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ECONOMIC BURDEN AND QUALITY OF LIFE OF FAMILY CAREGIVERS OF SCHIZOPHRENIC PATIENTS ATTENDING OUT PATIENT DEPARTMENT OF PSYCHIATRIC HOSPITALS IN GHANA

BY

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DECLARATION

I, Yaw Nyarko Opoku-Boateng, declare that except articles and books I have quoted, cited and duly acknowledged in references, all other information produced from this work is the result of my original research. No part of it has been offered for another degree in this university or elsewhere

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DATE DATE

DEDICATION

This work is dedicated to my parents Mr. Emmanuel Opoku-Boateng and Ms. Regina Okyere.

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My first gratitude goes to the Almighty God for His continual blessings and favour upon my life and strengthening me to complete this work.

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ABSTRACT

Background

Caregiving plays an important role in the management of severe mental health disabilities like schizophrenia. In many low - income settings where formal (or paid) caregiving is not prevalent, the economic and psychological burden borne by family members who play these roles often go unnoticed. . In the case of Ghana, where the Mental Health Act (2012) provides for de-institutionalization of mental health care, it is important to highlight the (especially economic and psychological) burden borne by family members in caring for people with severe mental health disabilities. There is paucity of studies on the burden of family caregiving for severe disabilities, and the current research fills this gap. The objective of this current study, therefore, is to estimate the economic burden and assess the quality of life of schizophrenia on family caregivers in Ghana.

Method

A cost analytic approach (Cost of illness) was used in estimating the economic burden and WHOQOL-BREF was employed to determine the quality of life. The primary source of data for this study included caregivers of patients who were diagnosed with schizophrenia at least six months before the commencement of the study and who present to any of the three psychiatric hospitals in Ghana

Economic burden was categorized direct costs (including medical and non-medical costs of seeking care), indirect costs (productivity losses to caregivers) and intangible costs (non-monetary costs such as stigma, pain, etc.). Direct costs were estimated using the direct economic costs of seeking care (e.g. medicines, consultations, travel, etc.). Indirect costs were estimated as the time (in hours) of productive time lost to caregiving multiplied by the daily wage. Intangible costs assessed using the Zarit Burden Interview.

Quality of life was assessed using the WHO Quality of Life tool (WHOQOL), which has four (4) domains namely, physical health, Psychological? implications, Social relationships and Environment.

Results

The total cost of caregiving for schizophrenic patients to the caregiver was estimated to be GHS 299,674.20 (USD 76,839.50). The indirect cost accounted for a greater proportion (82.5%) of the total cost of caregiving while the direct cost constituted the remaining 17.5% as indicated in the folder. The estimated direct cost for a month was GHS 52,521.20 (USD 13,467.00) of which the medical cost contributed GHS 33,744.20 (USD 8652.36), while the non- medical cost contributed GHS 18,777.00 (USD 4814.6). It was deduced that, the average total cost to the caregiver in treating schizophrenia was estimated as GHS 1065.80 (USD 151.8) for a month. The total quality of life of caregivers of schizophrenia was found to be low in all QoL domains relation to sex and was also clear that female caregivers have a lower quality of life. It was also found out that educational level?? have effect on the quality of life, the higher the educational level, the higher your quality of life. Lastly, it was also evident in the study that among the burdens, the intangible burden has the greatest adverse effect of the quality of life of the caregiver.

Conclusion

The cost of family caregiving for schizophrenia is huge and for that matter cannot be overlooked and as a result, the quality of life experienced by the caregivers is affected. A negative association was found between the cost components and the quality of life and more significantly was the intangible cost. . This study was done within the three psychiatric hospitals in Ghana and hence can be generalized to the entire population.

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LIST OF ABBREVIATIONS

COI	Cost of illness
GHS	Ghana Health Service
ICD-10	International Classification of Disease, 10th edition
NHIS	National Health Insurance Scheme
OPD	Out Patient Department
USD	United State Dollar
UK	United Kingdom
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
ZBI	Zarit Burden Interview

DEFINITION OF TERMS

Burden	The presence of problems, difficulties, challenges or adverse effects which affect the lives of psychiatric patients' caregivers
Caregiver	A person who has been living with the patient, and has been closely involved in his/her undertakings of daily living, healthcare, and social dealings for more than a year.
Delusion	Perceived belief that is false and cannot be changed in any way.
Direct cost	The values of all resources expended directly by caregivers in seeking healthcare
Hallucination	It is a major sign exhibited by a mental patient and is characterized by misinterpretation of objects seen.
Household	A group of people living in the same house and eating from the same pot.
Indirect cost	The cost of time spent out of normal work due to morbidity and mortality.
Quality of life	An individual's opinion of their situation in life in the framework of the beliefs and value systems in which they live and with respect to their goals, expectations, ideals and concerns.
Economic burden	The presence of problems, difficulties, challenges or adverse effects as a result of economic impact which affect the lives of psychiatric patients' caregivers

CHAPTER ONE

INTRODUCTION

1.1 Background study

Mental disorders is a global burden and continues to have a significant bearing/impact on health, social control, human rights and economic effects in all countries around the world (World Health Organisation, 2016a). The prevalence of mental disorder globally is about 10% of adults, and about 25% of the population suffers from mental disorder in one form or the other in an entire life time (WHO, 2001). In Ghana, the occurrence of mental illness is about 13% (Addo, Nonvignon, & Aikins, 2013). By some families in Africa, mental illness is often considered to be a curse and as such, people with mental disorders suffer the wrath of the people/family members and their upkeep is no more a concern to the family.

Schizophrenia is a serious psychological disorder which renders patient incapable of managing themselves and the environment or surroundings in which they find themselves. The World Health Organization approximates that 21 million people suffer from the illness worldwide (WHO, 2016), which can also be implied to mean that the same number of families are equally affected by the disorder. Schizophrenia is the most severe mental health illness, representing the eighth cause of disability in the world (Serretti, Mandelli, Bajo, Cavenini & Papili, 2009).

In the absence of adequate health personnel, appropriate medicines and infrastructure to take care of the patients, the burden on the family in caregiving has increased and this imparting on the quality of life. In developing countries the caregiving role is mostly played by family members; they do so by dedicating their time and energy in taking care of the affected family member. Again, according to Thara and Padmavati (2004), family caregivers play a substantial role in providing caregiving support to ill relatives.

The World Health Organization estimated that about 50% of schizophrenic patients are not receiving appropriate care and that 90% of such cases are found in the low and middle income countries (WHO, 2008). According to Aukst, Miro, Zvjezdana, Branimir & Vlatka., (2013), support for a relative with mental health illness impacts the quality of life of family caregivers, and concludes that the quality of life of caregivers of schizophrenic patients are lower compared to caregivers of patients with other psychiatric diagnoses. This is as a result of recent changes in family structures and rapid economic decline threatening the support available to chronic mental illness such as schizophrenia (Vikram Patel & Rangaswamy Thara, 2005).

The outcome of stressors on relatives caring for an ill person in the family has been termed as caregiver's burden. In trying to give the best possible care to the ill family member, caregivers most of the time, give up their quality of life to care for their relatives. Caregivers report conflicts of roles that necessitate them to rearrange their work schedules, to end up losing their jobs, to have to reduce the number of working hours or to take unpaid leave of absence.

1.2 Problem statement

Studies have shown that management of schizophrenia comes at a cost to families and society (Zhai, Guo, Chen, Zhao, & Su, 2013). Schizophrenia contributes a significant proportion of a country's expenditure on health care (Davies, Drummond, & Davies, (1990). In most developed countries, current health care expenses of schizophrenia accounts for 1.6% to 2.6% of the countries total health care budget, according to a study done by Zhai, Guo, Chen, Zhao & Su.,(2013).

Schizophrenia accounts for between 30%-35% of mental health cases reported at the OPD of the three psychiatric hospitals in Ghana (Accra Psychiatric Hospital, 2014; Ankaful

Psychiatric Hospital, 2014; Pantang Hospital, 2014). Family members have now taken the responsibility by providing care of their ill relatives Aukst et. al. (2013) due to the financial implications involved. These caregiving roles are mainly informal and as such the caregivers do not receive any monetary incentives. Studies have shown that the cost involved in caregiving is very significant, but there are no reliable estimates of the cost involved (Awad & Vorungati, 2008). These costs place a significant economic burden on the caregiver and one of the objectives of this research is to examine the economic burden of care giving for schizophrenic patients in psychiatric hospitals in Ghana.

Studies elsewhere have reported that the quality of life of caregivers of schizophrenic patients is worse compared to the other forms of mental disorders, according to Aukst et al. (2013). A study conducted by Rawat (2014), shows that the greater the level of economic burden of a caregiver, the lower the quality of life. Some of the other parameters that affect the quality of life of the caregiver are pain, anxiety, depression, stigmatization, discrimination and many more.

However, there is paucity in studies on the economic burden carried by caregivers in Ghana that estimate the cost involved in caregiving. There is therefore the need to assess the economic burden and the quality of life of caregivers of schizophrenic patients in Ghana.

1.3 Objectives of the Study

1.3.1 General Objective

The main objective of this research is to determine the economic burden and quality of life of caregivers of schizophrenic patients at the OPD psychiatric hospitals in Ghana

1.3.2 Specific Objectives

1. The study is to estimate the direct cost to the caregiver of a schizophrenic patient
2. The study is to estimate the indirect cost to the caregiver of a schizophrenic patient
3. The study is to describe the intangible cost to the caregiver of a schizophrenic patient
4. The study is to determine the quality of life of caregivers of schizophrenic patients
5. The study is to examine the relationship between the economic burden and the quality of life of caregivers of schizophrenic patients

1.4 Research questions

i. What are the direct costs associated with caregiving of schizophrenic patients at psychiatric hospitals in Ghana?

ii. What are the indirect costs associated with caregiving of schizophrenic patients at psychiatric hospitals in Ghana?

iii. What are the intangible costs associated with caregiving of schizophrenic patients at psychiatric hospital in Ghana?

iv. What is the quality of life of caregivers of schizophrenic patients at psychiatric hospitals in Ghana?

v. What is the relationship between the economic burden and the quality of life of caregivers of schizophrenic patients at psychiatric hospitals in Ghana?

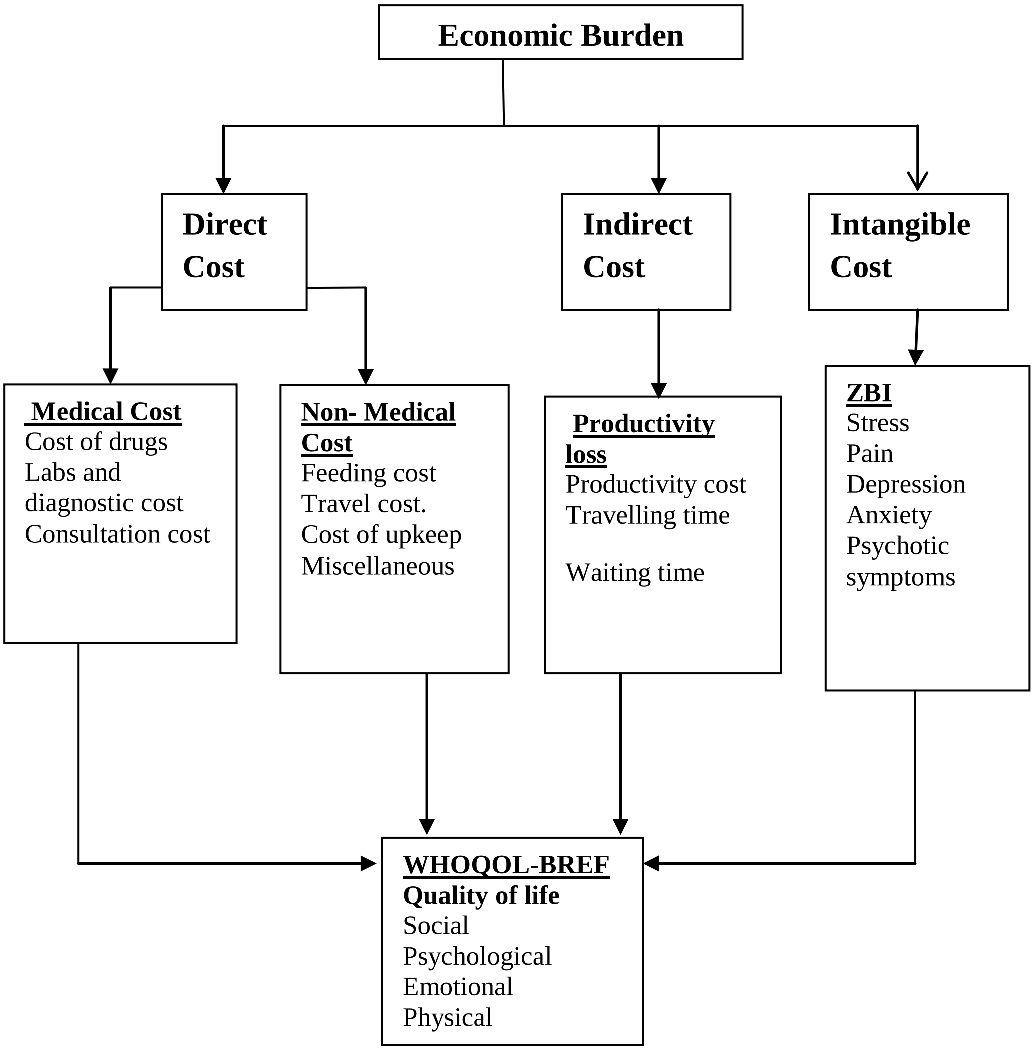
1.5 Conceptual Framework

The economic burden of diseases can be categorized into three (3) main groups, namely: direct cost, indirect cost and intangible cost.

The direct cost included the expenditure attributed to the patient in seeking medical care at the Out Patient Department (OPD) and this cost can be grouped into two (2) categories: treatment related cost and non- treatment related cost. The treatment related cost comprises the cost involved in the actual treatment, such as drugs, laboratory and diagnostics cost, therapy cost or the physician's consultation cost. Non-treatment cost involves transportation costs which include fares paid for transportation to and from the health facility, feeding cost which involves monies paid in exchange of food and drinks during the period of seeking medical care and the general upkeep of the patient like clothing, accommodation, and miscellaneous costs such as telephone bills and other utility bills during the time the patient seeks treatment. The non-treatment cost is not directly related to treatment cost but inflates the cost of the health seeking processes.

The indirect cost relates to the cost associated with loss of productivity due to the caregiving. This cost is incurred as a result of the caregiver not being able to go to work or having to reduce the number of working hours due to the illness and the number of hours or days the caregiver spends with the patient. Due to this, there is loss of earning due to non-productivity which contributes an indirect cost to the caregiver which in turn affects his/her quality of life.

Figure 1: Conceptual framework of quality of life and economic burden of care giving for schizophrenic patients



Another component of indirect cost to both the care giver and the patient is the travel time to the health facility and back and the time spent waiting at the health facility when seeking treatment.

The intangible cost aspect cannot be readily expressed in monetary terms because it also includes stress, depression, anxiety, financial difficulty and sometimes psychotic symptoms as a result of caregiving for such patients. From the above it is seen that the direct cost, indirect cost and the intangible cost all affect the quality of life of the caregiver. The quality of life of the caregiver is affected Psychologically, Emotionally, Financially, Physically and Socially.

1.6 Significance of the study

This research will help create awareness about schizophrenia and its challenges and also estimate the various costs involved in caring for a schizophrenic patient and the economic burden it imposes on the caregivers and its implications on their quality of life. This will highlight the important roles of family caregivers in the provision of comprehensive care for the marginalized population, provide recognition of the burden family caregivers carry and provide appropriate interventions for them in order to ensure the successful implementation of the community mental health care as stated in the Mental Health Act, (2012).

Moreover, this study will add to the meagre literature on the subject of caregiving of mental health patients in Ghana. In addition, this study will highlight the loss of productivity due to mental health and caregiving and will buttress the economic point of investing in mental health to avoid the productivity losses and thereby enhancing the economic development of the country at large.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of literature associated with the objectives of this study. It comprises the concept of schizophrenia, caregiving burden and quality of life, types of schizophrenia, signs and symptoms of schizophrenia, cost associated with schizophrenia and care giving for schizophrenic patients.

2.2 Concept of schizophrenia

Schizophrenia is a disabling form of mental illness (Zaprutko, Nowakowska, Kus, Bilobryvka & Rakhman., 2015). Schizophrenia is caused by an impairment in the brain which leads to distortions in the affected person's thinking, emotions and perceptions, it influences the ability to make coherent speech and also makes the person hear voices and suffer from delusions. Schizophrenia, as explained by World Health Organization, is a severe mental disorder affecting more than 21 million people worldwide (WHO, April 2016). In Ghana, according to Addo et al., (2013), the prevalence of mental illness is about 13%. Schizophrenia is prevalent in Africa and about 2.1 million people in Africa suffer from schizophrenia, while globally 1.5 million people are diagnosed with schizophrenia every year (Fleischhacker, Arango, Arteel, Barnes, & Carpenter., 2014). Again, according to Adeosun, (2013), globally, in every 100 people, one person suffers from schizophrenia . In Ghana about 32% of all mental health cases reported at the psychiatric hospitals are diagnosed of schizophrenia (Armenia, 2011). Schizophrenia is a potentially overwhelming illness with a colossal impact on the victims, their families, the health service systems and the broader society, M Knapp, (2000). Schizophrenia is an illness that has a lot of implications on the patient and the caregiver. It has an effect on the brain which limits the patient in coordinating himself and his environment which makes the patient always dependent on the caregiver; it renders the patient unproductive in terms of reasoning and earnings to add value to his/her life. According to Zhai et al., (2013), schizophrenia is a severe mental illness which is categorised by a significant disturbance in thinking, in perceptions, in emotions and in conduct. It makes the patient perceive things which do not exist and this makes it very difficult to have any meaningful interaction with the patient. Mortalities due to suicide in schizophrenic patients is higher relative to other mental health illnesses, the average life expectancy of patients with schizophrenia is lower than the general population with the average life expectancy age for men with schizophrenia being 37 years, while the average for those without schizophrenia is 43 years according to Davies, Drummond, & Davies., (1990).

2.2.1 Types of schizophrenia

Paranoid schizophrenia is considered to be the most ordinary subtype of schizophrenia. People with this type are considered to be more functional than the other subtypes of schizophrenia; they are able to engage in relationships and employment. However, they are marked by the presence of auditory hallucinations and delusional thoughts of conspiracy and persecution against them which makes them easily angry and hostile. Patients with paranoid schizophrenia do not easily exhibit their symptoms and they do that only when there is an exacerbation due to stress and pressure.

Disorganized schizophrenia, as the name implies, is predominantly associated with disorganized thought processes. It is also known as hebephrenic schizophrenia, where the affected person's speech becomes unintelligible due to disorderly thinking i.e. using and ordering of words in conversational sentences rather than difficulty in articulation. They may not show signs of delusion and hallucinations but exhibit emotions that do not correspond with the occasion.

Catatonic schizophrenic patients under this subtype of condition are characterised by their response to movements or activities. They can be catatonic stupor where voluntary activities or movement stops or catatonic excitement where activity or movement dramatically increases. The affected are mostly resistant to new ideas or to things they are used to, unusual repetition or mimicking of things like words or movement.

Undifferentiated schizophrenia is when patients have symptoms that are not adequately formed or precise enough to categorize them into any subtype. They exhibit symptoms of the other subtypes but not at significant levels to categorize into any subtype.

Residual schizophrenia is when patients no longer display prominent symptoms or the symptoms have lessened in severity. However, there are some signs of social withdrawal and loosening of friends and there may also be some little level of disordered thinking.

2.2.2 Signs and symptoms of schizophrenia

In every situation, to be able to provide solutions one should know the problems. The same applies to schizophrenia. In the management of schizophrenia, it is beneficial to identify the signs and symptoms. Schizophrenia appears in two forms i.e. it appears suddenly or acutely without warning signs, but in the majority of patients, it comes on slowly with warning signs and the person's functionality begins to decline to a point where there is an episode that manifests itself. According to Smith and Segal, (2015), some of the signs and symptoms of schizophrenia are

- Social withdrawal
- Resentment or suspiciousness
- Worsening of personal hygiene
- Flat, expressionless look
- Inability to cry or express joy

- Inappropriate laughter or crying
- Depression
- Insomnia or oversleeping
- Odd or absurd statements
- Forgetfulness, unable to concentrate
- Extreme reaction to criticism
- Strange use of words or way of speaking

These are signs and symptoms that can result from a series of complications and not only schizophrenia but they are a cause for anxiety. It is better to seek medical attention when someone experiences these symptoms and signs.

Delusion is a decisively held notion that a person has, notwithstanding clear and apparent evidence that it is not true. Delusions are exceptionally common in schizophrenia, befalling more than 90% of those with this disorder. High levels of stress is believed to be schizophrenia's triggering factor by aggregating the production of the hormone cortisol (Smith & Segal, 2015).

2.3 Concept of caregiving for schizophrenic patients

Caregiving in Africa is mostly done by family members and close associates like friends and relatives. Although, relatives are the most valued and the most dependable resources for the sick person and the family members play a significant role in assisting their mentally impaired relatives, family caregivers are not appreciated for seeking the well-being of the patient (Glozman, 2004).

The World Health Organization estimates that about 40-90% of schizophrenic patients live with their families (WHO 2008). A caregiver can therefore be defined as a person being part of the patient's family who takes responsibility for the patient and devotes his or her time to take care of the patient without getting any financial remuneration (Caqueo-Urízar, Gutierrez-Maldonado & Miranda-Castillo., 2009b). According to Caqueo-Urízar et al., (2009), the family has taken over the functions which are supposed to have been performed by psychiatric institutions. It is believed that patients get the best of care when they are being taken care of by family members or relatives and this also affects the quality of life of the family member or caregiver. It is estimated, for example, about 52 million Americans render services as informal caregivers of sick or incapacitated patients and they are mostly based in the homes of the patients where they administer complex medications and this bring a lot of burden on the caregivers (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). In developed countries, caregiving is not mainly by family members and are mostly rendered by professional care takers unlike in Africa and other developing countries where it is mostly done by family members. In Ghana, the caregiver role is mostly played by mothers of the patients or their wives and sometimes also played by the daughters of the patient. The males support by providing financial support in most of the cases. These caregivers perform an important role in commencing and maintaining patients connection with mental health services, and in sustaining them through long durations of recuperation (Knock, Kline, Schiffman, Maynard, & Reeves, 2011).

2.4 The burdens of caregiving for schizophrenic patients

Schizophrenia is a chronic illness which does not only affect the life of the patient, but it equally affects the caregiver as well. Since the patient cannot live an independent life, the caregiver's life is surrounding the life of the patient.

About 18% (approximately 1 billion) of the global population has a form of disability and it is estimated that low and middle income countries have the highest prevalence (Thrush, Hyder, & Hopkins, 2014). These persons with disabilities depend on other people, referred to as caregivers, for their daily activities and existence. . Family caregiver burden can be defined as the challenges or difficulties the caretaker goes through while caring for the ill patient (Li, Lambert, & Lambert, 2007). Dillehay and Sandys., (1990) explained burden of the caregiver as a mental state that arises from the mixture of physical and emotional work and social pressure, including the economic limitations that arise from taking care of the patients. Again, according to Chan, (2011) this burden can be defined as the outcome for those in close proximity with a severely troubled person with mental disability. Similarly, the term 'burden' can be explained as the presence of psychosocial and emotional problems or difficulties, worrying situations or considerable life changing events which affect the mental health balance of the family member or caregiver of a chronically ill patient (Madianos, Economou, Dafni, Koukia, & Palli., 2004). However, the caregiver and his burden are relegated to the background whereas the focus mainly rests on the persons with the disability. As caregivers struggle to combine work, family, and caregiving, they tend to forget taking proper care of themselves alongside (Chan, 2011).

Some authors classify the burden into two categories, the objective burden and the subjective burden. The objective burden shares the patient's symptoms, conduct, and socio-demographic features, and factors such as changes in domestic routine, family or public relations, work, leisure time, and physical health. The subjective burden is the mental health and subjective suffering among relatives (Reine, Tucci, Sapin, & Lancon, C, 2003). People suffering from schizophrenia and their caregivers suffer stigmatization, anxiety and other forms of abuses both verbally and physically. These abuses sometimes extend to the whole extended family of the patient and caregiver, as indicated by Caqueo-Urízar et al., (2014), that mental illness is a humiliation for families is still common and contributes to social isolation and it can be concluded that patients and their families experience discrimination as a result of mental illness.

Thrush et al., (2014), in their study also looked at the caregiver burden from a different dimension. They categorized it into social burden, psychological burden, financial burden, time burden and physical burden. They concluded that the burden on the caregiver from the physical, social and psychological influences are more significant than the burden of constraints on finance and time.. Among all these burdens, stigma against patients of schizophrenia and their caregivers is perceived to be the most dominant in all researches conducted globally. The experience from discrimination and stigmatization by caregivers is critical because some are not able to secure and maintain employment because, since their family member has a mental problem, it is perceived that they may also be suffering from the same fate merely that theirs has not occured yet. This is a very common perception in Africa which includes Ghana. Stigmatization is still a major canker to deal with by patients and caregivers of schizophrenia in both the developed and the developing world; it leads to isolation and dejection which can lead to low self-esteem and eventually leads to some victims committing suicide.

Generally, in developed countries, there are social interventions like financial benefits that are in place for the patient and for the caregiver as well (Awad & Voruganti, 2008), so it relieves some pressure from the care giver. In Sub- Saharan Africa, of which Ghana is part, unfortunately there are none of these interventional policies in place to assist the patient and the caregiver. This leads to an increase in the burden on the caregivers caring for these patients in Sub-Saharan Africa and Ghana.

2.5 Economic costs associated with caregiving for schizophrenia

The cost of the economic burden brought upon the caregiver is very significant and it affects his/her quality of life. A study done in Australia attests to the fact that schizophrenia is a very expensive illness to treat. According to the study schizophrenia affects not more than 10% of the number of patients suffering from myocardial infection, however, the cost of treating schizophrenia is 75% the estimated cost of treating myocardial infection (Davies et al., 1990). Byford, Barber, & Fiander, (2001) assessed factors influencing the cost involved in caring for patients with severe psychiatric illness. They found that the high cost was influenced by the age of the patient and the duration of the illness, although the study looked at the cost involved, it is clear that the higher cost will increase the burden of the caregiver and invariably affect the quality of life as well.

In developed countries where the health systems are well structured, there are mechanisms in place to estimate the cost associated with caring for a schizophrenic patient and the caregiver. However, in Sub-Saharan Africa, little has been done in estimating the cost involved. The economic burden resulting from schizophrenia according to Martin, Mangalore & Simon., (2004), who grouped them into direct cost, indirect cost and the intangible cost. The direct cost has two dimensions which include treatment related cost and non-treatment related cost. The treatment related cost includes expenditures incurred by directly paying money in seeking for medical care, this include consultation fees paid, laboratory and diagnostics done which were paid for directly and the cost of drugs for the patient. The non-treatment related cost involves travelling cost to the health facility and back home, cost incurred for feeding for both patient and caregiver during the period of seeking medical care and other miscellaneous expenses.

The indirect cost is basically based on loss of productivity, morbidity and premature mortality. This is as a result of the patient not being able to secure and maintain a job due to the illness, and again productivity loss due to the caregiver spending the hours due for working to earn an income on taking care of the patient. More so, productivity loss due to time spent on travelling to and from the health facility by the patient and the caregiver and the waiting times spent in the health facility in seeking medical care. Knapp et al., (2004) estimate productivity loss due to mortality as the product of the overall number of mortalities which occurred due to the illness and the average estimated earnings for the future anticipated for the patient if he/she were to be alive. Relationships suffer as a result of schizophrenia because people recoil and isolate themselves and cause persons with schizophrenia to be suspicious of people around them (Smith & Segal, 2014). The intangible cost cannot readily be quantified in monetary terms due to its nature. It involves the stress, depression, pain and anxiety the caregivers experience as well as the frustration they experience as a result of a relative suffering from schizophrenia.

2.5.1 Direct cost of caregiving

A study in Ghana by Addo et al., (2013) on household cost of mental health care in Ghana, where they adopted a cross-sectional design to collect data from Ho Municipal Hospital Psychiatric Unit showed that the total cost of mental health care for a three month duration was estimated as GHS60,752.18(US$34,518.27) with an average of US$180.72 per household. The direct cost was estimated to be GHS15, 939.80(US$9,056.70) making up 26% of the total cost. The total direct medical cost was found to be GHS12,701.00 (US$7,216.48) making up almost 21% of total medical cost. Cost of drugs was estimated to be 16% of the medical cost as well. Total direct non-medical cost was estimated to be GHS3,238.80(US$1,840.23) making up 5% of the total cost. Travel, food and accommodation cost were estimated to be contributing 4%, 0.8% and 0.1% of the total cost respectively.

Again, another study conducted in China by Zhai et al., (2013) investigating the economic cost of schizophrenia in two areas in China also suggests that the total cost involved in caring for schizophrenia per annum for a patient is US$2,586.21 of which direct cost was estimated to be US$862.81 accounting for 33% of the cost. The total direct medical cost was estimated to be US$714.86 making up 28% of the total cost while the non-medical cost was US$147.95 making up 6% of the total cost of caregiving. This study was carried out within a 12month period and was actually done in 2010. Though the direct medical cost was estimated using treatment cost and cost of other medical services, the study failed to highlight the various cost components of the direct medical cost and the direct non-medical cost and as such a true picture is not shown.

Rice and Miller, (1996) reported from a prevalence study undertaken in the United States that the estimated total cost of schizophrenia was US$22.8 billion in 1985. The direct cost which included institutionalization and ambulatory visits forming the direct medical cost and support cost which formed the direct non-medical cost included research, training and administration constituted 49% (US$11.1 billion) of the total cost. From this study it can be said that, the expenditure incurred by the caregiver and patient in seeking health care (travelling cost, feeding cost) were not factored in the costing thereby making the cost underestimated.

Sung, Cho, Hong, Hahm & Hyo., (2008), in their study to estimate the prevalence of schizophrenia and their associated cost involved with the illness in Korea in 2005 estimated the cost involved in treating schizophrenia to be US$3,174.8million of which direct cost accounted for US$539.7million which forms 17% of the total cost of caregiving. Direct medical cost was estimated to be US$418.7million which is 13%. The direct medical cost component was made up of outpatient care cost, inpatient care cost and pharmacy cost, however, it failed to give details of the outpatient and inpatient care cost to give a clear picture of what went into estimating the cost as this does not give a clear meaning to it. The direct non-medical cost was US$121.0 million which is 4% of the total cost and it included incarceration, community mental healthcare centres sanatoria, rehabilitation facilities, homeless shelters and transport cost. Again, the authors failed to include food cost as well as miscellaneous cost such as clothing and phone call bills.

2.5.2 Indirect cost of caregiving

Addo et al., (2013)**'s** study in Ghana estimated that the indirect cost contributes the greater proportion of the total cost in caregiving for schizophrenia. It was estimated in their study that, the indirect cost contributed 73.8% amounting to GHS 44,812.23 (US$25,461.56). In estimating the cost, the daily minimum wage in Ghana at 2012 was used and it involved productivity loss due to loss of employment, days lost by household due to caregiving, days lost to employed patient, and productivity loss due to travelling and waiting time.

Zhai et al. (2013) also estimated the total indirect cost per annum for caregivers of schizophrenic patients to be about 67% amounting to US$1723.40 of the total cost of caregiving. The estimation was done by analysing the cost as a result of lost working days by the patient and the caregiver which were estimated to be 39%(US$1,009.84) and almost 26% (US$663.93) respectively as well as value of destroyed properties contributing about 2%(US$49.63) of the indirect cost.

Rice and Miller, (1996) estimated the indirect cost accounted for 51% (US$11.7 billion). Indirect cost due to morbidity and mortality accounted for US$9.1 billion, while the other related cost (crime, social welfare management and cost of family assistance) accounted for the remaining US$2.6 billion of the indirect cost. Once again, the authors of this article failed to estimate the productive time lost due to unemployment as a result of caregiving, which this study intends to estimate.

Sung et al., (2008) estimated the total indirect cost of care giving of schizophrenia to be US$2, 635.1million in the year 2005. It constituted productivity loss due to unemployment as a result of caregiving and it was estimated to be US$1.798.2million forming 56.6% of the cost of caregiving. Reduced productivity at work also contributed USD 431.1million making 13.6% of the total cost of caregiving, premature mortality also contributed 8.6%

amounting to USD 273.6million as well as caregiver productivity loss was estimated as USD132.2million making 4.2% of the total cost.

2.5.3 Intangible cost of schizophrenia

The intangible cost, as mentioned earlier, cannot be measured in monetary terms and some costs are subjectively perceived by individuals as financial costs. They are usually related to anxiety, pain, loneliness or isolation, fear and suffering and it is the challenges that come with these which affects the quality of life of the caregiver. Several studies have tried to use an indirect way to examine the intangible cost of caregiving burden using the 22- item ZBI score. The ZBI score includes areas such as caregiver's health, mental health, finances, social life and the cordiality between the caregiver and the patient or care receiver. According to Morimoto, Schreiner, & Asano, (2003) higher caregiver burden is related to age, and sex, caregiving hours and the severity of the illness of the care recipient. The study further stated that the burden is higher in caregivers caring for younger patients than in caregivers caring for adult patients, it further indicated that the burden experienced by female caregivers are higher than that of their male counterparts.

2.6 Quality of life

Quality of Life is a new dimension in making a disability assessment and can be well thought-out as a result of health care and recuperation or a health status and a sign of functional infirmity, disease burden (either increase or decrease) or a demonstration of a social event and external settings as well as a subjective internal construct of self-assessment and psychological well-being not related closely to external factors (Glozman, 2004).

Until researchers began to involve the quality of life of caregivers in their studies, it was centred mainly on the patient. Quality of life of caregivers is an important part of health care which does not receive the attention it needs, it has however been relegated to the back ground. Many researchers concentrate mostly on the status and the quality of life of the patient and the care the patient is receiving leaving out the caregiver. Quality of life has many facets to it and as such it is very difficult to accept one universal definition.

The World Health Organization (2006) explains the model of Quality of Life as an individual's opinion of their situation in life in the framework of the beliefs and value systems in which they live and with respect to their goals, expectations, ideals and concerns. Again, the World Health Organization defines Health as a 'state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'; this has made the quality of life of caregivers of schizophrenic patients very important and worth determining because the health of the caregiver is equally important. A quality of life model consists of different dimensions: an individual's physical and emotional health, mental or psychological health and social well-being, achievement of personal aspirations and goals, economic stability and ability to perform daily activities without assistance (Caqueo-Urízar et al., 2009b).

Quality of life is a qualitative measure and as such cannot be measured directly, however an indirect mechanism can be employed to measure it by asking caregivers questions and their responses can then be measured and quantified and that is what this study will be using to measure the quality of life of caregivers. Some researchers have tried to evaluate the quality of life of caregivers by giving the questionnaire to the patients to answer on behalf of their caregivers or medical and social workers are given the forms to complete on how they assess the condition of the caregiver attending to the patient. However, this method has not been conclusive because the argument that the quality of life of one person should not be interpreted by a different person (Glozman, 2004). The measurement of quality of life incorporates the objective domain, the subjective domain or both.

The subjective domain is usually associated with well-being or life satisfaction of all areas of life while the objective component deals with living conditions and social functioning (Prigent, Simon, Durand-Zaleski, Leboyer, & Chevreul, 2014) and these are evaluated by a questionnaire to the caregivers and the patients. According to Arcia, Esta, & Imonson, (1996), though the objective domain is important in explaining the patient's level of health, the patient's subjective opinion and anticipation translate that objective assessment into actual quality of life experienced. Caregiver quality of life cannot be talked about without mentioning economic burden which comes with it and also contributes to the quality of life.

Many researchers who have studied the quality of life of caregivers used the Scale of Quality of Life of Caregivers (SQLC), which evaluates the quality of life under three main categories; (a) The professional activity i.e. the ability to take on responsibilities such as employment and other tasks, or the inability to do that due to caregiving, (b) The social and leisure undertakings and family condition of the caregiver, (c) The responsibility of the caregiver to assist the patient in daily activities and symptoms of depression. Caregivers of schizophrenic patients in Ghana face a lot of economic burdens since there is no social support system in place to support them. Therefore the survival and upkeep of the patient and the caregiver all depends on the caregiver. Research suggests that caregivers' demographics can be a contributory factor to their physical and mental health burden as well as quality of life (Li, Lambert & Lambert., 2007). The economic burden to caregiver from schizophrenia is enormous and affects the quality of life and it eventually affects the quality of care being offered to the patient as well. Again, according to Morimoto, Schreiner, and Asano, (2003), an increase in the economic burden is related to a decreased health-related quality of life, especially mental health.

2.7 Conclusion

From the many studies reviewed, it is evidently clear that the economic burden of care giving for schizophrenia is enormous and it ends up affecting the quality of life of the caregiver and should not be under-estimated. It was observed that due to the impact of schizophrenia, the patient is unable to commit to a job resulting in reduced or loss of earning. Due to the illness, the patient is stigmatized and the patient cannot perform usual household activities. The income of the family is also affected due to loss of productivity of the caregiver, this is because the time the care giver needs to work to earn an income is being spent taking care of the patient. In Ghana, the impact of schizophrenia will be experienced in stigmatization, a reduction in family earning, and the inability to maintain relationships.

In estimating the cost of schizophrenia, the direct treatment related and non- treatment related cost, indirect cost and intangible cost were measured. It was seen in all the articles reviewed that the proportion of estimates for indirect cost was higher than direct cost. In almost all the articles reviewed, the intangible cost was not factored into the analysis of the burden and this is a failure because the actual picture of the economic burden is not showcased but rather the financial picture. It was observed that most of the studies did not include the cost incurred by the caregiver especially the direct non-medical cost component in estimating the total cost of schizophrenia. It was also not clear in the few studies done in Africa, the percentage of healthcare budget allocated to mental health care which schizophrenia is part of.

Another important consideration is that the studies done in Africa, Europe and America refused to factor into their studies the quality of life of the caregiver of the schizophrenic patient. The few studies which factored in the quality of life of the caregiver failed to show the effect of the burden on the quality of life of the caregiver. This study intends to estimate the economic burden for caregivers of schizophrenia in Ghana and determine how the burden affects the quality of life of the caregiver which most studies have failed to do.

Moreover, it will attempt to fill the gap in the literature on the economic burden and quality of life of caregivers in low and middle income countries.

CHAPTER THREE

METHODS

3.1 Introduction

This chapter presents a description of the research methods used to help achieve the objectives of the study. This chapter encompasses the study design, study area, study population, research variables, sample and sampling techniques, sample size determination, study tool, quality control, data collection, data entry and processing, data analysis, ethical considerations /issues, assumptions and limitations.

3.2 Study Design

This study adopted a cross-sectional design using the cost of illness approach.

3.3 Study Area

The study was undertaken at three sites: the Accra, the Pantang and the Ankaful Psychiatric Hospitals, located in Adabraka and Pantang (both Greater Accra Region) and Cape Coast (Central Region). The Accra Psychiatric Hospital was commissioned in 1906 as the first psychiatric hospital in Ghana. With an initial bed capacity of 200, but it has been expanded and can accommodate 600 patients at any given time. The facility attends to patients from all over the country and surrounding countries like Togo, Burkina-Faso, Ivory Coast and Nigeria. The hospital has 4 wards (male, female, general and criminal) and each ward currently accommodates approximately 150 patients.

Ankaful Psychiatric Hospital is the next oldest psychiatric hospital in Ghana. It is located in Ankaful town in the jurisdiction of Cape-Coast Metropolitan Assembly in the Central Region of Ghana. The hospital was built in 1965 and serves patients from the Central, Western and Ashanti regions of Ghana and some neighbouring countries. The bed capacity of the hospital is between 300 and 350 beds.

Pantang Psychiatric Hospital was the next psychiatric hospital to be set up in Ghana after the Ankaful hospital. It is situated at Pantang near Accra under the Ga East Municipal Assembly of the Greater Accra Region of Ghana. It was established in 1975 and has a bed capacity of 500. This hospital also serves psychiatric patients from all over the country and from nearby countries. It is the largest among the three psychiatric hospitals in Ghana.

The study sites were chosen because they are the three psychiatric hospitals (all located in the southern part of the country) serving the country's population of approximately 25 million. Though some public hospitals see patients with mental illness on outpatient basis, most of those with severe mental conditions such as schizophrenia and who report to public hospitals are referred to one of the three psychiatric hospitals. It is important to note that, though all three hospitals are located in the southern part of the country, they serve about 85% of all mental cases in the country (WHO-AIMS, 2011)

3.4 Study Population

The population considered for this study was family caregivers of schizophrenic patients reporting to the Out Patient Department at each study site.

Inclusion criteria: Caregivers of schizophrenic patients who attended the OPD of the psychiatric hospitals with or without the patient within the duration of the study.

Exclusion criteria: Caregivers of patients who have been diagnosed with schizophrenia for less than 6 months were not included. Secondly, caregivers who were not the main caregivers were excluded.

3.5 Sample size determination

Based on Cochran (1963:75), the sample size was calculated as follows:

$$n_0 = (Deff)\frac{\left(Z_{\frac{\alpha}{2}}\right)^2 p(1-p)}{e^2}$$

Where n_0 is the minimum required sample size, Z^2 is an abscissa of the curve that cuts off an area $\propto$ at the tail (1 – α equals the desired confidence level, i.e, 95%), e is the desired level of precision, p is the estimated proportion of schizophrenic patients that is present in the population which was assumed to be 50% (i.e. default) since little is known about current proportion, and *Deff* is the design effect. For 95% confidence interval $Z_{\frac{\propto}{2}}$ is 1.96 and the level of precision "e" (margin error for the study was $\pm 5\%$). Assuming a design effect of 1.03, we have a minimum sample size

$$n_0 = 1.03 * \frac{1.96^2 \times 0.5 \times 0.5}{0.05^2} = 395.684 \approx 396.$$

Assuming a response rate of 90%, the final sample size was estimated to be 442. By using sampling proportionate to size of number of schizophrenic patients in a specific facility, the sample size required at each facility would be as follows.

Number of schizophrenic patients seen at Accra Psychiatric Hospital in 2015…….11,256

Number of schizophrenic patients seen at Pantang Psychiatric Hospital in 2015……6,780

Number of schizophrenic patients seen at Ankaful Psychiatric Hospital in 2015…… 3,660

With the assumption that each schizophrenic patient has one caregiver, then the sample size of caregivers of the various psychiatric hospitals was calculated separately by using the formula

$$\frac{\text{Number of caregivers of schizophrenic patients at hospital A}}{\text{Number of caregivers of schizophrenic patients in hospital A + B + C}} \text{ x } 442$$

A – Total number of caregivers in Accra psychiatric hospital (11,256)

B – Total number of caregivers of Pantang psychiatric hospital (6,780)

C – Total number of caregivers of Ankaful psychiatric hospital (3,660)

Hence,

Sample size for Accra Psychiatric Hospital is $\frac{11,256}{21698} \times 442 = 229$

Sample size for Pantang Psychiatric Hospital is $\frac{6780}{21698} \times 442 = 138$

Sample size for Ankaful Psychiatric Hospital is $\frac{3660}{21698} \times 442 = 75$

3.6 Sampling Technique

Caregivers were defined as members who supported most, if not wholly, the patient's daily care needs.

At each study site, folders of patients diagnosed with schizophrenia for at least a period 6 months were sorted and reviewed using the ICD-10 criteria, and caregivers who attended the hospital with the patients were identified. Caregivers who were identified were interviewed to determine whether they were the main caregivers or were representing the main caregivers. Those who were identified were used in the study. Respondents were interviewed until the required sample size was obtained.

3.7 Data collection tool and technique

A structured questionnaire (with closed-ended and open-ended questions) was used to collect data for this study. The questionnaire had sections on demography of the caregivers, questions on the economic burden (direct costs, indirect costs) on the caregiver and quality of life of the caregivers. The Zarit Burden Interview (ZBI) tool was used to collect data on intangible cost and had items on stress, pain, anxiety, depression.

The WHOQOL-BREF tool developed by the WHO was used to evaluate the quality of life of caregivers. The tool has four domains, namely: physical health, psychological health, social relationships and environment health. Each domain had a set of items under it; the physical domain had 7(seven) items under it, the psychological domain had 6 (six) items, social relationships had 3 (three) items, and the environment had 8 (eight) items and the domain score indicates the individual perception of quality of life under that domain.

The WHOQOL-BREF is made up of 26 questions and the scores are scaled 1-5 with the higher score predicting higher quality of life, The WHOQOL-BREF questionnaire tool contained 2 items from the overall Quality of life and General health and 24 items on satisfaction which is classified into 4 (four) main domains: Physical health has 7 (seven) items (DOM1), Psychological health with 6 (six) items (DOM2), Social relationships with 3 (three) items (DOM3), Environmental health with 8 (eight) items (DOM4). Each item is scored 1. The mean score of items within each domain is used to calculate the domain mean. The mean score of each domain is then multiplied by 4 (four) which then make it comparable with the WHOQOL-100.

3.8 Variables

Table 1: Description of study variables

Type of cost	Category of cost	Cost component
Direct cost	Medical cost	1. Cost of drugs 2. Laboratory and diagnostic cost 3. Cost of other therapies
	B. Non-medical cost	1. Travelling cost 2. Cost of food and drinks for patient and caregiver 3. Upkeep cost e.g. Accommodation 4. Miscellaneous cost e.g. Phone calls and utilities
Indirect cost	Cost due to productivity loss	1. Productivity loss to caregiver due to time travelling and waiting 2. Productivity loss to caregiver due to caring 3. Time or days loss to caregiver due to care 4. Productivity loss to caregiver due to loss of work

3.9 Quality control

Research Assistants (RAs) with basic knowledge of economics and schizophrenia underwent a three-day training during which they were introduced to the data collection tools. A pre-test was also undertaken Pantang Hospital. After the pre-test, the research team (comprising the student, supervisors and RAs) had a one-day meeting to discuss issues from the pre-test and adjust the questions accordingly. During data collection, to ensure compliance the data were monitored and validated daily before data entry. During the entry process, questionnaires that were not completely filled were not entered and the dataset cleaned after completing the entry before running the analysis.

3.9.1 Pre-data collection stage

Four research assistants , with adequate knowledge in the area under study, who could read and write English and could understand and be able to communicate in some local languages (Twi, Ga, Ewe and Hausa) were recruited and trained for three days. Training involved the explanation of the questionnaire, ethics and seeking informed consent from the participants of the study. Every single question in the questionnaire was explained to research assistants to avoid interviewer bias. They were trained to abide by the ethical guidelines of the study.

During the process of the training, the research assistants were given the opportunity to administer questionnaires at the pre-testing phase. Streamlining and additional explanations of the questionnaire were done based on the result of the pre-test. This was to guarantee that the questionnaire was well understood and administered correctly.

Before the final administration of the questionnaire to the study population, the questionnaire was pre-tested on caregivers who accompanied patients diagnosed with schizophrenia at the OPD of Pantang hospital. The pre-test exposed unforeseen problems such as repetition of questions, schizophrenic patients coming to the hospital without caregivers. It also gave the research assistants a better understanding of the questionnaire and the appropriate response for the questions asked.

3.9.2 Data collection stage

In ensuring adherence to research guidelines by research assistants, there was a daily visit to the study site. Questionnaires were checked to ascertain complete filling and incomplete questionnaires were discarded. Discussions were held with research assistants to know the difficulties and challenges so they could be addressed. The research assistants were given the questionnaires on a daily basis depending on the number projected for the day, and the questionnaires were coded.

3.9.3 Data entry and processing

Questionnaires which had been completely filled were coded within 24 hours upon receipt. Entry of the data was done and rechecked for errors using the Microsoft Excel. The data were then analysed using STATA and Microsoft Excel.

3.10 Data analysis

Descriptive statistics (mean, standard deviation) of study variables were presented. The socio-demographic features of the caregivers were described using frequency and percentages to find the distribution.

3.10.1 Cost analysis

Costs were analysed from the caregiver perspective and for a period of one month.

3.10.1.1 Direct cost estimation

Direct costs were estimated by adding up all the expenses made by actual payment for medical services within the last month. It was further grouped into medical cost and non-medical cost. Medical cost included the cost sum of drugs, consultations, laboratory investigations and diagnostics and other therapies.

The non-medical cost involved travelling cost to and from hospital, food for caregiver during the treatment period, accommodation for the caregiver when patient was on admission and miscellaneous costs which included telephone cost. The sum of medical related costs and non-medical related costs gave the total of direct cost.

3.10.1.2 Indirect cost estimation

Indirect costs were estimated based on Human Capital Approach or Income approach. Productivity loss was valued using the national daily minimum wage of GHS 8.00 per day (May 2016) for caregivers in the formal sector and local daily agricultural wage rate of GHS17.5 for informal sector caregivers. The time used for caregiving by the unemployed and student/apprentice was also considered and taken to be part of the informal sector. Travelling time was calculated by adding the total number of hours spent in travelling to and from the hospital and again productivity loss due to waiting is the sum of hours spent waiting and for treatment at the hospital (i.e. from the time caregiver and patient arrived at the hospital to the time they take their medications and leave the hospital).The time lost due to care giving (sum of productive hours lost in caring for the patient in a day) was also calculated and factored in the productivity loss.

Total indirect cost was estimated by summing the total time spent on caregiving multiplied by the respective wage rate. The results of the data was then tabulated and charted to give a visual representation of the findings on the study. Total economic cost was estimated by summing the direct and indirect cost. The mean total cost was also estimated.

3.10.1.3 Sensitivity analysis of the total cost

A sensitivity analysis was conducted to determine the robustness of the estimated costs. It helped to explore the sensitivity of results to any change in the variables which have some level of uncertainty. This was done by varying the cost of medicines and wages by increasing them by 3%, 5% and 7% respectively.

3.10.1.4 Intangible cost

Intangible costs were described using the short form of the ZBI by Bedard, Molloy & Squire., (2001) which was derived from the original 22 questions in ZBI. The intangible cost was analysed by summing the scores for all 12 items for each respondent to generate a maximum score of 48 and a minimum of 0. The overall score ranges between 0-48, which is further interpreted as 0-16 as low burden and above 16 high burden. This was presented in a pie chart to give a visual representation of the findings on the study. Also the mean response to each question was found for the caregivers in the study to find the average response.

3.10.2 Quality of life

Each item on the WHOQOL-BREF was rated from a score of 1-5 on a response scale, with 1 being the lowest and 5 being the highest. The total scores obtained under the domain were calculated and the mean score of the domain estimated. The mean score was then multiplied by four which convert scores to the range of 4-20 corresponding to WHOQOL-100 (The WHOQOL Group, 1996). The quality of life under the domain was then measured by the score obtained. The scores were scaled in a positive direction i.e. a higher score denotes a higher quality of life.

3.11 Regression Analysis

A linear regression analysis was used to determine the relationship between economic burden (direct cost, indirect cost and intangible cost) and quality of life of caregivers of schizophrenic patients, adjusting for each type of cost. Quality of life was used as dependent variable and the rest as independent variables. Mean differences of quality of life scores across demographic characteristics were assessed using the Kruskal-Wallis and Wilcoxon Rank Sum tests.

3.12 Ethical consideration/issues

Ethical approval for the study was allowed by Ghana Health Service Ethical Review Committee.

3.12.1 Approval from study area

Permission and approval was also sought from the administrations of Accra Psychiatric Hospital, Pantang Hospital and Ankaful Psychiatric Hospitals before data were collected.

3.12.2 Description of subjects involved in the study

The study population was the caregivers of patients who had been diagnosed with schizophrenia in the last 6 months and /or more prior to data collection. Data was collected from caregivers of identified patients.

3.12.3 Potential risk/benefits

The study population and the society stand to benefit enormously from the study. The study population (caregivers) had knowledge of their annual expenditure on caregiving for schizophrenic patients. Also, estimation of the economic burden of caregiving for schizophrenics can be used as a platform for sensitizing policymakers and opinion leaders about the economic burden of caregiving of schizophrenia. Moreover, the quality of life experienced by caregivers of schizophrenic patients is brought to bear for policy makers to intervene by implementing policies in supporting them.

Subsequently, programmes can be instituted to support good mental health, education on schizophrenia prevention, early detection and treatment of the disease. This can help minimise the incidence and prevalence of schizophrenia and the economic burden of caregiving to patients. Results of the economic burden of caregiving to patients will help make up to date decisions about their health and prevent schizophrenia as much as possible so as not to sustain the cost associated with it. This research posed no risk to the study population or the community.

3.12.4 Privacy/ confidentiality

Interviews were conducted in an enclosed setting to guarantee privacy. Data were also reported in aggregates to minimize the possibility of tracing information gathered back to the respondent (caregiver). This was done to make sure confidentiality of information received from the participants.

3.12.5 Compensation

On the average, each respondent was given an amount of GHS5 for refreshment. This was done after the questionnaire had been completely filled by the respondent.

3.12.6 Data storage and use

The questionnaires were coded and kept in a safe place. The data collected were coded and entered within 24hours of receiving them and were saved with a password which was known to only the principal researcher. All information received from respondents was kept by the principal researcher and copies were saved on an external hard drive and on a CD-ROM as well. The data collected will be kept by the principal researcher for 3-4 years to allow for publication of research after which the questionnaires will be destroyed.

3.12.7 Voluntary consent

Participation in this study was voluntary. Written consent was sought from each participant before taking information from them and they were allowed to opt out anytime they wanted to in the course of the study.

3.12.8 Conflict of interest

There is no conflict of interest in the study besides its academic and public health importance.

3.12.9 Proposal and funding information

The study is funded by the African Doctoral Dissertation Research Fellowship Programme, a collaborative program between African Population and Health Research Centre based in Nairobi and the International Development Research Centre based in Nairobi and the International Development Research Centre.

3.12.10 Assumptions

The following assumptions were made:

a. The national daily minimum wage for the country is reflective of the average income earned per day by the respondent or caregiver

b. All caregivers whose representatives were interviewed on their behalf because they could not come for review with the patient at the OPD were adequately represented.

c. The study also assumed that the productivity for employed caregivers including those who are self-employed is 8 hours in a day

d. Caregivers who were unemployed would have been engaged in agriculture or labour work if was not a caregiver and as such considered in the informal sector with the daily agriculture wage

3.12.11 Study limitations

The following limitations associated with this are study:

a. Almost half of the schizophrenic patients were attending the hospital for a re-fill of medications without the caregivers, making it difficult in getting the sample size. This situation necessitated an extension of the study in order to achieve the required sample.

b. The study was based on a recall period of one month. As such, some data regarding cost incurred and number of days spent on caregiving may be prone to bias.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results of the study. The chapter begins with socio-demographic characteristics of respondents. To achieve the objectives of the study, an analysis of the various results is presented subsequently

4.2 Socio-demographic characteristics of caregivers

A total of 444 questionnaires were administered to the caregivers of schizophrenic patients who reported at the three study sites. Table 2 shows that about 45% of respondents were aged 30-49 years and 37% of 50-69 years. There were about 6% of the respondents who were 70 years or more while 0.7% was below the age of 20years. The mean age was 47, about 57% of the respondents were females and 66% were married. Table 2 further shows that 22% of the respondents had tertiary education with 11% being graduates or postgraduates and 11% having certificate, diploma or post-diploma qualifications. About 34% of respondents had secondary education and 11% had no formal education while 32.8% had basic (primary and junior high school) education.

Table 2: Socio-demographic characteristics of caregivers

Characteristic	Number (%)
Sex	
Male	193 (43.5)
Female	251 (56.5)
Total	**444**
Age	
< 20	3 (0.7)
20-29	51 (11.5)
30-39	95 (21.4)
40-49	103 (23.2)
50-59	89 (20.0)
60-69	76 (17.1)
>69	27 (6.1)
Total	**444**
Marital Status	
Married	294 (66.2)
Single	150 (33.8)
Total	**444**
Religion	
Christian	393 (88.5)
Muslim	45 (10.1)
Traditionalist	2 (0.5)
Other	4 (0.9)
Total	**444**
Educational Level	
No education	50 (11.3)
Primary	146 (32.8)
Secondary	149 (33.6)
Tertiary-Graduate/Post Graduate	99 (22.3)
Total	**444**
Employment Status	
Self employed	240 (54.2)
Private sector	70 (15.8)
Public sector	41 (9.2)
Unemployed	78 (17.6)
Student/Apprentice	14 (3.2)
Total	**444**

In terms of employment status, it was discovered that the majority of the respondents or caregivers were self-employed constituting 54.1%, 15.8% were working in the private sector, 9.2% were employed in the public sector while 17.6% were said to be unemployed.

3.2% of the respondents were students or apprentices. It was again revealed that 98.9% of the respondents or caregivers were related to the patient while 1.1% was not related to the patient.

4.3 Direct cost of caregiving

The total direct cost to the caregiver per month to all caregivers was estimated to be GHS 52,521.20 (US$ 13,467.00), which is equivalent to 18% of the total cost to caregivers of schizophrenics. The average direct cost was GHS 118.40 (US$ 30.40) per month.

The total direct medical related cost for a month was estimated as GHS 33,744.32 (US$ 8652.40) with an average cost to a caregiver as GHS 76.05 (US$ 19.5) making up 11% of the total cost of schizophrenia for caregivers in this study. Drug costs constituted more than 75% of the direct medical cost, followed by the consultation fee of about 16%, then diagnostics and laboratory investigations follows at 5% while other costs related to direct medical cost accounted for the remaining 2% as shown in Table 4.

Table 4 further shows that the direct non-medical related cost was estimated to be GHS 18,777.00 (US$ 4814.6) with an average cost of GHS 42.3 (US$ 10.8) constituting 6% of the total cost to the caregiver in treating schizophrenia for a month. It comprises of transportation (76%), followed by meals 18% and lodging and other costs 6%.

4.4 Indirect cost of caregiving

The total estimated indirect cost of caregiving for schizophrenic patients for a month was GHS 247,153.00 (US$ 63,372.60) with an average cost of GHS 974.50 (US$ 242.90). The indirect costs account for about 83% of the total cost of caregiving for schizophrenia. The respondents from the informal sector accounted for about 86% productivity losses, losing a total of 96,616 productive hours in a month which is estimated as GHS 211589.00 (US$ 54,253.60) with an average of 309 hours estimated as GHS 676.01(US$ 173.10).

Productivity loss to the formal sector (about 14%) was estimated as 35,564 productive hours in a month estimated at GHS 35,564 (US$ 9,119.00) with an average of GHS 271.40(US$69.60). Therefore, the average indirect cost to a caregiver per month is estimated to be GHS 947.50 (US$ 242.90).

Table 3: Indirect cost to caregiving for schizophrenia

Productivity loss	**N**	**Days lost to caregiving**	**Time(hrs.) in a month for caregiving**	**SD**	**Cost (GHS)**	**Average cost (GHS)**	**Percentage (%)**
Formal sector	131	3456	35564	156.98	35564	271.5	14.4
Informal sector	313	8148	96616	157.39	211589	676	85.6
Total	**444**	**11604**	**132180**		**247153**	**947.5**	**100**

4.5 Total cost of caregiving

The total cost of caregiving for schizophrenic patients to all caregivers in the study sample was estimated to be GHS 299,674.20 (US$ 76,839.50) per month with an average of GHS 1,066 (US$273).

Table 4: Economic costs to caregiving for schizophrenia

Cost component	N	Cost (GHS)	Average cost (GHS)	SD	Percentage (%)
Direct cost					
Direct medical cost					
Consultation	444	5,503.00	12.40	27.39	1.8
Drugs	444	26,007.10	58.59	88.11	8.7
Lab/Diagnostics	442	1,670.00	3.81	21.00	0.5
Other	442	564.10	1.20	16.40	0.2
Sub total		**33,744.20**	**76.00**		11.2
Direct non- medical					
Transportation	444	14,334.72	32.30	37.50	4.8
Meals	442	3,288.28	7.42	21.70	1.1
Lodging	442	597.49	1.38	19.73	0.2
Miscellaneous	442	556.51	1.30	4.67	0.2
Sub total		**18777**	**42.30**		6.3
Total direct cost		**52,521.2**	**118.40**		**17.5**
Indirect Cost					0.0
Formal sector	131	35,564.00	271.50	157.01	11.9
Informal sector	313	211,589.00	676.00	344.68	70.6
Total indirect cost		**247,153.00**	**947.50**		**82.5**
TOTAL COST		**299,674.20**	**1,065.80**		**100**

*US$1.00 equivalent to GHS3.9 (Bank of Ghana average monthly interbank exchange rate, June 2016)

4.6 Sensitivity analysis of the cost of schizophrenic patients

A sensitivity analysis was performed to determine the robustness of the study estimates. The components on which the sensitivity analysis was done were the cost of drugs and the wages of the formal and informal sector. A one way sensitivity analysis was executed on the cost of drugs and wage loss while a two way sensitivity analysis was performed on both cost of drugs and wages. They were performed by changing the rise in cost of drugs and wages by 3%, 5% and 7% respectively. It is seen that when the drug cost was varied by 3%, 5%, and 7%, the total percentage increase was 0.01%, 0.04% and 0.04% respectively. There was no effect on both direct and indirect cost at a 3% increase, but the direct cost increased by 0.03% while the indirect cost decreased by 0.03%. Repeating the same process for wages, the percentage change in total cost varying at 3%, 5%, and 7% were 2.29%, 4.17% and 5.70% respectively. There was a percentage change in both direct and indirect cost at a 3% increase in the wage but there was a decrease of 0.67% in the direct cost while an increase of 0.67% in the indirect cost, similarly, varying at a 7% increase in the wage there was a decrease of 0.92% in the direct cost while the indirect cost increased by 0.92%.

Varying the cost of drugs and wages simultaneously at 3%, 5% and 7%, the corresponding percentage change in total cost were 2.3%, 4.17% and 5.71% respectively, while varying at the same 3%, there was a decrease of 0.39% in direct cost while indirect cost increased by 0.39%. There was no change in both direct and indirect cost varying at 5%, however, there was a decrease in direct cost by 0.91% while there was a 0.91% increase in indirect cost at a variance of 7%.

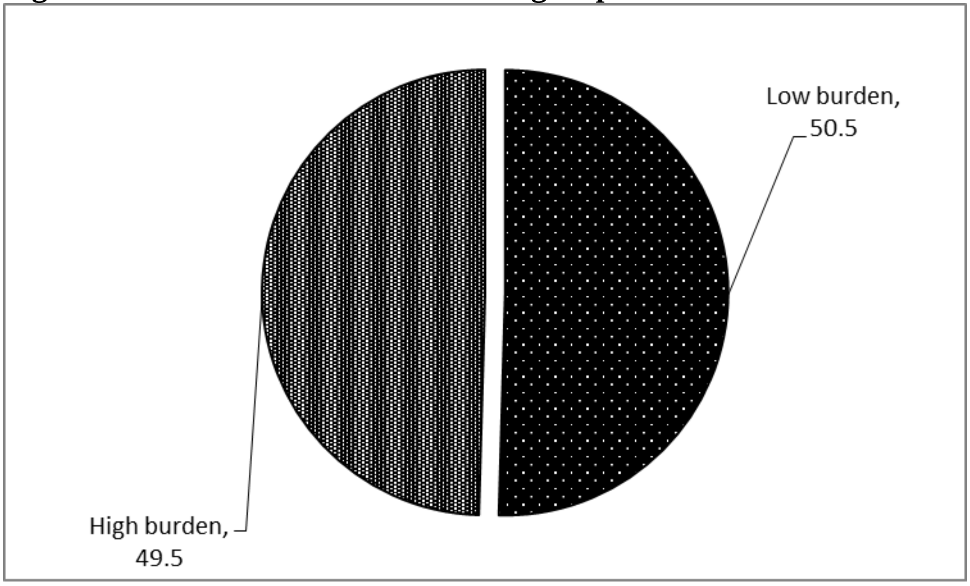
Table 5: Sensitivity analysis of total cost of caregiving

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		Direct	Indirect	Direct	Indirect
Base scenario		0	299,674.20	0.00	17.5	82.5	0.00	0.00
Variation (One-way SA)	Medication	3	299,691.13	0.01	17.5	82.5	0.00	0.00
		5	299,788.03	0.04	17.6	82.4	0.03	-0.03
		7	299,799.31	0.04	17.6	82.4	0.03	-0.03
Variation (One-way SA)	Wage rate	3	306,538.20	2.29	17.1	82.9	0.00	0.00
		5	312,166.02	4.17	16.9	83.1	-0.67	0.67
		7	316,741.32	5.70	16.6	83.4	-0.92	0.92
Multi-variation (Two-way SA)	Medication and Wage rate	3	306,555.13	2.30	17.1	82.9	-0.39	0.39
		5	312,194.23	4.17	16.9	83.1	0.00	0.00
		7	316,780.81	5.71	16.6	83.4	-0.91	0.91

4.7 Intangible cost of schizophrenia

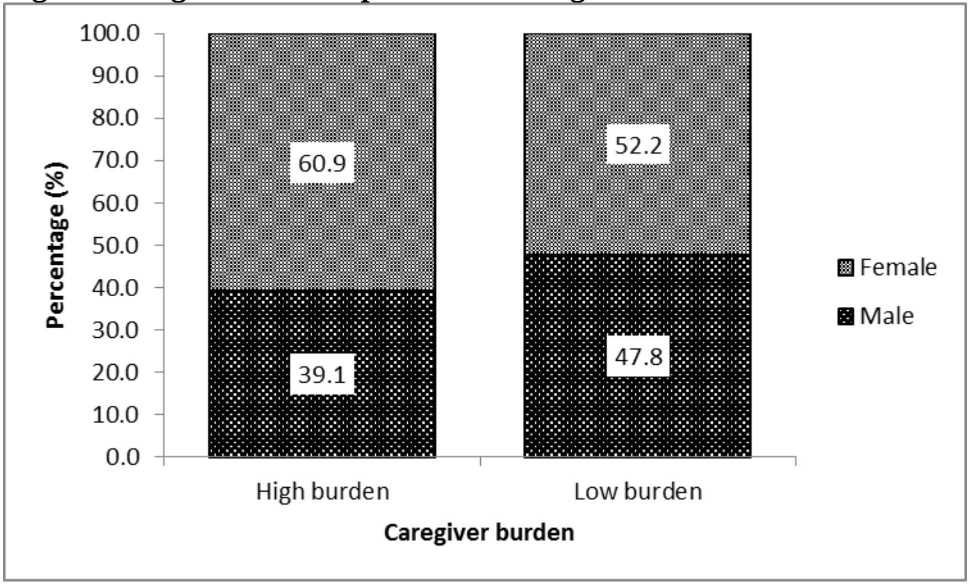
Figure 2 shows that 50.5% (i.e. 224) of the respondents reported low burden while 49.5% (i.e. 220) reported high burden as indicated in figure below.

Figure 2: Distribution of burden among respondents



The analysis also revealed that the burden in caregiving was significantly higher in females (60.9%) than in males (39.1%) among respondents reporting high burden (Figure 3)

Figure 3: High burden respondents among males and females



4.8 Caregiver quality of life

Table 6 below shows that the mean score across all domains were greater in persons with indices: male, unemployed, secondary education and married. Females had a lower quality of life of 27.1 compared to the males of 29.6 because they are the ones mostly doing all the activities in the house in addition to caregiving which puts greater pressure on them and therefore affects their quality of life. The unemployed was not concerned about reducing working hours or losing his/her job and as a result there will be less psychological stress on him/her that could reduce their quality of life. Lastly, those (who were) married had a better quality of life than the unmarried because there will be support from the partner which will reduce the stress on the caregiver. It is also seen that the mean score across all domains increases as caregivers educational level increases and this can be attributed to the caregiver having information and knowledge about the illness of the relative being cared for and as such the caregiver will able to handle the situation better and as a result becomes less stressed.

From the results of the multivariate linear regression model presented, it can be seen that sex and education were the only factors that were statistically significant across all the domains of quality of life. Age was statistically significant only in the social health domain, the average mean score decreased in consonance with the caregivers' ages, but increased after age 60 and this could be that the caregiver at that age is used to being with the patient alone and as a consequence, social relations do not necessarily matter anymore.

Table 6: Quality of life on background characteristics

	Physical		Psychological		Social		Environmental		Total	
	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value
Age***		0.303		0.257		<0.05		0.434		0.511
<30	20.1 (17.5)		31.6(24.1)		35.2(27.0)		33.6(23.3)		30.1(13.3)	
30 – 39	20.4 (17.6)		32.2(25.7)		30.2(24.6)		31.1(24.3)		28.5(11.7)	
40 – 49	19.7 (15.9)		26.2(22.2)		27.6(24.7)		37.2(25.9)		27.8(11.3)	
50 – 59	18.8 (14.4)		25.9(21.1)		23.4(21.2)		38.1(25.1)		26.6(12.1)	
60+	19.3 (15.5)		30.6(24.9)		31.6(24.6)		33.6(24.3)		28.8(12.2)	
Sex**		<0.001		<0.01		<0.05		<0.05		<0.05
Male	20.0 (16.1)		30.8(25.0)		31.0(26.3)		36.4(26.1)		29.6(12.6)	
Female	19.3 (16.1)		27.9(22.7)		27.7(22.9)		33.6(23.8)		27.1(11.5)	
Marital status**		0.270		0.330		0.071		0.436		0.863
Married	20.0(15.7)		30.0(24.1)		29.1(23.6)		33.6(24.7)		28.1(11.7)	
Single	19.0(16.4)		28.1(23.1)		29.4(26.1)		37.2(24.9)		28.4(12.5)	
Religion *		<0.05		0.872		0.486		0.270		0.972
Christian	19.1(15.4)		28.8(23.4)		29.6(24.6)		35.1(24.9)		28.2(11.9)	
Muslim	23.9(20.3)		31.6(26.6)		25.8(23.4)		32.5(24.4)		28.513.0)	
Education***		<0.01		<0.001		<0.001		<0.001		<0.001
None	19.1(16.4)		22.3(17.5)		23.2(19.4)		27.7(21.3)		23.1(8.4)	
Primary	19.5(17.9)		26.2(20.2)		23.5(22.1)		30.6(24.7)		24.9(11.5)	
Secondary	20.0(16.2)		28.3(22.5)		30.3(24.7)		35.4(23.7)		28.5(12.0)	
Tertiary	19.1(14.8)		36.1(29.1)		31.9(26.5)		38.9(28.3)		31.5(12.7)	
Employment***		0.703		0.140		0.911		0.247		0.558
Unemployed	21.4(19.0)		31.6(25.6)		32.0(25.2)		32.7(23.8)		29.4(13.8)	
Self-employed	19.6(15.7)		27.3(22.2)		29.0(24.6)		35.2(25.3)		27.8(11.3)	
Private sector	17.4(12.5)		32.2(26.4)		27.7(24.4)		38.0(26.1)		28.8(11.8)	
Public sector	19.6(16.3)		28.3(23.1)		26.6(22.5)		31.5(21.7)		26.6(12.3)	
Total	19.6 (16.0)		29.1(23.7)		29.2(24.5)		34.8(24.8)		28.2(12.0)	

*Other religions constituted 1% and was not considered in the analysis due to its insignificance

**Wilcoxon Rank Sum test used in determining the significance of difference

*** Kruskal-Wallis test used in determining significance of difference

Table 7: Linear regression results of quality of life domain scores on costs

Costs per domain	Unadjusted		Adjusted	
	Mean difference (95% CI)	p-value	Mean difference (95% CI)	p-value
Physical health vs.				
Direct (GHS)	-0.0091 (-0.0216, 0.0035)	0.155	-0.0083 (-0.0209, 0.0042)	0.194
Indirect (GHS)	0.0028 (-0.0014, 0.0071)	0.191	0.0030 (-0.0013, 0.0072)	0.174
Direct + Indirect (GHS)	0.0016 (-0.0025, 0.0058)	0.431	-	-
Intangible	-0.1280 (-0.2975, 0.0417)	0.138	-0.1332 (-0.3034, 0.0037)	0.125
Psychological health vs.				
Direct (GHS)	0.0236 (0.0051, 0.0420)	<0.05	0.0244 (0.0060, 0.0428)	<0.01
Indirect (GHS)	-0.0033 (-0.0097, 0.0030)	0.299	-0.0024 (-0.0087, 0.0039)	0.449
Direct + Indirect (GHS)	-0.0006 (-0.0067, 0.0055)	0.853	-	-
Intangible	-0.3269 (0.5764, -0.0773)	<0.01	-0.3420 (-0.5915, -.0925)	<0.01
Social health vs.				
Direct (GHS)	0.0086 (-0.0105, 0.0277)	0.377	0.0098 (-0.0094, 0.0289)	0.316
Indirect (GHS)	-0.0005 (-0.0070, 0.0060)	0.874	-0.0001, (-0.0067,0.0064)	0.964
Direct + Indirect (GHS)	0.0005 (-0.0057, 0.0067)	0.873	-	-
Intangible	-0.1366 (-0.3954, 0.1222)	0.300	-0.1381 (-0.3978, 0.1217)	0.297
Environmental health vs.				
Direct (GHS)	0.0109 (-0.0085, 0.0303)	0.269	0.0115 (-0.0080, 0.0310)	0.246
Indirect (GHS)	0.0013 (-0.0053, 0.0080)	0.689	0.0018 (-0.0049, 0.0084)	0.603
Direct + Indirect (GHS)	0.0024 (-0.0040, 0.0087)	0.460	-	-
Intangible	-0.1248 (-0.3873, 0.1377)	0.351	-0.1450 (-0.4090, 0.1190)	0.281
Total QoL vs.				
Direct (GHS)	0.0084 (-0.0009, 0.0177)	0.080	0.0092 (-0.0000, 0.0186)	0.051
Indirect (GHS)	0.0000 (-0.0031, 0.0033)	0.969	0.0005 (-0.0027, 0.0037)	0.748
Direct + Indirect (GHS)	0.0001 (0.0021, 0.0040)	0.536	-	-
Intangible	-0.0179 (-0.0305, -0.053)	<0.05	-0.1898 (-0.3161, -.0634)	<0.01

From the outcome of the linear regression in Table 7 above, the physical health domain had an inverse relationship with the direct and intangible cost which means that in every unit increase of direct and intangible cost, physical health is reduced by the corresponding coefficient. Meanwhile, there was a direct relationship with indirect cost and the sum of direct and indirect cost but were statistically not significant. The psychological health domain had an inverse relationship with indirect cost, intangible cost and the sum of direct and indirect cost, but was only statistically significant in the intangible cost. There was a direct relationship with direct cost and this was also seen to be statistically significant. This means that in every unit of direct cost increase, the psychological health goes higher by the corresponding coefficient. This can be explained by people's perception that the more one spends on health, the higher the chances of getting better.

The social health domain had an inverse relationship with indirect and intangible cost and a direct relationship with direct cost and the sum of direct and indirect cost, but they were all statistically insignificant. In the case of environmental health, there was a positive relationship with all, except the intangible cost, which had an inverse relationship and they were all statistically insignificant.

Regression of the total quality of life with the cost components, showed that there was a direct relationship between QoL and direct cost, indirect cost and the sum of direct and indirect cost, but they were statistically insignificant. However, against the intangible cost there was an inverse relationship which was statistically significant. This means the intangible cost has an adverse effect in the overall quality of life, more so than the direct and indirect cost.

CHAPTER FIVE

DISCUSSION

The outcomes of this study are consistent with the literature and modern research into caregiving, indicating that the economic burden and quality of life of caregivers is a global phenomenon.

The total estimated cost to the caregiver caring for the schizophrenic patient over a period of one month was GHS 299, 674.20 (US$76,834.50), with an average cost to a caregiver of GHS1 ,065.80 (US$151.80). The estimated direct cost accounted for about 18% of the total cost of caregiving and the indirect cost accounted for the rest. The intangible cost did not show a significant difference between high and low burdened caregivers, however females were found to be higher burdened.

The caregiver's quality of life was found to be low in all domains of the WHOQOL-BREF scale. From the results of the linear regression, it was seen that education and sex had a significant influence on quality of life. The higher one's educational level, the higher the quality of life. Though, the quality of life was low among both males and females, the males had a slightly better quality of life than the females. It was also found that the intangible cost had a greater undesirable impact on the quality of life among the direct, indirect and intangible costs.

5.1 Direct cost associated with caregiving

The estimated mean direct cost to the caregiver over a one month period was GHS 52,521 representing about 18% of the total cost involved in caregiving. This result of the present study is comparable to other studies carried out in other parts of the world, like Germany, South Korea, China and other countries. Knapp et al., (2004), showed that the direct cost of caregiving of schizophrenic patients in Germany accounted for 13% of the total cost.

The study in Germany involved estimated cost incurred solely by the patient, but not by the caregiver which this study conducted the research on. On the contrary, Rice and Miller (1996) estimate direct cost of schizophrenia in the United States to be about 53% of the total cost of US$ 32.5billion. Rice and Miller (1996) estimated direct cost for both inpatients and outpatients while this study estimated costs for outpatients only and this could be the reason for the increase in the proportion of the direct cost component.

Addo et al., (2013) estimated the direct cost to be 21% of the total cost of caregiving, which is higher that the results of this study (18%). The reasons for this difference could be the fact that Addo et al., (2013) based their study on household cost, while this study focussed on the caregivers. Again, Addo et al., (2013) estimated household cost of mental healthcare while this study focussed strictly on caregivers of schizophrenic patients. Moreover, the study done by Addo et al., (2013) did not take into accounts the estimated cost of diagnosing tests which could also contribute to the difference in the results. Lastly, the study done by Addo et al., (2013) was conducted at the psychiatric unit of the Ho Municipal Hospital, while this study was conducted in the main psychiatric hospitals in Ghana which serve as a referral point for the district and regional hospitals.

Further, Zhai, Guo, Chen, Zhao, and Su (2013) estimated the direct cost of caregiving of schizophrenia in China to be about 33% which is higher than the findings of this study which is about 18%. However, the various components detailing the direct medical and non-medical cost were not estimated, which makes it difficult to critically assess their findings. Lastly, the direct cost estimation of the study in China also included the in-patient cost and that can be the result of almost twice the percentage of direct cost of this study.

This study makes it clear that direct cost places a burden on the family caregiver and should not be ignored. Ghana seeks to follow international standards by deinstitutionalizing mental health care. However, the achievement of that policy will be difficult if measures are not introduced to absorb the direct cost burden away from the caregiver. Social intervention policies like the Livelihood Empowerment Against Poverty which transfer cash and health insurance should be extended to the caregivers to cushion them against the shocks of the direct cost.

It is significant to note that the cost burden may not be entirely attributed to the main caregiver because it is not clear whether the caregiver used any, of assets or belongings of the care receiver and also if the caregiver received any assistance, whether in cash or in kind from other members of the family, in taking care of the patient.

5.2 Indirect cost associated with caregiving

This study further founds that indirect cost, according to this study, accounted for about 82% of the total cost of caregiving of schizophrenia, which is also comparable to studies done in other countries. For instance, Knapp et al., (2004) reported indirect cost in Germany, one of the highest in the literature. The difference can be attributed to the summation of the productivity loss of both patient and the caregiver while this study dealt with only the caregiver.

Addo, Nonvignon, and Aikins (2013) estimated the total indirect cost as 74%, though this study was estimating the cost to the household. The cost to the caregiver was about 50% of the total cost and it is evident that the cost component of the indirect cost is very high and significant in the overall total cost. The study valued days lost to working patients, productive loss due to loss of employment, days lost due to caregiving by household members as well as travelling and waiting times to seek health care. Addo et al., (2013) in their estimation of the direct costs, did not include the productive time of the unemployed used in caregiving and this could be the reason why the indirect cost to the caregiver is lower than the result of this study.

Lastly, Zhai et al., (2013) also indicated that the indirect cost involved in their study accounted for 66.6% of the total cost of caregiving. In estimating the cost involved, the authors included value of damaged property, cost as a result of lost working days of both the patient and the caregiver as well as the mortality cost. However, the estimation did not include the cost involved in the reduction of the caregiver's working hours , the value of the time the unemployed caregiver spent on the patient as well as the travelling and waiting time spent in seeking medical care, has probably accounted for the low percentage of the total cost of caregiving due to indirect cost. It is clear that if there is an effective management of schizophrenia, especially in the acute phase, this can significantly reduce the productivity loss which forms the indirect cost of caregiving and can subsequently reduce the monthly expenditure to the caregiver.

This tells us that the indirect cost of caregiving places a significant burden on families and any attempt to present the cost of this, and by extension, any other severe mental health condition without presenting the family's productivity losses will greatly underestimate the actual burden on families. This study draws the attention of policy makers to the fact that any attempt to ameliorate the economic burden of mental health on families that do not account for the productivity losses for caregivers, may not be targeting the real issue.

5.3 Intangible cost of caregiving

This study further finds that beyond the cost and productivity losses that schizophrenia poses on the family caregivers, there are high levels of other burdens that are difficult to quantify. The families of schizophrenic patients are highly burdened both objectively such as difficulty in social and work activities as well as financial difficulty and subjectively such as depression, feeling of loss and anxiety Knock et al., (2011).

Again, Ohaeri, (2001) argues that caregiving is mostly carried out by female family caregivers and that the burden (e.g. psychological effect) experienced by females is higher compared to males, confirming the findings of the current study that 61% of caregivers who reported higher burden were females and 39% were males. Similarly, a study by Papastavrou, Charalambous, Tsangari, and Karayiannis, (2010) also concludes that in terms of gender, the female is more burdened. The study also confirms what is in the literature, namely that most caregivers experience chronic stress associated with the job of caregiving. This is evident in the responses, such as frustration, anxiety, guilt, fear, sadness and anger by the respondents.

It is clear that the economic burden of a caregiver's family cannot be determined without the intangible component. The study shows that the burden it poses is highly significant even more so than the direct cost component of the burden. The stress, pain and anxiety in caregiving should be critically looked at.

5.4 Quality of life of caregivers of schizophrenia

The study also found that, generally, caregivers of people with severe mental disorders reported low quality of life. This finding confirms previous studies (Aukst et al., (2013), Boyer, Caqueo-Urizer, Richieri, Lancon & Guitierrez-Maldonado., (2012). However, the quality of life described in the current study was lower than what was reported by Boyer at al., (2012) in Chile and France, implying that the general health care system in Ghana may be contributing to lower quality of life for caregivers as it grapples with providing adequate care for schizophrenic patients and the management of their conditions, together with non-existing incentives to family caregivers who play a vital role in the rehabilitation of the patients.

From this study it is seen that in all domains of QoL, the environmental health has the higher average mean score and the physical health has the least mean score indicating that daily activities of care givers are greatly affected due to caregiving as well as pain and discomfort, low energy and fatigue. The general low quality of life of caregivers of schizophrenic patients supports the argument that the quality of life of caregivers should be of importance to policy and decision makers in making laws that will provide a social support system to caregivers to improve their quality of life especially the elderly caregivers, the women and the unmarried. Improvement should be made in the educational sector, as this study has proved that education affects the quality of life of a person and the higher one's education, the higher the quality of life.

To help improve the quality of life of family caregivers, it is imperative to overcome the economic burden imposed as a result of caregiving. In order to achieve that, a comprehensive healthcare policy should be developed for mental health which will include the treatment and rehabilitation of mental health patients

5.5 Economic burden vs quality of life

This study finds that the economic burden has an adverse relationship with effect on most of the domains of quality of life, implying that caregivers with lower economic costs reported higher quality of life and vice versa. Specifically, intangible cost had an adverse effect on all the domains of quality of life, which confirms that stress, pain, depression and anxiety has a significant effect on the quality of life Caqueo-Urízar, Gutiérrez-Maldonado, and Miranda-Castillo, (2009) and this is statistically significant in the psychological health domain.

Contrary to expectations, direct cost had a positive and significant relationship with quality of life. Explanation for this relationship is not clear and may require further investigation.

In the case of total quality of life against cost, there was a statistically significant adverse association with intangible cost which tells us that the effect of an economic burden on quality of life largely depends in the intangible cost. Most of the time, emphasis and attention are given to the financial aspect of life, leaving the emotional and psychological aspect to chance. This study has concluded, based on the results of the linear regression in Table 8 that the emotional aspect of life constitutes a significant part of the quality of life.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

This study set out to determine the economic burden and the quality of life of caregivers of schizophrenic patients in Ghana. The economic burden of caregiving is not negligible, leaving total cost of GHS 299, 674.20, with 82% of that being indirect cost (i.e. constituting productivity losses to family caregivers). Treatment cost forms almost two-third of the total direct cost, with travelling cost to seek medical care and meals forming the rest of the direct cost.

Caregivers suffer a great deal of other non-quantifiable burdens (such as emotions, pain, stress etc.) in the role they play which affects their quality of life as well. Further, the caregivers reported lower quality of life.

6.2 Recommendations

From the findings of this study, there is a basis for the following recommendations:

1. It is important for Government's social protection programmes, such as the livelihood empowerment against poverty (LEAP), to consider family caregivers of people with mental disorders, as this could help to cushion them from the economic burden to help make the attempts of deinstitutionalization of mental health care in Ghana successful.
2. The National Health Insurance Authority should consider treatment of schizophrenia to help reduce the direct cost burden on the caregiver.
3. Recreational centres can be developed for both patients and family caregivers and counselling sessions can also be organized for the caregivers to relieve them of the psychological and emotional stress.

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APPENDICES

Appendix 1: Informed Consent Form

Project Title: Economic Burden and Quality of life of Caregivers of Schizophrenic Patients in Accra, Pantang and Ankaful Psychiatric Hospitals in Ghana

Background

My name is Yaw Nyarko Opoku-Boateng, a student of the School of Public Health, University of Ghana, Legon. I am conducting a study on the Economic Burden and Quality of life of Caregivers of Schizophrenic Patients in Accra, Pantang and Ankaful Psychiatric Hospitals in Ghana. The main objective is to determine the economic burden and quality of life of caregivers of schizophrenic patients of Accra, Pantang and Ankaful psychiatric hospitals.

Procedure

The study will involve answering questions from an open ended questionnaire about the cost incurred and WHOQOL-BREF questionnaire as a result of caregiving of schizophrenia. There will be no intimidation or coercion will be used to obtain response from participants. This is purely academic research which forms part of work for the award of a Master Degree in Public Health and will be appreciated if you could participate I this study.

Risks and Benefits

Both the study population and the society at large stand to benefit from the study. The study population will know how much they spend on their patients and policy makers will also know how much is spent on mental health. It will let policy makers and opinion leaders know the economic burden of schizophrenia. It will also create awareness about schizophrenia and mental health at large so that educative programs and sensitization projects can be instituted to educate people on prevention, early detection and treatment of schizophrenia.

This will help reduce the incidence and prevalence of schizophrenia to avoid the economic burden it comes along with. This research poses no risk to the study population or the society.

Right to Refuse

Participation in this study is voluntary and participants can choose not to answer any particular question or all questions. Participants are at liberty to withdraw from the study at any time. However, participants are encouraged to fully participate since answers provided are important to help the estimation.

Dissemination of Results

A gathering including hospital staff, patients, caregivers and other stakeholders of mental health will be held at the hospital to disseminate the findings of the study at the various hospitals. A copy of the study will be kept at the hospitals for reference.

Before taking Consent

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

If yes, please indicate it below

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………….

Voluntary Consent

I have read the information given above, or the information given above has been read to me and I understand. I have been given a chance to ask questions concerning the study; questions have been answered to my satisfaction. I now voluntarily agree, and also voluntarily agree for my relative to participate in this study knowing that I have the right to withdraw and also withdraw my relative from this study at any time without affecting future health care service.

…………………	………………………	………………	……………………
Caregiver Name	Signature	Thumbprint	Date
……………………	……………………….	………………	………………….
Witness Name	Signature	Thumbprint	Date
………………	……………………	………………	…………………
Name of Researcher	Signature	Thumbprint	Date
………………	……………………	………………	…………………
Name of interviewee	Signature	Thumbprint	Date

Interviewers Statement

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

The participant has fully agreed to participate in the study.

Signature of the interviewer ……………………………………………

Date ……………………………………………….

Address ……………………………………………….

……………………………………………….

If you have any question later please, contact

Researcher: Opoku-Boateng Yaw Nyarko (0205353385)

Administrator of GHS-ERC: Ms. Hannah Frimpong (0243235225/0507041223)

Appendix 2: Questionnaire

ECONOMIC BURDEN AND QUALITY OF LIFE OF FAMILY CAREGIVERS OF SCHIZOPHRENIC PATIENTS AT THE OUT PATIENT DEPARTMENT OF PSYCHIATRIC HOSPITALS IN GHANA

Dear Respondent,

I would like you to answer a number of questions regarding this patient's care. Your responses will be kept confidential and will not be held against you. You are also free to withdrawal or stop answering my questions at any time.

Please will you like to take part in this interview? 1. Yes/2 .No |___|

Name of Hospital:…………………………………………………………

Unique ID for Respondent |___||___||___||___|

Date of interview (dd/mm/yyyy): |___|___|______|

Interviewer Name:………………………………………..

No.	**Questions**	**Responses**
Section A	**Socio-demographic Information**	
1	Sex 1. Male 2. Female	|___|
2	Age	|___|___|___|
3	Marital Status 1. Married 2. Single	|___|
4	Religion 1. Christian 2. Muslim 3. Traditionalist 4. Other (specify)___________________________	|___|
5	Place of residence 1. Closer to the facility 2. Far from the facility	|___|
6	Education 1. No education 2. Primary level 3. Junior level 4. Secondary level – SHS 5. Secondary level - Technical 6. Secondary level - Vocational 7. Tertiary - Graduate / Post Graduate 8. Tertiary - Cert /Diploma/ Post Diploma 9. Refuse to answer 10. Don’t know	|___|
7	Employment status 1. Self employed 2. Private sector 3. Public sector	|___|

No.	**Questions**	**Responses**
	4. Unemployed 5. Student/Apprentice	
8	Occupation Please specify………………………………………..	
Section B	**Impact of patient's illness on household members**	
9	For how many months have you been taking care of this ill person?	|___| months |___| years
10	Are you related to this ill patient? 1. Yes 2. No	|___| **If No go to Q12**
11	Who is this person to you? 1. Child 2. Sibling 3. Other relative 4. Neighbor 5. Friend 6. Client 7. Other (specify):______________________	|___|
12	Does any other member of the family spend time to care for this person? 1. Yes 2. No **Note that this refers to family members who are not primary care givers but offer support*	|___|
13	Who this person? Specify_________________________	
14	How many days in week does this other family member spend to care for the patient? **Note if more than one family member , find accumulated days spent*	|___| days
15	How many hours in a day does this person spend with the patient? 1. Only morning 2. Morning to afternoon	|___|

<table>
<tr><th>No.</th><th colspan="2">Questions</th><th>Responses</th></tr>
<tr><td></td><td colspan="2">3. Afternoon to evening
4. Whole day
Note if more than one family member , find accumulated hours spent</td><td></td></tr>
<tr><td>Section C</td><td colspan="2">Burden of care on primary caregiver</td><td></td></tr>
<tr><td>16</td><td colspan="2">Are you paid for your services?
1. Yes
2. No</td><td>|___|
If no go to Q18</td></tr>
<tr><td>17</td><td colspan="2">How much are you paid per month for your services?
(8888. Don’t know)</td><td>GHS__________</td></tr>
<tr><td>18</td><td colspan="2">How many days in a week do you spend to care for the patient?</td><td>|___| days</td></tr>
<tr><td>19</td><td colspan="2">How many hours in a day do you spend with the patient?
1. Only morning
2. Morning to afternoon
3. Afternoon to evening
4. Whole day</td><td>|___|</td></tr>
<tr><td>20</td><td colspan="2">Have you stopped your normal work/ school/apprenticeship because of caregiving?
1. Yes
2. No</td><td>|___|
If yes go to Q23</td></tr>
<tr><td>21</td><td colspan="2">Have you cut back or reduced your normal daily working/schooling activities because of caregiving for client?
1. Yes
2. No</td><td>|___|
If No go to Q23</td></tr>
<tr><td>22</td><td colspan="2">How many hours did you have to reduce your normal activities in a day?
(8888. Don’t know)</td><td>|___| hours</td></tr>
<tr><td rowspan="2">23</td><td rowspan="2">What is your average monthly income?
(8888. Don’t know)</td><td>Usual income</td><td>GHS__________</td></tr>
<tr><td>Other works</td><td>GHS__________</td></tr>
</table>

No.	Questions		Responses
		Donations (Cash)	GHS__________
		Remittances	GHS__________
		In-kind	GHS__________
		TOTAL	GHS__________
24	Has there been a decrease in your income because of caregiving? 1. Yes 2. No		|___| If No go to Q26
18	What is the amount of income you lost because of caregiving over the last month? **(8888. Don't know)**		GHS__________

Read: Now I would like to know which of the following financing sources have you used over the past month to pay for any health and other expenditure related to patient's illness. If you cannot remember the exact payments please give your best estimates.

No	Question	Item	Amount
20	What are the sources of financing to pay for any health expenditure related to patient's illness over the past month?	Household income	GHS__________
		Contributions from relatives	GHS__________
		Household members pension	GHS__________
		Health insurance	GHS__________
		Household remittances	GHS__________
		Donations/Gifts	GHS__________
		Sale or transfer of household assets (e.g. gold, land, vehicles etc)	GHS__________
		Household savings and investments	GHS__________
		Borrowed money	GHS__________
		Other (please specify):	GHS__________

Appendix 3: Descriptive statistics of ZBI for caregivers

ZBI QUESTION	N	Minimum	Maximum	Mean	Std. Deviation
Do you feel that because of the time you spend with your relative that you don’t have enough time for Yourself?	444	0	4	1.83	1.26
Do you feel stressed between caring for your relative and trying to meet other responsibilities (Work /family)?	444	0	4	1.56	1.39
Do you feel angry when you are around the relative?	444	0	4	0.92	1.20
Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	444	0	4	0.85	1.27
Do you feel strained when you are around your relative?	444	0	4	0.89	1.17
Do you feel that your health has suffered because of your involvement with your relative?	444	0	4	0.93	1.21
Do you feel that you don’t have much privacy as you would like because of your relative?	444	0	4	0.80	1.18
Do you feel that your social life has suffered because you are caring for your relative?	444	0	4	1.16	1.26
Do you feel that you have lost control of your life since your relative’s illness?	444	0	4	0.96	1.23
Do you feel uncertain about what to do about your relative?	444	0	4	1.46	1.29
Do you feel you should be doing more for your relative?	444	0	4	2.66	1.20
Do you feel you could do a better job in caring for your relative?	444	0	4	2.94	1.19

Section D: Direct cost

I would like to ask you about out-of-pocket payments you made over the last month for this patient. Out-of-pocket payments are the total amount paid by you or your family members for patient's care, whether or not you have already received or expect to receive reimbursement for all or part of this paid amount. If you cannot remember the exact payments please give your best estimates.

	Direct costs	Type of costs	Out of pocket spending on medical and non-medical expenditures (GHS)
21	Medical osts	Consultations, admission and discharge fees	GHS__________
		Drugs	GHS__________
		Laboratory investigations & Diagnostic tests	GHS__________
		Other	GHS__________
22	Non-medical costs	Transportation	GHS__________
		Meals	GHS__________
		Lodging	GHS__________
		Miscellaneous (phone calls etc.)	GHS__________

Section E: Intangible Cost

ZARIT BURDEN INTERVIEW

Please kindly circle the one that best describe how you feel

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

Questions	N	R	S	QF	NA	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 the relative?	0	1	2	3	4	
4) Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4	
5) Do you feel strained when you are around your relative?	0	1	2	3	4	
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4	
7) Do you feel that you don't have has much privacy as you would like because of your relative?	0	1	2	3	4	
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4	
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
11) Do you feel you should be doing more for your relative?	0	1	2	3	4	
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	

*N=Never (0) R=Rarely (1) S=Sometimes (2) QF=Quite frequently (3) NA=Nearly always (4)

Section: F

WHOQOL-BREF

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

	Do you get the kind of support from others that you need?	Not at all	Not much	Moderately	A great deal	Completely
		1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Do you get the kind of support from others that you need?	Not at all	Not much	Moderately	A great deal	Completely
		1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme Amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10(F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11(F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12(F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13(F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14(F21.1)	To what extent do you have the	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal	1	2	3	4	5

	relationships?					
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THANK YOU FOR YOUR HELP

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the
number and date of this
Letter should be quoted.

My Ref. GHS/RDD/ERC/Admin/App
Your Ref. No.

Research & Development Division
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11th March, 2016

Opoku-Boateng Yaw Nyarko
University of Ghana
School of Public Health
Legon, Accra

ETHICS APPROVAL - ID NO: GHS-ERC: 68/12/15

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

"Economic Burden and Quality Of Life of Caregivers of Schizophrenic Patients at Ankaful, Pantang and Accra Psychiatric Hospital"

This approval requires that you submit yearly review of the protocol to the Committee and a final full review to the Ethics Review Committee (ERC) on completion of the study. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please note that this approval is given for a period of 12 months, beginning 11th March, 2016 to 10th March, 2017. However, you are required to request for renewal of your study if it lasts for more than 12 months.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED...
PROFESSOR MOSES AIKINS
(GHS-ERC VICE-CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra