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**PROVIDING MENTAL HEALTH CARE TO PATIENTS: EMOTIONAL, SOCIAL
AND ECONOMIC CONSEQUENCES ON CAREGIVERS**

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OF MASTER OF PUBLIC HEALTH (MPH) DEGREE**

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DECLARATION

I, Naa Adoley Addo hereby declare that this proposal is a result of my independent work. References to other works have been duly acknowledged. I further declare that this proposal has not been submitted for award of any degree in this institution and other universities elsewhere.

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(SUPERVISOR)

SIGNATURE

DATE

DEDICATION

I dedicate this work to the memory of my late dad, **Mr. Richard Mettle Addo**, the brave warrior. You were happy to see me start the programme and went all out for me. Unfortunately, the Lord called you into His bosom before my completion.

Your support and great faith in me pushed me even during the sad times of your demise. I know you are happy and proud of me. Your words, “hard work breaks no bones” and “you must learn very hard” will never depart from me. The work you started has only just begun, daddy. I will make you even more proud!

God bless you daddy! You will forever remain in our hearts. Rest in perfect peace!

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I made it by the Grace of God and I am eternally grateful for His mercies and faithfulness.

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ABSTRACT

Background: Mental illness is debilitating both to immediate families and the society at large. In Ghana, mental illness is not treated as a priority in healthcare. Persons caring for their mentally-ill relatives often feel burdened, helpless and sometimes ignored by other family members and the society. The main objective of this study is to examine the social, economic and emotional consequences on families as a result of taking care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital.

Methodology: This study used a qualitative research method that purposively sampled 10 caregivers who accompanied mentally-ill patients to the psychiatric hospital. Caregivers (comprising seven males and three females aged between 29 and 69 years) were interviewed with the aid of an interview guide. Interviews were recorded on audio, transcribed and themes analysed. NVivo 11 was used to analyze the data and emerging themes were identified.

Results: Themes related to emotions generated from the interviews were depression, strained marital relations, anxiety and psychological distress that could lead to physical ill-health such as hypertension. Economic related themes generated include loss of productive time, loss of economic value and a general reduced quality of life of both caregivers and their dependents. Social related themes that emerged from the interview are negative family effects, risk of isolation and stigmatization. Some additional themes generated included reduction in leisure, change in domestic routines and a reduction in physical activity. Mental illness often affects the caregiver's social life and economic problems arise frequently. Some of the consequences experienced were hard to bear and exerted considerable strain on care givers' lives. Despite this, majority remained committed to continuing to stay with and care for their patients.

Conclusion: The burden of caregivers should not be overlooked by clinicians, policy makers and the government. The provision of adequate emotional, economic and social support will significantly reduce caregiver burden.

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DEFINITION OF TERMINOLOGY

1. **Mental disorder:** A medical condition that disturbs an individual's reasoning, feeling, mood, disposition, ability to relate to others and every day functioning.
2. **Lack of insight:** The lack of ability of the affected individual to appreciate that symptoms of a mental illness are unreal or that the signs are as a result of the sickness.
3. **Hallucination:** A perception without an external stimulus. Hallucinations can happen in relation to any of the five senses. That is, the sense of touch, smell, taste, sight and hearing.
4. **Delusions:** An unequivocally held fixed but false belief that isn't shared by others from the patient's locality. These could be related to topics such as feeling of self-importance, sexual or religious delusions.
5. **Persecution**— When mentally-ill persons falsely believe they are victims of some form of danger or are the main focus of a conspiracy
6. **Passivity**— When mentally-ill patients falsely think that their thoughts or activities are being controlled by an external force or individual.
7. **Thought disorder**—an inability to utilise language in a sensible and coherent way which usually shows as distorted or unreasonable speech.
8. **Caregiver** A person who has been living with the patient for over a year and has been closely involved in his/her activities that affect their daily living, healthcare, emotional and social dealings for more than a year, without receiving remuneration for their efforts.
9. **Emotional Consequences:** The presence of symptoms such as depression, anxiety, insomnia and excessive worry that impair an individuals' functioning

and could result in physical ill-health of the individual, due to taking care of a mentally-ill patient.

10. **Economic consequences:** The presence of problems, difficulties, challenges, loss of opportunities to earn an income or adverse effects due to taking care of a mentally-ill patient.
11. **Social Consequences:** All forms of discrimination and stigma associated with mental illnesses which result in situations such as loss of friends, spousal desertion, exclusion from family and withdrawal or refusal of admission into schools.
12. **Mental health care-** This refers to the resources, treatments and interventions available to mentally-ill patients in order to be fully integrated into society and live a life as normal as possible.

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND

The 4th edition of the DSM (Diagnostic and Statistical Manual) by the American Psychiatric Association describes mental illness as clinically significant change in forms of behavioural or emotional functioning that are linked with an observed level of agony, grief (pain, bereavement), or injury in one or more parts of functioning (e.g. work, societal and domestic relations); and the foundation of the impairment may be biological, or environmental factors, or a combination of them (DSM – IV, 1999).

This area of health is very important as no one can function without an adequate state of mind. Mental illnesses include Bipolar Affective disorders, Schizophrenia, Depression, Mood disorders such as mania, personality disorders as well as intellectual disabilities.

Schizophrenia is known to be a chronic and frequently a disabling mental disorder that accounts for about one(1) per cent of the world's population affected with mental illnesses. (Insel, 2010). It is a mental illness that is among the world's top ten causes of long-term morbidity and in some cases, mortality. Symptoms associated with schizophrenia are apathy, psychosis, social withdrawal and cognitive impairment, which may lead to problems in social, personal and occupational functioning, and self-care. About one (1%) of the population is affected by schizophrenia, with similar rates across different countries, races, cultures and sexes. Schizophrenia may usually develop between the ages of sixteen (16) and thirty (30) years and would mostly persist throughout an affected individual's lifetime. Aetiological factors of schizophrenia are unknown, however, scientific evidence suggests genetic factors, early environmental influences (eg obstetric complications), and social

factors like poverty as contributory factors. There are no known biological alterations that are pathognomonic of schizophrenia, although research has shown that many pathophysiological differences exist in several brain structures. Antipsychotic medications are the mainstay for treating schizophrenia, but not the cure. A number of psychological and social treatments are also helpful, but not curative. These include cognitive-behaviour therapy for psychosis, family interventions, supported employment, social skills training, assertive community treatment, teaching illness self-management skills and integrated treatment for co-morbidities such as substance misuse (Mueser & McGurk, 2004).

Depression is known to cause significant distress and impairment in physical, social, occupational and other key areas of functioning. Women are estimated to be twice as likely as men to develop depression. (Stewart, Gucciardi, & Grace, 2004). According to the World Health Organisation (WHO), psychiatric disorders accounted for as much as twelve per cent (12%) of the total global disease burden in 2000. In the year 2020, it is estimated that this figure will rise to 15% , when unipolar depression is predicted to rise to second from the fourth most disabling health condition in the whole world (WHO, 2001). Using the World Health Organization formula for estimating the prevalence of psychiatric illness in any country, it is said that 10% of any given population experiences neuropsychiatric conditions and one per cent (1%) from severe mental illness at any particular time (WHO, 2001). It has been estimated that about 2.4 million people suffer from mental illness in Ghana . Ghana reported 1,500 records of suicide cases annually and this is caused by depression (The Daily Graphic, 2015). Ghana lacks adequate social support and funding for mental health, resulting in caregivers having to bear the socio-economic consequences of the disease.

A caregiver, defined here, is a person, typically a family member or friend, who helps a ill person with the physical care and management of a disease and doesn't receive remuneration for his or her services to the patient. The task of caregiving usually results in additional

responsibilities on the caregiver's daily life. These responsibilities occupy the caregiver's energy, time and attention, which is demanding and complex. This burden associated with caregiving, when prolonged, might affect the physical health of caregivers, causing symptoms, such as anxiety and depression, hypertension and may lead to a negative impact on their social life (Briggs, 2012).

In Ghana, when the consequences of providing care was estimated using the WHO Impact of Caregiving Scale, Independent sample t-tests, correlations and analysis of variance were utilized. The relationship between background characteristics and the consequences of caregiving were found. A Linear regression used to look at determinants of the burden of providing care showed that: The mean age of caregivers was sixty-one years (standard deviation 14.5), the male:female ratio was almost equal. Averagely, about two adults per household required care. Under five percent of caregivers who took part in the research got monetary support as well as emotional, physical and personal care support. The residence, financial provision, health and physical help to recipients of care and receipt of financial, physical and health support were critical determinants of the results of providing care. The research confirmed that the number of people who required care far out-weighed the number of people who provided care, thus demonstrating the high caregiver load in the nation. (Sanuade & Boatemaa, 2015).

1.2 PROBLEM STATEMENT

Mental health remains one of the health areas of concern that has been neglected for several years in Ghana. The Mental Health Act 2012 passed by the parliament of Ghana in the month of March 2012 is a noteworthy point of reference in tending to psychiatric disorders as a matter of public health concern and furthermore in the insurance of the human rights of

people living with psychiatric illnesses in Ghana. The last significant modification of the mental health law in the nation was in the late 1960s, bringing about the enactment of the Mental Health Decree, NRCD 30, in 1972(Forster, 1971).

This act was passed mainly to address the problem of funding mental health, amongst other things. The Act seeks to promote de-institutionalization and promote homecare as well as to provide free treatment for affected persons. However, though home care is being promoted, funding is woefully inadequate resulting in family members having to bear the socio-economic consequences of the disease.

The Mental Health Act proposes the setting up of a fund. Even though it is not clear how much funding would be required to run an effective and efficient mental health service, it is indeed clear that a lot is required. The health sector budgetary allocation for mental health is just over 2.2% versus the WHO-recommended 15%, a disproportionately small allocation even by the standards of a resource-constrained country. This shows how much mental health care is not regarded as a priority in this country (Omar et al., 2010).

These patients are mostly mentally-incapacitated to work and so their relatives have to bear the cost of care as well as cater for their needs and this becomes a burden for both patient and caregiver. If the issue of funding mental health is not made a priority, these numbers will certainly go up as caregivers may even become patients themselves as a result of the social, emotional and economic burden they may encounter.

1.3 RESEARCH QUESTIONS:

1. What are the social consequences as caregivers take care of mentally ill relatives attending the OPD of the Accra Psychiatric hospital?

2. What are the economic consequences as caregivers take care of mentally ill relatives attending the OPD of the Accra Psychiatric hospital?
3. What are the emotional consequences as caregivers take care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital?

1.4 MAIN OBJECTIVE

The main objective of this study is to examine the social, economic and emotional consequences on families as a result of taking care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital.

Specific Objectives:

- a. To examine the social consequences on caregivers as a result of taking care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital
- b. To examine the economic consequences on caregivers as a result of taking care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital
- c. To determine the emotional consequences on caregivers as a result of taking care of mentally-ill relatives attending the OPD of the Accra Psychiatric hospital

1.5 CONCEPTUAL FRAMEWORK

The public health burden arising from mental disorders across the world has been well documented. Mental diseases have considerable negative consequences on the quality of life of patients and their caregivers. Caregiver burden has been described as the overall physical, emotional, and financial costs of caring for a relative suffering from a mental condition. Caregivers' experiences encompass distress, stigma, worry, shame, and guilt. Most researchers and mental health professionals have concentrated much time and efforts on people living with Mental illnesses. There is now the need to focus on caregivers of patients with Mental conditions as well, especially in developing countries where health systems for managing mental health patients and their caregivers are lacking. In Ghana and other African countries, wide family networks including church societies provide support to individuals or groups of people when social problems such as death or disasters occur. Persons suffering from mental illness and their caregivers are marginalized such that these social support systems are virtually non-existent. Caregivers of mentally ill health patients have no choices but to carry their physical, emotional, spiritual, and financial needs solitarily. There is therefore the need for better understanding of caregiver experiences in providing care for their relatives affected by Mental illnesses. This will help health service providers and law-makers to better understand the needs of caregivers when targeted caregiver interventions are planned.

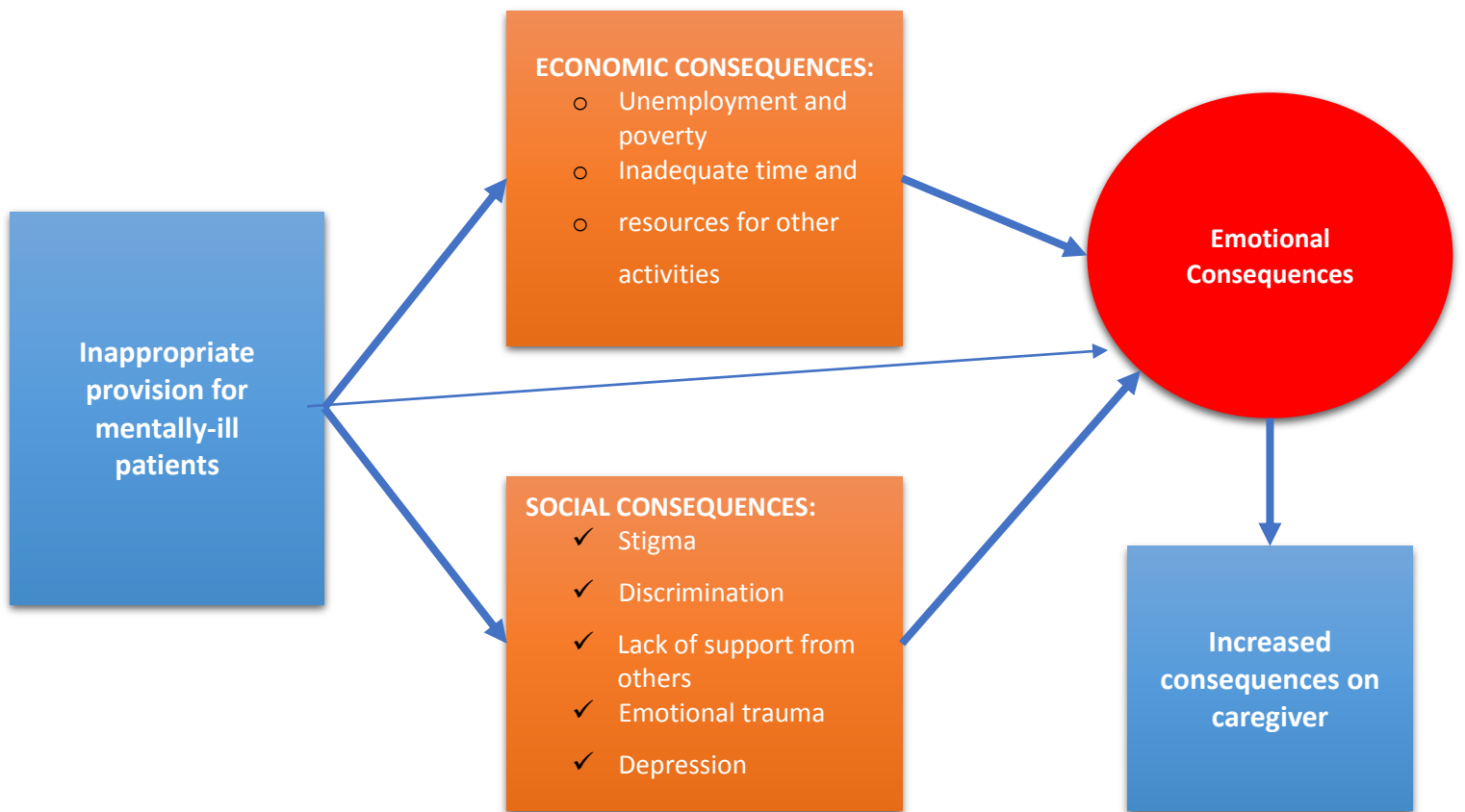


Figure 1: A conceptual framework for emotional, social and economic consequences on caregivers of mentally-ill patients.

Source: Author's original creation

JUSTIFICATION OF THE STUDY

The trauma experienced from mental disorders cannot be over-emphasized. The economic burden and mental agony on the family in particular are very significant. More importantly, the prevalence of mental disorders in the community is still rising. Whereas knowledge about other major health problems such as diabetes and Hypertension are common, there is the lack of the same degrees of knowledge about mental disorders.

Ghana lacks adequate social support for mental health patients. The society is such that the stigma on mentally-ill patients is very high and so getting employment is difficult. If they do find jobs, employers terminate their appointments when they find out they have a mental illness, especially if they have an episode at work, or, they become a laughing stock and get so embarrassed that they even quit on their own.

Most of these patients end up staying at home and being highly dependent on relatives (caregivers) as they are unable to purchase their own medications.

In addition, they are unable to provide basic needs such as food, shelter, clothing, transportation and even sometimes are unable to attend regular reviews on out-patient basis on their own.

Caregivers become obligated to provide all the above as well as transportation and time in order to improve the mental health status of patients. They also end up being stigmatized because of all the inconveniences they have to go through for their relatives and this may affect them emotionally, socially and economically. This study will help to bridge the knowledge gap and also impress on the law-makers the importance of funding mental health.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents a review of literature associated with the objectives of this study. It comprises literature on Global mental health, mental health in Africa, Mental health in Ghana and Caregiver factors that affect consequences. It also focuses on the social and economic and emotional consequences of caring for mentally-ill patients.

2.1 Global mental health

World Health Organisation (World Health Organisation, 1948) defines health as a state of complete physical, mental and social well-being and not merely the absence of diseases or infirmity. American Psychiatric Association in Diagnostic and Statistical Manual 4th edition (DSM – IV, 1999) describes mental illness as clinically significant patterns of behavioural or emotional functioning that are associated with some level of distress, suffering (pain, death), or impairment in one or more areas of functioning (e.g. work, social and family interactions); and the basis of the impairment may be biological, or environmental factors, or a combination of them. These references are classical in the field of psychiatry, and though old, cannot be overlooked in this study. The World Health Organization approximates that 21 million people suffer from the illness worldwide which can also be implied to mean that the same number of families are equally affected by the disorder. Evidence has shown that schizophrenia is the most severe mental health illness, representing the eighth(8th) cause of disability in the world (Serretti et al, 2009). Schizophrenia is a severe mental illness which causes a significant disturbance in thinking, in perceptions, in emotions and in conduct. It makes the patient perceive things which do not exist. Thus, it is very difficult to have any meaningful interaction with the patient (Guo et al., 2007).

The illness is characterized by the following symptoms:

Delusions, Hallucinations, Disorganized speech, Disorganized or catatonic behaviour, and Negative symptoms such as alogia or flattening of affect. The patient must have experienced at least two of the above symptoms and at least one of them should be delusions, hallucinations or disorganized speech for a specified period. Continuous signs of the disturbance must persist for at least 6 months, during which the patient must experience at least one continuous month of active symptoms. (American Psychiatric Association, 2013).

Schizophrenia is one of the most serious and frightening of all mental illnesses. There is no other mental disorder that arouses as much anxiety in the general public, the media, and doctors as Schizophrenia. Even though effective treatments are available, patients and their relatives often find it hard to access good care. In the United Kingdom, as in many parts of the world, this is often due to poor service provision, but sometimes it is simply down to misinformation. In Ghana, it is as a result of poor understanding and mis-prioritization of mental health. (Picchioni & Murray, 2007).

Almost half of all schizophrenics also present with a lifetime history of substance use disorders (SUD), a rate that is much higher than in unaffected individuals (Volkow, 2009). Affected patients may also have complications such as anxiety and depression. Although current treatments provide control rather than cure, long-term hospitalisation is not required and prognosis is better than traditionally assumed, once on medication (Jim van Os & Kapur, 2009).

Although great advances in pharmacotherapy of schizophrenia and related disorders have been made, a large percentage of persons with schizophrenia remain at least partially nonresponsive to treatment some relapsing even on medications, leading to increased morbidity and mortality, increased healthcare cost, and poor quality of life for affected

individuals as well as their caregivers (Van Sant & Buckley, 2011). Antipsychotics are however still the mainstay in the pharmacologic treatment of schizophrenia and have proven to be much efficacious (Tandon, Nasrallah, & Keshavan, 2010).

2.2 Mental health in Africa

Even though mental illnesses have recorded a high prevalence, they continue to remain a low priority in Africa. There have been little or no investigations of the views of stakeholders in Africa on why this is and what can be done (Omar et al, 2010). Stakeholders themselves simply have no interest.

Primary and secondary data sources from a situational analysis done on mental health services in the three countries (Ghana, Uganda and South Africa) were analysed. The findings indicated that significant challenges remain in integrating mental health care into primary health care. In Ghana, mental health care is not catered for by the national health insurance scheme. Poor implementation of policy, lack access to essential drugs and inadequate number of mental health specialists are some of the reasons found. (Bhana, Petersen, Baillie, Flisher, & The Mhapp Research Programme Consortium, 2010).

Majority (three-quarters) of the global mental health burden exists in low- and middle-income countries (LMICs), yet the lack of mental health services in these settings with poor settings is striking (Mendenhall et al., 2014).

Health policies in Africa just do not give much consideration to mental health and thus the difference between mental health care in developed countries and the under-developed ones.

It is time every country formulates a mental health policy based on its own social and cultural and economic realities. These policies must take into account the scope of mental

health problems, provide proven and affordable interventions, safeguard patients' rights, and ensure equity (Gureje & Alem, 2000).

In a study done in Malawi on mental illnesses, majority (63.3%) of respondents opined that they would be afraid to have a conversation with a mentally-ill person. 68.5% of participants said they would be able to maintain a friendship with a mentally-ill person. However, less than half: 8.1%, 18.6% and 40.6% of the respondents said they would be ashamed if their relative was diagnosed of a mental illness, marry an individual previously diagnosed of a psychiatric disorder and share a room with a mentally-ill person respectively. (Crabb et al., 2012)

In Nigeria, People with mental disorders were believed to be mentally retarded, a public nuisance and therefore were dangerous. This is what therefore informed majority of participants decision not to have social interactions with patients diagnosed with mental disorders (Gureje et al., 2005). About 83% reported that they would be afraid to have a conversation, 78% said that they would be upset or disturbed about working on the same job, 81% reported that they would not share a room, and 83% responded that they would feel ashamed if people knew that someone in their family had been diagnosed with a mental illness. only 17% reported that they could maintain friendship with a person with mental disorder (Gureje et al., 2005).

Also, a classical study which cannot be overlooked was of attitudes towards 10 physical and mental illnesses in the Ethiopian population by Mulatu (1999) revealed a gap in attitude depending upon the illness characteristics. Diagnoses with the strongest stigma attached were leprosy, schizophrenia and tuberculosis, with less than 20%, of the participants prepared to work with, be friends with or marry a person with schizophrenia. Less than 25% of the participants were prepared to work with, be friends with or marry a person with

leprosy and with less than 33%, of the participants were prepared to work with, be friends with or marry a person with tuberculosis.

2.3 Mental health in Ghana

In Ghana, the occurrence of mental illness has been found to be about 13% (Addo & Aikins, 2013)

The main burden of ill-health, as in many sub-Saharan countries, comprise communicable diseases, illnesses due to malnutrition and poor reproductive health. Even though these conditions are tackled, other diseases, such as mental disorders and substance misuse disorders, are also on the rise and thus becoming the focus of development efforts. In Ghana, it has been estimated that there are 2 166 000 individuals who have a mild to moderate mental disorder, with a further 650 000 suffering from a severe mental disorder, out of a population of 21.6 million (WHO, 2010). As at 2003, the country's mental health workforce consisted of only 9 psychiatrists (only 4 of whom worked in mental health services), 451 nurses and 160 community psychiatric nurses (The WHO World Mental Health Survey Consortium, 2004). At the moment, there are just 5 consultant psychiatrists in active service in the public sector and 11 retired psychiatrists in the country. Approximately 33 000 individuals are seen each year in Ghana by mental health services, there is an estimated treatment gap of 98% (Ofori-Atta & Ohene, 2014). Most mental healthcare is provided at the three large psychiatric hospitals, in the south of the country. However, efforts have been made to decentralize this system of care by providing community psychiatric units in every health facility. This is reflected in the ratio of out-patient attendance to admission, which is 4.64 for mental health, compared with 14.6 for all health conditions. In Ghana, it is estimated that about 32% of all mental health conditions reported at the psychiatric hospitals are diagnosed of schizophrenia (Osei, Roberts, & Crabb, 2011).

In Ghana, Ngissah (1975) compared the attitudes of 564 American High School and College students from Sacramento (California) with 280 Ghanaian High School and College Students from Accra towards the mentally ill. Results obtained show a more negative and rejecting attitudes towards mentally-ill persons in the Ghanaian sample. 57.9% of the Ghanaian respondents held the view that mental illness in the family brings shame on the family name and 57.5% that it was wise to keep it a secret as much as possible. 60.4% of the Ghanaian participants felt that mental illness is not an illness like other illnesses, 78.9% agreed that patients in mental hospital behaved like children and 71.8% subscribed to the opinion that anyone hospitalized for a mental illness should be banned from voting, thus taking away this basic human right. Sodzi-Tetteh (2007) concluded that the stigma towards mental illness is more serious than imaginable. He stressed that this stigma affects everything from the policy adoption stage through to commitment and implementation of the policy including community-based care. He argues that the plight of the mentally-ill patients would have been better if not for the neglect by politicians and Ghanaians as a whole (Sodzi-Tetteh, 2007).

2.4 Caregiver Factors that affect consequences

The World Health Organization estimates that about 40-90% of schizophrenic patients live with their families (World Health Organisation & Organization, 2008).

A caregiver can be defined as a person being part of the patient's family who takes responsibility for the patient and devotes his or her time to take care of the patient without getting any financial remuneration (Gutiérrez-Maldonado & Caqueo-Urizar, 2007).

Caregiving in Africa is mostly done by family members and close associates like friends and relatives. Although, relatives are the most valued and the most dependable resources for the sick person and the family members play a significant role in helping their mentally impaired

relatives, family caregivers are not appreciated for seeking the well-being of their patients and relatives.(Glozman & Glozman, 2004).

In health sciences, caregiver burden refers to the collective set of stressful exposures or “stressors” that the caregiver faces(Friedemann-Sánchez & Griffin, 2011). Previous studies identified factors that may influence caregivers’ burden. These included caregiver’s characteristics, care recipient characteristics, caregiver’s resources, and caregiver’s support characteristics. Caregiver characteristics, such as gender, age, and kinship to the care recipient, have consistently been associated with burden(Cumming, 2012).

Caregivers play an important role in the management of chronic mental illness in the community. Caring for patients with chronic mental illness like schizophrenia can cause deep emotional distress in the caregivers. However, the magnitude of the problem remains largely unknown in Sub-Saharan Africa and other developing countries (Yusuf & Nuhu, 2011).

A study in Iraq on mental health shows that the respondents have a fair knowledge on the factors that cause mental illness. Over half (51.32%) or (61.5%) of respondents agree that mental illness is caused by brain disease or genetic inheritance respectively and nearly half (46.39%) believe that substance abuse is the cause of mental illness and about two third (67.24%) believe mental illness is caused by something bad happening to you while less than a third (30.17%) thought mental illness is God’s punishment and nearly two third (59.23%) view personal weakness as the cause(Sadik, Abdulrahman, Bradley, & Jenkins, 2011).

A study on Caregivers' knowledge of etiology of mental illness in a tertiary health institution in Nigeria revealed that Majority (244 or 61.9%) of the respondents believed drug and alcohol misuse could cause mental illness, while the belief that it could be due to 'curse' were reported by only 75 (19.0%) respondents. Male gender was significantly associated

with belief that alcohol and drug misuse, stress, genetic inheritance, physical illness, and poverty were causes of mental illnesses. Higher educational status was also associated with alcohol and drug, traumatic events, stress, genetic inheritance, and physical abuse as causes of mental illness. Now, there is a better knowledge of mental illness among caregivers than the predominantly supernatural causes earlier attributed to mental illness by Nigerian communities. In order to sustain this, there is need for continuous psycho-education (Issa, Parakoyi, Yussuf, & Musa, 2008).

Another study in Nigeria revealed a remarkably poor knowledge about mental illness. Not only do they believe mental illness is due to possession by evil spirits or divine punishment, but there is also a widespread belief that misuse of drugs is the cause of mental illness. This view is not completely wrong. However, since this is only true for a very limited number of individuals affected with mental disorders. Since the public often views the misuse of drugs as moral failing, this belief may be translated to a notion of mental illness as being self-inflicted. Such a view is more likened to condemnation, where people are blamed for their conditions, rather than understanding (Gureje & Alem, 2000).

2.5 Social consequences of caring for mentally-ill patients.

Mental illness altogether influences socio-economic status of caregivers of patients. As per a research conducted by Grad (2010), more than fifty (50) per cent of the participants experienced deep and prolonged periods of intense worry to stressing over the patient. one out of every five of them attributed somatic symptoms like poor sleep, headaches, excessive irritability, and depression to their concern about their relative's conduct.

The recreational and social exercises of 33% of the families had been confined; almost a third had had their domestic routine disorganized (housework, shopping etc); about a quarter had had their earnings reduced by at least 10%, and a tenth by more than 50%. Information

gathered indicated that in one fourth of the families interviewed, some one had to quit their job or absent themselves from work in order to look after their mentally-ill relative. More than 33% of the children in such families were disturbed and irritated. Individuals with psychiatric disorders experience the ill effects of negative social states of mind which result from disgrace, stigma and misguided judgments of psychological wellness issues (Patrick W. Corrigan & Penn, 1997).

As indicated by Sodzi-Tetteh (2007), the vast majority do not want their relatives to specialize in mental health due to stigma attached to mental disorders. A few people decline to go for their relatives who have recovered from the illness from the hospital. However, others even give wrong addresses with the goal that they won't be followed. Shockingly, some health professionals trust that a patient with dysfunctional behavior can never genuinely be fully well.

A research on mental health investigated the delineation of mental illness through two primary government print media in Ghana from 2003 to 2012. Emphasis was placed on observing the daily papers' utilization of dialect to describe individuals with psychological disorders. Data obtained was analyzed with content analysis. Discoveries showed that in spite of the move to change the unfavourable and unacceptable discourse on mental illness, state-owned media in Ghana continue to use derogatory language to depict this populace. Negative descriptor words such as 'insane', 'mad' and 'mentally deranged' or 'dumb' keep on surfacing in print media. Shockingly, the use of this language has the tendency to propagate the stigmatization of mental disorders and undo some of the strides made in curbing the situation. Notwithstanding, the study noticed that there were a few occasions where the media tried to teach people in general on psychological illnesses in order to get rid of confusions and stigma and also to advocate for enhanced services as well as personnel

for that area. The study demonstrated how stigma keeps on dominating the discussion on mental disorders in Ghana (Mfoafo-M'Carthy, Sottie, & Gyan, 2016).

2.6 Economic consequences of caring for mentally-ill patients.

In 2009, about 66 million Americans (three in 10 U.S. households) revealed no less than one individual giving free care as a family caregiver. More adults with chronic conditions and disabilities find themselves at home than ever before, and family caregivers have a considerably more elevated amount of obligation. Looking after friends and family is related with a few advantages, including individual satisfaction. Be that as it may, providing care is likewise connected with physical, mental, and financial constraints. Essential care physicians can help in the identification, support, and treatment of caregivers by providing caregiver evaluations and interviews directed at recognizing high levels of burden as soon as caregivers are identified (Collins & Swartz, 2011).

Forty relatives of patients who were chosen from the South Verona Psychiatric Case Register and had interviews conducted for them. A structured evaluation tool was used. This determined objective burden, conduct of patients, adapting techniques, satisfaction and requirements for services. Positive and negative aspects of consequences were apparent, 92% of relatives were in touch with friends or relatives, 72% had no change to their family earnings, and 52% could deal with any family unit interruptions amid an emergency. The main negative effects for relatives included decreased recreational activities (57%) and psychological issues (67%). The main negative impacts were on relatives of patients who were male ($P = 0.016$), unemployed ($P = 0.013$) and determined to have psychosis (Samele & Manning, 2000).

Caregiver burden may come about as a result of providing care for patients with chronic illness. It can happen in any of the 43.5 million people offering help to midlife and older

grown-ups. The strain experienced by caregivers goes unnoticed by prescribers and other health workers. It was discovered that risk factors for caregiver burden included female sex, low educational attainment, living with the patient, longer number of hours spent giving care, depression, isolation from the society, financial constraints, and lack of choice in being a caregiver (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014).

Caregivers should be directed to appropriate resources for support, including national caregiving organizations, local area agencies on aging, Web sites, and respite care. Psychoeducational, skills-training, and therapeutic counseling interventions for caregivers of patients with chronic conditions such as dementia, cancer, stroke, and heart failure have shown small to moderate success in decreasing caregiver burden and increasing caregiver quality of life. Further research is needed to further identify strategies to offset caregiver stress, depression, and poor health outcomes. Additional support and anticipatory guidance for the care recipient and caregiver are particularly helpful during care transitions and at the care recipient's end of life (Collins & Swartz, 2011). A study done in Australia attests to the fact that schizophrenia is a very expensive illness to treat. According to the study schizophrenia affects not more than 10% of the number of patients suffering from myocardial infection, however, the cost of treating schizophrenia is 75% the estimated cost of treating myocardial infection (Davies et al., 1990).

In a study done by Rymer et al. (2002), dementia severity, functional impairment, awareness of memory deficit, and behavioral disturbance were measured and examined in relation to caregiver burden. Positive correlations were found between caregiver burden and both impaired awareness of memory deficit and behavioral disturbance. Regression analysis demonstrated that both impaired patient awareness of memory deficit and behavioural disturbance contributed to caregiver burden over and above dementia severity and functional impairment. However, when both were entered together into regression equations, only

behavioral disturbance contributed to caregiver burden. It was concluded that both patient awareness of memory deficit and behavioural disturbance impact caregiver burden, with behavioral disturbance making the greater contribution (Rymer et al., 2002).

In Nigeria, a study done showed that care giving is associated with emotional and cognitive transformations. The most important predictors of burden are problematical behaviour, disability and the severity of symptoms. Effective treatment is thus the first step to reduce burden. High expressed emotion may indicate the family's attempts to help the patient; and is mediated by controlling behaviour, stigma, burden, and caregiver perceptions of the patient's control over their own behaviour. Psycho-education is the most popular family intervention treatment (Ohaeri, 2003).

In Ghana, the burden of caregiving was measured using the WHO Impact of Caregiving Scale. Independent sample t-tests, correlations and analysis of variance were used to investigate associations between background characteristics and the burden of caregiving. Linear regression was used to examine determinants of the burden of caregiving. Results: The mean age of caregivers was 61 years (standard deviation 14.5), and the male:female ratio was approximately equal. On average, approximately two adults per household required care. Less than five percent of caregivers received financial, emotional, health, physical and personal care support. Place of residence, provision of financial, health and physical support to care recipients, and receipt of financial, physical and health support were significant determinants of the burden of caregiving. Conclusions: This study found a mismatch between the number of people needing care and the number of people providing care (Sanuade & Boatemaa, 2015).

2.7 Emotional consequences of caring for mentally-ill patients.

Caregivers of mental patients exhibit less satisfaction with quality of life largely due to some major emotional consequences. A review of literature revealed that care-giving is associated with emotional and cognitive transformations. They are frequently stressed and experience a lot of emotional burden (Fieldhouse & Conyett, 2012). The most important predictors of such burden are problematical behaviour, disability and the severity of such symptoms. According to a previous study by Grad and colleagues, more than half of caregivers in their study felt excessive anxiety due to worrying about the patient. A fifth of them attributed neurotic symptoms (insomnia, headaches, excessive irritability, and depression) to their concern about the patient's behaviour (Grad et al, 2010). Caregivers like family members or other relatives are central and provide not only practical help and personal care but also give emotional support, and they are suffering from plenty of challengeable tasks. These, eventually, cast out family caregivers into multidimensional problems prominently for mental distress like depression, anxiety, sleep problem and somatic disorder which are followed by physiologic changes and impaired health habits that ultimately lead to illness and possibly to death (Sintayehu, Mulat, Yohannis, Adera, & Fekade, 2015).

Effective treatment is thus the first step to reduce burden. High expressed emotion may indicate the family's attempts to help the patient; and is mediated by controlling behaviour, stigma, burden, and caregiver perceptions of the patient's control over their own behaviour. Psycho-education is the most popular family intervention treatment (Ohaeri, 2003). The study findings identified an array of coping strategies used by the family caregivers, including religious coping, emotional coping, acceptance, becoming engaged in leisure activities, and the use of traditional healing to help them cope with their mentally ill members.

In health sciences, caregiver burden refers to the collective set of stressful exposures or “stressors” that the caregiver faces (Friedemann-Sánchez & Griffin, 2011). Changes in the degree of depression experienced by caregivers have also been associated with the changes in disability and health status of their patients. As a chronic condition where episodes are frequent, these changes in patients’ well-being emotionally affect caregivers. Improvement in health, characterized by less visits to the hospital, bring joy and hope to caregivers. In a study exploring the experiences of informal family caregivers of persons with mental illness in a rural area in South Africa, data were collected through eight individual semistructured interviews of informal caregivers who cared for relatives with mental illness and collect medications monthly at a community clinic in the Makhuduthamaga local municipality in Limpopo. A qualitative research design was used, which was explorative, descriptive, and contextual. The data analysis revealed four major themes: (i) experiences of providing for physiological/physical needs; (ii) experiences of providing for emotional needs; (iii) experiences of providing for security needs; and (iv) experiences associated with the medical health-care programme. The study revealed that the experiences of family caregivers were conceptualized negatively, although the interview questions were intentionally neutral. This is believed to be due to the cultural explanatory models of mental illness prevalent in this region of South Africa. It is suggested that to increase compliance with medication, reduce relapse, and mitigate stigma associated mental illness, medical professionals need to incorporate aspects of cultural explanatory models into their explanations of the causes of illness. (Mavundla, Toth, & Mphelane, 2009).

In a study on Caregiver profiles and determinants of caregiving burden in Ghana by Sanuade et al (2015), it was found that less than five percent of caregivers received financial, emotional, health, physical and personal care support. Place of residence, provision of

financial, health and physical support to care recipients, and receipt of financial, physical and health support were significant determinants of the burden of caregiving.

Caregivers lack support and this has great impact on their emotions.

CHAPTER THREE

METHODOLOGY

3.0 INTRODUCTION

This chapter briefly presents some information about the study area, the design of the study, population and sampling technique. It also highlights data collection and analysing methods as well as ethical issues regarding the study.

3.1 STUDY AREA

This study was carried out at the out-patient department of the Accra Psychiatric hospital in Asylum down near Adabraka, about 500metres from the Greater Accra Regional hospital, Osu-Klottey district, Greater Accra region.

The Hospital was established as a Lunatic Asylum commissioned in 1906 for 200 inmates. It has undergone modifications to a Hospital with a bed capacity of 600. It used to have inpatients totalling 2,300 some time ago then later 1,200 (Annual performance review, Accra Psychiatric hospital, 2016). It functions under the Mental Health Authority which is semi-autonomous, as stipulated by the mental health act of 2012. The Hospital now operates within the whole catchment area of Accra Metropolitan, with a population of about 4.8 million extending to Tema, and some parts of Central, Eastern, Volta regions and the rest of the country.

The University of Ghana Medical School has a faculty established in the hospital for undergraduate training in psychiatry and postgraduate training under the West African College of Physicians(WACP).

3.2 DESIGN

A qualitative research design was employed to conduct the study amongst caregivers of patients visiting the Accra Psychiatric hospital for reviews at the OPD. This method was used because it was effective in obtaining specific information and opinions about caregivers of mentally-ill patients experiences during their care processes. It was also interpretive, gave clear reasons and understanding of the reality of the subject of burden on families (Polit & Beck, 2004). This study employed the narrative inquiry approach to describe the consequences. This provided individual stories to develop explore the problems by using inductive data analysis to learn about the meaning that participants hold about them through the identification of patterns or themes (Creswell, 2007).

3.3 POPULATION AND SAMPLE

A caregiver was defined as a family member of the patient who supported most, if not wholly, the patient's daily care needs physically, emotionally and financially. In the consulting room, folders of patients diagnosed with mental illness for at least 6 months were selected and caregivers who attended the hospital with the patients were identified. They were then asked to confirm if they were the main caregivers before the interview could proceed

3.4 SAMPLING TECHNIQUE

A purposive sampling method was used to select the 10 caregivers. To ensure adequate representation of all groups and to eliminate bias, caregivers were purposively selected based on their gender, age and socio-economic backgrounds. This was done by conducting a brief interview with them and asking them about their demographic information and their occupation as a proxy to determine their socio-economic background. . The interview was then conducted until at a certain point no new information was obtained and thus saturation attained. At This point, enough information had been obtained to answer the research

questions. In using purposive sampling, establishing rapport with participants to provide study access and yield valid data including the importance and elements of a good consent (Etikan, 2016). This is also needed to know the culture before one samples the population in order to find knowledgeable and reliable informants most efficiently.

3.5 INCLUSION AND EXCLUSION CRITERIA

Caregivers who had lived with the patient for greater than a year were included and those who refused to give written consent were excluded. Caregivers below age 18 were excluded in this study. It was ensured that every caregiver who participated in the study was not being paid for taking care of the patient.

3.6 DATA COLLECTION TOOLS

An interview guide was used to collect data relating to patient's illness and family income and employment; social and leisure activities of the family; domestic routine; health of primary caregiver; and relations with neighbours.

3.7 ETHICAL ISSUES

Ethics was sought from the Ghana Health Service Ethics Review Board (Ref number GHS-ERC067/01/18). Permission was also sought from authorities of the facility with a formal introductory letter obtained from the School of Public Health through the Social and Behavioural Science department. Informed consent was also sought from the caregivers/relatives before the interviews were conducted.

Informed consent

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

Confidentiality and Anonymity

Interviews were conducted in an enclosed setting to guarantee privacy. Names of caregivers were not used or recorded on the recorder in order to minimize the possibility of tracing information to respondent (caregiver). This was done to ensure confidentiality of information received from the participants.

Compensation

Each respondent was given an amount of GHS 5 for refreshment. This was done after the interview had been conducted using the interview guide.

Data storage and use

The recordings were transcribed and coded within 24 hours and subsequently kept in a safe cardboard of the staff office of the hospital on a password-protected laptop which was known only to the researcher. All information received from respondents by the principal researcher and copies were also saved on an external hard drive and on a CD-ROM. The data collected will be kept by the principal researcher for 3-4 years to allow for publication of research after which data on both the hard drive and CD-ROM will be deleted.

3.7 DATA ANALYSIS

The participants who were selected purposively were interviewed until saturation was attained by the 10th interview. At this point, answers from the caregivers had become repetitive and no new information was obtained. Thus, no one was interviewed beyond the tenth person.

They were all successfully interviewed and they all completed their interviews. The interviews were however conducted on different days for some of the caregivers. Interviews were done in the month of June 2018 and were all conducted by the researcher to ensure uniformity of information obtained. After caregivers of patients had signed the informed

consent, and permission sought, interviews were audio-recorded. The various responses were cleaned and errors corrected.

During the interview, questions were adequately explained to the respondents so as to avoid receiving vague or irrelevant answers. Respondents also had opportunity to clarify or adjust their responses for accuracy.

The one on one interview data were then transcribed by the researcher. Cross-checking of transcript with notes taken during the interviews contributed to the trustworthiness of the data. Transcripts were analysed using thematic analysis guided by the following research questions: What are the emotional, economic and social consequences for caregivers of mentally-ill patients attending the OPD of the Accra Psychiatric hospital. Data analysis were done by the researcher. All the transcripts were read through several times by the researcher, data were then coded and grouped into themes to enable abstraction and analysis. During the interviews, caregivers were given pseudonyms in order to further protect their true identity and to prevent tracing the information given back to them. They were also represented with codes that were serialized and each caregiver was represented by a figure ranging from 1-10. Qualitative research studies involve a continuous interplay between data collection and data analysis (Corbin & Strauss, 1994). For this reason, data analysis started from the first interview to begin identifying patterns, and to facilitate subsequent data collection. The first step in the data analysis process was transferring audio files to a password-protected laptop. Thematic analysis with NVivo 11 was used to organise the data and emerging themes were identified. Specific themes of interest included emotional, social and economic consequences of having a family member with mental health problems to families. In assigning codes for the primary documents, the research questions were referred to so that the codes could be related to the research questions. The transcribed data were then grouped

according to the themes developed from the subsequent familiarization with the data and participants' responses.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the findings of the study. The findings are described under four major themes which are in accordance with the study objectives. The chapter highlights the demographic characteristics of the participants and then the presentation of the themes identified.

4.2 Characteristics of participants

Ten participants comprising seven males and three females aged between 29 and 69 years participated in this study. Two out of the ten participants were aged below 40 years and the others more than 40 years. Seven out of the ten interviewees were married and were living with their spouses while two were single and another was separated from her husband. Most caregivers were very close relatives, that is, belonging to the nuclear families. One out of the ten caregivers belonged to the extended family of the patient. All caregivers had lived with the patients for between a period of one (1) year to thirty-three (33) years. Some had lived with the patients before the onset of the illness and others had to step in and take care of them after the illness started. One patient had been ill for six (6) months but the others ranged from one year to thirty-four (34) years, as duration of illness of the patients. Most of the participants lived in some part of Accra with the exception two who lived in Ho and Hohoe. Majority of the participants were gainfully employed or engaged in trading. Some were running their own businesses.

The estimated monthly income of the caregivers had the lowest being two hundred Ghana cedis (Ghc 200) and the highest being two thousand five hundred Ghana cedis (Ghc 2,500).

The highest earner was the Chief executive officer of his company while the least earner was an evangelist. However, one petty trader could not provide an estimate of the income generated from her selling of locally prepared drinks. Details of the demographic characteristics of participants are presented in Table 1.

Table 1: Details of caregivers(N=10)

Pseudonym	Interview date	Gender	Age (yrs)	Relationship To Patient	Marital Status	Place of Residence	Length of stay with patient	Number of years with illness	Occupation	Average monthly income(Ghc)
Mark	25/6/18	Male	54	Father	Married	Hohoe	21years	6 months	Trader	500
John	25/6/18	Male	49	Husband	Married	Kasoa	11years	6years	Evangelist	200
Tim	26/6/18	Male	54	Brother	Single	Kasoa	30years	30years	Public servant (accountant)	Below 2000
Daniel	26/6/18	Male	56	Brother	Married	Labone	5years	10years	Building contractor/ Secretary to chief	1000
Vivian	27/6/18	Female	58	Mother	Married	Achimota	10years	10years	Teacher	1200
Jerry	28/6/18	Male	69	Husband	Married	Kotobaabi	33years	5 years	CEO/Owner of Electrical Engineering company	2500
Ruth	28/6/18	Female		Wife	Married	Osu	20years	1 year	Petty trader	Not sure
Ken	28/6/18	Male	29	Son	Single	Abossey Okai	1 year	12 years	Graphic designer	1000-2000
Philip	29/6/18	Male	34	Nephew	Married	Bortianor	25years	34years	Procurement officer	1000
Mary	29/6/18	female	50	Mother	Separated	Ho	10years	31years	Caterer	1500

4.3 Summary of themes

All the data presented were obtained from interviews with these caregivers who attended the hospitals with their patients. The various themes were drawn from their statements made to questions posed by the researcher which were guided by an interview guide. These themes were emotional, social and economic consequences.

Under emotional consequences, sub themes generated include Depression, Anxiety, Strained marital relationships, psychological distress and physical ill-health.

Sub-themes generated under social consequences are family effects, risk of isolation, stigmatization, change in domestic routines, reduction in physical activity and reduced leisure

Sub-themes that were found under economic consequences are Loss of productive time, Loss of economic value and reduced quality of life.

4.3.1 Emotional consequences of caring for mentally-ill relatives

Caregivers in this study expressed marked emotional consequences experienced in their daily lives as they lived and cared for their mentally-ill relatives. Some of the emotional effects were worrying and frequently caused problems. Few relatives, however, could deal with such consequences though majority who couldn't deal with their emotional problems remained committed to caring for the patients. Caregivers mostly said they mainly endured without complaint but some wondered how long they could cope. There were four sub-themes discovered. These were depression, anxiety, strained marital relationships and psychological distress and ill-health.

Depression

Participants expressed deep worry about caring for relatives who were functionally impaired as a result of their mental illness and mentioned that they have experienced depression. Some said that this has been so especially because of the lack of understanding and the label that has been associated with the condition. Below are some of the excerpts of what some caregivers complained about:

“....First my mother did not allow me to come because of his behavior but I forced to come and it reached a certain stage I was not happy. I realized I was feeling too low and deeply sad anytime I am with him. It is extremely frustrating....Sometimes I feel very depressed. I mean, eerrm!!! Badly low in spirit...Do you get what I mean? When the illness comes.....he has to be forcibly brought home.” (Daniel)

“How can you live in a house with him and not feel depressed?” (John)

Another lamented;

—.....In actual fact, I will say thatwhat I've seen about the past 2 and half years, you have no idea. Sometimes,..... I get so so down in me, like, some depression ... or what? Sometimes she refuses to take her medication and I have to go the hospital.” (Jerry)

For a caregiver who took a deep breath when asked about how she has been affected, she simply responded as such:

“..Depressed? Yes a lot” (Ruth)

Relatives of mentally-ill patients mentioned the detrimental psychological effects they experienced. Some mentioned even neglecting their own health and eating poor-quality diet because of their depressed state. one caregiver said this:

“...I get so depressed that I cannot eat for long periods and take just bottle or two of beer” (Mary)

one participant intimated that caring for the mentally ill patient was more challenging than caring for a patient with physical disabilities. They will typically require more supervision and are less likely to express gratitude for the help they receive. This is an excerpt of the speech:

“It is even more depressing when you don't even receive thank you and she calls you names. For caring for accident victims, at least your thank you will not You won't miss that..”(Tim)

Strained marital relationships

Spouses had a lot of complains about the way their relationships have been affected. Marriage is to be enjoyed but some of the behaviour shown by patients was hard to bear, and negative symptoms such as misery, withdrawal, and worrying commonly caused problems. Interviewees mentioned that because they were the closest relatives to the patients, they experienced direct effects and their relationships were duly affected. Some participants felt that it was overwhelmingly affecting their sexual relationships with their partners and it was difficult to appreciate when a spouse was acting sad, angry, anxious or generally unpleasant and to attribute these to the illness. One has to exercise extreme caution and self-awareness when with the patient so as not to trigger unnecessary quarrels. They mentioned that it was difficult though important to separate one's spouse from their illness

and it was very natural to want to emotionally disconnect and safeguard one's self when one's spouse was exhibiting behaviour that seemed foreign from the person already known.

A caregiver said:

"When she is ill however she doesn't like me to come close..." (John)

Another added that:

"it affects me sleeping with her. Sometimes she used ... to just accuse me..Yes, the only way it affects me and if I am not careful we will just be fighting unnecessarily.."
(Jerry)

Though a participant alluded to the pride in fulfilling spousal responsibilities and enhanced closeness with a spouse receiver, the strain on their marriage could not be overemphasised.

"...my problem is that I expect a lot of improvement in his condition but I am not seeing that all..if he is asleep fine but...when he is awake and inside I call him out to meet our visitors. He is always sleeping, as a husband and I am his wife, I will concentrate on other things than us..."(Ruth)

Anxiety, Psychological Distress and Physical ill-health

Caregivers mentioned they experience psychological distress which could result in physical ill-health sometimes. Some mentioned that being a caregiver raised difficult personal issues about duty, responsibility, adequacy and guilt. Caring for a relative with a mental health problem was not a static process since the needs of the caregiver and recipient change as their condition changes. They said this could result in a lot of distress. They mentioned particularly adjusting to change, daily hassles and role strains. Carers have worried about whether their patients' basic needs have been met, which caused them a great deal of distress and sometimes anger towards self. Due to high burden and responsibilities, caregivers

experienced lower life satisfaction. It was mentioned that families who are caring for a mentally-ill relative are likely to experience high rates of physical ill health. There are some associated effects on the physical health of caregivers of mentally ill patients. Some relatives have suffered diseases such as migraines, diabetes and hypertension as a result of the stress they go through from caring for their patients. Sometimes, the strenuous nature of the care gets the better part of carers and their health gets affected. They said that they pay regular visits to the hospital for review and refill of their prescriptions. They had to keep to these tight schedules to ensure continuity of care for the patients. Some caregivers complained of frequent headaches resulting from poor sleep which they attributed largely to the taking care of their mentally-ill relatives. Some participants said they could not sleep well since their relatives were under their care and have had to get treatment themselves. One participant said:

“....Yes, it affects my sleep. Sometimes she used to talk whiles we are sleeping, accusing me that I have done a lot of things...” (Jerry)

Another added that:

“ I don't feel well at all, I cannot sleep...looking after him has been difficult. It's affecting my health” (Mark)

One participant said he had to adapt several times to the condition and this affected him:

“He changes a lot every time and I have to adjust...at first, it was bad but now it is much better. This is stressful because you have to change or adapt..” (Philip)

Some participant expressed his frustration this way:

“...it was not until she refused to take medication..... You have come to the hospital as soon as, you come and go many times. Transportation from the house to this place and we spend hours anytime. It takes us about 4 hours in all to see the doctor and go home” (Jerry)

Another caregiver added that:

“...by the grace of God, I don't think much and people have been advising me not to. Its terrible as you don't know whether you are doing the best for him. I can't do what I want to do. It's a responsibility...” (Vivian)

4.3.2 Social consequences of taking care of mentally ill relatives

According to the caregivers interviewed, they suffer social consequences as they care for their mentally ill patients. For many of them, despite the willingness to support their own family members, the social impact of their service was worrying.

Negative Family effects

The study revealed that there were consequences on the family as a result of living with a mentally-ill family member. Moreover, the study revealed that living with a mentally ill family member generated various societal responses. One of the responses was that society was callous with the families of mentally-ill. The community was unsympathetic, heartless, pitiless, or insensitive to families with a mentally ill family member. Among other consequences family members described the loss of freedom to socialize and participate in activities outside the home. Consequences highlighted were that caring for the mentally ill was a contractual obligation that left certain members in the family as their sole responsibility, duty, job, task, function, or liability.

One mother said:

“Formerly one other family member was supporting but now they’ve all left everything for me. He is my son, my job..” (Vivian)

A man who was looking after his mother said:

“There is no...no other support. She lives with me” (Ken)

Another man who was looking after his sister also had this to say:

“Hmm like I said, we live alone. I lock her up in the house, give her breakfast, lunch and supper together with instructions and then go to work. I am always worried about what may happen to her so I always rush home.” (Tim)

The family members interviewed also revealed another consequence that, it was unpleasant living with a mentally-ill family member. Family members used words like, terrible, disgusting and horrible as they expressed feeling resulting from living with a mentally ill family member.

A caregiver said:

“Sometimes he used to roam about and was very dirty and people would find him and him and bring him home...this is terrible” (Mary)

The other consequence to families was that mental illness became the prime focus and problem. Family members described living with a mentally ill family member as the biggest or largest problem the family had.

Risk of isolation

The study revealed that caregivers were at the risk of isolation from their communities. They had no friends from their immediate dwellings and people refused to freely associate with them. An interviewee explained as such:

“I am always worried about what may happen to her if I am no more. I don't even have friends.” (John)

one 54-year man mentioned that he could not keep a stable relationship because of caring for her sister. He had this to say:

“No, I am not married. It's because of her. I dedicated my whole life to taking care of her because everybody gave up. I couldn't marry because of her. She has been living with me for almost 30 years. The illness started over 30 years ago, when she was about to enter secondary school. I am now alone” (Tim)

Stigmatisation

The study revealed they experienced negative view, attitude, belief or actions placed on them which had negative effect. Usually, these behaviours were demeaning to them. They were often blamed wrong acts. At certain instances, the community blamed them for the occurrence of mental illness in their family member. When neighbours realised, they needed help with their patient, no one came to their aid. In a sad tone, one caregiver narrated:

“So every month we travel all the way here...we prefer here. Usually, we come the day before his review date and stay with my sister...and go back the following day. The neighbours behave somehow, they look at you somehow that is demeaning and distasteful...” (Mary)

Another added that:

“We have been ejected from previous rented houses...several times.... I am worried about the people in the area.. their attitude is not fine at all..as if we brought the disease on my sister. ” (Tim)

Some caregivers described societal response as discriminatory. A caregiver realised that people avoided them in the community. There was a misconception about the causes of mental illness and people held false impressions. He had this to say:

“..They said I am also sick...I mean, mad...” (Tim)

Reduction in physical activity

The study revealed that caregivers were socially restrained and could not be physically active as a result. During the interview, caregivers expressed concerns about some effects on their physical activities as they cared for their loved ones who happened to have psychiatric illness. They mentioned the effects on their physical activities. They usually have to keep an eye on these patients when they are around them so that, they can be adequately monitored. Some explained that, that is necessary because of past experience they have had where the mentally-ill patient had experienced sudden episodes and have led to serious consequences for them. This is more the case when the patient involved is a child. Some participants expressed their views in the following ways:

“..... actually, we are worried and you can't do anything but to sit around him..... we don't know how things will end” (Daniel)

An evangelist described how he has to hold on with all activities and just remain at home whenever his wife had a relapse:

“....when she is ill,....The only thing I am unable to do is to organize a church programme, I will have to stay with her till she is well before I do any physical activity... (John)

A mother narrates her frustration when asked about how this affected her movement:

“...You see....he was on admission for sometime, ...about a year. Hmm! During these times, it was difficult, you cannot do anything....movement...you are stuck”

(Vivian)

A 69 year old caregiver who had been taking care of his wife for five years said:

“Yes, the way it affects me is that I can't move out. When you want to move out she'll ask you several questions...” (Jerry)

Reduced leisure

To explore some specific effects of the social activities, some of the interviewees experienced some effects on leisure. They mentioned that the burdens of caring for a mentally-ill patient at home are considerable. They often affect the caring relative's leisure activities. It was difficult to engage in a lot of leisure activities when caring for them as a lot of dedication is required. It was explained that caring for such patients took a lot of time and leisure times are mostly spent with such patients. A lot of leisure time has to be sacrificed for caring for these patients. Caregivers have to prioritise for example taking their ill relatives to the hospital, supervising medication administration etc to engaging in leisure activities. It was practically impossible for carers to travel on vacation either alone or with their ill relatives since they were not sure of what would befall them. Excerpts of their concerns are provided below:

“...I can't travel, either alone or with him. I have to cut short my trips, I can't just do what I want to do.” (Vivian)

A young man expressed his frustration this way:

“ ...She is not making any effort to get on her feet. That is what worries me about her all the time and I can't even leave her to engage in any activities. She is more important to me so I just stay with her...” (Ken)

Routine domestic effects

There were complaints from some of the caregivers about the effect caring for mentally-ill individuals have had on domestic activities. Marriage is an institution in which people choose to live together because they can increase their utility by sharing and rearranging tasks, responsibilities and caring for children. Spouses in the study complained that they did not receive the required assistance required in the functioning of family life. They said they did not get enough time to contribute to household chores. A participant who was preparing to get married retorted:

“ Yes, It has affected my life, my wife to-be (fiancée) has a kid and even though I have rented a place for her, I can't sleep there. It affects my contribution to his upbringing especially and it bothers me a lot” (Ken)

A caregiver revealed another burden caring for the mental ill brings. Relatives have difficulties in understanding and coming to terms with illness-related behaviour at home. There has therefore been the need to obtain some form of training to adequately care for such relatives. It has become a part of domestic routines that requires mastery. A caregiver described his experience as below:

“With my uncle..... At first, it was bad but now it is much better....experience, I guess. After it became part of the domestic routines.” (Philip)

4.3.3 Economic consequences of taking care of mentally-ill relatives

The financial burdens of caring for a patient at home were considerable and resulted from mainly loss of productive time, and loss of economic value of caregivers. They had to meet the financial needs of the ill member besides meeting the treatment costs. Caregivers incurred regular cost on transportation, medicines, and living expenses. They mentioned that their mentally ill members did not engage in productive ventures and hence were huge financial burden on them. Most of them did not receive any support from elsewhere and had to bear their total cost. Most of the interviewees were self-employed and did not have regular incomes. They had to battle with bearing all the cost associated with caring for their relatives. Moreover, there have been economic distractions of their families as no proper financial planning can be made. Caring for these individuals also demands a lot of time and some interviewees mentioned the various effects it has had on their jobs. Some could not give their best to their trade as they cared for their loved ones. Below is an excerpt from a caregiver:

“..... Last medications cost us about 80 cedis. In all its about 100 cedis for a review because we pay twenty cedis for consultation.... Transportation costs 70 cedis in, 70 out. If you include taxi its 146 for us both.....Business is not good now so I make about 500 cedis profit a month. The whole month o!(Mark)

Loss of productive time

Three (3) out of the ten (10) interviewed worried about loss of working time because of caring for their ill relatives. Two more interviewees also mentioned that they could have engaged in more productive ventures if they were not caring for their mentally ill patients. They often have to sacrifice their economic activities to care of these patients. A caregiver narrated his experience:

“Normally we leave the house at 6am and get home 12pm, that’s about 6 hours. I could have been at work. And this is very regular It takes my time, the other time I had to leave because of time. It affects my work greatly..” (Daniel)

Another added that:

“We come here monthly but also see the psychologist in between but not all the time. I spend roughly 2 hours in and 2 hours out when coming to the hospital here. When she gets admitted that we spend 500 cedis on admission fee and even spend more on medications etc. during those periods, I have to even forgo more time with my job.” (John)

Angrily, this caregiver said:

“I am currently writing some exams but she doesn’t even allow me to study. She is not as calm as you see her to be. When she sees the doctor’s she is very well-behaved. She burnt my food yesterday.” (Tim)

Loss of Economic value

Caregivers mentioned that they had to spend out of their incomes to cater for their care recipients. These have sometimes resulted in financial problems. They secured treatment, buy medicines, provide food and shelter and other living expenses. Some feared it would introduce economic hardships into their families. Despite the low cost of treatment to the mentally ill patients in the country, there were other indirect costs associated with their care that should be borne by the caregivers. Usually, interviewees have had to suspend meeting their needs to provide resources for their ill members. Caregivers could not keep their jobs for a long time due to constant interruptions that result from spending more time caring for their relatives. A caregiver who had previously lost his job had this to say:

“I am an accountant with the audit or general’s department. It’s a new job I got. I lost my former job because of her. I was always asking for permission to bring her to the hospital or to take care of her. They even said I was also sick.” (Tim)

Participants lamented also on the huge expenses involved in taking care of their relatives.

One caregiver had this to say about that:

“The cost of the medications was about two hundred cedis, at first it was 134 and now its 220 cedis and then everyday I attend the hospital, there is transportation cost...and I am paid only 1000 cedis a month. How do I survive?” (Philip)

A middle-aged petty trader who was taking care of her husband said:

“...its just me and my children. I spend ten cedis, in and out... when we are coming, I take dropping (hired taxi) and then 200 cedis every month on drugs. And I sell sobolo.. I can’t say how much be because it varies from day to day. Sometimes by 3pm its all finished, sometimes even by 10 pm its not finished. It is very draining taking care of him..” (Ruth)

When asked if taking care of his mom was affordable, This caregiver said this in a disgruntled tone:

“Errrm! In terms of cost, I spend over 700 cedis every month to see the physician and then 100 for a dietician. The drugs alone are expensive...about 200 cedis here and there and what is worrying is she is not making any effort to get on her feet. That is what worries me about her all the time. Though I am doing my own job, I am a graphic designer and my income is not constant. Sometimes I only earn 1000 cedis in a month” (Ken)

Another caregiver said:

“I take 30 cedis daily for taxi and then drugs. I spend all by myself. Formerly my brother was supporting but he went on retirement so doesn't support anymore. His sister who supports me now, not really financially but in other ways.” (Vivian)

Reduced quality of life

Participants intimated that they could have better quality of life if they did not have to care for their mentally-ill relatives but because they spent a lot of money on their relatives, their own standard of living had to be compromised. A young man who was looking after his mother said:

“.....Yes, It has affected my life, my wife to-be has a kid It affects my contribution to his upbringing especially and it bothers me a lot” (Ken)

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the findings generated from the data collected which were in relation to the existing literature reviewed in the study area. The study was designed to examine the emotional, social and economic consequences on families as a result of taking care of mentally-ill relatives. The study was limited to caregivers who were relatives that attended clinic with their patients and shared their personal experiences.

The study found that the burden of care was more defined by their impacts and consequences on caregivers and they included the emotional, economic and social impact. There were embedded in these, subtle but distressing notions like shame, embarrassment, feelings of guilt, self-blame and self-pity (Awad & Voruganti 2008; Singh & Prajapati, 2013). The consequences of caring for the mentally-ill relative is a complex construct that authors agree challenges simple definition. Some researchers have categorized it as either subjective or objective (Awad & Voruganti, 2008). In this study, the objective burden of care included effects on household such as taking care of daily tasks whereas the subjective burden of care indicates the extent to which the caregivers perceived the burden of care. There are however explored important determinants and factors that likely contribute the caregiver's perception of the burden of care. In our study, though they were burdened, their cultural construct held them bound to accepting caring for their relatives as a responsibility. However, investigators have found other factors like male gender and ethnicity issues as subjective contributors to burden of care (Ozlu et al, 2015).

5.3 Emotional consequences of caring for mentally-ill relatives

From the study, it was revealed that caring for mentally-ill relatives was emotionally draining. This caused strained marital relationships, psychological distress, anxiety, excessive worry and in some cases, depression. According to a previous study, more than half of the informants felt excessive anxiety due, they said, to worrying about the patient. A fifth of them attributed neurotic symptoms (insomnia, headaches, excessive irritability, and depression) to their concern about the patient's behavior (Grad et al, 2010).

In Nigeria, a study done on The burden of caregiving in families with a mental illness: a review of 2002, *Current Opinion in Psychiatry*, showed that care-giving is associated with emotional and cognitive transformations. The most important predictors of burden are problematical behaviour, disability and the severity of symptoms. Effective treatment is thus the first step to reduce burden. High expressed emotion may indicate the family's attempts to help the patient; and is mediated by controlling behaviour, stigma, burden, and caregiver perceptions of the patient's control over their own behaviour. Psycho-education is the most popular family intervention treatment (Ohaeri, 2003). In health sciences, caregiver burden refers to the collective set of stressful exposures or "stressors" that the caregiver faces (Friedemann-Sánchez & Griffin, 2011).

Previous studies have identified factors that may influence caregivers' burden. These include; caregiver's characteristics, care recipient characteristics, caregiver's resources, and caregiver's support characteristics. (Chang, Chiou, & Chen, 2010) Caregiver characteristics, such as gender, age, and kinship to the care recipient, have consistently been associated with strain (Sanuade & Boatemaa, 2015). The study showed that nine out of ten caregivers were first relatives who were part of the nuclear family and one was part of the extended family. The closer relations experienced more burden as compared to the more distant ones.

Caregivers play an important role in the management of chronic mental illness in the community. Caring for patients with chronic mental illness like schizophrenia can cause emotional distress in the caregivers. However, the magnitude of the problem remains largely unknown in Sub-Saharan Africa and other developing countries (Yusuf & Nuhu, 2011).

5.4 Economic consequences of caring for mentally-ill relatives

The World Mental Health has stated that mental disorders occur commonly across the world and often impairs many countries financially (Kessler et al, 2011). In the United States for example, it is estimated to contribute 6.2% of the nation's health care cost (Insel, 2008). This study showed that treating and caring for patients with mental illnesses were expensive and a chronic venture, thus putting unnecessary strain on families. Most caregivers were not formally employed, had little disposable incomes with no external financial support especially from family members and so had to bear the financial burden alone. A study done in Australia attests to the fact that mental illness is a very expensive illness to treat (Bosanac & Castle, 2012). According to their study schizophrenia affects not more than 10% of the number of patients suffering from myocardial infection, however, the cost of treating schizophrenia was 75% the estimated cost of treating myocardial infection.

This study found that the main financial effects of caregivers included loss of productive time as it took them at least four hours once a month to see the doctor, in addition to the emergency visit. This led to disruptions in their work and business resulting in loss of income. Being a caregiver in some cases required full attention and therefore some could just not work and had to rely on their family members to support financially. The social and leisure activities of a third of the families had been restricted; nearly a third have had their domestic routine upset (housework, shopping and so on); about a quarter have had their income reduced by at least 10%, and a tenth by more than half.

Although the cost of caregiving was considered to be a significant part of incomes, there varied widely among families and there were no reliable estimates of the costs associated with such care. The financial burden of care is known to be a complex construct and would require appropriate methodology for its costing. Unlike other medical disorders, the costs of mental disorders are more ‘indirect’ than direct. The study revealed the direct costs as including medication, clinic visits or hospitalization. The indirect costs are those incurred through reduced production time, reduced educational attainment and cost associated with other consequences such serious mental illness leading to admissions (Inselet al, 2008). In the study, caregivers had to prepare to forego their economic activities to attend to episodes of severe ill health of their relatives. Such cost on the relatives were huge and investigators fear it could increase but there is an urgent need to develop reliable approaches to generate data that can inform in policy making and organization of care services.

Another important cost incurred related to the personal upkeep of the mentally ill patients. Usually, these patients do not generate incomes and hence caregivers are solely providers of feeding, clothing, shelter and other personal items.

In Ghana, the burden of caregiving was measured using the WHO Impact of Caregiving Scale. On average, approximately two adults per household required care. Less than five percent of caregivers received financial, emotional, health, physical and personal care support. Place of residence, provision of financial, health and physical support to care recipients, and receipt of financial, physical and health support were significant determinants of the burden of caregiving. Conclusions: This study found a mismatch between the number of people needing care and the number of people providing care.(Sanuade & Boatemaa, 2015). This study therefore confirms that caregivers are over-burdened and haven’t got the necessary emotional, physical and economic support.

5.5 Social consequences of caring for mentally-ill relatives.

The study revealed that caregivers suffered numerous social consequences. These include negative social effects on the family, risk of isolation of the family and stigmatization. In Ghana, Ngissah (1975) compared the attitudes of 564 American High School and College students from Sacramento (California) with 280 Ghanaian High School and College Students from Accra towards the mentally ill. Result shows a more negative and rejecting attitudes towards mentally ill persons in the Ghanaian sample. 57.9% of the Ghanaian respondents held the view that mental illness in the family brings shame on the family name and 57.5% that it is wise to keep it a secret as much as possible, 60.4% of the Ghanaian participants felt that mental illness is not an illness like other illnesses, 78.9% agreed that patients in mental hospital are like children and 71.8% subscribed to the opinion that anyone hospitalized for a mental illness should be banned from voting.

People with mental illnesses suffer from negative social attitudes which result from stigma and misconceptions of mental health problems (P W Corrigan & Penn, 1999). This study showed that attitude towards mental health hasn't changed and caregivers burden is increased as a result of social consequences especially stigma. Stigma is described as consisting of difficulties in knowledge (ignorance and misinformation), attitudes (prejudice) and behavior (discrimination) (CA et al, 2009). The findings in this study is also supported by the recognition of the attribute assigned to stigmatized person to be 'reduce from a whole and usual person to a tainted or discounted one' (Brohan et al, 2010). This phenomenon even originates from people who are supposed to know better. In a study of nurses with mental illness, it was discovered that nursing peers who generally considered the disease acceptable within the context of nursing culture, showed negative stereotyping (Peterson, 2017). Supervision and other opportunities for professional development of the participants in this study were connected with particular labels to negative characteristics that was based mainly

on cultural reactions to the conditions. Unfortunately, stigma has pernicious effects on the lives of people with serious mental illnesses of people with serious mental illnesses and may even interfere with mental health service use. Like an author wrote: Stigma of mental illness is an attribute that is deeply discrediting (Brohan et al.,2010). Accordingly, stigma is also known as a form of social deviance that leads others to judge an individual as illegitimate for participation in any social interaction (Elliott, Ziegler, Altman, & Scott, 1982).

With the attendant huge demands and challenges associated with caring for the mentally ill patient, it has been found out that family caregivers with greater family demands but less social support experienced higher degrees of caregiver burden (Hsiao, 2010). In our study, very little social support was obtained by the caregivers unlike in other studies (Chadda 2014; Turner & Brown 2010; Kilbourne et al., 2007)

The study revealed that caregivers of mentally-ill patients also experiences different physical effects. These includes physical ill health, reduction in physical activity, reduced leisure and some effects on ability to undertake routine domestic activities. In a study by Schulz et al (2008) which studied the physical and mental health effects on families of mentally ill patients, they also found evidence of health effects of caregiving. They noted that data gathered over two decades showed that it was a major public health issue that needed policymakers' interventions. Clinical observation and early empirical research further showed that assuming a caregiving role resulted in all the features of some form of mental illness (Tracy & Biegel, 1994). Another study also showed the important influence of mental health on caregiver's physical health and recommended the need for interventions for caregivers to target health in a holistic way (Chang, Chiou, & Chen, 2010).

LIMITATIONS OF THE STUDY

Though the study was generally insightful, some challenges were encountered which could be improved upon in further studies.

By the time a sample size of ten was attained, no new information was obtained and thus saturation was reached quite early.

Also, caregivers were mainly from Accra except two who were from the Volta region. This study cannot be generalized as people from all regions were not equally represented, especially those in the three northern regions that experience extreme poverty and lack of health personnel and facilities.

Some transcripts had to be translated from Twi to English before they were transcribed. As a result, some information may have been lost in the process.

CHAPTER SIX

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATION

6.1 Introduction

This is the final chapter, which comprises an overview of the study, emphasising the major findings to draw conclusions. This chapter will also make recommendations of the study and suggest areas for further research.

6.2 Summary Of Findings

Many caregivers were very close relatives of patients and they experienced numerous emotional, social and economic consequences that affected their lives. Moreover, there were other physical effects such as physical ill health as a result of caring for such relatives.

The emotional consequences for caregivers included depression, anxiety, strained marital relations and psychological distress that resulted in physical ill-health.

The economic consequences for caring mentally ill relatives included experiencing financial burden through the loss of productive time and loss of economic value to the family. Caregivers had to sacrifice economic activities to spend time to stay, monitor closely, send them treatment and regular reviews and generally care for the mentally-ill relatives. This resulted in reduced quality of life for both the caregivers and other members of the family, especially dependents of the caregiver.

The social consequences to caregivers included loss of freedom to socialize and risk of isolation where caregivers are neglected by other members of the family and community and perceived it as an obligation. They experienced stigmatization which was exhibited as negative attitudes and were often blamed by the community for societal ills. They also

experienced reduction in leisure as well as physical activity which was detrimental to their health.

Despite the numerous consequences of caring for mentally ill relatives, caregivers were committed and determined to continue to stay and care for their patients. They however would be happy to receive some form of support in order to lessen the consequences.,

6.3 Conclusions

Emotional Consequences of taking care of mentally-ill relatives

From the study, it was found that caring for mentally-ill relatives had dire emotional consequences. These consequences were found to include depression, strained marital relations, anxiety and psychological distress that could result in physical ill-health. Caregivers expressed that they found it difficult to sleep, had lost appetite and were extremely sad, especially when their patients had a relapse or there was no improvement in their condition. These consequences worsened with increasing duration of illness and length of stay with patient.

Social Consequences of taking care of mentally-ill relatives

Mental illness is known to be debilitating affecting both the patient, caregiver and the society in general. It could be chronic and may incapacitate affected individuals for life. Consequently, it often affects the caregiver's social life. It increases the risk of isolation from society as people shun the family, stigmatization is high and this results in reduced leisure activities. It also promotes physical inactivity and causes a change in domestic routines of families, as adjustments have to be made to accommodate the patient and his needs.

Economic Consequences of taking care of mentally-ill relatives

Financial problems arise frequently as a result of taking care of mentally-ill relatives. This includes loss of productive time, loss of economic value and reduced quality of life of caregivers and their families, especially dependents. This is because most caregivers spent most of their day taking care of their mentally-ill relatives and so do not have enough time to work and make sufficient funds. When they do, they spend most of their earnings attending to health needs of the patients, reducing the amount of money available to the rest of the family.

6.4 Recommendations

These include suggestions based on emotional, social and economic consequences that were observed in the study.

Recommendations to reduce emotional consequences

The Mental Health Authority has been established as the main body responsible for mental health in Ghana. The onus lies on the authority to improve upon mental health in Ghana. It is imperative that clinicians and mental healthcare providers who come into direct contact with caregivers try to ease the burden.

Caregiver burden should not be overlooked by clinicians and health care managers. Once a patient has a constant caregiver, clinicians must establish a relationship with the caregiver such that the caregiver can at any point voice out their emotions. Mental health care providers should make it a point to ask about the welfare of the caregivers accompanying patients and make an attempt to find out about their social circumstances.

The Mental health Authority in collaboration with Medical Directors and heads of hospitals especially psychiatric hospitals should consider the creation of support groups and

associations for caregivers, associations that could meet quarterly when they take their patients for review at the hospital. At these meetings, they can share their problems and may find solutions from others, especially the more experienced caregivers. This would also be a form of socialisation for some caregivers who hardly get the chance to do so. At these meetings, psychologists can also be invited to counsel caregivers on how to manage the stress associated with care-giving. Psychoeducational, skills-training, and therapeutic counseling interventions for caregivers of patients with chronic conditions such as schizophrenia will help to reduce the stress.

Medical Directors and heads of hospitals should organise psychologists and nurses to give open talks and educate the caregivers as they sit at the waiting area of the out-patient department of the hospital, waiting to be seen by a doctor.

Churches and religious organisations should recognise the impact of caregiving on the caregivers and support them. This could be through forming groups concerned with the welfare of such caregivers. The emotional, social and economic needs if subsidised by the church will help to lessen the consequences these caregivers experience in taking care of mentally-ill patients.

Recommendations to reduce social consequences

Education by various agencies including the ministry of health, mental health authority and the various psychiatric hospitals should be done on mental health issues. This can be done in hospitals, on television and radio, social media, web sites, market places and at health programmes.

Education could be in the form of short sketches, messages, talks and posters. The focus of the education should be making more people aware about mental illnesses, causes and treatments available. This will go a long way to reduce stigma in the society.

Recommendations to reduce economic consequences

The Mental Health Authority should impress on the government the need to pass the mental health bill which from the mental health act of 2012, will make mental health completely free as a result of levies that will be taken from workers' salaries and the consolidated fund. This will increase accessibility to mental health care and promote the well-being of patients and thus encourage good prognosis, eventually decreasing the burden on caregivers. This is imperative as most patients are in no position to earn an income and so depend solely on others for financial support.

Again, the Government needs to put Mental Health care on the National Health insurance system (NHIS). This will go a long way to reduce the consequences, especially the economic consequences of taking care of mentally-ill relatives.

Government, NGO'S and the Mental Health Authority should provide research grants for deeper research to be done on burden of caregivers

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APPENDICES

APPENDIX 1: INTERVIEW GUIDE

Initials..... Age.....

Sex.....

Marital Status.....

Home Location.....

Length of stay with patient.....

Duration of illness of patient.....

Occupation of caregiver.....

Frequency of visits to hospital.....

Time it takes to visit the hospital.....

Monthly cost of medications.....

Cost of transportation.....

Average income of caregiver.....

Stigma.....

Support from other family members.....

Quality of life of caregiver eg sleep pattern, feeling anxious, Ability to engage in other social activities, hosting friends at home, etc.....

APPENDIX 2: VOLUNTARY CONSENT FORM

Voluntary Consent

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

.....

Caregiver Name Signature Thumbprint Date

.....

Witness Name Signature Thumbprint Date

.....

Name of Researcher Signature Thumbprint Date

.....

Name of interviewee Signature Thumbprint Date

Interviewer’s Statement

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

Signature of the interviewer

Date

Address

.....

If you have any question later please, contact

Researcher: Naa Adoley Addo (0207049592)

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

Appendix 3**Table 2: A Table representing the codes and pseudonyms of participants**

CODE	PSEUDONYM
001	Mark
002	John
003	Tim
004	Daniel
005	Vivian
006	Jerry
007	Ruth
008	Ken
009	Philip
010	Mary

Appendix 4

Themes and Sub-Themes for consequences of caring for mentally- ill patients

Theme	Sub-Themes
Emotional consequences	<ul style="list-style-type: none"> • Depression • Strain in marital relationship • Psychological Distress and physical ill-health • Anxiety
Economic consequences	<ul style="list-style-type: none"> • Loss of productive time • Economic distractions • Reduced quality of life
Social consequences	<ul style="list-style-type: none"> • Family effects • Risk of isolation • Stigmatisation • Reduction in physical activity • Reduced leisure • Change in domestic routines

APPENDIX 5: ETHICAL APPROVAL

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

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



Research & Development Division
 Ghana Health Service
 P. O. Box MB 190
 Accra
 Tel: +233-302-681109
 Fax + 233-302-685424
 Email: ghserc@gmail.com
 22nd May, 2018

MyRef: GHS/RDD/ERC/Admin/App 18/289
 Your Ref. No.

Naa Adoley Addo
 University of Ghana
 School of Public Health
 Legon, Accra

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

GHS-ERC Number	GHS-ERC067/01/18
Project Title	Providing Mental Health Care to Patients: Social and Economic Consequences on Families
Approval Date	22 nd May, 2018
Expiry Date	21 st May, 2019
GHS-ERC Decision	Approved

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report **after completion** of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly 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