SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

HOUSEHOLD COST OF CAREGIVING FOR CHILDREN WITH ASTHMA ATTENDING PRINCESS MARIE LOUIS HOSPITAL IN ACCRA

BY

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10292903

A DISSERTATION SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF MASTERS OF PUBLIC HEALTH DEGREE

(MPH)

JULY, 2018

DECLARATION

I, Evelyn Acquaah hereby declare that apart from references to other people's work which have been duly acknowledged, this proposal was written independently by me and has not been submitted for the award of my degree in any institution.

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DEDICATION

This work is dedicated to God Almighty and to all family caregivers in Ghana. This work is also dedicated to Mr. Ezekiel Acquaah , Manuella, Ezekiel and Eliana Acquaah for their support and encouragement throughout this period for his support and encouragement throughout this period.

ACKNOWLEDGEMENTS

Thanks be to God almighty for the grace I received from Him to complete this programme. Special thanks to my supervisor, Dr. Genevieve C. Aryeetey for her guidance and supervision. I also want to express my sincere appreciation to all research assistants who helped me in this work, especially Wisdom Worwornyo, Alice Kporfor and Mavis Asare.

I want to say a very big thanks to the Management and staff of Princess Marie Louis Hospital and to all the family caregivers and their wards with Asthma at PML, Hospital who allowed me to use them for this research.

Finally, thanks to my family, for their support and encouragements through the years.

ABSTRACT

Introduction: Asthma is a chronic respiratory disease which has substantial financial and non-financial burden on sufferers, their families and the society. Family caregivers continue to be the primary source of care for children with asthma in Ghana which may have financial and psycho-social implications.

Aim: The objective of the study was to determine the household cost of caregiving for children with asthma at Princess Marie Louis Hospital in Accra.

Methods: A retrospective cross-sectional cost-of-care study was conducted among family caregivers at Princess Marie Louis Hospital. Ninety respondents completed an interviewer-administered questionnaire. Direct cost consisted of consultation, medication, diagnosis, treatment, travel cost and other medicals. Indirect cost was estimated using the human capital approach-i.e. the time value of days lost and waiting time due to caregiving. All costs were estimated using a recall period of one month or the last monthly visit. Intangible costs were assessed using the 12-item Zarit burden interview scale.

Results: The total average cost of caregiving for children with asthma in the sample was estimated at GHS5889.9 (USD 1277.1). This constituted of 93% (GHS 5472; USD 1140) being direct cost of caregiving and 7% (GHS 417.9; USD 87.1) being indirect cost. The major cost drivers of asthma cost were cost of medication (43.9%), treatment (17.8%) and absence from work (6.8%). Household was higher for male children (GHS 5586/ USD1163.8) than female children with asthma (GHS4749.8/USD 989.5). Cost also increased with age of children between 6 and 9 years bearing the highest cost (GHS 6274.8/USD1307.3) and those 1 year or less bearing the least cost (GHS 2004 / USD 417.5). Additionally, the cost was highest for children from poorest households (GHS 3217/ USD 670.3) whilst admission cases also led to high cost (GHS 7210.8/

USD 1502.3). About 45.6% had little or no burden whiles 46.7% had mild to moderate burden due to providing care.

Conclusion: The study showed the family caregivers for children with asthma are faced with financial challenges. There is therefore the need for an intervention from policy makers, for instance to make asthma treatment free or at a reduced cost to enable caregivers to continue to support and give care to children with asthma**.**

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LIST OFABBREVIATIONS

ADLs:	Activities of daily living
AARP:	American Association of Retired Persons.
ALLSA:	Allergy society of South Africa.
CCI:	Cost of care index
CDC:	Centers for disease control and prevention
CLTCRP:	Centre for long term care research and policy
ED:	Emergency department
EIB:	Exercise – induced bronchospasm
EPR – 3:	Expert panel report 3.
ETS:	Environmental tobacco smoke.
GBD:	Global burden of disease study
IDDLs:	Instrumental Activities of daily living
ISAAC:	International study of asthma and allergies in childhood.
NAC:	National Alliance for caregivers
NHLBI:	National Heart, Lung and blood institute
PML:	Princess Marie Louis Hospital.
SACAWG:	South African children asthma working group
US:	united States
USD:	United States Dollars
WHO:	World Health Organization
ZBI:	Zarit Burden Interview

DEFINITION OF TERMS

Family caregiver: A relative, friend or neighbour who provides including unpaid care to a dependent child with asthma.

Direct Cost: Actual out-of-pocket cost incurred by the caregiver as a result of caring for the child with asthma.

Indirect Cost: Cost associated with productivity and income losses as a result of giving care to the child with asthma.

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 child with asthma.

CHAPTER ONE

INTRODUCTION

1.0 Background

Over the past decade, cases of asthma and its prevalence continue to plague the world as one of the most serious respiratory diseases. The condition has been found to be more prevalent in developed countries, however, in recent times there has been an increase in the condition among populations in the developing world (Masoli et al., 2004). Globally, there are currently 300 million people suffering from asthma and it is estimated that by the year 2025 additional more than 100 million people would be suffering from asthma. The condition is known to affect people of all ages but painfully, it is very high among children under age five and then to decrease as people grow. Asthma is associated with a high disease burden. In children aged less than 5 years old and as well as in the mid-childhood ages, 5–14 years old there is a high prevalence worldwide with a significant relevance and even in these age groups is consider as one of the top chronic conditions causing disability-adjusted life years (DALYs).

Guo, Gao, Guo, Wen, & Zeng (2015) reported that, the prevalence of Asthma in children between the ages of 13-14 years in the year 2013 was 14.1% while in children between 6-7 years was 11.7% as per the report from the International Study of Asthma and Allergies in Children (ISAAC). In 2010, seven million children had asthma in Unite States of America and that's equal to one in every eleven children with an annual household cost for a child estimated at $1,039 in the year 2009 (United States National Center for Environmental, 2010).

In Australia, there are 2.4 million people suffering from asthma in 2015 representing 9.9% of the total population, of which of which 54% are female and 46% are male. The highest prevalence rate for asthma is reported among males aged 5-9 years at 14.6% (Deloitte, 2015). An estimate of asthma prevalence in Africa reveals an increasing prevalence the past two decades (Adeloye, Yee, & Rudan, 2013) . The Asthma Burden report has indicated that some 50 million cases of asthma are believed to prevail in Africa, with South Africa alone having a prevalence rate of about 8.1% in the year 2010. In many other developing countries, caregiving for the children with asthma lies largely in the households, with the family already playing an integral role in giving care. As such, the cost of care for the children with asthma is usually unmonitored.

In Ghana asthma is the third-ranking cause of hospitalization among children younger than 15 years (United States Environmental Protection Agency, 2015). An average of one out of every 10 school-age children has asthma. 10.5 million school days are missed each year due to asthma (United States Environmental Protection Agency, 2015). The average yearly cost of care for a child with asthma was $1,039 in 2009. (United States National Center for Environmental, 2010). The annual economic cost of asthma—including direct medical costs from hospital and indirect costs, such as lost school and work days—amounts to more than $56 billion annually (United States Protection Agency, 2015).

The incidence rate of asthma in Ghana has also been estimated at 1.5/1000 per year by the World Health Organization (W.H.O) and the causes have not been fully determined although there is a clear genetic contribution. Once diagnosed, adherence to asthma medication and avoidance of triggers can effectively mitigate symptoms and prevent asthma exacerbations (Farmer et al., 2015). With high quality health care, most children and adolescents with asthma can live an active and

normal life. Yet, many children and adolescents have uncontrolled asthma, with symptoms and exacerbations which may affect their daily life (Jonsson, 2015) Premature death, disability, loss of income and health-care expenditure due to asthma take a toll on families, communities and national health finances. In low- and middle-income countries many people cannot access treatment for asthma, because it is prohibitively expensive. Households often then spend a substantial share of their income on hospitalization to treat exacerbation and complication of asthma. To this end, this dissertation estimates the economic burden of caregiving provided by family members and friends for the children with asthma.

1.2 Problem statement

Asthma is a chronic disease that affects the airways in the lungs. During an asthma attack, airways become inflamed, making it hard to breathe. Asthma attacks can be mild, moderate, or serious and even life threatening (United States National Center for Environmental Health, 2010). Some of its symptoms include coughing, shortness of breath and wheezing tightness or pain in the chest. There's no cure for asthma. People with asthma can manage their disease with medical care and prevent attacks by avoiding triggers.(United States National Center for Environmental Health, 2010).

Recent statistics indicate that asthma infection is on the increase in Ghana affecting people of all ages. The disease poses a huge public health problem and is putting enormous pressure on existing healthcare facilities and available human resource in the healthcare sector. Asthma is the third-ranking cause of hospitalization among children younger than 15 years in Ghana (United States Environmental Protection Agency, 2015). Since majority of these children were enrolled in schools (88.9%), the prevalence of this disease among them is likely to affect their school

attendance. In school children, there will be lost school days, which lead to limitation on study performance, with consequent psychological effects.

Unfortunately, little is known about the household cost of caregiving for children with asthma in Ghana. This study therefore aims to estimate the household cost of family caregiving for children with asthma attending Princess Marie Louis Hospital in the Greater Accra region. With the knowledge of the cost incurred by caregivers in giving care to children with asthma gathered through this research, it will inform stakeholders, policy makers and the civil society on how to effectively allocate resources to programs associated in giving care to children with asthma.

1.3 General objective

1.3.1 General objective

The general objective of this study was to estimate the household cost of caregiving for children with asthma attending Princess Marie Louis Hospital.

1.3.2 Specific objective

Specifically, the study sought to;

1. Estimate the direct cost of caregiving for children with asthma.
2. Estimate the indirect cost of caregiving for children with asthma.
3. Assess the intangible cost of caregiving for children with asthma.
4. Estimate the difference in the burden of caregiving by socioeconomic status.

1.4 Research questions

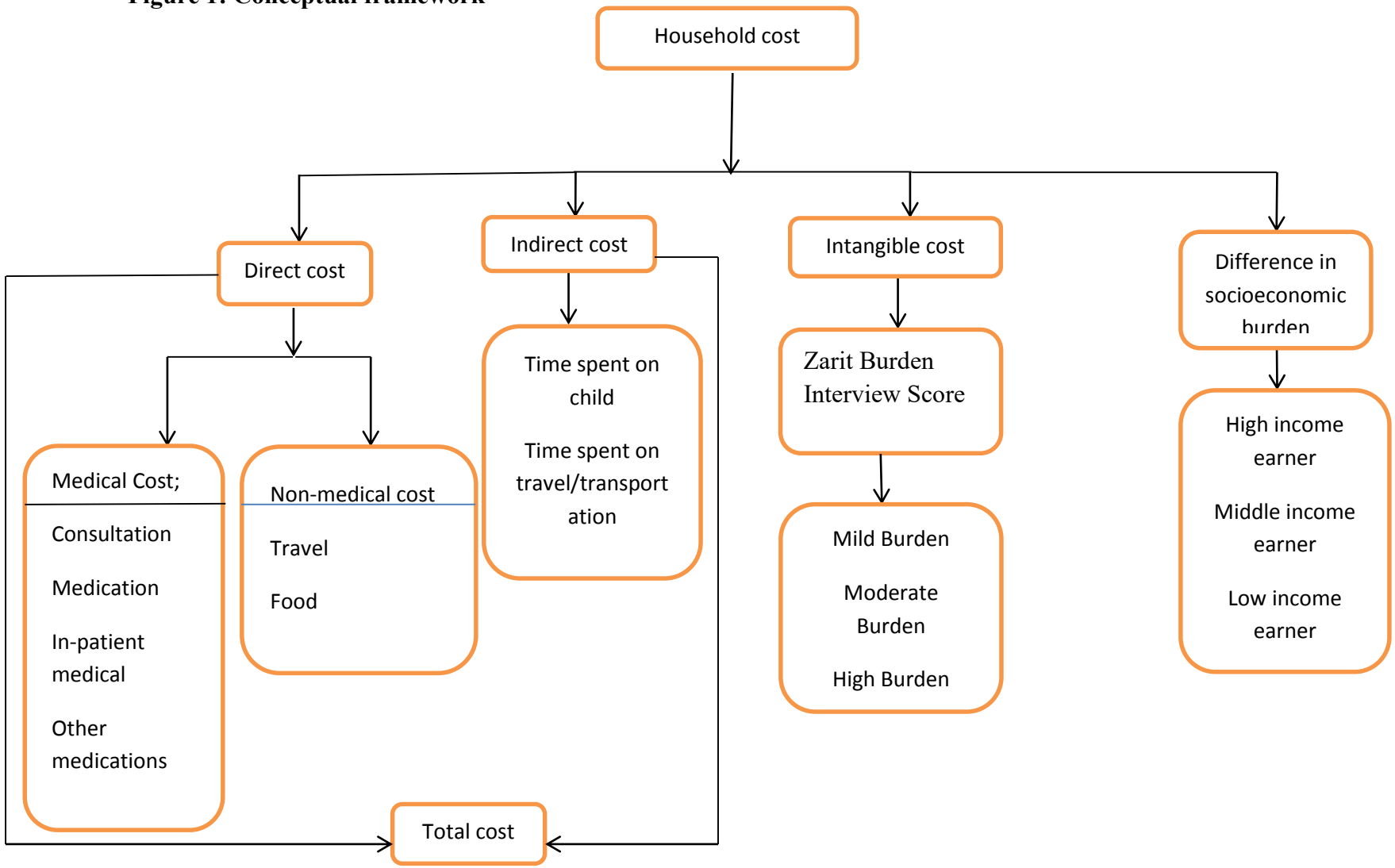
The study sought to answer the following questions;

1. What is the direct cost of caregiving for children with asthma?
2. What is the indirect cost of caregiving for children with asthma?
3. What is the intangible cost of caregiving for children with asthma?
4. What is the difference in the burden of caregiving by socioeconomic status?

1.5 Justification of study

With the growing evidence of asthma among children in Ghana and its associated household cost of caregivers, it is imperative to estimate and describe this burden. One way of sensitizing policy makers and stakeholders on the enormity of the household cost of caregivers for children with asthma and the need to allocate more attention and resource to them, is to estimate the cost of household cost of caregiving for children with asthma. The household cost of caregivers will be better appreciated when monetary value is estimated and known. This provides the needed motivation for the development of an appropriate policy framework to support caregivers for children with asthma in Ghana. The systematic cost-of-care study can provide valuable data for the relative socioeconomic cost of caregiving, which can inform an objective public policy framework. Also, knowledge of the economic cost of caregiving for children with asthma can help in strategic

Figure 1: Conceptual framework



1.6 Conceptual framework

The conceptual framework underlying this study is shown in Figure 1. Cost of caregiving for children with asthma was assessed from the perspective of the caregiver. Distinct from concerns over the societal or population-level burden of caregiving for the children with asthma, this perspective focused on the effects that caregiving can have on the family caregiver and the consumption possibilities of their households. Caregiving for children with asthma 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, caregiving for children with asthma can interfere with the consumption of non-market activities (e.g. giving up unpaid housework or leisure time to look after the children with asthma) which reduces the stock of health itself. Accordingly, analysis of the household cost of family caregiving for the children with asthma was categorized into four main domains of cost; direct costs, indirect costs, intangible costs and difference in socioeconomic burden as shown in Figure 1. Direct costs typically include the out-of-pocket expenditure incurred by caregivers in relation to cost of drugs, consultation fee, medical accommodation, and cost of laboratory investigation. It also includes the estimation of the total transportation cost and external family support. Indirect costs on the other hand, typically refer to the productivity losses incurred by the family caregiver. In addition, caregiver's time spent on the care of the recipient either for travel and waiting time was also estimated under indirect cost. The

total cost of caregiving for children with asthma was obtained by the summation of the economic value of both the direct and indirect costs.

Intangible costs were also assessed using the 12-item Zarit Burden Interview Scale. This scale is used to determine the burden of caregiving for various conditions including asthma. Difference in socioeconomic burden refers to the impact on the individual based on their socioeconomic status for instance high income earners, middle income earners; low income earners may have different impact.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter gives a general overview of asthma, has another section that highlights policies that support children with asthma, and gives the Global, African and Ghanaian contexts for caring for children with asthma, policies formulated to influence asthma caregiving. The chapter then gives a conclusion of general asthma care for children.

2.1 Overview of Asthma

Asthma as defined by Nurmagambetov, (2018) is a chronic disease of the airways which is mostly characterized by the periods of reversible airflow obstruction that mostly resulted in symptoms such as dyspnea, cough, chest tightness and wheeze. Additionally, Guo et al., (2015) also posited that, cases of asthma and its prevalence worldwide is constantly on the rise as it is considered one of the most serious respiratory diseases. People with asthma typically experience “wheezing”, a high-pitched whistling sound heard during breathing, especially when breathing out(Pedersen et al., 2011).

According to the Centers for Disease Control’s asthma affects the airways of the lungs and manifests in a variety of symptoms such as coughing, wheezing, chest tightness, and shortness of breath. It also says that a common misconception is that there is only one cause of these symptoms, but in reality there are two main causes. The one commonly felt by asthma sufferers is a tightening of the chest, the result of muscles around the airways tightening, making it hard to breathe; this is also called, “bronchoconstriction.” The other cause, which is not always noticed, is inflammation.

An asthmatic's lungs are always inflamed, but when they swell and become abnormally irritated, the amount of air taken in by the lungs decreases and makes it harder to breathe. In addition, thick mucus may be produced, partially blocking the airways and adding to the difficulty of breathing. Asthma is a severe chronic illness, but it is manageable (Centre for Disease Control, 2011). Patients with asthma may be exposed to multiple indoor allergens and environmental tobacco smoke (ETS) in their homes, which may contribute to increased asthma-related exacerbations. Many patients with asthma, particularly those who live in poverty and rely on emergency departments (EDs) as their primary source of healthcare, may not be receiving adequate education about asthma self-management and how to avoid environmental exposures to asthma triggers.(Journal of Asthma, 2010).

Curie & Bake (2012) posited that, asthmatic attacks on patients are mostly triggered by quite a variety of stimuli such as poor air quality, intense physical activity or exercise, damp air or cold as well as other environmental stimuli. The study also added that, there are proper treatments that could apply to reverse cases of asthmatic attacks despite these attacks being spontaneous in nature. This phenomenon, termed the 'asthma epidemic' (Maziak, 2005) has come with an enormous economic burden due to the significant health-care utilization associated with treatment of this condition (Bahadori et al., 2018). The Global Initiative for Asthma (GINA) estimates that the global prevalence of asthma ranges from 1 to 18% of the total population of different countries (GINA, 2004). The number of people with asthma in the world may be as high as 334 million. This figure comes from the most recent comprehensive analyses of the Global Burden of Disease Study (GBD) undertaken in 2008-2010. A lower figure of 235 million used in the Global Asthma

Report 2011 came from the most up-to-date GBD information available at that time based on analyses from 2000-2002 (ISAAC, 2011).

Between 2000 and 2003 the International Study of Asthma and Allergies in Childhood (ISAAC) Cycle 3, a large-scale international collaboration on asthma and atopic disease looking at over 700,000 children, found that about 14% of the world's children were likely to have had some sort of asthmatic symptoms in the past year (Lai et al., 2009). The majority of those reporting over 20% prevalence of asthmatic symptoms in children tended to be located in English-speaking and Latin American countries. The centers reporting prevalence lower than 5% were predominantly located in Asia, along the Eastern Mediterranean, and in Northern and Eastern Europe. While ISAAC showed that more developed countries had higher prevalence of asthmatic symptoms in children, it also suggested that less developed ones generally had higher rates of severe asthma and asthma mortality (Lai et al., 2009). Severe asthma among children with current wheeze was found to be significantly higher in Africa, the Eastern Mediterranean, and the Indian subcontinent than in English-speaking countries in ISAAC Phase 3 (ibid). Attempts to explain the disparity in asthma incidence between higher- and lower- income countries most notably include the hygiene hypothesis (Asher & Pearce, 2014). Other explanations, such as urbanization, have also been proposed (Boneberger et al., 2011).

It is well known that age is a strong predictor of future asthma risk. Infants and young children are more likely to develop the condition than adolescents and adults (Boehlke et al., 2014). The trend of asthma risk seems to peak during the pre-school years and decline into late childhood (King, Mannino & Holguin, 2004). The mean age of asthma diagnosis may have decreased in the past

decades; a birth cohort study in Ontario found a higher risk of being diagnosed as asthmatic in the first three years of life among children born after 1996 compared to those born between 1993-1995 (Radhakrishnan et al.2014).

Sex variations in asthma incidence have been reported in many studies (Genuneit, 2014). Male sex has been established as a risk factor for asthma incidence in young children and infants while females have been shown to have a higher risk of asthma in adolescence and beyond (Boehlke et al., 2014). The mechanisms behind this age-sex interaction have not yet been established, but differences in hygiene practices between younger males and females have been proposed as a factor (Clough, 2011). It has also been suggested that lung size and growth (Becklake & Kauffmann, 1999), physician diagnostic practices (Osman et al., 2007), and hormonal changes during puberty (Almqvist, Worm, Leynaert, 2008) may explain the differences in asthma risk between young males and females.

Asthma has a strong atopic component and, as such, is considered to be strongly related to other atopic diseases (Pearce et al., 1999). It has been suggested that approximately half of asthma cases are related to atopy (Pearce et al., 1999). Atopy, generally diagnosed by a positive response to skin prick testing, is a loosely-defined term that refers to IgE sensitization and a predisposition to IgE-mediated conditions such as hay fever, atopic eczema and atopic dermatitis. Sensitization to common allergens has been shown to increase the risk of asthma in children (Currie & Baker, 2012). There is also evidence that other atopic condition such as allergic rhinitis and eczema are associated with asthma risk as well (van der Hulst et al., 2007).

Increasing rates of obesity and overweight in the Western world have been roughly paralleled by increases in asthma and other atopic diseases (Curie & Baker, 2012). This has lead researchers to investigate the possible association between body weight and asthma incidence. Many studies have shown that both overweight and obese status confer higher asthma risk in childhood (Noal, et al., 2011). Other studies have shown a positive association between body mass index (BMI) growth and asthma risk (Papoutsakis et al., 2013). The underlying cause of this association is not yet known (Curie & Baker, 2011, Papoutsakis, et al., 2013). A 2013 systematic review and meta-analysis found that overweight children had a 19% increase in asthma risk over non-overweight ones; this effect increased to 102% when comparing obese and non-obese children (Chen, 2013). Interestingly, this association was found to be stronger in boys than in girls. It has been proposed that the mechanism behind this difference lies in differential pulmonary mechanics and sleep disordered breathing between the sexes; however, this has not yet been definitively shown.

Certain socio-economic factors such as parental education, parental occupation, and family income have been found to be associated with the incidence of asthma and wheeze during childhood (Williams et al., 2009; Spencer et al., 2012); however, the direction of this effect is not clear. Some studies have suggested that increasing family SES indicated by higher parental education, parental occupational prestige, and family income are either related to an increased risk of childhood asthma (Miyake et al., 2012) or have failed to show a clear association (Hancox, 2004). The former implication would be in line with the notion that asthma and wheeze are positively associated with a more affluent lifestyle (Curie & Baker, 2012). Other studies have shown a reversal effect, with lower SES levels generally increasing the risk of asthma and wheeze rather than decreasing it (Kozyrskyj, 2010; Gong, 2014). Understanding these factors may play a role in the primary

prevention of respiratory illness in children (Panico et al., 2014); however, confounding with other risk factors for asthma and wheeze may have led researchers to ascertain a spurious association with SES (Hancox, 2004). Home ownership, a factor strongly related to SES, has also been identified as a possible predictor of asthmatic symptoms in children (Sherriff et al, 2001).

Some studies have shown that children who attend daycare regularly are at less risk for developing asthma later in childhood and adolescence than those who do not (Nystad, 2000; Midodzi et al., 2010). Using the hygiene hypothesis' proposition that early life infections may lead to a decreased risk of atopic disease, the mechanism behind the apparent daycare effect has been attributed to high risk of respiratory infection among children who attend daycare regularly (Sangrador, 2007; de Meer, 2005). Indoor air quality at childcare centres may also play a role in this effect Von Hertzen et al., 2004). A 2014 study found that children who spent longer than 37.5 hours per week at daycare had a reduced risk of physician-diagnosed asthma by age 7 (OR = 0.6; 95% CI: [0.4-0.9]) but those whose weekly attendance did not reach that level had an increased risk (OR = 1.2; 95% CI: [1.1,1.6]) when compared to children who have never attended daycare (Cheng et al., 2014). The direction of the daycare effect on asthma risk is not completely clear, however, as some studies have shown that daycare attendance does not decrease and may increase the risk of asthma and wheeze (Cheng et al., 2014; Hagerhed-Engman et al., 2006). In addition, comparing studies on the potential daycare effect is difficult due to differential ascertainment of exposure between them, limiting the scope of any potential reviews (Nystad, 2000).

A wide study on passive smoke popular termed as second-hand smoke or environmental tobacco smoke have been conducted (Curie & Baker, 2011; Burke, 2012; Ponvert et al., 2007) with each

study clearly stating the risks involved exposure to this kind of passive smoke. These studies concluded that, passive smoke is a major risk factor for childhood asthma even though they all posited that, passive smoke can be avoided as it is considered as a removable risk. Al-Sayed & Ibrahim, (2014) also revealed in their study that, exposure to passive smoke which mostly emitted from cigarettes or any form of tobacco product does have a significant and adverse effect on almost all the organs in the human body. Al-Sayed & Ibrahim, (2014) also added their voice on the conclusion that, worldwide exposure to passive smoke is a major risk factor to childhood asthma.

Cook & Strachan, (1997) earlier assertion on issues of childhood asthma revealed in their study that, children with asthma who live with at least one parent who smokes stand higher risk of exacerbation (OR = 1.21; 95% CI: [1.10,1.34]) than children with asthma but do not have parents who smoke. The study also revealed that, children with asthma who had mothers who smoked stood a higher risk of aggravating their conditions than when their fathers are ones who engaged in the smoking even though both showed a significant evidence of aggravating the condition of the child. A systematic review revealed that, there are many evidences that, there is an increased risk of exacerbation of wheeze (Burke et al., 2012) and asthma (Tinuoye et al., 2013; Ferrante et al., 2014; Akinbami et al., 2013) and this is attributed to the exposure to passive tobacco smoke during childhood

Studies (Kausel et al., 2013; Barnig et al., 2013) have outlined clearly the high prevalence of asthma among children and this has been accompanied with wheezing symptoms. These studies found that, these cases of childhood asthma mostly occurred in urban areas as compared to those in the rural area. As a result, most of these had concluded that, childhood asthma and wheeze stand

a higher risk of exacerbation if they live in urban environments as compared to rural environments (Kausel et al., 2013). A study by (Barnig et al., 2013), attributed the reasons behind differences the prevalence rate of asthma between urban areas as compared to rural areas to issues of farm living and hygiene hypothesis, socio-economic or environmental factors (Rodriguez et al., 2011; Vlaski & lawson, 2015) and high levels of outdoor and indoor air pollutants which mostly occurred in urban areas (Hulin et al., 2010). Nevertheless, there are instances of cases of asthma exacerbation not being attributed to whether a patient lives in rural or urban areas and this has been attributed to issues of no evidence to support it.

2.2 Policies to support children with asthma

When children with asthma go off to school, their safety and the management of their condition becomes the shared responsibility of the family, their healthcare providers and school personnel. Most schools are very cognizant of the seriousness of asthma. Between 1990 and 2003, 38 asthma-related deaths in schools were reported in the United States. One study found that over 60 percent of asthma deaths in children came from a sudden asthma attack, rather than from the gradual worsening of symptoms (American Lung Association, 2014). Sudden attacks can be fatal within an hour. For a child who is struggling to breathe, the trip from the classroom or the playing field to the school health room for medication can be perilously far(Department of Health, Social and Public Safety, 2014). Allowing students to carry their quick-relief asthma inhalers with them during the school day can prevent or reduce the severity of asthma episodes, and is recommended practice in national guidelines for asthma management. (American Lung Association, 2014)

In the United States, The Human Medicines Regulations 2014, allows primary and secondary schools in the UK to keep a salbutamol inhaler for use in emergencies. The policy contained within

Supporting Pupils with Medication Needs recommends that as well as the reliever inhaler the child or young person should bring daily to school, all parents should provide a spare inhaler to the school. The change in legislation is not a change to this policy and schools can schools can continue to implement existing practices if they wish (American Lung Association, 2014). The change in legislation will allow an emergency salbutamol inhaler to be used if the pupil's prescribed inhaler and spare inhaler are not available (for example, because they are broken, or empty) and will broaden the choices open to schools as part of the pupil's wider asthma management plan. There is no compulsory requirement for schools to hold an inhaler for emergency use – this is a discretionary power enabling schools to do this if they wish. (Department of Health, Social and Public Safety, 2014). Recent evidence indicates that asthma self-management education is effective in improving outcomes of chronic asthma. Self-management education can reinforce the knowledge, attitudes, and skills to control student's asthma recognizes that pupils need to have immediate access to their reliever inhaler, will encourage and help children who have asthma to participate fully in all aspects of school life (Department of Health, Social and Public Safety, 2014). The policy requires that on admission to school, all parents/cares will be asked to complete an admission form giving full details of their child's asthma, regular medication, emergency contact numbers, family medical doctor and any relevant hospital details, A 'My Asthma Care Plan' is completed with parents, every child with an asthma diagnosis must have a reliever inhaler (blue) available in school and a spacer device if this is normally used. Most children will not need to use their reliever inhaler (blue) on a daily basis. If the child has experienced symptoms and has needed to use their inhaler, parent/carers will always be informed and a record kept. Parents/carers will always be informed if their child has an asthma attack. If pupils leave the premises for any activity they must have their reliever (blue) inhaler with them. Parents/carers need to check all

reliever inhalers/spacer devices regularly, confirming that the inhalers are in date and full of medication. Inhalers should not be stored where there is excessive heat or cold.

2.3 The concept of caregiving

In the literature, caregiving has been defined in several ways. Drentea (2007, p.172) defines caregiving 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 caregiving 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 caregiving 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 neighbor 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, caregiving has been classified as either informal or formal. 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 caregiving is classified as paid services of licensed or unlicensed strangers provided under the umbrella of a formal health care system (Connell, 2003). Caregivers are typically family members, friends, and neighbors. Indeed, caregiving of all types is also done by paid workers such

as nurses, social workers, and counselors. However, caregiving by these is paid work, and thus does not fall in the same category as the unpaid. Similarly, caregiving rarely refers to the daily care that parents provide for their children, because this is classified as parenting.

2.4 Ghanaian context of caring for the children with asthma

Asthma research in Ghana has focused mainly on children between the ages of 5-16 years with one published study that included adults. Different markers for the disease have been used such as clinician- diagnosed asthma, exercise-induced bronchospasm (EIB) as well as questionnaire-derived symptoms of asthma. Factors found to be associated with asthma in Ghana include atopic sensitization to environmental allergens, inner-city residence and socioeconomic differences. (Amoah et al., 2012). For the last 20 years, evidenced-based guidelines have been available to help clinicians evaluate and manage asthma. The National Heart, Lung, and Blood Institute (NHLBI) Expert Panel Report-3(EPR-3) suggests a four-step approach to asthma care, including assessment and monitoring, education, control of environmental and comorbid conditions, and medications. Despite the availability of these guidelines, their implementation in real-world settings has been poor, particularly for minority populations (Ross, 2015).

2.5 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 caregiving 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 children with asthma 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 child with Asthma needs support. It also captures demands on caregiver's time, such as coordinating paid labour, family life, and regular housework activities with caregiving. 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 children (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 caregiving create (Lai, 2010).

2.6 Determinants of caregivers' burden

Previous studies have identified factors that may influence caregivers' burden. These include; caregiver's characteristics and care recipient characteristics, caregiver's resources, and caregiver's

support characteristics (Carmichael et al., 2010; Thomson et al., 2008). 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. 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 labor 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 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 caregiving 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 caregiving, 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 neighborhood associations) use them to distribute caregiving 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 centers, 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.

2.7 Economic cost of family caregiving

2.7.1 Direct costs of family caregiving

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; cost of consultation, cost of medication, admission cost, treatment cost and cost of travel (Kleating et al., 2014). In South Korea, one study found that direct medical expenditure was $1009.8 million ($401 per child with asthma), including payments for prescribed medicine, hospital inpatient stay, hospital outpatient

care, emergency room visits, and office-based visits. Children with treated asthma had a total of 14.5 million school absence days; asthma accounts for 6.3 million school absence days (2.48 days per child with asthma). Parents' loss of productivity from asthma-related school absence days was $719.1 million ($285 per child with asthma). A total of 211 school-age children died of asthma during 1996, accounting for $264.7 million lifetime earnings lost ($105 per child with asthma). Total economic impact of asthma in school-age children was $1993.6 million ($791 per child with asthma).(Wang et al.,2005)

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. 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 constitutes a large proportion of out-of-pocket expenses, particularly in jurisdictions without prescription drug insurance plans (Fast et al., 2008).

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).

2.7.2 Indirect costs of family caregiving

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, three sub-categories of caregiving labor are usually highlighted; time spent with child, time lost from caregiver's work, time spent on travel/transportation (Kleating et al., 2014). Studies have been conducted in many countries in which the amount (incidence and time spent) of care labor 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). Time spent on child 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, 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. . One study estimated time spent with child at 649 hours

annually (Johnson & Lo Sasso, 2004). 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).

2.7.3 Intangible cost of family caregiving

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 caregiving for the children with asthma. Several authors have examined the intangible cost of the caregiving 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 caregiving. According to the authors (Krosberg & Cairl, 1986), the financial stress of caregiving for the children with asthma could be measured by asking family caregivers the following questions: (a) Do you agree that caring for your children with asthma 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 children with asthma relative? (c) Do you agree that your family and you cannot afford those little extras because of the expense of caring for your children with asthma relative? (d) Do you agree that caring for your children with asthma 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 caregiving. Lai (2012) further indicated that 40.3% of the family caregivers in his study agreed that caregiving 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 children with asthma.

2.8 Conclusion

Little research has explored the economic effects of family caregiving for the children with asthma 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 Financial Costs of Family Caregiving. In 2007, the economic value of family caregiving was estimated at $375 billion, which exceeds the total amount of 2007 Medicaid expenditures ($311 billion) and approaches the total expenditures in Medicare ($432 billion) (AARP Public Policy Institute, 2008). Total government cost of asthma is $27929.6 (Council, 2015) Very few of such

Cost-of-care study exist in the Sub-region, hence comparison of the economic burden of caregiving across nations in the Sub region has proven difficult. More studies on the economic cost of caregiving for the children with Asthma within African countries are needed to enable comparison across nations and regions with relatively similar socio demographic characteristics. Again, compared to developed countries, little information exists in developing countries on how caregiving affects rates of labor 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 labor market.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter covers the research design, study area, study variable, sample population, sampling arrangements, research instrument, data management and analysis, and ethical issues.

3.1 Study design

In this study, a cross-sectional cost-of-care design was used. A cross-sectional design is defined as a study carried out at one time point or over a short period (Levin, 2006). According to Levin (2006), cross-sectional studies are usually conducted to estimate the prevalence of the outcome of interest for a given population, commonly for the purposes of public health planning. One reason for using this study design is that in a cross-sectional study, data can also be collected on individual characteristics, including exposure to risk factors, alongside information about the outcome (Levin, 2006). Cross-sectional studies can be thought of as a "snapshot" of the frequency and characteristics of a condition in a population at a particular point in time.

In this study, caregivers of children with asthma who visited the Princess Marie Louis Hospital in Accra Central were recruited at one point in time and assessments made based on caregiving costs. This study used quantitative research approach defined as the systematic scientific investigation of quantitative properties and their relationships (Wadsworth, 1997). Quantitative studies are concerned with behaviours consisting of measures or observation scales (or both) and they focus on the cause-and-effect relationship between two variables (Krathwohl, 2004). Wadsworth (1997) stated that quantitative research is about “how many; to what extent, or how much aspect which involves counting and other data analysis. The objective of quantitative research is to develop and

employ mathematical models, theories, hypotheses concerning the natural phenomena (Sarantakos, 2005). Measurement process is key to quantitative research because it provides the basis for connection between empirical observation and mathematical expression of quantitative relationships (Gall et al., 2003). The reason for the use of quantitative methods was to quantify the direct and indirect cost of caregiving in order to know how much each household spends on caregiving for children with asthma.

3.2 Study area

This study was undertaken at the Princess Maria Louis Hospital (PML) which is managed by the Ghana Health Service. Princess Marie Louis Hospital is located at the central part of Accra in the Ashiedu Keteke District. The Ashiedu Keteke district is in the Accra Metropolitan Area of the Greater Accra region of Ghana. It is a 104-bed capacity hospital. It is made up of three unit namely: Emergency In-patient (wards) and Out – patient department. PML also have several clinics including asthma clinic which is held every Tuesday at the facility.

This health facility was chosen for the study because it is a children hospital specializing in the treatment of children diseases. Additionally, unlike other health facilities in the Accra Metropolis, it has an asthma clinic. Therefore most people suffering from asthma in the Accra Metropolitan Area go to this facility for treatment.

3.3 Study population

Family caregivers for the children with asthma attending hospital at Princess Marie Louis Hospital between May 2018 and June 2018 formed the study population for this study. The population

consists of caregivers and their children with asthma attending OPD/emergency, admissions, detention and those coming for regular reviews at the Princess Marie Louis Hospital

3.4 Sample size

Minimum sample size was obtained using the total number of children with asthma on PML records. The total number of children with asthma on PML records in 2016 was 120. The study assumed these children are usually accompanied by family caregivers. With this finite population (120) 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 children with asthma at the records department of PML)

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

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

$$n = \frac{120}{1 + 120(0.07)^2}$$

Based on the above calculation, a minimum sample size of 75 was obtained from the target Group. Using a non-response rate of 20%, the figure was further increased to 90 as the sample size.

3.4.1 Sampling procedure

Purposive sampling was used to select subjects from the PML records for interview. This sampling technique was used because the researcher intentionally selected only children with asthma from birth up to 15 years. Secondly, the researcher used purposive sampling in order to select only children who visited the Princess Marie Louis Hospital six months preceding the conduct of the study. The average number of children with asthma who visited the PML was estimated to be 30 per month. The study made use of the list of patients who visited the hospital in the months of May and June, 2018 and those who had visited the hospital six months earlier. In all, a total of 90 patients were selected. This consisted of 50 caregivers who were recruited during visitation to the hospital between the months of May and June 2018. They were recruited after the children were registered by the receptionist at the various hospital units. Another 40 caregivers were recruited from the list of asthmatic children who visited the health facility six months earlier. The names and contact of caregivers were obtained from the attendance book and their caregivers of the sampled children with asthma was contacted those who satisfied the inclusion criteria and consented to participate in the study were interviewed.

3.4.2 Inclusion and exclusion criteria

The study included family caregivers attending PML hospital with their children with asthma who provided care to their children (at birth to 15 years). For the purpose of this study, a family caregiver refers to a person who provided assistance, in the past one month. Caregivers receiving monetary payment for care-giving to the children with asthma, caregivers below the age of 18 years and caregivers who have spent less than a month providing care for the children with asthma were excluded from the study.

3.5 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 operationalized.

Table 1: Description of study variables

Cost type	Cost categories	Description
Direct cost	Medical Cost	
	Consultation	This is the summation of the costs of consultation and registration of the patients during the study period.
	Laboratory/ Diagnostics	This is the summation of the cost of laboratory tests requested for the patients during the study period.
	Medication	.This is the summation of the medications prescribed for the patients during the study period.
	Other Treatment	This is the summation of the costs of other treatments like nebulization received by the patients during the study period.
	Total medical cost	This is the summation of the total costs of consultation, laboratory/diagnostics, medication, other treatment received by the patients during the study period.
	Non-medical cost	
	Travel/ transportation	This is the summation of all travel costs like taxi fares and bus fares incurred by the patient's caregiver when travelling with patient to the hospital and from the hospital to their homes during the study period.
	Food	This is the summation of all costs incurred by the patient's caregiver on food items purchased due to their child's asthma condition during the study period
	Miscellaneous	This is the summation of all costs incurred by the patient's caregiver on other items such as telephone calls or other reliving agents purchased because of their asthma condition
	Total non-medical cost	This is the summation of travel costs, all food costs and all miscellaneous expenses incurred by the patient's caregiver due to the child's asthma condition.
Indirect cost	Productivity loss	

	Total travel time	This is the summation of the hours spent travelling to the hospital and hours spent travelling from the hospital to house.
	Valued travel time	This was estimated by multiplying the total travel time spent by patient caregivers who are employed by the hourly rate of the daily minimum wage.
	Total waiting and treatment time	This is the summation of the hours spent on waiting and treatment at the hospital.
	Value waiting and treatment	This was estimated by multiplying the total hours spent on waiting and treatment at the hospital by employed patient caregivers by the hourly rate of the daily minimum wage.
	Productivity days lost	This is the summation of the total number of days lost by patient caregivers who are employed
	Valued productivity days lost	This was estimated by multiplying the total number of days lost by patient's caregivers who are employed by the daily minimum wage.
	Total indirect cost	This is the summation of valued travel time, valued waiting and treatment time and valued productivity days lost by the patient caregivers
Intangible cost	Intangible cost	Zarit Burden Interview Score; Mild burden, Moderate burden, High burden

3.6 Data collection technique

Data were collected using a structured interviewer-administered questionnaire with both open-ended questions that required written responses and closed-ended questions providing predetermined options. The researcher after identifying prospective participants introduced and explained the purpose and benefit of the study after which a consent form was also read and signed by the participant. (Appendix A). Those who gave their consent to be part of the study were recruited and interviewed. Prospective participants who refused to participate were replaced by the next available person on the list. Data collection was carried out by the researcher with the help of two research assistants. The questionnaires were administered to family caregivers individually in

the form of a face-to-face interview. A meeting with research assistants was held at the end of each day of the data collection period where matters arising was discussed and completed questionnaires cross-checked for each research assistant to ensure completeness of questionnaire.

3.7 Quality control

To ensure that complete and accurate data was obtained, some measures were instituted during the pre-data collection stage, the data collection stage and the data entry and processing stage.

3.7.1 Pre-data collection stage

3.7.1.1 Training of research assistants

An individual with requisite background in medicine and who were able to speak two of the common local dialects (Twi and Ga) spoken in the study area was recruited to serve as research assistant for the study. The assistant was trained for two days. The assistant was trained in the explanation and administration of the questionnaire and ethical issues such as the need to obtain informed consent before interviewing the study participant to ensure that he recruits and relates with the participants in the appropriate manner.

3.7.2 Pretesting of questionnaire

The questionnaire was pretested on caregivers with children having asthma condition who attended hospital at Medina polyclinic, Accra. This was performed by the principal investigator and the trained research assistant. The questionnaires were pretested to identify ambiguity and other difficulties that the participants may encounter in responding to the questions and the

questionnaires were revised and restructured accordingly. The pretesting was done to assess the research assistant's administration of the questionnaires in order to prevent interview bias.

3.7.3 Data entry and processing

Data entry controls was put in place to serve as checks to prevent wrong entries and other errors. Completed questionnaires was coded and double entered in Epi Info7. Data was entered on the day it was collected by principal investigator. Data were cross checked for errors, cleaned and exported to Microsoft Excel 2010 and STATA version 15 for analysis.

3.8 Data Analysis

3.8.1 Estimation of direct costs

Direct cost was further categorized into direct medical cost and direct non-medical cost. Direct cost was estimated as follows; direct medical cost: This was estimated by determining the total number of caregivers who indicated having made out-of-pocket expense in this category. The average cost was determined using the total number of caregivers who reported having made out of pocket expense in this direct cost category.

3.8.1.1 Direct non-medical cost

Cost of in-patient care: The total cost incurred by these family caregivers in this category was determined as well as the average cost per month

Cost of travel/ transportation: 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 cost of in-patient care, the total cost of hospital supplies, the total travel/transportation 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 was derived by summing the total direct medical cost and the total direct non-medical cost for the month.

3.8.2 Indirect cost estimation

Indirect cost was estimated using the human capital approach which measures output losses by lost earnings (Addo, Nonvignon, & Akins, 2013). Productivity losses of family caregivers who were employed in the formal sector were valued using the national minimum wage rate in the country. Productivity losses of family caregivers in the informal sector were valued using the local casual labour wage rate. The total hours spent per month by family caregivers was 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 children with asthma within the period. This was then multiplied by the local casual worker wage rate. 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 on caregiving for the children with asthma within the period. This was multiplied by the national minimum wage rate. 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 would not no actual lost earnings. Besides, students were also not expected to be working.

3.8.3 Total cost estimation

The total cost of family caregiving for the children with asthma 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. (The exchange rate at the time of this study was conducted) to enable comparison with other international studies.

3.8.4 Sensitivity analysis of total cost

Sensitivity analysis was undertaken to ascertain the robustness of the results of the study. on which the sensitivity tests were conducted were the wage rate, costs of medication, travel cost and the food cost. One-way and two-way sensitivity tests were performed. These tests were performed by varying the minimum wage for the indirect costs and by increasing the amount of the cost of medication, travel and food by 5%, 10% and 25%. These components were chosen due to the uncertainties in the estimated values reported by the respondents.

3.8.5 Description of intangible Cost

Intangible cost for this study was assessed using the 12-item ZBI. The instrument (ZBI) has a range of total scores from 0 to 48 with higher scores representing a higher level of caregiving 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.

3.8.6 Estimation of socio-economic status

Socio-economic status of the respondents was estimated by using the Principal Component Analysis to generate wealth quintiles in STATA Version 15 from asset ownership of study participants by grouping them into high income earner, middle income earner and low income earner.

3.9 Ethical consideration

The following was observed during the study.

Ethical Clearance: Ethical clearance for the study was obtained from Ethical Review committee of the Research and Development Division of the Ghana Health Service.

Permission from study site: Permission was obtained from the various medical directors of PML before the research was conducted. Description of subject involved in the study: The study population was made up of caregivers for children with asthma attending hospital at PML and who would be receiving medical treatment during the period of the study.

3.9.1 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.

3.9.2 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 caregiving for the children with asthma. Also, estimation of the cost of family caregiving for the children with asthma can be used as a platform for sensitizing policymakers and opinion leaders about the economic burden of caregiving for the children with asthma.

3.9.3 Privacy and confidentiality

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

3.9.4 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 was 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 was kept by the principal investigator for 3-4 years to allow for publication of the research, after which questionnaires will be destroyed.

3.9.5 Voluntary withdrawal

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

3.9.6 Research funding Sources

The study was funded by the researcher.

3.9.7 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 recognized and appreciated.

3.9.8 Conflict of interest

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

3.9.9 Assumptions

The assumption that was made in the study is that the national daily minimum wage for the country is reflective of the average income earned per day by the respondent.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents the result of the data collected from the field. The analysis chapter is divided into seven sections. The first two sections present the socio-demographic and clinical characteristics of the children and the socio-demographic characteristics of the caregivers. The third and fourth sections feature the analysis of the direct household medical cost of asthma and the direct non-medical cost of asthma for households. The fifth and sixth sections analyze the indirect household cost of asthma care and the socio-demographic determinants of household cost of care giving whilst the last section analyses the intangible burden of asthma care for children.

4.1 Socio-demographic characteristics of respondents

This section of the chapter presents the demographic characteristics of the caregivers with asthmatic children under investigation. Two groups of socio-demographic characteristics were considered in this study. These were the socio-demographic characteristics of children with asthma and the socio-demographic characteristics of the caregivers.

4.1.1 Socio-demographic characteristics of children

The sex distribution shows that a slight majority of the children (55.6%) were males and 44.4% were females. Concerning the ages of the children with asthma, the results demonstrates it ranges from 7 months to 15 years with an average of 4 years. Most of them (41.1%) were between 1 and 3 years, followed by those between 4 and 6 years (30%).

Also, the results indicate that the large majority of the children (80.8%) were in primary school. However, 3.8% had Junior High School education and 15.4% were not in school at the time of data collection.

Further, estimation of the asthma cases for which the caregivers were giving care showed that 60.9% were Out Patient Department/Emergency cases, 26.4% were detention cases and 12.6% were admission cases.

Table 2: Socio-demographic Characteristics of Children

Socio-demographic Variables	**Freq. (N=90)**	**Percent**	**Mean**	**Std. Dev.**
Sex of Children				
Male	49	54.44		
Female	41	45.56		
Age(in years)				
≤ 1	8	9.5	4	3.347
2-5	47	56.0		
6-9	15	17.9		
10-13	13	15.5		
14 & above	1	0.1		
Educational status				
No education(below school going age)	12	15.38		
Primary	63	80.77		
Middle/JSS/JHS	3	3.85		
Socio-demographic Variables	**Freq. (N=90)**	**Percent**	**Mean**	**Std. Dev.**
Hospitalization status				
	53	58.9		
OPD/Emergency	23	25.5		
Detention	14	15.6		
Admission				
Health Insurance Cover	837			
		92.2		
Covered by NHIS		7.8		
Not Covered by NHIS				

4.1.2 Socio-demographic characteristics of caregivers

In relation to the caregivers, it was found that most of the caregivers (80%) were females. The educational attainment of the caregivers showed that 34.8% had Junior High School education, 32.6% had senior high school/technical education, 20.2% had tertiary education and 8.9% primary education and 3.3% had no formal education. The employment status of the caregivers also revealed that a majority of them (81%) were employed in various sectors of the formal and informal economy of the Ghana. On the other hand, 16.6% were unemployed and 2.4% were retirees.

The salaries of those employed ranged between a minimum of GHS 100 and a maximum of GHS 3000 per month.

Among the unemployed, it was found that 55.6% of them received monthly allowances from relatives whilst the remaining 44.4% did not receive such financial support. An average of GHS 237.5 was received by caregivers as monthly allowances and it ranged between GHS 50 and GHS 800. Overall, the average monthly salary of the caregivers (including allowances) was GHS 1046.

The majority of the caregivers (95%) were enrolled on the national health insurance scheme.

Table 3: Socio-demographic characteristics of caregivers

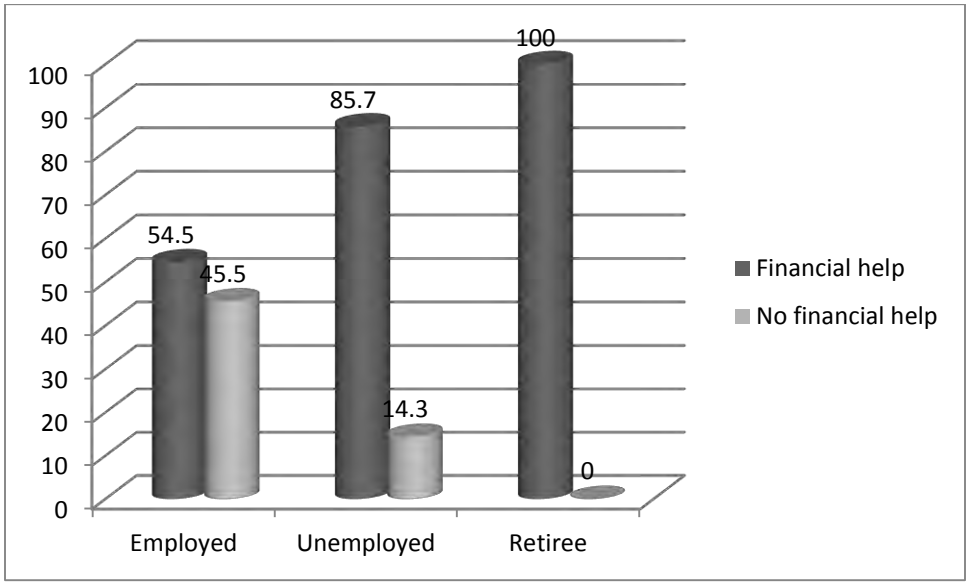
Variables	Freq.	Percent	Average	Std. Dev.
Age (in years)				
21-30	12	13.8	40	29.60
31-40	53	60.9		
41-50	11	12.6		
51-60	4	4.6		
61-70	4	4.6		
71 & above	2	2.3		
Educational status				
No education	3	3.37		
Primary	8	8.99		
Middle/JSS/JHS	31	34.83		

Variables	Freq.	Percent	Average	Std. Dev.
SSS/SHS/secondary/vocational/technical	29	32.58		
Tertiary	18	20.22		
Average income (In GHS)				
100-300	15	25	845.178	664.1413
400-700	19	31.9		
800-1000	12	20.0		
1101-1300	2	3.3		
1400 & above	12	20.0		
Employment status				
Employed	68	80.95		
Unemployed	14	16.67		
Retiree	2	2.38		
Allowances to support self and family				
Yes	10	55.56		
No	8	44.44		
Allowances received (in GHS)				
10-200	6	75	237.5	240.16
210-400	2	12.5		
410 & above	2	12.5		
Average monthly income (in GHS)				
100-500	12	41.4	1046.538	884.5968
600-1000	7	24.1		
1100-1500	5	17.2		
1500 & above	12	17.2		

4.1.3 Financial assistance caregiving for children with asthma

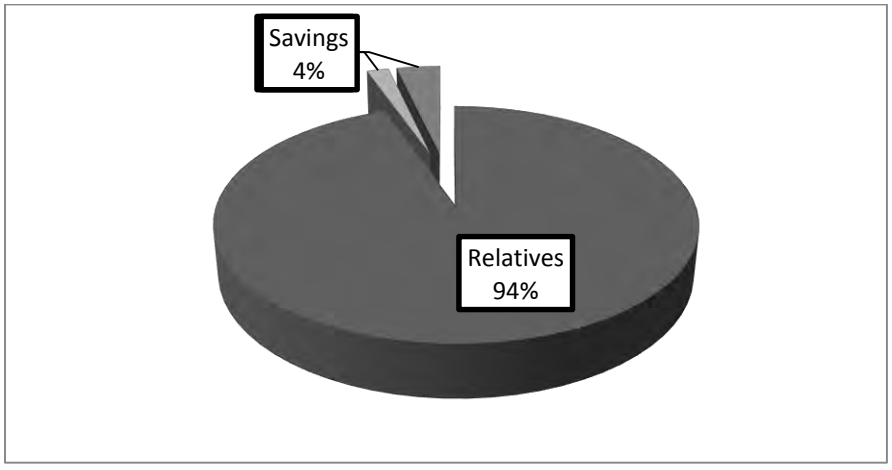
The results showed that 61.4% of caregivers received financial assistance from other sources to pay for the cost of the treatment of asthma. Further examination of the data revealed that gender and employment status had influence on dependence on financial assistance. More female caregivers (72.3%) than male caregivers (30.4%) depended on financial assistance in seeking care for children with asthma. Also, dependence on financial assistance for care giving was high among all occupational groups but was highest among retirees (100%), followed by unemployed (85.7%) but low among the employed (54.5%)

Figure 2 Employment status and dependence on financial assistance for asthma care



Caregivers received financial assistance from different sources. The large majority (98.3%) of the financial assistance were from , relatives (94.5%) and friends (1.8%). Only 2 out of 88 (1.7%) resorted to the use of savings to support the treatment of asthma.

Figure 3 Sources of financial assistance for asthma care



The analysis of the results indicated that the average financial assistance received by caregivers was GHS 139.26 (USD 29) and varies between GHS 50 and GHS 500. Majority of financial assistance (66.7%) were between GHS10 and GHS 100 followed by between GHS 110 and GHS 200 (18.5%). A few of the financial assistance (7.4% each) were between GHS 210 and GHS 300 as well as GHS 310 and above respectively.

Table 4: Amount of money received as finance assistance

Amount Received (in GHS)	Frequency	Percent
10-100	18	51.7
110-200	5	20.7
210-300	2	10.3
310 and above	2	17.3
Total	**27**	**100.0**

4.2 Direct medical cost of caregiving for children with asthma on households

The average cost of direct medical cost was GHS 4,644 (USD 967.5). The major cost item was medication which cost GHS 10517 (USD 2191.04) representing 66% of the direct medical cost and 43.9% of the average household cost of giving care. Treatment cost was estimated at GHS 972; cost of consultation was GHS 372 (USD 77.5and cost of registration was GHS 156 (32.5USD). Also, the cost of laboratory and other diagnostic tests was GHS 744 (USD 155).

Table 5: Direct medical cost of caregiving for children with asthma

Direct cost	Freq.	GHS	USD	% of Medical Cost	% of Total Cost
Registration	17	156	32.5	3.3	2.9
Consultation	66	372	77.5	8.0	6.8
Laboratory and other diagnostic tests	66	744	155	16.0	13.6
Medicines/drugs	90	2400	500	51.7	43.9
Other medications	33	972	202.5	20.1	17.8
Average		**4,644**	**967.5**	**100**	**84.9**

An interesting observation from the data was that the standard deviation for laboratory and diagnostic tests was 340. This wide dispersion is to be expected given that asthma treatment requires various laboratory and diagnostic tests during especially during exacerbation phase. Some of these laboratory tests during both exacerbations and maintenance phase are complete blood count, biochemical tests and urine analyses imaging tests include spirometry, electrocardiogram, chest X-ray and computerized tomography. .

4.2.1 Direct non-medical cost of caregiving for asthma on households

Direct non-medical cost also represents a substantial burden for families and households. The average of direct non-medical cost of giving care to children with asthma was estimated GHS **828**the equivalence of USD **172.5**. As evident in the table below, travel cost estimated at GHS 300 is a major component of the direct non-medical cost representing 36.2% followed by food cost (33.3 whilst the least cost component was miscellaneous items representing 26.1

Table 6: Direct non-medical cost of care giving for asthma children

Cost	Freq.	GHS	USD	% Non-medical	% of total cost
Travel cost	77	300	62.5	36.2	5.5
Food cost	69	276	57.5	33.3	5.0
Drinks/water cost	78	36	7.5	4.3	0.7
Miscellaneous items	12	216	45	26.1	3.9
Average		**828**	**172.5**	100.0	15.1

4.2.2 Average direct cost

As shown in the table below, the average of direct cost of caregiving for children with asthma was estimated at GHS 5,472(USD 1,140Direct medical cost formed the significant proportion of the direct cost representing 84.9% of direct cost whilst direct non-medical cost occupied the remaining 15.1%

Table 7: Average direct cost of households

Direct Cost	GHS	USD	Percentage
Direct Medical Cost	**4,644**	**967.5**	84.9
Direct Non-Medical	**828**	**172.5**	15.1
Average	5472	1140	100.0

4.3 Indirect cost of caregiving for children with asthma on households

Table 6 below presents information on the indirect cost of giving care for children with asthma. Absence from work is the single most single cost component forming more than 96% of the indirect cost.

Table 8: Indirect cost of giving care for children with asthma on households

Cost Items	Freq.	GHS	USD	% Indirect Cost	% of total Cost
Valued travel time	87	9.6	2.0	2.3	0.2
Valued waiting time	86	6.5	1.4	1.6	0.1
Valued absence from work	85	401.8	83.7	96.1	6.8
Average		417.9	87.1	100.0	7.1

4.4 Average cost of caregiving for children with asthma

The analysis has shown that overall, the average cost of caregiving for children with asthma per a household was GHS **5889.9 (USD 1227.1)**Total direct cost is estimated to be GHC 5472 (USD 1140)and forms 93% of the household cost of giving care to these children**.**

Table 9: Total cost of caregiving for children with asthma on households

Cost Component	Cost (in GHS)	Cost (in USSD)	Percent
Direct Cost	5472	1140	92.9
Indirect Cost	417.9	87.1	7.1
Total	**5889.9**	**1227.1**	**100.0**

Indirect Cost which was estimated to be GHS 417.9 (USD 87.1)represents 7% % of the household cost of giving care to children with asthma (See Table 10 and Figure 2).

Figure 4 Percentage of direct and indirect household cost of caregiving for children with asthma

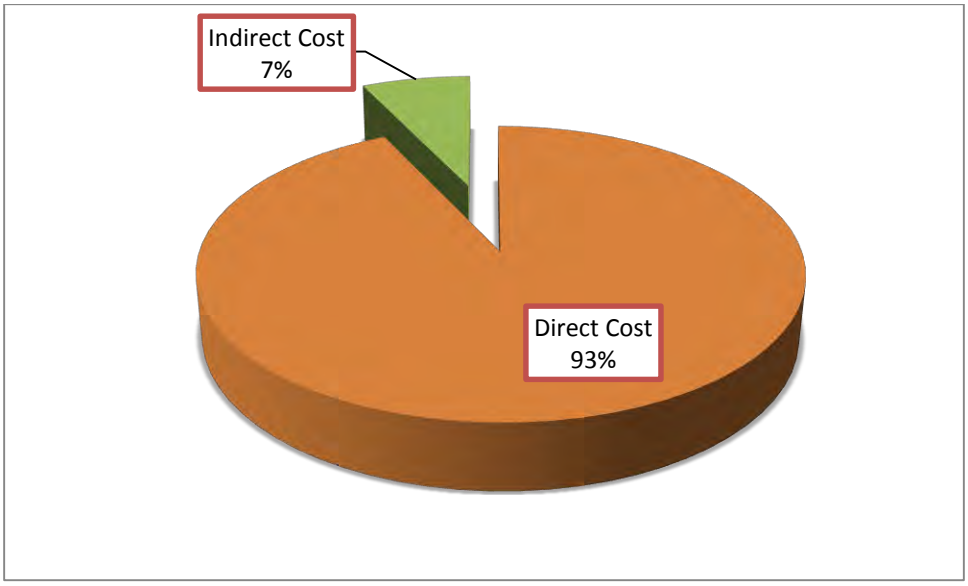


Table 10 Average cost of caregiving for children with Asthma

cost component	Freq. (n=90)	Cost GH₵	USD	Cost profile (%)
Direct Medical cost				
Registration	17	156	32.5	2.9
Consultation	66	372	77.5	6.8
Laboratory and other diagnostic tests	66	744	155	13.6
Medicines/drugs	90	2400	500	43.9
Treatment	33	972	202.5	17.8
Sub average		**4,644**	**967.5**	**84.9**
Direct Non- medical cost				
Travel cost		77	300	36.2
Food cost		69	276	33.3
Drinks/water cost		78	36	4.3
Other miscellaneous		12	216	26.1
Sub average		Total	**828**	100.0
Indirect cost			2.0	0.2
Valued travel time	87	9.6	1.4	0.1
Valued waiting time	86	6.5	83.7	6.8
Valued absent from work	85	401.8	87.1	
Sub average		417.9		7.1
AVERAGE COST		5889.9	1277.1	

Daily interbank US$ forex rate on 10th June, 2018 used was GHS 4.80.The national minimum wage per day (GHS 9.6) as at June, 2018 was used to value productivity days and time lost to caregiver.

4.5 Relationship between household cost for asthma care and others demographic characteristics

The results showed that there is much difference between the household cost for caregiving to male children and female children. Household cost is higher for male children with asthma (GHS 5586/USD 1163.8) than for female children with asthma (GHS 4749.6(989.5)). Indeed, households spend additional GHS 836.4 (USD 174.3) on boys than girls with asthma. However, the Chi-Square test (χ^2 = 0.541) showed that there is no significance difference between household cost for asthma treatment for boys and girls.

Table 11 : Sex of Child and household cost of caregiving to children with asthma

Sex of Patient	N=90	Cost (GHC)	Cost (USSD)	Value	df	Approx. Sig.
Male	49	5586	1163.8	79.875	81	.514
Female	41	4749.6	989.5			

Investigation into how the ages of the children affects the household cost of caregiving for children revealed that household cost increased with the age of children. The highest cost was on children between 2 and 5 years, followed by those between 6 and 9 years. The least amount is spent on children 1 year and below. The Pearson's Correlation test of significance (r= 0.713) showed that there is no significance difference between household cost for asthma treatment for children of different ages.

Table 12: Child's age and household cost of caregiving to children with asthma

Age Group	N=90	Cost (GHC)	Cost (USSD)	Value	Asymp. Std. Error[a]	Approx. T[b]	Approx. Sig.
≤ 1	8	2004	417.5	.039	.086	.370	.713[c]
2-5	46	3018	628.8				
6-9	15	6274.8	1307.3				
10 & above	14	3380.4	704.3				

Table 13 below presents information on the hospitalization status of children and the cost incurred by households. The results indicate that hospitalization is a major factor in determining household cost of caregiving. The cost was very high for households with children who were admitted to the

hospital. Indeed, the cost for households with asthma admitted children was twice that of households with children with OPD/Emergency asthma cases and those who were detained for less than 24 hours. However, the Chi-Square significance test ($(\chi^2 = 0.290)$) does not demonstrate that the hospitalization status does not influence the household treatment.

Table 13: Hospitalization status and household cost of caregiving to children with asthma

Hospitalization status	N=90	Cost (GHC)	Cost (USSD)	Value	df	Approx. Sig.
OPD	55	3338.4	695.5	171.45	162	.290
Detention	22	3310.8	689.8			
Admission	13	7210.8	1502.3			

The socio-economic group of care households also affected the cost of caregiving to children with asthma. The data as shown in Table 10 below demonstrates that different socio-economic groups incur different costs. Interestingly, an inverse/negative relationship was found between socio-economic status and the cost of giving care. Household cost of asthma care was highest among the poorest group, followed by the poor, then the middle income group with the highest income groups paying less for asthma care (See Table 13 below).

Table 14: Socio-economic status and household cost of caregiving to children with asthma

Hospitalization status	N=90	Cost (GHC)	Cost (USSD)	Value	df	Approx. Sig.
Poorest	25	3771.6	785.8	152.83	153	0.488
Poor	13	3217.2	670.3			
Middle	8	2538	527.8			
Rich	4	6871.2	1431.5			
Richest	3	3730.8	777.3			

4.6 Intangible cost of asthma

The psychological burden of caring for children with asthma was measured using the Zarit interview guide. The dominant burden of caregivers was mild to moderate burden (46.7%) followed by another significant percentage of caregivers (45.6) who had no to mild burden. Another 7.8% had high burden. Cumulatively, 54.4% of the caregivers had mild to moderate burden. This is an indication that the burden of caring for asthmatic children is mild to moderate among caregivers.

Table 15: Zarit burden interview for asthma caregivers

Burden	Freq.	Percentage
No to mild burden	41	45.6
Mild to moderate burden	42	46.7
High burden	7	7.8
Total	**90**	**100.0**

4.7 Sensitivity analysis of total cost of caregiving for children with asthma

Sensitivity analysis was performed to determine the robustness of the study. A variation of 5% and 10% of the cost of medication produced a percentage change of 2.4 and 4.8 respectively in the total cost. A variation of 25% of the cost of medication produced the highest percentage change of 12.1 in the total cost and -25.1 in the percentage change in the proportion of the direct cost. 23.4 changes in proportion of cost were produced in the proportion of indirect cost by the variations of the cost of medication. A variation of 5% and 10% in the wage rate produced 0.65% and 1.3% respectively in the total cost, 71.6% and 70.1% changes in proportion of direct cost and -66.6% and -65.3% changes in the indirect cost. A variation of 25% in the wage rate produced 3.2% change in the total cost and 66.2% and -61.6% in the proportion of the direct and indirect cost respectively. A variation of 5%, 10% and 25% of the cost of travel produced a percentage change of 0.35, 0.75 and 1.87 and 80.9%, 79.7%and 77.2% in the proportion of the direct and 75.3%, 74.3%, 71.8% in the proportion of the indirect cost. Lastly a variation of 5%, 10% and 25% of the cost of food produced a percentage change of 0.2, 0.4 and 0. 98 respectively and 90.0%, 89.6% and 88.2% in

the proportion of the direct and - 83.8%, -83.4% and -82.0% in the proportion change of the indirect cost.

A two-way sensitivity test was performed with multi-variation of the cost of medication, wage rate, travel cost and food cost. The results of the tests are shown in Table 16.

Table 16: Sensitivity analysis of total cost components

Scenario	Cost component	Percentage Change in Parameter (%)	Total Cost		Percentage in total cost	Proportions of total cost		Percentage change in proportions of cost	
			GHS	USD		Direct	Indirect	Direct	Indirect
Base scenario		0	10517	2191.04	0	48.2	51.8	0.0	0.0
Variation	Medication	5	11,042.85	2300.59	2.4	50.6	49.4	-5.0	4.6
		10	11,568.70	2410.15	4.8	53.1	46.9	-10.2	9.5
		25	13,146.25	2738.8	12.1	60.3	39.7	-25.1	23.4
Variation	Wage rate	5	2988.16	622.53	0.65	13.7	86.3	71.6	-66.6
		10	3130.51	652.19	1.3	14.4	85.6	70.1	-65.3
		25	3557.4	741.13	3.2	16.3	83.7	66.2	-61.6
Variation	Travel	5	1743	363.1	0.37	9.2	90.8	80.9	-75.3
		10	1826	380.4	0.75	9.7	90.3	79.9	-74.3
		25	2075	432.3	1.87	11	89	77.2	-71.8
Variation	Food	5	909.8	189.5	0.2	4.8	95.2	90.0	-83.8
		10	953.2	198.6	0.4	5	95	89.6	-83.4
		25	1083.1	225.6	0.98	5.7	94.3	88.2	-82.0

The cost of medication and the wage rate was varied by 5%, 10%, 25% increment respectively. The national minimum wage per day (GHS 9.6) as at June, 2018 was used to value productivity days lost to caregivers. Daily interbank US$ forex rate on 10th June, 2018 used was GHS4.8.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

This study investigated the cost of caregiving for children with asthma on households. Asthma being one of the most common chronic respiratory diseases in children creates significant financial, physical, social and psychological burdens for patients, households, families, the community and the healthcare system of the state.

5.1 Socio-demographic characteristics and clinical features

The study found that most of the children were males (55.6%). This result lends credence to other studies which found that asthma is more prevalent in male children than in females (1.5 to 2 times) (Pinto et al., 2010; National Jewish Health, 2009). In China male to female ratio of asthma disease is 1.75:1(Chen, 2003). Indeed, some studies have found that boys had twice the rate of asthma as girls (National Jewish Health, 2009). Interesting, the rates reverse once girls reach puberty (National Jewish Health, 2009).

In this study, the average age of children with asthma was 4 years. This is an indication that asthma was high among younger children than older ones as demonstrated by the fact that 54% were 4 years and below. Since majority of these children were enrolled in schools (88.9%), the prevalence of this disease among them is likely to affect their school attendance. In school children, there will be lost school days, which lead to limitation on study performance, with consequent psychological effects in asthmatic children.

Concerning the gender of caregivers, the analysis revealed that most those (80%) were females. Indeed, universally and throughout history women have being in the forefront of providing care for sick household members. This feminized caregiving role is still commonly perceived to be a part of "women's work" in societies throughout the world (Esplen, 2009). This perception persists despite more flexible sharing of household tasks by women and men (Hook, 2010). This finding is not surprising as in the Ghanaian and African cultural setting, the gender socialization stresses men working outside the home become the breadwinner of the family and not socialized to be a caregiver. Women on the other hand were socialized to be work within the domestic sphere and to assume the role of a caregiver. Additionally, theories of segregation of labour indicate that since women are more likely to stay at home it is natural for them to take up the caregiver role (Papastavrou et al., 2009). Sharma et al. (2016) buttress this point affirming that all over the world women are the predominant providers of informal care for family members with chronic medical conditions or disabilities, including the elderly and adults. The sociological explanation here is that there are several societal and cultural demands on women to adopt the role of a family-caregiver. For instance, in the United Stated 60% of caregivers of asthmatic children are women (National Alliance for Caregiving & AARP, 2015).

5.2 Direct cost of caregiving for children with asthma

In this study, the average direct cost was GHS**5,889.9** (USD **1227.1**This finding is similar to other studies found in literature. For instance, the average cost of asthma in the in the USA is 3,266 dollars (Nurmagambetov, Kuwahara & Paul Garbe, 2018), that of New Zealand is 2584 dollars (Rank et al., 2012), in Sweden the cost is 1315 dollars (Serra-Batlles et al, 1998) and in Hong

Kong the cost is $ 1010 (Lai et al., 2006). , It can be noted that the cost observed in this study is lower than those observed by studies done in developed countries as described.

In this study, cost of medication which was GHS 2,400(USD 500.00) was the key cost driver of the direct cost representing 51.7% of the direct medical cost and 43.9 of the total household cost of giving care. Several studies have observed that medication costs are the largest cost component of direct costs in North America and Europe, ranging from 51% in USA to 68% in Canada (Barnett & Nurmagambetov, 2011) and in Europe from 45% in Spain to 84% in Germany (Accordini et al., 2013). In Turkey, one study noted that medication cost was very high at 81% of direct cost (Celik et al., 2004). In the US, Bui et al. (2017) observed that in children with asthma, medication costs account for over 47% of all medical costs associated with asthma, which is very close to the 43.9% estimate in this study.

Also in this study, the direct cost (GHC 5,472/USD 1,140) constituted 93% of the total cost of asthma. Indeed, most studies on the cost of asthma have observed that direct cost are higher than the indirect cost (Ismaila et al., 2013, Bedouch et al., 2012; Lee et al., 2011; Cisternas et al., 2003). However, this finding contradicts that of Accordini et al. (2013) whose study in England estimated the average cost of asthma care at €1,583 with indirect accounting for 62.5% of the total cost.

The direct medical cost observed in this study (GHC 5,472/USD 1,140) could have been higher than this given that the 95.4% of the children with asthma were enrolled on the national health insurance scheme, which covers 95% of the disease burden in Ghana as well as services such as outpatient services, most in-patient services, including specialist care, hospital accommodation (general ward); emergency care; and all drugs on the centrally-established National Health Insurance Authority (NHIA) Medicines List. However, patients must pay for laboratory services and medications that were not covered by the National Health Insurance Scheme.

It was also observed that the cost travel and food took contributed significantly to the direct non-medical cost. Travel cost alone formed 36.22% of the direct non-medical cost whilst food constituted 33.3%. These are hidden cost of asthma care yet have serious implications on the ability of households to afford the essentials, particularly certain medications for children with asthma.

5.3 Indirect cost of caregiving for children with asthma

In this study the indirect cost of asthma was GHS 417 (USD 87.1) which accounted for 13.6% of the total cost, similar to lower trend of indirect cost associated with asthma found in studies in Germany (Aumann et al., 2014), Canada (Ismaila, et al., 2013); South Korea (Lee et al. 2011), the US (Rank, 2012) and Spain (Martínez-Moragón, 2009). The only exception was Accordini et al. (2013) which found the indirect cost of asthma to be higher (62.5%) in 11 European countries communities.

An interesting finding from this study was that care giving for children with asthma restricted the participation of caregivers in economic activities resulting in absenteeism. Indeed, on average caregivers were absent from work for 7.4 days, The cost of lost working days in this study was GHS 401.8 (USD 83.7) and accounted for 96.1% of the indirect cost. Asthma has been shown to restrict the working days of sufferers and in this study it has an indirect effect on caregivers of children with asthma. This is because patients need some free periods for rehabilitation whilst in some cases especially in retirement from work as a result of the incapacity to have normal productive life (Nunes et al., 2017). According to the Global Asthma Report (2014) this phenomenon contributes greatly to indirect cost which is also reflection of the disability-adjusted life year (DALY), a measure of the overall disease burden expressed as the number of years lost to ill-health, disability or early death.

The issue of work absenteeism causes great productivity losses. For instance Ojeda et al. (2013) found that asthma contributed to an average of 14 absenteeism days annually, Sadatsafavi et al. (2014) observed that asthma condition led to 13 days; Goetzel et al. (2004) found 12 absent days gper year and Wang et al. (2003) it led to 10.6 absenteeism days annually. Absenteeism from work in particular is not only a great loss to individuals and households but also a huge loss to economies of countries. Rasmussen, Sweeny and Sheenan (2016) estimated the economic cost due to productivity losses arising from absenteeism, presenteeism and early retirement due to ill health to be between 5.2% and 8.5% of the Gross Domestic Products of most developed economies. For instance in the UK, sick absences alone is estimated to cost UK business firms 29 billion British Pounds a year, with workers taking an average of 6.6 days off each year (CIPD, 2015; PWD Research 2013).

This serious implication can occur here is not only the financial cost, but also on the education of children with the condition of asthma. Since majority of the children with asthma were in school, spending 3.3 days in the hospital due to admission, OPD attendance and detention as well as staying home for 7.4 days means that they have missed schools. This will in a long way affect the learning ability of these children likely to result in poor grades for them which will greatly affect their chances of getting good jobs in their adult life and therefore denied them the chance of living a fulfilled life. Asthma has been identified as the most common cause of school absenteeism due to chronic conditions (Wang et al, 2005). This American study found that asthma accounts for 2.48 days of missed school per child with asthma. When other impacts were included (such as parents taking time off work to care for their child, and future lost earnings due to childhood mortality from asthma), the total economic costs were $791 per child with asthma. Moonie et al (2006) has

identified that up to 35% of school absences have been attributed to asthma-related symptoms among school-aged children.

5.4 Socio-economic status and cost of asthma care

An important finding in this study was that socio-demographic features affected household cost of asthma care. In terms of gender, there is a wide variation between the household cost for male children with asthma (GHS 5586/ USD1163.8) and female children with asthma (GHS 4749.6/USD 989.5). This finding contrasts the findings of Ghaffari (2014) and Delloitte Economics (2015) who found that total cost of asthma treatment was higher for females' children than males. Deloitte Economics (2015) found that total cost per a person in Australia in 2015 were slightly more for females ($579) compared to males ($459). The high cost observed in this study can be attributed to the high prevalence of male children (55.6% against 44.4% females) in the study, which drives up the cost of the disease for this group.

Also, it was noted that the cost of asthma increases with age, with the highest cost among children aged 2 and 5 years and least among children 1 year and below. This could be attributed to the fact most health care services are free for children under 1 year even without the payment of the health insurance premium. Therefore, older children between 2 years and above are required to pay for laboratory, consultation and admission costs if they are not enrolled on the National Health Insurance. Similar result was found in an Australian study which observed that total costs of asthma are highest in the 5-9-year-old male age group but lowest for children under 4 years (Deloitte Economics, 2015).

Lastly, the socio-economic status of households also had significant effect on the cost of asthma for children. In this study, the poorer the households, the more cost they have to pay for asthma,

with the poorest group shouldering the highest cost of asthma. Previous studies have confirmed this result. It has been shown by past studies that persons with incomes 100% of the poverty threshold have significantly higher medical costs because of asthma than those with higher incomes (Nurmagambetov et al. 2017). A reasonable explanation for this is that people with lower incomes often live in places with higher concentrations of environmental asthma triggers (Alhanti et al., 2016; Kattan et al., 2005). Indoor and outdoor environmental pollution are major factors contributing to higher risk for asthma attacks and higher cost of asthma (Nurmagambetov et al. 2017; Alhanti et al., 2016) This is because with increasing urbanization in Ghana and everywhere in the developing, the poor live in poor areas with high population concentration and are therefore exposed to acute respiratory infections, and/or occupational irritants/allergens and tobacco consumption and/or passive exposure, among others (Akinbami et al., 2012; Aligne et al, 2000). Additionally, such poor people are economically disadvantaged and this prevents them from buying controller medication, have inadequate financial resources to enable them access outpatient health professionals and/or equipment. Unfortunately, this study observed that only a few of the caregivers/ households had landed properties that are of high economic value which can be used as collateral to secure funding to pay for treatment of asthma in the event of a serious asthma attack. The implication is that a large majority of the caregivers cannot secure credit from financial institutions if collaterals are demanded and this further exacerbates not only the poor financial position of the caregivers but also the health of the asthmatic child.

5.5 Intangible burden of asthma

Various intangible burden of the cost of asthma were observed in this study. There were social, emotional and human costs of the asthma care. It was found that 54.5% of the caregivers had moderate to high burden. Previous studies have observed that caregivers of children with a chronic

illness may experience poor sleep quality (Meltzer & Mindell, 2006), family conflict (Chen et al., 2015), anxiety, depression (Malm-Buatsi et al., 2015), financial stress (Rodrigue et al., 1997), and lower quality of life (Salvador et al., 2015). The mild to moderate burden among the caregivers is an indication of the poor well-being of the caregivers which research has shown has negative effects on the children with chronic conditions such as asthma (Armstrong et al., 2005). Therefore it is safe to conclude that it is not only the individuals who are impacted by giving care to asthmatic children (Caicedo, 2013), but also some households and families are affected by having a child with a chronic conditions such as asthma. Additionally, the intangible component of the cost constrains and limits the life not only of the sufferers but also of the caregivers affecting their performance in work, productivity and psychological state of mind.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.0 CONCLUSION

This study provides evidence of a high economic burden and financial stress among family caregivers for the children with asthma. Although many family caregivers are committed to taking care of their children with asthma condition, their commitments and filial obligations should however, not be taken for granted, since asthma is a lifelong condition and its management makes a huge demand resource available to individuals, households and the society at large. These financial challenges and economic burden of family caregivers with children with asthma as shown in this study, if unaddressed, could further weaken the family support system for the children with asthma. This study therefore concludes that, it is imperative to address the financial needs and security of family caregivers with children with asthma. 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 children with asthma. In addition, it is also important to address the context of the family caregivers who are females, who invariably bear a higher care giving burden. It is therefore important that asthma care is given high priority in national health policy and planning in order to promote easy and affordable access to preventive and curative care in Ghana.

6.1 RECOMMENDATION

The study makes the following suggestions for improving management, treatment and finance of asthma care for both children and adults in Ghana.

1. 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 with asthma children. These studies should investigate the extent to which they may be at high risk of poverty and inability to sustain their caregiving obligations.
2. Treatment of asthma should be made free due to the high cost which many parents and caregivers cannot afford.
3. Since asthma medications is the major cost component of the household cost, the inclusion of all asthma related or the major asthma medications in the medicine list of the NHIS will go a long way to alleviate the economic burden of asthma care on households. This should be a matter of priority especially for children under 15 years with asthma.

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APPENDICES

Appendix A: Informed Consent Form

Project Title: Household cost of caregiving for children with asthma in selected hospitals in Accra.

Background

My name is Evelyn Acquaah, a student from University of Ghana, legon. I am conducting a study on the household cost of caregiving for children with asthma in selected Hospitals in Accra. The main objective of this study is to estimate the household cost of caregiving for children with asthma in selected Hospitals in Accra.

Procedures

The study will involve answering questions from a structured questionnaire about the cost incurred by a care giver of a patient seeking medical health care. No coercion will be used to obtain response from participants. It will be appreciated if you could participate in this study. This is an academic research which forms part of my work for the award of Masters Degree in Public Health.

Risks and Benefits

The study population and other stakeholders in the medical health care will benefit from this study. The study population, the estimation will show the effect of asthma disease on patient who attends the selected hospitals in Accra especially to identify the costs involved in treating such diseases and loss of productivity due to the disease in order to influence stakeholders to take more preventive than curative measures towards asthma condition. There are no risks associated with the study.

Right to Refuse

Participation in this study is voluntary. You are allowed to answer any individual question or all the questions. You can withdraw from the study at any time however; you are encouraged to fully participate in the study.

Anonymity and confidentiality

The information obtained in this study will be kept confidential and will not be accessed by an unauthorized person.

Dissemination of Results

A Durbar will be held at the hospital that is PML to disseminate the findings of the study. A copy of the study will be kept at the hospital for reference.

Before taking the consent

Do you have any concerns about the study that you wish to be addressed?

Yes ☐
No ☐

If yes, please indicate your concern below.

……

……

If you have any questions later please, contact Evelyn Acquaah (0243111878, or eveacquaah @ yahoo.com) or The Ghana Health Service Ethical Review Committee administrator Hannah Frimpong (0243235225 or 0507041223).

Voluntary Consent

I have read the information given or the given information has been read and duly explained to me. My concerns about this study have been addressed. I now voluntarily agree to participate in

this study knowing that I have the right to withdraw from the study at any time without it affecting my ability to access medical health care at this facility in the future.

……. …… …….. ……..

(Name of participant) (Signature) (Thumbprint) (Date)

……. ……. …….. …….

(Name of Researcher) (Signature) (Thumbprint) (Date)

Interviewer's Statement

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

The participant has agreed to fully participant in this study.

Signature of Research Assistant……

Date……

Address……..

APPENDIX B: QUESTIONAIRE

Dear Respondent,

This is a research carried out on ***Household cost of care giving for children with asthma attending Princess Marie Louis Hospital in Accra.*** I will therefore like to take a few minutes of your precious time to answer these questions. You are assured that the answers you give will be strictly confidential and your name will not be mentioned in my research reports. Thank you. (THIS IS BRIEF INTRODUCTION).

Qn. No.	Questions	Response
		Respondent ID: |___|___|___|
Section 1	**Socio-demographic information**	
1	What is the sex of your child 1. Male 2. Female	|___|
2	What is your child's age in years (i.e. age at last birthday)?	_____|_____| years
3	What is the highest level of school of your child? 1. No education 2. Primary 3. Middle/JSS/JHS	|_____|
4	Category of patient 1. OPD/Emergency 2. Detention 3. Admission	|_____|
5	What is your sex 1. Male 2. Female	|___|
6	What is your age in years (i.e. age at last birthday)?	|___|___| years
7	What is the highest level of school you attended? 1. No education 2. Primary 3. Middle/JSS/JHS 4. SSS/SHS/Secondary/Vocational/Technical 5. Tertiary	|___|
8	What is your current marital status? 1. Married 2. Not married	|___|

9	What is your average income per month	|___|
10	What is your employment status? 1. Employed 2. Unemployed (*If **Unemployed**, answer Qns. 6 & 7)* 3. Student/Apprentice 4. Housewife 5. Retiree	|___|
11	If Unemployed, why are you not working now? 1. Unable to work due to illness 2. Other (please specify)..……	|___|
12	If Unemployed, have you been looking for a job in the last 6 months? 1. Yes 2. No	|___|
13	If employed, in which sector are you employed? 1. Formal sector 2. Informal sector	|___|
14	If Employed, what is your average monthly income? (i.e., salary plus other monies from other sources)	GHS …….
Section 2	**Direct cost information**	
15	***Medical cost: how much did you spend/pay for during your last hospital visit or in the past … month(s) (choose as appropriate depending on chosen costing period) ….***	GHS
	(a) Registration	
	(b) Consultation	
	(c) Laboratory & other diagnostic tests	
	(d) Medicines/drugs	
	(e) Treatment	
	(f) Others, specify	
16	***Non-medical cost: how much did you spend/pay for (you and accompanying relative)….***	GHS
	(a) Travel cost (to and from the facility)	
	(b) Food cost	
	(c) Drinks/water cost	

	(d) Other miscellaneous costs (i.e., phone calls/phone credits used due to this illness)	
17	**Did you rely on financial help from other source(s) for treatment, apart from normal income?** **1. Yes** **2. No**	
18	**What are the sources (multiple responses possible)?** **1. Relative** **2. Friend** **3. Savings** **4. Loan/Grant** **5. Other (Specify)**	
19	**How much money did you receive from the identified source(s)?**	
Section 3	**Indirect cost information**	
20	How many days have you absent from work (if applicable) in the last month because of your illness (i.e. treatment, recovery)?	|___|___|___| days
21	How many minutes did you spend travelling to and from the health facility?	|___|___|___| Mins.
22	How many minutes did you spend waiting before you were called to see the doctor or health officer for treatment?	|___|___|___| Mins.
23	Did anyone accompany you from home to the health facility? 1. Yes 2. No	|___|
24	If anyone did accompany you to the health facility, what is his or her employment status? 1. Employed 2. Unemployed 3. Student 4. Housewife 5. Retired	
25	Did the person who accompanied you, come with you from the house and stayed with you for treatment and take you back home? 1. Yes 2.	|___|
	IF YES IN Qn16, USE SAME TIME AS THE PATIENT SEE Qns 12 & 13	
26	If No in Qn16, how many hours/minutes in total did he/she travel to and fro to be with you in the health facility?	|___|___|___| Mins.

27	If No in Qn16, how many hours/minutes in total did he/she spend with you when you were receiving treatment in the health facility?	|___|___|___| Mins.
28	Did someone in your household have to take care of you while you were ill? 1. Yes 2. No	|___|
29	If Yes in Qn 19, how many days did he/she have to take care of you?	|___|___| days

Intangible Burden Questionnaire

I will ask you few questions and you are to respond on the 5-scale item from Never, Rarely, Sometimes, Quite frequently and Nearly always.

ZARIT BURDEN INTERVIEW (Please circle the response that best describes how you feel)						
	Never	rarely	sometimes	Quite frequently	Nearly always	Score
30. 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	
31. Do you feel stressed between caring for your relative and trying to meet other responsibilities	0	1	2	3	4	
32. Do you feel angry when you are around the relative?	0	1	2	3	4	
33. Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4	
34. Do you feel strained when you are around your relative?	0	1	2	3	4	
35. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4	
36. Do you feel that you don't have has						

much privacy as you would like because of your relative?	0	1	2	3	4	
37. Do you feel that your social life has sufferedbecause you are caring for your relative?	0	1	2	3	4	
38. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4	
39. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
40. Do you feel you should be doing more for your relative?	0	1	2	3	4	
41. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	

Appendix C: Statement for respondent

This statement is applicable to those who request for translation

I attest that I have in the presence of the participant (undersigned/thumb printed), translated the purpose, aims, objectives and benefits of this research from the English language to the local language he/she best understands.

The respondent may confirm an understanding of the purpose, aims, objectives and benefits of this research and is willing to participate.

Name of witness: ……..

Signature: ……

Name of participant: ……

Signature/thumbprint: …….

Name of Researcher:…….

Signature:…….

Name of participant: ……

Signature/thumbprint: …….

Name of Researcher:…….

Signature:…….