Experiences of Family Caregivers

SCHOOL OF NURSING AND MIDWIFERY

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

LEGON

CARING FOR PATIENTS WITH DEMENTIA: EXPERIENCES OF FAMILY CAREGIVERS IN THE TEMEA METROPOLIS

BY

AGNES DELALI AMA AGUDU

10233049

THIS THESIS IS SUBMITTED TO THE SCHOOL OF NURSING AND MIDWIFERY COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF MASTER OF PHILOSOPHY DEGREE IN

NURSING

JULY, 2017
DECLARATION

I declare that this thesis is my own work produced from research undertaken under supervision.

This thesis/dissertation has not been submitted in any form for any degree or diploma at any university or other institution of tertiary education. Authors and Publishers whose works have been utilized in this study have been duly acknowledged in the text and list of references.

................................................. ..............................................
Agnes Delali Ama Agudu Date
(Student)

................................................. ..............................................
Mr. Jibril Muhammad Amin Date
(1st Supervisor)

................................................. ..............................................
Dr. Samuel Atindanbila Date
(2nd Supervisor)
DEDICATION

This thesis is dedicated to all family caregivers of patients with dementia and also to my family for their immense support and prayers throughout this two-year journey.
ACKNOWLEDGEMENT

Glory be to God in the highest for His grace, mercies, faithfulness and guidance to the end of this programme. My special thanks also go to the head and staff of the Community Psychiatric Unit, Tema General Hospital for their great support and cooperation during this study. For the participants of the study, I will be forever grateful to you for making this research possible. Thank you for your willingness, trustworthiness and genuineness for opening up to share your experiences with me. I would like to thank my entire family for their unending support and encouragement. My husband, Gottfried and our children have been loving and patient. Appreciation goes to my parents and other family members for believing in me and cheering me on throughout this process. I am also very grateful to my sister, Sena and my godfather Pastor Ellick Addison for constantly being my source of inspiration and unconditional love. I would also like to thank my supervisors: Mr. Jibril Muhammad Amin, Dr. Samuel Atindanbila and Rev. Alexander Attiogbe for being very patient and encouraging mentors. Their guidance and wisdom were instrumental in supporting me to complete this work. I am also thankful to the Dean, Prof. Ernestina Donkor and all the lecturers as well as administrative staff especially Ms. Regina Ankrah for their expert advice and guidance throughout this study. Many thanks go to Dr. Akwesi Osei for endorsing my study leave forms for this programme.

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<table>
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychiatric Symptoms of Dementia</td>
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<td>CHPS</td>
<td>Community-based Health Planning and Services</td>
</tr>
<tr>
<td>EOD</td>
<td>Early Onset Dementia</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>GIMPA</td>
<td>Ghana Institute of Management and Public Administration</td>
</tr>
<tr>
<td>KNUST</td>
<td>Kwame Nkrumah University of Science and Technology</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>MHA</td>
<td>Mental Health Authority</td>
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<tr>
<td>NMC</td>
<td>Nursing and Midwifery Council</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>US</td>
<td>United States</td>
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<td>USA</td>
<td>United States of America</td>
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<tr>
<td>USD</td>
<td>United States Dollars</td>
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<tr>
<td>TMA</td>
<td>Tema Metropolitan Assembly</td>
</tr>
<tr>
<td>TOR</td>
<td>Tema Oil Refinery</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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ABSTRACT
The aim of the study was to explore and describe the psychological, physical, financial and social experiences of family caregivers in caring for patients with dementia using the qualitative approach in the Tema Metropolis. Purposive sampling technique was used to select a sample size of ten participants who were family caregivers caring for patients diagnosed with dementia. Data was collected by audiotaped interview and transcribed verbatim, coded and data analysis was done using thematic content analysis. Four major themes and twenty-six sub-themes emerged. The family caregivers went through frustration, worry, demanding caregiving role, physical and verbal abuse by the care recipients. There was also early retirement and loss of job leading to insufficient finances and loneliness, which some caregivers referred to as imprisonment. In spite of all these problems, the caregivers expressed a feeling of satisfaction in their caregiving role. Based on these findings, it was recommended that policy makers must ensure that all the psychiatric units of the Regional Hospitals together with their community psychiatric units in the country have trained clinical psychologists to aid in the counselling of family caregivers of patients with dementia. Furthermore, they should make available vehicles and motor cycles to enable the community psychiatric nurses deliver care to dementia patients in the comfort of their homes. This will decrease the frustration level of family caregivers and also gain the opportunity to educate the community about dementia, early detection and management.
CHAPTER ONE

1.0 Introduction

This chapter presents the background of the study, the problem statement, purpose of the study, objectives of the study and the research questions that will guide the researcher to achieve the set objectives. Furthermore, the significance of the study as well as the operational definitions are also included in this chapter.

1.1 Background

A great number of patients with dementia (70% to 81%) live in the community (He, Sengupta, Velkoff, & DeBarros, 2005) and roughly 75% of these elderly are cared for by family and friends (Schulz & Martire, 2004). An American report revealed that nearly 10 million caregivers in the country care for elderly living with one type of dementia disease or the other in 2007 (McKhann, Knopman, Chertkow, Hyman, Jack, Kawas ... & Mohs, 2011). The majority of those caregivers are spouses, followed by children and children-in-law, specifically females. The term caregiver refers to anyone who offers support to another person who is, to some extent, helpless and needs help. The care recipients can be a grandfather or spouse with dementia disease (Alliance, 2001). 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).

Giving care to individuals with dementia can be very challenging, overwhelming and sometimes frustrating. Dementia is an umbrella term, used to describe a syndrome that can have many different causes and is associated with ageing (van der Steen, Radbruch, Hertogh, de Boer,
Hughes, Larkin... & Koopmans, 2014). The proportion and absolute number of older people in populations around the world are increasing intensely. Sub-Saharan Africa already has double the number of older adults than northern Europe, and this figure is expected to grow faster than anywhere else, increasing from 46 million in 2015 to 157 million by 2050 (Organization, 2015). Furthermore, life expectancy at age 60 in Sub-Saharan Africa is 16 years for women and 14 years for men, suggesting that for those who survive the earlier dangers of life, have a long old age. Older people in Sub-Saharan Africa also have several roles that are critical for continued socioeconomic development (Organization, 2015).

Kupeli, Leavey, Harrington, Lord, King, Nazareth ... and Jones (2016) defined dementia as a progressive, neurodegenerative disease. The syndrome is characterized by gradual decline in cognitive abilities in the brain which include memory, attention, language, planning, judgement, spatial skills, social skills and behavioural or psychiatric symptoms such as depression, anxiety, delusion, agitation and apathy (Farrow, Ellis, Matters, & Australia, 2013). It is not common in people under 60 years of age. Nearly 1 in 14 people aged 65 years and over have some form of dementia; this rises to 1 in 5 of those aged 80 years and more (Knapp, Comas-Herrera, Somani, & Banerjee, 2007). Dementia caregivers compared with other caregivers experience higher levels of psychological distress and lower levels of confidence (Schulz, & Martire, 2004). Caring for an elderly person with dementia is more stressful than caring for a physically-impaired elderly. Dementia is overwhelming for caregivers and adequate support is required for them.

Types of dementia include Alzheimer’s disease which is the most common form (about 60% of all dementias) and Vascular dementia, which is a Mixed dementia (Alzheimer’s and vascular) which accounts for about 27% of all dementias. There is also Dementia with Lewy Bodies which specifically exhibits fluctuating cognitive impairment, visual hallucinations, spontaneous
parkinsonism, relatively spared memory and cognitive loss related to attention and visuospatial problems. Finally Rare Dementias, which include frontal-lobe dementia and Huntington’s disease (Bamford, Eccles, Steen, & Robinson, 2007). One of the early symptoms of dementia is memory loss. Middle symptoms include speech and communication difficulties, difficulties in performing activities of daily living, difficulty with independent living, whereas late symptoms can be entire loss of communication or patient can no longer recognize loved ones or may mistake them for someone else (Bamford, Eccles, Steen, & Robinson, 2007).

Prince, Wimo, Guerchet, Ali, Wu, and Prina (2015) estimated that there are 46.8 million people with dementia worldwide, with numbers projected to almost double every 20 years. Projections in 2015, showed an expected 9.9 million fresh cases of dementia, corresponding to one every 3.2 seconds. In a study conducted by Alzheimer’s Society (2014), it was discovered that the United Kingdom alone has currently, 850,000 people living with dementia, and this figure will rise to over two million by 2051. A global cost of dementia in 2015, was estimated at US$818bn, with gigantic quality of life effects on both patients living with dementia, their families and caregivers.

The number of patients with dementia are increasing, the regional distribution of new dementia cases is 4.9 million (49% of the total) in Asia, 2.5 million (25%) in Europe, 1.7 million (18%) in the Americas, and 0.8 million (8%) in Africa. This signifies that 5.8 – 7 million family, friends and neighbours (Noelker & Whitlatch, 2005; Spector, Fleischman, Pezzin, & Spillman, 2000) render care to the elderly over 65 years who need support with daily activities. Family caregivers who are not paid are likely to be the largest source of long-term care services in the United States and there are likely to be about 37 million caregivers by 2050, an increase of 85% from 2000 (Kemper, Komisar, & Alexxih, 2005).
Dementia is related to caring long hours for patients and demanding caregiving role. Researchers revealed that caregivers of patients with dementia are extremely burdened than other caregivers (McKhann, Knopman, Chertkow, Hyman, Jack, Kawas ... & Mohs, 2011). Physically, there is an evidence that dementia caregivers neglect their own health, such as not getting enough sleep, poor nutrition and having low immune system, exposing them to illness (Vitaliano, Zhang, & Scanlan, 2003). Findings of a survey of dementia caregivers of about 277 in the US in 2003, showed that one quarter provided 40 hours of care per week (compared with 16% for non-dementia caregivers). Tasks such as bathing, feeding, and assisting with toileting were done by 65 percent of caregivers. Alzheimer’s Association USA (2007) observed that for over a year, caregivers who were committed to the caregiving role were two thirds and over, followed by one third who sustained the role for five years or more.

Caregivers caring for patients living with dementia in low or middle income countries were noted to devote three to six hours of their time a day for the caregiving role, and also spend three to nine hours attending to their daily needs. Weekly, a total of eleven to twenty-five percent of caregivers spend over eleven hours delivering extra unpaid care for patients (Prince, 2004). People who live in large households, distribute care among individuals, resulting in the main caregiver feeling less stressed. Prince (2004) further indicated that, the effect is small and only applies to cohabitating primary caregivers. Additionally, while there may be a number of care managers involved, most of the hands-on day to-day caring is still likely to be left to an individual (Schulz & Martire, 2004). Literature has shown many studies carried out in the area of caregiving but most of them were conducted in the high income countries. In Ghana, the researcher has not yet come across any published research on the experiences of family caregivers of patients with dementia. The model used for this study is Poulshock and Deimling model of caregiver strain, 1984.
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1.2. Problem Statement

Older people in populations around the world are increasing intensely. In 2012, the proportion of people aged 60 years or older in Japan exceeded 30%. By the middle of the century, many countries will have a similar proportion of older people to that of Japan (W.H.O, 2015).

Sub-Saharan Africa already has double the number of older adults than northern Europe, and this figure is expected to grow faster than anywhere else, increasing from 46 million in 2015 to 157 million by 2050. Furthermore, life expectancy at age 60 in Sub-Saharan Africa is 16 years for women and 14 years for men, suggesting that those who survive the earlier dangers of life, will have long old age (W.H.O, 2015). Ghana has one of the highest proportions of persons aged 60 years and more in Sub-Saharan Africa. In Ghana, the proportion of the elderly increased from 4.9 percent in 1960 to 7.2 percent in 2000, while the number rose from 0.3 million to 1.4 million over the same period. Projection results indicate that by 2050, the aged population will account for 14.1 percent of the total population (Mba, 2010).

World Health Organization (2012) reveals that the world’s population is ageing and improvement in health care in the past century have contributed to people living longer and healthier lives. However, this has also resulted in an increase in the number of people with dementia. There is a lack of knowledge and consideration of dementia at some levels in several nations resulting in stigmatization, obstructions to diagnosis and care, affecting caregivers, families and societies physically, psychologically and economically. W.H.O. (2012), emphasizes on dementia being considered as part of public health agenda in all countries.

In the Accra Psychiatric Hospital, caregiving for the mentally ill is usually at two levels: institutional care and community care. Patients are normally admitted to the hospital when they pose a danger to themselves or their relatives at home. They are usually discharged after a few days or weeks for care to continue at home in the community, after relatives have been informed
about their condition. It is sometimes common that when patients are on admission, some relatives do not visit until discharge and some refuse to come for them after discharge, without any explanation to the Accra Psychiatric Hospital. This prevents the hospital from admitting patients who genuinely need admission due to fear of abandonment and overcrowding. Meanwhile, as part of the aim of Mental Health Act 846, enacted in 2012 care delivery to the mental patients should be done in the comfort of their homes to reduce institutionalization. Patients with dementia are now becoming the hospital’s responsibility whilst the hospital does not have enough funds to cater for them (M.H.A, 2015). This has resulted in the need for the researcher to find out why the relatives of patients with dementia are reluctant to come for their discharged patients. There are some studies done in this area but in high income countries and not in the Ghanaian context.

1.3. Purpose of the Study

The purpose of this study was to explore and describe the experiences of family caregivers caring for patients with dementia in the Tema Metropolis.

1.4. Objectives of the Study

The following were the objectives of the study:

1. To explore the psychological experiences of family caregivers caring for patients with dementia.

2. To identify the physical experiences of family caregivers caring for patients with dementia.

3. To explore the financial experiences of family caregivers caring for patients with dementia.

4. To identify the social experiences of family caregivers caring for patients with dementia.
1.5. Research Questions

The research questions for the study were:

1. What are the psychological experiences of family caregivers caring for patients with dementia?

2. What are the physical experiences of family caregivers caring for patients with dementia?

3. What are the financial experiences of family caregivers caring for patients with dementia?

4. What are the social experiences of family caregivers caring for patients with dementia?

1.6 Significance of the Study

The findings of this research will help educate health professionals, especially the community psychiatric nurses to have a better understanding of the caregiver role of patients with dementia, and to improve upon the quality of life of the caregivers in the community. Similarly, the findings will enable nurse educators to train nurses for efficient and effective nursing care of patients with dementia in the communities. Furthermore, the findings of this study will call for the formation of advocacy groups for caregivers and their patients with dementia so that their peculiar problems will be addressed promptly by the appropriate quarters. Additionally, the findings will encourage policy makers to design a policy to support caregivers in caring for patients with dementia. Likewise, the findings from this study may lead to the development of a policy to train family caregivers in caring for patients with dementia at home. Finally, the researcher hopes that the findings of the study will add knowledge to the discipline of nursing regarding how to support caregivers caring for patients with dementia.
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1.7 Operational Definitions

The following were the operational definitions of the study:

1. **Patients with Dementia** – people who are between 60 and more years old diagnosed with dementia by a psychiatrist.

2. **Family Caregivers** – family members directly involved in the day to day activities of the patient with dementia between the ages of 25 to 74 years in the Tema metropolis. They may include daughter, son, granddaughter, spouse and daughter-in-law.

3. **Experience** – the frustrations, worrying, embarrassment, satisfaction, physical attacks, loss of job and coping events which family caregivers go through in caring for patients with dementia in the Tema Metropolis.
CHAPTER TWO

2.0 LITERATURE REVIEW

The literature review is divided into three parts: Introduction, Conceptual Framework and Related Literature.

2.1. Introduction

This literature review is to explore the experiences of family caregivers caring for patients with dementia. The related literature was reviewed under four headings: the psychological experiences of family caregivers caring for patients with dementia, the physical experiences of family caregivers caring for patients with dementia, the financial experiences of the family caregivers caring for patients with dementia and the social experiences of family caregivers caring for patients with dementia.

The literature search was conducted using electronic databases such as CINAHL Complete, EBSCOhost, Google Scholar, Sage Journals Online, PUBMED, JSTOR and ScienceDirect. The keywords used in the search included: dementia caregiver, burden of family caregivers, types of caregivers, types of dementia, caregivers’ experience, physical, financial cost, psychosocial, psychological and social support; they were used either individually or in combination. This helped to identify relevant studies on the experiences of family caregivers caring for patients with dementia. The search identified many published studies on experiences of caregivers, but mostly in high income countries with a few in low or middle income countries. In the next paragraph, the conceptual framework used for the study will be described.
2.2 Conceptual Framework

The conceptual framework that guided this study was Poulshock and Deimling caregiver strain model modified (Poulshock & Deimling, 1984). This model was used in a study conducted by Brodaty and Donkin, (2009). Permission was sought from Professor Henry Brodaty to use the model in this current study and was granted by him (see correspondence attached as appendix F).

Figure 1: Conceptual Framework

Poulshock and Deimling model of caregiver strain, 1984 (modified)

All the constructs in the model were used but emphasis was laid on the fourth construct (Caregiver strain) by the researcher in the literature review and these were psychological, physical, financial and social. The researcher used caregiver ‘experiences’ instead of caregiver ‘strain’ due to the focus of the current study. The change of word helped to provide in-depth information into the fourth construct. The model dwelt mostly on negative effects and support of dementia.
caregivers while the caregiver experiences explored both the positive and negative experiences of dementia caregivers. The four constructs of the caregiver strain are explained below. These are compared with the findings of the current study in the discussion chapter.

In the model a patient suffering from dementia exhibits problem behaviours which makes the patient dependent on the caregiver. This problem behaviours lead to a burden on the caregiver, which manifests as strain in so many ways that can be worsened or improved by mature coping mechanisms. The caregiver strain are expressed as psychological morbidity, physical morbidity, social isolation and financial burden. The two types of burden defined under this model are objective and subjective burden. Objective burden is the dependency of the person with dementia and the level of behavioural disturbance. Subjective burden is the assessment of strain by the caregiver and involves their evaluation of the physical and emotional impact, their psychological state, and resources (Gonyea, O’Connor, Carruth, & Boyle, 2005; Sanders, 2005). Subjective strain is associated with objective strain (Campbell et al., 2008).

Burden can lead to psychological morbidity, resulting in depression and anxiety (Campbell et al., 2008; Cooper, Katona, Orrell, & Livingston, 2006; Gaugler, Roth, Haley, & Mittelman, 2008). A strong relationship between dementia caregiving role and negative effects on psychological health has been proven in numerous studies (Campbell et al., 2008; Cooper, Katona, Orrell, & Livingston, 2006; Gaugler et al., 2008). Compared to other carers, dementia carers experience higher levels of psychological distress and lower levels of self-efficacy and subjective well-being. These differences are more when compared to non-carers (Pinquart & Sörensen, 2003a; Schoenmakers, Buntinx, & Delepeleire, 2010). Factors that may regulate the existence of symptoms are: being female, being a husband or wife caregiver, extra stressful life proceedings, physical health, family history of mental health issues, excellent bonding between caregiver and
Experiences of Family Caregivers

care recipient, life gratification, low levels of self-esteem and mastery, high neuroticism, and levels of behavioural and psychological symptoms of dementia (Campbell et al., 2008).

There is a high danger of health problems for patients living with dementia caregivers, comprising cardiovascular problems, lower immunity, poorer immune response to vaccine, slower wound healing, higher levels of chronic conditions (such as diabetes, arthritis, ulcers, and anemia) and frequent hospital appointments (Schulz & Martire, 2004; Segerstrom, Schipper, & Greenberg, 2008; Vedhara et al., 2003; Vitaliano et al., 2003; Wilson et al., 2007). There are several reports on dementia caregivers’ physical health problems than non-caregivers. Those with psychological morbidity and greater burden are more likely to have poor physical health and a higher risk of mortality (Sunmin Lee, Colditz, Berkman, & Kawachi, 2003). The reasons for poorer health may be physiological or because caregivers have lower healthy behaviours such as exercise, and are more likely to smoke, drink alcohol and soft-drinks, eat fast food, and sleeplessness, thereby placing themselves at risk of further health problems (Hoffman, Lee, & Mendez-Luck, 2012; Schulz & Williamson, 1997).

Caregivers often misplace the contacts of friends which leads to loneliness (Cooper, Owens, Katona, & Livingston, 2008; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; López & Crespo, 2008; Lowery et al., 2000; Markowitz, Guterman, Sadik, & Papadopoulos, 2003; Riedijk et al., 2006). Caregivers tend to sacrifice their source of entertainment, spend little time with friends and family, early retirement or reduce working hours at work (Leong, Madjar, & Fiveash, 2001). Caregivers who are content with their relationships show less negative psychological symptoms (Lowery et al., 2000). Caregivers receive a lot of support from people when there is a good psychosocial intervention.
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The costs involved in caring for a patient with dementia are very high. Direct costs in dementia care include frequent journeys to the hospital for treatment, investigations, medication and delivery of personal, nursing and residential care. The worldwide direct costs of dementia, estimated in 2003 was 156 billion USD, representing over 5000 USD per person with dementia, which is a fraction of the total costs (Wimo, Jonsson, & Winblad, 2006). Cost approximations may ignore the considerable hidden unpaid costs borne by caregivers. Indirect costs include loss of earnings by patients and family caregivers as they resign or cut down occupation, hours of informal care and mortality burden (Economics, 2003). The economic disadvantage associated with caregiving in the low-income settings is significant (Prince, 2004). Wimo and colleagues (2006) estimated that direct costs of dementia in emerging markets and low-income countries totaled 13 billion USD in 2003. Total costs, including those borne by families are likely to be much higher.

2.3 Related Literature

2.3.1 Psychological Experiences of Family Caregivers Caring for Patients with Dementia.

Pinquart and Sorensen (2003) revealed that the increased number of people with dementia has a public health implication which is connected to psychological morbidity of caregivers in the form of burden, general psychological distress and depressive symptomatology. Chan, Ng et al. (2010) conducted a qualitative study of Chinese caregivers of patients with dementia in Hong Kong. The objectives of the study was to report caregivers of patients living with dementia lived experiences and also to explore their needs. Four focused groups were interviewed, each group made up of 6-7 caregivers adding up to a total of 27 participants. The findings of the study indicated that, caregiving is so demanding and challenging as reported in other high income countries (Patterson et al., 1998). The findings were analyzed in themes and emotional burden experienced by family members was also the most demanding theme that emerged from the four
focus groups. 70% of the participants reported psychological distress and 58% reported disturbed mood. Some of the negative emotional responses were grief, sadness, anxiety, anger, guilt, blame, fear and embarrassment (Patterson et al., 1998). The caregivers also gave detailed accounts of behavioural and psychological problems they encountered when giving care. These included agitation, irritation, aggression, obstinacy, withdrawal, insomnia and abnormal perception (Mok et al., 2005). Furthermore, providing care 24 hours, all year round was so demanding for caregivers and a major source of burden. The researcher observed that, this study had relevant findings but could not be generalized, looking at the number of participants compared with the total population of Hong Kong (Chan et al., 2010). Similarly, the study was conducted in Chinese but the report was translated and compiled in English which may suggest that some vital information could have been ignored in the process of translation, making the results incomplete.

A longitudinal study with a sample size of 44 caregivers was conducted (Razani et al., 2014), with the purpose of examining whether variations in patient daily activity skill and caregiver psychological distress (specifically depression, anxiety and hostility) foretell a rise in precise phases of caregiver burden over a year. The results showed that dementia was advanced and led to great cognitive impairment which decreased the ability to perform daily activity, and increased psychological distress (Berger, Bernhardt, Weimer, Peters, Kratzsch, & Frolich, 2005). The pattern of variation in patient and caregiver characteristics was found to foretell variations in various phases of caregiver burden in the study. Consistent with previous research, there were adequate relationships between patient functioning and caregiver symptoms of depression and anxiety, and caregiver burden (Epstein-Lubow, Davis, Miller, & Tremont, 2008; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). Some limitations of this study which the researcher observed were
the small sample size, which made the findings non generalizable. Also, the majority of the patients were men, whilst the majority of the caregivers were women. This suggests gender biases.

van Vliet, de Vugt, Bakker, Koopmans, and Verhey (2010), carried out a literature search of seventeen (17) articles on psychosocial impact of Early Onset Dementia (EOD) on family caregivers. The methodology used was a cross-sectional quantitative research by means of quality criteria for observational studies (Mallen, Peat, & Croft, 2006). Findings revealed that EOD caregivers have high levels of burden and depression (Arai, Matsumoto, Ikeda, & Arai, 2007).

Several studies have reported on the negative psychological and emotional effects of caring for patients with dementia. Examples are poor emotional well-being, social isolation, a feeling of frustration, grief and guilt (Harris & Keady, 2004; Williams, Cameron, & Dearden, 2001). The current researcher observed that almost all the studies used had small sample sizes which do not befit a quantitative research sample size and this can affect generalization. However, the researchers’ effort at putting all the articles together is recommendable.

A systematic literature review of 207 studies with the aim of analyzing what factors determine the development of depression in caregivers of elderly patients with dementia was conducted in Belgium (Schoenmakers et al., 2010). Findings of the study were that depression in elderly patients with dementia is higher than in non-caregivers and also caregivers of patients with non-dementia related chronic illnesses or psychiatric patients. Depression occurs in one in three of caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses. Changing role patterns, the continuous mourning process of the caregiver for a relative with dementia and the uncontrollable nature of the illness render caring for a patient with dementia an exceptional situation. The researcher of this
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current study believes the researchers of the study have done well by putting together all these studies. The findings of the study were insightful.

In another study which was a secondary analysis (controlled group) of interviews collected from a longitudinal caregiver skill-training intervention for caregivers of those with degenerative diseases (parent study) was conducted. The purpose was to explore how the experiences of spousal caregivers of patients living with dementia differed. The sample size was 21 spousal caregivers in the USA (Shim, Barroso, & Davis, 2012). The results of the study showed that three groups of caregivers were identified based on how they described their experiences: negative, ambivalent and positive groups. The negative group described both past and present relationships with their spouse in negative terms and did not take proper care of their patients. They focused on their own unmet needs rather than their patients’. Besides, they complained of high caregiving burden. On the other hand, the ambivalent group talked about lost relationship but still expressed a feeling of satisfaction in being able to care for the spouse. At the same time, they had mixed feelings about caregiving and struggled accepting the fact that their partners could no longer love them back. The positive group saw love in their relations before and during the illness. Their attention was on the present and the fact that their spouse is alive and catered for by them. They showed satisfaction with the caregiving role rather than being highly burdened. They understood the condition of their partner and needed no reward. The sample size of 21 participants for a qualitative study was good and the research method used enabled the caregivers to express themselves well to meet the aim of the study.

Moreover, family caregivers may be encouraged to deliver care as a sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures, or in rare instances, greed (Sanders, 2005). Caregivers who are attracted by a sense of duty, guilt, or social and cultural norms
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are more likely to resent their role and suffer greater psychological distress than caregivers with more positive drives (Pyke & Bengtson, 1996). Caregivers experience less problem, great health, relationships and social support if they value their caregiving role (Cohen, Colantonio, & Vernich, 2002).

The negative aspect of the caregiving role for patients with dementia has become more obvious, but linked with positive moods (Cohen, Colantonio, & Vernich, 2002). The negative aspects had high levels of depression and anxiety and also showed increased rates of mood disorders, with about one-third of individuals diagnosed with depression (Schulz & Martire 2004). Besides, Sanders (2005) revealed that caregivers within 55 and 90 percent, gained positive experiences such as enjoying closeness, sharing activities, feeling a mutual bond, spiritual and personal development, increased faith, and achievements and full control. However, ethnicity, education, gender and age can influence the way caregivers view their role. It is said that feeling more positive towards caregiving role means, the person has a lower educational level and resources, very sociable, old and with good health (Rapp & Chao, 2000).

2.3.2 Physical Experiences of Family Caregivers Caring for Patients with Dementia.

In Japan, Hirano et al. (2011) conducted a cross-sectional survey of 50 elderly caregivers living with patients diagnosed with dementia, aimed at identifying factors associated with lower physical activity in the elderly caregivers. The findings showed that more than half of the caregivers were suffering from hypertension, followed by hypercholesterolemia, diabetes and cancer. This was due to higher burden in caring for their patients which was associated with lower activity levels. This finding was supported by (Pinquart & Sörensen, 2003b) who revealed that, the time spent for caregiving and providing care has been described as a stressful experience that
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may wear away psychological well-being and physical health of caregivers. Adams (2008), affirmed that, caregivers with high care burden may have less temporal or psychological capacity to spare time for physical activities and may be prone to feel physically fatigued by a sense of burden. Care burden, he said was associated with depressive mood, and depressive mood generally lowers the level of physical activity (Wise, Adams-Campbell, Palmer, & Rosenberg, 2006). The researcher observed that, the assessments of the physical activity levels of caregivers depend on self-reported scoring and the natural inconsistencies in subjective assessments may have affected the results. Also, the sample size of 50 caregivers was too small, a longitudinal intervention involving more participants would have been appropriate to probe the effects of increased physical activities on care burden.

A one year follow up longitudinal study of active and former caregiver groups with a total number of 720 were recruited. Recruitment was done through advertisements placed in two magazines with nationwide circulation throughout the whole of Germany. After twelve months, 681 participants were reinterviewed (Gräsel, 2002). The findings of the study showed that the most frequent illnesses used as a baseline for both groups of caregivers were Hypertension, Low back pain or intervertebral disk lesion, Thyropathy Monoarthrosis or monoarthritis, Ischemic heart disease, Other disorders of the cardiovascular system, Osteoporosis, Polyarthritis, Headache syndrome and Diseases of the venous system. Statistics showed that active caregivers suffer more of those conditions than former caregivers. This is because the former caregivers now have enough time for hospital check-ups increasing health service utilization. Indicating that when caregiving role ends there is a decreased anguish from physical complaints. These variations occur in the first 6 months when caring ends. However, their health service utilization increases later for regular checkups, since they now have a lot of time at their disposal (Gräsel, 2002). The physical health
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of former caregivers improves in the long term once they cease to provide home care. This study’s findings can be generalized due to the recruitment which was mainly through advertisements placed in two magazines and circulated in the whole of Germany and also the sample size of 681 participants was good.

A review of the literature from 12 selected studies was conducted and the design of the studies was longitudinal studies published in English. The selection and appraisal processes were performed by two reviewers independently. The aim was to explore the available literature investigating the Quality of Life of older family carers (aged less and equal to 60) and the association of family carers’ age and Quality of Life outcomes in a dementia patient (de Oliveira, Vass, & Aubeeluck, 2015). Older family caregivers provide full-time care over long periods leading to a reduction in their own self-care and poor family relationship quality. The caregivers have indicated increased levels of depression, higher risk of cognitive deterioration and higher death risk when compared with non-caring older adults’ controls (Covinsky et al., 2003).

Researchers have identified differences in younger and older family carers regarding the following; caring context, such as co-residing, and the potential impact of caring on health and other psychosocial factors, socio demographic aspects, depression levels, living arrangements and self-rated health over time (Chen, Cohen, & Kasen, 2007; Covinsky et al., 2003; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). World Health Organization (Group, 1995) defined Quality of Life as the “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Group, 1995). This is a multidimensional concept that put together facts about physical health, psychological state and level of independence, social relationships, personal
beliefs and relationship with the environment in which people live (Bruvik, Ulstein, Ranhoff, & Engedal, 2012).

Caring in old age is observed as a chronic stressor due to the continuous physically and emotionally challenging role of caring and the mixture of factors such as loss, disability, prolonged distress and stress (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010). The physical strains of caring and biological weaknesses of the older family carers may cause high risk for physical health difficulties, leading to a reduced Quality of Life (Richardson, Lee, Berg-Weger, & Grossberg, 2013; Schulz & Martire, 2004). The findings of the twelve selected studies revealed lower Quality of Life and also majority of the studies showed a negative relationship between carer’s age and Quality of Life outcomes. Lower physical component summary of Health Related Quality of Life was allied with carers’ advanced age. Other variables related to lower Quality of Life were female gender, care recipient behaviour, co-residence, long time caring and lower education. The majority linked negative aspects of caring with the lower Quality of Life outcomes, such as burden, depression, anxiety and stress. A few studies considered positive aspects in caring, such as coping, sense of unity and hope. All the negative aspects impacted on carers’ Quality of Life.

A cross-sectional study at Memory Clinic in Roozbeh Hospital in Iran with a sample size of 153 participants was conducted (Abdollahpour, Noroozian, Nedjat, & Majdzadeh, 2012). The aim was to evaluate the caregiver burden and the factors influencing it among caregivers. Findings revealed the presence of moderate to higher levels of burden, in about 50% and more caregivers of patients with dementia. This was due to the severity of the condition of the patients, leading to them being supported with activities of daily living which have significant impact on patients and as well as their caregivers. Furthermore, gender and educational level also increase caregiver burden. In the study caregivers of female patients with dementia reported high level of burden than
caregivers of male patients with dementia. Also, caregivers of patients with no educational level complained of high rates of burden than patients with any form of educational background.

2.3.3 Financial Experiences of Family Caregivers Caring for Patients with Dementia.

Financial costs are the direct temporary costs associated with paying for the caregiving expenses, whilst others are related to losing money at work due to one having to perform a caregiving role (Lai, 2012). Not all the financial costs could be measured using money, some costs are subjectively indicated by individuals as perceived financial costs. van Vliet et al. (2010) buttressed the above point by talking about the impact on workforce participation and finances both for patients and caregivers (Harris & Keady, 2004). Their employment is affected resulting in early retirement or reduced working hours leading to financial difficulty due to the illness.

A study to examine the effects of perceived financial costs on caregiving burden experienced by family caregivers was conducted by Lai (2012). Telephone interviews were conducted using a structured questionnaire, with a targeted population of family caregivers and a sample size of 340 in Calgary, Alberta. Family caregiving can be expensive (Acton & Kang, 2001; Aoun, Kristjanson, Currow, & Hudson, 2005; Hickenbottom et al., 2002; Langa, Valenstein, Fendrick, Kabeto, & Vijan, 2004; Panda & Coleman, 2001) but little experimental and observational research have studied the effect of financial costs on family caregiving burden. The findings of the research showed that the time required to competently care for a frail elderly relative often amounts to a full-time job. Matching with workmates who are not caregivers, family carers had to take more time off work, often are called from work regarding family issues, absent themselves from work, took more time off without pay, and worked fewer hours than desired (Schulz et al., 2003). Productivity at work will be affected by family caregivers’ workers, because
they will be more tired, have to take more days off, and have to leave work earlier then closing time to attend to their care recipient. Caregivers may miss out on career advancement and promotion opportunities because of their caregiving responsibilities at home, some have left the job to focus more on caring for their relative.

Daily costs of caregiving also affect the finances of family caregivers (Hayman et al., 2001; White-Means & Rubin, 2004). Other expenditures of caregiving are transportation, nonprescription medications, medical supplies, prescription medications, equipment, and homemaking supplies (Forbes & Neufeld, 2008; Hollander, Liu, & Chappell, 2009). The perceived financial cost and caregivers’ burden when measured revealed that 40.3% caregivers dip into their savings to care for the care recipients, 40% of the caregivers indicated that they could not afford those little extras due to the expenses involved in caring for the care recipient, 38.5% emphasized that their family or they gave up needs at the expense of providing care, and 36.8% of the caregivers indicated that caring for the care recipient was too costly (Lai, 2012).

The findings of this study are very impressing, since it was conducted in a whole locality. The study can be used as a baseline to conduct a similar research in other localities. Some limitations that the researcher observed were the use of a telephone survey may have exempted family caregivers who were too tired to attend to telephone calls, or those not at home when the interviewers called, or those who could not speak English language. The use of telephone directories for recruitment could also have omitted family caregivers who had not registered their telephone numbers, those without a telephone, or those who used mobile telephones instead of landline telephones. The use of the caregivers as a proxy to collect data on the number of illnesses that the care recipients have may not accurately capture the health status of the care recipients, which could have a direct effect on the financial costs of family caregiving.
Care needs are frequently covered by informal caregivers who are mainly family members of the care recipient. Taking changes in family composition and population aging into account, it can be predicted that, in the near future, informal caregivers will no longer be able to respond to the care needs of people with dementia (Hurd, Martorell, Delavande, Mullen, & Langa, 2013) due to the expensive nature of care. Farré et al. (2015), performed a cross-sectional study of patients living at home with their informal caregivers. Care services rendered by the caregivers were unpaid and had no defined market (Jorgensen, Cabanas, Oliva, Rejas, & Leon, 2007). Patients were included from three primary care centres participating in a home care programme in Barcelona (Spain) with 174 participants. Data was collected on both the patient and informal caregiver through structured interviews corresponding to specific questionnaires covering the variables of interest (Verbeek et al., 2012). Data collection was carried out between November, 2010 and April, 2012. Statistically significant correlations between dementia costs and illness severity, dependency in activities of daily living, comorbidity, and behavioural disturbance were observed; there was a high cost between dementia care and these measures (Farré et al., 2015).

Care recipients suffering from dementia with severe behavioural disturbance require the most resources. The most frequently used resource contributing to this cost is informal caregiver time dedicated to assistance with activities of daily living (Farré et al., 2015). This is in line with other international studies (Gustavsson et al., 2011; Wimo et al., 2013) where at 198.83 hours per month, was equal to an average monthly cost of 1214.86 Euro, indicating large proportion of care cost in relation to informal care. These figures are consistent not only with recent Spanish studies (Coduras et al., 2010; Peña-Longobardo & Oliva-Moreno, 2015), but also with other European research highlighting the economic impact of informal care from the social point of view accounting for 70–80% of total dementia care costs (Coduras et al., 2010; Jorgensen et al., 2007).
It is important to emphasize the impact of behavioural disorders, which is a determinant factor in total costs in dementia care. These have an effect on caregiver global burden, caregivers have to dedicate up to 3.5 hours extra per day compared with caregivers looking after patients who do not suffer from these symptoms (Murman & Colenda, 2005; Wimo et al., 2013). The only limitation observed was that while carrying out a basic or personal or instrumental activity, the patient is supervised (Schwarzkopf et al., 2011), and most caregiver participants provide care round-the-clock and their time should have been cost-effective but was not. Taking these supervisory hours into account, the informal care cost calculation could have increased the contribution of total costs, and also increased their importance with respect to other resources.

2.3.4 Social Experiences of Family Caregivers Caring for Patients with Dementia.

Waite, Bebbington, Skelton-Robinson, and Orrell (2004), conducted a study which aimed at investigating the interrelationships between life events, depression and social support in carers of people with dementia. This was a cross-sectional quantitative study with 72 participants as caregivers. The results showed that 61 caregivers believed that the relationship between the carer and the individual with dementia (patient) is dominantly controlled by the patient. Caregivers who stay with patients in the same house spend more time with care recipient, thereby having greater responsibility in carrying out caregiving role.

Live-in caregivers are influenced by the nature of the relationship with the care recipients. In effect spousal caregivers record more depression than non-spouses. Continuous strain of caregiving may supposedly make caregivers more defenseless to the impact of life events, and exposing them to depression. Besides, there is some evidence of steadiness in the effects of stressors and psychosocial variables on the stress response over a six-month period (Vedhara,
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Shanks, Anderson, & Lightman, 2000). Life events connected to caregiving may be more associated with psychological distress (Owen et al., 2002).

Another social experience which is equally important was revealed in the study of van Vliet et al. (2010) where Early Onset Dementia (EOD) brings about family conflicts. Caregivers report children who had been in conflict with their ill parent. Children also experience difficulties at school due to ill parent (Harris & Keady, 2004).

Szinovacz (2003), indicated in a descriptive exploratory qualitative study of 17 adolescents between the ages of 12-19 years who stay with a care recipient (diagnosed with dementia) and caregiver. This study focused on adolescents’ exposure to care situations involving relatives with dementias. The main purpose of the study was to identify changes in parent–adolescent relationships and in family dynamics when a family member with dementia moves into the household. Families were identified by distributing fliers to various community agencies as well as to physicians, churches, and schools. The caregivers were typically the adolescents’ mothers, but in one family, the father (when the mother was the care recipient) and in another the grandfather provided care.

The findings of the study showed that the relationships with the main caregiver (typically the adolescent’s mother, but in a few cases, a father or grandfather) was strongly affected by the care situation. The adolescents reported closer relationships before their relative moved into the house, but the stresses experienced by caregivers more often led to decline in their relationship with the adolescents. This confirmed the findings of the study of MaloneBeach, Otani, and DeGenova (1999) which stated that, young adults in caregiving families reported lower affectional solidarity than those in non-caregiving families. Besides, typical strains in parent–child
relationships during the teenage years may be aggravated when mothers turn their attention to the care recipient or are stressed by their caregiving responsibilities. On a positive side, caregiving parents may also serve as positive role models that foster feelings of obligation for aging family members in the younger generation (Piercy & Chapman, 2001). The analyses of this study yielded two main features relating to the adolescents’ relationship with the caregiver that is positive and negative relationship features (Szinovacz, 2003).

Positive features the adolescents talked about were bonding, empathy, and restraint and negative relationship features talked about included lack of attention, fewer activities, strictness, arguments, temper, and irritation or impatience. Obviously the negative outweighs the positives, indicating a deterioration in relationship. Caregivers’ anger, the demands they put on the adolescents or their devotion to the care recipient, often aroused feelings of stress and anger in the adolescents. Caregivers’ stress is displaced on other family members, including the adolescents. Conflict with their caregiving parents’ stress (as observed by the adolescents), and seeing their parent out of control, was an experience destined to induce feelings of anxiety and stress in the adolescent. The study was qualitative and exploratory and could not be generalized, however, it provided some insights that could guide future larger scale investigations on how caregiving influences caregivers’ children.

On the other hand, it is believed that race has some effect on the caregiving role. Comparing with white Americans, African-Americans are known to identify more strongly with traditional values and culture for caregiving, creating a learning environment for their children to emulate religious beliefs, family teachings and expectations, and to provide care together rather than individual caregiving systems (Pyke & Bengtson, 1996). Also, the African-American community does not provide formal institutional care (Dilworth-Anderson et al., 2005). Care providers
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provide hands-on care, maintaining personal hygiene, assisting with finances and other daily activities.

2.4 Summary of Literature Review

One model was used for this study. There were several constructs of the model but only fourth construct was used by the researcher. The word ‘experiences’ was used instead of ‘strain’, which helped the researcher to gain in-depth information for this study. The literature reviewed revealed that the experiences of family caregivers caring for patients with dementia has psychological, physical, financial and social effects on the caregiver. Most of the findings were based on studies from high income countries and just a few from lower or middle income countries. There were qualitative and quantitative studies with good sample sizes. On the other hand, there were some studies with poor sample sizes. There is a wide gap in existing knowledge about experiences of family caregivers of patients with dementia in the Ghanaian context. In the current study, information about the experiences of family caregivers of patients with dementia was explored and detailed description given. It is hoped that the findings of the study will aid in developing interventions that will address the needs of family caregivers and their recipients as well. In the next chapter, detailed descriptions of the methodology used in the study will be presented.
CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter describes the research setting, research design, target population, sample size and sampling technique, procedure for data collection and method of data analysis. It also includes rigour (trustworthiness), ethical considerations and limitation of the study.

3.2 Research Design

The design used for this study was qualitative of the exploratory descriptive approach. It is a design used to reveal a targeted audiences’ range of behaviour and the perceptions that drive it and an example was the experiences of family caregivers of patients with dementia (Mayan, 2001, 2016). This design uses in-depth studies of small groups of people to guide and support the objectives of a research. Denzin and Lincoln (2005) describe qualitative research as involving “… an interpretive naturalistic approach to the world. The researcher in this study studied the family caregivers in their natural settings and described their experiences in terms of the meanings they brought to the researcher.” (p. 3). The results of qualitative research are descriptive rather than predictive. This design was chosen because it was exploratory, descriptive and was used to gain a deeper understanding of the underlying motives, views, and drives of family caregivers in rendering care to patients with dementia. This design was also used to uncover developments in thought and opinions, and delve deeper into their experiences of the caregivers.
3.3 Research Setting

The research setting was chosen because it is one of the most functioning Community Psychiatric Units in the Tema General Hospital which is highly patronized and the researcher happened to work at this unit for six weeks. During the working period, a lot of patients living with dementia came for review with their relatives. The researcher decided to recruit participants in the facilities since they have the numbers of the population that are of interest for the study. The site chosen for the study was the Tema Metropolis.

Tema was created out of a cluster of small fishing villages located around where the Meridian Hotel is situated. History has it that “Torman”, as it was originally called was founded by a migrating people called the ‘Kpeshie’s’ who were Ga-Dangmes. The traditional people were later relocated to their present location at Tema Manhean in 1961 when the Tema Harbour was constructed. However due to migration, the dominant ethnic groups are the Akan, Ga-Dangme and Ewe. There are a few groups of the Mole-Dagbani and the Guans.

Tema Metropolis is a coastal district situated about 30 kilometers East of Accra, the Capital City of Ghana. The Greenwich Meridian passes through the Metropolis, which meets the equator in the Gulf of Guinea. It shares boundaries in the northeast with the Dangme West District, south-west by Ledzokuku Krowor Municipal, north-west by Adenta Municipal and Ga East Municipal, north by the Akuapim South District and south by the Gulf of Guinea. The Ashaiman Municipal is an in-lock enclave within the Tema Metropolis. The Metropolis covers an area of about 87.8 km² with Tema as its capital. The population, according to the 2010 Population and Housing Census, is 292,773. Furthermore, 100 percent of the population live in urban localities. The Metropolis has a household population of 285,139 with a total number of 70,797 households.
Politically, Tema Metropolis had been demarcated into three Sub-Metropolitan Councils namely; Tema West, Tema East and Tema Central. This metropolis is grouped into twenty-six communities. The most popular and busiest communities are Communities 1, 2, 4, 7, 8, 9, and 13 (Sakumono).

The country’s biggest port and harbour facilities are located in Tema and contribute substantially to the revenue of the state. Tema is locally nicknamed the "Harbour Town" because of its status as Ghana's largest seaport. Tema harbour was opened in 1962 and handles Ghanaian imports and exports. Furthermore, it is also a traffic junction, dealing with transit cargo destined for the landlocked countries of Burkina Faso, Mali and Niger. There is also a fishing harbour at the eastern end of the town's commercial harbour to encourage the development of the local fishing industry. There is also a large plot of land near the port designated as a Free zone enclave which the government of Ghana uses for production of goods of which 70 percent is for export with 30 percent for local consumption.

Tema is now a major trading centre, it is linked to Accra by a highway and railway. Tema serves as the industrial centre of Ghana with over 500 industries that produce aluminium, steel, processed fish, refined petroleum, textile, chemicals, food products, and cement. Major companies operating in Tema include, Tema Oil Refinery (TOR), Nestlé Ghana Limited., Wahome Steel Limited, and Tema Shipyard. Their main work is fishing, trading, white-collar jobs and farming. The informal sector is the largest employer in the Metropolis. Out of the 338 schools in the Metropolis, 185 are private whiles 153 are public schools. Also, the Metropolis has one fully fledged private university, the Datalink University, and satellite campuses for three universities namely Presbyterian University, GIMPA and KNUST.
Currently, there are six (6) public health facilities in the Tema Metropolitan Area comprising Tema General Hospital, Tema Polyclinic, one Health Centre, one Health Post, a CHPS Compound and one TMA Women and Children hospital. There are also two (2) quasi-government facilities and about 50 private health facilities, including hospitals, clinics and maternity homes, spread all over the Metropolis. These private facilities cater mainly for the health needs of the industrial workers and their dependants.

The study was conducted at the Psychiatric Unit of the Tema General Hospital. Tema General Hospital is a district/ regional hospital situated in the Tema metropolis, precisely Tema Community Nine (9). Constructed in 1954 and the largest public health institution in the metropolis, it serves the whole of the Tema metropolis and neighbouring towns such as Ashaiman, Afienya, Big Ada, Sege and Kisseh. It is a referral centre for surrounding private and company clinics. The hospital has a nursing staff strength of about three hundred and eighty-six (386), fourteen (14) wards with a bed capacity of two hundred and ninety-four (294). It also provides a 24-hour specialist and general services on both in and outpatient basis. There are seventeen clinical departments in the hospital among which are: Surgical, Medical, Reproductive and Child Welfare and Community Psychiatry, where this study was conducted.

The Community Psychiatric unit is adjacent to the Chest Clinic in the hospital. This unit has one large cubicle divided into two by a partition, where the nurses use one part and the other part is for the Clinical Psychiatric Officer. Four cabinets are for patients’ folders. They offer treatment for new cases of mentally ill patients who visit the hospital and review referral cases from the three Psychiatric Hospitals in the country. Furthermore, they give health talks at the hospital Out Patient Department every morning and at the schools in the community. They also
visit and care for their patients in the comfort of their homes. This unit has one clinical psychiatric officer, four community psychiatric nurses and two community psychiatric officers.

### 3.4 Target Population

The target population used for this study was family caregivers in the Tema Metropolis who were involved in the day to day care of patients with dementia. They were fifteen (15) in number.

### 3.5 Accessible Population

The family caregivers who met the inclusion criteria were ten (10) in total. These were the participants the researcher worked with in the study at the Tema Metropolis.

#### 3.5.1. Inclusion Criteria

The following were the inclusion criteria for the study:

1. Family caregivers who were caring for patients diagnosed with dementia.
2. Family caregivers who could express themselves in Twi, Ewe, Ga and English language.
3. Family caregivers who consented to take part in the study.
4. Family caregivers who had been in the caregiving role for six months and more.
5. Family caregivers who were within the ages of twenty and more years and not suffering from any mental illness.
3.5.2. Exclusion Criteria

The exclusion criteria included:

1. Family caregivers who were not from Tema metropolis.
2. Family caregivers who were not Ghanaians.
3. Family caregivers whose care recipients had passed away.

3.6 Sample Size

The sample size of the study was ten (10) and this was determined by saturation of data collected (Sandelowski, 2000). This was when there was no new information emerging from the family caregivers after the tenth interview and also there were repetitions of information confirming previously collected data from caregivers.

3.7 Sampling Technique

Purposive sampling technique also called judgmental, selective or subjective sampling was used for this study. The goal of purposive sampling is to focus on particular characteristics of a population that are of interest, which enable the researcher to answer the research questions. This technique helped the researcher to rely on her judgement and selected the family caregivers of patients suffering from dementia who met the inclusion criteria for this study.

An introductory letter used by the researcher to seek permission was from the School of Nursing and Midwifery, Legon. The purpose of the study with a copy of the ethical clearance were used to recruit participants at the Tema General Hospital. The hospital’s administrator approved it and sent a copy to the Deputy Director of Nursing Services (DDNS) who in turn sent a copy to the in-charge of the Community Psychiatric Unit. The researcher then visited the community psychiatric unit when permission was granted and communicated the details of the
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research to the nurses. The researcher was given the record book of the unit to get the phone numbers of the particular caregivers she was looking for. The nurses then called the caregivers and arranged for a meeting together with the researcher. Twenty caregivers were identified and agreed to have the meeting but in their various homes. Fifteen homes of the participants were located within five days with the help of the community psychiatric nurses during their home visits. The purpose of the research was explained to the caregivers including every detail on the information sheet and consent form (Appendix A) and were allowed to freely volunteer to participate. The participants who agreed to participate were informed about the data collection and given consent forms to sign or thumb print. The researcher during the visit also arranged for dates and places where the interviews would take place. All the participants preferred the interviews to be done in their homes since the researcher had located their homes.

3.8 Tools for Data Collection

Qualitative research uses semi-structured interviews and observations to gather data (Whiting, 2008). Face-to-face in-depth interview using an interview guide was used as a data collecting tool for this study. The interview guide was divided into two main sections. Section A comprised of participants’ demographic data and section B comprised of the main questions using open ended questions (Fouché & Delport, 2005). Section A was used to develop a cordial relationship with the caregivers and section B to get information about the caregivers’ experiences. The interview guide was pretested on two participants and the number added to the actual study. Audiotape for recording interviews was used. A clinical psychologist was on standby to counsel any participants where there is recount of events accompanied by emotions.
3.9 Procedure/Method of Data Collection

An in-depth face-to-face interview which covered the objectives of the study was used to enable participants express their feelings and thoughts without holding back (Mayan, 2009). The interview started with already prepared semi structured interview guide developed from the objectives of the study, research questions and the literature review of the study. There was probing of responses and redirecting of open ended questions. The interviews were done at the convenience of the participants, in the comfort of their homes. Seven of the interviews were conducted in “Twi” (local dialect), one in “Ewe” (local dialect) and two in English. The researcher could speak and understand the local dialects but could not write, therefore an expert in the local dialects and English was employed; confidentiality of the study was communicated to the expert accordingly. Each section of the interview lasted about forty-five (45) minutes to one (1) hour per participant. The conversations were recorded with a tape recorder with the permission of the participants. Non-verbal communication were observed and detailed documentation done in the field notes. Participants were encouraged by the researcher to feel at ease to express their opinion since the conversation will remain between the two of them, the translator and the supervisors of the study. Participants were also advised not to identify themselves or mention names in the process of describing their feelings to ensure anonymity.

All participants shed tears throughout the interviewing process. Six of them cried profusely to the extent that the researcher stopped the recording and they were calmed down by a clinical psychologist until they were relaxed before continuing with the interview. The participants showed a feeling of relief and joy at the end of the interview section so none of them were referred for further counselling. The researcher tried as much as possible to talk less and listened more. Fifteen participants were recruited for this study but only ten participants were interviewed because by the tenth participant there was no new information coming but repetition of responses made by
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previous participants (Sandelowski, 2000). Apart from the interviews of the first two participants used in the pretesting of the interview guide which were conducted twice before meeting the objectives of the study, the remaining eight interviews were conducted once and the participants were thanked for their participation.

3.10 Pretesting of Interview Guide

A pre-test was done to find out if the interview guide guide (Appendix B) used was comprehensive enough to explore the experiences of family caregivers to meet the research objectives. Two family caregivers caring for patients with dementia were used in the pre-testing, recruited from the Tema General Hospital. They requested the researcher to interview them in their homes. The interview was done a second time before the researcher met the objectives of the study. The results of the pretesting helped the researcher to amend the original interview guide, asked for further explanations and clarifications when certain statements were made, allay anxiety and gain confidence to do the subsequent interviews.

3.11 Data Management

The data that was collected from the interview on a tape recorder was played back and transcribed verbatim and typed on the computer and later played back for modification where possible. Each participant was assigned a number (P.1 through P.10) in order of recruitment into the study. Some of the interviews were transcribed from “Ewe” and “Twi” (local dialects) to English based on the meaning the participants attached to it. The researcher employed a person competent in “Ewe” and “Twi” (local dialects) and English language to ensure translation while maintaining confidentiality; this was to ensure truthfulness. Each of the transcribed interviews was coded, labelled and saved in a file on the researcher’s computer protected by a password. They were coded according to the order in which they were interviewed. The soft copy of the
transcripts was saved also on an external hard drive to serve as a backup. They were kept together with the field notes and the transcripts were also kept away from the reach of anybody in a secured cabinet.

3.12 Data Analysis

The data collected was transcribed from the audio tape verbatim and translated into English language by a translator who was an expert in the two local dialects (Twi and Ewe). Latent content analysis was used in organizing and integrating narrative information according to emerging themes and concepts. Thematic content analysis described by Braun and Clarke (2006) was also used to analyze the data together with the field notes. Content analysis is the process of forming and putting together descriptive information according to emerging themes and concepts. It involves the process of identification, coding, and categorizing primary patterns found in the data. The researcher developed the major themes from the objectives of the study and read the transcripts severally to be able to identify the codes in the data. Coding of the responses to each question was done by identifying persistent words, phrases and concepts and these were achieved with the help of the major themes identified. The words, phrases and concepts were put together under the major themes as sub-themes which were identified by colours (purple, red, green and orange). The coloured codes were then put into categories (themes and sub-themes) with all liked colours together and a summary was done for each category. Some sub-themes were misarranged under the major themes but with the help of the supervisor and through mutual understanding with the researcher they were rearranged. Each transcript and the field notes were analyzed thematically in order to cover all transcripts and get an accurate description of the caregivers’ experiences in their caregiving.
3.13 Rigour or Trustworthiness

Credibility, dependability, confirmability, transferability and authenticity are the major criteria for establishing trustworthiness in qualitative research (Guba & Lincoln, 1981, 1989). It was also revealed by Mayan (2001) that rigour can be established by the following: prolonged engagement, participant or member checks, journal writing, peer review, and audit trail. Strategies that were used by the researcher to demonstrate rigour in this study were credibility, transferability, dependability, confirmability and authenticity.

**Credibility** is achieved when the data of the study is real and this was ensured by prolonged engagement with the family caregivers at the research setting, by purposefully choosing family caregivers of patients with dementia who met the inclusion criteria, establishing rapport through the demographic data (Appendices B) and developing relationship with the caregivers (Barusch, Gringeri, & George, 2011). It was also achieved through persistent observation by identifying from the responses of the interviews those elements (codes) that were most related to the experiences of the caregivers. The codes were put into themes that emerged and also supported by direct quotes from the caregivers which were used at the data analysis (Lincoln & Guba, 1985). Furthermore, the supervisors listened to some of the interviews recorded, looked through the printed out transcripts and identified some codes independently. These codes were then compared with the researcher’s codes and some sub-themes were rearranged since they were misarranged. This was done by mutual understanding between the supervisors and researcher.

The expectation for determining whether the findings are transferable rests with potential users of the findings (Barusch et al., 2011). To strengthen transferability, the researcher ensured detailed descriptions of the research design, research methodology and the findings of the study. This will enable other researchers to transfer the conclusions of the study to fit into similar context.
Dependability ensures that the study can be replicated by another researcher and this was met by describing the full background of participants, also the researcher’s report provided and the detailed description of the methodology of the research.

Confirmability of the findings was ensured by audit trail which was the record of all the steps taken in the research interview, from beginning to end, including all the responses and decisions made during the entire process of the interview. This made it possible for the caregivers to examine the data and confirm ownership of responses. All the non-verbal cues observed were documented in the field notes. The aim was to illustrate as clearly as possible the evidence and thought process that led to the conclusions drawn in the study.

Authenticity was ensured by the researcher presenting exactly the experiences of the caregivers in their care role in the manner that was expressed and understood by the caregivers.

3.14 Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) at the Noguchi Memorial Institute for Medical Research (NMIMR), University of Ghana, Legon. Ethical approval (Appendix C) was granted after initial submission and defense of the proposal at the School of Nursing, Legon. Permission was sought from the Tema Metropolitan Health Directorate and the Tema General Hospital. Then the Community Psychiatric Unit in the hospital with an introductory letter from the School of Nursing & Midwifery College of Health Sciences, University of Ghana, Legon, a copy of the research proposal and ethical approval letter. Contacts with the participants were made possible through the Community Psychiatric Unit after reviewing a copy of the proposal. The participants who agreed to participate were given verbal explanation of the objectives and purpose of the study in their preferred languages (Twi, Ewe and English) a week
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before data collection. Upon agreement to participate, they were asked to either sign or thumbprint a consent form. Each participant was informed that he or she could choose not to continue the study anytime he or she so wished despite signing the consent form and there are no penalties. It was ensured that information given by any of the participants in this study was held in confidence, not publicly reported in a manner that would identify them (anonymity), and also made accessible to anybody except the researcher, translator and supervisors. Anonymity was ensured by assigning a letter and numbers (P. 1 to P. 10) to each participant during recruitment. The typed transcripts were kept in a computer protected by a password. The participants were informed that, the data collected, consent forms, audiotapes, transcripts and any other document related to this study would be kept in a cabinet away from the reach of anyone. The electronic data would be kept in a database protected by a pass word for at least five years after the study. The participants were also informed that if in future the data should be used, ethical clearance would be required for that purpose. The researcher employed the services of a clinical psychologist for participants during the interviewing process which helped them to calm down. The participants were filled with joy after sharing their experiences and none was referred for further counselling after the interview by the clinical psychologist.
CHAPTER FOUR

4.0 Findings

4.1. Introduction

This chapter describes the findings from the data generated from the participants on their experiences in caring for patients with dementia. Experiences that were common to all the participants as well as peculiar experiences of individual participants are also presented. A face-to-face interview was done, using the interview guide to collect data from ten caregivers and transcribed verbatim. Using content analysis, four themes that emerged from the data were organized to reflect the constructs in Poulshock and Deimling Caregivers Strain Model, 1984(modified). These were: Psychological Experiences, Physical Experiences, Financial Experiences and Social Experiences. These main themes and their sub-themes are presented with anonymised verbatim quotations from the participants. All the interviews lasted between forty-five (45) minutes to one-hour and took place in the caregivers’ homes, because it happened to be the chosen site of the caregivers. This chapter begins with the participants’ characteristics, and then, the key findings under their varying themes and subthemes.

4.2. Participants’ Characteristics

A summary of the demographic data of the participants are shown in appendix F. Table 1, which is presented at the end of this thesis (pg.135)

The study population consisted of ten caregivers, nine females and one male. The average age of the caregivers was approximately fifty years, the highest age being seventy-four years and the least was twenty-five years old. The majority of participants were aged between forty to seventy-four years old which suggests most of the caregivers were in their forties and above. Relationship wise,
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four were wives, three were daughters, one a daughter-in-law; there was also a granddaughter and a son. In terms of education, three were graduates, four were middle school leavers, one a primary school leaver whereas two had no formal education. Six caregivers were unemployed, three on retirement and one was self-employed (a baker). All participants were Christians and the common language spoken was ‘‘Twi’’ and English, besides some of them could speak ‘‘Buem’’, ‘‘Fanti’’, ‘‘Ewe’’ and ‘‘Ga-Adangbe’’. Participants’ number of years in the care role ranged between ten months to eight years with the average years approximately being four (4) years.

4.3 Emerging Themes

The aim of the study was to explore the psychological, physical, financial and social experiences of family caregivers caring for patients with dementia and also to describe those experiences from their perspective. The analyses of the experiences discovered some major themes and sub-themes. The themes and sub-themes that emerged included:

1. Psychological Experiences

- frustration
- embarrassment
- worrying
- mentally depressed
- withdrawal,
- coping,
- satisfaction,
- hope
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2. Physical Experiences
   - demanding
   - physical aggression
   - sleeplessness
   - fatigue

3. Financial Experiences
   - Early retirement
   - loss of money
   - insufficient income
   - financial uncertainty

4. Social Experience
   - Bonding
   - family support
   - family conflict
   - social support
   - spiritual attack
   - selflessness
   - loneliness
   - empathy
   - difficulty to study
   - lack of parental love
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To answer the first research question: ‘What are the psychological experiences of family caregivers caring for patients with dementia,’ one theme emerged: ‘psychological experiences’ with eight sub-themes. These are presented in the following paragraphs.

4.3.1 Psychological Experiences

The findings showed that caregivers go through certain psychological experiences in their care of family members suffering from dementia. Psychological is defined by the Dictionary.com as, “dealing with, or affecting the mind, especially as a function of awareness, feeling, or motivation”. Medical definition of Psychological (Merriam-Webster.com, n.d.) states “characteristic of, directed toward, influencing, arising in, or acting through the mind especially in its affective or cognitive functions”. The above definitions suggest that the family caregivers go through some emotional experiences in caring for their patients. These experiences categorized as sub-themes under this major theme are quoted and presented in the following paragraphs.

I. Frustration

The caregivers described their caregiving role as frustrating. The nature of the illness makes the care recipient wander about, have illusions, become very stubborn, confused, hallucinate and most of the time forgetful. These are some of the symptoms associated with dementia and their severity makes the care recipient behave in a manner which is inappropriate. These always keep the caregivers on their toes, wondering what to do at one point or the other and talking most of the time. There were feelings of anger, irritation, and agitation expressed whiles trying to correct these behaviours of the care recipient. These, the caregivers described as frustrating. Another aspect of the caregiving which was frustrating to the caregivers was when their care role to the care recipient was not appreciated by other members in the family. This was
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where other family members tended to find faults and shout about petty mistakes the caregivers commit during the caregiving role. In describing these experiences, the caregivers had this to say:

A participant narrated her experience of how the care recipient refused to listen to her advice:

*At times she gets up at night and wants to get out of the room, I talk her out of it but she will not listen to me. I had to get up and use my body to block the door to prevent her from going out but she has some strength which enables her to struggle with me at the door post insisting we go out together. If I refuse to go out with her she shouts on top of her voice for a long time until she is tired, then stops.*

Another participant lamented how she was insulted by the care recipient and her husband;

*Other times I insist she baths if she is not showing any intention of doing it, but she insults me very well before she does it. This continues throughout the day, picking on me for no reason. At times when my husband comes from work and asks her if she had eaten, even though she had eaten, she told him no and that she had not taken anything the whole day. My husband gets angry and talks to me rudely, if I try to make him understand it was not true, he will not accept my word. For my husband, his mum is always right.*

A participant also echoed what she does when care recipient refused to listen to her:

*When I try correcting the wrong behaviour and grandmother refuses to listen, I leave her to continue until she is tired herself and stop it. If I insist she stops she gets angry and talks rudely to me.*

A wife could not believe what was happening to her husband and had this to say:

*This is a man who was very neat, baths twice a day, washes his clothes and irons them himself, folds all his clothes and arranges them in a manner that he can take them with ease. Now, he does not remember how to do all those things which he formerly did with ease and I have to do all these for him, hmmm………… (She sighed), this is unbelievable!*
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My husband’s behaviour was irritating, she lamented:

At times he calms down when he takes the medication, other times he takes it alright but does not calm down. He becomes restless, we coax him to sit down, he gets up again, we hold him to sit and we go through this process over and over again till he calms down before we are free, especially me, which is very frustrating.

A participant narrated how her husband got lost:

……. So we went to community number one together, he went to the bank to take his money and I went to the market to do my marketing. When we were ready to come home I remembered I needed to buy salted fish (koobi). I asked him to wait for me by the rest of the items whiles I get the fish. When I returned my husband was not there, I searched everywhere in the market even told some of the market women to help me in the search; others made announcements but he was nowhere to be found.

A grand-daughter echoed the restlessness of her grandmother:

……. she cannot stay at one place for a long time due to the nature of her job before getting ill. ... Now that she is ill, she still does that, roaming aimlessly and we are afraid of her getting lost because of her illness. ... She sleeps a while then goes out to roam when she wakes up. When I try to stop her, she gets angry and tells me she is not a child but this is so frustrating. Other days I followed her unknown to her but she caught me once and got very angry with me saying she is not a child to be followed about. At times she gets lost and brought home by strangers.

A wife explained her frustrations:

Once we were sleeping at night in the bedroom and he told me some people were calling him. So we came out from the room to see the people outside but there was no one there. I asked him to go to bed and immediately he lay on the bed he got up and said the people were outside again. We went out and came back in but this time he did not lie on the bed rather sat up talking to himself the whole night. This continued for three days and it was frustrating me so I took him to a private clinic but we were referred to the Accra Psychiatric Hospital.
A participant lamented about the illusions of her care recipient:

_When I lay a mat on the floor for her to sleep, she hits her head on the floor continuously which might hurt her if I ask her to stop, she will not listen to me. When my children go close to her to play with her, she sends them away claiming they are goats and animals. I tell her they are not animals but your grandchildren and human beings but she insisted they are animals!_

A wife who is a retired cook echoed how irritating her husband’s behaviour was:

_Other times he says he has given something of his to someone, shouting and forcing the person to give back his item but in reality he has not given anything out, creating false alarm, quarrels and talking rudely. This behaviour of my husband is very irritating and frustrating._

II. Embarrassment

All the caregivers described some aspect of the caring role as embarrassing. Embarrassment is regarded as one of the self-conscious emotions, accompanied by guilt, shame, and pride. The family caregivers in the study went through shame and guilt in their state of embarrassment. Evidence were instances where the care recipients quarreled with neighbours for no reason leading to disgrace and disrespect towards caregivers by some neighbours in the community. Others were when the care recipients shout in the middle of the night disturbing the sleep of neighbours. Also, the care recipients destroyed properties belonging to neighbours. The caregivers expressed their state of embarrassment as follows;
Some caregivers, a daughter-in-law and a daughter explained how their care recipients shout:

When we got home, at night she started shouting on top of her voice for no apparent reason even when we gave her the medication it did not stop her from shouting and disturbing neighbours.

She reacts by shouting on top of her voice saying we should open the door for her to go out, disturbing neighbours and even attempting to beat my children but they ran away from her.

A wife who was a caregiver echoed how her husband disturbs neighbours:

He shouted on top of his voice till day break, saying ‘they are killing me ooooo, they are coming’ repeatedly; disturbing everybody.

A retired wife narrated her embarrassment as:

You see, this man lying there excuse me to say, was a very prominent man in Ghana. He was one of the big men in the Agriculture sector. He has traveled to several African and European countries. Also in this community everyone knows him as a prominent and educated man. So when he goes out without wearing shoes and not well dressed, I feel very bad and ashamed.

She continued;

When neighbours see him dressed inappropriately and start asking me what is wrong with him, I feel so bad.

A granddaughter lamented how her grandmother misbehaves in the neighbourhood:

At times she will go and misbehave somewhere in the neighborhood, then neighbours will come yelling at me in the house as if I was the one who did it. Some neighbours respect me a lot but because of grandmother they come here talking rudely to me. The sad thing about this problem is that grandmother cannot remember what she did when you ask her. This conduct is very bad and it happens severally and it’s disgraceful.
She added that:

She talks a lot and shouts on top of her voice too, disturbing neighbours at night.
...

Another caregiver narrated her shame:

No, we used to go to church but I stopped because whilst the service was going on with my eyes closed during prayer time my husband strips himself naked in the process. I feel so ashamed and embarrassed about it.

She continued by saying:

Most of the time, I do not see him because my eyes are closed but the person standing next to me draws my attention to him. I quickly cover him and we go home. At times when he removes his clothes and I want to put it back on him he gets angry and attempts to beat me up.

A participant expressed her shame this way:

When I ask her to eat she says no, come and brush your teeth she says no, can I wear your clothes for you she says no. So I asked why she was behaving that way but no response. When I force to bath for her, she shouts on top of her voice disturbing neighbours till I am done bathing her. When I ask why she was shouting after bathing for her she says she was not shouting......

A caregiver lamented how bad she feels:

At midnight she shouts on top of her voice and disturbs neighbours around. I rub her back gently for some time to calm her down when she is restless. .... I feel bad.

The only male in this study explained how he feels when his mother shouts a loud:

When she shouts and talks it is so loud that people hear her and I do not feel okay (shedding tears as he expresses himself and at the same time swallowing his last words)
Another participant reported her husband’s hallucinations:

\[\ldots\text{ sometime past my husband said he has given him money to keep for him but it was not true. Our grandson sells in the kiosk in front of the house my husband became aggressive and destroyed the kiosk because he said our grandson has taken his money, later when he calmed down he realized what he had done and paid a carpenter to fix it for him.}\]

III. Worrying

Some caregivers worry a lot in caring for their husbands, mothers, grandmother and mother-in-law. Worrying is defined by Association (2013), as an uncontrollable, excessive, out of proportion to the actual problem, pervasive, present most of the time, focused on several topics and as involving high levels of distress and significant interference with functioning.

Worry is described as extreme, intense, connecting multiple sources, happening within days to six months or more and harming (Lee, Ma, Tsang, & Kwok, 2009). Nevertheless, worrying is a negative mental activity that is often unnecessary and can lead to a major anxiety disorder. As a matter of fact, one of the criterion for anxiety disorders is excessive worrying. Some caregivers worrying was based on the fact that their care recipient might get lost and would not find them again, expressing a feeling of guilt, grief and blame. Others were worried about the intensity of the symptoms of dementia their care recipients were exhibiting. The caregivers expressed how they feel as follows:

A participant expressed her worrying in the form of anxiety:

\[\text{You see this house does not have a big gate where one can lock if necessary and because of her behaviour I was told that if she gets out of the house I cannot find her.\ldots\text{ I am very worried but what can I do, she is my mother I cannot abandon her now that she is ill and go to work. What if I return from work and she is lost\ldots? She could have gone anywhere and I have to go and look for her, where would I have gone to look for her?}\]
Another participant who is a daughter-in-law believes her care recipient does not like her that is why she behaves badly towards her. She demonstrated her worrying in the form of dislike and echoed:

*I am very worried about this whole thing because when my husband wanted to marry me she did not like me; neither did she agree to our marriage. I still believe she does not like me that is why she is behaving this way towards me. At times when I go close to bath and change her dirty clothes, she screams and shouts at me to leave her alone. But when her daughters visit her she does not do those things to them. I believe her behaviour towards me is linked to the day I entered their family.*

A caregiver worries about not being able to sleep, she had this to say:

*What is worrying me is occasions when he will not sleep for us to also sleep. If it is money to buy medication for him that is no problem, we can buy it easily*

Another caregiver’s worry was fear of the unknown and she whispered:

*Previously I was worried about the situation and I think a lot. If this man gets lost how am I going to explain it to his family members to understand? They will not take it kindly so I take my husband everywhere I go.*

A grand-daughter was worried because her grandma was too forgetful and she says:

*... I was worried about certain behaviours I observed. When you give her money to count for you, she could not do it properly as she used to do. When you ask her how much money she is holding in her hands even though she counted it, she will say to you I do not know. She became so forgetful to the extent that she could not remember those who owe her money. The directions to their various homes could not be remembered either, leading to huge financial loss to her business.*
She continued to say:

... If I try to stop her by making sure the main gate is locked she becomes very aggressive, climbs up the stairs to the top of the house and attempts to jump down to the next house. This is scary because she might die from jumping down. We then try to restrain her and this continues throughout the night to early morning preventing all of us from sleeping.

A participant lamented on how she could not handle her husband’s behaviour:

One day I realized my husband could not remember how to write again, someone who could write so well. I could not handle it so I felt ill again and was admitted to the same hospital I was sent to the first time. I was given five infusions and the doctor told me to get ready for my death because I worry too much.

She continued to say that:

......when I see his friends he began life with, how they have succeeded in life and what has become of my husband I could not bear it....

A caregiver who is a daughter explained how she cares for her mother alone:

I was very worried because of my mother’s illness. Someone who could do everything for herself formerly but now everything is being done for her and it is worrying. Taking care of her alone it’s not been easy for me.

Another daughter was worried about how her mother has changed:

I get worried because my mother has changed a lot. This illness has turn my mother to a different person. At times she defecates on herself and if I do not notice it early she sits in it for a long time before I see it (shedding tears).
The only male caregiver in the study lamented on how his mother leaves the house unnoticed:

It got to a time my mother (he was in tears) leaves the house to sit at a place away from the house... I was the only one who knew where to find her, at a football park I used to play. I go and meet her there and bring her home.

He continued to say:

From there, I knew something was wrong and I was very worried. When I was talking to her, her answering was off, was not giving me eye contact, her face looked like she was in a different world so to speak, she looked confused that was when I noticed that something was wrong with my mother (in tears) and started sending her to the hospital.

IV. Mentally Depressed

The caregivers go through a lot of sadness in their care role. Some of the caregivers became sad when they observed their care recipients behaved inappropriately. Others became sad because they did not have enough money to care for their care recipients. A few became sad because their efforts in their care role were not appreciated. Some caregivers expressed their sadness as follows:

A daughter-in-law explained how her mother-in-law yells at her:

I still feel she naturally does not like me (tears in her eyes) because she talks calmly to her daughters when they visit but yells rather at me who is trying to make her comfortable in the house. Her daughters do not stay with us, they visit once awhile even my husband is very busy he does not spend enough time with his mother, she is beginning to forget her son (my husband) as I speak to you.

Another caregiver who is a wife complained of how her care recipient never worked:

My husband brought with him two vehicles from the UK and he worked with these vehicles but when the cars got damaged my husband never worked again. For the past 30 to 35 years I struggled to look after the children single handedly till now (shedding tears).
She continued:

All my prayers to God was divine strength to take care of my grandchildren when
I retire. I least expected my husband to fall ill in such a manner. I have really
suffered, gone through hell to take care of the children, now that I am on
retirement to rest, look at the problem that has befallen me (tears flowing down
her cheeks). My husband is ill and cannot remember anything even the wrong
behaviours. His junior sister died recently and when we went for the funeral, he
did not recognize any family member in the village.

A caregiver expressed how sad she felt when she could not find her husband:

From 9.00am to 12.00 noon, there was no sign of finding my husband, I started
crying inside the market. What am I going to tell the family members, I knelt down
in the middle of the market and prayed for God’s help. The way he was neatly
dressed even when someone sees him, that person might not know he is missing.

A grand-daughter described her grandmother as a ‘child’; she expressed:

I feel very sad (rubbing tears off her eyes) comparing her life before, when she
had her business and living her life the way she wants and now behaving like a
child. You know, taking care of a child is very difficult and tiring. This is how
grandmother has become.

A caregiver reported how she feels because of lack of money:

(She was weeping whilst talking) The thing is that I was working but stopped
because of my mother’s illness. Now I have to wait for someone to give money
before I can take care of our mother, this is depressing. My prayer is that God
continues blessing this person so she can get money to support us always.

Another caregiver echoed her sadness:

My mother’s illness fills my heart with grief (participant started shedding tears).
A son who is a caregiver expressed his emotions:

*It affects me emotionally; I do cry a lot* (he was shedding tears as he talked to the researcher). *In fact, we all do cry... my brothers too when her condition is not good.*

V. Withdrawal

Some care recipients due to the obstinacy accompanying their behaviour, refuse to do what their caregivers ask them to do at times. The caregivers being under pressure of caring also tried to give the care recipient their space to do what they felt like doing when such behaviours were observed. The caregivers did so because when they insisted the care recipient stopped any problematic behaviour, they became aggressive towards them. Other caregivers sent the care recipients to their extended families if they were with their nuclear families. The caregivers had this to say about their experiences:

A caregiver shared why she does not force her care recipient to do anything:

*(she giggled) she sometimes hits me when I insist she does anything so now I do not force her to brush, bath or do anything; she does it as and when she pleases. At times she decides to bath two or three times in a day.*

*She continued:*

*Other times I lock the doors up and sleep leaving her to sleep when she is ready. Most of the times she wants to do things at her own pace whether I talk or not, so I allow her.*

A caregiver echoed why she does prevent her from going out:

*..... If I prevent her from using the main gate, then she will climb up the stairs to the top and that will be dangerous for her. She is using this stair to have her way.*
Besides I cannot follow her around always, so I give her some space to do what she wants to do by permitting her to go out.

She continued to say:

......when she starts doing these things I do not stop her because she will not listen so I leave her alone but she stops when she is tired then goes to sleep.

A wife decided to send her husband to his extended family:

*Oooool, Hmmmmm...* (She sighed). *How should I say it, it’s worrying and I have decided to take him to the village and give him to his relatives.*

A daughter said what she does when the care recipient refuses to calm down:

*Other times she will not calm down so I leave her to continue shouting till she is tired and stops herself.....*

**VI. Coping**

The caregivers after all they go through with their care recipients’ behaviours try to be patient with them, calm down with the caregiving role and correct them with love.

Some caregivers had this to say:

A daughter shared how she calms her care recipient down:

......even then I have to stay awake and be talking to her until she calms down.

A wife talked about the intervention of her son:

*Our son intervenes when I try to coax his daddy not to go out but due to our son’s condition, he does not understand his father’s behaviour so he forcibly prevents him from going out*

Another wife likened her coping skill to a ‘child ‘and said:
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I accepted my husband’s condition and began joking and playing with him like a child when he shows any inappropriate behaviour.

A daughter explained her coping skills:

I rub her back gently for some time to calm her down when she is restless.

A wife’s coping skills is coaxing:

I coax him to calm him down when he is behaving inappropriately.

She continued:

....... I have been married to him since I was 21 years old when he was a young soldier, I have forgotten his age then. We have eight children, three men and five women all alive. He was perfectly okay and now that he is old with this illness I cannot complain I have accepted it.

She added:

When he is talking unnecessarily and shouting that he cannot find something, I tell him to be calm and that I would find it for him. He calms down and after few minutes forgets he was even looking for something. When I try to challenge him pointing it out that nothing was missing he becomes very aggressive and beats me severely.

VII. Satisfaction

Some caregivers in rendering care to the care recipients felt complete and satisfied.

They believed that they had played their caregiving role well for the care recipient. A caregiver had this to say:

A caregiver expressed her satisfaction in her care role by sacrificing herself:

So if I look at all these things she had done for us and today the devil has brought this illness on her, I cannot turn my back on her. If she had done nothing for me at
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all, she gave birth to me and made me who I am today that is why I am sacrificing myself to take care of her.

She added:

I want to take care of her the way God will want me to do, so that if even she dies out of this illness, I will have the satisfaction that I have done my part for her.

VIII. Hope

Even though the condition of care recipients was not encouraging, the caregivers still believed that the illness will be cured. Hope was expressed as follows:

A caregiver compared her care recipient to others in the vicinity:

Hmmmmmmmm... (She sighed). My dear the diagnosis did not scare me because in this vicinity I heard a lot of the elderly are suffering from this same condition, some are lost and are still not found but my husband is still with us to the glory of God.

A grand-daughter explained how care recipient remembers their house number:

Most people in this community know her and she never forgets our house number no matter what. We have stayed in this community for more than 30 years. For her not to forget the house number, is God’s way of helping us.

Another caregiver believed God will heal the care recipient:

I convinced myself that it is just an illness and he will be healed in the name of God.

A daughter believed God will help her mother:

...... it is worrying but what can I do. It is only God that can help me.
A son believed all will be well:

*My mother would get used to the old age and the sickness that comes with it and also when we pray alongside all will be well,*

He continued:

*I do not really care about what people think about my mother though, but it does worry me and I know it will be well.*

A 70-year-old caregiver prayed for husband to get well:

*I pray this illness should go back to where it came from so my husband will be well again. I am also ill as I sit here, I have this anal growth which needs surgery and I am thinking about it including my husband’s condition. I am praying that God will heal the two of us.*

In quest to answer the second research question: ‘What are the physical experiences of family caregivers caring for patients with dementia’ one theme emerged: ‘physical experiences’ with four sub-themes. These are presented in the following paragraphs.

**4.3.2 Physical Experiences**

Family caregivers assist the care recipient in their activities of daily living that is, helping them to brush their teeth, bathing and dressing, feeding, serving prescribed medication, taking them in and out of hospital for treatment, following them about in their state of restlessness, keeping awake with them when they refuse to sleep. Some caregivers were beaten during their caregiving role by the care recipients which ended them up in the hospital for treatment. Other caregivers talked about how tiring the caregiving role is and the extra work it brings to them.
The caregivers expressed their opinions in the following sub-themes identified. These were demanding, physical aggression, sleeplessness and fatigue.

I. Demanding

Caregivers put in a lot of effort, time, attention and skill in their care role just to make their care recipients comfortable and not get hurt which gives extra work. Some caregivers were separated from their nuclear family to their extended family to take care of their care recipient. Other caregivers took up the role of parenting even though they are not yet parents themselves. The caregivers gave a 24-hour care to their care recipient leading to a lot of stress and frequent hospitalization of the caregivers. This was what the caregivers had to say:

A caregiver who was a daughter echoed:

....so I am always with her keeping an eye on her but if I will go anywhere my brother also helps in caring for her.

She continued to say:

When I want to go out because my brother does not go to work daily he takes care of our mother till I am back but we take her to the hospital together when she needs to see the doctor for her medicine.... I have also accepted it being her only daughter among nine males. It is my responsibility to care for her.
She added:

*If I think about my mother’s condition, there is nothing I can do. I cannot leave her alone to sell in the market. You saw me sleeping by her when you came in. She becomes restless when she wakes up and no one is by her, both day and night. For that matter there is no way I can leave her to work.*

A daughter-in-law lamented how her mother-in-law broke a computer:

*She removes everything in her bag and scatters them in the room and throws the bag away. She puts her things together in smaller portions in a rubber bags other times she sits by the bag till I am back from where I went to. Once she broke the children’s computer before I got back. When I return, I had to clean the house and put everything at its original place before I continue with my house chores.*

She continued:

*She packs her bags at times in the afternoon and attempts to leave the house, we stop her by locking the doors. Then I go and take the bag from her and put them back where I keep l but she repeats the process over and over again until she is tired. This is what I am going through in caring for her.*

A wife expressed how she had to do everything for her husband:

*...he started finding it difficult to have his bath himself, even when he was forced to bath he could not do it properly. Wearing and changing his clothes was also a problem for him. He no longer knew where to find his pants and will not want to eat his meal, I had to do all these for him.*

She continued to say:

*...he defecated in the living room stepped on it and spread it to the bed rooms, my house help and I had to clean the whole house because the stench was unbearable.*
Then she echoed how she had to keep an eye on him all the time:

*You see how he is sitting down quietly looking at you (researcher). If you were not here he will climb upstairs and downstairs more than twenty times, wandering in and out of all the bedrooms and then to the kitchen severally. When I ask him to sit down, he does it for few minutes then gets up and starts stripping himself naked and I have to redress him again. Keeping an eye on him and following him throughout the process.*

Another wife lamented about how she suffers looking for care recipient when he gets lost:

*....at times I sleep for few minutes and on waking up realises he is nowhere to be found in the house. Then I had to go out looking for him with my children. If he is ill and at home, I am not worried because I can call on the family members to pay him a visit but the getting lost makes me suffer looking everywhere for him.*

She continued:

*.... some women selling tubers of yam in the market offered me some food to eat because they knew me and thought I will be hungry but I could not eat under such intense stress.*

A 28-year-old grand-daughter described what she meant by demanding:

*When I want her to bath even though she can walk to the bathroom, I hold her hand and escort her otherwise she will not go. Then give her the sponge, if I do not take the soap for her to put on the sponge, she will put the toothpaste instead. I had to ask her to put the toothpaste on the tooth brush and paste before she does it.*

She continued by saying her grandmother behaves like a child:

*After bathing I had to groom her because if I leave the pomade with her she ends up playing with it like a child. Wearing her dress too the same, had to be done for her or else she plays with it and walks about naked in the room. All these things if I am not with her she will not do. Before she eats I have to sit by her and make sure she eats the food.*
Furthermore, she added that:

*In the process of eating she will not touch the fish on the food, when I ask her grandma will you not eat your fish. She will then ask me where the fish is, meanwhile the fish is on the food. When she wants to sleep I have to lay by her on the bed to coax her to sleep (by patting her back and whispering to her saying, sleep grandma) before I go to my room to sleep. Even though she is strong and walks about on her own, you have to help her do everything.*

Another caregiver described her husband’s behaviour as that of a ‘child’:

*... defecates and urinates on himself just like a child would and I have to clean him as many times as he does it.*

She continued:

*I bake the bread alone early in the morning, supply them to my customers and quickly come back home before 9.00am to attend to my husband. He normally sleeps long hours and wakes up around 9.00am in the morning, so I lock him up, go to my customers’ homes for the delivery on foot and get home early before he wakes up. It is very stressful for me but what can I do?*

A daughter who is a caregiver left her nuclear family to care for her mother:

*...so I had to leave my husband and children to stay with my mother in the village.*

Another caregiver lamented about general weakness of care recipient:

*She cannot walk on her own we have to lift her all the time, look at my mum, she is big and heavy too. We move her around in a wheel chair. She cannot call you to attend nature’s call so she wears pampers to prevent her from soiling her clothes. This requires constant checking on her to see if she has soiled herself.*
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She continued:

*My senior sister comes here early morning to help me bath her because of my mum’s condition (she stopped walking when she got this illness) we have to carry her in and out of the wash room and bedroom. After that I feed her and make her comfortable in a chair before she goes to work then I continue with the care until my sister returns in the evening to help me carry her into the bedroom.*

A 25-year-old son echoed about his assistance to do everything for his mother:

*... she could not go to the bathroom unattended, could not do anything without assistance especially when she shouts all night, in the day she looks very weak and has to be assisted in everything she does.*

A 70-year-old caregiver who was a wife lamented about following her husband out:

*At times when he is wandering and there is no one to follow him around I do that so he does not get lost.*

### II. Physical Aggression

Caregivers revealed how they were verbally and physically abused by care recipients whilst rendering care to them. Aggression is defined by social psychologists as behaviour that is intended to harm another individual who does not wish to be harmed (Baron & Richardson, 1994). There are two types namely physical and nonphysical aggression. Physical aggression is harming others physically for example hitting, kicking, stabbing, or shooting them. Nonphysical aggression does not include physical harm. Nonphysical aggression consists of verbal aggression (yelling, screaming, swearing, and name calling). Some caregivers suffered continuous slaps in their faces, others were hit from behind on their arms and a few were threatened with kitchen knives and louvre blades. There were some cases of verbal assault and wrestling at door post with care recipients in an attempt to prevent them from going out in the middle of the night. Some caregivers narrated their stories as follows:
A daughter-in-law lamented about her physical abuse by her mother-in-law:

When she wakes up in the morning I ask her to brush her teeth and have her bath before I give her food. As for the brushing she refuses at times and when I insist she hits me very hard at my back so I do not force her again to do anything.

She continued:

Few weeks ago, she hit me on my left shoulder and for five consecutive days I could not lift up my hand. This was because I was preventing her from going out of the house.

Another caregiver echoed how she was threatened with a knife:

Formerly I was sleeping in the same room with him then he started becoming violent, threatening me with a knife. He nearly stabbed my son-in-law with a knife during one of his threats.

She continued:

My husband was removing the Louvre blades in the rooms and when any one tries to get closer he tries to cut him with it. He even bit my hand (right thumb), look at it (showing it to the researcher) and also bit the young man’s back in the process.

A 74 year old wife lamented about how she was beaten by care recipient:

.... he wakes up in the middle of the night and wants to go out of the house. We sleep in the same room so I lock the door to prevent him from going out. He gets angry and attempts to beat me. I threatened to report him to my relatives yet he beats me all the same.
A grand-daughter commented about the temper tantrum of her grandmother:

... she becomes aggressive when hungry, throwing sauce pans or anything she lays her hands on. If care is not taken she hurts, you with the things she throws about. We make sure she is not hungry, eats in the morning, around 12.00noon, and another one before supper.

Another caregiver was threatened with a knife:

He quarrels with me for no reason, beats the children without any cause and threatens me with a knife.

A wife reiterated the problem she encounters when her husband forgets something:

At times he beats me because he cannot find his money and assumes I have stolen it. He always forgets where he puts his things and suspects someone of stealing them. He talks a lot putting unnecessary stress and picking quarrels with everybody in the house especially, me.

She continued, she was slapped continuously by care recipient:

When he beats me I fall ill and I am taken to the hospital by my senior son. He warned him not to beat me again and threatened to take me away from him. My husband said he did not know he beats me, in fact evidence was there, my face was swollen because he slapped me continuously. It affected my eyes also and I go for checkups from time to time.

She added:

At times when his medication gets finished and I want us to go to the hospital for more he refuses to go saying he is not sick. If I insist we will end up quarrelling, then he will beat me. When I tell the doctor, he says he cannot give him medication without seeing him. I do not want to report him to the children but if he becomes aggressive without the medication it is difficult to handle him.
She emphasized on what she does to stop being abused physically by her husband:

_He does not force to have sex with me but whenever he asks for it and I refuse he gets angry and talks rudely to me but I do not mind him because if I say anything in his anger he will beat me. At my age if he wants to do this to me then I will die._

### III. Sleeplessness

Caregivers were not able to sleep if care recipient refused to sleep and talk to themselves all night. Sleeping becomes impossible for caregivers when the symptoms of dementia are severe increasing inappropriate behaviours of care recipient. Caregivers had to stay awake to help control these behaviours before they get out of hand. Caregivers had this to say:

A caregiver recounted her sitting on bed with care recipient till day break:

_At times she sleeps when she is calm, other days she sits on the bed till day break and I have no option but to sit with her on the bed._

Another caregiver commented about the wandering behaviour of care recipient:

_She does not sleep too. In the night she wanders for a long time whiles everyone is asleep but I have to stay awake with her._

A caregiver described her sleep disturbances:

_Hmmmmmmmm...... (She sighed) we sleep in the same room, she does not sleep at night and will get angry when I insist she goes to bed. At times I stay awake waiting for her to sleep before I sleep._
A wife lamented about her interrupted sleep:

_The big problem is that he does not sleep at night. He bangs at the door the whole night, like this_ (she got up to demonstrate how her husband does it) _banging sound making it impossible for me to sleep either._

A grand-daughter explained how her sleep was interrupted:

_In the night when we are all asleep, she wakes us up and insults us very well, making it impossible for us to sleep._

The only male and a son in this study echoed about late sleeping time:

_I stay awake with her till she catches some sleep around 2.00am then I can also sleep._

**IV. Fatigue**

The caregiving role needs a lot of time and patience for it to be effective. The process causes prolonged exertion on the caregivers leading to tiredness, physical illness or disease. A few caregivers employed the services of a house help to assist them in the caregiving role. The caregivers expressed their experiences as follows:

A caregiver explained how she had to be strong for her care recipient:

_At times I feel bodily pains and tired as a result of the care I give to my mother but after sleeping I feel a bit okay not totally well, I cannot complain. Once in a long while I feel dizzy but go to the hospital for medication and leave mother in the care of my brother._
Another caregiver took a house help because she needed help from someone:

> From January to March 2016 I was very ill (high blood pressure) due to my husband’s condition, I could not get up from bed, bodily pains, could not even carry my grandchild so I was forced to take a house help, could not walk properly to the market.

A wife who is a caregiver was advised to care for her husband as a child:

> I feel severe pains in my chest. So I reported sick at a clinic near our junction. The doctor after listening to my husband’s problem advised me to take care of my husband like I will do for my child or I will die and will not be able to help my husband.

She continued:

> ... I have been admitted five times because of what I go through as a result of my husband’s illness.

A caregiver who is a daughter fell ill because of the care recipient:

> .... high blood pressure. The doctor told me if I continue worrying about my mum’s illness, I will die and my mother will be left alone with no one to care for her. So I should relax, accept her condition and pray for God to give me strength to care for her. After the doctor’s advice, I stopped worrying and devoted the energy to caring for her.

Another daughter who is a caregiver recounted how her mother suffered injury because of her:

> My sister does not stay here with us. At times she does not come because she says she is tired then I have to bath her alone and my mother is heavy and I find it difficult carrying her alone. I tried once to carry her but she fell down and hurt her left foot, look at the wound (showing it to the researcher and started crying again). So now whenever she is not coming to help I just wipe her in the chair to prevent any accident.
She continued:

_Hmmmmmmmm...... (She sighed) when I take her for review then I also report sick. I feel bodily pain which is so severe that I cannot do anything._

In the search to answer the third research question: ‘What are the financial experiences of family caregivers caring for patients with dementia’ one theme emerged: ‘financial experiences’ with four sub-themes. These are presented in the following paragraphs.

### 4.3.3 Financial Experiences

Financial experiences are the third major theme identified after the interview. Some caregivers went through certain financial hardship in caring for their care recipient. The caregivers who were on retirement after public service and were on monthly pension benefits depended on their working children to support them. Those self-employed caregivers who were not able to plan their pension because of the ailment of their care recipients were finding cost of living very difficult. Some caregivers went for early retirement due to the severity of the illness of care recipient which was time consuming. Others lost money because they left their businesses in the hands of friends who could not manage them. Those caregivers who did not have anyone to take care of their businesses closed them down permanently. Some did not have money to take transport to the hospital for treatment. Most caregivers relied on family members and friends for money. On the other hand, at times family members and friends were not available to give them money, but good neighbours were around to support. Each caregiver had a peculiar way to handle the various sub-themes listed below. They are early retirement, loss of money, insufficient income and financial uncertainty.
I. Early Retirement

Early Retirement is defined by Obeng-Nyarko (2011) as retirement before the normal age, which is generally between 55 and 65. Early retirement may occur because a person attains financial security for the remainder of his/her life before most of his/her peers. Unfortunately, it may also occur due to injury or inability to work in one’s field. People with early retirement will qualify for pension or government benefits, but generally they are less than those who retire at full age. Most of the caregivers were self-employed and did not plan for their retirement, they quit their jobs because of the caregiving role. Due to the early retirement, some caregivers were having financial crisis and could not meet the needs of their care recipients. A few caregivers had this to say:

A daughter who was a caregiver stopped working:

*As a result of my mother’s condition I stopped going to the market to sell so I can take care of her.*

She continued to narrate her difficulty:

*Things are difficult (did not have money to support the care of her mother) for me but I cannot leave my mother alone and go to the market to sell and not care for her.*

Some caregivers lamented why they stopped working:

*I was working but stopped because of my mother’s condition.*

*I was selling smoked fish but stopped because of my mother’s illness.*
II. Loss of Money

Some caregivers lost money in their quest to care for their relatives. They abandoned their work and left it in the hands of friends who ended up mismanaging it. Others did not leave it for friends but stopped going to work for a few weeks and in effect lost their customers. Some care recipients destroyed things in the house which needed to be fixed immediately and caregivers used the little money they had to manage the house to fix the problem. This was how some caregivers expressed themselves.

A caregiver narrated how she left her job:

One day I was selling fish in the market when my grandchild called me to attend to my mother who was complaining of headache. I left the goods with a friend and rushed to the house to attend to my mum. I gave her some paracetamol tablets immediately but after some time had passed she was still complaining of the headache. So we took her to the Tema General Hospital to see a doctor.

A caregiver commented about what she went through by preventing her husband from going out:

Later we started locking the door to prevent him from going out but he went for a knife to help him break open the door. At times he uses pestle (used for pounding fufu) to force the door open or anything that can help him open the door. Then I have to look for money to repair what he has damaged since all these are not planned for.
Another caregiver indicated her loss was caused by distractions from care recipient:

My husband has lost his job because of this illness and I also did not have time to concentrate on my business due to my caregiving role, I did not have enough customers. In the beginning, he was very aggressive and going out of the house unannounced and these prevented me from focusing on my business. In effect our financial status was very bad, what to eat and buy his medication is a big problem.

III. Insufficient Income

Most of the caregivers, because they had no jobs relied on friends, neighbours and family members for money to cater for the care recipient. The money they gave them was not enough to buy all their needs for the house. Some of them became financially handicapped to the extent of not having money to buy food, adult diapers or take care recipient for review in the hospital. The caregivers were not able to go to the hospital when ill or buy prescribed medication if they were able to visit the hospital because of insufficient income. This was what some had to say:

A daughter believing God for help:

By the grace of God when other family members visit us they give some money to care for her which I use to cook for all of us.

Furthermore, she continued:

If my brothers were alive they would have been helping me care for my mother financially but they are all dead leaving the mason who only works on available contracts and the last born who is not working.
Another caregiver who was a daughter complained of lack of financial support:

*Initially my siblings were all contributing but now only one of them is helping me financially which is not enough.*

She continued:

*Someone comes at all cost by God’s grace but what they give at times is not enough. That is why I do not bring her of late to the hospital for her regular review. We do not have enough for food and transport. I take a taxi to and from the hospital each time we visit which is very expensive.*

Similarly, a caregiver explained her lack of money:

*Buying her pampers for her to use is another problem since I do not have enough money to do that all the time.*

She continued:

*... the medication they gave me I could not buy it and the prescription is lying in the room. By the grace of God, I got some herbal medicine and it helped.*

Another caregiver disclosed the source of his funds:

*My senior brother, takes care of all our bills. When I was doing my service I supported a little bit. He is now married and has two children he needs to support his nuclear family. At times when I do not have money I go to my step sister to take some money. Not enough but okay.... so the little money we have we manage it.*

A pensioner who was a caregiver described how they managed:

*My husband’s pension money comes monthly and my children also put themselves together and bring us something small. I was operating a chop bar but stopped because of old age so we try to manage with the small money that we have, our medications and other needs are managed within his pension money and the little our children send us. You know, my children also have their families to support.*
IV. Financial Uncertainty

Some caregivers at times did not know where to get money to buy food and clothes for their care recipients. The family members who promised to send them money disappointed them. This made things very difficult for the caregivers and some even sacrificed their daily food for their care recipients. Other caregivers were supported by neighbours who had their interest at heart because at times family members failed to send money.

A caregiver narrated how she got money:

This is a problem (participant said this crying). At times neighbours come to give me money to take care of her and other times my siblings bring a little money when they get some then I manage it.

She continued:

If money does not come from my siblings, friends and neighbours, I sacrifice my food for a couple of days so that my mum can have enough to eat at least until someone comes to our rescue.

Another caregiver explained why her not working has affected them:

Now I do not work because of her condition. Of late extended families do not support each other as before. We are only supported once in a long while with 10 Ghana cedis or 5 Ghana cedis when they pay us visit. This is why I said that things are difficult.
In an attempt to answer the fourth research question: ‘What are the social experiences of family caregivers caring for patients with dementia’ one theme emerged: ‘social experiences’ with ten sub-themes. These are presented in the following paragraphs.

4.3.4 Social Experiences

The caregivers went through certain social realities and they expressed in the following sub-themes. They were bonding, family support, family conflict, social support, spiritual attack, selflessness, loneliness, empathy, difficulty to study and lack of parental love.

I. Bonding

The care role of the family caregivers brought closeness between the care recipient and them. The caregivers were always with the care recipients for various reasons. Some related their closeness to the dangers in their community. A few caregivers observed that the ill-health of the care recipients’ strengthened the relationship between external family members and the caregivers. Other caregivers’ attachment to their care recipients were likened to the relationship between a mother and a child. This was how they reported their bonding:

A caregiver explained her acceptance to her caregiving role:

*People tell me she is like this because of her age so I should stay with her all the time, and I have accepted it. You can see the front of our house is a busy road and it will be dangerous for her if left unattended.*

Another caregiver talked about how care recipient got fresh air:

*At times my husband’s nephew who stays here with us takes his grandmother for a walk to get fresh air outside the house.*
A wife shared how care recipient and she were admitted into the hospital together:

*One time I reported sick at the hospital and I needed to be admitted. I told the doctor I have a sick husband at home and could not leave him unattended. So the doctor permitted my husband to be brought to the hospital with me and he was taken back home in the evening when my senior son closed from work.*

A grand-daughter put everything of hers on hold to attend to her grandmother:

*Other times she goes to my mother’s shop quarrels with her and goes home earlier than expected, I had to cut my outing short and rush back home to take care of her.*

She continued to explain, by comparing her bonding to ‘mother and child’ relationship:

*...when I was doing my national service, I had to tell my aunty who was also working at the industrial area to come and play the care role for me. While at work I am thinking of how to get home early to relieve my aunty. Now I am done with the service but when I go out to look for job and leave her with someone, I had to come back early to relieve the person; just like a mother who has left her child with someone.*

**II. Family Support**

Some caregivers were assisted by nuclear and extended family members in cash and in kind. Some family members gave money to the caregivers to help in caring for their care recipient. Other members advised the caregivers in their care role and also showed appreciation for rendering care to a family member. Furthermore, some members helped in the care role by helping to restrain care recipients in their aggressive state. Below is the expression of individual’s experiences with family members.
A caregiver indicated how they got food to eat:

_Hmmmmmmm... (she sighed, tears in her eyes), by the grace of God a family member definitely comes and gives us small money which I use to prepare some food for all of us including my brother._

Another caregiver who was assisted by family members said:

_My daughter, my son-in-law, my house help and I are taking care of him. We take turns in caring and calming him down when he is restless. Two months ago when he was aggressive, my son-in-law’s junior brother who came for a visit helped me to restrain him._

She continued:

_I have spoken to the family head; he says I should bring him. The family head says that my husband has a lot of cousins in the village who will help take good care of him, there are empty rooms for him to sleep but he asked me for time to make the necessary arrangements._

A wife who is a caregiver indicated how her husband was taken care of:

_I have another daughter who is a student and stays in this house. She takes care of him whilst I am away till I am back. My special son (mentally disturbed) and my daughter-in-law who stays here also helps in his care._

She continued to express her relief:

_Gradually the family members became aware of his condition. Now even family meetings are being held in this house, so I have a relief at least the family knows what is happening. They have recommended and congratulated me for my endurance in taking good care of their brother._

The grand-daughter talked about family support as:

_Yes, at times I go out but let her go to my mother’s shop to stay with her. She goes to my mother’s shop everyday but comes home alone to eat and sleep. So if I know I will be out I tell my mother to keep an eye on her._
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She also added:

*My mother’s siblings put money together to take care of her. They are five in number, three females and two males but one male is deceased. The hospital bills are paid by them; with the feeding they give me the money to do the marketing. At times they do the marketing for me then I cook the food and refrigerate it.*

Other caregivers talked about how the family supported them:

*My sister came for my husband to her house to care for him when I was ill and admitted to the hospital until I recovered.*

*Hmmmmmmmm….. (she sighed), my sister’s daughter stays with me, she is a student and at times when I have to go to the hospital she stays home and take care of my mother for me.*

A caregiver described how he got ‘a mother and father’ substitute:

*My second senior brother has been like a mother and a father to me all these years (participant shed tears as he spoke about his second senior brother). He paid my senior high school fees, bought my books, clothes, fed mum and I, because dad was with another woman. He encouraged me to study hard at school. He did everything for me and I share my feelings with him whether good or bad. If I am feeling sad and I need to cry it out, my brother is there to cry with me, precisely we are very close.*

III. Family conflict

Family members having different views or beliefs that do not meet causes conflict. Occasionally conflict occurs when there is misunderstanding among members and a wrong conclusion is made. When conflict is not resolved peacefully, there is argument and resentment. It is normal to have conflicts sometimes, to help respect each other’s space and not step on the toes of people. Conflict that is prolonged leads to stress and damages
relationships. Some caregivers went through a lot of misunderstandings with other members in the family in caring for their care recipients. Some of the conflicts were the support of money and who brings how much, who to care for the care recipient and at what time, some problematic behaviours of the care recipients which are only known by caregivers, bringing an in-law suffering from dementia to stay with the nuclear family without proper discussion between spouses and the decision of step parents to take spouses to a mental institution to seek help. Some caregivers had this to share:

A daughter-in-law narrated how decisions were taken behind her:

She was in the village and fell ill before last Christmas celebration so she was brought here to stay with us by my husband without discussing it with me as a wife.

She continued:

... my husband knows and still thinks I am just making up stories against his mother. Once she came out of the house unknown to me ... went to the back of the house with her bag and jumped over the wall to the next house...I saw her and run after her, brought her back home through the main gate. When my husband came home from work and I reported the incidence to him, he said it was impossible for his mother to jump the wall because she is not strong enough to do that.

She added:

...as usual my husband did not believe it when I told him and I got so angry. This attitude of my husband is making me very angry at him each time his mother behaves inappropriately. It brought a huge argument between us because my husband thinks I am making them up. He says I do not like his mother and I am lying about her behaviour....so we quarreled.
A caregiver also expressed her dilemma:

*I then told his children about my plan for their father but they forbade me from taking their dad to the psychiatric hospital saying, their father is not mentally ill. I called his brother to discuss the matter with him and he permitted me to go ahead with the plan.*

She added:

*The other children of my husband (step children) did not help in his care, they said it is me who is married to their father and unfortunately he is sick so it is my responsibility to take care of him alone.*

A caregiver explained how other family members refused the caregiving role:

*I have a sister in the village who could help but she stopped being nice to our mother immediately she fell ill.*

A daughter lamented about her siblings’ anger:

*When our review date is due and my siblings have not yet sent money I call them and demand the money from them. They get angry with me and say I am putting too much pressure on them. They have also forgotten that it is only me staying here with her and if she becomes aggressive because her medication is finished it is me who will face the danger.*

She added:

*... because of the friction between my siblings and me, I feel like leaving my mum in their care and move out of the house but my siblings are always busy. They come to see how she is doing and leave. They are not able to stay with her for a long time. So when I look at all these behaviours I decide to stay and care for her (immediately the participant ended her sentence, her mother who was sitting by us throughout the interview, shouted out the name of the participant, in a thin, weak voice and said thank you for your care. Participant wept profusely).*
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The only male in the study lamented about how his aunts neglected his mother:

…but because they are her sisters and will take good care of her but they were not doing it but added more stress to mother’s condition. They just came doing nothing for my mother, refuse to fetch water for her to bath, it was like they come to add to her condition so I sent my mother’s sisters away because they were not helping the situation.

A 70-year-old wife talked about her grandson’s help:

My grandchild is also here with us. At times if I want to go to church, or to hospital when I am ill he takes care of him till I am back.

She continued:

So when he refused to go for his medication I tell my children and they come and take him to the hospital for it.

She added:

Yes, the extended family are aware of his condition, they come once a while to visit and they call us if they cannot visit. They appreciate the way I am taking care of their brother by thanking me each time we talk on phone or they visit us.
IV. Social Support

Community members showed their support by giving some donations to the caregivers to take care of their care recipients. Also, some already had some knowledge about dementia so they advised the caregivers about the illness and where to get professional help. Some neighbours go out of their way to help find care recipient when they go missing. Some caregivers reported what support was rendered to them by their neighbours and friends in the pages below.

A caregiver was advised by neighbours to have patience with care recipient:

I have been told by people that this condition of my mother is due to old age and her behaviour will not change to normal again. Also I should have patience and care for her.

A wife expressed her view about care:

We just have to be vigilant in caring for him so he will not go out of the house unattended. Even though he had gotten lost three times already since he was diagnosed, it all lasted for four hours but by God’s grace neighbours found him for us. This is what I like about this community we know each other so well.

She continued:

...that was why we took him to the General Hospital, but some friends’ advised we take him to the Psychiatric Hospital at Pantang. Someone told me there is a psychiatric unit at the General Hospital so we took him and the doctor gave a final diagnosis as Dementia

A wife told her story about church:

I do not go to church again because my pastor said if you have a sick partner at home, we should not leave them alone at home and come to church. My husband too does not go to church, he is a catholic so his Reverend Father comes to serve
him communion every time; I go to church of Pentecost and my pastor comes with my communion from time to time and also pray for us.

She continued:

... at the same time news had gone viral in the community that my husband was lost so when the taxi was passing through the community to the next community, he was noticed in the taxi by one of the neighbors who was standing by the road side so he stopped the taxi and took my husband home.

A grand-daughter talked about how strangers brought her grandmother home:

Whenever she is in an environment which is not familiar to her, she mentions her house number to any stranger she sees and God being so good a stranger brings her home.

V. Spiritual Attack

Some of the care recipients see things which are not real and also perceive things but interpret it wrongly. They continue to experience these things so much that the caregivers perceived it as they being spiritually tormented. The care recipients are then prayed for by caregivers and also taken to prayer camps to be prayed for. These are some of the experiences narrated by the caregivers.

A wife talked about her husband’s false alarm:

What we observed was that, he most of the time will tell you to look in the compound some people have come into the house and are watching us through the window, when we go and verify we do not see anyone. He will go on and say that they are standing by him tormenting him. This continues for a while so I thought at the time that it was spiritually inclined and that he was being attacked spiritually. So we started praying with him at night, having night vigils for him.
Another caregiver thought the illness was spiritual:

\[\text{We were asked to come for review but my husband said he was not mad and for that matter he will not go back there again. We started going for prayers because I thought it was spiritual and visiting private hospitals when the need arose.}\]

VI. Selflessness

Some caregivers sacrificed their happiness for the care recipients by taking care of them even when they (caregivers) are not feeling well. Others gave up their food for care recipient so they could have enough food to eat. A few caregivers follow care recipients around town to prevent them from getting lost. Some caregivers had this to say:

A wife who could not bear to see her husband in his situation said:

\[\ldots \text{I thought I was going to die but I had to stand up and take care of my husband. When he wakes up I make sure he has his bath, give him an ironed dress to wear and sit him down to eat, naturally he does not like food he eats very little at a time so I have to force him to eat. This I did every day till now.}\]

A daughter who loved her mother said:

\[\text{By the grace of God, I have not been admitted in the hospital before but I feel very tired and ill at times which requires medical attention but there is no one home to take care of my mother for me to go to the hospital (cried a bit) so I do not go to the hospital because of my mother’s condition.}\]
A 70-year-old wife explained how she kept vigilant:

*No I do not go anywhere for the fear of him getting lost. He got lost once but was able to locate home after wandering in town for a while. If he wants to go visit a friend, I ask my last child to follow him so he does not get lost or I go with him if our son is not at home.*

**VII. Loneliness**

Some caregivers could not go out from the house to do anything because of the severity of the illness of their care recipients. The symptoms of dementia are such that the caregivers have to be extra vigilant in their caregiving role to prevent them from any form of danger. In doing so, the caregivers themselves forgo any kind of entertainment making them feel dejected, lonely or ‘imprisoned’ as some caregivers referred to the caregiving role. A prison, according to the caregivers is a place where one loses his or her freedom to do anything. The prisoners take orders from the prison officials watching over them. In the same way, caregivers felt their lives were being controlled by their care recipients; the activities of daily living take all their time. Some also felt lonely because they did not have their old friends anymore therefore have nobody to share their problems with leading to depression. The caregivers had this to say.

A wife described her loneliness as ‘**imprisonment**’ and said:

*Hahahahaha…… (She laughed), He has put me in PRISON.*

She continued:

*I cannot go anywhere. I only go to church or a funeral if my son-in-law is at home. We have shared the responsibility on Sundays, when my daughter and her husband go to church for two Sundays then I also do the same for two Sundays.*
She added:

_I do not go for any celebrations, weddings or engagements since I came for retirement two years ago. That is why I say I was in PRISON. Since I came home for retirement for the past two years, I do not go out for any celebration (tears in her eyes); I am a PRISONER in my own house._

Another caregiver likened her loneliness to ‘_imprisonment_’ and added:

_.... I am in PRISON. I do not go anywhere but stay at home to nurse him all the time._

A caregiver, who is a wife echoed her loneliness:

_No, I do not go anywhere apart from my bread delivery to my customers early mornings._

A daughter who is a caregiver talked about how she could not leave her care recipient alone:

_I do not go anywhere because of her condition. I do everything for her, brush her teeth, bath for her, dress her and feed her so I do not leave her alone._

Another daughter needed someone to help in her caregiving role:

_I could not go anywhere looking at my mother’s condition. As I am talking to you my best friend is dead and the funeral is ongoing today but I could not go because of my mother_ (she burst into tears again but researcher managed to calm her down). _If there was someone with me here I would have gone._

A son, as a caregiver lamented about how he did not have anyone to talk to:

_Well, not that no body hears something or not but I have friends around, I have been in this neighbourhood since childhood but none of them ask me why my mother does that. They do not want to know because they feel when they ask it will hurt me so I also feel it is just my burden._
VIII. Empathy

A senior lecturer in psychology Steve Taylor (2015) revealed that there are two types of empathy. The first is called shallow empathy and is defined as the ability to “put yourself in someone else’s shoes,” or see the world through someone else’s eyes, or to read their emotions. He emphasized that, this type of empathy is identified as cognitive ability which suggests that a problem can be solved based on past experiences. Thus empathy in this sense does not automatically imply goodness but it just makes an individual understand the emotions of another individual. The second type of empathy is called deep empathy and it is the ability not just to imagine (as in cognitive ability) but to actually feel what other people are experiencing. The family caregivers have deep empathy because they sense the feelings and emotions of their care recipients so much that they were willing to care for them with all of their heart. Other caregivers fell ill during their caregiving role but ignored their illnesses and focused on their care recipients. This is what they had to say:

A caregiver explained how she put herself together for the care recipient:

>I put myself together for him because I could not afford to be lying in bed when my husband is in this state, I try to be strong for him.

A daughter indicated how she took care of her mother:

>No, we were not told how to manage her but I put myself in her shoes and say to myself that I will take care of her the way I would want to be taken care of if I had this condition.
She continued:

*My friends ask me if I am the only one in the family who is sympathetic or if I am the only child but it is not like that if in future God gives me a child and I fall ill and my child turns her back on me, I will be very bitter so I am just putting myself in his shoes.*

A 70-year-old wife reported about how tenants in the compound house understood the care recipient:

*We have stayed in this compound house for a long time and every tenant knows him very well, so when he started accusing them of stealing his money and provoking them, they all realized there was something wrong with him so they do not mind him.*

**IX. Difficulty to Study**

A caregiver could not study at school after hearing the diagnosis and observing the inappropriate behaviour of his mother. This was what he had to say:

*Yes, it affected my studies when I was in my final year in the secondary school. I used to lie in my bed thinking about mother, her condition and feeling sad instead of studying. I would then call my senior brother and he would encourage me.*

**X. Lack of Parental Love**

Some caregivers explained that because of the condition of the care recipients who were their spouses and parents they do not feel loved. Some caregivers’ children were beaten without any cause by care recipients. Other caregivers said they missed the opportunity of been advised by their parents (care recipients) just like other parents who were not ill do.
A wife explained that her husband beats their child without cause:

My son too when his daddy wants to go out and I am coaxing him not to go, my son due to his condition does not understand his daddy’s behaviour so he forcibly prevents him from going out. The dad beats him without any cause and this breaks my heart.

A son said he only expects wellness:

When she takes her medication and calms down, I get all the love I need from her, we chat, she jokes, just like back in the days. I just accepted her the way she is and not expecting anything more from her than her wellness (in tears).

4.4 Summary of Findings

The above findings were based on data generated from narrations of participants attending and receiving treatment at the Community Psychiatric Unit of the Tema General Hospital. The findings brought to light the challenges family caregivers caring for patients with dementia go through and how vulnerable it made them. The family caregivers went through some psychological experiences such as frustration due to the care recipients’ problematic behaviours. The caregivers were embarrassed by care recipients quarreling and fighting neighbours without just cause, which led to the caregivers losing respect before their neighbours. These triggered a feeling of worry and depression on the part of the caregivers. Some caregivers decided to relax and be calm about the caregiving role so that they did not overburden themselves. In the midst of all this stress other caregivers managed to cope with the inappropriate behaviours of the care recipients.

The caregiving role was demanding, causing sleepless nights for caregivers which led to fatigue and subsequently to physical illness. Most of the caregivers were verbally and physical abused but found satisfaction in the caregiving role because of the good deeds exhibited by the care recipients.
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before their illness. There was financial hardship during the caregiving role due to the caregivers quitting their jobs to cater to the needs of care recipients. Extended family members also helped in cash or kind to look after the care recipients. Family conflicts were inevitable where turns in rendering care was required. A table of summary of the themes and sub-themes is shown as appendix G. The next chapter will discuss in detail the findings and how the model helped the current study.
CHAPTER FIVE

5.0 DISCUSSION OF STUDY FINDINGS

5.1 Introduction

This chapter discusses the findings of this study in relation to existing studies. The purpose of this study was to explore the experiences of family caregivers caring for patients with dementia in the Tema Metropolis. The main themes that emerged from the data included psychological, physical, financial and social experiences with their sub-themes which reflected the constructs in the conceptual model used for this study. The objectives of this study were:

1. To explore the psychological experiences of family caregivers caring for patients with dementia.
2. To identify the physical experiences of family caregivers caring for patients with dementia.
3. To explore the financial experiences of family caregivers caring for patients with dementia.
4. To identify the social experiences of family caregivers caring for patients with dementia.

5.2 Psychological Experiences

Caregivers play a major role in supporting family members during illness and dementia is not an exception. The task of caregiving leaves the caregiver with no option but to go through certain unavoidable experiences that can be clustered as psychological. One of the objectives of the study was to explore the psychological experiences of family caregivers caring for patients with dementia. From the analysed data, some of the experiences the family caregivers encountered in their caregiving role were described as frustrating, embarrassing, worrying, mentally depressing, withdrawal, coping, satisfying and hopeful.

This finding is consistent with the findings of Chan Ng et al. (2010) in whose study 75% of caregivers reported of having psychological distress with some emotional responses including...
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grief, sadness, anxiety, anger, guilt, blame, fear and embarrassment. The caregivers in addition encountered behavioural and psychological problems when rendering care and these were; agitation, irritation, aggression, obstinacy, withdrawal, insomnia, abnormal perception. They described the care role as demanding. Even though in some instances the terminology used were not the same, experiences such as agitation, abnormal perception, anger, obstinacy and irritation were described as frustrating in the current study. Guilt, anxiety, grief and blame were also described as worrying to the caregivers. Insomnia and the demanding nature of caregiving were discussed under, physical experiences. These findings also agree with those of Razani, Corona et al. (2014), whose findings showed that dementia is advancing in severity leading to increased cognitive deficiency which brings down the ability to do activities of daily living, giving rise to psychological distress, depression, anxiety and burden of the caregivers. Another finding in the current study revealed that caregivers described their experiences as burdensome because they were all associated with some form of stress. In line with the study by van Vliet et al. (2010) which revealed that caregivers go through high burden, depression, negative psychological and emotional effects, feeling of frustration, grief or guilt, loneliness or social isolation and poor emotional wellbeing, the current study sees loneliness or social isolation in the social experiences. The researcher’s findings were similar to all the three studies mentioned earlier.

The similarities of the findings imply that sometimes geographical location may not matter much in caregiving for patients with dementia. Also, irrespective of one’s role as a formal or informal caregiver, it is likely to go through psychological experiences of varying degrees. None mentioned ‘satisfaction’ which was also a psychological experience in this study. The caregivers complained about their experiences and how burdensome they were yet, they talked about gaining satisfaction in their caregiving role due to the past sacrifices the care recipients made for them as
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parents. This implies that the caregivers had accepted the caregiving role no matter how difficult it was. This is consistent with the findings of a study by Shim, Barroso and Davis (2012), whose findings revealed three groups of spousal caregivers who described their experiences as being negative, ambivalent and positive.

The positive group saw love and satisfaction in their caregiving role, their focus was on the fact that their spouses were alive and were been catered for by them. The ambivalent and negative groups saw a burden in their caregiving role. The similarity in the study compared to current study was that, caregivers gained satisfaction in their caregiving role. However, the differences were that the study revealed only spousal satisfaction while current study revealed spousal, children and grand-children satisfaction.

5. 3 Physical Experiences

Caregivers of patients with dementia go through a lot of physical problems in caring for their care recipients. They develop changes in their whole body which manifest physically. The caregivers need energy, endurance and strength to render quality care to their patients but due to the nature of their role, achieving this purpose becomes very difficult. Exploring the physical experiences of family caregivers caring for patients with dementia, is the second objective of this study. The findings of the study revealed that caregiver’s role was demanding, there was physical aggression, a feeling of sleeplessness and fatigue.

In line with the study of Hirano, Suzuki et al., (2011), the findings of the study showed that more than 50% of the caregivers were suffering from hypertension, hypercholesterolemia, diabetes and cancer which was due to the higher burden of caring for care recipients. The higher burden was supported by other studies (Pinquart &
Sorensen, 2003 and Adams, 2008). Furthermore, the finding also associated higher burden to lower activity level (Wise et al., 2006). In the current study, the findings revealed that higher burden led to fatigue (higher activity) which exposed caregivers to physical illness (hypertension). The family caregivers in the current study, with an average age of approximately 50 years described their activities of daily living as very stressful which led to tiredness and weakness because of extra work. Comparatively the study may have gotten their results based on the purpose of their study.

The findings of the current study were again compared to another study (Gräsel, 2002). The findings of the study showed that active caregivers suffer more of these diseases (Hypertension, Low back pain or intervertebral disk lesion, Thyropathy Monoarthrosis, Ischemic heart disease, cardiovascular system diseases, Osteoporosis, Polyarthritis, Headache syndrome and Diseases of the venous system) than formal caregivers. It indicates that formal caregivers are now able to pay attention to their health status when caring ends reducing physical complaints. These findings in the study is similar to the findings in the current study but the current study discussed physical illness in the light of ‘fatigue’. De Oliveira, Vass et al., (2015) study from 12 selected studies revealed lower quality of life and a negative relationship between carer’s age and Quality of Life outcomes. It revealed that older caregivers take care of their care recipients more than they care for themselves leading to poor relationships (McGarry & Arthur, 2001 and Quinn, Clare et al., 2009).

Additionally, majority linked negative aspects of caring with the lower Quality of Life outcomes, such as burden, depression, anxiety and stress. The similarities in the findings of the studies compared with current findings shows that human beings are the same everywhere irrespective of complexion, culture or destination. When the body is over
worked it becomes tired and weak leading to physical illnesses. However, one significant revelation in this study which was not evident in the previous studies was physical aggression. This was where some caregivers were threatened, assaulted and beaten, with destruction of some properties by the care recipients. The other studies might not have explored this area due to their research methodology or purpose of their studies.

5.4 Financial Experiences

Caring affects the work and finances of caregivers (Haddock, Zimmerman, Lyness, & Ziemba, 2006). Financial costs are the direct temporary costs associated with paying for the caregiving expenses, whilst others are related to losing money at work due to one having to perform a caregiving role (Lai, 2012). Most caregivers experienced financial restraints because they did not have time to plan their retirement. This was due to the sudden illness of their care recipients. Another objective of this study was to explore the financial experiences of family caregivers caring for patients with dementia. From the findings, some of the experiences they encountered were early retirement, loss of money, insufficient income and financial uncertainty due to their caregiving role. These findings supported those of other studies including that of Lai (2012) which indicated that in taking good care of a patient with dementia, caregivers need to do it on full-time basis. This means caregivers have to stop their primary jobs for the caregiving role of their patients. To buttress the findings, it was found that when compared with workmates who were not caregivers, family caregivers had to take more time off work, often were called from work regarding family issues, absent themselves from work, took more time off without pay and worked fewer hours than desired (Schulz et al., 2003).

The findings of the current study are consistent with that of Schulz et al. (2003). However, while Schulz et al. (2003) highlighted findings such as taking time off and absence from work, the
current study noted experiences of caregivers in the light of loss of money and early retirement. Farré et al. (2015) revealed in their study that, there was high cost between dementia care and illness severity, dependency in activities of daily living, comorbidity, and behavioral disturbance. In addition, the study also showed that, informal caregiver time spent with activities of daily living costs about 198.83 hours per month, and corresponds to an average monthly cost of 1214.86 Euro. These figures were affirmed by some international studies including recent Spanish studies and other European research work (Gustavason, Brinck et al., 2011, Wimo, Reed et al., 2013, Coduras, Rabasa et al., 2010, Pena-Longobardo & Oliva-Moreno, 2015 and Jorgensen, Cabanas et al., 2007). The results of the current study are consistent with all three studies compared, however the experiences in terms of cost related to hours spent rendering care daily was not explored by the researcher in this study because of the focus of the study. Future research therefore, is required to investigate the cost with regards to time the family caregivers spend in their caregiving role in Ghana.

5.5 Social experiences

Caregivers became attached to their care recipients in the process of caregiving. The attachment enabled the caregivers to seek help for care recipients when there was any kind of crisis. This help came from family members, friends and neighbours. Looking for help sometimes ended up in some misunderstanding and confusion among siblings, friends and neighbours. Another objective of this study was to explore the social experiences of family caregivers caring for patients with dementia. The results of the current study showed that family caregivers experienced bonding, gained family and social support, experienced family conflicts and spiritual attacks. There were also expression of selflessness, a feeling of loneliness and empathy. Some
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caregivers experienced difficulty to study because they were worried about the condition of the care recipients. Other caregivers felt lack of parental love because of the parents’ illness.

Another study of interest which shared some similarities with current findings is the study of van Vliet, de Vugt et al., (2010) whose findings showed that Early Onset Dementia (EOD) brings about family conflicts. In addition, caregivers reported that children were in conflict with care recipients. Also, children experienced difficulties at school due to ill parent (Harris & Keady, 2004). The children might be angry with the care recipient because the caregiver (who may be a mother or father) may be giving all the attention to the care recipient. In the current study a caregiver explained how he could not learn at school when he heard that his mother was suffering from dementia but he was able to write the exams because of his senior brother’s encouragement.

Szinovacz (2003) revealed in his study that the relationships between the adolescents and the caregiver (typically the adolescent’s mother, but in a few cases, a father or grandfather) was strongly affected by the caregiving role. To give a better understanding of the findings, the analysis of the study developed two features; positive and negative relationships. With the positive features, the adolescents talked about bonding, empathy, and restraint whilst the negative features talked about lack of attention, fewer activities, strictness, arguments, temper, and irritation or impatience. The negative features outweighed the positive features indicating poor relationship. The findings of the study are similar to the findings of the current study where negative features such as fewer activities, strictness, arguments, temper, irritation and impatience were discussed under family conflicts and the positive features such as bonding and empathy were analysed individually under chapter four of this study. Restraint was analysed under demanding, a sub-theme of physical experience.
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Comparing these studies, the researcher observed that they have a strong relationship with each other. The first study focused on high responsibility in performing caregiving role whilst the second and the third were about family conflicts generated in performing the caregiving role. None of the studies however talked about ‘spiritual attack’ which happened to be one of the findings under this section. For some caregivers, during the early onset of dementia, they experienced symptoms such as illusion and visual hallucinations. These were misunderstood as evil spirits attacking them and therefore night prayers were organized by the entire family to drive away the evil spirits.

In Ghana, beliefs and cultural practices have a great influence on illness and health behaviour. Ghanaians fear diseases because they believe that disease is not natural. When a young energetic, healthy person falls ill, they think something must be wrong. If the disease progresses and appears incurable, it is believed something evil has been committed by the victim or another agent. To be sick, the traditional Ghanaian has the conviction that the disease is evil and comes from the devil (Asare-Danso, 2005).

Ghanaians make distinction among various diseases. If a child is born deformed, it is perceived to be sinful or moral misbehaviour of the child’s parents. Such children in the past were killed because it was believed they carried with them the evidence of sin. There are two kinds of adult illnesses: unclean diseases and the other not categorized: The unclean diseases are epilepsy, leprosy, smallpox, insanity, excessive diarrhea and swelling of the body. The unclean diseases are a disgrace to the victims and their relatives, so victims are hidden from neighbours. This act worsens their condition and the victims may die if interventions are not taken. Ghanaians also believe that diseases are a curse and for that matter the victims should not be mocked, because in doing so the disease can be transferred (Asare-Danso, 2005).
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Furthermore, a typical traditional Ghanaian also believes that diseases can be caused by God. It is said that certain misdeeds that God hates if they are committed repeatedly by our leaders then the entire nation will be punished with the outbreak of communicable diseases. In such cases, the whole nation, tribe or community might come together and make a joint sacrifice to God, without any regards to western medicine (Asare-Danso, 2005).

Ghanaians believe in disease-carrying agents called divinities. The followers of these divinities are punished with disease conditions if they violate their rules. Similarly, they punish anyone who is not part of them but tries to harm any of their followers. There are ancestral spirits who also bring diseases into various communities because it is believed that ancestors are originators of most laws, taboos customs of Ghanaian communities. Sorcerers are disease causing agents. They are evil people who use tangible objects and make incantations but the results of the spells are physical. In addition, there are other disease causing agents called witches. These are more evil than sorcerers. The sorcerers act with physical objects but witches acts in consent with other witches and it is believed that they eat human flesh and drink human blood spiritually. In Ghana the common belief is that witches only bewitch very close family members (Asare-Danso, 2005). This worldview of the traditional Ghanaian is the reason why some of the family caregivers with dementia in this current study were of the opinion that the devil has brought the illness to their care recipients

5.6. Model justification

Poulshock and Deimling (1984) model of caregiver strain modified was very useful for this study. The model concentrated on the burden or negative effects (depression, anxiety, distress, stress, physical illness, social isolation and high cost of dementia care) family caregivers go through during their caregiving role. The researcher used ‘caregiver experiences’ for the model
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instead of ‘caregiver strain’ since this helped to explore both positive (coping, satisfaction, hope, bonding, family support, social support and empathy) and negative (frustration, embarrassment, worrying, mentally depressed, withdrawal, demanding, physical aggression, sleeplessness, fatigue, early retirement, loss of money, insufficient income, financial uncertainty, family conflicts, spiritual attack, selflessness, loneliness, difficulty to study and lack of parental love) experiences of family caregivers in caring for patients with dementia. However, the researcher observed that some negative experiences (embarrassment, withdrawal, physical aggression, family conflicts and financial uncertainty) found in the current study were not mentioned in the model. Nonetheless the constructs in the model helped the researcher to meet all the objectives of this study and also made it possible for proper organization of the work (thesis).

Furthermore, the researcher observed that using the words ‘caregiver strain or burden’ would have limited the study to only negative experiences of the caregiving role. Other models encountered in the search for a model were Transactional Model of Stress and Coping (Lazarus & Folkman, 1984); the Stress Process and Coping Model (Haley, Levine, Brown, & et al., 1987; Haley, Roth, Coleton, & et al., 1996); the Two-Dimensional Model of Psychosocial Morbidity (Poulshock & Deimling, 1984); and the Stress Process Model of Alzheimer’s disease Caregiver’s Stress (Pearlin, Mullan, Semple, & Skaff, 1990). These frameworks incorporate both patient and caregiver characteristics; they have dementia-specific measures on one side and caregiver resources on the other. However, the researcher used the present model because it helped to achieve the aim of this study. The researcher could not use the other models because they could not answer all the research questions of the study.
CHAPTER SIX

This chapter presents the summary of the whole study. It also highlighted the implications for clinical nursing practice, education, policy and future research. Limitations, conclusion as well as recommendations encountered during the study are presented.

6.1 Summary

A qualitative study exploring the experiences of Ghanaian family caregivers caring for patients with dementia was used. Purposive sampling technique was used to recruit the family caregivers. Nine (9) Ghanaian women and a man living in the Tema Metropolis whose relatives were receiving treatment at the Psychiatric unit of the Tema General Hospital were engaged.

With the exception of the first two participants who were interviewed twice, the rest were interviewed once and data was analyzed using content analysis. The four themes that emerged in this study were psychological experiences, physical experiences, financial experiences and social experiences. Caring for patients diagnosed with dementia is a difficult task that disrupts the personal life of the family caregivers. Assisting with the activities of daily living and coping with problematic behavioural symptoms associated with dementia exposes the family caregivers to a lot of stress leading to psychological burden and physical illness. Exploring the experiences of family caregivers revealed a number of issues consistent with the findings of other studies, however, there were also new discoveries peculiar to the Ghanaian context. In this study it was revealed that financial insufficiency is among the problems that initiate worrying in family caregivers coupled with the demanding nature of the activities of daily living where the caregiver’s life is controlled by the care recipients indicating that the caregiving role is burdensome.
6.2 Implications of the Study’s Findings

The findings of this study had four implications namely; implication for clinical nursing practice, education, policy and avenues for future research. The next section presents the implications highlighted.

6.2.1 Implications for Clinical Nursing Practice

Understanding the problem family caregivers of patients with dementia go through will provide nurses with insight to plan their management so that caregivers will be happy to give quality care to their care recipients. Nurses can use these findings to view the caregiver as a potential patient, recognize when caregivers reach the state where their psychological, physical, financial and sociological burden are overwhelming and to guide them through these experiences so they do not lose their lives. These experiences provide insight into the specific needs of the caregivers. Partnership between the health professionals and the caregivers should be built. Visiting caregivers in the community once a week by the community psychiatric nurses should be emphasized since it is part of their job description. This helps caregivers to feel they are not alone and can discuss their problems with the nurses. Nurses must note that the same intensity of care and attention given to the care recipients, should be given to the family caregivers. Nurses should educate caregivers on the signs and symptoms of dementia, how to manage the care recipients from the day of diagnosis and also should make caregivers aware of the resources available to them. It is important that nurses provide this information to enhance coping skills of the caregivers as well as what to do in case of emergency so that they will be more relaxed in rendering care to patients with dementia.
The nurse must also be sensitive to the vulnerability of the caregivers from their experiences of caregiving and tolerate them when caregivers become angry, defensive or confused. A feeling of empathy towards caregivers changes the support that the nurses are capable of providing to them. Recognizing when the caregiver starts experiencing psychological, physical, financial and social burden would allow nurses to understand, access, diagnose and implement care for the specific needs of caregivers in each state.

6.2.2 Implications for Education
Community Psychiatric Nurses already in the system should be trained and educated based on the findings of this study. The findings can help in developing a curriculum to train more qualified degree nurses by offering a one year post graduate programme in dementia care and caregiving role. The course should be community oriented where graduate students do their practical solely in the community and are given the opportunity to work in the community after the course. This can increase the number of trained nurses with specialty in dementia care and caregiving role and in effect close the gap between health professionals and family caregivers. This programme can help put together expert nurses in this field, psychiatrists, nutritionists, pharmacists and counsellors to form an association which will serve as an advocacy group for caregivers and their care recipients to help reduce the caregiver burden.

6.2.3 Implications for Policy
The Mental Health Authority should collaborate with the Ministry of Health to make money and other resources available to the National Deputy Community Psychiatric Unit in-charge to forward it to the community psychiatric nurses in all the regions. This is to enable free movement into the community to visit their patients without thinking of where to get money and other logistics for smooth running of home visits. This will help early detection of psychiatric
emergencies and treatment to prevent high cost of admissions into the psychiatric hospitals and to help reduce institutionalization. Psychiatric Health professionals should liaise with the Advocacy Group for patients with dementia and their caregivers to make available psychotropic medications in all Regional Hospitals and psychiatric hospitals so caregivers will not have to buy them in private pharmacies which are very expensive. These medications bring under control some of the symptoms of in patients with dementia so their caregivers will not be too stressed during caregiving. Policy makers should develop policy which enhance dementia care in order to improve the social well-being and quality of life patients living with dementia and their caregivers.

6.2.4. Implications for Future Research

The findings of the study revealed some areas that will be useful for future research. For instance, the sub-themes that emerged from the study can be further explored to gain more in-depth and understanding of these experiences. They are as follows:

1. The experiences of male family caregivers caring for patients with dementia.
2. Comparing the experiences of female family caregivers to male caregivers.
3. Cost involved in caring for patients with dementia and how their caregivers manage.
4. Intervention strategies to assist caregivers of patients with dementia in Ghana.
5. Experiences of the female spouses caring for patients with dementia.

6.3. Limitation of the study

The sample size just like most qualitative studies cannot be representative of the population of family caregivers caring for patients with dementia in Ghana. Purposeful sampling technique was used in the sampling of ten participants meaning there were other participants whose experiences would have enhanced the findings of the study. Some of the findings in this study
were transcribed from ‘‘Twi’’ and ‘‘Ewe’’ to English by an expert. However, transcribing those from English to the local languages again was not done because it was too expensive for the researcher. Moreover, the researcher understood the two local dialects very well but could not write them and this knowledge helped to agree on the outcome of transcription.

The participants requested to be interviewed in their homes so the researcher and some of the community psychiatric nurses took a taxi to the various communities to trace their homes because the nurses do not know the homes of the participants and this was also expensive. The demographic characteristics presented more females than males making the study gender biased. In the midst of these limitations, the results should be seen as an addition of literature and knowledge of the experiences of family caregivers caring for patients with dementia in Ghana.

6.4 Conclusion
In conclusion, family caregivers go through psychological burden, physical aggression and illness, financial uncertainties as well as social isolation which was termed by some caregivers as ‘‘imprisonment’’. This implies that caregivers are potential patients and are as vulnerable as their care recipients looking at all these experiences. These caregivers voluntarily take up the caregiving role when they are medically fit then a few months into the role, their physical health begins to deteriorate due to lack of rest, sleep and intense worrying. Even though caregivers talk of satisfaction, this alone cannot cure them when their physical health begins to deteriorate. The caregivers should be taken care of as well as the care recipients. Some caregivers who were spouses of care recipients in the current research said they want to send their care recipients back to their extended family because they were tired of caring. Yes, their marriage vows talked about ‘‘for better for worse’’ but the worse in this case might kill them leaving the care recipients to be catered for by their family members (extended family). Why would they not let care recipients go so they
Experiences of Family Caregivers

stay alive? If this is disregarded, in future most family caregivers will not take up the responsibility and our elderly with dementia will be abandoned on the streets of the country. What will be said of Ghana, a country which cannot take care of the elderly when they are acutely ill? In Ghana, there are no nursing homes for the elderly with dementia where those who can afford would utilize them when family caregivers refuse to take care of the elderly who are living with dementia. If there were homes, what then happens to those who could not afford it and what will happen to the economy of the nation? A stitch in time saves nine.

6.5. Recommendations

Based on the findings of the study the following recommendations were made:

6.5.1. Ministry of Health (MOH) in collaboration with Mental Health Authority (MHA):

1. Most family caregivers complained of not having sufficient money to come for review. Based on these findings, the researcher recommends that policy makers should make available vehicles and motor cycles to enable the community psychiatric nurses deliver care to dementia patients in the comfort of their homes. This will decrease the frustration level of family caregivers and also help educate the community about dementia, early detection and management.

2. Family caregivers shed tears throughout the interview section showing signs of depressed mood due to their caregiving role. Based on these findings, the researcher recommends that policy makers should train more clinical psychologists and distribute them into the various communities so they can form part of the community psychiatric nurses’ team visiting the community. These will aid in the counselling of the family caregivers caring for patients with dementia and help calm down their stress level.
3. The family caregivers complained of difficulties in the management of their care recipients. Based on these findings of the study, the researcher recommends that policy makers should facilitate post graduate courses on dementia and its management with the Ministry of Education in the public universities. This will increase the number of nurses who have specialised in dementia care for effective management of dementia patients and their family caregivers.

4. Should supply adequate psychotropic medications and logistics to all regional and district health centres where psychiatry care is delivered. This will prevent caregivers from spending the little money they have for transporting their care recipients to the regional hospitals for review instead of walking to the nearby district health centres in their community.

5. Based on the knowledge gap in the area of family caregivers caring for patients with dementia in Ghana, policy makers should facilitate sponsorship of research in this area. This would increase knowledge levels and create awareness of the experiences of caregivers in the communities.

6.5.2. Nursing and Midwifery Council (NMC)

1. Should insist on public education on dementia and caregiving by qualified specialized nurses to create awareness of the condition in schools, lorry stations and offices.

2. Should bargain for a transportation allowance for community psychiatric nurses through the Mental Health Authority to the Ministry of Finance, since they have the bargaining power.
3. Should revamp their supervisory team and appoint nurses who are knowledgeable in dementia care and caregiving role to supervise these nurses.

4. Should be part of the advocacy group for the dementia patients and caregivers.

5. Should organize recruitment and training sections for community psychiatric nurses already in the system on dementia care and caregiving role.
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REFERENCES


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APPENDICES

APPENDIX A: Consent Form

NMIMR-IRB CONSENT FORM TEMPLATE

Title: Caring for Patients with Dementia: Experiences of Family Caregivers at the Tema Metropolis

Principal Investigator: Agnes Delali Agudu MPhil candidate

Address: University of Ghana, School of Nursing, Legon

General Information about Research

This research seek to explore and describe the experiences of family caregivers in caring for patients with dementia. You have been selected for this study because you are caring for a patient suffering from dementia. You can decide not to participate if you are not comfortable at any point in time. The researcher will interview you at your own convenience and at a place of your choice. If you are recruited and for one reason or the other decide not to continue, you are free to do so. The questions asked will be centred on your experiences gained in caring for your patients. You can speak any language you are comfortable with. If the researcher does not understand, an interpreter may be employed to do so. The interview will take between forty-five minutes to one hour. It will be audio taped with your permission so the researcher can be able to write word for word your explanations and show them back to you to examine if that is what you really want to say.

Possible Risks and Discomforts

There are no risk in this research but participants may show some emotions when narrating the stress or burden they go through when rendering care. In case of expression of emotions by any participant, a clinical psychologist will be present at the interview session to help.

Ebenezer Teithee Kpalam (Clinical Psychologist)

Kinder Foundation

VALID UNTIL
12 JUL 2017

1
Experiences of Family Caregivers

Box dd 93 Dodowa
Phone: 0208617292
E-mail:e.kpalam@kinderfound.org

Possible Benefits
The findings of this study will add knowledge to the nursing discipline to educate the participants on how to care for their patients.

Confidentiality
The interview will be done in your place of choice and free from interference preferably in privacy. Your names will not be written on the interview guide and you will not be named in any report. All information of yours will be kept in personal computer with a password out of reach of anybody except the researcher and the supervisors for at least five years and then burnt, including the audiotapes.

Compensation
There are no compensations for participating in this study.

Voluntary Participation and Right to Leave the Research
Participation in this research is voluntary. Your refusal to participate will not affect the help the nurses give you in this hospital.

Contacts for Additional Information
Please if you have any questions about the study you may contact the following persons:

Dr. Samuel Atindanbila (PhD), Department of Psychology, University of Ghana, Box LG 84
Legon-Accra
0277532705/ 0546620102

Mr. Jibril Muhammed Amin (Lecturer, Mental Health), School of Nursing, College of Health Sciences
University of Ghana, Legon
0244595447

VALID UNTIL
12 JUL 2017
APPROVED DOCUMENT
Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.mimcom.org

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (name of research) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date __________________________ Name and signature or mark of volunteer

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

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

Date __________________________ Name and signature of witness

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

Data Collection Instruments (i.e. Interview Guide, Questionnaire, etc)

Interview Guide

Section A

Demographic Data

Initials.................................................................

Age.................................................................

Sex .................................................................

Marital Status ...................................................

Level of Education .............................................

Language Spoken ............................................... 

Occupation ....................................................... 

Religion..............................................................

Number of Years in Caring Role.............................

Section B

1. How do you know your patient is suffering from this condition?
    Probe

2. Please can you tell me how you felt after the diagnosis?
    Probe

3. Please what are some of the behaviours presented by your patient?
    Probe

   * How do you manage them?
Experiences of Family Caregivers

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH (NMIMR)
COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON

INSTITUTIONAL REVIEW BOARD

4. Please do you think is a burden? Probe. Why?

5. Please how does this affect you psychologically? Probe.

6. Please how does caring for your patient with dementia affect you physically? Probe

7. How does caring for patient with dementia affect you socially and financially? Probe
APPENDIX C: Ethical Clearance

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Established 1979

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UG1, GH

My Ref. No: DF 22
Your Ref. No:

13th July, 2016

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 0001824
IRB 00001276
NMIMR-IRB CPN 113/15-16
IORG 0000908

On 13th July 2016, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL: Caring for Patients with Dementia: Experiences of Family Caregivers at the Tema Metropolis

PRINCIPAL INVESTIGATOR: Agnes Delali Agudu, MPhil Cand.

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

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

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

This certificate is valid till 12th July, 2017. You are to submit annual reports for continuing review.

Signature of Chair: __________________________
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)
APPENDIX D: Introductory Letter

UNIVERSITY OF GHANA
SCHOOL OF NURSING

Ref. No.: SON/EF/11 ........................................... July 18, 2016

The Medical Director
Tema General Hospital
Tema.

Dear Sir/Madam,

INTRODUCTORY LETTER

I write to introduce to you Agnes Agudu, an MPhil student of the School of Nursing, College of Health Sciences, University of Ghana, Legon. She is seeking your permission to collect data for her research on the topic “Caring for Patients with Dementia: Experiences of Family Caregivers in the Tema Metropolis.”

I should be most grateful if you could kindly assist her with the information that she may require.

Thank you.

Yours faithfully,

Amin Muhammad Jibril (Mr.)
SUPERVISOR

Cc: The In-charge
Community Psychiatric Unit
Tema General Hospital
APPENDIX E: Correspondence with Professor Brodaty

My name is Agnes Agudu a second year MPhil nursing student. I want to use a
Model (Poulshock and Deimling model of caregiver strain, modified) cited in your
Clinical research, ‘family caregivers of people with dementia’.
Can you please grant me the permission or link me up with the appropriate quarters.
Thank you.
Counting on your support. God bless you.

Henry Brodaty <h.brodaty@unsw.edu.au>

7 Jun to me

Agnes
You have my permission
Pls acknowledge us and Poulshock & Deimling

Henry Brodaty
Scientia Professor of Ageing and Mental Health,
Director, Dementia Collaborative Research Centre
Co-Director, CHeBA (Centre for Healthy Brain Ageing)
University of New South Wales

Post:
Room 302b, AGSM
UNSW
Sydney 2052
Tel +61-2/02 9385 2585
Fax 61-2/02 9385 2200
e: h.brodaty@unsw.edu.au
DCRCs: www.dementiaresearch.org.au
CHeBA: www.cheba.unsw.edu.au
Maintain Your Brain study: www.maintainyourbrain.org
**APPENDIX F: Table 1. Participant Characteristics**

<table>
<thead>
<tr>
<th>Name of Participants</th>
<th>Age</th>
<th>Sex</th>
<th>Marital Status</th>
<th>Level of Education</th>
<th>Language Spoken</th>
<th>Occupation</th>
<th>Religion</th>
<th>Relationship with Patient</th>
<th>Number of Years in Caring Role</th>
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<tr>
<td>P. 1</td>
<td>52</td>
<td>F</td>
<td>Divorced</td>
<td>Primary Six</td>
<td>Ewe, Twi</td>
<td>unemployed</td>
<td>Christian</td>
<td>Daughter</td>
<td>2 ½ years</td>
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<td>P. 2</td>
<td>52</td>
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<td>Married</td>
<td>Middle School</td>
<td>Twi, English</td>
<td>unemployed</td>
<td>Christian</td>
<td>Daughter-in-Law</td>
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<td>P. 3</td>
<td>61</td>
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<td>Married</td>
<td>Middle School</td>
<td>Twi, Ga, English</td>
<td>Retired Nurse</td>
<td>Christian</td>
<td>Wife</td>
<td>1 years</td>
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<td>74</td>
<td>F</td>
<td>Married</td>
<td>Commercial College</td>
<td>Twi, Krobo, Ewe, English</td>
<td>Retired Typist</td>
<td>Christian</td>
<td>Wife</td>
<td>4 years</td>
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<td>P.5</td>
<td>28</td>
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<td>Not Married</td>
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<td>Twi, Fanti, English</td>
<td>Unemployed</td>
<td>Christian</td>
<td>Granddaughter</td>
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<td>P.6</td>
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<td>Married</td>
<td>Middle School</td>
<td>Twi, Buem, English</td>
<td>Baker</td>
<td>Christian</td>
<td>Wife</td>
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<tr>
<td>P. 7</td>
<td>45</td>
<td>F</td>
<td>Married</td>
<td>None</td>
<td>Twi, Ga, Dangbe</td>
<td>unemployed</td>
<td>Christian</td>
<td>Daughter</td>
<td>2 years</td>
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<tr>
<td>P. 8</td>
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<td>Christian</td>
<td>Daughter</td>
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<tr>
<td>P. 9</td>
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<td>M</td>
<td>Not Married</td>
<td>University</td>
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<td>Christian</td>
<td>Son</td>
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<td>Retired cook</td>
<td>Christian</td>
<td>Wife</td>
<td>3 years</td>
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### APPENDIX G: Table 2. Summary of Theme

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
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<tbody>
<tr>
<td>Psychological Experiences</td>
<td>frustration, embarrassment, worrying, mentally depressed, withdrawal, coping, satisfaction, hope</td>
</tr>
<tr>
<td>Physical Experiences</td>
<td>Demanding, physical aggression, sleeplessness, fatigue.</td>
</tr>
<tr>
<td>Financial Experiences</td>
<td>Early retirement, loss of money, insufficient income, financial uncertainty.</td>
</tr>
<tr>
<td>Social Experiences</td>
<td>Bonding, family support, family conflict, social support, spiritual attack, selflessness, loneliness, empathy, difficulty to study, lack of parental love</td>
</tr>
</tbody>
</table>