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ECONOMIC BURDEN AND QUALITY OF LIFE OF PRIMARY CAREGIVERS OF LYMPHOMA PATIENTS ATTENDING THE PAEDIATRIC CANCER UNIT AT KOMFO ANOKYE TEACHING HOSPITAL

BY

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DECLARATION

I, Cromwell Prince Dawson do hereby declare that excluding precise references which have been duly acknowledged, the work was entirely done by me. This work is as a result of my own research toward the award of Master of Public Health Degree and that, to the best of my knowledge, it contains no material previously published by another person nor material which has been accepted for the award of any other degree of the University or elsewhere.

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DATE

DEDICATION

I dedicate this work to God Almighty, my family and friends. A special feeling of gratitude to my parents Mr. Oliver Abeiku Cromwell and Mrs. Elizabeth Yalley for their words of encouragement always. There is no doubt in my mind that without their support and counsel I could not have completed this dissertation.

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ABSTRACT

BACKGROUND: Lymphoma is a type of blood cancer that affects the white blood cells**.**Lymphoma is a major cause of high morbidity and mortality rates worldwide with over 350,000 cases yearly. In sub- Saharan Africa, its high incidence rate has been attributed to the high prevalence of malaria and HIV/ AIDS thereby increasing the burden of the disease. Lymphoma is the highest contributor among the top four cancers with leukemia, eye and kidney cancers, which together account for 70% predominant childhood cancers in Ghana. Lymphoma patients demand intensive care requiring support of primary caregivers and as a result, affect their quality of life.

OBJECTIVE: The objective of the study was to determine the economic burden and quality of life of primary caregivers of lymphoma patients.

Method: The study was a cross- sectional study involving primary caregivers of lymphoma patients attending the pediatric cancer unit at KomfoAnokye Teaching Hospital. The study adopted a cost- of- illness approach using a sample size of 156 primary caregivers. Direct cost was categorized into medical and non- medical cost incurred by primary caregivers over a month period. Indirect cost was estimated as the value of productive days lost to primary caregivers. Zarit Burden Interview was used to determine primary caregiver burden (intangible cost) while EUROHIS- QoL was used to determine the quality of life of primary caregivers. Data was entered into Microsoft Excel and Stata version 15 for analysis.

RESULT: The median cost per month incurred by primary caregivers of lymphoma patients was estimated at GHS 1,957.92 (USD 409.61) of which median direct cost was GHS 1,895.00 (USD 396.44) per caregiver in a month representing 97% of the total cost profile. Median indirect cost per caregiver was estimated at GHS 62.92 (USD 13.16) in a month and represented 3% of the cost profile. Time spent by unemployed and student caregivers were not valued as they were not making any actual earnings. Male primary caregivers reported high caregiver burden than females with 94% of primary caregivers reporting high and 6% reporting low caregiver burden. Females recorded lower quality of life than males. Out of 156 primary caregivers, 85.26% recorded low quality of life, 11.24% recorded moderate quality of life and smaller proportion of 3.21% recorded high quality of life.

CONCLUSION: The result showed that most primary caregivers were burdened with the care they provide to their care recipients as they incur huge medical and non-medical cost. The study also found out that some primary caregivers had to reduce workload due to the burden that comes with caring for lymphoma patients which mostly affect their quality of life. Although majority of primary caregivers were females, men reported being burdened psychologically than the females and more females reported to have lower quality of life than the male primary caregivers.

Key words: Burden, Quality of life, Lymphoma, Direct cost, Indirect cost, Intangible cost.

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LIST OF ABBREVIATIONS

ADL…….. …… Activity of Daily Living

AIDS……. Acquired Immuno Deficiency Syndrome

HIV…… Human Immunodeficiency Virus

KATH…… KomfoAnokye Teaching Hospital

LMICs……..... Low and Middle Income Countries

QoL…… Quality of Life

USA…….. United States of America

WHO……..World Health Organization

WHO EUROHIS QoL……World Health Organization European Quality of Life

ZBI……. Zarit Burden Interview

NHL…… Non- Hodgkin Lymphoma

CHAPTER ONE

INTRODUCTION

1.1 Background

Lymphoma is a malignant neoplastic disease of the lymphatic system which mostly affects the lymph cell white blood cells. These lymphocytes play a major role in the immune system by fighting infections and diseases in the physical structure of the body. Lymphoma can occur at any age, but very common in children between the ages of 2 to 14 years and young adults between the ages of 15 to 24 years. Lymphomas occur in two types; the Hodgkin and non-Hodgkin lymphoma. The non- Hodgkin lymphomas are the most common accounting for about 90% of lymphoma cases worldwide (Lymphoma Research Foundation, 2016). In 2012, out of the 14.1 million cancer cases that were recorded, 452,000 were lymphoma cases and it represented 3.2% of the total cancer cases globally (WCRF International, 2015). According to the American Cancer Society (2015), 500 children up to age 14 are diagnosed with lymphomas yearly in United States of America (USA).

The prevalence of lymphoma varies widely among countries and regions. It is very common in developed as compared to developing countries. There is a high incidence rate of lymphoma in Australia, Western and Northern Europe, Northern America and Eastern Africa(Torre et al., 2015). The highest incidence rates of lymphoma in Africa are due to the high incidence of malaria and AIDS which cause a subtype of NHL in children called Burritt's lymphoma. Thus, repeated malaria infection makes an individual susceptible to lymphoma and also there is a high risk of an AIDS patient developing lymphoma(Orem et al., 2007).

According to the Leukemia and Lymphoma Society (2017), there are an estimated 816,634 people living with or abatting from lymphoma in the US. Non - Hodgkin lymphoma is the most common with an estimated rate over 7.5 per 100,000 and mortality rates over 5.7 per 100,000 in the eastern parts of Africa. Lymphoma is classified as one of the top four cancers in Africa and it is more prevalent in males than females.In Ghana, lymphoma is one of the top four cancers including leukemia, eye and kidney cancers, which together account for about 70% of all childhood cancers in the country (Ghana News Agency, 2017). Quality data on cancer in developing countries has become a challenge despite the significance of such registries in informing and facilitating cancer prevention and control programmes. This has led to difficulties in estimating prevalence of cancer diseases in these countries. However, GLOBOCAN has estimated lymphoma (Non- Hodgkin) as one of the leading cancers in both males and females (Laryea et al., 2014). A study by Segbefia, Renner, Adomakoh& Welbeck (2013) on the pattern of childhood cancers found that, out of the 495 new cases reported at KBTH in 2011, lymphomas represented 30.7% of them making it the predominant cancer diagnosed in children.

The treatment depends on how early the predicament is reported to the hospital because when it gets to the latter stages of the diseases where only palliative care could be given instead of curative treatment, the burden of the disease increases on both patient and the primary caregiver. Lymphoma treatment modalities include chemotherapy, radiotherapy, peripheral stem cell transplantation and surgery (Deniz &Inci, 2015). The main intent of these treatment modalities is extending life, controlling treatment- related reactions and enhancing personal satisfaction (Akdemir&Birol, 2004). Treatment of lymphoma is associated with direct and indirect cost which increases with the disease progression. Most cases are reported late and as a result seen

during end stages where only palliative care could be offered, thus a lifetime treatment till the death of the patient.

Lymphoma cancer primarily places a demand on primary caregivers who take up the responsibility to provide care to patients (Akosile, 2013). Caring for cancer patients is becoming increasingly common due to its rising incidence. This places a responsibility on family to provide psychosocial, economic and emotional needs for patients. Thus, caring for lymphoma patient demands some financial commitment in terms of the acquisition of medicines, paying for medical bills and other expenses which normally are too heavy to bear by primary caregivers (Joo, Dunet, Fang & Wang, 2015).

Primary caregivers in LMICs are largely family members, many of whom become economically unproductive as they devote their time to the upkeep of their patients. As a result, it affect the quality of life of these primary caregivers. Again, majority of lymphoma patients in Ghana are children below the ages of 19 who require intensive care.

This study seeks to investigate the burden and quality of life primary caregivers of patients, particularly children with lymphoma.

1.2 Problem Statement

Caring for lymphoma patient places a huge responsibility on the family to provide psychosocial, emotional and economic needs for the patient. Primary caregivers in Ghana are mostly family members, many of whom remain economically unproductive as they must sacrifice their time for the upkeep of the patient (Mortey, 2017). Caring for lymphoma patients add up to the problems of the caregivers. This may cause caregivers to be in despair, limited and also pose a challenge to them in meeting their own needs. This situation can cause their quality of life to reduce and may

result in psychological problems. This can affect the well being of both the caregiver and the patient because their health may be neglected (Ferhanoglu, Bolaman, &Soysal, 2013).

Most Lymphoma cases in Africa, especially Ghana occur in children between the ages of 2 to 14 years and young adult between the ages of 15 to 24 years and as a result, the burden associated with the disease increases to both patient and caregiver especially when the disease reaches the latter stage. This comes with stress to the caregiver as the patient has to be taken to the hospital for checkups and consultation all the time, resulting in productivity loss. Productivity is lost when caregivers spend more time with the patient than at the workplace. The Ghana News Agency (2016) reported that, most of these cancer cases were presented at a late stage where only palliative care could be offered. High cost of treatment led to over 40 percent of the patients abandoning treatment because of the cost the families had to bear.

The incidence of lymphoma will have two immediate potential effects on the primary caregiver; the primary caregiver may have to reduce the normal level of productive activity, whether paid or unpaid and the household may need to consume an additional or extra health services or goods at the detriment of other equally essential goods and services (Jamison et al., 2009). These may adversely affect the quality of life of the primary caregiver by affecting his/her physiological and psychological well-being as they become financially burdened. The financial and non-financial burden involved makes caregivers prone to other health risk such as, depression, anxiety which affects their quality of life.

Primary caregivers are considered to be helpers in the care process without being acknowledged as people who go through the pains in providing care to the patient. The economic burden of lymphoma; direct, indirect and intangible cost and quality of life of primary caregivers have

received little or no attention in Ghana despite the immense effect caregiving has on quality of life. Limited evidence exist in Ghana and other LMICs. Hence, this study seeks to determine the economic burden of lymphoma patients on primary caregivers and how this influences their quality of life.

1.3 Study objectives

1.3.1 General objective

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

1.3.2 Specific objectives

Specifically, this study sought to;

1. Estimate direct cost incurred by primary caregivers of lymphoma patients
2. Estimate indirect cost incurred by primary caregivers of lymphoma patients
3. Describe intangible cost incurred by primary caregivers of lymphoma patients
4. Determine the quality of life of primary caregivers of lymphoma patients

1.4 Research questions

The study sought answers to the following research questions:

1. What is the direct cost incurred by primary caregivers of lymphoma patients?
2. What is the indirect cost, i.e. productivity loss to primary caregivers of lymphoma patients?
3. What are the intangible costs incurred by primary caregivers of lymphoma patients?

4. What is the quality of life of primary caregivers of lymphoma patients?

1.5 Justification

Lymphoma has become one of the most common types of cancers in Ghana especially among children and it has become a public health issue which needs to be explored.However, there is paucity of studies exploring the economic burden (in terms of cost and quality of life) of lymphoma on households and primary caregivers in Ghana.

In view of the scarce available information on the prevalence of lymphoma and cost associated with it among people inGhana, this study will contribute to fill in the knowledge gaps in relation to the burden and the quality of life of primary caregivers of lymphoma patients. Lymphoma incidence in a household reduces the economic activity of the primary caregiver.

Therefore, it is important to assess the economic implications and intangible cost to the primary caregivers. This study will provide essential findings, which will in turn be very useful in understanding the real issues and concerns of primary caregivers. It is also expected to provide the most relevant information to policy makers in order to facilitate policies on lymphoma care.

1.6 Conceptual framework

The conceptual framework as illustrated in the figure 1.1 depicts the burden and quality of life of primary caregivers of lymphoma patients. For the purpose of this study, economic burden associated with lymphoma refers to the cost involved, which is divided into three main components; direct, indirect and intangible cost. With the incidence of lymphoma in a family, the household or family who represent the primary caregivers incurs cost in the form of medical, consultation, drug purchases, chemotherapy sessions and also laboratory test. These constitute the direct cost. Indirect cost is the productivity loss to the primary caregiver and is essential in

measuring the cost of illness. It involves the travel time from house to hospital and waiting time at the hospital. Intangible cost on the other hand is defined as the stress and pain caregivers go through because of the disease. The incidence of lymphoma may affect the quality of life of primary caregiver in terms of their physical and psychological health.

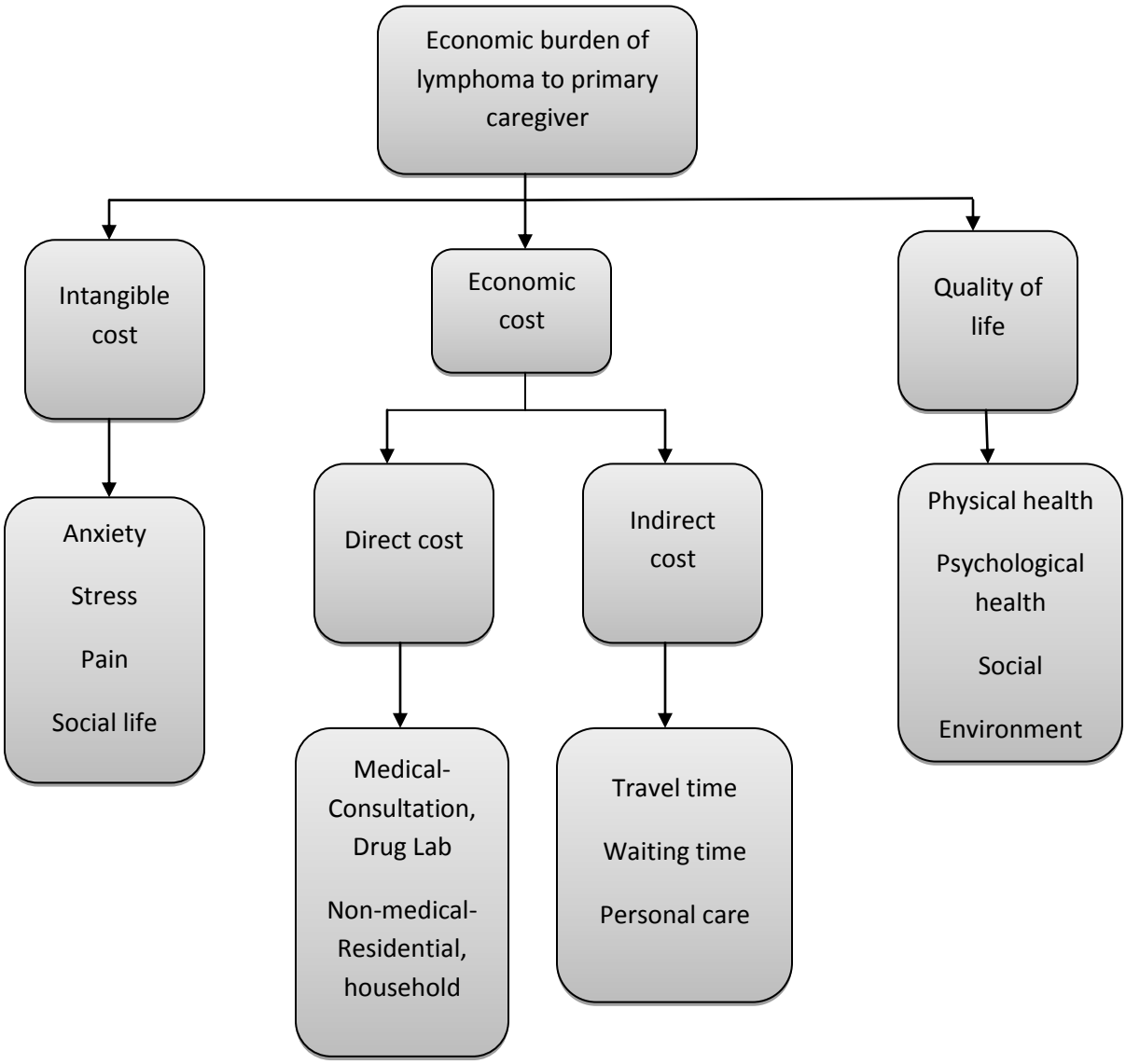

Figure 1.1: Diagram of the Conceptual Framework

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews relevant literature related to the burden of lymphoma on primary caregivers. It will provide an overview of lymphoma, its associated issues and the caregiving for the lymphoma patient. It also discusses how lymphoma patient becomes a burden to their caregivers. Furthermore, this chapter gives an insight about the quality of life of these caregivers. The review concludes by stating the crucial roles that caregivers play across the health continuum.

2.2 Definition and Scope of lymphoma

Cancer begins when there is an uncontrolled reproduction of abnormal cells in the body that thrives well and spread instead of dying as they would in the lifespan of a normal cell (Lymphoma research foundation, 2016).

Lymphoma is a type of blood cancer which takes place in cells called lymphocytes. These lymphocytes contain the white blood cells which are responsible for protecting the body against infections and diseases (American Cancer Society, 2015). Lymphoma is the most widely recognized blood cancers often coupled with the rapid spread of the cancerous lymphocytes from the lymph nodes to other parts of the body, thus rendering the body feeble in fighting against infections. Symptoms include continous fever without infection, night sweats, fever and chills, weight reduction and loss of appetite, unusual itching, persevering fatigue and pain in lymph nodes after drinking alcohol. Other signs that can show Non-Hodgkin lymphoma are persistent coughing, shortness of breath, pain or swelling of the abdomen (MacGill, 2017). Lymphoma can

therefore make one vulnerable to various diseases or infections as they affect lymph system that fight against germs and bacterial infections in the body. Lymphoma has two major types; the Hodgkin and Non- Hodgkin Lymphomas.

The Hodgkin lymphoma is a lymphoid malignancy of B- cell origin and it can be grouped into the nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) or classical Hodgkin lymphoma (CHL) in accordance with 2008 WHO classification(Summary, Relevance, & Mediterranean, 2014). The non- Hodgkin which is the most prevalent of all lymphomas is the type of blood cancer that originates in cells of the lymphatic system. It has can be categorized into 60 different subtypes,but most of these fall into two groups of NHL known as the B- cell lymphoma and the T- cell lymphoma (Cancer Support Community, 2017).The causes of lymphoma are not known, but indeed there are some risk factors that expose an individual to lymphoma.These risk factors include age, sex, immunodeficiency, malaria, chemicals, viral and bacterial infections.

Treatment for lymphoma is normally dependent on the stage of the disease. When the development is slow or indolent, it only requires watchful waiting and usually no treatment is issued and the primary method of lymphoma treatment when required is chemotherapy(American Cancer Society, 2015). This involves the use of drugs to kill or destroy cancer cells to attain and maintain optimal physical, psychological and overall quality of life of patients.

2.3 Burden of Lymphoma

Lymphoma is a worldwide health issue with a comparatively high morbidity and mortality rates. According to World Cancer Research Fund International (2012), there was an estimated 452, 000 new cases of lymphoma worldwide representing 3.2% of all cancers in 2012. This resulted in over 200,000 deaths. Available data from WHO cancer mortality database shows that, lymphoma resulted in an estimated 21, 306 death, which was equivalent to 7.5% of all deaths from cancer (WHO, 2013). This situation puts pressure on health facilities as hospital admissions will increase and thereby increasing government expenditures on the provision of medical facilities.

Research indicated that, the increase risk of lymphoma in the USA was directly associated with HIV. Thus, out of the 115,643 cases of lymphoma diagnosed in 2009, 5.9% were infected with HIV (Shiels et al., 2013).Approximately, about 170 people are diagnosed with lymphoma daily and 75 die of the disease (Factors, n.d.). Studies indicate that cancer patients go through psychological effects such as depression, distress and despair. Most of these patients as a result depend on caregivers in performing daily activities. Again, the survival years of aggressive lymphoma presented as late stage after diagnosis has been estimated between eight to ten years due to palliative care given instead of curative treatment.

Lymphoma (non- Hodgkin) is among the top five cancers in Africa. There are high mortality rates from infectious diseases compared to NCDs. However, frequency of NCDs is soaring rapidly and it is predicted to cause almost seventy- five percent as many deaths as communicable diseases (Daniel, Ncal-ip--, & Hirsch, n.d.). Overall, 541,800 deaths were recorded which was ascribed to cancer i.e., 78% of people in Africa diagnosed with cancer, died from their disease in 2008 and the age-standardized incidence rate for cancer in Africa was 12.1/100,000 populace of which lymphoma cases were included (GLOBOCAN database, 2012). Lymphoma is rated to be

predominant in developed parts of the world than developing countries. However, the burden and mortality rates associated with lymphoma are increasing in developing nations especially African countries. Denny et al., (2013) points out that, the increasing mortality rates is due to the prevalence of the high risk factors, unavailability of diagnostic and therapeutic interventions, low quality of health care service and personnels. They also added that, lymphoma cancer in developing nations is usually diagnosed at advanced stages making treatment, where available, largely ineffective.

According to Ci, La, Y, & Welbeck.,J. (2013), lymphoma is the most predominant childhood cancer in Ghana which is estimated to be 30.7% of all paediatric cancers reported at the Korle-Bu teaching hospital.Graphiq (2013) reports states that, lymphoma peaks normally at age 70 and above in Ghana which has a mortality rate of 37.2 per 100,000 population. In Ghana, the prevalence of lymphoma seems higher among rural dwellers as compared to urban areas. Thus , the rates of referral were more of the rural areas than those from urban areas and this was attributed to the high incidence of malaria in rural areas being a factor in causing lymphoma (Laryea et al.,2014).Referable to the prevalence of lymphoma in Ghana accompanied with functional restraint such general weakness and depression, patients are therefore left at the mercy of primary health care providers for assistance which often arrives with its associated price.

2.4 Burden of lymphoma on primary caregivers

Caregiver burden refers to the description of the adverse response to the effect of care on a primary caregiver's social, occupational and personal roles and this incorporates the caregivers response to physical, psychological, social and financial difficulties(Chua et al., 2016). But for the purpose of this study, economic burden refers to the cost borne by primary caregivers as a

results of providing care to lymphoma patients and this include the direct, indirect and intangible cost.

Lymphoma has an impact not only on the life of the patient, but also on the lives of their primary caregivers.Generally, caring for a cancer patient is a very demanding and challenging task. These primary caregivers normally represent the families of the patients. Caring for cancer patient becomes a burden as extends from diagnosis to treatment of the disease(Given et al., 2004). Treatment usually involves regular visits to the health facility for monitoring of the disease. Lymphoma cancer presentssome severe symptoms to the patient that renders a patient very weak in caring for themselves. Thus, a lymphoma patientdepends on primary caregivers.

Lymphoma is rated among high contributors to mortality from cancer diseases in Africa yearly with Non- Hodgkin lymphoma resulting in 18,923 deaths in 2012 (Olsen, 2015).This is related with an untold adversity for both the patients and caregivers who are also dealing with significant financial constraints and difficult social conditions considerably greater than in the developed world with better care facilities (Yusuf, Adamu& Nuhu, 2010). They also point out that, primary care givers are the hidden patients as they go through psychological and physical problems in caring for their patients. According to Olusanjo & Chiebuka(2016), high level of burden is placed caregivers are determined by age, gender and the severity of disability. With age, caring for younger patient demands a lot of time and care compared to older patients all things being equal. Connor et al., (2007) said the burden of Caregiving could predispose caregivers to extreme exhaustion and have an undesirable influence on their well-being. Thus, caregivers go through great stress associated with care burden which often leads to depression. Primary caregivers of lymphoma cancer patients especially children have a huge task in delivering care to them day and night (Aparecida et al., 2011). Therefore, caregivers do not get much time to take

care of themselves and attain their needs. Primary caregivers play a significant role in providing emotional support for patientwhich serves as a psychological boost to their recovery.Caring for a patient often creates a deepened sense of belonging and closeness i.e. increases satisfaction and intimacy. However, the anxiety associated with dealing with a serious illness such as lymphoma combined with the burden of caregiving can create tension in the relationship and stress for the primary caregiver (Caregivers & Tumors, n.d.). They assert that caregivers must be able to deal with the new life of their patients where most are unable to function well.

Primary caregivers of lymphoma patients do not deal only with the obligation of the patient's physical and emotional welfare, but also with their own emotional and social problems that the ailment comes with (Deniz & Inci, 2015). They also point that, the lengthy recovery period involved, possible side-effects of treatment and the home caregiving after treatment of patients can cause considerable and significant interruptions and disorders to primary caregivers' lives. Terakye (2011) indicates that lymphoma patients often go through relapses and require progressive and aggressive treatment methods, resulting in an increased caregiving stress for family members.

Caregiving also involves economic and financial losses which are a challenge related to lymphoma. This burden involves productivity loss and health care cost. Productivity loss refers to the number of productive hour caregivers spend with their patients. This leads to an income

loss definitely. A survey in Singapore among primary caregivers in 2016 indicates that, fifty percent of caregivers are found in the working class of the country's population i.e. people

aged below 50. This survey also purported that, one in five caregivers had to stop work in order to cater for their sick aged relatives and one in four reported the negative effect it had on their

finances. Grigis et al., (2013) point out that, caregiving poses a problem by minimizing a person's chance of being employed, and many caregivers become uproductive due to caring activities, take days-off work without any wages, have few working hours or work from home to take care of their patient. They explained further that, these reductions in income and productivity leads to social seclusion and long- term is deemed to have negative impact on savings of caregiver. The healthcare cost involves the budget that goes into accessing health facility. Thus, the cost that extends from diagnosis to treatment of the disease. This cost is totally borne by the primary caregiver unless some of these costs is covered by an insurance. Lymphoma treatment involves large number of visit to hospital i.e. transportation and meals which increases the financial burden besides the direct medical expenses (Lukhmana, Bhasin, Chhabra, & Bhatia, 2015).

2.5 Scope of caregiving

Caregiving is a common task which incorporates different and several activities, with almost everyone providing care at any point in life.Caregiving has no general definition. However, it comes with a huge experience of distress, especially when care is being provided to someone whose illness is chronic. Distress associated with caregiving involves frequent communication with health professionals, administering medications and managing patients' behavior and providing emotional support (Kurtz et al., 2002).

Roles (2015) described caregiving as giving support and assistance to family members or acquaintances with physical, emotional and psychological need for their positive development in whatever condition they find themselves.

Caregiving as defined by Greenlee& Scharlach (2002) constitutes caring for an individuals emotional and physical well- being which encompasses long- term caregiving for an individual with a chronic disease such as cancer or an individual who is physically disabled and one whose illness is acute and erratic. Caregiving in most part of the world has fallen on the shoulders of family members where it is most dominated by women. They are therefore recognized the primary caregivers of their patients. Lymphoma incidence in a family demand intensive care. Thus, family members take up the responsibility of caregiving from the diagnosis of the disease to its treatment. According to the American Cancer Society (2017), approximately one person is diagnosed of blood cancer in the US and lymphoma is expected to account for 10.2 percent of all cancers in 2017. This statistic depicts an increasing caregiving accompanied with its burden in the US. Caregiving for lymphoma patient include regular visits to a health facility and seeking information about state of the disease from a health professional always.

2.6 Quality of life of Primary Caregivers of lymphoma patients

According to World Health Organization QOL (1998), quality of life (QoL) is defined as the individuals' understanding and impression of his or her position in life in relation to cultural setting and in accordance with value systems in which they live, regarding their goals, expectations and wants. Quality of life according to WHO, also takes into account a person's physical health, psychological well- being, personal beliefs, level of independence, social relationships and environmental health. These factors used in assessing the quality of life of an individual affect his or her health status. A national plan to improve the state of health for people in America, regarded health as a major aspect of the quality of life and that it mirrors a personal feeling of physical and psychological health and the capacity to respond to factors in the physical and social environments (National Centre for Health Statistics, 2010).

Most of the attention and concentration is placed on patients when lymphoma occurs and the personal satisfaction of caregivers is ignored. Meanwhile, quality of life of caregivers is directly associated with the patient quality of life. Thus, if QoL of primary caregiver is low, there is high possibility of patient QoL also reducing, thereby worsening the disease. Lymphoma as type of cancer results in low quality of life of caregivers according to various literatures. According to the result of a research byChua et al., (2016), they point out that, Caregiving burden has an adverse impact on the primary caregivers emotional, physical, financial well- being and their quality of life in totality. They further explained, this is due to the fact that most primary caregivers are usually unprepared for the difficulties they may face as the sudden news of cancer hit them. Lymphoma is coupled with high burden of Caregiving, which simultaneously lead to decreased quality of life, risk of melancholy and activity impairment.

2.7 Tools used for assessing psychological burden of caregivers.

Caregiver assessment is an organized way of obtaining relevant information about the condition of a caregiver with the aim of ascertaining the specific problem, needs, strength and resources of the primary caregiver as well as their ability to meet the needs of their patient (Feinburg &Hauser, 2012). With the existence of chronic diseases such as cancer diseases and its related long- term treatment, caregivers are bound to go through psychological, physical and emotional

challenges. Most researchers have measured these effects with various methods such as the Family Burden Interview (FBI), Caregiving Burden Scale (CBS), the Zarit Burden Interview (ZBI) and Caregiver Well-Being scale. These tools are deemed to be standardized and validated instrument used in evaluating the burden of a disease and quality of life of primary caregivers.Rubira et al., (2012) used Caregiving Burden Scale to assess the burden of 200 caregivers of children and adolescent with chemotherapy treatment for cancer.

The Family Burden Interview is used in evaluating the existence and intensity of specific challenges or stresses for caregivers. The caregiver rates the disability and behavior of patients. The interview comprises of 4- point scale and response ranges from “not serious at all” to “very serious”. The interview is made up of 15 questions (Morycz, 1985). The ZBI helps provide a single summary that quantifies the effect of Caregiving on the lives of primary caregivers. The interview is made up of 22 questions on a 5- point Likert scale with responses ranging from “not at all” to “extremely”. Each response is quantified and a low total score indicates little or no burden and vice versa (Zarit et al., 1980).

The Caregiving Burden Scale is a scale developed by Gerritson& Ende (1994). It contains two subscales of which one measure the quality of the relationship between primary caregiver and patient r, and the other assess the concerns of caregiving with items like, “I never feel free from the care of my spouse” and “I feel pleased about my interactions with my spouse.” It is developed on 5- point Likert scale, with responses ranging from “disagree very much” to “agree very much”. It is made up of 13 items.

These tools for evaluating the burden and quality of life are reckoned to be applicable and practicable in various settings, reliable and valid with it being used more in literatures. Rubin & Babbie (2015) define validity as the level to which anpractical measure effectively reveals the true meaning of the concept under study and reliability as level of achieving the same or similar results if a particular method or procedure is applied repeatedly to the same object. They further explained that, to reduce misrepresentations and falsifications of measuring something different from the original, it is always best to test for the validity and reliability of the edited scale.

2.8 Tools used for assessing the quality of life of caregivers of cancer patients

Primary caregivers have become progressively tasked with the provision of home care for cancer patients. Most research analysts have documented the distress or burden of primary caregivers; notwithstanding, little has been done to assess the more extensive effect of caregiving on quality of life (QoL). Methods used to measure these effects include are the World Health Organization Quality of Life (WHOQoL), Caregiver quality of life index- cancer (CQOLC), General Health Survey Questionnaire SF-36 (GHSQ) and Caregiver Oncology Quality of Life questionnaire (CarGOQoL).

The WHOQoL – 100 AND WHOQoL- BREF are also instruments used in measuring the quality of life in different situations and population groups. They contain questions that are graded on a 5 point Likert scale with increasing scores being representative of increasing quality

of life. It follows that assessment of well- being and its related impact must not only measure the variations in disease frequency and intensity but must also take into consideration an evaluation

of well- being and this could be assessed by measuring the enhancement in the quality of life related to caregiving (WHO, 1998).

The Caregiver Quality of Life Index- Cancer (CQOLC) scale is a 35-item cancer-specific instrument that assesses the carer of a cancer patient's quality of life, that is, some of the physical, social, emotional, and financial aspects of well-being, and functioning.

Caregiver Oncology Quality of Life questionnaire (CarGOQoL)contains 29 items selected assessed 10 dimensions: psychological well-being, burden, relationship with health care,

administration and finances, coping, physical well-being, self-esteem, leisure time, social support and private life. (Minaya et al., 2012)

The instrument is designed to provide a valid and reliable measure of caregivers of cancer patients' quality of life as these caregivers are key actors he provision of health care.

2.9 Economic Cost of illness

Cost of illness (COI) is also known as the economic impact of a disease. COI estimates the total cost of illness incurred by a disease or a condition. It accounts for the direct cost, indirect cost and the intangible cost. The cost involved in the diagnosis to the treatment of lymphoma is not only borne by patients and family, but also by the government who are responsible for providing interventions and the allocation of resources to health care facilities (Jo, 2014). (Lim, Chan, & Wee, n.d.) estimated the direct medical cost of lymphoma to caregivers in Singapore using three categories; cost of drugs, lab procedures and consultation. They reported the average direct medical cost to be S$,2771 with gender, age and ethnicity having no relationship with direct medical cost. Hayman et al., (2001) estimated indirect cost of caregiving to cancer patients by assuming an average hourly wage of $8.17 for all caregivers and their estimated indirect cost was $1200 per patient yearly. This would make it difficult to evaluate the validity of this cost study since assumption was made that all caregivers earned the hourly wage but it could be different in reality as some primary caregivers may be unemployed. Intangible cost which is also the burden involved in caregiving, according to Jun, Eric, & Chan (2015) in their study found that, indirect cost had a significant correlation with caregivers' quality of life although most of the caregivers reported minimal burden in Brazil.

2.9.1Direct cost of treating lymphoma

Direct cost refers to the use of resources of a certain value to directly influence the provision of treatment (Anders et al., 2013). It comprises of the medical cost such as inpatient visits, emergency department visits, outpatient visits, prescription drugs, medical equipment, and home health services and non-medical cost which include child care and travel expenses associated with receiving treatment and special education costs if psychological capacity is weakened by the illness (CDC, 2014).

Direct cost incurred by the treatment oflymphoma is dependent on the health system of a country. Thus, where there is an insurance cover for part or full treatment of disease, government bear the cost and where there is no insurance, total direct cost is borne by the individual.

In many developing countries such as Ghana, insurance does not cover the treatment of cancer disease thereby leading to many patients and family abandoning treatment due to its accompanied high direct cost.

Globally, mortality rates associated with cancer diseases are very high compared to AIDS, tuberculosis and malaria combined. This has resulted in the astronomical expenditure of various governments on cancer. According to Bello et al., (2013), It is estimated that, the US spends more than $120 billion cancer care every year and this is expected to be very high as WHO (2003) project that, total cancer cases worldwide could increase by 50 percent in the year 2020. The contribution of cancer cases to mortality rates in Africa is generally low due to its low incidence rates as compared to other parts of the world. However, cancer burden is expected to rise above 85% by the year 2030 in sub- Saharan Africa because of increase in the older population by 2030. Cancer treatment in Ghana from the diagnosis to its treatment is over USD

700 without taking into account the prices of necessary medicines to be used in the treatment.In 2010, according to the World Cancer Leaders' summit (2014), the global cost of preventing and treating cancer was approximately USD 1.16 trillion.

Lymphoma is rated among the predominant cancer diseases globally. In the US and UK for instance, it is the most prevalent type of blood malignancies and huge projections have been made about its incidence. Lymphoma is among the top 5 cancer disease in Africa with a comparatively high incidence and mortality rates.

As the cost of its treatment to the government increases, the burden also increases to the individual. In 2010, the prevalence cost of lymphoma in the US was estimated to be USD 12.1 billion with its treatment ranging between USD 16,000 and USD 30,000per month (K. Robin Yabroff, Jennifer Lund, Deanna Kepka, 2014). In SouthAfrica, the cost incurred in treating lymphoma with all the stages from diagnosis to treatment inclusive is estimated to be USD 6,647.27 (Stefan & Stones, 2009), thus the direct cost to the individual. Lymphoma in Ghana is very high and common among children. The total cost of treating lymphoma in a child is estimated to be GHS 1,500 with the exclusion of necessary drugs prescribed for treatment. In Nigeria, the direct cost of treating Burkitt's lymphoma to primary caregivers was estimated to be USD 103.8 per child and this was more than twice the minimum monthly wage of USD 42.3 for state employees (Meremikwu et al., 2005). They further explained that, 63% of the total direct cost was made up of the cost of drugs.

Direct cost of lymphoma on the individual will depend on thestage of the disease, radiotherapy, second-line chemotherapy and hospitalization (Stefan & Stones, 2009).

2.9.2 Indirect cost

Indirect cost as defined by Tarricone (2006), refers to the loss of productivity caused by the occurrence of an illness. Productivity loss is typically measured using the human capital approach. This approach takes into account a caregiver's production potential based on average wages and it also makes adjustment for household productivity (CDC, 2014). Indirect cost could be very significant as several studies have suggested that estimated indirect cost could be three times higher than direct costs, usually accounting for up to 80% of the total cost of treatment of a disease (Xie et al., 2014). In 2007, the overall indirect cost incurred for the treatment of cancer was estimated at $130.2 billion, representing 60% of the overall cost involved(Schilling, Parks, & Deeter, 2011).According to Habibian and Dehghani (2016), the mean indirect cost incurred by lymphoma patients and their caregivers was estimated to be $16,152.60 which was based on the time spent by both patient and caregiver. In an analysis of the the cost of illness of lymphoma in Germany, Reis et al., (2006) estimated the total indirect cost of lymphoma 473 billion Euros with 44,000 productive years lost. A review conducted by Bennett & Calhoun(2007), estimated the mean indirect costs of lymphoma to be $1,200–$1,500 for patients who had outpatient care only and $1,840–$3,730 for patients who had inpatient care for this ailment.

Lymphoma in essence leads to loss of productivity to both patients (lymphoma patient who are in the economically active ages) and caregivers and this is due to the number of days of lost by staying at home.

2.9.3 Intangible cost

Intangible cost refers to the psychological pain and distress that both patients and caregivers go through as disease occurs. Intangible costs are seldom evaluated in COI studies due to

measurement challenges and its accompanied controversies (Jo, 2014), however, Xie et al., (2014) employed a contingent valuation method (CVM) which was based on the willingness to pay approach to quantify intangible cost. The contributions of primary caregivers are not made without taking a toll on their mental and physical health as caring for lymphoma patients can negatively impact both physical and emotional well-being (Greenlee & Scharlach, 2002).

According to Goyal et al., (2015), intangible cost may also be in the form of psychological costs, pain and suffering, and change in social functioning and this component of cost is mostly difficult to estimate as monetary value is not assigned usually.

2.10 Conclusion

The burden of lymphoma and its related impact on the quality of life of primary caregivers are evidentlyassociated and cannot be underestimated as current literature demonstrates a substantial global increase. The various literature shows how the incidence of lymphoma in a household creates tension and distress among family members. This has been attributed to the fact that, family members who act as the primary caregiver prepare to take up a new and sudden

challenge of caregiving. This negatively affect the personal satisfaction of the caregiver as it increases household's expenditure on healthcare instead of spending on other goods and services like food, clothing, etc. Caregivers also experience productivity loss as they have to make time for their patients. Lymphoma patient demand intensive care and this causes caregivers to sometimes give up their work to care for their wards with the hope of getting well.

Most studies on burden and quality of life of primary caregivers of lymphoma patients have been carried out in other countries, with little known about it in Ghana though these caregivers play major role in the life of the patient who are usually children. They are sometimes referred to as

the “hidden patient”. This is because they also go through emotional and psychological pains making them liable to depression and other mental illness. This study therefore seeks to assess the burden and quality of life of primary caregivers of lymphoma patients in Ghana.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter covers the research methodologywhich entails; the study area, study design, study variables, study population, sample size calculation,sampling method, data collection technique and tools, quality control, data processing and analysis, study limitation and ethical considerations.

3.2 Study area

The study was conducted at the KomfoAnokye Teaching Hospital (KATH), found in Kumasi, which is 250 kilometers north of the nation's capital, Accra. The hospital started as a regional hospital in 1955 with less than 500 beds but became a teaching hospital in 1975 and now has more than 1200 beds. KATH provides training for medical and allied health students from Kwame Nkrumah University of Science and Technology (KNUST) in Kumasi and other Nurses and Midwives from training colleges in the country. In addition, it is a training centre for the Ghana Post Graduate College of Physicians and Surgeons and the West African College of Physicians and Surgeons.

The hospital, which is a referral point, has a catchment populace of in excess of 10 million. In 2008, the hospital recorded an out-patient department (OPD) attendance of 483,462 and 58,000 in-patients admissions. KATH has staff strength of 2,700 employees. The Komfo Anokye Teaching Hospital was selected for this study because it is one of the few hospitals with specialized unit for lymphoma and other childhood cancers which is the paediaric cancer unit.. The paediatric cancer unit is part of the Child Health directorate in KATH.The department of Child Health established in 1983 has stayed focused and committed to the provision of the best

Paediatric Services to all children within the Kumasi Metropolis and beyond. On a yearly basis the department gives variety of services to nearly 11,276 in-patient and 20,239 out-patients.The Directorate is mandated to undertake pediatric specialist and subspecialist medical care, training of graduate and post graduate medical students in paediatric medicine and conduct research. The Department also provides out- patient specialist clinic services such as Cardiology, Endocrinology, Sickle cell, Neurology, Renal, Asthma, TB and HIV. (Accessed at: www.kathhsp.org)

3.3 Study design

The study was a cross- sectional study design using cost-of-illness approach.

3.4 Study variables

The study variables included the direct cost, indirect cost, i.e. productivity loss, intangible cost and quality of life. Details of the study variables are in Table 1.

Table 3.1. Description of study variables

Cost Type	Cost Categories	Description
Direct cost	Medical cost	Cost incurred on medication, consultation, treatment, laboratory
	Non- medical cost	
	Household supplies	Expenditure on food
	Travel and transportation	Expenditure on transportation to or from hospital, with or for patient
Productivity loss/ indirect cost	Productivity time loss on;	
	Travel / transport	Productivity loss due to travelling

	Job loss Caregiving	Productivity loss due to loss of work Productivity time spent on feeding, serving medicine to patient
Intangible cost	Caregiving burden causing; Anxiety Stress Pain Social life	Zarit burden interview score
Quality of life	Caregiver's QoL such as; Physical Psychological health Social Environment	WHO EUROHIS- QoL

3.5 Study population

Primary caregivers of lymphoma patients (below 18 years) at the paediatric oncology of KATH constituted the population for the study. The primary caregiver was the one who assisted lymphoma patients at home for activities of daily living.

3.5.1 Inclusion criteria

Inclusion criteria was as follows:

1. All caregivers accompanying patients diagnosed of lymphoma undergoing treatment for at least one month were included in the study.
2. Primary caregiver who had provided care to patient for at least one month.

3.5.2 Exclusion criteria

The following will be the exclusion criteria

1. Secondary caregivers were excluded from the study.
2. Primary caregivers who had not provided care for a minimum of one month were be excluded.

3.6 Sample size calculation

The entire population of caregivers of lymphoma patients, particularly in children in the past two years were interviewed. The entire population was 156.

3.7 Sampling procedure

Caregivers of all 156 patients were interviewed. This was done by getting the folders of lymphoma patients in the past 2 years who came for review at the clinic.

Data were collected from respondents for a period of six weeks every Monday to Friday from 7am to 4pm. About 5 to 10 questionnaires were completed each day. Primary caregivers who did not come for review during the period were called to be interviewed at arranged location.

3.8 Data collection tools and techniques

Interviewer – administered questionnaire comprising both open and close ended questions were used to collect data from respondents. The questionnaire was divided into six different sections containing mostly closed- ended questions in order to facilitate data processing.

Section A consisted of background information of caregiver. Questions on socio- demographic data included caregiver's age, sex, marital status, educational level, and employment status being

a primary caregiver, length of caregiving, monthly income, vicinity and relationship with care recipient.

Section B comprised questions on care recipient's age, sex, caregiving task, such as assistance with activity of daily living (ADL).

SECTION C was made up of direct cost i.e. out-of-pocket expenses such as care recipient's medical supplies, consultation, laboratory test and diagnostics, travel expenses with care recipient as well as financing sources used to pay for health care cost such as health insurance and donations.

Indirect cost was captured under Section D with question being asked on time spent on personal care of care recipient, transportation, waiting for treatment and time spent on treatment at the facility.

Section E on burden of care contained items on stress, pain, anxiety and depression. Caregivers were asked to indicate the impact of the care receiver's condition on his or her personal life by indicating how they felt by circling how they feel under each Zarit burden item.

Section F was made up of questions on quality of life of primary caregivers. The WHO EUROHIS- QoL Index will be used. The WHO EUROHIS- QoL is an 8 item index graded on a 5 point Likert scale with increasing scores being indicative of increasing quality of life. It was composed by first revising the numerical codes assigned to the responses to questions on QoL. In the dataset, "1" indicated very satisfied, "2" for satisfied, "3" stood for neither satisfied nor dissatisfied, "4" for dissatisfied and "5" stood for very dissatisfied. The caregivers were asked to circle the appropriate response which best describes how the felt. Each of the item was answered

on a 5 point scale with 1 = Not at all, 2 = A little, 3 = Moderately, 4= Mostly and 5 = Completely with corresponding scores of 1 to

5 respectively. The WHO EUROHIS- QoL has 3 domains, namely: psychological, social and physical health. Each domain had a set of items under it; psychological domain had 4 items under it, social and physical had 2 items each under their domain. The domain score gave an indication of the perception of an individual's quality of life under that domain. The questions were categorized under the domains for further relational analysis.

3.9 Quality control

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

3.10 Data processing

Completed questionnaires was serialized and coded within 24 hours of collection. Data was collected from the field daily and checked for completeness. They were entered and cross-checked for errors three times using Microsoft Excel. Microsoft Excel and Stata version 15 was used to analyze the data.

3.11 Data analysis

Data analysis with respect to the data on caregivers was analyzed using Microsoft Excel and Stata version 15. Background characteristics of participants were analyzed using descriptive

statistics (mean, standard deviation). Sensitivity analysis was conducted to ascertain the robustness of the cost estimates. Caregiver's socio- demography were described using frequency tables and percentages to find the distribution.

3.12 Cost analysis

Cost was analyzed based on the caregiver's view point and information provided for a period of one month.

3.12.1 Estimation of direct cost

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

Direct medical cost was the cost incurred on medical services such as consultation, diagnosis, medication, radiotherapy and other health care interventions.

Direct non- medical cost included cost incurred on residential care, travelling (to and from hospital), household supplies, food and water. The total direct cost was then estimated by summing up all the out-of-pocket expenses made by primary caregiver.

3.12.2 Indirect cost estimation

The total hours spent by primary caregivers per week was determined and multiplied by four to derive the total hours spent caring for lymphoma patients in a month. Then, indirect cost to an employed caregiver was valued by using the prevailing national daily minimum wage of GHS 9.68 during the data collection period for primary caregivers.

Indirect cost to students/ apprentices and unemployed primary caregivers was presented as the total hours spent. This was not valued since they have no actual earnings.

3.12.3 Total cost

Total cost of primary caregivers were estimated by adding up the total cost incurred on the direct medical, direct non- medical and indirect cost over the past month. All estimated costs were converted into USD using the current exchange rate at the time analysis was done in order to compare with other international studies.

3.12.4 Sensitivity analysis

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

3.12.4 Intangible cost

The 12- item ZBI developed by Bedard et al., (2001) was adopted and used to describe intangible cost. The 12- item ZBI is the short version of the original 22 ZBI developed by (Zarit, Orr &Zarit, 1985). The total score ranges from 0-48, 0 being the minimum score and 48 being the maximum score. The total score was derived by adding all individual scores for each question from 1 to 12. Scores less/equal to 16 were categorized as low burden and scores over 16 were

categorized as high burden. A pie-chart was used to show responses of respondents and a frequency distribution table was used to show the mean burden score.

3.12.5 Quality of life

The quality of life of caregivers were estimated using the WHO EUROHIS- QoL. The EUROHIS QoL responses were graded on 5 likert scale which was reverse- coded giving positive responses higher numerical codes. The new code for individual responses were then summed up to generate the WHO EUROHIS- QoL index for each respondent. Higher responses indicated higher quality of life and vice versa, with the sum of scores ranging from a minimum 8 and a maximum of 40. The scores were then re- categorized into "Low", "Moderate", and "High". Sum of individual scores from 30-40 was considered as "High" category, "Moderate" as 19-29 and "Low" as 8-19.

3.13 Ethical consideration

Ethical clearance was sought from the KomfoAnokye Teaching Hospital review board. Also, permission was sought from the hospital administration of KATH and finally, informed consent was sought from the primary caregivers of lymphoma patients before questionnaires are administered to them.

3.13.1 Anonymity and confidentiality

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

3.13.2 Voluntary withdrawal

Permission was sought from participants by giving each participant a written consent form seeking their consent to participate in the study. Each participant was required to append their signature before information is taken from them. Participants consent to participate in the study was purely voluntary. Under no obligation was a participant be coerced to partake in the study against his or her will and they had the right to withdraw from the study at any point in time. The contributions of the participants were appreciated and the benefit of partaking was explained to them.

3.14 Data storage and usage

Serial numbers as well as codes were given to each questionnaire and data entry was done within 24hours. Printed questionnaires was locked in a safe locker while the soft copy of data was stored on an external hard drive as well as logged on to a google drive for safe keeping. Access was made only through a password. Devices used for storage such as an external hard drive was used for only that purpose and were kept safe under a locker. Both hard and soft copy data were kept by the principal investigator for a period of 3-4 years to allow for publication after which data will be destroyed by burning the printed questionnaires and deleting all soft copy data previously stored from devices.

3.15 Potential risks or benefits

Undertaking a study on the burden and quality of life of primary caregivers of lymphoma patients is believed to inform the public and policy makers since they play a significant role in the healthcare system.The study will enable policy makers to make better and effective health care planning and allocation of resources to such areas that will help these primary caregivers

and also strengthen the health system. The study will pose no potential risk to the individuals under study, the facility or the public

3.16 Study limitations

Obtaining complete and accurate records was expected to be a challenge for all patients as time spent on travelling and waiting time as well total number of days lost was based on the recall of caregivers of lymphoma patients.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the findings of the study. The chapter shows the background characteristics of the primary caregivers of lymphoma patients attending the paediatric cancer unit at Komfo Anokye Teaching Hospital. The chapter further shows estimates of direct and indirect cost incurred by caregivers and their quality of life.

4.2 Socio-demographic characteristics of primary caregivers

Table 2 shows that most of the primary caregivers were females and represented 120 (76.9%) while the males were 36 (23.1%). The table also shows that 21 (13.5%) primary caregivers were below 30 years of age and 114 (73%) primary caregivers were aged 30-50 years. 21 (3.5%) primary caregivers were above 50 years. The table further shows that 38 (24.4%) primary caregivers were unmarried and 118 (75.6%) married. Majority of caregivers were co-resident primary caregivers 135 (86.5%) while 17 (10.9%) and 4 (2.6%) were nearby and long distance primary caregivers. Most of the care recipients were children of primary caregivers 108 (69.2%), 19 (12.2%) were grandchildren, 16 (10.3%) were siblings and 13 (8.3%) were nephew/niece of primary caregivers. The average hours per day primary caregivers spend caring for care recipients was 7.9 hours. Most of the care recipients were males 93 (59.6%) whilst 63 (40.4%) were females. 77 (49.4%) of the care recipients were below 7 years, 66 (42.3) were aged from 7 years to 12 years and 13 (8.3%) were aged from 13 years to 18 years.

Table 4.2: Socio-demographic characteristics of caregivers

Characteristic	Number	Percentage (%)
Sex		
Male	36	23.1
Female	120	76.9
Age		
< 30	21	13.5
30-50	114	73
>50	21	13.5
Marital Status		
Single	38	24.4
Married	118	75.6
Educational Level		
No formal education	25	16.1
Primary	19	12.2
JHS/JSS/Middle	42	26.9
SHS/SS/TECH/Vocational	40	25.6
Tertiary	30	19.2
Employment Status		
Unemployed	21	13.5
Private	20	12.8
Public sector	37	23.7
Self employed	73	46.8
Student/ apprentice	5	3.2
Total	**156**	**100**
Monthly income		

< GHS 500	51	32.7
GHS500-1000	42	26.9
> GHS1000	63	40.4
Mean income (95%CI)	GHS952.33(840.61-1064.05)	
Relation to Caregiver		
Nephew/Niece	13	8.3
Child	108	69.2
Grandchild	19	12.2
Sibliing	16	10.3
Distance from care recipient		
Long distance	4	2.6
Nearby	17	10.9
Co-resident	135	86.5
Number of days/week for caring		
Two	1	0.6
Three	3	1.9
Four	8	5.2
Five	15	9.7
Six	11	7.1
Seven	117	75.5
Hours per day		
Total	1219	
Mean	7.8	
Financial status		
Gotten better		
Stayed the same	24	15.4
Gotten worse	132	84.6
Care Recipient age		

<7	77	49.4
7-12	66	42.3
13-18	13	8.3
Care recipient sex		
Male	93	59.6
Female	63	40.4

4.3 Cost of caregiving for lymphoma patients

4.3.1 Direct Cost

The median direct cost per month of caregiving for lymphoma patients was estimated at GHS 1,957.92 (USD 409.39) accounted for 97.0% of the cost profile. The median total direct medical cost per month for primary caregivers of lymphoma patients was estimated at GHS 1,825.00 (USD 381.810) and this represented 89.9% of the cost profile. Expenses on food recorded the lowest cost profile of 3.3%. Transportation cost per month constituted 3.8% of the cost profile with a median cost of GHS70 (USD I4.64).

Table 4.3: Direct cost of primary caregivers per month

Cost component	N	Cost (GHS)	Cost (USD)	Average cost (GHS)	Average cost (USD)	Median cost	Median cost (USD)	Cost profile(%)
Direct cost								
Direct medical cost								
Medications	156	157,490	32,947.70	1009.55	211.20	950	198.74	43.7
Consultation	70	1,750	366.11	25	5.23	25	5.23	1.1
Labs and Diagnostics	156	113,210	23,684.10	725.71	151.82	550	115.06	31.4
Admission	67	22,600	4728.03	337.31	70.57	300	62.67	14.6
Medical cost	156	295,050.00	61,725.94	2,097.57	395.68	1,825.00	381.80	90.8

sub total		**295,050.00**	**61,725.94**	**2,097.57**	**395.68**	**1,825.00**	**381.80**	**90.8**
Direct non medical								
Other_food	20	1,385.00	289.75	69.25	14.49	0.00	0.00	3.0
Transportation	156	12,587.00	2,633.26	80.69	16.88	70.00	14.64	3.5
Sub total		**13,972.00**	**2,923.01**	**149.94**	**31.37**	**70.00**	**14.64**	**6.5**
Total direct cost		**309,022.00**	**6,4648.95**	**2,041.28**	**427.05**	**1,895.00**	**396.44**	**97.3**

4.3.2 Indirect cost of primary caregivers

The total indirect cost to primary caregivers of lymphoma patients was GHS 8,243.00 (USD 1,724.48) per month.

The median indirect cost for primary caregivers was GHS 62.92 (USD13.62) which represented 3.0% of the cost profile. This excluded the time cost of unemployed and student primary caregivers as they were not making actual earnings from their employment status.

Table 4.4: Indirect cost per month of primary caregivers

Indirect Cost								
Cost component	**N**	**Cost (GHS)**	**Cost (USD)**	**Average cost (GHS)**	**Average cost (USD)**	**Median cost**	**Median cost (USD)**	**Cost profile(%)**
Time spent on personal care	130	2,390.56	500.12	18.39	3.85	19.36	4.05	0.8
Time spent on transportation	130	2,358.69	493.45	18.14	3.80	19.36	4.05	0.7
Time spent on waiting	130	930.97	194.76	7.16	1.50	4.84	1.01	0.3
Time spent on treatment	130	2,562.78	536.15	19.71	4.12	19.36	4.05	0.9
Total indirect cost		**8,243.00**	**1,724.48**	**63.41**	**13.27**	**62.92**	**13.16**	**2.7**

Total time (hours) spent per month by primary caregivers of lymphoma patients was 7182.07 hours. Time spent on personal care and time spent on treatment at the facility was 2093 hours

and 2257 hours respectively. Time spent on waiting for medical care at the facility recorded the lowest with 858.40 hours. Time spent on transportation to and from the facility with care recipient was 1973.67 hours.

Table 4.5: Hours spent by primary caregivers

Category	**Frequency (n)**	**Total time spent (Hrs)/month**	**Average time spent per month (SD)**	**Median time spent/ month**
Time spent on personal care	156	2379.00	15.3 (8.0)	16.0
Time spent on transportation	156	2311.67	14.8 (7.7)	16.0
Time spent on waiting	156	923.73	5.9 (3.6)	4.0
Time spent on treatment	156	2539.00	16.3 (9.0)	16.0
Total		**8153.40**	**52.3**	**52**

Table 4.6: Time spent by different occupational categories

Employment status	**Total hours spent**	**Total cost**
Unemployed	1120.01	
Private sector	1136.33	1,374.96
Public sector	1733.73	2,097.82
Self employed	3942.33	4,770.22
Student	221	
Total	8153.40	8,243.00

*time by student and unemployed caregivers were not valued and are not part of indirect cost.

4.3.3 Total Cost

The total cost of caregiving incurred by primary caregivers in the study was estimated at GHS 317,625.00 (USD 66,373.43). Median total cost was GHS1,957.92 (USD 409.61). Figure 4.2 shows proportion of the cost profile covered by the total and indirect cost. The direct cost represented 97% of the cost profile which was higher than the indirect cost with 3%.

Table 4.7: Cost profile

Cost component	Cost (GHS)	Cost (USD)	Cost profile (%)
Direct cost	309,022.00	64,648.95	97.3
Indirect cost	8243.00	1724.48	2.7
Total cost	317,625.00	66,373.43	100

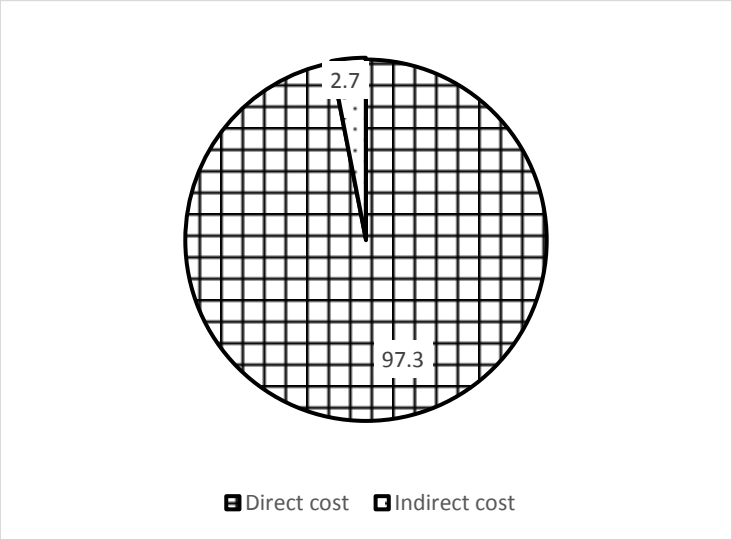

Figure 4.2: Proportions of total cost

4.3.3 Intangible cost

Burden on primary caregiver

The results showed that 6% reported a low caregiver burden while 94% of the respondents reported a high caregiver burden. This is shown in figure 3 below.

Figure 4.3: Burden among primary caregivers

Figure 4.4 shows the mean burden score for both males and females. Male respondent reported a relatively higher burden (mean of 26.6) compared to females (mean of 26.2).

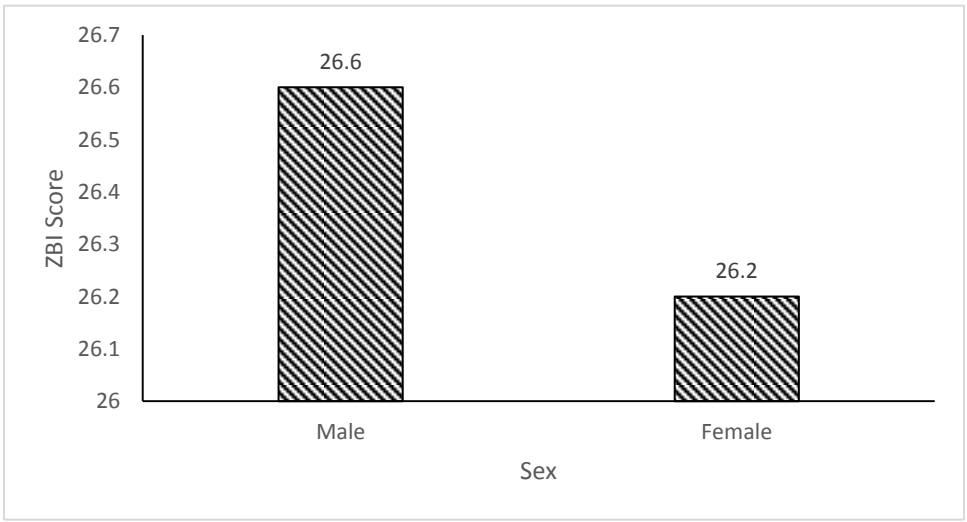

Figure 4.4: Caregiver burden by sex

4.4 Sensitivity analysis

Sensitivity analysis performed on medication, laboratory test/diagnostics and wage to determine the robustness of cost estimated in the study. This was done by performing a one way sensitivity analysis by increasing the cost of medication, laboratory test/diagnostics and wages by 3%, 5% and 7% to vary their cost respectively. The result indicated that, at base scenario, percentage in parameter was zero (0) with percentage change in total cost remaining zero (0). Proportion of direct cost and indirect cost were 97.4 and 2.6 respectively with percentage changes in their cost remaining zero (0). However, with a variation in the items by 3%, 5% and 7%, there was increase in percentage change in total cost at 7%, 11.4% and 17.8% respectively with a recorded increase in proportion of total cost for direct and indirect cost. There was 0.1%, 0.2% and 0.3% changes in the proportion for direct cost when it was increased by 3%, 5% and 7% respectively. There was an opposite occurrence for indirect cost with respect to the percentage change in proportions of cost as indicated in the results -0.1%, -0.2% and -0.3% at a percentage change in parameter of 3, 5 and 7 respectively.

The result indicated the same proportion of total direct cost for wages at 97.3 when varied by 3% and 5% with a decrease to 97.2 when increased by 7%. Percentage change in proportions of cost for both direct and indirect remained the same at percentage change in parameter of 3 and 5 whilst it decreased and increased at percentage change in parameter of 7 for direct and indirect cost respectively.

Multi-variation was performed concurrently for medication, laboratory test/ diagnostics and wages at 3%, 5% and 7% which indicated a percentage change in total cost at an increasing rate of 2.6%, 7.1% and 13.6%. Proportion of total cost for direct cost increased constantly when varied at 3%, 5% and 7%. Indirect cost however decreased constantly 2.6, 2.5 and 2.4 at a

percentage change in parameter of 3, 5 and 7 respectively. There was no percentage change in proportion of cost for both direct and indirect at 3%. However, percentage change in proportions of cost increased at 5% and 7% for direct cost whilst it decreased for indirect cost.

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

Table 4.8: Sensitivity analysis of total cost of primary caregivers

Scenario	Cost component	Percentage change in parameter	Total cost		Percentage change in total cost	Proportion of total cost		Percentage change in proportions of cost	
			GHS	USD		Direct	Indirect	Direct	Indirect
Base scenario		0	317,265.00	66,373.43	0.0	97.4	2.6	0	0
Variation (One-way Sensitivity Analysis)	Medication	3	339,358.00	70,995.40	7.0	97.5	2.5	0.1	-0.1
		5	353,299.05	73,911.94	11.4	97.6	2.4	0.2	-0.2
		7	373,792.40	78,199.25	17.8	97.7	2.3	0.3	-0.3
Variation (One-way Sensitivity Analysis)	Wage rate	3	317,512.29	66,425.17	0.1	97.3	2.7	-0.1	0.1
		5	317,677.15	66,459.66	0.1	97.3	2.7	-0.1	0.1
		7	317,842.01	66,494.15	0.2	97.2	2.8	-0.2	0.2
Multi-variation (Multi-way	Medication and Wage rate	3	325,633.29	68,124.12	2.6	97.4	2.6	0.0	0.0
		5	339,739.20	71,075.15	7.1	97.5	2.5	0.1	-0.1

Sensitivity Analysis)		7	360,397.41	75,396.95	13.6	97.6	2.4	0.2	-0.2

4.5 Caregiver quality of life

Figure 4.5 shows that 5 (3.2%) of the respondents reported high quality of life while 18 (11.5%) reported moderate quality of life and 133 (85.3%) reported low quality of life.

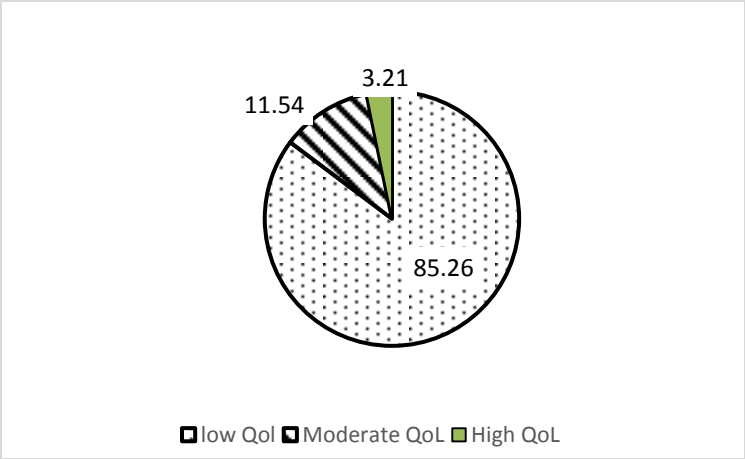

Figure 4.5: Quality of life distribution

The table below present the mean score of quality of life. There was a significant difference in employment status. Primary caregivers in the private sector had a relatively higher quality of life with a mean score of 19.0 compared to primary caregivers who were unemployed (16.6) and students (16.4) as they recorded the lowest. This is attributed to the fact that, most private sector caregivers spent less time with their care recipient and work throughout their normal productive hours. They mostly leave their care recipient to be cared for by others as they go to work and resume caregiving process after work. Primary caregivers who earned monthly income over GHS 1,000 had high quality of life (18.1) compared to those who earned from GHS 500 - GHS 1,000 (16.5) and those who earened less than GHS 500 (16.8). This significant difference could be attributed to the fact caregivers who earned over GHS 1,000 were able to afford some of the cost that comes with caregiving as compared to those in the other income groups.

Table 4.9: Quality of life of background characteristics of primary caregivers

Characteristics	Psychological		Physical		Social		Total QoL	
	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value
Sex								
Male	9.9 (2.3)	0.52	4.4 (1.4)	0.14	4.0 (1.4)	0.06	18.3 (4.4)	0.07
Female	9.5 (1.9)		4.0 (1.2)		3.5 (1.0)		16.9 (3.0)	
Age								
<30	10 (2.5)	0.42	4.2 (1.5)	0.03	3.9 (1.0)	0.21	18.1 (3.9)	0.25
30-50	9.6 (2.0)		4.2 (1.2)		3.5 (1.2)		17.3 (3.5)	
>50	9.1 (1.8)		3.5 (1.2)		3.7 (0.7)		16.2 (2.5)	
Marital status								
Single	9.6 (2.1)	0.92	4.1 (1.3)	1.00	3.5 (1.0)	0.44	17.1 (3.3)	0.73
Married	9.6 (2.0)		4.1 (1.3)		3.6 (1.1)		17.3 (3.5)	
Educational level								
No formal education	9.8 (2.7)	0.32	3.7 (1.5)	0.04	3.6 (1.3)	0.72	17.2 (4.8)	0.08
Primary	9.0 (1.7)		3.7 (1.0)		3.3 (0.7)		16.0 (2.0)	
JHS/JSS/Middle	9.4 (1.7)		4.1 (1.1)		3.6 (1.0)		17.0 (2.7)	
SHS/SSS/Tech	9.3 (1.6)		4.1 (1.2)		3.6 (1.0)		17.0 (2.6)	

Tertiary	10.2 (2.4)		4.7 (1.4)		3.9 (1.4)		18.8 (4.3)	
Employment status								
Unemployed	9.4 (2.5)	0.30	3.5 (1.0)	0.23	3.5 (1.0)	0.23	16.6 (3.8)	0.03
Private sector	10.2 (1.9)		4.2 (1.4)		4.2 (1.4)		19.0 (3.7)	
Public sector	10.0 (2.3)		3.7 (1.1)		3.7 (1.1)		17.8 (3.7)	
Self employed	9.3 (1.8)		3.5 (1.0)		3.5 (1.0)		16.7 (3.5)	
Student/apprentice	9.4 (2.0)		3.2 (1.1)		3.2 (1.1)		16.4 (2.5)	
Monthly income								
<500	9.3 (2.2)	0.7	4.0 (1.3)	0.15	3.5 (1.1)	0.28	16.8 (3.7)	0.03
500-1000	9.3 (1.5)		3.8 (1.1)		3.5 (0.9)		16.5 (2.1)	
>1000	10.0 (2.1)		4.3 (1.1)		3.8 (1.3)		18.1 (3.7)	

CHAPTER FIVE

DISCUSSION

5.1 Introduction

In this chapter, the results of the study in chapter four are discussed in relation to literature. Thus, the results are compared to literature including empirical literature. In respect to the comparison, the similarities and differences in the current study and literature are identified and explained. The chapter begins with the discussion of results on cost of caregiving by primary caregivers of lymphoma patients in accordance to the objectives. The cost components considered are total cost, direct, indirect and intangible cost. The discussion ends with the quality of life of primary caregivers of lymphoma patients.

5.2 Cost of lymphoma on caregivers

With regards to the current findings in the study, average cost of caregiving per month was estimated to be GHS 2,104.69 equivalent to USD 440.31 per caregiver. The difference in cost on primary caregivers arises due to differences in the stages of disease and as result cost increases with severity. Most of this cost increases are from the caregiving time which increases with severity and admission of patients.

Findings in the current study are remarkably similar to those reported in prior studies of specific cost components of the total cost. For instance, a study estimated the mean monthly direct cost per caregiver to be between USD 1,000 and USD 1,800 which was dependant on the phase of the disease (Van Houtven et al., 2010). Another study also reported that total cost incurred by primary caregivers of lymphoma patient is USD 6,400 per patients in its treatment with an average total indirect cost between USD 1,000 and USD 1,500 (Bennett & Calhoun, 2007). The

high cost involved was attributed to the fact that, the study involved older patients. The average cost estimated in the current study differs comparably to other studies which estimated higher cost. The difference in the cost estimations could be attributed to difference in expenditure for caregivers of different patients.

Most caregivers of the current study stayed with their care recipient at the hospital when they are admitted. Studies have shown that, suffering from lymphoma is accompanied with both medical and non-medical cost of which part is borne by caregivers. A study conducted on the cost of lymphoma have shown that, the incidence of cancer and its treatment result in loss of financial resources and opportunities for patients, families and society as a whole (Yabroff et al.,2014). The current study support the assertion made in previous literature that caring for lymphoma patients comes along with huge cost and burden on the caregiver.

The discussions about burden of primary caregivers of lymphoma patients are very important as it provides a strong comparison among cost and consequences of interventions and programs in economic evaluations (Habibian & dehghani, 2016). The current study used the cost-of-illness approach in evaluating the economic burden of primary caregivers which was similar to the approach that was identified by (Round, Jones, & Morris, 2015). Though limited in scope as to the categories used under the cost components, there is a similarity in the result obtained in the current study and such studies. A study by Mumford et al., (2018) highlighted the significance of estimating the productivity loss as it does not have an impact on the primary caregiver only but the society as a whole. They further explained that, indirect cost increases when traveling to facility for care involves much time with admission also being an important factor of indirect cost.

Therefore, it can be concluded that most patient of caregiver in this current research are having a more severe lymphoma cases.

The average medical cost per month in the current study was GHS 189.35 (USD 395.68) being 89.9% of the cost profile and average non-medical cost was GHS 149.94 (USD 31.37) being proportional to 6.6% of the cost profile.

Out-of-pocket expenses associated with caregiving are really a significant factor in evaluating the economic burden to the caregivers. It is probably because of such huge financial cost or burdens that 40% of families of cancer patients had to abandon treatment as they could not bear the expenses that comes with it according to a report by Ghana News Agency (2016). With regards to findings in the current study, high proportion of caregiver's income go into direct cost as average income of caregivers (GHS 952.33; 95% CI of 840.61-1064.05) is lower than the average direct cost (GHS 1,895.00) though all the cost were not borne by the caregivers alone. Some had contributions from relatives, remittances, gifts and donations. This cost involved is incurred from the diagnosis to its treatment and the explanation given was because most of the cases were reported at the latter phases.

However, the estimation that 89.9% of the average cost of caregivers made up of direct medical cost is in line with findings in prior studies. The estimation of direct medical cost reported in a similar study was 84% of the total cost (Bennett & Calhoun, 2007). They also estimated the mean medical cost to be USD 5,704 and USD 17,869 per year in USA. for outpatients and inpatients respectively which is similar to the average monthly direct medical cost estimated in the current study GHS 1,891.35 (USD 395.68). This is equivalent to USD 4,748.16 per year. Another study by (Lim et al., n.d.) also estimated annualized total direct cost as S$ 331,742 with

a median direct cost being S$ 2271 and confidence interval of S$1,112 ± S$5,796. The estimations in the previous study are similar to current result in the research. Also categories used in estimating the direct medical cost component in most literature is however similar to the current study. That is, the expenses on drugs or medicines, laboratory tests and diagnostics, consultation and hospitalization.

Although the direct cost estimate is in the range of some estimates recorded in previous studies, it is also less other studies such as a study by Van Houtven et al., (2010) who estimated the direct out-of-pocket expenses of caregivers of lymphoma patients to be between USD 100 and USD 150 per month. This could be because of the different approaches used in determining cost estimates in various literatures as well as the focus of some of these studies. For example, the current study has a clear focus on determining the direct cost incurred by primary caregivers of lymphoma patients. In the literature, most studies that provide absolute cost have only estimated direct cost without specifying who they are referring to whether the primary caregiver, secondary caregiver or the patient rendering their focus unclear.

5.4 Indirect cost

Yabroff & Kim (2009) estimated the total time cost to primary caregivers within two years after diagnosis of lymphoma as USD 59,613 with a 95% confidence interval of USD 40,750 and USD 90,670 for the entire population under study. Hayman et al., (2001) also reported that, cancer treatment was associated with an increase of 3.1 hours per week of caregiving which translates into an absolute average yearly cost of USD 1,200 per patients. These estimates are in contrast with the current study where average indirect cost of caregiving was determined to be GHS 63.41 per month. This was equivalent to USD 159.19 per year with average of 13 hours spent on

caregiving per week. The reason as stated in previous study was the difference in minimum wage rates for different countries.

Majority of the primary caregivers in the current study indicated spending more time on transportation to and from the hospital and time spent on treatment at the facility. This finding is similar to a study by Bennett & Calhoun, (2007) whose findings also showed that most informal caregivers are burdened with traveling cost and hospitalization of their patient which cause them to withdraw from their work.

The estimation of indirect cost in the current study did not value the time spent on caregiving by student and unemployed primary caregivers as they had no actual earnings and were not expected to be working. Some previous studies have incorporated time spent by all primary caregivers in calculating indirect cost without taking into consideration the different employment status. For instance, a study by Van Houtven et al., (2010) calculated the indirect cost by using self reported hourly wage rates for employed caregivers and used the minimum wage rate for caregivers who are not working. This can lead to overestimation of the indirect cost which in turn would affect the total cost. Hayman et al., (2001) also estimated indirect cost by multiplying time spent by all primary caregivers with an average hourly wage of $8.17 which was an assumption. This could also result in overestimation and low confidence in the final results of the study. The current study used the productivity days lost to an employed caregivers and this was estimated by using the current minimum wage of Ghana (GHS 9.68) as at the time the study was being conducted. This has therefore been the differences in the indirect cost estimates between the current study and other previous studies.

5.5 Intangible cost of caregivers of lymphoma patients

The findings in the study showed that 94% of primary caregivers were highly burdened and 6% were less burdened with the care provided to lymphoma patients. The findings are supported by Chua et al., (2016), who reported a high burden of care among caregivers in Singapore. Lukhmana, Bhasin, Chhabra, & Bhatia (2015) in their study reported that, a low proportion (43%) of cancer caregivers are highly burdened whilst a high proportion (57%) of caregivers are less burdened in New Delhi. This was explained in the study as due to the fact that, most of the caregivers were related to the patients and their caregiving were seen as an obvious extension of their normal roles in the relationship, thus it was not viewed as distinct roles. This is in contrast with the findings in the current study.

Although most of the primary caregivers in the study were females, male caregivers were highly burdened than female. These gender characteristics are similar to other previous studies such as Rubira et al., (2012) who reported 88.7% of caregivers being females in their study.

The reason for high burdened caregivers in the current study could be attributed to poor health, lack of family or social support, financial stress and caring for patients who require intensive assistance or with high symptom distress.

5.6 Quality of life of primary caregivers of lymphoma patients

The present study results show that lymphoma has great and significant impact on the quality of life of primary caregivers as only 5 (3.21%) out of the caregivers recorded a high quality of life

With the remaining 18 (11.54%) and 133 (85.26%) reporting moderate and low quality of life respectively. Female caregivers had a significantly lower QoL than male primary caregivers.

The findings confirm previous study conducted by Aparecida et al., (2011) where they found that, most caregivers were females and lower quality of life than male. They further showed that, most of these caregivers had sought medical care at least once in the year. Previous study by Lim et al., (2016) reported that primary caregivers in developing nations are comparatively lower quality of life than their counterpart in the developed world and that QoL was worse with primary caregivers who cared for advanced-stage lymphoma. Chua et al., (2016) also reported that burden had a direct relationship with QoL and as a result, caregivers who are highly burdened are faced with low QoL concurrently. The general low quality of life in this study affirms the idea that, caregivers are indeed hidden patients and thus need to be trained and supported to improve their quality of life.

5.6 Implications of the findings

According to the study, caregivers are burdened most with direct medical cost compared to the other cost components including direct non- medical and indirect cost. This conclusion could be referenced from the proportions of the cost profile each represented. Direct medical cost incurred by caregivers could be reduced by incorporating some of the medications for lymphoma treatment into the National Health Insurance Scheme (NHIS). This is because medicines used in the treatment process were the most expensive with an average of GHS1,009.55 per month to a caregiver with none being covered by NHIS. When factored into NHIS where some medications would be covered, cost burden on caregivers would reduce and as a result improve quality of life of primary caregivers. From the study findings, indirect cost accounted for 3% of the cost profile which could be indicative of its low contribution to the overall cost burden on caregivers.

There were limitations to this study. The study involved recalling of some of the responses especially with regards to time spent on various caregiving activities such as travelling and

personal care and also some expenses made were recalled by caregivers. This might not be accurate and exact, but it was a good representation of the burden of caregivers. Caregivers also became sentimental in responding to the questions and as a result, could lead to exaggeration of some estimates. Furthermore, different stages of lymphoma led to different caregiver burden. However, due to constraints of the study objectives, the overall burden on caregivers was estimated.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

The study sought to determine the economic burden and quality of life of primary caregivers of lymphoma patients attending the paediatric cancer unit at KomfoAnokye Teaching Hospital. It can therefore be concluded that, most primary caregivers were related to the lymphoma patients and are burdened with the care they provide to their care recipients as they incur huge medical and non-medical cost. The study also found out that some primary caregivers had to reduce workload due to the burden that comes with caring for lymphoma patients which mostly affect their quality of life. Although majority of primary caregivers were females, men reported being burdened than the females and more females reported to have lower quality of life than the male primary caregivers.

6.2 Recommendation

The study makes the following recommendations based on the study findings;

1. There should be supportive care interventions for caregivers inorder to ameliorate burden and enhance their quality of life as a result. Supportive care interventions could include psychoeducational training on how to cope, communicate and handle problems associated with caregiving.
2. National Health Insurance Scheme should factor the cost of some expensive medications into its cost components to reduce direct out-of-pocket expenditure made by caregivers in the course of caregiving to lymphoma patients.

3. There should be regular general education on the importance of reporting early symptoms of unknown diseases by caregivers to health facilities. This would help reduce some caregiver burden as initial stage of the disease is less costly compared to latter stages where the disease becomes serious and demand intensive care as reported in the study.

6.3.1 Identified area of research

- Future research should be conducted on factors contributing high burden among male caregivers of lymphoma patients in Ghana.

REFERENCES

Akdemir, N., & Birol, L. (2004). Internal disease and nursing care. Ankara, Turkey: Sistem Offset

Akosile. (2013). Health Care: Current Reviews. *Health Care Current Reviews, 1.* https://doi.org/10.4172/hccr.1000105

American Cancer Society. (2015). What Is Lymphoma of the Skin ? Retrieved from https://www.cancer.org/cancer/skin-lymphoma/about/what-is-lymphoma-of-the-skin.html

Aparecida, E., Do, R., Santo, E., Aparecida, M., Gaíva, M., Espinosa, M. M., … Belasco, S. (2011). Taking Care of Children With Cancer: Evaluation of the Caregivers' Burden and Quality of Life. *Rev. Latino-Am.Enfermagem*, *19*(3), 515–22. https://doi.org/10.1590/S0104-11692011000300010

Bello, I. O., Odedina, F., Rebbeck, T. R., Harford, J., Dangou, J. M., Denny, L., & Dewole, I. F. (2013). Challenges and opportunities in cancer control in Africa: A perspective from the African Organisation for Research and Training in Cancer. *The Lancet Oncology, 14*(4), e142-e151. http://dx.doi.org/10.1016/S1470-2045(12)70482-5

Bennet, C., & Calhoun, E. (2007). Evaluating the total costs of chemotherapy-induced febrile neutropenia: results from a pilot study with community oncology cancer patients.*The oncologist*, *12*(4), 478- 483. http://theoncologist.alphamedpress.org/content/12/4/478.full

Cancer Support Community. (2017). Non-Hodgkin Lymphoma. Retrieved from https://www.cancersupportcommunity.org/learn-about-cancer-types/non-hodgkin-lymphoma#tab1

Caregivers, F., & Tumors, B. (n.d.). Orientation to Caregiving. *Integrative Medicine*.

CDC. (2014). Economic Impact Analysis Cost of Illness : The Second of a Five-Part Series: part 2, 1–49. Retrieved from http://www.cdc.gov/dhdsp/programs/spha/economic_evaluation/module_ii/podcast_ii.pdf

Chua, C. K. T., Wu, J. T., Yeewong, Y., Qu, L., Tan, Y. Y., Neo, P. S. H., & Pang, G. S. (2016). Caregiving and its resulting effects???The care study to evaluate the effects of caregiving on caregivers of patients with advanced cancer in Singapore. *Cancers*, *8*(11), 1–11. https://doi.org/10.3390/cancers8110105

Ci, S., La, R., Y, D.-A., & Welbeck J. (2013). Changing Pattern of Childhood Cancers At Korle Bu Teaching Hospital, Accra, Ghana. *Postgraduate Medical Journal of Ghana*, *2*(2), 65–67.

Connor, M. D., Walker, R., Modi, G., & Warlow, C. P. (2007). Burden of stroke in black populations in sub- Saharan Africa. *Lancet Neurology*, *6*(3), 269- 278. https://doi.org/10.1016S1474-4422(07)70002-9

Daniel, A., Ncal-ip--, O., & Hirsch, D. (n.d.). Edited by. https://doi.org/10.1016/S0065-2156(09)70001-8

Deniz, H., & Inci, F. (2015). The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheric stem cell transplantation. *Journal of Psychosocial Oncology*, *33*(3), 250–262. https://doi.org/10.1080/07347332.2015.1019660

Denny, L., Adewole, I., Odedina, F., Rebbeck, T., Williams, M. J., Martin, D., … Brown, B. (2013). Cancer Plan for the African Continent 2013-2017. *African Organisation for Research and Training in Cancer (AORTIC).*

Factors, R. (n.d.). WHAT ' S LYMPHOMA ?

Ferhanoglu, B., Bolaman, A. Z., & Soysal, T. (2013). Lymphoma. Turkish Journal of Hematology, 3, 226–236.

Feinberg & Hauser.(2012). AARP Fact Sheet. 1

Ghana News Agency. (2017). Children, about 250,000, develop cancer annually. *Health news*. Retrieved from https://www.modernghana.com/news/675585/children-about-250000-develop-cancer-annually.html

Gerritsen, J. C., & Ende, P.C. (1994). The development of a caregiving burden scale. *Age and Ageing,* 23, 483-491.

Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and Depression Among Caregivers of Patients With Cancer at the End of Life. *Oncology Nursing Forum*, *31*(6), 1105–1117. https://doi.org/10.1188/04.ONF.1105-1117

Globocan database (2012): Estimated cancer incidence, mortality and prevalence worldwide. Retrieved from http://globocan.iarc.fr/Default.aspx

Graphiq. (2013). Non-Hodgkin Lymphoma in Ghana. Statistics, Demographics Affected. HealthGrove. Retrieved from http://global-disease-burden.healthgrove.com/l/39912/Non-Hodgkin-Lymphoma-in-Ghana

Girgis, A., Lambert, S., Johnson, C., Waller, A., Currow, D. (2013). Physical, Psychosocial, Relationship, and Economic Burden of Caring for People With Cancer: A Review. *Journal of Oncology Practice,* *9*(4), 197-202. http://jop.ascopubs.org/cgi/doi/10.1200/JOP.2012.000690

Greenlee, J., & Scharlach, A. (2002). Caregivers' Characteristics and Needs.

Goyal, N., Male, S., A1 Wafai., Bellamkonda, S., & Zand, R. (2015). Cost burden of stroke mimics and transcient ischemic attack after intravenous tissue plasminogen activator treatment. *Journal of Stroke and Cerebrovascular Diseases, 24*(4), 828- 833. http://doi.org/10.1016/j.jstrokecerebrovasdis.2014.11.023

Habiban, M., &Dehghani, M. (2016). IEV versus ESHAP for Treatment of the Patients with Relapsed/Refractory Hodgkin and Non-Hodgkin's Lymphoma in Iran: A Cost-Effectiveness Analysis. *Chemotherapy: Open Access*, *5*(4). https://www.omicsgroup.org/journals/iev-versus-eshap-for-treatment-of-the-patients-with-relapsedrefractoryhodgkin-and-nonhodgkins-lymphoma-in-iran-a-costeffectiveness-2167-7700-1000217.php?aid=81324

Hayman, J.A., Langa, K.M., Kabeto, M.U.,Katz, S.H., DeMonner, S.M., & Chernew, M.E. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. J Clin Oncol, *19*, 3219– 3225.

Jamison, D.T., Summers, L.H., Alleyne, G., Arrow, K.J., Berkley, S., Binagwaho, A., … O'Brien, J.C. (2009). A World Converging within a Generation Policy Brief # 2 : The Returns to Investing in Health. *Geneva: World Health Organization, 1*(1),2-3

Jo, C. (2014). Cost- of- illness studies: concepts, scopes and methods. *Clinical and molecular hepatology, 20*(4), 327- 337. http://doi.org/10.3350/cmh.2014.20.4.327

Joo, H., Dunet, D. O., Fang, J., & Wang, G. (2015). Cost of Informal Caregiving Associated with Stroke among Elderly in the United States, *83*(20), 1831-1837. https//do.org/10.1212/WNL.0000000000000986.

K. Robin Yabroff, Jennifer Lund, Deanna Kepka, A. M. (2014). Economic Burden of Cancer in the US. *Cancer Epidemiol Biomarkers Prev.*, *DOI: 10.11*(301), 1–18. https://doi.org/10.1158/1055-9965.EPI-11-0650.Economic

Kurtz, M., Kurtz, J., Stommel, M., Given, C. W.,& Given, B. (2002). Predictors of depressive symptomatology of geriatric patients with lung cancer – a longitudinal analysis. *Psycho-Oncology*, *11*, 12–22. PubMed: 11835589

Laryea, D. O., Awuah, B., Amoako, Y. A., Dogbe, J., Larsen-reindorf, R., Ansong, D., …

Martin, I. K. (2014). Cancer incidence in Ghana , 2012 : Evidence from a population-based cancer registry, *14*(1), 1-8

Leukemia & Lymphoma Society. (2017). Facts and statistics. Retrieved from http://www.lls.org/facts-and-statistics/facts-and-statistics-overview

Lim, Y. X. M., Chan, A., & Wee, H. L. (n.d.). Direct Cost of Lymphoma in Singapore : A Retrospective Database Analysis from an Asian Cancer Centre ' s Perspective, 1–4.

Lim, H. A., Tan, J. Y. S., Chua, J., Yoong, R. K. L., Lim, S. E., Kua, E. H., Mahendran, R. (2016). Quality of life of family caregivers of cancer patients in Singapore and globally. Singapore Med. J.

Llamas, M., Silvestrini, E., Eikins, C., Juneau, J., Turner, T., Connolly, K., … Schulman, T. (2015). How Much Cancer Costs. Retrieved from https://www.drugwatch.com/2015/10/07/cost-of-cancer/

Lukhmana, S., Bhasin, S., Chhabra, P., & Bhatia, M. (2015). Family caregivers' burden: A hospital based study in 2010 among cancer patients from Delhi. *Indian Journal of Cancer*, *52*(1), 146. https://doi.org/10.4103/0019-509X.175584

Lymphoma Research Foundation. (2016). Overview of Hodgkin Lymphoma. Retrieved from http://www.lymphoma.org/site/pp.asp?c=bkLTKaOQLmK8E&b=6300137&gclid=Cj0KCQjwg7HPBRDUARIsAMeR_0i87bjqi5QFKwrSBohK0qigPhrA06f3B5zEmX5WAtlIWtaP6RhEacUaAv7tEALw_wcB

MacGill, M. (2017). Lymphoma: Types, causes, and treatment. Retrieved from https://www.medicalnewstoday.com/articles/146136.php

Meremikwu, M. M., Ehiri, J. E., Nkanga, D. G., Udoh, E. E., Ikpatt, O. F., &Alaje, E. O. (2005). Socioeconomic constraints to effective management of Burkitt's lymphoma in south-eastern

Nigeria. *Tropical Medicine and International Health, 10*(1), 92-98.

Minaya, P., Baumstarck, K., Berbis, J., Goncalves, A., Barlesi, F., Michel, G., …Auquier, P. (2012). The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer.*48*(6), 904-911. doi: 10.1016/j.ejca.2011.09.010

Mortey, E. P. (2017). Burden and quality of life of primary caregivers of stroke patients attending Tema General Hospital. Unpublished masters dissertation, University of Ghana.

Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: possible predictors and model development.*Research on Aging*, 7, 329-361.

Mumford, V., Baysari, M. T., Kalinin, D., Raban, M. Z., Mccullagh, C., Karnon, J., & Westbrook, J. I. (2018). Measuring the fi nancial and productivity burden of paediatric hospitalisation on the wider family network, 1–10. https://doi.org/10.1111/jpc.13923

Olusanjo, A. C., & Chiebuka, O. E. (2016). Burden, Health And Quality Of Life Of Nigerian Stroke CaregiversBurden, Health And Quality Of Life Of Nigerian Stroke Caregivers. *Health Care : Current Reviews*, *4*(2), 1–5. https://doi.org/10.4172/hccr.1000105

Orem, J., Mbidde, E. K., Lambert, B., De Sanjose, S., & Weiderpass, E. (2007). Burkitt's lymphoma in Africa, a review of the epidemiology and etiology. *African Health Sciences*, *7*(3), 166-175. doi: 10.5555/afhs.2007.7.3.166

Parkin. (2008). Cancer in indigenous Africans. *Lancet Oncology, 9*, 683-92.

Reis, A., Ihle, P., Paulus, U., Ferber, L.V., Diehl, V.,& Walshe, R. (2006). Cost of illness of malignant lymphoma in Germany.Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/16968321

Roles, T. (2015). What is Caregiving ? Good Mental Health for Everyone.

Round, J., Jones, L., & Morris, S. (2015). Estimating the cost of caring for people with cancer at the end of life : A modelling study, 175–176. https://doi.org/10.1177/0269216315595203

Rubin, A.,& Babbie, E. (2015). Research Methods for Social Work.

Rubira, E. A., Marcon, S. R., Silva, A. G., Aparecida, M., Gaíva, M., & Espinosa, M. M. (2012). Burden and Quality of Life of Caregivers of Children and Adolescents With Chemotherapy Treatment for Cancer. *Acta paul. enferm*, *25*(4), 567-563. doi:10.1590/S0103-21002012005000020

Segbefia, C., Renner, L., Dei-Adomakoh, Y., & Welbeck, J. (2013). Changing Pattern of Childhood Cancers At Korle Bu Teaching Hospital, Accra, Ghana. *Postgraduate Medical Journal of Ghana*, *2*(2), 65-67.

Shiels, M. S., Engels, E. A., Linet, M. S., Clarke, C. A., Li, J., Hall, H. I., … Morton, L. M. (2013). The epidemic of non-Hodgkin lymphoma in the United States: Disentangling the effect of HIV, 1992-2009. *Cancer Epidemiology Biomarkers and Prevention*, *22*(6), 1069–1078. https://doi.org/10.1158/1055-9965.EPI-13-0040

Schilling, M., Parks, C., & Deeter, R. G. (2011). Costs and outcomes associated with hospitalized cancer patients with neutropenic complications: A retrospective study. *Experimental and Therapeutic Medicine*, *2*(5), 859-866.

Stefan, D. C., & Stones, D. (2009). How much does it cost to treat children with Hodgkin lymphoma in Africa? Retrived from https://www.ncbi.nlm.nih.gov/pubmed/19197725

Summary, E., Relevance, P. H., & Mediterranean, E. (2014). Hodgkin Lymphoma (Adult).

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-tieulent, J., & Jemal, A. (2015). Global Cancer Statistics, 2012. *CA: A Cancer Journal of Clinicians.*, *65*(2), 87–108.

https://doi.org/10.3322/caac.21262.

Van Houtven, C. H., Ramsey, S. D., Hornbrook, M. C., Atienza, A. A., & van Ryn, M. (2010). Economic burden for informal caregivers of lung and colorectal cancer patients. *The Oncologist*, *15*(8), 883–893. https://doi.org/10.1634/theoncologist.2010-0005

Weitzner, M. A., Jacobsen, P. B., Wagner, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index–Cancer (CQOLC) Scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. Quality of Life Research, 8, 55–63.http://dx.doi.org/10.13072/midss.388

World Cancer Leaders Summit. (2014). Economic cost for cancer control. Retrieved from https://www.uicc.org/world-cancer-leaders-summit-2014-report

World Health Organization. (2003). Global cancer rates could increase by 50% to 15 million by 2020. Retrived from http://www.who.int/mediacentre/news/releases/2003/pr27/en/

World Health Organization. (1998). WHOQOL: measuring quality of life. *Psychol Med*, *28*(3), 551–558. https://doi.org/10.5.12

World Health Organization. (2013). WHO: cancer mortality database (IARC) http://www-dep.iarc.fr/WHOdb/WHOdb.htm

World Cancer Research Fund International. (2015). Cancer facts and figures: Worldwide data. Retrieved from http://www.wcrf.org/int/cancer-facts-figures/worldwide-data

Xie, L., Kariburyo, M. F., Du, J., & Baser, O. (2014). Assessing the economic burden and health care utilization of U.S. Medicare patients diagnosed with melanoma. *Value in Health*, *17 (7)*, A625. https://doi.org/10.1016/j.jval.2015.03.1158

Yabroff, K. R., Lund, J., Kepka, D. A. M. (2014). Economic Burden of Cancer in the US. *Cancer Epidemiol Biomarkers Prev.*, *DOI: 10.11*(301), 1–18. https://doi.org/10.1158/1055-

9965.EPI-11-0650.Economic

Yabroff, K.R, & Kim, Y. (2009) Time costs associated with informal caregiving for cancer survivors. Cancer *115*(21), 4362-4373.

Yusuf, A. J., Adamu, A.,& Nuhu, F. T. (2010) Caregiver burden among poor caregivers of patients with cancer in an urban African setting. *Psychooncology*, *20*(9), 2-5.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649 -655

APPENDICES

APPENDIX 1:PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Title of Research:

Economic Burden and quality of life of Primary Caregivers of Lymphoma patients attending the Paediatric Cancer Unit atKomfoAnokye Teaching Hospital.

Name and Affiliation of Researcher:

This study is being conducted by Prince Dawson Cromwell of the University of Ghana, Accra.

Background of the study

Lymphoma is a major public health problem in terms of morbidity and mortality. In Africa, it has become one of the most prevalent cancers, especially in Ghana where it is very predominant in children. Lymphoma is often associated with an increased burden on primary caregivers. A large number of patients abandon treatment because of the huge cost families have to bear. These related situations affect the quality of life of primary caregivers as they become burdened with caring for their patients.

Purpose of research

The main objective of this research is to determine the burden of caregiving and quality of life of primary caregivers of lymphoma patients.

Procedure of research

A simple random sampling of patients will be used to generate 144 participants from the folders of patients in the hospital. A random number will be generated to aid in the selection of participant to avoid impartial selection and participants selected will be primary caregivers who have provided care to patients for at least one month. A selected participant will be required to answer questions from a questionnaire comprising open and close ended questions on the cost incurred and quality of life as a result of caregiving to lymphoma patients. The answers provided will be analyzed to determine the cost incurred and quality of life primary caregivers of lymphoma patients.

Risk

The study will pose no potential risk to the individual under study, the facility or the public.

Benefit(s)

Both the study population and society stand to benefit from this study. The study population will know how much money they spend in a month on caring for their patients. Policy makers on the other hand will know the economic burden of lymphoma, thus better make effective health care planning and allocation of resources that will help strengthen the health system. The research will consequently educate individuals and the public of lymphoma as well as draw up programs to help support caregivers of lymphoma patients.

Confidentiality

Information obtained will be used purely for the purpose of research thus anonymity and confidentiality will be strictly adhered to as names of study participants will be used for any public report. Questionnaires will be designed such that it will not include the name of

participants, likewise information gathered from a participant will not be disclosed to another participant.

Voluntariness

Your consent to participate in the study should be purely voluntary. Under no obligation will you be coerced to partake in the study against your will and you have the right to withdraw from the study at any point in time.

Alternatives to participation

Refusing to participate in this study will not have effect on you concerning your treatment at the hospital.

Withdrawal from the research

If you indeed decide to take part, you are allowed to withdraw whenever you wish to, and are also allowed to skip answering any of the questions that you are not very comfortable with.

Consequences of withdrawal

There will be no penalty or loss of care to you, if you choose to withdraw. However, please note that, some of the information that may have been obtained from you will be modified and used in publications. These cannot be removed anymore. I do promise to make good faith effort to comply with your wishes as much as practicable.

Compensation

No compensation in the form of gift or payment will be made to you. Your contributions will be appreciated and the benefit of partaking in the study will be explained to you.

Contacts

In case you have any questions later, please do not hesitate to contact Prince Dawson Cromwell (Name of Researcher), Department of Health Policy, Planning and Management, School of Public Health, University of Ghana. (Tel: 0272494353/ 0501356816) Email: princedawson2@gmail.com

Also, if you need further clarifications about this study please, kindly contact:

The Office of the Chairman

Committee on Human Research and Publication Ethics, Kumasi

Tel: 03220 63248 or 020 5453785

CONSENT FORM

Statement of person obtaining informed consent:

I have fully explained this research to _____ and have given sufficient information about the study, including that on procedures, risks and benefits, to enable the prospective participant make an informed decision to or not to participate.

DATE: _____ NAME: _____

Statement of person giving consent:

I have read the information on this study/research or have had it translated into a language I understand. I have also talked it over with the interviewer to my satisfaction.

I understand that my participation is voluntary (not compulsory).

I know enough about the purpose, methods, risks and benefits of the research study to decide that I want to take part in it.

I understand that I may freely stop being part of this study at any time without having to explain myself.

I have received a copy of this information leaflet and consent form to keep for myself.

NAME:_____

DATE: _____ SIGNATURE/THUMB PRINT: _____

Statement of person witnessing consent (Process for Non-Literate Participants):

I _____ (Name of Witness) certify that information given to

_____ (Name of Participant), in the local language, is a true reflection of what l have read from the study Participant Information Leaflet, attached.

WITNESS' SIGNATURE (maintain if participant is non-literate): _____

APPENDIX 2:QUESTIONNAIRE

BURDEN AND QUALITY OF LIFE OF PRIMARY CAREGIVERS OF LYMPHOMA PATIENTS ATTENDING THE PAEDIATRIC CANCER UNIT AT KOMFO ANOKYE TEACHING HOSPITAL

Dear Respondent,

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

Respondent ID ……...

Date of interview ……

SOCIO-DEMOGRAPHIC DATA

Section A. Background information of caregiver

No	Questions	Response
1.	Sex 1. Male 2. Female	☐
2.	Age	……years
3.	Marital status 1. Single 2. Married	☐
4.	Highest level of education 1. No formal education 2. Primary level 3. Middle/ JSS/ JHS 4. SSS/ SHS/ TECH/ Vocational 5. Tertiary	☐
5.	What is your employment status? 1. Unemployed 2. Private sector 3. Public sector 4. Self employed 5. Student/ apprentice 6. Retired	☐

6.	Are you the primary caregiver of this patient? 1. Yes 2. No	☐
7.	How long have you been a caregiver to this person?	……
8.	Thinking about your care recipient, what is your relationship to him/ her? 1. Nephew/ Niece 2. Child 3. Grandchild 4. Sibling 5. Other (Specify) ……	☐
9.	Are you paid for your caregiving services? 1. Yes 2. No	☐
10.	Which of the following best describe your caregiving task? 1. Long distance care provider (30 minutes from the recipient by any means of transport) 2. Nearby care provider 3. Co- resident care provider	☐
11.	What is your monthly income from main occupation?	GHS…….
12.	How much do you receive from other sources of income in a month?	GHS……..
13.	How many days in a **WEEK** do you spend to care for the patient?	……days
14.	On average, how many hours per daydo you spend caring for the patient?	…….hours
15.	Have you had to reduce normal workload because of caregiving for patient? 1. Yes 2. No	.....

16.	If YES, by how many hours per week?	……..
17.	Since you began giving care to your recipient, would you say your finances have….? 1. Gotten better? 2. Stayed the same? 3. Gotten worse?	

Section B. Background information of care recipient

18.	Sex 1. Male 2. Female	
19.	What is your care recipient's age?	……years
20.	Do you assist your care recipient to perform any of the following task- taking a bath, using the toilet, walking inside the house, dressing up, sitting up etc. on a regular basis? 1. Yes 2. No	
21.	Do you assist your care recipient on a regular basis with any of the following- transportation, housework, medical management or arranging for outside services to help him or her? 1. Yes 2. No	

Section C. Direct cost: Out- of– pocket expenses

21.	In the past month, have you had any out- of –pocket expenses for …?		In a typical month, how much do you spend that? Average will be fine
		Answer 1. Yes 2. No	AMOUNT (GHS)
	a. Drugs/ Medicines.		.....
	b. Consultation		……..
	c. Laboratory Test/ Diagnostics		……..
	d. Travel / transportation for/ with your		

	care recipient to seek care?		.....
	e. Other (Please specify) …….		……..

Please I would like you to know which of the following financing sources you have used over the past month to pay for any health and other expenditure related to patient's illness. Please give your best estimate if you cannot the exact payments.

	What are the other sources of financing to pay for any cost related to patient's illness over the past month?	AMOUNT (GHS)
22.	1. Contribution from relatives	
	2. Health Insurance	
	3. Remittances	
	4. Donations/ Gift	
	5. Sale or transfer of assets (E.g. land, vehicle etc.)	
	6. Borrowed money	
	Other (please specify) …….	

SECTION D. INDIRECT COST

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

No.	Category	Answer 1. Yes 2. No	Number of Hours
23.	a. Time spent on personal care		
	b. Time spent on travel/ transportation to and from the facility		
	c. Time spent on waiting for medical care		
	d. Time spent on treatment at the facility		
	e. Other (please specify)		

SECTION E. ZARIT BURDEN INTERVIEW

Please answer the questions below by circling the appropriate response which best describes how you feel in relation to the child's condition.

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

Section F. Quality of life of primary caregivers (WHO EUROHIS – QoL INDEX)

Please answer the questions below by circling the appropriate response which best describes how you feel in relation to the child's condition.

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

Thank you very much for your time