

**KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY,
KUMASI-GHANA.**

COLLEGE OF HEALTH SCIENCES

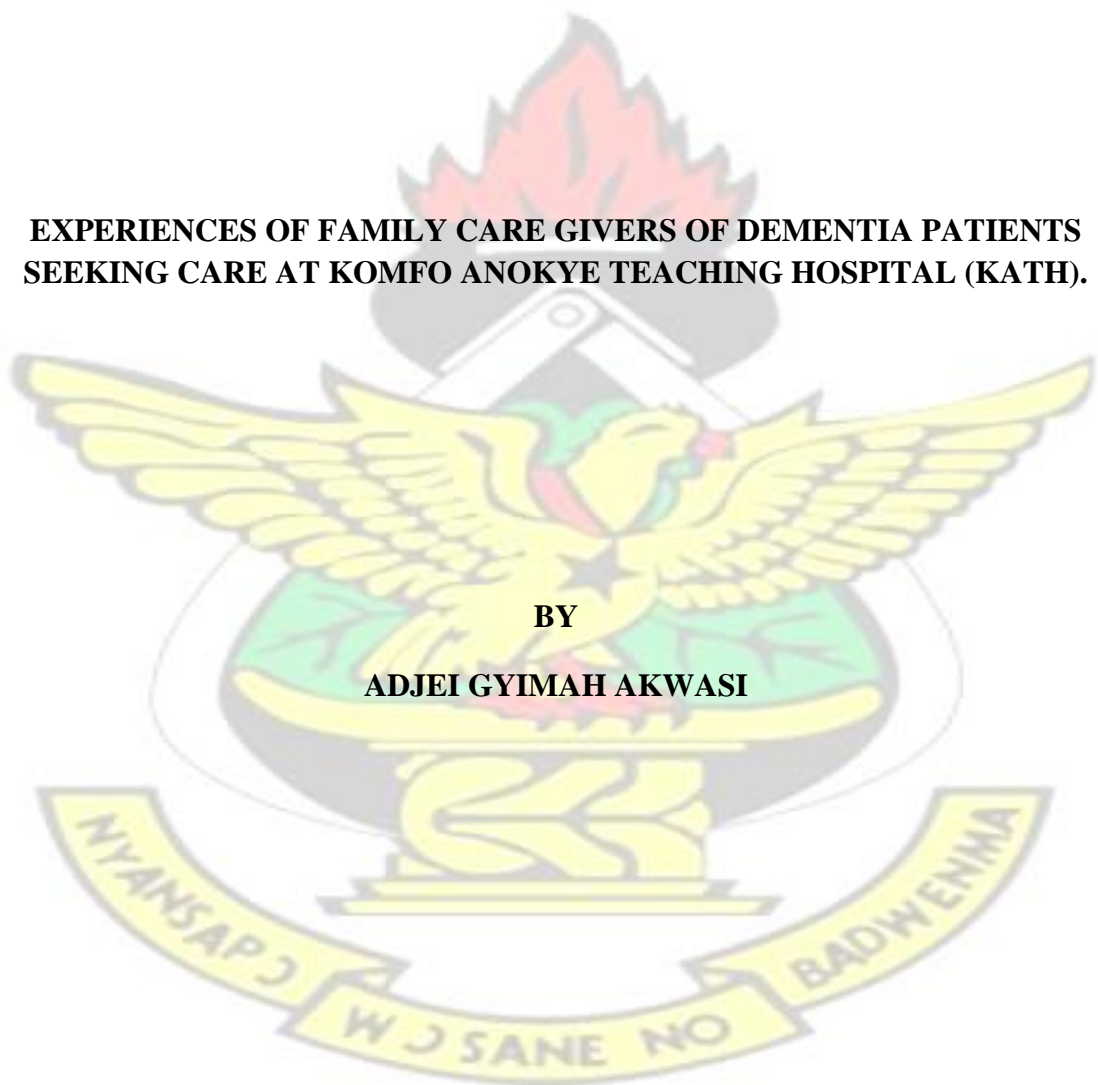
SCHOOL OF PUBLIC HEALTH

DEPARTMENT OF HEALTH PROMOTION AND DISABILITY STUDIES

**EXPERIENCES OF FAMILY CARE GIVERS OF DEMENTIA PATIENTS
SEEKING CARE AT KOMFO ANOKYE TEACHING HOSPITAL (KATH).**

BY

ADJEI GYIMAH AKWASI



JUNE 2019

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KNUST

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**A THESIS SUBMITTED TO THE DEPARTMENT OF HEALTH
PROMOTION, SCHOOL OF PUBLIC HEALTH, KWAME NKRUMAH
UNIVERSITY OF SCIENCE AND TECHNOLOGY IN FULFILMENT OF
PARTIAL REQUIREMENT FOR THE DEGREE OF MASTER OF
PHILOSOPHY IN DISABILITY, REHABILITATION AND DEVELOPMENT**

JUNE 2019

DECLARATION

I hereby declare that this thesis is entirely my own original work and it does not have previously published materials by another person, or material which has been accepted in the university or any other university, except where due acknowledgment has been made in the text.

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DEDICATION

This work is dedicated to the Lord Almighty for His innumerable support towards my success.

ACKNOWLEDGEMENT

I would like to express my warm gratitude to my supervisor, Dr Appiah-Brempong Emmanuel, for his contribution towards the completion of this work, many thanks to Mr. Paul Okyere for his help in all kind which has led to the successful completion of the entire work.

I would also like to thank the Staff of the Ghana National Petroleum Corporation for their financial support through my graduate education. Lastly, I would like to thank all my participants, especially, the head of Psychiatric Unit of Komfo Anokye Teaching Mrs. Ruth Owusu Antwi, for their countless and selfless support throughout the study period. Finally, all accolades to my mom, Mrs. Felicia Adjei, for your support and advice in their relentless times of my life.



ABBREVIATIONS AND ACRONYM

WHO- World Health Organisation

KATH- Komfo Ankoye Teaching Hospital

WCCL- Ways of Coping Checklist

SDG- Sustainable Development Goals

Definition of terms

Family Caregivers: Family member who is responsible for taking care of the demented patient. (GMH, 2012)

The various needs were adapted from the work of Abraham Maslow, A theory of human motivation (1943)

Needs: Support that caregivers require to effectively take care of patients.

Physiological Needs (**Physical Needs**): Food, Water, Shelter, Clothing, Sleep, Breathing

Safety and Security (**Financial Needs**): Health, Employment, Property, Family and Social Stability

Love and Belonging (**Social Needs**): Friendship, Family, Intimacy, Sense of connection

Self-esteem and Self Actualization (**Psychological needs**): Confidence, Achievement, morality, Acceptance Experience purpose, Meaning and inner potential.

ABSTRACT

Psychosocial disabilities affect various people worldwide. Dementia which is synonymous to ageing affects all, irrespective of social status. Dementia poses a threat to the individual and nation in all, as the cost of caring is exceedingly huge. This study examines the experiences of family caregivers of dementia patients, the support services available to them as caregivers and the coping strategies they employed while under stress from the care giving duties.

The study employed phenomenological design using a qualitative method. Purposive and availability sampling techniques were used to select 18 participants for the study. In-depth interviews were conducted with the participants at Komfo Anokye Teaching Hospital in the Ashanti Region of Ghana. Data was analysed using interpretive phenomenological analysis.

This study has demonstrated that family caregivers of dementia patients go through a lot of challenges and do not meet their daily needs that would make life and caring easy for them. The challenges reported were in forms of health, social, economic and psychological challenges. These challenges coupled with their needs made caregiving very difficult. Also, positive reappraisal was the most used coping strategy employed by some of the caregivers when under stress. Again, there was no government or nongovernment support services available to them as caregivers but the support services they needed as family caregivers was in the form of financial and psychological support. It was recommended that there should be a rethinking of how caregiving is constructed in Ghana, their health and well-being of caregivers should be a paramount aspect of patient well-being as stipulated in the Ghana Mental Health Act. This will help achieve the united nations Convention on the Rights of Person with

Disability, who stipulates the well-being of caregivers is paramount in their convention and ensuring Ghana meeting the Sustainable Development Goal 3 of ensuring healthy lives and promoting well-being for all at all ages by 2030.

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CHAPTER ONE

INTRODUCTION

1.1 Background

The “invisible second patients”, often referred to as the family caregivers of people with dementia, play critical role to the quality of life of the care recipient (Am and Iryani, 2018). Caregivers are the pivotal support system of care for individuals with dementia at home (Brodaty and Donkin, 2009). Family caregivers experience positive as well as negative reactions in caregiving situations, yet much less has been written about the positive aspects of caregiving (Cohen et al., 2002). Most recently, there has been a growing research interest in the rewards and satisfactions associated with family caregiving (Nolan et al., 1996; Archbold, 1992; Deeken et al., 2003; Savage and Bailey, 2004). The principal causes of disability and decreased quality of life among the elderly and leading obstacles to successful aging are Alzheimer and Dementia (Katzman, 1976; Ewbank, 1999). Female caregivers of elderly dementia patients who experience depression have high vulnerability to stress, experience decreased self-esteem and increased despair, and in severe cases, contemplate suicide (Kim et al., 2006).

Family caregivers of dementia patients experience depression at least once in their life cycle and are reported to be diagnosed with either depression or anxiety disorder at a rate 2-3 times higher than the public (Wright, 1993). Caregivers of dementia patients lose interest in work or life due to the burden and stress, lose hope, consider themselves worthless, and show depression symptoms. The frequent problematic behavior's and low social support for the elderly with dementia increase the burden and depression of caregivers (Sung et al., 2006). In a study by Amirkhanyan and Wolf (2006), reported that taking care of elderly dementia patients decreased life satisfaction and increased

depression among caregivers and reduces quality of life. Caring for a dementia patient as compared to caring for other sickness can have huge higher levels of psychological distress and lower levels of confidence (Schulz and Martire, 2004).

A study in North America reported that over 10 million caregivers in the country care for elderly living with one type of dementia disease or the other in 2007 (McKhann et al., 2011). Most of caregivers were spouses, followed by children and children-in-law, specifically females. Caregivers aid patients in their daily living, can provide crisis intervention, and let the team know of early warning signs of relapse. Many relatives also serve as advocates for patients needs and rights (Intagliata et al., 1986). Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends and neighbours who give care. These persons can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately (Alliance, 2001).

Caregiving for a member of the family who is suffering from dementia can be stressful (Schulz et al., 1990). Dementia is an umbrella term, used to describe a syndrome that can have many different causes and is associated with ageing (van der Steen et al., 2014). A clear majority of patients with dementia (70% - 81%) live in the global community (Brandt et al., 2005) and approximately 75% of this elderly are cared for by family members and friends (Schulz and Martire, 2004). Dementia is a growing public health concern and is one of the most common diseases in the elderly and a most important cause of disability and mortality (Agüero-Torres et al., 1998). Because of the possible increase in the number of dementia patients in the years to come, estimate shows that the cost of care for dementia will increase by 85% in 2030, possibly making it the most expensive disease of our society (Alzheimer's Disease International, 2010).

The World Health Organization (W.H.O) report on ageing and health (2015), the global cost of dementia was pegged around US \$604 billion and this number may increase significantly by 2050. The financial and health consequences of demented patients on their family, caregivers and society is enormous (Kochanek et al., 2004; Teri et al, 1998; Teri et al, 2000; and Baumgarten et al, 1994)

Projections suggest that by 2040, 71% of older adults will be residing in developing countries will have one form of dementia (Hendrie et al., 2001). In different parts of the world, informal care provided by family, friends and the community are the cornerstone of the care system. In less developed countries in the world, these informal care costs prevail, accounting for 58% of all costs in low-income and 65% of all costs in middle-income countries, compared with 40% in high-income countries. Wimo et al., 2013). In high-income countries, the direct costs of social care (professional care in the community, and the costs of residential and nursing home care) account for the largest element of costs – 42%, compared with only 4% in less developed countries where such services are not generally available (Wimo et al., 2013). In less developed countries, the economic strain on family caregivers is considerable due to the larger, extended families. Naturally, around a fifth of caregivers have cut back on paid work, and paid care workers are becoming common in some cities, adding to the economic burden of families. (Wimo et al., 2013)

The leading chronic disease contributors to disability, and, particularly, dependence among older people globally are dementia and cognitive impairment. While older people can often cope well, and remain reasonably independent even with marked physical disability, the onset of cognitive impairment quickly compromises their ability to carry out complex but essential tasks in daily life. In addition, people living with

dementia will increasingly have difficulty to meet their basic personal care needs (Prince et al., 2013).

1.2 Problem Statement

Though dementia is a major health problem in old age and has become a cause of considerable public health concern, especially in Ghana, there is still a considerable gap in knowledge about the experiences of caregivers (Kalaria et al, 2008; Chandra et al., 2001) Examining the perspectives and experiences of family care givers of dementia patients at komfo Anokye Teaching hospital would provide relevant empirical information for health practitioners and gerontologist in Ghana The principal purpose of this study was to bridge this knowledge gap and add to existing body of knowledge by examining the experiences of family care givers of dementia patients seeking care at Komfo Anokye. The study design employed sought seek to examine the experiences of family care givers of dementia patients in Ashanti Region of Ghana and would reflect the real life-time experiences of family caregivers. Again, some of the findings would be presented at conferences and published in top journals to add to existing knowledge and literature., The Sustainable Development Goals (SDG) agenda 2030 which emphasises on protecting the rights and dignity of older persons and ensuring their full participation in society, is a solid justification for a research of this nature to be done.

1.3 Research Questions

- What are the needs of family caregivers of dementia patients?
- What Coping strategies do family caregivers of dementia patients employ in caregiving?
- What support services are available for family caregivers of dementia patients?

1.4 Research Objectives

1.4.1 Principal Objective

- This study sought to determine the experiences of family caregivers of people living with dementia who seek care at Komfo Anokye Teaching Hospital in Kumasi.

1.4.2 Specific Objectives;

Specifically, it sought to;

1. Explore the needs of family caregivers of dementia patients.
2. Identify the coping strategies of family caregivers of dementia patients.
3. Assess the support services available to family caregivers of dementia patients.

1.5 Significance of the study

The Ghana Mental Health Decree 1972 gives family caregivers important roles in admission and treatment of their relatives but does not have a laid down procedure to cater for the needs and struggles of the family caregivers as well (GMH, 1972). In a more revised Mental Health Act 2012, complaints from patients, their relatives or caregivers shall be made and documented by a senior mental health personnel and the complaints shall be reported to the head of the facility who shall take appropriate action within forty-eight hours, but only the complaints of the patients are registered, without taking the concerns of needs of caregivers as pertained in the Act and caregivers suffer in silence and in pain. (GMH, 2012)

One reason often assigned to explain research into ageing is the increase in number of the aged population and their predicaments (Makoni, 2008; Balcombe and Sinclair, 2001). Considering the increasing aged population, the World Health Organization has

advocated that comprehensive public health response should be tailored to address the health needs of the aged (World Health Organization, 2015b).

In the Ghanaian setting, few studies on the experiences of family care givers and its associated factors have been conducted to delve into this issue (Agudu, 2017; Spittel and Wolf-Ostermann, 2013; Appiah, 2017). For instance, (Agudu, 2017) did conducted a qualitative study to investigate the experiences of family care givers of dementia patients. The study did not concentrate on the coping strategies of care giving and the support services needed for the care givers. Appiah (2017) probed into the care options available and how technology can be used to publicize them for care givers of dementia patients. The researcher did not focus much on the care givers experiences but on medical practioners and the technological impact that could influence care giving and effects of socio-economic factors in utilization of different health care services among older adults. However, most of these Ghanaian studies are (Agudu, 2017; Spittel, 2013; Appiah,2017; kwankye2013; Fournier, 2011). None of these studies was based on a phenomenology design to explore the experiences of care givers of dementia patients. Admittedly, phenomenology approach is recommendable in exploring the experiences of family care givers of dementia patients since attempt to use the social issues (particularly experiences) and the complexities of human behaviours may require certain aspect of qualitative approach in social research.

1.6 Scope of the study

Geographically, the study was conducted in the Komfo Anokye Teaching Hospital, Psychiatric Unit. Basically, the study was delimited to only Komfo Anokye Teaching Hospital as it is the main referral point for all hospital from the Northern part of Ghana. Contextually, the study centred on experiences of family caregivers of dementia

patients. The study examined the needs of the family caregivers in the context of Abraham Maslow hierarchy of needs, that is, physical, social, psychological and financial needs. Secondly, the study sought to capture the coping strategies family caregivers employed when under any stress from their care giving duties. Lastly, the study considered support services available to the family caregivers.

1.7 Structure of the Study

The study was made up of six chapters. Chapter one dealt with the background to the study, the problem statement, and research objectives, the significance of the study and how the study was organized. Chapter two consisted of the review of literature related to the study. Chapter three presented the methodology; study setting, method, and design used, population and sample size, sampling technique, data collection tool, data processing and analysis, credibility and trustworthiness of data and ethical consideration. Chapter four presented the results of the findings while chapter five focuses on the discussions of the findings. Chapter six dealt with the conclusion and recommendations for action.

Table 1.1 : Overview of work

Chapter	Structure	Contents
1	Introduction	Introduction, problem statement, objectives, research objectives, significance of the study and scope of the study.
2	Theory and literature	Review of related literature, conceptual and theoretical frameworks

3	Research methodology and profile of the study area	research philosophy, research design, study variables, unit of analyses, sampling techniques and procedure, inclusion criteria, sources of data, data collection instruments and procedure, validity and reliability, ethical consideration, data management and analysis and description of the study
4	Results	Results on prevalence, patterns, predictors and barriers of health care use.
5	Discussion	Discussions in light of the literature review, conceptual and theoretical frameworks.
6	Conclusion recommendation	Lessons learnt, implications for practice and policy and way forward.

and

Source: Author's construct, 2018 **CHAPTER TWO**

LITERATURE REVIEW

2.1 Introduction

This chapter gives a detailed analysis of literature relating to the study. The literature review is intended to give a holistic understanding of what has been done in the area of investigation. Review of relevant literature was done under the following subtopics: the theoretical framework; definition of dementia, types of dementia, dementia care in Ghana, physiological needs, psychological needs, social needs, financial needs, coping strategies and support services.

2.2 A theory of Needs

This study used the Abraham Maslow's Hierarchy of needs theory (Maslow, 1948) to explain the experiences of family caregivers of dementia patients in the area of needs of family caregivers, coping strategies family caregivers employ in giving care and the support services available to family caregivers. Maslow extended his theory to include

observations of humans' innate curiosity in coming up with the human needs. The needs of the caregivers were the support that caregivers require to effectively take care of patients. According to Abraham Maslow, the physiological needs (physical Needs) were food, water, shelter, clothing, sleep, breathing. The safety and security which the researcher termed as financial needs were the health, employment, property, family and social stability. Again, the Love and Belonging (Social Needs) were the Friendship, Family, Intimacy, Sense of connection. The last need which is the Self-esteem and Self Actualization was christened as Psychological needs. The Psychological needs comprised of confidence, achievement, morality, acceptance experience purpose, meaning and inner potential. The researcher examined the needs assessment in relation to the phenomenological theory to assess or determined their lived experiences and get a holistic feel of their actual realization. The study was not much interested in how each need could trigger the other needs in hierarchical order but how their experiences of their needs affect their daily care giving duties. In principle, phenomenology does not produce empirical or theoretical observations; rather, it offers accounts of time, body, space and human relations as people experience them, altered by health and illness (van Manen, 1990; 2011, Earle, 2010). This was the main basis for the researcher opting to undertake the research in relation to the needs of Maslow to get the experience altered by health.

2.3 Definition of Family Caregivers

Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends and neighbours who give care. These persons can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately (Alliance, 2001).

Majority of caregivers are spouses, followed by children and children-in-law, specifically females. Caregivers aid patients in their daily living, can provide crisis intervention, and let the team know of early warning signs of relapse. Many relatives also serve as advocates for patients needs and rights (Intagliata, Willer, & Egri, 1986).

Lubkin and Larsen, 2006 defined the informal caregiver as anyone who provides care without pay and who usually has personal ties with the care recipient. „Informal caregiver“ is a term used interchangeably with „family caregiver“ and can include family, friends or neighbours. The family caregiver also faces the demands of their own employment and other family responsibilities apart from those of caregiving.

Dorian et al., (2008) used the term „primary caregiver“ and expanded the definition to cover the contact time. Primary caregiver was defined a family relative with the greatest responsibility in caring for the patient

This study will use the term family caregiver to represent a family member who is the primary caregiver and has the responsibility to take care of their relatives with psychiatric conditions and people who live with their dementia relatives and are unpaid for the care giving.

2.4 Dementia

The word „dementia“ first appeared in the vernacular in Blanchard’s popular Physical Dictionary (1726) as an equivalent of anaea or extinction of the imagination and judgment. According to Diderot, 1765, the usage of the word has also been found in the French Encyclopaedia. The term „dementia“ simply meant being out of one’s mind (Berrios, 1987).

In the 19th century, Dr. Philippe Pinel had a patient in her early thirties who was showing some strange symptoms for someone in her age group. She had lost the ability to speak and couldn't walk (Pinel, 1806). She also had forgotten how to use such everyday items as a comb, knife or fork. Pinel described this woman's condition as "démence," or an incoherence of mental faculties. It is assumed or believed that, the word "dementia" had association with this condition of the woman. Dementia is a neurodegenerative disorder which is irreversible (Berrios, 1990). It is an umbrella term which describes the symptoms, usually of a chronic or progressive nature, which occur when the brain is damaged because of one or more illnesses (World Health Organization, 2012).

In the early twentieth century, Auguste D, a patient of Alois Alzheimer, was a 51-year old woman with a 5-year history of progressive cognitive impairment, hallucinations, delusions, and severely impaired social functioning. After her death on April 8, 1906, Alzheimer identified in her brain amyloid plaques, neurofibrillary tangles, and arteriosclerotic changes. World Alzheimer's Day, Sept 21, 2006, marks the centenary of the identification and naming of the clinico-pathological entity that we now recognise to be the main cause of dementia syndrome, and one of the most burdensome conditions of later life (Ferri et al., 2005). This shows that, dementia has its root as far back in the 18th century and findings conducted into it was pioneered by western ideas.

2.4.1 Types of Dementia

A study conducted on dementia in sub-Saharan Africa shown a higher prevalence in urban as compared to rural areas. The prevalence was from 2 - 3.7% in rural Nigeria and Benin to 6 - 7.6% in cities in Central Africa (Guerchet et al., 2012). In South Africa, it is assumed that by 2030 proportion of South Africans aged over 60 years will have

increased 11% with an associated rise in cases of dementia. (De Jager et al., 2015). As predicted, this percentage is expected to rise to 71% by 2050 (Ferri et al., 2005).

Dementia is highly related to aging, with figures replicating with every 5 years of age (Jorm, 1990; Henderson et al., 1994) and currently there is no cure. In the 2010 population and housing census, it was indicated that, the population for the ageing in Ghana has increased up to 87% from 1960 to 2010 (GSS, 2014). A study conducted by Wimo et al., 2007 indicated that the number of persons living with dementia in Ghana was approximately 39,916 people. Another study by Wimo et al., 2010 indicated Costs of dementia in 2009 for Ghana as a country was \$87.9million, with persons living with dementia increasing to 45,302 as at the time.

Alzheimer's Australia (2012) identified some types of dementia namely: Alzheimer's disease, vascular dementia, dementia with Lewy bodies, Parkinson's disease dementia and Front temporal dementia. Alzheimer's disease is characterized by two abnormalities in the brain – amyloid plaques and neurofibrillary tangles. The plaques are abnormal clumps of a protein called beta amyloid. The tangles are bundles of twisted filaments made up of a protein called tau. Plaques and tangles stop communication between nerve cells and cause them to die. This constitute about twothirds cases of dementia.

Alzheimer's Australia (2012, Ibid) portrays that vascular dementia is cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several mini-strokes occurring over time. These mini-strokes are also called transient ischemic attacks (TIAs). Parkinson's disease progresses most people to develop dementia. When cognitive symptoms appear first, this is diagnosed as dementia with Lewy bodies. Fronto temporal dementia involves progressive damage

to the frontal and/or temporal lobes of the brain. There are two main presentations of fronto temporal dementia –frontal (involving behavioural symptoms and personality changes) and temporal (involving language impairments).

According to, Palmer et al., (2003) longitudinal studies have consistently demonstrated that patients with an amnesic type of mild cognitive impairment are likely to develop dementia at an annual rate of 12 to 15 %. At post mortem examination over 80 % of these subjects show neuro-pathological changes consistent with Alzheimer's disease, whereas fronto-temporal degenerations, Parkinson's disease, and cerebro-vascular disease are rare causes (Morris et al., 2001). The temporo-parietal type is characterized by impairments of memory, orientation, language, recognition and handling of objects (Whitehouse, 1986). While most people with Parkinson's disease do not develop dementia, 15-30% of people with Parkinson's disease will develop a type of dementia closely resembling dementia with Lewy bodies (Parkinson's disease Society, 2008).

According to Longley and Warner, (2002) approximately 50% of all people with dementia have Alzheimer's disease followed by vascular dementia (with or without Alzheimer features) and dementia with Lewy bodies (Iliffe et al., 2009)

2.4.2 Dementia Care in Ghana

In the early 19th century, patients suffering from dementia in Ghana were tagged as witches (Spittel and Wolf-Ostermann, 2013). Before that time, the only existing treatment was performed by traditional/faith-based healers and creating witch camps to enslave them. The first mental hospital was built in the capital, Accra, and during a long time the Accra Psychiatric Hospital was the only mental hospital in West Africa. The

hospital fast became overcrowded but has gone through several changes during the past decades, such as more educated employees and a higher number of staff

(Ewusi-Mensah, 2001). Today's psychiatric care in Ghana lacks a lot of resources when it comes to facilities, education and modern treatment methods. Currently, Ghana has three public psychiatric hospitals (Accra Psychiatric Hospital, Ankafu Psychiatric Hospital, and Pantang Psychiatric Hospital) with a total capacity to treat 1800 people. WHO (2017) estimated that 650,000 Ghanaians suffer from severe mental conditions and that 2.17 million more Ghanaians are suffering from moderate to mild mental disorders.) A study conducted by Wimo et al., (2007) indicated that the number of persons living with dementia in Ghana was approximately 39,916 people. Another study by Wimo indicated Costs of dementia in 2009 for Ghana as a country was \$87.9million, with persons living with dementia increasing to 45,302 as at the time This leads to a treatment gap of 98% of the affected population (Barke et al., 2011).

In a study by Spittel and Wolf-Ostermann, (2013) the research revealed that people in Ghana grow increasingly older and develop dementia. Furthermore, 46% of the survey respondents already met people who were in need of permanent care and support, most of them (71 %) with dementia. So far there are not any aged care facilities and skilled experts in geriatrics to take care of the dementia. Besides that, the public does not even know much about the disease. People in Ghana still accuse and condemn demented people to witchcraft which consequently must live in witchcamps or are beaten and killed.

In a study by Fournier (2011) from January to December 2010, at the Accra Psychiatric Hospital they recorded new patients of 258 having dementia with male 79 and female 179. In a news published by Ghana News Agency, Mrs Esther Dey, the

Executive Director of Alzheimer's Ghana, said the dangers of excessive use of mercury in "galamsay", which was a major cause of dementia in Ghana. Again, Dr Akwasi Osei, CEO of Mental Health Authority, said that the nation had not done well at all in terms of taking care of its aged persons and giving them the required professional and mental health care. Findings of a study conducted by Tabi et al., (2006) concluded that making decision regarding health care is a complex process which involves a wide spectrum of influences from traditional culture, religion, education, finance and economics, and family and friends. Physical, Psychological, Social and Financial Consequences of Caregiving.

Physical, Psychological Social and financial Consequences of caregiving

Even though research has generally broadened to look at the issues that caregivers encounter from conditions or subpopulations discussed earlier, one is able to identify four common domains that have been noted to lead to adverse consequences across most caregiving situations. They are the physical impacts on caregiving, the psychological impacts on caregiving, the consequences of caregiving on one's own family and social life, and the financial implications of performing a caregiving role in a long-term.

2.4.3 Physical Health of Family Caregivers

Brazil et al., (2010) asserted that physical health can be defined as an individual ability to fully carry out customary or expected duties for their age, sex, and social roles in their society. Regarding physical health, earlier studies were quick to identify that the considerable stress in caregiving that can lead to adverse impacts on one's physical wellbeing in clinically measurable ways (Animwaa, 2013; Grant et al., 2002; Schulz et al., 1995). Caregiving stress can result in blood pressure elevations Hirano et al. 2011

and greater risk of developing Hypertension, Low back pain or intervertebral disk lesion, Thyropathy Monoarthrosis, Ischemic heart disease, cardiovascular system diseases, Osteoporosis, Polyarthrititis, Headache syndrome and Diseases of the venous system (Gräsel, 2002). Caregiving stress can lead to a caregiver being deprived of food, warm, and clothes for family caregivers (Shaji et al., 2002). A study by Allen-Holmes et al., (2000) indicated pertaining to the physical health of caregivers, many are factors can prompt a severe physical health with traits leading to a psychological illness The stress of being a caregiver can therefore reduce the ability of one's own immune system to function optimally, making the caregiver more susceptible to infections and illness.

Creado et al., (2006) in comparing the level of functioning of caregiving in chronic schizophrenia with coping and burden in caregivers reported that high proportions of caregiver (68.8%) experienced at least one physical problem in one year before the study. However, approximately 12% of the caregivers had used outpatient and other services in that year.

Grant (1999) disclosed that caregiving may impact physical health by producing alterations in the sympathoadrenal medullary system, which is activated in the presence of a stressor. Short-term activation of this system results in a rise in plasma epinephrine and nor epinephrine, which in turn acts to speed metabolism, alter immune functioning, and increase heart rate and blood pressure in a transient manner.

In addition, Schulz and Beach, (1999) in their research, "Caregiving as a risk for mortality", studied the caregiver health effects of 392 older spousal caregivers and reported that caregivers who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregiving controls. They further stated

that physical health effects may be more difficult to detect because they take longer to develop and may not appear until after the caregiving role has been relinquished.

2.5 Psychological Health of Family Caregivers

The potential adverse consequences of caregiving on psychological health have also been investigated. A study by Shaji et al., (2002) which indicated, most caregivers reported psychological symptoms. General weakness and fatigability were reported by 15 (88%) and depressed mood was reported by 16 (94%) of caregivers. Five caregivers had suicidal ideation and one had tried. The caregiver who committed suicide had received a diagnosis of major depressive disorder earlier and was advised to take antidepressants. Most of the caregivers felt that their psychological well-being was adversely affected by the stress and strain of care giving.

Caregivers have been noted to have an increased risk of developing depressive disorders or suffering from significant depressive symptoms, when they are compared to matched control groups and population norms (Schulz et al., 1995; Haley & Bailey, 1999). Caregivers also report significant decrements in other indicators of psychological well-being. A study by Vaingankar et al., (2013) in whose study of caregivers reported of having psychological distress with some emotional responses including grief, sadness, anxiety, anger, guilt, blame, fear and embarrassment. Pinqart and Sörensen (2003) also stated that emotional experiences are the biggest challenge faced by caregivers.

2.6 Social Burden of Family Caregivers

With the physical and psychological impacts aside, caregiving has also been acknowledged to have very serious implications for the quality of relationships and cohesiveness between the caregiver and other close members of the caregiver's family as well as the society. One notable consequence is that performing caregiving duties

can drastically reduce the amount of time available for the caregiver to interact with their other family members, and friends (NAC & AARP, 2004). Supervision of a care recipient often leads to substantial reductions in the vacations, hobbies, and leisure activities that a caregiver can independently undertake, a consequence that may worsen over time as the care recipient becomes increasingly incapacitated (NAC & AARP, 2004). Furthermore, as social contacts become increasingly difficult to be adequately nurtured and, social interaction and participation in social activities decline, caregivers face Family during caregiving duties (Shaji et al., 2002). The fact that the time when caregiving duties are getting more demanding, is likely to coincide with less social support being readily accessible, is one of the most unfortunate social outcomes of the caregiving experience (Perkins et al., 2007). Since many caregivers become socially isolated in the course of adopting the caregiving role (Pinquart & Sorensen, 2006)

2.7 Financial Burden of Family Caregivers

The decision to undertake caregiving duties can result in substantial financial penalties to the primary caregiver and their family (Langa et al., 2001). Financial difficulties can arise from being unable to fully participate in the workforce, due to inflexible scheduling demands and the inability to undertake work outside of the home setting. Another factor is that the level of supervision and care provided depending upon the caregiving scenario can be unpredictable, leading to difficulty in securing continuous employment with benefits, or cessation of employment due to increased caregiving responsibilities (Schulz et al, 2003). A further consideration is that an alternative caregiver is required to fill-in for the primary caregiver. If a formal caregiver is employed, then the financial benefit derived from the outside employment is reduced.

Otherwise, one has to find an alternative caregiver, who has the time and resources to freely commit to the caregiving duties in the absence of the primary caregiver.

The “career” of a caregiver can span many years and therefore the earning capacity of a primary caregiver, coupled with out of pocket expenses that can accrue with caregiving, can greatly interfere with the financial status of the primary caregiver and indeed the rest of their family. This can place a chronic financial strain on the caregiver, which can lead to an inability to invest for their current personal and future retirement needs, or even the abandonment of planned retirement in response to the caregiving role.

2.8 Coping Strategies of Family care givers

Coping strategies are behavioural and psychological efforts employed to overcome, tolerate or reduce the impact of stressful events (Cooper et al., 2008) .Caregivers of people with dementia experience high rates of clinically significant anxiety (10–35%) and depression (10–34%) (Cooper et al., 2008). Two of the more active researchers on coping over the past decade are Folkman and Lazarus ((Lazarus and Folkman, 1984; Folkman & Lazarus, 1980,1985). They suggest that coping has two major functions, namely, "the regulation of distressing emotions (emotion-focused coping) and doing something to change for the better the problem causing the distress (problem-focused coping)" (Folkman & Lazarus, 1985, p. 152) and also between active or approach and passive or avoidance coping (Moos et al., 1990). Problem-focused coping is oriented toward resolving challenges, while emotion-focused coping is geared to managing emotions. Approach coping includes attempts to reappraise, modify, and solve problems, while avoidance coping is related to attempts to avoid problems and engage in indirect attempts to reduce distress. Both approach and avoidance coping can be

classified as either behavioural or cognitive (Moos et al., 1990). Both types of coping may use both behavioural and cognitive reaction modalities. These two coping dimensions closely match a distinction that is quite prevalent in the coping literature (Billings and Moos, 1981; 1984; Pearlin and Schooler, 1978; (Wong and Reker, 1984).

Coping skills were also found to significantly reduce depression and stress among caregivers while also reducing behavioural problems (Marriott et al., 2000). Zarit and Zarit (1982) concluded that "interventions to improve the coping ability of caregivers and the support they receive may relieve the physical and emotional burden they are experiencing". Younger caregivers are also more likely than older caregivers to come up with solutions to problems, probably because they have more knowledge and resources than older caregivers and caregivers with poorer health are less likely to use wishful thinking or avoidance to cope with distress (Kramer, 1993). One resource which has been found to facilitate coping is leisure involvement (Sneegas, 1988)

Bass, (2002) and Folkman, (2008) pointed out that coping strategies alone are not effective against caregiver stress, and that the response will depend on the nature of stressors. However, Greenglass (2002) has observed that the management of stress by coping increases the quality of life.

The researcher used the various component of Coping strategies, a coping strategy tool will be adapted, known as The Ways of Coping Checklist (WCCL). The Ways of Coping Checklist (WCCL) is a relatively new measure of coping that was derived from Lazarus' transactional model of stress (Aldwin et al., 1980); Folkman and Lazarus, 1980). The tool is a 66-item checklist of stress and coping pattern. In this model an event is considered stressful when a person appraises it as potentially dangerous to his or her psychological well-being (Lazarus, 1966). Such an appraisal may be influenced

by a person's beliefs or personality and generate cognitive expectancies which affect both emotion and behaviour. The tool was used qualitatively to assess the ways caregivers of dementia patients cope under stress from their care giving duties. In arriving at the coping strategies of caregivers of dementia patients, the research used some component of the WCCL such as Confrontive Coping, Distancing, Self-controlling, seeking social support, Accepting Responsibility, Escape Avoidance, Planful problem-solving and Positive reappraisal.

Some of the caregivers had never used Confrontive coping strategy to any stress or psychological hiccup they had encounter while in their care giving duties. Some of the participant's emphasises that they had used Distancing coping strategy while in their care giving duty. The caregivers used some components of Distancing strategy thus, „Went on as if nothing had happened“, „didn't let it get to me; refused to think too much about it“, „Made light of the situation; refused to get too serious about it“. **2.9**

Support systems available for family care givers of dementia patients

Providing effective interventions to reduce care burden is a vital aspect in providing quality care to dementia patients. Dementia caregivers have different needs; therefore, cannot assume that the same intervention will work among caregivers of various backgrounds and cultures (Gallagher-Thompson et al., 2003). Belle et al. 2006, said that, Caregivers with high school education or less responded more favourably to the interventions than those with higher education.

One of the vital support systems available to caregivers of dementia patients in (Wright, Pratt & Schmall ,1985) the faith-based support. Wright et.al. 1985 noted that, Families who use "spiritual support" as a support system seek advice from clergy, attend

church services, participate in church activities, and express faith in God to enrich their relationship with the individuals involved and with God. (Wright, Pratt & Schmall, 1985).

Care and support from family members, as well as from friends and neighbours, are typically referred to as informal social support. The structure of the informal network is often used as an indicator of social support (Burton et al., 1995). Informal support can be one of the vital support services available to care givers.

Selwood et al., (2007) systematically reviewed short- and long-term psychological interventions for caregivers suggested that teaching caregivers coping strategies is an effective method for relieving caregiver burden and that one-to-one teaching is more effective than group sessions. The authors found no evidence for the efficacy of interventions solely containing an educational component, group behavioural therapy or supportive therapy (Selwood et al, 2007).

Psychosocial interventions for caregivers in combination with cholinesterase inhibitor therapy for the patient have also proved successful for reducing caregiver depression. Combined drug and psychosocial approaches in the management of patients with AD may be more effective in reducing caregiver burden, though further studies are warranted (Mittelman et al., 2008).

Telephone based support programmes could be practical low-cost interventions for reducing caregiver burden in some situations. For example, in a study that investigated an automated telephone support system for caregiving spouses of patients with disruptive behaviour, tele-support showed significant benefits when compared with a usual care control group (Mahoney et al., 2003)

Most currently available interventions are “face to-face” interventions, but the predicted increase in the number of people with dementia has led to concerns about whether the current labour force can cope with such an increased future demand (Macdonald and Cooper, 2006).

E-health interventions could be an efficient alternative to continue to provide education and support for informal caregivers (Glueckauf and Loomis, 2003; MartinCarrasco et al., 2009) at reduced costs (Lewis et al., 2010). In addition, interventions offered via the Internet likely exhibit a lower threshold of access for participation because informal caregivers can access help in the privacy of their own homes without leaving their loved ones alone. Technology can also reach people who are isolated and have difficulties accessing traditional services (Serafini et al., 2007). Internet interventions might help future informal caregivers cope with the challenges of caring for a person with dementia and, thus, may keep patients at home if possible (Robinson et al., 2009).

There is increasing recognition that psychosocial interventions make an essential contribution to dementia care (Bird et al, 2009; Graff et al., 2006; Livingston et al 2005; Mittelman, et al., 2006; Pinquart & Sorensen, 2006; Sorensen et al., 2002; Spector et al., 2003; Teri et al 2005, 2005; Woods et al, 2005) and may be cost effective (Knapp et al., 2006).

Psychosocial interventions may target the person with dementia, their family carer or staff and may cover a range of domains such as mood, well-being and behaviour. The re-definition of traditional approaches to rehabilitation has recently been applied to dementia care (Marshall, 2005; Mountain, 2005).

Education, social support, counselling and multi-component programs are major strategies of interventions needed by family caregivers (Acton & Winter, 2002; Visser-

Meily et al,2005). Providing education is the most common intervention and nurses are often assumed as the most appropriate persons for providing caregiver education (Wiles et al., 1998). The reported outcome indicators for the interventions vary in different studies, including increasing caregiving knowledge and skills, coping strategies, caregiver strain or burden, quality of life, quality of care and family function.

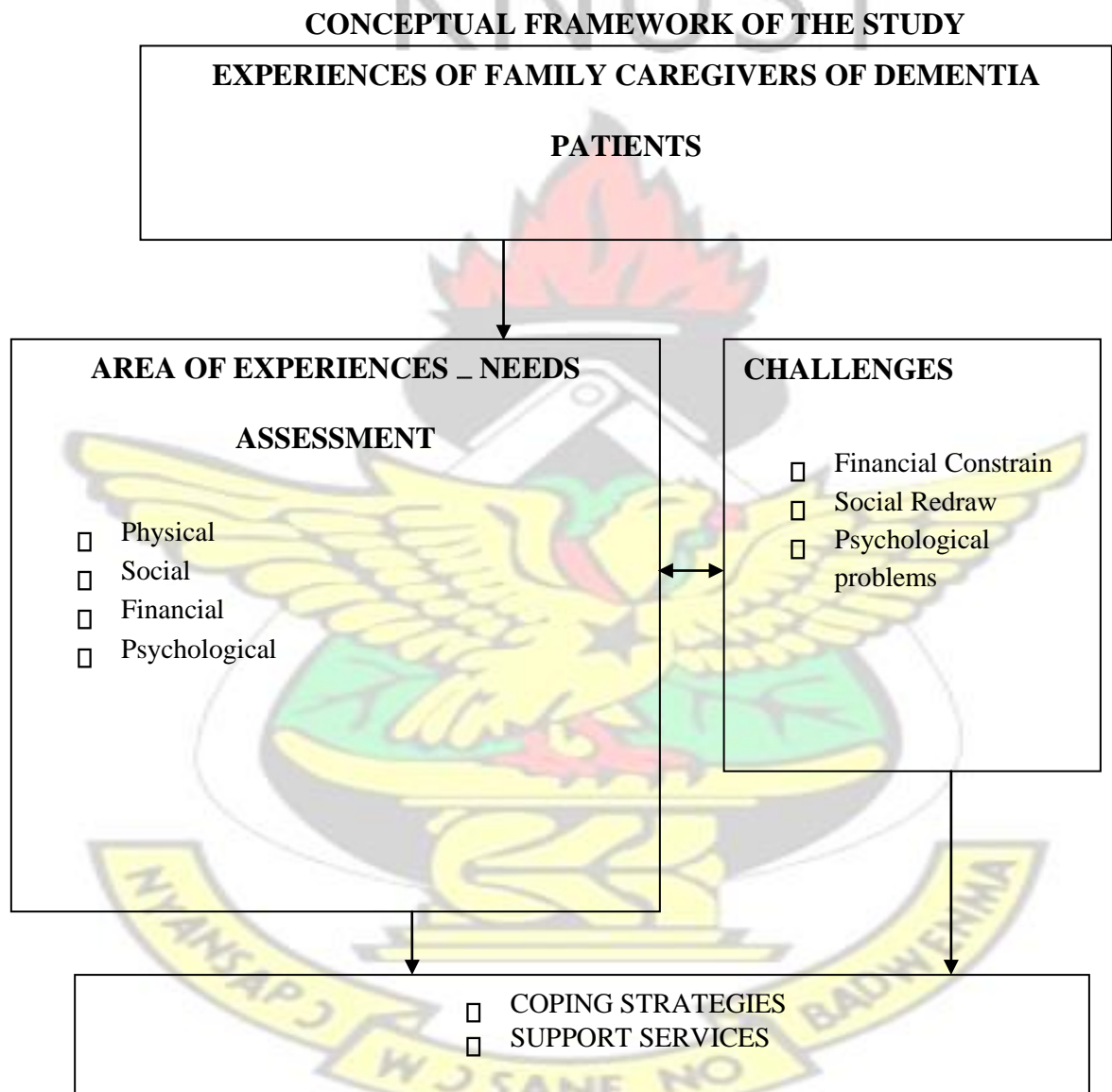


Figure 2.1 Conceptual Framework of The Study Source: Author's construct, 2018

The conceptual Framework describes the ideas that underpin the study and how the expected outcome could be realised. The main themes under which the research was

conceptualised were the needs of the family caregivers and how these affected their daily lived experiences. They are the physical impacts on caregiving, the psychological impacts on caregiving, the consequences of caregiving on one's own family and social life, as well as the financial implications of performing a caregiving role in a long-term. All these were assessed to explore how they affected the caregiver; and the coping strategies adopted and support services provided to cater for their needs.

2.9.1 Conclusion

This chapter captured literature on the various needs of caregivers in relation to physical, social, psychological and financial needs. A brief history of dementia was underlined in this session and caregivers' burdens were reviewed. The various coping strategies were also provided in this chapter. A rigorous analysis of Support services available for the caregivers was also provided.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter discussed the method employed for the study. This included the research setting, study type and design, population and sample size, sampling technique, data analysis, credibility and trustworthiness of the data, and ethical consideration

3.2 Research design

Research design forms the methodological framework for the study. All other components of the methodology were chosen based on the design employed (Maxwell, 2008). In the opinion of Bhattacharjee (2012), research design could be described as a

“blueprint” for empirical research aimed at answering specific research questions or testing specific hypotheses and must specify at least three processes: the data collection process, the instrument development process and the sampling process.

The study employed a phenomenological design because Van Manen (1990), explained that phenomenological approach to a study aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. Creswell and Poth, (2017) asserted that phenomenological research is well suited in situations where the goal is to understand people’s „common or shared“ experiences. He also points out that the analysis of experiences is important to understanding „practices or policies or to develop deeper features of the phenomenon“ (Creswell and Poth, 2017 p. 60) .Van Manen explained, „Phenomenology asks for the very nature of a phenomenon, for that which makes a some- „thing“ what it is – and without which it could not be what it is Van Manen 1990, p.10) The job of the phenomenologist is to deeply explain and interpret a phenomenon so that the reader can understand the „lived quality and significance of the experiences in a fuller or deeper manner“(Van Manen 1990 p.10) . Phenomenology also takes this experiential essence and carries with it a „moral force“ that may influence others“ actions and choices (Van Manen 1990). My primary target was that by understanding family caregiver’s experiences through phenomenological study, our appreciation of their experiences would be better valued.

3.3 Study Population

The total number of patients who visited the Komfo Anokye Psychiatric Hospital for evaluation from 1st January 2018 to 24th December 2018 were One hundred and fiftysix (156). A total of nineteen(19) dementia patients have visited the hospital from 1st January 2019 to 5th February 2019 for psychiatric evaluation. The various forms of

dementia cases reported at the psychiatric unit were, vascular Dementia, Senile Dementia, Alzheimer's and Pseudo Dementia. Vascular dementia reported the highest with a total of one hundred and twenty-eight (128), Senile dementia followed with a number of twenty (20) patients, Alzheimer's with a number of seven (7) and Pseudo dementia with a number of one (1) dementia patients.

The target population for this study comprised of family caregivers of dementia patients who took their dementia patients to hospital at Komfo Anokye Teaching Hospital(KATH).

3.4 Sampling and Sampling Techniques

Purposive sampling technique was used, to select family caregivers of dementia patients to provide the necessary data for the study .The specific characteristics that warranted a purposive sampling are captured under the heading eligibility criteria.

This technique allowed the researcher to pick a selected group of individuals most appropriate to answer the questions and select the specific information sources required to gain insight into the research study. An availability sampling was also used to select 18 participants, of which 13 were females and 5 were males. The participants were sampled from the population of patients who visited the Komfo Anokye Psychiatric Hospital for evaluation.

3.5 Eligibility criteria

In selecting the participants for the study, the research set the following criteria for inclusion:

1. The family caregiver should be able to express him or herself either in Twi (the local dialect of the area), English language or both.
2. Family caregivers must have been involved in caregiving for at least a year to provide detailed responses for the research.

3. Participants should be 18 years or over, to constitutionally be matured to answer question.

3.6 Data collection instruments and procedure

Since the study employed a phenomenological approach in examining the experience of family care givers of dementia patients, an in-depth interview guide was employed. The main questions covered in the interview guide include the needs of family caregivers of dementia patients, coping strategies employed in giving care and the support services available. Between December and January 2019, the study interviews were conducted at Komfo Anokye Teaching Hospital (KATH); Psychiatric Unit after approval from the Research and Development unit of KATH was sort and given for the principal investigator to commence research.

3.7 In-depth interview

In-depth interview guides were used to seek qualitative data from the respondents. In interview, the interviewee is granted the opportunity to talk freely about the events, behaviours and belief in relation to the objective of the study (Saunders et al., 2009). Where further clarification was needed, respondents would be probed. In the opinion of Saunders et al., (2009), respondents may use words in a way and the opportunity to probe these meanings will add significant and depth to the data the researcher may need. Hence, it may lead to discussion into other areas that might have skipped the attention of the researcher but are significant for understanding, and which help the researcher to address the study objectives and questions (Saunders et al., 2009). The interviews were tape Recorded.

3.8 Data Analysis

Data were analysed by screening and reviewing all the field and interview notes for understanding. Predominant themes were collated and then analysed using interpretive phenomenological analysis. Interpretative phenomenological analysis (IPA) recognizes that different people perceive the world in very different ways, dependent on their individual personalities, prior life experiences and motivations. It attempts to explore/understand/make sense of the subjective meanings of events/ experiences and states of the individual participants themselves. (Smith and Osborn, 2004). The analysis constitutes transcribing, reading, reflective writing, and interpreting rigorously (Laverty, 2003). The transcription was done verbatim, that is there were no omission of any part of the original recording when transcribing. Upon examining the transcript and listening to the audio tapes severally to get a glimpse of the surrounding and setting in which the interview was conducted. Each reading and listening helped to get a new insight into the study. The reading was done by the research and his one assistant as helper. The themes were derived directly from the experiences obtained from interacting with the respondents rather than the prior theoretical standpoint of the researchers. These themes were compared to the responses to identify common trends, similarities and differences. The interpretive phenomenological analysis provided the opportunity to identify, analyse and report patterns within the data and help to organize and describe the data in rich detail.

Direct quotations from the respondents were used to support the analysis.

3.9 Credibility and Trustworthiness of the Data

A consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews developed by Tong, Sainsbury, & Craig (2007) was adopted as a checklist to underpin all interviews and the qualitative procedure. This checklist

assesses the credibility and trustworthiness of the data and is a strong and scientific analysis of credibility and trustworthiness in data collection.

3.10 Reliability of the Data

A pilot study was conducted for 13 family care givers at South Suntereso Hospital. The 13 family care givers comprised 4 males and 9 females: they were interviewed for thirty minutes on 6th November 2018 in the morning starting from 9:00am to 9:30am, since their evaluation starts at 10 am, so had to be done earlier. Trustworthiness was adopted to ensure reliability and validity. Trustworthiness in this study was ensured by emphasising strongly on credibility, transferability, confirmability and dependability using purposive sampling, member checks were done.

Ethics Consideration

Ethical clearance for fieldwork was, obtained from the Committee on Human Research Publication and Ethics. The Clearance number: CHRPE/AP/070/19, School of Medical Sciences at the Kwame Nkrumah University Science and Technology (KNUST) and Komfo Anokye Teaching Hospital (KATH), Kumasi with the Clearance number: RD/CR19/005. The purpose, potential benefits and risks of the study, were explained to the participants and they were well informed that they had the right not to withdraw from the study any time they felt not to participate in the study. The Nuremberg Code established the concept of „voluntary consent“ in human experimentation and has since served as a model for developing and accessing ethical practices in the social and behavioral sciences (Coontz,1999). Respondents were also assured of strict confidentiality of the data they would provide. Participation in the study was declared voluntary and study participants were given the freedom to opt out of the study anytime they deem fit (Coontz,1999).

3.11 Study Area

Komfo Anokye teaching Hospital (KATH) is in Kumasi, the regional capital of Ashanti region. Kumasi had a population of 4,780,380 as at December 31, 2000(KMA, 2000) KATH have several departments within the same environment, including, ENT department, psychiatric, Physiotherapy, eye department, child health department etc. The psychiatric unit house a hand-full of patients but majority of the patients commute daily to visit the hospital for evaluation.

3.12 Conclusion

This chapter described how information for the study was gathered. It explained the study setting, the methods and design used, population and sample size, sampling technique, data collection tools, data processing and analysis, credibility and trustworthiness of data and ethical consideration. Chapter four presents the findings from the interviews and the observations.

CHAPTER FOUR

4 RESULTS

4.1 Introduction

The previous chapter was devoted to the methodological framework of the study. This chapter of the study focused on the analyses of the data collected from the field with the caregivers of dementia patients through interviews at the Komfo Anokye Psychiatric Hospital. Basically, the aim of the study was to look at the needs of family caregivers, the coping strategies used when under difficult conditions and the support services available for them as caregivers. With this aim in mind, the specific objectives of the study were in three folds and these were: a) Explore the needs of family caregivers of

dementia patients b) Identify the coping strategies of family caregivers of dementia patients. c) Assess the support services available to family caregivers of dementia patients

4.2 Background of Participants

A total of eighteen (18) participants who were all family caregivers of mentally ill people were interviewed and they played various roles as mothers, fathers and siblings to the patients.

4.2.1 Gender

The findings showed that out of the eighteen (18) participants, thirteen (13) representing 72% were females and five (5) representing 28% were males. Proportionately, the number of females giving care was more than the number of males at the facility.

4.2.2 Age

It was found that only two (2) representing 11% participants were above 70 years. The mean age of the participants was 52.1 and the standard deviation for the participants were 7.95.

4.2.3 Education

The study revealed that, 11% of the participants were school drop-outs, 17% of the participants have had primary school education, while 17% of them indicated they went up to junior high school and 11% were identified as having attained tertiary education. Majority of the participants were identified as having no formal education, that is almost half of them representing 44% participants.

4.2.4 Occupation

The study revealed that 50% of the participants had no job or work

Religion

In relation to religion, most of the caregivers were regarded as being affiliated to a certain religion denomination, only 11% participants did not have any religious association. More than half of the participants were regarded as Christian representing 72% and 17% were Muslims.

4.2.5 Marital Status and Other Interests

Finally, it was found that, caregivers had other competing interest aside caregiving. Majority of the participants 67% were married with children and even those who were single, co-habituating and separated had children and other relatives to fend for. Also concerning caregivers' relationship to patients, it was identified that more mothers were caregivers. Other relationships found were, father, brother, sister, uncle and paid person to do the caregiving job.

4.2.6 Number of years spent providing care

The study indicated that majority if the participants, that is 56% of them have been providing care between first to fifth year, while 33% of the participants have provided care within 10years duration. The Longest servicing caregivers have been providing care for the relatives from 10 to 15 years now.

Table 4.1 Background of Participants

Demographic Variables	Frequency (n=18)	Percentage (%)
Gender		
Female	13	72%
Male	5	28%
Age		
30-40	4	22%
41-50	5	28%
51-60	4	22%
61-70	3	17%
71-80	2	11%
Education		
School dropout	2	11%
Primary school	3	17%
Junior high school	3	17%
Tertiary education	2	11%
No formal education	8	44%
Occupation		
Farmers	1	6%
Traders	1	6%
Civil servants	1	6%
Private workers	6	32%
No Occupation	9	50%
Religion		
Christian	13	72%
Muslims	3	17%
Other religions denominations	2	11%
Marital Status		
Married	12	67%
Single	2	11%
Co-habituating	2	11%
Separated	2	11%
<u>No of Years spent giving care 1-5 years</u>		
	10	56%
6-10 years	6	33%
11-15 years	2	11%

Source: Author's construct, 2018**4.3 Needs of Dementia Caregivers.**

From the findings the researcher identified four main needs, that is, Physical need, Social needs, Psychological needs and Financial needs.

4.3.1 Physical Needs of Family Caregivers

Abraham Maslow's (1943) book, „A Theory of Human Motivation“, identified Physical needs as the Physiological Needs (Physical Needs) which includes food, water, shelter, disposal of bodily waste, clothing, sleep, sex and breathing. In many instances family caregivers jeopardise themselves in pursuit of the wellbeing of their patients. The research participants were asked some questions that made it possible to get a concise feel of their physical needs; some daily activities they performed as family caregivers, as caregivers the challenges they faced in their daily care giving and how their patients were involved in their care.

4.3.2 Activities performed by Family Caregivers

The caregivers explained that patients with mild conditions assisted in the caregiving like their oral care, physical cleanliness of the patients and feeding. Patients with severe conditions made it tough for caregivers, as caregivers performed almost all activities. The activities performed by caregivers were different depending on the patient's conditions and how severe or serious the condition of the patient was. The attention given to the males was more difficult than the females as most of the males were reported to be aggressive because they become disoriented, having difficulty recognizing friends or family members, identifying what time or day it is, or even misplacing items.

The participants recounted:

„When she faced the condition, she cannot do anything. In terms of bathing, brushing and other stuff is done by me. She starts by talking to herself and

difficult to talk to her. In terms of daily living is very difficult but my son take care of her also. Is not easy my brother we have been married for 43 years and I tell you that commitment of „for better for worst“ is not easy.” (Participant 6)

“We have a house help who is been paid to help us cook, bath and dress my wife. My wife cannot do anything for herself and is totally incapacitated” (Participant 7)

“Daily and functional living activities is done by herself in terms of bathing and brushing. But in terms of feeding, I cook the food for her and make sure she eats”.
(Participant 16)

“When we wake up in the morning, I feed him food but does activities like bathing, brushing and daily disposable of waste by himself.” (Participant 9)

4.4 Physical Challenges of Family Caregivers

In weighing the amount of physical challenges the caregivers go through could be equated to the condition of the patients, that is, they face highly vulnerable situation without no medical personnel noticing. These situations make it difficult for caregivers to deliver their duties effectively and carefully. Some of the challenges caregivers faced while giving care to their patients included, inability to sleep, lack of sexual intercourse and high blood pressure, deteriorating relationships, fatigue and severe pain.

Some participants narrated:

“She wakes up at night and talks, for three continuous nights you cannot sleep. If I have to sleep, I only do it in the day time and lock the doors so she cannot move out. ”

(Participant 8)

„She is a bit violent and sometimes leaves the house. The relationship between our children especially the females have deteriorated since she left the house for four days and we could not find her and was at a church, where the Pastor proclaimed her as witches and she said she is not a witch so it turns violent and the police had to be called in to solve the case which ended in court. „

(Participant 18)

„Her condition started three years ago and as the only woman in Ghana currently, I have to take care of her and I also have a family and a husband but can you imagine I only had sex with my husband twice last year and he is a man, he have needs but I cannot go to Accra always to see him because of my mother.““ *(Participant 15)*

“At times he doesn’t talk to you for like 3 days and he gets angry easily, it has not been a fruitful year for me, I think my blood pressure has gone up since he was diagnosed with dementia. ” (Participant 9)

“She sometimes attempts to run away, when the condition becomes critical, I can’t leave her to anywhere, I am stuck at home always.” (Participant 11)

In some adverse situations, some participants expressed the joy, passion and happiness in giving care and knowing the fact that their dementia relatives are not well.

A few participants recounted:

‘‘At first it was difficult to accept the situation but now am okay with the condition.’’

(Participant 8)

‘‘She becomes sad and angry and removes the pampers and sometimes urinate on herself and even defecate on herself, is very difficult but still she’s my mother and did same for me as a child so I am repaying her with same love. ‘’ (Participant 2)

*‘‘Sometimes some of utterance may irritate you but I know it’s because of the condition
’’ (Participant 16)*

4.5 Social Needs of Family Caregivers

The study examined the social needs of family caregivers, the social activities they engage in aside giving care, their level of insight into patients’ medical condition and the social challenges they meet as a result of giving care.

4.5.1 Social Activities of Family Caregivers

Social gatherings like funerals, engagements and weddings, church services, family meetings, association meetings. were the social activities listed as caregivers used to attend. Conversely, almost all the participants expressed that, their participation in social activities was slowed down and not fully understood since they played roles as family caregivers to their relatives with dementia. Also, time was the major factor, family caregivers expressed as the force behind their inability to fully participate in social activities. A section of the participants had laid down criterion of their schedule time as to when and where to attend the social gatherings and the time to return. The study further found that, apart from family caregivers directly engaging in social activities, like funerals, they also access society resources as members of the society like, going to the market, farm, fetching water etc.

Some participants recounted:

“I can’t remember the last time I went to a funeral or wedding, I cannot leave her here by herself and is difficult.” (Participant 6)

“At first usually once a month I have drinks with my friends but for three years I cannot interact with anyone, because I cannot go and leave her indoors.” (Participant 11)

“We have a house help, so I go out freely for weddings and funerals but for church service I always go. ” (Participant 8)

“When I want to go out, I leave her in the room locked so that he doesn’t go anywhere. Especially when I am going to the bank for money, our children usually send money to us. ” (Participant 10)

A few participants explained that, attending to medical and rehabilitation care with patients is a social activity they had to deal with. As part of the social activities, it was also found that some participants saw visiting the clinic as a huge social activity they had to deal with.

A participant recounted;

“Even hospital check-ups are a serious issue, cos we have to take trotro three times to get to Komfo Ankoye, so imagine she talk and is not making meaning, someone will be staring strangely at you.” (Participant 1)

4.5.2 Social Challenges of Family Caregivers

Previous research had reported that family caregivers of dementia patients face several public backlashes (Ae-Ngibisei, et al., 2015; Shankar and Muthuswamy, 2007; Tawiah, et al., 2015).

The study examined the social problems family caregivers face in their quest to providing care for their relatives with dementia. Participants cited some of the challenges they faced to as: support from society, ridicule and mockery, alienation and rejection.

Two participants viewed society mocking as a cause for isolation from family members:

“ the town people were calling her witch, so we have to vacate the village and settle in Kumasi, because she was talking and didn’t make any sense” (Participant 13)

“We had to take her away from our hometown because she talks all over and it was same with my grandmother too, so the town people were saying, their family curse is madness in old age, aside that society is friendly.” (Participant 7)

Some participants expressed the rejection from friends as a result of the patient’s condition and withdrawn from certain social gatherings.

One participant explained:

„With the reaction from family, there isn’t any problem but most of my friends insist that I should take her to the family, because I have done my part of caring for her. With all the pressure from friends I still do believe that is not right to do because is not her fault for this condition. So, I always become sad of the way my friend behaves and say about my wife. So of late they do not come and visit me again and sometimes go for kotoko meeting alone as we went together always for years. „ (Participant 4)

It was identified that some people from the society often provided financial benefits to the patients. This was due to the instrumental role the patients played in people's life and seeing her now made them reciprocate the impact the patients had in others' life.

One participant recounted;

“Reaction from outside is not bad. My mother is an educationist. People see her and me and sometimes gives us money that it was reported she was sick, and they are sorry for ‘MADAM’.” (Participant 16)

Also, two participants in effect to reduce pressure from the society made it possible to hide the condition from the family and friends of their relatives. She noted that;

“So, most people do not really know if she is really sick or not, family and friends did not know she wasn't feeling well, and I have made sure people do not know of her condition. She lives freely. ” (Participant 7)

“I don't communicate to others about the condition of my mother. ” (Participant 11)

The research noted that due to available time on the part of the family caregivers, they are usually indoors, some resorted to sleeping and others who are the faith believers praying to their God. Some expressed the joy they have being at home and watching these television series and sometimes call in at radio talk shows to get social with the outside world.

4.6 Psychological Needs of Family Caregivers

The mental capacity that motivate people to achieve goals and perform certain activities defined the boundaries for what was meant to be psychological needs. A study by Tawiah et al., (2015) on the patients and their caregivers in Ghana found that the experiences of family caregivers of mentally impaired patients face a lot of emotional trauma. The study examined the knowledge some caregivers had about the condition of their

relatives and the psychological challenges family caregivers faced in the process of providing care.

4.6.1 Insight into patients' medical condition

The research(as a measure of assessing the social needs of family caregivers) explored participants level of insight into patients' medical condition. Questions were asked about caregivers' knowledge on patients' diagnosis, drugs, food to be consumed and out of bounds behaviors. Majority (11) of the participants explained that they were informed about patients' out of bounds behaviors by medical officers.

Almost all participants indicated that they had little knowledge on patients' diagnosis.

Some participants explained:

“When we talk, and she says something that’s not correct I detect her sickness has come” (Participant 14)

“At times he wakes up at night and can’t sleep then I know the condition has come again.” (Participant 5)

“For me when my mother’s mood changes and she sits down quietly for hours, I know the condition has come, so I make her rest for a while. ” (Participant 3)

4.6.2 Psychological Challenges of Family Caregivers

Caring for dementia patients may bring some psychological interruption for the caregiver and this anomaly normally goes unnoticed. Family caregivers experienced a lot of psychological stress and agony. Participants mentioned some of the following psychological challenges; stress as a result of finance, shock and sadness.

Some participants recounted:

„Psychologically, it has affected me because without the sickness, he used to assist me by selling the farm goods we produce but now I have to do it everything by myself, when is getting to farming day, I start to think of him and keeps mute the day before, is worrying to know he is here bot not here with me. „“ (Participant 15)

“Almost every day to clinic visit, I start thinking because her bills and drugs are very expensive, even now the drug they gave us for her during our last visit, I haven’t bought them, I have to come to the village and see if my cocoa money is ready. ” (Participant 12)

“We have married for 43 years and she never shouted at me but when the sickness comes, she treats me as if I am not there, but now I know is the condition so, I don’t think as I used to, am okay.” (Participant 10)

4.6.3 Financial Needs of family caregivers

Family caregivers in their quest to providing care for their relatives put their financial standard at risk. Since everything about the conditions demands a financial sacrifice, caregivers go through a lot of emotional distress in meeting their financial needs. In arriving at the financial needs of family caregivers, participants were asked about their routine in relation to employment, healthcare expenditure, thus the sources of funds for their healthcare and family stability in the society.

4.6.4 Employment duties of Family caregivers of dementia Patient’s

Many researchers have been specifically concerned with the contributions made by informal caregivers and how employment impinges on these contributions (Brody and Schoonover, 1986; Cantor, 1983; Doty et al., 1998; Gibeau and Anastas, 1989;

Scharlach, 1994). Family caregivers managing patients with mild conditions expressed their ability to be employed within the day but those with patients whose conditions are severe made it emphatic that they were not employed. Some stated that they had meaningful employment until the conditions of their relatives emerged. Only one of the patients indicated that they made money from the caregiving duties, as they were sorted after by the family members to take care of their relatives.

Participants expressed their concerns as:

“Since the condition in 2003, I have not been employed but it was left with only two years for retirement, so I wanted to go into farming but now I cannot, so we survive on my pension fund and small small from my children. ” (Participant 3)

“My mother’s condition is not that serious, so I have a shop in front of our house, where I sell provisions. The shop fetches a little, as we can depend on it for our daily consumption but sometimes the drugs are expensive, but I manage” (Participant 17)

“My brothers and sisters are in abroad am the only one left here, so when her condition came I had to move and stay with her, since then I haven’t worked but every month they send me money through Western Union or mobile money, At least my husband understands, so financially, is okay for now. ” (Participant 6)

The participants that were tasked to look after the dementia patients for a living said:

“My auntie called me if I will look after some old woman and I said yes and she told me, they will pay you, so I came and they pay me for looking after her but is difficult, she can talk plenty it doesn’t make sense, if not for the money I would have left but my brother in school looks after me for money. ” (Participant 11)

4.6.5 Healthcare Expenditure

With healthcare expenditure the researchers examined the amount of money involved in hospital evaluation visit, transportation, drugs, scan, laboratory and accommodation.

Participants were asked some imperative questions to ascertain how they provided care and its effect on their healthcare expenditure.

Some of the participants recounted:

“We have registered the national Health Insurance, which they say is free for 70 years and above, they don’t take anything from us but for scan, laboratory and Drugs we pay, which is the most expensive ones too.” (Participant 4)

“Her condition is draining me, I mean, I have spent a lot of money on her, you can buy one drug for 350gh cedis and is not the only cost.” (Participant 18)

“She got lost for days and went to some church and was blamed to be a witch and some issues happened and it turn into a court case and we paid huge money, is because of her condition we paid that money, due to that her relationship with our daughters have deteriorated, I survive to look after her with my pension money and is difficult.” (Participant 8)

4.6.6 Coping Strategies of Family Care Givers Dementia patients

On the question of coping strategies respondents adopted as caregivers of dementia patients indicated various strategies such as: Positive reappraisal, distancing, selfcontrolling, escape avoidance, accepting responsibility.

Respondents gave some of their responses as:

“When she shouts at me, I do not react, because I know is the condition. At first, I was very worried but now I know is because she is sick.” (Participant 11)

“He removed the pampers and urinated on the floor, I just clean it and move on. He was a decent man and PAPA would never do that, so I didn’t take it seriously.” (Participant 16)

Some of the participants used major components within the Self-Controlling coping strategy technique. The components include, „I tried to keep my feelings to myself“,

„Kept others from knowing how bad things were“ The participants narrated as follows:

“I don’t discuss anything with anyone unless close and immediate family members, who would like to know how she is faring” (Participant 1)

“So, most people don’t really know is she is really not fine, even family and friends, did not know she wasn’t feeling well, and I have made sure people don’t know of her condition” (Participant 7)

“I don’t want a lot of people to know about his conditions, so I don’t talk to people about her condition except when one comes to the house to see her for herself. ” (Participant 5)

Again, participants used some components of the Seeking Social support .The various components used under the Seeking Social Support include, „Talked to someone to find out more about the situation, „Talked to someone who could do something concrete about the problem“, „I asked a relative or friend I respected for advice“ “I got professional help“, „Talked to someone about how I was feeling“ The participants recounted:

“My sister in-law is a nurse, so sometimes I talk to her about my mother’s condition and she advices me on many things, so now I know if her mood changes are normal.” (Participant 8)

“When we go to the hospital, some guy, he comes with his mother or so, I don’t know, but we talk and he encourages me, I think their reaction is the same, am okay now. ” (Participant17)

“Some nurse who is a guy at your hospital, I have his number so if the situation is difficult, I call him and he explains things, he is very helpful. ” (Participant 15)

Only one of the participants responded with using the Escape-Avoidance component of the Coping Strategy tool in managing the psychological hiccup they go through during

their care giving duties. The various sub-components of Escape-Avoidance includes: „“
Slept more than usual,

... If I have to sleep, I only do it in the day time and lock the doors so she cannot move out. That's the only time I can sleep and sleep well and I do it very often, I don't want to lose weight ‘‘ (Participant 14)

The most used component under the Coping strategy tool was Positive Reappraisal. Participants used at least almost all the sub-components of the positive Reappraisal and they included; „“Changed or grew as a person in a good way““, „“ I prayed““. Some participants recounted;

‘‘I do think a lot about the condition, hoping that she gets well but now I don't allow myself so much because I know Allah is in control. ‘‘ (Participant 15)

‘‘At first, I used to think a lot about the issue but now I have been able to adapt to the situation. To overcome the thinking, I pray with her or by myself. ‘‘ (Participant 9)

‘‘I used to take her to churches for healing, but now I have stopped all those. Now I rely on the hospital intervention for the management of her condition. ‘‘ (Participant 3)

‘‘For prayers it really helps me and her, such that at times, she doesn't want to eat but after praying with her, she is fine and eats well. ‘‘ (Participant 5)

‘‘I listen to radio preaching's and television as well; it has really help me in knowing god is in control, so I relax at times. ‘‘ (Participant 12)

4.7 Support Services available for the Family Caregivers

The study explored from participants, what they need in their physical, social, psychological and financial needs to promote their wellbeing. Various support services were outlined by the participants to meet their needs in caregiving. At least almost the participants indicated the ultimate support need they want is a financial support. They also said they needed assistants to help when they occupied with something. Some also indicated a better understanding of their relative's conditions and the things that trigger the conditions. Other participants wanted family support in difficult times.

Participants said:

“What I really need is financial support especially you can't leave him alone to do anything like work. Therefore, if you really want to have time ad work you can't, you have to always be with him. ” (Participant 18)

“In terms of support, my siblings help me to cater for her as well as our children also assist. I told the church about his condition since he is an elder, but nothing was done, the support I need especially is financial support. ” (Participant 6)

“So, at this moment the only thing I need is someone who understands me and can talk to, because my sisters and brothers cater for the medical bills. ” (Participant 11)

“At least their health services should be free so that we caretakers can be free of financial constraints.” (Participant 18)

“The family support is there aside me helping, my other siblings also support her financially when needed” (Participant 9)

‘‘For now, I need an assistance to help me when am busy doing something else. ‘‘
(Participant 2)

‘‘There should be a help line we call when we in trouble aside coming to the hospital, so we talk to the person for guidance, is difficult sometimes.’’ (Participant 13)

‘‘We are five children in all, currently am the only one looking at her, all I want is at least my siblings should come visit us, two of them are in Kumasi, one of them called me, some pastor said, our mother is the cause of her woes, can you imagine, is very sad, so they don’t visit us’’. (Participant 9)

Some participants also narrated that talking to their clergy was a paramount support to ease themselves as they could rely on what the Bibles says and gives them enough strength.

‘‘Our Pastor knows about my mother’s condition and normally comes over every Wednesday after mid-week services to pray and talk to us, I feel calmed after our meeting’’ (Participant 7)

‘‘One church elder is a nurse and he understand the condition better, so he helps me with anything worrying my mind and prays with me always’’ (Participant 10)

4.8 Conclusion

The findings from the study indicated that, participants have similar physical, social, psychological and financial needs. The various strategies employed to cope with any stress from the care giving duties, positive reappraisal was the most used. Majority of participants revealed that they needed financial support and enough information about their relative’s conditions.

CHAPTER FIVE

DISCUSSIONS

5.1 Introduction

The purpose of this study was to explore the experiences of family caregivers of dementia patients at Komfo Anokye Teaching Hospital. This section provides a summary of the key findings and discussion of the findings.

5.2 Demographic Analysis

Findings of the study showed that majority of family caregivers of the dementia (72%) patients were known to be females. This confirms with other research (Shaji et al., 2002; Yee and Schulz, 2000; Miller and Cafasso, 1992; López et al., 2005) which indicated that more females or women are engaged in dementia caregiving than their male counterpart. This could be due to the naturally inherent caring behavior of women and the motherly instinct. Proportionally, it was reported that most of the dementia patients were also females and is in accordance with national and foreign studies on dementia (Lopes and Bottino, 2002; Campbell et al., 2008). The reason may be because women live longer than men as reported in our Population and Housing Census. Again, dementia is more associated and prevalent among elderly women (George-Carey et al., 2012 ; Vale and Miranda, 2002) With respect to the age most caregivers between the ages of 30 to 50 were either daughters or daughter in-law but not necessarily sons and son-in-law.. (Montgomery, 1992). It was indicated that most of the family caregivers had no formal education and only a handful had some form of education be it, primary school, junior high and tertiary education. Most of them were private workers and majority of them had no employment and did the care giving fulltime, relying on

support from diverse people. Religion formed a basic core of their faith in life and most prayed to God or Allah for a change in their relative's condition.

5.3 The Needs of Family Caregivers of Dementia Patients

5.3.1 Physical Needs

Respondents indicated that their job of caregiving often made them experience high blood pressure, lack of sexual activity, inability to sleep, tiredness and too much thinking. Most family caregivers said they were deprived of food and other physiological needs such as water and clothes not because they could not afford but the caregiving role made it difficult for them to eat at home or at the hospital. Findings of the present study are consistent with others which indicated deprivation of food, warm, and clothes for family caregivers (Shaji et al. 2002).

With respect to physical health of family caregivers of dementia patients, some previous studies reported that stress from caregiving duties or role had adverse effect on the physical health of the caregivers (Gräsel 2002) where it was indicated that, active caregivers suffer more of these diseases like Hypertension, Low back pain or intervertebral disk lesion, Thyropathy Monoarthrosis, Ischemic heart disease, cardiovascular system diseases, Osteoporosis, Polyarthrititis, Headache syndrome and Diseases of the venous system. Again, a study by Hirano et al. (2011) indicated that, almost half of the caregivers were suffering from hypertension, as a result of their caregiving duties. Also, a study by Allen-Holmes et al., (2000) indicated pertaining to the physical health of caregivers, many are factors can prompt a severe physical health with traits leading to a psychological illness. Also, blood pressure elevations can happen as a result of Caregiving stress (King et al., 1994). Another serious physical health concern with caregiving is greater risk of developing cardiovascular disease (Lee et al., 2003).

Again, studies by Schulz et al., 1995; Schulz and Martire, 2004 suggest that family caregivers tend to suffer from depression and other negative mental health and physical health problems at higher rates than non-caregivers. This prompted the need to assess the physical needs and challenges of the caregivers and help increase their physical health as family caregivers.

As the study revealed that majority of caregivers lose sleep and have limited time to rest, it becomes needful as a physical measure that family caregivers find time to sleep and relax. Participants noted that they needed to sleep and take breaks in their roles as family caregivers. This confirms the recommendation by the World Federation for Mental Health (2014) that caregivers should be taking periodic breaks to do something that gives them enjoyment and peace, even if it is only a 10-minute break. Having enough sleep and rest is also an effective way of releasing stress, which Kiecolt-Glaser et al., (1991) posit can lead to compromised functioning of the immune system and more specifically, increase the healing time for standardized wounds.

Key among the physical needs of family caregivers is medical attention since some participants reported having experienced rise in their blood pressure and other ailments. During the interview session, it was detected through observation that majority of the caregivers experienced physical health risks which they were not aware of them to have medical attention alongside their dementia relatives is eminent.

There is therefore the need for respondents to also expressed the need to have a helping hands in order to effectively provide care to their dementia relatives.. Family caregivers in addition to providing care for their dementia relatives often have other competing roles of care-giving like, mothers and fathers to children, husbands and wives, family

heads and work duties among others . It is therefore necessary that family caregivers are physically assisted in providing care to their mentally ill relatives

5.3.2 Social Needs

The findings from the study indicated that family members, experienced family conflicts, feeling of loneliness, rejection of their self-worth by friends and family members and ridicule and mockery, alienation and rejection. These findings support findings of Shaji et.al. (2002) who recounted that family caregivers are left out of the social gathering due to their caregiving duties. Results of the study showed that caregivers could not attend various social gatherings due to their roles in caregiving for their dementia relatives. These findings are consistent with a study by Shaji et.al (2002), which emphasized that caregivers' social lives are often hampered by their inability to go out to attend, important functions like marriages. Perkins et.al (2007) have emphasized that whenever caregiving duties are getting more demanding, that is the time that caregivers are likely to receive challenging social support.

A study of interest which shared some similarities with current findings is the study of Shaji et al., (2002) whose findings reported that family conflict was commonly encountered during caregiving duties. Pertaining to interacting with the society, caregivers noted that knowledge about the condition limit their participation in societal activities. This is because people tend to ask more questions about the condition and sometimes associate it with societal and cultural interpretation which creates misrepresentation of the condition and social stigma for the caregivers. As caregivers gained more knowledge of the disease, they provided better quality of care and ensure quality social integration for them this is in concordances with some studies by Studies by de Andrade et al., 2009, Araújo et al., 2004 and (Bocchi et al., 2010. When caregivers

did not adequately understand the several possible manifestations of the dementing process, exhaustion and family conflicts are more probable for the caregiver Araujo et al., 2004. Since caregivers live in a social world and care giving exists in the societal arena, care givers should be provided with quality social care, adequate knowledge about the condition, mental change and family support.

It was found that family caregivers had little or no insight in their relatives' medical condition, which affects the efficacy of care they provided. For instance, Cahill et al., 2006 noted that having information about the medical condition would help caregivers on important aspects in patient's care such as what patients can consume and what behaviours they can engage in at certain times.

Wei et al., (2012) examined, the health education needs of family caregivers are mostly unmet. Other studies also indicated that knowledge about dementia can also help family members cope with caregiving support for dementia patients (Chien et al., 2001; Chien and Norman, 2003; Costello et al., 2007; Howerton et al., 2007; Jewell and Stein, 2002).

Respondents indicated the need to have insight into patient's conditions so as to be informed about some important details about their individual needs such as: what patients can or cannot consume and what behaviours are suitable for their condition. Winter and Gitlin, (2007) asserted that the food one eats has the potential to affect our mental health and wellbeing at every stage of one's life.

The stigma that attaches dementia, especially with most being tagged as witches and mad people exposes family caregivers to social rejection leaving them with emotional downturns. They therefore crave for the society to provide them with warmth and affection. Also, family caregivers need to be included in the various social activities so as to make them feel loved and appreciated for the care they provide.

Respondents indicated that members of society associated „dementia“ with witchcraft, curse and sorcery. As indicated in the results, some participants recounted their experiences to move their relatives from their town to another location due to name calling as witch. These findings are consistent with a study by Spittel and WolfOstermann, 2013, which said, in the northern part of Ghana, most dementia patients are tagged as witches and some are even in witch camps. Societal mental change involves alterations in the fabric of society which encompasses the social setting, people’s mentality and the ways things are done. Family caregivers indicated an imminent change in people’s negative mentality about dementia and the stigma they attach to it is imperative for their caregiving duties. It was found that society was more superstitious with the interpretation they gave to dementia other than being practical and scientific. If people’s minds are sensitized on dementia, caregivers and their demented relatives will get to live in societies free of discrimination against the demented and their families. Mental change can however be achieved through public education and understanding by people. A study by World Health Organization (2005) & Tawiah et al., (2015) concluded that mental health education needs to be intensified at the community level.

5.3.3 Psychological Needs

The mental capacity that motivate people to achieve goals and perform certain activities defined the boundaries for was meant to be psychological needs. A study by Tawiah et al., 2015 on the patients and their caregivers in Ghana expressed that the experiences of family caregivers of mentally impaired patients face a lot of emotional trauma. Family caregivers experience a lot of psychological stress and agony, particularly stress from overthinking and finance and tremor, grief, depressing. Frustration and fatigue due to demanding caregiving role.

The findings from this study is consistent with a study by Shaji et al., 2002, which indicated, most caregivers reported psychological symptoms. General weakness and fatigability were reported by 15 (88%) and depressed mood was reported by 16 (94%) of caregivers. Five caregivers had suicidal ideation and one had made an attempt. The caregiver who committed suicide had received a diagnosis of major depressive disorder earlier and was advised to take antidepressants. Most of the caregivers felt that their psychological well-being was adversely affected by the stress and strain of care giving. These findings are consistent with the findings of Vaingankar et al., (2013) which reported that caregivers reported of having psychological distress such as grief, sadness, anxiety, anger, guilt, blame, fear and embarrassment. These results support previous research that has shown that emotional experiences are the biggest challenge faced by caregivers (Pinquart and Sörensen, 2003)

5.3.4 Financial needs

The findings from this study showed that caregivers were saddled with financial constraints as a result of unemployment and full time caregiving. This is consistent with findings of a study from Gratao et al., (2010), which indicated that financial constraint was a major challenge for caregivers of demented patients. Respondents also reported that financial constraints as a result of lost employment.

The carers stated that constant worry about their standard of living often made them stressful. Vaingankar et al., (2013), stated that Caregivers need financial assistance to help them solve their financial problems. Findings of Vaingankar et al., (2013), are consistent with the present findings as caregivers recounted that they needed financial support to cater for drugs and scans.

Coping Strategy

Coping strategies are behavioural and psychological efforts employed to overcome, tolerate or reduce the impact of stressful events (Cooper et al., 2008). A study by Marriott et al., 2000 recounted, coping skills were also found to significantly reduce depression and stress among caregivers. This study sought to examine the different coping methods family caregivers of dementia patients used in reducing depression, stress, psychological hiccup and behavioural problems. The researcher used the various components of coping strategies, a coping strategy proposed, known as The Ways of Coping Checklist (WCCL). The Ways of Coping Checklist (WCCL) is a relatively new measure of coping that was derived from Lazarus' transactional model of stress (Aldwin et al., 1980; Folkman and Lazarus, 1980).

The tool was used qualitatively to assess the ways caregivers of dementia patients coped under stress from their care giving duties. In arriving at the coping strategies of caregivers of dementia patients, the research used some components of the WCCL such as confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, planful problem-solving and positive reappraisal.

5.3.5 Adequate Rest (Escape Avoidance)

The study showed that the caregiving role limits family caregivers to less rest. Adequate rest is very necessary to avert possible stress situations. The World Federation for Mental Health (2014) identified that caregivers should be taking periodic breaks to do something that gives them enjoyment and peace, even if it is only a 10-minute break, can help recharge you for the rest of the day. Such measures are necessary conditions to reduce stressors and our findings support caregivers using the escape avoidance coping strategy to reduce stress by way of sleeping more often.

5.3.6 Love and Affection (Distancing)

Responses from family caregivers show that need resorted to distancing coping strategy in order to deal with stress and not feel sad and worry much. Distancing is the bedrock of what family caregivers need, as they go on daily activities as if nothing that happen and refused to think too much about the situation. When the caregivers make light of situation and do not let the situation get to them, they get to release much stress and ease a lot of tension that come with their role. This enables them to share their psychological and emotional burden with others. Previous studies by Folkman et al., 1986; Schmidt et al., 2002; Cheng and Cheung, 2005 indicated that occasional distancing from the stressor in less controllable situations can often be better managed by changing one's emotional response through emotion-focused strategies. Also, a study by Au et al., 2010, of caregiver of dementia patients in Hong Kong normally resorted to Distancing coping strategy.

5.3.7 Counseling and Interaction (Seeking social support)

Social support has the strong potential to help us understand the dynamics and interactions between individuals and their social environment (Albee, 1982; Armstrong et al., 2005; Orford, 2000) Family caregivers also need assistance in the form of counseling and interactions that will psych them up and build their mental and emotional faculties to contain all the difficulties that come with caregiving. Counselling services for family caregivers of individuals with dementia were beneficial in allowing caregivers to express their feelings and concerns, to learn more about their loved one's illness, and to obtain guidance and advice related to caregiver issues (Bloch et al., 1995) and was in accordance with our findings as caregivers talk to people about the condition and find more about the situation.

5.3.8 Positive Reappraisal

Using „positive reappraisal“ as a coping strategy was positively related to measures of hopefulness and confidence and negatively to anxiety (Carver et al., 1989). This could be drawn from our findings as participants were hopeful and had high confidence by praying to a high God, their relative conditions would change and also, they would feel better as a caregiver.

5.3.9 Support services available for family caregivers

Dementia caregivers have different needs; therefore, one cannot assume that the same support service would work among caregivers of various backgrounds and cultures (Gallagher-Thompson et al., 2003). Most of the participants recounted, that the only support service they needed was financial stability. Psychologically some wanted to talk to more professional personnel about their personal and relative's issues concerning the condition. Another crucial support service participants reported was more of home-based support coming from the family members around them. Few participants reported seeking counsel from the clergy in difficult times of their caring giving role.

The findings of the study were consistent with other literature indicating some participants resorted to speaking to a clergy about their struggles in private than sharing it openly. One of the vital support systems available to the caregivers of dementia patients in a paper by Wright et al., (1985) was faith-based support. The paper notified that, families who use "spiritual support" as a support system seek advice from the clergy, attend church services, participate in church activities, and express faith in God. In effect it enriches their relationship with the individuals involved and with God. (Wright et al., 1985).

Again, family support was recognised as part of the support services needed for some family caregivers of dementia patients. Crucial among the needs of family caregivers is family support. Family support comprises the general contribution and show of commitment and togetherness in the caregiving process. According to family caregivers this show of support is compensatory enough for the troubles they face and make them not feel they have been left on the hook. It was however found that family support for caregivers is erratic leaving, the few individuals volunteering as caregivers to do everything. Care and support from family members, as well as from friends and neighbours, are typically referred to as informal social support. The structure of the informal network is often used as an indicator of social support (Burton et al., 1995). Informal support can be one of the vital support services available to care givers. Also, some participants recounted the availability of a help-line to call when in times of distress would be a vital support service. That's is using e-Health interventions would be very efficient for the family caregivers. This can help provide education and easily assess support services at home for their relatives. A study by (Mahoney, Tarlow and Jones, 2003) reported telephone-based support programmes could be practical low-cost interventions for reducing caregiver burden in some situations. This tele-support will provide significant benefits when compared with a usual care control group. Another study another how using telephone and help-lines can help the caregivers said, the predicted increase in the number of people with dementia has led to concerns about whether the current labour force can cope with such an increased future demand and so tele support can help close that gap (Macdonald and Cooper, 2007). E-health interventions could be an efficient alternative to continue to provide education and support for the informal caregivers (Glueckauf and Loomis, 2003; Martin-Carrasco et al., 2009) at reduced costs (Lewis et al., 2010).

Family caregivers also require medical assistance concerning their psychological health. This is true because of the many psychological hiccups that come with their roles. Health facilities should be on the lookout for depressive signs in caregivers as they take patients to medical screening. This study is consistent with a study by (Prince et al., 2013) which indicates people living with dementia will increasingly have difficulty to meet their basic personal care needs and as well as their carers.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Introduction

This chapter presented the conclusion and recommendation necessary for the findings of the study.

Conclusion

The purpose of this phenomenological research was to explore the experiences of family caregivers of dementia patients. The study addressed three key areas: (1) needs of the family caregivers of dementia patients, (2) the coping strategies employed in managing stress that comes with the care giving role, and (3) support services available for the family caregivers of dementia patients.

The findings showed that, family caregivers needs were not met on a daily and continual basis. Pertaining to the physical needs of the family caregivers, it was known that the activities performed daily by caregivers in ensuring the wellbeing of their relatives take a heavy toll on their physical being, there by affecting their health as caregivers. Some caregivers provide care without taking their health into consideration, giving almost 24 hours of their day in care giving duties. This role as care giving is very demanding when

the condition is severe dementia. Nevertheless, some expressed joy and passion for their care giving

As social needs are met through satisfactory relations, it was known that caregiver's relations with the social world has diminished as a result of their caregiving role. Almost half of the participants recounted they have stopped going for social gathering and meetings due to their care giving roles. Some participants claimed they can be idle for several hours around the patients for all day and the main activity is to see the needs of their care recipient are meet.. This makes it difficult to go out and be a more social being. There were no time available for the caregivers to enjoy such social gatherings and only a few family members were willing to step in and support with the care. Some society members had no knowledge about dementia and resorted to who did not understands the condition, mockery and ridiculing the caregivers of their relative's condition. Some expressed withdrawal from friends as a result of their relative's condition. The family caregivers needed insight about their relative's condition and some psychological challenges as stress resulting from financial needs and cost of care. Financial needs had traits in almost all the needs examined be it from physical, social to psychological needs. This was due to the inability employment duties of the family caregivers as most of them were unemployed and the healthcare expenditure for the condition was very costly.

Concerning the coping strategies employed by family caregivers of dementia patients, it was found that most caregivers used the Adequate Rest (Escape Avoidance), Love and Affection (Distancing), Counseling and Interaction (Seeking social support) and Positive Reappraisal (Praying). These strategies helped overcome, tolerate or reduce the impact of stressful events that came with the caregiving role.

Regarding the support services, family caregivers reported they normally seek support from Faith based approach, that is, talking to their clergy. Also, E-health intervention was expressed as some of the support services needed to help them improve the care of their relatives.

This is one of the first studies in Ghana investigating the experiences of family caregivers of dementia in relation to assessing their needs, the coping strategies employed and the support services available. The current study depicts a detailed analysis of the views of a multicultural and ethnically diverse population from the study prefecture. It could contribute partly to the attainment of Sustainable Development Goal 3 in addition to helping policymakers design and formulate policies that aim to address the existing barriers to healthcare utilization in the study area.

6.2 Policy recommendations

Based on the findings of the study, the following policy recommendations are provided:

6.2.1 Enrolling more Dementia patients and their relatives unto the Livelihood

Empowerment Against Poverty (LEAP) grant

The study revealed that poverty remained the major barriers to healthcare use among the dementia patients and their relatives in the study area. Despite some people receiving grants, the dementia patients and their relatives had no idea about this social intervention policy meant for their financial problem to address a more pressing barrier to healthcare. Although the limited grant receive from the LEAP is not enough as other beneficiaries complain, it would be beneficial for the dementia patients to enjoy such social intervention in order to get finance to cater for the needs. It is recommended that the government enrol more dementia patients unto the intervention programme

6.2.2 .Enrolling more dementia patients unto the NHIS platform

The study found that some of the dementia patients were having active health insurance cards. However, the cost incurred at the facilities often exceeded what the insurance could pay for and as a result, users were required to pay for the additional charges. Few of the dementia patients who were not having valid or active health insurance were, therefore, required to pay the full bill whenever they visited hospital and those who were unable to pay were prevented from accessing healthcare. This prevented few respondents who had not renewed their insurance from using healthcare services. It is therefore recommended that, more dementia patient should be enroll on the LEAP program, so the caregivers can use the cash intervention program to subsidize their hospital cost and any other related cost.

6.2.3 Full integration of caregiving in the healthcare system

Due to the conditions of most dementia patients, they would require assistance in terms of seeking healthcare. Most of the dementia patients needed someone to assist them before they could either walk or board a vehicle to the hospital. At the same time, at the health facility the dementia patients would again need someone to do errands. The dementia patients need people who would always be available to take them to the healthcare facility. Due to the absence of people to go with them to the health facility a good number of them delay in seeking healthcare services. In most cases, some of the dementia patients could not walk neither do they explain their health conditions and adhere to treatment effectively. Although it is enshrined in the

Ghana Mental Health Act 849, where caregivers have right to the patient's admission and treatment, most health workers ignore the importance of caregivers and neglect their needs, as they form integral part of the treatment process. It is recommended, therefore that, Ghana Health Services and Ministry of Health indicate their commitment

to integrate caregiving in the healthcare system but enforcing the requisite contribution of caregivers to the treatment process.

6.2.4 Education and awareness Creation on Social Intervention programmes by NCCE, Ministry of Gender and social protection and Disability Groups.

For a higher health care utilisation of the dementia patients it is recommended that Ghana Health Services and other vital stakeholders, intensify the education and awareness creation on some Social intervention programmes like, LEAP, Disability Common Fund and the NHIS. Since most dementia patients and their caregivers have no idea of these social intervention programmes and their benefit to the treatment process of their relatives, the awareness creation would help most of them in terms of financing the care of the patients.

6.2.5 Disability Common Fund

Since the dementia patients fall within the sphere of Cognitive disability, is it their prerogative to assess the intervention programme at their district level and get some cash benefits to support their healthcare and daily needs. This falls on Disability practitioners and social workers within each district to help identify various disability forms and help enrol them for disability benefits especially those with mental illness who are cared for by their relatives.

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APPENDICES

Appendix A



KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS



Our Ref: CHRPE/AP/070/19

26th February, 2019.

Mr. Adjei Gyimah Akwasi
Post Office Box 1037
KNUST-KUMASI.

Dear Sir,

LETTER OF APPROVAL

Protocol Title: *"Experiences of Family Caregivers of Dementia Patients."*

Proposed Site: *Department of Psychiatry, Komfo Anokye Teaching Hospital.*

Sponsor: *Principal Investigator.*

Your submission to the Committee on Human Research, Publications and Ethics on the above-named protocol refers.

The Committee reviewed the following documents:


- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Questionnaire and Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning 26th February, 2019 to 25th February, 2020 renewable thereafter. The Committee may however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Yours faithfully,



Rev. Prof. John Appiah-Poku.
Honorary Secretary
FOR: CHAIRMAN

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: chrpe.knust.kath@gmail.com / chrpe@knust.edu.gh



KOMFO ANOKYE TEACHING HOSPITAL
RESEARCH AND DEVELOPMENT UNIT (R & D)
CERTIFICATE OF REGISTRATION

REG. NO: *RD/CR19/005*

This is to certify that

Prof/Dr/Mrs/Mr/Ms. *Adjei Gyimah Akwasi*
has registered his/her proposed study titled *Experiences of Family
Caregivers of Dementia Patients*
with the Research and Development Unit.

Date: *14-January-2019*

Name of issuing officer

Mr. Bernard Arhin

Signature

K/17/0667587

*Receipt number must tally with pay-in slip from the bank

Note

This certificate does not constitute ethical clearance for the conduct of the study but proof of registration of study with KATH. Ethical clearance from the Committee of Human Research, Publications and Ethics (CHRPE) is required to conduct the study in KATH. Copies of all relevant regulatory approvals including CHRPE must be submitted to the R&D Unit prior to commencement of the study.

Version RD/REG-01ST JUNE, 2018

Please note: All previous versions of the certificate of registration becomes obsolete.

Form expires 30TH JUNE, 2019

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY.

SCHOOL OF PUBLIC HEALTH

DEPARTMENT OF HEALTH PROMOTION AND DISABILITY

MSc. DISABILITY, REHABILITATION AND DEVELOPMENT STUDIES

TITLE: A RESEARCH ON EXPERIENCES OF FAMILY CARE GIVERS OF DEMENTIA PATIENTS AT KOMFO ANOKYE TEACHING HOSPITAL (KATH)

INTERVIEW GUIDE FOR FAMILY CARE GIVERS OF DEMENTIA PATIENTS.

Introduction Good Morning or Afternoon, I am a final year student in MPhil Disability, Rehabilitation and Development programme at the Kwame Nkrumah University of Science and Technology (KNUST), undertaking a research to gather evidence on experiences of family caregivers of dementia patients at Komfo Anokye Teaching Hospital (KATH). The study is intended purely for academic purpose and forms part of the requirement for the award of Master of Philosophy in the field of Disability, Rehabilitation and development.

Any information, answer or views expressed in the interviews shall be treated with complete confidentiality. It is my hope that you will co-operate with me and answer the question as accurate as possible so that I can gather accurate information on the topic as it will contribute to a great cause.

Thank you for your cooperation

SECTION 1

A. Background information:

- Age range: 18-28 ☐ 29-39 ☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ above 70 ☐
- Gender of caregiver.....
- Educational level of caregiver.....
- Occupation of caregiver.....
- Marital status of caregiver.....
- Disability: Mobility impaired ☐ Hearing Impaired ☐ Visually impaired ☐ other, please state.....
- Religious affiliation of caregiver

- Gender of patient
- Educational level patient
- Marital status of patient
- Relationship of caregiver to patient
- Length of care
- Languages spoken

SECTION 2

A. Physical needs of Family Care Givers

1. Please tell me what a typical day is like for you as a caregiver
2. Tell me how you maintain the patient „s activities of daily living like oral care, physical cleanliness, nutrition and elimination.
3. Is there anything else you would want to add? E.g. Problems, stigma, negative reaction from people, etc
4. Please tell me how the patient participate / influence in the care.

Probes: ☐ Resist to grooming? ☐ React violently? ☐ Threatens to harm himself, you or others?

5. Please tell me how it is like in providing care to patients.

Probes: ☐ Is it irritable?

6. What are some of your physical needs as a Family Care Giver, eg Food, Water, Shelter, Clothing, Sleep, Breathing

B. Social needs of Family Care Givers for dementia patients

7. Please tell us how your care giving role has affected your social life eg. Friendship, Family, Intimacy, Sense of connection, Health, Employment, Property, Family and Social Stability
8. The demands of a care giving role can be challenging. Please tell us how you cope with it so it does not affect your social relationships.
9. Please, in what ways do you need support so that you can have a normal social life?

C. Psychological needs of Family Care Givers for dementia patients

10. How has your role as a Family Care Giver affected your psychological health eg. Confidence, Achievement, morality, Acceptance Experience purpose, Meaning and inner potential
11. The demands of a care giving role can be challenging. Please tell us how you cope with it so it does not affect your psychological health.
12. Please, in what ways do you need support so that you can avoid the psychological consequences associated with your role.

D. Financial needs of Family Care Givers for dementia patients

13. How has your role as a Family Care Giver affected your financial need

Probe:

Do you work currently or previously?

How do you cater for your family?

How do you cater for the financial cost of caring for your relative?

Does anyone help with any finance towards the care of your relatives?

SECTION 3

COPING STRATEGIES EMPLOYED BY CAREGIVERS

14. How do you cope with the stress associated with care giving duties

Probe:

Do you talked to someone to find out about the situation?

Did you got professional help and did what they recommended?

Did you Talk to someone who could do something about the problem?

Did you hoped a miracle would happen?

Did you go on as if nothing had happened?

Did you Kept my feelings to myself?

Do you Sleep more than usual?

Did you Kept others from knowing how bad things were?

SECTION 4

A. SUPPORT SYSTEMS AVAILABLE

15. Are there any social, medical and financial intervention for you as care giver

16. Do you take your patients to church for prayers concerning their illness

17. Do you have any group you talk to apart from medical practitioners on your issues

18. Please, in what ways do you need support

COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	

Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant the knowledge of interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical</i>			

<i>framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. faceto-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			

Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for	
		comment and/or	
Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	

Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357