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ECONOMIC BURDEN OF CARING FOR CHILDREN WITH MENTAL DISORDERS ATTENDING PSYCHIATRIC HOSPITALS IN GHANA

BY

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DECLARATION

I, SEWU PETER NARH, declare that except articles and books I have cited, quoted, and duly acknowledged in references, all other information produced from this study 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

DEDICATION

I dedicate this work to Mrs. Grace Agbashie and the husband Mr. Moses Agbashie and the entire Sewu Family.

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ABSTRACT

Background

Family caregivers play a very important role in the management of severe mental disorders in children which has a huge economic burden on the family and the caregivers.

This study aimed to estimate the economic burden of caring for children with mental disorders attending Psychiatric hospitals in Ghana.

Method

The study adopted the Cost of Illness Analysis Approach in estimating economic burden. The 12-item Zarit Burden Interview and EUROHIS-QOL (WHO-8) were used to assess the intangible cost and the quality of life of the caregivers respectively. Data was collected from 210 caregivers of children with mental disorders attending psychiatric hospitals in Ghana for the last six months. The economic burden was categorized into direct costs (both direct medical costs and direct non-medical costs), indirect cost (comprises of time of travel, productivity loss due, waiting time) and intangible costs (non-monetary costs such as pains, anxiety, stress, stigma etc.), and direct cost (cost of consultation, diagnosis, drugs, etc.). The indirect costs were estimated using the productive time lost by employed workers multiplied by the daily minimum wage of the country.

Results

The overall unit cost for caregiving for a child with mental disorders was GHS 826.62 (USD 169.06) per month. The average indirect cost for caregiving per child was estimated at GHS 129.17 (USD 25.83) per month, representing 15% of the total cost. Averagely, the direct non-medical cost for caring for a child per month was estimated at GHS 313.15 (USD 62.63) representing 37% of the total cost of the cost incurred by caregivers. Direct medical cost per child was estimated at GHS 402.97 (USD 80.59) per month representing 48% of the total cost of caregiving. The results of the Zarit Burden test revealed that 35.7% of the caregivers reported low burden while 64.3% reported high burden. A high burden was found among female caregivers than in male caregivers.

The EUROHIS QOL tool revealed a low quality of life across all the domains of a mean score of 24.7. Sex, marital status, and education were found to significantly influence the quality of life of caregivers with male having a lower quality of life (mean score of 24.1) as compared to female who recorded a mean score of 24.9 .

Conclusion

The cost incurred by caregivers of children with mental disorders in Ghana is enormous and cannot be overlooked. The gravity of the burden affects the quality of life of the caregivers. This has led to more of the caregivers reporting lower quality of life. The results of this study could be generalized for the entire population of Ghana since the three main Psychiatric Hospitals in Ghana.

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LIST OF ABBREVIATIONS

BOD ……………… Burden of Disease

COI…………………Cost of illness

DALY ………………Disability Adjusted Life Year

GHS…………………Ghana Health Service

ICD-10 …………….. International Classification of diseases 10th edition

NHIS………………National Health Insurance Scheme

OPD………………Out Patient Department

SSA ……………… Sub-Saharan Africa

USD……………… United State Dollar

UK………………… United Kingdom

WHO……………… .World Health Organization

WHOQOL…………World Health Organization Quality of Life

WHOQOL-BREF……World Health Organization Quality of Life Abbreviated version

EUROHIS-QOL…… European Health Interview Survey-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 living with a patient, and has been closely involved in undertakings of daily living, healthcare, and other social activities.

Direct cost- this comprises of the values of all resources expended directly by caregivers while seeking healthcare

Household- this refers to a group of people living in the same house and share many things in common

Indirect cost -The cost of time spent out of normal work due to sickness or death.

Quality of life- This refers to the opinion and perceptions of individual's situation in life in the framework of the beliefs and value systems in which they live in relation to their expectations, goals, ideas and concerns

Economic burden –This refers to the presence of problems challenges, difficulties, or adverse effects as a result of economic impact

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

The mental health of children and adolescents has been given poor attention by many countries and this may result in adverse disorders with lifelong consequences, greatly undermining compliance with health regimes as well as reduces the society's safety capabilities and productivity (WHO, 2003).

Mental disorder is a major public health problem globally and, significantly affecting the cognition and behavioral pattern, perception, and emotions of persons (Addo, Agyemang, Tozan, & Nonvignon, 2018). A person may be considered as having mental disorder if he/she is identified to be experiencing a severe role and functional impairment which results in normal working disabilities. The incidence of mental disorders has increasingly attracted public health interest due to the enormous negative impact of stigma and discrimination it imprints on the family and relatives of victims (Tawiah, Adongo, & Aikins, 2015).

Moreover, the Global Burden of Diseases in a recent study shows that an estimate of 32.4% and 13.0% years lost to disability (YLDs) and disability-adjusted life years (DALYs) respectively, are as a result of mental illness (Whiteford et al., 2013). These percentages are equal to that of the cases for cardiovascular and circulatory related diseases (Opoku-Boateng et al., 2017).

It is known worldwide that most countries do not put much attention to mental health concerns, and this is evident in their annual health budget allocation of 5% in High-Income Countries (HIC) and 1 % in Low –and - Medium Income Countries to mental health

(Bhana, Petersen, Baillie, & Flisher, 2010). The case is worse in the African context considering a report by the World Health Organization (WHO) depicting that 70% of the African countries allocate less than 1% of their entire health expenses to mental health (Bhana et al., 2010).

Kleintjes et. al (2010) document that the prevalence of mental illness among children and adolescents is estimated to be equal to that recorded in adult. Mental disorders in children and adolescents are also associated with Stigmatization and discrimination which worsen the burden associated with the illness.

Opoku- Boateng et al., (2017) indicated caregiving and the major role it plays in the management of mental disorders especially while such members are living with their families. This, as stated, for instance, is based on economic hardship of the families and also social structures. In their documentation, problems associated with the health system, which include low patient and staff ratio, lack of good infrastructure, contributes highly to a higher burden of caring for mentally disabled people.

Mental health policies have over the past two decades shifted its focus from state institutional management of mental illness to homes due to the issues of deinstitutionalization. The implication is that the role of health professionals is now to be performed by family caregivers (Addo et al., 2018). Addo et al. (2018) documented that giving care to mentally disabled patients affects the caregiver in many endeavors, such as socio-economic status and the quality of life. For instance, they have to provide emotional, financial and physical support and this sometimes becomes unbearable. The upbringing of a child with special health care needs greatly affects the financial stability of the family (Busch & Barry, 2007). Family caregivers will have to sometimes relinquish their jobs to stay home and attend to the patient, spend more time with them, and provide them with social support. This places a great burden on them.

1.2 Problem Statement

In developing countries like Ghana, mental disorders among children are not given much public attention as it should despite the fact that many children are suffering from the menace (Bhana et al., 2010). A systematic review to assess the prevalence of mental health problems among children in sub-Sahara Africa revealed that 14.3% of the children are suffering from mental health conditions (Melissa, Anisha, Mina & Paul 2016). A study in Indian for instance documented that the prevalence rate of mental disorders among children ranging from 2.6 to 35.6%. A comparative study also reported a rate of 9.4% in a sample of 1403 rural children aged 8 -12 years (Srinath, Girimaji, Gururaj, Seshadri, & Subbakrishna, 2005).

Researchers do not dwell much on mental disorders among children and adolescents as compared with that of the mental illness in adults. Meanwhile, mental disorder in children places a huge economic burden on parents and relations that might seek medical attention for their patients. The economic burden may include reduced work productivity, direct cost on medical bills and household-related expenses (Busch & Barry, 2007). The nature of the burden of the condition affects the quality of life of the caregivers and the entire family.

It is, therefore, necessary to embark on this research to estimate the economic burden and quality of life of caregivers of children with mental disorder.

1.3 Study objectives

This sections presents the general objective and the specific objectives of the study.

1.3.1 General objective

The general objective of this study was to estimate the economic burden of caring for children with mental disorders attending Psychiatric Hospitals in Ghana.

1.3.2 Specific Objectives

The specific objectives of the study were:

1. To estimate the direct costs associated with caregiving for children with mental disorders
2. To estimate the indirect costs associated with caregiving for children with mental disorders
3. To determine the intangible costs associated with caregiving for children with mental disorders
4. To assess the quality of life of caregivers of children with mental disorders.

1.4 Research Questions

1. What are the direct costs associated with caring for children with mental disorders by caregivers in Ghana?
2. What are the indirect costs associated with caring for children with mental disorders by caregivers in Ghana?
3. What are the intangible costs associated with caring for children with mental disorders by caregivers in Ghana?

4. How does the burden of caregiving affect the quality of life of caregivers of children with mental disorders ?

1.5 Justification of the study

The onset and chronic presence of mental disorders in children can be a very stressful event which is likely to put caregivers and the entire family members into a series of crises. Families that seek to move from the crises to early recovery in their patients have been identified to be influenced by their interactions with mental health professionals. This is likely to influence the outcome of the illness positively and the patients are more likely to recover from the crisis and cope with the condition.

Previous studies have not focused much on the direct cost, indirect cost, intangible cost and the quality of life of caregivers of children with mental disorders in Ghana and that is what this study seeks to address.

It is, therefore, necessary to conduct this research to estimate the economic burden and quality of life of caregivers of children with mental disorders. The findings of this research will provide a clear understanding and enlightenment on the gravity of the crises to caregivers and the necessary support they need in order to cope with the condition. Mental health is a public health concern and there is the need to create the awareness of the public on the entirety of the crises and how sensitive the condition is so that the public can appreciate it.

Moreover, the findings are expected to provide relevant information which would guide policymakers to make an informed decision concerning mental disorders especially in terms of resource allocation.

This study will serve as a reference for further research in a similar field by other interested students and other researchers.

1.6 Conceptual Framework

Caring for children involve considerable resources. But the demands for the needed resources are often increased when caring for a child with mental disability. The demands for caring have implications on economic status, physical health and psychological effect of the caregiver thereby affecting household consumption pattern.

The cost of providing care for children with mental disorders was assessed from the caregiver's perspective. The perspective examined were directly the various aspects of the cost of the ailment on the family. The cost incurred by family caregivers of children with mental disabilities seeking healthcare services at the outpatient department (OPD) can be categorized into three main areas as seen in Figure 1. These include direct cost, indirect cost, and intangible cost.

The direct cost is the actual expenses incurred while seeking OPD treatment by patients. The direct cost is again classified into two, the cost which is directly associated with treatment which is called medical cost and those not directly associated with a treatment called non-medical cost. The medical cost includes the cost incurred for consultation, cost for medication, and cost for laboratory and diagnosis services and miscellaneous for other therapies. The non-medical costs include cost of transportation of the caregiver and the patient, cost of feeding, and cost of residential facilities.

The indirect cost incurred by caregivers of children with mental disorders include time loss to productivity leading to loss of earning, absenteeism from work, time spent while they accompany the patient to the health facility to seek medical attention, traveling and waiting time at the health facility

The intangible costs incurred by the caregivers encompasses the costs which cannot be directly expressed in monetary terms. They include anxiety, relationship, strain, social life, anger, and any form of insecurity imposed on the caregiver due to the disease condition.

All these costs place a huge economic burden and affect the quality of life of the caregiver seeking medical care for their patients.

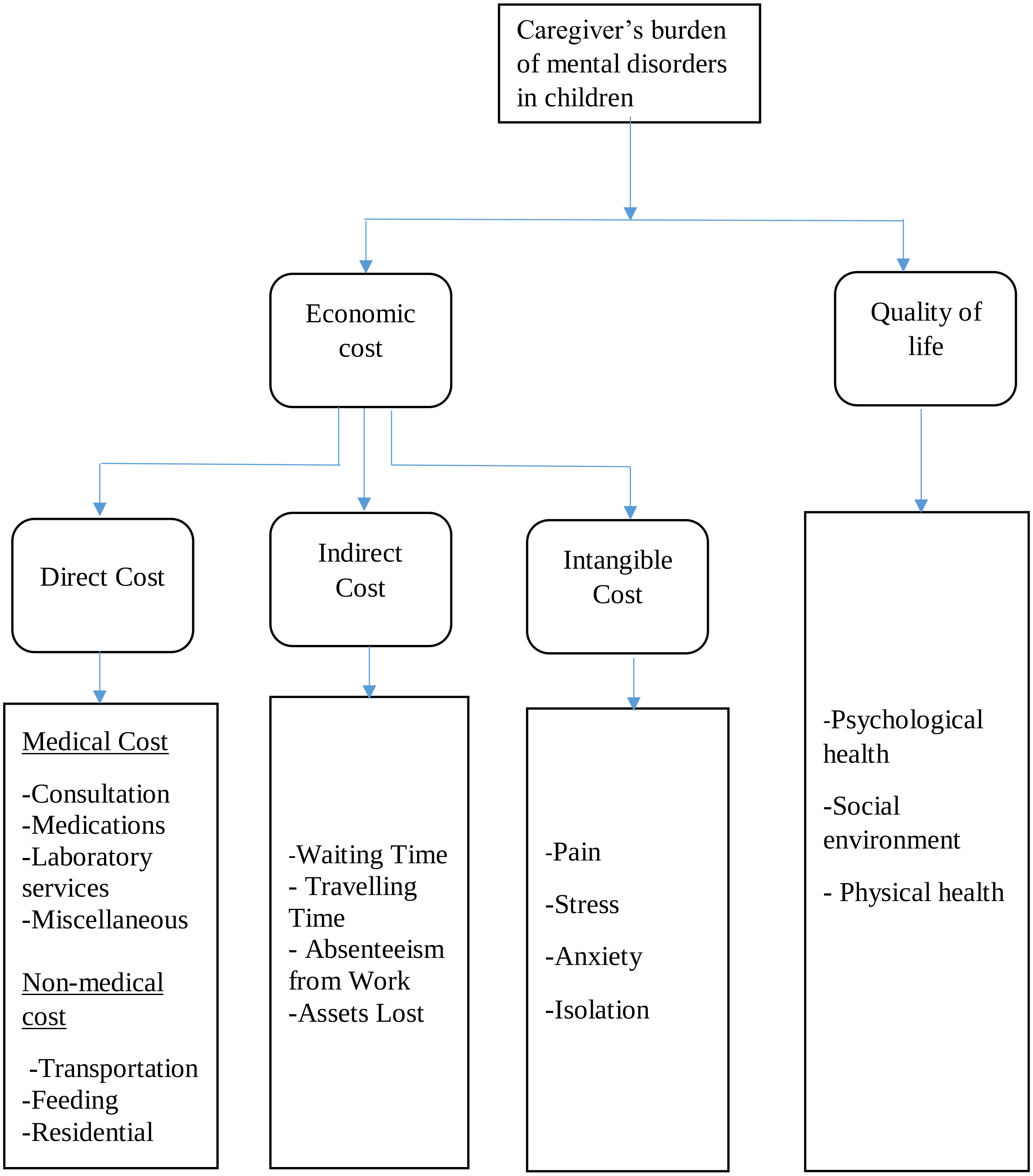

Figure 1: Conceptual framework for the economic burden of caregiving for Children with

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter seeks to review relevant literature related to the economic burden and quality of life of caregivers of children with mental disorders. It covers the various objectives of the topic. It comprises of the concept of mental disorders in children, types of mental disorders in children, the burden of mental disorders in children, the cost of mental disorders and the quality of life of caregivers.

2.2 Burden of mental disorders in children

Children and adolescents worldwide constitute almost a third (2·2 billion individuals) of the total population and about 90% of them are found in Low-Income and Middle-Income Countries (LMIC), where they constitute 50% of the population of those countries (Kieling *et al*., (2011).

The prevalence of common mental disorders seem to increase in children and adolescents and many people are noted to experience such a disorder by young adulthood stage. Mental disorder in children and adolescents increases the risk of developing the disorder later in adult, and adults with mental disorder usually have experienced their first episode in adolescence (Eyre & Thapar, 2014). Studies that reviewed the prevalenace of mental health conditions estimated that mental disorders is suffered by approximately one out of every five children and adolescents (Reiss, 2013). Reiss's (2013) study has again shown that higher levels of behavioral conditions were found among pre-school children that are from low-income families and among adolescents that are living in poverty.

Mental Health Disorders (MHDs) affect 20% of children and youth worldwide (Fortnum et al., 2018). However, the gap between the availability and the essence of mental health services, which is also called the "treatment gap" exceeds 75% in most countries worldwide (Whiteford et al., 2013).

2.3 Types of Mental disorders in Children

Mental disorders in children and adolescents can be considered in several ways. One way of considering these disorders is viewing it in a prioritized manner on the basis of the frequencies they occur, therapeutic possibilities, long term care effects it pose to the victims, and degree of impact (Wille, Resch, Bullinger, & Schulte-markwort, 2008). From this view, mental disorders in children that pose a major concern include learning disorders, Attention-deficit/hyperactive disorder (ADHD), and the suicide associated with it. Other conditions include conduct disorder, psychosis, pervasive development disorders, eating disorders, anxiety disorders, depression, attachment disorders, and substance abuse (Ambikile & Outwater, 2012).

These mental disorders are typically characterized by substantial limitations in adaptive behaviour and intellectual functioning. These children experience delay in development, which may cause an obstruction in their social, conceptual, practical and personal life skills. Although children and adolescents with mental disorders may acquire some skills through intervention of their parents, the skills acquired may not be adequate to perform certain tasks expected of children of their age group (Ambikile & Outwater, 2012).

2.4 Caregiver's burden and mental disorders in children

Caregiver's burden refers to the consequences of those in close contact with people suffering from severe mental disabilities. Caregivers' burden of children with mental disorders has been identified as determining the feasibility of discharging a patient back into the community or to refine the concept of caregiving and its underlying structure and components (Chan, 2011).

The burden of caregiving could be explained based on its physical, emotional, financial, and social duties and diseases with a high disability level can affect dramatically not only the patient but also the caregiver who caters and provides the necessary support for the patient. Most studies agree that a minimum requirement to be considered as a 'family caregiver' is that the individual must not be paid to render care to the patient. Other literatures used the term 'informal caregiver' interchangeably with 'family caregiver' to reflect this lack of compensation (Abjs Mums Ac, 2015). When family caregivers are well supported the care they provide in the community (for instance, have informational, emotional and instrumental resources), can offset the challenges they experience. This eventually leads to the provision of higher quality care and better functional recovery processes and community reintegration of the individual with mental disabilities (Bastawrous, 2013).

Any family that records the occurrence of the incidence has no choice than to adapt to this new situation. The course of this role is defined and can be changed during the course of the disorder. Although caregiving experience of the condition has positive impacts on the patients, it is considered as a multi-dimensional, complex concept that is mostly interpreted as negative (Betül & Küçük, 2016). Parents of children with mental disorders may target themselves of societal discrimination, including being treated with less respect as compared with others, receiving poorer services at facilities such as markets, restaurant, lorry station, or feeling criticized and insulted leading to embarrassment (Song, Mailick, & Greenberg, 2018).

2.5 Costs of caring for children with mental disorders.

A study has shown that the cost involved in the treatment of diseases as measured in terms of disability-adjusted life years, is very high in mental health even as compared with cardiovascular diseases and the rates appear to be increasing, even among very young children between the ages of 2-4 years (Larson et al., 2004). The economic burden of mental health in children on the caregiver include poverty and child caregiving that interferes with various income-generating activities in the family, and extra expenses that are directly or indirectly associated with the illness of the child (Ambikile & Outwater, 2012). A study by Opoku- Boateng *et al*, (2017) categorized the economic costs of caring for people with mental disorders as direct costs, indirect costs and intangible costs.

2.5.1 Direct cost of children with mental disorders

The direct costs refer to all costs that are incurred due to medical management of the disease. These costs are related to the use of resources as a direct result of the treatment and health caregiving process (Yousefi, Arani, & Sahabi, 2014). The direct cost can also be classified as direct medical cost and direct non-medical cost (Chong, 2017). The direct medical cost includes the cost of purchasing drugs, payment for admissions, and complementary diagnostic tests (Yousefi et al., 2014).

The direct non-medical cost involves the cost of transportation, feeding, residence (Opoku-Boateng et al., 2017) Another study also classified the cost incurred due to damage to properties as a result of the ailment as part of direct cost (Thavorncharoensap et al., 2010). The direct costs associated with giving care to people with a mental disorder is very high (Ambikile & Outwater, 2012). Another study has also identified the broad array of direct costs incurred by the family with a disabled child to include payment for special medical care, home renovation, durable medical equipment, rehabilitative and case management services, educational services, and parental respite care (Busch & Barry, 2007).

A study conducted in Shanghai showed that there were increases in the yearly trend of hospitalization for mental disabilities among all age groups (from 10919 to 14054) and this resulted in a total cost from US$ 23.56 to 42.13 million per year in 2015). The study also stated that most direct medical related costs were mainly spent on medical drugs. The research estimated that without government intervention, the average monthly cost per admission was likely to rise to US$7394.17 and the overall health expenditure for mental health would exceed US$100.52 million by 2030 (Chen *et a*l, 2017).

A study done in Ghana to determine the “economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana” estimated US$30 as the mean monthly direct cost which represented about 18% of the total cost used in giving care to the patients (Opoku-Boateng et al., 2017). A study that investigated the economic costs incurred for outpatients with schizophrenia patients in Taiwan documented that, approximately, the average annual total cost for management of the ailment was US$16,576 per patient. And the direct costs associated was 13% of the total costs involved.

Another study showed the direct cost of schizophrenia, one of the leading mental disorders in their respective countries: France (€ 1 581milion), Spain (€1 044 million) UK (£714 million) USA ($ 32 051milion) (Tajima-pozo *et al*., 2015). Other study showed that in 2011, the total expenditure for hospitalization of patients with mental disorders per admission had reached 10 522 Chinese Yuan (CNY) in some provinces of China and this accounted for 48.2% of the per capita disposable income of the urban residents and 151% of the per capita disposable income of those that reside in rural areas (Chen et al., 2017). Another study estimated 37% as the direct cost of the €798 billion of the total cost estimated for illness associated with brain and mental disorders in Europe in 2010 (Gustavsson et al., 2011). In their research, Lavelle et al., (2014) revealed that the additional cost of caring for any child which is diagnosed of Autism Spectrum Disorders (ASD) which include health care, ASD related therapy, education, caregivers time and family coordinated services in total was as huge as USD 17081 per year. According to the researchers, if this cost was applied to the projected number of 673000 children aged 3 to 17 suffering from ASD in the United States, the total societal costs of giving care for the age group of children was USD 11.5 billion in the year 2011(Lavelle et al., 2014). Another study in China revealed that the per case per annum total costs, for the treatment of schizophrenic patients amounted to US $2586.21 with the estimated direct cost to US$ 862.81(33.4%) (Zhai, Guo, Chen, Zhao, & Su, 2013).

2.5.2 Indirect cost of caregiving

The indirect cost refers to the various costs incurred not as a result of direct medical management of the disease condtions but rather of other losses incurred such as lost to productivity, lost wages, and costs resulting from the need for home caregiving and childcare that would not have been incurred if the patient had not been taken ill (Yousefi et al., 2014). A study that investigated the "economic costs of outpatients with schizophrenia in Taiwan" documented that the average annual total cost for the management of the ailment was approximately US$16,576 per patient. And the indirect costs associated was 87% of the total costs (I. Hui Lee et al., 2008).

A study in Europe estimated the cost of brain disorders and documented €798 billion as the total cost of such disorders in 2010. And 40% was attributed to indirect costs of the patients' production losses and the per capita cost of treating disorders of the brain was €1550 while €5.2 were for child/adolescent disorders (Gustavsson et al., 2011)

Another study investigated the cost of caregiving for schizophrenia in some parts of the world and revealed the following as the indirect cost: France (€ 2 214 million), Spain (€ 926 million), UK (£ 1886 million), USA ($ 32 378 million) (Tajima-pozo et al., 2015). The indirect per patient per annum cost for the treatment of schizophrenia patients was estimated to be US$ 1723.40 (66.6%) of the entire cost of caregiving in China (Zhai et al., 2013)

2.5.3 Intangible costs

These category of costs are those that result in the deterioration in the quality of life of patients, the families, and friends due to health-related factors, such as pain or suffering anxiety, distress. These costs are sometimes extremely difficult to quantify (Press, 2016). The behavior of a patient who is receiving care is a factor that is capable of increasing the amount of stress and strain on the life of the caregiver. Furthermore, a long period of caregiving for chronic patients could result in burden. The impact of this burden could eventually lead to family conflicts and decreased the social function of both the caregivers and the patients. The burden of caregiving is so huge that it places lasting emotional distress on the caregivers where most of them complain of loss of normal life (Knock, Kline, Schiffman, Maynard, & Reeves, 2011).

The ability to assess the amount of strain on the caregivers is a very important element that can give a better clues to appreciate the intensity of the obstacle (Abjs Mums Ac, 2015). The Zarit Burden Interview (ZBI) therefore is the most consistently used measure of caregiver burden in such burdens (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). The Short and a screening version of the Zarit Burden Interview which is made up of 12-items was developed in 2001 from the older version of the Zarit Interview which formerly had 22-items (M. et al., 2001). The 12-items ZBI tool is suitable across diagnostic groups suffering from cognitive impairment in adults, and could be used for, longitudinal, cross-sectional, and intervention studies(Ballesteros et al., 2012).

The reliability and the validity of the Zarit Burden Interview was tested in several countries including Singapore where it was used to “assess the level of burden experienced by caregivers of patients with dementia” (PWD) in 2010 and it was concluded that it was valid and reliable (Seng & Luo, 2010). The tool was also used in Ghana by Opoku-Boateng et al., (2017) who investigated the “economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana”. Study revealed that caring for people with mental conditions such as schizophrenia places a high burden on family members. According to the study, the mean caregiver burden (measured using the

ZBI) was found to be 16.95 on a scale which ranged from 0–48, with 49% of the primary caregivers recording high burden (Opoku-Boateng et al., 2017).

Moderate to severe caregiver burden on caregivers characterized by huge productivity loss financial constraint, and lost employment were the findings of Addo et. al., (2018) on the economic burden of schizophrenia on caregivers in sub –Sahara Africa. The study also revealed that the severity of a patient's condition, caregiver's level of income, their employment status, and duration of mental illness were reported to be a negative impact on the economic burden experienced by caregivers of people with mental conditions (Addo et al., 2018).

2.6 Quality of life of Caregivers of children with mental disorders.

The quality of life according to the World Health Organization – Quality of Life (WHO-QOL Group (1995)) is the individual's view of their position and role in life within cultural context, and the value systems in which they are living in relation to their personal expectation, concerns, standards, and goals, (WHO Group, 1995). Six main domains were derived from the quality of life tool which include the the caregiver's physical health, psychological health, level of independence, social relationship, spiritual and environmental health (WHO Group, 1995).

The evaluation of the quality of life of a patient provides new and essential information that could serve as a guide for researchers, clinicians, and patients in treatment decisions and prognosis (Schiavoli et al., 2014). Measuring the quality of life is a key outcome for health services and it reflects a person's core sense of wellbeing and satisfaction with life within the environment they live in and the conditions they find themselves. It is also a reflection of the aspects of life beyond health status (such as finances, housing, relationships, social support systems), which are social determinants relating directly to maintaining health conditions, supporting recovery (Caqueo-Urízar et al., 2017).

Most studies have focused on the quality of life of patients of various disease conditions with only a few focusing on the quality of life of caregivers. There are several tools for measuring the quality of life. The widest instrument used by research among the lots is the World Health Organization Quality of Life Abbrevieted Version (WHOQOL-BREF) questionnaire which has 26-items on a five-point response scale. (Da Rocha, Power, Bushnell, & Fleck, 2012). The short version of the WHOQOL-100 and WHOQOL-BREF tools European Health Interview Survey – Quality of Life (EUROHIS-QOL) which has 8-items index was used to access the quality of life of caregivers of children with mental disorders with structure and assessment of the EUROHIS-QOL following exactly that of the parent WHOQOL-BREF tool (Da Rocha et al., 2012).

The EUROHIS-QOL (WHO-8) is easy and fast in detecting the overall quality of life of caregivers. Some questions contained in the 8 item list include (eg, “How satisfied are you with your health?”; “Have you enough energy for everyday life?”), with 2 items per quality of life QOL domain (social, psychological, physical, and environmental), with the answers being scored on a 5-point Likert scale which ranges from 1 (not at all/very dissatisfied) to 5 (completely/very satisfied), with a lower score showing low quality of life and higher score indicating better QOL (Da Rocha et al., 2012). The EUROHIS-QOL tool was used to assess the quality of life of caregivers in some European countries, Brazil, Latin America, Israel, among others and has proven cross-culture validity and was recommended that it could be used in any part of the world (Pires, Fleck, Power, & Da Rocha, 2018).

A cross-culture study that compared the quality of life of caregivers of people suffering from schizophrenia among the Chilean and French families revealed a low quality of life among the caregivers (Boyer et al., 2012). The study of Opoku-Boateng et. al., (2017) in Ghana also revealed a low quality of life among the caregivers of schizophrenia patients. According the researchers, caregivers who had the support of the family members and those that had a higher level of education had a high quality of life as compared with others who did not. Another study which examined the quality of life and the parental concern of children with autism revealed that parents whose wards suffered from the condition showed a higher burden and a diminished quality of life (L. C. Lee, Harrington, Louie, & Newschaffer, 2008). Addo et al., (2018) in their study to estimate the economic burden of caregiving of persons with severe mental disorders in sub-Sahara Africa revealed that the burden of direct and indirect costs incurred by caregivers severely affects their quality of life directly or indirectly. A study in Croatia revealed that caregivers of patients suffering from schizophrenia usually experienced diminishing quality of life (A, Miro, Zvjezdana, Branimir, & Vlatka, 2013). A study in Hong Kong also revealed that relatives and caregivers with lower education caring for people suffering from mental illness suffer a low quality of life. (Wong, Lam, Chan, & Chan, 2012)

2.7 Summary of the Chapter

It was evident from the numerous studies reviewed, that caring for children with mental disorders places a huge economic burden on the caregivers which eventually affects their quality of life. It was evident that the impact of mental disorders in children make it difficult for them to perform normal duties such as eating, walking, washing, working, going to school, among others and would, therefore, need assistance from their caregivers and relatives. This makes the caregivers unable to commit to normal work leading to a reduction in their earnings. Much of the time that needs to be spent by the caregivers at work is rather spent on caregiving leading to loss of productivity of the caregivers resulting in a reduction in their income. The disease is also associated with a stigma which makes it difficult for their family to maintain the relationship in society.

In estimating the cost of mental disorders in children, the direct treatment-related cost, direct non-treatment related cost, indirect cost, and intangible costs were seen to be measured in all the studies. It is observed from the majority of the studies that the indirect cost was higher than the direct cost. The intangible cost placed on the families and caregivers were identified to be experiencing high burden of the disease, which in turn affects their quality of life.

It is believed that children with the condition will rather need more time from their caregivers in carring out their activities and this would increase the burden of the disease. But it was also observed that the majority of the studies reviewed focused on the caregivers of adults with mental disorders than that of children with the condition. Again, most of the studies in Africa and from other parts of the world failed to address the impact of the burden of caregiving of children with mental disorders on the quality of life of caregivers. This has created a gap. This study, which is expected to fill that gap was aimed at estimating the economic burden of the disease and the quality of life of the caregivers of children with mental disorders.

CHAPTER THREE

METHODS

3.1 Introduction

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

3.2 Study Design

The research adopted a cross-sectional study design using the cost of illness analysis approach.

3.3 The study area

There are three Public Psychiatric hospitals in Ghana which are all located in the Southern stretch of the country (two are located in the capital city of the country and the other at Cape Coast). These hospitals namely: Accra Psychiatric Hospitals, Pantang Psychiatric Hospitals, and Ankaful Psychiatric Hospitals render services to the entire estimated population of twenty-five (25) million. Even though some public hospitals attend to patients with mental disabilities on OPD basis, most of such cases are referred to any of these specialized psychiatric hospitals based on the severity of the condition (Gloria et al., 2018). This study was conducted at these three psychiatric hospitals

Accra Psychiatric Hospital which is situated at Adabraka in the Greater Accra Region is a 600-bed hospital which was commissioned in 1906 as the first psychiatric hospital in Ghana.

The Pantang Psychiatric Hospital is also situated in Pantang, a town about 1.6 kilometers off the Accra- Aburi road and 25 kilometers from Accra Central of the Greater Accra Region of Ghana. It was established in 1975 and has a bed capacity of 500. The hospital receives psychiatric patients from all over Ghana and a few cases from neighboring countries such as Togo, Benin, Burkina-Faso, Ivory Coast and Nigeria. The Ankaful Psychiatric Hospital is also located in Komenda, precisely a village called Ankaful where it derives its name. The hospital is approximately 12.5km and 6km away from Cape Coast and from Elmina respectively.

3.4 Study population

The study population comprised of family (primary) caregivers of children with mental disorders who reported to the Outpatient Department at each study sites. The family caregivers who visited any of the three institutions during the study period were identified by the help of Nurses on duty and approached for the collection of relevant information needed for the study.

3.5 Inclusion and exclusion criteria

3.5.1 Inclusion criteria

The study included unpaid family members caring for children diagnosed with any mental disorder. The children according to this study were people below 19 years of age. The caregivers were primary caregivers who had provided care to the patients for at least six months prior to the study period who were willing to participate in the study as well.

3.5.2 Exclusion criteria

Relatives who were not primary caregivers and people who spent less than one month in their role as caregivers were excluded.

3.6 Study variables

Data collection comprised of : in-person caregiver surveys with structured questions using standardized assessment tools.

Table 1: Quanitative assessment areas and tools

Dependent variable /Assessment area	**Assessment tool**
Economic burden	***Direct costs*** (medical and non-medical costs related to the care of the patient)
	Indirect costs (waiting time, productivity losses due to caregiving)
	Household assets and possessions
Intangible costs	Zarit Burden Interview (ZBI) (used in measuring stress, pain, anxiety, and depression)
Quality of life	EUROHIS- QOL (WHO-8)
Independent variable	
Clinical factors	Disorder type, duration of illness, past hospitalizations
Socio-demographics	Child age and sex; caregiver age, sex, education, employment status, health insurance coverage.
Caregiving characteristics	Time spent caregiving, caregiving assistance, monthly income, Source of funds for caregiving

3.7 Sampling

This section comprises of how the sample size was determined, the sampling technique used, data collection techniques and tools

3.7.1 Sample size determination

The prevalence of children with mental disorders in Sub-Sahara Africa is 14.3% (Melissa et. al, 2016). Adopting sample size formula by Cochran for cross-sectional study:

$$n = \frac{(Z_{\frac{\propto}{2}})2 \ p(1-p)}{e^2}$$

where n is the minimum sample size required for the number of caregivers

p is the prevalence of mental disorders among children in Sub-Sahara Africa =14.3%

$Z\propto /2 = 1.96$ is the standard normal variate since α=5% at 95% Confidence Level

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

Inputting the above into equation (1), the minimum sample size for primary caregivers required for this study was given as:

$$n=\frac{1.96^2 \times 0.143 \times (1-0.857)}{0.05^2} = 188.31$$

Assuming 10% nonresponse rate =18.8

Total = 207

Total number of children with mental disorders who reported at Accra Psychiatric Hospital in 2018 was 1317.

Total number of children with mental disorders who reported at Ankaful Psychiatric Hospital in 2018 was 745.

Total number of children with mental disorders who reported at Pantang Psychiatric Hospital in 2018 was118.

Total number of patients for the three facilities in 2018 = 1317+745+118

=2180.

And this was calculated as

Accra (N=1317), n= $\frac{1317}{2180}$ x 207 = 125.05

= 126

Ankaful (N=745), n = $\frac{745}{2180}$ x 207 = 71

Pantang (N=118), n = $\frac{118}{2180}$ x 207 =12

Total sample size = 126+71+12 =209

The total sample size used 210.

3.7.2 Sampling technique

A person was classified as a caregiver if he or she mostly provided the basic support, if not wholly, in the daily caring needs of the patient. At each study site, folders of children who were diagnosed with mental disorders for at least the past six months were identified using ICD-10 criteria and the caregivers who came to the facilities with the patients were identified. Identified caregivers were further interrogated to be sure if they were the actual primary caregivers or they came to represent the main caregivers. Those found to be the actual caregivers were involved in the study till a minimum of 126 was reached for Accra Psychiatric Hospital, 12 and 71 for Pantang and Accra Psychiatric hospitals respectively making a total of 210 caregivers at all the three study sites.

3.7.3 Data collection techniques and tools

Data was collected each day at various facilities. About two months (May and June, 2019) were used to collect the data. Two research assitants helped in the data collection at each of the facilities. Follow-ups were made and meetings held to address the challenges being confronted with the data collection process.

A face-to-face interview using a structured questionnaire was the main instrument that was used in collecting the data from the respondents for this study. The questionnaires were interviewer-administerd by the help of research assistants. About 20 -25 minutes was used to interview each of the repondents per questionnaire. The questionnaire was divided into different sections. Section A of the questionnaire was designed to gather information on the socio-demographic characteristics of the caregivers. The B portion focused on the impact of the patient's illness on household members and section C also focused on gathering data on the burden of care for children with mental disabilities on Primary caregivers. Direct medical cost (consultation, diagnosis, drugs, etc.) and direct non-medical cost (cost of traveling, accommodation, food, etc) were collected by the section D portion of the questionnaire. While section E was meant to collect information on indirect cost of caregiving (loss to productivity due to caregiving, waiting time, absenteeism, etc) section G and F were designed to focus on the intangible cost of caregiving using Zarit Burden Interview (ZBI) and Quality of life of the caregivers using the EUROHIS-QOL tools respectively. The ZBI is a Likert scale for measuring the stress, pain, and anxiety experienced by the caregivers of children with mental disorders. Patients' physical and psychological pain, social isolation anxiety, stress, due to the mental disability were assessed. It has responses ranging from a minimum of 0 to a maximum of 4. It has a score ranging from 0-48 with 0-16 categorized as a low burden and 17-48 classified as a high burden.

The shortened version of the WHOQOL-100 and WHOQOL-BREF tools (EUROHIS-QOL) which has 8-items index was used to assess the caregiver's quality of life of children with mental disorders. The EUROHIS-QOL (WHO-8) is easy and fast in detecting the overall quality of life of caregivers. Some questions contained in the 8 item list include (eg, "How satisfied are you with your health?"; "Have you enough energy for everyday life?"), with 2 items per quality of life QOL domain (social, psychological, physical, and environmental), with the answers beings scored on a 5-point Likert scale which ranges from 1 (not at all/very dissatisfied) to 5 (completely/very satisfied), with a lower score showing low quality of life and higher score indicating better QOL (Da Rocha et al., 2012).

3.8 Data quality assurance

3.8.1 Training of research assistants

The field workers that assisted in the data collection process were trained prior to the commencement of the data collection. The training focused on: Making sure that the research assistants understood clearly the objectives of the study. It was also purposed at enabling them to build an understanding of the survey tools used, how to do effective interpretation and administering of the questionnaire. It also focused on assessing the capacity of the field workers to perform the survey tasks assigned to them. The research assistants were trained in the translation and interpretation of the questionnaires in the local dialects. The languages included Fante and Twi for those in Ankaful Psychiatric Hospital and Ga-Adangme, Twi, Ewe for those who went to Pantang and Accra Psychiatric Hospitals. Practice on how to administer the questionnaires, how to seek their consent and how to assure participants of their confidentiality was attempted several times to avoid any bias or any form of challenges associated with studies.

3.8.2 Data entry and management

Data entry controls were put in place to serve as checks in order to prevent wrong entries and other errors. Completed questionnaires were coded within 24 hours of collection by the researchers. Data were entered into Microsoft Excel 2016 and cross-checked twice for the avoidance of errors, cleaned and exported to Stata Version 15 for analysis.

3.9 Data Analysis

The socio-demographic characteristics of the primary caregivers of children with mental disorders were described using frequencies and percentages to find the distribution. The various costs that were estimated were the cost incurred by caregivers for a period of one month prior to the study.

3.10 Cost analysis

Analysis on costs were made from the caregiver's perspective for a period of one month.

3.10.1 Direct Cost Estimation

The direct costs incurred by caregivers were estimated by summing all actual payments made directly on medical items and services by the caregiver during the period of last month visitation to the hospital with the patient. The direct cost was further categorized into direct medical (treatment-related) cost and direct non-medical (non-treatment-related) cost. Direct medical (treatment) related cost included the sum of diagnostic tests, cost of drugs purchased, cost of discharge, consultation charges and other therapies.

The total direct non- medical cost (non-treatment related) comprised of the sum of the cost of travel, cost of accommodation (rent), and cost of food for both the caregiver and patient during treatment and other costs. The cost of accommodation and food for caregivers when the client was on admission or traveling were altogether termed as other costs. The sum of direct medical cost (treatment-related cost) and direct non-medical cost (non-treatment related cost) gave the total direct cost.

The direct treatment-related cost was estimated as follows:

Cost of medicines: This was determined by summing all the out-of-pocket expenditure incurred by the caregivers on drugs during their last visit to the various hospitals.

Cost of consultation: This was estimated by summing the cost incurred by caregivers as treatment cost for consulting the physicians during the last visit with a psychiatric condition.

Cost of diagnostics: This was estimated by summation of all the costs incurred by the caregiver on behalf of the patient on all laboratory test during the last visit.

Cost of other therapies: This was calculated by adding all the costs incurred by the caregiver on other therapies such as electroconvulsive therapy psychotherapy, among others during their last visit to the hospital

The total direct treatment-related cost of caregiving for children with mental disorders was then obtained by summing the total cost of the consultation, drugs purchased, laboratory tests, and other therapies.

Direct non-medical (non-treatment) related cost of caregiving was estimated as follows:

Cost of travel: This was calculated by adding the travel cost incurred by the caregivers in seeking medical attention at the various psychiatric hospitals for a period of one month.

Cost of food for patient and caregiver during treatment: This was calculated by summing all the costs incurred on food by the caregiver for both the patient and the caregiver during the treatment period of one month.

The total direct non-treatment related cost of caregiving was calculated by adding the travel cost, cost of food for caregiver and patient during the treatment period and other costs.

The total direct cost was determined by adding the total direct treatment-related cost and total direct non-medical (non-treatment related) cost. The average cost of each of the variables in the direct cost was found as well as the percentages to find the distribution of the total cost of caregiving for children with mental disabilities.

3.10.2 Indirect Cost Estimation

The Human Capital Approach (HCA) was used to estimate the indirect cost of caregiving on caregivers. The Human Capital Approach measures output losses by lost earnings as a result of the loss of productivity or unavailability for work. The productivity losses of the family caregivers in the informal sector were estimated using the minimum daily/hourly wage rate of Ghana at the time of the study (i.e. GHS 10.65 /day). Productivity losses of family caregivers in informal employment were estimated using the same minimum wage value for formal sector employees for the purpose of this study since the casual labour pay at the informal sector was not consistent in the various fields of works. The total hour spent by the caregivers per month was obtained by multiplying the total hours spent by the caregiver per week by four. If there were more than one caregiver for patients, their total time lost per period were calculated. The total time spent in terms of hours by these caregivers in each sub-category was estimated and the average number of hours spent per month was obtained. The time used for caregiving by the unemployed and student/apprentice was also considered and taken to be part of the informal sector.

Analysis of intangible cost: Intangible cost is difficult to quantify directly. The analysis of intangible burden was done using the short version of **Zarit Caregiver Burden Interview (ZBI-12)** (Bedard et al., 2001)**,** which is a Likert scale for measuring the stress, pain, and anxiety experienced by the caregivers of children with mental disorders. Patients' physical and psychological pain, social isolation anxiety, stress, due to the mental disability were assessed. These variables were measured by summing the various scores for all the 12 items for each caregiver to generate a maximum score of 48 and a minimum of 0. Interpretation of scores was a 0-16 low burden and above 16 high burdens. These scores were presented in a pie chart to give a visual representation of the findings of the study.

3.10.3 Quality of Life

The quality of life of the caregivers of children with mental disorders attending the three psychiatric hospitals was assessed using the EUROHIS-QOL (WHO-8) (Da Rocha et al., 2012). This tool has 8-items with a minimum value of 1 and a maximum of 5 The EUROHIS-QOL (WHO-8) is easy and fast in detecting the overall quality of life of caregivers. Some questions contained in the 8-item list included (Eg, "How satisfied are you with your health?"; "Have you enough energy for everyday life?"), with 2 items per quality of life QOL domain (social, psychological, physical, and environmental), with the answers beings scored on a 5-point Likert scale ranging from 1 (not at all/very dissatisfied) to 5 (completely/very satisfied), with a lower score showing low quality of life and higher score indicating better QOL (Da Rocha et al., 2012).

The score of quality of life was presented in a pie chart to enhance the visual representation of the finding of the study at a glance.

3.10.4 Sensitivity analysis of total cost

A sensitivity analysis was done to ascertain the robustness of the results of the study. This analysis determines how different values of an independent variable are likely to affect a particular dependent variable under a given set of assumptions. This test was conducted on drug and wage rate due to the uncertainties in the respondents estimated values. Drug and wage rate were varied individually by an increase of 5%, 7% and 10% as determined by the researcher

3.11 Ethical Consideration/Issues

3.11.1 Noguchie Memorial Institue for Medical Research- Institutional Review Board

Ethical approval for the study was sought from the Noguchie Memorial Institue for Medical Research- Institutional Review Board before the commencement of the study.

3.11.2 Approval from study site

Introductory letters were obtained from the School of Public Health to seek permission and approval from the hospital administration of Accra, Pantang and Ankaful Psychiatric hospital before the data collection commenced.

3.11.3 Informed consent

Informed consent was sought from caregivers of children with mental disorders before engaging them in the study. All caregivers who did not show interest in the study or had other concerns as to why they were dissatisfied with the study were not interviewed.

3.11.4 Declaration of Conflict of Interest

Apart from the study being of public health importance, I the researcher had no personal interest as far as this study was concerned.

3.12 Potential risk/benefits and compensation

This research was not intended to pose any risk to either the study population or community. The results of this study are expected to be beneficial to both the population and the community in several ways. Firstly, the study would provide the population with information about the estimated cost of caring for children with mental disabilities per month. Furthermore, been able to quantify the cost of caring for children with mental disabilities would inform policymakers and government about the economic burden associated with this disease. This would aid in planning and budgeting for savaging such cases. There was no compensation for participants that were involved in the study other than a word of appreciation.

3.13 Privacy and confidentiality

The purpose of the study was explained to the participants. They were informed and assured that their identity and privacy would be protected. The confidentiality of the participants was protected by using codes to identify them on each of the questionnaires instead of their names. Questionnaires were administed in enclosed places to avoid any intimidation and interference from onlookers.

3.14 Data usage and storage

Questionnaires were packed into sealed envelopes and securely kept in a cupboard that was securely locked by the principal investigator. Data collected were coded and entered within 24 hours of collection and well secured with a password. All data collected for this study would be kept by the principal investigator for about 2 to 3 years to allow for publication of the work, after which the hard copies of questionnaires would be destroyed permanently.

3.15 Voluntary withdrawal

The participants were given the liberty to opt-out of the study at any stage, in case they were no longer interested in the study. Such decisions attracted no sanctions of any form on any of the caregivers.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the analyzed results of the study. The chapter shows the socio-demographic information of the respondents. Various results that seek to address each of the objectives are subsequently presented. Results are shown using tables and charts. In all, a total of 210 caregivers of children suffering from mental disorders attending Pantang, Ankaful and Accra Psychiatric Hospital in Ghana were involved in the study. The response rate was 100% (210/210).

4.2 Socio-demographic characteristics of caregivers

As shown in Table 4.1, the majority of the respondents were females which constituted 114(54.3%) of the total respondents interviewed while the males were 96(45.7%). The mean age of the caregivers was 40.4 years (95% CI: 38.7- 42.0) and a standard deviation of 12.6. Majority of the caregivers (n=66) (31.4%) were in the range of 46-55 years. Only 10% (n=21) of the respondents were above 56 years of age with 40% (n=96) below 25 years. Majority of the caregivers 55.7% (n=117) were married with 35.7% (n=75) been single while 5.7% (n=12), 2.9% (6) were divorced and widow/widowers respectively. The mean time caregivers spend from their various destinations to facilities for caregiving was 3.2 hours (95% CI: 2.9-3.6) with the majority of the people 52.9% (n=111) spending between 2-3hours to the facility. Christians formed the bulk of the caregivers 71.4% (n=150), while Muslims represented 21.4% (n=45) and traditionalist representing the least 6.2% (n=13). Majority of the caregivers had Tertiary–Cert/Diploma/Post diploma education 56.7% (n=119) and 24.3% (n=51) had Tertiary-Graduate/post Graduate education. Only 1.9% (n=4) and 1.0% (n=2) of the caregivers had no education and primary education respectively. The bulk of the caregivers, 50% (n=105) were employed at the Public Sector while 14.8% (n=31) were self-employed. Only 0.9% (n=2) were unemployed while 7.1% (n=15) were students/apprentice. It was also revealed that majority of the caregivers were taking care of their own children and this represented 84.3% (n=115) while 15.2% (32) of the caregivers were in charge of their siblings. 12.9% were their in-laws with the least 9.1% (19) taking care of their grandchildren.

Majority of the caregivers, 52.38% (n=110) revealed spending 5-7 days per week in caregiving while the rest, 47.62% (n=100) revealed spending 2-4 days for caregiving. Again, 53.8% (n= 113) of the primary caregivers reported spending a period of 1-5 hours per day for caregiving and 41.9% spent between 6-10 hours while only 4.29% reported spending beyond 11 hours per day.

Majority revealed a monthly source of funds for financing caregiving which exceeded GHs 2000 (USD 400) and this represented 57.2% of the caregivers interviewed while 7.2% revealed monthly financing source ranging between GHS 501–GHS 1000 and this represented the minority. Only a few of the caregiver revealed giving care for a duration up to one year or less representing 12.4%(26) while the majority of them revealed giving care for more than one your to five years and this represents 64.3%.

Table 2: Sociodemographic Characteristics of caregivers

Characteristics	Number	Percentage (%)
Sex		
male	96.0	45.7
female	114.0	54.3
Age		
≤ 25	40.0	19.1
26-35	39.0	18.6
36-45	44.0	21.0
46-55	66.0	31.4
≥ 56	21.0	10.0
Marital status		
married	117.0	55.7
single	75.0	35.7
Divorced	12.0	5.7
widow/widower	6.0	2.9
Religion		
Christianity	150.0	71.4
Muslims	45.0	21.4
Traditionalist	13.0	6.2
Other	2.0	1.0
Educational status		
No education	4	1.9
Primary education	2	0.95
Junior High	12	5.71
Secondary/Tech/Voc	22	10.48
Tertiary-Cert/Diploma/Post Diploma	119	56.67
Tertiary- Graduate/Postgraduate	51	24.29
Employment Status		
Self employed	31	14.76
Private	57	27.14
Public Sector	105	50
Unemployed	2	0.95
Student/apprentice	15	7.14
No. of years Being a Caregiver		
≤ one year	26	12.38
more than 1 to 5 years	135	64.29
More than 5 years	49	23.33

Monthly Source of financing		
<GHS 500	15	7.21
GHS 500-1000	21	10.1
Charateristics	Number	Percentage
>GHS 1000	172	82.69
Relationship with patient		
Child	115	54.76
Sibling	32	15.24
Grandchild	19	9.05
In-law	27	12.86
Other	17	8.1
Total	210	100

4.3 Socio-demographic characteristics of care recipients

The mean age of the care recipients was 15 years (95% CI: 14.5 – 15.5) with the majority being in the age range of 16-19 years representing 57.6% (n=121) and the least age from 1-5 years of age. More of the patients 51.9% (n=109) were males as compared to 48.1% (101) that were females89.5% (n=188) of the caregivers reported assisting the patients mostly in activities such as bathing, walking, sitting, transportation, medication and house works while only 10.5% (n=22) of the caregivers reported not assisting the patients in such activities.

Table 3: Socio-demographic characteristics of care recipients

Characteristics of care recipient	Number	Percent (%)
Age of care recipient		
< 6 yrs	9	4.29
6-10yrs	15	7.14
11-15 yrs	65	30.95
16-19yrs	121	57.62
Sex of care recipient		
Male	109	51.9
Female	101	48.1
Assisted in bathing,walking,sitting dressing, etc		
Yes	188	89.52
No	22	10.48
Total	210	100

4.4 Direct medical cost

The direct medical cost comprised of the summation of all costs for consultation, discharge, drugs diagnosis and other charges incurred directly that were related to treatment within one month. The unit cost for consultation per child was GHS 114.16 (USD 22.83) representing 14% of the total cost. The cost for drugs and diagnosis per child per month was also estimated as GHS 135.32 (USD 27.06) representing 16% and GHS 125.74 (USD 25.15) representing 15% respectively. The total direct cost related to treatments for children with mental disorders per month for the entire population in the study accounted for GHS 84623.00 (USD 16924.60). Averagely, the direct cost of medical treatment per child per month was revealed to be GHs 402.97 (USD 80.59) which represents 48% of the entire cost of treatment.

4.5 Direct Non- medical cost

On average, the direct non-medical related cost per month was found to be GHS 313.15 (USD 62.63) representing 37% of the total cost for treatment. This cost comprised of the cost for household supplies, residential cost, and transportation. The total cost for household supplies was estimated as GHS 99.02 (USD 19.80) per child per month representing 12% of the total cost. The total cost of transportation per child was GHS 84.63 (USD 16.93) representing 10% per month. The total unit cost making up the direct non-medical related cost accounted for GHS 65761.00 (USD 13152.20) of treatment and this represented 37% of the total cost. The direct non-medical cost category was found to be the second highest after direct medical cost of treatment for children with mental disorders in Ghana.

4.6 Indirect cost of caregiving

Table 4: Productivity loss due to caregiving

Productivity loss	Time(hrs)	SD	Cost GHS	Cost (USD)	Average Cost (GHS)	Average cost (USD)	%
Formal sector	13336	412.66	17753.6	3550.72	109.6	21.92	65%
Informal Sector	4096	364.89	5452.8	1090.56	113.6	22.72	20%
Sub Total	17432	777.55	23206.4	4641.28	223.12	44.638	..
Time spent by other relatives	2944		3919.2	783.84	18.66	3.73	15%
Total	20376		27125.6	5425.12	129.17	25.8	100

- Time for students and unemployed were not considered because they have no market value.

The average time lost to productivity by caregivers in the informal sector per month was 85.3 hours, which was estimated at GHS 113.6 (USD 22.72). This represented 20% of the time loss.

The average time lost to the productivity of the caregivers from the formal sector per month was also found to be 82.3 hours, which accounted for GHS 109.6 (USD 21.9) representing 65% of the time loss. Family caregivers who helped in the caregiving apart from the primary caregivers also recorded an average time loss of 14 hours per month which was worth GHS 18.66 (USD 3.73), representing 15 % of the time loss.

Cost component	**N (210)**	**Cost(GHS)**	**Cost(USD)**	**Average(GHS)**	**Average (USD)**	**Cost Profile (%)**
Direct Medical Cost						
consultation		23973.00	4794.60	114.16	22.83	0.14
Discharge		1778.00	355.60	8.47	1.69	0.01
drugs		28417.00	5683.40	135.32	27.06	0.16
Laboratory		26405.00	5281.00	125.74	25.15	0.15
Other		4050.00	810.00	19.29	3.86	0.02
Sub Total		**84623.00**	**16924.60**	**402.97**	**80.59**	0.48
Direct Non medical						
Household supplies		20795.00	4159.00	99.02	19.80	0.12
Residential Care		25493.00	5098.60	121.40	24.28	0.14
Transportation		17773.00	3554.60	84.63	16.93	0.10
Other Expenses		1700.00	340.00	8.10	1.62	0.01
Sub Total (Direct Non-medical cost)		**65761.00**	**13152.20**	**313.15**	**62.63**	**0.37**
Indirect Cost						
Days lost to work in hours		5985.30	1197.06	28.50	5.70	0.03
Days lost to to school		1400.48	280.10	6.67	1.33	0.01
Time Spent on Household Activities		4952.25	990.45	23.58	4.72	0.03
Time spent on Travelling /Transportation		4361.18	872.24	20.77	4.15	0.02
Productive lost due to waitiing		5207.85	1041.57	24.80	4.96	0.03
other time spent with care recipent /leisure etc		1299.30	259.86	6.19	1.24	0.01
Time spent by other relatives apart from primary caregivers		3919.20	783.84	18.66	3.73	0.02
Sub Total (indirect cost)		**27125.55**	**5425.11**	**129.17**	**25.83**	**0.15**
Total Cost		**177509.55**	**35501.91**	**845.28**	**169.06**	**1.00**
Actual Total Cost by Primary caregivers		173590.35	34718.07	826.62	165.32	

*USD1 = GHs 5.00 (Exchange rate as at the time of the study – May, 2019)

4.7 Total cost of caregiving for children with mental disorders

On average, GHS 826.62 (USD165.32) per month was spent by the primary caregivers on caring for children with mental disorders. The time spent by relatives of family members to help primary caregivers accounted for GHS 3,919.20 (USD 783.84), which was GHS 18.66 (USD 3.73) on an average basis and this represented 2%. Therefore the cost of caregiving per child is the summation of cost of primary caregiver and time of the other family member which was found to be GHS 177,509.55 (USD 3,501.91) which on average basis cost GHS 845.28 (USD 169.06) per month. From the results, the direct cost of treatment per child per month accounted for the highest amount incurred in care provision GHS 402.97 (USD 80.59) representing 48% followed by direct non-medical cost GHS 313.15 (USD 62.63) representing 37% of the total cost. The indirect medical cost was found to be the least among the costs which accounted for GHS 129.17 (USD 25.83) and this represented 15% of the total cost incurred in caregiving by the caregivers for treatment per month for a child suffering mental diorders.

4.8 Sensitivity analysis of total cost of caring for children with mental diorders.

A sensitivity analysis was performed to ascertain the robustness of the various cost estimates obtained from the study. The components used for the sensitivity analysis were the cost of drugs and the wages of the formal and informal sector. A one way sensitivity analysis was first performed on the cost of drugs and wages of caregivers. This was executed by varying the cost of drugs and wages by 3%, 5%, and 10% respectively. It was seen from the result that when the drug cost was varied by 3%, 5%, and 7%, the total percentage increase was 2.5%, 4.2%, and 5.9% respectively. It was observed that at 3% varying cost of drugs, the percentage change in direct cost was increased by 0.4% and indirect cost was decreased by 0.4%. Direct cost has also been increased by 0.6% and indirect cost has decreased by 0.6 at 5% change. At a percentage change at 7%, the direct cost of drugs was increased by 0.9% and indirect cost has decreased by 0.9%.

The wage rate variation at 3%, 5% and 7% had also produced a change in total cost at 0.5%, 0.8%, and 1.1% respectively. It was observed that a percentage decrease of 0.4%, 0.6%, and 0.9% occurred in all the direct cost at 3%, 5%, and 7% variations respectively for drugs while an increase of 0.4%, 0.6%, and 0.9% were recorded at 3%, 5%, and 7% variations respectively for drugs.

Variation of drugs cost and wage rate at 3%, 5%, and 7% had recoded a change of 3%, 5%, and 7% respectively in total drugs cost while there was no effect on either direct cost or indirect cost across.

Table 5: Sensitivity Analysis of cost of caring for children with mental disorders

scenario	**cost component**	**% change in parameter**	**Total cost**		**Percentage change in total cost**	**Proportion of total cost**		**Percentage change in proportions of cost**	
			GHS	USD		Direct	Indirect	Direct	Indirect
Base scenario		0	177,509.55	35,501.91	0.0	84.7	15.3	0	0
Variation (One-way Sensitivity Analysis)	Medication	3	182,021.07	36,404.21	2.5	85.1	14.9	0.4	-0.4
		5	185,028.75	37,005.75	4.2	85.3	14.7	0.6	-0.6
		7	188,036.43	37,607.29	5.9	85.6	14.4	0.9	-0.9
Variation (One-way Sensitivity Analysis)	Wage rate	3	178,323.32	35,664.66	0.5	84.3	15.7	-0.4	0.4
		5	178,865.83	35,773.17	0.8	84.1	15.9	-0.6	0.6
		7	179,408.34	35,881.67	1.1	83.8	16.2	-0.9	0.9
Multi-variation (Multi-way Sensitivity Analysis)	Medication and Wage rate	3	182,834.84	36,566.97	3.0	84.7	15.3	0.0	0.0
		5	186,385.03	37,277.01	5.0	84.7	15.3	0.0	0.0
		7	189,935.22	37,987.04	7.0	84.7	15.3	0.0	0.0

4.9 Intangible cost

The standard scale for rating the ZBI has a lower limit of 0 and an upper limit of 48. All scores from 0-16 were considered low burden and all scores greater than 16 up to 48 were considered a high burden. The results, therefore, revealed that 35.7% reported low burden with 64.3% reporting high burden. The result again reported high burden in female caregivers than in male caregivers.

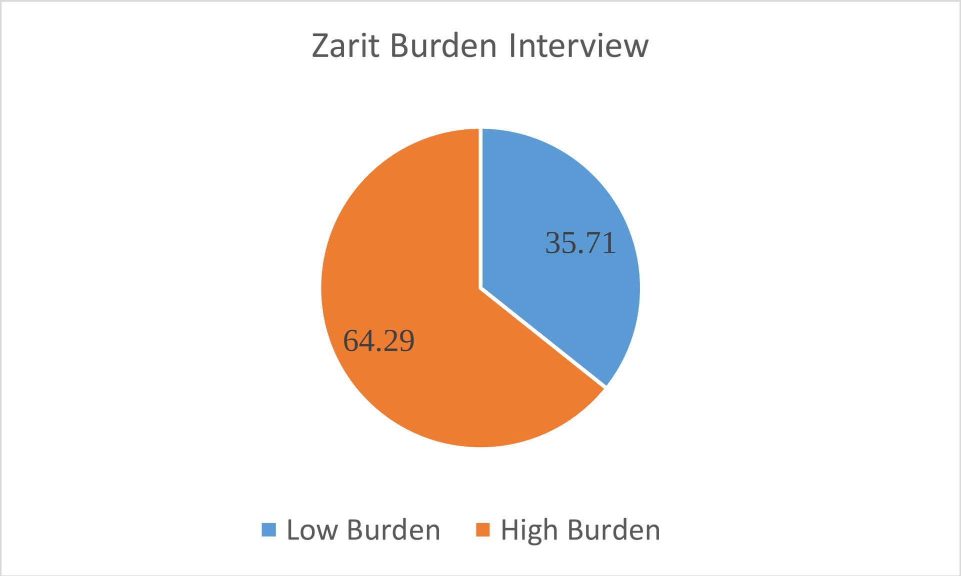

Figure 2: Burden of caregiving on primary caregivers

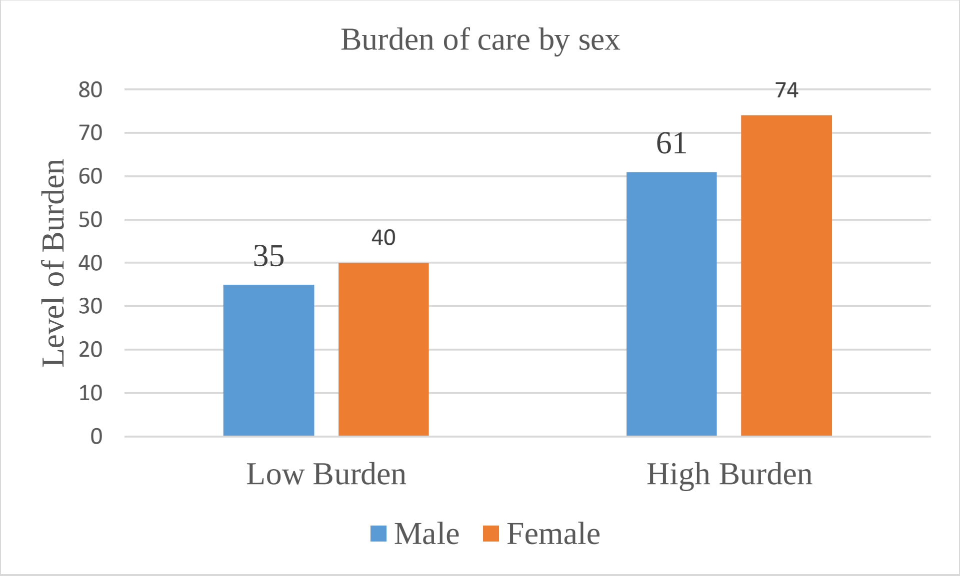

Figure 3: Burden of care by sex

4.10 Quality of life of caregivers

The results of the mean score of the quality of life of primary caregivers of children with mental disorders are presented in Table 6 below. From the results, the overall mean score for quality of life was 24.7 meaning on a whole, caregivers of children with mental disorders have a low quality of life. Across the four quality of life domains, environmental health has recorded the lowest quality of life (5.8) while physical health and social health both recorded the highest (6.3) each. Males had a lower quality of life (24.1) as compared with females (24.9). This could be attributed to the fact that it is not their main duty to give care, so any little effort will put pressure and frustration on them leading to low quality of life. People within the age group 26-35 years recorded a lower quality of life whilst those above 56 years recording a higher quality of life. This may be attributed to the fact that the caregivers in the 26-35 years age group were more likely to be actively working so caring for patients will affect their time and loss to productivity as compared with those above age 56years.

Married caregivers had a higher quality of life than those who were not married because those married may have support from their partners in giving care. Apart from those who had no formal education had a higher quality of life than those with primary education, the quality of life of caregivers increases as the level of education of caregivers increases. This could be because as the level of education increases, caregivers obtain more information and knowledge of handling issues of children with the condition and will, therefore, reduce the stress on them and the entire family.

Primary caregivers at the public sector recorded the highest quality of life because they were able to reschedule working time, workday or night and were therefore able to receive their monthly salary which could reduce the economic stress on them.

Table 6: Quality of life on background characteristics of caregivers

	Psychological		Physical		Social		Environment		Total	
Characteristics	**Mean(SD)**	**P-value**	**Mean(SD)**	**P-value**	**Mean(SD)**	**P-value**	**Mean(SD)**	**P-value**	**Mean(SD)**	**P-value**
Age		0.79		0.801		0.611		0.39		0.802
≤ 25	6.2(1.90)		6.0(2.09)		6.6(2.25)		5.8(1.88)		24.7(6.51)	
26-35	5.8(1.86)		6.46(2.21)		6.2(2.23)		5.4(1.75)		24.0(5.15)	
36-45	6.4(2.06)		6.1(2.22)		6.4(2.32)		5.7(1.89)		24.7(7.06)	
46-55	6.1(2.12)		6.4(1.96)		6.0(1.97)		5.8(1.84)		24.4(6.17)	
≥ 56	6.3(2.53)		6.0(1.90)		6.6(1.90)		6.1(1.77)		25.1(6.04)	
Sex		0.068		0.88		0.257		0.243		0.339
Male	6.1(1.9)		6.2(1.94)		6.1(2.02)		5.6(1.69)		24.1(5.60)	
Female	6.3(2.2)		6.3(2.19)		6.5(2.23)		5.9(1.94		24.9(6.66)	
Marital status		0.55		0.058		0.85		0.478		0.268
Married	6.2(2.25)		6.5(2.09)		6.4(2.22)		5.9(1.86)		25.7(6.63)	
Single	6.3(1.79)		5.9(2.17)		6.3(2.19)		5.5(0.81)		23.9(5.94)	
Religion		0.412		0.9		0.095		0.964		0.367
Christianity	6.3(2.13)		6.2(2.13)		6.4(2.02)		5.9(1.77)		24.8(6.4)	
Muslim	6.2(1.75)		6.6(1.89)		6.2(2.47)		5.2(1.93)		24.2(5.7)	
Traditionalist	5.9(2.14)		5.9(1.55)		5.5(1.99)		6.1(1.71)			
Educational Level		0.933		0.037		0.103		< 0.001		0.111
No Formal Education	6.5(0.57)		6.0(0.81)		5.3(0.96)		5.0(1.83)		22.8(2.6)	
Primary Education	6.0(1.41)		3.0(1.41)		5.0(0.00)		3.5(2.12)		17.5(0.7	
JHS/JSS	6.0(2.17)		5.8(2.04)		6.0(1.34)		5.3(1.82)		23.1(5.8)	
SSS/Tech/Voc	6.2(2.18)		5.6(2.32)		6.1(1.98)		6.5(2.22)		24.5(6.5)	
Tertiary-Diploma/Post Diploma	6.2(2.09)		6.3(2.16)		6.4(2.32)		5.7(1.8)		24.6(6.6)	

Charecteristics										
Tertiary-Graduate	Psychological		Physical		Social		Environmental		Total	
Post-Graduate	6.2(6.06)		6.5(1.75)		6.6(2.02)		5.8(1.74)		25.2(5.5)	
		P-value		P-value		P-value		P-value		P-value
Employment status		0.404		0.141		0.505		0.505		0.409
Unemployment	5.5(0.71)		4.0(1.41)		5.0(0.00)		4.5(2.12)		19.0(4.24)	
Self-employed	5.9(1.82)		5.2(1.77)		5.8(1.61)		5.6(2.01)		22.5(4.91)	
Private sector	6.1(2.22)		6.4(2.07)		6.4(2.26)		5.9(1.84)		24.8(6.39)	
Public Sector	6.4(2.1)		6.6(2.07)		6.5(2.18)		5.8(1.73)		25.3(6.45)	
Apprentice/Students	6.2(1.57)		6.0(2.17)		6.1(2.42)		5.3(2.22)		23.6(5.5)	
Monthly income for financing		0.628		0.546		0.684		0.458		0.554
<GHS 500	6.5(2.33)		6.7(2.09)		6.3(2.14)		5.5(2.06)		25.0(5.98)	
GHS 500-1000	6.2(1.79)		6.2(2.25)		6.0(2.02)		5.5(1.89)		24.09(6.55)	
>GHS 1000	6.2(2.05)		6.2(2.029)		6.4(2.14)		5.8(1.80)		24.60(6.15)	
Total	6.2(2.06)		6.3(2.07)		6.3(2.14)		5.8(1.84)		24.7(6.20)	

The results of the linear regression on background characteristics shows from table 8 showed that being in age groups 26-35 years and 46-55 years had an adverse effect on the quality of life of caregivers. Respondents in the age groups 26-35 years and 46-55 years had a decreased quality of life of 0.67 and 0.24 respectively as compared with those who were 25years and below. Meanwhile, being in age groups 36-45 years and those from 56 years and above had a positive association with quality of life. None of the age groups, however, was significant.

Also being a female though not statistically significant increases the quality of life of a caregiver by 0.82 as compared to being a male. Those who were single, divorced and widows/widowers were all found to have an adverse effect on the quality of life as compared to those who were married. Singles recorded a decrease quality of life of 1.1 whilst divorced caregivers had a decreased QOL by 0.63 and widows/widowers had a reduced quality of life by 1.71. Apart from primary education that had an adverse effect on the quality of life as compared to those without any level of education, all other levels of education had positive effects on the quality of life. As the educational levels of the caregivers' increased, there was an increase in the quality of life. But none of the levels was statistically significant.

Concerning employment status, only those who were not employed showed a negative relationship with quality of life while all other sectors such as private, self-employed, and student/apprentice showed a positive relationship. Those who work in the public sector had the highest relationship with quality of life (2.7) as compared to those who were self-employed. The Zarit burden Interview recorded an adverse effect on the quality of life of caregivers. A unit increase in the burden on caregivers decreased the quality of life by 0.06. Direct cost showed a positive association with the quality of life while the indirect and intangible costs showed an adverse relationship with the quality of life, though all the cost domains were statistically insignificant. A unit increase in idirect cost increases the quality of life by 0.0007 while a unit increase in indirect and intangible costs decreased the quality of life of respondents by 0.001 and 0.058 respectively.

Characteristics	**Unadjusted**		**Adjusted**	
	Mean diifernce (95%)	**P-value**	**Mean difference (95%)**	**P-value**
Age				
<= 25	Ref		Ref	
26-35	-0.6744(-3.4496 2.1009)	0.632	-0.2821(-3.2581 2.6945)	0.852
36-45	.07273 (-2.6215 2.7670)	0.958	-0.3665(-3.4598 2.7268)	0.815
46-55	-0.2456(-2.7166, 2.2257)	0.845	-0.7129(-3.5991 2.1733)	0.627
>= 56	0.4905 (-2.8329 3.8138)	0.771	0.2236(-3.6484 4.0955)	0.909
Sex				
Male	Ref		Ref	
Female	0.8240(-0.8705 2.5185)	0.339	0.9981(-0.8447 2.8408)	0.287
Marital status				
Married	Ref		Ref	
Single	-1.1094(-2.9242, 0.7054)	0.23	-0.9172(-3.1369, 1.3025)	0.416
divorced	-0.6261(-4.3450, 3.0929)	0.74	-0.3337(-4.2179, 3.5504)	0.866
widow/widower	-1.7094 (-6.8451, 3.4263)	0.512	-1.1009(-6.6310, 4.4291)	0.695
Level of education				
No formal education	Ref		Ref	
Primary education	-5.25 (-15.8647, 5.3646)	0.331	-4.7175 (-15.7712, 6.3362)	0.401
Junior High	0.3333 (-6.7431, 7.4098)	0.926	0.0862 (-7.4401, 7.6124)	0.982
SSS/Tec/Voc	1.75(-4.9122, 8.4122)	0.605	-0.0859 (-7.2131, 7.0414)	0.981
Tertiary- cert/Diploma /Post Diploma	1.8803 (-4.3503, 8.1108)	0.552	-0.2423 (-7.1891, 6.7045)	0.945
Tertiary - Graduate /Post Graduate	2.4461 (-3.9181, 8.81024)	0.449	0.1326(-6.8825, 7.1476)	0.97
Employment status				
Self employment	Ref		Ref	
Private sector	2.2733(-.4372 , 4.9840)	0.1	2.2441 (-1.1630, 5.6512)	0.195
Public sector	2.7696 (0.2868, 5.2523)	0.029	2.6849 (-0.4726, 5.8425)	0.095
Unemployment	-3.5161 (-12.3774, 5.3452)	0.435	-3.0187 (-12.4794, 6.4419)	0.53
Students/Apprentice	1.0839(-2.7364, 4.9041)	0.577	1.6889(-2.8652, 6.2431)	0.465
Zarit Burden Interview	-0.0588 (-0.1582, 0.0406)	0.245	-0.0283 (-0.3326, 0.27601)	0.855
Direct cost	0.0007 (-0.002, 0.0027)	0.513	0.0005(-0.0018, 0.0028)	0.685
Indirect cost	-0.0010 (-0.0029, 0.0009)	0.305	-0.0008 (-0.0028, 0.0013)	0.455
Intangle cost	-0.0582 (-0.1583, 0.0419)	0.253	-0.0243 (-0.3319, 0.2834)	0.876

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This Chapter entails the discussion of the results as presented in Chapter Four. The discussion of the various findings is based on the objectives and in relation to literature. Here the results of these findings are compared with the literature in an attempt to provide explanations to differences and similarities that are detected between them. The discussion started with the cost of caregiving of children with mental disabilities. This cost is categorized into total medical cost which comprises of direct medical and direct non-medical cost, indirect cost, intangible cost and ended with the assessment of the quality of life of the caregivers. The overall unit cost for caregiving for a child with mental disorders was found to be GHS 845.28 (USD 169.06) per month. Averagely, the direct medical cost of treatment for a child suffering from mental disorders was found to be GHS 402.97 (USD 80.59) which represented 48% of the total cost of treatment. The direct non-medical cost for caring for a child per month was aslso estimated at GHS 313.15 (USD 62.63) representing 37% of the total cost of the cost incurred by caregivers. The direct cost of treatment which comprises of the summation of direct medical cost and direct non-medical cost of treatment was estimated as GHS 716.12 (USD 143.22) which represented 85% of the total cost of treatment. The average indirect cost for caregiving per child was estimated at GHS 129.17 (USD 25.83) per month. This represented 15% of the total cost of the monthly caregiving for children with mental disorders.

The quality of life of caregivers was found to be low across all the domains. Sex, marital status, and education were found to significantly influence the quality of life of caregivers. Though both males and females have recorded a low quality of life means scores, males had a lower quality of life as compared to the females. For education level, apart from those without any form of education that was higher than those who had a primary school education, quality of life has increased as the educational level of caregivers increases. Those who were married were also found to have a better quality of life than those who were single. It was also found that indirect and intangible costs contributed greatly to the low quality of life of caregivers

5.2 Direct cost associated with caregiving

The estimated mean cost directly associated with caregiving for a child with mental disorders for one month was GHS 716.12 (USD 143.22). This formed 85% of the total cost incurred in caregiving over the period of one month. This cost is more than the direct estimated mean cost of caregiving by Opoku-Boateng et al., (2017) in Ghana for schizophrenia patients which was found to be USD30 which made up of 18% of the total cost per month. The differences could be attributed to the fact that, while the work of Opoku-Boateng et al., (2017) was on the caregivers of adults patients with schizophrenia, this part particular study was on the caregivers of children and adolescent and so the expenditure on children is likely to be more as compared to adults. Another study by Tajima-pozo *et al*., (2015) revealed that the direct cost of caregiving for patients suffering from schizophrenia in the United States was USD 32051 million per year which is likely to be higher than the direct cost of this study. This is because the study done in the United States was focused on the cost for the total population of patients for the whole years while this was focused on just one month. Furthermore, some diagnostic costs in Ghana are highly subsidized.

Gustavsson et al., (2011) reported that, the direct cost associated with the treatment of patients with brain and mental disorders in Europe constituted 37% of the entire medical cost for the year 2010. This cost estimate is also likely to be less than the 41% estimated by this particular study. A study in China revealed that out of the US $2586.21 per case per annum total costs, for the treatment of schizophrenic patients, direct cost alone was estimated at US$862.81 (33.4%). These findings though expressed in annum correlates with the finding that there is a high direct cost in caregiving for caring for people with mental disorders.

5.3 Indirect cost of caregiving

The total time spent by primary caregivers as estimated in monitory terms by this study was GHS 129.17 (USD 25.83) per child per month which represented 15% of the entire cost. This was achieved by valuing the days lost to productivity by employed workers, waiting time, traveling time, time lost by any other employed relative apart from the primary caregiver in providing care to the patient. Though this cost is high, it did not exceed the finding of a study done in Ghana by Opoku-Boateng et al., (2017) on schizophrenia patients that revealed an indirect cost of care for the patients per month at 82.5% of the total cost incurred in caregiving by caregivers.

This 15% indirect cost was less than the total indirect cost of productivity lost to caregivers which was reported to be 40% annually in Europe according to Gustavsson et al., (2011). The reason could be that while the study in Europe was done in adult and the indirect was also estimated per annum, this particular study done in Ghana focused on children and with the indirect cost expressed per month. In a study conducted in China to asses the economic burden on caregivers of schizophrenia patients by Zhai et al., (2013), the indirect cost for caregiving per annum accounted for 66.6% of the entire cost of care per patient which is higher than the finding of this study. The result could be that, the productivity loss due to caregiving, traveling time, and time loss due to waiting is very high on caregivers caring for adult suffering from mental disorders than children because, caregivers are likely to spend more time in the provision of the needs of adults as compared to children who are more likely to accept every condition they find themselves..

5.4 Intangible cost of caregiving

Beyond the cost and productivity loss due to absenteeism, waiting and travels, this study sought to assess the intangible cost that caregiving posed to the family members that are difficult to quantify. Caring for people with mental disorders places a lot of stress, anxiety, pains and depression on the family members (Press, 2016).

The result of the Zarit Burden Interview, which measures the burden on the caregivers revealed that 64.3% of the respondents reported a high burden. This result is higher than the 49% burden reported by Opoku-Boateng et al., (2017). This could be attributed to the fact that this research focused on caregivers of children with mental disorders while the patients in the study of Opoku-Boateng et al (2017) were adults with schizophrenia. Children with mental health conditions require more attention in carrying out their daily activities than adults. The result by sex also shows that there is a high burden among female caregivers as compared to male caregiving. This could be as a result of the fact that women spend more time with the patients in the role of caregivers than men.

Moreover, the proportion of women caregivers according to this study was higher (54.3 %) than men (45.7%) so definitely, women are more likely to experience higher burden in caregiving as compared to men. Also, the result of this study agrees with the finding of Knock et al., (2011) that caring for people suffering from mental disorders places huge emotional distress on the primary caregivers and family members where most caregivers report that they are restricted from participation in active activities from the society. It is therefore evident that caring for children with mental disabilities posses huge burden of family members and the burden is relatively high in females as compared to the male caregivers.

5.5 Quality of life of caregivers of children with mental disabilities.

This study found that, on a whole, caregivers of children suffering from mental disorders reported a low quality of life. This finding agrees with previous studies (Boyer et al., 2012). This study revealed that, across all the domains of QOL, both physical health and social health recorded the highest quality of life indicating that the caregivers were somehow having the energy to perform their daily activities and were also satisfied with their personal relationships. Environmental health has recorded the least mean score indicating that the caregivers do not have enough funds to meet the caring demands of their patients. It also indicates that caregivers were not satisfied with their living conditions. From this study, the overall quality of life of caregivers of children suffering from mental disorders supports the argument that policymakers need to place importance on mental health by making laws that could provide enabling environment and social support systems for patients and caregivers so as to reduce the burden of caregiving which will eventually improve the quality of life of caregivers.

This study revealed a high quality of life among female caregivers than males which was different from the outcome of Opoku-Boateng et al., (2017) whose finding reported a higher QOL in males than females. The burden was high in males leading to low QOL because they might not have the necessary skills in care provision as compared to females. Apart from those without any formal education which was higher than those with primary education, though statistically not significant, quality of life is also seen to increase as the educational level of caregivers increased. This confirms the study of Caqueo-Urízar et al., (2017). This means that the education sector could be used as a tool to orient people on handling cases of mental health which will reduce the burden and improve the quality of life of caregivers and patients.

The challenges of mental health care could also be resolved if policymakers focus on making comprehensive healthcare policies which will include rehabilitation and treatments of patients with mental disorders.

5.6 Economic burden vs quality of life

The study results showed that the economic burden of caring for children with mental disorders had an adverse relationship on most of the domains of quality of life. Caregivers with high economic cost had a low quality of life and vice versa. Apart from the environmental health domain, intangible cost though not statistically significant, had an adverse effect on all other quality of life domains, which was consistent with other studies that caregivers burden such as pains, anxiety, depression, and stress significantly affects the quality of life of caregivers (Boyer et al., 2012, Caqueo-Urízar et al., 2017). The sum of the indirect and direct cost was also seen having adverse effects on the quality of life across all the domains except in the psychological domain. Apart from the psychological domain, the direct medical cost was seen to have adverse effects on the quality of life across all the domains and this effect is statistically significant in the environmental health domain.

Based on the findings, it was evident that indirect and intangible costs mostly affected the increases in the burden of care and affected the quality of life of caregivers adversely. But in most studies, the focus was placed on the financial aspect without giving much attention to emotional issues such as depression, anxiety, stress, and pains. Form the linear regression results in table 8, this study concludes that emotional aspects contribute significantly to the quality of life of caregivers of children with mental disorders.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

This section presents the conclusion, contribution to knowledge, recommendations and the limitations to the study.

6.2 Conclusion

This study aims at investigating the economic burden and the quality of life of caregivers of children with mental disorders attending psychiatric hospitals in Ghana. The findings from this study show that the economic cost of care placed on the family due to the disease is high. The overall unit cost for caregiving for a child with mental disorders was found to be GHS 845.28 (USD 169.06) per month. Averagely, the direct medical cost of treatment for a child suffering from mental disorders was found to be GHS 402.97 (USD 80.59) which represented 48% of the total cost of treatment. The direct non-medical cost for caring for a child per month was also estimated at GHS 313.15 (USD 62.63) which represented 37% of the total cost of the cost incurred by caregivers. The direct cost of treatment which comprised of the summation of direct medical cost and direct non-medical cost of treatment was estimated as GHS 716.12 (USD 143.22) which represented 85% of the total cost of treatment. The average indirect cost for caregiving per child was estimated at GHS 129.17 (USD 25.83) per month. This represented 15% of the total cost of the monthly caregiving for children with mental disorders. The total estimated cost for the entire sample was GHS 177509.55 (USD 35501.91).

The results of the Zarit Burden test revealed that 35.7% of the caregivers reported low burden while 64.3% reported high burden. A high burden was found among female caregivers than in males caregivers.The this suggest that the non-quantifiable burden and emotional distress such as anxiety, stress, pain, etc. that are imposed on caregivers as a result of caring for children with mental disorders in Ghana are enormous. The gravity of the burden affects the quality of life. This has led to more of the caregivers reporting a low quality of life. Indirect and intangible cost were found to have an adverse effect on the quality of life of the caregiver. As the level of education of caregivers increase, they were found to have a better quality of life. The caregivers who were married had a better quality of life than those who were not married.

6.3 Contribution to knowledge

The study makes some contribution to knowledge in the area of provision of quality healthcare for children with mental disorders in Ghana. It also pointed out that much of the productive time of caregivers which could have been used profitably to positively affect the economy is spent on caregiving, and this is not healthy to the nation as a whole.

6.4 Recommendations

The following are the recommendations based on the results of the study.

1. More counseling services and educational campaign against the stigma of mental health should be done in Ghana by the Ghana health service and religious groups. This will help to relieve the patients and the caregivers form the emotional distress and psychological instability they go through as a result of the ailment.
2. Mental health should be made totally free by the Government so that the government will bear the cost since the time spent by caregivers is huge. Their absence from work and other beneficial activities will have an effect on the economy in the long run.
3. Deinstitutionalization of mental healthcare services should be made effective in Ghana by the Government so that patients and caregivers seeking treatment would not travel far to access health care service.

6.5 Limitations to the study

1. Some of the information being demanded in the questionnaire were considered sensitive by the caregivers and this made it difficult to release such information.
2. Most of the caregivers had no written records of the expenses and activities of caregiving for children with mental disorders within the previous months and it made recall of relevant information very difficult.
3. Some caregivers had the perception their involvement in the study would enable them secure funding which would alleviate their financial burden while caring for children with mental disorders.

6.6 Future Research

1. A future research reseach should consider coping behaviours of caregivers of children with mental disorders in the society.
2. A research targeted at the stakeholders and intitutions responsible for the mental health sector should be conducted to ascertain their level of preparedness and ways of improving the sector especially in caring for children with mental disorders.

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APPENDECES

Appendix 1: Linear regression of quality of life domains aagainst cost

Cost per Domain	Unadjusted		Adjusted	
	Mean Difference (95% CI)	P-Value	Mean Difference (95% CI)	P-Value
Psychological vs				
Direct (GHS)	0.0004(-0.0003, 0.0010)	0.301	0.0002(-0.0008, 0.0012)	0.697
Indirect (GHS)	0.0013 (-0.0025, 0.005)	0.503	0.0012(-0.0030, 0.0054)	0.585
Direct + Indirect (GHS)	0.0004(-0.0003, 0.001)	0.274	0.0001(-0.0006, 0.0008)	0.766
Intangible Cost	-0.0260 (-0.0591, 0.0071)	0.124	-0.0278(-0.0613, 0.0057)	0.104
Physical vs				
Direct (GHS)	0.0002 (-0.0006, 0.0009)	0.651	0.0006(-0.0005, 0.0012)	0.289
Indirect (GHS)	-0.0017(-0.0056, 0.0023)	0.404	-0.0013(-0.0055, 0.003)	0.555
Direct + Indirect (GHS)	-0.0001(-0.0006, 0.0008)	0.772	-0.0003(-0.001, 0.003)	0.396
Intangible Cost	-0.0111 (-0.0455, 0.0216)	0.483	-0.010(-0.0447, 0.0241)	0.596
Social vs				
Direct (GHS)	0.0001(-0.0006, 0.0008)	0.807	0.0002(-0.0008, 0.0012)	0.689
Indirect (GHS)	-0.0011(-0.0052, 0.0029)	0.718	-0.0009(-0.0008, 0.0153)	0.689
Direct + Indirect (GHS)	-0.0001(-0.0006, 0.0007)	0.574	- 0.0001(-0.0008, 0.0006)	0.835
Intangible Cost	-0.0208 (-0.0553, 0.0137)	0.236	-0.0197(-0.0547, 0.0153)	0.269
Environment vs				
Direct (GHS)	0.0001(-0.0005, 0.0007)	0.799	0.0010(-0.0001, 0.0019)	<0.028
Indirect (GHS)	-0.0009(-0.0025, -0.0044)	0.594	0.0024(-0.0013, 0.0062)	0.193
Direct + Indirect (GHS)	-0.0001 (-0.0005, 0.0007)	0.740	-0.0009(-0.0014, 0.0003)	< 0.004
Intangible Cost	0.0006 (-0.0292, 0.0303)	0.971	0.0004(-0.0292, 0.0300)	0.978

2 Apenddix 2: Questionnaire

Dear Respondent,

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

Name of Hospital ……………………….

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

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

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

Interviewer Name:………………………………………..

Section A	**Socio-demographic Information**	Response
1.	Sex 1. Male |___| 2. Female |___|	
2.	What is your age in years (i.e. age at last birthday)?	…………………………………… … years
3.	Marital status 1. Married |___| 2. Single |___| 3. Divorced |___| 4. Widow/widower |___|	
4.	Place of residence 1. Rural area |___| 2. Urban |___|	

<table>
<tr><td>5.</td><td colspan="2">How do you get to the health facility?
1. Walking |___| 2. Bicycle |___| 3. Vehicle |___|
4. Others (specify) …………………………</td></tr>
<tr><td>6.</td><td>How long does it take you to travel to the facility using the above means of transport you mentioned?</td><td>……………… hours</td></tr>
<tr><td>7.</td><td colspan="2">Religion
1. Christian |___| 2. Muslim |___| 3. Traditionalist |___|
4. Others (specify) … …………………………</td></tr>
<tr><td>8.</td><td>What is your current level of education?
1. No education
2. Primary level
3. Junior level
4. Secondary/Technical / Voc level
5. Tertiary - Cer /Diploma/ Post Diploma
6. Tertiary - Graduate / Post Graduate
7. Others (Specify)
………………………………………</td><td>|___|</td></tr>
<tr><td>9.</td><td colspan="2">Employment status
1. Self-employed |___| 2. Private sector |___| 3. Public sector |___|
4. Unemployed |___| 5. Student/ apprentice |___|</td></tr>
</table>

<table>
<tr><td></td><td colspan="2"></td></tr>
<tr><td>10.</td><td colspan="2">If employed, what is your occupation, that is, what kind of work do you mainly do?
1. Dressmaker |___| 2. Hairdresser |___| 3. Teacher |___| 4. Banker |___|
5. Lawyer |___| 6.Others (Specify)……………………………………………..</td></tr>
<tr><td>Section B</td><td>Impact of Patient's illness on household members.</td><td></td></tr>
<tr><td>11.</td><td>How old is the care recipient?</td><td>………………….. age in years</td></tr>
<tr><td>12.</td><td colspan="2">What is the Sex of care recipient?
1. Male |___| 2. Female |___|</td></tr>
<tr><td>13.</td><td>Which of these cases category is your patient?
1. OPD
2. Admission / inpatient</td><td>|___|</td></tr>
<tr><td>14.</td><td>If the patient is on admission, for how long now?</td><td>……………………</td></tr>
<tr><td>15.</td><td>Are you the primary caregiver?
1. Yes
2. No</td><td>|___|</td></tr>
<tr><td>16.</td><td>Are you related to this ill patient?
1. Yes
2. No</td><td>|___|</td></tr>
<tr><td>17.</td><td colspan="2">What is your relationship with the patient?
1. Child |___| 2. Sibling |___| 3. Grandchild |___| 4. In-law |___| 5.
Others (Specify) …………………….</td></tr>
</table>

18.	Which of the following best describe your care-giving task? 1. Long distance care provider 2. Co- resident care provider 3. Nearby care provider	|___|
19.	Do you assist your care recipient to perform any of the following task – taking a bath, using the toilet, walking inside the house, dressing up, sitting up etc. on a regular basis? Yes 2. No	|___|
20.	Do you assist your care recipient on a regular basis with any of the following – transportation, meal preparation, managing finances, shopping, housework, medication management, or arranging for outside services to help him or her? 1. Yes 2. No	|___|
21.	How long have you been a caregiver to this person?	………………………… years
22.	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*	|___|
23.	Who is this person to the patient? Specify_________________ _	
24.	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
25.	How many hours in a day does this person spend with the patient? **Note if more than one family member , find accumulated hours spent*	…………………… hours
Section C	**Burden of care on primary caregiver**	
26.	Are you paid for the work you do in giving care for the patient?? 1. Yes 2. No	|___|
27.	If yes How much are you paid?	

		GHS……………………………… …
28.	How many days in a week do you spend to care for the patient?	……………………………….. days
29.	How many hours in a day do you spend with the patient?	……………………… Hours
30.	Have you stopped work/school/apprenticeship because of caregiving? 1. Yes 2. No	|___|
31.	Have you had to cut down normal working/schooling activities because of giving care to the patient? 1. Yes 2. No	|___|
32.	How many hours did you have to reduce your normal activities in a day?	……………………….. hours
33.	Have you employed another person to take care of your usual business in your absence? 1. Yes	|___|

	2. No		
34.	If the answer to 33 is Yes, How much do you pay the person?	GHS________	
35.	What is/are your average monthly income and source (s)?	**Source**	**Amount (GHS)**
		Famer	GHS________
		Salary	GHS________
		Pension	GHS________
		Insurance	GHS________
		Relatives	GHS________
		Remittances/donation	GHS________
		Others Specify	GHS________
		TOTAL	GHS________
36.	Has there been decrease in income because of caregiving? 1. Yes 2. No	|___|	
37.	If the answer in 36 is yes, By how much?	GHS…………………………	
38.	What is the source of financing the patient?	**Source**	**Amount (GHS)**
		Salary	GHS________

		Pension	GHS________
		Health Insurance	GHS________
		Relatives	GHS________
		Remittances/ donation	GHS________
		Borrowed money	GHS________
		Others(Specify)	GHS________
		TOTAL	GHS________
Section D	**Direct cost** **Medical cost**		
39.	How much did you spend on the following through seeking treatment for your last visit?	**Category**	Amount (GHS)
		Consultation, admission,	GHS________
		discharge fee	GHS________
		Drug	GHS________
		Laboratory investigation Diagnosis test	GHS________

		Others (Specify)	GHS________
		Total	GHS________
	Non-medical cost	***In a typical month, how much do you spend on that.*** ***An average will be fine.***	
40.	**category**		**Amount (GHS)**
	a. Your care recipients' household supplies (food, water, household goods, or clothing)		GHS________
	b. Your care recipient's residential care (housing payments, rent, or utilities)		GHS________
	c. Travel / transportation for / with your care recipient?		GHS________
	d. Other (Please specify)………………..		GHS________
		Total	GHS________
Section E	**Indirect cost**	**Category**	**Number of hours**
41.	*Do you spend time helping your care recipient in any of the following within the week?*		

	a. Days lost to work due to caregiving (*apart from treatment related time lost)*		
	b. Days lost to school due to caregiving (*apart from treatment related time lost*		
	c.. Time spent on household activities and other errands		
	d. Time spent on travelling / transportation		
	e. Productivity loss due to waiting time		
	f. Other time spent with care recipient (leisure etc.)		
	TOTAL		
42.	How do you pay for expenses if you are financially drained? 1. Cutting down on other expenses 2. Using savings 3. Borrowing 4. Selling assets 5. Asking for donations from friends and relatives 6. Others (specify)……………..	|___|	

SECTION F. ZARIT BURDEN INTERVIEW

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

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

Section G: **Quality of life of primary caregiver (WHO EUROHIS - QOL INDEX)**

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

		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
1.	How would you rate your quality of life?	1	2	3	4	5
2.	How satisfied are you with your health?	1	2	3	4	5
3.	Do you have enough energy for everyday life?	1	2	3	4	5
4.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
5.	How satisfied are you with yourself?	1	2	3	4	5
6.	How satisfied are you with your personal relationships?	1	2	3	4	5

7.	Have you enough money to meet your needs?	1	2	3	4	5
8.	How satisfied are you with the conditions of your living place?	1	2	3	4	5