SCHOOL OF PUBLIC HEALTH
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA

BURDEN AND QUALITY OF LIFE OF PRIMARY CAREGIVERS OF STROKE PATIENTS ATTENDING TEMEA GENERAL HOSPITAL

BY
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JULY, 2017
DECLARATION

I, Mortey Elli Patience do hereby declare that with the exception of the references duly cited from books, journals and articles, the work was entirely done by me. This work is as a result of my own research toward the award of Master of Public Health Degree and has never been presented either in whole or part for any other degree in this University or elsewhere.

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MORTEY ELLI PATIENCE DR. JUSTICE NONVIGNON

(STUDENT) (SUPERVISOR)

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DATE DATE
DEDICATION

This work is dedicated to God Almighty, my parents especially my dad Mr. Elli Joseph Mortey and my sister.
ACKNOWLEDGEMENT

Glory to God! My sincere thanks goes to the Almighty God for His favor, provision and seeing me through my entire year of training.

I acknowledge my supervisor Dr. Justice Nonvignon for his guidance and time taken to supervise me. I am also grateful to Dr. Genevieve Aryeetey and Prof. Moses Aikins for their immerse contribution to make this work successful. I thank all lecturers and staffs of the department of Health Policy, Planning and Management for their support in diverse ways.

I appreciate the Medical Director and Hospital administrator of Tema General Hospital for permitting me to carry out my research in the facility. I also thank the head of the physiotherapy unit Mrs. Mercy Nketia-Kyere as well as other staffs within the unit and the facility as a whole. Thanks to my parents and sister, for their prayers and support had a positive impact in my life.
ABSTRACT

Background
Stroke is a sudden loss of brain function resulting from a break in the flow of blood or raptured blood vessels resulting in death of brain cells in the affected area. It is a major cause of disability and deaths globally. In sub-Saharan Africa, the burden is higher with low deaths and increase burden. Stroke is one of the leading cause of deaths in Ghana. A large number of stroke patients are sent home after discharge and primary caregivers are faced with the burden of caring for them which affect the quality of life of primary caregivers. Interventions are needed to manage the condition in order to reduce new cases of stroke and reduce deaths among stroke patients. The objective of the study was to determine the burden of caregiving and quality of life of primary caregivers of stroke patients.

Method
The study adopted a cost-of-illness approach using cross-sectional data from 140 primary caregivers of stroke patients. Direct costs were estimated by classifying it into direct medical and non-direct medical cost incurred by primary caregivers over a month. Indirect cost was estimated as the value of productive days lost to caregivers. Zarit burden interview was used to determine primary caregiver burden (intangible costs) while WHO EUROHIS-QoL was used to determine the quality of life of the primary caregivers. Data was entered into Epi Info 7 and Microsoft excel version 2010 for analysis. The results were presented using descriptive statistics.
Results

The average total cost per month for caregiving for the Stroke patients to the primary caregiver was estimated at GHS 1,875.53 (USD 430.17) of which 90.6% GHS 1,699.02 (USD 389.68) being direct average cost and 9.4% GHS 176.52 (USD 40.49) being indirect average cost. Male primary caregivers reported a higher caregiver burden than females with 91% primary caregivers reporting high burden and 9% reporting low caregiver burden. Females recorded lower quality of life than males. Out of a total of 140 primary caregivers, 37% primary caregivers recorded low quality of life, 60.7% recorded moderate quality of life and a smaller proportion of 1.4% caregivers recorded high quality of life.

Conclusion

The result showed that most primary caregivers were related to the stroke patients and were burdened with the care they provided to stroke patients as they incurred huge medical and non-medical cost. The study also found out that some primary caregivers had to stop their work or education due to the burden that came with caring for the stroke patient which invariably affected their quality of life. Although majority of primary caregivers were females, men reported being burdened than the females, and more females reported to have lower quality of life than the male primary caregivers. The cost associated with stroke was high which must be addressed to enable caregivers continue caring for stroke patients.

Key Words: Burden, Quality of life, Stroke, Direct cost, Indirect cost, Intangible cost, Productivity loss.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>GHS</td>
<td>Ghana Health Service</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WHO EURO-HIS-QoL</td>
<td>World Health Organization European Quality of Life</td>
</tr>
<tr>
<td>TGH</td>
<td>Tema General Hospital</td>
</tr>
<tr>
<td>WPAI</td>
<td>Work Productivity and Activity Impairment</td>
</tr>
<tr>
<td>ADL</td>
<td>Activity of Daily Living</td>
</tr>
<tr>
<td>ZBI</td>
<td>Zarit Burden Interview</td>
</tr>
<tr>
<td>LMICs</td>
<td>Low and Middle Income Countries</td>
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</table>
# DEFINITION OF TERMS

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Burden</td>
<td>The manifestation of a health problem accompanied with disturbances and challenges which has a negative effect on the life of primary caregivers</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>The perception of stress and fatigue associated with negative feelings and subsequent strain experienced as a result of caring for a person with special needs or chronically sick</td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>An individual who assist the patient at home mostly and provide care for at least a month</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Individuals perception of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectation, standards and concerns</td>
</tr>
<tr>
<td>Direct cost</td>
<td>Expenses made by primary caregiver for healthcare intervention</td>
</tr>
<tr>
<td>Indirect cost</td>
<td>Productivity, income and wage loss to the primary caregiver caring for a stroke patient</td>
</tr>
<tr>
<td>Intangible cost</td>
<td>Unquantifiable cost relating to an identifiable source that may include pain, stress, anxiety, emotion and cannot be expressed in monetary terms borne by a primary caregiver caring for a stroke patient</td>
</tr>
<tr>
<td>Productivity loss</td>
<td>Productivity, income and wage loss to the primary caregiver caring for a stroke patient</td>
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CHAPTER ONE

INTRODUCTION

1.1 Background

Stroke is a sudden interruption in the blood supply to the brain that affects people globally resulting in major disabilities and deaths (WHO, 2005). Disability from stroke leads to loss of cognition and inability to perform activities of daily living (Mokashi & Vivekanand, 2005). Stroke is mostly prevalent to people in their mid-ages to late adulthood but due to some lifestyle patterns, stroke is increasingly experienced by people in their early thirties (Benjamin et al., 2016). Globally, stroke accounts for about 5.2 million deaths every year and affects the physiology of affected individuals (Nag & Ghosh, 2014). There are some regional and country-wide variations with respect to the proportion of deaths coming from stroke. A study by Feigin et al., (2015) have indicated that the incidence of the disease adjusted to the World Health Organization (WHO) world standard population, ranged from 66 per every 100,000 populations per year in Australia during 2009-2010 to a 119 per every 100,000 populations per year in New Zealand during 2011-2012. Deaths from stroke is estimated at seven times higher in low income countries than high income countries (Krishnamurthi et al., 2013). The statistics are however expected to vary over time due to differences in prognosis, prevalence of risk factors and treatment strategies as well as knowledge of the pathological type (Krishnamurthi et al., 2013).

In the absence of public health intervention, it is estimated that new cases of stroke will increase to about 23 million with an associated 7.8 million deaths occurring by the year 2030 for which many efforts are needed for its management in order not to lose productive energy for the growth of the economy (Mukherjee & Patil, 2011).
In many LMICs, there are marked incidences of the burden of stroke. According to Mukherjee & Patil (2011), about 16.9 million stroke cases were recorded globally in 2010 with 70 percent of the occurrence reported in LMICs. Stroke cases in southern India and the rural parts of South Africa have doubled over the years (Moran, Sacco, & Truelsen, 2015).

In sub-Saharan Africa, the burden is higher, although, the absolute number of stroke deaths remains low yet the burden of stroke is higher than it is in high income countries (Connor, Walker, Modi & Warlow, 2007). In Ghana, stroke is one of the leading causes of deaths (CDC, 2013). A review of the in-patients’ records of Komfo Anokye Teaching Hospital in Ghana put the figures at 9.1% and 13.2% of adult admission and deaths respectively in the hospital’s medical ward resulting from stroke (Agyemang, Aikins, Edusei, Nkum & Ogedegbe, 2012). Also, according to the most recent report by the Ghana Health Service (GHS), stroke is among the 10 conditions usually reported at the physiotherapy unit of Tema General Hospital with an annual hospital attendance of 5,017 in 2013 (Tema General Hospital, 2013).

A study by Evers, Struijs, Genugten, Jager & Bos (2004), found that globally, countries spend about 0.27% of GDP and 3% of total health cost on stroke thus, drawing awareness toward economic burden of stroke internationally. The total projection made on direct and indirect cost of stroke in Unites States was USD 65.5 billion in 2008 (Rosamond et al., 2008). A similar study in United Kingdom showed a 49% indirect cost representing £8.9 billion and 24% direct cost valued at £4.4 billion on the national health cost of UK (Aka, Uire, & Olfe, 2009).

Stroke, primarily, places a demand on primary caregivers who take up the responsibility to provide care to patients (Akosile, 2013). Caring for a stroke patient is increasingly becoming common with the responsibility on the family to provide psychosocial, emotional and economic
needs for patients. Primary caregivers in LMICs are largely family members, many of whom remain economically unproductive as they must devote their time to the upkeep of the patients.

Again, the need to support patients also impacts the quality of life of caregivers but very little is known about the quality of life of these caregivers (Duci, Ajdini, & Dhembo, 2014). More so, providing for stroke patients demands some financial commitment in terms of medical bills and other expenses which may not be available (Joo, Dunet, Fang, & Wang, 2015; Nogueira, Helena, Caliri, Aparecida, & Dantas 2012).

Against the background knowledge that caregivers play crucial roles in the life of stroke patients.

1.2 Problem statement

Majority of stroke patients in the world have caregivers who cater for them because the condition causes major disabilities including functional dependence, rendering them incapable of providing basic care for themselves (Aparecida, Rodrigues, Roberto, & Fabrício-wehbe, 2013). The phenomenon of caregivers caring for survivors of stroke stricken patients has become widespread in many households (Duci et al., 2014). Stroke which often affects patient’s cognition causing physical and emotional change in their lives generates pressure and stress for caregivers, rendering care to stroke survivors burdensome (Qiu & Li, 2008). This could be extreme and may negatively affect caregiver’s health, predisposing them to risk of burnout and impact negatively on their quality of life (QOL) (Ski, 2007).

Given et al., (2004) posits that early attempts to help caregivers received limited attention since, the burden and needs of caregivers continue to be poorly understood. A study by Saban & Hogan (2012) indicated that family caregivers could be faced with difficulties in terms of adapting to the role of caregiving.
The evidence in the Ghanaian context however, seems to be under-researched as available search show few related empirical studies such as {Stroke: A brain attack by (Gund, Jagtap, Ingale, & Patil, 2013), Burden of stroke in black populations in sub-Saharan Africa (Connor et al., 2007)}. More so, little is known about the quality of life of caregivers of stroke patients in Ghana. Hence, this study seeks to determine the burden of stroke patients on their primary caregivers and their quality of life.

1.3 Study objectives

1.3.1 General objective

The general objective of this study is to determine the burden of caregiving and quality of life of primary caregivers of stroke patients.

1.3.2 Specific objectives

Specifically, this study seek to:

1. Estimate direct cost incurred by primary caregivers to stroke patients
2. Estimate indirect cost i.e. productivity loss to primary caregivers of stroke patients (indirect cost)
3. Describe intangible cost incurred by primary caregivers to stroke patients
4. Determine the quality of life of primary caregivers of stroke patients

1.4 Research questions

The overarching research question that is driving the study aims to find out the burden and quality of life of primary caregivers of stroke patients. To delineate a clear picture of the general question, the study seeks answers to the following specific questions;
i. What is the direct cost incurred by primary caregivers of stroke patients?

ii. What is the indirect cost i.e. productivity loss to primary caregivers of stroke patients?

iii. What are the intangible costs incurred by primary caregivers of stroke patients?

iv. What is the quality of life of primary caregivers of stroke patients?

1.5 Justification of the study

Owing to the increased prevalence of stroke among people in Ghana, stroke and its related issues have become a public health concern that needs to be explored. Aside that, responding to the demands of stroke patients leads to productivity loss by primary caregivers as patients require much time and attention. For this reason, it becomes logical to understand what productivity implications as well as the intangible cost that caregivers face. As one of the most devastating of all neurological diseases which leads to impairment, disability or death, it comes with huge cost particularly in developing countries.

The rehabilitation services primary caregivers provide is important for these patients as it enables them to live longer.

By conducting a study on the burden and quality of life of caregivers of stroke patients, it is expected that the study’s findings will give a better understanding and information into issues primary caregivers face. It is also expected that the study will fill in gap in literature as well as provide policy makers the relevant information to make informed decisions on policies concerning stroke care.
1.6 Conceptual framework

The burden can be discussed under two main categories which are the productivity loss and intangible cost incurred by primary caregivers. The productivity loss captures the hours that primary caregivers could spend on economic activities but are spent primarily on attending to patients.

Figure 1: Diagram of the Conceptual Framework
CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews relevant literature related to the burden of stroke on caregivers. It provides an overview of stroke, its related issues and the caregiving for stroke patients. It also discusses how stroke patients are a burden to their caregivers. Furthermore, the chapter gives an empirical account of the quality of life of caregivers. The review concludes by stating the crucial roles that caregivers play across the health care continuum.

2.2 Burden of stroke

Stroke, also known as cerebrovascular accident occurs due to an interruption in the supply of blood to the brain when a blood vessel gets blocked by a clot. Unlike other organs, the brain needs constant supply of oxygen and glucose which is always available in the bloodstream as it is unable to build up stocks, thus, a break in the interruption of regular supply of oxygen and glucose can cause death of brain cells which does not receive adequate blood supply needed by the brain.

According to Owolabi et al., (2015), stroke is a sudden death of some brain cells resulting from lack of oxygen due to blockage or rapture of an artery in the brain when the blood flows. It has a sudden onset which is life – threatening and causes disabilities in the life of an individual (Atel et al., 2006). Stroke to Tortora & Derrickson (2011) is the most common brain disorder often characterized by sudden neurological symptoms such as loss of sensation or paralysis ensuing from obliteration of brain tissues. Some symptoms include sudden headache, dizziness and weakness of face, numbness of face, arm or leg, difficulty or inability to talk, visual impairment,
and loss of coordination. Disabilities caused by stroke range from mild to severe resulting in performing physical activities, poor or lost cognition and behavioral problems which affects an individual’s health, work and social relationships (Hadidi & Lindquist, 2009).

Irimia, Meyer, & Teasell (2010) are of the view that the primary method of stroke treatment is rehabilitation. This involves activities aimed towards enabling patients with disabilities to attain and maintain their optimal physical, psychological, intellectual, sensory and social function to build their self-confidence and independence (WHO, 2008).

According to Goldstein et al., (2011), there are some risk factors which are common to stroke. These are lifestyle risk factors, medical risk factors, and the third lumped as other factors. Lifestyle risk factors include: physical inactivity, overweight or obesity, binge or heavy drinking, illicit use of drugs such as methamphetamines and cocaine. Medical risk factors such as high blood pressure of 120/80 millimeters of mercury (mm Hg), diabetes, high cholesterol, cigarette smoking or secondary smoking (exposure), cardiovascular diseases including heart defects and abnormal heart rhythm, sleep apnea. Other factors such as age 55 and above, family history of stroke or heart attack, gender (higher in men than women).

Stroke is a global health problem causing major disabilities and death. The total number of annual deaths due to stroke is more than 17 million, approximately 29% of all deaths worldwide are as a result of stroke (Fuster & Kelly 2010). Available document from the National Institute for Health and Clinical Excellence (Nice, 2010) show that the first incidence of ischemia occurred in 98,000 people per year in UK. The document further indicates that 2% cases of stroke among persons in England and Wales. This has been able to cause major disabilities associated with increased hospital admissions. Stroke constitutes the third most widespread cause of disability-adjusted life-years (DALYs) (Lozano et al., 2010). Research indicates that the top
cause of disability in UK is as a result of stroke for which 900,000 or more persons. Of this, about 20% of affected individuals lose their life within 30 days of first attack. The statistics indicates that about a half of the 900,000 patients rely on caregivers to perform activities of daily living. Again, between 60-70% of victims lose their lives after 3 years. Nice (2010) gives an estimated national cost incurred on stroke to be approximately £ 7 billion per year.

According to Srinath & Yusuf (1998) stroke is a major cause of death in developing countries. More specifically, the (WHO, 2008) has estimated that deaths from stroke occur in developing countries at about 80% rate. Epidemiological assessment conducted four decades ago has indicated an increase in the episodes of stroke in developed nations. Some study however, indicated an increase in the incidence of stroke in developing countries. The cause of the increase rate of incidence in developing countries is attributed to knowledge deficit and inability to identify and manage risk of the disease (Feigin, Lawes, Bennett, Barker-collo, & Parag, 2009).

It has been noted that burden and mortality cases of stroke vary across countries. Generally, low-income countries have a higher burden and mortality related cases than high income countries. Specifically, the WHO in 2001 associated 85.5% of the total stroke cases with developing countries. This has constituted the disability adjusted life year (DALYs) in low and middle income countries seven times higher compared to high–income countries (Johnston, Mendis, & Mathers, 2009). Walker et al., (2000) point out that the case fatality rate for stroke among Sub-Saharan Africa (SSA) can be higher than developed nations. Wiredu & Nyame (2001), add that while cerebral hemorrhage is the reason behind top fatalities due to stroke in Sub-Saharan Africa, in developed nations, stroke deaths results from cerebral infarction.

According to Cooper et al., (2005), stroke ranked sixth in Ashanti region, Ghana with it being the most common contributing factor to death in Ghana as at 2003. Further studies conducted by
Aikins (2007) saw stroke ranking amongst the top four causes of death in Ghana. Agyemang et al., (2012) in another study also suggested that the condition is increasing. Considering the high prevalence of stroke in Ghana accompanied with functional limitation due to decreased mobility, cognitive impairment, depression and changes in the life of affected individuals, patients are thus left at the mercy of caregivers for assistance which often comes with its associated cost (Williams, Galea, & Winter, 2001).

2.3 Burden of stroke on caregivers

Stroke has a great impact not only on the life of patients but also on the lives of their caregivers. Klinedinst et al., (2009), records that caring for a patient is a difficult task. They think this is even much difficult with stroke patients since individuals attacked with a stroke can barely do anything for themselves. Instead, stroke patients depend on caregivers for the rest of their life. As a result, caregiving presents challenges for caregivers of stroke survivors. The relationship, age, gender and severity of disability according to Co et al., (2013) places a higher burden on caregivers. The explanation provided is that, the average time for caregiving is longer in younger patients than older patients all things being equal. Because younger patients have more years to live with the disease. Again, to a person with more social relations, the burden of caregiving could be shared among different relatives who may act as caregivers. These factors thus interact to determine the burden in caregivers. In a study, Connor et al., (2007) said the burden of caregiving could predispose caregivers to extreme exhaustion and have a negative impact on their health. Caregivers can experience high levels of stress and care burden which oftentimes contributes to symptoms of depression and burnout (Phyllis, Robison & Dempster-McClain 1995). The risk for caregiver depression increases as the length of the caregiving affiliation
increases, which have a negative impact on the health status of the care recipient whose health and emotional wellbeing may decline (Schulz, O’Brien, Bookwala, & Fleissner, 1995).

Through a non-linear perspective, Ghazzawi, Kuziemsky & O’ Sullivan (2016) found that caregivers most especially the primary ones play a significant role in the management of patients. They assert that caregivers are able to contain the behaviors of their patients most of which are intolerable as the patients are unable to do most of the things for themselves. They aver that the family needs a critical time to adjust so they could better understand the new life of the patients. It is noted that there are some unique inter-relations between the information, supports, services, roles and the complexity that exist at the family level (Akosile, Okoye, & Odunowo, 2009). This has the potential to positively impact continuity of services, and may inform the quality of care for the stroke patients.

The complex adaptive system is used to illuminate the complex nature of the relations that exist at the family level. This helps to shape the relationship that exists between them. Continuity of care relevant and is impactful on the life of the patients as it helps to transit between the health care settings. However, this also depends on the complex demand put brought by finances to address some cost, closeness to the facility and the various unforeseen barriers that could emerge in the process (Ghazzawi et al., 2016). Cameron et al., (2014) indicate that the families at this time assume the role of a ‘gatekeeper’ of information and support services. Their role is complex as they have to deal with all that which pertains to the health of the patients. Even though the hospital could address the therapy needs of the patients, it becomes their responsibility to take care of the patients outside of the hospital settings. Without private insurance, it becomes difficult to pay for the responsibility (Campbell et al., 2014).
Economic losses are an integral part of the challenges that is associated with stroke. These burdens relate to productivity loss, healthcare costs and nursing care costs. Productivity losses refer to a stroke victim’s absence from gainful employment or economic engagement during the initial stages of stroke till death or permanent disability to both the caregivers and the patients (Hommel, Chevreul, & Woimant, 2013). There is a corresponding income loss when there is a productivity loss. Hommel et al., (2013) identify that survivors out of the stroke patients who died require an average sick leave. Benefits payments for sick patient would have to be paid to patients who are in employment. There are also health care costs as well as the nursing care cost. Nursing care cost is the use of health care services. For instance, social support service and residential care homes for disabled frail persons. A literature review by (Joo, George, Fang, & Wang, 2014), show that indirect cost account for a significant proportion of the economic burden of stroke. This is consistent with contextual studies in the U.S and Spain that show that the total cost is made up of high indirect costs (Joo et al., 2014).

2.4 Complex Adaptive System

Various theories and models provide a better outlook of the caregiving process. They see sustainable delivery of health care across the health continuum in various ways. The theories contend that caregiving is one of managing relations which will reduce health problems thereby leading to enhanced quality of life. Some of these theories are: complex adaptive system, continuity of care theory and a tool, quality of life.

The complex adaptive systems theory is an approach to problem solving. It recognizes complexity of organizations, neural structures and systems and notes the relationship between and within the inter-related parts (Kannampallil, Schauer, Cohen, & Patel, 2011). The Complex adaptive system is found within the systems theory. The theory observes that complex adaptive
systems could build the resilience of the caregiving process and might worsen it should some conditions go contrary. Seen from one angle if productivity is lost as a result of a primary caregiver not being in a productive economy, this might impact on the health of the patient. Inversely, if the patient is a bread winner and is incapacitated by stroke, the family of the patient stands to be in economic and financial distress. This is likely to affect the caregiver who depends on the benevolence of the patient. The complex adaptive system is understood to mean some form of complex social relation where a member depends on the other and there is a trickle-down effect of this relationship.

The complex adaptive system is seen as a complex inter-relating components of a system. Elements common to the system are feedback, communications, behaviours, co-evolution and simple rules (Ghazzawi, Kuziemsky, & O’ Sullivan, 2016). Complex Adaptive System has been applied to study behaviors in a system. It works on the principle that as a system becomes one, the number of components and interactions within each component increases within the system (Edgren & Barnard, 2012).

2.5 Caregiving and quality of life

The term “caregiving” encompasses a wide range of experiences and situations. There is no universal definition for caregiving. However, caregiving takes into account attending to an individual’s physical and emotional health. It usually involves a long term caregiving for an individual with chronic illness or physical disability. Pearlin, Mullan, Semple, & Skaff (1990) defined caregiving as the “behavioral expression of (one’s) commitment to the well-being or protection of another person”. Caregiving as defined by Drentea (2007) constitutes care provision to family members or friends faced with psychological, physical or developmental needs as well as providing emotional support to patients. Unless in some special cases, often
times, family members are the primary caregivers of stroke patients. They give social support and assist the patient across the health care settings (Cameron & Gignac, 2008).

Quality of life (QoL) reflects well-being. Caring for a stroke patient with its associated problems could become burdensome and may negatively affect the health and quality of life of the caregiver. Villunger et al., (2003) reports that caregiver’s turn to have a reduced quality life through extreme exhaustion which eventually affects the quality of care they render to stroke patients. The Bredemeier, Wagner, Agranonik, Perez, & Fleck (2014), defines quality of life in line with WHO as 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.

Studies conducted by Bredemeier et al., (2014), indicate that stroke has an immense impact on the quality of life of caregivers who provide long–term day–to–day care especially for patients with disabling conditions and put excessive strain on caregiver. Caregivers need professional attention and support so as to maintain their own physical and emotional health and well–being.

2.6 Methods use for assessing burden and quality of life of caregivers

Due to persistence of chronic diseases and the long time as well as the complex processes involve in treatment, there are various effects on the functional ability, the psychological, the physiological, the lifestyle changes, and the independence status of caregivers of patients with chronic diseases. A host of scholarly work has assessed these effects. Different studies use different methods in such assessments. Examples of such methods include the caregiver burden questionnaire (CBQ), the Family Need Questionnaire (FNQ), the Zarit Burden Interview Schedule (ZBIS), Coping Checklist (CCL) and the World Health Organization Quality of Life–BREF (WHOQOL-BREF) interview Schedule (Gill, Reifsteck, Adams, & Shang, 2015; Kumar, Kaur, & Reddemma, 2015a; Lícia De Lima I et al., 2014; Mashayekhi, Pilevarzadeh, & Rafati,
This tools are mostly used to collect quantitative data from a cross section of the population. Authors like Gill et al., 2015; Lícia De Lima I et al., (2014) have used different combinations of these tools like the CBQ, ZBIS, CCL and WHO QOL-BREF to assess the quality of life of caregivers at the same time and they have produced same or similar results. Example, Roncada et al., (2015) used both the WHO QOL-BRIEF and the ZBIS to assess the quality of life of 68 caregivers divided into 2 groups for research purposes. Similar results were obtained for both groups in both methods.

The ZBIS is a scale developed to help researchers and practitioners measure burden on caregivers providing care to especially the sick. The scale is made up of 22 questions with each having answers that varies from 0=never to 4=nearly always. In the values for the scores which range from 0-21, 21-40, 41-60 and 61-88, a low score indicates little or no burden and vice versa (Zarit, Reever, 1980) (Hébert, Bravo, & Préville, 2000; Zarit, Reever, 1980). The WHOQOL-BREF is also another scale for measuring burden and QOL of caregivers. The instrument is a 26-item generic questionnaire that is self-administered (Skevington, Lotfy, & O’Connell, 2004). The WHOQOL -100 scale can be analyzed from two perspectives. There is a perspective that consider four domains consisting of physical health, psychological health, social relations and environment. There is also a perspective that considers six domains consisting of physical health, psychological health, level of independence, social relationships, environment, and the spiritual (Gill, Chang, Murphy, Speed, Hammond, Rodriguez, Shang, 2011).

The family FNQ is a series of items reflecting the family needs of caregivers. There are 40 items in all that provide information on the extent to which family needs of caregivers are perceived to be important (Serio, Kreutzer, & Witol 1997). All the 40 Items are grouped into six independent domains which are Health information (with 12 items), Emotional support (with 8 items), and
Instrumental support (with 5 items), Professional support (with 7 items), Community support network (with 7 items), and Involvement in care (with just 1 item). FNQ is a 4-point scale starting from 1 (Not Important) to 4 (Very important). Scores are grouped from (0-40), (41-80), (81-120), and (121-160) higher score indicating more importance of a particular need (Kumar, Kaur, & Reddemma, 2015b).

The CCL is a scale develop by (Rao & Subbakrishna, 1989). It is relatively comprehensive (compared to the FQN) comprising of 70 item and with more domains-7- as well. The domains are Problem Solving (with10 items), Distraction Positive and Distraction Negative (with 14 and 9 items respectively), Religion/Faith (9 items), Denial/Blame, Acceptance (with11 items each), and Social Support (with 6 items). Scores for each item is either yes (indicating presence of a particular coping behaviour) or no (indicating absence of a particular coping behaviour). Scores range from 0-70 with higher scores indicative of more use of a coping behaviour (Kumar et al., 2015b).

The challenge with almost all the tools for assessing the burden and quality on life of caregivers is that they are generic instruments that may be totally or at least partially inapplicable to certain specific situations. In order for them to be applicable to specific situations, permissions are usually allowed for major and minor modifications. However, this has the potential of compounding the situation as the edited versions may end up measuring something very different from the original. To minimize such distortions, it is always necessary to test for the validity and the reliability of the new version of an edited scale.

2.7 Cost of illness

Cost of illness (COI), also termed burden of disease (BOD) comprise the impact and effect of disease on the health of individuals, communities, regions as well as countries. COI is the total
cost incurred in the treatment of disease. The cost can be categorized into direct, indirect, and intangible cost. Treatment of stroke comes with a cost which ranges from disabilities, injuries, rehabilitation among other complications. The cost of treatment of stroke is borne not only by the individual but caregivers as well as the government for which interventions as well as allocation of resources for healthcare are made by government despite its limited resources (Jo, 2014; Teng et al., 2003).

Primary caregiver provision of day-to-day care for stroke survivors is important towards meeting the needs of survivors including activities of daily living (ADL) previously performed by the survivor (Sumathipala, Radcliffe, Sadler, 2011). This can however be a financial and personal cost to the caregiver. Financial cost is estimated to range between 14% to 23% or AUS$42.5 million and 90% leisure time for provision of care (Dewey et al., 2002). According to (El, Mullan, 2013; Tooth, McKenna, Barnett, 2005), personal cost include impact on quality of life, anxiety and depression which has the propensity to affect caregiver relationship within and outside the family as well as ability to participate in work and leisure. This study examines the cost using the direct, indirect and intangible cost. However, indirect cost and productivity loss will be used interchangeably.

2.8 The direct cost of treating stroke

There is an extensive literature on the cost analysis of the disease stroke around the world (mostly in developed countries like United Kingdom, United States of America, Sweden etc.) (Liu, Wang, Lawrence Wong, & Wang, 2011; Lloyd-Jones et al., 2010; Lloyd-Sherlock, 2010; Saka, Mcguire, & Wolfe, 2009). While some of these studies are concerned with the direct cost of the disease to the individual and to the government, other studies have their focus on the
indirect cost with yet some literature focusing on the intangible cost as well. This section provides a review of literature on the cost structure of stroke.

The direct cost of stroke whether will be borne by the individual or the government normally depends on the health system of a country. Where there is government health insurance, the cost is borne by the government and where there is no government health insurance nor any form of social protection for stroke patients, the cost of the disease is born by the individual (Saka et al., 2009).

The direct cost of stroke to the government has been very high and still remains. In most countries, it amounts to a large chunk of the total cost of treating the disease. Before the turn of the current century, the direct cost of stroke amounted to about 49% of the government total expenditure on the disease in UK. Specifically, the UK government spending was approximately £4.4 billion on the total £9 billion stroke expenses (Saka et al., 2009). In 2006, in US, the government paid a total of USD 3.9 billion (i.e. USD 7,449 per discharge) to Medicare beneficiaries for just a short stay in a hospital facility (Lloyd-Jones et al., 2010). Short stays are usually for mild strokes. However, in its more severe form, about USD 140,048 was estimated per patient for treatment or disease management (Lloyd-Jones et al., 2010). Race is said to have a relation with the cost as per average cost for stroke patients has been estimated at USD 25,782.00 for blacks, USD 17,201 for Hispanics and USD 15,597 for non-Hispanic whites (Lloyd-Jones et al., 2010).

Just as the direct cost to the government is very high, so is the direct cost to the individual. In 2004, it was found that the present value of the direct cost for an average stroke patient in Sweden was SEK513,800 which was by then approximately USD 56,024 (Ghatnekar, Persson, Glader, & Terént, 2004). Similar research has indicated that the average individual direct cost of
the disease has always been on the high side especially in Europe. Example, Kolominsky-Rabas et al., (2006) reported 43,129 EUR per patient in Germany in 2006, and Spieler, Amarenc & Lanoe (2002) reported €13,409 per year for each patient in France. The cost is however relatively less in developing countries. Example, in China, a study conducted by Kaur, Kwatra, Kaur, & Pandian, (2014) indicated a relatively low direct cost of USD 3,626 to the individual.

The indirect cost of the disease also seems to vary from country to country. The cost has been found to range from as low as USD 904.00 to as high as USD 23,451.00. Example, in an analysis of the indirect cost of the disease condition, Joo et al., (2014) recently conducted a review in which it was indicated that the indirect cost per patient on caregivers is about USD 904.00 in Thailand (Riewpaiboon, Riewpaiboon, Ponsoongnern, & Van den Berg, 2009). The cost of treating the same disease condition in Netherland is USD 23,451.00 (Van Den Berg et al., 2006). Other studies in other developed parts of the world indicate that the indirect cost in developed countries which is relatively higher that developing countries is normally above USD 10,000.00 (Hickenbottom, Fendrick, Katch, Kabeto, Katz & Langa 2002; Lindgren, Glader & Jönsson, 2008; Fox, Gazzaniga, Karter, 1996).

It is realized that the cost of stroke depends on factors such as severity of the disease, length of stay in the hospital, purchasing power parities (PPP) and several other factors (Köberlein, Beifus, Schaffert, & Finger 2013).

2.9 Intangible cost

An intangible cost is the burden of illness of affected persons and caregivers. The intangible cost among other things is specifically, loss of well-being or loss of quality of life. In research, the intangible cost has normally been captured using questionnaires and expressed in DALYs (Köberlein et al., 2013). Intangible cost may also be in a form of pain, decreased quality of life
and other important problems suffered by patients as a result of the disease (Kang, Lim, Suh, & Liew, 2011). According to Goyal, Male, Al Wafai, Bellamkonda, & Zand (2015), intangible cost may also be in a form of psychological costs, pain and suffering, and change in social functioning. It is mostly difficult to calculate intangible cost, normally monetary value is not assigned (Goyal et al., 2015; Köberlein et al., 2013).

2.10 Quality of life

According to Whoqol Group (1995), quality of life (QoL) encompasses how an individual perceives his or her position in life in relation to cultural context and in accordance with the value systems in which they live relative to their goals, expectations and desires. There are six main domains derived from QoL which are physical health, psychological health, social relationships, level of independence, environmental health and spiritual health (Whoqol Group, 1995). The individual’s perception comprises of three domains which are the physical (functional capacity), psychological (satisfaction, well-being) and social needs (leisure, social, family support) (Whoqol Group, 1995).

Health as defined in the WHO constitution which came into force in 1948 is a state of complete physical (functional/ work capacity), mental (satisfaction) and social wellbeing and not merely the absence of disease or infirmity (Constitution of the World Health Organization, 2005). It is noted that majority of research carried out focused more on patient QoL with less attention being paid to the QoL of caregivers.

Stroke is said to be among the top leading cause of diseases often accompanied with disability and a reduced QoL. Several research has been undertaken globally in a bid to address the lives of individuals with chronic health problems. For research studies of chronic disease including stroke, health related quality of life is an important outcome parameter. The emphasis usually
lies on patients, with less attention given to the caregivers. Previous studies conducted on QoL in stroke caregivers, found a trend of decreased physical, psychological and social components score in the QoL of caregivers otherwise perceived as burden of care (Costa, Costa, Fernandes, Martins, & Brito, 2015).

There are several instruments used in assessing the QoL by most researchers’ in their studies. The most widely used is the World Health Organization Quality of Life- WHOQoL questionnaire which is very useful in studies involving chronic diseases such as stroke, epidemiological studies as well as in clinical trials and also in evaluating the effectiveness of treatments and disease control. The tool is developed into six broad domains comprising physical, psychological, level of independence, social relationships, environment and spiritual/religion/personal beliefs. There are several sub-domains of QoL within each QoL domain. Example within the physical domain are facets as pain and discomfort, energy and fatigue. According to Hung, Huang, Chen, & Liao, 2012; Mccullagh et al., (2005), caregivers undergo a high burden as they provide care to stroke or survivors’ especially those with disabling condition which in turn reduce their QoL. For purposes of this study, WHOEUROHIS-QoL is being used. Other researchers such as Brodaty & Donkin, 2009; Schiavolin et al., (2014) also used it in their studies.

2.11 Conclusion

The burden of stroke and its effect on the quality of life of primary caregivers of stroke patients is on the rise as evidence in the various reviewed literature indicating an increase globally. The various literature show how severe stroke can impact an individual’s life causing various form of disabilities and rendering the affected individual incapable of performing activities of daily living (ADL) for him or herself but depend on people for support for the rest of life in which the
role is usually performed by a caregiver. This has a negative impact on the quality of life of the caregiver and significantly reduces household income since every little money got is spent on caring for the patient as the caregiver are unable to work productively to earn money but spend most of the time assisting patient with the hope that the health will be restored.

Although studies have been carried out in other countries on the burden and quality of life of primary caregivers of stroke patients thus increasing awareness in such countries, little is known about the burden and quality of life of caregivers of stroke patients in Ghana. This research will endeavor to answer such questions since caregivers are vital to health care and often referred to as “silent patients,” yet they are largely ignored by the health care system, and thus are at risk for depression and other illness, a need to inform the public and policy makers since they play a role in the health.
CHAPTER THREE

METHODOLOGY

3.1 Introduction

The chapter covers the research approach which includes; the study area, study design, study variables, study population, sample size, sampling procedure, data collection techniques, quality control, data processing and analysis, ethical considerations, description of subjects, potential risk / benefits and finally data usage and storage.

3.2 Study area

The study was conducted at the physiotherapy department of Tema General Hospital. The hospital is located within Tema Metropolitan area of the Greater Accra region of Ghana. It is the largest public health institution in the metropolis. It is a major referral point for all other clinics and hospitals in Tema Metropolis and beyond. It is also the first point of call for all industrial and road traffic accidents. The hospital serves a projected population of 403,943. It was constructed in the year 1954 to cater for workers putting up the Tema Harbor. In 1962, the hospital was handed over to the government of Ghana.

The catchment area includes the whole of Tema metropolis, its surrounding satellite towns and villages and extensions as far as Ashaiman, Sakumono, Lashibi, Nungua, Kpone and Prampram. There are ten wards with a total of 280 beds. The hospital provides a twenty-four-hour service to both out-patients and in-patients.

The department of physiotherapy attends to about 1,210 patients seeking various physiotherapy services per month with an average attendance rate of about 55 patients per day. According to
the 2013 annual report, 20 stroke patients visit the physiotherapy daily (TGH Annual Report, 2013).

3.3 Study design

The study was a cross-sectional study design. Cost-of-illness approach was used to estimate intangible cost incurred by primary caregivers and EUROHIS-QoL was used to determine the quality of life of primary caregivers.

3.4 Study variables

The variables in this study were direct cost, productivity loss, intangible cost and Quality of life. Details of the study variables are in the Table 1.

**Table 1: Description of study variables**

<table>
<thead>
<tr>
<th>Cost Type</th>
<th>Cost categories</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct cost</td>
<td>Medical cost</td>
<td>Medical cost incurred on medication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Consultation, treatment, laboratory</td>
</tr>
<tr>
<td></td>
<td>Non-medical cost</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Residential care</td>
<td>Payment for rent, utilities, housing</td>
</tr>
<tr>
<td></td>
<td>Household supplies</td>
<td>Payment for food, water, household goods, clothing</td>
</tr>
<tr>
<td></td>
<td>Travel and transportation</td>
<td>Payment for transportation to or from, with or for patient</td>
</tr>
<tr>
<td>Productivity loss/Indirect cost</td>
<td>Productivity time loss on;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Travel / transport</td>
<td>Productivity loss due to travelling and waiting</td>
</tr>
<tr>
<td></td>
<td>Job loss</td>
<td>Productivity loss due to loss of work</td>
</tr>
<tr>
<td>Intangible cost</td>
<td>Caregiving burden causing;</td>
<td>Zarit burden interview score</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Caregiver’s QoL such as;</td>
<td>WHO EUROHIS-QoL</td>
</tr>
<tr>
<td>Stress</td>
<td>Physical</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>Psychological health</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Environment</td>
<td></td>
</tr>
</tbody>
</table>

### 3.5 Study population

Primary caregivers of stroke patients at the physiotherapy department attending Tema General Hospital constituted the population used for the study. The primary caregiver is the one who assists the stroke patient at home for ADL.

### 3.6 Sample size determination

Adopting sample size formula by Cochran for cross-sectional study:

\[
N = \frac{\left(\frac{Z_{\alpha}}{2}\right)^2 P(1 - P)}{e^2}
\]

Where:
n is the minimum sample size required for the number of caregivers

p is the prevalence of stroke in Ghana p=9.1% (Donkor, 2014)

\[ Z_{\alpha/2} = 1.96 \] is the standard normal variate since \( \alpha=5\% \) at 95\% Confidence Level

\[ e^2 = 5\% \] is the acceptable margin of error

Inputting the above into equation (1), the minimum sample size for primary caregivers required for this study is given by

\[
n = \frac{(1.96)^2 \times 0.091(1 - 0.091)}{(0.05)^2} = 127
\]

A 10\% non-response rate was assumed and estimated at 12.7. This was therefore added to the sample size initially calculated.

\[ N = \frac{10}{100} \times \text{desired} / \text{actual sample size} \]

\[
N = \frac{10}{100} \times 127 = 12.7
\]

\[ N = 12.7 + 127 = 139.7 \]

\[ N = 140 \]

A sample of 140 primary caregivers were interviewed.

3.7 Sampling procedure

A simple random sampling was used to select respondents. Sample was taken from caregivers who assisted patients to the physiotherapy at TGH. Caregivers were randomly selected by a simple random sampling in other to avoid bias. This was done by getting the folders of stroke
patients who were receiving services at the physiotherapy unit. A total of 400 patients were obtained which served as the sample frame. The selection of patients from the database was done by generating 140 participants from a sample frame of 400 with the help of a random number to impartially select the 140 primary caregivers of stroke patients to be sampled while they wait for the turn of their patient at the physiotherapy OPD. The first primary caregiver to visit the facility was informed, upon consenting to be part of the study, he/she was used as a reference point to begin the study with. Selection was done on each caregiver per the computed interval until the entire sample size calculated for is exhausted. When selected primary caregiver was available, the next primary caregiver who followed in the queue directly was chosen without altering the sample interval.

Data were collected from respondents for a period of six weeks every Monday to Friday from 7am to 4pm. 5 to 10 data were gathered each day. An arrangement was made with patients and relatives to conveniently meet for a face-to-face interview with primary caregivers who could not assist patients to the facility on a day in their various homes.

3.8 Sampling frame

This was done by obtaining the register of all stroke patients to determine the number of patients to select caregivers for the study.

3.9 Inclusion criteria

Inclusion criteria were as follows:

i. All caregivers accompanying patients diagnosed of stroke undergoing rehabilitation at the physiotherapy department were included in the study.

ii. Primary caregiver who had provided care to patient for at least one month.
3.10 Exclusion criteria

The following were the exclusion criteria.

i. Secondary caregivers were ruled out from the study.

ii. Primary caregivers who had not served a minimum of one month were excluded.

3.11 Data collection tools and techniques

A written questionnaire comprising both open and close ended questions was used to collect data from respondents. This comprised the socio-demographic information of respondents and other sections used to get information from respondents on their productivity loss. The questionnaire was divided into six different sections containing mostly closed-ended questions in order to facilitate the processing of the data. Section A consisted of background information of caregiver. Questions on socio-demographic data included caregiver’s age, sex, marital status, educational level, and employment status, being a primary caregiver, length of caregiving, monthly income, vicinity and relationship with care recipient. Section B comprised questions on care recipient’s age, sex, caregiving task such as assistance with activity of daily living (ADL). Section C Comprised Direct cost – out-of-pocket expenses such as care recipients medical care and supplies, household supplies such as food and water, rent and utility, travel expenses with care recipient as well as financing sources used to pay for healthcare cost such as health insurance and donations. Productivity loss was captured under Section D with question asked on time spent on personal care of care recipient, household activities and other errands, transportation and leisure time with care recipient. The Zarit Burden Interview (ZBI) tool was used to collect data in Section E on burden of care and had items on stress, pain, anxiety, depression. Caregivers were asked to indicate the impact of the care receiver’s condition on his or her life by indicating how they felt by circling how they felt under each Zarit Burden Item. Section F consisted questions
on quality of life of primary caregivers. The WHO EUROHIS-QoL Index was used. The WHO EUROHIS-QoL is an 8 item index graded on a 5 point Likert scale, with increasing scores being indicative of increasing QoL. It was composed by first revising the numerical codes assigned to the responses contained in the SAGE dataset to questions on QoL. In the dataset, “1” indicated very satisfied, “2” is for satisfied, “3” stands for neither satisfied nor dissatisfied, “4” is dissatisfied and “5” indicated very dissatisfied. The caregivers were asked to circle the appropriate response which best described how they felt. Each of the item was answered on a 5-point scale with 1= Not at all, 2= A little, 3= Moderately, 4= Mostly, and 5= Completely with corresponding scores of 1 to 5 respectively. The WHO EUROHIS-QoL has 3 domains, namely: psychological, social and physical health. Each domain had a set of items under it; psychological domain had 4 (four) items under it, social and physical had 2 (two) items each under their domain. The domain score gave an indication of the perception of individual’s quality of life under that domain. The questions were categorized under the domains for further relational analysis.

### 3.12 Quality control

Research Assistants (RAs) were trained for data collection. They were monitored daily to ensure compliance and uniformity. All completed data were validated and entered daily. This way it became possible to ensure quality of data generated. A pre-test was also undertaken at Lekma Hospital. The rational for pretesting the questionnaire was to ensure that respondents would understand the questions, and identify possible problems with the completion of the questionnaire. Minor problems were identified and revisions to the questionnaire were made.
3.13 Data entry and processing

Completed questionnaires were serialized and coded within 24 hours of collection. Data were collected from the field daily and checked for completeness. They were entered and cross-checked for errors three times using Epi Info 7. Epi Info 7 and Microsoft Excel version 2010 were used for analyzing data.

3.14 Data analysis

All analysis with respect to the data on caregivers were analyzed using Epi Info 7 and Microsoft Excel 2010. Background characteristics of participants were analyzed using descriptive statistics (mean, standard deviation). Sensitivity analysis was conducted to ascertain the robustness of the results of the study. Caregivers socio-demography were described using frequency and percentages to find the distribution.

3.14.1 Cost analysis

Cost was analyzed based on the primary caregivers’ view point and information provided for a period of one month.

3.14.2 Estimation of direct cost

Direct cost was classified as direct medical cost and direct non-medical cost. It was then estimated by adding up total cost incurred on medical care cost and non-medical cost incurred over the past month.

Direct medical cost was the money paid for medical services such as consultation, diagnosis, medication, physiotherapy and other health care interventions.
Direct non-medical cost included cost incurred on residential care, travelling (to and from hospital), household supplies, food and water. The total direct cost was then determined by adding up all out-of-pocket expenses made by primary caregivers.

3.14.3 **Productivity loss estimation (Indirect cost)**

The productivity days lost to an employed caregiver was valued by using the national daily minimum wage of GHS 8.80 (January, 2017) per day for primary caregivers who were employed in the formal sector. The local daily agriculture or casual wage rate of GHS 2.40 per hour was used to value productivity loss to primary caregivers in the informal sector. The total hours spent by primary caregivers per week was determined and multiplied by four to derive the total hours spent caring for stroke patients in a month.

Productivity loss by students/apprentices and unemployed primary caregivers was derived by estimating the total hours spent per month by primary caregivers. This was not valued since they had no actual earnings and were not expected to be working.

3.14.4 **Total cost**

Total cost of primary caregivers was estimated by adding up the total cost incurred on the direct medical, direct non-medical and indirect cost over the past month. All estimated costs were converted into USD using an exchange rate of GHS 4.30 (the exchange rate at the time the study was being conducted) in other to compare the study with other international studies.

3.14.5 **Intangible cost**

The 12-item ZBI developed by Bédard et al., (2001) was adopted and used to describe intangible cost. The 12-item ZBI is the short version of the original 22 ZBI developed by (Zarit, Orr & Zarit 1985). The total score ranges from 0-48, 0 being the minimum score and 48 being the maximum score. The total score is derived by adding all individual scores for each question from 1 to 12.
Scores below 16 were categorized as low burden and scores over 16 were categorized as high burden. A pie-chart was used to show responses of respondent and a frequency distribution table was used to show the mean burden score.

### 3.14.6 Quality of life

The quality of life of caregivers was estimated using the WHO EUROHIS-QoL. The EUROHIS-QoL responses were reverse-coded giving positive responses higher numerical codes. The new code for individual responses were then summed up to generate the WHO EUROHIS-QoL quality of life index for each respondent. Higher responses then indicated higher quality of life and vice versa, with the scores ranging from a minimum 8 and a maximum of 40. The sores were then re-categorized into “Low”, “Moderate”, and “High”. Scores from 30-40 were considered as “High” category, “Moderate” as (19-29) category and “Low” as (8-19) category.

### 3.14.7 Sensitivity analysis

Sensitivity analysis was performed to determine the robustness of the estimated cost results. The test was done by performing one-way sensitivity analysis (variation) and a multi-way sensitivity analysis (multi-variation) on medication and wages. That was due to the uncertainties in the cost estimates reported by primary caregivers and the standard wage rates used for formal and informal primary caregivers. The cost of medication and wages were respectively increased by 3%, 5% and 7% to vary their cost.

### 3.15 Ethical considerations

Ethical clearance was sought from the Ghana Health Service Ethics Review Committee of the Ghana Health Service. Also, permission was sought from the hospital administration of Tema
General Hospital and finally, Informed consent was sought from the primary caregivers of stroke patients before questionnaires were administered to them.

3.15.1 Potential risks or benefits

Undertaking a study on the burden and quality of life of primary caregivers of stroke patients was believed to inform the public and policy makers since they played a role in the healthcare system. It was envisaged also that the study will enable policy makers to make better and effective health care planning and allocation of resources to such areas that will help caregivers and also strengthen the health system. The study posed no potential risk to the individuals under study, the facility or the public.

3.15.2 Anonymity and confidentiality

Information obtained was used purely for the purpose of research thus anonymity and confidentiality was strictly adhered to as names of study participants were not used for any public report. Questionnaires were designed such that it did not include the name of participants, likewise, information gathered from a participant was not disclosed to another participant.

3.15.3 Voluntary withdrawal

Permission was sought from participants by giving each participant a written consent form seeking their consent to participate in the study. Each participant was required to append their signature before information was taken from them. Participants consent to participate in the study was purely voluntary. Under no obligation was a participant forced or coerced to partake in the study against his or her will and study participants had the right or liberty to withdraw from the study at any point in time and there was no penalty for withdrawal.
3.15.4 Compensation

No compensation in the form of gift or payment was made to any study participant. The contributions of participants were appreciated and the benefit of partaking in the study was explained to them.

3.16 Data storage and usage

Serial numbers as well as codes were given to each questionnaire and data entered within 24 hours. Printed questionnaires were locked in a safe locker while the soft copy of data were stored on a pen drive, an external hard drive as well as logged on to a google drive for safe keeping. All data stored in a soft copy form was protected. Access is made possible only through password. The devices used for the storages (i.e. the pen drive and the external hard drive) were used for only that purpose and they were stored under a locked key. Both hard and soft copy data will be kept by the principal investigator for a period of 3-4 years to allow for publication after which data will be destroyed by burning the printed questionnaires and deleting all soft copy data previously stored from devices.

3.17 Declaration of conflict of interest

I declare that I have no personal interest with regards to the study. The study was purely for academic purpose and for public health importance.

3.18 Funding information

The study was self - financed.
3.19 Limitations

The total number of days lost as well as time spent with regards to caregiving, travelling and waiting time for physiotherapy services were based on the recall of caregivers of stroke patients which might not be accurate and exact.
CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the findings of the study. The chapter shows the background characteristics of caregivers of stroke patients attending Tema General Hospital. The chapter captures estimate of direct and indirect costs of caregivers.

4.2 Socio-demographic characteristic of caregivers

Table 2 shows that most of the primary caregivers were females and constituted 102 (72.9%) while the males were 38 (27.1%). The table further shows that 55 (39.3%) primary caregivers were below age 35 years while 51 (36.4%) and 18 (12.9%) aged 35-40 years and 45-55 years respectively. 16 (11.4%) primary caregivers were above the age 55 years. The table further shows that 83 (59.3%) primary caregivers were married and 57 (40.7%) unmarried. Majority of caregivers were co-resident primary caregivers 132 (94.3%) and primary caregivers 8 (5.3%) being nearby care providers.
Table 2: Socio-demographic characteristics of primary caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percentage(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
<td>27.1</td>
</tr>
<tr>
<td>Female</td>
<td>102</td>
<td>72.9</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 35</td>
<td>55</td>
<td>39.3</td>
</tr>
<tr>
<td>35-44</td>
<td>51</td>
<td>36.4</td>
</tr>
<tr>
<td>45-55</td>
<td>18</td>
<td>12.9</td>
</tr>
<tr>
<td>&gt;55</td>
<td>16</td>
<td>11.4</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>83</td>
<td>59.3</td>
</tr>
<tr>
<td>Married</td>
<td>57</td>
<td>40.7</td>
</tr>
<tr>
<td><strong>Educational Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal Education</td>
<td>10</td>
<td>7.1</td>
</tr>
<tr>
<td>Primary Level</td>
<td>18</td>
<td>12.9</td>
</tr>
<tr>
<td>Middle/JSS/JHS</td>
<td>59</td>
<td>42.1</td>
</tr>
<tr>
<td>SSS/SHS/Tech/Vocational</td>
<td>33</td>
<td>23.6</td>
</tr>
<tr>
<td>Tertiary</td>
<td>20</td>
<td>14.2</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self Employed</td>
<td>67</td>
<td>47.9</td>
</tr>
<tr>
<td>Private Sector</td>
<td>30</td>
<td>21.4</td>
</tr>
<tr>
<td>Public Sector</td>
<td>13</td>
<td>9.3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20</td>
<td>14.3</td>
</tr>
<tr>
<td>Student/Apprentice</td>
<td>10</td>
<td>7.1</td>
</tr>
<tr>
<td><strong>Monthly income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; GHS 500</td>
<td>19</td>
<td>18.3</td>
</tr>
<tr>
<td>GHS500-1000</td>
<td>68</td>
<td>65.4</td>
</tr>
<tr>
<td>&gt; GHS1000</td>
<td>17</td>
<td>16.3</td>
</tr>
<tr>
<td><em>Mean income (95%CI)</em></td>
<td>GHS 755.81 (GHS 691.99 - GHS 819.64)</td>
<td></td>
</tr>
<tr>
<td><strong>Relation to Caregiver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>17</td>
<td>12.9</td>
</tr>
<tr>
<td>Child</td>
<td>96</td>
<td>72.7</td>
</tr>
<tr>
<td>Grandchild</td>
<td>4</td>
<td>3.0</td>
</tr>
<tr>
<td>Sibling</td>
<td>15</td>
<td>11.4</td>
</tr>
<tr>
<td><strong>Caregiving task</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-resident care provider</td>
<td>132</td>
<td>94.3</td>
</tr>
<tr>
<td>Nearby care provider</td>
<td>8</td>
<td>5.3</td>
</tr>
</tbody>
</table>
4.3 Cost of caregiving for stroke patients

4.3.1 Direct cost

The average total direct cost of caregiving for stroke patients was estimated at GHS 1,699.02 (USD 389.68) per month, which constituted 90.6% of the cost profile. The average total direct medical cost per month of primary caregivers was estimated at GHS 779.11 (USD 178.70) with a cost profile of 51.1% is recorded for a month. Residential care expenses recorded the lowest cost profile of 1.0% and an average cost of GHS185.83 (USD 42.62). Household supplies constituted 27.7% of the direct non-medical cost component while transportation recorded 48.9%.

Table 3: Direct cost per month of primary caregivers

<table>
<thead>
<tr>
<th>Cost component</th>
<th>N</th>
<th>Cost (GHS)</th>
<th>Cost (USD)</th>
<th>Cost profile(%)</th>
<th>Average cost (GHS)</th>
<th>Average cost (USD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct cost</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct medical cost</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical cost (medicines, consultations etc.)</td>
<td>140</td>
<td>109076.00</td>
<td>25017.43</td>
<td>51.1</td>
<td>779.11</td>
<td>178.70</td>
</tr>
<tr>
<td>Sub total</td>
<td></td>
<td>109076.00</td>
<td>25017.43</td>
<td>51.1</td>
<td>779.11</td>
<td>178.70</td>
</tr>
<tr>
<td>Direct non-medical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household supplies</td>
<td>139</td>
<td>59280.00</td>
<td>13596.33</td>
<td>27.7</td>
<td>426.47</td>
<td>97.82</td>
</tr>
<tr>
<td>Residential care expenses</td>
<td>12</td>
<td>2230.00</td>
<td>511.47</td>
<td>1.0</td>
<td>185.83</td>
<td>42.62</td>
</tr>
<tr>
<td>Transportation</td>
<td>140</td>
<td>43063.00</td>
<td>9876.83</td>
<td>20.2</td>
<td>307.59</td>
<td>70.55</td>
</tr>
<tr>
<td>Sub total</td>
<td></td>
<td>104573.00</td>
<td>23984.63</td>
<td>48.9</td>
<td>919.90</td>
<td>210.99</td>
</tr>
<tr>
<td>Total direct cost</td>
<td></td>
<td>213649.00</td>
<td>49002.06</td>
<td>100.0</td>
<td>1699.02</td>
<td>389.68</td>
</tr>
</tbody>
</table>

4.3.2 Indirect cost of primary caregivers

The total indirect cost of caregiving to stroke patients was estimated at GHS 22,824.80 (USD 5,235.05) per month with an average of GHS 176.52 (USD 40.49). Average cost of caregiving per month was estimated at GHS 176.52 (USD 40.49).
Table 4: Indirect cost per month of primary caregivers

<table>
<thead>
<tr>
<th>Cost component</th>
<th>N</th>
<th>Cost (GHS)</th>
<th>Cost (USD)</th>
<th>Cost profile (%)</th>
<th>Average cost (GHS)</th>
<th>Average cost (USD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indirect Cost</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on personal care</td>
<td>131</td>
<td>8464.00</td>
<td>1941.28</td>
<td>37.1</td>
<td>64.61</td>
<td>14.82</td>
</tr>
<tr>
<td>Time spent on house activities</td>
<td>131</td>
<td>9374.40</td>
<td>2150.09</td>
<td>41.1</td>
<td>71.56</td>
<td>16.41</td>
</tr>
<tr>
<td>Travel time</td>
<td>130</td>
<td>3143.60</td>
<td>721.01</td>
<td>13.8</td>
<td>24.18</td>
<td>5.55</td>
</tr>
<tr>
<td>Time spent with the care recipient</td>
<td>114</td>
<td>1842.80</td>
<td>422.66</td>
<td>8.1</td>
<td>16.16</td>
<td>3.71</td>
</tr>
<tr>
<td>Total indirect cost</td>
<td>228</td>
<td>24.80</td>
<td>5235.05</td>
<td>100.0</td>
<td>176.52</td>
<td>40.49</td>
</tr>
</tbody>
</table>

Total time (hours) spent per month by primary caregivers of stroke patients is 13,020 hours. Time spent on personal care and time spent on household activities were 4,744 hours and 5,328 hours respectively. The lowest time spent on caregiving was recorded in travel time and time spent with care recipient within a month.

Table 5: Hours spent by primary caregivers

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency n (%)</th>
<th>Total time spent (Hrs)/month</th>
<th>Average time spent per month (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time spent on personal care</td>
<td>130 (93%)</td>
<td>4,744.00</td>
<td>36.1 (5.2)</td>
</tr>
<tr>
<td>Time spent on house activities</td>
<td>130 (93%)</td>
<td>5,328.00</td>
<td>40.6 (6.0)</td>
</tr>
<tr>
<td>Travel time</td>
<td>129 (92%)</td>
<td>1,892.00</td>
<td>14.6 (3.9)</td>
</tr>
<tr>
<td>Time spent with the care recipient</td>
<td>114 (81%)</td>
<td>1,056.00</td>
<td>9.3 (2.2)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>13,020.00</td>
<td>100.6</td>
</tr>
</tbody>
</table>

Table 6: Time spent by different occupational categories

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Total Hours spent</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self employed</td>
<td>6632</td>
<td>15916.8</td>
</tr>
<tr>
<td>Private sector</td>
<td>2968</td>
<td>3264.8</td>
</tr>
<tr>
<td>Public sector</td>
<td>968</td>
<td>1064.8</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2344</td>
<td>2578.4</td>
</tr>
<tr>
<td>Student/Apprentice</td>
<td>108</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>13020</td>
<td>22824.8*</td>
</tr>
</tbody>
</table>

* time by student/apprentice were not valued and are not part of indirect cost.
Figure 2 shows that, the total direct cost profile recorded 90.6 %, representing a higher proportion of the cost profile while that of total indirect cost had a low record of 9.4 %.

4.3.3 Intangible cost

Burden of primary caregiver

The results indicated that 9% of respondents reported a low caregiver burden while 91% of the respondents reported a high burden. This is shown in Figure 3 below.
Figure 3: Burden among primary caregivers

Figure 4: Caregiver burden by sex

Figure 4 shows the mean burden score of both males and females. There is a high burden score with a mean of (23) among male primary caregivers than female caregivers whose mean score is (21.8).
4.4 Sensitivity analysis

Sensitivity analysis was performed on medication and wages to determine the robustness of cost estimated in the study. This was done by performing a one-way sensitivity analysis (variation) by increasing the cost of medication and wages by 3%, 5% and 7% to vary their cost respectively. The result indicated that, at the base scenario, percentage in parameter was zero (0) with percentage change in total cost remaining zero (0). Proportion of direct cost and indirect cost were 90.3 and 9.7 respectively with percentage change in direct cost remaining zero (0). However, when the items were varied at 3%, 5% and 7%, there was an increase in percentage change in total cost at 1.4%, 2.3% and 3.2% respectively with a recorded increase in proportion of total cost for direct and indirect cost. There was an opposite occurrence with respect to the percentage change in proportions of cost for both direct and indirect cost as indicated in the result with a recorded increase of 0.1%, 0.2% and 0.3% for direct cost at a percentage change in parameter of 3, 5 and 7 respectively, with an observation in a drop in percentages for same with respect to direct cost.

The result indicated decrease in the proportion of total direct cost for wages at 90.0, 89.9 and 89.7 and a decrease in percentage change in proportion of direct cost and an increase in the result of indirect cost.

Multi-variation performed simultaneously for medication and wages at 3%, 5% and 7% indicated a change in percentage in total cost at an increasing rate at 1.7%, 2.8% and 3.9%. Proportion of total cost for direct cost increased at 3% while it continued to decrease at both 5% and 7%. Indirect cost however reduced at both 3% and 5% however, it increased at 7%. At 3%, 5% and 7% percentage in parameter, there was a decrease in the percentage change in all proportions of cost for direct cost while the opposite was recorded for indirect cost.
Table 8 shows the results of the percentage changes in the proportions of total cost when various cost components were varied.
Table 7: Sensitivity analysis of total cost of primary caregivers

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Cost component</th>
<th>Percentage change in parameter</th>
<th>Total cost</th>
<th>Percentage change in total cost</th>
<th>Proportion of total cost</th>
<th>Percentage change in proportions of cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>GHS</td>
<td>USD</td>
<td>Direct</td>
<td>Indirect</td>
</tr>
<tr>
<td>Base scenario</td>
<td></td>
<td>0</td>
<td>236,592.60</td>
<td>54,264.36</td>
<td>0.0</td>
<td>90.3</td>
</tr>
<tr>
<td>Variation (One-way</td>
<td>Medication</td>
<td>3</td>
<td>239,864.88</td>
<td>55,014.88</td>
<td>1.4</td>
<td>90.4</td>
</tr>
<tr>
<td>Sensitivity Analysis)</td>
<td></td>
<td>5</td>
<td>242,046.40</td>
<td>55,515.23</td>
<td>2.3</td>
<td>90.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
<td>244,227.92</td>
<td>56,015.58</td>
<td>3.2</td>
<td>90.6</td>
</tr>
<tr>
<td>Variation (One-way</td>
<td>Wage rate</td>
<td>3</td>
<td>237,280.91</td>
<td>54,422.23</td>
<td>0.3</td>
<td>90.0</td>
</tr>
<tr>
<td>Sensitivity Analysis)</td>
<td></td>
<td>5</td>
<td>237,739.78</td>
<td>54,527.47</td>
<td>0.5</td>
<td>89.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
<td>238,198.65</td>
<td>54,632.72</td>
<td>0.7</td>
<td>89.7</td>
</tr>
<tr>
<td>Multi-variation</td>
<td>Medication</td>
<td>3</td>
<td>240,553.19</td>
<td>55,172.75</td>
<td>1.7</td>
<td>90.2</td>
</tr>
<tr>
<td>(Multi-way Sensitivity</td>
<td>and Wage rate</td>
<td>5</td>
<td>243,193.58</td>
<td>55,778.34</td>
<td>2.8</td>
<td>90.1</td>
</tr>
<tr>
<td>Analysis)</td>
<td></td>
<td>7</td>
<td>245,833.97</td>
<td>56,383.94</td>
<td>3.9</td>
<td>90.0</td>
</tr>
</tbody>
</table>
4.5 Caregiver quality of life

Figure 5: shows that 1.4% (i.e. 1.9) of the respondents reported high quality of life while 60.7% (i.e. 85) of respondents reported 37.9% (i.e. 53)

![Figure 5: Quality of life distribution](image)

The mean score of quality of life is presented in Table 7 below. Females recorded a lower quality of life of 20.0 (3.2) than males whose score was 21.0 (3.5) out of the total score of 40. This is attributed to the fact that, apart from providing care to stroke patients, the females had additional responsibilities to perform activities for the household. Caregivers aged 50 years and above had lower quality of life unlike caregivers with age less than 29 years which could be attributed to the fact that primary caregivers above 50 years had less energy and higher care responsibilities than those age 29 years and below. Caregivers who were married had higher quality of life than non-married caregivers because married had support from their partners. Primary caregivers with primary education scored the highest with respect to caregiving which is attributed to the fact that majority of them were met during the time the research was being conducted. Caregivers in the public sector had the opportunity to work during the night hours and are able to earn their monthly salary thus scoring a higher quality of life.
Table 8: Quality of life on background characteristics of primary caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Psychological</th>
<th>Social</th>
<th>Physical</th>
<th>Total QoL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>p-value</td>
<td>Mean (SD)</td>
<td>p-value</td>
</tr>
<tr>
<td><strong>Sex</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10.9 (2.0)</td>
<td>0.2</td>
<td>4.9 (1.1)</td>
<td>0.2</td>
</tr>
<tr>
<td>Female</td>
<td>10.5 (1.7)</td>
<td></td>
<td>4.6 (1.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 29</td>
<td>10.7 (2.3)</td>
<td>0.88</td>
<td>4.7 (1.3)</td>
<td>0.9</td>
</tr>
<tr>
<td>30-49</td>
<td>10.7 (1.6)</td>
<td></td>
<td>4.7 (1.0)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>10.4 (1.9)</td>
<td></td>
<td>4.7 (0.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>10.5 (1.7)</td>
<td>0.2</td>
<td>4.7 (1.1)</td>
<td>0.8</td>
</tr>
<tr>
<td>Married</td>
<td>10.8 (1.9)</td>
<td></td>
<td>4.7 (0.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Educational Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal Education</td>
<td>10.9 (1.4)</td>
<td>0.2</td>
<td>4.6 (0.8)</td>
<td>0.2</td>
</tr>
<tr>
<td>Primary</td>
<td>10.8 (1.8)</td>
<td></td>
<td>4.6 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Middle/JSS/JHS</td>
<td>10.1 (1.5)</td>
<td></td>
<td>4.5 (1.0)</td>
<td></td>
</tr>
<tr>
<td>SSS/SHS/ Tech Vocational</td>
<td>10.8 (1.3)</td>
<td></td>
<td>4.7 (0.7)</td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>11.6 (2.8)</td>
<td></td>
<td>5.4 (1.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self Employed</td>
<td>10.9 (1.4)</td>
<td>0.4</td>
<td>4.7 (0.9)</td>
<td>0.4</td>
</tr>
<tr>
<td>Private Sector</td>
<td>10.8 (1.8)</td>
<td></td>
<td>4.6 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Public Sector</td>
<td>10.1 (1.5)</td>
<td></td>
<td>5.4 (1.5)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 0.8 (1.3)</td>
<td></td>
<td>4.5 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Student/Apprentice</td>
<td>11.6 (2.8)</td>
<td></td>
<td>4.5 (0.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Monthly income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; GHS 500</td>
<td>10.9</td>
<td>0.0</td>
<td>4.9 (0.8)</td>
<td>0.0</td>
</tr>
</tbody>
</table>

University of Ghana  http://ugspace.ug.edu.gh
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Psychological Mean (SD)</th>
<th>p-value</th>
<th>Social Mean (SD)</th>
<th>p-value</th>
<th>Physical Mean (SD)</th>
<th>p-value</th>
<th>Total QoL Mean (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1.5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(27)</td>
<td></td>
</tr>
<tr>
<td>GHS500-1000</td>
<td>10.3 (1.3)</td>
<td></td>
<td>4.6 (0.9)</td>
<td></td>
<td>5.0 (0.9)</td>
<td></td>
<td>19.9 (2.4)</td>
<td></td>
</tr>
<tr>
<td>&gt;GHS1000</td>
<td>12.2 (2.9)</td>
<td></td>
<td>5.6 (1.6)</td>
<td></td>
<td>5.6 (1.5)</td>
<td></td>
<td>23.4 (5.7)</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: *Wilcoxon Rank Sum test used to determine statistical significance in mean difference for two response

**Kruskal-Wallis test used to determine statistical significance in mean difference for more than two response
CHAPTER FIVE

DISCUSSION

5.1 Introduction

In this chapter, the results presented in chapter four are discussed. The discussion is in relation to the literature. In each case, the results of the current study are compared with the literature including empirical literature. In discussing, differences and similarities in the current findings and the literature are identified and explanations provided. In accordance with the objectives of the study, the chapter starts with the discussion of results on the cost of giving care to stroke patients on the caregiver. Some costs considered are total cost, direct and indirect costs as well as intangible cost. The discussion then proceeded and ended with the sensitivity analysis of the caregiver.

5.2 Cost of stroke on caregivers

Both theoretical literature and empirical studies conducted on the cost of stroke have identified that, suffering from the disease comes along with medical and non-medical cost burden, part of which is also borne by the caregivers of the patients (Co et al., 2013; Ganapathy et al., 2015; İçağasioğlu et al., 2017; Mishra, Mishra, & Gajjar, 2016; Mittmann et al., 2012; Moore, Zhu, & Clipp, 2001; Van Den Berg, Brouwer, & Koopmanschap, 2004). The current study thus supports assertions made in previous literature that caring for stroke patients comes along with a lot of cost and burden on the caregiver.

Studies have suggested that caregiving cost for stroke patients should not be neglected in economic evaluations of health care programs (Moore et al., 2001; Van Den Berg et al., 2004). Some studies provided gestures as to what constitute the components of this cost. Though limited in scope, there is still a similarity in the current results and such studies. Specifically, the cost
components in the current study were the same components that were identified by (Van Den Berg et al., 2004). Moore et al., (2001) identified the components of cost on caregivers as being related to time inputs by relatives and friends of care recipients. This is because they thought time is not easy to value, they did not estimate actual costs attached to these components, however this current study estimated for time in monetary terms.

Other research findings further estimated and computed for specific costs attached to the components of the total cost. For instance, a study estimated the mean total lost-productivity cost per caregiver is USD 835 per month and more than USD 10,000 per year; with nearly 72% attributable to absenteeism of the caregivers to work (Ganapathy et al., 2015). Another study reported an annual cost on caregivers to be USD 18,385 per patient and that the greater portion of this cost are caregiving time (USD 6,295) and caregiver's lost earnings (USD 10,709) (Moore et al., 2001). The average cost estimated in this current study is in contrast to other studies which estimated higher costs Evers et al., (2004). Reasons for the difference in the cost estimated could be attributed to difference in expenditure for caregivers of different patients. Specifically, an average cost of GHS 1,875.53 (USD 430.17) per month is incurred by the caregiver in the current study.

A cue for explaining the higher total cost in the current study compared to similar cost in previous studies has perhaps been given by (Moore et al., 2001). According to them, difference in cost on caregivers arise as a result of differences in the severity of the disease such that “costs increase with disease severity and problem behavior. Most of this cost increase derives from the increased caregiving time required for the provision of physical care”. Therefore, it might be that the disease condition of patients whose caregivers were studied in the current research are more severe compared to those in previous studies.
5.3 Direct cost

In the current study, average medical cost per month was GHS 779.11 (USD 178.70) being 41.5% of the cost profile and average non-medical cost GHS 919.90 (USD 210.99) being 49% of the cost profile.

According to Mishra et al., (2016), the financial costs associated with caregiving is a significant factor in caregiving burden to the caregivers. It is probably as a result of this huge burden that 40% of the family caregivers in a study by Lai (2012) indicated that they and their families could not afford those little extras because of the expenses to care for the care receiver. They were thus found to have gone ahead to give up because of the expenses incurred in providing care (Lai, 2012).

However, the estimation that 41.5% of the average cost of caregivers is made up of direct cost is in line and probably lesser compared to findings in other literature. The percentage of the direct care cost recorded in literature account for 50% the total cost (Saka et al., 2009). In absolute cost terms, whiles the current study estimated the average direct cost per month to be GHS 779.11 (USD 178.70), İçağasıoğlu et al., (2017) in a study in Sweden estimated direct cost as 4,606.47±2,849.65 USD, while Mittmann et al., (2012) in Canada estimated direct cost to range from USD 74,353 to USD 107,883 for disabling strokes and USD 48,339 for non-disabling strokes.

That is to say, as the direct cost estimate in the current study is in the same range of estimates in some studies, it is also less in other studies. The difference could easily arise from the differences in the methodology of the studies as well as the focus of the studies. Example, the current study has a clear focus of estimating the direct cost that is borne by the primary caregiver. In the literature however, all the studies that have provided absolute estimates have only mentioned
‘estimation of direct cost’. Their focus is thus not clear. One could not determine whether the direct cost being referred to are cost borne by primary caregivers alone, secondary caregivers alone, or both primary and secondary caregivers.

5.4 **Indirect cost**

A recent review by Joo et al., (2014) has indicated that the annual per patient indirect cost on caregivers of stroke ranges from USD 904.00 in Thailand (Riewpaiboon et al., 2009) to USD23,451.00 in Netherlands (Van Den Berg et al., 2006). In developed countries, the indirect cost is relatively higher (mostly more than USD 10,000.00) (Fox, Gazzaniga, Karter, 1996; Hickenbottom, Fendrick, Kutcher, Kabeto, Katz, 2002; Lindgren, Glader, 2008) compared to similar cost in developing countries like Thailand (Riewpaiboon et al., 2009).

Majority of the primary caregivers in the study indicated having spent time to assist stroke patients in performing various activities such as personal care and performance of household activities. This finding is in line with the study of Ganapathy et al., (2015) whose findings also indicated that caregivers of stroke patients incurred some form of indirect cost in the care they provided to a stroke patient. The findings in the current study show average indirect cost was estimated at GHS 176.52 (USD 40.49) per month. This indicates that the indirect cost is in line with previous trends of cost analysis. A difference however arises when the annual average cost of GHS 1,699.02 (USD 389.68) in the current study is found to be slightly higher than the highest estimate of indirect cost in the literature which was found to be USD 1,453.00 in another developing country-Thailand. This differences may not be able to be explained by lapse of time alone. It is not of much wonder that in developing countries, there are differences in cost of living leading to differences in cost of bills. It could also be that, the differences are fully or partly explained by differences in the severity of the disease conditions (Moore et al., 2001).
The methods for calculating the costs can also not be ruled out as a possible cause of the differences. For instance, the current study used the productivity days lost to an employed caregiver and this was estimated by calculating the average productivity days’ earnings lost to a caregiver using the current minimum wage of Ghana (GHS 8.80) as at January 2017, whiles unemployed caregivers cost was estimated by using the current agriculture wage of Ghana (GHS 2.40) to calculate the average earnings lost. Same methods were not used in previous calculations in the literature. While Joo et al., (2014) did their calculations using the consumer price indices (CPI), Riewpaiboon et al., (2009) were not very specific on the method used in their calculations.

5.5 **Intangible cost of caregivers of stroke patients**

The findings in the study indicated that 91% of primary caregivers were highly burdened and 9% were less burdened with the care provided to a stoke patient. The findings are somewhat supported by (Kumar et al., 2015a), who reported a high burden of care among caregivers. Jaracz, Grabowska-Fudala, Gorna, & Kozubsiki (2014) in their study found that a high proportion of stroke caregivers experience considerable burden as the current study findings indicates. Although female primary caregivers in this study were more than males, yet, male primary caregivers reported high burden than females which is similar with the gender findings in other previous studies. Bakicilarindaki & Yiikii (2013), recorded more stroke caregivers being females in their study. This can be attributed to the fact that women are well-thought-out to be more emotional, sympathetic and sensitive thus, their ability to establish close and strong bonds and cope with difficulties associated with caregiving than men (Bakicilarindaki & Yiikii, 2013).
5.6 Quality of life of caregivers of stroke patients

Caregiving is a complex multidimensional activity. The present study results show that stroke has a profound effect on the QoL of primary caregivers as only 2 (1.4%) out of the caregivers recorded a high QoL with the remaining 85 (60.7%) and 53 (37.9%) reporting moderate and low QoL respectively. Female primary caregivers had a significantly lower QoL than male primary caregiver. This is similar to studies by (Persson et al., 2015; Visser-Meily et al., 2009). QoL for primary caregivers in the social health was the least, followed by physical health and psychological health. The findings confirm previous study conducted by Fatoye, Komolafe & Adewuya (2006), which reported good quality of life in the psychological health followed by physical and social health aspects of quality of life of caregivers. The general low quality of life of primary caregivers in the study supports the idea that caregivers should be trained and supported to enhance their quality of life.
CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

The study sought to determine the burden and quality of life of primary caregivers of stroke patients attending Tema General Hospital. Stroke is a chronic disease that leaves the patient in the disease condition for the rest of his/her life. Taking care of a stroke patient is a herculean task that leaves the caregiver in a very stressful situation for relatively long time. This chapter summarizes the entire study. It includes summary of the purpose and objectives, summary of the methods for conducting the study as well as summary of the results. The chapter also have the conclusions and recommendations for the study. The recommendations include recommendations for policy and directions for future research.

6.2 Conclusion

It can be concluded that, most primary caregivers were related to the stroke patients and are burdened with the care they provide to stroke patients as they incur huge medical and non-medical cost. The study also found out that some primary caregivers had to stop their work or education due to the burden that comes with caring for the stroke patient which invariably affect their quality of life. Although majority of primary caregivers were females, men reported being burdened than the females, and more females reported to have lower quality of life than the male primary caregivers.
6.3 **Recommendations**

Caring for stroke patients especially, disabled ones, is a source of chronic stress accompanied with huge out-of-pocket payments to primary caregivers all of which leads to caregiving burden and affects primary caregivers’ quality life.

The study recommends that:

**6.3.1 Policy**

1. Expansion of care for stroke patients using existing close-to-client health care services like the community-based health planning and services (CHPS) strategy could reduce travel time and lessen burden on caregivers.

2. National Health Insurance Scheme should factor the cost of some expensive stroke medication into its cost component to reduce the direct-out of pocket expenses borne by primary caregivers.

**6.3.2 Research**

1. Future research should be conducted on factors contributing to high burden among male caregivers of stroke patients in Ghana.
REFERENCES


Tema General Hospital, G. H. S. (2013). *Physiotherapy Department Annual Reports*.


APPENDICES

Appendix 1: Informed Consent Form

Project Title:

Burden and quality of life of primary caregivers of stroke patients attending Tema General Hospital

Background

I am Mortey Elli Patience, a student from the School of Public Health, University of Ghana, Legon. I am conducting a research on the economic burden and quality of life of primary caregivers attending Tema General Hospital, Ghana. The main objective of the research is to determine the economic burden and quality of life of primary caregivers attending Tema General Hospital.

Procedures

The study will involve answering questions from a questionnaire comprising open and close ended questions on the cost incurred and the quality of life as a result of caregiving to stroke patients. Respondents will not be forced to respond to questions. You are therefore encouraged to participate in this study since your input is much appreciated. This is purely an academic research forming part of the requirement for the award of a Master of Public Health Degree.

Risk and Benefits

Both the study population and society stand to benefit from this study. The study population will know how much money they spend in a month on caring for their patients. Policy makers on the other hand will know the economic burden of stroke, thus better make effective health care planning and allocation of resources that will help strengthen the health system. The research
will consequently, educate individuals and the public of stroke as well as draw up programs to help support caregivers of stroke patients. This research will pose no risk to the study population or society.

**Right to Refuse**

Participation in this study is voluntary. Participants may decide whether or not to answer a particular question or all questions. Participants have the right and are at liberty to withdraw from the study at any point however, participants are encouraged to participate fully since your answers provided are important to help estimate the direct and indirect cost.

**Dissemination of Results**

A meeting, including hospital staff, caregivers, patients and other stakeholders of caregivers will be held at the hospital training unit to disseminate the findings of the study. A copy of the study will be kept at the hospital library for reference.

**Before taking Consent**

Do you have any question you wish to ask concerning the study? Yes / No

If you answer *yes* to the above, please indicate your question below

……………………………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
Voluntary Consent

I have read the information given above, or the information above has been read to me and I understand. I have been permitted to ask questions pertaining to the study; questions have been answered to my satisfaction. I now voluntarily agree, and also voluntarily agree for my relative to participate in this study knowing that I have the right to withdraw and also withdraw my relative from this study at any point in time without any penalty whatsoever.

................................................. ................................................. ................................................. Date

Name of caregiver  Signature  Thumbprint  Date

................................................. ................................................. ................................................. Date

Name of witness  Signature  Thumbprint  Date

................................................. ................................................. ................................................. Date

Name of researcher  Signature  Thumbprint  Date

................................................. ................................................. ................................................. Date

Name of interviewee  Signature  Thumbprint  Date
Interviewer’s Statement

I, the undersigned, have explained this consent form to the subject in English language / Ga / Twi, and that she / he understands the purpose of the study, procedures to be followed, as well as the risks and benefits of the study.

The participant has fully agreed to participate in the study.

Signature of Interviewer ……………………………………………………..

Date …………………………………………………………………………..

Address ………………………………………………………………………

If you have any questions later please, contact

Researcher: Mortey Elli Patience (0206654560)

Hannah Frimpong

GHS-ERC Administrator

Office: + 233 302 681109

Mobile: 233 (0) 243235225 or 0507041223

Email: Hannah.Frimpong@ghsmail.org
APPENDIX 2: Questionnaire

BURDEN AND QUALITY OF LIFE OF PRIMARY CAREGIVERS OF STROKE PATIENTS ATTENDING TEMAA GENERAL HOSPITAL

Dear Respondent,

I would like you to answer a number of questions regarding this patient care. You are assured that the answers you give will be strictly confidential and will not be held against you. You are also free to withdraw or stop answering my questions at any time.

Unique ID for Respondent ...........................................

Date of interview ............................................

Instructions

SOCIO-DEMOGRAPHIC DATA

Section A. Background information of caregiver

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Male</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>2. Female</td>
<td>[ ]</td>
</tr>
<tr>
<td>2.</td>
<td>Age</td>
<td>........................ years</td>
</tr>
<tr>
<td>3.</td>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Single</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>2. Married</td>
<td>[ ]</td>
</tr>
<tr>
<td>4.</td>
<td>Highest level of education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. No formal education</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>2. Primary level</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>3. Middle / JSS / JHS</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>4. SSS / SHS / Tech / Vocational</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td>5. Tertiary</td>
<td>[ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>
| 5. | **What is your employment status?**  
|   | 1. Self employed  
|   | 2. Private sector  
|   | 3. Public sector  
|   | 4. Unemployed  
|   | 5. Student / apprentice |
| 6. | **Are you the primary caregiver?**  
|   | 1. Yes  
|   | 2. No |
| 7. | **How long have you been a caregiver to this person?**  
|   |   |
| 8. | **Thinking about your care recipient, what is your relationship to him / her?**  
|   | 1. Spouse  
|   | 2. Child  
|   | 3. Grandchild  
|   | 4. Sibling  
|   | 5. Daughter / son in law  
|   | Other (Specify)  
| 9. | **Which of the following best describe your care giving task?**  
|   | 1. Long distance care provider  
|   | 2. Co-resident care provider  
|   | 3. Nearby care provider |
| 10. | **Are you paid for your services?**  
|   | 1. Yes  
|   | 2. No |
| 11. | **What is your monthly income?** |
|   | GHS  
| 12. | **How much do you receive from other sources of income in a month?** |
|   | GHS  
| 13. | **How many days in a WEEK do you spend to care for the patient?**  
|   |   days |
| 14. | **How many hours in a WEEK do you spend with the patient?**  
|   |   hours |
| 15. | **Have you stopped your normal work / school / apprenticeship because of caregiving for patient?**  
|   | 1. Yes  
|   | 2. No |
| 16. | **Since you began giving care to your recipient, would you say your finances have...?**  
|   | 1. Gotten better  
|   | 2. Stayed the same  
|   | 3. Gotten worse |
### Background information of care recipient

17. Sex  
   1. Male  
   2. Female

18. What is your care recipients age?  
   ........................................ years

19. Do you assist your care recipient to perform any of the following task – taking a bath, using the toilet, walking inside the house, dressing up, sitting up etc. on a regular basis?

20. Do you assist your care recipient on a regular basis with any of the following – transportation, meal preparation, managing finances, shopping, housework, medication management, or arranging for outside services to help him or her?  
   1. Yes  
   2. No

### SECTION C. Direct cost: Out-of-pocket expenses

21. In the past month, have you had any out-of-pocket expenses for…?  
   In a typical month, how much do you spend on that. An average will be fine.

<table>
<thead>
<tr>
<th>Answer</th>
<th>AMOUNT (GHS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
<td></td>
</tr>
<tr>
<td>2. No</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Amount (GHS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Your care recipient’s medical care, medical supplies, and other health services</td>
<td></td>
</tr>
<tr>
<td>b. Your care recipients’ household supplies (food, water, household goods, or clothing)</td>
<td></td>
</tr>
<tr>
<td>c. Your care recipient’s residential care (housing payments, rent, or utilities)</td>
<td></td>
</tr>
<tr>
<td>d. Travel / transportation for / with your care recipient?</td>
<td></td>
</tr>
<tr>
<td>e. Other (Please specify)</td>
<td></td>
</tr>
</tbody>
</table>
Please I would like to know which of the following *financing sources you have used* over the past month to pay for any health and other expenditure related to patient’s illness. Please give your best estimate if you cannot remember the exact payments.

<table>
<thead>
<tr>
<th>What are the sources of financing to pay for any health cost related to patient’s illness over the past month?</th>
<th>AMOUNT (GHS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Contributions from relatives</td>
<td></td>
</tr>
<tr>
<td>2. Health insurance</td>
<td></td>
</tr>
<tr>
<td>3. Remittances</td>
<td></td>
</tr>
<tr>
<td>4. Donations / Gift</td>
<td></td>
</tr>
<tr>
<td>5. Sale or transfer of asset (e.g. Land, vehicle etc.)</td>
<td></td>
</tr>
<tr>
<td>6. Borrowed money</td>
<td></td>
</tr>
<tr>
<td>7. Patient’s pension / other income</td>
<td></td>
</tr>
<tr>
<td>8. Sale of patient’s asset</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

**SECTION D. PRODUCTIVITY LOSS**

Do you spend time helping your care recipient in any of the following within the week? How many hours do you spend helping your care recipient?

<table>
<thead>
<tr>
<th>No.</th>
<th>Category</th>
<th>Answer 1. Yes</th>
<th>Number of Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>23.</td>
<td>a. Time spent on personal care</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. Time spent on household activities and other errands</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c. Time spent on travel / transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>d. Other time spent with care recipient (leisure etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>e. Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**SECTION E. ZARIT BURDEN INTERVIEW**

Please answer the questions below by **circling** the appropriate response which best describes how you feel.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite frequently</th>
<th>Nearly always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work / family)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Do you feel that your relative currently affects your relationship with family member or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. Do you feel that you don’t have much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. Do you feel that you have lost control of your life since your relative’s illness?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Do you feel uncertain about what to do with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. Do you feel you should be doing more for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. Do you feel you could do a better job in caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
Section F. Quality of life of primary caregiver (WHO EUROHIS - QoL INDEX)

Please answer the questions below by circling the appropriate response which best describes how you feel.

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>How would you rate your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>How satisfied are you with your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3.</td>
<td>Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4.</td>
<td>How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>How satisfied are you with your personal relationships?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7.</td>
<td>Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>How satisfied are you with the conditions of your living place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Thank you very much for your time.