SCHOOL OF NURSING AND MIDWIFERY
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# EXPERIENCES OF FAMILY CAREGIVERS OF PATIENTS WITH END STAGE RENAL DISEASE IN THE ACCRA METROPOLIS, GHANA.

BY

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# DECLARATION

I declare that this thesis is my own work produced from research undertaken under supervision. This thesis/dissertation has not been submitted in any form for any degree or diploma at any university or other institutions of tertiary education. Authors and Publishers whose works have been utilized in this study have been duly acknowledged in the text and list of reference.

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## DEDICATION

This thesis is dedicated to all family caregivers of patients undergoing dialysis. My wonderful husband Sedem Ofori. My beautiful children Kimathy Sedem, Kemet Dzifa and Selasie Ofori for their patience and love during all those times I had to leave them behind to work on my thesis. I also dedicate this to my mother and Father, Davis Yaw Asante and Mariam Abdullah. To my wonderful sisters Babsy, Hilary, Hawa and Miama for their monumental support and prayers throughout this journey. The love of God and family is the spice of life and surely above all things.

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# ABSTRACT

End-Stage Renal Disease (ESRD) has been on the rise and is a major public health concern. It affects both family caregivers and their patients adversely. The near-death nature of ESRD coupled with its impact on quality of life has compelled family caregivers to provide needed care from as basic as personal hygiene to complex care like wound care both in and out of health facilities. The level of participation of these family caregivers, however, is undefined and their experiences in their caregiving role are not properly understood. This among other challenges has confused the role played. Given this, the study sought to explore the experiences of family caregivers of patients with ESRD using the Caregiver Health Model. This study employed an exploratory descriptive qualitative design situated within the constructivist paradigm. Purposive sampling technique aided in the recruitment of fifteen (15) participants from The Trust Hospital. Data was collected using a semi-structured interview guide via a face-to-face interview model. The interviews were audio-recorded. Thematic Analysis was used to review interviews, code, and group the themes. Thematic analysis was aided by using constructs of the caregiver health model while ensuring the trustworthiness of data was through member check. Family Caregiver experiences were reflected in the narratives, which highlighted caregivers' needs, tasks, competencies, beliefs, attitudes, and health behaviors as was expected. According to study findings, Family caregivers encountered numerous challenges which they believed could be bearable with support. An emergent theme was identified overreaching the constructs of the used framework.

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| | |
|---|---|
| AM – | Alternative Medicine |
| CGHM - | Care Giver Health Model |
| CKD- | Chronic Kidney Disease |
| ESRD- | End Stage Renal Disease |
| GHS - | Ghana Health Service |
| IRB - | Institutional Review Board |
| MOH - | Ministry of Health |
| NHS- | National Health System |
| NMC - | Nurses and Midwifery Council |
| UK - | United Kingdom |
| WHO - | World Health Organization |

# CHAPTER ONE

# INTRODUCTION

This chapter gives a primer on the background of the study. It also touches on the problem statement, objectives, research questions for this study, the purpose of the study, and the significance of the study to nursing practice, policy makers, and research.

## 1.1 Background

ESRD is a chronic, progressive and irreversible kidney disease, where the kidneys can no longer function on their own. Persons with ESRD must receive dialysis or kidney transplantation to survive for more than a few weeks (WHO, 2017). Patients may experience a wide range variety of symptoms as kidney failure progresses. These include fatigue, drowsiness, decrease in urination or inability to urinate, dry skin, itchy skin, headache, weight loss, nausea, and easy bruising (Ji-Cheng et al., 2019). The chronic and progressive development of ESRD as a terminal disease remains a significant threat that contributes to a reduced quality of life and premature mortality (Hoang, Green & Bonner, 2018; Ji-Cheng et al., 2019). The debilitating nature of the disease and standards of medical care which entails consistent and careful monitoring for signs of the disease progression and early referrals to specialists for dialysis or possible renal transplant has made it a life-threatening and worth global public health attention (Lappin, 2020).

According to Ji-Cheng et al. (2019), the global estimated prevalence of CKD is 13.4%, and patients with end-stage renal disease (ESRD) are estimated between 4.9 million and 7.1 million. Unlike patients in developed countries who might benefit from Medicare, in less developed countries such as Ghana, patients, and family caregivers bear the huge burden of care without government support (Kusi et al., 2020; Kekrebesi, 2021; Oyegbile & Brysiewiez, 2017). Further failure to enroll the treatment of ESRD onto the National Health Insurance scheme has left families to bear all the cost of care. This has resulted in increased care dependency with an estimated 349 million people being care-dependent worldwide (WHO, 2017). The situation is further exacerbated because of the numerous hospitalizations, increased healthcare costs, and numerous metabolic changes among others have led to this state of affairs, namely, care dependency.

In sub-Saharan Africa and Latin America, the burden of ESRD is progressing at a faster rate with an estimated number of people receiving renal replacement therapy to be 2 to 5 million (WHO, 2017); and projected to reach 5·10 million by 2030 (Stanifer et al 2014).

Care dependency is a hallmark in the management of ESRD with family caregivers standing in as advocates for the patients, especially in Ghana. The rapid increase of ESRD has rendered it a global public health problem. In Ghana, an estimated 13.3% prevalence of ESRD has been reported (Adjei et al. 2018). The progressive increase in ESRD cases augments an increase in the burden on an already overwhelmed and in some cases deplorable healthcare system across the length and breadth of the country. Apart from that, due to financial constraints faced by patients and family members in the healthcare system, health personnel do not often provide quality and subsidized care to patients (Adjei et al. 2018; Dondorp, Iyer & Schultz, 2016). The caregiving environment in most hospitals rarely has access to enough resources to fund their operations. This often makes it mandatory for the family caregiver to resort to providing formal and informal care for patients with ESRD, at home and in the hospitals (Khosravan, Mazlom, Abdollahzade, Jamali, & Mansoorian, 2014). Consequently, family caregivers suffer the burden associated with these healthcare deficits which leads to caregiver burden (Dondorp, Iyer, & Schultz, 2016).

While in wealthy nations such as the United States and the United Kingdom, family carers may get social assistance in the form of a caregiver's allowance, emotional, informational, and psychological support, this is not the case in developing countries. (Hudson and Aranda, 2013; US Department of Health and Human Services, 2012), it is often not the case in developing countries like Ghana. It is a stated fact that, despite caregivers being saddled with providing the majority of patients with physical, emotional, financial, and social care needs throughout the continuum of care be it in hospitals or at home, they rarely receive remuneration (Collins & Swartz, 2011). The family becomes apprehensive about the future when they come to terms with the chronic nature and an ending caregiving role of ESRD of their loved ones. This can result in a significant disturbance in the family structure and function.

Family caregivers often experience emotional instability, despair, and never-ending grief as their patients' health deteriorates (Nakken, Spruit, Wouters, Schols & Janssen, 2015). Spouse caregivers are typically more stressed than other carers, since long-term caregiving can sabotage marital happiness (Bauer & Sousa-Poza, 2015). Chronic diseases can lead to a loss of control and severe reliance, rendering family members unable to operate adequately and neglecting personal care.

There seem to be significant research findings on family caregiving from developed countries (Kekrebesi, 2021; Stanifer et al., 2014). However, this cannot be said of developing countries such as Ghana, where there seems to be a paucity of studies on the experiences of family caregivers of ESRD patients. Despite the significant role they play in the management of their sick members, they appear to be “hidden caregivers” with their experiences rarely explored. The study, therefore, sought to describe the experiences of family caregivers providing care for patients with ESRD in the Greater Accra metropolis; using Caregiver Health Model as the organizing framework.

## 1.2 Problem Statement

The researcher's interest in this study emerged from her experience and encounters with family caregivers during her line of work as a nurse at the emergency unit.Caregivers, of renal patients especially, sometimes ended up being hospitalized during hospital visits while some confessed to going as far taking their patients medication mostly pain killers to relieve pain and discomforts without seeing a doctor.

This along with reviewed statistics which indicated that ESRD has been on the increase among young people lately. The ages of these patients usually fall between twenty (20) and fifty (50) years in sub-Saharan African countries (Adjei et al., 2018). According to current studies, the prevalence of CKD in Ghana is 13.3 percent (Adjei et al., 2018). Because most patients cannot afford dialysis, the development of CKD to end-stage renal disease (ESRD) is a significant burden on the healthcare system in most LMICs. Patients with ESRD have a lower quality of life as a result of this. When a person is diagnosed with a fatal illness at the age specified above, family caregivers are frequently called upon to provide extensive, long-term care (Arogundade, 2013). As a result of this development, family caregivers must step in to assist relatives with ESRD in maintaining and improving their quality of life by caring for them. They remain "hidden caregivers" whose burdens are less known. The paucity of literature on the experiences of family caregivers of patients with end-stage renal failure in Ghana gives the cue that the area has not been given the needed attention. As such, the main aim of this study is to explore and describe the experiences of family caregivers of patients with end-stage renal failure in Accra.

### 1.3 Objectives of Study

1. Describe the needs of family caregivers of patients living with end-stage renal disease in Accra

2. Assess caregivers' tasks and competencies in taking care of patients living with end-stage renal disease in Accra.

3. Investigate the beliefs and attitudes of family caregivers of patients living with end-stage renal Disease in Accra

4. Explore health behaviors of family caregivers of patients living with end-stage renal disease in Accra.

### 1.4 Research Questions

The following research questions were formulated to guide the study.

1. What are the needs of family caregivers and their effect on them and their relatives living with end-stage renal disease in Accra?

2. How does the competency in task performance affect caregiver roles in taking care of patients living with end-stage renal disease in Accra?

3. What role do family caregivers' beliefs and attitudes play in their caregiving responsibilities?

4. What are some of the health behaviors of family caregivers of patients living with end-stage renal disease in Accra?

### 1.5 Significance of the Study

Family Caregivers experience numerous challenges as a result of their caregiving roles. The burden of caregivers has serious implications on both the caregiver and the care recipient. Experiences related to needs, task performance, health behaviors, and beliefs and attitudes have an important connection to the general well-being of caregivers and the care they render to their sick relatives. Given this, as I have already intimated this study seeks to give an insight into the essence of family caregiving for patients living with ESRD. The study will serve as an evidence-based report which will elucidate the experiences and needs of family caregivers of patients with end-stage renal disease. This will among other things help in strategizing and adapting interventions to help enhance the skills and address the needs of family caregivers. The findings and recommendations of this study will shape the family caregiving sector and recognize it as an integral part of healthcare services in developing countries so to speak. In addition to that, the study will add up to the existing body of knowledge in the field of nursing and healthcare. Finally, the findings of the study will help in improving nursing practice and communication concerning ensuring equity and universal healthcare support for patients with ESRD.

## 1.6 Delimitation of the Study

The study focused on issues that border on the stress level, burden, and anxieties of family caregivers. The study also attempts modestly explore the roles that social conventions and cultural values play in motivating people to take family caregiving duties.

In this regard, a further attempt is made to identify whether the task and competence of family caregivers have any negative and positive impact on the well-being and health of the family caregiver and the care recipient. In terms of geography, the study was undertaken in the Greater Accra Region. The Greater Accra Metropolis was chosen for the collection of data because it has a majority of cases of family caregivers' burden and lived experiences. This stems from the banal fact that there exist hospitals in the region that have some of the facilities that are needed to treat patients with ESRD. Also, it is one of the regions populated with many indigenes from the other regions.

## 1.7 Limitation of the Study

It is most of the data gathered are anecdotal records. Given that, it will be out of place to place all our trust in the findings of this study. This suggests that the validity and reliability of the could somewhat be tentative. Be that as it may, I have reason to believe that if similar studies could be carried out in other regional capitals and districts and the findings of these various studies thereof could be compared with this very study. This may give us a fair idea and enough grounds to generalize the outcomes of the studies. Thus, it can be argued that this study could serve as a point of reference for future studies so to speak.

## 1.8 Operational Definition of Terms

**Family**: A person not necessarily related by blood to an ESRD patient

**Patient:** A person who is care-dependent because of illness.

**Family Caregiver**: An unpaid relative or friend with no formal training who provides care at home and assists in the activities of daily living for the patient with end-stage renal disease.

**Care Dependent:** An ill person's need for support to deal with a self-care deficit on account of a chronic ailment.

**Health Care Providers**: A formally trained and certified person who provides health care services to the public.

**Health Care Team**: Healthcare professionals from different disciplines who come together to contribute to patient care and treatment through the use of their combined expertise.

**Experiences:** A subjective interpretation of an encounter faced by the family caregiver of an ESRD patient which has left a lasting impression on their perception of life and role.

**Patients Living With ESRD:** A person who is on dialysis and needs support in attending to basic care needs and formal treatment.

# CHAPTER TWO

# LITERATURE REVIEW

## 2.1 Introduction

This chapter describes the philosophical underpinnings and (or) the theoretical framework of the study, a description of the Caregiver Health Model (CGHM), and a review of relevant literature in support of the study.

## 2.2 Conceptual Framework

The conceptual framework serves as a guide to exploring to adduce evidence and answers to the research question. The CGHM embodies a biopsychosocial model. These models were adopted to serve as a possible guide for this study including the Biopsychosocial model, the Biopsychosocial-Spiritual model, and the CGHM.

The Biopsychosocial model, to begin with, was propounded by George. L Engel. It generally reflects the complex connections between the biopsychosocial (biological, psychological, and social) factors and illness and how healthcare services are delivered. Unlike the traditional biomedical models which focus on pathophysiology and biological approaches to identifying the causes, spread, and cure of disease, the biopsychosocial approach places emphasis on the importance of understanding disease and health in the fullest of the world. This understanding is borne out in a socio-cultural milieu. Scholars have claimed that cultural values play a vital role in understanding, preventing, and curtailing the production and spread of diseases in our current world (Benatar & Brock, 2011, pp. 1- 10). What the above posits is that there seems to be a positive correlation, inverse correlation, or both between social conditions and the production, spread, control, and prevention of diseases (McMillen 2016). Again, the WHO defines health as follows 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity (WHO 1980). This definition invariably ties in with the claim that health is not entirely a biological phenomenon. The foregoing further justifies why the researcher opted to use The CGHM which entails the biopsychosocial model components.

The Biopsychosocial-Spiritual model on the other hand was advocated by Siddal (Siddal et al 2015). His model was an adaptation of Engel's work which focused primarily on the importance of spirituality in pain management for persons receiving end-of-life care. This framework's fundamental premise is that a person's pain experience may be influenced by biological, psychological, social, and spiritual variables in their surroundings. Against this background, the CGHM was chosen and used as a guide for this study. The above models were side-lined because unlike the CGHM, which entails constructs that can be used to ascertain and measure needs, roles, and their effects on caregivers, the other models are more focused on biological constructs.

The CGHM was advocated by Weierbach and Cao in 2016. It came up as the most advantageous of all the other models and was adopted for this study.

### 2.2.1 Theoretical Framework

The theoretical position of this study is premised on the banal fact that caregivers' needs, tasks, competency, beliefs and attitudes, and health behaviors in an environment shape the overall experiences of the caregiver either positively or negatively. Because of this, a holistic approach was employed in exploring caregivers' experiences using the CGHM as a tool to measure these experiences.

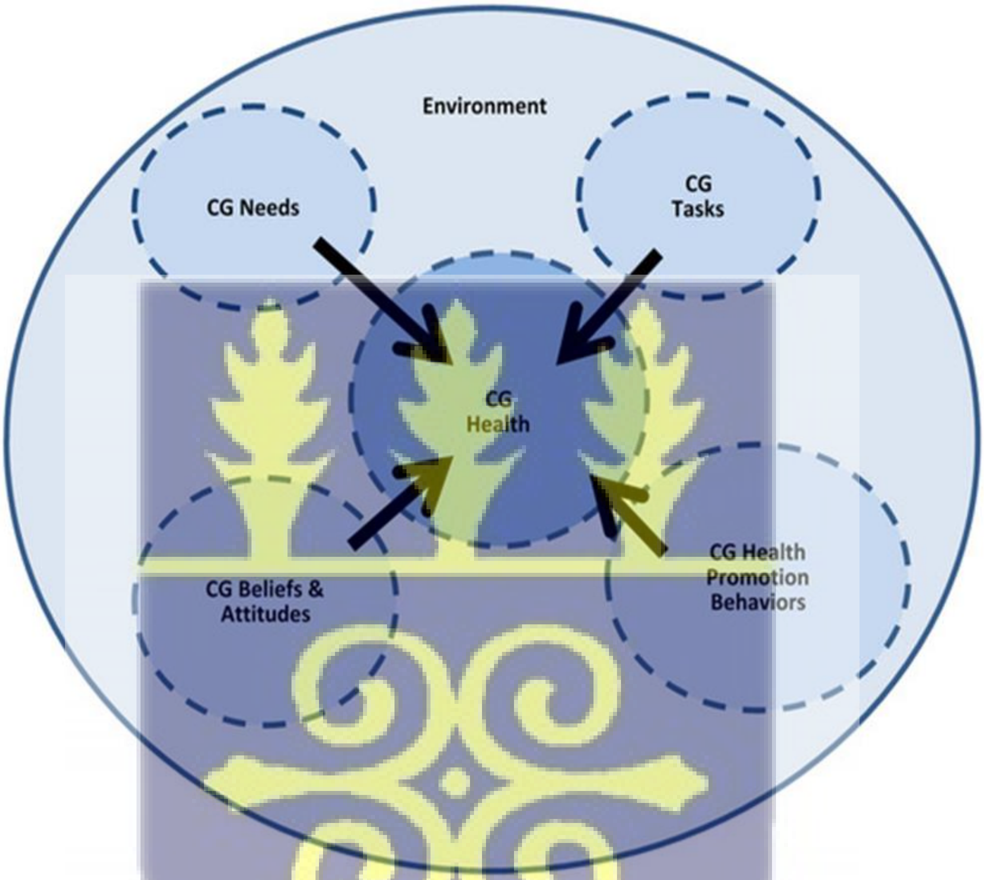

**Figure 2.1: Care Giver Health Model**

Source: Weierbach and Cao (2016)

The CGHM was designed for use among caregivers of elderly patients. It is a model conceived as a health holistic phenomenon with four determinants (s) that borders on the health status of an individual. Be that as it may, in this study we intend to focus on the experiences of the family caregiver. The CGHM was developed after a review of caregiver health literature which mainly focused on the care provided by caregivers in the U.S. The US healthcare system has a system that is predominantly centered on the health care needs of the individual secondary prevention, not on primary and tertiary care or the needs of the family caregiver.

Previous findings of the CGHM indicated higher levels of caregiving have been found to impact caregivers' mental health, physical health, and health-risk behaviors (Weierbach & Yan, 2016; Tingey, Lum, Morean, Franklin., & Bentley, 2020). The model highlights the interaction of the four factors in determining the overall experiences of the caregiver. Thus, it is arguably accurate to adopt this model in gathering data that is pertinent to the objectives of this study. In addition to that, beliefs and social conventions influence the actions of many a family caregiver. In Ghana, it is universally held that the individual is born into a community. The community they are born into largely becomes their family. As such, it is expected that the individual need to understand the notion that in matters, the interest of those in the community is paramount. Thus, the communal needs and good supersede the individual's needs. This situation has created an expected practice that coerces many family members to overlook their own needs and attend to the needs of others first before their own. It is not surprising then that many family caregivers have been taken for granted but rarely complain. Cultural factors and social conventions have played a moral role in creating this level of silence among well-meaning family caregivers (Gyekye, 2003). This makes it somewhat obvious why this study has opted for CGHM to measure all facets of health, namely, how needs, skills, and burden often affects their roles socially, physically, and biologically to mention but a few.

## 2.3 Literature Review

It is common knowledge that the role of family caregivers in the lives of patients with chronic diseases transcends all cultural boundaries and this phenomenon is as old as the history of sentient beings like humans.

However, the setting of this study is Ghana, in particular Greater Accra, the capital city of Ghana to be precise. It has been established that the burden of family caregivers has increased immensely due to many factors as it has already been intimated in the introduction. As a result, policymakers, scholars, industry players, and medical practitioners will seem to agree that the burden of these caregivers is primarily due to financial constraints and the prowess of the caregivers. While this reading is accurate, it appears the socio-cultural factors of a given society seem to plunge family caregivers into various degrees of pain and suffering. It is given this, that this study seeks to use the CGHM with the aim of not neglecting any aspect of the experiences of the caregivers while aiming to achieve a holistic understanding of the phenomenon among family caregivers in the Greater Accra region.

In effect, this chapter seeks to examine the plethora of views mentioned in this work and to note how these views help to explain the causes of the burden on family caregivers, and its effects on patients and the caregivers. The aim is to explore how caregiver challenges could be understood and reduced to the barest minimum if not overcome. Instead of this, a modest attempt was made to review relevant literature in this regard. The review of the literature was organized and premised on the objectives and questions set for the study as stated above.

### 2.3.1 Family Caregiver Needs

The literature shows that caregiving to all patients cannot be downplayed in healthcare services in this globalized world. It constitutes an integral part of healthcare service. A study has shown that patients who receive quality and professional care invariably get some improved and a positive psychological disposition while they strive to recuperate. Caregiving is said to have some impacts on the stress level of caregivers.

This stress level is hinged largely on the burden of caregiving. Some caregivers have a low positive experience in their caregiving roles because they were often some psychological issues such as including depression and anxiety. A study involving informal caregivers who care for patients with chronic diseases and are often burdened shows mostly health behaviors such as depression, identity loss, and role captivity. While family caregivers whose needs have been moderately met in their caregiving roles experience less burden. This second group of caregivers rarely will experience depression, identity loss, and role captivity (Walker, Powers, & Bisconti 2016). There is a whole range of studies that dwelled on qualitative methodologies in particular using in-depth interviews to elicit responses from caregivers. The scholars observed varied facets needs and experiences of family caregivers. It was established that family caregivers who attend relatives with old relatives with the disease are confronted with needs such as follow-up emotional stress, inadequate finance, and worry. Despite these challenges there seem some level of confidence and positive experiences on the account of family caregivers. These experiences and satisfaction emanated from the shared mutual bond they have as caregivers. Aside from this, the family caregivers often feel that they are paying for all the good deeds the care recipients had done them in time past. And this gives them some level of satisfaction. In addition, some participants observed that despite the social support they receive from the larger community, they never would afford to smile and have fun while their tedious duties as caregivers. What is demured with Gray et al. (2016) is their claim that if caregivers are made to conceive suffering as an inevitable phenomenon that will in itself enable caregivers to endure and cope with burden and stress. This burden of a caregiver is a social responsibility. Thus, making them understand that caring for someone you love brings pains and frustration is neither here nor there.

If the pains can be a shared responsibility, then there seems to be a way out of the pains and burden that these caregivers are often plunged into or subjected to (Gray, Hahn, Thapsuwan & Thongcharoenchupong, 2016; Peacock et al. 2014; Netto, Jenny & Philip, 2009). Also, according to Roth, Dilworth-Anderson, Huang, Gross, and Gitlin (2015), African Americans exude and exhibit positive attitudes in their caregiving duties than Hispanic native Americans. They further established female caregivers outnumber male caregivers. It can be surmised that women are often burdened with the responsibilities of caring for their loved ones who are bedridden with chronic diseases. This itself seems to corroborate the claim that many social and cultural factors play up in the burden of family caregivers. As such, a holistic approach is needed to research the phenomenon.

In addition to the above, a study conducted by Khosravan, Mazlom, Abdollahzade, Jamali and Mansoorian (2014), revealed most hospitalized patients receive nursing care from unskilled and non-professional nurses. This stems from the fact that most patients who are living with the near-death disease often become dependent and burdened with family caregivers to care for them due to financial difficulties. Hence, the level of care that ought to be given to patients with End-Stage Renal Disease (ESRD) is often not met. Financial constraints on the part of patients in most African countries have made it impossible for patients to have access to quality healthcare services albeit being bedridden with chronic diseases. The situation has left some family caregivers no option but to render formal and informal care for patients with ESRD. This implies that family caregivers who care for patients with ESRD have the burden of meetings their own needs, and the health needs of their patients (Oyegbile & Brysiewicz, 2017).

Nkuranyabahizi et al (2021) conducted a descriptive qualitative study to learn more about family carers' experiences and needs. They also discover that caregivers of patients with End-Stage Renal Disease (ESRD) in Rwanda face spiritual and personal challenges, as suggested by previous research (e.g. Gray, Hahn, Thapsuwan & Thongcharoenchupong, 2016; Peacock et al. 2009; Netto, Jenny & Philip, 2009). Disease trajectory also exposed caregivers to inevitable care roles that further increased and intensified their caregiving tasks and responsibilities. This invariably leads to a need for social and professional support. Again, an explorative cross-sectional study on caregivers' perspectives revealed that people with end-stage renal disease who are on dialysis have many needs. These needs include the inability to cope with the health system navigation, palliative care perceptions, caregiver burden, decision-making, and symptom management.

The study further highlighted that the demanding nature of the caregiver role makes them restless (Maddalena et al., 2018).

In furtherance of the above, a mixed-methods and a systematic review conducted by Hoang, Green, & Bonner (2018) to analyze studies done about the perspectives and experiences of family members and friends who provide support for adults down with ESRD showed that these caregivers are overburden. The study further established that the burden of informal caregivers continues to remain increasingly high coupled with its associated problems such as depression and anxiety, lower quality of life, and poor sleep routines. Additionally, a 2015 cross-sectional study was undertaken to compare the caregiver burden of a patient with ESRD who are either on hemodialysis therapy or have renal transplants. It was discovered that caregivers of patients who are undergoing hemodialysis treatment have a greater burden. They often have a higher level of anxiety, depression, and poor sleep which adversely affect their lives (Avşar et al., 2015).

A pilot study conducted by Grapsa et al. (2014) to describe the characteristics of caregivers of patients with chronic diseases, assess their perceived burden, and investigate factors influencing this burden showed that the caregivers were extremely worried about their patients' problems.

### 2.3.2 Caregivers' Task and Competencies

A caregiver's responsibility isn't just to perform presumed activities of daily living but rather a task that needs a variety of competency and adequate resources depending on what is to be done. Performing tasks, as simple as it sounds may trigger a succession of anxiety, confusion, depression, and burnout syndrome among others when there's a knowledge deficit in preparedness toward task performance especially so when it involves the life of another person or a loved one. With every task comes challenges. In the case of ESRD, its symptom management nature affects the work to be done daily as complications are inevitable. Challenges faced by Family caregivers are endless since they are not professionals nor do they have the requisite skill to face challenges squarely when they arise.

As a nurse at the emergency unit for a considerable time, it was observed that the majority of readmissions were advocated by family caregivers due to a lack of confidence in their skills in taking care of their patients. Even in instances when financial constraints were a deciding factor for admission, which most of the time was, many family caregivers opted for professional care over theirs. It was realized from interactions with some family caregivers that this decision was mostly born out of a plain lack of confidence in their skills and competency which spells a big gap in the relationship between health professionals and family caregivers.

According to Faronbi, Faronbi, Ayamolowo and Olaogun (2019), the experience of caregivers of older people in Nigeria posit that family members are key to providing care to the aged. This is because their tasks comprise addressing daily routine problems, changing position, helping with movement, bathing, and grooming and feeding. Thus, the absence of these caregivers implies that these victims could perform social functions that they had performed when they were in good health. Similarly, a study by Kusi et al. (2020) which sought to explore and describe the caregiver's motivations and experiences among family caregivers of patients living with advanced breast cancer using showed that the patient was supported daily. In supporting these patients, caregivers were tasked with symptom management by monitoring activities such as home-based wound care, drug administration, and pain management. Another explorative study conducted by Sousa et al (2021) measure the dynamics of caregiving with references to situations faced by family caregivers at a given time. It was recorded that caregivers acknowledged having more caregiving tasks with little time for tasks they presumed were more meaningful to them. They outlined additional tasks such as errands to the pharmacy, an increased habit of disinfection, and care of fistula sites. Some caregivers were often tasked to accompany the patient to healthcare facilities for dialysis. These duties were done with the help of ambulances.

Another qualitative descriptive study by Jeyathevan et al. (2019) sought to identify relevant skills needed to enhance family caregiver competency. The findings from their study showed that if caregivers feel competent because they possess the skills needed, this is often reflected in the care provided to care recipients. The study observed among other things that self-worth and efficacy in performing caregiving tasks could only be realized providing family caregivers have adequate trained. These will boost their competency level and give some satisfaction in their jobs will help reduce the stress level of both the care recipient and family caregivers. This implies that the health and well-being of both caregivers and care recipients will be immensely improved. While at this, it also presupposes that less competent caregivers who exhibit limited knowledge and skills needed to attend to the health needs of patients with ESRD have adverse effects on the caregiver and care recipients' health. Also, a literature review of studies with 40% or more samples of African American patients with ESRD concluded that support from their family (informal caregivers) is critical in their survival. The study suggests that survival among ESRD patients is determined by the quality of support from the family. Given that, it can be surmised that the absence of family support for patients with ESRD has amounted to the recent increase mortality rate of people with ESRD (Holder, 1997). It appears that the skills and competence of family caregivers are very key to maintaining their health and improving the health of their care recipient relatives.

## 2.4 Belief, Attitudes, and Health behaviors of Family Caregivers

Attitude is controlled by the beliefs of a person. A person's belief system is formed based on occurrences that produced an impact either positive or negative. These beliefs are memorized and become a part of oneself possibly influencing their attitudes and way of life

Kusi, Boamah, Dzomeku, Apiribu, and Duodu (2020), to begin with, conducted a study to ascertain the motivation for assuming caregiving roles. It was observed that socio-cultural values influence or motivated them to take up the role. In other words, it is has become an accepted practice that family members socially and conventionally obligated to care for and support their sick relatives. Some participants were reported to have assumed the role because they were the elder of the daughters in the family or mothers of the patients. Thus, conventionally women are seen as caregivers. In Ghana, for instance, informal caregivers (family caregivers) believe it is a cultural norm to look after their sick relatives. Some assertions by participants that attest to the foregoing as cited in Kusi et al (2020) are as follow: "Oh! She is my wife. . . if I don't take care of her, who will? It is just my social obligation as a husband to take care of her" and "She is my mother, my family. . . it is my socio-cultural responsibility to take care of her. . . That is the reason I am the one taking care of her." It can thus be inferred that beliefs and cultural values play a pivotal role in influencing or motivating people to accept family caregiving responsibilities. Also, in the same study, it was observed that caregiving was conceived as a means of reciprocity. That is, as repayment of a good deed gotten from the patient.

Moreover, a study by Faronbi, Faronbi, Ayamolowo, and Olaogun (2019) revealed that some family caregivers denied the immense burden that comes with caring for their sick family members. Data in their study suggested that caregivers often do not acknowledge or realize it immediately. However, as the sickness of their relative steadily deteriorates and progresses, it becomes burdensome combined with work.

Eventually, stress level increases, and financial crises and social life are adversely affected. This phenomenon affects the health of the caregiver.

Williams et al. (2019) conducted a study that focused on exploring the experiences associated with burden, depressive symptoms, and perceived health in six male caregivers of persons with end-stage renal disease (ESRD). A positive caregiver experience emerged which posits that caregivers are committed to giving care to ESRD recipients and are emotionally gratified. Most of the caregivers stated that they feel good about their roles as caregivers with one participant expressing an emotional benefit from just being "able to help them." This seems to indicate that people can be emotionally stable and less burdened if they are committed to taking care of their sick relatives. In a study conducted by Byers, et al (2011) caregivers on they manage depressive symptoms and promote healthy behaviors. It emerged that healthy nutrition, exercise, and modifying stress were discovered as a way of promoting good health. Similarly, a study by Oliveira et al (2019) revealed factors that help to promote a healthy lifestyle among family caregivers comprise physical activity and balanced dieting. It was established that these behaviors adhered to help to reduce caregivers’ depression and burden. It was further revealed that psychological preparedness and adherence to self-care was necessary recipe for health promotion. Therefore, health promotion was not solely ensured by physical activity and a balanced diet. The implication is that inadequate psychological and social support can impede the achievement of optimum health promotion.

### 2.5 Summary and conclusion were drawn from the literature review

From the studies discussed above, it is evident that caregivers of sick relatives with chronic diseases are large females. These caregivers often experience many a challenge in the course of discharging their duties. The literature shows that there have been several studies conducted on how caregiving improves the health of the care recipients however very little has been done on the burden of caregivers in Ghana. Thus, the experiences of the caregivers of ESRD patients have been neglected for so long a time. Thus, this study will be the first to address the gap found in the literature. It modestly attempts to explore caregivers’ experiences with reference patients with ESRD patients in the capital of Ghana, Greater Accra. The studies reviewed showed that caregivers offer support to their patients and to some extent, develop personal growth through the care. However, more studies should be carried out to inform healthcare stakeholders to provide support for informal caregivers who take care of patients with ESRD. This will help reduce the burden of financial constraints, incompetence, and depressive symptoms to the barest minimum.

# CHAPTER THREE

# METHODOLOGY

## 3.0 Introduction

Methodology embodies the steps and approach within which the study will be conducted. It comprises of the research design, the research setting, the procedures, and methods for data collection. This chapter defines the research population, the sample size and the data collection and analysis. It further details the research rigor and ethical considerations.

## 3.1 Study Design

Following the aims of the study which was to capture the subjective and lived experiences of family caregivers, a qualitative descriptive study design situated within a constructivist paradigm, was used in this study. Constructivism supplements that reality is determined by an individual's experiences (Alexander Riegler 2012) . The qualitative descriptive design due to its holistic approach promotes the collection of rich data by using various sources like opinions, attitudes, and perspectives to achieve a deeper understanding of an individual's thought process hence data is collected in its natural setting in the absence of interventions or manipulations. A qualitative design helps in understanding the subjective experiences of the individual concerning their thought processes through acquired context and not just outcomes like a quantitative study (Sutton and Austin 2015)

This design also allows a researcher to provide insights into what, why, and how of the research procedure. A qualitative descriptive design allows researchers to contextualize how the participants perceived their activities, environment, and role within the context of the study while providing a picture of what naturally occurred (Hunter, McCallum, & Howes 2019)

This gives a better understanding of the need for the research. This research was carried out amongst family caregivers of patients with ESRD in the Accra metropolis. It was expected that this design would elicit in-depth information about the lived experiences of family caregivers and bring up issues that quantitative research methods could adduce adequately.

## 3.2 Study Setting

This study was carried out in the Accra Metropolis in the Greater Accra region. Accra is also the capital of the Republic of Ghana on the Atlantic coast of West Africa. It covers an area of 225.67 km2 (87.13 sq mi) with an estimated urban population of 4.2 million as of 2020. It is organized into 12 local government districts, 11 municipal districts, and the Accra Metropolitan District, which is the only district within the capital to be granted city status. Accra is the most densely populated city in Ghana inhabited by about 4 million people which makes it the thirteenth-largest metropolitan area in Africa. It is a multi-religious metropolis with Christians forming the majority.

Recruitment of participants was done at the dialysis unit and kidney clinic. The Trust Hospital was established in 1992 as a not-for-profit health facility to provide healthcare to SSNIT staff and their dependents. The facility was later upgraded into a full-fledged hospital to extend its services to the general public. It was later incorporated in November 2010 as The Trust Hospital Company Limited currently with three Hospitals- The Trust Hospital main, The Trust Specialist Hospital, and The Trust Mother and Child Hospital and six (6) Satellite Clinics. It serves as a referral site for most clinics and hospitals due to its well-managed specialist clinic system. The kidney clinic is one of the most patronized specialist clinics in the hospital which takes place twice a week on Wednesdays and Saturdays. The fully functional dialysis unit works 6 times a week and on an emergency basis. The facility provides a wide range of renal procedures in an organized and sterile environment. Patients are booked and seen on appointment for both inpatient and outpatients which ensures shorter waiting time and reduction in crowding hence maintaining patient privacy and comfort. This study setting was ideal for gathering rich data since all calibers of patients come for their kidney services in this facility due to convenience and the good services provided. .

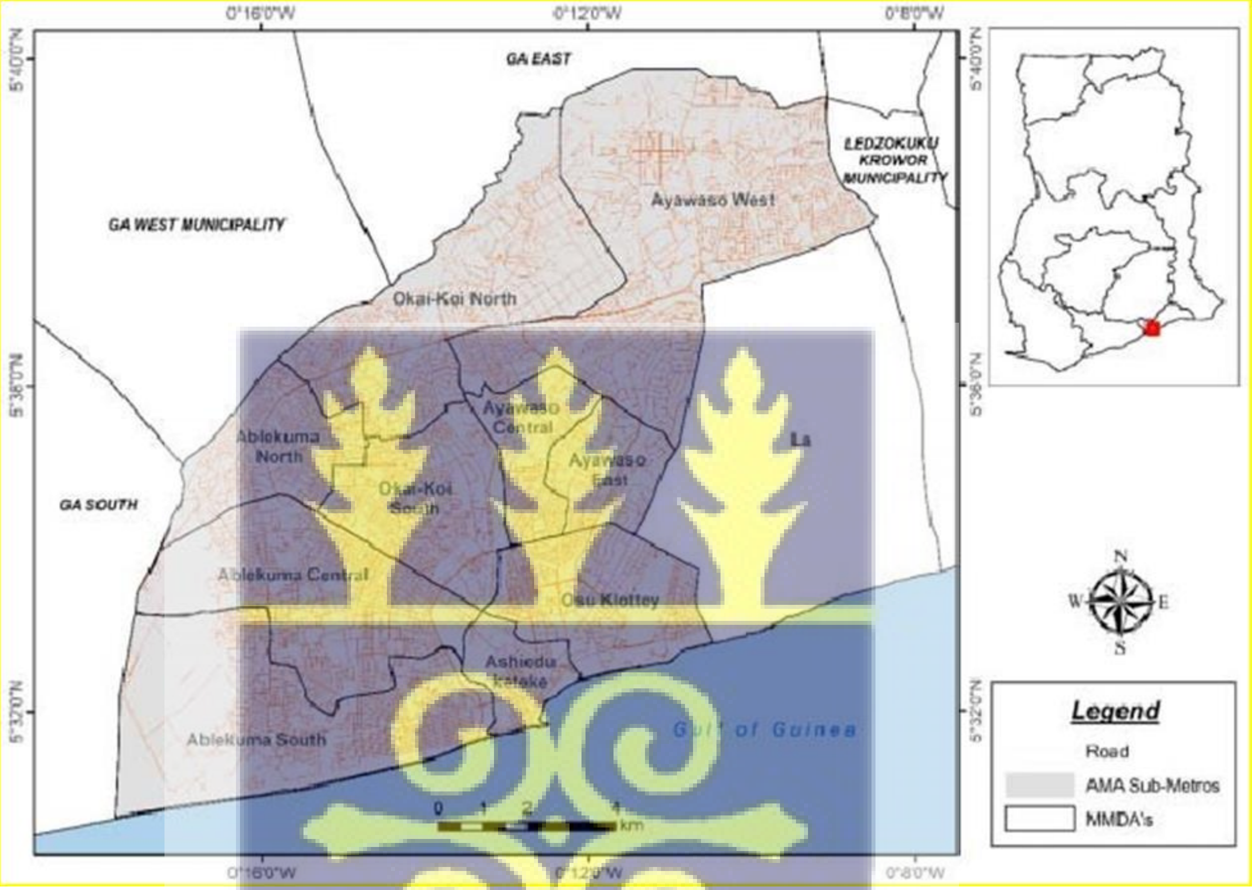

**Figure 3.1:** **Map of Accra metropolis**

### 3.3 Research Population

The research population for the study consisted of family caregivers aged 25 and above who live with and accompany patients to the kidney clinic and dialysis unit at The Trust Hospital regularly.Starting age of 25 was preferred because it striked a balance to alleviate inexperience and with increased chances of rich life experiences which will have an impact on caregiver perspective.

### 3.3.1 Inclusion Criteria

These are characteristics that qualified participants to partake in a study. For this study the inclusion criteria were;

1. Family caregivers who lived with patients with ESRD.
2. Participants who were 25 years - above and attended kidney clinic or dialysis sessions with the patient.
3. A participant with a caring experience of 6months and more. This was to ascertain that the family caregiver had a wealth of experience and information for data needed for the study.
4. Participants that were willing to sign a consent form for the study

### 3.3.2 Exclusion Criteria

1. Caregivers with a history of mental instability.
2. Family caregivers who did not give consent.
3. Family caregivers living out of the Accra metropolis.

## 3.4 Sampling Technique and Sample Size

Recruitment of participants was done by purposive sampling. Purposive sampling refers to selecting research participants that can speak to the research aims and who have knowledge and experience of the phenomenon under scrutiny (Doyle, McCabe, Keogh, Brady& McCann 2020) because of the influence of heterogeneity of the population on sampling and subsequent data collection and analysis need to be considered (Palinkas et al., 2015). The use of this sampling technique is appropriate because the study is specifically focused on the family caregivers' who are in direct and constant contact with patients with ESRD at The Trust hospital.

The sample size will depend on the richness of the information provided by participants until the point where no new ideas or information is gained. Even though saturation will determine the actual sample size, a targeted sample size of 15 participants will be ideal.

### 3.5 Instrument for Data Collection

A semi-structured interview was developed and used for the collection of data. The interview guide (Appendix C) was in two parts. The first part focused on demographic data of participants, which comprised age, sex, the highest level of education, employment status, and religion. The first part of the interview guide was intended to help establish rapport with the research participants to get rich and appropriate data for the subsequent sections of the interview guide. The second part section B consisted of open-ended questions with probes that were used to explore the experiences of family caregivers of ESRD patients. The main questions asked were;

1. What are the specific needs of the family caregiver?
2. What are the challenges faced in satisfying these needs?
3. How do the family caregivers execute tasks related to patient care?
4. What is the level of competency required to accomplish these tasks?
5. What are the beliefs and attitudes of family caregivers?
6. What effects do these beliefs and attitudes have on the caregiving?
7. What are the family caregivers' learned health behaviors?
8. What are the benefits and safety of the health behaviors?

These questions helped in answering the main objectives during the interview and gave more diverse views during the interview. An in-depth interview has the advantage of obtaining detailed information which is fuller and richer from the subjects (Polit & Beck, 2010).

According to Khan, (2012), the interview method is used to collect data from participants through face-face interaction and can record the participants' responses which can later be cross-checked for clarity. With the use of a semi-structured interview, participants will be able to express themselves without any inhibition while allowing the researcher to use probes

### 3.6 Data Collection Procedures

Data collection is a major component of a research process. The method or the instrument is chosen based on the nature of the problem (Ellis & Levy 2009). The primary data in this study was collected through individual face-to-face interviews.

First of all, a proposal and an introductory letter from the School of Nursing were presented to the Noguchi memorial institute for ethical clearance. Permission was sought from The Trust Hospital with attached copies of the ethical approval letter from the Ethical Review Board of Noguchi, the introductory and supervisory support letters from the School of Nursing & Midwifery, University of Ghana. Consent was also sought from The Trust hospital to undertake the study in their facility after approval was given by Noguchi Memorial Institute to commence research. The researcher conducted two practice interviews with two family caregivers at Providence Hospital. Feedback from supervisors enriched interview skills in the actual study.

The participants were given a permission form that included information about the trial, the purpose for the investigation, potential benefits, potential hazards, and a signature page. After receiving all necessary explanations and having everything explained to them in a language they could understand, interested participants signed the permission form. Participants were given the chance to ask any questions they had about the study. Participants were advised that their decision to participate in the study was entirely voluntary, and that they may withdraw at any moment throughout the inquiry without affecting their treatment regimen or how health care workers treated them. They were, however, assured anonymity and secrecy in exchange for the information they provided.

Participants were given random pseudo names based on their time of recruitment. A semi-structured interview guide was used to direct the recorded interviews conducted for data collection. Interviews involved face-to-face conversations with social distance observed as well as all other current COVID-19 protocols. Permission to record was sought from the participants with the assurance of total privacy and confidentiality. Voice recorders were used to record all interviews for transcription and analysis. Participants were also given the needed space without interruption to elaborate on their total experiences. The interviews were conducted in Twi and English depending on the participant's preferred language**.** Participants' body language and all non-verbal communication during interviews were documented in a field notebook. The field note was used to record mannerisms, gestures, and non-verbal cues as participants narrated their experiences and this enhanced analysis of data. Probes were used to elicit in-depth information from the participants as well. Each session lasted between 40-and 60 minutes Interviews were temporally suspended for participants who showed signs of emotional distress. The service of a clinical psychologist was made available to participants at no cost to them in the event of an emotional breakdown during the interview but there was no such event that warranted the service of the psychologist.

All interviews were transcribed before the next interview which helped to identify new information given by other participants, identify a point of saturation, and improve the line of questioning in subsequent interviews.

### 3.7 Data Management

Research data management concerns the organization of data, from its entry into the research cycle through to the dissemination and archiving of valuable results. It aims to ensure reliable verification of results and permits new and innovative research built on existing information (Whyte & Tedds, 2011). Research data management is important because data is a valuable resource whose production requires time and money (Kllapi, Sitaridi, Tsangaris & Ioannidis 2011). Pseudo names for each participant were created and chosen randomly. Recordings and transcriptions were saved with assigned pseudo names. Compiled data was stored on a computer and backed up on external hard drives by the researcher. The computers and drives were protected with a password available only to the researchers. Aliases were given to participants and demographic data was kept separated from the interviewed data. Data was stored alongside audio recordings and remained so until 5 years.

## 3.8 Data Analysis

Data collection and analysis were done concurrently to observe the principle of inductive reasoning. Data analysis was done using the Thematic Analysis technique. Thematic analysis is an independent qualitative descriptive approach that is mainly described as "a method for identifying, analyzing and reporting patterns (themes) within data" (Braun & Clarke, 2006). It has also been introduced as a qualitative descriptive method that provides core skills to researchers for conducting many other forms of qualitative analysis. Thematic analysis is suggested as a flexible and useful research tool that provides a rich and detailed, yet complex, account of the data (Braun & Clarke, 2006). According to Vaismoradi et al ( 2013) thematic analysis provides a purely qualitative account of the data that is richer and more detailed, unlike content analysis which allows the researcher to analyze data qualitatively as well as being able to quantify the data hence the choice to use thematic analysis in gathering the rich data needed for this study. The steps below originally coined by Braun and Clarkes 2006 were followed right from acquiring data through to data analysis and reporting.

Familiarising with Data Transcription was the highlight of this step and helped the researcher immerse in the information acquired through interviews. Transcribing data converts qualitative data and information given during interviews into a text-based format which makes analysis of data easy and shareable. It also made patterns easy to find and highlight trends. The recorded interviews were transcribed verbatim. All interviews conducted in the twi language were translated and transcribed into English by the researcher and a translator to avoid data distortion

- **Generating Initial Codes**

After transcription and identification of patterns, codes were generated from the transcripts based on the conceptual framework through repeated reading and reasoning. The codes were made up of words and phrases. All data relevant to identified codes were collated systematically as well as all other interesting features.

- **Searching for Themes**

The generated codes were grouped into sub-themes and the subthemes were also put under potential themes systematically making sure all codes subthemes and potential themes are in line with the aims of the research and also the framework guiding the research.

- **Reviewing Themes**

Potential themes were reviewed by recounting codes and subthemes. Themes that did not have adequate data to support them collapsed.

- **Defining and Naming Themes**

Themes were named using the chosen framework as a guide. Themes were named taking into consideration the construct of the framework while using ongoing analysis to refine the specifics and clear definition of each theme as well as the overall narrative backing each theme

- **Producing the Report**

This was the final step in the data processing and analysis. Guided by the framework, a vivid selection, using compelling examples from narratives given by participants, was used in producing the final report. Analysis concerning set research questions and comparison with previous literature was used to strike contrast and affirmatives in the report writing.

### 3.9 Ethical Issues

The fundamental goal of any study is to protect the participant's rights, safety, and dignity, hence the Noguchi Memorial Institute of Medical Research's Institutional Review Board (IRB) was consulted for ethical approval. S Hospital in Osu was approached for permission with an introductory letter from the University of Ghana's School of Nursing, as well as a copy of the ethical approval and the research proposal. Some days before data collection, the goal, objectives, and possible advantages and dangers were described to participants in simple language as well as the language of choice, which was between Twi and English. This allowed them time to think about whether or not they wanted to take part. After everything had been described to them in the language they best understood, individuals who readily accepted to participate in the study were handed consent papers to sign or thumbprint. After the inclusion criteria were used to recruit individuals, this was the result. Answers were given to all questions bothering participants concerning the study. Participants were advised that their participation in the trial was entirely voluntary, and they were allowed to withdraw at any point during the study with no consequences to themselves, their treatment regimen, or the health employee's behavior toward them. They were guaranteed anonymity and confidentiality of the information provided. They were labeled P1-P15 based on when they were recruited.

### 3.10 Rigour / Trustworthiness

The extent to which the researcher strives for excellence with adherence to ethics, detail, and accuracy is termed Rigour or Trustworthiness. Credibility, dependability, confirmability, transferability, and authenticity are the major criteria for establishing trustworthiness in qualitative research (Guba & Lincoln, 1981, 1989) and this was employed in this study. According to Mayan (2001), rigor can be established by the following; prolonged engagement, participant or member checks, journal writing, peer review, and audit trail. According to Parahoo (2006), even though rigor can be difficult to determine in qualitative research, researchers want their findings to reflect the truthfulness of the phenomenon they are studying which contributes to knowledge that others benefit from. The researcher used the framework by Guba and Lincoln (1985) to ensure the trustworthiness of this study.

**Credibility**: Credibility focuses on the truth and value relating to the findings of the study and the representation of these (Topping, 2006). The researcher with the use of semi-structured interviewing techniques, audio recordings of the interviews, and verbatim quotes ensured increased accuracy of the descriptions of participants"' perspectives''(Streubert & Carpenter, 2007). Credibility was achieved with the realness of the data in the study and this was ensured by prolonged engagement with the family caregivers in the research setting. Purposeful recruitment of family caregivers of ESRD patients who met the inclusion criteria, establishing rapport through the demographic data, and developing a relationship with the caregivers improved credibility.

**Dependability**: This is concerned with the stability of data over time. This means that the study findings can be replicated with similar participants in a similar context by other researchers. The researcher used an audit trail to ascertain the dependability of the study. This involved tracking and recording decisions that may influence the study so that data examination can be done by an external individual (Streubert & Carpenter, 2007). All recordings made in the study along with all other information put were under lock and key.

**Confirmability:** It refers to the data that represents the information submitted by the participants. The research had no biases or subjectivity; the findings were representative of the participant's voice (Polit & Beck, 2010). After transcription and analysis, participants were given the opportunity to clarify information and affirm ownership of replies. Following the transcription, four participants were interviewed again in their different places of comfort to clarify and validate claims made during the interview.

**Transferability:** Involves the extent to which the findings of a qualitative study can be useful to similar groups or situations (Parahoo, 2006). At all times during this study, attention was strictly paid to detail, and adherence to procedures while ensuring accuracy and consistency during the research process. The researcher ensured detailed descriptions of the research design used, research methodology, and hence study findings to enable other researchers to transfer the conclusions of the study to fit into a similar context. Accurate records of all interactions with participants were kept to achieve transferability.

# CHAPTER FOUR

# FINDINGS

## 4.0 Introduction

This chapter presents the findings of data generated from the participants who met the inclusion criteria of this study. With the guidance of the 2016 Caregiver Health Model (CGHM) by Florence M.Weierbach and Cao Y, sub-themes were grouped under the major themes after data analysis using the thematic analysis. The 4 major themes that developed were; Caregiver needs experiences, Task Performance experiences, Belief and attitudinal experiences, Health promotion experiences, and an emerging theme which was Alternate care experiences. Detailed accounts of the background of participants were captured along with incognito verbatim quotations.

## 4.1 Background of Participants

The study population comprised fifteen (15) participants of which nine (9) were females. The ages of the participants ranged from 27- 58 years.

In terms of ethnicity, nine (9) out of the number were Akans of various tribal inclinations such as Asante, Akuapim, Fantes, and Kwahu. Two (2) were Ewes and 4 were Ga/ Adanbge. Almost all the participants could speak more than one language. Six (6)could speak at least one other Ghanaian language in addition to English and twi which was the language used for all the interviews depending on the participant's strength and preference.4 participants could speak three Ghanaian languages in addition to twi and English while the remaining 5 spoke only one Ghanaian language and English.

Education-wise, all of the participants had obtained some form of formal education. 7 participants were form-4 graduates, 6 were university graduates, while 2 were attended but were unable to graduate from secondary school. Also, 9 out of 15 participants were unemployed and were solely taking care of their sick relatives. 5 were gainfully employed while 1 worked on a contract basis. Eight of the participants were married, 2 were widowed, 2 were single and 2 were divorced and 1 was separated. 5 participants had grown-up children, 8 had children ranging between the ages of 4years and 17years while 2 had no children at all. This can be seen in the table below:

:

**Table 4.1: Description of Study Population**

| PSEUDO NAME | AGE | SEX | ETHNICITY | LANGUAGE SPOKEN | EDUCATIONAL BACKGROUND | MARITAL STATUS | RELIGION | OCCUPATION |
|---|---|---|---|---|---|---|---|---|
| 1.CICI | 52 | F | GA | 5 | FORM 4 GRAD | WD | CH | UE |
| 2. FII | 31 | M | AKAN | 2 | DEGREE GRAD | MD | CH | EMPLOYED |
| 3.NEENE | 51 | F | EWE | 5 | FORM 4 GRAD | D | CH | UE |
| 4. MIMI | 50 | F | AKAN | 4 | FROM 4 GRAD | D | CH | EMPLOYED |
| 5.MONA | 35 | F | AKAN | 4 | DEGREE GRAD | SP | CH | UE |
| 6.ARIANA | 48 | F | AKAN | 2 | FORM 4 GRAD | D | CH | UE |
| 7. NIMO | 40 | M | ADANGBE | 2 | SECONDARY GRAD | MD | CH | SE |
| 8.EMMA | 52 | M | AKAN | 5 | FORM 4 GRAD | MD | CH | UE |
| 9.BOI | 48 | M | GA | 5 | FORM 4 GRAD | MD | CH | UE |
| 10.FAFA | 33 | F | EWE | 4 | DEGREE GRAD | MD | CH | SE |
| 11.SIMI | 39 | F | AKAN | 2 | DEGREE GRAD | WD | CH | UE |
| 12.KEMI | 37 | F | AKAN | 5 | DEGREE GRAD | S | CH | UE |
| 13.MODA | 54 | F | AKAN | 2 | FORM 4 GRAD | MD | CH | UE |
| 14.RALF | 41 | M | GA | 5 | DEGREE GRAD | MD | CH | MARKETING OFFICER |
| 15.TIMI | 32 | M | AKAN | 4 | SECONDARY GRAD | MD | CH | UE |

**KEY**

| | | |
|---|---|---|
| **WD – Widowed,** | **SP - Separated,** | **D - Divorced** |
| **S - Single,** | **MD- Married** | **CH -Christian** |
| **SE –Self-employed** | **UE - Unemployed** | |

## 4.2 Organisation of Themes and Subthemes

Following the data analysis, the concepts that emerged were classified into themes and sub-themes to reflect the experiences of caregivers of persons with ESRD. Employing thematic analysis, four major themes and fifteen sub-themes emerged in conformity with the research objectives for this study.

The analysis revealed themes that described their experience of giving care to relatives as Caregiver needs experiences, Task Performance experiences, Belief and attitudinal experiences, Health promotion experiences, and an emerging theme which was Alternate care experiences. The main themes and sub-themes can be found in the table below (Table 4.2):

**Table 4.2: Themes and Sub-Themes**

| THEMES | SUBTHEMES |
|---|---|
| **Experiences with Caregivers Needs** | - Physical Support<br>- Financial Support<br>- Disconnection from others<br>• Social isolation<br>• "Don't respect my views"<br>• Invasion of Privacy |
| **Task Performance Experience** | - Inability to perform certain tasks<br>- Anxiety in performing Tasks |
| **Beliefs and Attitudes** | - Sense of hope<br>- Positive mentality<br>- Acceptance<br>- Spirituality |
| **Health Promotion** | - Providing care at the detriment of self-health<br>- Increase awareness in health and wellness<br>- Financial constraints preventing caregivers access to quality care |
| **ALTERNATIVE CARE (EMERGING THEME)** | - Herbal Care<br>- Homeopathic Care<br>- Diet Therapy |

## 4.3 Experiences with Caregiver Needs

Participants described their care experience from a day-to-day perspective. All participants narrated their daily activities and the challenges they faced but still had to make sure they are giving the best of care to their relatives. They all talked about helping their sick relatives with simple activities like walking, bathing and maintaining their hygiene. The majority of the participants also talked about rendering care alone with very little to no help from other relatives. It was obvious that some were much more dependent than others. The needs of family caregivers birthed 3 sub-themes, which were an unending physical burden, financial burden and support and disconnection from others which further birthed three sub-sub themes namely social isolation, "don't respect my views" and inversion of privacy.

### 4.3.1 Physical Support

Participants described the intense physical burden they experience in rendering care to their relatives with ESRD. They opined that, caring for relatives can be tiresome and unending. This has made participants to call for support. Some explained that an extra helping hand would go a long way to help reduce the tiredness they felt from lifting, feeding and helping the patient with their daily activities. They recounted:

> *"It's not easy taking care of her alone. if you look at my size and her size you can see she's far heavier than me. At least if there's even one person to help me from time to time, it will be better" (**Cici**)*

> *"Even though am taking it one step at a time, my sister, taking care of her is not as simple as it sounds. sometimes you are soo tired but because there's no one to help you have to get up and do what needs to be done" (**Nene**)*

### 4.3.2 Obligation to Care for Relatives with ESRD

Most participants feel providing care to close relatives with ESRD is a responsibility that one has to perform for a family member in need. According to them, society expects you to reciprocate care to persons who took care of you when you needed it. The participant felt it was their duty to take on the care role hence any physical discomfort such as tiredness and fatigue was not an excuse to neglect those responsibilities. They felt happy knowing they can fully take care of their patient without anybody's help. Some expressed this as follows:

> "*She's my big sister and she is sick, so whether am tired or not I still have to help her when she needs something" (**Moda**)*

> *"As for my mother, no matter how tired I am even if I have crawl on the floor, I prefer to take care of her because I owe it to her and no one will take care of her like me. i don't even want them to." (**Fii**)*

According to the participants, even when they feel strained and stressed in taking care of their sick relatives, they didn't want to be seen complaining. Below is how it was expressed:

> "*Even when am tired, I don't want her to see it because I don't want it to look like am complaining or don't want to help. So I will just keep quiet and do what I have to do" (**TIMI**)*

> *"This one I call it suffer in silence, because you don't want him to know you are tired. He will feel bad. If there's someone to help fine but there's no one else around to help so ……" (**BOI**)*

Despite how tiring caregiving for relatives with ESRD can be, participants thinks providing care to love ones is an obligation that must be rendered to relatives in need. This highlights caregivers sense of obligation to be there for love ones in terms of need.

### 4.3.2 Financial Support

All the participants asserted that caring for relatives with ESRD is financially demanding. Cost related to dialysis was a burden family caregivers were saddled with. They considered financial support be an important intervention. They had this to say:

> "*My main concern is paying for the dialysis. She usually has 3 sessions every week and it's not cheap. The money I pay every week is almost half my salary as a seamstress. It's a headache for me because I now have to ask family members for help which I don't want to do" (**MIMI**)*

> "*We were given a payment plan by the dialysis unit. Even with that we still have arrears to pay. All my brothers help with the payment from time to time but still it's not easy. I cannot even save money for anything. All my money goes into paying dialysis and other medication.*"(**RALF**)

Some participants lamented on how they sometimes default their dialysis sessions due to lack of funds. Two participants recount:

> "*One time for almost two weeks, we couldn't go for the dialysis. Things got really bad and we came on admission. The cost of dialysis is too much to bear. It is one of my main worries. There's no help coming in too so it's just overwhelming sometimes" (***NEENE***)*

> ***"****Everything is about money, dialysis, medication, the diet…….everything. If you don't make sure these things are available then the condition gets worse. Always thinking of ways to make money to support. Money doesn't come easy ooo!"(***MODA***)*

This highlights the financial burden that relatives experience in caring for persons with end-stage renal disease. It further highlights the need for financial support to assist caregivers meet their financial obligations.

### 4.3.3 Disconnection from Others

Societal support used to be an integral part of care however participant explained that was not the case anymore. According to the participants, they feel isolated from society and explained that societal expectations and interference rather increased their burden instead of lessening it. Three subthemes that emerged were social isolation, "don't respect my views" and inversion of privacy.

#### *4.3.3.1 Social Isolation*

Participants recounted how demanding caregiving to their relatives had imposed restrictions on their social life. According to them, caregiving has separated them from activities that make life meaningful. This has negatively affected their interpersonal relationship with others due to their caregiving role. Some of them had this to say:

> "*I haven't attended any function for the past 2 years. Am always at home because I don't want to be too far away from her" (***MONA***)*

> *"I can say I haven't gone for any program in a very long time. I have gotten used to staying at home with him most of the time. I even feel funny when I have to step out of the house" (***EME***)*

Another participant said:

> *"If we are not in the hospital we are at home. I was calculating last time and I realized, wow! It is been a long time since I went out" (**ARIANA**)*

Participants think the vulnerability of persons with ESRD makes it difficult to attend social functions. This is how a participant recounted it:

> *"I don't usually attend functions unless it is a walking distance. If there's an emergency I have to be around. So really, I don't even remember when I last went to a program." (**FAFA**)*

Despite caregiving being intense and burdensome, some family members think your absence in social functions is intentional. They frown or complain on seeing you. According to them, even when they attend the social function and decide to leave early, they are met with unreceptive responses. They recounted as follows:

> "*Sometimes when there is a wedding or naming ceremony and you can't attend, the family members think you just don't want attend. But that is not the case. I also wish I could step out and meet people but I can't" (**MODA**)*
>
> "*You know how people think sometimes, they want you to come and help with cooking and others for programs so when you go late "wahala"! Instead of wasting my time to come so you complain I'd rather not come at all. I will stay home with my mother and take care of her" (**SIMI**)*
>
> *"I don't go to programs anymore. All people do complain about the other functions you missed forgetting you have responsibilities.*"(**RALPH**)

From the narration, participants felt isolated and less understood due to the intense and time-consuming nature of caregiving of persons living with ESRD.

#### *4.3.3.2 "Don't respect my views"*

Participants expressed disappointment in the way their extended family treat their views. They felt some family members disregarded their views or decisions due to the financial assistance that they provide. They expressed:

> "*Family members sometimes refuse to help because they know you are in need and want you to take what they say. When you refuse certain decisions then you are on*

> *your own. I feel they don't respect my decisions because they help with the bills sometimes so as much as I can I don't ask for help."*(**NENE**)

> *"Our family head once told me if I want to make my own decisions then I shouldn't call them for help. All because I refused the herbal treatment they were suggesting for my dad"* (**TIMI**)

Participant also talked about being treated poorly by family because of financial assistance.

> *"Familiarity they say breeds contempt. When you ask people for help especially when it is financial they start acting funny toward you. Sometimes they don't even pick your calls because they think you will ask for money. They want to talk to you anyhow because they are your helpers. I just pray to God to help me endure"* (**KEMI**)

Some participant also felt people from their social circles didn't respect them because they were unemployed. They felt betrayed because they wish people will give them recognition for the efforts they put into their role of caring for their love ones.

> *"I agreed to stay at home with my aunty because she asked me to. Nobody was willing to stay and take care of her. But sometimes my cousins act like they are rather doing me a favor. Taking care of her is hard but I do it because she my aunt and I care about her. I wish people will see what I go through to take care of her. It's not about money ooo, they should just recognize my efforts!"*(**CICI**)

> *"People come to visit my uncle and they want to treat me like a house boy. When they needed someone to take care of him they all claimed they were busy. One other uncle once told me it is because of property that's why am taking care of my uncle and it really hurts me sometimes because I have never taken anything from my uncle all these two years I have been taking care of him. I work from home and my uncle specifically begged me to stay with him no matter what. I wish my family members will understand that it's not easy carrying him, sleeping in hospital chairs while on admission and all that .if it's easy why are they not doing it. They don't even appreciate your efforts"* (**RALF**)

#### *4.3.3.3 Invasion of Privacy*

Participant expressed an undying wish for privacy. Participants recounted unpleasant occasions where family members and neighbors interfered in decision-making even when it was not welcome. Some had this to say:

> “*Just because I asked for some help sometimes, people feel like they can interfere. Some family members even want to decide which hospital to attend. These are some of the reasons why I avoid getting help from them” **(BOI)***
>
> *“As much as I can I don’t encourage family members to get close to us. They ask too many questions. They even use visiting my father as an excuse to interrogate me trying to know my job status and even my salary. They don’t know where to draw the line. All this because of the little help they will give” **(FII)***
>
> *“Sometimes I don’t know who our friends are. Africans don’t understand what the concept of privacy is. Some things are private I wish my family and friends will understand that .It does not matter if they give support or not.”**(MONA)***

Participants also made the insinuation that some family members refused to lend any form of help because they were not allowed to interfere in decision-making and private issues. A participant explained:

> “*We haven’t gotten any help from our family members because I refused to give them lab results. They even wanted me to tell the doctor to request for AIDS test. When I refused they stopped calling and supporting. It’s ok though because we have peace of mind. We don’t need to explain ourselves to anyone.( **NEENE)***

### 4.4 Task Performance Experiences

Family caregivers threw some light on the a wide range of task they perform ranging from wound dressing, administration of medication, personal care, checking vital sign and continuous monitoring of sick relative. Four sub-themes came up which were Inadequate education, Lack of professional help, confidence and anxiety.

#### 4.4.1 Inability to perform certain tasks

According to participants, their apparent lack of knowledge on the condition and treatment has resulted in situation where they are unable to perform certain tasks for their sick relatives. They claimed of receiving no or inadequate education from health professionals on the management of their sick relatives. They emphasized on how they wished doctors and nurses will be much more willing and prompt in teaching them some tasks. Some recounted as follows:

> *"Apart from teaching us how to give my sister medication they don't say anything else"* **(SIMI)**
>
> *"They only taught us how to give the medications but I learnt from another patient's relative that there are ways to lift her and change the diaper so you don't get tired easily"* **(CICI)**
>
> *"I learnt literally everything on my own. How to monitor her vitals and even the some of the foods she can't eat, I learnt it on my own"* **(EME)**
>
> *"I think they should teach us petty petty things when we are discharged from the hospital, like how to turn them without hurting your back, because it's hard figuring everything out on your own."* **(TIMI)**

Though, the participants admitted having inadequate knowledge, they have no choice than to perform tasks on their sick relatives. They elaborated that because they haven't been formally trained they sometimes doubt themselves and their skills in performing the needed task. Some expressed that:

> *"I usually do things the best way I know how, I know am not doing it the best way but it's better than not doing it at all!!"* **(RALF)**
>
> *"The care I give I use "takashi", you understand! Am just trying to do my best"* **(FAFA)**

Some participants demonstrated a willingness to search for information on the internet to inform their care interventions. Below is how a participant expressed it:

> *"I usually watch videos on how to care for a sick person. How to turn them and things to look out for. I have learnt a lot from youtube too. So am able to some things with confidence because it works for me."* **(MIMI)**

The above narrations suggest that caregivers receive inadequate education on the disease process and skills necessary for caregiving thus, affecting the quality of care. It further demonstrates the need for health professionals to provide adequate education for relatives giving care to their sick relatives.

### 4.4.2 Anxiety in Performing Tasks

All participants admitted feeling anxious when performing tasks on their sick relatives. According to them, the tendency for patients with ESRD to easily get infection or condition getting worse makes them scared when performing a task such as personal hygiene needs that involved getting in contact with catheter site and medication administration. They expressed:

> *"Am always afraid when am bathing her, the nurse told me kidney patients easily get infection from the catheter so I have to be extra careful"* ***(CICI)***

> *"He had a serious infection on two occasions. We thought he was going to die so am always scared when he's at home because I try my best but he still gets sick sometimes"* ***(FII)***

Another one had this to say:

> *"I always pray to God so I don't make any mistake thats can worsen his sickness especially when am giving him his medication. Side effect can happen at any time you know"* ***(BOI)***

### 4.5 Beliefs and Attitude

Beliefs and attitudes is the driving force of every person. A person's belief influences their attitude towards situations as well as coping. The four subthemes identified in support of this theme were sense of hope, positive mentality, acceptance and spirituality.

#### 4.5.1 Sense of Hope

Most participants opined that interaction with other caregivers and patients convince them that once there's life there's hope. They maintained that hope kept them encouraged to continue rendering care to their sick relatives. According to them, stories from other patient who had been on dialysis for years and were still alive gave hope that things could get better. Below is how some expressed this:

> *"One time I met a lady who says she been on dialysis for 6 years. She looked fine so am sure my mother too will be ok"* ***(ARIANA)***

> "*Not everyone has the opportunity to even afford dialysis. So we are hopeful things can get better"* ***(SIMI)***

Furthermore, some participants were insistent that some situations were better than other and that it was important to be hopeful despite the odds.

> "*How can you be alive and say there's no hope? Even people who can are stuck in bed are saying they have hope how much more me .as for me I know anything can happen at any time so whether is for good or bad I will be hopeful until the end"* ***(CICI)***

Few expressed that they had no choice but to be hopeful. They further explained that they had no say in the end but being hopeful was what kept them strong. She opined:

> "*There's very little I can do my dear sister. All I can do is pray and be hopeful for things to get better."****(KEMI)***

### 4.5.2 Positive Mentality

Participants opined having a positive mindset is an attribute that enable them to continue their caregiving role to their love ones. They recounted numerous occasions when keeping a positive attitude kept them through their lowest point. They recounted that:

> *"On certain days, before I step out of bed, I just tell myself today will be a better day."* ***(MONA)***
>
> *"Why worry myself over things I have no control over. i do my best and tell myself there's light at the end of the tunnel"****(MIMI)***

Some participants established the shock expressed by others because of the lack of self-pity people expect them to portray. They explained how often people thought they should always be unhappy because of the situation in which they find themselves.

> "*Sometimes people look at me and wonder how I can be so cheerful when my only daughter is soo sick and on dialysis. They keep telling me am strong. I believe in taking life one day at a time"* ***(KEMI)***
>
> *"The days I decide to step out for a function, people won't stop reminding me that I have a sick husband at home who needs attention. I quickly tell them this is not the place for such discussions and move on with my day. i don't waste my time with their negativity"****(FAFA)***

Again, participants acknowledged that keeping a positive mentality allowed them to think differently about everything even when things are not going their way. Some had these to say:

> "*Anytime we ended up on admission due to complications. I just tell myself, at long last some expert care so I can rest a little even though it's quite stressful being on admission sometimes, (laughs) hahahah!"*(**NEENE**)

> *"One day I got home and found my husband very week, I took him to the hospital and it happened that he had an infection. As a tired as I was and even rest I was soo happy I decided to take him to the hospital otherwise the story I will be telling you now would have been different"* (**MONA**)

This seem to suggest the important role positive mentality helps caregivers to cope with the stress of taking care of their sick relatives.

### 4.5.3 Acceptance

All participants showed acceptance of their current reality and were ready to do their best to beat the odds if possible. Acceptance is the final stage of grieving. People go through denial, anger, bargaining, depression and then finally acceptance. Grieving persons go through this these stages in an attempt to process change and protect themselves while they adapt to a new reality. Below is how it was captured:

> *"I understand there's no cure for this disease. So I do what needs to be done and tell myself whatever happens is meant to be"* **(KEMI)**

> *"We were told there was no cure for kidney disease at this stage and that the best that can be done is management. Whatever happens at the end of the day I cannot control it. I just keep hoping things get better* (**BOI**)

Participant recounted the stress they went through before coming to terms with the disease. They narrated how they rejected the news and how they sought second opinions in hopes that the diagnosis was false.

> *"When we were first told, I flat out rejected the diagnosis and took my husband to Nyaho hospital for a second opinion. I just couldn't believe my healthy husband could have end stage kidney disease. Not even early oooo! End stage. Aaaaah! It was not easy for me then but now am ok!"*(**MONA**)

Some participant explained how long it took them to accept the truth and adjust their life style to be able to care for their relative. They recounted:

> *"My dear, as a mother it took me over a year to accept the reality."***(KEMI)**

> *"I struggled a lot to accept that my son at his age kidney disease, for over six months i denied it and didn't want him to continue with the dialysis. Every day I asked what I have done wrong to deserve this!! I accepted later to stay strong for my son"* **(NENE)**

> *" First when they told us we said no to dialysis even after seeking second opinion but about 4month down the line I realized am doing him more harm than good. I accepted my situation and let him go for the dialysis and am glad I did."***(MIMI)**

### 4.5.4 Spirituality

Participants claim divine empowerment from God enabled them to endure the burden associated with caring for their sick relatives. According to them, God is their source of strength. Spirituality is an individualized sense of connection to something bigger than one's self. This may help a person interpret the actual meaning of life and a person's worth and place in this life. Below is how some narrated this:

> *"Without God I don't think I'll have the strength to endure these problems i am facing."***(MONA)**

> *"Through it all,I give thanks to God almighty for giving me the strength to face my problems squarely. He is the reason why my husband is still here."***(ARIANA)**

The reference strengths however were not limited to the physical but to emotional and mental strength.

> *"Due to God's mercies even the way I think is different now. At first things used to worry me quickly but now am able to tell myself take it easy and I become ok"* **(MODA)**

Participants also mentioned prayer as a point of contact with their God. They were impressed how much praying has drawn them closer to God and given them needed results.

> *"All I have to do is bow my head and pray to God and I know he will answer. If you believe great things happen."***(CICI)**

> *"Like I said before, I pray to God for calmness. Whenever I pray things get better no matter how i am feeling."*

A participant insinuated they believed God only heard them through prayer and that without prayer things only got worse. She elaborated that she had no choice but pray because God won't help her deal with her problems if she didn't pray. According to her these problems embodied her caregiving role which was the main concern presently. She said:

> *"I pray a lot to God because I know if I don't pray bad things will happen. At least if I pray I know am doing my best so God can do the rest."(***EMMA***)*

Some participants also narrated some spiritual encounters that encouraged them to keep believing they are loved by God. They narrated:

> "*One time my husband collapsed and needed emergency dialysis as soon as possible but we couldn't get a slot. We were supposed to wait for 4 hours to see if we can get one. I prayed to God for favor and within 30minutes we got a slot because one of the patients ended up doing 1hour. That is how much God loves me .I know this for sure.*"(**FAFA**)

> *"My mother was on admission in a very bad condition. Even the doctors were trying to psyche us for the worst case scenario. But prayed that night and told God to help me because I don't know what I will do without my mother. Within a week, we were discharged home. So I know that there is power in prayer and God has done a lot for me and my family and for that am grateful." (***KEMI***)*

Some participants also expressed their disappointment in their current situation because they felt God had abandoned them despite everything they had done to make God 'happy'

> *"Sometimes I ask myself why? What at all has my family done to deserve this? I go church, I pay my tithe and am always ready to help others so why will God allow this to happen to us. But in all things I still give thanks to God. Ones there is life there is hope. That all I can say"(***TIMI***)*

> "*Sometimes I feel God does not hear me cries other times I think he hears me but in all things I hold steadfast because true Christians go through trials and I hope I will overcome mine*"(**CICI**)

The above accounts emphasize the significant role faith plays in caregivers' motive and motivation to begin, and to then continue, in the caregiving role.

## 4.6 Health Promotion

This is access to information that assists individuals to make informed choices and have control of their health. Three subthemes that emerged were lack of education, Health awareness and financial restraints.

### 4.6.1 Providing care at the detriment of self-health

Participants expressed that the provision of care to their sick relatives is done at the detriment of their health and comfort. According to them, the intense nature of the caregiving role often makes them to ignore their own health challenges. They expressed this as follows:

> *"So one time, I casually asked the doctor after he took care of mama that oh I have stiffness in my neck very often what could be the cause? All he said was let us concentrate on the patient for the meantime!" (**NEENE**)*
>
> *"When we go on admission, because there's no place to rest, I usually have a lot of body pains and swelling of my feet. So I one time asked why my feet go numb. All the nurses said were you are just tired! No advise, nothing" (**ARIANA**)*

Some claimed they were unable to make time for their personal check up because of their caregiving role.

> *"I used to go for checkup but after sometime I stopped because there is no one to stay with her when am not around and she might need something."(**MONA**)*
>
> *"Oh as for me I haven't been to the hospital for checkup for two years now .i buy my BP medication from the pharmacy because I don't have free time"(**MODA**)*

Some participants were also worried about the unwillingness of health professionals to take time in explaining things to them about their health.

> *"A doctor walked in one time when we were on admission and told me to go home and let someone else come. When I asked why he just said, why you also want to get sick. It made me very upset. Instead of him explaining to me why I should go he is telling me I will get sick" (**SIMI**)*

Participants also expressed displeasure when health professional gave the impression that certain things are difficult to understand.

> *"I complained to a doctor about my headache and asked for a possible cause of the recurrent headache. He just said it happens and that I should get some paracetamol. i asked for better explanation and he told me the explanation is difficult so later. Ahhh!* (**BOI**)

A participant revealed that he preferred to buy over the counter drugs because they wish to avoid being 'snubbed' at the hospital when they asked questions.

> *"I don't know why I should pay consultation fee when all they do is buy this, pay this! They will not even explain your labs to you when you ask"*(**NENE**)

This implies that the total involvement of family caregivers in caregiving contribute in making them ignore their health. Also, health professionals fail to provide adequate education to influence a positive health behavior for caregivers.

### 4.6.2 Increase awareness in health and wellness

Some of the participants opined that the sudden occurrence of the caregiver role had greatly enlightened them. They explained that their caregiver role had rather encouraged them to take their health seriously because they didn't want to fall sick too. Below is how expressed it:

> *"Ever since my husband got sick, I really pay attention to my health because i now understand that health is our greatest treasure. At first I wasn't taking my health serious."*(**FAFA**)

> *"Before I used buy medicine for body pain and others from the pharmacy. But since my sister got sick I have just stopped. I try to go to the hospital for better care."*(**KEMI**)

> *"My dear, I now pay attention to health issues. I listen to the health programs on TV . I also constantly read a lot about health and diet especially and I must say I wish I had started earlier."*(**MIMI**)

Again, other comments also indicated caregiver roles had helped in making drastic health changes that had improved health and stamina.

> *"I had to change my diet because of my husband so he doesn't feel left out when am eating something that looks tasty and he has to eat something dry. But it is the best decision I have ever made because changing my diet has greatly improved health."(**FAFA**)*

> *"I have stopped taking so many things because I realized they are not good for me. I drink more water and take more vegetables and fruits. My own blood pressures are way better than they used be even my doctor mentions its stable now when I go for checkup."(**RALF**)*

Furthermore, a participant explained that she used the least opportunity she gets to also educate others on the importance of eating healthy and frequent checkup so others can also benefit from it.

> *"I have benefited from enlightening myself on good health and living. So any time I get the opportunity I try to educate others too. Especially when am waiting for my husband to finish dialysis I just talk to some of the other relatives and they appreciate it."(**MONA**)*

Participants seem to have become aware of the need to engage in healthy lifestyle to prevent disease and complications. They gave recognition to health awareness as an added important part of their live which has helped them immensely.

### 4.6.3 Financial constraints preventing caregivers access to quality care

One of the subthemes that resonated across all participants and posed a great challenge was financial restraints. Participants linked their inability to patronize good quality healthcare to financial restraints. Some participants wished to access health care as much as they could but were unable to due to scarcity of resource.

> *"Its not that I don't want to go for checkup. I wish I could but going to the hospital is all about money now. After dialysis for my mother and other things you don't even have money to do much"(**KEMI**)*

> *"Because theres so much to cater for sometimes I forgo my checkup. The actual problem is sometimes by the time I don't feel well there's no money so you just get some paracetamol from the pharmacy. When its serious then I can go to the hospital."(**NEENE**)*

Other participant also explained how they preferred to keep money until they fell sick before going to the hospital to prevent wastage.

> *"I usually want to keep the little money I save for a rainy day. What if I spend everything on my checkup and then later my mother needs to buy some medication.so I'd rather keep the money until I fall ill then I will go."(**MIMI666**)*

## 4.7 Alternate Care Experinces (Emerging Theme)

Through vigorous questioning and probing alternate care experiences emerged. It had subthemes as herbal care, homeopathic treatment and diet therapy.

### 4.7.1 Herbal Care

Participants discussed their experiences with alternate care mentioning the bad choices they had made with some herbal treatments and others. According to them, their choice to use herbal medication made the condition of their sick relatives to worsen. They narrated:

> "*We were encouraged by some family and friends to try herbal medication. It worsened our case because at first we didn't need dialysis but after the herbal medication the condition became worse. It has really pained me because it didn't have to get to this. I really regret that decision*"(**BOI**)

Some participants mentioned the hostility they faced from family members when they refused to resort to alternative medicine for their patients.

> *"I had to fight tooth and nail to prevent my husband's family from taking him to a herbalist. I stood my grounds and refused. Up to now they don't talk to me but am happy I didn't let them have their way because my husband is doing better and they can see it for themselves. They still don't talk to me buts ok! Herbal medication is a big no no for me" (**CICI**)*
>
> *"One I went out briefly to get something came back and my brothers had carried my mother away to see a herbalist. I found out where they went and brought her back. It is been almost 1 year now they don't even call to check on my mother or send any support. They just left all the burden for me to carry but I know I will be fine."(**ARIANA**)*

### 4.7.2 Homeopathic Care

Participants further narrated the negative effect of adopting homeopathic medicine. They claim the use of this alternative almost made them loose their love ones or worsen the state of their condition. They had this to say:

> *"We went in to try homeopathic medicine. We spent soo much money without any results. The condition got worse and the frequency of dialysis had to increase. After this incidence I just decided to stick to what works for us."(**MIMI**)*
>
> *"Right from the beginning when my cousins suggested homeopathic medicine. I said no but later I said it won't hurt to try. We almost lost my dad prematurely because of herbal medication. I shouldn't have allowed them to give him those medications" (**TIMI**)*

Some participants also claim homeopathic treatment was a total waste of time and money on their account. Two of them had this to say:

> "*We wasted so much money on homeopathic treatments to no avail. We decided to come for the dialysis as suggested. After two session of dialysis my father could speak and sit up on his own. For lack of knowledge my dear!"(**EME**)*
>
> *"Homeopathic care is so expensive but we thought it was a better option until things got out of hand and they themselves told us to go for dialysis. I think they just wasted our time. i will never advise anyone to seek that treatment. They just wasted our time or should I say we just wasted our own time" (**MONA**)*

This seems to suggest that caregivers do not believe the use of herbal or homeopathic medicine were good alternative to the treatment of ESRD.

### 4.7.3 Diet Therapy

Majority of participant recounted the positive effects dietary changes contributed to improving the condition of their sick relatives thus reducing the intensity of their care giving roles. They recounted:

> "*At first my husband was so weak. We had to carry him out of bed, bath him and all that. We were introduced to a type of diet by another dialysis patient who no longer needs dialysis. We started the diet which was mostly raw fruits and vegetables. My husband has improved considerably. He can now drive and go to work and hospital. His dialysis session has even reduced to twice a week. Even the kidney doctor was very impressed with his improvement. No swelling of the feet."(**FAFA**)*

> *"I did a lot of research when my sister got sick. i found out that her diet could be useful in healing her so I changed her diet to salads, fruits with little carbohydrates. She has gotten way better than when we started. She usually couldn't walk around but now she can walk to the wash room and do small small things. I don't need to do as much for her as before"* (***MIMI***)

The narration highlights the important role dietary modification plays in the management of patients with end-stage renal disease.

### 4.8 Chapter Summary

The above findings are based on data generated from accounts given by participants who give the care to end-stage kidney patients. The findings conveyed the perspectives of the family caregivers, the many challenges they encountered in caregiving, and how expansively these challenges can be resolved to find solutions to diminish the negative effects of caregiving. The outcomes of this study will contribute to current information and address some of the gaps in family caregivers' everyday experiences. The Caregiver Health Model served as the theoretical foundation for this research. Needs, tasks, beliefs and attitudes, and health promotion within the patient's surroundings are the constructs that make up the framework. All the major themes that emerged from the narratives were fully supported by the conceptual framework. All themes and subthemes fell within the conceptual framework except for the subthemes health neglect which collapsed because it didn't have enough data to support it. An emerging theme alternate care was added during the study because it frequently came up during narration from participants.

# CHAPTER FIVE

# DISCUSSION OF FINDINGS

## 5.1 Introduction

The findings of the investigation on available literature are discussed in this chapter. The study's major goal was to learn more about and characterize the experiences of family caregivers in Accra who were caring for patients with end-stage renal illness. The goal of this study was to learn more about the experiences of family carers of ESRD patients. The conceptual framework served as a guide. Five key topics emerged from a thematic analysis. These included needs and experiences, beliefs and attitudes, health promotion experiences, task performance experiences, and a developing topic, alternative care experiences. Family caregiving has been a hallmark in providing quality health services to patients with various diseases. Despite this fact, the sector has not seen the needed attention and the policy windows that have been available over the years. In recent times, emphasis has been placed on family-centered healthcare. This has drawn attention to the important role the family caregiver plays in health care delivery in all countries (Kekrebesi, 2021). The goal of health care management for ESRD patients is to generally give supportive, symptomatic, and preventive measures while alleviating pains and discomfort. This is to help allow patients to live meaningful lives. ESRD management is also aimed at reducing complications to extending the life of the individual through multidimensional approaches. This management regime is mostly taken up by family caregivers both during institutionalized care and home care.

## 5.2 Experiences with Caregivers' Needs

In this study, caregiving for patients with ESRD could be intense and burdensome, thus resulting in unending physical burden and stress. The study revealed that assisting patients with daily activities such as lifting patients, bed baths and other hygiene needs, feeding, changing position in bed periodically, and sometimes even monitoring patients' condition to give feedback to nurses when the condition of their patient changed often result in physical stress. Consistent with this study, other studies found that caring for sick patients can exert immense stress on relatives (Khosravan, et al., 2014; Faronbi et al., 2019). This implies that caregivers may develop physical or psychological consequences of particularly intense caregiving roles. There is therefore the need to support caregivers in the performance of their roles.

Furthermore, the continuous care provision disconnected caregivers from engaging in social activities resulting in social isolation. This may result in negative psychological consequences. Similarly, other studies observed that the caregiving role often disconnects relatives from social interactions and the achievement of life goals (Hudson & Aranda, 2013; Zhang, 2019). There is therefore the need for the provision of adequate social support services to ensure continuous caregiving without compromising the caregiver's health and wellbeing.

Apart from that, further findings from the study showed that family caregivers of ESRD patients regarded financial support as an important need. Even though participants mention other needs, financial support was deemed as a major need due to the high cost of dialysis and medication. They argued that getting financial support reduced their overall burden by half. This finding support earlier studies that report that financial support was an important intervention to help reduce the burden associated with caring for persons with ESRD (Avşar et al., 2015; Adjei, Stronks, & Adu, et al., 2018). This seems to breed situations where caregivers lose their autonomy with regards to decision making resulting in interference, invasion of privacy, and lack of social respect.

The study further revealed that participants feel obliged to provide care to family members in need despite how burdensome providing such could be. All participants showed no regrets in taking up their caregiving role which they categorized as a duty they felt fulfillment in reciprocating. This is in line with studies conducted in Nigeria and Ghana, where relatives feel it was a moral obligation to care for their sick relatives (Kusi et al., 2020; Oyegbile & Brysiewiez, 2017; Vincent-Onabajo, Ali, & Hamzat, 2013). This highlights the integral role family caregivers play in beginning and continuing care for persons with ESRD. There is therefore the need to recognize and empower them to give adequate care to their sick relatives.

## 5.3 Task Performance Experience

Participants reported that they were not having adequate knowledge of the disease process and the basic skills to perform certain roles. Caregiving involves a lot of tasks that need to be performed with some level of skill. However, family caregivers find themselves performing these duties without any prior knowledge and technical know-how thus expressing general concern about a lack of competency in task performance. Areas with the most concerns were medication administration and emergencies. Similarly, Faronbi et al (2019), established in a study that the daily task of family caregivers involved assessing the medical needs of the dependent person, assisting with basic needs, providing companionship, housekeeping, preparing meals, assisting with the transfer, and mobility, and transportation. In some instances, it was noted that wound dressing was part of their task. This also resonates with a study by Avsar et al (2015), which identified caregivers helping their patients at home with many activities of daily life, including transportation to dialysis centers, symptom management, mobility, dressing, and preparing an appropriate renal diet to be some of the tasks performed. This indicates the magnitude of family caregiver importance in nursing care thus the need to enhance their capability to manage the caregiving tasks.

Participants were displeased with the education given in the hospital concerning patient care. According to the participants, the dilemma they face anytime there was an emergency was largely symptom management like rigor and hypoglycemia which is quite common in ESRD patients. Symptom management was observed as an important and most feared task performed by the family caregiver. Family caregivers acknowledged the importance of performing a task well and how important it was to prolong the life of their patient. This finding seems to support earlier studies in time past (Holder 1997) which indicated that family caregivers craved for better understanding of their caregiving duties through education from the formal healthcare team. Participants in the study indicated their lack of confidence in their competency was a result of scanty knowledge concerning their care role. The majority of participants acknowledged that some form of intentional education for emergencies would pave way for them to render quality and wholesome care to their patients and improve their confidence in task performance. Participants' education on what was expected of them would prepare them for the inevitable. This finding agrees with a study conducted by Ercole et al (2020).

Also, in this study, the data indicated that caregivers experienced some levels of anxiety due to task performance. Participants divulged that due to low confidence and inadequate knowledge in their caregiving role they tend to become anxious in performing certain caregiving tasks. Some of the tasks that caused anxiety included wound dressing, medicine administration, and emergencies like sudden collapse and respiratory distress. These findings were consistent with research by Moss et al., (2019). These scholars observed that caregiver anxiety may not be apparent but could exist at high levels. Their research findings concluded that rendering professional help by providing caregivers with education and resources was a sure way to allay the anxiety of caregivers. It appears through training, caregivers' confidence and competence could be boosted when performing their duties. Professional help employing education and effective communication could be an effective tool in improving caregiver confidence and alleviating anxiety which has a direct effect on caregiver competence and positive task performance outcomes.

### 5.4 Beliefs and Attitudes

Beliefs are assumptions or opinions that a person embraces and regards as true about any concept or person based on their past experiences. Beliefs may be regarded as signals that give purpose, meaning, and direction to our existence or lives. A belief usually shapes a person's attitude in the way a person feels or reacts to an occurrence or a matter at hand. A lot of times, attitudes and beliefs may form personal barriers that may cause a negative or positive reaction to caregiving. In this study, some attitudinal changes were noted. The data show that there existed positive reactions towards caregiving roles. According to the participants, they discovered that keeping a positive mentality and maintaining a sense of hope helped them immensely and was a motivator in improving their caregiving role. Finding from this study showed that family caregivers kept an open mind concerning their roles as caregivers and dealt with issues as they progressed through self-assurance. Most participants in this study endorsed the concept of unhappiness as draining and depressing hence they chose to be optimistic which helped them give out their best in caring for their patients. This finding is in sync with the findings of a study conducted by Nicola Hermanto & David C. Zuroff (2016). Also, another study found that self-reassurance promoted self-compassion which is associated with positive psychological functioning. This among other things includes greater purpose in life, low perceived stress, and high life satisfaction (Neely, Schallert, Mohammed, Roberts, & Chen, 2009). The foregoing findings are consistent with the findings of this study.

Several studies have come out with important findings on spirituality as an important aspect of caregiving and this current study was no exception. The spiritual aspect of caregiving is a pillar if caregiving is looked at more holistically and comprehensively with the widely accepted view that man is made up of mind, body, and spirit (Dedeli & Kaptan, 2013; Holt & McClure, 2006; Taylor et al., 2013). All participants sought God's counsel for direction and enlightenment in facing caregiver challenges. This belief in a higher power empowered them to find meaning in their existence on earth. Religious beliefs and practices were a core pillar in the lives of participants who believed that without the presence of God in their lives their current situation could have been worse. Participants explained that they were placed in their caregiving role for a purpose and described their caregiving role as satisfying and rewarding (Tarlow et al., 2004). Participants acknowledged that their positive attitude to caregiving was embedded in their spirituality and belief that God was with them always and this gave them peace of mind reduced their stress and improved their general well-being as well as that of their care recipients. This finding confirms a study on positive feelings of caregivers by Hodge and Fei Sun (2012).

## 5.5 Health Promotion

Health promotion involves improving and taking control of one's health. Health-promoting and self-care comprise the actions taken by individuals to improve their health, maintain good functioning, and increase well-being, in response to illness or simply to promote good health (UK NHS, 2019). Health promotion thrives and births positive outcomes when persons are equipped with a supportive environment and personal skills to aid in the achievement of optimum through building healthy public policies. Participants in this study were fully aware of what constituted living and being healthy. However, there were challenges in accessing healthcare. This ranges from dissatisfaction with the information provided by healthcare professionals to a lack of education from health facilities. Findings from this study revealed a presumed unwillingness on the part of healthcare providers in providing in-depth information concerning their health and that of their patients as well. This finding undergirds the findings of Bahrami, M. et al (2014).

Again, findings from this current study disclosed that caregivers despite their many challenges made time to have health checks because they understood their importance. Participants in this current study admitted that their interest in living healthier was rekindled by the current condition of their patients. According to their narration check-ups although not too frequent, dietary and lifestyle changes were their way of staying healthy. Contrary to these findings, studies report that caregivers do not give importance to their health which was not the case with this current study (Faronbi et al., 2019; Oyegbile & Brysiewiez, 2017; Vincent-Onabajo, Ali, & Hamzat, 2013). This seems to suggest that caregivers are increasingly becoming conscious of the need to maintain good health as the cost and dynamics of the ESRD change.

### 5.6 Alternate Care (Medicine) Experiences

Alternative Medicine (AM) is defined as a group of diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional medicine (Barnes 2007). This includes herbal, homeopathy, chiropractic, dietary supplements, and naturopathy among others. The resort to AM is largely influenced by social, cultural, economic, and traditional factors (Hussain et al 2013). In Ghana, AM are mostly referred to as traditional medicines introduced in 1992 by MOH. In the year 2000, a traditional medicine act (Act 575) was publicized to help control and regulate the practice of traditional medicine. A study by Agyei-Baffour et al (2017) investigated integrating herbal medicine into mainstream healthcare in Ghana. They observed that clients' acceptability, perceptions, and disclosure of use were somewhat higher. This finding was consistent with findings from this current study which had only one out of the 15 participants who did not resort to herbal care as a complementary remedy. Also, their study proved that herbal medicine users did not disclose the use of herbal medicine to their allopathic care providers, this also ties in with the findings of this study.

## 5.7 Chapter Summary

Family caregivers provide emotional support and comprehensive care to other family members who cannot function independently. The problems identified in this study were inextricably connected. ESRD causes kidney dysfunction which results in adverse health problems and outcomes causing ESRD patients to rely heavily on help from family caregivers. The unending burden associated with providing care for sick relatives could be intense and burdensome thus resulting in the development of physical or psychological consequences. Also, disconnection with self and social activities was identified, which, if overlooked, might negatively impact a family caregiver's quality of life and social interactions.

Family caregiving is a complex roles to play hence caregivers need specialized knowledge and skills relevant to their particular tasks. This as we have seen above boosts the confidence of caregivers when they realize they have the competence to discharge their duties. Caregiver preparedness is essential and can promote positive healthcare outcomes which are the ultimate aim of every healthcare facility as a social institution. However, the evidence adduced in this study shows that most family caregivers are not trained and hence lack the relevant skills, knowledge, and competence to discharge their duties. Also, family caregivers are often saddled with the responsibilities of professional nurses whereas the irony is that they were not trained, nor do they receive training on the jobs. This development caused anxiety and self-doubt in family caregivers. Thus, it is somewhat obvious that intentional education and training for family caregivers is a *sine qua non* that should the attention of all stakeholders and practitioners in the healthcare service. Also, financial constraints were a major problem for family caregivers. Lack of funds impeded the level of care provided to a patient concerning dialysis, special diet, and medications. This exacerbated the suffering and the burden brought to bear on family caregivers.

Furthermore, a gap in family caregivers' satisfaction was built mainly on knowledge deficit on account of inconsistency and misinformation from healthcare providers. Reluctance to divulge information on disease conditions, current treatment, and other matters of importance affected care outcomes negatively and prevented them from making informed choices. All in all, family caregivers exhibited a considerable amount of resilience in performing their caregiving roles. The subject of stress was regarded as a normal phenomenon with emphasis on professional help, education, financial support, acceptance, and dependence on God as major pillars of caregiving in this current study.

# CHAPTER SIX

# SUMMARY

This chapter embodies a complete summary of the entire study. It also describes and sheds light on implications for nursing practice, policy, and avenues of future research. Limitations of the study, recommendations, and finally the conclusion of this study will be captured.

## 6.1 Summary

The perspectives of family caregivers of patients with ESRD residing in the Accra Metropolis were investigated using a qualitative method and an exploratory-descriptive design. The renal clinic and dialysis department of The Trust Hospital in Osu were used to recruit participants. Participants who satisfied the inclusion criteria were contacted after receiving a thorough explanation of the study in the language they preferred. For this study, a total of fifteen (15) people were recruited. With the participants' permission, one-on-one audiotaped interviews were performed. The interviews were transcribed verbatim and analyzed using theme analysis in real time. The study was guided by The CareGiver Health Model by Florence M. Weierbach and Cao Y. 2016. Five themes emerged from the narratives of participants using thematic analysis with one of the themes being an emerging theme. These were, Needs experiences, Beliefs and attitude experiences, Health promotion experiences, Task performance experiences, and an emerging theme which was Alternate care experiences. In exploring the caregiver experiences of patients with ESRD, subthemes emerged which supported the major themes.

Most of the findings from this current study were consistent with other kinds of literature. Firstly, three subthemes and 3 sub-subtheme emerged to support the first major theme. These were physical support, Financial Support, Disconnection from others, and sub-sub themes of Social isolation, “Don’t respect my views”, Invasion of Privacy.

Participants identified needing physical support when it came to performing certain tasks specifically ones that involved a lot of physical strength which they end up having to do the alone plurality of the time because there's no one to help or assist. The study also showed one of the limiting needs of caregivers was financial support. Participants expressed concern about the cost of care associated with end-stage renal disease. According to participant's majority of their problems stemmed from financial burdens and inadequate financial support. The study found that although participants craved social support they were ready to live in isolation to preserve their privacy. Participants acknowledged that having people around to help financially and give emotional support was ideal but later realized all support they got from family and sometimes even friends came with conditions. The majority of participants also insisted family members who supported them financially tried to control their affairs and had no respect for them or their privacy which they concluded pushed them to isolate themselves from social functions and gatherings. They blamed these manipulations on a lack of financial independence due to costs associated with frequent check-ups, dialysis, and medications.

Secondly, the study confirmed the volume and extent of tasks performed by caregivers. Caregivers performed tasks ranging from highly skilled tasks like wound dressing to lower-skilled tasks like assisting patients with mobility both during hospital admission and at home. The challenges identified were Inability to perform certain tasks and Anxiety in performing Tasks. Participants in this study believed even though they were able to execute needed tasks the best way they knew how some level of intentional education in preparing them adequately for instances such as emergencies would go a long way to prevent unwarranted anxiety. Competency, according to all participants was not a great strength concerning technicalities and skills they don't possess. However, performing certain tasks over time gives them a false sense of competency which collapses when faced with emergencies beyond their knowledge. Professional help and adequate education on the scope of their caregiving role was a major request to help boost their confidence in task performance while allowing them to give the requisite care to their patients. The subject of overburdening and stress was refuted in this study based on narration from a participant who maintained their stress levels were not overwhelming due to their positive approach to caregiving.

Thirdly, Participants found meaning and purpose in life through keeping faith in God. Spirituality, according to participants helped them to develop a positive mentality towards caregiving which gave them a sense of hope to put in their best. Participants acknowledged that their spirituality allowed them to persevere no matter the circumstance faced, through acceptance, knowing that what will be will be and that it was the will of God. Acceptance according to caregivers in this study opened them up to a broader way of thinking with new ideas concerning their care regimen/schedule and the knowledge that whatever the prognosis maybe was out of their control. Participants also believed their roles as caregivers were not by accident but through the machination of God's work hence they felt fulfilled in their caregiving roles.

Fourthly, Participants expressed a lot of concern regarding education. Their main issues were in line with health professionals not giving the requisite information under the guise that it was too complicated to understand which according to participants only furnished them with shallow information that wasn't so helpful when the need arose. All participants acknowledged that soliciting information concerning their health or that of their patients was most often brushed aside by health professionals. Their curiosity to know more only solicited negative attitudes from some healthcare professionals most of the time. Caregivers elaborated that despite challenges encountered in their caregiving role, they made time for a check-up and made changes to their diet to keep them healthy.

The habit of intentional exercise however was not inculcated into their healthy way of living because participants in this study viewed their caregiving role as a form of exercise on its own. Financial restraints were also a challenge according to a participant which hindered their true intention to live a healthy life. Participants, however, did agree that when it came to who deserved health care first in times of financial crisis they always put their patients first and resorted to over-the-counter medications until such a time that they can afford to go for checkups. Despite all these setbacks participants acknowledged the importance of frequent check-ups and the consequences of self-medication.

Last but not the least, Alternative care was an emerging theme. Participants kept bringing up the concept of alternative treatment like homeopathy, and herbal and diet therapy. Participants recounted the pressure from family and friends to seek herbal or homeopathy treatment which according to them aggravated their patient’s condition. Most participants had at one point sought alternative treatment for their patients as well as themselves but returned to dialysis sessions for their patients when the condition worsened. Diet therapy on the other hand was a much more welcomed concept in which all participants indulged. A good diet therapy coupled dialysis session, according to some participants, improved the kidney health of their patients . Some participants even mentioned that their dialysis sessions had been reduced from 3 to 2 sessions due to the diet therapy. The concept of diet therapy was a positive option and more popular among younger patients with younger caregivers in this study.

## 6.2 Implication

The study identified useful implications such as nursing education, nursing practice and policy-making. The study also offers an opportunity for future investigations.

### 6.2.1 Implication for nursing education

Nurses form the majority of healthcare providers and are in constant interaction with patients and their caregivers hence adequate knowledge on the expectations and needs of family caregivers will be of great benefit to the caregivers and their patients as well as other family members. Caregivers play an important role in the care of patients both in and out of the hospital hence their general wellbeing must be as important as that of the patient to the healthcare team and most especially the nurse. Caregiving presents with challenges to both caregiver and receiver and must be handled with sensitivity. Education on holistic care involving caregiver wellbeing must be reinforced in curriculums in nurses training as well as frequent workshops to serve as professional development on the ever changing care needs of both family caregivers and their patients. Psychology in training curriculums must be intensified to help nurses in the process of anticipating and tending to individualized health needs among family caregivers and their patients hereby personalizing care and nurturing long term benefits. These recommendations are not restricted to only nurses but also other health team members such as doctors, biomedical scientist, pharmacist and other support staffs to improve their communication and understanding of caregiver needs and provide help appropriately.

### 6.2.2 Implication for clinical practice

ESRD management requires a determined effort to ensure holistic and coordinated management. Focus on individualized family centered care will improve the family caregiver understanding of their roles, improve communication and eliminate miscommunications. Family-centered care ensures the health and well-being of patients and their families through a respectful partnership by honoring the cultures, beliefs, strengths and expertise from both sides. Health care workers must desist from acts that are perceived as disrespectful and demeaning. Caregivers must be treated with empathy and respect to validate the importance of their contribution to the formal healthcare team. Also nurses should provide hands-on training for caregivers and give detailed discharge education to prevent anxiety and knowledge deficit.

### 6.2.3 Implications for policy

Policymakers must put in efforts to enroll ESRD treatment on the national health insurance scheme and provide subsidized dialysis cost for ESRD patients to reduce the financial burden of caregivers as well as the patients themselves since cost associated with hospitalization and dialysis impedes effective management. The findings of this study revealed high cost related to accessing kidney care which is mostly a privatized business in the health care sector. Hence, efforts by the government to increase government-funded dialysis units and kidney clinics will reduce high cost associated with care thereby reducing the financial burden of family caregivers which was a major problem identified in this current study as well as previous studies.

### 6.2.4 Implication for future research

Considering the themes that emerged from the narratives, useful areas of future research emanated:

Alternative care was an emerging theme that could use further exploration to whole fully understand the positive and negative of effects of alternate treatment with respect to homeopathy, herbal and diet therapy which will serve as a great opportunity for future research to debunk myths and scientifically prove or disprove current assumptions.

Further study on the relationship between spirituality and anxiety/stress management in the Ghanaian context is also a laudable area that deserves further investigation. Assumptions deduced from this current study acknowledge that comfort is sought in a superior being, which brings resilience and emotional strength to cope effectively with stress.

### 6.3. Limitation of the study

The use of the qualitative methodology in this study makes finding not be generalizable to the larger family caregiver population even though the qualitative study does not aim at generalizing findings (Lincoln & Guba, 1985). Fifteen participants were recruited using the purposive sampling technique which may suggest there were other family caregivers whose experiences would be different because perspectives are strongly influenced by the epistemological and ontological orientation of contributors (Seale 1999). However Male and female demographics were adequately represented but on the religious facet, all the participants were Christians except one. Diversity in religious orientation may have enriched the findings gathered from the spiritual experiences that were shared.

### 6.4 Conclusion

The overall experiences of family caregivers identify a gap in Education, professional support, and Communication which leads to misinformation, anxiety and lack of confidence in executing the family caregiver role for desired outcomes. Social isolation according to this study was deliberately practiced by family caregivers and their patients on account of lack of privacy and social respect from friends and family because of financial support given. Needed training for staff, prompt access to information, and specialist care along with a multi-dimensional approach is a good start to tackling the numerous challenges faced by family caregivers. Health professionals must assist family caregivers gain requisite knowledge and build capabilities while taking cultural and ethnic differences into consideration. The Caregiver Health Model which was adopted for this study should be maintained as an approach in addressing these challenges. All constructs in the model were supportive of the findings of this current study though some of the findings fell outside the model. Assimilating community/home visit in ESRD management could prove a useful tool in providing ultimate care to patients and social/professional support to family caregivers. Defective caregiver confidence/competence and unavailable reliable source of information causes anxiety and uncertainty which goes on to affect patient care outcome and quality of care. Effective management protocols and equipping family caregivers with in-depth information promote planning, implementation and intervention which increases caregiver confidence thereby minimizing anxiety and stress for better patient and caregiver outcomes.

### 6.5 Recommendations

The following recommendations were made based on the findings of this study.

### 6.5.1 Ministry of Health (MOH)

- Ministry of Health must institutionalize ESRD services in all hospitals across the country.
- Ministry of Health is required to build a specialist hospital and dialysis units at subsidized cost for ESRD patients and their family for all matters relating to Kidney issues.
- Ministry of Health should incorporate community visits into the management of ESRD cases to handle the better management and support family caregivers.
- Adequate specialist renal nurses must be trained by the Ghana College of Nursing and Midwifery
- Ministry of Health must adopt a policy of subsidized emergency dialysis services for ESRD patients and free health screening for family caregiver periodically.

### 6.5.2 Ghana Health Service (GHS)

- Ghana Health Service must ensure the concept of Family medicine is strengthened in all hospitals to promote care that is not only patient focused but family-centered hereby facilitating effective information and communication flow.

- Ghana Health Service must establish in-service training for all family caregivers to impact knowledge on dealing with emergencies.
- Doctors, pharmacist, biomedical scientists, and physiotherapists, radiotherapist and other support staffs should be trained on family support.

### 6.5.3 Nursing and Midwifery Council (NMC)

- Nursing and Midwifery Council must inculcate family nursing/counselling and training section into the curriculum of nurses and midwives

### 6.5.4 The Trust Hospital and Other Hospitals

- All staff should have good customer care training as well as basic counselling training to help support family caregivers.
- Doctors and nurses at primary medical care centers must include family caregiver education as part of patients treatment plan
- All hospitals must engage in family-centered care with focus on effective communication and counselling as a form of support for family caregivers as well as their patients.
- Nurses and Midwives should maintain strong advocacy for family caregivers to highlight their needs to other health professionals for satisfactory and better health care services as well as outcomes.
- Hospital must nurture a good relationship with other health institution for easy referral of cases and specialist support for swift care to support caregivers in acquiring prompt care for their patients.

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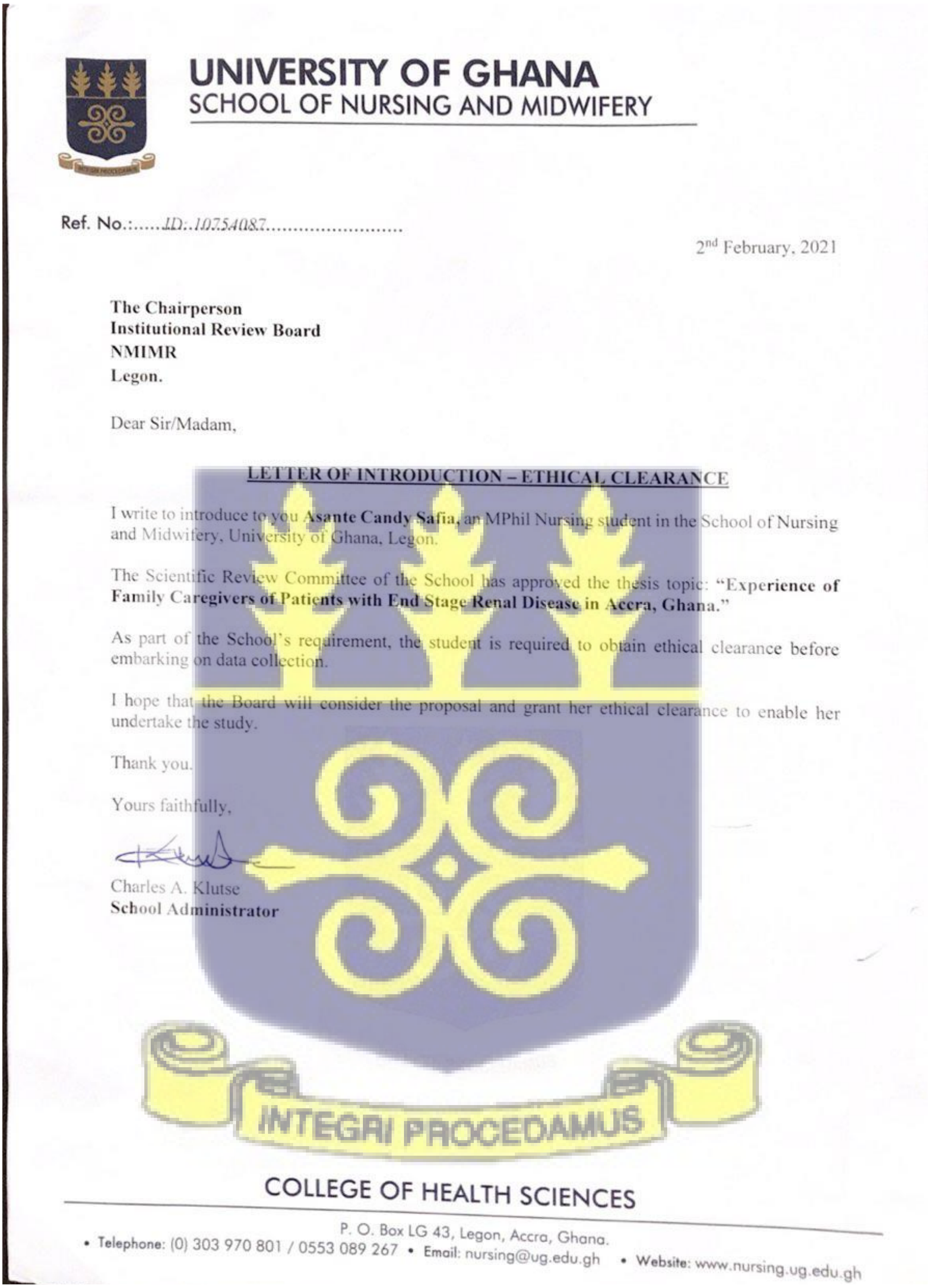
# APPENDICES

## Appendix A: Letter of Introdduction



UNIVERSITY OF GHANA
SCHOOL OF NURSING AND MIDWIFERY

Ref. No.:......ID: 10754087..........................

2nd February, 2021

**The Chairperson**
**Institutional Review Board**
**NMIMR**
**Legon.**

Dear Sir/Madam,

**LETTER OF INTRODUCTION – ETHICAL CLEARANCE**

I write to introduce to you **Asante Candy Safia**, an MPhil Nursing student in the School of Nursing and Midwifery, University of Ghana, Legon.

The Scientific Review Committee of the School has approved the thesis topic: **"Experience of Family Caregivers of Patients with End Stage Renal Disease in Accra, Ghana."**

As part of the School's requirement, the student is required to obtain ethical clearance before embarking on data collection.

I hope that the Board will consider the proposal and grant her ethical clearance to enable her undertake the study.

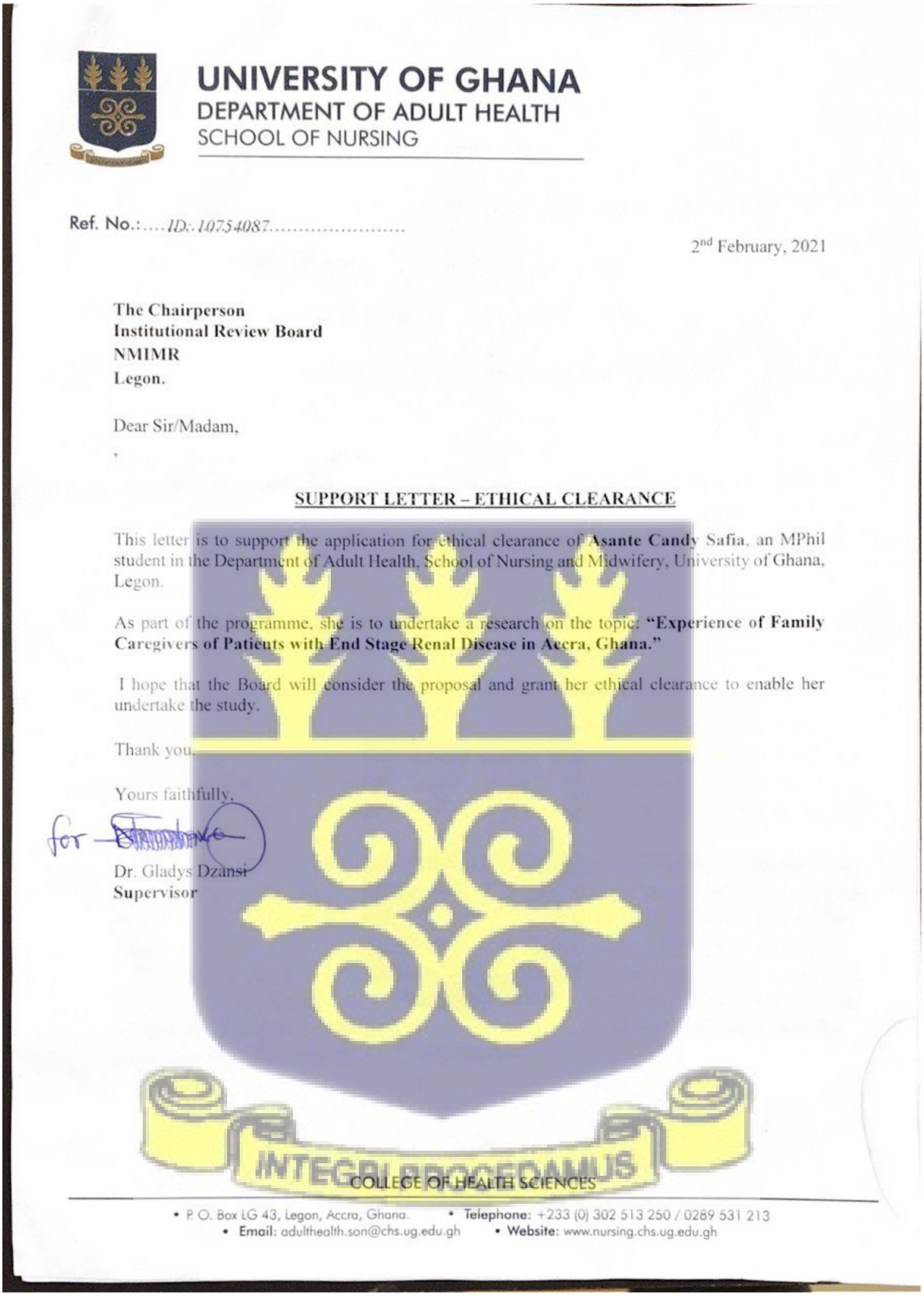
Thank you.

Yours faithfully,

Charles A. Klutse
**School Administrator**

COLLEGE OF HEALTH SCIENCES
P. O. Box LG 43, Legon, Accra, Ghana.
• Telephone: (0) 303 970 801 / 0553 089 267 • Email: nursing@ug.edu.gh • Website: www.nursing.ug.edu.gh

## Appendix B: Support Letter



UNIVERSITY OF GHANA
DEPARTMENT OF ADULT HEALTH
SCHOOL OF NURSING

Ref. No.:.....ID: 10754087.......................

2nd February, 2021

**The Chairperson**
**Institutional Review Board**
**NMIMR**
**Legon.**

Dear Sir/Madam,

**SUPPORT LETTER – ETHICAL CLEARANCE**

This letter is to support the application for ethical clearance of **Asante Candy** Safia, an MPhil student in the Department of Adult Health, School of Nursing and Midwifery, University of Ghana, Legon.

As part of the programme, she is to undertake a research on the topic: **"Experience of Family Caregivers of Patients with End Stage Renal Disease in Accra, Ghana."**

I hope that the Board will consider the proposal and grant her ethical clearance to enable her undertake the study.

Thank you.

Yours faithfully,

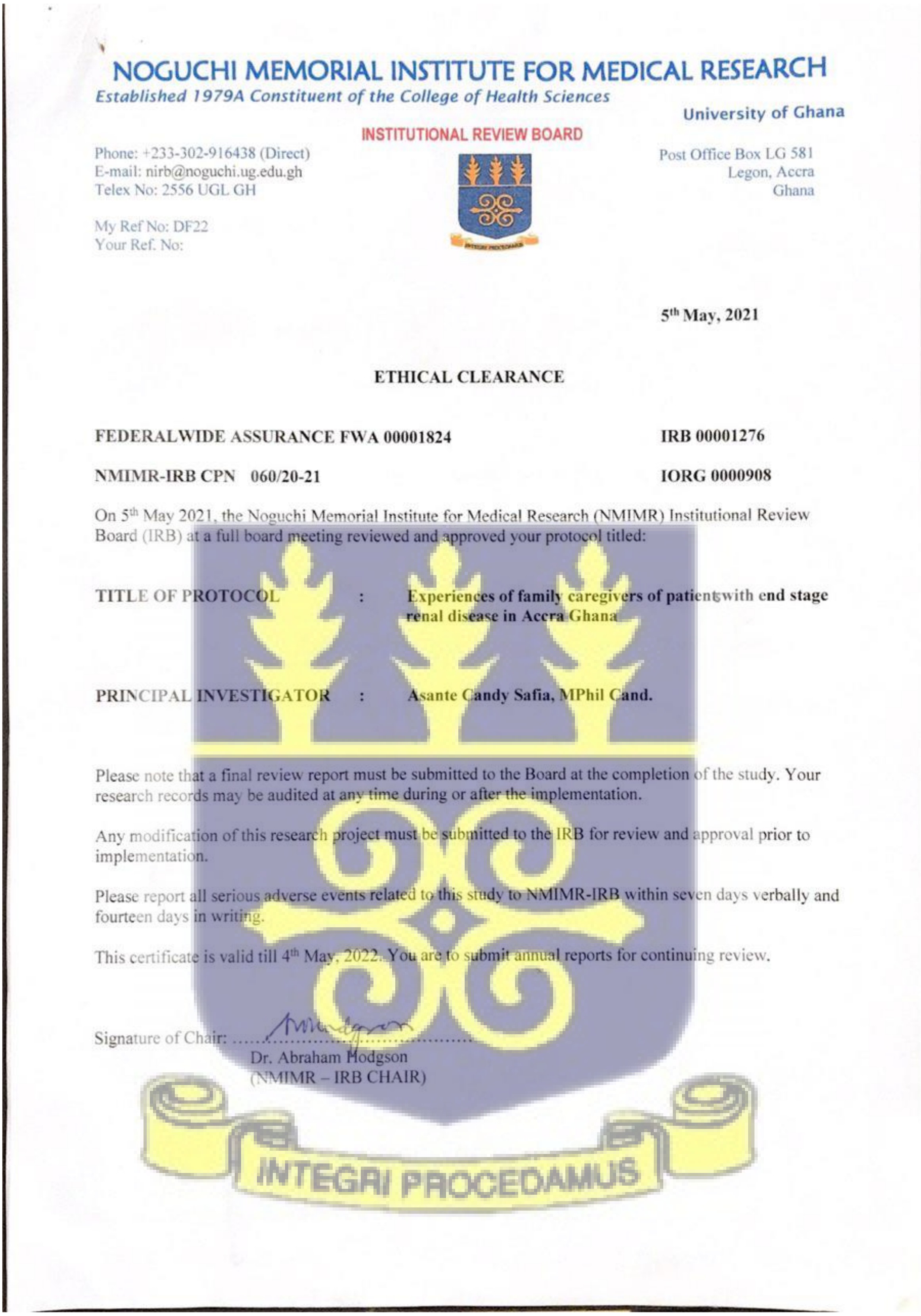
for

Dr. Gladys Dzansi
**Supervisor**

COLLEGE OF HEALTH SCIENCES

• P. O. Box LG 43, Legon, Accra, Ghana. • **Telephone:** +233 (0) 302 513 250 / 0289 531 213
• **Email:** adulthealth.son@chs.ug.edu.gh • **Website:** www.nursing.chs.ug.edu.gh

## Appendix C: Ethical Clearance



NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
*Established 1979A Constituent of the College of Health Sciences*
University of Ghana
INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
E-mail: nirb@noguchi.ug.edu.gh
Telex No: 2556 UGL GH

Post Office Box LG 581
Legon, Accra
Ghana

My Ref No: DF22
Your Ref. No:

**5th May, 2021**

**ETHICAL CLEARANCE**

**FEDERALWIDE ASSURANCE FWA 00001824** **IRB 00001276**

**NMIMR-IRB CPN 060/20-21** **IORG 0000908**

On 5th May 2021, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

| | | |
|---|---|---|
| TITLE OF PROTOCOL | : | **Experiences of family caregivers of patients with end stage renal disease in Accra Ghana** |
| PRINCIPAL INVESTIGATOR | : | **Asante Candy Safia, MPhil Cand.** |

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

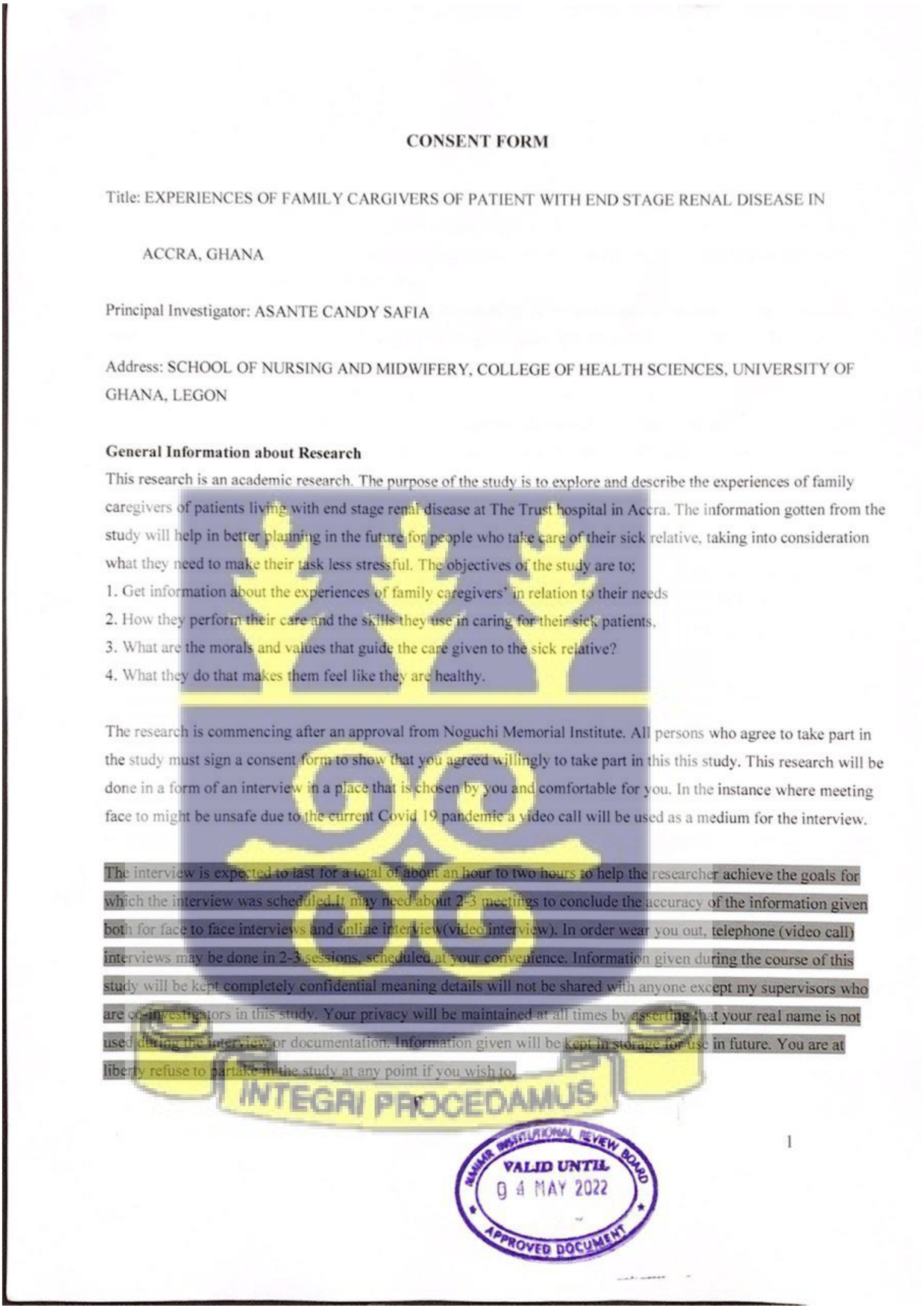
Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 4th May, 2022. You are to submit annual reports for continuing review.

Signature of Chair: ……………………………………
Dr. Abraham Hodgson
(NMIMR – IRB CHAIR)

**Appenddix D:**



## CONSENT FORM

Title: EXPERIENCES OF FAMILY CARGIVERS OF PATIENT WITH END STAGE RENAL DISEASE IN ACCRA, GHANA

Principal Investigator: ASANTE CANDY SAFIA

Address: SCHOOL OF NURSING AND MIDWIFERY, COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON

**General Information about Research**

This research is an academic research. The purpose of the study is to explore and describe the experiences of family caregivers of patients living with end stage renal disease at The Trust hospital in Accra. The information gotten from the study will help in better planning in the future for people who take care of their sick relative, taking into consideration what they need to make their task less stressful. The objectives of the study are to;

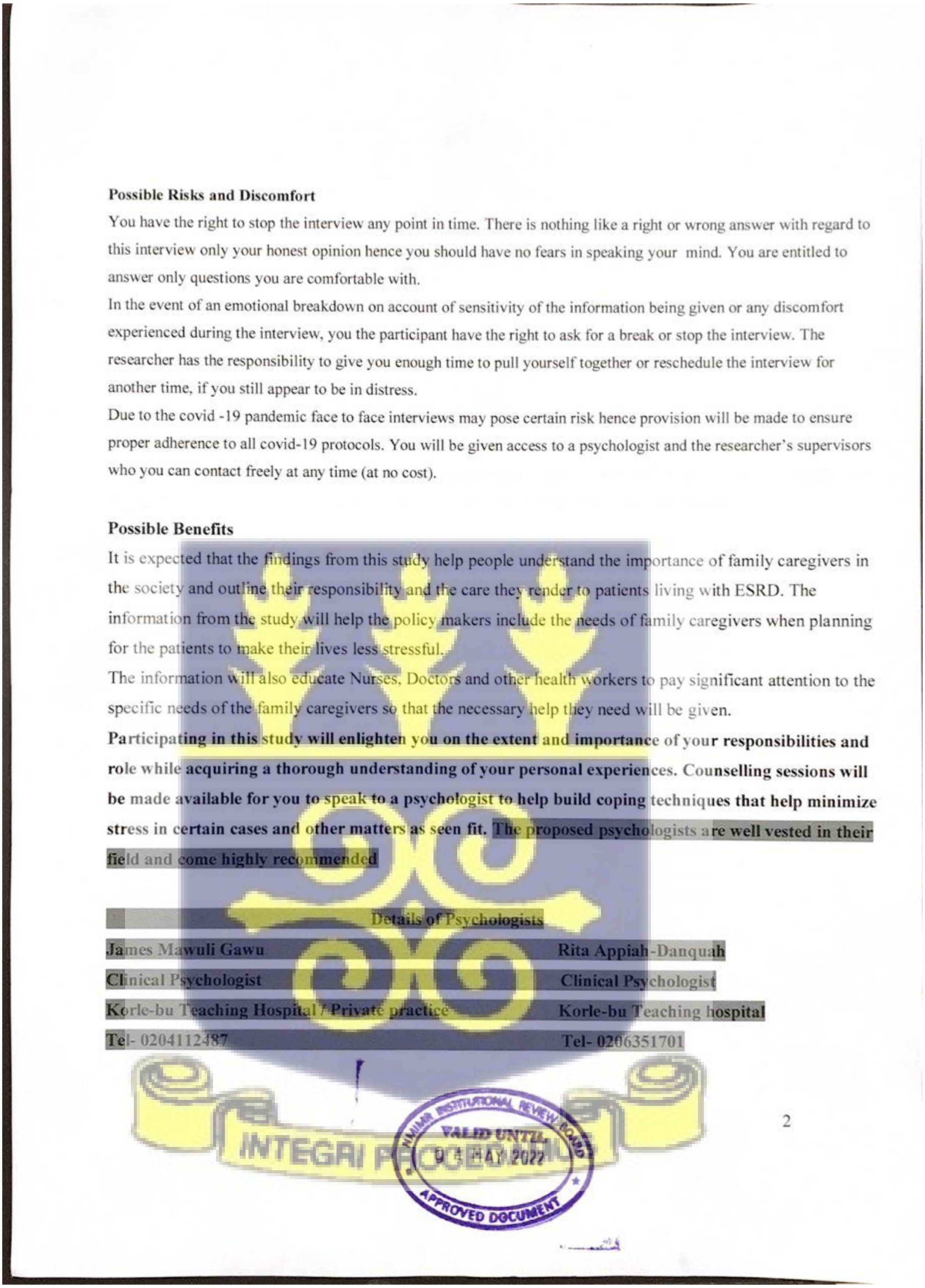
1. Get information about the experiences of family caregivers' in relation to their needs
2. How they perform their care and the skills they use in caring for their sick patients.
3. What are the morals and values that guide the care given to the sick relative?
4. What they do that makes them feel like they are healthy.

The research is commencing after an approval from Noguchi Memorial Institute. All persons who agree to take part in the study must sign a consent form to show that you agreed willingly to take part in this this study. This research will be done in a form of an interview in a place that is chosen by you and comfortable for you. In the instance where meeting face to might be unsafe due to the current Covid 19 pandemic a video call will be used as a medium for the interview.

The interview is expected to last for a total of about an hour to two hours to help the researcher achieve the goals for which the interview was scheduled.It may need about 2-3 meetings to conclude the accuracy of the information given both for face to face interviews and online interview(video interview). In order wear you out, telephone (video call) interviews may be done in 2-3 sessions, scheduled at your convenience. Information given during the course of this study will be kept completely confidential meaning details will not be shared with anyone except my supervisors who are co-investigators in this study. Your privacy will be maintained at all times by asserting that your real name is not used during the interview or documentation. Information given will be kept in storage for use in future. You are at liberty refuse to partake in the study at any point if you wish to.

1

VALID UNTIL
04 MAY 2022
APPROVED DOCUMENT



**Possible Risks and Discomfort**

You have the right to stop the interview any point in time. There is nothing like a right or wrong answer with regard to this interview only your honest opinion hence you should have no fears in speaking your mind. You are entitled to answer only questions you are comfortable with.

In the event of an emotional breakdown on account of sensitivity of the information being given or any discomfort experienced during the interview, you the participant have the right to ask for a break or stop the interview. The researcher has the responsibility to give you enough time to pull yourself together or reschedule the interview for another time, if you still appear to be in distress.

Due to the covid -19 pandemic face to face interviews may pose certain risk hence provision will be made to ensure proper adherence to all covid-19 protocols. You will be given access to a psychologist and the researcher's supervisors who you can contact freely at any time (at no cost).

**Possible Benefits**

It is expected that the findings from this study help people understand the importance of family caregivers in the society and outline their responsibility and the care they render to patients living with ESRD. The information from the study will help the policy makers include the needs of family caregivers when planning for the patients to make their lives less stressful.

The information will also educate Nurses, Doctors and other health workers to pay significant attention to the specific needs of the family caregivers so that the necessary help they need will be given.

**Participating in this study will enlighten you on the extent and importance of your responsibilities and role while acquiring a thorough understanding of your personal experiences. Counselling sessions will be made available for you to speak to a psychologist to help build coping techniques that help minimize stress in certain cases and other matters as seen fit. The proposed psychologists are well vested in their field and come highly recommended**

**Details of Psychologists**

| | |
|---|---|
| **James Mawuli Gawu** | **Rita Appiah-Danquah** |
| **Clinical Psychologist** | **Clinical Psychologist** |
| **Korle-bu Teaching Hospital / Private practice** | **Korle-bu Teaching hospital** |
| **Tel- 0204112487** | **Tel- 0206351701** |

NMIMR INSTITUTIONAL REVIEW BOARD
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04 MAY 2022
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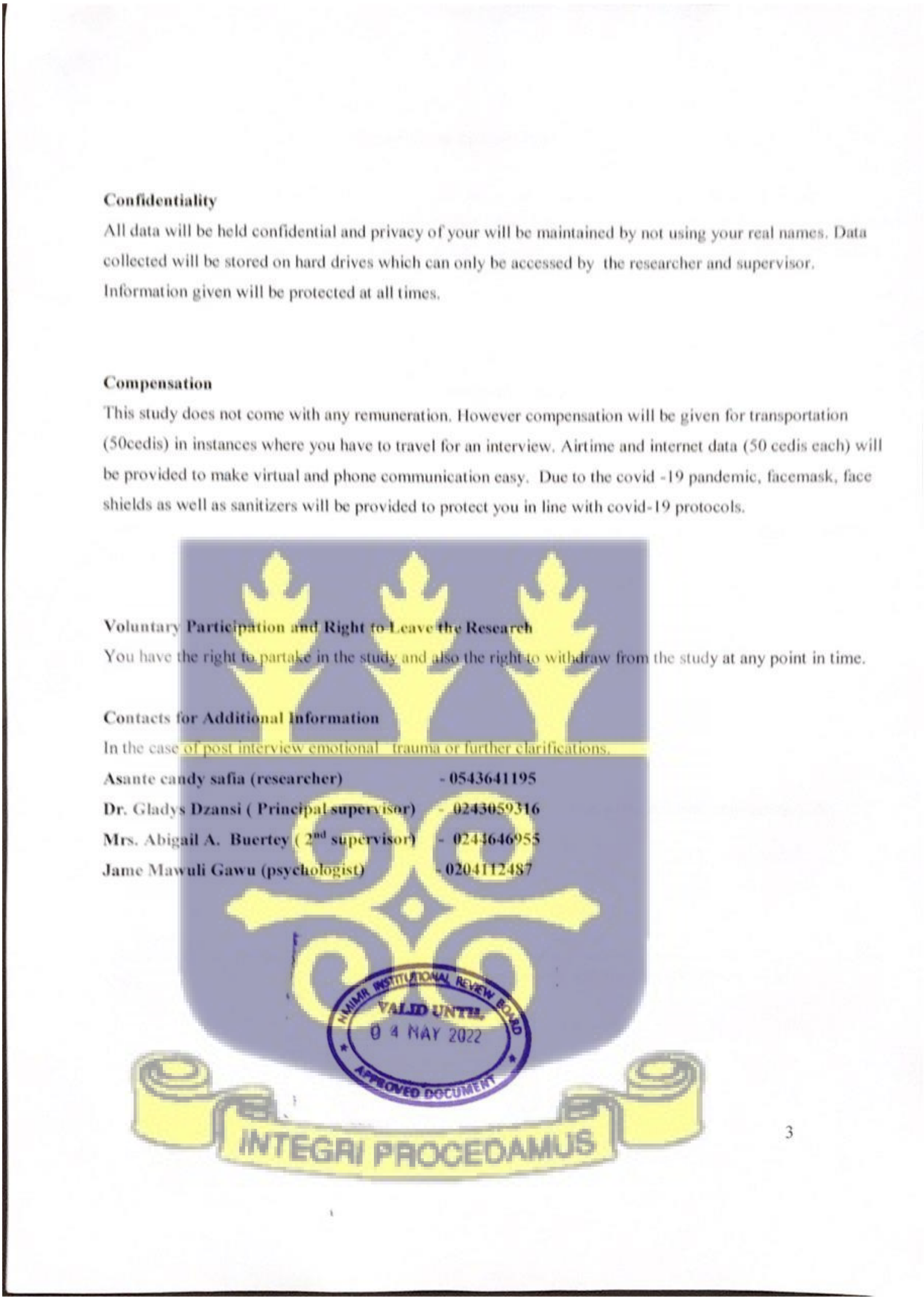

**Confidentiality**

All data will be held confidential and privacy of your will be maintained by not using your real names. Data collected will be stored on hard drives which can only be accessed by the researcher and supervisor. Information given will be protected at all times.

**Compensation**

This study does not come with any remuneration. However compensation will be given for transportation (50cedis) in instances where you have to travel for an interview. Airtime and internet data (50 cedis each) will be provided to make virtual and phone communication easy. Due to the covid -19 pandemic, facemask, face shields as well as sanitizers will be provided to protect you in line with covid-19 protocols.

**Voluntary Participation and Right to Leave the Research**

You have the right to partake in the study and also the right to withdraw from the study at any point in time.

**Contacts for Additional Information**

In the case of post interview emotional trauma or further clarifications.

| | |
|---|---|
| **Asante candy safia (researcher)** | **- 0543641195** |
| **Dr. Gladys Dzansi ( Principal supervisor)** | **- 0243059316** |
| **Mrs. Abigail A. Buertey ( 2nd supervisor)** | **- 0244646955** |
| **Jame Mawuli Gawu (psychologist)** | **- 0204112487** |

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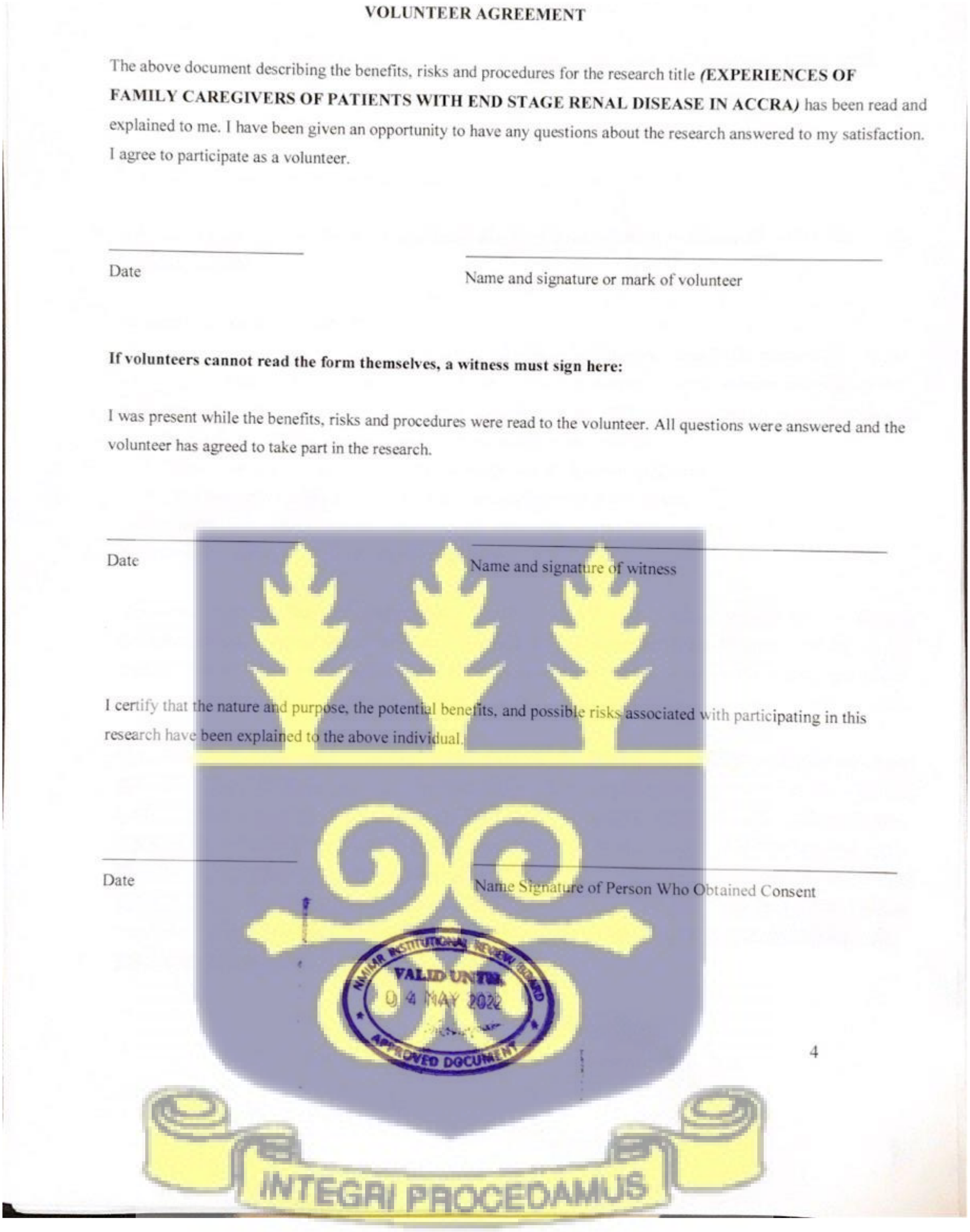
## Appendix F



**VOLUNTEER AGREEMENT**

The above document describing the benefits, risks and procedures for the research title ***(*EXPERIENCES OF FAMILY CAREGIVERS OF PATIENTS WITH END STAGE RENAL DISEASE IN ACCRA*)*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date

Name and signature or mark of volunteer

**If volunteers cannot read the form themselves, a witness must sign here:**

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date

Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date

Name Signature of Person Who Obtained Consent

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04 MAY 2022
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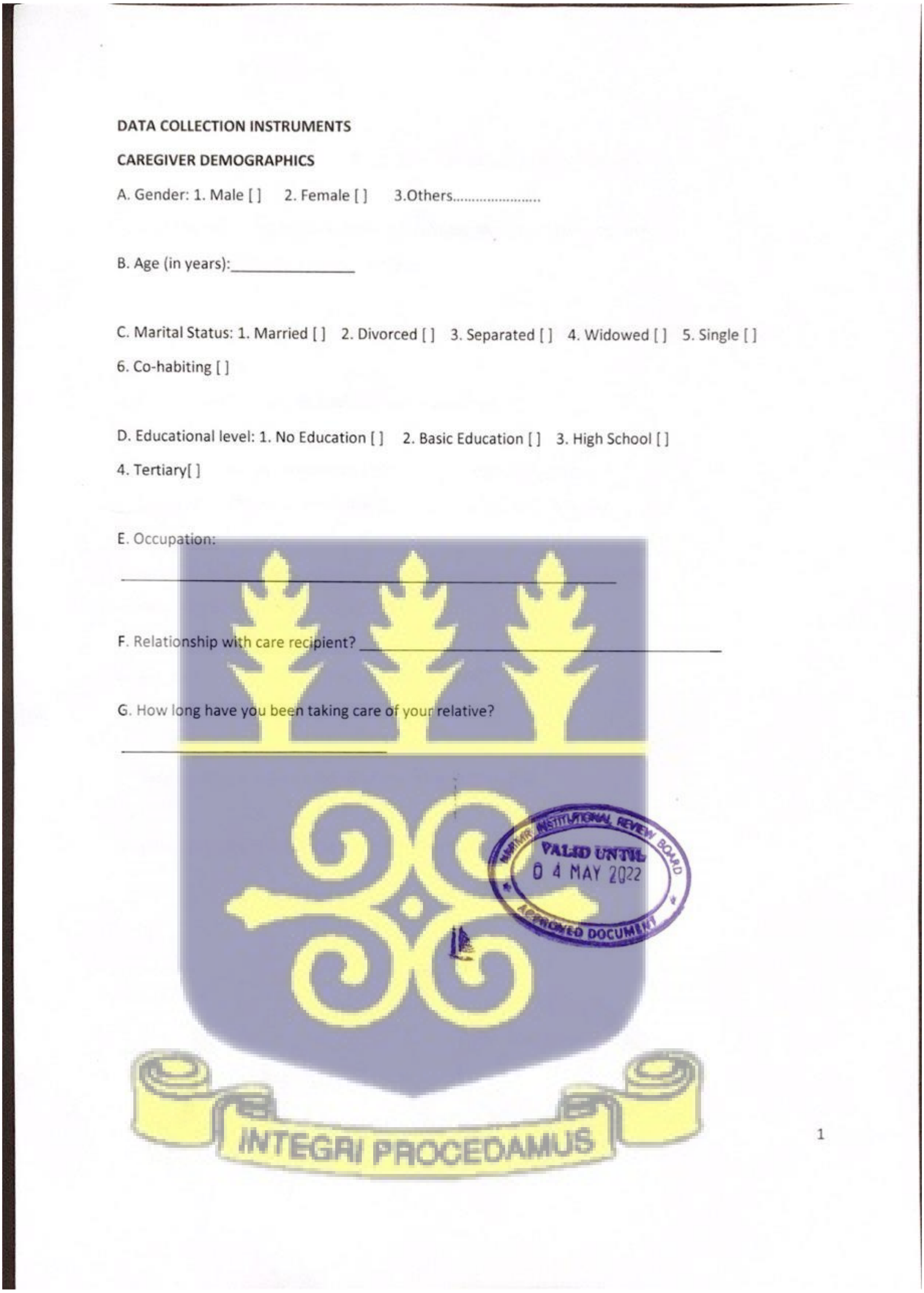

## DATA COLLECTION INSTRUMENTS

## CAREGIVER DEMOGRAPHICS

A. Gender: 1. Male [ ]  2. Female [ ]  3.Others.......................

B. Age (in years):_______________

C. Marital Status: 1. Married [ ]  2. Divorced [ ]  3. Separated [ ]  4. Widowed [ ]  5. Single [ ]
6. Co-habiting [ ]

D. Educational level: 1. No Education [ ]  2. Basic Education [ ]  3. High School [ ]
4. Tertiary[ ]

E. Occupation:

_____________________________________________

F. Relationship with care recipient? ________________________________

G. How long have you been taking care of your relative?

________________________

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0 4 MAY 2022
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## INTERVIEW GUIDE

1. Please share with me what you do for your sick relative on day-to-day basis

2. Please share with me your caregiving experiences about your everyday needs

Probes: physical support, educational support

3. What are some of your experiences with regards to your performance of care and how well you perform these tasks?

Probes: competency and confidence in performing task

4. How did you gain the knowledge of caring for someone in this way?

Probes; self-taught, educated by healthcare team, learnt by observation

5. What do you think being healthy is about and what do you do to stay healthy?

Probes: frequent check-ups, diet, exercise

6. Does taking care of your relative give you fulfilment?

Probes: achievements, sense of hope

7. Were you taught about caring for others while growing up?

8. Is there anything else you will like to talk share with me?