.4, SD = 13.43). Range: 19 – 69 years		
Marital Status		
	Single	30 (31.3)
	Married	64 (66.7)
	Divorced	1 (1.0)
	Widowed	1 (1.0)
Relationship with patient		
	Parent	9 (9.4)
	Spouse	31 (32.3)
	Son / Daughter	42 (43.8)
	Brother / Sister	12 (12.5)
	Others	2 (2.1)
Living status		
	Same residence as patients	76 (79.2)
	Separate residences	20 (20.8)
Contact times of caregivers with patient per day		
	1 – 2	12 (12.5)
	3 – 4	78 (81.3)
	5 – 6	6 (6.3)
Ethnicity		
	Yoruba	78 (81.3)
	Igbo	12 (12.5)

	Hausa	1 (1.0)
	Others	5 (5.2)
<b>Religion</b>		
	Christianity	72 (75.0)
	Islam	23 (24.0)
	Traditional worshipper	1 (1.0)

### **Burden of caregiving among participants according to the sub-scales**

In this study, the mean burden for the sample was 50.18 out of a possible score of 88 indicating a moderate to severe burden (the highest total score was 81 and the lowest 12) (Table 2). Five (5.3%) participants indicated they experienced little or no burden, while 27 (28.1%) reported a mild to moderate burden with a score of 21-40. For the score of 41-60, 30 (31.3%) participants indicated a moderate to severe burden, while 34 (35.4%) participants indicated a severe burden.

**Table 2: Sub-scales of burden of caregiving among participant**

Items	Never n(%)	Rarely n(%)	Sometimes n(%)	Often frequently n(%)	Nearly Always n(%)
<b>Burden in the relationship</b>					
Do you feel that your relative asks for more help than he or she needs?	18(18.8)	9(9.4)	36(37.5)	29(30.2)	4(4.2)
Do you feel that your relative is dependent upon you?	17(17.7)	5(5.2)	15(15.6)	27(28.1)	32(33.3)
Do you feel you don't have as much privacy as you would like, because of your relative?	14(14.6)	7(7.3)	19(19.8)	37(38.5)	19(19.8)
Do you feel that your relative seems to expect you to take care of him or her as if you were the only one he or she could depend on?	9(9.4)	6(6.3)	15(15.6)	42(43.8)	24(25.0)
Do you wish that you could just leave the care of your relative to someone else?	22(22.9)	4(4.2)	12(12.5)	28(29.2)	30(31.3)
Do you feel that you should be doing more for your relative?	11(11.5)	12(12.5)	17(17.7)	28(29.2)	28(29.2)
<b>Emotional wellbeing</b>					
Do you feel that because of the time you spend with your relative, you don't have enough time?	2(2.1)	8(8.3)	31(32.3)	41(42.7)	14(14.6)
Do you feel embarrassed about your relative's behaviour?	53(55.2)	21(21.9)	10(10.4)	9(9.4)	3(3.1)
Do you feel angry when you are around your relatives?	36(37.5)	21(21.9)	22(22.9)	14(14.6)	3(3.1)
Do you feel strained when you are around your relatives?	24(25.0)	4 (4.2)	17(17.7)	29(30.2)	22(22.9)
Do you feel that your health has suffered because of your involvement with your relative?	19(19.8)	6 (6.3)	27(28.1)	28(29.2)	16(16.7)
Do you feel that you could do a better job caring for your relative?	11(11.5)	12(12.5)	12(12.5)	28(29.2)	33(34.4)
Overall, how burdened do you feel in caring for your relative?	6(6.3)	2(2.1)	9(9.4)	14(15.6)	65(66.7)
<b>Social and family life</b>					
Do you feel stressed between caring for your relative and trying to meet other responsibilities?	6(6.3)	2(2.1)	26(27.1)	45(46.9)	17(17.7)
Do you feel that your relative currently affects your relationship with other family members?	36(37.5)	12(12.5)	25(26.0)	17(17.7)	6(6.3)
Do you feel that your social life has suffered because you are caring for your relative?	13(13.5)	3(3.1)	14(14.6)	40(41.7)	26(27.1)
Do you feel uncomfortable having your friends over because of your relative?	25(26.0)	16(16.7)	38(39.6)	14(14.6)	3(3.1)
<b>Finances</b>					
Do you feel you don't have enough money to care for your relative, in addition to the rest of your expenses?	8(8.3)	1(1.0)	18(18.8)	22(22.9)	47(49.0)
<b>Loss of control over one's life</b>					
Are you afraid about what the future holds for your relative?	13(13.5)	6(6.3)	23(24.0)	32(33.3)	22(22.9)
Do you feel that you will be unable to take care of your relative for much longer?	17(17.7)	6(6.3)	20(20.8)	31(32.3)	22(22.9)
Do you feel that you have lost control of your life since your relative's sickness?	17(17.7)	8(8.3)	18(18.8)	33(34.4)	20(20.8)
Do you feel uncertain about what to do about your relative?	12(12.7)	10(10.4)	16(16.7)	34(35.4)	24(25.0)



An independent sample t-test was conducted to compare the differences in the mean score of burden of caregiving according to the participants' gender and living status. The results as presented in Table 3 indicated that female caregivers ( $M = 51.59$ ,  $SD = 18.39$ ) experienced more burden of caregiving than their male counterparts ( $M = 48.98$ ,  $SD = 16.96$ ). However, this difference was not strong enough to yield any statistical significance [ $t(94) = 0.71$ ]. According to living status, caregivers living with patients ( $M = 50.72$ ,  $SD = 17.05$ ) experienced more burden of caregiving than those who live in separate residence ( $M = 49.65$ ,  $SD = 20.74$ ), although this difference was not statistically significant [ $t(94) = 0.24$ ]. A one-way analysis of variance (ANOVA) indicated that there were no statistical significant differences in the burden of caregiving according to marital status, educational levels, religion, ethnicity, working status, relationship with patients, and duration of contact with patient (Table 3).

**Table 3: Differences in burden of caregiving by demographic characteristics**

<b>Variables</b>	<b>Mean</b>	<b>SD</b>	<b>Test values</b>	<b><i>p</i>-values</b>
Gender				
Male	48.98	16.96	0.71 <sup>a</sup>	0.480
Female	51.59	18.39		
Marital Status				
Single	48.70	18.23	0.60 <sup>b</sup>	0.619
Married	51.77	17.72		
Divorced	35.00	-----		
Widowed	39.00	-----		
Education Level				
Elementary school	55.20	16.86	0.96 <sup>b</sup>	0.450
Secondary school	47.83	18.02		
Polytechnic	45.48	18.18		
University	53.80	17.90		
Postgraduate	51.18	17.61		
Other	60.50	9.19		
Religion				
Christianity	49.24	17.42	0.80 <sup>b</sup>	.453
Islam	54.00	19.00		
Traditional	61.00	-----		
Ethnicity				
Yoruba	51.33	18.51	1.14 <sup>b</sup>	.339
Igbo	51.50	10.90		
Hausa	34.00	-----		
Other	38.40	17.60		
Working status				
Full-time paid job	55.50	17.56	0.75 <sup>b</sup>	0.588
part-time paid job	46.67	13.63		
Self-employed	47.27	19.22		
Do not work	51.57	16.66		
Retire	46.86	14.82		
Other	51.33	27.06		
Relationship with patient				
Parent	45.67	13.01	0.63 <sup>b</sup>	0.643
Spouse	52.52	16.48		
Son/daughter	51.74	18.57		
brother/sister	46.17	19.75		
Other	41.00	35.36		
Living status				
Same residence as patients	50.72	17.05	0.24 <sup>a</sup>	0.811
Separate residences	49.65	20.74		
Duration of contact with patient			0.64 <sup>b</sup>	0.527
3-5 times a week	49.99	16.70		
1-2 times a week	49.83	21.39		
1-3 times a week	58.50	22.64		

## **QUALITATIVE RESULT**

Fifteen participants were interviewed with their experiences of caregiving revealed the following categories: total dependence, acceptance of caregiving role, competing responsibilities, financial sacrifice and “not making mistakes” (Table 4), the responses for each being detailed further.

**Table 4: Demographics of interview participants**

<b>Participants ID</b>	<b>Characteristics of participants</b>
1.	Female, 41 years, Yoruba, Moslem, elementary school leaver, married, self-employed, sibling, lived in same residence, provided care for 11 hours daily for 12 months
2.	Female, 25 years, Yoruba, Christian, Diploma holder, single, employed, adult child, lived in same residence, spent 14 hours per day caring, and provided care for 6 months
3.	Male, 25 years, Yoruba, Christian, post-graduate student, single, unemployed, adult child, lived in same residence, spent 14 hours per day caring, and provided care for 13 months
4.	Male, 45 years, Yoruba, Moslem, elementary school leaver, married, self-employed, adult child, lived in separate residence, spent 12 hours per day caring, and provided care for 9 months
5.	Female, 39 years, Igbo, Christian, married, elementary school leaver, self-employed, spouse, lived in same residence, spent 14 hours per day caring, and provided care for 7 months
6.	Female, 60 years, Yoruba, Moslem, married, no education, self-employed, spouse, lived in same residence, spent 14 hours per day caring, and provided care for 48 months
7.	Female, 19 years, Yoruba, Christian, University undergraduate, single, schooling, sibling, lived in same residence, spent 13 hours per day caring, and provided care for 7 months
8.	Female, 69 years, Twi, Ghanaian, Christian, married, retiree, spouse, lived in same residence, spent 9 hours per day caring, and provided care for 10 months
9.	Female, 58 years, Yoruba, Christian, married, retiree, spouse, lived in same residence, spent 10 hours per day caring, and provided care for 16 months
10.	Male, 41 years, Yoruba, Moslem, university graduate, married, full time paid job, adult child, lived in separate residence, spent 12 hours per day caring, and provided care for 18 months
11.	Female, 38 years, Yoruba, Christianity, married, Diploma holder, full time paid job, spouse, lived in same residence, spent 13 hours per day caring, and provided care for 16 months
12.	Female, 49 years, Yoruba, Christian, secondary school leaver, married, retiree, spouse, lived in same residence, spent 11 hours per day caring, and provided care for 16 months,
13.	Female, 48 years, Yoruba, Christian, no education, married, self-employed, mother, lived in same residence, spent 11 hours per day caring, and provided care for 22 months
14.	Male, 44 years, Urhobo, Christian, Higher National Diploma holder, married, self-employed, spouse, lived in same residence, spent 10 hours per day caring, and provided care for 22 months
15.	Female, 58 years, Yoruba, Moslem, Secondary school leaver, married, self-employed, spouse, lived in same residence, spent 8 hours per day caring, and provided care for 16 months

### **Total dependence**

Participants described how extreme care dependency imposed a burden on their lives. As the patient's health deteriorated, they depended more and more on family caregivers to provide all forms of care, including activities of daily living. A participant explains:

I am like everything to him and do everything that will make him feel better. For some time now he stopped doing those things he could do by himself....it's quite frustrating for me (**Caregiver 09**).

Another participant said:

He feels weak regularly, unable to attend to his physical care, even going to the toilet is a problem for him. Then he lost his memory, and stopped giving himself injection for "sugar in urine" (i.e. Insulin) and I have to do all those for him. (**Caregiver 06**)

### **Acceptance of the caregiving role**

Within the domain of emotional wellbeing, one category that emerged from the qualitative data was that prolonged caregiving led to the acceptance of the caregiving role among family caregivers and their sick relatives. Participants' acceptance of their role appears to have helped them not to feel embarrassed or angry during caregiving.

The qualitative data supported these findings, with participants explaining:

I am not embarrassed to take care of him because of my commitment to my marital vows. I will stand by him...rain or sunshine. (**Caregiver 15**)

Another participant said:

I am not angry taking care of him. He is a kind person.....he loves me and our children. He loves my extended family. He always takes care of us. (**Caregiver 05**)

Another participant said:

I am her son and one of the reasons why you raise kids is that when you are old your kids should take care of you. So I am doing what I am supposed to do. **(Caregiver 04)**

### **Competing responsibilities**

Participants revealed that caregiving for their relatives increased their experience of burden. They narrated how combining domestic responsibilities with caregiving and career obligations increased their experience of burden.

One participant said:

I must call him from my working place to be sure that he is doing fine. He had crisis before that necessitated emergency admission. But for my timely intervention, he may have died before now. I find it difficult to pay attention to what I am doing in my workplace. Many times I made costly mistakes at work because I was always thinking of him. **(Caregiver 01)**

Another reported:

I care for my mother in the hospital throughout the night and rushes home early in the morning to prepare my siblings for school. Many times, I slept off in the bus and missed my destination. When I get home late my siblings will be upset with me, complaining that they will be late to school **(Caregiver 02)**.

### **Financial sacrifice**

A number of participants described how they sacrificed their savings, investment and retirement benefits because of substantial health care cost as clinical procedures for managing ESRD are expensive and lengthy. Most patients and their family caregivers are unable to afford the medical bills and must source for the money or their relative might not be able to access necessary care. Participants described how they were impoverished due to unending payments for huge medical expenses.

One participant said:

We started spending money many years ago when he developed hypertension, then diabetes and then kidney disease. In fact, kidney disease started immediately after his retirement, it was as if the disease was waiting for him to collect his retirement benefits. We spent his retirement benefits and savings to pay medical bills. When the money finished, I spent my business capital and proceeds... Recently, we took a soft loan from the bank to pay his medical bill as we are retirees, we do not have enough income to continue taking treatment and I am just confused....I sit here in the hospital and I am disturbed about the consequences of not being able to settle the bank loan. (Caregiver 12)

Another reported:

I sold the family's car at a ridiculous amount, because I was desperate to pay her medical bills. (Caregiver 14)

One noted that:

I sold a piece of land that belongs to my mother in order to settle her medical bills. In my tribe it is unacceptable to sell land as a means of offsetting medical bills or paying off debt. Unfortunately, I have sold it and I am afraid of how my siblings will react when they know about it in the future. They will ask questions and I will suffer a lot of embarrassment and humiliation as a result of my actions. (Caregiver 02)

### **“Not making mistakes”**

Participants narrated how complex and complicated caregiving activities evoked confusion as the participants' responsibilities were considerable and needed to be carried out without making mistakes. A family caregiver said:

Because she is taking drugs for hypertension, diabetes, peptic ulcer disease and kidney disease, I am always afraid I might give her the incorrect type or amount. I feel stressed up because I have to do many sensitive things at specific times without making mistakes. (Caregiver 07)

Another reported:

Someone must be around him always otherwise he might wander away from the house..... We don't want him to get missing so we keep watch over him. Taking care of him demands vigilance.

Participants experienced a burden as caregiving to patients with ESRD was exhausting, time consuming and continuous, requiring constant follow-up during the day and at night.

## **INTEGRATING THE RESULTS**

Results revealed the experiences of caregiving as described by the family caregivers from the quantitative and qualitative data.

### **Burden in the relationship**

Responses regarding the domain of burden in the relationship were high, as participant indicated that patients depend on them sometimes, frequently and nearly always. Responses from the qualitative data also indicated that patients depend totally on family caregivers for provision of all forms of care. The participants explained that this experience had negative consequences on the physical and psychosocial aspects of their lives.

### **Emotional well-being**

Results from the quantitative study revealed that participants were overburdened with care whereas in the open ended responses participants revealed that they accepted their caregiving role as caregiving become prolonged. Participants also derived fulfillment and satisfaction from caregiving as chronic illness is usually perceived as a family affair, and the family caregivers felt they were doing what they needed to do for their sick relatives.

### **Social and family life**

Stress between caring “*for your relative and trying to meet other responsibilities*” in this domain was a major source of burden to participants with disruption in social life scoring high in the ZBI measurement. From the interview, participants indicated that commitments,



such as meeting career goals, and attending to domestic and social responsibilities, competed with their caregiving responsibilities, which increased their experience of burden.

### **Finances**

Regarding finances, the participants indicated that they do not have enough money to settle medical cost. From the qualitative data, participants revealed that they sacrificed financially in order to provide care to their sick relatives. Uncertainties around sourcing for fund and prolonged payment of substantial amount for treatment increased the participants' experience of burden.

Another participant experienced burden as a result of the cultural implications of selling a piece of land to settle medical bills and its future implications. The participant's defiance of cultural rules in order to meet financial obligations related to prolonged caregiving increased their burden of care. Although the sale of property appears to meet the immediate financial need, contravention of cultural rules has implication for the caregivers' future, which further increased their experience of caregiver burden.

### **Loss of control over one's life**

During the interviews, the participants revealed that they lost control of their lives, this being corroborated in the responses from the qualitative data. Participants experienced burden as they provided complex and complicated care, which must be done without making mistakes, especially when serving medications.

## **DISCUSSION**

The study findings revealed that the majority of family caregivers were females adult children of the patients, belonged to the Yoruba ethnic group and lived in the same residence with the patients. The mean age of participants was 40 years and the mean ZBI score revealed a moderate to severe burden on all domains associated with care, as identified by Zarit et al. (1980). A study by Yusuf, Adamu and Nuhu (2011) among caregivers of cancer patients in an urban African setting revealed high levels of burden in the mean score. The same outcome

was indicated in a study on family caregivers of patients with schizophrenia in Nigeria, where the mean score revealed a high burden among family caregivers (Adeosun, 2013).

Participants revealed that the burden developed in the relationship when care-recipients depended totally on them for provision of all forms of care. Previous studies highlighted that the burden developed in the relationship when the caregiving demand increased, especially among patients who lost their functional ability (Brinda, Rajkumar, Enemark, Attermann and Jacob, 2014; Akpan-Idiok and Anarado, 2014; Byrd, Spencer and Goins, 2011). As care-recipients become sicker, the time spent on providing caregiving increases, invariably encouraging care dependency (Noble, Kelly and Hudson, 2013).

Resident family caregivers, in particular, experienced a more of a burden in the relationship than those who lived in separate residences. Studies revealed that family caregivers with adequate support interventions experienced less burden (Collins and Swartz, 2011). In particular, family caregivers providing care in multigenerational family settings, especially in resource-constrained settings had some respite from caregiving when other family members volunteer to assist, while those who had the financial means paid for assistance when there is the need for it (Yusuf et al., 2011).

Of course, participants' acceptance of the caregiving role is not out of place in a culture that forbids divorce or separation based on the sickness or ill-health of a spouse (Muoghalu and Jegede, 2010). Most cultures in Nigeria, especially the Yoruba's, socialise members into concealing emotional pain associated with caregiving, since the family bond appears to take pre-eminence over personal comfort when one member of the family is sick (Yankuzo, 2014). A study among Swedish family caregivers of patients living with chronic illnesses highlighted that illness is perceived as being a family affair, and that whatever happened to one happened to all, thus increasing the understanding and acceptance of behavioural responses accompanying the disease (Årestedt, Persson and Benzein, 2014). On the contrary, studies on family caregivers of patients with Alzheimer's disease underlined that family caregivers were embarrassed and angry during caregiving as patients manifested multiple

embarrassing behavioural and cognitive symptoms (Reed, Belger, Dell'Agnello, Wimo, Argimon, Bruno et al., 2014).

Responses from the quantitative data showed that participants experienced stress, as caregiving competed with other responsibilities, thereby increasing their experience of burden. The majority of the participants are females, who fulfilled multiple gender-related responsibilities for their families and patient. Studies (Erlingsson, Magnusson and Hanson, 2011; Byrd et al., 2011) revealed that family caregivers experienced career retrogression, job loss, marital disruption and crisis in the family systems while they strive to balance caregiving with other responsibilities.

The responses showed that participants sacrificed financially due to unending payments of substantial medical bills. They obtained loans and sold off properties to pay medical bills in a country where government support is extremely limited. Consistent with studies from Malawi and other low to medium income countries, participants revealed that the financial strain was the most common burden experienced by family caregivers as government support is non-existent (Arogundade, 2013; Hoffman, Mofolo, Salima, Hoffman, Zadronzny, Martinson et al., 2012; Agaba and Tzamaloukas, 2012; Nugent et al., 2011; Yusuf et al., 2011). Contrary to the current study findings, studies documented that family caregivers in developed economies enjoyed various forms of support from government, enabling them to continue caregiving without compromising their finances, health and wellbeing (Northouse et al., 2012; Epiphaniou, Hamilton, Bridger, Robinson, Rob, Beynon et al., 2012)

Regarding the domain of loss of control over lives, participants felt that this had occurred when their relatives became sick. As family caregivers provide complex care to care-recipients with ESRD who have other conditions, being vigilant and not making mistakes in selecting the correct doses of medications increased their experience of burden. Family caregivers experiencing doubt about their competencies to provide care are likely to benefit from support interventions that enable them to continue with their own lives while providing

care to their sick relatives (Sautter, Tulsy, Johnson, Olsen, Burton-Chase, Hoff Linqvist et al., 2014; Noble et al., 2013).

## **RECOMMENDATIONS**

The study indicates that family caregivers experienced physical and psychosocial burden, with support groups from for the family members being a possible mechanism to address their various caregiving experiences. Health care providers can play an important role in referring caregivers to additional resources, where they are available, or motivating for them when they are not. Such resources might alleviate the significant source of burden, and provide motivation for family caregivers to continue caregiving without compromising their health and wellbeing. Knowing that caregiver burden is so high in this study emphasizes the need to look at this important population with a larger study, not only for patients with ESRD, but for all those affected by terminal illnesses who are unable to access adequate institutional care.

## **LIMITATION OF STUDY**

The limited sample size of this study, and the fact that the study was only conducted at three sites does not permit generalization of the findings. Another limitation of the study is that questionnaires were administered while participants provided care near the patient's bedside and in the out-patient department, which may have influenced their responses.

## **CONCLUSION**

The outcome of this study revealed that participants experienced a moderate to severe burden of care. Participants' physical, psycho-social and financial aspects of life were affected by caregiving of patients with ESRD. These findings have significant implications for family caregivers' health and their ability to continue caregiving. The availability of psychosocial support in particular may lead to a reduction in the level of their burden of care. Government of low-middle income countries needs to improve their health care system in order to respond to ESRD patient's needs and provide adequate support for their family caregivers.

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## CONFLICT OF INTEREST

None

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### **3.1. Synopsis of the article**

This article reports on the objective: to measure caregiver burden and explore experiences of the burden of care for ESRD family caregivers in South-West Nigeria.

In Cycle One the study revealed that family caregivers experienced moderate to severe caregiver burden which is very high compared to the rest of the world (Adeosun, 2013). Nurses therefore need to develop psychosocial support groups where caregivers can voice their needs and have them addressed either virtually or physically. Nurses need to provide them with information, as family caregivers are often unaware of the resources that are available.

The action research involved various people as part of the research team who were involved at all stages of the study. Action research was used to initiate change in practice by collaboration with the people concerned. The mixed method consisted of questionnaires and unstructured interview to provide an in-depth indication of the caregiver burden. The results showed that family caregivers experienced moderate to severe caregiver burden in all domains of care which indicated the need to initiate a change in practice.

The conceptual framework selected for the study contented that background and contextual factors contributed to the experiences of stress among family caregiver's. A lack of resources in low / middle income countries contributes to the family caregiver's experiences of caregiver burden. Caregiver burden, being a multidimensional construct, affected all aspects of life of the family caregivers, depleted their physical, social, emotional, financial and spiritual resources and impoverished them.

The Zarit Burden Interview questionnaire provided baseline quantitative information and indicated that family caregivers experienced moderate to severe caregiver burden, which is very high compared to the rest of the world. Qualitative data was collected through interviews to enable family caregivers to explore their burden of care. Content analysis was used to analyse the qualitative data and a predetermined framework was used for the codes based on the conceptual framework and the domains of caregiver burden. Data were initially



analysed separately and then combined to enrich and complement findings. These findings were utilised to contribute to developing the components of a model to manage caregiver burden. The reviewer's report of this article has just been released and corrections are made accordingly.

## CHAPTER FOUR: MANUSCRIPT TWO

Oyegbile, Y.O and Petra Brysiewicz. (2016). Family caregiver's experiences of providing care to Patients with End-Stage Renal Disease in South-West Nigeria.

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ORIGINAL ARTICLE

### Family caregiver's experiences of providing care to patients with End-Stage Renal Disease in South-West Nigeria

Yemisi Okikiade Oyegbile and Petra Brysiewicz

**Aims and objectives.** To describe the experiences of family caregivers providing care for patients living with End-Stage Renal Disease in Nigeria

**Background.** Family caregiving is where an unpaid volunteer, usually a close family member, attends to the needs of a loved one with a chronic, disabling illness within the home. Much research has been conducted in the area of family caregiving in high-income countries. However, the same cannot be said for many of the low-resource, multicultural African countries.

**Design.** Qualitative descriptive study.

**Method.** This qualitative descriptive study used manifest content analysis to analyse data from semi-structured, individual interviews, with 15 purposively selected family caregivers. Two tertiary institutions providing renal care in South-Western Nigeria: the research setting for this study.

**Result.** Five categories were identified, and these included disconnectedness with self and others, never-ending burden, 'a fool being tossed around', obligation to care and promoting a closer relationship.

**Conclusion.** Experiences associated with the caregiving of patients diagnosed with End-Stage Renal Disease evoked a number of emotions from the family caregivers, and the study revealed that caregiving imposed some burdens that are specific to low-resource countries on participants.

**Relevance to clinical practice.** Nurses need to engage family caregivers on disease-specific teachings that might promote understanding of the disease process and role expectation. Family caregivers may benefit from social support services.

**Key words:** caregiver burden, End-Stage Renal Disease, experiences, family caregivers

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#### Introduction

Family caregiving is where an unpaid volunteer, usually a close family member, attends to the physical, emotional, spiritual, financial and any other needs of a loved one with a chronic, disabling illness in the home (Collins & Swartz

2011). While most high-resource countries support citizens through many institutionalised care services for such chronically ill persons, the same cannot be said for many low-resource countries like Nigeria, where family caregiving is a necessity (Brinda *et al.* 2014). In much of Africa, care is usually provided by family members at home for cultural

**Authors:** Yemisi Okikiade Oyegbile, MPH, PhD Student, University of KwaZulu-Natal, Durban; Petra Brysiewicz, Professor, Emergency Care Nursing, University of KwaZulu-Natal, Durban, South Africa

**Correspondence:** Yemisi Okikiade Oyegbile, PhD Student, University of KwaZulu-Natal, Durban 4041, South Africa. Telephone: +27 725301161.  
E-mail: 212516461@stu.ukzn.ac.za  
Twitter: @YOyegbile

**What does this paper contribute to the wider global clinical community?**

- Experiences of family caregivers of patients with End Stage Renal Disease in resource-limited countries are substantially burdensome on emotional, social, physical and financial aspects of life
- Social support services must be provided for family caregivers to continue caregiving

and filial reasons, but, more importantly, often due to lack of resources in hospitals (Yusuf *et al.* 2011). Parents often socialise children into this role earlier on in their life (Taulili *et al.* 2014).

## Background

End-Stage Renal Disease (ESRD) is a chronic, progressive, irreversible disease of the kidneys (Odubanjo *et al.* 2011a) with a prevalence of approximately 8–10% of hospital admissions in Nigeria (Ulasi & Ijoma 2010). The cost of treatment and hospitalisation for ESRD patients are often prohibitive, with the additional problems of limited access of patients to health care (Nugent *et al.* 2011). Studies (Ulasi & Ijoma 2010, Odubanjo *et al.* 2011b) show that access to dialysis is about 22.2% among the general populace. Arogundade *et al.* (2011) reported that 6.8% of patients who started dialysis could not afford the treatment for longer than three months. Unlike patients in developed nations who might benefit from Medicaid or Medicare, in Nigeria patients and family caregivers bear the huge burden of care without government support (Arogundade *et al.* 2011). Furthermore, enrolment for health insurance which could lessen the financial burden of ESRD is limited to workers in the formal sector of the economy, therefore leaving people in the informal sector to bear all the cost of care (Arogundade *et al.* 2011, Odubanjo *et al.* 2011b).

For these reasons, many resource-limited countries, such as Nigeria, require family caregivers to play a substantial role in the management of their sick family members (Okafor & Kankam 2012). They are also expected to create space in their daily lives to perform many healthcare procedures and duties similar to those provided by healthcare professionals (Mackenzie & Greenwood 2012).

Caregiving for patients with ESRD requires many different caregiving tasks, and many of them are labour-intensive and technologically driven. Such tasks include management of symptoms, performing activities of daily living, pain management, mobility assistance and management of comorbidities and complications in patients with ESRD (Fassett *et al.* 2011). Due to inadequate health personnel at hospitals, family caregivers are required to provide care at home and in the hospital to their sick relatives (Akpan-Idiok & Anarado 2014, Asakitikpi 2016). Hence, they must have special ability, knowledge, physical and psychosocial strength to perform these tasks and to cope with the demand of caregiving without jeopardising their own health (Given *et al.* 2012).

In countries like the USA, Australia and the UK, family caregivers might receive social support in the form of a caregiver's allowance, emotional, informational and

psychological support (Australian Government, 2010, US Department of Health and Human Services, 2012; Hudson & Aranda 2013). However, given the realities of the situation in Africa, this is most often not the case, as family caregivers have to play active roles in caring for their loved ones, while bearing the substantial burden associated with caregiving (Federal Ministry of Health, 2010, Okoye 2012). As family caregivers come to terms with the chronic nature of ESRD and recognise that their loved ones now have to begin to receive palliative care, they face the reality that their caregiving role may last a lifetime and they may become apprehensive about the future (Noble *et al.* 2013).

Family systems usually experience a significant level of disturbance in the family structure and function as a consequence of the chronic illness of a family member (Crespo *et al.* 2013), so creating disruptions in the family structure, instability in family functionality, or exaggeration of pre-existing domestic issues (Schipper & Abma 2011). Deterioration in patients' health status usually leads to emotional instability, depression and endless grieving in family caregivers (Nakken *et al.* 2015). Spousal caregivers usually feel more burdened than other caregivers as prolonged caregiving might impede marital satisfaction (Bauer & Sousa-Poza 2015). Chronic illnesses may cause loss of control and extreme dependence, which may have a negative effect on members of the family, so making them unable to function properly including a complete neglect of personal care (Hickman & Douglas 2010).

There is some evidence from research within the area of family caregiving in a number of high-income countries (Crespo *et al.* 2013, Noble *et al.* 2013). However, this is not the case for many low-resource and multicultural African countries. In particular, no study has documented the experiences of family caregivers of patients with ESRD in Nigeria. Although family caregivers play such a significant role, they appear to be 'hidden patients', who are often neglected by healthcare professionals, and yet, they are in need of support during the caregiving process (Hudson *et al.* 2013). The aim of the study was to describe the experiences of family caregivers providing care for patients with ESRD in Nigeria. This is part of a larger action research study guided by the Stress Process Model (Aneshensel *et al.* 1995) to manage caregiver burden among family caregivers of patients with ESRD in Nigeria.

## Methods

### Design

This qualitative descriptive study was part of a larger action research study towards developing a model to manage caregiver burden.

### Settings and recruitment

The study was conducted in two tertiary hospitals in the urban areas of South-West Nigeria. These hospitals are referral centres for patients (including patients with ESRD) from other hospitals in need of specialised care in South-West region of Nigeria. The hospitals were specifically chosen because they also have designated departments and outpatient clinics attending to patients specifically with renal diseases. Participants were included if they met the following criteria: were over 18 years of age, had been caregivers to patients with ESRD for at least six months, and were not receiving any salary or remuneration from government or family members for providing the care. One member of the family who was identified by the care-recipients as being the primary caregiver, who met the inclusion criteria and was willing to participate, was interviewed.

### Ethical consideration

This study was approved by the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (REF: BE226/14), where the researcher is a student, as well as ethics committees of the two hospitals in Nigeria. Participants were asked to provide written informed consent prior to participation in the study and were informed that they could withdraw from further participation in the study at any time, without any form of recrimination. They were also assured of anonymity and that no data could be traced back to them. Emotional support was provided to any participants who experienced discomfort while re-telling their stories of caregiving and the researcher was able to recognise signs of emotional distress. Five such participants were referred to Medical Social Workers (MSWs) in the research settings where they were provided with counselling services.

### Data collection process

- Registered nurses on the wards assisted the researcher to identify patients diagnosed with ESRD.
- The researcher introduced herself and the study.
- The researcher asked patients to identify their family caregivers.
- The researcher requested willing participants to complete an informed consent form, and a convenient meeting was scheduled.
- Some family caregivers refused to participate in the study as they were not emotionally ready to talk about their experiences.

Unstructured individual interviews were conducted between January–May 2015 by the researcher (YO) in either Yoruba (local language) or English, depending on the preference of participants. Due to resource constraints, there was no private room to conduct the interview, so the researcher created a private space at the end of the medical ward and the interview began with a general question: 'Can you tell me the story of looking after your loved one with ESRD?' Additional probing questions, such as 'What is it all about? How has it been looking after him?', were then asked to explore the participant's experiences to clarify their responses (Ritchie *et al.* 2013).

During the interviews, several participants expressed emotional reactions by being silent, looking down at their hands, taking deep breaths or by weeping openly. On those occasions, the researcher tried to be supportive by being silent and listening attentively, offering comfort, offering a glass of water and by referring some family caregivers to MSWs for psychological counselling. Each interview lasted 30–45 minutes, and follow-up verification interviews were conducted to clarify the data obtained (Ritchie *et al.* 2013). Interviews were audio-taped and transcribed verbatim at the end of each day. Data collection was discontinued after conducting 15 interviews, as the participants were all describing very similar experiences and no new findings, or concepts were emerging from the data (Francis *et al.* 2009).

### Data analysis

This qualitative study employed a manifest content analysis approach (Graneheim & Lundman 2004). This analyses the content aspect of the data and describes the visible, obvious components of the data with the aim of interpreting the data at a minimal level of abstraction while focusing on answering the research questions (Graneheim & Lundman 2004). In the process, codes, subcategories and categories are generated (Graneheim & Lundman 2004). During the process, the interview transcripts were read line-by-line several times, to achieve data immersion while reflecting on the data analysis. The developing categories and subcategories that emerged from the individual interviews were discussed, formulated and reformulated following discussions with a more experienced qualitative researcher (PB) (Graneheim & Lundman 2004).

### Trustworthiness

Trustworthiness was established by ensuring credibility, transferability, dependability and confirmability (Lincoln &

Guba 1985). Credibility was obtained through prolonged engagement with the participants as the researcher spent 17 weeks interacting with the participants to develop a rapport so that the participants felt comfortable and that the 'truth' was captured (Shenton 2004). Participants were encouraged to re-tell their stories 'as it is' and were continually reassured that there were no right or wrong answers (Ritchie *et al.* 2013).

Regular debriefing sessions were held with the research supervisor (PB) to review the activities of the study, suggest new plans of action, to make appropriate changes and discuss the categories emerging from the data. Participants were individually presented with feedback from their interview, and were asked whether they agreed with the interpretation of data, and whether the data accurately reflected their experiences of caregiving. Most of the participants agreed that the interpretations were a true reflection of the reality, while some small changes were made to some of the interview data. Most of the participants interviewed using Yoruba language were not able to read and write, and that informed the follow-up interview with all participants irrespective of their literacy level. A follow-up interview was the only option as many participants were not willing to read transcript in such emotionally laden circumstances. To ensure transferability, the researcher provided thick descriptions of all aspects of the study so that the reader could make an informed decision as to whether the findings were transferable to another settings (Shenton 2004). Dependability is necessary to ensure consistency and stability of the data over time and under different conditions (Lincoln & Guba 1985). An audit trail was embarked upon by the researcher, and a thorough detailing of reflections of events observed during the data collection period was undertaken including the decisions taken. To ensure confirmability, relevant participant 'voices' were selected and integrated into the findings to attempt to accurately describe the findings (Lincoln & Guba 1985).

## Results

The family caregivers in this study were spouses, significant others, parent and adult children of the sick person who were purposively selected. Of the 15 participants interviewed, 11 were female while 4 were male. See Table 1 for a description of the participants' demographic data.

Five categories emerged from the data: disconnection with others and self, never-ending burden, 'a fool being tossed around', obligation to care and promoting a closer relationship.

**Table 1** Demographic data of participants

Demographics	Family caregivers (n)
Gender	
Female	11
Male	4
Mean age in years	44 (range 20–70)
Marital status	
Married	12
Single	3
Relationship with care-recipients	
Spouse	8
Adult child	4
Sibling	2
Mother	1
Residence	
Same residence	13
Separate residence	2
Estimated hours of caregiving per day	20.7 (range 11–24)
Estimated months of caregiving	14.5 (range 6–48)

### Disconnection with others and self

Participants described how relentless caregiving had imposed restrictions on all aspects of their lives. Participants complained that caregiving delayed their ability to make progress in life, forced them to defer life issues and separated them from those activities that made life meaningful and worth living. While they provided care, their peers have moved on with life. One participant said:

Whereas my classmates are in the university learning and studying for the forth-coming major exams, I am in the hospital giving care to my sister. If I don't write this exam it's going to affect me. I mean ... I may repeat this session. (Family caregiver 07)

Another participant said:

I abandoned my search for [a] job because I have to provide care. I felt that my future plan has been jeopardised since it is impossible for me to apply for a job from the hospital environment. My colleagues are employed and making future plans while I am here providing care. (Family caregiver 03)

I feel left out of the happenings in the church and among my friends. I was in the hospital providing care when my niece got married. When my friend's daughter graduated from the university I was taking care of my husband in the hospital. There is no other thing I am doing now than to provide care. I was supposed to lead the women meeting at the church; I could not do it because I was taking care of my husband. This task has left me out of everything...separated me from my grandchildren, friends and church members. (Family caregiver 08)

Although caregiving is intense and burdensome, participants provided care at the detriment of their health and comfort. A family caregiver stated that:

My day begins and ends taking care of him [family member]. I feel tired always. I have even developed severe back pain in the process. Since he hardly remembers anything again, I always pay closer attention to where he is and what he is doing. As you know ... he must not wander out of the house. (Family caregiver 05)

Total involvement of family caregivers in caregiving often led them to ignore their own health challenges. Several family caregivers described how they were themselves unwell, but deferred seeking intervention. A participant explained:

I have not been able to see my physician since my husband was admitted into the hospital. My medication is finished ... I am not feeling well at all ... I am already hearing the beatings of my heart. Anyway, I hope to see my doctor after his discharge from the hospital. (Family caregiver 08)

#### Never-ending burden

Several participants described the relentless burden they experienced regarding the caregiving they provided:

I have been doing this for 48 months now. The question I asked myself is when am I going to stop doing the same thing over and over again? When is this caregiving going to stop? I don't like doing this anymore! Initially it was hypertension, then diabetes, and now kidney disease. I expect him to be cured of one disease before another showed up, but it is not like that. I have been managing these diseases over a long period and I am fed up with this experience. (Family caregiver 06)

Caring for patients with ESRD requires vigilance at all times. The acute, life-threatening changes that could occur in vital signs usually demand emergency responses. Therefore, constant follow-up throughout the day and night is crucial. In describing this experience associated with care, one participant said:

I do not stay with my father [the patient] in the same house. So I always keep my cell phone active throughout the night in case he has urgent needs that must be met before the day breaks. I hardly sleep ... deeply since I know there might be one issue or another ... during the night. I always feel tired and weak in the morning. (Family caregiver 10)

For many participants, the constant thought of the imminent loss of their loved ones to death makes grieving an unending burden of everyday living. They expressed grief and sadness especially when a patient's condition was life-threatening. A family caregiver said:

I always cry throughout the night. As I stay in the hospital providing care I see patients die from similar diagnosis as my husband. I cry because I know that it is just a matter of time ... it will soon be my turn ... to mourn the death of my husband ... I cry because life will be difficult for me and my children in the event of his death. (Family caregiver 11)

#### 'A fool being tossed around'

Participants described how their apparent lack of knowledge regarding the medical condition, treatment and role expectation often resulted in situations where they were left feeling foolish. They also felt they were treated as fools by healthcare staff.

A participant explained:

I have no idea of what the disease is all about. I feel embarrassed when I don't know what I need to know. I am concerned that nurses are not telling me anything. ... since they are the ones knowledgeable in health matters. (Family caregiver 05)

Another one said:

I just sit here like a robot. Nurses asked me to buy items that my mother needed. They never told me why she needed them. They ordered me to pay for dialysis, laboratory investigations and other things. I don't like it when I do not know the reason behind my actions. I am sad to see myself as a fool being tossed around. (Family caregiver 03)

A participant described how he was used by the nurse as a splint to stabilise his relative's hand during intravenous therapy administration:

Nurses ask me to hold her hand ... the one that is used for infusion. I held it for several hours ... I can't imagine myself being treated this way. (Family caregiver 01)

On several occasions, dialysing equipment developed fault, which necessitated discontinuation of the procedure. When the procedure recommenced, participants were required to repeat payment, which made them feel that they were being treated as fools. A participant related the story:

After paying for dialysis, nurses started the procedure and then the machine developed some faults which made them stop the procedure ... but on the following day when she [relative with ESRD] was taken there to complete the process that started yesterday, nurses demanded another full payment from me. They took me for granted ... am I a fool that will pay for a service that was not completed? (Family caregiver 14)

### Obligation to care

Providing care to a loved one was seen by some participants as being part of what they must do to a family member in need. Reciprocating the care once enjoyed from the patient often served as compelling reasons for the caregiver to begin, and to then continue, in the caregiving role. One participant said:

I saw him [my father] provide care to my grandfather, when I was growing up. He took care of him for a prolonged period of time. I just said to myself I need to do this because I want my children also to take care of me when I am sick or old. To me, it is good to reciprocate good cultural values, so that it can be sustained. (Family caregiver 10)

Although many of the caregivers felt obliged to carry out the necessary caregiving tasks, this in turn created conflict in terms of cultural beliefs. One participant said:

In my culture, children are forbidden from seeing the nakedness of their parents. I am sad when I see her exposed body every day. I always remember that it is unacceptable in our culture to see a parent's nakedness. But if I do not provide care for her, who else will? I am afraid for my life because of the repercussions of the taboo on me. (Family caregiver 02)

### Promoting a closer relationship

Many participants reported that the time spent with the care-recipient promoted a closer relationship between them and the patient. A participant explained:

The time I spent taking care of my mother provided opportunity for us to share concerns, cry over shoulders and laugh about successes. I relate easily with many of her success stories and learn from the shortcomings of her life. It's indeed a time of recounting events, learning and making adjustments. She appreciates the care I provided for her and that made her share sensitive information with me. (Family caregiver 02)

A participant went further to explain that this closer relationship provided fulfilment in her marriage:

I feel fulfilled that I am able to provide care to my husband ... of 30 years ... He is a good, loving, caring and reliable companion. He smiles all the time because he is happy. The type of care I provide for him makes him happy and it has strengthened our love for each other. (Family caregiver 15)

The participant also described how this closer relationship extended to other members of the family as well:

I know almost everything I need to know about my siblings since our mother's illness started. We talked regularly on the phone, they share vital information about their financial life, as well as other aspects of life with me. We discussed intimately all issues of life, especially as it affects our mother. I wonder if I could ever know so much about them if not for our mother's sickness. (Family caregiver 03)

Participants narrated how appreciation of a job well done led to closer relationship:

We are closer more than before the sickness began. Because of the good care I am giving to her and the fact that I stayed with her most of the time, she appreciates everything I am doing for her and she prays regularly that my children shall also take good care of me. (Family caregiver 04)

### Discussion

In this study, caregiving for patients with ESRD delayed achievement of life goals, and resulted in the abandonment of hopes and aspirations, thus ultimately leading to a significant source of burden to family caregivers. Furthermore, continuous care-provision disconnected family caregivers from engaging in social activities, social relationships and prevented them from seeking intervention for medical problems (Girgis *et al.* 2012, Northouse *et al.* 2012). Although studies emphasised that family caregivers need help to continue caregiving, they are usually not the focus of care for healthcare professionals (Hudson & Aranda 2013). Consequently, family caregivers may develop physical or psychological consequences of particularly intense caregiving experiences; however, studies have shown that family caregivers with adequate social support services were able to continue caregiving without compromising their own health, well-being and future aspirations (Northouse *et al.* 2012).

Consistent with this study, other studies found that care-provision to patients with ESRD overwhelmed the family caregivers as a result of its unending nature (Goldberg & Rickler 2011, Gillick 2013). The never-ending burden experienced by participants in this study was related to prolonged provision of substantial care with no end in sight, being ever vigilant, during the day and at night, in anticipation of emergency calls which resultantly disturbed the sleep of caregivers and compromised their peace of mind (Lutz *et al.* 2011, Crespo *et al.* 2013).

The imminent loss of a loved one, particularly the breadwinner of the family, traumatised participants, thus contributing significantly to the emotional burden they experienced. In particular, female spouses experienced

emotional distress as a result of the dual role they played as spouse and caregiver (Mystakidou *et al.* 2013). In contrast to the current study, Girgis *et al.* (2012); Collins and Swartz (2011) reported that family caregivers, with adequate family support and social networks, took breaks from caregiving and shared responsibilities of care with other family members. These family caregivers considered the experience as being beneficial, rewarding and satisfying (Nakken *et al.* 2015).

Participants reported they felt like 'a fool being tossed around' and they were displeased because they lacked knowledge of the disease process and performed roles and responsibilities without prior preparation or know-how. Non-availability of basic medical supplies and equipment, the use of obsolete equipment in some instances, and insufficient healthcare personnel are prevalent in state hospitals in many countries of Africa, including Nigeria (Agaba & Tzamaloukas 2012, Obansa & Orimisan 2013). For these reasons, family members become very important in getting actively involved in providing the actual care. This is in line with studies conducted in Nigeria and Malawi, where relatives performed basic and professional care for their sick family members (Hoffman *et al.* 2012, Vincent-Onabajo *et al.* 2013). Family caregivers, as an integral part of providing care, rely on nurses to empower them with adequate knowledge and the skills necessary for caregiving, and a positive outcome for patients and an improved quality of life for family caregivers (Eggenberger *et al.* 2011).

Participants narrated that they contravened some significant cultural beliefs for care-provision. Among the Yoruba tribe of Nigeria, it is forbidden for children to see the nakedness of their parent. However, participants contravened cultural laws for caregiving, as no one else could provide the care (Yusuf *et al.* 2011, Vincent-Onabajo *et al.* 2013). Previous studies on these findings are scarce. However, findings by del-Pino-casado *et al.* (2011) could provide some explanations. The study revealed that family caregivers' sense of dedication to caregiving increased when care dependency increased, and with little or no support from the government they felt that they were obliged to provide care without considering the consequences that might follow their actions (del-Pino-casado *et al.* 2011, Hudson & Aranda 2013, Brinda *et al.* 2014). More so in Nigeria, where hospice and palliative care are nonexistent, family caregiving becomes imperative for the care of chronically sick persons (Yusuf *et al.* 2011). On the contrary, in a study in sub-Saharan Africa among the patients with HIV/AIDS, the authors argue that the cultural value of mutual obligation to care disintegrated when several family members were affected by the illness simultaneously,

leaving no one to provide care to patients needing the end-of-life care (Gysels *et al.* 2011).

In contrast to previous studies, a prolonged time of caregiving had a positive benefit for patients and family members. This is consistent with previous studies where a prolonged time of caregiving promoted a closer relationship among caregivers and patients (Wagner *et al.* 2011, Girgis *et al.* 2012). In this study, a possible narrative for the closer relationship during caregiving is that caregivers rendered quality care, spent quality time together and used caregiving time for meaningful discussions on life issues (Erlingsson *et al.* 2011). In particular, participants, who provided care to their spouse, derived fulfilment from doing so to a loved one in time of need and in line with the fulfilment of marital vows (Ågård *et al.* 2015). In contrast to our study, prolonged caregiving of close family members invoked negative emotional, physical, social and financial consequences in family caregivers. Compassion for the sick and fear of loss produced serious mental health issues among family caregivers (Bauer & Sousa-Poza 2015).

## Conclusion

Experiences associated with the caregiving of patients diagnosed with ESRD evoked many emotions and had serious emotional and physical consequences for family caregivers. Disconnection with self and others were significant and common, which, if overlooked, might negatively impact on a family caregiver's quality of life and delay future achievements. The unending burden associated with care produced caregiver burden among family caregivers. To resolve the problem, establishing psycho-educational support groups could empower family caregivers with the necessary knowledge and emotional support needed for successful caregiving.

## Relevance to clinical practice

Nurses need to incorporate caregiver teaching that is focused on ESRD process and role expectation of caregivers at different stages. Written information in the form of a booklet detailing the stages of ESRD, a simple definition of common concepts in renal care, referral services available and the needs of patients at each stage of the disease, would be valuable. Nurses could also facilitate the organisation of psycho-educational support groups in partnership with family caregivers of patients with ESRD. This support group might provide an avenue for illness-specific training and support for family caregivers. As psycho-educational support services for family caregivers of patients with



ESRD are relatively new in Nigeria, nurses might need to gain skills in starting and sustaining such a process.

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### Contributions

Study design: YO, PB; Data collection: YO; Data analysis: YO, PB; Manuscript preparation: YO, PB.

### Conflict of interest

None.

Original article

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#### **4.18. Synopsis of the article**

This article addressed the objective: to describe the family caregivers' experiences of providing care to patients with End-Stage Renal Disease. This article described the in-depth exploration of what it really means to be a family caregiver. In order to develop a model it was appropriate to listen to the people that the model was intended for. The best way to get this done was through individual in-depth interviews with the participants that allowed the researcher (and reader) to really 'feel' what it was like to be a family caregiver. Manifest content analysis identified and described the family caregivers' experiences and identified categories and sub-categories. This then served to assist with the emergence of relationships between the crucial concepts which then served as the building block for the model's development.

Pragmatism was the lens through which the researcher keeps on focusing on the problem and the solution to the problems. Action research was part of Cycle Two and together with the research team, it was decided that following the establishment of the need for research in Cycle One, further in-depth exploration of the experiences of caregiving was needed. This cycle of action research allowed the research team to uncover five categories namely: disconnection with self and others and self, never ending burden, 'a fool being tossed around', obligation to care and promoting a closer relationship. This data was essential in forming the basis for the crucial concepts of the intervention model.

The conceptual framework guiding the study also reminded the research team to always consider the area under investigation comprehensively, that is, to examine the background and contextual factors, the stressors, the moderators in order to affect the outcome.

The caregiving experience evoked a great deal of emotions for the caregivers who also revealed the specific challenges in carrying out this task in a low-resource country. The findings suggest that nurses need to engage with the family caregivers of patients with ESRD in order to improve their knowledge and their role expectations. It was also suggested that these caregivers could benefit from social support strategies.

The role of culture and cultural obligation to provide care imposed significant burden of care on family caregivers. Although caregiving to their sick relatives promoted closer relationship, it produced caregiver burden for these family caregivers. Financial constraints also affected family caregiver's role and increased their experience of burden.

## CHAPTER FIVE MANUSCRIPT THREE

**Yemisi Okikiade Oyegbile & Petra Brysiewicz. Developing and implementing an Intervention Model to Manage Caregiver Burden. *Submitted to Health SA Gesondheid***

### **Abstract**

**Introduction:** Family caregivers of patients with End-Stage Renal Disease (ESRD) play a significant role in providing substantial care for a prolonged period of time for their sick relatives, often with very limited resources, making it a difficult environment. Government support for family caregivers of patients with ESRD is scarce in Nigeria, increasing their vulnerability to caregiver burden and its consequences.

**Aim:** To develop and implement an intervention model to manage the caregiver burden experienced by the family caregivers of patients with ESRD in Nigeria.

**Design:** An action research study using a complimentary mixed method approach was used to develop this model.

**Method:** Quantitative data was collected to measure the extent of caregiver burden using a Zarit Burden Interview questionnaire for 96 family caregivers, while individual in-depth interviews with 15 participants provided the qualitative data.

**Results:** Integrating the quantitative and qualitative data led to the identification of four moderators to manage the caregiver burden in this study, namely, increasing caregivers' identity and recognition; increasing knowledge through education; increasing participation at support groups and increasing social connection and engagement. The Managing Caregiver Burden Model was synthesized from these findings, using stressors and associated moderators of caregiving, and the role played by culture and finance in this context to develop an intervention model. On completion of the model and the resulting moderators, an implementation checklist was used by registered nurses to implement the concepts in the model with the family caregivers during the model implementation phase.

**Conclusion:** Family caregivers of patients with End-Stage Renal Disease need to be supported by nurses during the caregiving process. Nurses can assist by attending to some of their needs to prevent the family caregivers from being overwhelmed by their caregiving role.

**Key words:** *family caregivers, caregiver burden, intervention model, action research, Nigeria.*

## **INTRODUCTION**

Caregiving, as an ever changing experience, with a peculiar history and an unpredictable future, evokes numerous emotions, often inflicting deleterious consequences on family caregivers (Aneshensel, Pearlin, Mullan, Zarit and Whitlatch, 1995; Bastawrous, 2013). End-Stage Renal Disease (ESRD) is a condition of the kidneys that is characterised by the irreversible loss of renal function to a degree sufficient to render the patient permanently dependent on dialysis, renal replacement therapy and family caregivers for the providing care (Odubanjo, Oluwasola and Kadiri, 2011). Caregiving refers to the care provided to a sick, diseased or disabled person, the intensity and duration of which depends on the needs of the patient (Longacre, Ross and Fang, 2014). Family caregiving is providing care by family or friends, without the person receiving any remuneration or formal training for doing so, according to Nakken, Spruit, Wouters, Schols and Janssen (2015).

Caregiving to patients with ESRD is resource intensive, time consuming, and goes on for a long time, requiring an indefinite commitment of a family caregiver to caring for a loved one from diagnosis till death (Noble, Kelly and Hudson, 2013). As the patients' health deteriorates significantly at the end of life stage, the demand for caregiving increases, and the more likely that family caregiver's experiences caregiver burden, adds Noble et al. (2013). Peculiar to most low-income countries, government support for these family caregivers is often very limited or non-existent, increasing their vulnerability to physical, social, and emotional burdens (Brinda, Rajkumar, Enemark, Attermann and Jacob, 2014; Dondorp, Iyer and Schultz, 2016; Hannon, Zimmermann, Knaul, Powell, Mwangi-Powell and Rodin, 2016; Thrush and Hyder, 2014).

Caregiving occurring in a resource-limited environment is restrictive and challenging, compelling family caregivers to fully participate in care-provision (Dondorp et al., 2016). Inadequate health care personnel in hospitals, the need to provide care as a form of

reciprocity and mutuality made family caregivers play a significant role in providing intense care to their sick relatives (Oyegbile and Brysiewicz, 2017). In Nigeria, family caregivers settled medical bills out-of-pocket as health insurance policy covers those working in the formal sector of the economy, exposing the informal sector to the risks of substantial medical costs (Olakunde, 2012). Whereas the governments of high income countries provide support in terms of covering costs for dialysis and renal replacement for patients with ESRD, the same cannot be said of patients in low-middle income countries, where family caregivers bear the huge cost of care (Arogundade, 2013; Cruz, 2016; Family Caregiver Alliance, 2011). This extraordinary demands for extensive caregiving can exerts considerable consequences on all aspects family caregivers' lives, making them experience caregiver burden (Garlo, O'Leary, Van Ness and Fried, 2010).

Although there are models documented in literature for the family caregivers of patients with ESRD in high resource countries, (Australian Government, 2010), they are resource-driven, thus making them unsuitable for a resource-limited country, such as Nigeria which is a multi-cultural, multi-ethnic, multi-religious, resource-limited country (Obansa and Orimisan, 2013; World Bank Group, 2016; World Health Statistics, 2014). The way of life of people, their race, religion, socio-economic and ethnic orientations need to be considered while developing a model.

A study was undertaken to explore and describe the family caregiver's experience of caregiver burden found that those who provided prolonged, intense and extensive caregiving to their sick relatives, a role often imposed on them by their culture, developed moderate to severe forms of caregiver burden in all domains of care (Oyegbile and Brysiewicz, 2017). As the main interface with the health care system occurs with nurses, they are ideally positioned to assist family caregivers to manage their caregiver burden.

## **AIM**

To develop and implement an intervention model to be used by nurses to manage the caregiver burden experienced by the family caregivers of patients with ESRD in Nigeria.

The conceptual framework underpinning this study was the Stress Process Model by Aneshensel et al. (1995), which consisted of background and contextual factors, stressors, moderators and outcomes, specifically to illustrate the relationship that exists between these components.

## **DEVELOPMENT OF THE MODEL**

Mutual collaborative action research guided this study, with the six member research team comprising of two family caregivers, two nurses, one medical doctor and the researcher, all of whom actively participated in developing the model and initiating the change in practice (Holloway and Wheeler, 2010; McNiff and Whitehead, 2010). Inclusion criteria for this study included family caregivers and nurses. The Managing Caregiver Burden Model (MCBM) was developed from the findings of data obtained from questionnaires, interviews, workshops and research meeting. The intention being to develop a model with stressors, moderators and outcomes, with a checklist of actions to enable nurses use the model to manage the caregiver burden. The participants were required to identify stressors that were associated with this role, and moderators, these being suggestions about how to overcome them and the qualitative data was obtained through in-depth interviews from family caregivers.

The study consisted of four cycles: Cycle One established the need for the study, measured the caregiver burden and highlight the discrepancies in the burden levels between low income and high income countries (Oyegbile & Prof. Petra Brysiewicz Unpublished). The quantitative data do identify stressors from the caregivers using the Zarit Burden Interview (ZBI) questionnaire (Zarit, Reever and Bach-Peterson, 1980). The interview consisted of open-ended questions to enable comparison with studies in developing countries and inclusion of the results into the model.

In Cycle Two, the in-depth individual interviews obtained qualitative data from fifteen family caregivers, and revealed that family caregiving was informed by cultural and financial expectations. Within this context, five categories emerged as describing the family



caregivers experiences, namely; disconnection with self and others, never ending burden, ‘a fool being tossed around’, obligation to care, and promoting closer relationships (Oyegbile and Brysiewicz, 2017).

In Cycle Three, the intervention model was developed from the data through the collaborative effort of the research team members, and was guided by the knowledge development process of Chinn and Kramer (2011). The model was developed and validated by the members of the research team using the question items on Annexure 11 to guide the discussion. This was done before the model was presented to practicing nurses at a workshop that took place at a private renal care hospital for patients with ESRD in South-West Nigeria.

The outcome of both data collection exercises were stressors (difficulties experienced in the course of providing care to sick relatives that could be directly related to caregiving or indirectly related to caregiving (Pearlin, 2010) and moderators. Moderators are the personal and social resources available to family caregivers that help to modify the causal relationship between the stressors and the outcomes (Pearlin, 2010). Stressors and moderators informed the activities that were included in the implementation checklist that was developed to accompany the model (See Table 1). In Cycle Four, members of the research team participated in developing a model’s implementation checklist to operationalize the model. This enabled the nurses to manage the caregiver burden, being piloted in one research setting for six weeks.

## **ETHICAL CONSIDERATIONS**

Approval for this study was provided by the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC 226/14) and from the participating private sector institution in Nigeria. Privacy and confidentiality of the information were maintained to ensure that no data could be traced back to the participants or institutions. Participants gave permission to participate in the study.

## **MODEL ASSUMPTIONS**

For the model to be useful in this context certain assumptions were accepted:

1. There will always be some degree of difficulty for family caregivers providing care for ESRD patients.
2. Caregiving is resource-intensive, often inflicting serious consequences on all aspects of the family caregiver's lives.
3. Part of the cultural aspects in this context dictates that caregiving is obligatory.

## **DESCRIPTION OF THE MODEL**

The Managing Caregiver Burden Model (MCBM), as shown in Figure 1, illustrates the three components namely: stressors, moderators and outcome for family caregivers who have been affected. This intervention model was based on the Stress Process Model that underpinned the study, which illustrates the interaction between the crucial concepts to manage caregiver burden. Stressors are problems experienced by family caregivers in the process of providing care and were identified by the family caregivers in Cycles One and Two of the study as those things that could produce serious outcomes for family caregivers.

An increasing number of moderators, as indicated by the unidirectional arrow, were potentially perceived by the participants to alter the process of the stressors that lead to caregiver burden. These moderators were perceived to reduce the caregiver burden experienced by family caregivers. The bi-directional arrow situated between the moderators and the outcome is to illustrate the fact that these may have an influence on each other. Culture and finance are threads running through the model, indicating that these two concepts have a profound influence on all its components. Nurses and family caregivers must therefore take measures to identify their influences and address them appropriately.

**Insert Figure 1: Managing Caregiver Burden Model (MCBM) Oyegbile & Petra Brysiewicz (Unpublished) here.**

## **MODERATORS**

The synthesis of quantitative and qualitative data informed the identification of the moderators to manage caregiver burden, which could occur at any time, individually or collectively. The literature was reviewed to identify similarities and differences in the concepts before a decision was made about what was included. Four moderators were identified that could assist in dealing with their stressors.

### **Increasing social connection and engagement**

The data from the interviews revealed that family caregivers perceived themselves as perpetually providing care, with no time to attend to personal needs. This separated them from those activities that made their lives meaningful and worth living. Although they felt obliged to provide care, this created conflict between achievement of life aspirations and the restrictions placed on their lives as a result of prolonged duration and the time spent in caregiving.

No other activity takes place in my life except caregiving. I am always making sure that he is well taken care of. I do all sorts of things just to make sure he is well taken care of. I am like everything to him and [do] everything that will make him feel better. I do not have time for myself...(Caregiver 01).

Family caregivers who provide prolonged care often ignored their own needs for physical and emotional care; they experienced disconnection with themselves and others as they were engrossed in the caregiving role, according to Moore and Gillespie (2014). To lessen this, a number of authors (Eslami, Rabiei, Abedi, Shirani and Masoudi, 2016) suggest that family caregivers must create time to participate in social, family, and spiritual activities in order to derive joy, hope and renewed relationships with others in the community. van der Lee, Bakker, Duivenvoorden and Dröes (2014) agree, stating that family caregivers must connect socially in society and engage with resources in the community to ensure adequate self-care.

For these reasons, significant others and nurses need to collaborate with family caregivers to create space for them to increase their social connection and engagement, which ultimately might lead to improved self-care, emotional well-being and participation in community life activities (Deek, Nouredine, Newton, Inglis, MacDonald and Davidson, 2016). Such connection could provide respite and a renewal of energy to continue caregiving unabated.

### **Increasing participation in support groups**

The participants revealed that a lack of support increased the experiences of caregiver burden for family caregivers.

Providing care for her is a challenge for me. I am all by myself, I feel the pain alone and cry alone, I provide care in the hospital and run around sourcing for money to settle medical bills.... (Ummm).... My father left us and relocated to another town when my mother's sickness failed to go. He has not called or visited us since [he left] two years ago. I feel sad because I have nobody to run to for assistance. I feel abandoned, isolated, and lonely all the time (**Caregiver 02**).

Prolonged caregiving can deplete a family caregiver's resources, impacting negatively on all aspects of their lives. Kelly (2010) explained the relevance of support groups as a place where family caregivers can feel supported. A support group can facilitate relationships in which they discuss the issues of caregiving openly, express their fears and concerns, and listen to other caregivers' experiences (Northouse, Katapodi, Song, Zhang and Mood, 2010). Support groups accomplish this by providing information on available resources, individual counselling, and educational services (Northouse, Williams, Given and McCorkle, 2012). These resources can be useful ways for family caregivers to develop therapeutic relationships and open communication among members. Although participation in support groups can be beneficial, some family caregivers experienced a loss of privacy in the process, while others said it was ineffective and discouraging (Wittenberg-Lyles, Washington, Demiris, Oliver and Shaunfield, 2014; Wong, Ki, Maharaj, Brown, Davis and Apolinsky, 2014).

## **Increasing knowledge through education**

Family caregivers perceived themselves as ‘fools being tossed around’ as they were not knowledgeable in terms of the disease process, needs of their patients or prognosis. Most participants stated that health care professionals did not provide information regarding their relative’s disease status. The only time they interacted with them was when they needed to settle medical bills or when their sick relatives needed medical supplies that had to be purchased from a pharmacy shop outside the hospital.

Nurses only call me to go buy one thing or another. I have no idea of what her needs are.....when doctors come.....they speak medical jargons and go.....I wonder if what they say could help my mother.....I think someone should talk to me **(Caregiver 14)**.

Another participant said:

Although nurses are trying their best.....but they need to do more in terms of providing information.....since most of us are novices. I really need to be educated on how long this illness will take? What other type of care can I provide to give her some peace.....? I desire to know..... **(Caregiver 04)**

Another participant said:

We have spent our fortune on these diseases.....and they are not resolving at all. His retirement benefits was used to pay up his medical bills.....I am spending my business capital to pay for medical bills.....it's painful! (SOBS)..... **(Caregiver 12)**

Knowledge to assist with managing caregiver burden needs to provide family caregivers with information on the disease process, symptom management, referral services and available resources that support caregiving (Gladsam, Timm and Vittrup, 2010). Family members are often anxious, apprehensive and may experience depression due to a lack of information about the disease process, the needs of the patients at different stages of the

disease, referrals and other services that may be beneficial to the patients recovery (Gaeeni, Farahani, Seyedfatemi and Mohammadi, 2015).

Knowing about the financial implications related to providing care for ESRD patients might prepare family caregivers and their sick relatives adequately and thereby reduce the experiences of burden. For this reason, nurses should inform family caregivers about the changing needs of the patients and show them how they can provide assistance that supports positive outcomes for their sick relatives. Research has shown that educational interventions empowered family caregivers with the required knowledge, engendered their emotional stability and the adoption of suitable coping skills (Epiphaniou, Hamilton, Bridger, Robinson, Rob, Beynon et al., 2012; Northouse et al., 2012). Gaeeni et al. (2015), added that this is beneficial because well-informed family caregivers might develop more positive responses to caregiving, make future plans and be better prepared for patient outcomes.

### **Increasing caregiver's identity and recognition**

The interviews revealed that family caregivers seemed to change the way they perceived themselves, namely as someone perpetually providing care. Family caregivers also complained that their sick relatives and other family members did not appreciate their caregiving efforts.

I have been doing this for some time now, it's like there is no end to it.....My life revolves around him and the four medical conditions....hypertension, diabetes, kidney disease and leg ulcers.....(sobs).....(**Caregiver 11**).

Another participant said:

I feel very angry and frustrated when my father doesn't say 'thank you' for the care I give him. He never appreciates the fact that I gave up many things to take care of him. He is a complainant per excellence! He complains about almost everything I do in the process of giving care. It is either the food is not warm enough or that he prefers someone over the other to feed him (**Caregiver 10**).

Strained relationships between family caregivers, and their sick relatives, as well as between them and their significant others could be discouraging for family caregivers and result in them experiencing caregiver burden (Ngangana, Davis, Burns, Mcgee and Montgomery, 2016). Studies have highlighted that significant others and healthcare professionals are better positioned to acknowledge and recognise the family caregivers' enormous role and responsibilities (Aoun, Deas, Toye, Ewing, Grande and Stajduhar, 2015). Family caregivers could change their perception of themselves from someone perpetually performing caregiving responsibilities to someone that is recognised for playing a significant role in the life of their loved ones, Moore and Gillespie (2014); Skovdal and Andreouli (2011). Health care professionals can encourage family caregivers to take time off temporarily from caregiving so as to regain their self-identity, address their personal needs and request assistance or support when needed (Aoun et al., 2015; Northouse et al., 2012). By increasing caregivers' identity and recognition, they can improve their self-esteem, find meaning and satisfaction in the caregiving experience (Mystakidou, Parpa, Panagiotou, Tsilika, Galanos and Gouliamos, 2013; Skovdal and Andreouli, 2011), and maintain an adequate sense of self.

## **Culture**

In this study, culture was one of the threads connecting the family caregivers' experiences of caregiving and caregiver burden. Cultural expectations and a preference for family care over institutionalised care placed the huge burden of care on family caregivers, specifically the women (McCleary and Blain, 2013; Okoye and Asa, 2011). Data from Cycle Three revealed that family caregivers who were compelled by culture to provide care for their sick relatives experienced caregiver burden, and a fear of contravention of cultural taboos increased their experience of caregiver burden for these family caregivers (Årestedt, Persson and Benzein, 2014). Although family caregiving promotes the continuity of cultural practices and the sustenance of values and traditions, support could be provided to manage their caregiver burden (Friedemann, Buckwalter, Newman and Mauro, 2013).

## **Finance**

The availability of financial resources plays an important role in providing adequate care to patients with ESRD, especially in low / middle income countries. Caregiving for ESRD patients is resource intensive, and family caregivers experienced economic burden in the process, this being identified in Cycles Two and Three as one of the stressors or challenges of providing care to their sick relatives. In Nigeria, family caregivers have to settle medical bills, buy surgical supplies and medication before their loved ones is treated. This often places the burden of responsibility for the cost of care directly on family caregivers, and if patients die, it becomes the family caregivers fault.

Dondorp et al. (2016); Karopadi, Mason, Rettore and Ronco (2013) substantiated this, stating that the economic burden of ESRD in low income countries was substantial and prohibitive, impoverishing family caregivers and increasing their vulnerabilities to financial burden. Whereas basic renal care might be affordable and accessible in high income countries, the same cannot be said of low-middle income countries where the cost is prohibitive and access to care is limited (Dondorp et al., 2016). Inadequate numbers of health care personnel also limit patients' access to expert care. Brinda et al. (2014); Hoffman, Mofolo, Salima, Hoffman, Zadronzny, Martinson et al. (2012) assert that this lack also compels family caregivers to provide all forms of care, including professional levels of care. Although nurses do not have the capacity to meet the financial obligations of the family caregivers, they can assist them by helping them to feel supported and encouraged through participation in support group.

## **MODEL IMPLEMENTATION**

Following the development of the model, it was implemented in a hospital in South West Nigeria, as this hospital showed an interest in the study. The intention was to develop a checklist for nurses to use when engaging with the model. Family caregivers and nurses providing care to patients with ESRD participated in Cycle Four. On days chosen for the model implementation, a nurse volunteer approached a family caregiver, sought his / her



verbal consent, and using the implementation checklist, implemented the model. Selecting the participants for the model implementation was based on the family caregivers' interest and willingness to participate. Seven family caregivers and three registered nurses participated in the model implementation phase of the study. The volunteer nurse and willing family caregiver decided on a convenient time to implement the model, which took place in the patients' private rooms in the ward using the implementation checklist. The researcher was there to witness the process and participated in the model implementation when volunteer nurses were unavailable.

Verbal feedback provided by nurses and family caregivers indicated that they were delighted to have a model to manage the caregiver burden. In particular, family caregivers were excited that the model provided an opportunity for them to talk to the nurses, this being the first time it ever happened, with some requesting more time as they had many things to talk about. A number of family caregivers stated that many of their fears, needs, and anxieties could have been addressed if the intervention model had been implemented earlier in their caregiving experience. While an insufficient number of nursing staff was a challenge at the hospital, the implementation cycle progressed as scheduled. Nurses reported that the implementation checklist made it possible for them to implement the intervention model to manage caregiver burden. They find the implementation checklist useful in starting and continuing a conversation with family caregivers. Nurses reported that the checklist guided them to address issues affecting family caregivers individually.

## **REFLECTIONS, LIMITATIONS AND AREAS FOR FURTHER RESEARCH**

At the start of the study, family caregivers perceived nurses as 'unapproachable individuals', this having limited their interaction with them. By the end of the study, some had initiated discussions with nurses regarding their concerns, fears and challenges, and they appeared to be willing to continue providing care to their sick relatives. The mixed methodology and inclusion of various role players resulted in the emergence of the model's concepts and their relationships. The conceptual framework that guided the study suggested the relationship

between the stressors and the moderators that led to the final outcome. Verbal feedback revealed that the family caregivers were excited to have a model to manage the caregiver burden experienced. Nurses were also excited about its potential as a resource to improve patient care, having not realized the extent to which the family caregivers were affected by their responsibilities.

A limitation was that the model was implemented in one research setting. This warrants further research to determine how effective it is to assist in managing caregiver burden.

## **CONCLUSION**

This study has revealed that family caregivers providing care to their sick relatives in resource limited setting need support from nurses during the process of caregiving, often not receiving sufficient advice and assistance to ensure that their family members receive the best possible care.

## **AUTHOR'S CONTRIBUTION**

The study was conceptualized by both authors. YOO collected the data and implemented the model. PB was the research supervisor. Both authors prepared and approved the final manuscript.

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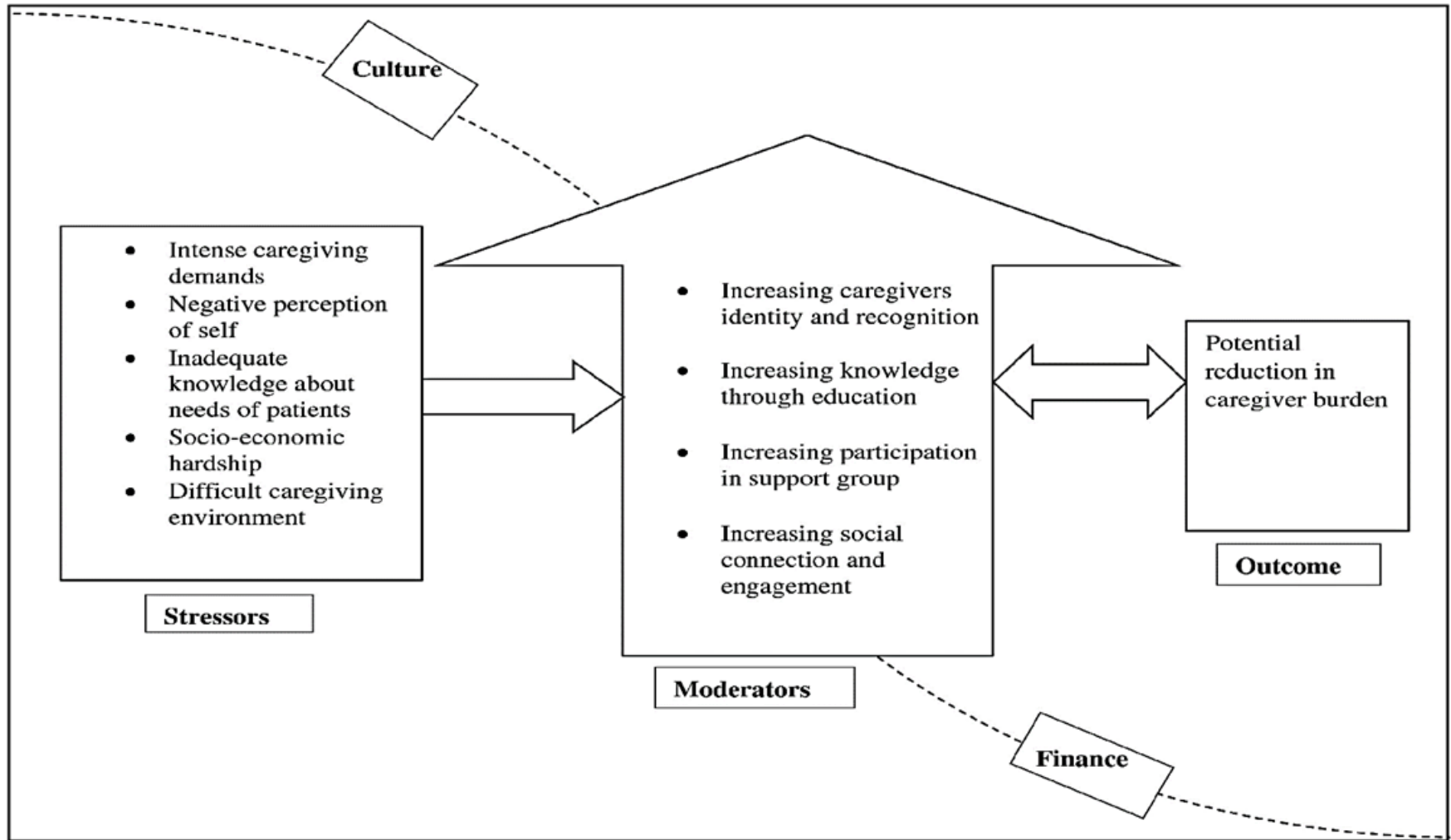


Figure 1: Managing Caregiver Burden Model (Oyegbile & Petra Brysiewicz, Unpublished)

**Table 1: Implementation checklist**

Activities required for the implementation of the model

Instruction: please check (X) the box when you complete the activity

S/N	Activities	Yes	No
	Address family caregiver by name or surname and title (if applicable).		
	Create rapport by explaining the purpose of meeting.		
	Show concern towards her / his well-being.		
	Recognize active role being played by family caregiver		
	Appreciate him / her in the presence of patient		
	Encourage patient to also acknowledge and appreciate family caregiver's		
	Attribute positive meaning to the caregiving role and responsibilities		
	Encourage family caregiver to ask for help when needed		
	Assess level of family caregiver's knowledge on ESRD management		
	Provide simple, basic information on specific care requirement for patients with ESRD.		
	Provide or reinforce information regarding dialysis, renal replacement therapy etc		
	Provide contact details of hospital staff to call in an emergency		
	Discuss the prognosis (outcome) of ESRD with the family caregiver in a manner consistent with their values and preferences		
	Permit family caregiver to ask questions		
	Describe what support group is and highlight its significance		
	Inform him / her about services and benefits of support group		
	Inform him / her to sign up for membership when the hospital starts one.		
	Ask if family caregivers have enough time to rest.		
	Encourage him / her to ask for help when needed.		
	Set aside time to meet your own needs		
	Refer family caregivers to Medical Social Worker that can provide support for future care needs and options		
	Engage in healthy lifestyle activities like sleep, exercise, adequate diet		
	Take time off caregiving activities		
	Ask / respond to questions		

## **5.1. Synopsis of the article**

This article addressed the objective to: develop and implement an intervention model to manage the caregiver burden experienced by the family caregivers of patients with End-Stage Renal Disease in Nigeria.

In this study, pragmatism helped to find ways to manage caregiver burden experienced by these family caregivers.

The action research approach guided the process that led to the development and implementation of the model, and further development of the implementation checklist (See Table 1 Chapter Five).

The conceptual framework helped to guide the development and description of the model. It also helped to illustrate the relationship between the crucial concepts in the model and it facilitated the logical connections among these crucial concepts.

During the model development, there was an attempt by the research team to provide nurses with a way in which to use the model in their everyday practice. The research team really tried to critically reflect on the model as it was being developed in different stages through the cycle. And each time they asked themselves, is the tool simple enough for the nurses to understand and are nurses going to be able to use it? Are the concepts well defined to foster easy comprehension to the extent that it will bring about the desired change?

Nurses worked with family caregivers to implement the model using the implementation checklist. Verbal feedback indicated that the family caregivers were delighted to have a model to manage their caregiver burden. The nurse manager of the hospital made plans to start a family caregiver to family caregiver peer telephone support system for the family caregivers of patients with ESRD in the hospital



## **CHAPTER SIX: SYNTHESIS, CONCLUSIONS AND RECOMMENDATIONS**

### **6.1. Overview of the study**

This chapter answers the research question and indicates the extent to which the aim was achieved. It does this by reviewing the findings of each objective, as presented in the three manuscripts of this study. The chapter concludes by outlining the study limitations, providing recommendations and indicating the significance of the study.

ESRD is a condition of the kidneys that requires prolonged treatment with dialysis and renal replacement therapy and is associated with various forms of challenges for family caregivers (Alnazly, 2016). As ESRD progress gradually into severe morbidity, the intensity of care-provision usually increases overtime, with caregivers often experiencing significant level of caregiver burden (Adelman, Tmanova, Delgado, Dion and Lachs, 2014). Family caregivers may experience caregiver burden as a consequence of prolonged intensive caregiving, this being complicated by their often living with the affected person, and not leaving at the end of the day and having a break from their responsibilities (Gansevoort, Correa-Rotter, Hemmelgarn, Jafar, Heerspink, Mann et al., 2013)

### **6.2. Synthesis of findings**

#### **6.2.1. Objective 1: Exploring the extent of caregiver burden**

With respect to Objective 1, Cycle One explored and described the caregiver burden experienced by the family caregivers, and established the need to develop and implement an intervention model to manage caregiver burden. Using the Zarit Burden Interview questionnaire, together with researcher field notes, the findings revealed that family caregivers experienced moderate to severe caregiver burden in all domains of care compared to other parts of the world (Adeosun, 2013).

Studies by Yusuf, Adamu and Nuhu (2011); Yusuf, Nuhu and Akinbiyi (2009), had similar findings to this study, and showed that the family caregivers of cancer patients in Nigeria experienced high level of burden and psychological morbidity related to a lack of financial support to provide care. Their findings are similar in terms of the extent of caregiver burden of patients with ESRD in Nigeria, and constituted part of the crucial concepts included in the model to manage caregiver burden (Chapters Two and Three).

The study revealed that increasing caregiver participation in support groups appears to help them manage their experiences of caregiver burden. In Cycle One, the family caregivers experienced moderate to severe caregiver burden, as measured by the ZBI questionnaire, while Cycle Two went further to describe the experiences of these family caregiver, which were not explored in Cycle One.

In Cycle One, the participants, invited to be research team members consisted of four family caregivers, two registered nurses, and the researcher. The invited family caregivers appreciated that someone was interested in their opinions and experiences, as well as in their caregiving roles. This stimulated their interest and they were enthusiastic about participating in the study.

### **6.2.2. Objective 2: Describe the caregiving experience of family caregivers**

With respect to Objective 2 / Cycle Two, in-depth interviews and field notes were used to collect data and document researcher's personal observations, which facilitated self-reflection as the study progressed. Through the qualitative data, five of caregivers experiences were identified namely; disconnection with others and self; never ending burden; 'a fool being tossed around' feeling obliged to provide care and the need to promote closer relationships. The qualitative aspect of the study was used to build on the quantitative data, and assisted in identifying the relationships between the crucial concepts that were later used in the model that was developed to manage the caregiver burden (Chapter Five).

Consistent with another study by McCleary and Blain (2013), cultural expectations dictated that caregiving was obligatory in Nigeria, however, the contravention of some significant

cultural practices associated with this role increased the family caregivers' burden (Chapter Four) (Årestedt, Persson and Benzein, 2014). In addition, the cost of providing care to patients with ESRD is substantial, with family caregiver being required to pay for services and buy necessary medical supplies before their sick relatives can access care. It was also suggested that these caregiver could benefit from social support strategies. As Cycle One measured the extent of caregiver burden, Cycle Two went further to detail deeper experiences of caregiving.

At the beginning of this cycle, a large number of family caregivers were not ready emotionally to talk about their experience of caregiving, but by the end of the study, many had engaged in discussion with the nurses and were delighted to have a model to manage their burden.

### **6.2.3. Objective 3. Develop an intervention model to manage caregiver burden**

Regarding Objective 3, the model was developed by involving a research team who reviewed the findings from the quantitative and qualitative data obtained in Cycles One and Two. A critique of the literature was also done to identify any commonalities with the study finding, which supported the crucial concepts that were identified in the study, and the relationship between them. The findings from Cycles One and Two were also reviewed together, with the research team members agreeing that the model addressed the caregiver burden (Locke, Alcorn and O'Neill, 2013).

The intention of the model was to reduce the caregiver burden for those with relative who have ESRD in Nigeria. The use of SPM as the conceptual framework guided the process that established the relationship between the background and contextual factors, stressors, outcomes and moderators in the model.

The research team members engaged in critical reflection to identify and refine the four components of the model, and to describe the relationships between them. The team members saw fit to develop an implementation checklist for nurse to accompany the model and enable its implementation. The research team members attempt to see that the model is

clear enough for nurses to understand and use, that the concepts were clearly defined and that the model was relevant to bring about the desired change in practice.

#### **6.2.4. Objective 4: Implement the model**

The model implementation took place in a private hospital that provided facilities, where the staff showed an interest in implementing the model. The family caregivers of patients with ESRD, and the nurses who worked in the relevant ward participated in the implementation process. The feedback, suggestions, comments, similarities and differences provided by research team members at the model development stage was useful in implementing the model.

Family caregivers were delighted to have a model to assist with managing their caregiver burden. The model implementation process enabled nurses to be aware of the burden that family caregivers experienced, and at the end of the study, the Nurse Manager of the hospital proposed a family caregiver to family caregiver support by telephone system to the hospital management. This was done to provide peer support to those providing care to family members with ESRD, the intention that they learn from others experiences and engage with those who understand what they are going through.

### **6.3. Methodological discussion**

The nature of action research meant that the direction of the study was not assumed at the outset, but that the results of each cycle informed the next. The absence of data on which to base this study meant that it contained an exploratory component that could not necessarily be directed. This approach allowed discussions to take place between the family caregivers and the researcher and other team players, which enabled the concepts identified in this project to be refined and put into practice (Locke et al., 2013).

The action research method was invaluable, as it assisted the research team members to critically think throughout the study and refined concepts. It also allowed the model to be validated with an implementation checklist being generated that was used during the

implementation process, which enabled the concepts in the model to be implemented (Table I Chapter Five). The research team members met regularly and engaged in the three elements of action research, these being systematic inquiry, professional practice intervention, and participation and change Herr and Anderson (2015). The participation and collaboration of research team members and relevant stakeholders, whose practice, knowledge, identities and constraints were affected by the study, contributed to the change in practice, which was the focus of this study. This collaboration was at time challenging, as the researcher and the nurses needed to work together to change their perceptions of family caregivers; and family caregivers needed to overcome their perceptions of nurses as ‘unapproachable individuals’. Nonetheless, the study appeared to change their viewpoints and allowed for better interaction among the nurses and the family caregiver’s.

Mutual collaborative action research approach was used, with all members of the research team guiding all stages of the study. The researcher accessed the literature and drafted the initial model to use as a discussing document by the research team members (McNiff and Whitehead, 2010).

With this action research study, pragmatism enabled the research team decide on the objectives of the study and the appropriate methods to use in achieving them. This ensured that the research team focused on identifying practical ways to solve the study problem by always thinking about the solution. In addition the SPM was used as the conceptual framework as it provides frameworks within which to understand the course of stress of caregiving and actions to mitigate its consequences on family caregivers. Depicting the relationship between the factors in the SPM assisted in explaining the context under which the stress process unfolds, as well as the role of resources that could contain the proliferation of caregiving related stressors. The SPM provided the factors that need to be explored and enabled the researcher to understand the interaction of the various factors within and outside of caregiving that contributed to the experience of caregiver burden. The relationship between these factors, namely; background and contextual factors, stressors, moderators and outcomes also guided the development of the model. The knowledge and development process of Chinn and Kramer (2011) was useful in developing the intervention model.

The nature of complementary mixed method research allowed for the collection of quantitative and qualitative data and the integration of both sets of data at the interpretation of findings stage (Heyvaert, Maes and Onghena, 2013). In addition, the collection of different types of data allowed for further investigation into the many challenges and many cultural nuances associated with caregiving in this context. All this worked together to produce the crucial concepts and the relationship between them in the model to manage the caregiver burden. In the study, action research was used to develop the model where all the research team members collaborated to bring about the change in practice. This was done so that the model was authentic and had more chance of being accepted.

#### **6.4. Uniqueness of the study**

The study has made a number of significant contributions to the field of ESRD caregiving:

- It has contributed to the existing body of knowledge by developing a Managing Caregiver Burden Model for family caregivers providing care for ESRD patients in a multi-cultural, multi-religious, multi-ethnic resource-limited environment in Nigeria.
- Having explored and described the burden experienced by the family caregivers of patients with ESRD, it has documented their unique experiences in Nigeria, specifically their lack of knowledge about the disease progress and prognosis.
- The study developed an intervention model to manage the burden experienced by the family caregivers of patients with ESRD and provided an implementation checklist for nurses to use the concepts in the model.
- The nurses and caregivers initially engaged in very little discussion, with communication usually only being one-way, namely from the nurse to the caregiver. Communication patterns changed, from initially being instructions from the nurses to family caregiver about paying bills or buying medical supplies, to discussions about the patient, their care, and caregivers concerns.
- Once the model and its implementation checklist had been implemented, the family caregivers were able to communicate with the nurses, and appreciated having a

framework to manage their caregiver burden. This happened because their knowledge about the disease and how to care for their affected family members increased with improved communication.

- The Managing Caregiver Burden Model (MCBM) appeared to increase awareness among nurses of the consequences of caregiver burden on the family caregivers. The model may therefore serve as a tool to manage the caregiver burden experienced by the family caregivers of patients with ESRD in resource constrained setting.
- By the end of the study, the nurse manager of the implementation site was making plans to present a proposal to the hospital management about starting a family caregiver to family caregiver peer telephone support system for the family caregivers of the patients with ESRD. This happened because the nurses perceived that family caregivers' participation in support groups appeared to help them manage their caregiver burden. Family caregivers were excited that they have a model to manage caregiver burden.

## **6.5. Recommendations**

The findings from this study informed the following recommendations in areas of research, education and practice:

### **6.5.1. Research recommendations**

1. As the study was conducted in one region of Nigeria, the findings cannot be generalized to other regions. It is recommended that similar studies be carried out in other regions of the country to allow for a comparison of the results.
2. The study did not evaluate the outcome of the model on family caregivers. The model needs to be tested empirically so that it can be modified and extended. The model should be regarded as a tool to build upon, rather than as something to be followed.

### **6.5.2. Education recommendations**

1. Hospitals providing renal care should consider starting family caregiver to family caregiver peer education programs designed to manage the caregiver burden
2. There is a need to equip nurses with the required skills to increase the knowledge of family caregivers on the disease progression. Such skills could be acquired through periodic continuing professional educational programs.
3. The intervention model to manage the caregiver burden in the caregivers of patient with ESRD should be included as part of the curriculum for general nursing training in Africa and in Nigeria and other resource constrained settings.
4. Nurses working in the clinical arena should guide student nurses in the utilisation of the model.
5. The study found that family caregivers feel a culturally instilled obligation to care for their sick relatives. For that reason, nurses should provide the necessary support to allow the family caregivers to fulfill their responsibilities.

### **6.5.3. Practice recommendations**

1. Nurses are expected to provide knowledge about the disease progression to create realistic expectations to prevent uncertainties associated with the disease prognosis and responsibilities of care. One way of doing this is to engage with the family caregivers early on in the course of the patient's illness, and to provide the information required by the family caregivers and permitted by the nursing professional ethics. This may serve to enhance a therapeutic relationship between family caregivers and professional nurses.
2. Family caregivers should be encouraged to approach significant others to stand-in when necessary, so that they can have a break and be able to connect socially in the community.



#### **6.4. Strength of the study**

The strengths of the study are as follows:

- Pragmatism, being the research paradigm underpinning the study, allowed finding solution to a real world problem.
- Mixed method allowed flexibility in the data collection process, the use of different types of data enriched the understanding of the topic and promoted collaboration among the research team members.
- Mixed method research was relevant and helpful in achieving the study objective which is to develop an intervention model to manage caregiver burden. Integration of the findings from the quantitative and qualitative methods (complementary) assisted in providing further depth to the findings. Complementary mixed method research allowed integration of the findings at the data collection and during the interpretation of the findings. This was valuable in identifying the crucial concepts and the relationships that emerged in the model to manage the caregiver burden.
- Action research was valuable as it allowed the collaboration of research team members whose practice, knowledge and identities were affected by the study. It contributed to the strength of the study, as their participation brought about the desired change in practice, even after the researcher leaves the area.
- The data was obtained from family caregivers with different attributes and experiences. This contributed to the richness of the data and was thus suitable for the achieving the study objectives.

#### **6.5. Limitations of the study**

- The study findings cannot be generalised as they are specific to a small number of participants and the study was conducted in one region of the country. It is recommended that other research be conducted elsewhere in Nigeria to allow for comparisons and to refine the model.

- The small sample size of this study limited the statistical description of responses from the participants; however, this was due to the uniqueness of the population chosen. A larger study should be considered, as this small sample has shown a high level of caregiver burden.
- The impact of the model in reducing caregiver burden was not evaluated. Further research is needed to evaluate its impact and document the findings.
- Quantitative data was collected near patient's bedside and in the out-patients department while providing care to the patient. This could have influenced participant's responses to the questions.

## **6.6. Conclusion of the study**

At the completion of this study, it was evident that the family caregivers of patients with ESRD in Nigeria experienced moderate to severe burden in all domains of care these being higher than those reported elsewhere. Although family caregivers experienced burden, they continued to provide care for their sick relatives for various reasons. This was done at the expense of their own needs and they experienced caregiver burden as a consequence of prolonged caregiving to their chronically sick relatives. As family caregiving for chronically sick patients is culturally acceptable and practiced in Nigeria, and other resource constrained environments, family caregivers should be supported to enable them to continue to provide care without compromising their health. The development of an effective intervention model that can improve the quality of life of the caregiver and their patients is essential if the high burdens of caregiving are to be reduced.

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## ANNEXURES

### ANNEXURE 1: STUDY APPROVAL FROM BREC, UNIVERSITY OF KWAZULU-NATAL



RESEARCH OFFICE  
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION  
Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 260-4609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

13 January 2015

Mrs Yemisí Oyegbile  
P.O Box 701368  
Overport  
Durban  
4067  
[Yemibayo.2005@gmail.com](mailto:Yemibayo.2005@gmail.com)

Dear Mrs Oyegbile

**PROTOCOL: Developing an intervention model to manage caregiver burden among family caregivers of patients living with End Stage Renal Disease in Nigeria. REF: BE226/14**

#### EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 24 April 2014.

The study was provisionally approved pending appropriate responses to queries raised. Your responses received on 15 December 2014 to queries raised on 30 June 2014 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 13 January 2015 at the following sites only: University College Hospital, Ibadan Oyo State, Nigeria; Ladoke Akintola University of Technology Teaching Hospital, Osogbo Osun State, Nigeria; St. Nicholas Hospital, Lagos, Nigeria

This approval is valid for one year from 13 January 2015. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on **10 February 2015**.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

  
Professor V Rambiritch  
Deputy Chair: Biomedical Research Ethics Committee

ANNEXURE 2: ETHICS APPROVAL FROM RESEARCH SETTING ONE

RESEARCH ETHICS COMMITTEE

Address: P.M.B 5092, Osoybo  
035-200769,  
e-mail: researchethicscommittee\_lth@gmail.com



LTH/REC/2014/11/26/188

Our Ref:

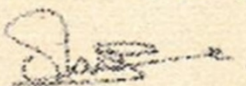
Your Ref:

Date:

26<sup>th</sup> November, 2014

PROF. OLUWADIYA K.S CHAIRMAN  
MRS SAM-ASIEGBU Y.U SECRETARY

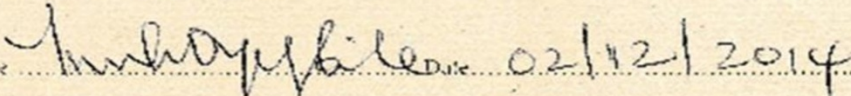
CLEARANCE CERTIFICATE

<b>PROTOCOL NUMBER</b>	LTH/EC/2014/11/0188
<b>PROJECT TITLE:</b>	<i>Developing an Intervention Model to Manage Caregiver Burden in Family Caregivers of Patients Living with End-Stage Renal Disease in Nigeria</i>
<b>INVESTIGATOR(S):</b>	Mrs. Oyeghile, Yemisi Odekinde
<b>DEPARTMENT / INSTITUTION:</b>	School of Nursing and Public Health, University of KwaZulu-Natal, Howard College Campus, Durban, South – Africa
<b>SUBMISSION OF PROTOCOL:</b>	SEPTEMBER, 2014
<b>FINAL CONSIDERATION:</b>	NOVEMBER, 2014
<b>DECISION OF THE COMMITTEE:</b>	<b>APPROVED</b>
<b>CHAIRMAN:</b>	Prof. Oluwadiya K. S (FMCS)
<b>SIGNATURE &amp; DATE:</b>	 26 <sup>th</sup> November 2014

NOTE: THE COMMITTEE IS EXEMPTED FROM LIABILITY OF THE PROPOSAL, AND THIS CERTIFICATE WILL BE REVOKED IF PROTOCOLS STATED IN THE PROPOSAL IS DEVIATED FROM.



DECLARATION BY INVESTIGATOR (S)

PROTOCOL NUMBER (Please quote in all enquiries): LTH/EC/2014/11/0188  
*To be completed in five and three copies returned to the secretary, Ethics and Research Committee, Ladolesin University of Technology Teaching Hospital, Osoybo*  
I/We fully understand the conditions under which I/we are authorized to conduct the above – mentioned research and I/We will ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/We undertake to resubmit the protocol to the Ethics and Research Committee.

Signature  Date 02/12/2014

DR. ADENIYI A.O | DR. AMOJOLE E.D | DR. OLAYINKA B. | DR. EGBURANTA E.A | DR. OFARINCO O.P | DR. ADEKUNLE F.A | DR. OYEMER O.A | DR. ADEYI A.A  
MRS. AKINRINDE C | MRS. MURPHY M.A | DR. OWOJARI O.A | MRS. ADEYEYI A.D | MRS. OYEWOLE T.A | MRS. OYEDUN O. | MRS. ADEYEYI O. | MRS. LAWAL R.O

## ANNEXURE 3: ETHICS APPROVAL FROM RESEARCH SETTING TWO

**INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)**

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UIUCH EC Registration Number: NHREC/05/01/21068a

**NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW**

**Re: Developing an Intervention model to Manage caregiver Burden in Family Caregivers of Patients living with end-stage renal Disease in Nigeria**

UIUCH Ethics Committee assigned number: UIUCH/14/0316

Name of Principal Investigator: **Yemisi O. Oyegbile**

Address of Principal Investigator: School of Nursing and Public Health,  
University of KwaZulu-Natal,  
Howard College Campus, Durban,  
South Africa


Date of receipt of valid application: 25/09/2014

Date of meeting when final determination on ethical approval was made: N/A

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and *given full approval by the UIUCH Ethics Committee.*

This approval dates from 26/11/2014 to 25/11/2015. If there is delay in starting the research, please inform the UIUCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the UIUCH EC assigned number and duration of UIUCH EC approval of the study.* It is expected that you submit your annual report as well as an annual request for the project renewal to the UIUCH EC early in order to obtain renewal of your approval to avoid disruption of your research.

*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 including ensuring that all adverse events are reported promptly to the UIUCH EC. No changes are permitted in the research without prior approval by the UIUCH EC except in circumstances outlined in the Code. The UIUCH EC reserves the right to conduct compliance visit to your research site without previous notification.*



**Dr. W. O. Balogun**  
Vice-Chairman, UIUCH Ethics Committee  
E-mail: [wbhino@ynrc.co.za](mailto:wbhino@ynrc.co.za)

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**▪ Drug and Cancer Research Unit    Environmental Sciences & Toxicology    ▪ Genetics & Cancer Research    ▪ Molecular Entomology**  
**▪ Malaria Research    ▪ Pharmaceutical Research    ▪ Environmental Health    ▪ Bioethics    ▪ Epidemiological Research Services**  
**▪ Non-communicable Unit    ▪ Palliative Care    ▪ HIV/AIDS**

## ANNEXURE 4: ETHICS APPROVAL FROM RESEARCH SETTING THREE

TEL: (01) 2718881-3, 7641415-20  
08022908494, 08039261258

57, CAMPBELL STREET  
P. O. BOX 2016, LAGOS  
www.sainicholashospital.com

September 3, 2014

Yemisi Okikiade Oyegbile  
Student No: 212516461  
School of Nursing and Public Health  
University of KwaZulu-Natal  
Howard College Campus  
Durban 4001

Dear Mrs Oyegbile

**RE: ETHICAL APPROVAL**

Your letter dated July 31 2014 refers.

We write to confirm approval by the Ethics Committee through the Medical Director for your proposed investigation on: "DEVELOPING AN INTERVENTION MODEL FOR FAMILY CAREGIVERS OF PATIENTS WITH END-STAGE RENAL DISEASE IN NIGERIA".

However, the approval is subject to your acceptance of the following condition in writing:

1. That the information gathered will be used strictly for research purpose and will be kept confidential
2. That we would be informed of the findings at conclusion of the studies.

Thank you.

Yours faithfully  
FOR: ST. NICHOLAS HOSPITAL

  
DR EBUN BAMGBOYE FWACP  
CLINICAL DIRECTOR

VICTORIA ISLAND: 2NH CLINICS 7th ETIM INYANG CRESCENT, VI, LAGOS

Chief Executive Officer: CHIEF DR. M. A. MARKODINMI, O.R., C.M.G., M.A., M.D., F.R.C.O.S.  
Clinical Director: DR. DAGO WAJERODUNMI, M.B., B.S., M.R.C.O.G.  
DR. EBUN BAMGBOYE, M.B., B.S., FWACP  
Medical: MRS. D. O. FAHOLA, SRN, SRM, FGD (tooth Reg) Dip (Adm)

## **ANNEXURE 5 INFORMED CONSENT FORM**

**Title of the research:** Developing an intervention model for the family caregivers of patients with End Stage Renal Disease in Nigeria.

**Name(s) and affiliation(s) of researcher(s):** This study is being conducted by Mrs. Yemisi Oyegbile and Prof. Petra Brysiewicz of the School of Nursing and Public Health, University of KwaZulu-Natal, Howard College Campus, Durban, South Africa.

**Sponsor(s) of research:** This study is sponsored by the University of KwaZulu-Natal Durban, South Africa.

**Purpose(s) of research:** The purpose of the study is to explore the caregiver burden experienced by the family caregivers of patients with End-Stage Renal Disease in Nigeria and to develop an intervention model to manage this burden.

**Procedure of the research, what shall be required of each participant and approximate total number of participants that would be involved in the research:**

The study will go through four cycles: Cycle One will involve organising a focus group discussion and collect quantitative data with the use of the Zarit Burden Interview. Cycle Two will involve interviewing eligible and willing participants. Cycle Three involves research team members engaged in a workshop to develop an intervention model while Cycle Four will focus on the implementation of the model. You will be required to engage in the first two cycles of the study. If need be you may be engaged in the Cycle Four of the study.

**Expected duration of research and of participant(s)' involvement:** In total, we expect you to be involved in this research for 6-8 months.

**Risk(s):** It is anticipated that there may be some discomfort while family caregivers re-tell their stories during the interview, and possibly at other times during the field study. For this reason, the researcher plans to see a Medical Social Worker in the research setting in order to pick up verbal and non-verbal cues indicating that a family caregiver is experiencing psychological discomfort, and when referral is inevitable. Family caregivers could be allowed to take some water, tea or coffee to relieve discomfort during the interview. In other instances, the interview session could be suspended while the family caregiver is referred to a Medical Social Worker or to a priest if preferred. The hospital Chaplain (Christians) or



Imam (Muslim) could be consulted to provide spiritual support. In other instances, family caregivers could prefer to discuss with

**Costs to the participants, if any, of joining the research:** Your participation in this study will not cost you money; however, it will require your time.

**Benefits:** The goal of this research is to find ways of providing support for family caregivers in the course of providing care to a chronically ill relative.

**Confidentiality:** All information collected in this study will be given code numbers and no names will be recorded. This cannot be linked to you in any way and your name or any other identifier will not be used in any publication or reports from this study. As part of our responsibility to conduct this research properly, officials from UKZN, South Africa may have access to these records.

**Voluntariness:** Your participation in this research is entirely voluntary

**Alternatives to participation:** If you choose not to participate, this will not affect your relative's treatment in this hospital in any way.

**Due inducement(s):** You will not be paid any fees or compensated in any way for participation in this research.

**Consequences of participants' decision to withdraw from research and procedure for orderly termination of participation:** You can choose to withdraw from the research at any time. Please note that some of the information that has been obtained about you before you chose to withdraw may have been modified or used in reports and publications. These cannot be removed once used for these purposes, however, the researchers promise to comply with your wishes as much as is practicable.

**Modality of providing treatments and action(s) to be taken in case of injury or adverse event(s):** You will not suffer any injury as a result of your participation in this research.

**What happens to research participants and communities when the research is over?** The outcome of the research will be published in a journal and you can request a copy without any financial commitment on your part. During the course of this research, you will be informed about any information that may affect your continued participation.

**Statement about sharing of benefits among researchers and whether this includes or excludes research participants:** Since this research is going to develop an intervention

model, the University of KwaZulu-Natal shall own it. There is no plan to contact any participant now or in future about its benefits.

**Any apparent or potential conflict of interests:** No conflicts of interest.

**Statement of person obtaining informed consent:**

I \_\_\_\_\_ have fully explained this research to the potential participant and have given sufficient information, including the risks and benefits, for them to make an informed decision.

Signature \_\_\_\_\_ Date: \_\_\_\_\_

**Statement of person giving consent:**

I have read the description of the research or have had it translated into a language I understand. I have also talked it over with the doctor to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks and benefits of the research study to judge that I want to take part in it. I understand that I may freely stop being part of this study at any time. I have received a copy of this consent form and an additional information sheet to keep for myself.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Detailed contact information of researcher(s) institutional BREC:**

This research has been approved by the

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research office, Westville Campus

Govan Mbeki Building

University of KwaZulu-Natal

Private Bag X 54001, Durban 4000

KwaZulu-Natal, South Africa

Tel: +27312604769

Fax: +27312604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

In addition, if you have any questions about your participation in this research, you can contact the principal investigator Yemisi Oyegbile on 08098323300 and email: [yemibayo.2005@gmail.com](mailto:yemibayo.2005@gmail.com). You can also contact the ethics committee of LAUTECH at [researchethicscommittee.lth@gmail.com](mailto:researchethicscommittee.lth@gmail.com)

**PLEASE KEEP A COPY OF THE SIGNED INFORMED CONSENT WITH YOU.**

**ANNEXURE 6: INFORMATION SHEET AND CONSENT FORM FOR SURVEY  
(YORUBA VERSION)**

**IFOWOSI IWE LATI KO PA NINU IMO IWADI**

AKORI: Si se agbekale eto lati toju ipenija ti o do ju ko awon molebi eni ti nse aisan kindinrin ni apa gusu ti Naijeria

EREDI: Eredi eko yii ni lati se iwadi inira ti awon molebi alaisan kindinrin do ju ko ati lati se agbekale eto lati ran won lowo.

**EWU ATI IFA TI O WA NINU IWADI YII:**

Ti mo ba ko pa ninu iwadi yii, o see se ki nmo do ju ko ewu kankan. Ti mo ba ko pa ninu iwadi yii, ma wa ninu awon ti yoo ran oniwadi yii lowo lati ran awon molebi awon ti nse aisan kindinrin lowo ni apa gusu Naijeria.

**GBEDEKE AWON TI O LE KO PA NINI IWADI YII:**

Okunrin abi Obinrin ti o je omo odun mejidinlogun tabi ti o dagba ju be lo

Eni naa gbodo je molebi ti o ti toju alaisan kindinrin fun osu mefa tabi ju bee lo

Iru eni be ko gbodo mo gba owo osu nitori wipe o ntoju alaisan naa

O gbodo lee se ipinu lati gba lati ko pa ninu iwadi yii leyin igbati O ba ti ni oye nipa iwadi naa

**ETO ATI KO PA NINU IWADI YII:**

Leyin igbati mo ba ti pegede lati kopa ninu iwadi yii, o se se ki nwa ninu awon ti yoo je igbimo alabesekele iwadi yii.

**AJEMONU:**

Mi o ni gba owo tabi ajemonu kankan nitori wipe mo kopa ninu iwadi yii.

**IPA ASIRI MO:**

Oruko mi ko ni han si elomiran ge ge bi o ti se wa ni nu takada iwadi yii nitori wi pe onka numba ni oniwadi yii yoo lo lati da mi mo. Iyaafin Yemisi Oyegbile ati Kofeso Petra Brysiewicz nikan ni yoo ni ase lati ri oruko mi. Enikankan ko ni lo oruko mi ninu akosile ti gbogbo eniyan yoo ni ase lati ka. Oni wadi yii ti fi da mi loju wipe gbogbo iwe ti o ni se pelu iwadi yii, ti oruko mi ti han ni yoo fi pa mo dara dara ti enikankan ki yoo ni ase ati ri ni hofisi oniwadi yii. Ati wi pe gbogbo iwe ti oniwadi yii ba lo ni yoo baje ni odun marun leyin iwadi yii.

**ETO LATI MO KO PA MO NINU IWADI:**

Mo ni eto lati kopa ninu iwadi yii, mo si ni eto lati mo ko pa ninu iwadi yii. Mo ni eto lati fi ikopa mi ninu iwadi yii sile nigba ti o ba wu mi lai ni ipalara kankan.

**ABAJADE IWADI:**

Mo ni anfaani ati mo abajade iwadi yii lai san owo kankan sugbon mo gbodo bee re fun.

**IFOWOSI ATOKANWA:**

Mo ti ka gbogbo iroyin ti o wa ninu iwe yii, mo si ni oye ohun ti oni wadi fe kin se. Mo ni idaniloju wipe tokantokan ni mo fi fara mo lati ko pa ninu iwadi yii ati wipe mo ni agbara lati mo ko pa mo ninu iwadi yii lai ni ipalara kankan. Ni won igbati mo ni oye yii, mo fi tokan tokan fi owo mi si lati ko pa ninu iwadi yii

Mo mo wipe mo le pe Iyaafin Oyegbile ti mo ba ni ibeere kankan ti oni se pelu iwadi yii ni ori ero ibanisoro yii 08098323300

Oruko at ibuwolu Olukopa \_\_\_\_\_

Ojo \_\_\_\_\_

Oruko oluwadi ati ibuwolu \_\_\_\_\_

Ojo \_\_\_\_\_

Adiresi ile eko nla oluwadi ti o fi owo si imo ijinle yii ti mo le pe ni

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research office, Westville Campus

Govan Mbeki Building

University of KwaZulu-Natal

Private Bag X 54001, Durban 4000

KwaZulu-Natal, South Africa

Tel: +27312604769

Fax: +27312604609

Email: [PREC@ukzn.ac.za](mailto:PREC@ukzn.ac.za)

Pelu pelu, mo le pe oluwadi Yemisi Oyegbile ni pa se onka yii 08098323300 ati leta ayelukara: [yemibayo.2005@gmail.com](mailto:yemibayo.2005@gmail.com). Mo si le ko leta ayelukara si LAUTECH at [researchethicscommittee.lth@gmail.com](mailto:researchethicscommittee.lth@gmail.com)

**E JOWO YOO DARA TI E BA PA ABALA KAN NINU IWE YII MO.**

## ANNEXURE 7: ZARIT BURDEN INTERVIEW QUESTIONNAIRE

Dear family caregiver,

I am a PhD student developing an intervention model to manage the burden among the family caregivers of patients with end-stage renal disease in Nigeria. I will appreciate it if you could complete this questionnaire sincerely as there are no wrong or right answers. All responses you provide will be used solely for the purpose of research. Do not indicate your name or initials. I will appreciate it if you answer all of the questions.

### DEMOGRAPHIC CHARACTERISTICS

**INSTRUCTION:** Please check the appropriate response

1. Age of caregiver:
2. Ethnicity:
  - Yoruba
  - Igbo
  - Hausa
  - Others specify.....
3. Religion:
  - Christianity
  - Islam
  - Traditional
  - Others specify.....
4. Sex:
  - a) Male
  - b) Female
5. Marital status:
  - Single
  - Married
  - Separated
  - Divorced
  - Widowed
6. Educational level:
  - Elementary school
  - Secondary school
  - Technical school
  - University
  - Post graduate
  - Others specify.....
7. Working status

- a) Full-time paid job
  - b) Part-time paid job
  - c) Full-time unpaid job
  - d) Part-time unpaid job
  - e) Do not work
  - f) Others specify
8. Relationship with patient
- a) Parent
  - b) Spouse
  - c) Son/daughter
  - d) Brother/sister
  - e) Other relatives
  - f) Friend
  - g) Others specify.....
9. Living status:
- a) Same residence as patients
  - b) Separate residencies
10. Contact with patient
- a) 1-2 times a week
  - b) 3-4 times a week
  - c) 5-6 times a week
  - d) Less than once a month
  - e) Others specify.....

Total duration of the caregiving.....

**INSTRUCTIONS:**

*The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate by ticking (√) how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.*

S/N	Question	Never 0	Rarely 1	Sometimes	Quite frequently 3	Nearly always 4	Score
1.	Do you feel that your relative asks for more help than he or she needs?						
2.	Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?						
3.	Do you feel stressed between caring for your relative e and trying to meet other						

S/N	Question	Never 0	Rarely 1	Sometimes	Quite frequently 3	Nearly always 4	Score
	responsibilities for your family and work?						
4.	Do you feel embarrassed about your relative's behaviour?						
5.	Do you feel angry when you are around your relatives?						
6.	Do you feel that your relative currently affects your relationship with other family members?						
7.	Are you afraid of what the future holds for your relative?						
8.	Do you feel that your relative is dependent upon you?						
9.	Do you feel strained when you are around your relatives?						
10.	Do you feel that your health has suffered because of your involvement with your relative?						
11.	Do you feel you don't have as much privacy as you would like, because of your relative?						
12.	Do you feel that your social life has suffered because you are caring for your relative?						
13.	Do you feel uncomfortable having your friends over because of your relative?						
14.	Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?						
15.	Do you feel you don't have enough money to care for your relative, in addition to the rest of your expenses?						
16.	Do you feel that you will be unable to take care of your relative much longer?						

S/N	Question	Never 0	Rarely 1	Sometimes	Quite frequently 3	Nearly always 4	Score
17.	Do you feel that you have lost control of your life since your relative's sickness?						
18.	Do you wish that you could just leave the care of your relative to someone else?						
19.	Do you feel uncertain about what to do about your relative?						
20.	Do you feel that you should be doing more for your relative?						
21.	Do you feel that you could do a better job caring for your relative?						
22.	Overall, how burdened do you feel in caring for your relative?						

(Zarit et al., 1980)



## ANNEXURE 8: YORUBA LANGUAGE VERSION OF THE QUESTIONNAIRE

Molebi alaisan owon,

Mo je omo ile iwe ti o nka eko ijinle lati se agbekale imo ti yoo ran awon molebi alaisan kindinrin ti o n do ju ko ipenija ti o room itoju irufe awon alaisan be ni Ile Nigeria lowo. Yoo je ife okan mi ti o ba le ko pa ninu ibeere yii nitoripe yoo ran mi lowo lopolopo. Kosi idahun ti o dara tabi eyi ti ko dara. Ohun ti mo fe ni wi pe ki e se olotito idahun yin. Gbogbo ohun ti e ba ko si ibi yii ni ma lo fun eko ni kan. E ma se ko oruko yin abi inagije sibe. Sugbon iranlowo nla ni yoo je fun mi ti e bape se idahun si gbogbo ibeere mi. E se pupo.

ITOSONA: Fi amin yii (✓) si iwaju esi oro eyi to ba je mo tire ninu awon idahun si ti o wa ni egbe re yii

### Idanimo ti Olutoju

1. Ojo ori Olutoju: (E fi owo yin ko sibe).....
2. Eya: a). Yoruba  Igbo  Hausa  Eyamiran
3. Esin: Onigbagbo  Musulumi  Elesin Ibile  Esin miran
4. Eya ara: Okunrin  Obinrin
5. Marital status: Omidan / Okunrin  Abileko  YaraOsu  Opo
6. Ile-Iwe ti o ka: Ile-Iwe alako bere  Girama  Ile-Iwe Ero   
Yunifasiti  EkoIjinle  Omiran
7. Ise: Osise-Osu  Ise ilare ti o ngbaowo  O kosise
8. Bawo ni e se je pelu alaisan yii
  - a). Obi re
  - b). Oko/Iyawo re
  - c). Omokunrin / Omobinrin
  - d). Aburo
  - e). Molebi
  - f). Ore
9. Ibugbe yin  
Ile kanna pelu alaisan   
Ile Otooto pelu alaisan
10. Asiko ti o lo pelu alaisan
  - a) Emeta si emarun ni ose kan
  - b) ekan si emeji ni ose kan
  - c) ekan si emeta ni ose kan
  - d) ekan ni osu kan
11. Gbogbo wakati ti o lo nigba ti o toju alaisan yii.....

## IFOROWERO LORI IPENIJA

### ITOSONA:

*Iwon yii ni awon oro ti o fi asehan bi iriri awon eniyan se je ti won ban toju elomiran. Leyin orokookan ti o ni akori bii: koseleri, kii saba sele, a ma sele nigbamiran, a ma sele le kookan, a ma seleni gbogbo igba. Mo feki o mu okan pere ninu awon oro yii ki o si fi amin (X) si eyi ti o ba se alafihan bi iriri re se je nitori wipe o nse itoju molebi re ti o nse aisan kindinrin. Kosi wipe esi kan dara tabi esi kan ko dara.*

Onka	Ibeere	Ko se leri 0	Kiisabas ele 1	A ma selenigbamiran 2	A ma sele le kookan 3	A ma selenigbog boigba 4	Arop o
Eni.	Nje o ro wipe molebi re nbeere iranlowo ju bi o se nilo lo?						
Eji.	Nje o ro wipe nitori asiko ti o nlo pelu molebi re, iwo paapaa ko ni asiko to to fun ara re?						
Eta.	Nje o ni idamu okan abi ti ara nitori wipe o nko itoju molebi re ti o nse aisan ati itoju ile ti re naa ati ibi ise re papo?						
Erin	Nje o oju ma nti o nitori ihuwasi abi aisan molebi re ti ko lo yii?						
Arun.	Nje inu a ma bi o ti o ba wa ni odo molebi re ti o nse aisan?						
Efa.	Nje o ro wipe itoju molebi re tin se aisan da wahala le ni arin molebi yoku?						

Onka	Ibeere	Ko se leri 0	Kiisabas ele 1	A ma selenigbami ran 2	A ma sele le kookan 3	A ma selenigbog boigba 4	Arop o
Eje.	Nje eru a ma ba e nitori ojo ola molebi re ti o nse aisan yii?						
Ejo.	Nje o ro wipe molebi re yii da ra le o pupo ju?						
Esan	Nje o ma nre o nigba ti o ba wa pelu molebi re ti o nse aisan yii?						
Ewa.	Nje o ro wipe o ko le se itoju ara re bi o ti wu o nitori wipe o ntoju molebi re yii?						
Moka nla.	Nje o ro wipe o ko nii paramo ti o daju nitori wipe o ntoju molebi re yii?						
Mejila	Nje o ro wipe o ko le se ifarakinra pelu awon ore abi molebi yoo ku nitori wipe o ntoju molebi re?						
Metal a.	Nje o ma nfe ki awon ore wa ki enigbati o ban toju molebi re yii?						
Merin la.	Nje o ro wipe molebi re feki iwonikan ma tojuohun bi igba to je wipe iwonikan ni eni ti o le gbara le tabi toju re?						

Onka	Ibeere	Ko se leri 0	Kiisabas ele 1	A ma selenigbami ran 2	A ma sele le kookan 3	A ma selenigbog boigba 4	Arop o
Meed ogun.	Nje o ro wipe o koni owo ti o to lati ko itoju molebi re yii pelu agba ile ti re naa?						
Merin dinlog un	Nje o ro wipe o koni le toju molebi re yii fun igba pipe?						
metad inlogu n.	Nje o ro wipe oro aye re ti do juru lati igba ti o ti ntoju molebi re yii?						
Mejidi nlogu n.	Njeyoowu o ki o kan fi itojumolebi re siikawoelomira n?						
Okand inlogu n.	Nje okan re a ma daru nipa nkan ti o ye ki o se fun molebi re yii?						
Ogun.	Nje o ro wipe o ye ki o le pe se itoju ti o gbongbon fun molebi re yii ju bi o ti nse nisinsiyii lo?						
okanle logun	Nje o ro wipe o le toju molebi re ju bi o tin se nisinsiyii lo						
Mejile logun.	Ni ako tan, bawo ni o se rii penija ti o n do juko nitori wipe o ntoju molebi re?						

## **ANNEXURE 9: INTERVIEW SCHEDULE**

**Introduction:** Dear Family Caregiver, I am Yemisi Oyegbile, a PhD student developing an intervention model to manage the caregiver burden among the family caregivers of patients with End-Stage Renal Disease in Nigeria. It is my intention that the outcome of this research will benefit the family caregivers of patients with end stage renal disease in terms of providing intervention that will assist them to go through the caregiving situation with less or no burden. I am aware that people have different experiences in terms of providing care for patients with End-Stage Renal Disease. I will appreciate it if you will respond to the questions I will be asking you as best as you can. All responses you provide will be used solely for the purpose of research.

**DEMOGRAPHIC CHARACTERISTICS:** to be completed by the researcher

1. Age of caregiver:
2. Ethnicity:
3. Religion:
4. Sex:
5. Marital status:
6. Educational level
7. Working status
8. Relationship with patient
9. Living status
10. Contact with informant
11. Total duration of the caregiving.....

### **Major Interview Questions:**

I am here to listen to your experience of caring for your relative that is sick with ESRD.

- Can you tell me the story of looking after your loved one with ESRD?
- What is it all about? How has it been, looking after him / her?

Looking after your loved one with ESRD can have its good and bad side. Can you tell me more about this?

- beneficial aspect
- difficult aspect

People have different reasons for volunteering to be family caregivers to people who are living with ESRD.

- Can you tell me how you become the caregiver? Or
- Why did the caregiving responsibility of this person fall on you?
- What is your motivation in caring for this relative of yours?

Thanks

## **ANNEXURE 10: FOCUS GROUP DISCUSSION: CAREGIVERS**

Welcome and introduction

- Introduce yourself
- Allow participants to introduce themselves

Ask these questions and allow responses from participants:

- a. I am looking at family members who are looking after loved ones with ESRD. I am looking at how easy it is to be a family caregiver. Do you think this research is relevant? Are there other important issues?
- b. I am looking for people to be members of my research team; let me know if you are willing to join.
- c. Any changes?

## **ANNEXURE 11 FOCUS GROUP DISCUSSION GUIDE: RESEARCH TEAM**

Welcome

Introduce yourself

Allow participants to introduce themselves.

From the data collected what type of intervention model is emerging?

- a) What are the processes of developing an intervention model in literature? Do they reflect in the current model?
- b) What are the essential components of the intervention model in the context of a resource limited setting?
- c) Does the current intervention model address the needs identified by caregivers?
- d) Has the current model outlined the stressors, outcomes and moderators of an intervention model to address caregiver burden?
- e) Any other information?



## **ANNEXURE 12: COPY OF INTERVIEW TRANSCRIPT**

**Name of study:** Developing an intervention model to manage caregiver burden among the family caregivers of patients living with End-Stage Renal Disease in South-Western Nigeria

**STUDY COMPONENT:** Key Informant

Participant initials / code: ZB / FC 01

Interviewer initials: YO

Age of caregiver: 41 years

Ethnicity: Yoruba

Religion: Islam

Gender: Female

Marital Status: Married

Living with Patient: Yes

Educational level: Elementary school

Working status: Self employed

Relationship with Patients: Sibling

Living status with patients: Same residence as patient

Contact with patients: 3-5 times a week

Total duration of care: 11 hours daily for 12months

Interview began: 9:45am

Interview ended: 10: 30am

Duration: 45 minutes

Date of interview: 27/1/2015

---

### **Beginning of the interview**

**YO: Good morning to you madam**

ZB: Um, good morning.

**YO: How are you doing?**

ZB: Well, I am doing well.

**YO: Ok, that is good.**

ZB: Thank you

**YO: I am a nurse and student of the University of KwaZulu-Natal, Durban conducting a study on family caregivers of patients who find it difficult to pass urine (Kidney problems). I am here to ask you questions about the care you are providing for your sick sibling. Would you permit me to ask you some questions please?**

ZB: Yes, you may ask your questions, I hope I will be able to provide answers to you.

**YO: I hope so but before we go on....I would like you to sign this consent form for me please?**

ZB: What for?

**YO: Signing the informed consent form confirms that you agreed to participate in the interview voluntarily**

ZB: Ok, bring the paper, let me sign it.

**YO: The questions focus on the care you are providing for your brother. I am here to listen to your experience of caring for your brother that is sick with kidney problem. Can you tell me the story of looking after him?**

ZB: (Ummm)..... (Paused). I knew about his illness some months ago. He has been going to the hospital for one ailment or another. Doctors gave different diagnoses until he came to this hospital where it was confirmed that he had problems with his kidneys. He is my sibling. He lives in another town..... but when the illness started he moved to the town where I live and started living with my family. I have been caring for him for about a year now. It has not been easy..... (LOOKS DOWN). I watch over him during the day and at night. Since the patient is restless, nurses instructed me to stabilise the hand that is used for infusion. Therefore, I sit beside him while holding his hand for as long as thirty-six hours at a stretch. My body aches, my legs swells up, my back is badly affected and my hand becomes stiff most times. I wake up very early in the morning to bathe him, assist him with cleaning his mouth. Sometimes when he is strong enough he is able to care for himself. Another thing I do is to prepare his food because he eats types of food different from what I prepare for other members of my family. Selecting different food items during grocery shopping is tasking and expensive for us to keep up with. But what can I do? I just buy whatever I can afford. After I make sure that he is clean, I also prepare my kids for school and I get myself ready for work. My husband takes the kids to school in our car while I go to work by taking

public transport because our places of work and the children's school are not on the same axis. By the time I get to work, I am already tired..... (PAUSED) (YAWNING) and struggling to keep up with the demands of work I have to do. At my place of work, I must call him to know how he is doing otherwise my mind will not be at peace.

**YO: Why do you have to call him from your place of work?**

ZB: I must call him from my working place to be sure that he is doing fine. He has had crisis before that necessitated emergency admission. But for my timely intervention, he may have died before now. I find it difficult to pay attention to what I am doing in my workplace. Many times I made costly mistakes at work because I was always thinking of him. Doing this has been very stressful..... (LOOKS DOWN AND SOBS). (UMMMM) my sister, (referring to the researcher) it has not been easy..... When a disease stays for a long time, it is usually difficult for the patient and person(s) providing care. (SOBS).....

**YO: I apologise for reminding you of these stories. But I have to do this to help you and others who might be in this situation in the future. Would you like to drink water?**

ZB: Yes, please let me drink water.

**YO: (I handed one bottle of water to her and patted her back). Would you like to meet with a Medical Social Worker?**

ZB: Yes, but may not be necessary now, may be later. I have been looking for an opportunity to talk to someone about this.....so it is good you came.

**YO: Ok**

ZB: (She continued to answer the question). But for our closeness before the sickness began,.....I must confess.....it has not been easy.....(PAUSED). Now that he is admitted into the hospital, sometimes I feel like not staying with him in the hospital to care for him because I am usually tired from the previous day's troubles..... but..... I have to because I am the only sibling around him that can help him. But let us face reality, I am tired..... I wish I never have to care for someone as sick as this. His state of health demands that I wake up at night to provide care. The care I provide usually takes between one or two hours. So after caring for him, I find it difficult to sleep again. I usually experience headaches and easily feel tired when I get to my place of work the following morning because of lack of enough hours of sleep. Another area of concern is that now that he is

hospitalised, I could not find a reliable person to stand-in for me in my business. Shop attendants that I employ steal my money. They go late to work as well. I have lost many customers to other competitors. How do I survive this stage? (She sobs again).....

**YO: (I kept quiet.....patted her back.....) Sorry for all these experiences.....**

ZB: (SOBS REPEATEDLY).....

**YO: Would you like us to discontinue this interview and meet at another date convenient for you?**

ZB: Let us continue.....there may never be any convenient day other than today...are you embarrassed with my crying? This is what I do every day.... I cry all the time.

**YO: I know you may have more experience to share. Are you comfortable to tell me more of your stories, please?**

ZB: I have not been able to go to the mosque regularly. I could not attend my friend's daughter's wedding some weeks ago because I was the one providing care to him in the hospital. I could not attend the Parent Teachers Association meeting of the school where my children attend. I am just confused! I have not been able to take some rest. I feel tired..... (UMMM).....(UMMMM)..... Staying in the hospital is another challenge.....I am not comfortable lying on a couch throughout the night..... My back hurts, my leg swells..... but I am doing it for the sake of my sibling.....how else can I demonstrate my love to him than go through this difficult time with him?

**YO: (PAUSED) Yeah. I understand..... Looking after your loved one with kidney disease could have its good and bad sides. Can you tell me more about this? You may address the beneficial or difficult aspect first depending on your choice.**

ZB: It is not a funny thing to do but I am happy that I could assist my sick sibling. We are together in this.....good and bad side of life requires assistance from family members. I cannot abandon him now..... Although I am not finding it easy to provide care for him, I will care for him until.....he gets better or anything happens. Either good or bad.....I also realise that my taking care of him now makes me get closer to him, he shares his concerns with me.....(UMMMMM).

**YO: Difficult aspect:**

ZB: I am struggling to maintain my life because of my brother's illness. (She (PAUSED) for about a minute.....) I have lost my customers to other competitors. I find it difficult to travel to replenish the goods in my shop. My shop assistants are not faithful.....they steal money from daily proceeds because I am not always with them. I lost many customers to competitors..... (UMMMM)... I do not have enough money to sustain myself and the business. It has been difficult paying the hospital bills.....the cost of dialysis is killing..... I thank God that other siblings are sending some money to me to pay medical bills I could not imagine how to sustain his treatment of kidney problems..... (UMMMM).....

**YO: I quite agree with you. But are you considering speaking with the Medical Social Worker on this issue and many others bothering your mind?**

ZB: I have been to the Medical Social Worker.....she counselled me and promised to help me.....but I am yet to receive any help from her.

**YO: Ok, let us hope for the best. Try and go to her office after this interview, she might be waiting for you.**

ZB: Ok

**YO: People have different reasons for volunteering to be family caregivers to people who are living with kidney disease. Can you tell me how you become the caregiver?**

ZB: it is a long story.....His wife divorced him some years back....., he lives by himself, he has no other close person to take care of him. I adopted his first child about five years ago before he became ill. I am the only sibling living close to him in the South-Western part of Nigeria. Other siblings live in the Northern part of the country, which is very far. Other family members suggested that I should bring him to live with my family and that is what I did.

**YO: Ok. What is your motivation in caring for your brother?**

ZB: He is my sibling and has been a source of support to me. I am motivated to care for him because that is the best thing I could do for him now.

**YO: Since you have been providing care, what form of support have you received? Such support may be from the government, organisations, or individuals.**

ZB: Initially, he paid for his medical treatment from his disengagement fund for some time but could not cope again when all his savings finished. Currently, my other siblings send money to add to whatever I am spending to sustain him. I have not received any support from the government.

**YO: In what area of care do you think you would need support? Or what type of support do you think you would need now?**

ZB: The cost of dialysis and the medications that go along with the treatment are very expensive.....I wish the government could subsidise or provide it for free. Diseases like this are so complicated.....you have to measure urine, cook food different from what other people eat, change their position.....you are literally with them 24/7.....I don't understand this.....then you have to accompany them to the hospital and listen to the doctors' English.....in fact it is not easy at all.....

**YO: (PAUSED) I quite understand your feelings....., I wish you and your brother all the best. Please find time to meet with the Medical Social Worker as soon as you can. Except if you have questions, we have come to the end of the interview.**

ZB: Thanks, I have no question. I will try and meet with the Medical Social Worker soonest.

**YO: I appreciate your time.**

---

**End of interview**

## ANNEXURE 13: PROOF OF THESIS EDITING



7 Woodlands Rd  
GLENWOOD  
DURBAN  
4001  
083 415 2531

16 January 2017

Reg. No. 2006/156780/23

Yemisi Oyegbile

### **EDITING OF RESEARCH DISSERTATION OF YEMISI OYEBILE**

I have an MA in English from University of Natal (now UKZN) and have been performing editing services through my company for eleven years. My company regularly edits the research dissertations, articles and theses of the School of Nursing, Environmental Studies and various other schools and disciplines at the University of KwaZulu-Natal and other institutions, as well as editing for publishing firms and private individuals on contract.

I hereby confirm that Pauline Fogg edited the thesis of **Yemisi Oyegbile** titled *"Developing an Intervention Model to Manage Caregiver Burden experienced by Family Caregivers of Patients living with End-Stage Renal Disease in Nigeria"* on behalf of WordWeavers cc and commented on the anomalies she was unable to rectify in the MS Word Track Changes and review mode by insertion of comment balloons prior to returning the document to the author. Corrections were made in respect of grammar, punctuation, spelling, syntax, tense and language usage as well as to sense and flow. An editing report and additional comments were provided to assist with corrections. At the instruction of the student, Chapters 2 and 3 were not edited (due to previous editing) however the synopses of Chapters 2 and 4 were edited upon request.

I trust that the document will prove acceptable in terms of editing criteria.

Yours faithfully

**C Eberle**  
Catherine P. Eberle (MA: University of Natal)

## ANNEXURE 14: RECERTIFICATION OF ETHICAL APPROVAL



UNIVERSITY OF  
KWAZULU-NATAL

INYUVESI  
YAKWAZULU-NATALI

RESEARCH OFFICE  
Biomedical Research Ethics Administration  
Westville Campus, Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 2604609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Website <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

19 January 2017

Mrs Yemisi Oyegbile  
P.O Box 701368  
Overport  
Durban  
4067  
[Yemibayo.2005@gmail.com](mailto:Yemibayo.2005@gmail.com)

Dear Mrs Oyegbile

**PROTOCOL: Developing an intervention model to manage caregiver burden among family caregivers of patients living with End Stage Renal Disease in Nigeria. REF: BE226/14**

### RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 13 January 2017  
Expiration of Ethical Approval: 12 January 2018

I wish to advise you that your application for Recertification received on 15 January 2017 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

This approval will be ratified by a full Committee at its meeting taking place on 14 February 2017.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Mrs A Marimuthu'.

Mrs A Marimuthu  
Senior Administrator: Biomedical Research Ethics



ANNEXURE 15: DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS FOR QUALITATIVE DATA

Table 1: Demographic data of participants

Demographics	Family caregivers (n)
<b>Gender</b>	
Female	11
Male	4
Mean age in years	44 (range 20-70)
<b>Marital status</b>	
Married	12
Single	3
<b>Relationship with care-recipients</b>	
Spouse	8
Adult child	4
Sibling	2
Mother	1
<b>Residence</b>	
Same residence	13
Separate residence	2
Estimated hours of caregiving per day	20.7 (range 11 -24)
Estimated months of caregiving	14.5 (range 6 – 48)
<b>Religion</b>	
Christianity	10
Islam	5
<b>Ethnicity</b>	
Yoruba	12
Igbo	1
Urhobo	1
Twi (Ghanaian)	1
<b>Working status</b>	
Self-employed	8
Unemployed	1
Retired	2
Schooling	1
Paid job	3
<b>Educational status</b>	
Elementary	3
Secondary school leaver	2
Post-graduate student	1
University graduate	2
No education	2
Diploma	5

## ANNEXURE 16: CATEGORIES AND SUB-CATEGORIES OF QUALITATIVE DATA

The interview text was sorted into five content areas: disconnection with life, never ending burden, a fool being tossed around, obligation to care and promoting a closer relationship. Experiences with caregiving were elicited by asking: can you tell me how it is taking care of your sick relative? Other questions such as, How has it been looking after your loved one with ESRD were asked to elicit responses from participants. Interview scripts were read line by line several times to understand the whole interview. The text about caregiving experiences were extracted and align together into a text, which constituted the unit of analysis. The text was further divided into meaning unit and condensed. The condensed meaning units were abstracted and labelled with a code. The various codes were compared based on differences and similarities and sorted into categories and sub-categories, which constitute the manifest content. The tentative categories were discussed by two researchers and revised. The underlying meaning was formulated into categories (Graneheim and Lundman, 2004).

Data was analyzed using manifest content analysis to explore caregiving experiences. The following categories and sub-categories were identified: Data was analyzed using manifest content analysis to explore caregiving experiences. It is suitable for analysing complex and significant nursing phenomenon through reporting and describing categories (Vaismoradi, Turunen and Bondas, 2013). Interview transcripts were read line by line several times to achieve data immersion (Elo and Kyngäs, 2008). While reflecting on the data analysis, the researcher validated findings with participants and checked with the research supervisor on the categories and sub-categories that emerged from individual interviews. Similar words were classified into the groups they belong to (Graneheim and Lundman, 2004).

Categories	Sub-categories	Quotations
	Life passing by	Whereas my classmates are in the university learning and studying for the forth-coming major exams, I am in the hospital giving care to my sister, if I don't write this exam it's going to affect me. I mean...I may repeat this session. <b>Family caregiver 07</b>
	Separated from community	"I feel left out of the happenings in the church and among my friends. I was in the hospital providing care when my niece got married. When my friend's daughter graduated from the university I was taking care of my husband in the hospital. There is no other thing I am doing now than to provide care. I was supposed to lead the women meeting at the church; I could not do it because I was taking care of my husband. This task has left me out of everything...separated me from my grandchildren, friends and church members" <b>Family caregiver 08</b>
	Relentless care	I have been doing this for forty-eight months now. The question I asked myself is when am I going to stop doing the same thing over and over again? When is this caregiving going to stop? I don't like doing this anymore! Initially it was hypertension, then later diabetes and now kidney disease. I expect him to be cured of one disease before another showed up but it is not like that. I have been managing these diseases over a long period and I am fed up with this experience". <b>Family caregiver 06</b>
	Vigilance	I don't stay with my father [the patient] in the same house. So I always keep my cell phone active throughout the night in case he has urgent needs that must be met before the day breaks. I hardly sleep...deeply since I know there might be one issue or another...during the night.

		I always feel tired and weak in the morning <b>Family caregiver 10</b>
	Imminent loss of a loved one	I always cry throughout the night. As I stay in the hospital providing care I see patients die from similar diagnosis as my husband. I cry because I know that it is just a matter of time... it will soon be my turn...to mourn the death of my husband...I cry because life will be difficult for me and my children in the event of his death. <b>Family caregiver 11</b>
	Lack of knowledge about disease process	<p>I have no idea of what the disease is all about. I felt embarrassed when I don't know what I need to know. I am concerned that nurses are not telling me anything...since they are the ones knowledgeable in health matters". I don't like it when I do not know the reason behind my actions. I am sad to see myself as a fool being tossed around. <b>Family caregiver 05</b></p> <p>I just sit here like a robot. Nurses asked me to buy items that my mother needed. They never told me why she needed them. They order me to pay for dialysis and laboratory investigations and other things. <b>Family caregiver 03</b></p> <p>After paying for dialysis, nurses started the procedure and then the machine developed some faults which made them stop the procedure ... but on the following day when she [relative with ESRD] was taken there to complete the process that started yesterday, nurses demanded another full payment from me. They took me for granted ... am I a fool that will pay for a service that was not completed? <b>Family caregiver 14</b></p>
	Used as a splint	Nurses asked me to hold her hand...the one that is used for infusion. I held it for

		several hours...I can't imagine myself being treated this way <b>Family caregiver 01</b>
Obligation to care	Reciprocity	I saw him [my father] provide care to my grandfather, when I was growing up. He took care of him for a prolonged period of time. I just said to myself I need to do this because I want my children to also take care of me when I am sick or old. To me, it is good to reciprocate good virtues so that it can be sustained". <b>Family caregiver 10</b>
	Contravening cultural values	In my culture, children are forbidden from seeing the nakedness of their parents. I am sad when I see her exposed body every day. I always remember that it is unacceptable in our culture to see a parent's nakedness. But if I do not provide care for her, who else will? I am afraid for my life because of the repercussions of the taboo on my <b>Family caregiver 02.</b>
	Closer relationship	The time I spend taking care of my mother provided opportunity for us to share concerns, cry over our shoulders and laugh about successes. I relate easily with many of her success stories and learn from the shortcomings of her life. It's indeed a time of recounting events, learning and making adjustments. She appreciates the care I provided for her and that made her to share sensitive information with me. <b>Family caregiver 15</b>
	Intimacy	I know almost everything I need to know about my siblings since our mother's illness started. We talk regularly on phone, they share vital information about their financial life as well as other aspects of life with me. We discussed intimately on all issues of life, especially as it affects our mother. I wonder if I could ever know so much about them if not for our mother's sickness". <b>Family caregiver 03.</b>
	Fulfilment in marriage	I feel fulfilled that I am able to provide care to my husband ... of 30 years ... He is a

		good, loving, caring, and reliable companion. He smiles all the time because he is happy. The type of care I provide for him makes him happy and it has strengthened our love for each other <b>Family caregiver 15</b>
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## ANNEXURE 17: ACTION RESEARCH

In developing a model to manage caregiver burden, an action research approach was adopted using a mixed method. According to (Dick, 2006) action research is self-reflexive, self-critical and critical enquiry undertaken by professionals to improve the rationality of their own practices, their understanding of these practices and the wider contexts of practice. Reason and Bradbury (2008) argue that action research is grounded in a participatory worldview emerging at the present historical moment. The research is a participative, democratic process concerned with developing practical knowledge in the pursuit of worthwhile human purposes (McNiff, 2013). Action research can be illustrated as one of research methodologies which are based on change and understanding at the same time.

According to Wicks, Reason and Bradbury (2008) the most common reason for choosing action research is participation, action and change. The current study was based on partnership between the researcher and study participants engaging a cyclical process (O'Brien, 2001). The investigator and participants took action together through a collaborative enquiry and took decision together on the change that is apparent during the research process (Wicks et al., 2008)

Action research was chosen for this study because it engages co-learning as a primary aspect of the research process (O'Brien, 2001). In the perspective of (Creswell, 2009) action research helps to solve practical problems in a specific location and improve the situation. In this study as participants traverse four cycles of the study, ideas were shared by people from different backgrounds facing different or similar challenges of life as the process itself is educative and empowering.

Action research is characterized by cyclical review of action followed by reflection, often ending in improvement of the understanding and uses methods such as modelling (Dick, 2006). Action research acknowledges complex contexts or can be used with complex problems in complex adaptive systems. Participation, as well as iterative cycles of action and reflection, promote convergence to a greater understanding (Dick, 2006). Once

explored, action can be deliberately inserted to the situation to develop it, and its resulting effect observed. Reflection on the change and resultant effects are then made to produce potential further action. Assessment, action and reflection are key elements of the research methodology. Dick (2006) confirms that the action-research-design serves a dual purpose, namely, to yield simultaneous change and understanding.

Action research permits the investigator the right to select an appropriate method depending on the research questions (Denzin and Lincoln, 2000). As an overarching methodology, the action research cycle supports evaluation of questions, planning, fieldwork, followed by analysis and reflection (McNiff, 2013). Action research has been revealed to take diverse theoretical structure (McNiff, 2013). Action research is becoming popular model for research in social and health sciences, particularly those involving primary care Creswell (2009).