SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

ECONOMIC BURDEN OF CAREGIVING FOR SCHIZOPHRENIC PATIENTS AT OUTPATIENT DEPARTMENT OF PANTANG HOSPITAL

BY

SYBIL DECKER

10507015

THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF MASTER OF PUBLIC HEALTH (MPH) DEGREE

JULY 2015

DECLARATION

I hereby declare that with the exception of articles and books which I have quoted, cited and duly acknowledged in references, all other information produced from this work is the result of my original research. No part of it has been presented for another degree in this university or elsewhere.

…….. ……

SYBIL DECKER **DATE**

(STUDENT)

…… ……

DR. JUSTICE NONVIGNON **DATE**

(SUPERVISOR)

DEDICATION

This work is dedicated to my daughter, Michaela.

ACKNOWLEDGEMENT

My first gratitude goes to the Almighty God for His continual blessings and favour upon my life. My Lord I am forever grateful to you for this opportunity and the strength to complete this work.

My sincere gratitude goes to my supervisors Dr. Nonvignon, Dr. Aryeetey and Professor Moses Aikins who challenged me to the completion and success of this work. Thank you for your insight and guidance. To the staff of the Department of Health Policy, Planning and Management, I say thank you for your assistance.

I am also grateful to my entire family, whose love, encouragement and support in numerous ways led to the completion of this work. The Decker's family thank you for believing in me and being there for me always. I couldn't have made it without you guys. Thank you for your prayers and support. Lots of love and God richly bless you.

Further, I say thank you to everyone whose name was not mentioned but who was instrumental in the completion of this work. And to my colleagues, thank you for your love and support and company. It's a privilege to be part of the class.

This dissertation received financial support from the Christian Health Association of Ghana (CHAG) through the CHAG/DFID Mental Health Dissertation Grant and is duly acknowledged.

ABSTRACT

Background

Schizophrenia is a challenging disorder that makes it difficult for one to distinguish between what is real and unreal, think clearly, manage emotions, relate to others, and function normally. This study aims at examining the economic burden of care giving for schizophrenic patients at the Pantang hospital to help provide credible and essential information that can assist in policy making. The study has its objectives as to estimate the direct cost of caregiving, estimate the indirect cost of caregiving and to determine the intangible cost of caregiving.

Methods

The study adopted the cross-sectional survey and the cost analytic approach to generalize the research results and draw conclusions. The population for this study comprised of the caregivers of patients diagnosed with schizophrenia at the Pantang hospital. Thus, a sample size of 110 respondents were selected for this study using the purposive sampling method. A questionnaire and the Zarit Burden Interview (ZBI) were the tools that were employed by this study. Data was analysed using Microsoft Excel and SPSS. Direct cost was estimated from treatment related cost and non-treatment related cost such as cost of drug and travel cost respectively for the last review. Indirect cost was estimated by valuing productivity losses to caregivers for period of one month. To describe the intangible cost the short form of ZBI which has twelve negative framed questions each with a five point likert response from 0(never) to 4(nearly always) was adopted.

Results

The total cost for caregiving of schizophrenic patients estimated was GHS20, 874.80(USD 4,744.28), with direct cost and indirect cost constituting 86% and 14% respectively. Total direct treatment related cost was estimated GHS11,255.00 (USD2557.9517) and non-treatment related cost was GHS6,639.80 (USD1509.05) whereas estimated indirect cost for the employed was GHS2980.00(USD 677.28) and that of the student/apprentice and unemployed were not valued because they have no market price. Intangible cost was high as for caregivers as they represented 55%.

Conclusion

Cost of caregiving for schizophrenic patients per month is huge and this cannot be overlooked. Even though this study is limited to a single facility and hence cannot be generalized to the entire population, it provides useful information for similar populations (i.e. caregivers of persons with mental conditions). Therefore there is a need for further studies in economic burden for caregiver across the country to help make a better generalization of results.

TABLE OF CONTENTS

Content **Page**

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CMHC	Community Mental Health Centres
COI	Cost of illness
CPN	Community Psychiatry Nurses
GHS	Ghana Cedis
ICD-10	International classification of disease, 10th edition
OPD	Outpatient department
SPSS	Statistical Package for Social Sciences
USD	United State Dollar
WHO	World Health Organisation
ZBI	Zarit Burden Interview

DEFINITION OF TERMS

Anhedonia	Someone who lacks interest in activities
Burden	The presence of problems, difficulties or adverse effects which affect the lives of psychiatric patients' caregivers.
Caregiver	Someone who has been living with the patient, and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.
Delusion	Perceived belief that is false and cannot change by any form.
Direct cost	The values of all resources expended directly by caregivers in seeking care.
Hallucination	It is a major sign exhibited by a mental patient and is characterized by misinterpretation of objects seen.
Household	A group of people living in the same house and eating from the same pot.
Indirect cost	The cost of time spent out of normal work due to morbidity and mortality.

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

Schizophrenia is a severe psychotic disorder characterized by significant disturbances in thinking, perception, emotions and behaviour (Zhai et al, 2013). It is associated with a significant and long-lasting health, social, and financial burden due to expenditures for hospitalization, treatment and rehabilitation, reduced and lost productivity (Peng et al, 2011).A caregiver can be defined as a family member who has been living with a patient, and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year (Department of Health and Human Services DHHS, 2005).

According to Thara and Padmavati (2004), family caregivers play a major role in providing caregiving assistance to ill persons and their families. They usually sacrifice their physical as well as emotional needs to provide the best possible care for the family member who is ill (Basheer et al, 2005). The world Health Organization has estimated that about 40-90% of patients with schizophrenia live with their families (WHO 2008). Thus, the family is said to be the major support system in providing care for the mentally ill in the community. Although many families show a strong resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored. The effect of stressors on family members caring for an ill person in the family has been referred to as caregiver's burden. In an effort to provide the best possible care for a family member, caregivers often sacrifice their own physical and emotional needs, and the emotional and

physical experiences involved with providing care can strain even the most capable person (Basheer et al 2005). Almost one-third of caregivers balance employment and caregiving responsibilities, and of this group, two-thirds report conflicts in roles that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence.

In developing countries, the extended family provides care for these patients in the face of poor mental health facilities (WHO 2008). However, recent changes in family structures and rapid economic decline in such countries are threatening the support available to patients with chronic mental illness such as schizophrenia (Patel et al, 2006). The high cost of schizophrenia imposes a disease burden on themselves, health care providers, their families and the wider society .Burden of psychiatry is said to be the problems, difficulties or adverse effects which affect the lives of the caregivers of psychiatric patients (Thara et al, 1998). Schizophrenia is associated with a significant and long-lasting health, social, and financial burden due to expenditures for hospitalization, treatment and rehabilitation, reduced and lost productivity (Peng et al, 2011). Thus, caregivers of schizophrenic patients are confronted with cost which can be classified as direct, indirect and intangible cost (O'Malley et al, 2011). The costs do not act as an economic burden on the caregiver**.** Rather these costs in total can be regarded as the burden of caregiving for schizophrenics. This study aims at examining the economic burden of caregiving for schizophrenic patients of Pantang hospital.

1.2 Statement of problem

Schizophrenia accounts for 32% of all mental cases reporting to the three psychiatric hospital in Ghana (Roberts, Asare, Mogan, Adjase, & Osei, 2013). Most families in recent times have taken over the role of taking care of mentally ill patients and this is playing a significant role in development and evaluation of health programs and policies (Clark & Drake, 1994). In developing countries, most caregivers (informal) commit most of their time to this role without receiving any economic retribution (Dwyer et al, 1994). Studies have shown that the cost of caregiving is significant, however, there are no reliable estimates of the costs associated with such care (Awad &Voruganti, 2008). Also, the economic burden imposed on families can contribute to poverty (Knapp et al, 2004). There is paucity of studies on the economic burden of care giving for schizophrenic patients in Ghana. This study therefore seek to contribute to existing literature or bridge the knowledge gap on the burden of care imposed on caregivers of persons with schizophrenia. Consequently, this study aims at examining the economic burden of caregiving for schizophrenic patients at the Pantang hospital to help provide credible and essential information that can assist in policy making.

1.3 Study objectives

1.3.1 General objective

The general objective of the study was to determine the economic burden of caregiving for schizophrenic patients of Pantang hospital.

1.3.2 Specific objectives

The specific objectives were to:

1. Estimate the direct cost of caregiving for schizophrenic patients.
2. Estimate the indirect cost of caregiving for schizophrenic patients.
3. Determine the intangible cost of caregiving for schizophrenic patients.

1.3.3 Research questions

The research questions were:

i. What is the direct cost associated with caregiving for schizophrenic patients of Pantang hospital?

ii. What is the indirect cost associated with caregiving for schizophrenic patients of Pantang hospital?

iii. What is the intangible cost associated with caregiving for schizophrenic patients of Pantang hospital?

1.4 Conceptual Framework

The cost incurred by caregivers of schizophrenic patients seeking outpatient department (OPD) based services can be classified into three broad categories as shown in Figure 1. These are the direct cost, indirect cost and intangible cost. The direct cost refers to the actual expenditure incurred by patients in respect of seeking OPD treatments. The direct cost can be categorized into treatment related cost and non- treatment related cost. Treatment related cost describes the cost of seeking actual treatment such as consultation, medication, diagnostics and other therapies. The non-treatment related cost refers to other costs that contribute to seeking care. These include food/ drinks and transportation. Other cost refers to the cost of accommodation, food and clothing for the caregiver during admission of patient. Food or drinks which are also known as feeding cost refer to the payment for food and drinks by patients and caregivers from food sellers while seeking treatment. Transportation cost refers to the to and fro cost of travels or bus fares of patients and caregivers from home to Pantang hospital. It excludes cost of transportation to hospital to seek care for other sicknesses.

The loss of productivity is an indirect costs incurred in relation to the loss of caregiver's working time or absence from work as a result of the disease condition. It also includes the number of days the caregiver spends with the schizophrenic patient. Loss of earnings due to non-productivity of the caregiver also constitutes one of the indirect costs inherent in accessing mental care. Also waiting and travelling time refers to the time used by the caregiver and the patient in waiting for treatment and travelling to and fro the facility in seeking treatment.

The intangible costs describe costs which cannot be directly expressed in monetary terms and it includes, anger, stress, relationship, strain, social life, privacy, control, health and uncertainness borne by patients and caregivers as a result of the disease condition. Schizophrenics and caregivers expend direct, indirect and intangible cost in accessing treatment at the OPD.

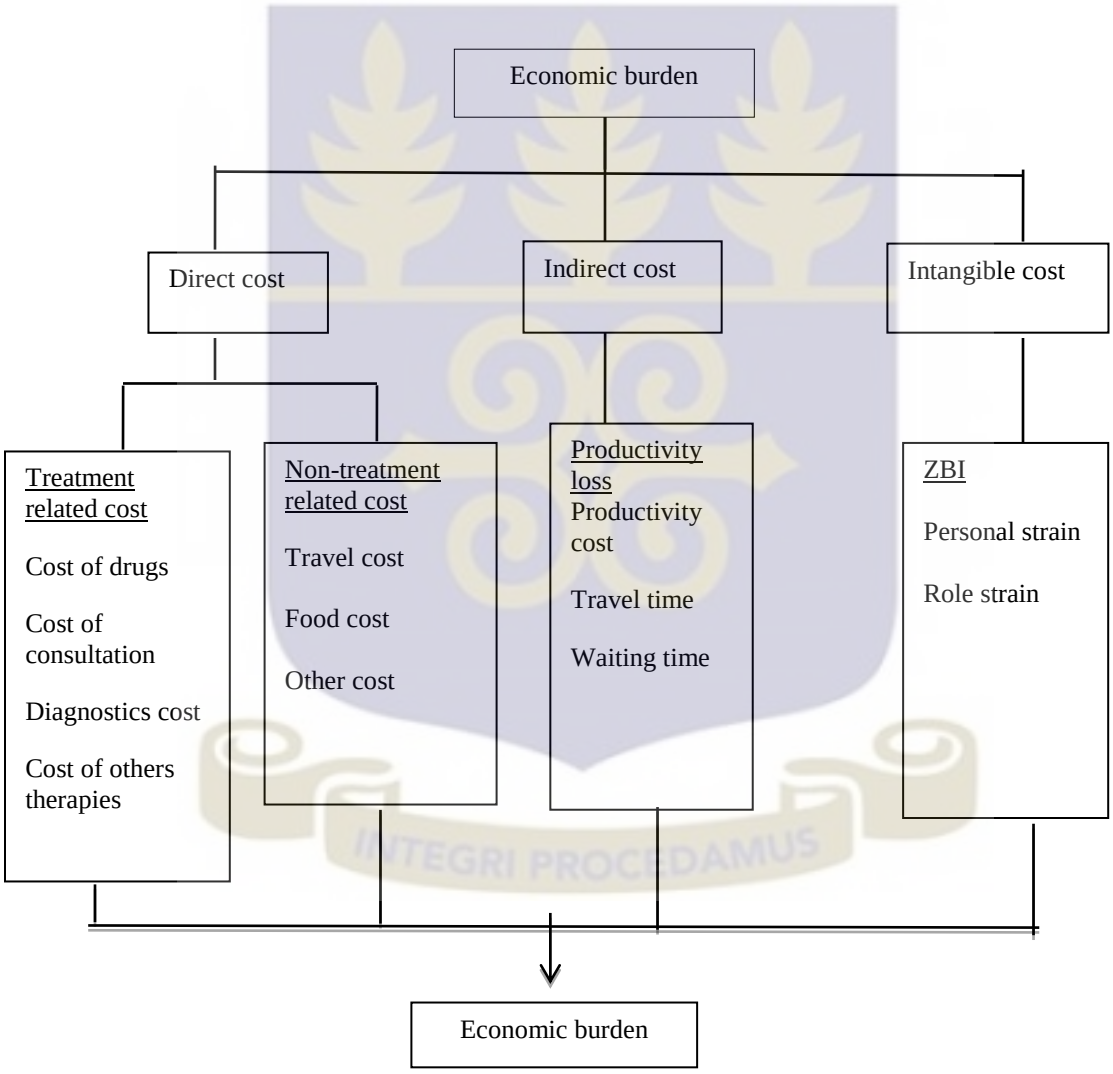

Figure 1: Conceptual framework for the economic burden of caregiving for schizophrenic patient

1.5 Significance of the study

With schizophrenia as the major cause of mental illness, there is a need to estimate and describe the burden of caregiving. A way of sensitizing policy makers and stakeholders on the enormity of the economic burden of caring for schizophrenics and the need to allocate more attention and resources to it is to estimate the economic burden on caregivers who virtually live a part of the patient's life. This study is aimed at creating awareness on the economic burden of caring for schizophrenic patients. Burden of mental illness on caregivers will be more appreciated when monetary value is estimated and known (Sainsbury Centre for Mental Health, 2003). Furthermore the findings of this study will contribute to knowledge and assist policy makers to design appropriate health policies to help reduce the economic burden of caring for schizophrenic patients.

Further, knowledge of cost in caring for the schizophrenics at the outpatients department of Pantang hospital can be used for strategic planning and budgeting for programs such as community psychiatric care that will ensure reduction of the cost borne by caregivers. Furthermore it can be used to allocate resources geared towards education of the public especially caregivers of schizophrenics with the aim of decreasing the incidence of the disease condition. Also it can be a source of motivation to the society at large to make informed decisions that will enhance and promote good mental health once they know the cost borne in caregiving.

Finally, the study will serve as a reference for researchers and also students who would like to further research on this topic especially in Ghana.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of literature related to the objectives this study. It comprises the concept of Schizophrenia and caregiving burden, types of schizophrenia, signs and symptoms of schizophrenia, costs associated with Schizophrenia and caregiving for Schizophrenics.

2.2 Concept of Schizophrenia

Schizophrenia is a challenging disorder that makes it difficult to distinguish between what is real and unreal, think clearly, manage emotions, relate to others, and function normally (Smith & Segal, 2014). Schizophrenia, as explained by Zhai et al (2013), is a chronic, devastating mental disorder characterized by distortions of thinking and perception. Schizophrenia is a brain disorder that affects the way a person acts, thinks and sees the world. People with schizophrenia have an altered perception of reality, often a significant loss of contact with reality. They may see or hear things that don't exist, speak in strange or confusing ways, believe that others are trying to harm them, or feel like they're being constantly watched. With such a blurred line between the real and the imaginary, schizophrenia makes it difficult to negotiate the activities of daily life (Smith & Segal, 2014). Consequently, Knapp et al (2004) described Schizophrenia as a chronic disease associated with a significant and long-lasting health, social, and financial burden, not only for patients but also for families, other caregivers and the wider society. They noted that Schizophrenia can be a devastating disease with wide-ranging and long-lasting

impacts on people with the illness, their family and the society as a whole. According to Jablensky (1986), approximately 7.0 to 9.0 per 1000 population worldwide suffers from schizophrenia, the onset of which is typically late adolescence and early adulthood. It affects both males and females equally. The cause of the disease condition is unknown but it is believed that there are several factors that contribute to the occurrence of the disease. These factors include genetic and environmental factors which interact together to cause the disease condition. According to Martyn-Yellowe (1992), Schizophrenia is one of the most devastating psychiatric disorders, which leads to long-term and progressive disability in many individuals. These disabilities bring onerous burden on the patients as well as their caregivers.

According to Thara and Padmavati (2004), a caregiver has been defined as a family member who has been living with the patient, and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.

Burden may be defined as the presence of problems, difficulties or adverse effects which affect the lives of psychiatric patients' caregivers. The treatment for schizophrenia is still a major clinical challenge to psychiatrists. There is no cure for schizophrenic patients, however, there are medications to relieve patients of their major and bizarre symptoms.

The characterized psychotic symptoms associated with schizophrenia include hallucination and delusion, inappropriate affect, loss of association and this has made the treatment more complex as Zhai et al (2013) notes. As noted by Keng (2005), a specialist healthcare intervention and targeted treatment is required because of its devastating symptoms. Poor personal and social functioning often associated with the illness

generates a need for support in the activities of daily living. There is considerable agreement that caregivers are extensively burdened by the demanding and often unsupported caregiving role that they saw no end to (Kreisman & Joy, 1974).

2.3 Types of schizophrenia

Paranoid Schizophrenia is marked by suspiciousness, projection, delusions which are tied with hallucinations. Sometimes they exhibit aggressiveness and utterances may be disconnected and fragmented. Paranoid schizophrenic does not demonstrate incoherence, marked loosening of association, catatonic behaviour, grossly disorganized behaviour and flat or inappropriate affect

Catatonic Schizophrenia appears in two major forms namely catatonic stupor and the excitement stage. The stupor stage is characterized by depression, immobility, mutism and negativism whereas the excitement stage is characterized by unorganized, excessive, impulsive and sometimes destructive behaviour.

Disorganized Schizophrenia also known as hebephrenic schizophrenia has an insidious onset that usually begins in adolescence. Client has a shallow and inappropriate emotion, withdraws from social links, smiles and giggles in a silly manner. Also client has fragmented speech which is sometimes incoherent. Hallucinations and delusion may be bizarre; if present they are transient and not well-organized.

Undifferentiated schizophrenia refers to less severe psychotic symptoms that cannot be classified in the types described above or to symptoms that meet the criteria for more than one of the other schizophrenia categories

Residual type of schizophrenia is diagnosed when one has had at least one episode of schizophrenia but does not display acute psychotic symptoms. They exhibit social withdrawal, blunted affect, eccentric behaviour, disordered thinking and loosening of associations.

2.4 Signs and symptoms of schizophrenia

In the management of schizophrenia, it is essential to first identify the signs and symptoms. Subsequently, help could be sought immediately and the treatment must be stuck to. Schizophrenia in some people appears suddenly and without warning. But for most, it comes on slowly, with subtle warning signs and a gradual decline in functioning long before the first severe episode.

In this early phase, people with schizophrenia often seem eccentric, unmotivated, emotionless, and reclusive. They isolate themselves, start neglecting their appearance, say peculiar things, and show a general indifference to life. They may abandon hobbies and activities, and their performance at work or school deteriorates.

According to Smith & Segal, (2014) some of the early signs of schizophrenia include; social withdrawal, hostility or suspiciousness, deterioration of personal hygiene, flat affect, expressionless gaze, inability to cry or express joy, inappropriate laughter or crying, depression, oversleeping or insomnia, odd or irrational statements, forgetful; unable to concentrate, extreme reaction to criticism, strange use of words or way of speaking among others.

While these warning signs can result from a number of problems—not just schizophrenia—they are cause for concern. When out-of-the-ordinary behavior is causing problems in your life or the life of a loved one, seek medical advice. If schizophrenia or another mental problem is the cause, treatment will help.

Also, delusion is among the essential signs shown by the condition. Delusion is a firmly-held idea that a person has despite clear and obvious evidence that it is not true. Delusions are extremely common in schizophrenia, occurring in more than 90% of those who have the disorder. Often, these delusions involve illogical or bizarre ideas or fantasies. Common schizophrenic delusions include: erotomanic, grandiose, jealous, persecutory, somatic and unspecified. High levels of stress are believed to trigger schizophrenia by increasing the body's production of the hormone cortisol (Smith & Segal, 2014).

2.5 Concept of caregiving for schizophrenic patients

World Health Organization estimated that about 40 - 90% of patients with schizophrenia live with their families (WHO 2008). In developing countries, the extended family provides care for these patients in the face of poor mental health facilities. On the other hand, recent changes in family structures and rapid economic decline in such countries are threatening the support available to patients with chronic mental illness (Patel et al, 2006). According to Yusuf et al (2009), there are a lot of burdens on the relatives of patients with schizophrenia. Such burdens include financial, stigma and negative patient behaviour being more prominent. Keng (2005) notes that people with schizophrenia may

find it difficult to secure paid employment or to hold on to jobs when they get them. This situation poses financial difficulties. As a result, many schizophrenia sufferers face impoverished lives and lifestyles. There is also be large burden on the families and care givers since they will have to cater for the patient as well as pay some of the direct care services. Similarly, the caregivers' own employment chances and quality of life may be compromised.

2.6 Caregiving burden for Schizophrenics

The issue of caregiving for patients with mental disorders is a great concern thus, numerous studies (Cornwall &Scott, 1995; Horowitz & Reinhard, 1995). With the chronic stress associated with the task of caring, it is common for families to have emotional responses such as anxiety, fear, guilt, stigma, frustration, anger, and sadness to say the least (Caqueo-Urízar, 2011). Frequently, burden of care is more defined by its impacts and consequences on caregivers Loukissa (1995). According to Bevans, & Sternberg (2012), in addition to the emotional, psychological, physical and economic impact, the concept of burden of care involves subtle, but distressing notions such as shame, embarrassment, feelings of guilt and self-blame. According to Bevans, & Sternberg (2012), some caregivers have multiple caregiving responsibilities, and when they are overburdened show severe emotional distress, significant fatigue, sleep impairment and difficulty maintaining focus. Caregivers could be professional or informal caregivers. Professional caregivers include physicians and nurses while informal caregivers are normally family members or friends (NAC, 2009). Biegel and Milligen (1992) report the issue about behaviours of the patients and their management often

creates ongoing tensions between the patients and their families. Caregivers often have to tolerate abusive or assaultive behaviours, mood swings, and unpredictability, socially offensive or embarrassing situations. Negative symptoms of a motivation, apathy or anhedonia, often leave the caregivers in despair. Lefley (1996), a researcher as well as a family member adds another aspect to the issue. She pointed out that: "Perhaps, the most devastating stressor for families, however, is learning how to cope with the patient's own anguish over an impoverished life". The absence of cure and how chronic it is makes it the major mental health problem facing contemporary society (Lefley 1996).

One- third of caregivers balance employment and caregiving responsibilities, and of this group, two-thirds report conflicts in roles that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence (Basheer et al 2005).

In a study by Panayiotopoulos et al. (2013) involving caregivers either living in rural or urban areas of the district of Nicosia, the capital of the Republic of Cyprus who were attending regular meetings with their allocated Community Psychiatric Nurses (CPN) in Community Mental Health Centres (CMHC), concluded that families under great stress would give up and reject the mentally ill individuals who would become outcasts socially. Consequently, the study concluded that the health systems need to aim to the development of psychosocial provisions for both family caregivers and patients as to decrease the family burden rates and increase the possibility of smooth transition to the society. The issue of families acting as caregivers lead to circumstances where families are confronted with multifaceted problems such as fear and anxiety in relation to the patient's symptoms and the cost of treatment at home (Hasui et al, 2002).

A study by Adelman, et al (2014) revealed that risk factors for caregiver burden include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver. Also, study conducted by Marsh et al., 1996 (as cited in Van Wijngaarden, Schene & Koeter, 2003), reveled instances where a family member said "that this terrible disease stigmatises everything". Another study with a Latin American sample Amitsis (2012) evidenced that relatives of patients with schizophrenia showed high levels of burden as a result of their care task. Also, burden of family caregivers leads to negative consequences not only for themselves, but also for patients, other family members, and health care system (Sapouna, et al, 2006). The WHO recent report on the impact of economic crisis on mental health is Matsaganis' (2011) claim that the current financial crisis and the measures to counter it are affecting the welfare state profoundly, and in various aspects (McDonell et al, 2003). As Igberase et al., 2010 (as cited in Steudte, Stalder & Dettenborn, 2011) have clearly shown that caregivers of patients with schizophrenia experience immense burden. They also suggest that Public health education as well as targeted interventions in the area of employment, financial and other support for persons with mental disorders would help to ameliorate this burden.

2.7 Costs associated with Schizophrenia

Management of schizophrenia is devastating both to hospital staff and caregiver. According to Knapp et al (2004), estimates of costs are based on prevalence or incidence data. Prevalence-based studies estimate the economic burden to society during a given period of time, usually a year, generated by every prevalent case. The value of resources

used or lost during a specified time period is measured, irrespective of the time of onset. Incidence-based studies, on the other hand, estimate the lifetime costs resulting from an illness or disorder for all cases with onset in a given base year. Knapp et al (2004) further explained that cost of illness identify three main categories of costs: (a) direct costs, for which payments are made, (b) indirect costs, for which resources are lost, and (c) intangible costs, which describe the drawbacks of an illness such as pain or depression. Direct costs cover expenditures for hospital and nursing home care, physician and other professional services, drugs, and appliances are generally estimated as the product of the number or amount of services used and the unit price or charge. Indirect costs are wholly dominated by the value of lost productivity due to morbidity and premature mortality. Their study further identify the comparison of international cost findings that are grouped by countries under national total, direct, and indirect costs; direct, indirect, and total costs per patient per year; costs of inpatient services; costs of drugs; costs of lost productivity; mortality costs; family impact costs and criminal justice system costs. Relationships suffer because people with schizophrenia often withdraw and isolate themselves and paranoia can also cause a person with schizophrenia to be suspicious of friends and family (Smith and Segal, 2014). Basheer et al (2005) noted that the emotional impact of any psychiatric disorder on family or primary caregivers can vary from frustration, anxiety, fear, depression and guilt to grief. Because caregiving is such an emotionally draining experience, caregivers have high rates of depression when compared to the general population. Research on family caregivers of mentally ill relatives has historically focused on negative aspects of caregiving, often described as caregiver burden.

2.8 Direct cost of caregiving

Addo, Nonvignon & Aikins, (2012) conducted a study in Ghana on household cost of mental health care of patients attending Ho municipal hospital in Ghana. A cross-sectional study design was adopted and data collected from the psychiatric unit of Ho municipal hospital using the standard cost of illness which revealed that the total cost of health care for the three month period was estimated as GHS60,752.18 (USD34, 518.27). Total direct cost estimated was GHS15,939.80 (USD9,056.70) representing 26% of cost profile of mental health. Total direct medical cost was estimated GHS12,701.00 (USD7, 216.48) constituting 20.9% of total medical cost. Cost of drugs was estimated as 16.2%. Also total direct non-medical was estimated GHS3,238.80 (USD 1,840.23) making 5.3% of the total cost profile. Travel cost was estimated GHS2,114.20 (USD 1,201.25), food and accommodation during admission was also estimated GHS507.60 (USD288.41) and GHS40.00 (USD22.73) respectively.

Also Zhai et al, (2013) in a study done in China to evaluate the economic cost of treatment of schizophrenic patients estimated total direct cost as USD406.38 ± 311.13with direct medical cost constituting USD267.70 ± 255.66 (27.6%) and direct non-medical cost making up USD 138.68 ± 114.58 (5.8%). The period of study was of 12 months and referred to 2010. Two centers took part in the project; one from northern China and another from southern China. All participants were out-patients or in-patients with schizophrenia from the two centers. The total direct cost per case per annum was estimated as 33.4% of the total cost with the direct medical and non - medical cost forming 27.6% and 5.8% respectively. The direct medical cost was estimated using treatment costs and cost of other medical services.

Furthermore, Somaiya et al, (2014) assessed and compared the average annual cost of illness of outpatients with bipolar disorder and schizophrenia using the bottom-up approach. The study sampled 53 schizophrenic outpatients and assessed over a period of 9 months but the cost estimates were annualized. The annual total cost of care for schizophrenia was estimated Indian rupees 48,059 (USD961.18). Direct cost for schizophrenia was USD215.30 (22.4%)of the total cost and the cost incurred included the cost of travel, cost of lodging, cost of food, money spent on paperwork, investigation, drugs bought, cost of other modalities of treatment, hospitalization and treatment from any other source.

Similarly, Desai (2011), estimated the direct and indirect costs of treating schizophrenia for community-dwelling United States residents where patients with a diagnosis of schizophrenia (ICD-9 code 295) or other non-organic psychoses (ICD-9 code 298) between January 1, 2005 and December 31, 2008 were identified from the Medical Expenditure Panel Survey (MEPS). The study revealed that the weighted average number of patients with schizophrenia identified for each year was $757,893. The annual direct and indirect costs were estimated at $3.96 billion and $15.35 billion respectively. The mean annual direct medical schizophrenia-related cost was $5,586. Likewise, for each one-year increase in age, patients were 5.7% less likely to be in the high-cost group. The study also revealed that patients with a spouse were 77.7% less likely than patients without a spouse to be in the high cost.

Similarly, in the United States, Gunderson and Mosher (1975) provided one of the first estimates of the costs of schizophrenia, calculating minimum and maximum values of

each cost component. The annual direct cost to the nation was estimated to be between $2 and $4 billion in 1975.

Rice and Miller (1996), in their prevalence-based study, provided one of the most comprehensive cost estimates for schizophrenia internationally and a reminder that this disorder has wide-ranging impacts. Their estimation of the total cost of schizophrenia was $22.8 billion in 1985.Direct treatment (institutionalization and ambulatory visits) and support costs (research, training, and administration) constituted 49 percent of the total, amounting to $11.1 billion.

2.9 Indirect cost of caregiving

Addo et al. (2012) used the human capital approach (HCA) to estimate the indirect cost of mental patients attending Ho municipal hospital as GHS44, 812.23 (USD25, 461.56) constituting 74% of the total cost. Indirect cost comprised of days lost to employed patient, productivity loss due to lost of employment, days loss by household due to caregiving, days lost by household members, travelling time and waiting time. These were valued using the daily minimum wage for 2012.

Zhai et al. (2013) estimated the total indirect cost per annum for caregivers of schizophrenic patients using HCA as US$1723.40 (66.6%) at the level of OPD. The estimation was done by calculating production losses due to illness. To evaluate losses of production the average wages of local population was used. Also out of the costs incurred losses due to working days and disability amounted toUSD1, 536.21 ± 956.77 out of which caregivers' loss was estimated as USD 599.73 ±702.85.

Somaiya et al. (2014) estimated USD745.88 (77.6%) as the annual total indirect cost of treatment borne by schizophrenic patients and their families. The indirect cost incurred by the patient and caregiver included loss of earnings of the patient, loss of earnings of caregivers and increased household expenditure due to illness.

In the United States, Gunderson and Mosher (1975) provided the indirect cost estimate was between $8.5 and $11.4 billion. Also the indirect costs forgone as a result of patients' morbidity and mortality comprised 40% of the total ($9.1 billion); while other related costs such as crime, social welfare administration, and the cost of family care giving accounted for most of the other 11.1 percent and are part of the indirect costs.

2.10 Intangible cost

Not all economic costs could be measured by monetary values as some costs are subjectively indicated by individuals as perceived by financial costs. Several authors have examined the intangible cost of caregiving burden using 22-item ZBI (Zarit et al., 1980). The instrument covers areas including caregiver's health, psychological well-being, social life, finances and relationship between the caregiver and care receiver.

Over the years several authors have adopted the abridged versions of the 22-item ZBI, notable among them is the 12-item ZBI developed by Bedard et al., 2001.The 12-item of this brief ZBI were selected as those with the highest item-total correlations. Similar to the original measure, these authors contend that responses to their brief ZBI reflect two distinct factors (personal strain and role strain) with acceptable indices of internal consistency for both (i.e. a 5.88 and a 5.78 respectively)

Likewise, a study by Abdul-Kareem (2009) on caregiver burden among relatives of patients with schizophrenia in Katsina, where a total of 129 primary caregivers of patients with schizophrenia attending the outpatient clinic of Katsina State Psychiatric Hospital. They were interviewed using a socio-demographic data collection sheet and the Zarit Burden Interview (ZBI), the study revealed that level of the burden experienced was significantly associated with place of residence and family size. Thus the study concluded the Schizophrenia is associated with a high level of caregiver burden.

A study by Byford et al. (2001) looked at factors influencing the cost of caring for patients with severe psychiatric illness. The study found that higher costs were influenced by the age of the patient and the duration of the illness. Although the study looked at the financial costs, it is inevitable that a higher cost of care will translate to a higher burden for the caregiver.

Ratnawati et al (2014) conducted a study on the relationship of burden with characteristic sociodemographic caregiver in schizophrenic patients in Indonesia. The objective of the study was to establish the relationship between family caregiver burden and sociodemographic characteristics such as age, sex, education level, etc. A total of 118 caregivers of schizophrenic patients attending the outpatient department in Pempropsu mental health hospital were involved in the study using sociodemographic data collection sheet and the ZBI. 84 (71%) out of the total number of caregivers used for the study were females and male 34 (29%) with burden of 78% and 22% respectively indicating that that women have a high burden as compared to their male counterparts

2.11 Conclusion

From the literature reviewed, it is evident that the economic burden of caregiving for schizophrenia is huge and cannot be under estimated. The impact of caregiving for schizophrenic patient is seen in the inability of caregivers to be committed to their job leading to reduced earnings. Stigmatization and reduced ability to perform usual house chores is another challenge to caregivers. Caregivers of schizophrenic patients struggle to establish and maintain relationships. The family is also affected through reduced productivity and reduced household income. Cost borne by the society or nation is seen in the payments of disability funds, reduced taxation reduction in labour force. In Ghana, the impact of schizophrenia on the caregiver may be seen in reduced earnings and household income, stigmatization, reduced ability to perform effectively at work and at home and maintain relationships.

Though there are studies assessing the burden of mental health on households in Ghana, there is limited literature assessing the economic burden of caregiving for schizophrenics. Further, there is paucity of the studies assessing the economic burden of schizophrenia on caregivers in low and lower-middle income countries. Therefore, this fills these gaps by estimating the economic burden of caregiving on caregivers caring for schizophrenic patients at the outpatient department.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents a description of the research methods 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 using cost of illness analysis.

3.3 Study Area

Pantang hospital is the largest of the three psychiatric hospitals in the republic of Ghana. The hospital is located near Pantang Village from which it derives its name in the Ga East Municipal Assembly of the Greater Accra Region of Ghana. The hospital is 1.6 km off the Main Accra – Aburi trunk road and about 26km from the Central Business area of Accra, the capital city of Ghana. The hospital was commissioned in 1975 while partially completed as a regional Psychiatric Hospital with a bed capacity of five hundred (500) at the time. Currently, there are thirty (30) operational departments. 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. Ten (10) admission wards are currently in operation (seven male and three female wards) with each ward having a bed

capacity of fifty (50). In addition to the psychiatric wing, it has a drug treatment rehabilitation centre, physical OPD, HIV centre, antenatal department, occupation therapy department and a nurses' training schools.

3.4 Variables

Table 1 provides the description of the study variables. It encompasses the type of cost and the explanation of the categories of costs that were estimated for a period of one month in the study. Furthermore, the table describes the components of the cost incurred by caregivers, which were added up to obtain the direct and indirect costs. The intangible costs were also described.

Table 1: Description of study variables

Type of Cost	Category of Cost	Description
Direct cost	Medical cost	1. Cost of consultation. 2. Cost of drugs. 3. Cost of diagnostics. 4. Cost of other therapies.
	Non-medical cost	1. Cost of travel 2. Cost of food and drinks for patients and caregiver 3. Other cost includes food and accommodation for caregiver.
Indirect cost	Cost of productivity loss	1. Productivity loss due to waiting time 2. Productivity loss due to travelling time. 3. Days lost to caring for patient
Intangible cost	Intangible cost	1. Role strain 2. Personal strain

3.5 Study Population

The population of the study was the caregivers of patients diagnosed with schizophrenia and attending the outpatient department of Pantang hospital. A total number of 12,090 out-patients were seen in the year 2013.

3.6 Sample size determination

Pantang annual report (2013) estimated that a total of 12,090 clients who were diagnosed of schizophrenia came for review at the OPD. Based on this estimation, the minimum sample size will be calculated using the following formula:

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

at a confident interval of 90% and 0.1 margin of error.

Source: (EDIS, 2012)

Where N= Total Population of the Caregivers = 12,090, 1 = Constant, e = Margin of error (0.1) and n = Sample Size

$$n = \frac{12090}{1+12090(0.1)^2} \qquad n = \frac{12090}{1+12090(0.01)} \qquad n = \frac{12090}{121.9} \qquad n = 99.99$$

Hence, the sample size is approximately one hundred (100) caregivers. This figure was further rounded up to 110 (using 10% of the sample size calculated) to offset possible effects of non-response.

3.7 Sampling technique

According to the sample size calculation, out of a population of 12,090 care givers who visited the OPD in 2013 a sample size of not less than approximately 110 was appropriate for the study. This number is in accordance with the views of Dillman (2000) who reported that a sample size of 100 and above is sufficient to present good concise research findings and also, provide good representation of the population or organization or any subject investigated. Consequently, caregivers were defined as members who assisted with most, if not all, the patient's daily care needs. Sample inclusion was limited to caregivers of schizophrenic patients who reported to the psychiatric OPD with or without their patients during the period of study.

Patients' folders retrieved from the records were reviewed to select those diagnosed with schizophrenia according to ICD-10 criteria and caregivers who accompanied these patients to the facility were identified. Those present were further asked if they were actual caregivers or were representing the main caregivers. Those found to be the actual caregivers were used in the study till a minimum of 110 caregivers were obtained and used for a period not less than a month and those who were not the actual caregivers were excluded. It was found out that approximately 54% (151) of schizophrenic patients report with their caregivers for review. Although purposive sampling method comes with a weakness of bias on the part of the researcher it very useful for situations where you need to reach a targeted sample quickly and where sampling for proportionality is not the primary concern. The researcher chooses the sample based on who they think would be appropriate for the study. This is used primarily when there is a limited number of people

that have expertise in the area being researched. Above all it also has the strength of enabling the selection of respondents that are vital to answering the research questions.

3.8 Study tool

A structured questionnaire was the main instrument that was used for this study. The questionnaire comprised of close ended questions. The questionnaire was divided into sections. Section A focused on the socio-demographic information from the respondents whiles the subsequent sections contained questions aimed at addressing the main objective of the study. The short form of the Zarit Burden Interview (ZBI) by Bedard et al. (2001) which was derived from the 22 item ZBI by Zarit, Orr and Zarit (1985) has 12 item questions was also adopted to the third specific objective of the study. This instrument was designed to include the factors most frequently mentioned by caregivers as problem areas in providing care for schizophrenic patients. These factors can further be categorized into two main domains namely role strain and personal strain. Responses were rated from 0 - 4, based on the level of distress.

3.9 Quality control

Research assistants with basic knowledge in schizophrenia and economics as well as a data entry clerk were engaged and trained prior to administering the questionnaire. All completed data were validated daily before data entry. All uncompleted questionnaire were not entered. After data entry process the dataset was cleaned before running the analysis.

3.10 Pre-data collection stage

3.10.1 Training of research assistants and Pre-testing of questionnaire

Four research assistants, with knowledge on the study topic, who could read and write English and understood some local dialect (Twi, Ewe, Hausa and Ga) were recruited and trained for a period of two days. Training entailed explanation of the questionnaire, ethics and seeking informed consent from study participants. Each question in the questionnaire was explained to research assistants to prevent interviewer bias. They were trained to conform to the ethical guidelines of the study.

On the second day of training, they were given the opportunity to administer questionnaires at the pre-testing phase. Restructuring and further explanation of questionnaire was done based on the outcome of the pre-test. This was to ensure that questionnaire was well understood and administered accurately.

Before final administration of the questionnaire to the study population, the questionnaire was pre-tested on caregivers who accompanied patients' diagnosed schizophrenia at the outpatient department of Pantang hospital. The test revealed unanticipated problems such as repetition of some questions, restructuring some questions to reflect it intended meaning and addition of some specific questions. It also gave the research assistants a better understanding of the questionnaire and the appropriate response for each question asked.

3.11 Data collection stage

Data was collected on daily basis and meetings were held after data collection where matters arising were discussed and completed questionnaires were cross checked to ensure completeness of questionnaire. Coded questionnaires were given to the research assistants on daily basis after the day's work according to the number of questionnaires projected to be administered the following day.

3.12 Data entry and processing

Completed questionnaires were coded within 24 hours. Data were cross checked for errors twice before entering into the database of Microsoft Excel 2013 was used to analyse it.

3.13 Data Analysis

The socio-demographic characteristics of the caregivers were described using frequency and percentages to find the distribution. All cost estimated were cost incurred by caregivers for a period of one month preceding the study.

3.13.1 Direct Cost Estimation

Direct cost was estimated by summing all actual cost incurred directly on medical goods and services by the caregiver during the last visit to the hospital. Direct cost was further categorized into treatment related and non- treatment related cost. Direct treatment

related cost included the sum of cost of drugs, diagnostic tests and consultation (psychiatric) and other therapies.

The sum of travel cost, food for caregiver and patient during treatment and other cost, which included the cost of accommodation and food for caregiver when client is on admission accounted for the total direct non- treatment related cost. The sum of treatment related cost and non-treatment related cost gave the total of direct cost.

Direct treatment related cost was estimated as follows:

Cost of medicines: This was calculated by summing the cost incurred by caregiver on drugs during the last visit to the hospital.

Cost of consultation: This was calculated by summing the cost incurred by caregiver as treatment cost for consultation of psychiatric condition during last visit.

Cost of diagnostics: This was calculated by summing the cost incurred by caregiver on diagnostic test during the last visit.

Cost of other therapies: This was calculated by summing the cost incurred by caregiver on other therapies such as psychotherapy, electroconvulsive therapy, etc. in the last visit.

The total direct treatment related cost was obtained by summing the total cost of drugs, diagnostics, consultation and other therapies.

Direct non-treatment related cost was estimated as follows:

Travel cost: This was calculated by summing the travel cost incurred by caregiver in seeking treatment at Pantang hospital for a period of one month.

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

Other cost: This was calculated by summing all other cost which includes caregiver's cost on accommodation during admission of patient i.e. food, clothing, etc. for a period of a month.

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

Total direct cost was calculated by summing the total direct treatment related cost and total direct non-treatment related cost. The average cost of each variable in the direct cost was found as well as the percentage to find the distribution of the total cost.

3.13.2 Indirect Cost Estimation

The use of human capital approach (HCA) measured output loss by lost earrings for a period of one month. Productivity loss was valued using minimum daily wage of GHS 6.00 per day for working class caregivers. For the unemployed and students their productivity loss was not valued because they have no market value. The study acknowledges that assigning zero market value to unemployed and students may be an understatement of the true indirect cost. However this was due to methodological limitations. Travel time was calculated by summing the total number of hours spent travelling to and fro the hospital.' Productivity loss due to waiting is the sum of hours spent waiting for treatment at the hospital (i.e. from the time caregiver and patient arrived at the hospital to the time they take their medication and finally leave the hospital). The productivity loss due to caregiving is the sum of productive hours lost in caring for the patient in a day. These various variables were valued in terms of money using the daily minimum wage of GHS6.00 for only the working class. Total indirect cost was estimated

by summing the total cost of travel time, waiting time and days lost as a result of caregiving. The total number of days lost to caregivers was obtained as well. The results of the processed data were presented in tables and chart to give a visual representation of the findings on the study. The cost estimated was also converted into USD using an exchange rate of GHS4.40 (the rate at the time study was conducted) to be able to compare results with other international studies.

The total amount was estimated by summing the direct and indirect cost. The mean total cost was also estimated.

Table 2: Estimation of caregiver's indirect cost

Category	Cost estimation approach
Productivity loss due to travelling time	Total number of hours spent by caregiver travelling to seek treatment.
Productivity loss due to waiting time	Total number of hours spent by caregiver as waiting time in seeking treatment at the hospital during the last visit.
Days lost to work due to caregiving	Total number of days lost to caregiver as a result of caring for the patient for a period of one month.
Days lost to students/apprentices	Total number of days lost to student/apprentice as a result of caring for the patient for a period of one month.

3.11.3 Sensitivity analysis of the total cost

Sensitivity analysis was conducted to determine the robustness of the estimated costs. It helps to explore the sensitivity of results to any change in the variables which have some level of uncertainty. This was done by varying the component of cost of medicines and diagnostic test and the valuation of productivity.

3.13.4 Analysis of intangible cost

Intangible cost were described using the short form of Zarit Burden interview (ZBI) by Bedard (Bedard et al, 2001) which was derived from the original ZBI 22 questionnaire. Intangible cost was analysed by summing the scores for all 12 items for each respondent to generate a maximum score of 48 and a minimum of 0. Interpretation of scores were 0-16 low burden and above 16 high burden. This was presented in pie chart to give a visual representation of the findings on the study. Also the mean response to each question was found for the caregivers in the study to find the average response.

3.14 Ethical consideration/issues

3.14.1 Ghana Health Service Ethical Approval

Before the commencement of data collection, ethical approval for the study was sought from the Ghana Health Service Ethical Review Committee of the Research and Development Division of the Ghana Health Services.

3.14.2 Approval from study area

Permission and approval was sought from the hospital administration of Pantang hospital before data were collected.

3.14.3 Description of subjects involved in the study

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

3.14.4 Potential risks/benefits

Both the study population and the society stand to benefit from the study. Study population had knowledge of their annual expenditure on caregiving for schizophrenics. Also estimation of the economic burden of caregiving for schizophrenics can be used as a platform for sensitizing policymakers and opinion leaders about the economic burden of caregiving of schizophrenia. Subsequently, programs can be instituted to promote good mental health, education on prevention of schizophrenia, early detection and treatment of schizophrenia. This can help reduce the incidence and prevalence of schizophrenia, and the economic burden of caregiving to the patient. Results of the economic burden of caregiving to patients will help make informed decisions about their health and prevent schizophrenia as much as possible so as not to incur the cost associated with schizophrenia. This research posed no potential risk to the study population or society.

3.14.5 Privacy/confidentiality

Interviews were conducted in an enclosed place to ensure privacy. Data were also reported in aggregates to reduce possibility of tracing information gathered back to respondents. This was done to ensure confidentiality of information that was collected from participants.

3.14.6 Compensation

No compensation was given to caregivers for participating in this research. Their inputs were however recognized and appreciated.

3.14.7 Data storage and use

Questionnaires were coded and kept under lock and key in a cupboard, and the key was kept by the principal investigator. Data collected were coded and entered within 24 hours of collection, and was saved under a password known to only the principal investigator. Soft copy of data was stored on a CD-ROM and external hard drive as well. All data collected were kept by the principal investigator for 3-4 years to allow for publication of research, after which questionnaires will be destroyed.

3.14.8 Voluntary consent

Written consent was sought from study participants before data was collected from them. Participation was absolutely voluntary. Respondents were given the opportunity to stop anytime they were tired or opt out of the study.

3.14.9 Conflict of interest

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

3.14.10 Assumptions

In this study, the following assumptions were made:

a. The views of representative caregivers (i.e. those standing in for primary caregivers) were taken as the views of the caregivers they represented.
b. Further, the study assumed that the national minimum wage for the country is reflective of the average income earned per day by respondents.
c. The study also assumed that the productivity for employed caregivers including those who are self-employed is 8 hours in a day and that of student/apprentice is 24 hours, and that the unemployed would have earned the minimum wage if they had been employed.

3.15 Study Limitations

a. Number of days lost and time spent in caregiving, travelling and waiting for treatment were based on the recall of caregivers, which might not be accurate.
b. Cost was also based on recall of caregivers, which might not be accurate.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results obtained from the data analysis. The socio-demographic information of the respondents is first presented. The various results aimed at addressing the objectives of the study are subsequently presented. A total number of 110 questionnaires were administered to the caregivers of schizophrenic patients who reported for review at the Pantang psychiatric outpatient department. There was a 100% response rate.

4.2 Socio-demographic characteristics of caregivers

Table 3 presents the demography of the respondents used for the study. As shown in the table, about 58% of respondents were between 40-59years.Respondents in the age groups 20-39years and ≥60years were 27% and 15% respectively. The reported mean age is 47.76 years and the median age is 49 years. Majority of the respondent interviewed were females, representing 58.2% whereas the male respondents constituted 41.8% of the total respondents. Of all respondents, 61.8% were married, 21.8% were single and 10.9% were divorced whiles 5.5% were widowed. Thus, the results seem to suggest that majority of the respondents married. Majority of the respondents were Christians making up 85.5% of the total number of respondents.

The results revealed that 29.1% of the respondents had middle/JSS/JHS, 27.9% had SSS/SHS level of education, 20.0% had tertiary education, 14.4% had no education and

9.1% had primary education. Thus majority of the respondents had basic education. It was further revealed that 65.5% of the respondents were self-employed, 12.7% were employed in the private sector, 10.9% were unemployed, 7.3% were employed in the public sector and 3.6% were students/apprentice. Hence majority of the respondents were self-employed. It was revealed that 40.0% respondents cared for patients who were their children, 20.0% cared for their parents, 18.2% cared for siblings, 9.1% cared for other relatives, 7.3% cared for spouses, 3.6% cared for in-laws and 1.8% cared for grandchildren. Hence majority of the respondents cared for their children

Table 3: Socio-demographic characteristics of caregiver

	Frequency(n=110)	Percentage (%)
Sex		
Male	46	41.8
Female	64	58.2
Age		
20-39	30	27.3
40-59	64	58.2
≥60	16	14.5
Marital status		
Married	68	61.8
Single	42	38.2
Religion		
Christian	94	85.5
Muslim	10	9.1
Other	6	5.5
Educational level		
No education	16	14.5
Primary level	10	9.1
Middle/JSS/JHS*	32	29.1
SSS/SHS**	30	27.3
Tertiary	22	20
Employment status		
Self employed	72	65.5
Private sector	14	12.7
Public sector	8	7.3
Unemployed	12	10.9
Student/apprentice	4	3.6
What is your relationship with the patient?		
Spouse	8	7.3
Child	44	40.0
In-law	4	3.6
Grandchild	2	1.8
Sibling	20	18.2
Parents	22	20.0
Others	10	9.1

***Middle/JSS/JHS means middle school/Junior Secondary School/Junior High School**
****SSS/SHS means Senior Secondary School/Senior High School**

4.3 Direct cost of caregiving

Table 2 shows the results of the direct and indirect cost of care giving. The total direct cost to the care giver per month was estimated GHS 17,894.80 making up 86% of the total cost for schizophrenics. The average direct cost was GHS145.30 (Table 4).

4.3.1 Direct treatment related cost

The total direct treatment related cost for a month was estimated GHS11, 255.00 making up 54% of the total estimated cost of treating schizophrenia for caregivers in this study. In seeking treatment for schizophrenia the cost of drugs accounted for the biggest component 46 % in treatment related cost followed by the cost of diagnostic test 5%, then cost of others 1% with the least being the cost of consultation 3%.

4.3.2 Direct non-treatment related cost

The non - treatment related cost accounted for the major cost GHS6, 639.80 of the total direct cost in treating schizophrenia in a month. It consists of travel cost GHS3, 373.80 which forms the major cost among the non-treatment related as shown in Table 4. The cost of food during treatment and other cost like accommodation for caregiver during admission represented GHS1, 912 and GHS1, 354respectively.

Table 4: Cost of caregiver

Cost component	Cost (GHS)	Cost (USD)	*Average cost (GHS)	*Average cost (USD)	Percentage (%)
Direct cost					
Treatment related cost					
Consultation	614.00	139.55	5.90	1.34	2.9
Drugs	9,525.00	2164.77	91.50	20.80	45.6
Diagnostics test	1,020.00	231.82	31.90	7.25	4.9
Others	96.00	21.82	16.00	3.64	0.5
Subtotal	**11,255.00**	**2557.95**	**145.30**	**33.02**	**53.9**
Non-treatment related cost					
Travel cost	3,373.80	766.77	33.10	7.52	16.2
Food cost during treatment	\ 1,912.00	434.55	22.20	5.05	9.2
Other cost (accommodation)	1,354.00	307.73	48.40	11.00	6.5
Subtotal	**6,639.80**	**1509.05**	**103.70**	**23.57**	**31.8**
Total direct cost	**17,894.80**	**4067.00**	**249.00**	**56.59**	**85.7**
Indirect cost					
Days lost to work	2352.00	534.55	**42.00**	9.55	11.3
waiting hours	276.40	62.82	**2.94**	0.67	1.3
travelling hours	351.60	79.91	**3.82**	0.87	1.7
Total indirect cost	**2980.00**	**677.28**	**48.76**	**11.09**	**14.3**
TOTAL COST	**20,874.80**	**4744.28**	**297.76**	**67.68**	**100.0**

***USD exchange rate used was equivalent to GHS 4.40**

4.4 Indirect cost of caregiving

Total indirect cost of caregiving for schizophrenic patients for a month in Pantang Hospital was estimated GHS2,980.00 with an average of GHS48.76. Working class caregivers who form the highest cost of productivity loss losses a total of 286 days which is estimated GHS1,922.25 (USD436.88). Likewise, the indirect cost of caregiving included days lost to work due to care giving (GHS2,352), productivity lost due to waiting time GHS276.40 (USD62.82) and productivity lost due to travelling time GHS351.60 (USD79.91).

Table 5: Valued productivity loss for caregivers

Employment status	Days lost to work due to Caregiving (hours)	Waiting (hours)	Travelling (hours)	Total (hours)	Cost(GH)	Cost ($)
Unemployed	0	18	44.6	62.6		
Student/ apprentice	32	10	8	50		
Self employed	1312	204.4	225	1741.4	1305.75	296.76
Private	672	30	48	750	562.5	127.84
Public	32	14	26	72	54	12.27

4.4.1 Total productive days lost to caregivers

Table 6 shows the productivity days lost to caregivers as a result of seeking treatment for schizophrenic patients. The total number of productive days lost by the respondents who are employed and students was 366. This was the sum of the number of days absent from either school or work due to caregiving. The average days lost for an employed caregiver and a student/apprentice was 4 days in a month. Total number of productive days lost was 392.04 days.

Table 6: Caregivers productive days lost

Category		Days lost
Treatment		
Waiting Time	Unemployed	0.75
	Student/Apprentice	0.42
	Employed	10.35
Travelling Time	Unemployed	1.83
	Student/Apprentice	0.33
	Employed	12.46
Sub-total		26.14
Caregiving		
Days lost	School	80
	Work	286
Sub-total		366
Total		392.04

4.5 Total cost of caregiving for schizophrenic patients

The total cost of caregiving for schizophrenic patients was estimated to be GHS20,875.80 (USD 4744.28). Direct cost accounted for the higher proportion 86% of the total cost of caregiving whilst the indirect cost made up of the remaining cost 14% as shown in Figure 2. Estimated direct cost was GHS 17, 894.80(USD1, 509.05) of which medical cost contributed GHS11,255(USD 2557.95) while non-medical contributed GHS6,639.80 (USD 1509.05) as indirect cost was GHS2, 980. The average total cost of treating schizophrenia was estimated was GHS297.76 (USD67.68).

	Sales
Direct Cost	14
Indirect Cost	86

Figure 2: Total cost of caregiving for schizophrenic patients

4.6 Sensitivity analysis of the cost of schizophrenia

Sensitivity analysis was performed to determine the robustness of the study. The components on which the sensitivity analyses were performed were the cost of drug and diagnostic. One-way sensitivity test was performed. The test was performed by varying the increase in cost of drugs and diagnostic test by 5%, 10%and 25%. A variation of 5%, 10% and 25% of cost of drugs produced percentages of 2.3, 4.6 and 11.4 respectively. A variation of 25% produced the highest percentage change of 11.4 in the total cost and 1.5 in the percentage change in proportion of direct cost. The results of the test is shown in Table 7.

Table 7: Sensitivity analysis of total cost of caregiving

Scenario	Cost component	% change in parameter	Total cost		% change in total cost	% change in proportion total cost		Proportion of total cost (%)	
			GHS	USD*		DIRECT	INDIRECT	DIRECT	INDIRECT
Baseline scenario		0	20874.80	4744.28	0	0.00	0.00	85.7	14.3
*Variation	Drugs	5	21351.05	4852.51	2.3	0.3	-0.3	86.0	14.0
		10	21827.30	4960.75	4.6	0.6	-0.6	86.3	13.7
		25	23256.05	5285.47	11.4	1.5	-1.5	87.2	12.8
*Variation	Diagnostic test	5	20925.80	4755.86	0.2	0.2	-0.1	85.8	14.2
		10	20926.20	4755.95	0.2	0.1	-0.1	85.8	14.2
		25	21129.80	4802.23	1.2	0.1	-0.2	85.9	14.1

4.7 Intangible cost of schizophrenia

Table 6 shows the descriptive statistics for the responses for the Zarit scale burden. As shown in the table the sample number is 110 with a minimum value of 0.00 and maximum value of 4.00. Likewise, the various mean estimate for the various response is shown in the table together with the standard deviation. The internal consistency of the Zarit Caregiver Burden Interview was high (Cronbach's a 0.818). The Zarit burden scale analysis reveal that 50 care givers representing 45.5% were low burdened whiles 60 care givers representing 54.5% were high burdened as shown in figure 3. The results of the study shows that majority of the caregivers were high burden. Furthermore the intangible cost of caregiving was high in female caregivers than male caregivers as shown in figure 4.

Table 8: Descriptive statistics of ZBI for caregivers

ZBI QUESTION	N	Minimum	Maximum	Mean	Std. Deviation
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	110	0	4	1.93	1.73
Do you feel stressed between caring for your relative and try to meet other responsibilities (work/family)?	110	0	4	1.87	1.60
Do you feel angry when you are around the relative?	110	0	4	0.84	1.28
Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	110	0	4	1.24	1.61
Do you feel strained when you are around your relative?	110	0	4	1.42	1.68
Do you feel that your health has suffered because of your involvement with your relative?	110	0	4	1.16	1.55
Do you feel that you don’t have much privacy as you would like because of your relative?	110	0	4	1.36	1.58
Do you feel that your social life has suffered because you are caring for you relative?	110	0	4	1.24	1.58
Do you feel that you have lost control of your life since you relative's illness?	110	0	4	1.27	1.53
Do you feel uncertain about what to do about your relative?	110	0	4	1.47	1.55
Do you feel you should be doing more for your relative?	110	0	4	2.62	1.74
Do you feel you could do a better job in caring for your relative?	110	0	4	2.13	1.83
Valid N (listwise)	110				

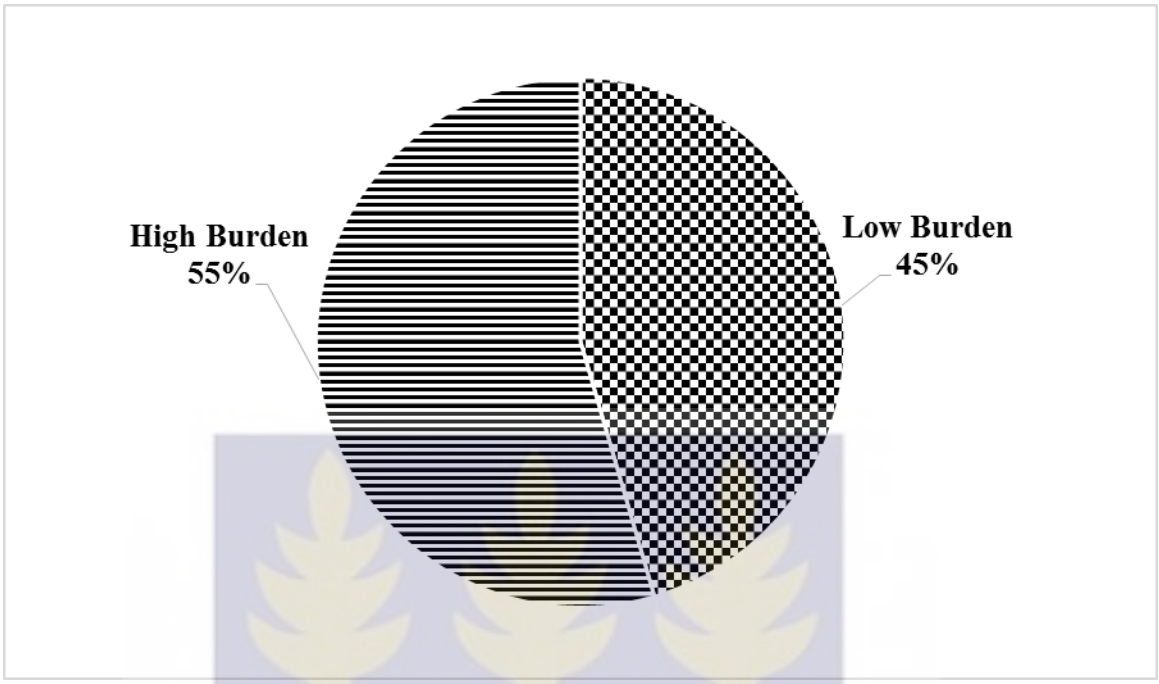

Figure 3: Percentage of burden on caregivers

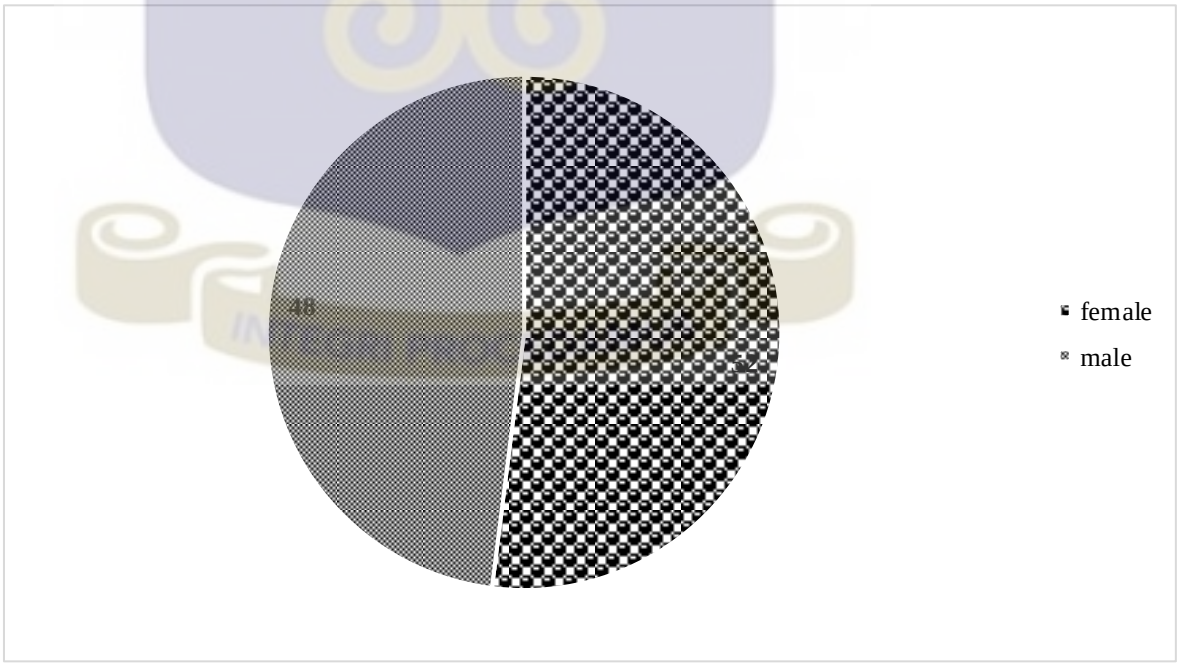

Figure 4: Percentage of burden of caregiving in sex

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The total cost of caregiving over a period of one month was estimated to be GHSGHS20,875.80 (USD 4744.28). The estimated direct cost accounted for 90.30% of the total cost of caregiving. The estimated treatment related cost was GHS11, 255 ($2,557.95) constituting 62.90% of the estimated direct cost of caregiving. The estimated indirect cost was GHS 1, 922.25 ($436.87) making up 9.70% of the estimated total cost of caregiving.

5.2 Direct cost associated with caregiving

The estimated direct cost of caregiving over a period of one month was 86% of the total cost of caregiving. This is more than the direct cost estimated by Addo et al (2012) which made up 21% of the total cost over a three month period. This can be attributed to the fact that Addo et al (2012) based their research work on household cost whereas this research work was based on the caregivers. Addo et al (2012) estimated household cost of mental healthcare in general whereas this study specifically focused on caregivers of schizophrenic patients.

Addo et al (2012) did not estimate for cost of diagnosing tests which formed 5% of this study. The study done by Addo et al (2012) was conducted at the psychiatric unit of the Ho Municipal hospital whereas this study was done at the Pantang hospital which is a referral hospital attracting people from far distances hence increasing cost of travelling. Cost of drugs as estimated by Addo et al. (2012) was 16.25% of the total cost of mental

healthcare whereas the cost of drugs estimated in this research was 45.63% of the total cost of caregiving.

Similarly, Zhai et al (2013) estimated the total direct cost of treatment of schizophrenics per case per annum to be 33.4% of the total cost of treatment with the direct medical and non – medical cost being 27.6% and 5.8% respectively. These figures are lower than the estimated corresponding figures in this study as a result of the study acknowledging the fact that the sample seems not to be representative of the cost of schizophrenic patients in China (mainland). The sample was not quite large, the focus was on only patients and only two centers were selected. Zhai et al acknowledged that cost of medicines formed the main part of direct medical cost confirming the findings in this study despite the fact that the study did not categorically outline the breakdown of the cost of the direct cost but only defined direct medical costs as cost of treatment and other costs of medical services and direct non-medical costs as all other resource use related to a disease.

A study by Somaiya et al (2014) estimated direct cost of caregiving for schizophrenic as 22.4% which is similar to the findings of Addo et al. (2012) but far smaller than the direct cost in this study which estimated 85.7%. This can be attributed to reduced direct medical cost by the Indian central government funded institute, in which health care is provided at a subsidized rate. A fee of 10 Rupees is charged at the first visit for consultation and subsequent visits are free of charges. Also dispensary of the hospital provides few drugs free of cost and for the same patients have to visit the hospital monthly for the refills. However, if medication other than the free antipsychotics is prescribed for a patient, they have to pay from their pocket and are generally cheaper (Cameron et al., 2009; Suleiman

et al., 1997). Further, some diagnostic tests like brain scan are highly subsidized resulting in the vast difference in direct cost.

It is possible that some direct costs of treating schizophrenic patients may have been borne by other individuals or organizations in which cost borne by the caregiver does not represent the true cost of treatment. However it must be emphasized that the focus of the current study was on cost borne the caregiver and not other sources.

5.3 Indirect cost associated with caregiving

The indirect cost as reported by Addo et al. (2012) was high (74%) as compared to this study (14%) as a result of the cost component they estimated under indirect cost. They valued days lost to working patients, productivity loss due to loss of employment, days loss due to caregiving by household members in addition to valued travelling and waiting time which was valued in this study.

Zhai et al (2013) estimated the total indirect cost as 66.6%. Out of the total indirect cost the unemployed accounted for USD10.67 and student/apprentice accounted for USD8.52whereas this study did not because there is no market value price for them. The study revealed that the self-employed productivity loss was higher as in the study by Zhai et al (2013).Also Zhai et al (2013)confirmed that the cost of productivity loss due to lost working days and disability formed a highest proportion. Schizophrenia is correlated to loss of working days. However Zhai et al (2013) used the HCA to calculate for the indirect just as this study. Indirect costs components estimated by Zhai et al constituted value of damaged properties and the costs due to lost working-days and disability incurred by patients and caregivers whereas this study accounted for productivity days

loss to only caregivers. The caregivers cost for indirect cost was estimated 25.6% in the study by Zhai et al (2013) for both patients and caregiver whereas the study estimated 14% for only the caregiver.

Furthermore a study by Somaiya et al (2014)estimated indirect cost to be 77.6% which includes cost incurred by the patient and caregiver such as loss of earnings of the patient, loss of earnings of caregivers, increased household expenditure due to illness. In both studies indirect costs were calculated using the human capital approach principle and future mortality costs were not calculated because of the difficulty in obtaining requisite data.

5.4 Intangible cost associated with caregiving

The findings of the study using the Zarit Burden Interview analysis revealed that the there is a high level of burden on the caregivers of schizophrenics at Pantang Hospital. This result is supported by findings made by Abdul Kareem (2009) on caregiver burden among relatives of patients with schizophrenia in Katsina, which revealed that Schizophrenia is associated with a high level of caregiver burden.

Also a study by Caqueo-Urízar, (2011) revealed that most caregivers experience chronic stress associated with the task of caring. This is seen in emotional responses such as anxiety, fear, guilt, stigma, frustration, anger, and sadness.

Furthermore a study by Ratnawati et al., (2014) showed that there was a significant difference between the two genders in terms of burden of caregiving. Female caregivers had higher burden (78%) of caregiving compared with male caregivers just as this study revealed. It can be explained by social gender role and hormonal factors related to social

role. Women were predominant in caregiving, in other words, women spent more time in caregiving than men. In terms of hormonal factors, oxytocin hormone also contributed in distress and women's need to nurture. When caring for patient with schizophrenia, women experience distress, their oxytocin levels and nurture needs increase but at the same time she had to pay more attention to the patient.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The main aim of this study was to determine economic burden of care giving for schizophrenic patients at Pantang hospital. The cost of illness of schizophrenia in caregiving is enormous and places great burden on caregivers. The direct cost constituted more than three-quarters of the total cost with the cost of treatment constituting more than half of the direct treatment related cost. Travel cost in seeking treatment at the hospital also contributed one-fifth of the total cost of treatment. The valued days lost to employed caregivers contributed more than half of the indirect cost. Despite limitations to the study and other studies cited, the cost of caregiving for schizophrenic patients is high as results of the studies show that schizophrenia cause a substantial economic burden to healthcare systems, community, other caregivers and society.

Caregivers suffer emotionally in their role play and private life as a result of caring for schizophrenics most especially in their acute state. Effective management of the disease condition can reduce the indirect cost of caregiving thereby reducing the monthly expenditure on the care.

6.2 Recommendations

The conclusions drawn from the results of this study forms the basis for the following recommendations:

1. The study found that the burden on the care givers was high. Thus, psycho-educational support groups for caregivers could be encouraged in communities to help reduce their level of burden. Community psychiatric nurses could be tasked with ensuring that these groups are formed and are functional.

2. The study also revealed that the medical cost on the caregivers was high. Thus, government could enroll treatment of psychiatric diseases on the NHIS to alleviate the financial burden on patients, their caregivers and hospital administrators.

3. There should be adequately trained psychiatric nurses in communities to manage uncomplicated cases at the community level to decrease travel cost and productive days lost.

REFERENCES

Addo, R., Nonvignon, J., Aikins, M., (2013). Household cost of mental health care in Ghana. *The Journal of Mental Health Policy and Economics*, 16, 151-159.

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver Burden: A Clinical Review. *JAMA*, 311(10), 1052-1060.

Amitsis, G. (2012). *Developing activation discourses in an era of fiscal constraints – Policy challenges for the rudimentary Greek Welfare State*. In European Social Policy Network, 10th Annual conference. Edinburgh; http://www.espanet2012.info/schedule/saturday_900_-_1030.

Awad, A. G., and Voruganti, L. N. (2008). The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics*, 26 (2), 149-162.

Basheer, S., Niazi, R. S., Minhas, F. A., Najam, N. (2005). Depression and anxiety in the caregivers of mentally ill patients, JPPS. *Journal of Pakistan Psychiatric Society*, 2 (1), 27.

Bedard, M., Molloy, B., Squire, L., Dubois, S., Lever, J., &O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. The Gerontologist, 41(5), 652–657.

Bevans, M. F. and Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA*, 307 (4), 398–403.

Biegel, D. E. and Milligen, S. E. (1992). *The Role of Race in Family Caregiving with Persons with Mental Illness: Burden, Support System and the Use of Self Help.* Cleveland, OH: Mandell School of Applied Social Sciences.

Byford, S., Barber, J. A., Fiander, M., Marshall, S. & Green, J. (2001). Factors that influence the cost of caring for patients with severe psychotic illness. *British Journal of Psychiatry*, 178, 441 – 447.

Caqueo-Urízar, A., Maldonado, J. G., Ferrer-García, M. Attitudes and burden in relatives of patients with schizophrenia in a middle income country.

Clark, R., & Drake, R. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal*, 30, 145-163.

Cornwall, P. L., & Scott, J (1995). Burden of care, psychological distress and satisfaction with services in the relatives of acutely mentally disordered adults. *Social Psychiatry Epidemiology*, 31, 345-348.

Department of Health and Human Services (2005). Glossary of aging terms. Retrieved March 1, 2007. Available from URL:http://eldercare.gov/eldercare/public/resources/glossary.aspDesai, P. R (2011). *Estimation of direct and indirect costs of treating schizophrenia for community-dwelling US residents*. Unpublished thesis submitted to the University of Texas at Austin.

Department of Health and Human Services (2005). Glossary of aging terms. [Accessed on 4th November, 2014]. Available from URL:http://eldercare.gov/eldercare/public/resources/gloss ary.asp.

Dillman, D. (2000). Mail and internet surveys: The tailored design method, 2nd edition, Wiley Cop., NY.

Dwyer, J., Lee, G., Jankowski, T. (1994). Reciprocity, elder satisfaction and caregiver Stress and burden: The Exchange of Aid in the Family Caregiving Relationship. Journal of Marriage and Family, 56:35-43.

Gunderson, J. G., and Mosher, L. R. (1975). *The cost of schizophrenia. American Journal of Psychiatry,* 132:901-906.

Hasui, C., Sakamoto, S., Sugiura, T., & Miyata, R. (2002). Burden on family members of the mentally Ill: a naturalistic study in Japan. *Comprehensive Psychiatry*, 43 (3), 219-222. PubMed Abstract | Publisher Full Text.

Horowitz, A. L, & Reinhard, S. C. (1995). Ethnic differences in caregiving duties and among parents and siblings of persons with severe mental illnesses. *J Health Social Behaviour*, 36, 138-150. Publisher Full Text.

Jablensky, A. (1986).Epidemiology of schizophrenia: a European perspective. *Schizophrenic Bull*, 12 (1), 52-73.

Knapp, M., Mangalore, R. and Simon, J. (2004). The global costs of schizophrenia. *Schizophrenia Bulletin*, Vol. 30, No. 2, 279-293.

Kreisman, D. E. & Joy, V. D. (1974). Family response to the mental illness of a relative: A review of the literature. *Schizophrenia Bulletin*, 10, 34 – 57.

Lefley, H. (1996). *Family caregiving in mental illness.* Thousand Oaks, CA: Sage.

Loukissa, D. A. (1995). Family burden in chronic mental illness: a review of research studies. *J Advance Nursing*, 21, 248-255.

Martyn-Yellowe, I. S. (1992). The burden of schizophrenia on the family: a study from Nigeria. *British Journal of Psychiatry*, 161 (6), 779-782.

Matsaganis, M. (2011). The welfare state and the crisis: the case of Greece**.** *Journal European Society Policy*, 21 (5)**,** 501-512.

McDonell, M., Short, R. A., & Berry, C. (2003). Burden in schizophrenia caregivers: impact of family psycho-education and awareness of patient suicidality. *Family Process*, 42, 91-103.

O'Malley, A. J., Frank, R. G., & Normand, S. L. (2011). Estimating cost-offsets of new medications: use of new antipsychotics and mental health costs for schizophrenia. *Stat Med*, 30 (16).

Panayiotopoulos, C., Pavlakis, A. and Apostolou, M. (2013). Family burden of schizophrenic patients and the welfare system; the case of Cyprus. *International Journal of Mental Health Systems*, 1186/1752-4458-7-13.

Pantang Hospital Annual Report, 2013.

Patel, V., Cohen, A., Thara, R., & Gureje, O. (2006). Is the outcome of schizophrenia really better in developing countries? *Rev Bras Psiquiart,* 28 (2), 149-152.

Peng, X., Ascher-Svanum, H., & Faries, D. (2011). Decline in hospitalization risk and health care cost after initiation of depot antipsychotics in the treatment of schizophrenia. *Clinicoecon Outcomes Res*, 3, 9–14.

Ratnawati, D. M., Husada, M. S., & Loebis, B. (2014). Relationship of Burden with Characteristic Sociodemographic Caregiver in Schizophrenic patients. *Journal of Biology, Agriculture and Healthcare*. Retrieved from http://iiste.org/Journals/index.php/JBAH/article/view/15734

Roberts, D. M., Asare, P. J. B., Mogan, C., Adjase, D. E. T., & Osei, D. A. (2013). T he mental health system in Ghana, (June), 1–75.

Rice, D. P., & Miller, L. S. (1996).The economic burden of schizophrenia: Conceptual and methodological issues and cost estimates. In: Moscarelli, M.; Rupp, A.; and Sartorius, N., eds. *Handbook of Mental Health Economics and Health Policy.* Vol. 1. Chichester, U.K.: John Wiley and Sons.

Sahoo, S., Brahma, P. K., & Mohapatra, P. K. (2010). Burden of caregiver's among the mentally ill and diabetic patients – a comparative study. *Orissa Journal of psychiatry*, 39-47.

Sainsburg Centre for Mental Health. (2003).The economic and social cost of mental health problems in 2002/03. Retrieved December 9, from centre for mental health website: http://www.centreformentalhealth.org.uk/pdfs/costsofmentalillnesspolicypaper3.pdf.

Sapouna, B. Schene, A. H., & Dafermos, B. (2006). Burden of family members and other people who care of patients with major psychiatric disorders in Crete: a new area for general medicine in Greece. *Primary Health Care*, 18 (3), 113-124.

Somaiya, M., Grover, S., Chakrabarti, S., & Avasthi, A. (2014). Comparative study of cost of care of outpatients with bipolar disorder and schizophrenia. *Asian Journal of Psychiatry*, *12*, 125–33. http://doi.org/10.1016/j.ajp.2014.08.003.

Smith, M. and Segal, J. (2014). *Understanding Schizophrenia: Symptoms, Types, Causes, and Early Warning Signs*. Retrieved from http://www.helpguide.org/articles/schizophrenia/schizophrenia-signs-types-and-causes.htm. Accessed 24th November, 2014.

Steudte, S., Stalder, T., & Dettenborn, L., (2011). Decreased hair cortisol concentrations in generalized anxiety disorder. *Psychiatry Res*., 30, 186 (2–3), 10–314.

Thara R, Padmavati R, Kumar S, Srinivasan L. (1998). Burden Assessment Schedule. Instrument to assess burden on caregivers of the chronically mentally ill. *Indian Journal of Psychiatry*, 40, 21-9.

Thara, R. Padmavati, T. N. Srinivasan. (2004). Focus on psychiatry in India. *British Journal of Psychiatry*, 18 (4), 366- 73.

Van-Wijngaarden, B., Schene, H. A., & Koeter, W. J. M. (2003). *People with schizophrenia in five countries: conceptual similarities and intercultural differences in family caregiving*.

World Health Organization (2008). *Nations for Mental Illness: Schizophrenia and Public Health.* Geneva: World Health Organization. Accessed from www.who.int/media/en/55pdf.

World Health Organization (2008). *Mental Health Atlas*. Geneva: World Health Organization. www.globalatlast.who.int/globalatlast/default.asp.

World Health Organization. Nations for Mental Illness: Schizophrenia and Public Health. Geneva: *World Health Organization. www.who.int/media/en/55pdf (accessed 24th November 2014).*

Wu, E. Q., Birnbaum, H. G., Shi, L., Ball, D. E., Kessler, R. C., Moulis, M., & Aggarwal, J. (2005). The Economic Burden of Schizophrenia in the United States in 2002. *The Journal of Clinical Psychiatry*, *66*(9), 1122–1129. Retrieved from http://www.psychiatrist.com/JCP/article/Pages/2005/v66n09/v66n0906.aspx.

Zhai, J., Guo, X., Chen, M., Zhao, J. and SuZhai, Z. (2013). An investigation of economic costs of schizophrenia in two areas of China. *International Journal of Mental Health Systems*, 2-8

APPENDICES

Appendix I: Informed Consent Form

Project Title: Economic burden of caregiving for schizophrenic patients at the outpatients department of Pantang hospital.

Background

My name is Sybil Decker, a student from the School of Public Health, University of Ghana, Legon. I am conducting a study on the economic burden of caregiving for schizophrenic patients at the outpatient department of Pantang Hospital. The main objective is to determine the economic burden of caregiving for schizophrenic patients at the outpatient department of Pantang Hospital.

Procedures

The study will involve answering questions from an open ended questionnaire about the cost incurred as a result of caregiving for schizophrenic patient. No coercion will be used to obtain response from participants. It will be appreciated if you could participate in this study. This is purely academic research which forms part of my work for the award of a Masters Degree in Public Health.

Risks and Benefits

Both the study population and the society stand to benefit from this study. Study population will know how much they spend in a month on mental health care. Also estimate of the economic burden of caregiving for schizophrenic patients can open a platform for sensitizing policy makers and opinion leaders about the economic burden of

schizophrenia. Subsequently, programs can be instituted to promote good mental health, education on prevention of schizophrenia, early detection and treatment of schizophrenia. This can help reduce the incidence and prevalence of schizophrenia and the burden of caregiving. Knowledge of economic burden of caregiving by the society will help them make informed decisions about their health and prevent schizophrenia as much as possible so as not to incur the cost associated with it. This research will pose no potential risk to study population or the society.

Right to Refuse

Participation in this study is voluntary and you can choose not to answer any individual question or all questions. You are at liberty to withdraw from the study at any time. However, I will encourage you to fully participate in the study since your answers are important to help estimate

Dissemination of Results

A durbar, including hospital staff, patients' caregivers and other stakeholders of mental health, will be held at the hospital to disseminate the findings of the study at Pantang Hospital. A copy of the study will be kept in the hospital as reference.

Before taking Consent

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

If yes, please, indicate the questions below

……

……

……

……..

Voluntary Consent

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

…….. …….. …… ……

Name of caregiver Signature Thumbprint Date

…… …….. …… ……

Name of witness Signature Thumbprint Date

…… …….. …… ……

Name of researcher Signature Thumbprint Date

…… …….. …… ……..

Name of interviewee Signature Thumbprint Date

Interviewers Statement

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

The participant has fully agreed to participate in the study.

Signature of Interviewer ……

Date ……

Address ……

If you have any questions later please, contact

Researcher: Sybil Decker (0244073740).

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

Appendix II: Questionnaire

ECONOMIC BURDEN OF CAREGIVING FOR SCHIZOPHRENIC PATIENTS AT THE OUTPATIENTS DEPARTMENT OF PANTANG HOSPITAL

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.

Unique identifier for respondents……

Date of interview …….

Hospital …….

	Question	**Response**
Section A	**Socio-demographic Information**	
1.	Sex a. Male b. Female	
2.	Age	
3.	Marital status a. Married b. Single c. Divorced d. Widowed	

4.	Religion a. Christian b. Muslim c. Traditionalist d. Others(specify)	
5.	What is your current level of education? a. No education b. Primary level c. Middle/JSS/JHS d. SSS/SHS e. Tertiary	
6.	Employment status a. Self employed b. Private sector c. Public sector d. Unemployed e. Student/ apprentice	
7.	What is your relationship with the patient? a. Spouse b. Child c. In-law	

	d. Grandchild e. Sibling f. Other (specify)……	
Section B	**Cost of Caregiver**	
8.	Are you paid for the work you do? a. Yes b. No	
9.	How much are you paid?	
10.	How many hours do you take to care for relative/client in a day?	
11.	Does any other member from the household care for your client/ relative? a. Yes b. No	
12.	How many hours does she/he spend to take care of client /relative in a day	
13.	Have you stopped work/school/apprenticeship because	

	of caregiving? a. Yes b. No		
14.	Have you cut down normal working/schooling activities? a. Yes b. No		
15.	By how many hours/days in a month?		
16.	What is/are your source(s) of income per month?	Source	Amount **(**GHS**)**
		Salary	
		Pension	
		Relatives	
		Insurance	
		Remittances(Gifts/ donations)	
		Others (specify) …….....	
		Total	
17.	Has there been decrease in income? a. Yes b. No		

18.	By how much?		
19.	What is the source of financing the patient?	**Source**	**Amount (GHS)**
		Salary	
		Relatives	
		Pension	
		Insurance	
		Remittances(gifts and donations)	
		Others(specify) ……..	
		Total	
Section C	**Direct cost Medical cost**		
20.	How much did you spend on the following through seeking treatment for your last visit?	**Category**	**Amount GHS**
		Consultation	
		Drugs	
		Diagnostic tests	
		Others (specify) …….	

		Total	
21.	**Non-medical cost**	**Cost category**	**Amount GHS**
		Travel cost (T&T)	
		Food cost during treatment	
		Other cost (food, accommodation, etc.) of caregiver	
		Total	
Section D	**Indirect cost**	**Category**	**Number of hours**
		Days lost to work due to caregiving.	
		Days lost to school due to caregiving.	
		Productivity loss due to waiting time.	
		Productivity loss due to travelling time.	
		Total	
Section	**Coping strategy**		

E		
24.	How do you pay for expenses if you are financially drained? a. Cutting down on other expenses b. Using savings c. Borrowing d. Selling assets e. Asking for donations from friends and relatives f. Others (specify)……..	

Section F

ZARIT BURDEN INTERVIEW

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

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

Appendix III GHS-ERC Ethical Approval

GHANA HEALTH SERVICE ETHICAL REVIEW COMMITTEE

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

My Ref. :GHS-ERC: 3
Your Ref. No.

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Tel: +233-302-681109
Fax + 233-302-685424
Email:Hannah.Frimpong@ghsmail.org

30th March, 2015

Sybil Decker
School of Public Health
University of Ghana
Legon, Accra

ETHICAL APPROVAL - ID NO: GHS-ERC: 112/02/15

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

"Economic Burden of Caregiving for Schizophrenic Patients at Outpatients Department of Pantang Hospital"

This approval requires that you inform the Ethical Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethical Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

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

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

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

1

Please note that this approval is given for a period of 12 months, beginning March 30th 2015 to March 29th 2016.

However, you are required to request for renewal of your study if it lasts for more than 12 months.

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

SIGNED.....

DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

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

2