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ECONOMIC BURDEN OF FAMILY CARE-GIVING FOR THE ELDERLY AT THE GA-EAST MUNICIPALITY, GHANA.

BY

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DECLARATION

I, Nortey Stephen Tettey, hereby declare that except for references made to other people's work which have been duly acknowledged, this work is the result of my own research undertaken under supervision and that it has neither in part nor in whole been presented for another degree elsewhere.

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Date:……..

DEDICATION

This work is dedicated to God Almighty and to all family caregivers in Ghana. This work is also dedicated to Miss Eunice Arthur for her support and encouragement throughout this period.

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ABSTRACT

Introduction: Family caregivers continue to be the primary source of care for the elderly in Ghana. However, their care-related economic burden is often overlooked.

Aim: The objective of the study was to estimate the economic burden of family care-giving for the elderly in the Ga-East Municipality.

Methods: A retrospective cross-sectional cost-of-care study was conducted among family caregivers in the Ga-East Municipality. A simple random sample of 98 respondents completed an interviewer-administered questionnaire. Total out-of-pocket cost of care-giving for the past one month was obtained. A human capital approach was used to estimate indirect cost of care-giving. Intangible costs were assessed using the 12-item Zarit burden interview and the financial cost dimension of the cost of care index.

Results: The total cost per month of family caregivers of the elderly in the sample was estimated at GHS60,603.04 (USD14,568.03). This constituted of 66% (GHS 40,104.00; USD9,640.38) being direct cost of care-giving and 34% (GHS20,499.04; USD4927.65) being indirect cost. The estimated average amount of direct cost expenses per month was GHS481.39 (USD115.72). Majority (78%) of the family caregivers in this study reported a high level of care-giving burden with females reporting a relatively higher level than males. Most of these family caregivers also reported a high level of financial stress as a result of care-giving for their elderly relative.

Conclusion: The financial challenges and economic burden of family caregivers as shown in this study, if unaddressed, would further hinder their capacity and endurance to support the elders in their community. Policies and programs are needed to address the financial needs and security of these family caregivers.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES AND MAPS

LIST OF ABBREVIATIONS

AALF: Akrowa Aged Life Foundation

AARP: American Association of Retired Persons

ADL: Activities of Daily Living

AU: African Unity

CCI: Cost of Care Index

CLTCRP: Centre for Long Term Care Research and Policy

CG: Care Giver

CR: Care Recipient

GHS: Ghana Cedis

GSGDA: Ghana Shared Growth and Development Agenda

GSS: Ghana Statistical Service

IADL: Instrumental Activities of Daily Living

ILO: International Labour Organisation

ICPD: International Conference on Population and Development

LEAP: Livelihood Empowerment against Poverty

MESW: Ministry for Employment and Social Welfare

MIPAA: Madrid International Plan of Action on Ageing

NAC: National Alliance for Caregivers

UK: United Kingdom

UN: United Nations

US: United States

USD: United States Dollars

WHO: World Health Organisation

ZBI: Zarit Burden Interview

DEFINITION OF TERMS

Elderly:	An individual aged 60 years or above who depends on other relatives for support in order to carry out some activities of daily living (ADL) and some other Instrumental Activities of Daily Living (IADL).
Family caregiver:	A relative, friend or neighbour who provides a wide range of unpaid care to a dependent elderly individual.
Care-giving:	The actions of providing care to an elderly individual.
Direct Cost:	Actual out-of-pocket expenditure incurred by the caregiver as a result of caring for the elderly.
Indirect Cost:	Cost associated with productivity and income losses as a result of giving care to the elderly.
Intangible Cost:	Costs which cannot be directly expressed in monetary terms and may include pain, stress, anxiety and other emotional sufferings borne by the caregiver as a result of giving care to the elderly.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Over the past decade, population ageing has become a major public health issue, occurring in nearly all the countries of the world. Population ageing results from decreasing mortality and most importantly, declining fertility (Mba, 2010). This process leads to a relative reduction in the proportion of children and to an increase in the share of people in the main working ages and of elderly persons in the population.

The global share of the elderly (people aged 60 years or over) increased from 9.2% in 1990 to 11.7% in 2013 and will continue to grow as a proportion of the world population, reaching 21.1 % by 2050 (United Nations, 2013). Globally, the number of elderly people is expected to more than double, from 841 million people in 2013 to more than 2 billion in 2050. Elderly persons are projected to exceed the number of children for the first time in 2047 (United Nations, 2013).

Presently, the greatest increase in the number of elderly people is occurring in the developing countries and Ghana is not an exception. The population of the elderly in Ghana has increased seven-and-half times from 1960 (213,477) to 2010 (1,643,381), constituting 6.7% of the total national population in 2010 (Ghana Statistical Service, 2013). It has been projected that by 2050, nearly eight in 10 of the world's elderly population will live in the less developed regions of the world (United Nations, 2013). In most of these developing countries, poverty is high among elderly people, sometimes higher than that of the population as a whole, especially in countries with limited coverage of social security systems.

Population ageing has major social and economic consequences. The old-age support ratios (number of working-age adults per elderly person in the population) are already low in some developing countries, and are expected to continue to fall in the coming decades with ensuing economic pressures on support systems for elderly persons (United Nations, 2013). Also, while people are living longer lives almost everywhere, the prevalence of non-communicable diseases and disability increase as populations age (United Nations, 2013).

This demographic trend that predict for future decades sharp rises in the numbers and proportion of elderly people has led to considerable attention being paid to issues of population ageing. This overwhelming interest has been driven in part by the notion that costs to society will escalate with the increasing population of dependent elderly people. Indeed, concerns about the rising costs of care needs among people who are ageing with disabilities have been well documented (World Health Organization, 2011).

In most developed countries, formal care costs for the elderly are closely monitored. Reports from these regions indicate that government expenditure has grown faster than gross domestic product, and that the status quo of state involvement in care-giving for the elderly is unsustainable, and hence responsibilities for care need to be shared between families and the state (Hagist & Kotlikoff, 2006; UK Parliament, 2013). However, in Ghana and many other developing countries, care-giving for the elderly lies largely in the informal sector, with the family already playing an integral role in giving care to the elderly. As such, the cost of care for the elderly is usually unmonitored.

Family care for an elderly relative is by no means a new phenomenon, and has indeed typified most societies throughout history (Carmichael et al., 2010). However, it is now being provided for longer periods. Furthermore, it is increasingly likely that most individuals will at some time play the role of a caregiver; thus caring for a disabled or sick elderly relative. Researchers and policy makers have expressed concern about the sustainability of the caring capacity of the family in the face of population ageing as well as structural changes in families including divorce (Han, Ganong & Coleman., 2009), geographic mobility (Keefe et al., 2012), economic pressure and high labour force participation rates (Lai, 2010).

Against the background of the high levels of concern about escalating costs of care-giving for the elderly and the sustainability of the caring capacity of the family in the face of increasing economic pressure, it seems timely to include the family care sector more centrally in the debate about the economic costs of population ageing. To this end, this dissertation estimates the economic burden of care-giving provided by family members and friends for the elderly.

1.2 Problem statement

Several studies have consistently documented care-giving burden and its effects on family caregivers for the elderly. These studies have brought to light the psychological, social, and health consequences of the care-giving burden (Feinberg et al., 2011; Badasu, 2012; Lai, 2012). Consequently, these studies have provided an important impetus to the development of social policies such as caregiver support groups and respite services in many countries (Döhner, 2006).

However, these studies provided relatively little conceptual or empirical understanding on the economic costs incurred by family caregivers of the elderly. Moreover, the few

studies that sought to do that were all conducted in high income counties. These studies usually focused on the economic effect of family care-giving on the employer, national income and cost to the society but not the cost to the family caregiver. This is partly because family care-giving and support to the elderly usually lie outside the market economy and is socially and politically invisible. Hence, its economic value is not generally acknowledged.

However, studies have documented that in Ghana, deficit in care-giving for the elderly in urban settings is becoming a major challenge to human wellbeing (Badasu 2012, Baataar 2012, Dsane 2011). This is in part related to the substantial health-care and other related costs associated with family care-giving for the elderly. Apart from the fact that the elderly themselves may not be economically active, most caregivers of the elderly are also unable to continue working because of the burden of care, and many rely on friends and family for support (Dsane, 2011).

Unfortunately, very little is known on the economic burden of family care-giving for the elderly in Ghana. Hence, economic and social interventions for family caregivers of the elderly even if they exist, might be out of target. Thus, this study aims to estimate the economic burden of family caregivers for the elderly in the Ga-East Municipality, as well as the specific proportions of total cost attributable to direct, indirect and intangible costs of care-giving.

1.3 Study objectives

1.3.1 General objective

The general objective of this study was to estimate the economic burden of family care-giving for the elderly in the Ga-East Municipality.

1.3.2 Specific objective

Specifically, the study sought to;

1. Estimate the direct cost of family care-giving for the elderly in the Ga-East Municipality.
2. Estimate the indirect cost of family care-giving for the elderly in the Ga-East Municipality.
3. Describe the intangible cost of family care-giving for the elderly in the Ga-East Municipality.

1.4 Research questions

The study sought to answer the following questions;

1. What is the direct cost of family care-giving for the elderly in the Ga-East Municipality?
2. What is the indirect cost of family care-giving for the elderly in the Ga-East Municipality?
3. What is the intangible cost of family care-giving for the elderly in the Ga-East Municipality?

1.5 Justification of study

With the growing evidence of Population ageing in Ghana and its associated economic burden on family caregivers, it is imperative to estimate and describe this burden. One way of sensitising policy makers and stakeholders on the enormity of the economic burden of family caregivers for the elderly and the need to allocate more attention and resource to them, is to estimate the cost of family care-giving for the elderly.

The burden of family caregivers will be better appreciated when monetary value is estimated and known. This may provide the needed impetus for the development of an appropriate policy framework to support family caregivers for the elderly in Ghana. The building of such efficient care-giving support systems for the elderly requires public health and policy intelligence to incorporate a comprehensive estimation of the costs of care-giving. Thus, this systematic cost-of-care study can provide valuable data for the relative socioeconomic burden of care-giving, which can inform an objective public policy framework.

Also, knowledge of the economic cost of care-giving for the elderly can help in strategic planning and budgeting for caregivers' support groups, which can ensure a reduction of the cost borne by family caregivers for the elderly. Subsequently, stakeholders, policy makers and the civil society can effectively allocate resources to programs that are cost effective with the knowledge of the cost incurred by family caregivers in giving care to the elderly.

In addition, there is paucity of studies on the economic burden of care-giving for the elderly in Ghana and Africa as a whole. This study therefore adds new knowledge to the existing knowledge on care-giving for the elderly. The study also provides the needed impetus for further research in the area of care-giving for the elderly in Ghana.

1.6 Conceptual framework

The conceptual framework underlying this study's analysis of the economic burden of family care-giving for the elderly is shown in Figure 1. Cost of care-giving for the elderly was assessed from the microeconomic perspective of the family caregiver. Distinct from concerns over the societal or population-level burden of care-giving for the elderly, this perspective focused in particular on the impoverishing and other

economic effects that care-giving can have on the family caregiver and the consumption possibilities of their households.

Care-giving for sick or disabled elderly person typically leads to increased household expenditure on health services and goods, and may also reduce time spent producing income that allows them to consume market goods. In response to this change in income and/or expenditure, family caregivers may reduce their consumption of other goods and/or liquidate household savings or assets and by so doing diminish their opportunities to generate the stock of financial and physical capital that will enable them to maintain or increase their consumption possibilities in the future. Furthermore, care-giving for the elderly can interfere with the consumption of non-market activities (e.g. giving up unpaid housework or leisure time to look after the sick or disabled elderly person) which reduces the stock of health itself.

Accordingly, analysis of the economic burden of family care-giving for the elderly was categorized into three main domains of cost; direct costs, indirect costs and intangible costs as shown in Figure 1. All cost expended in care-giving for the elderly fall in these categories. Direct costs typically includes the out-of-pocket expenditure incurred by caregivers in relation to residential care, household supplies, transportation, medical care and financial transfers as a result of care-giving for the frail elderly person.

Indirect costs on the other hand, typically refers to the productivity losses incurred by the family caregiver as a result of care-giving for the elderly relative. Thus, indirect cost involves the estimation of the total time spent on personal care, time spent on household activities, time spent on transportation/travel, as well as the time spent with the care recipient. These were valued by using the human capital approach.

Intangible costs associated with care-giving typically refers to the family caregivers' perceived level of distress, demands, and the pressure associated with care-giving roles, responsibilities, and tasks. These were determined by using the Zarit Burden Interview (ZBI) scale and the financial cost dimension of the Cost of Care Index (CCI).

The total cost of care-giving for the elderly was obtained by the summation of the economic value of both the direct and indirect costs.

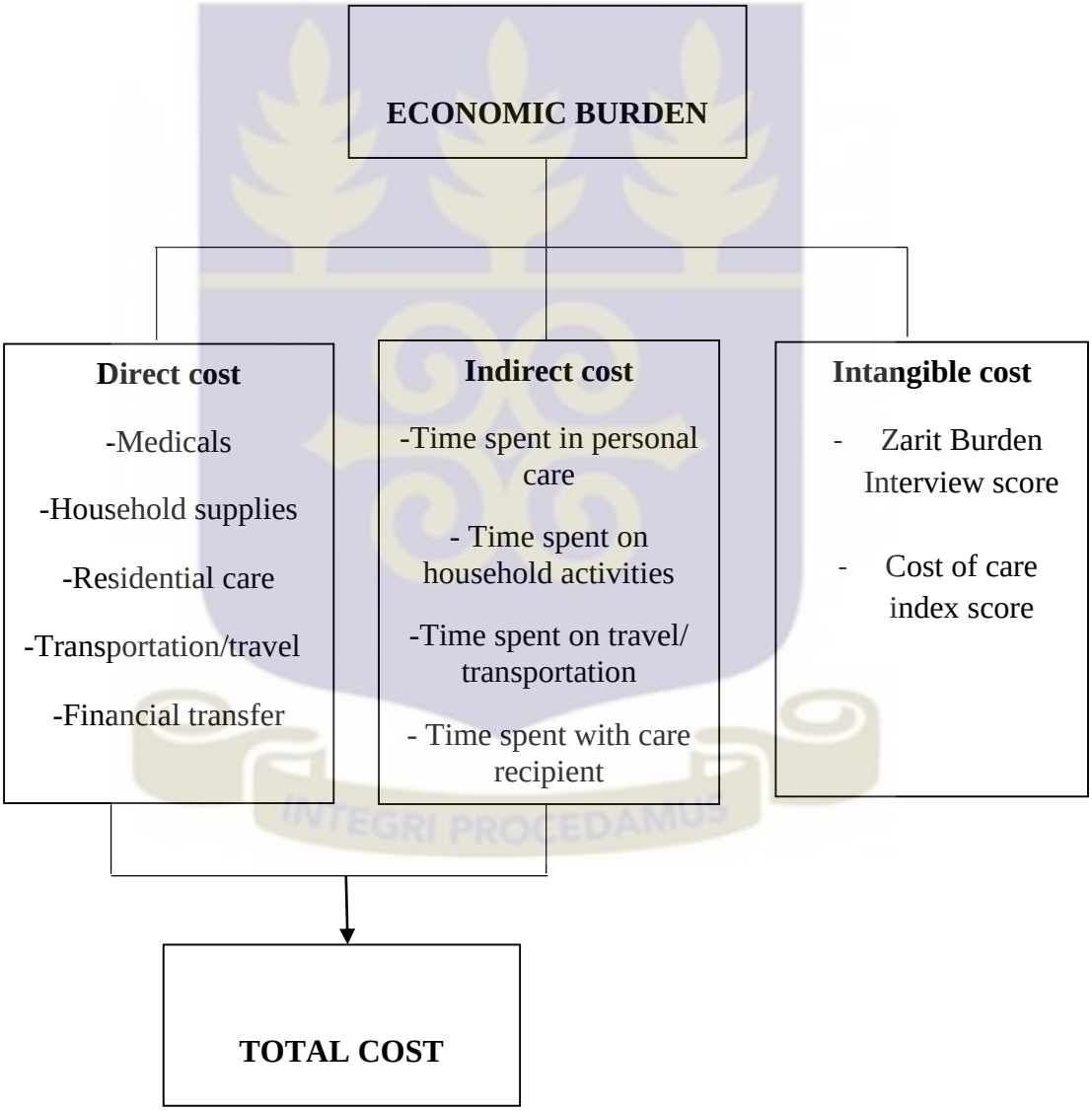

Figure 1: Conceptual framework for the economic burden of caregiving

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

Population ageing, which entails an increasing share of elderly persons in the population, is a major global demographic trend which will intensify during the twenty-first century. The concept elderly refers to a category of adults who have attained advanced ages, 60 or 65 years. The United Nations uses 60 years to refer to the elderly. In the developed countries where life expectancy is high and the age of retirement from active public economic activity is 65 years, the elderly are defined as persons aged 65 years and above. In developing countries on the other hand, since life expectancy is lower and the age of retirement is 60 years, the elderly are considered as persons aged 60 years and above (GSS, 2013).

Population ageing is taking place almost everywhere, but its extent and speed vary. In most developed countries, the population has been ageing for many decades, while in developing countries, population ageing has taken place relatively recently, as mortality and fertility levels have decreased (UN, 2013). Currently, the most aged populations are in the developed countries, however the larger proportion of older persons reside in developing countries (UN, 2013).

Naturally, as one ages, the functional capacities of the individual may deteriorate. This is in part related to the concomitant health problems associated with ageing. This leads to most elderly people depending on other relatives for support in order to carry out some activities of daily living (ADL) and some other Instrumental Activities of Daily Living (IADL). Thus, the elderly are considered as a vulnerable group of individuals who need to be supported by family and society at large (WHO, 2011).

2.2 Policies to support the elderly

Issues related to population ageing and elderly persons have played an important role in several major international conferences during the past two decades, including the International Conference on Population and Development (ICPD) held in 1994, which recognized the economic and social impact of population ageing in all societies (International Labour Organization, 2011). Subsequently, the key actions for the further implementation of the programme of action of the ICPD, adopted in 1999, reiterated the need for all countries to address the significant consequences of population ageing in the coming decades.

Continental efforts to address the consequences of an ageing population in Africa started during the 1999 Session of the African Unity (AU) Labour and Social Affairs Commission that was held in Windhoek, Namibia. Collaboration between HelpAge International, Africa Development Centre and the AU Policy Framework and Plan of Action on Ageing in Africa was drafted and finalized during the 38th Ordinary Session of the Assembly of Heads of State and Government in Durban, South Africa in July 2002. The Policy Framework binds all AU member countries to develop policies on ageing and is already being used as a guide in the formulation of national policies. The goal of the Policy Framework and Plan of Action is to serve as a guide to AU Member States to design, implement, monitor and evaluate appropriate integrated national policies and programmes to meet the needs of elderly people (Ministry for Employment and Social Welfare, 2010).

The Madrid International Plan of Action on Ageing (MIPAA) which Ghana adopted addressed three main areas which are 1) elderly persons and development; 2) health and well-being into old age and 3) enabling a supportive environment for ageing (MIPAA, 2007). The Plan called for continuous and successful adjustment to an ageing world.

This success is measured in terms of development and improvement in quality of life for older persons as well as sustainability of various systems that underpin the quality of well-being throughout the life course.

The Ghana Shared Growth and Development Agenda (GSGDA) has indicated the national strategies for addressing the concerns of the aged in Ghana. This includes the development of a national policy on ageing, which will ensure the active participation of older persons in society and development; protect rights of the aged; strengthen the family and community to provide adequate support to older persons; reduce poverty among older persons; improve health, nutrition and well-being of older persons; improve income security and enhanced social welfare for older persons; ensure adequate attention to gender variations in ageing; strengthen research, information gathering and processing, and co-ordination and management of data on older persons; strengthen capacity to formulate, implement, monitor and evaluate policies on ageing; and improve funding of programmes on older persons to ensure sustainability of policy implementation (Ministry for Employment and Social Welfare, 2010) . Although the national ageing policy was developed in 2010, it has not been fully implemented.

2.3 The concept of care-giving

The concept of care-giving has been widely studied from multidisciplinary perspectives, including nursing, sociology, and psychology. Research has well documented that the concept of care-giving lacks a universal definition and thus, makes it difficult to assess the concept of care-giving as well as compare the results of care-giving research (Hermanns & Mastel-Smith, 2012).

In the literature, care-giving has been defined in several ways. Drentea (2007, p.172) defines care-giving as 'the act of providing unpaid assistance and support to family

members or acquaintances who have physical, psychological, or developmental needs'. Himmelweit (2008, p.581) defines care-giving as "the provision of personal services to meet the physical and mental needs that allow a person to function at a socially determined acceptable level of capability, comfort, and safety." Furthermore, Hermanns & Mastel-Smith (2012, p.5) define care-giving as 'actions one does on behalf of another individual who is unable to do those actions for himself or herself.'

Accordingly, a caregiver has been defined as someone who is responsible for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age (Himmelweit, 2008). Savage & Bailey (2004) more precisely define a caregiver as a relative, friend or neighbour who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living. This present study therefore considers the definition of a caregiver in the light of the definition given by Savage & Bailey (2004).

In literature, care-giving has been classified as either informal or formal. According to Blum & Sherman (2010) informal care-giving is complex and the relationships are dynamic. Hudson & Payne (2009) defined informal caregivers as any relatives, friends, or partners who have a significant relationship with and provide assistance to an individual with a life-threatening, incurable illness. In contrast, formal care-giving is classified as paid services of licensed or unlicensed strangers provided under the umbrella of a formal health care system (Connell, 2003). It is worth noting that the various types of care-giving typically contained elements related to the act of care-giving or tasks performed of care-giving, which makes the concept difficult to identify (Hermanns & Mastel-Smith, 2012).

Sociologists generally limit their discussion of care-giving to unpaid workers. Caregivers are typically family members, friends, and neighbours. Indeed, care-giving of all types is also done by paid workers such as nurses, social workers, and counsellors. However, care-giving by these is paid work, and thus does not fall in the same category as the unpaid. Similarly, care-giving rarely refers to the daily care that parents provide for their children, because this is classified as parenting; however, caring for a disabled adult would be considered care-giving because it is outside of the norm of expectations for older adults (Drentea, 2007).

2.4 Global context of caring for the elderly

For various reasons, care-giving for the elderly has become a rapidly growing and more visible problem at the global level (United Nations, 2013). Some of the reasons for this includes: the rising numbers and proportions of population over sixty, developments in illness patterns partly as a result of changing modes of disease transmission and modern diets and lifestyles, and improvements in many medical treatments and technologies available which may serve to prolong the life of the very sick (Oppong et al., 2009).

Longer life expectancy implies that older people living longer, as healthy and autonomous persons, and also more people surviving into old age for much longer periods (Hill et al., 2008). These older adult sometimes suffer debilitating illnesses and survive as frail elderly, with greater needs for daily help and care. Influences of such changes are being felt all over the world. Both men and women may have great difficulty coping with the demands of caring for an elderly family member, as well as their employment demands and meeting the regular needs of relatives, including dependent children (Oppong et al., 2009).

2.5 African context of caring for the elderly

In most African societies, age is one of the basis for the ascription of status and also one of the underlying dimensions by which social interaction is regulated. In traditional African societies, the care and support of elderly persons are provided by the family members, especially the wives, sons, daughters, sons-in-law, and daughters-in-law (Ogwumike & Aboderin, 2005). This care-giving according to Okoye (2012) was backed not simply by the emotional bonds of relationship emerging out of blood relationship or marital relationship but by the force of pervasive influence of traditional values, norms and behaviour which were not simply practised as a matter of routine but also deified. The care of the elders was the moral imperative which was considered not only material bliss but also spiritual salvation (Ajala, 2006).

Therefore in the traditional African society, the elderly knew no poverty because there was the extended family, where children, parents and grandparents lived together. Children and grandparents interacted with benefits to one another, and parents could make the necessary material provision and also see to it that any special care needed by the elderly in the household was made available (Aboderin, 2005).

However, the process of urbanisation and industrialisation, as well as the emphasis on nuclear family and neo local residence have brought about increase in the mobility of younger generation and physical isolation of the elderly from their families (Egwu, 2013). Although traditional caring and social support mechanisms for the elderly now appear to be declining, it is however well established that, family members play a major role in providing care-giving assistance to the elderly in Africa (Aboderin, 2005).

2.6 Ghanaian context of caring for the elderly

Traditionally, the family has held the exclusive responsibility for the material support of the old in Ghana. The duty of the young, especially of adult children, to provide such support is enshrined in the customary moral code and encapsulated in the proverb ‘‘When your elders take care of you while you cut your teeth, you must in turn take care of them while they are losing theirs’’ (Oppong et al, 2009).

Majority of elderly Ghanaians are generally taken care of by their children or grandchildren (Sackey, 2005). Ghanaians pride themselves in taking care of their older people and regard institutionalized care and euthanasia in “Western” countries as unfortunate developments, indications of a declining willingness to care for the elderly (Van der Geest, 2002).

According to Van der Geest (2002), among the Kwahu (Akan) caring for the sick is the responsibility of the children before the ‘abusua’ (family) and in their absence the wives can offer care. According to Sackey (2005), at least 50 % of elderly men are nursed and cared for by their wives. Responsibilities of individuals in the area of health care can be found in proverbs, adages and myths and the seriousness attached to these ensures the smooth running of social relations in the cultural setting (Sackey, 2005). However, like many other African countries, studies have shown that various social and economic pressures are reducing the amount of unpaid care families are able and willing to provide to the elderly (Benjamin et al., 2008; Sackey, 2005).

2.7 Policies formulated to influence care-giving.

Research in this area is not well-developed, especially in regards to care-giving for the elderly. Conventions established by international organizations and then proposed, ratified, and legislated by nations can serve as a starting point for alleviating care-giving

barriers to participation in the workforce, reducing the negative health and economic consequences of care-giving, and distributing care-giving more evenly between men and women (Lai, 2012; NAC 2010).

Workplace policies, caregiver services, and caregiver payments are the three main types of supportive policies for caregivers that nations can implement (Arksey, 2007). Research has shown that although providing payments to caregivers allows them to remain at home with care recipients and is the strategy followed by countries most interested in reducing healthcare expenditures, such payments provide an incentive for those with little income to leave the labour force and thus place caregivers in further financial vulnerability when payments end (Arksey, 2007; Lilly et al., 2007). Whether any of these policies or any combination of these policies reduce caregiver burden, strain, and financial penalties in cost-effective ways has been much less explored in either developed or developing nations.

2.8 Caregiver burden

In health sciences, caregiver burden refers to the collective set of stressful exposures or "stressors" that the caregiver faces (Friedemann-Sánchez & Griffin, 2013). Although care-giving has positive effects on caregivers, such as an improved sense of strength in the face of adversity, a sense of accomplishment, and emotional closeness to the care recipient (Balducci et al., 2008), the health sciences have focused more on those less-desired effects of care-giving that are amenable to intervention.

In economics literature, the term burden as traditionally used in the health field, includes both health and economic components. It is thus a multi-dimensional concept, which incorporates the physical, cognitive, and economic load that the caregivers for the elderly bear (Friedemann-Sánchez & Griffin, 2013). Burden is considered dynamic,

a process that changes over time as the caregiver's and the elderly's circumstances change. It is measured by assessing the different objective and subjective stressors that caregivers often experience (Friedemann-Sánchez & Griffin, 2013).

Objective burden includes the number of hours in a given period of time spent on care-giving and the tasks for which the elderly needs support. It also captures demands on caregiver's time, such as coordinating paid labour, family life, and regular housework activities with care-giving. It also includes the lack of time for employment, social, leisure, and educational activities as well as the economic (direct and indirect) and opportunity costs of care-giving. These include paying for food, shelter, transportation and health-related expenses associated with providing and managing care for the elderly (Friedemann-Sánchez & Griffin, 2013).

Subjective burden on the other hand includes the perceived demands that caregivers experience, including their emotional reactions to providing care, such as anger and embarrassment, feelings of entrapment, and a lack of control over one's life, time for leisure and socialization, and privacy. Subjective burden also captures the emotional reactions to role conflict, life imbalance, and overload that care-giving create (Lai, 2010).

2.9 Determinants of caregivers' burden

Previous studies have identified factors that may influence caregivers' burden. These include; caregiver's characteristics, care recipient characteristics, caregiver's resources, and caregiver's support characteristics (Carmichael et al., 2010; Thomson et al., 2008).

Caregiver characteristics

Caregiver characteristics, such as gender, age, and kinship to the care recipient, have consistently been associated with strain (Lai, 2012). Strong evidence exists that among

all caregivers in the United States and Europe, women have poorer physical and mental health outcomes than men (Himmelweit & Land, 2008). This is in part because women are more often the primary caregivers, provide more intensive care to care recipients across all levels of need, and are more likely to provide care to the sickest care recipients and those with the greatest needs, including those needing assistance with ADLs and IADLs. Family caregivers and women have been shown to have lower earnings than non-caregivers and men who are caregivers (Carmichael et al., 2010).

Additionally, background characteristics of the elderly such as age, health condition or disease and its severity have been shown to be strong predictors of poor health outcomes and economic burden for family caregivers (Knight et al., 2002; Lee & Kolomer, 2005). These factors are often indicators of the time, physical, emotional, and cognitive labour that care recipients require and the kinds of material goods and services care recipients need (Lai, 2010). What is not known however, is how these affect human capabilities of the caregiver, including the relationship between participation in paid labour and caregiver strain and how it varies by care recipient characteristics. However, what is known is that the amount of time family caregivers spend in that role determines both health and economic outcomes (Bittman et al., 2007, Lai 2012).

Also, caregiver's intra-personal resources are often conceptualized and examined as a means of buffering the relationship between economic burden and outcomes of care-giving (Smerglia et al., 2007). When caregivers have well developed intra-personal resources, they can better manage stressors, reduce burden, and improve outcomes (Friedemann-Sánchez & Griffin, 2013). Intra-personal resources often categorized as educational resources, such as health literacy or the ability to access adequate and accurate information, or as cognitive resources, such as mastery (the individual perception that one is able to master certain tasks) and self-efficacy (the confidence in

being able to perform tasks) and often addressed by training family caregivers in a timely and culturally appropriate way (McClendon et al., 2004; Evercare & NAC, 2007). In the United States, lessons from care-giving interventions for chronic conditions suggest that meeting the educational needs of family caregivers can improve caregiver's knowledge and self-efficacy, which have been shown to be the most effective interventions for improving well-being among family caregivers for the elderly (Gilliam & Steffen, 2006, Rabinowitz et al., 2006). Few studies on the economics of care-giving, however, take into account the social, cognitive, and emotional factors when studying the financial and economic decisions of caregivers, thus, leaving gaps in our understanding of how intra-personal resources affect financial outcomes for family caregivers.

Previous studies have also shown that family caregivers who have social and community resources (e.g., friends and extended family, non-profit organizations, and neighbourhood associations) use them to distribute care-giving activities and as emotional support (Smerglia et al., 2007). Thus, meeting the resource and social support needs of caregivers plays a positive role on caregiver health and economic outcome, as it can decrease their perceived burden and distress and increase life satisfaction (Van Ryn et al., 2010, Upton & Reed, 2006). Community centres, formal social support groups, and educational campaigns can be effective interventions (Van Ryn et al., 2010). However, very little is known on the availability and effectiveness of such support system in developing countries.

2.10 Economic cost of family caregiving

The costs of family care-giving for the elderly was first assessed by Fast et al. (1990). These authors made an early attempt to address the conceptual gaps with respect to

care-giving for the elderly. Based on what was then a small body of literature on the costs of care, they developed a taxonomy of the domains of costs to a broad set of stakeholders including care receivers, caregivers and their families, the formal care sector and society (Kleating et al., 2014). Subsequent other studies have highlighted the economic costs of family care-giving as having direct, indirect and intangible cost domains (Evercare & NAC, 2007; Dew, 2008; Kleating et al., 2014; Lai, 2010).

Although, these domains of costs may not be totally exhaustive and might require caution and sensitivity to contextual relevance, it has however, proven to be a useful lens by which economic costs of care-giving for the elderly may be examined. This study therefore examines the economic burden of care-giving for the elderly using these cost domains.

2.10.1 Direct costs of family care-giving

These may also be referred to as out-of-pocket costs. These are expenses made by the family caregivers that would not have been made in the absence of their care responsibilities. The extant literature suggests that they occur in five sub-categories: medical care; residential care; Household supplies, transportation/ travel and financial transfer (Kleating et al., 2014). However, there is not yet sufficient evidence about each sub-category to be confident that this is the definitive classification.

While there have been some key studies published recently on this type of care-related cost, the overall state of knowledge has not expanded greatly since the development of the Fast et al. (1990) taxonomy of costs in the 1990s. This lack of progress is partly due to methodological challenges in gathering detailed caregiver expenditure data over time. For the most part, the evidence remains largely descriptive with only a few attempts at explaining wide variations in estimates (Kleating et al., 2014).

Nonetheless, this limited body of research suggests strongly that out-of-pocket expenditure can be a significant source of costs for caregivers. However, estimates of how many caregivers make care-related out-of-pocket expenditure vary widely. In Canada, estimates range from 35% in a population-based study (Duncan et al., 2013) to 80% in a study of family caregivers to high needs care receivers (Fast et al., 2008). In the United Kingdom, 58% of family caregivers reported incurring out-of-pocket expenses associated with caring for an elderly with a disability or illness (Carers UK, 2007). Variations in findings can be attributed to the jurisdiction, type and intensity of care being provided, and the types of costs measured. These are factors that will require further examination.

Similarly, estimates of amounts of care-related out-of-pocket expenditure also vary widely, ranging from USD1,532 (You et al., 2008) to more than USD12,000 per year on items such as groceries, medicines, care attendants, and long distance travel (Evercare & NAC, 2007). In one recent Canadian study, maximum expenditure reached USD120,000 for caregivers to elderly with high care needs (Fast et al., 2008).

These findings suggest that out-of-pocket costs can be substantial for some caregivers, but there has been no systematic evaluation of factors influencing these costs. Furthermore, there is little information about the extent to which these expenditures create financial and other hardships for caregivers. However Duncan et al. (2013) did report that family caregivers with less financial means have significant care-related expenses that represent a larger proportion of their household income compared to those family caregivers with higher incomes.

Medical care include fees or other costs related to purchasing services provided by professionals (e.g., physiotherapist, dietician, geriatrician etc.) and for acute care

situations (e.g., hospital stays, diagnostic or laboratory services). There is a growing body of evidence about caregivers' expenditure on these services. Medical care cost constitute a large proportion of out-of-pocket expenses, particularly in jurisdictions without prescription drug insurance plans (Fast et al., 2008). In the US, 21% of caregivers' annual out-of-pocket expenses went to medication costs (Evercare & NAC, 2007). In a sample of Canadian caregivers, 71% reported paying for non-prescription medications, and 43% for prescription medications (Decima Research, 2002).

Residential care include home maintenance and modification as well as utility cost for the care receiver. There is evidence of additional costs for utilities and other regular household expenses when a care receiver co-resides with their caregiver (Carers UK, 2007; Duxbury et al., 2009; Fast et al., 2008). There is less information about whether caregivers living at a distance contribute to the household expenses of care recipients.

Household supplies include food, clothing and personal items for the care receiver and personal care products (incontinence and wound care supplies, etc). Personal items such as food, clothing, household goods and bedding accounted for 15.7% of expenses, or USD868 annually, for caregivers in the US (Evercare & NAC, 2007).

Transportation and travel expenditures include taxis, fuel, accommodation and meals that family caregivers incur in traveling to, traveling with, or traveling for the care receiver. One study found that caregivers spent 10% of their total care-related out-of-pocket expenses, or an average of USD551 annually, on travel (Evercare & NAC, 2007). In another study, 81% of family caregivers reported transportation costs associated with care-giving (Decima Research, 2002).

There has not been sufficient research on financial transfers from caregiver to care receiver, although research on these transfers has potential to inform understanding of

care-related out-of-pocket costs. For example, a study reported that 15% of women caregivers transferred an average of USD696 to their parents in the previous 12 months (Johnson & Lo Sasso, 2004).The purpose of such transfers is not always identified. Further examination to determine how much they may be contributing to household expenses on care-giving is warranted.

2.10.2 Indirect costs of family care-giving

Indirect costs refer to time spent by family caregivers performing tasks and providing services to the care receiver because of that person's long-term disability or chronic illness. While there has been much documentation of the social and health consequences of care (Fisher et al., 2011; Ho et al., 2009), there has been much less investigation of the economic consequences of care labour. This may reflect an ongoing reluctance to make public the 'private' work of families (Folbre et al., 2013).

As with other domains of care-related costs, there is great variability in estimates of the occurrence and magnitude of care labour undertaken by family caregivers. In this case, the variability arises from inconsistencies in the way in which care labour is defined operationally (e.g., which care tasks are included) and from deficiencies in data collection methodology. However, four sub-categories of care-giving labour are usually highlighted; time spent on personal care, time spent on household activities, time spent on travel/transportation and time spent with the care receiver (Kleating et al., 2014)

Studies have been conducted in many countries in which the amount (incidence and time spent) of care labour undertaken by family caregivers was estimated. In most of these studies, estimates of time spent varied widely as a result of inclusion criteria for family caregivers and care tasks. For example, UK research showed that 1.8 million of its 6.5 million caregivers provided over 20 hours of care per week (Carers UK, 2007)

while 34 million caregivers in the US provided an average of 21 hours of care per week (NAC, MetLife Foundation & CLTCRP, 2011). In contrast, in a Canadian survey, family caregivers aged 45 and older reported spending an average of between 7.0 and 8.9 hours per week on a specified set of care tasks which excluded time spent getting to the care receiver (Fast et al., 2013).

Time spent on personal care involves time spent in face-to-face activities that are important to the quality of life, or even the survival, of the care recipient. Personal care activities identified in the literature include; feeding, dressing, bathing and toileting, changing bandages and giving medicines (Fast et al., 2013, Kleating et al., 2014, Lai, 2010). Much of the extant literature has probed on such questions as the proportion of caregivers who engage in different types of tasks. Relatively few studies report on the amount of time spent on personal care. One study estimated time spent on personal care at 649 hours annually (Johnson & Lo Sasso, 2004).

Time spent with care recipient involves time spent being a companion; facilitating social interactions and reducing social isolation. Overseeing the status of the care receiver, checking in with them, and problem solving with or for them. This is a commonly identified care task. Estimates of participation rates range from 41.4% (Fast et al., 2008) to 92.4% (Port et al., 2005).

Time spent on travel/ transportation is usually high among family caregivers who do not live with their caregiver (Fast et al., 2013). This means that a considerable amount of time may be spent traveling to the care receiver in order to provide care. In a study of work-life conflict of employed Canadians, Duxbury et al. (2009) found that, of the 34.4 hours per week spent caring for older adults, 4.1 hours were spent commuting. However, time spent getting to and from care receivers is unlikely to be a significant

cost domain in developing countries where caregivers usually co-resides with their care recipient (Oppong, 2009).

Time spent on household activities includes the time caregivers spend organizing and maintaining living conditions for the care recipient. This include time spent on meal preparation, washing, cleaning or shopping on behalf of care recipient. A number of studies have found that a majority of caregivers are involved in household activities for the care recipients. One study estimated time spent on household activities at 345 hours annually (Johnson & Lo Sasso, 2004).

2.10.3 Intangible cost of family care-giving

Not all economic costs could be measured by monetary values as some costs are subjectively indicated by individuals as perceived financial costs. The intangible costs domain of the taxonomy of costs covers this aspect of the economic burden of care-giving for the elderly. Several authors have examined the intangible cost of the care-giving burden using the 22-item ZBI (Zarit et al., 1980). The instrument covers areas including caregiver's health, psychological well-being, social life, finances, and the relationship between the caregiver and care receiver. Several authors have examined the factor structure of the ZBI. Some examples are the two-factor model of personal strain and role strain (Hébert et al., 2000), the three-factor model of embarrassment/anger, patient's dependency, and self-criticism (Knight et al., 2002), and the five-factor model of sacrifice and strain, inadequacy, embarrassment/ anger, dependency, and loss of control (Lai, 2007).

Over the years several authors have developed abridged versions of the 22-item ZBI, notable among them is the 12-item ZBI developed by Bedard et al., (2001). The 12 items of this brief ZBI were selected as those with the highest item-total correlations.

Similar to the original measure, these authors contend that responses to their brief ZBI reflect two distinct factors (personal strain and role strain) with acceptable indices of internal consistency for both (i.e., a 5 .88 and a 5 .78, respectively). On the basis of various analyses, other studies (O'Rourke et al., 2003; Schreiner et al., 2006; Ballesteros et al., 2012) have concluded that the scale remains an effective measure of caregiver burden despite its relative brevity.

However, it may be argued that the ZBI does not directly relate to a specific domain of "economic burden " (Lai ,2012). Consequently, the financial cost dimension of the CCI developed by Krosberg and Cairl in 1986, has been proposed to be a more direct measurement of the caregiver's perceived economic burden of care-giving. According to the authors (Krosberg & Cairl, 1986), the financial stress of care-giving for the elderly could be measured by asking family caregivers the following questions: (a) Do you agree that caring for your elderly relative is causing you to dip into savings meant for other things? (b) Do you agree that your family and you must give up necessities because of the expense of caring for your elderly relative? (c) Do you agree that your family and you cannot afford those little extras because of the expense of caring for your elderly relative? (d) Do you agree that caring for your elderly relative is too expensive? Family caregivers were asked to respond to each question by choosing an answer among a 4-point scale—strongly disagree, disagree, agree, and strongly agree, with corresponding scores of 1 to 4, respectively. All responses were summed to form a total score range of 4 to 16, with higher scores indicating greater level of financial stress.

Lai (2012), who also utilized this approach in determining family caregivers' financial stress argued that, the four specific items used for measuring costs of care were related

to actual financial spending, such as dipping into savings, giving up necessities, not being able to afford little extras, and costs being too expensive. These items indicated how one rates his or her perception of spending and expenditure patterns related to care-giving. Lai (2012), further indicated that 40.3% of the family caregivers in his study agreed that care-giving for the care receiver was causing them to dip into savings. Again, 40% of the family caregivers indicated that they and their families could not afford those little extras because of the expenses to care for the care receiver. Another similar proportion (36.8%) of the family caregivers indicated that caring for the care receiver was too expensive. This present study therefore considered the use of both the 12-item ZBI and the financial cost dimension of the CCI in measuring the intangible cost of care-giving for the elderly.

2.11 Conclusion

Little research has explored the economic effects of family care-giving for the elderly in Africa. One of the few studies explored the economic cost of home-based care in Botswana and found that more often than not, women are involved in care-giving activities. The study also estimated the economic cost of care-giving to be USD4818.46 (Mmopelwa, 2012). Very few of such cost-of-care study exist in the Sub-region, hence comparison of the economic burden of care-giving across nations in the Sub region has proven difficult. More studies on the economic cost of care-giving for the elderly within African countries are needed to enable comparison across nations and regions with relatively similar sociodemographic characteristics.

Again, compared to developed countries, little information exists in developing countries on how care-giving affects rates of labour force participation and earnings lost by caregivers. Research into this area can enhance our understanding on the effect of care-giving on family caregivers and the labour market.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter outlines the methods used in gathering data for this study, the rationale for the choice and the techniques used to analyse the information. It covers the research design, study area, study variable, sample population, sampling arrangements, research instrument, data management and analysis, and ethical issues.

3.2 Study design

In this study, a retrospective cross-sectional cost-of-care design was used. Eligible caregivers for the elderly were recruited at one point in time and assessments were made based on care-giving costs within the past one month.

3.3 Study area

This study was undertaken in the Ga-East Municipality of Ghana. The area is located at the northern part of the Greater Accra Region as shown in figure 2. It is one of the 16 districts in the Greater Accra Region and covers a land area of about 85sq km.

The Municipality is boarded on the west by the Ga West Municipality, on the east by the La Nkwantanag Municipality, the south by Accra Metropolitan Assembly and the north by the Nsawam Adoagiri District Assembly. The Ga East Municipal has a population of 147,742 according to the 2010 national population and housing census, out of which 72,987 (49%) are males and 74,755 (51%) are females. The elderly accounts for 4.5% (6,650) of the population in the municipality. There are about 50 settlements in the municipality, with Abokobi, a well-known community as the municipal capital. The area was considered for the study due to the presence of a support group for the aged which served as an entry into the vicinity.

3.4 Study population

Family caregivers for the elderly living within the Ga-East Municipality between May, 2015 and June, 2015 formed the study population for this study.

3.5 Sampling

3.5.1 Sampling frame

The family caregivers used for the study were recruited from the Akrowa Aged Life Foundation (AALF) register. The AALF is a not-for-profit organisation with the aim of introducing a home care system for the elderly in Ghana. The organisation's vision is to create a future for the elderly, giving them a sense of belonging in society and proper treatment. The foundation works with volunteers and experts from both Ghana and Denmark to build this system in Ghana. The foundation attends to about 160 elderly people leaving within the Ga-East Municipality whom they visit on a regular basis.

The foundation, having worked within the Municipality for over 5 years has developed a trusted relationship with the elderly and their family caregivers. Hence, they served as a good entry into the community. Additionally, the foundation works closely with the caregivers of elderly persons who due to their physical, psychological or developmental needs require support and assistance from their family members.

Bearing in mind the trusted relationship between the foundation and the family caregivers, as well as the peculiar characteristics of the elderly persons they attend to, the list of elderly on the AALF register was used as the sampling frame for this study. The register has a total number of 160 elderly persons living within the Ga-East Municipality. Out of this number, a sample was selected for the study.

3.5.2 Sample size

Minimum sample size was obtained using the total number of older persons on the AALF register. The total number of elderly person on the AALF register as at 2014 was 160. The study assumed most of these elderly people had family caregivers.

With this finite population (160), the sample size for the caregivers was determined by adopting the following statistical formula for minimum sample size calculation (Yamane, 1967):

$$n = \frac{N}{1 + N\,(e)^2}$$

N = the sampling frame (i.e. the total number of elderly people on the AALF register)

e = the margin of error. 7% (0.07) was used.

n = the minimum sample size of caregivers needed for the study.

From the above;

$$n = \frac{160}{1 + 160\,(0.07)^2}$$

Based on the above calculation, a minimum sample size of 89 was obtained from the target group. This was approximated to 90 and using a non-response rate of 20%, the figure was further increased to 108 as the sample size. The additional 18 was to make room for possible incomplete questionnaires and non-respondents, especially due to the possibility of not meeting some of the caregivers at home as at the time of visit.

3.5.3 Sampling procedure

Probability sampling technique was used to select subjects from the AALF register for interview. In quantitative research, probability sampling is done to ensure an accurate representation of the actual population being studied. Probability sampling in which a form of random selection is used enables the researcher to predict the probability that each element of the population will be included in the sample. It also allows for generalisability, which implies that the degree to which the sample represents the population affects the degree to which the study's result can be generalised to the entire population.

The Foundation has a list of 160 elderly persons living within the Ga-East Municipality whom they visit on a regular basis. Using the Foundation's register as a sampling frame, the identification numbers of the elderly persons on the register were used to generate random numbers in Microsoft Excel RAND. A computerised random sample of 108 identification numbers were drawn. Subsequently, using their residential addresses and contact information, caregivers of the sampled elderly persons were contacted and interviewed upon consenting to the study. Caregivers who did not meet the inclusion criteria, were unable to be identified or declined from the study were replaced with the next available caregiver on the list who qualifies for the study.

The random sampling technique used enabled the researcher to give every elderly person on the list and their caregivers an equal chance of participating in the study.

3.5.4 Inclusion and exclusion criteria

The study included family caregivers living within the Ga-East Municipality who provided care to an elderly person (60 years of age and older). For the purpose of this study, a family caregiver refers to a person who provided assistance, in the past one

month, with at least one care-giving task because of a long-term health condition of the care recipient without receiving any financial payment.

Caregivers receiving monetary payment for care-giving to the elderly, caregivers below the age of 18 years and caregivers who have spent less than a month providing care for the elderly were excluded from the study.

3.6 Study Variable

Table 1 shows the description of the study variables. It contains the type of cost and the description of the categories of costs and how they were operationalised.

Table 1: Description of study variables

Cost type	Cost categories	Description
Direct cost	Medical cost	
	Medical care	Cost associated with medications, health supplies, consultation, treatments and therapies.
	Non-medical cost	
	Residential care	Cost associated with rent, utilities and other housing expenses
	Household supplies	Cost associated with food, clothing, toiletries and personal items.
	Travel/ transportation	Cost associated with travelling to, with or for the care recipient.
	Financial transfer	Cost associated with occasional monetary transfer from caregiver to care recipient.
Indirect cost	Productivity loss as a result of ;	
	Time spent on personal care	Time spent helping care recipient with feeding, going to the toilet, bathing, changing bandages and giving medicines.
	Time spent on household activities	Time spent on meal preparation, washing, cleaning or shopping on behalf of care recipient.
	Time on travel/ transportation	Time spent in travelling to, with or for the care recipient.
	Time spent with care recipient	Time spent being a companion; facilitating social interactions and reducing social isolation.
Intangible cost	Care-giving burden	
	Care-giving burden	Zarit burden interview score
	Financial stress	Financial dimension of cost of care index score

3.7 Data collection procedure

Data in this study were collected by using a structured interviewer-administered questionnaire with both open-ended questions that required written responses and closed-ended questions providing predetermined options. The structured approach allowed the researcher to compute exact percentages. Structured data collection generally produces data that are easily quantified.

The researcher after contacting a prospective participants, introduced himself and explained the purpose and benefit of the study to the prospective participants with the help of an informed consent sheet (Appendix A). Those who could read were provided with the informed consent sheet and for those who could not read, the sheet was explained to them in a language they could understand. After the explanation, those who agreed to take part in the study endorsed an informed consent form (Appendix A). Those who gave their consent to be part of the study were recruited and interviewed using a questionnaire. Prospective participants who did not give their consent to be part of the study were replaced by the next available person on the list.

Data collection was carried out by the researcher himself with the help of three research assistants. The questionnaires were administered to family caregivers individually in the form of a face-to-face interview. A meeting with all research assistants was held at the end of each day of the data collection period where matters arising were discussed and completed questionnaires were cross-checked for each research assistant to ensure completeness of questionnaire. On the average, a total of six questionnaires were completed within a day. In all, a total of 98 questionnaires were successfully completed.

3.7.1 Data gathering tool

A structured questionnaire was used in this study to collect data from the respondents. It was considered an appropriate tool that allowed the respondent to give a self-report at free will. The structured questionnaire was developed by the researcher. The objectives of the study, the conceptual framework and the literature review guided the researcher in the formulation of the questions. Questions requiring both open-ended and close-ended responses were included to enable as much information as possible to be captured (Appendix B). The questionnaire was divided into five different sections containing mostly closed-ended questions in order to facilitate the processing of the data.

Section A: Background information of care recipient

Questions regarding the care recipient's age, sex, and assistance with ADL and IADL.

Section B: Background information of care giver

Questions in this section dealt with care giver's age, sex, marital status, educational level, and employment status, being a primary caregiver, duration of care-giving, monthly income, geographic proximity and relationship with care recipient.

Section C: Indirect costs

Questions in this section dealt with the loss hours involved in giving care to the elderly. Lost hours as a result of time spent on personal care, time spent on household activities, time spent on travel/transportation and time spent with the care recipient were covered.

Section D: Direct cost – out-of-pocket expenses

This section consisted of questions with regard to the out-of-pocket expenses involved in giving care to the elderly. Out-of-pocket expenses in the areas of medical care, household supplies, residential care, transportation/travel and financial transfer were covered.

Section E: Intangible cost

This section adopted the 12-item ZBI questionnaire and the financial dimension of the CCI questionnaire. The 12-item ZBI covers areas on personal strain and role strain. The caregivers were asked to indicate the impact of the care receiver's condition on his or her life by specifying how often they felt the way that was described by each item. Each of the item was answered on a 5-point scale with 0=never, 1=rarely, 2= sometimes, 3=quite frequently, and 4=always.

The financial dimension of the CCI was also used in this section. It covers areas on financial stress to the family caregiver. Family caregivers were asked to respond to each question by choosing an answer among a 4-point scale- strongly disagree, disagree, agree and strongly agree, with corresponding scores of 1 to 4 respectively.

3.8 Quality control

3.8.1 Pre-testing of questionnaire

The questionnaire was pre-tested at Kpone, a town in the Kpone Katamanso district with a relatively similar sociodemographic characteristics as the study area. Seven caregivers who did not form part of the final sample undertook the pilot. The purpose of 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.

3.8.2 Validity and reliability

Before implementing the study, the researcher ensured that the measurement procedures and the measurement instrument had acceptable levels of reliability and validity. The researcher developed the instrument after an in-depth literature review.

The conceptual framework was incorporated into the construction and formulation of items in the questionnaire.

Validity of the research instrument was evaluated for content and construct validity. The content validity of the questionnaire was determined by the literature review as well as by the judgement of some faculty members in the School of Public Health. Construct validity which is usually concerned with the underlying concept of the study was performed by the researcher and confirmed by the supervisor for the study.

In order to ensure reliability of the research instrument, good rapport was ensured so that family caregivers would provide correct data. The research assistants were also well trained by the researcher before embarking on the study. All completed questionnaires were cross-checked daily before data entry.

3.8.3 Data entry and processing

Completed questionnaire were serialised and coded within 24 hours of collection. Data were entered and cross-checked for errors twice by entering it using Microsoft Excel 2010 and Epi Info version 3.4.2 before running the analysis.

3.9 Data analysis

The data were analysed using Microsoft Excel 2010 and STATA 12. Descriptive statistics were used to analyse background characteristics of participants and to describe the intangible cost of care-giving. Cost analysis was used to estimate the direct, indirect cost and total cost of care-giving for the elderly. Sensitivity analysis was undertaken to ascertain the robustness of the results of the study.

3.9.1 Direct cost estimation

Direct cost was further categorised into direct medical cost and direct non-medical cost. Direct cost was estimated as follows;

Direct medical cost

Cost of medicals: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The total cost incurred by these family caregivers per month in this category was determined. The average cost per month was determined using the total number of caregivers who reported having made out of pocket expense in this direct cost category.

Direct non-medical cost

Cost of Residential care: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The total cost incurred by these family caregivers per month in this category was determined as well as the average cost per month.

Cost of Household supplies: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The total cost incurred by these family caregivers per month in this category was determined as well as the average cost per month.

Cost of travel/ transportation: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The total cost incurred by these family caregivers per month in this category was determined as well as the average cost per month.

Cost of financial transfer: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The total cost incurred by these family caregivers per month in this category was determined as well as the average cost per month.

The total direct non-medical cost per month was calculated by summing up the total residential care cost, the total household supplies cost, the total travel/transportation cost and the total financial transfer cost per month of the family caregivers in the study.

The total average direct cost per month was determined by summing up the average monthly expense for each direct medical and non-medical cost category. The total direct cost per month was derived by summing the total direct medical cost and the total direct non-medical cost for the month.

3.9.2 Indirect cost estimation

Indirect cost was estimated using the human capital approach which measures output losses by lost earnings. Productivity losses of family caregivers who were employed in the formal sector was valued using the national minimum wage rate in the country (i.e. GHS0.88 per hour). Productivity losses of family caregivers in the informal sector were valued using the local casual labour wage rate (i.e. GHS1.88 per hour). The total hours spent per month by family caregivers were derived by multiplying the total hours spent per week by four. The total number of caregivers who indicated having spent time helping their care recipient in each indirect cost sub-category was determined. The total number of hours spent by these family caregivers in each sub-category was determined as well as the average number of hours spent per month.

Productivity loss by family caregivers in the informal sector (self-employed): This was derived by the summation of the estimated total hours per month spent by family caregivers in this category on care-giving for the elderly within the period. This was then multiplied by the local casual worker wage rate of GHS1.88.

Productivity loss by family caregivers in the formal sector: This was derived by the summation of the estimated monthly total hours spent by family caregivers in this

category on care-giving for the elderly within the period. This was multiplied by the national minimum wage rate of GHS0.88.

Productivity loss by students/apprentices and caregivers who were unemployed: total hours spent per month by family caregivers in these categories were estimated, however, these were not valued because they had no actual lost earnings. Besides, students were also not expected to be working.

3.9.3 Total cost estimation

The total cost of family care-giving for the elderly per month was estimated by the summation of the total direct costs per month and total indirect costs per month incurred by the family caregivers in the study. All estimated costs were further converted into USD using an exchange rate of GHS4.16 (the exchange rate at the time this study was conducted) to enable comparison with other international studies.

3.9.4 Sensitivity analysis of total cost

Sensitivity analysis was undertaken to ascertain the robustness of the results of the study. Indirect cost and the cost of household supplies were components on which cost sensitivity tests were conducted. These components were chosen due to the uncertainties in the estimated values reported by the respondents. Household supplies component was varied by 10%. Indirect cost was first varied by using the local casual labour wage rate per hour for all employed caregivers and subsequently varied using the national minimum wage rate per hour for all employed caregivers. Another variation was done by valuing the time of the unemployed respondents in the sample (assuming they were self-employed), by using the local casual labour wage rate per hour. A multi-variation was carried out by varying both household supplies of the direct cost by an

increase of 10% and using the local casual worker wage rate per hour to value the productivity losses of the employed caregivers in the study sample.

3.9.5 Description of intangible Cost

Intangible cost for this study was assessed using the 12-item ZBI and the financial dimension of the CCI. The instrument (ZBI) has a range of total scores from 0 to 48 with higher scores representing a higher level of care-giving burden. The original authors of this abridged version proposed a cut of point of 16 (Bédard et al., 2001). Family caregivers with a score of less than 16 were classified as low burden and those with a score of 16 or above were classified as high burden.

The financial dimension of the CCI has a total score range of 4 to 16, with higher scores indicating higher level of financial stress. Proportions of family caregivers who reported positively on each of the four items were estimated.

3.10. Ethical consideration

In ensuring ethical acceptability of the study, the researcher ensured that the research was designed, conducted and reported in accordance with recognised scientific competence and ethical approval.

3.10.1 Ethical approval

Ethical approval for the study was obtained from the Ghana Health Service Ethical Review Committee.

3.10.2 Informed consent

An informed consent form was developed based on the WHO guidelines of informed consent (Appendix A). The form had two parts. The first part was an information sheet which covered basic details like title of the research, academic institution, and name of the researcher and research guide. Further, it covered introduction of the researcher and

the purpose of study, voluntary participation and procedure of interview, confidentiality, right to refuse or withdraw and contact information of the researcher. This part was to be retained by the respondent. The second part consists of certificate of consent which covers statement of the respondent duly signed and in case of illiterate respondent thumb print in the presence of a witness and also a statement of the researcher. The respondents' right to informed consent was respected and endorsed by the researcher.

3.10.3 Potential risks/benefits

The study posed no risk or harm to any of the participants and this was clearly explained to the participants. However, both the study population and society stood to benefit from the study. Study population had knowledge of their monthly expenditure on care-giving for the elderly. Also, estimation of the cost of family care-giving for the elderly can be used as a platform for sensitising policymakers and opinion leaders about the economic burden of care-giving for the elderly.

3.10.4 Privacy and confidentiality

Each respondent was interviewed on an individual basis to maintain privacy and confidentiality. The researcher also ensured that the respondents' anonymity was maintained. No names would be linked to any responses. No information obtained from the respondents would be reported in a manner that could possibly identify the respondents. The information collected from the respondents was treated as confidential.

3.10.5 Data storage and Usage

Questionnaires were coded and kept under lock and key in a cupboard, and the key was kept by the principal investigator. Data collected were coded and entered within 24

hours of collection, and was saved under a password known to only the principal investigator. Soft copy of data was stored on a CD-ROM and external hard drive as well. All data collected will be kept by the principal investigator for 3-4 years to allow for publication of the research, after which questionnaires will be destroyed.

3.10.6 Voluntary withdrawal

The participants had opportunity to withdraw at any time from the study if he/she so wishes without any penalty.

3.10.7 Research funding Sources

The study was funded by the researcher.

3.10.8 Compensation

No financial benefit or any other material benefit was given to participants before or after the interviews or administration of questionnaire. Their inputs were however recognised and appreciated.

3.10.9 Conflict of interest

Apart from its academic and public health importance, I have no other personal interest in this study.

3.11 Limitations of the study

Although a random sample was used, the localised and selective nature of the sample did not allow the findings to be generalised to family caregivers in other localities in Ghana.

Also, the study used a subjective method which predominantly depended on the recall abilities of the family caregivers and hence could have been affected by recall bias.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents the findings of this study. It shows the background characteristics of the elderly (care recipients) and their care givers. The chapter also covers the direct and indirect costs estimates as well as the total cost estimate for the caregivers in this study. It shows the results of the sensitivity analysis and further describes the intangible cost of family care-giving for the elderly in this study. The study had a response rate of 90% (98 out of 108 caregivers responded). All questionnaires were completely and correctly answered.

4.2 Background characteristics of care recipients

Table 2 shows that 67% of the care recipients were females and 33% were males. The youngest and oldest among them were all females, aged 60 years and 106 years respectively. The mean age among them was 78.5 ± 10.5years. The proportion of care recipients who required assistance with at least one form of ADL was 52%. All the care recipients in the sample required assistance with some forms of IADLs.

Table 2: Care recipients' background characteristics

Background characteristic	Number (n)	Percent (%)
Sex		
Male	32	32.6
Female	66	67.4
Age		
60 – 74 (young old)	36	36.7
75 – 84 (old-old)	35	35.7
85 and above (very old)	27	27.6
Assistance with		
ADL	51	52.0
IADL	98	100

4.3 Background characteristics of caregivers

More than two-thirds (68%) of the caregivers were female. Approximately, 43% of the caregivers were within 30 and 44 years of age, 28% were within 18 and 29 years old, and 21% were within 45 and 60 years old as shown in Table 3. Forty-six percent (46%) of the caregivers interviewed were currently married with 36% being single (never married) caregivers.

More than three-quarters (89%) of the caregivers reported having highest education level of junior secondary or above. Among the caregivers in this study, more than half (56%) reported being self-employed and about 25% reported being either unemployed, students or apprentices. More than two-thirds (68%) reported a personal monthly income of GHS100.00 to GHS499.00.

About 85% of the caregivers identified themselves as primary caregivers whereas the remaining respondents considered themselves as secondary caregivers, meaning that another person was providing the major care responsibilities, and the respondent was playing a supplementary role. Fifty-five percent (55%) of the caregivers reported being a child of the care receiver. Spousal caregivers accounted for only 6% of all caregivers.

Table 3 also shows that, More than half (57 %) of the caregivers reported a duration of care-giving within one and four years and, 22% reported a duration within five and nine years. More than three quarters (78%) of the caregivers co-resided with their care recipient and 14% reported being nearby-caregivers. Approximately, 62% of the caregivers indicated that, their finances have gotten worse as a result of care-giving for their elderly relative.

Table 3: Caregivers' background characteristics

Background characteristic	Number (n)	Percent (%)
Sex		
Male	31	31.6
Female	67	68.4
Age		
18 – 29	27	27.6
30 – 44	42	42.9
45 – 60	21	21.4
Above 60	8	8.1
Marital Status		
Single	35	35.7
Married	45	45.9
Divorced	10	10.2
Widowed	8	8.2
Education		
No education	6	6.1
Primary	5	5.1
Middle/JHS/JSS	60	61.2
SSS/SHS	12	12.3
Tertiary	15	15.3
Employment		
Self employed	55	56.1
Private sector	13	13.3
Public sector	6	6.1
Unemployed	15	15.3
Student/Apprentice	9	9.2
Relationship with CR		
Spouse	6	6.1
Child	54	55.1
Grandchild	23	23.5
Sibling	14	14.3
Daughter/Son-in-law	1	1.0
Care-giving status		
Primary CG	83	84.7
Secondary CG	15	15.3
Duration of care		
Less than 1 year	8	8.2
1 – 4 years	56	57.2
5 – 9 years	22	22.4
10 years and above	12	12.2
Residence status		
Long distance CG	8	8.2
Co-resident CG	77	78.5
Nearby CG	13	13.3
CG personal income		
Less than GHS 100	9	9.2
GHS 100 - GHS 499	67	68.4
GHS 500 - GHS 999	16	16.3
GHS 1000 - GHS 1999	4	4.1
GHS 2000 and above	2	2.0
Impact on CG finances		
Gotten worse	61	62.2
Stayed the same	36	36.7
Gotten better	1	1.1

4.4 Cost of care-giving for the elderly

4.4.1 Direct cost

Direct cost of care-giving for the elderly was estimated at GHS40,104.00 (USD 9,641.35) making up 66.2 % of the total cost profile of care-giving for the elderly in the study sample. The average total direct cost per month of caregivers was estimated at GHS481.39 (USD115.72). Table 4 shows the direct cost expenses per month of family caregivers.

Table 4: Direct cost per month of family caregivers

Direct cost category	Number n (%)	Total Amount (GHS)	Total Amount (USD)	Average Amount (GHS)	Average Amount (USD)
Medical cost					
Medical care	78(80)	8,604.00	2068.27	110.30	26.51
Non-medical cost					
Household supplies	97(99)	25,050.00	6021.63	258.25	62.07
Residential care	83(85)	3,091.00	743.02	37.12	8.92
Transport/travel	44(45)	2,194.00	527.40	46.59	11.20
Financial transfer	40(41)	1,165.00	280.05	29.13	7.00
TOTAL		**40,104.00**	**9640.38**	**481.39**	**115.72**

More than three-quarters of the caregivers reported having made expenses on medical care (80%), residential care (85%) or household supplies (99%), with household supplies having the highest occurrence and average amount (GHS 258.25). Financial transfer had the lowest occurrence (41%) and lowest average amount (GHS 29.13).

4.4.2 Indirect cost

Indirect cost of care-giving for the elderly was estimated at GHS20,449.04 (USD 4927.65), making up 34% of the total cost profile of care-giving for the elderly in the sample. The average care-giving time per month for a caregiver was estimated at 219.5 ± 25.9 hours. Table 5 shows the hours spent by family caregivers per month in each indirect cost category.

Table 5 : Hours spent by caregivers

Indirect cost categories	Frequency n (%)	Total time spent per month (h)	Average time spent per month mean h (SD)
Time spent with on personal care	97(99)	9796	101.3 (9.1)
Time spent on household activities	83(83)	5760	69.4 (8.7)
Time spent on travel/ transportation	34(35)	748	22.0 (3.8)
Time spent with care recipient	62(63)	1596	26.8 (4.3)
TOTAL		**17900**	**219.5 (25.9)**

Of the time spent by family caregivers in giving care to the elderly, time spent on personal care and time spent on household activities constituted the highest occurrence and proportion. Family caregivers in the sample spent a total of 17900 hours on care-giving for their care recipients within the month.

Table 6: Indirect cost by employment categories

Employment category	Total time spent (hours)	Valued time spent (GHS)
Self employed	9228	17,348.64
Private sector	2504	2,203.52
Public sector	1076	946.88
Unemployed	3192	-
Student/Apprentice	1900	-
Total	**17900**	**20,449.04**

4.4.3 Total cost

The total monthly cost of care-giving for the elderly was estimated at GHS60,603.04 (USD14,568.03). Direct cost constituted the higher proportion (66%), of the total cost as shown in Figure 2. Indirect cost made up the remaining (34%). Table 7 displays the cost profile of family caregivers for the elderly in the study population. The estimated average amount of direct cost expenses per month was GHS481.39 (USD115.72).

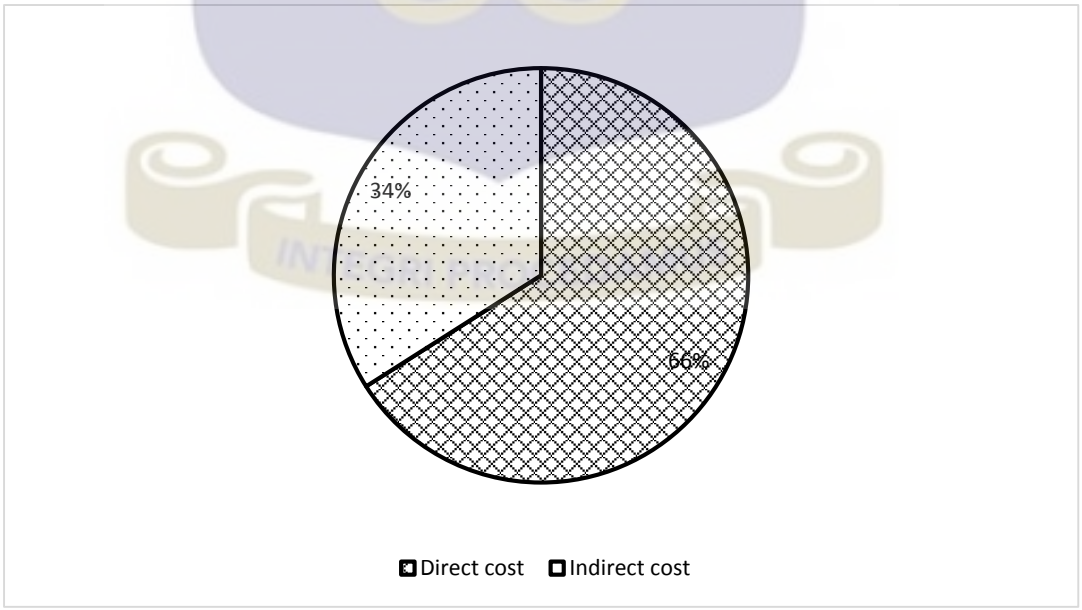

Figure 2: Proportions of total cost

Table 7: Cost profile of family caregivers

Cost category	Cost		Cost Profile (%)
	GHS	USD*	
Direct Cost			
Medical			
Medical care	8,604.00	2,068.27	14.2
Non- medical			
Household supplies	25,050.00	6,021.63	41.3
Residential care	3,091.00	743.03	5.1
Transport	2,194.00	527.40	3.6
Financial transfer	1,165.00	280.05	1.9
Sub-total	**40,104.00**	**9,640.38**	**66.2**
Indirect Cost			
Valued time spent on personal care	11,323.68	2,722.04	18.7
Valued time spent on household activities	6,505.60	1,563.85	10.7
Valued time spent on travel/ transportation	792.32	190.46	1.3
Valued time spent with care recipient	1,877.44	451.31	3.1
Sub-total	**20,499.04**	**4,927.65**	**33.8**
TOTAL	**60,603.04**	**14,568.03**	**100**

*USD exchange rate used was 4.16

4.4.4 Intangible cost

Care-giving burden (Zarit burden interview)

The care-giving burden scores reported by the family caregivers ranged from 5 to 46, with a mean of 23.1± 9.4. More than three quarters (78%) of the family caregivers reported a high burden score. The remaining (22%) reported a low burden score as shown in figure 3. A relatively higher burden level was observed among female caregivers.

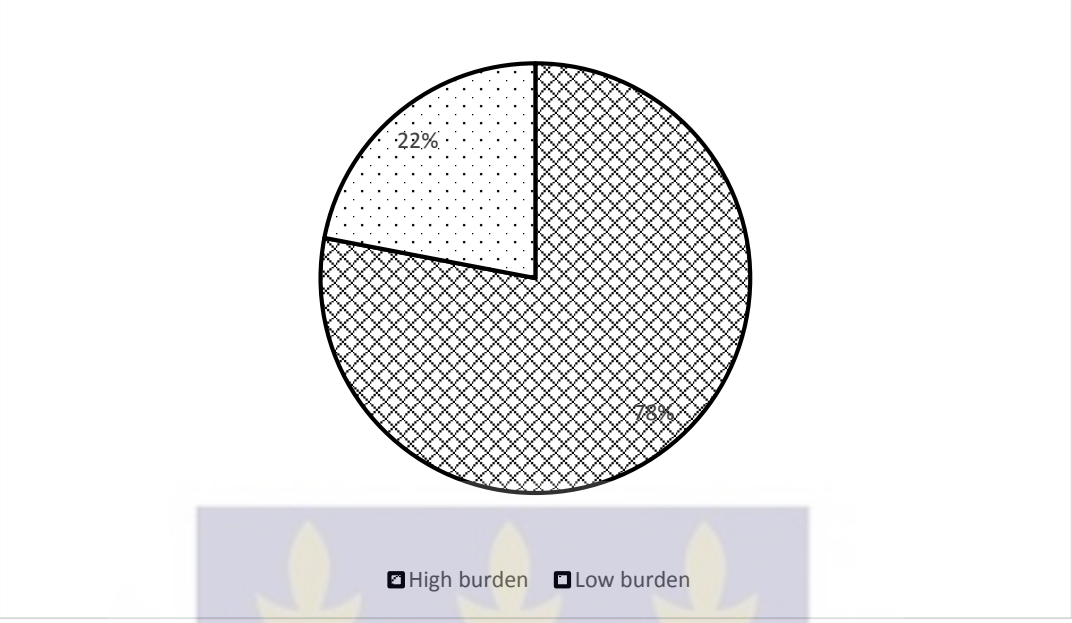

Figure 3: family caregivers' burden level

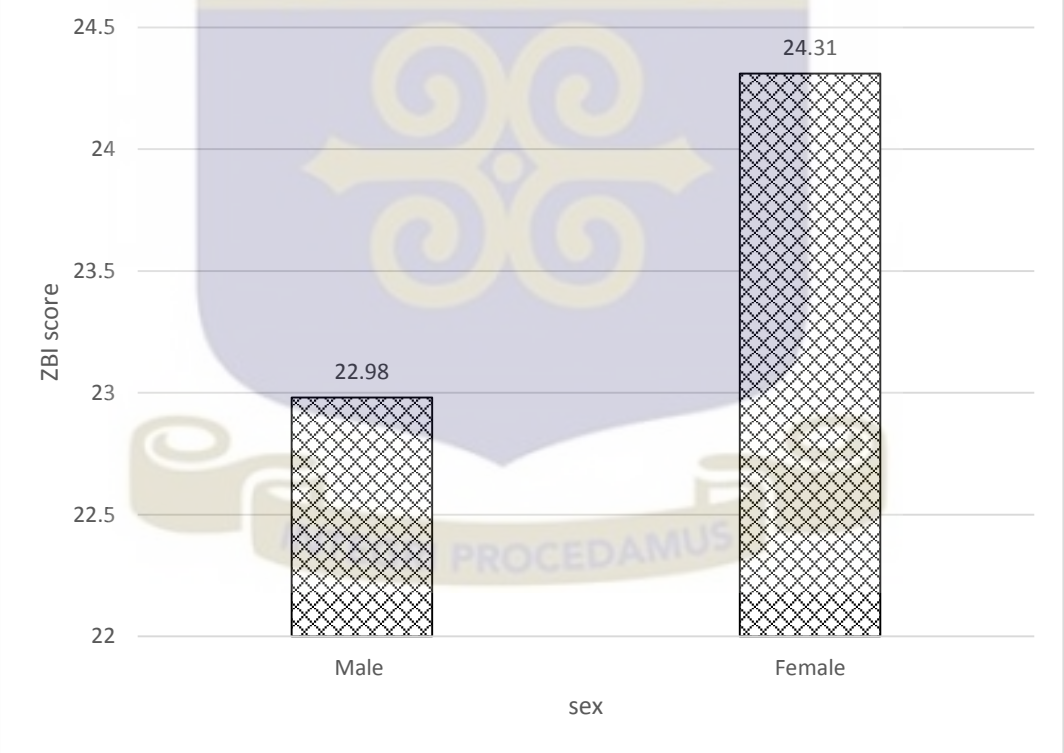

Figure 4: Average ZBI score by sex of family caregivers

Figure 4 shows that, for both male and female, family caregivers reported a high care-giving burden with females reporting a relatively higher burden level than males.

Financial stress (Cost of care index)

Along the potential score range between 0 and 4, a mean of 3.07±0.01 was reported. The results of the individual items indicated that 80% of family caregivers agreed that care-giving for the care recipient was causing them to dip into savings. Again, 66% of the family caregivers indicated that they and their families could not afford those little extras because of expenses to care for the care recipient. Over a half (59%) indicated that their family or they had to give up necessities because of the expense to provide care. More than three quarters (87%) of the caregivers indicated that caring for the care recipient was too expensive.

4.5 Sensitivity analysis of total cost of care-giving for the elderly.

Table 8 shows the results of the percentage changes in the proportions of total cost when various cost components were varied.

Table 8: Sensitivity analysis of total cost components

Changed parameter or cost component	**Percentage change in parameter (%)**	**Percentage change in total cost (%)**	**Percentage change in proportions total cost (%)**		**Proportions of total cost (%)**	
			Direct cost	Indirect cost	Direct cost	Indirect cost
Base scenario	0.00	0.00	0.00	0.00	66.2	33.8
Cost of Household supplies	+2.3	+4.0	+1.3	-1.3	67.5	32.5
Indirect cost (local casual labour wage)	+2.6	+9.6	-2.6	+2.6	63.6	36.4
Indirect cost (Minimum wage)	-14.3	-14.5	+14.3	-14.3	80.5	19.5
Indirect cost (valuation of unemployed)	+10.7	+21.0	-10.7	+10.7	55.5	44.5
Multi variation (Household supplies & casual labour wage)	+4.9	+6.8	-3.8	+3.8	62.4	37.6

CHAPTER FIVE

5.0 DISCUSSION

5.1 Introduction

This chapter discusses the findings this study. The total cost per month of family care-giving for the elderly in the sample was estimated at GHS60,603.04. This constituted of 66% (GHS40,104.00) being direct cost of care-giving and 34% (GHS20,499.04) being indirect cost. More than three-quarters (78%) of the family caregivers in this study reported a high level of care-giving burden. About 62% of these family caregivers also reported a high level of financial stress as a result of care-giving for their elderly relative

5.2 Direct cost of care-giving for the elderly

The findings of this study suggest that direct cost (out-of-pocket expenses) is a major source of cost of family caregivers of the elderly. All respondents in the study indicated that they had helped the care recipient financially by paying for one or more expenses, most commonly for household supplies (99%), residential care (85%) and medical care (80%). The highest average amounts paid by a family caregiver per month was for household supplies (GHS258.25) and medication (GHS110.30).

The estimated average amount of direct cost expenses per month was GHS481.39 (USD115.72). However, a vast majority (78%) of the family caregivers in this study reported a monthly income of less than GHS500. This strongly suggests that most of these family caregivers spend a larger proportion of their income on care-related expenses. Accordingly, this is indicative of a high financial stress and may consequently explain the high burden level reported by most caregivers in this study. Similarly, Duncan et al. (2013) reported that those caregivers with less financial means

have significant care-related expenses that represent a larger proportion of their household income compared to those caregivers with higher incomes.

On average, family caregivers in this study estimated they had spent GHS110.30 (USD26.51) per month on medical related costs. This accounted for 14% of the total cost profile of family caregivers in this study. This is smaller than the 21% reported by Evercare and NAC (2007). This slight difference may be attributed to the differences in jurisdiction and the types of medical cost being measured. It has been shown that medical cost constitute a large proportion of out-of-pocket expenses, particularly in jurisdictions without prescription drug insurance plans (Fast et al., 2008). Again, whereas this study considered medical cost as costs associated with medications, health supplies, consultation, treatments and therapies, the Evercare and NAC (2007) study included other costs such as respite and home care in this cost category. Additionally, the Evercare and NAC (2007) study was a national study with a relatively larger sample size, unlike this current study which had a relatively smaller sample size.

As was expected, non-medical costs accounted for the larger amount of the direct cost, with cost of household supplies constituting the highest proportion of the direct cost. The estimated average monthly cost of household supplies to a family caregiver was GHS258.25 (USD62.07). This constituted 41.3% of the total cost profile and more than half of the estimated average monthly out-of-pocket expenses of the caregivers. However, household supplies accounted for only 15.7% of expenses or USD72.33 per month for caregivers in the US (Evercare and NAC, 2007). It can be argued that, the differences in jurisdiction may account for this disparity. Nonetheless, these findings suggest that most of the family caregivers in this study spend a larger proportion of their income on household supplies. However, there is little information about the extent to which these expenses may create financial and other hardships for these family

caregivers. There is therefore the need for further investigation into this category of care-related cost to family caregivers.

Contrary to expectations, residential care cost incurred by the caregivers in this study was relatively small. The estimated average monthly residential care cost was GHS37.12 (USD8.92). This accounted for only 5% of the total cost. There is however, evidence of additional costs for utilities, rent and other housing expenses when the care recipient co-resides with their caregiver (Carers UK, 2007; Duxbury et al., 2009; Fast et al.,2008). For example, in a US study with majority of the caregivers co-residing with their care recipient, the average cost for those who reported out-of-pocket expenditure for residential care was estimated at USD980 per month. In the current study, more than three-quarters (78%) of the caregivers co-resided with their care recipient with only 14% reported being nearby-caregivers. Accordingly, it was expected that residential care cost would have constituted a substantial proportion of the total cost of care-giving for the family caregivers in this study. However, this was not the case. This can be explained by the fact that, most of the elderly in Ghana live in family houses where they do not usually pay for rent (Mba, 2010). Cost of utility and other housing expenses are collectively borne by other family members and hence caregivers are unlikely to spend much in this category.

Cost of transportation and travel constituted 3.6% of the total cost profile of the family caregivers in this study. The findings suggest that transportation does not constitute a substantial proportion of the total cost of care-giving for the elderly. This is however, contrary to the findings of Lauzier and colleagues who reported transportation and travel to be a substantial cost category among family caregivers (Lauzier et al.,2010). Another study found that family caregivers spent as much as 10% of their total care-related out-of-pocket expenses on transportation and travel (Evercare and NAC, 2007).

The differences in jurisdiction may partly account for the observed difference in the estimates of this current study and that of the previous studies. Again, most (78%) of the family caregivers in this study co-resided with the care recipient and may not need to incur any cost on transportation to get to their care recipient.

Financial transfer constituted the smallest proportion (2%) of the total out-of-pocket cost of care-giving for the elderly in this study. There has not been sufficient research on financial transfer from caregiver to care receiver to enable comparison across studies. One study however, reported that 15% of family caregivers transferred an average of USD58 to their care recipients in the past month (Johnson & Lo Sasso, 2004). This current study estimated that 41% of the family caregivers spent an average amount of GHS29.13 (USD7.00) on financial transfer to their care recipients. This amount differs markedly from that of the previous studies. This may be explained in part by the fact that three out of four (78%) of the family caregivers in this study co-resided with their care recipient. Hence, they were directly responsible for the purchase of any item the care recipient might require and may not need to give out money directly to the care recipient.

In general, this study adds credence to the already existing evidence that care-related out-of-pocket cost of family caregivers for the elderly is substantial. It constitutes the larger proportion of the total cost of care-giving and can threaten the economic security of most family caregivers, particularly those with low income earnings. Further investigations of both immediate and long term outcomes of out-of-pocket costs of family caregivers are needed to determine the extent to which they may be at high risk of poverty and inability to sustain their care-giving obligations.

5.2 Indirect costs of care-giving for the elderly

The indirect costs of care-giving for the elderly encompass opportunity costs of giving care to the elderly. The findings of this study suggest that indirect cost forms a substantial source of cost for family caregivers in this study. All respondents in the study indicated that they have spent time in helping their care recipient in the performance of one task or the other, with time spent on personal care (99%) and time spent on household activities (83%) being the most reported occurrence.

On average, the family caregivers in this study spent 219.5 ± 25.9 hours in a month or 54.9±6.5 hour per week giving care to their elderly relative. In contrast, in a UK survey, family caregivers for the elderly provided about 20.0 hours of care per week (Carers, 2007). Another study in the US reported that family caregivers provided an average of 21.0 hours of care per week (NAC, AARP & MetLife Foundation, 2009). This relatively high level of time spent in care-giving by family caregivers in this study can partly be explained in part by the fact that most (85%) of the caregivers in this study were primary caregivers. Thus, they were more likely to spend more time with the care recipient. Also, the vast majority (79%) of them were also co-resident caregivers. It has been reported that co-resident caregivers particularly find it difficult to disaggregate time spent in care tasks from other household duties (Fast et al., 2008). This may lead to over reporting of time spent by the family caregivers in this study in giving care to the elderly.

Also, these variations may be attributed to the differences in jurisdiction, the inconsistencies in the operational definition of care-giving labour (eg., which care-giving tasks are included) and the differences in data collection methodology with most of these previous studies being telephone surveys. However, a better comparison would have been with studies conducted in Africa with relatively similar background

characteristics of family caregivers. However, there has been much less investigation of the economic burden of family care-giving for the elderly in Africa. This may reflect an ongoing reluctance to make public the 'private' work of families (Folbre et al., 2013). Further investigation into this type of cost may be needful in other African countries to enable comparison across similar jurisdiction.

Additionally, the findings of this study suggest that the family caregivers in the study spent a substantial amount of their time providing care for the elderly. However, time is a finite resource such that spending time on one activity makes it unavailable for any other purpose. Thus time spent in care may involve reductions in time spent in other activities such as employment, education, accumulation of human capital and personal care or leisure. Empirically, studies have shown negative effects of family care-giving responsibilities on hours worked and participation in the labour market (Evandrou & Glaser, 2004; Heitmueller & Inglis, 2007). Studies have also shown that family caregivers with substantial care responsibilities are less likely to be employed than non-caregivers with lighter responsibilities (Lilly et al., 2007; Thomson et al., 2008), and they are also more likely to work fewer hours and experience wage penalties (Heitmueller & Inglis, 2007; Thomson et al., 2008). These previous findings are consistent with the findings of this current study. Majority (56%) of the family caregivers in this study were employed in the informal sector and a substantial proportion (15%) were completely unemployed. Accordingly, majority (78%) of the family caregivers in this study earned less than GHS 500 a month. This may be explained in part by the fact that, due to their care-giving responsibilities, most of these family caregivers reduce their hours for work and participation in the labour market, consequently leading to a reduction in their monthly income.

However, a question that emerges from this study is the direction of causation between care-giving for the elderly and participation in the paid labour force. Do people leave paid employment to assume care-giving (employment status as an outcome), or do they take on care-giving in the absence of employment opportunities or employment (employment status as a determinant)? Further investigation is needed to clarify the complex relationship between care-giving and employment opportunities or employment.

For this study, the indirect cost of care-giving was valued as the opportunity cost (foregone wages) due to care-giving for the elderly. Indeed, many may argue that family care-giving for the elderly is 'freely' provided by the family caregivers whose rewards lie in their fulfilment of family obligations and reciprocity to the care recipient and hence its evaluation may not be appropriate. However, the investigator is of the view that care-giving labour by these family caregivers is valuable. Estimates of the monthly time spent in family care-giving to the elderly in this study suggest that most family caregivers undertake the equivalent of a part-time or even a full time job to give care to their elderly relative. Aggregation of this time spent in family care-giving for the elderly in any national economy can be equivalent of several full-time jobs. Hence, the time costs of care should be a major focus in economic evaluations, especially in subsequent studies, in an attempt to account for the national cost of family care-giving in Ghana.

This current study therefore estimated the indirect cost of family care-giving for the elderly at GHS20,499.04 (USD4,927.65) per month. This constitutes one-third of the total cost of care-giving for the elderly in this study. Indeed, this represents a substantial amount of foregone benefits or earnings to the family caregivers in this study. Few attempts have been made to estimate the value of unpaid care. This includes Feinberg et al. (2011) who valued time of family caregivers at USD450 billion per year.

Similarly, Hollander et al. (2009) also estimated costs of care labour between USD9 million and USD21 million. As compared to the indirect costs estimate of this study, the estimates of these previous studies are substantially larger. However, it should be noted that these studies were national surveys with a very large sample of caregivers and these estimates were calculated per year. Unlike this current study which happens to be a community study with a relatively small sample of caregivers and with estimates of indirect cost per a month of care to the elderly.

In general, this study shows that indirect costs of care-giving for the elderly is considerable. These findings concur that the provision of family care to the elderly can negatively impact on employment, income and financial stress for the family caregiver. This further points to the need for support for family caregivers of the elderly. Policy makers have to consider the specific cost related challenges in family care-giving and to design appropriate programs for the family caregivers.

5.3 Intangible costs of care-giving for the elderly

An overwhelming 78% of the family caregivers in this study reported a high level of burden. This finding echoes the findings in some previous studies which indicated that family caregivers are more likely to have a higher burden when compared to those without caring responsibilities (Edwards et al., 2008; Lee & Grarnotnev, 2007). This is particularly the case for family caregivers providing intensive levels of care (Young, Grundy & Jitlal, 2006). Considering the fact that more than half (52%) of the elderly in this study needed assistance with one form of ADL or the other, it was not surprising that most of the caregivers in this study reported a high level of care-giving burden.

These findings suggest that the work of family caregiving can be stressful. This stress can adversely harm both the caregiver and the care recipient. The demanding work of

caregiving can put these family caregivers at risk of engaging in harmful behaviours toward their care recipients. This has been particularly reported among caregivers of elderly persons with cognitive impairments (Miller et al., 2006). When caregivers themselves are distressed, burdened, or depressed, they might leave elders alone for long periods of time, ignore them, or fail to provide any companionship or interaction (Fulmer, 2005). Again, it has also been reported by Annerstedt and colleagues that, when caregivers have a high level of burden, caregiving becomes inadequate (Annerstedt et al., 2000). This implies that most of the elderly in this study may be receiving inadequate care due to the high level of burden their caregivers are bearing.

Conversely, declines in caregiver health have been particularly associated with caregivers who perceive themselves as burdened (Lai, 2012). Previous studies have reported that such caregivers are at higher risk for fatigue and sleep disturbances, lower immune functioning, slower wound healing, increased insulin levels and blood pressure, altered lipid profiles, and higher risks for cardiovascular disease (Cannuscio et al., 2002; Lee, Colditz & Berkman, 2003; Beach, Schulz & Yee, 2000). Thus, such high level of burden reported by caregivers in this study poses a threat to the overall health of these caregivers, which can compromise their ability to continue to be caregivers. If caregivers are to be enabled to continue providing care for the elderly, relief from the distress and burden of maintaining the required care must be considered.

Additionally, this study also showed that care-giving burden was relatively higher among females than males. This compares with the findings of some previous studies that shows that the traditional role of care-giving is often expected of and performed by females (Aboderin, 2005; Calasanti & King, 2007). Other explanations of the higher levels of care-giving burden experienced by female caregivers probably include as indicated in previous studies, the multiple caring roles of women (Wallace et al., 2003)

and other gender-related challenges, such as spending more time with care recipient than male caregivers (Chiou et al., 2005), receiving less assistance with care-giving tasks, and spending more time on intensive personal care and domestic chores (Zhan & Montgomery, 2003). All these point to the need for support for family caregivers especially female caregivers. Our society tends to feel very comfortable with treating family care-giving particularly care provided by females as a familial obligation (Lai, 2012), without paying adequate attention to the needs of female caregivers. It is important for policy makers to address the unique care-giving stress and challenges family caregivers particularly females face while providing care.

Family caregivers in this study also indicated a high level of financial stress. Indeed, nearly two-thirds (62%) of the family caregivers in this study reported a worse state of financial well-being as a result of care-giving for their elderly relative. Majority of the family caregivers in this study reported dipping into saving (80%), not being able to afford those little extras (66%), and giving up necessities (59%). These findings compares slightly with the findings of Lai (2012) who reported proportions of 40%, 40% and 38.5% respectively.

This high incidence of financial stress among these family caregivers was however, not unexpected. Previous studies have consistently shown that, among family caregivers, caring for 20 hours or more per week was associated with a higher risk of financial stress (Thomson et al., 2008). Most of the caregivers in this study were primary caregivers who provided more than 20 hours of care per week. This could reduce participation in the labour market leading to a reduction in their monthly income and consequently increased financial stress. It was therefore not surprising that an overwhelming majority (87%) of the family caregivers in this study indicated that caring for their elderly relative was too expensive.

In general, the evidence of high burden and increased financial stress for family caregivers in this study is compelling and it is likely to be an indicator of substantial costs associated with care-giving for the elderly. Further studies are required to identify the determinants and outcomes of this burden and financial stress that caregivers encounter and how policy could assist in defraying the expenses associated with them.

Overall, the evidence of a high economic burden among family caregivers has been highlighted in this study with the total cost of care-giving being estimated at GHS60,603.04 (USD14,568.03).This shows that, the costs of care-giving for the elderly are considerable and direct costs may contribute immensely to the economic burden of family caregivers in this study. The study also reveals a high level of care-giving burden and financial stress among family caregivers with females having a relatively higher burden than males. There is therefore a need for further investigations and appropriate policy interventions to address these challenges of family caregivers of the elderly in our society.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study provides evidence of a high economic burden and financial stress among family caregivers for the elderly. Although many family caregivers are committed to taking care of their older family members and relatives, their commitments and filial obligations should however, not be taken for granted. Especially, as we seek to achieve the national vision of creating an enabling environment where people age with security and dignity. These financial challenges and economic burden of family caregivers as shown in this study, if unaddressed, could further weaken the family support system for the elderly. This study therefore concludes that, it is imperative to address the financial needs and security of family caregivers of the elderly. It is particularly important to address the context of the direct cost borne by these family caregivers, which forms the larger proportion of the total cost of care-giving for the elderly. In addition, it is also important to address the context of the family caregivers who are female, who invariably bear a higher care-giving burden.

6.2 Recommendations

From the study conclusions, the following recommendations are made;

Social grants programmes like the Livelihood Empowerment Against Poverty (LEAP), should be expanded to cover more elderly people in the society as this source of financial support can help lessen the financial burden that care-giving for the elderly brings on the family caregiver.

Policy makers should in the long term, consider reviewing tax policies to enhance the provision of tax concessions for those supporting the elderly, as a way of helping strengthen the family support system for the elderly and subsequently encouraging family support for the elderly.

Future studies should explore the immediate and long term outcomes of the economic burden and financial stress as highlighted in this study on the caregivers and the elderly. These studies should investigate the extent to which they may be at high risk of poverty and inability to sustain their care-giving obligations.

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APPENDICES

Appendix A: Consent form

INFORMED CONSENT

Project Title: Economic burden of family care-giving for the elderly at the Ga- East Municipality, Ghana.

Background
My name is Nortey Stephen Tettey, a student from the School of Public Health, University of Ghana, Legon. I am conducting a study on the economic burden of family caregiving for the elderly at the Ga East Municipality, Ghana. The main objective is to estimate the economic burden of care giving for the elderly at the Ga East Municipality.

Procedures
The study will involve answering questions from a questionnaire about the cost incurred as a result of care-giving for the elderly. No coercion will be used to obtain response from respondent. It will be appreciated if you could participate in this study. This is purely an academic research which forms part of the requirement for the award of a Master's Degree in Public Health.

Risks and Benefits
Both the study population and the society stand to benefit from this study. Study population will know how much they spend in a month on elderly care-giving. Also, estimate of the economic burden of care-giving for the elderly can open a platform for sensitizing policy makers and opinion leaders about the economic burden of care-giving for the elderly. Subsequently, programs can be implemented to support family caregivers in caring for the elderly. This research will pose no potential risk to study population or the society.

Right to Refuse
Participation in this study is voluntary and you can choose not to answer any individual question or all questions. You are at liberty to withdraw from the study at any time. However, I will encourage you to fully participate in the study since your answers are important to help determine the economic burden of care-giving for the elderly.

Dissemination of Results
A durbar, including the elderly, elderly caregivers and other stakeholders of elderly care, will be held at Abokobi to disseminate the findings of the study. A copy of the study will be kept at the Akrowa Aged Life foundation as reference.

Do you have any questions you wish to ask about the study? Yes/No

If yes, please, indicate the questions 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 given a chance to ask questions concerning this 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 time without any consequences.

…….....	……	…….	……
Name of caregiver	Signature	Thumbprint	Date
……	……..	……	……
Name of witness	Signature	Thumbprint	Date
……	……..	……	……
Name of researcher	Signature	Thumbprint	Date
……	……..	……	…….
Name of interviewee	Signature	Thumbprint	Date

Interviewer's Statement

I, the undersigned, have explained this consent to the subject in English language/ Twi/ Ga, 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

Stephen Tettey Nortey (0249148476).

Ms. Hannah Frimpong (0243235225/0507041223)

Appendix B: Questionnaire

ECONOMIC BURDEN OF FAMILY CARE-GIVING FOR THE ELDERLY AT THE GA-EAST MUNICIPALITY, GHANA.

Dear Respondent,

I would like to take a little time with you to answer these questions. You are assured that the answers you give will be strictly confidential and would not be held against you.

Unique identifier for respondents …….

Date of interview …….

Locality ……..

	QUESTION	RESPONSE
Section A	**Background information of care recipient**	
1.	Gender 1. Male 2. Female	☐
2.	What is your care recipient's current age?	……
3.	Do you assist your care recipient on a regular basis to perform any of the following tasks -taking a bath, walking inside the house, dressing up, standing up from bed/ chair, using the toilet in the house or eating? 1. Yes 2. No	☐
4.	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 B	**Background information of care giver**	
5.	Gender 1. Male 2. Female	☐

6.	What is your current age?	……
7.	What is your marital Status? 1. Single 2. Married 3. Divorced 4. Widowed	☐
8.	What is your highest level of education? 1. No education 2. Primary level 3. Middle/JSS/JHS 4. SSS/SHS 5. Tertiary	☐
9.	What is your employment status? 1. Self employed 2. Private sector 3. Public sector 4. Unemployed 5. Student / apprentice	☐
10.	Are you the primary caregiver? 1. Yes 2. No	☐
11.	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) ……	☐
12.	For how long have you been giving care to your care recipient? Your best estimate is fine.	……
13.	Which of the following best describe your care-giving task? 1. Long distance care provider 2. Co-resident care provider 3. Nearby care provider	☐
14.	What is your monthly salary?	……
15.	How much do you receive from other sources of income in a month?	……
16.	Since you began giving care to your care recipient would you say your finances have…? 1. Gotten better 2. Stayed the same 3. Gotten worse	☐

Section D	Indirect cost: Productivity loss		
17.	In a typical week, do you spend time helping your care recipient in any of the following ways? And how many hours in total do you spend helping your care recipient in that way? Your best estimate is fine.		
	Category	Answer 1. Yes 2. No	Number of Hours
	a. Time spent on personal care		
	b. Time spent on household activities		
	c. Time spent travel/transportation		
	d. Time spent with care recipient		
	e. Other (please specify)		

Section E	Direct cost : out-of-pocket expenses		
23	In the past one month, have you had any out-of-pocket expenses for ….?		In a typical month, how much do you spend on that? An average is fine.
		Answer 1. Yes 2. No	AMOUNT
	a. Your care recipient's medical care, medical supplies, and other health care services		
	b. Your care recipient's household supplies (food, water, household goods, or clothing)		.
	c. Your care recipient's residential care (housing payments, rent, or utilities)		
	e. Travel/transportation for/ with your care recipient?		
	f. Financial transfer to your care recipient?		
	g. Other (Please specify)……		

Section F	Intangible cost

COST OF CARE INDEX

(please circle the response that best describes how you feel)

	Strongly disagree	Disagree	Agree	Strongly agree
1. Do you agree that caring for your care receiver is causing you to dip into savings meant for other things?	1	2	3	4
2. Do you agree that your family and you must give up necessities because of the expense of caring for your elderly relative.	1	2	3	4

3. Do you agree that your family and you cannot afford those little extras because of the expense of caring for your elderly relative?	1	2	3	4
4. Do you agree that caring for your elderly relative is too expensive?	1	2	3	4

ZARIT BURDEN INTERVIEW
(Please circle the response that best describes how you feel

	never	rarely	sometimes	Quite frequently	Nearly always	score
1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
2. Do you feel stressed between caring for your relative and trying tomeet other responsibilities (work/family)?	0	1	2	3	4	
3. Do you feel angry when you are around the relative?	0	1	2	3	4	
4. Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4	
5. Do you feel strained when you are around your relative?	0	1	2	3	4	
6. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4	
7. Do you feel that you don't have has much privacy as you would like because of your relative?	0	1	2	3	4	
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
9. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4	
10. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
11. Do you feel you should be doing more for your relative?	0	1	2	3	4	
12. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	