SCHOOL OF PUBLIC HEALTH, COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON

THE BURDEN OF MENTAL HEALTH CARE ON FAMILY CAREGIVERS IN THE TAMALE METROPOLIS

BY

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DECLARATION

I, YUSSIF HAMDAN ADAM, hereby declare that, this thesis is my own work from a study carried out in Tamale, the capital city of the Northern region of Ghana. This thesis was written under the supervision of my academic supervisors, Professor Stephen Collins Ahorlu, Dr. Ibrahim Abdallah, Dr. Emmanuel Asampong, and Dr. Franklin Glozah. As far as I am aware, this thesis has not been submitted in part or in whole to any University for the award of any degree or certificate.

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DEDICATION

The thesis is dedicated to my wife Sirina Musah, for the adoration during those daunting periods in the course of the PhD journey, and also for the sacrifices she made during my long absence from home; and to all the individuals taking care of the sick, for the sacrifices, steadfastness, empathy, devotion and being there for them. Looking after the ill person, especially with a mental illness can be daunting and create a lot of difficulties. I am touched by your staunch devotion to duty and responsibility, in the face of physical, financial and emotional difficulties that you are confronted with. You provide an important contribution to the sustenance of human dignity, and your sacrifices has caught the attention of many.

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ABSTRACT

Background: Caring for mentally ill relatives could have adverse effects for caregivers, care-recipients, and society in general, and may contributes to psychiatric morbidity. Despite the general acknowledgement of the adverse consequences of caring for mentally ill persons for individuals and society, a vacuum still exists in research to assess the problem, strategies and policies to address mental health related caregiver burden in Ghana. This study sought to examine the experiences of family caregivers in their care giving roles to relatives with mental illness in order to engineer programmes targeted at contributing to improving and maintaining the quality of life among this critical population in Ghana.

Methods: A cross-sectional study design that employed mixed methods was used for the conduct of the research. An EMIC questionnaire, Zarit Burden Interview scale, General Health Questionnaire (GHQ12), Family Stigma Scale (FSS) and key Informant Interview guide were used to collect quantitative data from 293 respondents and qualitative data from ten key-informants. Correlational and hierarchical multiple linear regression analyses were used to examine the relationship between the independent and dependent variables of the study.

Results: The finding of the study was that, caregiver burden is rife among caregivers of mentally ill relatives in the Tamale metropolitan area. All caregivers interviewed in this study agreed that they experienced negative emotional, psycho-social, financial and physiological effects in their daily lives on account of taking care for a mentally ill individual who is a relative.

Conclusion: Caregiving role-strain, low self-efficacy, feeling overwhelmed, learned-helplessness, and moral guilt were established as predicting factors for caregiver burden at 5% level of significance in the study area.

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LIST OF ABBREVIATIONS

Abbreviation	**Meaning**
ABS	Australian Bureau of Statistics
ADL	Activities of Daily Living
CPO	Community Psychiatric Officer
DALY	Disability Adjusted Life Years
EMIC	Explanatory Model Interview Catalogue
ERC	Ethical Review Committee
FSS	Family Stigma Scale
GAF	Global Assessment of Functioning
GBD	Global Burden of Disease
GHQ	General Health Questionnaire
GHS	Ghana Health Service
GSS	Ghana Statistical Service
H	Helplessness
HS	Help-Seeking
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Disease
IDIs	In-depth Interviews
IQR	Inter Quartile Range
KMO	Kaizer Meyer Olkins
LB	Level of Burden
LMIICs	Low- and Middle-Income Countries
LSE	Low Self-Efficacy
LTSS	Long-Term Services and Support
MG	Moral Guilt
MSA	Measure of Sampling Adequacy
NGO	Non-governmental Organisation
NHIS	National Health Insurance Scheme
OW	Overwhelmed
PC	Perceived Causes
PCV	Primary Care Version
PD	Pattern of Distress
PNO	Psychiatric Nursing Officer
QoL	Quality of Life
RS	Role Strain
SDGs	Sustainable Development Goals
SUPPORT	Study to Understand Patient Presences for Outcomes and Risk of treatment Trials
TCH	Tamale Central Hospital
TCHPU	Tamale Central Hospital Psychiatric Unit

THDSS	Tamale Health and Demographic Surveillance System
TTH	Tamale Teaching Hospital
TWH	Tamale West Hospital
WFMH	World Federation of Mental Health
WHO	World Health Organisation
YLD	Years Lived with Disability
ZBCS	Zarit Burden of Care Scale

CHAPTER ONE

INTRODUCTION

1.1 Background

The World Health Organization (WHO) defines health as a condition of complete physical, mental, and social well-being, rather than simply the absence of sickness or disability (WHO, 2014; WHO, 2013). Thus, mental health is a critical component of health, which the WHO defines as a state of well-being in which each individual realizes his or her full potential, is capable of coping with normal life stresses, is capable of working productively and fruitfully, and is capable of contributing to his or her community (WHO, 2014). In light of this definition, it is worth emphasising that the absence of mental health diseases does not always imply the presence of mental health (Keyes, 2005). Thus, people suffering from mental diseases can also benefit from and contribute to human welfare, allowing them to maintain a reasonable standard of living despite the limitations imposed by their disabilities (Keyes, 2005).

Mental illness entails significant public health challenges that affect not just those who are afflicted, but also their family and the communities in which they reside. The global mental health care agenda emphasises community-based care while downplaying institutional care. As a result, numerous countries have begun deinstitutionalising mental health care. In Ghana, the deinstitutionalisation of mental health care services has shifted the responsibility and accountability for caring for persons with mental disorders away from health care professionals and onto informal caregivers who have little or no training in caring for people with mental disorders (Opoku-Boateng et. al., 2017).

Mental health disorders such as severe depression, bipolar disorder, and schizophrenia are serious disease states that have a tendency to deteriorate and result in impairments in multiple areas of functioning (Fekadu et al., 2019). Mental problems can impair productivity and are associated with an increased risk of physical illness co-morbidity and death. The debilitating effects of mental diseases reach well beyond the individual suffering from the disorder to their family members and the community in which they live. The impact may be greater in low- and middle-income countries (LMICs), where there is a significant treatment gap for mental diseases (Ae-Ngibise et al., 2015; Jenkins et al., 2008). In LMICs, community members or families may bear the weight of caring for relatives who suffer from mental illness, with consequences extending well beyond generations (Fekadu et al., 2019; Ae-Ngibise et al., 2015; Jenkins et al., 2008).

Providing care for someone with a mental illness has a significant financial cost in terms of social relationships, income-generating activities, and work, as well as psychological well-being (Thornicroft & Patel, 2014). Many families may fear for their future health and the distress and humiliation associated with caring for family who suffer from mental illness. Caregivers of individuals with mental disorders may suffer from serious physical health problems and require more medical attention than families who are not affected by such tragedies (Thornicroft & Patel, 2014).

Fekadu et al. (2019) discovered that mental diseases have intergenerational repercussions. As a result, children born to adults who have mental problems may have an increased risk of having both physical and mental illness. This could be due to hereditary vulnerability, the strain of caring for unwell relatives, financial challenges, or the stigma involved with caring for someone who is mentally ill and doubles as a relative. The effect on children is cumulative and has a long-term effect on their adult health and relationships. These concealed and unrecognised consequences may have an influence on the person who is ill, the primary caregiver, and the community at large. These implications may be more severe in LMICs, where the kinship system is more extensive, with fewer or no safety nets and a high level of shame and prejudice.

Mental health disorders account for a significant portion of the worldwide burden of disease (Vigo et al., 2016; Mathers et al., 2008), and this burden is a result of the illness's debilitating character, not only for those who are ill but also for family caregivers (Heller et al., 1997). Prior to the early 1950s, institutionalisation of individuals suffering from mental illness was the norm in many parts of the world, but by the late 1950's and beyond, the process of de-institutionalisation had shifted the care and treatment of mental health patients away from hospitals and toward their communities of residence (Alzahrani et al., 2017; Thompson Jr. & Doll, 1982). The move had a significant impact on the mental health care system, particularly on main caregivers for people with mental illness. This is because family members are required to accept entire responsibility for the care and management of their mentally ill relatives, a task for which they were not fully prepared (Sartorius, 1996).

In the Ghanaian context, deinstitutionalisation of mental health treatment (Ghana Mental Health Act 2012 - Act 846) was an important milestone in the country's mental health care reform. The idea was to establish and enable community-based care and treatment for those suffering from mental illness, while also attempting to alleviate the overcrowding of Ghana's three public psychiatric hospitals, which are located in two regions of southern Ghana. This initiative has encountered obstacles ranging from inadequate infrastructure to insufficient fiscal and human resources in the field of mental health care (Kretchy et al., 2018). With slightly more than 90% of patients suffering from mental health care diseases receiving care from family members, the role of informal carers in this deinstitutionalisation effort is critical (Chadda, 2014).

The Tamale Central Hospital Psychiatric Unit (TCHPU), which is situated in the study setting, has a register of individuals with mental health disorders. A total of 1084 family/primary caregivers and their relatives suffering from various types of mental health disorders like depression, schizophrenia, and bipolar disorders were recorded respectively in the case register for the period of January to December 2018. This alarming situation among other considerations therefore informed the choice of the study setting.

Depression, which is a major component of mental health disorders, is responsible for about 300 million cases of mental disorders globally and is the single largest contributor to the global disease burden (WHO, 2017). The majority of mental diseases, including depression, are connected with an elevated risk of suicide or suicidal ideation, and the global suicide rate is increasing as a result of untreated mental health disorders (Lancet, 2016). Over 800,000 people die each year as a result of suicide, with suicide being the second leading cause of mortality among 15 to 29-year-olds (Lancet, 2016). This issue is critical in Low and Middle-Income Countries (LMICs), which account for more than 70% of the worldwide mental health burden (Alloh et al., 2018).

Though all nations are touched by the problem of mental health illnesses, some nations are disproportionately afflicted, particularly those that have experienced natural disasters that result in economic distress and poverty (Alloh et al., 2018). Nations experiencing such difficulties are disproportionately located in LMICs, making it more difficult for them to achieve the Sustainable Development Goals (SDGs) targets by 2030; particularly goal 3, which reaffirmed the commitment to reduce untimely deaths from non-communicable diseases by a third, particularly mental health well-being, which continues to be a significant gap for sustainable development (WHO, 2015). As a result, it is critical to prioritise mental health issues in these countries by addressing stigma and discrimination, negative sociocultural practices, gender inequity, and poverty in order to scale up recovery in access to mental health care (WHO, 2015).

According to WHO (2015), there is a manpower shortage in LMICs to support persons suffering from mental health illnesses; for example, there is an estimated 1 health worker per 100,000 people in LMICs, compared to more than 50 in High-Income Countries (HICs). There is a significant shortage of health staff, with about 239,000 health care personnel estimated to be required for adequate care in LMICs. For instance, Nigeria has only 150 psychiatrists (less than one per million inhabitants) and only five psychiatric nurses per 100,000 people, despite the country's population of more than 186 million (Alloh et al., 2018). Ghana has only three psychiatric hospitals located in two regions of southern Ghana (two in Greater Accra and one in Central), serving a population of around 32 million people. Ghana's 2012 Mental Health Act (Act 846), on the other hand, seeks to promote community-based care while de-emphasising institutional-based care, with the goal of decongesting the country's three psychiatric hospitals, however this has yet to be implemented.

1.2 Problem Statement

The estimated prevalence of mental health disorders for the adult population is 13% in Ghana (National Academies of Sciences, Engineering & Medicine., 2016; WHO, 2015), and accordingly, only two individuals out of every one hundred with mental health disorders will get the needed care. Inadequate care and treatment can lead to a vicious cycle poverty and social exclusion for those suffering from the disorder and their family members. Of the estimated 32 million Ghanaians, 3% are suffering from severe mental health disorders whilst 10% are suffering from mild to moderate mental health disorders (National Academies of Sciences, Engineering & Medicine., 2016 ; WHO, 2015). Mental health disorders are a leading cause of YLD in Ghana, behind iron deficient anemia (National Academies of Sciences, Engineering & Medicine., 2016).The treatment coverage for the whole country is estimated to be only 2% of the population, leaving a treatment gap of 98% of expected mental disorders (WHO, 2015). This staggering data will have a ripple effect on the expected informal caregivers that will be tasked with the challenge of shouldering responsibility of caring for the unfortunate relatives who will fall as victims to the disease.

The increasing incidence of mental health conditions coupled with the deinstitutionalisation of mental health care requires structural arrangements at home to cater for physical, mental and psychological needs of people with mental illness. This may therefore have adverse effects on informal health care providers. Nortey et al. (2017), found that, 78% of family caregivers experienced high level of caregiving burden with females reporting experiencing a comparatively higher levels of burden as compared to their male counter-parts among Ghanaian study participants. A significant contributory factor to mental health problems in LMICs is stigma and discrimination against people with mental illness and their family members. Hence, informal caregivers may try to shelf the problem of mental illness from community members which may impede soliciting information and facilitating treatment for those suffering from mental illness. This is because, they are tagged, ostracised and even mistreated. Although a little over 70% of individuals suffering from mental health disorders report experiencing stigma and discrimination in the UK, this is much worse in LMICs where human rights abuse is high, coupled with a high level of ignorance about mental health disorders (Alloh et al., 2018).

The lack of knowledge about mental health disorders in the society promote the development of slandering and tagging of people suffering from mental disorders in society which festers prejudiced behaviour. Tagging of the mentally-ill with name-calling that are discrediting and associated with curses from “gods” or bad spirits are common phenomena in our societies today, and these are motivated by the high level of ignorance about the disease found in our communities today. Okpalauwaekwe et al. (2017), found that, socio-cultural beliefs and practices in some LMICs have contributed to the experience of burden among informal caregivers and their relatives suffering from the disorder. Psychiatric conditions are believed to be caused by the spell of the super natural or evil spirits, and "karma" which is thought to be the spell of the gods or spirits for the atonement of sins victims of the disorder or their family members had committed in the past (Okpalauwaekwe et al., 2017). In Ghana, Tawiah et al. (2015), found cases of stigma and discrimination among informal caregivers and their mentally ill relatives, with over 90% of study participants suffering from stigma and discrimination associated with mental disorders. The participants in this study reportedly employed various coping strategies like prayers in order to lessen the burdens they experienced. Caregiver demographic characteristics (age, education, gender, income) were found to have a relationship with caregiver burden among the study participants in Ghana (Sanuade & Boatemaa, 2015).

The Tamale Central Hospital Psychiatric Unit (TCHPU), which is situated in the study setting, has a register of individuals with mental health disorders. A total of 1084 family/primary caregivers and their relatives suffering from various types of mental health disorders like depression, schizophrenia, and bipolar disorders were recorded respectively in the case register for the period of January to December 2018. This alarming situation among other considerations therefore informed the choice of the study setting.

The study therefore sought to explore the lived-experiences of informal caregivers of individuals suffering from mental health disorders in order to assess the perceived burden among informal caregivers, with a view to generate data that will contribute towards designing culturally relevant and sensitive interventions in order to make better the wellbeing of informal caregivers and their relatives suffering from mental health disorders.

1.3 Research Questions

The following are the study's research questions:

(1) What care experiences exacerbate family caregivers' burden whilst caring for relatives who suffer from mental health disorders?

(2) What sociocultural behaviours exacerbate caregiver strain whilst caring for a family member with mental health disorders?

(3) Does caring for relatives who have mental health problems laden with stigma and discrimination?

(4) What sociodemographic factors contribute to the burden of informal caregivers?

(5) How do family caregivers cope with the difficulties and obstacles inherent in caring for relatives who suffer from mental health disorders?

1.4 Study Objectives

1.4.1 General Objective

To assess the burden of mental health care on family caregivers in the Tamale Metropolis.

1.4.2 Specific objectives

(1) To measure the level of burden suffered by family caregivers

(2) To explore sociocultural practices that contribute to the experience of caregiver burden

(3) To investigate the presence of affiliate stigma borne by family caregivers as a consequence of caring for relatives who are suffering from mental health disorders

(4) To identify socio-demographic characteristics that affect health outcomes among family caregivers

(5) To explore the coping strategies used by family caregivers when they are taking care of their relatives who are suffering from mental health disorders.

1.6 Justification of the Study

Although caregiving has always been an important part of our society, a lot of issues have heightened the necessity for informal caregiving in the society today and for the future. Firstly, enhancement in health care, nutrition and education in the past several decades have led to significant increase in life expectancy to 62.4 years in Ghana, and this figure was projected to rise to 70 years by 2020 (Ghana Statistical service (GSS), 2014) leading to growth in the ageing population. As Ghanaians are expected to live longer, they shall experience the increased need for caregivers for the associated chronic health challenges they may succumb to. More than half of the older adult population may need support for basic daily and personal care needs, and informal caregivers may be the ones to cater for such health needs. Secondly, older adults in the society today are not necessarily the sole beneficiaries of care, but are most often care providers themselves. Again, in the past several decades, consciousness of the disability community has been awakened, raising concerns about the significance of having a compassionate and benign treatment protocols for people suffering from mental health conditions. Consequently, a clarion call for the deinstitutionalisation of the treatment for mental health disorders has set the tone for a global agenda on mental health care that seeks to promote community-based care for mental illness whilst de-emphasising institutionalised-based care. This drive for community management of mental illness has shifted the responsibility of care to informal caregivers, culminating in the increased need for family caregivers to support relatives suffering from mental health disorders.

In Africa, extensive kinship nexus that include religious associations offer assistance to people during famine (Kaunonen, Tarkka, Hautamäki, & Paunonen, 2000; Weber, Joseph and Fournier, 1985) or disaster (Porter et al., 2008). Such systems of support are non – existent for disease conditions such as mental health disorders, which is highly stigmatised (Tawiah et al., 2015b). As a result, informal caregivers of relatives suffering from mental health disorders have little options but to go on with their physical, psychological and financial difficulties by themselves (Johnson, 2015; Lawton, Brody, & Saperstein, 1989). With these imminent repercussions, it is significant to have a better insight into family caregiving duties and responsibilities.

Worldwide, informal caregivers will keep on playing this significant role as a result of the increased life expectancy, and also the fact that health and social service systems are resource challenged. The role of informal caregivers in this community-based management strategy will be more important than ever before, because interpersonal relationship affect responses to treatment and relapse rates (Opoku-Boateng et al., 2017). More than ever before, informal caregivers will be in high demand to take care of individuals suffering from mental health disorders and other disease conditions. Taking this precarious situation into account, the family caregiver's peculiar situation must be deeply explored in order to have a better appreciation of the debilitating impact of informal caregiving, as much of existing researches on care giving in families living with mental illness have been conducted in developed countries, and the current study is looking forward to add-up data to this line of study.

Robinson et al. (2008), observed that, though the needs of caregivers who are burdened by the mental illness of family members are to be attended too, the records show that current responses are limited and therefore caregivers are neglected. This situation contradicts the current dispensation in mental health service which considers these needs only in connection to how they may benefit the mentally ill patient. For instance, even though the informal caregiver may have had repeated visits to the health facility with the care recipient, the health care workers may not have taken notice of the debilitating consequences of caring for the mentally ill on the family caregiver's well-being (Kristjanson, 2004). Studies (Oshodi et al., 2012) have advocated for the need for health care workers to adopt a strategy that does not only concentrate on the patient but must be inclusive of the caregiver as well. This is because, caregiving has a considerable impact on the general well-being of the caregiver.

Therefore, in order to design programmes seeking to contributing to ameliorating the informal caregiver's situation, then it is of prime significance to fathom the family caregivers' situation in the context of the caregivers themselves. Furthermore, there is the need to widen our horizon on their day-to-day situation, the difficulties they face, the stigma and discrimination they experience, the joys and sorrows, and their coping strategies. Fathoming the multi-ethnic and intrinsic dimensions of caregiver burden could inform research on the intricate exigencies of the burden of care; and finally, innovative mediation strategies can be put in place to relief the burdens as well as enhance the well-being of informal caregivers in Ghana and the world over.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The intention of this section is to probe the principles, experiential, and evolutionary issues connected to informal caregiver burden and stress. Family caregiving has been tied-up to several bodily, psychological, socioeconomic difficulties, stigma and discrimination, causing pain and reduced well-being among informal caregivers. The caregiver's context and environment, which include sociodemographic variables, act as antecedents to stressors involving physical, psychological, and emotional demands of caregiving which may take a significant toll on the caregiver's quality of life. The key variables of interest for this research were the independent and dependent variables. The independent variables are environment and context, primary and secondary stressors related to the demands of caregiving, caregiver's appraisal of ability to cope, and the availability and use of resources. The dependent variable is the caregiver's health outcome.

2.1.1 Theoretical Foundation

The transactional stress theory serves as the overarching theoretical framework for the investigation (Lazarus & Folkman, 1984). According to this paradigm, stress occurs when an individual's current situation's expectations outweigh his or her skills. When a person feels danger, he or she will initiate primary and secondary appraisals of the impending situation. Primary evaluation is the process of determining if a situation is damaging, a threat, or a challenge (Lazarus & Folkman, 1984). Simultaneously, the individual does a secondary assessment by evaluating his or her capability or strength to withstand the inherent threat. Stress is experienced when the individual's coping resources or capabilities is not adequate enough to withstand or control the inherent danger (Lazarus & Folkman, 1984). The more pessimistic view the individual has about the inherent danger, the more unpleasant the stress response will be. For instance, the caregiving role can result in untold hardship stemming from increased tasks and duties which may antagonise several roles and duties. This supportive role may result in missed opportunities for recreation, social activities and employment. The care provider's difficulties may be exacerbated as a result of insufficient health care experience in managing the condition, as well as insufficient adaptability schemes to alleviate the difficulties associated with assuming that role (Lazarus & Folkman, 1984; Pearlin et al., 1990), resulting in distress.

The stress model developed by Lazarus and Folkman (1984) was significant in conceptualising the reciprocal relationship between caregiving and stress. Other scholars have expanded the scope of Lazarus and Folkman's stress theory in order to better understand how stress manifests itself among providers of care support to populations suffering from mental illness (Haley et al., 1995, 1987; Lazarus & Folkman, 1984; Pearlin et al., 1990; Vitaliano, 1997). Numerous articulations of the distress model are intended to analyse the impact of distress on care providers (Haley et al., 1996; Lazarus & Folkman, 1984; Pearlin et al., 1990; Vitaliano, Ustundag, & Borson, 2017; Zarit, Reever, Bach-Peterson, 1980). Zarit, Reever, and Bach-Peterson (1980) developed the burden instrument to quantify the impact of caregiver distress on caregivers. A study of caregivers for individuals with mental health conditions found that appraisal, coping responses, and social support were all significant indicators of caregiver wellbeing.

Vitaliano et al., (2017), offered a hypothetical framework of stress to measure stress and burden amidst helpmates of people suffering from Alzheimers diseases. The framework is derived from a blue print that postulates that "Distress = exposure to stressor + vulnerability/psychological, and social resources (P.392)". The framework is indicative of caregivers' stress as reaction to duties and tasks involved in caring that leads to the experience of burden. Susceptibility to distress is the care provider's reaction of the patients bodily, psychological, and mental health condition (Vitaliano et al., 2017). Care provider susceptibility is the caregivers bodily, cognitive, and psychological effect of the difficulties of caring; and caregivers' resources are the intrinsic motivations, self-efficacy, social support networks and safety nets that are available to the individual (Vitaliano et al., 2017). The framework of stress has therefore alluded to the fact that caregiver burden was associated to the appraisal of caregiving duties and tasks as stressful and burdening or as part of kinship social network and moral obligations.

Vitaliano, (1997) investigated the long-term consequences of burden among 95 participants caring for people suffering from Alzheimer's disease in a study, findings from the study revealed about two (2) years later of an appreciable deterioration of patients' health condition, with a simultaneous rise in caregiving duties. More than a quarter of care providers experienced mild to moderate levels of depression or anxiety. There were no changes in the parameters that were used to evaluate care providers' bodily health, adaptability and resilience.

2.1.2 Theoretical Framework

The Transactional theory of stress and coping is used widely in stress and burden research. The theory has its foundation in cognitive neuroscience psychology, and has been commonly referred to as the appraisal theory or the transactional theory of stress and coping (Lazarus & Folkman, 1984). Four underlying constructs are imbedded in the theory, these are psychological stress, appraisal, coping and health consequences. The effect of stress on wellbeing is the central theme of the theory. The appraisal theory suggests that, people and their settings or surroundings interact in a mutually shared relationship, and that stress only takes place if the relationship takes its toll on the individual's coping resources and thereby jeopardises the individual's physiological and psychological health.

Pearlin, Mullan, Semple, & Skaff, (1990), use of the appraisal theory has given the foundation for conceiving distress and burden among providers of care. The foundation is the basis for which distress and burden among informal care providers has been studied covering diverse disease conditions like schizophrenia, Parkinson's disease, autism, dementia, cancer, and stroke among others. Individuals are however affected differently depending on their responses to the stressful situation, these responses to stress will eventually impact on caregiver's wellbeing. According to Lazarus & Folkman, (1984), stress takes place when people experience peculiar circumstances that is deemed to be overtasking to their capabilities and thereby endangering the individuals physiological, mental, or psychological health (Lazarus & Folkman's, 1984).

Pearlin et al., (1990), however cautions that, their concept of caregiver stress and burden must not be construed as an event or episode, but should be seen rather as a process comprising of conditions, situations, exposures, reactions and makeshifts or stopgaps that are considerably different among different caregivers; and are ultimately different in their effects on caregivers' wellbeing. The impact of stress on caregivers is however not necessarily permanent, modifications of some variables may lead to transitions in others. A lot has been investigated on the mediating role of some factors in the stress process and how they are assessed and appraised. Much however, remains to be explored as to how they determine and direct the course of informal caregivers' lives (Pearlin et al., 1990). Consequently, the intention of this study is to identify and build on the lacuna in the literature about caregiver stress and burden rather than something to be perpetuated. The findings of the study hopefully will add to a more comprehensive view about what informal caregiving entails and what its costs are, especially, from this part of the world. In this regard and in line with the literature review, the conceptual framework for burden of mental health care on family caregivers is given in figure 2.1

2.1.3 Conceptual Framework

Drawing from the framework in figure 2.1, the independent variables consisted of the following; (a) background and context including socio-demographic characteristics, (b) stressors implicating caregiving demands, (c) caregiver's coping evaluation and use of safety nets, and (d) caregiver burden as dependent variable. To illustrate a comprehensive grasp of the themes, the following section provides the thematic and functional descriptions of the variables in the study.

2.1.4 Background and Context

To a very large extent, all our fascinations about the detrimental impact of informal caregiving on individuals caring for their love ones are potentially mediated by some key features of the caregiver. The impact of attributes like age, gender, employment and income, including educational attainment, are supposed to be interspersed throughout the entirety of the stress process. These features demonstrate how individuals navigate inside their closures with uneven rationing of benefits, entitlements, chances, and responsibilities (Pearlin et al., 1990).

Pearlin et al. (1990), have intimated that, background and contextual precedents of stress are socio-demographic features, experience of caregiving, and caregiver safety net configuration. The background and circumstances of the caregiver are precedents in the stress process that influence and affect wellbeing or caregiver burden (Emanuel et al., 2000; Given et al., 2005;

Haley et al., 1987; Kim et al., 2012; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Sato et al., 1996). The background characteristics and other factors implicated in the caregiver stress process theory and examined in this study were age of caregiver, gender, income level, education, marital status, relationship to patient, issue (children) in marriage, caregiver status and employment.

2.1.5 Care Demands

Demands of the caregiving situation are influenced by several conditions or situation. In the first place, it starts with the severity of the care recipient's health condition that necessitates care giving. In other words, the patient's condition of health such as bodily disability, mental dysfunction, its severity and related problem behaviours informs the need for and type of care. This therefore impacts on the burden of care experienced by the informal caregiver, but also there are several other mediums that mediates care needs and burden. Secondly, the caregiver makes a prime evaluation of the situation to determine the type of care required of him or her (Yates et al., 1999). This is because the relationship between need and care is a function of the caregiver's appraisal, the higher the care responsibility expected, the more strenuous the care activities will be required, hence higher caregiver burden experienced. As a consequence of the difficulties arising from the caregiving situation, other care related problems of the caregiver come into force and giving rise to caregiver burden. Other related problems of the caregiver are consequences of the caregiving situation which are typically familial problems in nature, and also problems of conjoining other time consuming activities like social and occupational activities (Yates et al., 1999).

2.1.6 Primary stressors

Care giving difficulties that have demonstrated to mediate caregiver burden are the severity of and the associated activities involved in resolving the patient's health needs. Studies have indicated that so many informal caregivers give support to their care recipients in the area of cooking, toileting, bathing and administering medication (NAC, 2009). For instance, a study by Levine (2000), among informal caregivers in the USA found that, about half of the participants administered medication whilst other participants change dressings for their care recipients. It is possible that those caring for their terminally ill relatives may be involved in even more strenuous level of activities all geared towards alleviating the suffering of their loved ones.

Emerging research interest in caregiving shows that care recipient suffering also has a harmful effect on informal caregivers. Research evidence demonstrates that a family caregiver's feeling of care recipient's suffering leads to depression and burden more than several folds the impact of the care recipient's mental and physical impairments, and upsetting behaviours (Schulz et al., 2008). The researchers also intimated that differences in feeling of patient's suffering were closely correlated to differences in family caregiver's depression and burden (Schulz et al., 2008). Another study by Amirkhanyan & Wolf, (2003), involving children of elderly care recipients found that, non-caregivers relatives of comparable disabilities experienced depressive symptoms similar to the informal caregivers. This means that, having a parent suffering from mental health disorders had more devastating impact on family caregivers' mental health as compared to other caregiving contexts. It is therefore believed that, suffering contributes to empathy or the perception of fellow-feeling for the suffering care recipient, in addition to the yearning for quick relief to the suffering patient. Empathy may end up engendering grieve and moral guilt especially if the family caregiver has a feeling of low self-efficacy and overwhelmed at alleviating pain of the loved one (Stetz, Brown & Brown, 2004).

2.1.7 Secondary stressors

The major strains of caregiving usually lead to other minor under-appreciated set of strains. This is because people are usually obligated to play other important social roles and responsibilities in addition to the caregiving roles. For instance, their social roles as household-heads like husband/wives or fathers/mothers and opinion leaders coincides with caregiving at different points in time and places. In normal situations, the family caregiver is able to support and provide stability among the competing tasks and duties of parenting, such as taking care of children and husband, and engaging in income generating activities for life sustenance in addition to caring for a sick family member. Yet, the buildup and overall cost of caregiving can overwhelm and impair other areas of life. Other intricacies of the life course may be jeopardised, especially where there are disagreements among family members on the course and type of care to be provided for the care recipient (Dilworth-Anderson et al., 2005). Family disputes may arise because caregiving is already beset with anxious moments for all family members, and in particular the primary caregiver (Stephens et al., 2001). Furthermore, several family caregivers describe the caregiving duties as time consuming with no spare time for recreation (Mor et al., 1994).

Caregivers also experience substantial amount of financial costs. For example, in a study among informal caregivers, Covinsky, Kenneth, and Goldman (1994), found that about 20% of the informal caregivers had terminated their jobs whilst 31% lost their income in the final days of their care recipient's illness. Another study intimated that, more than 30% of the family caregivers spent about 10% of their earnings on their care recipients (Emanuel et al., 2000). Financial difficulty is not the only issue faced by family caregivers but they are also impacted negatively by the care recipient's care needs; this is because caregivers who are so engrossed with financial concerns may pay less attention to the care recipient's needs (Kristjanson et al., 1998). Caregiving dynamics could also be over stretched, for instance, as cronies and relatives take up caregiving roles, they easily abdicate or change former roles that could fundamentally modify kinship trajectories like child bearing roles and seeking employment for livelihood (Kramer & Lambert, 1999).

2.1.8 Caregiving Appraisals

A number of caregiver characteristics like gender, age, marital status, religious affiliations or the caregiver's self-assessment associated with the caregiving duties, may all shape the development of health consequences of caregiving (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Evaluation of the consequences of the caregiving situation are significant because it may offer better explanation to perceived caregiving health outcomes than concentrating on the core difficulties imbedded in the caregiving roles (Haley et al., 1996). When confronted with caregiving duties and responsibilities caregivers make an evaluation of the associated difficulties of the duties and tasks imposed by their caregiving roles, and also make a further assessment of whether or not they have what it takes to withstand the pressures and the hardships associated with the caregiving duties. If they think that the caregiving duties are so difficult to handle, stress will be felt. Anxiety and behavioural reactions will be produced leading to negative health consequences. Kinship variations in their caregiving evaluations have also been suggested; as compared to white caregivers, people of African and American ancestry associate a more compassionate and beneficial effects of caregiving (Haley et al., 2004).

Many caregiver variables may help in alleviating the experience of stress and burden among informal caregivers; these include, inborn inspirational attitude to providing care, the existence of social safety nets such as "familism" and the use of religion and a spiritual basis to provide care (Pinquart & Sörensen, 2005). Perspectives about providing care also contribute to caregiving evaluations, for example, Western Cultures place significant value on self-reliance whilst non-western cultures place much significance on communalism, sharing or "we feeling", such that the wellbeing of one family member is the collective responsibility of all (familism). Familism therefore contributes to sick family members getting the needed care and attention from relatives and neighbours (Aranda & Knight, 1997; Pinquart & Sörensen, 2005). Furthermore, many more researchers have demonstrated that compared to white caregivers, people of African American ancestry advocate for a more robust customary and cultural orientation of caregiving doctrines (Dilworth-Anderson et al., 2002, 2005).

2.1.9 Social support:

Social support is the nexus that gives resources both in kind and cash to caregivers with the aim of supporting them to cope with the impact of caring for their relatives suffering from mental illness (Cohen, 2004). Social support may include financial and emotional assistance that are directed at individual specific caregiver needs such as showing empathy or offering a listening ear as well as lessening the financial burdens to individual caregivers who may be stigmatised and discriminated against because of mental health disorders (Chang et al., 2001; Cohen, 2004). Although the availability of bigger kinship nexus might portray adequate social resources for caregivers, this kinship nexus may also lead to the enormous difficulties as witnessed in Hispanic caregivers (Hebert & Schulz, 2006). Informal caregivers may feel ashamed agreeing to feelings that they consider unacceptable (Cox & Monk, 1993).

Furthermore, in spite of the availability of sizeable relatives and kin among Latinos, caregivers among Latino families do not have the leverage of family support due to apathy as compared to white caregivers who seek information or discuss their perceptions or anxieties with individuals among their nexus (Phillips et al., 2000). Familial nexus could also contribute negatively to the pursuit of formal care especially if there are perceived latent ethos surrounding the condition.

2.1.10 Outcomes of providing care

As noted in the literature, the debilitating effect of caring for individuals with mental health disorders on informal caregivers include the caregivers' welfare and quality of life, particularly their physical and cognitive functioning, as well as their capacity to maintain their societal duties and responsibilities (Pearlin et al., 1990). On the cognitive level, they refer to their level of awareness, attentiveness, and focus required to complete the work without losing their bearings (Pearlin et al., 1990).

A major aspect of Lazarus theory is the examination of the effects of stress on an individual's wellness and social duty. Lazarus and Folkman (1984) suggest that ineffective coping or management of tough or taxing conditions might result in mutations in one's physiology, emotion, or psychology, hence jeopardising health by enabling maladaptive health behaviours such as alcoholism and drug addiction. Furthermore, people experiencing stress may impair or leave prior healthy behaviours (e.g., adequate rest and sleep), or perpetrate unsafe health behaviours like not eating regularly and at appointed times (Lazarus & Folkman, 1984). When stress is experienced for longer duration, it takes its toll on bodily function, mental health, occupation as well as social responsibilities (Lazarus & Folkman, 1984).

Evidence shows that, caregivers of mentally ill individuals often suffer negative health effects including, psychological, recreational and social functioning because of their caregiving responsibilities. The evidence however demonstrates significant personality differences in caregiving health consequences (Lazarus & Folkman, 1984). The stress-process model has also been explored to flag hazardous as well as insulating factors that demonstrates these divergences as shown in the framework in figure 2.1

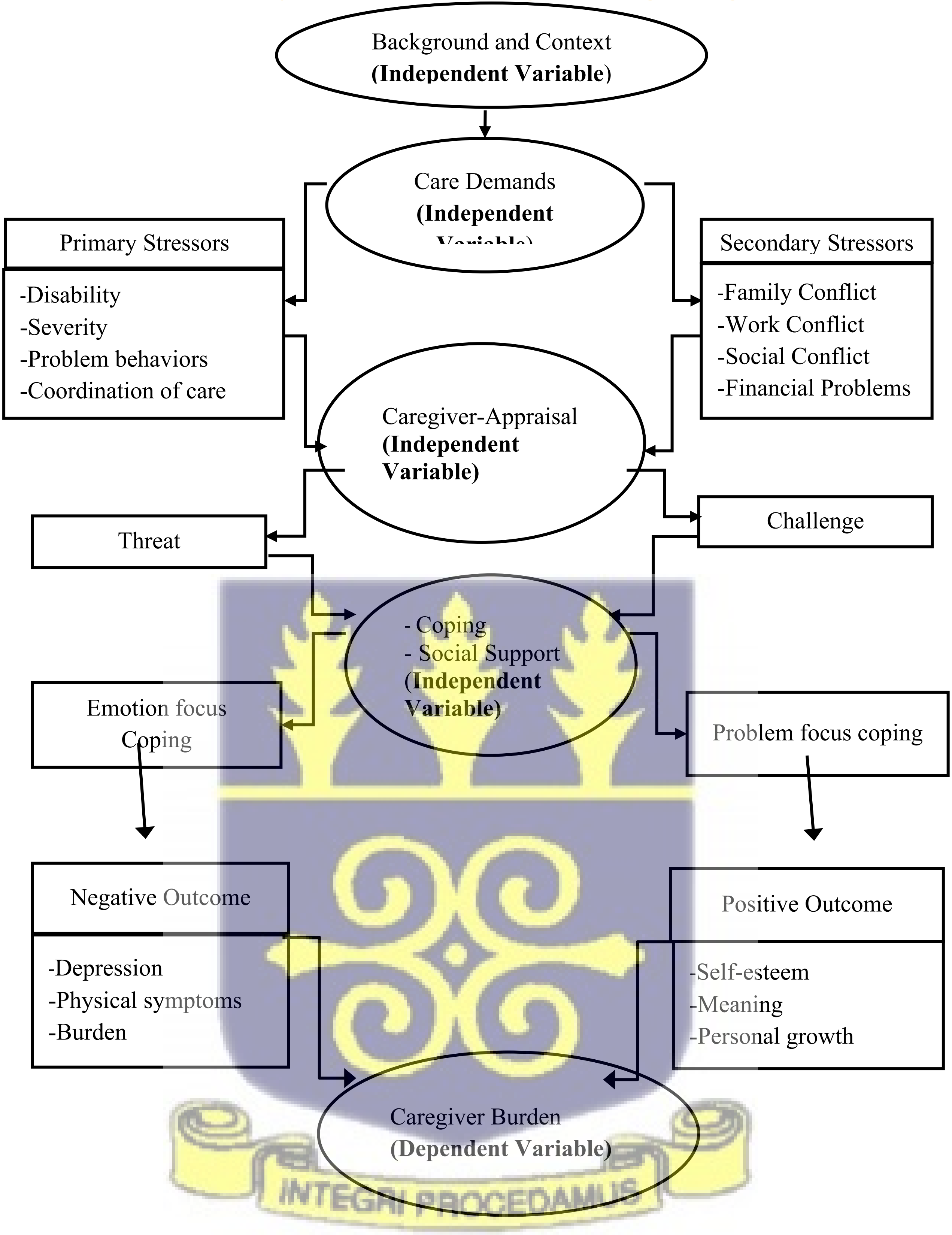


Figure 2.1: Conceptual Framework for Burden of Mental Healthcare on Family caregivers

Source: Field Data (2020)

2.2 Mental Health Disorders

Mental health illnesses account for 13% of disability-adjusted life years worldwide (Vigo et al., 2016), but there is a global gap in meeting the requisite individuals' mental health requirements. For example, whereas the global burden of mental and behavioral diseases increased by 38% between 1990 and 2010 (Murray et al., 2013), more than 70% of this increase is due to mental health diseases in low- and middle-income nations (Lopez et al., 2006). In Ghana, mental health diseases account for roughly 13% of the adult population (WHO, 2012), and a sizable portion of the budgetary allocation for mental health (approximately 80%) is devoted to the upkeep of the country's three public psychiatric hospitals, all of which are located in the country's southern region. Because the Ghana National Health Insurance Scheme (NHIS) does not cover psychiatric services, care for mental health disorders is provided free of charge at public psychiatric facilities. Although drugs must be purchased privately when supplies at state psychiatric facilities run out without recourse to reimbursement, as is frequently the case (Kretchy et al., 2018).

2.2.1 Types of Mental Health Disorders

Schizophrenia, paranoid disorders, depression, anxiety disorders, and panic disorders are only a few of the mental health illnesses. Stressful events can result in general mental health illnesses (Patten, 1991), but they can also result from other experiences; stressful experiences do not always result in mental illness. Numerous persons suffer with subliminal mental health diseases, which are substandard mental health conditions that do not reach the threshold for designation as a mental illness. Mental health disorders and subliminal mental health disorders affect a sizable proportion of the population (Murray et al., 2012). Mental illness is a word that is frequently used to refer to depression and anxiety disorders (also referred to as general mental health diseases), as well as schizophrenia and bipolar disorder (sometimes referred to as acute mental health diseases) (WHO, 2014). Mental illness and mental health disorders will be used interchangeably throughout this research to imply or denote the same mental health disease or condition.

The predominance and social diffusion or propagation of mental health diseases have received much research attention in high-income countries (WHO, 2014; WHO, 2013). Whilst there is an upsurge in the acknowledgement of the problem of mental illness in less developed countries, a critical dearth continues to persist in research to assess the enigma, scheme and modus operandi to address mental illness. There is the urgent need therefore, to increase the precedence conferred on forestalling mental illness, and to the espousing of evidence-based good mental health practice. Globally, a change in direction is required to forestalling general mental health diseases like schizophrenia and paranoid disorders by espousing of evidence-based good mental health practices around the world, in addition to ameliorating treatment of prevailing diseases. Evidence-based practice is required since a lot of the sources and motivating factors of mental illness are found within social, economic and political realms, and in the circumstances of daily life (WHO, 2014).

2.2.2. Depression

Depression is a heterogeneous and etiologically complex psychiatric syndrome, often manifested by anxiety disorders, substance use disorders, attention deficit hyperactivity disorder (ADHD), and other co-morbid psychiatric diseases, shows a strong gender dimorphism and often impacts people with low socioeconomic status (Labonté et al., 2017)]. Depression and depressive symptoms are the most common psychological problems in the world, impacting over 300 million people of all ages (4.4% of the world's population), with an 18.4% increase in people suffering from depression between 2005 and 2015 (Lancet, 2016). The World Health Organisation (WHO) predicts that depression will be the leading cause of disability and a significant contributor to the global disease burden by 2030. Depression is a major factor associated with suicide, leading to 800,000 deaths annually (WHO, 2017). The burden of depression is a complex concept with different connotations, encompassing the burden on the patient, caregiver, healthcare system, society and the economy. Several studies have assessed the relationship between personal and socioeconomic variables, such as gender, age, marital status, education, income level, employment status and social class, and the occurrence of depressive disorders (WHO, 2017). The results of epidemiological studies show that personal and socioeconomic factors are associated with differences in the prevalence of depressive disorders. Moreover, the prevalence of these factors may change over different periods of time over the years and is often associated with economic changes or crises (Ruiz-Pérez et al., 2017). Depressive disorders sometimes run-in families, with many members being affected. Having a chronic physical illness, or another mental disorder, also raises the risk of depression. Certain factors, such as a supportive family, social or religious environment, may protect against depression. Depression is a multifactorial cause disorder. The relative contribution of each factor may be different in each case. The various factors identified to be involved in the causation of depression include, genetic, environment and life events (Polak et al., 2022).

Treatment and management of depression is aimed at reversing the underlying condition and when this can be achieved the results are very satisfactory. In drug-induced conditions, stopping the offending agent may be all that is required. Similarly, treating an infectious illness with antibiotics may be sufficient to relieve all accompanying depressive symptoms. If the underlying cause cannot be reversed, depression may still respond to antidepressant medication (Chaturvedi, 2021).

2.2.3 Schizophrenia

Schizophrenia is a severe mental illness (SMI) affecting more than 21 million people worldwide that frequently leads to a persistent disability and impaired cognitive, social, and emotional functioning (WHO, 2018). Schizophrenia is currently conceptualised as being characterized by at least positive symptoms (such as delusions and hallucinations), negative symptoms (including anhedonia, alogia, avolition, and social withdrawal), and cognitive symptoms (such as deficits in attention, processing speed, verbal learning, visuospatial learning, problem solving, working memory, and cognitive flexibility) (Menon, 2020). Moreover, social cognition (including emotional intelligence, facial emotion recognition, emotion evaluation, and social inference) impairment may significantly impact the functional recovery in schizophrenia patients, due to the negative effects on interpersonal relationships, community adjustment, and vocational functioning (Green et al., 2020). Schizophrenic patients may also experience higher rates of co-occurring medical and/or mental illnesses, such as substance use disorders (mainly alcohol and cannabis), with prevalence rates of up to 41% (Hunt et al., 2018). Due to a disordered lifestyle, unhealthy diet, lack of exercise, smoking, the adverse effects of antipsychotic treatment, limited access to medical care, and the psychiatric illness itself (Nielsen et al., 2021), patients with schizophrenia are more likely to have a metabolic syndrome, a cardiovascular disease, diabetes, other endocrinopathies, an immune disease, and pulmonary illness, in particular, chronic obstructive pulmonary disease (Misiak et al., 2021). The concomitant comorbidity with other mental disorders determines the higher rates in symptomatology relapse, hospitalisations, suicidality, and family and social issues (such as higher rates of incarceration due to mental disorder relapse, treatment discontinuation, higher impulsivity and violent behaviours, and so forth), as well as a higher risk of negative outcomes in the short-term, including higher mortality rates (Drake et al., 2020). A very recent meta- analysis showed that all causes of mortality were increased in people with schizophrenia, compared to the control group. The specific causes of mortality included suicide, injury, poisoning, pulmonary diseases, endocrine diseases, respiratory diseases, urogenital diseases, diabetes, cancer, and cardio-cerebrovascular causes (Correll et al., 2022). Moreover, it has also been found that treatment with an antipsychotic (AP) drug, in particular with second-generation long-acting injectable antipsychotics (SGA-LAIs), seems to be protective against all causes of mortality (Correll et al., 2022).

However, schizophrenia is a syndrome including a collection of signs and symptoms with heterogeneous etiology, etiopathogenesis, and psychopathological mechanisms that are potentially implicated, with many research directions and pathways currently under investigation (Insel, 2010). There are several emerging neurobiological research directions that are suggested to be implicated in the pathogenesis of schizophrenia that could also be helpful in the clinical characterisation of the disease. Finally, recent evidence supports the concept that schizophrenia represents a multifactorial disorder that results from a complex interplay between additive and interactive genetic and environmental determinants, displaying a highly variable and heterogeneous clinical presentation (Gur, 2022). Therefore, due to the absence of clear boundaries and the multiplicity of implicated etiological factors, pathophysiological mechanisms, and hypotheses (Cannon, 2022), the schizophrenia concept has been more recently broadened to a spectrum concept in the DSM-5 (and the recently released DSM-5-TR) (Del Barrio, 2016).

2.2.4 Bipolar Disorder

Bipolar disorder is a chronic and complex mood disorder that is characterised by a mixture of manic (bipolar mania), hypomanic and depressive (bipolar depression) episodes, with significant subsyndromal symptoms that commonly present between major mood episodes (Geddes, 2005). Ranked among the leading causes of worldwide disability, bipolar I disorder has been consistently associated with significant medical and psychiatric comorbidity, premature mortality, high levels of functional disability and reduced quality of life (Blanco et al., 2017). On the bipolar spectrum, bipolar depression is the leading cause of morbidity in patients with bipolar disorder; at least 50% of patients initially present with a depressive episode (Mitchell et al., 2008). Even with treatment, bipolar depression accounts for the majority of time spent unwell with the disorder and it is an important contributor to long-term dysfunction, psychosocial impairment and loss of work productivity. In light of reports that up to 10% of all visits to primary care are depression related and as many as 64% of all clinical encounters for depression occur in this setting rather than in specialty care (Unützer & Park, 2012). The prevalence of bipolar disorder decreases with increasing age and education level, while its prevalence is higher in unemployed and disabled individuals than in employed individuals; prevalence does not appear to be consistently related to race/ethnicity or income (Merikangas et al., 2007). Depressive and subsyndromal depressive symptoms are very common in bipolar disorder and it is noteworthy that patients spend considerably more time ill with depression (34% of the time) than with elevated/mixed symptoms (12% of the time) (S. Miller et al., 2014).

The significant burdens of bipolar disorder for individual patients, caregivers and society are the result of socioeconomic and psychosocial factors. Due to the pervasiveness of depressive symptoms over time and higher indirect costs, a greater proportion of the overall costs of bipolar disorder are attributed to depressive symptoms than to manic or mixed symptoms; manic and mixed symptoms account for higher direct costs because of higher inpatient treatment expenses (Miller et al., 2014). The burden of bipolar depression in the workplace is consequential. Patients with bipolar disorder and at least one past-year depressive episode had greater levels of absenteeism, presenteeism and total lost work days than patients with only manic/hypomanic episodes during the past year (Kessler et al., 2006). Furthermore, unemployed individuals with bipolar disorder compared with those who are employed had significantly greater severity of depressive, but not manic, symptoms and employed individuals with at least one major depressive episode missed an additional 4 days of work per months than those without depressive symptoms (Simon et al., 2008). Beyond the workplace, depressive symptoms related to bipolar disorder are associated with considerable impairment in domains of individual functioning (e.g. social, household, interpersonal relationships) and quality of life (Rosa et al., 2010). Subsyndromal depression, which is almost ubiquitous between major mood episodes, has also been associated with poorer outcomes among patients with bipolar disorder (Goldberg & Harrow, 2011).

The limited number of approved treatments for bipolar depression is of clinical concern since not all patients respond to available treatment options and response may decrease over time. A comprehensive literature review found consistent evidence suggesting that pharmacological and psychosocial treatment in the earlier stage of illness resulted in better outcomes for response, relapse rate, time to recurrence, symptomatic recovery, remission, psychosocial functioning and employment (Joyce et al., 2016). The potential for drug–drug interactions is a particular concern for patients with bipolar disorder, who tend to have complex and varied treatment regimens (Keck et al., 2005). Given the long term, chronic, progressive nature of bipolar disorder and the level of associated impairment, a strategy that combines pharmacological treatment, psychosocial intervention and lifestyle approaches is recommended beginning at the first episode (Roger & Joseph, 2019).

2.2.5 Burden of Mental Health Care

Worldwide, there is a shift toward community-based treatment for psychiatric patients rather than institutionalised care, and this shift in health policy may come with higher demands on family caregivers. This is because family members are important to this transformation, particularly in Africa, where the kindship nexus provides a significant amount of mental and financial support to the sick individual (Ndetei et al., 2009). Mental illness has a detrimental effect on both sufferers and their relatives (Oshodi et al., 2012). Taking care of the mentally ill entails a slew of complications that can affect virtually every part of the informal job worker's life, which may be referred to as "family load." The term "family load" refers to the manifestation of difficulties or adverse effects affecting the lives of informal caregivers of individuals with mental health illnesses, who are typically household or family members. Family caregivers are unpaid caregivers who assist individuals who are experiencing difficulties with daily activities as a result of physical, mental, or psychological problems. They are typically family members who provide support to individuals who are experiencing difficulties with daily activities as a result of physical, mental, or psychological problems. Without such assistance, individuals with disabilities may be unable to maintain themselves (Vitaliano et al., 2003). The informal caregiver load has been defined as the whole physical, psychological, emotional, social, and financial costs associated with caring for those who have a health condition, most frequently mental illness (World Federation of Mental Health, 2010).

Distress, perplexity, tension, wrath, adversity, stigma, and discrimination all constitute a burden (Vitaliano et al., 2003). The distress of the informal caregiver includes humiliation, embarrassment, remorse, and a sense of learned-helplessness (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015). Caregivers have been found to be concerned about the display of disorderly behaviour and attempted self-harm by care receivers. Occasionally, caregivers wonder if they contributed to the patient's illness. According to Oshodi et al. (2012), around a third of family caregivers experience heightened levels of anxiety or depression as a result of their caring duty.

Clinical observation demonstrates that assuming the caretaker role can be unpleasant and taxing (Schulz & Sherwood, 2008). According to Walke et al. (2018), a study in India examined caregiver burden among 320 caregivers and discovered that the effects of care resulted in severe burden in 40.9 percent of cases and moderate burden in 59.1 percent of cases. Significant strain was noted in the areas of physical and cognitive health, partner relationships, and outside support. The following degree of hardship was felt in the areas of shouldering responsibilities, everyday activities and maneuvering of caregivers, and care recipient behaviour. The least burden was noted in the area of help to the care recipient and his or her family (Walke et al., 2018). Another study from Iran indicated that when the Zarit Burden interview schedule was used to assess caregiver hardship, majority of the main caregivers experienced moderate to severe burden (Hajebi et al., 2019).

For example, caring for someone who has a mental illness possesses all the characteristics of a chronic stress event. It results in prolonged physical and mental discomfort, happens with a high degree of erratic behaviour and unmanageability, has the potential to produce secondary stress in numerous areas of life, such as occupation and kinship nexus, and typically requires a high degree of attentiveness. Caregiving requires a certain level of awareness. Caregiving satisfies all of the criteria for chronic stress to the point where it is used as a model for investigating the health consequences of chronic stress (Vitaliano et al., 2003). Caregivers are important components of public health care; relatives are frequently tapped as the primary source of home care and assistance for aging family members, delivering services that would cost billions of dollars annually if they had to be acquired (Schulz & Sherwood, 2008). Mental health disorders and its associated issues frequently have an adverse effect on people's psychological, emotional, and mental capacities, diminishing their social capital and output and increasing their reliance on support (Commonwealth Department of Health and Aged Care, 2000). While caregiving evaluations may have an effect on the difficulty of caregiving, they are frequently influenced by a variety of characteristics, including the caregiver's age, gender, income, relationship to the patient, and global assessment of functioning (GAF). It has been demonstrated that negative caregiver ratings have an effect on caregiver distress. In industrialised economies, caregivers have been observed to be able to cope with the impact of mental disorders on informal caregivers through the use of practical coping mechanisms. Additionally, it is found that assessing caregiver strain might heighten health care workers' and administrators' awareness of the importance of reducing such hardships and responsibilities in society (Schulz & Sherwood, 2008).

Caregivers of persons who suffer from mental illness bear a heavy burden. While researchers and advocates have developed many services and mediation protocols to mitigate the impact of caregiving, these interventions have not resulted in the expected outcome of adequately alleviating the burdens of this vulnerable population (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Gallagher et al., 2011; Gaugler, 2010; Harding, List, Epiphaniou, & Jones, 2012; Pearlin et al., 1990; Vitaliano et al., 2003; Zarit, Reever, Bach-Peterson, 1980). Stress and burden on family caregivers have resulted in physical and emotional difficulties as a result of socioeconomic insecurity, stigma and discrimination, and the neglect of recreational and income-generating activities in order to care for a sick family member (Goode, Haley, Roth, & Ford, 1998; Pearlin et al., 1990; Pinquart & Sörensen, 2007; Vitaliano et al., 2003; Zarit, Reever, Bach-Peterson, 1980).

Numerous relatives who spend their time, care, and protection to sick family members have made a significant contribution to society since the dawn of time. While family carers provide these far-reaching services to society and Kin, they do so at a significant personal sacrifice. There is a growing body of data that caring for a mentally ill relative can be taxing and unpleasant for many informal carers, possibly contributing to psychiatric illness (Schulz & Beach, 1999). Additionally, it has been established that the combination of bereavement, extended anguish, the physical demands of caregiving, and elder caregivers' biological vulnerabilities may impair their physiological functioning and raise their risk of developing health problems (Vitaliano, 1997).

In Ghana, the practice of psychiatry has evolved over several decades, progressing from a purely folk routine to one characterised by modern health care procedures. According to Adam (2010), however, cultural perceptions on superstition and mental illness persist in a number of societies and kinships, influencing and impeding the treatment and management of mental illness, as well as the health outcomes of caregivers. This is because despite the availability of traditional health delivery systems like hospitals and clinics, many people (individuals and families) continue to rely on religious healing practices for their mental health needs. Religion and religious views and practices are inextricably linked to how mental illness and treatment are perceived in society; religious beliefs and practices thus have substantial implications for mental health seeking in communities. According to studies, prayers are thought to have curative as well as preventative effect on overall well-being and mental health especially among Muslims (Coker, 2006). Religious beliefs are so enticing and satisfying that many adherents' diets are heavily impacted by their religious convictions (Spector, 2002). Religion and an adherent's commitment influence and shape not only the function of faith in the healing process, but also the response to a certain treatment and the healing outcome. Each of these strands, religion, ethnic origin, and culture, is woven into the fabric of how each individual responds to treatment and rehabilitation (Spector, 2002).

2.3 Defining Family caregivers

The requirement for assistance with daily activities is not an inescapable consequence of age (Feder, 2012; He, Wan and Larsen, 2014; Schulz, 2016; Stone, 2015). Physical health and functioning limitations, as well as mental and psychological health issues, are the primary underlying elements or reasons why elderly individuals require aid and support from others. However, living longer is frequently associated with diseases that impair a person's capacity to do daily activities. As individuals age, their chances of developing physical or mental health conditions are increased thereby interfering with their ability to function independently, without needing help from others (Wolff & Jacobs, 2015). Between the ages of 85 and 89years, for example, over half of elderly people (58.5%) benefit from informal caregiver support due to health impairments. From age 90 years and above, only a few people (24%) may not require assistance from others (Freedman & Spillman, 2014).

Informal caregiving is the representation of responsibilities, duties and tasks involved in giving support to family members who have fallen prey to illness and are not able to support themselves. Whilst caring is the affective constituent of an individual's devotion to the well-being of another, caregiving is the behavioural expression of this devotion. Therefore, taking care of an individual is a continuation of the show of devotion to that person; in other words, caring and caregiving are inherent to kinship societies in which individuals thrive to protect and advance one another’s welfare (Pearlin et al., 1990).

Family caregivers are the individual carers who may not be compensated for rendering caregiver services to people that are taken ill. These individuals are often family members or relatives who give support to relatives (care recipients) that are taken ill and struggling to cope with activities of daily living because of their present health condition. In the absence of support, these care recipients are unable to care for themselves because of their physical, mental and psychological state of health. Even though caregiving demands are contingent on the specific needs of each individual, it often entails assisting with the management of the conditions of living, such as washing, cooking, feeding, dressing, or higher-level activities such as giving medication (Vitaliano, Zhang, & Scanlan, 2003). Generally, providing care hinges on mutual respect and devotion to life and the perception that individuals have an inalienable right to live and to function to their optimum potential of physical and mental capacities. The main aim of providing care is to enhance wellbeing by protecting, managing and promoting the individual’s most vital needs or ingredients to survival (Bridges, 1998). In this research, the word family 'caregivers' is used interchangeably with 'carers' to denote the same meaning; and it is also reserved for informal caregiving which is provided by a family member who may not be compensated for such services, rather than by a health care provider who is reimbursed for services.

Family caregiving has been the mainstay of protection for individuals in poor health conditions since prehistoric times; and though informal caregivers have been of socioeconomic value to society, they will even be of more importance in the future (Vitaliano et al., 2003) . Given the fundamental role and responsibilities they carry on their shoulders, there have been some concerns from both government agencies and researchers about caring for and paying attention to the informal caregiver health. One important presumption that is fundamental to this consideration has been that, the unpleasant and depressive effects of providing care could negatively impact on caregiver's ability to provide care. Furthermore, researchers have been apprehensive about caregivers' own health and about their ability to take care for, or of themselves may be compromised (Vitaliano et al., 2003). For example, one psychosocial effect of providing care is perceived burden, which is a consequence of the physical, mental, psychological, social and financial difficulties felt by the informal caregivers looking after their mentally ill relatives. (George & Gwyther, 1986).

The informal caregiver exerts so much strain as far as meeting the health needs and welfare of care recipients at the expense of their own well-being. The utter neglect of the informal caregiver's own health arrangements, social responsibilities and recreation have negative consequences on the caregiver's physical, mental, social and familial well-being (Glozman, 2004; Haley, Levine, Brown, & Bartolucci, 1987; Kristjanson, 2004; Lim & Zebrack, 2004; Pearlin, Mullan, Semple, & Skaff, 1990).

2.3.1 Family Caregiver Experience of Mental Illness

Numerous research have been conducted to determine the influence of mental health care on the informal caregiver with the goal of identifying certain disabling infirmities among diverse groups of caregivers (Vitaliano et al., 2003). By and large, there is consensus that informal caregiving is associated with poor mental health outcomes. A large-scale Australian survey corroborates this (Edwards, 2009). Edwards (2009) examined 1002 caregivers and discovered that those caring for relatives with one or more infirmities, such as acquired brain injury, physical, mental, or psychiatric conditions, had significantly higher rates of mental health symptomatology, including depression, than the general population. Other than the care recipients, relatives of caregivers reported depression symptoms as well, with the risk being greatest during the first year of care. Another study (Cummins & Hughes, 2007) on the mental well-being of informal caregivers discovered that caregivers, on average, had worse collective wellbeing than any other group previously studied (including sole parents and individuals who were not working). Additionally, approximately half of caregivers were reported to be seriously depressed. Numerous factors, including unemployment, physical health problems, lack of social support, and financial difficulties, may contribute to caregivers' poorer mental health than those who do not provide care (Cummins & Hughes, 2007). Magliano et al. (2002) discovered that more than half of caregivers of Schizophrenic patients expressed feelings of loss, depression, abandoned hobbies, and had difficulty taking vacations due to the individual's mental health needs. These outcomes reflect the impact of informal carers' caregiving on their mental health, but they may also serve as risk factors for more serious mental health disorders.

According to the prevalent conceptual model of caregiving (stress-coping process), the development and course of chronic disease and physical handicap are stressful for both the patient and caregiver. As a result, the stress-coping model framework can be utilised to research caregiving burden. Objective stressors within this paradigm include the patient's physical limitations, mental health challenges, and behavioural behaviours, as well as the type and degree of care delivered. These stressors induce psychological distress and deteriorated health behaviours, stimulating physiological responses that culminate in sickness and death (Vitaliano et al., 2003). The impact on the caregiver's health outcome is mediated by personality differences in resources and susceptibilities such as socioeconomic status, prior health state, and the level of social support (Hebert & Schulz, 2006).

Numerous outcome result estimations have been examined, including cellular and organic physiological baseline estimates, global physical and psychological health status indicators, and self-reported self-habits. These findings have been linked to main stressors such as the duration and type of care offered, as well as the patients' functional and mental capacities, as well as secondary stressors such as financial and familial strife. As a result, the caregiver may experience psychological discomfort, unhealthy lifestyle choices, physiological effects, psychiatric disease, and mortality (Christakis & Allison, 2006; Pinquart & Soerensen, 2007; Schulz & Sherwood, 2008; Schulz & Beach, 1999; Vitaliano et al., 2003).

Physical repercussions of caregiving are typically less severe than psychological consequences, regardless of whether they are quantified using global self-report instruments or physiological measures such as stress hormone levels. Though there have been relatively few studies examining the relationship between caregiving and health habits, investigators have discovered evidence of poor health behaviours such as neglecting their own health care appointments and poor eating habits among caregivers who provide basic activities of daily living (ADL) such as toileting and feeding (Schulz et al., 2008). Psychological well-being measures such as depression and stress have been the most frequently investigated outcomes of caregiving. These studies have frequently discovered that age, money, employment, and social support all have a significant effect size. Elderly caregivers, low-income individuals, and those with a low kinship support nexus all report poorer psychological and physical health outcomes than younger caregivers, those with a higher income, and those with a stronger kinship support nexus (Schulz et al., 2008; Vitaliano et al., 2003).

2.3.2 Impact of Caregiving on the Carer

Caregiving affects everybody irrespective of ethnicity, language, tribe, culture or nation; providing care has become a daily phenomenon for several individuals around the world. Although named differently in different parts of the world, these care providers, caregivers or carers give care to relatives or friends each passing day, because without support they may not be able to function independently as a consequence of aging or disability. The support they give may be unpaid, and usually unrecognised and undervalued. In several countries, informal care is the traditional and most basic source of care support to immediate and extended family, rather than institutions providing care to their loved ones who fall prey to illness or old age (World Federation of Mental Health, 2010).

The detrimental effect of providing care on informal caregivers has been supported in the literature. This was demonstrated in a comparative study of well-being among caregivers and non-caregivers (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998). The investigators found less life satisfaction, less positive affect, and more negative affect among care providers in comparison to non-care providers, irrespective of age or income status. In another study (ABS, 2018), about 30% of care providers were found to have impaired well-being and depression. Furthermore, a review of 41 studies on the impact of caring for patients suffering from dementia found an increased incidence of psychiatric morbidity with high levels of depression among the caregivers (Schulz, O’Brien, Bookwala, & Fleissner, 1995).

Studies (Lundh, 1999; Nolan, Mike , Grant, Gordon & Keady, 1996), have also reported the positive effects of providing care, to account for the perceived satisfaction of performing the caregiver role. The finding showed among others that, giving pleasure to the patient, keeping the dignity and optimising the capacities of the patient, perceived enhanced relationship with patient, meeting role expectations to kinship, sharing mutual love and support with patient, and perceived personal development. In a study (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998), about 84% of care providers said they experienced happiness and fulfilment from caring for their loved ones. Results from (Ashworth & Baker, 2000), found evidence of improved self-regard and self-respect, and increased sense of closeness to their loved ones for providing care to them. Furthermore, 33% of care providers experienced a perceived sense of contentment and renewed closeness to the patients for providing care for them (ABS, 2018). It is therefore expected that, the beneficial effect of caregiving could have an overriding positive impact on the caregivers' general health outcomes.

Turner & Findlay (2012), study of Caregiving effects among Canadian participants revealed a massive-positive effects on the lives of caregivers. Although a proportionately smaller care-providers reported worsening health effects of providing care (8%), more than half (56%) faced problems and challenges. When participants were quizzed about difficult experiences of caregiving, 17%, indicated that caregiving was emotionally tasking, 12% reported not having leisure time to themselves, 10% said they experienced psychological distress, whist 7% experienced physical fatigue. In total, 95% of the care-providers experienced beneficial effects; 30% experienced self-esteem, 26% enjoyed providing support, and 19% perceived a sense of closeness to the patient (Turner & Findlay, 2012).

2.3.3 Caregiver Stress, Anxiety and Depression

Globally, care providers are affected by the daily task of caring for their loved ones and this takes a heavy burden on their mental and psychological health. Distress, depression and anxiety are frequent among care providers; to the extent that, to watch a loved one struggle due to illness, without adequate resources like social support network and financial resources can be overwhelming and therefore has a negative impact on caregivers' health (World Federation of Mental Health, 2010). Another study discovered a favourable correlation between caregivers' well-being and the severity of behavioural issues and the duration of care in Alzheimer's disease. Increased levels of depression and anxiety were shown to be proportionate to the severity of the patient's condition among carers (Ferrara et al., 2008).

As caregivers strive to combine job, family responsibilities, and caring, their own health is sometimes overlooked or ignored. Apart from a lack of social support, financial, and emotional resources, several caregivers frequently endure psychological anguish, anxiety, and depression following their first year of caregiving (World Federation of Mental Health, 2010). The psychological and emotional toll of giving care is well documented throughout the world, with females and marginalized groups, as well as low-income workers, bearing a disproportionate share of the burden (World Federation of Mental Health, 2010). The consequences of female caregivers' intensive caregiving can be worthwhile, with studies demonstrating that women in their middle and older years who provided care for a disabled spouse were nearly six times as likely to experience anxiety and depressive symptoms as those who did not provide care (World Federation of Mental Health, 2010).

2.3.4 Family Caregiver Experience of Stigma

Although limited consideration has been given to internalised stigma amidst informal care providers of patient suffering from mental health disorders, it has been demonstrated that, outside public and self-stigma, stigma affects informal care providers (Werner & Shulman, 2015). A study was conducted among informal care providers of individuals with mental health impairments to examine the frequency and use of diverse adaptive schemes, among others, they explored the function of these adaptive schemes in moderating the association between affiliate stigma and care provider burden. The findings demonstrated that, affiliate stigma and informal care provider burden were significantly related (van der Sanden et al., 2016).

Stigma has been defined as a collection of preconceived notions about discrimination, injustice, intolerance, and biased social institutions that are approved by a sizable population regarding a discredited segment (Corrigan, 2000). The earliest and most well-known sort of stigma is public stigma, which calls attention to the broader population's prejudice against stigmatised individuals (Link & Struening, 1997; Phelan et al., 1998). A second type of stigma is self-stigma, which focuses on individuals' internalisation of society's judgments about them (Corrigan & Watson, 2002). Due to the fact that stigma affects people who are close to the stigmatised individual (Goffman, 1963), a third type of stigma exists—that is, stigma by association and family stigma is one example of this. It refers to the stigma experienced by family members as a result of their association with a stigmatised relative (Larson & Corrigan, 2008).

In mental health treatment, caregivers' stigma is defined as associative or courtesy stigma or affiliate stigma (Goffman, 1963; Mehta, 1988). Associative or courtesy stigma refers to the process through which an individual becomes stigmatised as a result of his or her association with another stigmatised individual (Goffman, 1963; Mehta, 1988). Individuals associated with stigmatised individuals are personally impacted by the public stigma that exists in society, which is referred to as affiliate stigma. As a result, associates may experience discomfort, dissatisfaction, and helplessness as a result of their association with the stigmatised individual and sense a negative influence on themselves (Mak & Cheung, 2008). As a result of affiliate stigma's cognitive and affective impacts, carers may behave in attempt to prevent association by concealing their position from others, withdrawing from relationships, and isolating themselves from the targeted persons. This stigma may result in discomfort and powerlessness, concealing of the condition, withdrawal from social relationships, and avoidance of the patient, all of which may result in treatment seeking being delayed or discontinued (Helgason, 1990; Loebel, Lieberman, Alvir, Mayerhoff, Geisler, 1992; Mak & Cheung, 2008). Thus, affiliate stigma is composed of three interconnected components: cognitions, feelings, and behavioural responses.

In the United States, 56% of family members of mentally ill individuals reported feeling stigmatised (Angermeyer et al., 2003). Another survey found that 70% and 43% of carers stated that the majority of people disregarded people with mental illness and their families, respectively (Struening, Perlick, Link, Hellman, Herman & Sirey, 2001). Another study found that 30% of carers for the mentally ill refuse to disclose the patients' mental health status to anybody other than close relatives and friends in order to avoid encountering unpleasant, hurtful, and insulting attitudes. Whilst 49.0 percent will withhold information from the media, 49.5 percent will withhold information from the general public and healthcare practitioners as well. Health care providers handled family 'differently' (43.9%) and 'as less capable' (43.8%). (Mental Health Council of Australia, 2011). The characteristics of relatives of mentally ill individuals suit the concept of stigma associated with mental illness quite well. For example, family members are more likely to conceal the disease from strangers if they do not live with the ill relative, particularly if the victim is female and exhibits severe symptoms. Short-term mental illness and family members with a higher level of education are connected with increased avoidance by others (Phelan et al., 1998). There is a positive correlation between caregiver stigma and depression (Magaa, Garca, Hernánd & Cortez, 2007), suicidal thoughts (stman & Kjellin, 2002), thoughts that the patient would be better off dead (stman & Kjellin, 2002), caregiver burden (Magaa, Garca, Hernánd & Cortez, 2007), and delay in seeking help (Magaa, Garca, Hernánd (Fernando, 2010).

A study in Ghana demonstrated a strong correlation between mental illness and stigma on the one hand, and discrimination on the other, among those diagnosed with mental illness and their carers (Tawiah et al., 2015a). Economic, psychological, and social stigma were all acknowledged as manifestations of stigma by participants. Seventy-two percent of reported stigma was social in nature, ranging from familial blame to derision and mockery. Economic stigma was mostly induced by a lack of food access (14%), whereas psychological stigma was caused by a loss of self-esteem (13%). Discrimination against people with mental problems was primarily economic (46%) and social (54%) (Tawiah et al., 2015a). Another study conducted in Singapore found that practically all main carers (95 percent) experienced affiliate stigma when their care recipient had psychiatric disorders (Zhang et al., 2018). The study discovered that parents of patients with mental illness felt more stigmatised than siblings or spouses. Parents are considered as more accountable for their children's mental health development, and hence having a mental illness might reflect adversely on the individual's family and cause the family shame (Zhang et al., 2018).

2.4 Factors Associated with Caregiver Burden

Several variables that moderate the effects of caring on informal care providers' health are associated with background and context of caregiving situation itself, such as the age of caregiver, gender, educational status, income and employment, among others (Savage & Bailey, 2004).

2.4.1 Age of Caregivers

Age is significantly related to how informal care providers perceives caring to be distressful (Pearlin et al., 1990; Sato et al., 1996). The anxiety for the associated physical and psychological functioning of the care-provider and the patient comes with age (Pearlin et al., 1990). Sato et al. (1996), examined the effect of psychological distress and burden with a sample 58 informal care providers and their patients', and observed a positive correlation between care providers age and the duration it took in the caring role. Sato et al. (1996), intimated that, there was a likelihood for more elderly care providers to experience physical and mental health problems after caring for people with poor health conditions for longer duration. Given et al. (2005), also examined 152 care providers of cancer patients and found that, children of care providers in their mid-forties experienced depression, whilst care providers between the age range of 35 and 44 showed signs of abdicating their role. They intimated that, female care providers for cancer patients experienced more burden as compared to spouse care providers (Given et al., 2005).

Kim et al. (2012), investigated demographic variables that mediated care provider distress after five years of providing care amidst 1,218 care providers. Care provider's age, income and employment status, and care recipients physical and psychological health were important indicators of care providers wellbeing. Though, younger care providers as compared to the elderly care providers experienced better mental and physical health, the younger care providers however experienced worst emotional distress (Kim et al., 2012).

2.4.2 Gender of the Caregiver

According to the World Federation of Mental Health (2010), carers are more likely to be female than male in many parts of the world, and approximately 80% of caregivers globally are female. They are typically the patients' mothers, wives, or daughters and have a poor income. Thus, the second global challenge is the requirement for a thorough awareness of the needs and concerns of female caregivers, as well as the development of strategies to assist female caregivers. According to the World Federation of Mental Health (2010), as more caregivers are required globally in the future, more guys are anticipated to become caregivers. Taking on a caregiving role may imply a role reversal, a shift in many cultures' established gender roles within the family. At the moment, research on the male caregiver position is lacking, and little is known about the quantity and health of male caregivers. Additional research is needed to determine the influence of male caregiver roles on their life (World Federation of Mental Health, 2010).

The caregiving literature repeatedly demonstrates that female caregivers are more burdened than male caregivers (Swinkels et al., 2019; Marks et al., 2002; McDonnell & Ryan, 2013; Penning & Wu, 2016; Pinquart & Sorensen, 2006; Yee & Schulz, 2000). Sex disparities in caregiver load have been claimed in a variety of ways; first, because men and women live in distinct circumstances and environments, resulting in an unequal distribution of rights, rewards, blame, and liabilities in society. Due to these significant disparities in sex roles, individuals are subject to suffering in varying degrees and severity (Pearlin et al., 1990). This uneven allocation of social and economic resources may drive women into the care provider positions more frequently than men, and thus impeding their growth in other dimensions of live. Women generally dispense more of their time on providing care, and thus are susceptible and, are affected by the harmful consequences of health care provision which may account for some of the reasons why women experience higher care provider burden (Pinquart & Sorensen, 2006; Yee & Schulz, 2000).

Secondly, it is said that, in addition to the disproportionate distribution of burden situation, women and men perceive care provision differently (Calasanti, 2010; McDonnell & Ryan, 2013). The differences in gender outcomes on caregiver burden also emanates from the differences in approaches to how men and women deal with the care provision situations, even if the circumstances were similar (Hong & Coogle, 2016),

2.4.3 Relationship between Caregiver and Care recipient

The bond between the care provider and the patient has been observed to play a significant role in connection to the repercussions of providing care. Spouse care providers reportedly experienced lower positive affect as compared to parents and older relatives who doubled as caregivers (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998). Parents experienced better satisfaction than spouses in their caregiving roles, whilst spouses also experienced better satisfaction as compared to older relatives. Furthermore, parents and spouses experienced more intimate relationship with the care- recipient as compared to other relatives. Results from a study that examined caregivers of dementia patients reported that, being the care recipient's spouse was significantly related to experiencing depression (Schulz et al., 1995). Furthermore, Nolan, Mike , Grant, Gordon & Keady, (1996) noted that, there were variations in the feeling of fulfillment among caregivers who were spouses of the patient in comparison to those who were off-springs of the patient. Living with the patient was related to more unpleasant and depressive consequences on quality of life and less life fulfillment as compared to living at a different place (ABS, 2018).

Similarly, Baronet (1999) found that living at the same place with an individual suffering from a mental health condition enhanced the risk of undergoing through stress and burden. However, how intimate the bond between the care provider and patient seems to be significant; parents and spouses tended to be more positively engaged in providing care as compared to children (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998). How close and intimate the bond is between the care provider and patient is significantly related to the experience of psychiatric symptoms and burden (Braithwaite, 2000), and the quality and attachment of the bond are all influential in the achievement and fulfillment of live goals (Carruth et al., 1997). It has also been intimated that, depressive symptoms, anger and resentment may be a consequence of an intimate relationship between the care- provider and care recipient (Carruth et al., 1997).

2.4.4 Nature of Care Recipient's Disability

It has been argued that various features of the effects of providing care on the care provider's mental health can be distinguished contingent on the degree of the patient's disability. For instance, providing care to an individual with a mental illness may entail a measure of ambivalence for the care provider, a dearth in self-mastery and maneuvering by the care recipient (Bigby & Ozanne, 1999). For care providers looking after dementia patients, there is a loss of the individual who once was, especially for those observing the gradual decline of that person. For care providers who are biological parents or have offspring with disabilities, they may have to accept that their child may not develop normally, and that developmental milestones celebrated by other parents may be distressing for them. As caregivers who are adults with disabilities age, they experience an additional worry about who will look after their children when they are no longer able to (Bigby & Ozanne, 1999).

Schofield, Bloch, Herrman, Murphy, Nankervis, and Singh (1998) observed that caregivers for cognitively stable adults with a physical handicap may have a stronger level of wellbeing than caregivers for cognitively impaired individuals. According to the findings of a study (Hoare, Harris, Jackson, & Kerley, 1998), more distress among caregivers of cognitively impaired children was associated with increased impairment in the children. Additionally, the presence of maladaptive behavioural issues in dementia patients was associated with an increase in caregiver depression (Schulz et al., 1995). However, when mothers of individuals with mental illness were compared to mothers of adults with cognitive impairments, the latter group reported more pleasure and intimacy with the patient than mothers of adults with mental illness (Greenberg, Seltzer, & Greenley, 1993). In the latter study, moms of people with mental illness stated that their patients had more maladaptive behavioural issues (Greenberg et al., 1993).

2.4.5 The Stage in the Caregiving Process

It has been demonstrated that, the situation or circumstances under which the care providers find themselves in their caregiving roles determines the outcome of caregiving on their mental and psychological health (Avison & Turner, 1993). For the case of those providing care to dementia patients, care providers may go through several stages as a consequence of providing care. These may include noticing, discounting, suspecting, searching for explanation, recounting, going through it, and turning it over (Nolan, Mike , Grant, Gordon & Keady, 1996). Varying health consequences for providing care is to be envisaged at every stage of the caregiving process. The duration of providing care and peculiar circumstances the care provider finds himself or herself has to be taken into consideration when planning for support services for care providers (Nolan, Mike , Grant, Gordon & Keady, 1996).

2.5 Moderators of the Impact of Caregiving

Numerous factors can mitigate the impact of mental illness on caregivers, and these characteristics must be considered when developing strategies to support individual caregivers. Moderating elements include carers' financial condition, their level of social support, their coping skills, and their own sense of mastery or self-esteem. Several of these elements might be classified as coping responses, coping resources, or coping strategies (Nolan, Mike, Grant, Gordon & Keady, 1996). Coping resources are the kind of resources that people use to deal with situations. They include one's financial situation and available social support. Coping techniques are the means by which individuals cope (Nolan, Mike, Grant, Gordon & Keady, 1996). The literature demonstrates that mediating factors play a substantial influence. Pearlin, Mullan, Semple, and Skaff, (1990) hypothesised that, while coping and social support cannot account for all of the variation in the pressures experienced by different carers in similar conditions, they can play a significant explanatory role. Dunn and colleagues observed in a study involving parents of autistic children that stressors were not a direct predictor of unfavourable outcomes but were modulated by social support and coping style (Dunn, Burbine, Tracy, Clint, 2001).

2.5.1 Socio-cultural Factors

Studies (Miller, 1994) show that, western countries have an inclination towards being independent and nonconformists, whilst societies that are tied to historical and indigenous cultural heritage have a leaning towards dependency and sociocentricism, a division which is associated with different ideas or notions of interdependence among individuals of common kinship nexus, and who share a cultural bondage and therefore have a responsibility to other individuals recognised and identified as family and clan. These rings therefore have implications for the caregiver and care recipient relationships. Studies show that people of libertarian orientations have an independent moral code and conduct which gives prominence to individualistic and self-reliance tendencies; whilst individuals in conformist and interdependent cultural orientations have a duty-based moral code and conduct that emphasises obligatory support systems and responsibilities to one another as kin (Miller, 1994). Those codes of conduct and beliefs determines how role obligations are enacted and transacted among community members and families, and therefore influencing the care provider and care recipient relationship when a family member fall sick (Miller, 1994).

Consequently, in libertarian and nonconformist societies, a sick individual’s acceptance of family assistance could be emotionally troubling to the sick person in particular because he or she may have an inclination to independence and self-reliance. Receiving support from others could be interpreted as a form of powerlessness, impotence, meekness and spinelessness. In indigenous and conformist cultures however, the mutual perception of oneness and acceptance of reciprocal obligations makes it simply comfortable for people to admit the sick role and also to receive family support without difficulty. Consequently, when sickness befalls a family member, both the recipient of care and care provider envisage and look forward to other kinsmen to participate in all the processes leading to the restoration of normal health (Miller, 1994).

Almost all cross-ethnic comparisons of burden between caregivers from individualistic and collectivist cultural blocs have revealed a lower association between subjective burden and experience in African American families with people who have psychiatric impairments than in white American families (Horwitz & Reinhard, 1995; Pickett, Vraniak, Cook, & Cohler, 1993; Pruchno, Patrick, & Burant, 1997; Stueve, Vine, & Struening, 1997). These studies attribute the majority of these findings to the social support nexus among African Americans and the mutual support networks imbedded in interdependence and reciprocal connections (Pruchno et al., 1997). However, Pickett et al. found that the magnitude of the social support nexus was not significant (1993). The study (Pickett et al.,1993) discovered that African American parents of seriously impaired mentally ill individuals had much greater levels of coping mastery and self-esteem than white parents. They implied that possible supporting resources may occasionally have unfavourable consequences. Pickett et al (1993)'s study revealed that Black American families were disheartened by the limited assistance they received from family members, despite the supposed availability of a bigger social support nexus. Despite these seemingly contradicting data, African American caregivers were typically associated with lower levels of burden and suffering than white American caregivers in all published studies (Lefley, 1998). Black caregivers reported receiving much less support from their family members than white carers. Despite these apparent contradictions, black carers reported less hardship and sadness than white caregivers in all of the research reviewed (Lefley, 1998).

Additionally, individuals believe in supernatural elements contributing to mental disease (Mohd et al., 2014). For example, Mohd et al. (2014) discovered evidence of supernatural and mystical beliefs connected with mental illness in Malaysian research of carers of mentally ill patients. They discovered that the majority of study participants attributed their patients' mental illness to a "curse from God" or the punishment for previous sins (karma), loss of mental strength, incitement of "Jin," an imbalance of "chi," or the incitement of evil spirits. These beliefs were observed across ethnic groups (Mohd et al., 2014). According to Byaruhanga et al. (2008), over 90% of mental health patients and their carers who sought treatment at a hospital first visited with indigenous healers. While some patients and caregivers continue to consult these indigenous healers during hospitalisation, others express an interest in consulting them after discharge to undertake specific rituals or ceremonies. The majority of people believe that witchcraft, sorcery, the evil eye, breaching taboos, and neglecting ancestoral spirit ceremonies all contribute to mental illness. Numerous indigenous therapeutic modalities are perceived to be "effective" due to their integration into local, social, and cultural contexts (Byaruhanga et al., 2008). This may accurately explain why traditional healers are consulted.

2.5.2 The Relationship Between Sociodemographic Factors and the Burden of Caregiver

Siddiqui and Khalid (2019) conducted a study in which they studied the association between caregivers' sociodemographic characteristics (marital status, education, housing, and income) and caregiver burden among 120 Pakistanis. The results indicated that caregivers who were married (t=-2.98, p < 0.01), less educated (t =5.48, p < 0.01), lived in rural areas (t = -7.99, p < 0.01), and had a lower monthly income (t = -4.95, p < 0.01) faced a significantly greater caregiver burden than caregivers who were unmarried, had more education, lived-in urban areas, and earned a higher monthly income. Caregivers' marital status, education, geographic location, and income explained 16% of the variance in caregivers' burden (F (4, 78) = 12.08, p < 0.01). (Siddiqui & Khalid, 2019).

Jeyagurunathan et al. (2017) conducted a cross-sectional study in Singapore to explore the correlation between demographic characteristics (education, employment, marital status, and relationship to patient) and quality of life (QOL) and psychological burden among 350 caregivers of mentally ill relatives. Sociodemographic correlates (education, occupation, marital status, and relationship to patient) were found to be strongly linked with caregiver burden and QOL respectively. Caregivers with lower levels of education were considerably more likely to report experiencing more psychological distress and having a worse quality of life in the physical, psychosocial, and environmental domains.

They implied that higher educational attainment of caregivers was associated with higher income jobs, which may have contributed to the increased wellbeing. Employment was found to have a beneficial effect on QoL. The implication was that employed individuals may have had a stronger social support network, which may have had a beneficial effect on psychological suffering (Jeyagurunathan et al., 2017).

In terms of caregiver relationship to the patient, whilst those who cared for their son/daughter had a lower likelihood of depression symptoms, those who cared for their spouses (i.e. spousal caregivers) as opposed to parental carers also had lower psychological domain scores. Jeyagurunathan et al. (2017) proposed an explanation for the differences seen between these two groups. They suggested that, in comparison to parents, spousal carers may have lost their confidant, economic support, co-manager of the household, and child-rearing aid, which may have contributed to their poorer psychological domain ratings.

A thorough evaluation of the epidemiological literature on common mental diseases and poverty in low- and middle-income countries discovered that more than 70% of the 115-research examined indicated positive relationships between a variety of poverty variables and common mental disorders. The association's strength varied according to the type of poverty measure used (Lund et al., 2010). In several studies, debt was found to explain the link between poor income and mental problems. Population research conducted in England, Wales, and Scotland discovered that the more indebted individuals were, the more likely they were to suffer from a mental disease, even when income and other sociodemographic characteristics were adjusted for (Jenkins et al., 2008). According to a review of population surveys conducted in European countries, greater rates of common mental disorders (depression and anxiety) are connected with low educational attainment, material disadvantage, and unemployment, as well as social isolation in older adults (Fryers et al., 2005). The social distribution of common mental diseases exhibits a distinct social class gradient, which is more pronounced in women than in men (McManus et al., 2009).

2.5.3 Social Support

Social assistance can be provided on an ad hoc basis by family, friends, neighbours, and religious organisations, or it can be provided formally by institutions and agencies (Dunst, Trivette & Deal, 1988). There is much evidence in the literature suggesting that the amount and quality of social support available to care providers plays a critical role in moderating the success of care provision. Schofield, Bloch, Herrman, Murphy, Nankervis, and Singh (1998) hypothesised that caregivers with a greater social support nexus had greater life fulfillment and less resentment and anger than caregivers with a smaller social support nexus. Dunst, Trivette, and Cross (1986) found that accomplishment and fulfillment with 18 forms of social assistance (both ceremonial and informal) were significant indicators of emotional well-being in parents of disabled children. However, other research findings indicate that the mediating effect of social support varies (Baronet, 1999). However, empirical research (Deal & McWilliam, 1989) indicates that it is the quality of social support that matters, not its quantity. The finding may help to explain some of the literature's inconsistencies. The research has identified two domains of social support that appear to be fundamental to the notion (Pearlin et al., 1990); these are instrumental and expressive social support. Different items assess the availability of instrumental help, such as if someone assists the care provider in caring for the patient or assists with home duties. Expressive social support is quantified by items that reflect an individual's perceived availability as a caring, trustworthy, uplifting, and confidant (Pearlin et al., 1990).

2.5.4 Coping Mechanisms Employed by Caregivers

Turnbull (1993, p.11) provides an insightful description of coping as "the actions or thoughts that people use to enhance their feeling of well-being and avoid being injured by stressful demands." Informal caregivers employ a diverse range of coping strategies (Lundh, 1999; Nolan, Mike, Grant, Gordon, & Keady, 1996), with data indicating that some strategies are more beneficial in certain circumstances than others (Olshevski & Katz, 1999). As a result, it demonstrates that informal caregivers' ability to cope with stress varies (Lefley, 1997) and that distinct coping strategies should be used at various stages of care provision (Nolan, Mike, Grant, Gordon & Keady, 1996). The use of escape avoidance as a coping mechanism has been linked to increased levels of depression among parents of autistic children, whereas confrontative coping has been linked to decreased levels of sadness (Dunn, Burbine, Tracy & Clint, 2001). Avoidance coping has also been found to be significantly associated with depression among caregivers of dementia patients (Haley et al., 1996). A study of caregivers for children with severe impairments discovered that caregivers who experienced high levels of distress and low self-esteem used emotion-focused coping strategies more frequently than caregivers who had a higher level of self-esteem and also used task-focused coping strategies more frequently (Hoare et al., 1998).

Twigg and Atkin (1994), on the other hand, do not view the chores and responsibilities associated with providing care to relatives as fundamentally distressing; rather, they remark that it is a duty and obligation to serve one another in times of need. Thus, the essence of this type of care giving is the provision of all necessary activities of daily living focused toward survival (Twigg & Atkin, 1994). For example, Endrawes et al. (2007) observed that Egyptian kin have a proclivity to continue caring for unwell relatives despite problems such as mental suffering, physical discomfort, helplessness, and financial issues (Endrawes et al., 2007). Additionally, Haque (2004) highlighted that they think that caring for a sick family member is God's will and that they would be rewarded for their good efforts in this world or the afterlife. Naturally, this reflects the collectivist nature of Muslim society as a whole (Haque, 2004).

2.5.5 Self-efficacy or a sense of mastery

As Folkman, Schaefer, and Lazarus (1979) describe, a significant resource for dealing with or managing issues is the universal or peculiar belief, which include a sense of mastery or self-efficacy and religious or spiritual belief. In general, lower levels of self-esteem and mastery are associated with dementia symptomatology (Schulz et al., 1995). The results of a study (Avison & Turner, 1993) assessing the buffering effect of self-efficacy on varied groups of care providers revealed significant differences. Enhancing people's feeling of self-efficacy strengthens them, and it is believed to be the only sort of assistance that is truly sustainable.

2.6 Psychosocial and Cognitive Factors in Caregiver Stress and Burden

Research (Pearlin et al., 1981) demonstrates that psychosocial sources of stress can be traced all the way to the very edges of human societies, its structures and traditions. However, as one approaches the individual experience, one might consider stress as emerging from two main situations: the occurrence of distinct life events and the presence of relatively continuous issues. Among these, the study of life events has almost certainly garnered the most attention in recent years (Pearlin et al., 1981). It is suggested that events do not always have an immediate effect on people but may instead exert their influence through a broader framework of life pressures. Thus, the two primary drivers of stress, exciting experiences and chronic stresses, may interact to produce stress. This convergence occurs in two ways, one of which is represented by Brown and Harris's findings (1978). They documented cases in which seemingly insignificant life circumstances induced depressive episodes. After accounting for such instances, they found that life events can serve to highlight the negative consequences of life difficulties, and that it is the new meaning of existing problems that causes misery. From this vantage point, life events contribute to stress by distorting the meaning of ongoing life strains. Pearlin et al. describe a second mechanism in which life experiences and life strains intersect (1981). Their research indicates that life events can generate new strains or exacerbate existing strains, and it is these new or exacerbated strains that result in stress.

Although numerous factors can contribute to the worsening of life pressures, important life events stand out as significant precursors. For instance, additional pressures can be observed in marriage, motherhood, and among people caring for mentally ill individuals who double as family. These persons face psychological and cognitive phenomena or experiences such as role strains, low self-efficacy, learned helplessness, moral guilt, and feeling overwhelmed as a result of their caretaker roles for relatives who require assistance to function successfully in society (Pearlin et al., 1981). These psychosocial and cognitive events may act as powerful motivators for caregiver stress and burden prediction (Heslin & Klehe, 2006).

2.6.1 Role Strains and Burden Among Informal Caregivers

Role strain refers to the perceived difficulty in carrying out role responsibilities. Role relations are viewed as a series of "role bargains" and as a continuous process of selection among alternative role behaviours in which each individual strives to alleviate his or her role strain. These choices influence how all institutions of human society are assigned roles, responsibilities, and duties (Goode, 1960). Role strain is a critical process that connects experiences to stress. As previously stated, (Pearlin et al., 1981), incidents can result in undesirable changes to the more persistent circumstances of people's lives; these unpleasant changes then serve to amplify the level of stress experienced by people. Thus, events produce stress not just by directly requiring readjustment, but also by indirectly exacerbating role stresses. If disruptive job occurrences are used as an example, one should discover that they do enhance role stresses and that when people encounter intensified strains, they also become more susceptible to an intensified load (Pearlin et al., 1981).

Specifically, life events and the role pressures they cause are more likely to result in stress if they also result in a loss of self-esteem. In this context, two components of self-concept are particularly relevant: mastery and self-esteem. The term "mastery" refers to the degree to which individuals see themselves to be in control of the forces that have a substantial impact on their life. Self-esteem, on the other hand, refers to one's assessment of one's own self-worth (Pearlin et al., 1981).

Thus, self-protection and enhancement are key goals for which humans strive. The persistent presence of severely unpleasant conditions, as embodied in role strains, appears to act as a means of dismantling the insulation that protects the self from external threats (Kaplan, 1970). Persistent role strains can confront individuals with unflinching evidence of their own failures or lack of accomplishment, as well as with unavoidable confirmation of their powerlessness to modify their life' unfavourable conditions. Under these circumstances, individuals become subject to self-esteem loss and the eroding of mastery. In the ensuing problems associated with providing care to a mentally disabled individual, the caregiver's aspects of self are considered as the final stage in the process leading to caregiver stress (Pearlin et al., 1981).

It should be highlighted that the concept of role strain encompasses two overlapping issues (Sieber, 1974). These are role conflict and role overload. The former pertains to time restrictions; as role commitments expand, an individual may eventually face a time constraint that causes him or her to prioritise certain roles above others. On the other hand, role conflict refers to divergent expectations regardless of time constraints. At times, ego must choose between A and B expectations, because compliance with one will contradict the expectations of the other. According to these perspectives, multiplication of roles imposes a double weight of overload and conflict, as the more responsibilities one acquires, the greater the likelihood of running out of time and encountering role partners with contradictory expectations (Sieber, 1974).

2.6.2 Caregivers' Self-Efficacy as a Coping Strategy

Self-efficacy is described as a person's belief in his or her capacity to do a task successfully (Bandura, 1997). Along with the goals that individuals set, self-efficacy is one of the strongest predictors of how well an individual will succeed in practically any endeavour. Self-efficacy is a significant determinant of an individual's effort, tenacity, strategising, as well as subsequent training and work success. Apart from being highly predictive, self-efficacy can also be improved in order to reap the benefits of its performance-enhancing properties (Heslin & Klehe, 2006).

When individuals actively care for a relative or friend who is ill, disabled, or otherwise requires special attention, they may develop anxious or depressed when they regard themselves as unable to manage painful occurrences or obtain what they value greatly. As a result, self-efficacy is also associated with stress and occupational burnout. Low self-efficacy, in particular, can easily result in feelings of helplessness and hopelessness over one's ability to learn how to manage more effectively with the obstacles and demands of caregiving. When this occurs, low self-efficacy can be stressful and sad, impairing the performance of even the most gifted individuals (Heslin & Klehe, 2006).

Self-efficacy has an effect on how individuals feel, think, and act. In terms of emotion, low self-efficacy has been linked to depression, anxiety, and helplessness. Additionally, these persons have a low self-esteem and have gloomy views of their successes and personal progress. In terms of cognitive processes and academic performance, a high sense of competence facilitates them. Self-efficacy can either increase or decrease motivation to act. Individuals with a high sense of self-efficacy pick more difficult assignments. They establish greater goals for themselves and adhere to them (Locke & Latham, 1990). In thinking, actions are predestined, and individuals predict either positive or gloomy events based on their self-efficacy level. Once an action is taken, those with a strong sense of self-efficacy invest more effort and continue longer than those with a low sense of self-efficacy. When setbacks occur, the former bounce back more quickly and remain committed to their objectives. Additionally, self-efficacy enables individuals to choose tough circumstances, investigate their surroundings, and create novel scenarios. Capacity can be obtained by mastery, experience, vicarious experience, verbal persuasion, or physiological feedback (Conner & Norman, 1995).

2.6.3 Learned Helplessness and Coping

Learned helplessness is a cognitive, psychological and behavioural state of mind which is a consequence of a person losing reasonable control under one condition, and wrongly, misjudging and thinking that he or she will not be able to exercise reasonable control in other circumstances. This situation could implicate and obliterate the discharge of health mediation and essential services to care recipients, because the care provider with this type of condition may wrongfully presume that no amount of caregiving support or mediation can be of any help to the care recipient (Flannery, 2002). According to the theory, individuals susceptible to hysterical situations soon believe that their actions or mediation effort are inconsequential to planned health outcomes; and that this behaviour may give rise to motivational, cognitive, and emotional consequences of histrionic personality disorder. As a result, this behaviour may foster an expectation that actions would be fruitless, generalise to novel settings, and obstruct future learning (Seligman, 1975).

In the context of parenting children with disabilities, melancholy mood has been connected with emotion-focused coping strategies such as wishful thinking, denial, or avoidance. However, it has been discovered that emotion-focused coping strategies reduce the association between social stressors and stress outcomes in caregivers of children with developmental disabilities. The distinction between problem-focused and emotion-focused coping did not account for the observed differences in coping reactions (Carona et al., 2014).

Studies of parents of disabled offspring focused on a single coping strategy of behavioural inattention in order to examine a specific coping behaviour that has been associated with sadness, powerlessness, and helplessness in a diverse group of people. Behavioural inattention is a coping mechanism that involves reducing one's capacity to deal with a stressor or completely abandoning attempts to achieve goals that are being thwarted by a stressor (Carver et al., 1989). The study's findings indicated that caregiver burden was associated with a parent's quality of life via behavioural disengagement coping. The findings indicate that parents of children with cognitive-developmental disorders, such as high distress, may have difficulties with their coping mechanisms (Carver et al., 1989).

2.6.4 Moral Guilt as a Coping Mechanism

Guilt has been characterised as "the dysphoric emotion connected with the knowledge that one has violated an important moral or social standard in one's life" (Kugler, Karen; Jones, 1992). Additionally, the sensation of moral guilt has been considered as a causative factor in caregiver melancholy and suffering (Boye et al., 2002; Spillers et al., 2008), and some researchers regard guilt to be a significant emotion for caregiver outcomes, aggravating distress levels (Brodaty, 2007). A study of nine research involving 9,847 caregivers of elderly relatives across twenty nations indicated that caregivers' feelings of shame and worthlessness were strongly linked with caregiver stress and depressive symptoms (Del-Pino-Casado et al., 2019). This finding is consistent with previous reviews (Geng et al., 2018; Zhu & Jiang, 2018).

Gonyea et al. (2008) examined guilt feelings in 66 caregivers for elderly family members by analysing their replies to a questionnaire. The findings indicated that guilt feelings significantly contributed to caregiver burden in this study population. Additionally, guilt was examined among caregivers of dementia patients, where guilt was found to be a significant predictor of caregiver stress. Zarit et al. (1980) and Ankri et al. (2005) identified a guilt item in the Zarit burden scale using main component analysis. They discovered that the scale was significantly connected with the patient's maladaptive issues, such as verbal aggression and depressed mood (Zarit et al., 1980; Ankri et al., 2005).

2.6.5 Feeling Overwhelmed with Caregiving

Overwhelmed is a universal human life sensation associated with poor living quality. From a human being standpoint, all persons choose whether or not to feel overwhelmed at times. Thus, it is critical to comprehend the experience of feeling overwhelmed from a variety of angles (Kabigting, 2019). Feeling overwhelmed has been variably defined psychoanalytically as being suffocated, engulfed, swamped, drowned, shattered, and ensnared (Hurvich, 2000). Hurvich (2000) emphasises how these notions depict a loss of cognitive and physical control. Feeling overwhelmed has also been demonstrated in the research to indicate a persistent sensation of unease, isolation, and loneliness. Individuals who have felt overwhelmed have frequently been described as helpless (Hopps et al., 1995). Hopps et al. (1995) established this through a retrospective examination of 178 chosen clinical cases of overwhelmed clients. They suggested that overwhelmed clients had a sense of powerlessness and a loss of control (Hopps et al., 1995).

Overwhelmed was further defined as the responsibility of accepting oneself (Pierce, 2016). Pierce (2016) conducted a phenomenological data analysis on five participants and discovered themes of loneliness and overload. When these individuals, ranging in age from 25 to 35 years, described their own experiences, they expressed concern and doubt about themselves and reality. This resulted in the overarching theme of feeling overwhelmed by myself (Pierce, 2016).

2.7 Summary and Conclusion

Following a review of evidence-based studies, it became clear that caring for a relative who suffers from a mental health problem has significant psychosocial, emotional, physical, and financial implications, culminating in caregiver burden. The global mental health care agenda emphasises community-based care whilst downplaying institutionalised care. As a result, numerous countries have begun deinstitutionalising mental health care services.

Ghana has also embraced the global policy of deinstitutionalisation with the passing of the mental health act, 2012 (act 846), which has shifted the obligation for caring for people with mental health illnesses to informal caregivers with little or no training in mental health care. The rising prevalence of mental health problems and the deinstitutionalisation of mental health care in Ghana necessitate structural arrangements in communities to provide safety nets at home for the physical, mental, emotional, psychological, and financial needs of family caregivers and their mentally ill relatives. Although little study has been conducted on the internalised features of stigma (affiliate stigma) experienced by family caregivers of individuals with mental illness, it has been proven once again that stigma can affect family members in addition to public and self-stigma. As a result, this may have a detrimental influence on the health of informal caregivers in Ghana.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This section presents the methods used for the study. It describes the principles underpinning the choice of the design of the study. The section also presents the design of the study, study setting, study population, respondents' selection, sample size determination, norms governing participants selection, instruments used for data collection, data analysis and ethical issues among others.

3.2 Principles underpinning the study

A significant factor to consider in the research process is the theoretical basis of the study, as this gives the justification for the choice of the method used. The main theoretical grounding to be considered are the philosophy of existence and the theory of knowledge (Teddlie & Tashakkori, 2010). The philosophy of existence (ontology) relates to the quality or essence of truth (realism) that the investigator examines, and also how the truth can be evaluated; whilst the theory of knowledge (epistemology) examines the relationship between the investigator and what has been investigated (Creswell, 2009). Such theoretical models inform and guide the outline of the research and the method used to grasp and to appreciate the insight of what the study proposes to examine.

The notation of reality customarily give rise to a division in research approaches; namely, quantitative and qualitative approaches, with a contemporary approach that blends the two approaches (pragmatism). The quantitative research study functions on the empirical principle, which upholds the perspective that truth (reality) is one, fixed and measurable through rigorous methodological criteria. Whilst the qualitative research design functions on the ethnomethodological or constructionist ideology which holds the perspective that truth (reality) is subjective and varied (Bernard, 2006).

The notion of epistemology however considers the manner in which information is obtained by investigating or interrogating the association between the investigator and the investigated. In championing the empiricist (quantitative) paradigm to investigation, the researcher embarks on the examination of reality by keeping a distance between himself or herself (the investigator) and what is investigated. Differing from this view point, interpretivists (qualitative) strategists seek to minimize the distance between the researcher and what is being investigated (Creswell, 2009). The current study therefore adopted the pragmatist study design that seeks to blend the empiricist (quantitative) and constructionist (qualitative) designs whilst employing the sequential method (Bowling, 2014), so that the researcher could explore not only the magnitude of the issue but also the meaning the situation brings to the caregivers. Informed by this ideological underpinning, my philosophical viewpoint about the experience of the burden of mental health care on family caregivers is not static or uniform but varies perspectively depending on the individuals involved, as experiences are shaped by beliefs and experiences of individuals and the cultural contexts in which individuals live. It was therefore imperative to get closer to the communities to interact with the participants and gain a deeper understanding of their lived-experiences in order to construct this reality.

3.3 Study Design

A cross-sectional and phenomenological research designs were used while combining quantitative and qualitative methods of data collection. In a cross-sectional study, data is acquired from representatives of a population at a particular time in order to assist towards identifying issues of concern to the communities and to humanity as well (Hall. 2008).

Phenomenology however involves the investigation of "Phenomena"; circumstances, events or episodes as perceived by our subjective minds. Phenomenology investigates perceptions from the individual's viewpoint (Smith 2006).

The use of quantitative studies is more appropriate for the type of research where the investigator plans to study events or circumstances by empirical (objective) evaluations, and where research findings are presented with facts and figures (Williams, 2007). Qualitative studies on the other hand seeks to interrogate situations holistically through first-hand experience by getting closer to the episodes of interest, and the research findings are presented in textual format (Creswell, 2009; Williams, 2007). Consequently, the pragmatist methodological approach to research (blend of quantitative and qualitative methods) are used for collecting data, analysis, and presentation of findings (Creswell and Garrett, 2008; Teddlie and Tashakkori, 2010; Williams, 2007).

3.4 Study Area

The setting of the study was the Tamale Metropolis with a resident population of about 360, 579. Tamale is the capital city of the Northern region and it is Ghana's third largest city and the fastest-growing city in West Africa. The city is located 600 km (370 mi) north of Accra. Most residents of Tamale are Muslims, as reflected by the multitude of mosques in the town. Due to its central location, Tamale serves as a hub for all administrative and commercial activities in the Northern region, doubling as the political, economic and financial capital of the Northern region. The city hosts regional branches of financial institutions and a considerable number of international non-governmental organizations (NGOs) (Ghana Statistical Service, 2012).

There are three main government hospitals in Tamale; the Tamale Teaching Hospital (TTH), Tamale West Hospital (TWH), Tamale Central Hospital (TCH), and 15 private hospitals and clinics dotted around the city. While TWH and TTH attend to patients with mental health conditions on outpatient basis, those with severe forms such as schizophrenia are usually referred to the Tamale Central Hospital which has gained fame for providing mental health services in the study area and also serves as the referral point for close-by districts. These services are provided by a psychiatrist and fifteen psychiatric nurses, who are supplied with psychotropic medications for routine care of mental health services. Only patients with valid ID cards of Ghana National Health Insurance Scheme are able to access these services. The mental health unit of the Tamale Central Hospital also provide some form of social support programmes and counseling services for patients with mental and neurological disorders and their caregivers with the support of some donor partners.

3.5 Quantitative Method

3.5.1 Study Population

The study involved residents of the Tamale metropolis who are registered as part of the Tamale Health and Demographic Surveillance System (THDSS). The THDSS provides longitudinal data of residents in the study area and maintains a register of residents diagnosed with mental and neurological disorders and their caregivers. This case register is updated every 3 to 6 months and allows for monitoring of demographic changes, for example, mortality, prevalence, and incidence of mental illness over time in the catchment area. It also allows for easy location and follow-up of patients during outreach programmes. New patients who are identified during outreach programmes by Community Psychiatric Officers (CPO) and Psychiatric Nursing Officers (PNO) are recorded in the medical disorders case register/book. In total, 1084 family/primary caregivers and their relatives with various kinds of mental disorders such as, schizophrenia, depression and bipolar disorders were registered in the mental health case register for the period of January to December 2018. The diagnoses of these mental disorders were made by the psychiatrist using the International Classification of Diseases, 10th edition, primary care version for mental disorders (ICD-10, PCV).

3.5.2 Respondent Identification and Selection

An estimated 322 family caregivers of relatives with mental disorders who were registered on the THDSS database and satisfied the eligibility requirements were identified and enrolled for the study through a stratified sampling technique from the finite population (1084). Caregivers who lived with care recipients or were in active-care of the care recipients, and were identified as primary care providers by care recipients themselves or other family members were selected for participation. The selection of respondents was done through a simple random sampling technique (lottery method). Respondents who satisfied the inclusion criteria were identified in their homes, and at the facility (those who visited the facility with their relatives for review) and sought for their informed consent to be part of the study. This was done with the support of the PNOs who have the register/records of their clients with their contact details as well as that of their primary/family caregivers.

3.5.3 Inclusion criteria:

To be eligible for selection, the following requirements were strictly observed;

1) Respondents' mentally ill relatives should have been diagnosed with a mental health condition using the International Classification of Diseases (ICD) criteria, 10th edition, primary care version for mental disorders (ICD-10, PCV) such as, schizophrenia, depression or bipolar disorder, etc.
2) Respondents should have been living with and/or actively involved in the care of the patient for at least six months prior to start of study.
3) Respondents should have been at least 18 years' old at the time of recruitment.

3.5.4 Exclusion criteria:

1) Respondents' relatives should not have had a diagnosis of any other chronic medical comorbidity like diabetes, hypertension in the past. The rationale for this was to eliminate the possible confounding effect of these medical conditions on the phenomenon of interest (mental illness), and this was ensured at the facility where the recruitment took place.
2) Respondents' relatives with comorbid substance dependence, organic brain syndrome and mental retardation were excluded at the point of recruitment in order to control for the confounding effects of those conditions on the study. This was determined by the Psychiatric Nursing Officers (research assistants) by reviewing the medical histories of the respondents' relatives.

3.5.5 Independent and Dependent Variables

A hierarchical multiple regression (HMR) was used to determine how the independent variables predicted the dependent variable at different steps whilst controlling for all other independent variables in the equation. Drawing from caregiver stress theory (Pearlin et al., 1990), independent variables from the hierarchical regression model were as follows: (a) environment and context including sociodemographic characteristics, (b) stressors involving demands of caregiving, (c) caregiver's appraisal of ability to cope with demands of caregiving, (d) caregiver's use of social support resources, and (e) negative consequences of caregiving that affect the caregiver's health outcome as the single dependent variable of the study. The first four blocks of variables acted as antecedents to the stress process and influenced the impact of stress on the caregiver throughout the caregiving experience.

Caregiver burden was consistent with the outcome variable in the caregiver stress process theory (Pearlin et al., 1990).

3.5.6 Sample Size Determination

The sample population for the study was determined by the use of the Yamane formula (Yamane, 1967), at 95% level of confidence. After computation, 293 respondent population was determined from a sample frame of 1084 care providers. At 95% level of confidence, the margin of error of 0.05 was the expected value for the study. A stratified sample method was then used to determine the sample allocation to each stratum based on proportional allocation from the finite population representing 434 male and 650 female. Yamane's formula for calculating sample size has been used in many health researches in Ghana and Nigeria respectively (Nortey et al., 2017; Adefunke, 2015). This formula is suitable for both categorical and continuous variables, and applicable when the confidence coefficient is 95% with a population proportion of 0.05 (Anokye, 2020).

Yamane's formula: $n = \frac{N}{1+N(e)^2}$

Where; N = the sample frame

e = the margin of error, 5% (0.05).

n = the minimum sample population

From the above:

$$n = \frac{1084}{1+1084(0.05)^2}$$

n= 292.1832884097

n≈ 293

From the formula, a minimum population of 293 was determined. The sample population was increased to 322 caregivers. The twenty-nine (29) participants were added to account for possible non-respondents and incomplete questionnaire. With a response rate of 91% in the study, 293 questionnaires were successfully completed.

The major reason that contributed to the decline in the sample size from 322 to 293 was due to unwillingness and inaccessibility of some of the primary caregivers as a result of their choice to withdraw from the study in spite of their expressed consent and seeming enthusiasm to participate at the point of enrolment. For example, the researcher repeatedly visited the homes of the would-be respondents up to three times at least, but to no avail in spite of agreed scheduled appointments. Others also blatantly refused to pick up calls from the researcher after several attempts to contact them on phone. After consulting and a critical look at the literature, it was clear that when such situations arise, field studies could continue if there was proof that incorporating statistical analyses into the study design could compensate for the non-response and increase confidence in the results (Marcellus, 2004).

Dupuis et al. (2019), asserted that in health studies and psychiatric epidemiology in particular, mental health issues represent a major factor in attrition and non-response, making the groups of interest underestimated and less representative, and also lowering the statistical power of the analyses. Non-response has been broadly defined as the failure of subjects to complete their participation in a study following enrolment (Given et al., 1990). Despite the fact that systematic research on attrition and non-response remains scarce, several studies have shown that mental health disorders have a significant association with non-response, and therefore non-response bias must always be suspected in such studies (Saiepour et al., 2019; Dupuis et al., 2019; Gnambs & Kaspar, 2016; Dupuis et al,, 2015). This is because, systematic psychiatric studies are particularly likely to cover sensitive and emotionally imbedded questions (e.g., concerning drug use, past traumatic experiences, stigma, sexual life, etc.) that are well-known to cause attrition and non-response (Gnambs & Kaspar, 2016).

It is universally acknowledged among the research community that, non-response presents a challenge in psychiatric epidemiological research, especially where participants have a low desire to share information about their mentally impaired relatives, or may feel embarrassed about their own predicaments, will invariably have a negative influence on non-response (Lamersa et at., 2012). Several studies have demonstrated that, stigmatising conditions and disorders of mental health are associated with higher rates of non-response (Fanner et al., 1994).

In order to address the non-response situation on the ground, literature (Marcellus, 2004; Flick, 1988; Alhassan & Nokoe, 2016; DiCiccio & Efron, 1996) suggests incorporating statistical analyses into the study design to increase confidence in the results. Flick (1988), has intimated that, rather than approaching non-response as a nuisance, researchers should treat it as a legitimate part of the phenomenon of interest. Alhassan & Nokoe (2016), argue that, one of the useful tools that can compensate for non-response is the use of bootstrapping, it is an appropriate technique for checking and controlling the stability of the results.

Among other considerations, the central limit theorem (Douglas & Robert, 1996), intimate that a sample size of 100 is statistically large enough for the conduct of a quantitative research study, hence the decision to continue with the data analysis with the sample size of 293.

3.5.7 Sampling Procedure

Stratified sampling method was used for the quantitative study. This is because, the total number of family caregivers was made up of both males and female comprising of 434 males and 650 females in the proportion of 40% and 60% respectively. There was therefore the need to investigate the perceived level of burden from the family caregivers while maintaining the proportional representation of the gender distribution in the sample frame. Therefore, the finite population (1084) was divided into two groups according to gender (male and female), and this comprised of 434 and 650 male and female in the ratio of 0.4 to 0.6 respectively. Simple random sampling (lottery method) was then used to select each stratum based on the minimum sample size (293) represented by 117 and 176 for the male and female samples respectively. The purpose of this was to solicit the experiences of the study respondents in their natural distribution as represented in the sample frame. Table 1.1 below illustrates the sample allocation to strata based on proportional allocation.

Table 3.1: Sample allocation to strata based on proportional allocation

Population	N_i	N_i/N	$n_i = (N_i/N) \times n$
Male	434	0.4	$n1 = 0.4 \times 293 = 117$
Female	650	0.6	$n2 = 0.6 \times 293 = 176$
Total	1084	1.00	n = 293

Ni = Sampling proportion of stratum
ni = Number of units sampled from stratum
n = Sample size
N = Sampling frame
N1 + N2 = N (1084)
n1 + n2 = n (293)

3.6 Quantitative Data Collection Instruments

Four main research tools were used to collect data for this research. This includes; EMIC questionnaire, Zarit Burden of Care schedule, General Health Questionnaire and, Family Stigma Scale. The tools were all designed in English and translated into a local language (Dagbanlli) and back translated into English language for the purpose of administering it to those who could not read and understand the English language. Prior to the use of the research tools on the field, two days training workshop was organized for the community psychiatric nursing officers (CPNO) who served as research assistants for the study, particularly, in the use of the data collection tools.

3.6.1 The Explanatory Model Interview Catalogue for Cultural Epidemiology (EMIC)

The EMIC questionnaire in appendix 1, based on the framework of the explanatory model interview catalogue (EMIC) for cultural epidemiology (Weiss, 2001) was used to assess socio-demographic and sociocultural information that were of relevance to caregiver burden. The EMIC questionnaire contained 25 items or questions with multiple response options on each item. These were made up of socio-demographic information, perceived cause of illness, stigma and discrimination, coping strategies, caregiving experience, sources of medication supplements, sources of support, etc. These were used to examine caregiver related experience of giving care to their mentally ill relatives, the meanings of the experiences to them and how it affects their behaviour. A total of 293 respondents of family caregivers of persons living with mental illness were probed to examine their lived-experiences and to explore contextual issues relating to caregiving. The severity of burden associated with caregiving was also explored for each participant, and emerging themes bordering on caregiving burden including participant's experiences of caregiving inventory and ways of coping as well as the level of support available to caregivers were explored. Basic demographic information such as age, sex, marital status, occupation, educational level, ethnicity, relationship to patient, religious orientation, diagnosis of patient, hours spent with patient and place of residence were all included in the EMIC Interview Schedule and administered to the participants. The impact of the caregiving role on caregivers' finances, emotion, social relations, time, and health were all assessed. Complementary components of the data set included categorical and numeric data for quantitative comparative analysis and narrative data for qualitative thematic analysis. Ahorlu et al., (2005) successfully used the EMIC tool to conduct research on malaria in southern Ghana, and therefore validated the tool which was adopted for the study.

The questionnaire was pretested on 10 randomly selected participants with the goal of determining its suitability on the actual sample, and to make modifications, if necessary, especially with respect to clarity and duration of the questionnaire on each participant. After the pretesting, the time allocation for the administration of questionnaire on each participant was modified to two hours per session instead of the one and half hours projected. Data on these cases were not included in the final sample. Two Psychiatric Nursing Officers from the Tamale Central Hospital who were well known to the participants were employed as research assistants for the study, and in total there were three facilitators including one moderator, one note taker and one observer. Nine (9) months were used for data collection (from January-September, 2019) and an average of two caregivers were interviewed per day and interviews lasted for about two hours per session where all the other instruments were consecutively administered, including, Zarit burden of care scale (BOC), General Health Questionnaire-12 (GHQ12) and Family Stigma Scale (FSS).

3.6.2 Burden of Care (BOC) Schedule

To assess the level of caregiver burden, an adopted Burden of Care Schedule (BOC) also known as Zarit Burden Interview scale in appendix 2, was used to measure the severity of burden for the study. The instrument was initially developed by Zarit to assess the level of burden experienced by the principal caregivers of older persons with senile dementia and disabled persons (Zarit, et al., 1980), and later used in a family participatory study in Israel (Rudnick, 2004). This was used in a Ghanaian study (Opoku-Boateng et al., 2017) and among Nigerian samples, and has been found to be reliable (Oshodi et al., 2012).The face validity of the BOC schedule was found to be good. The internal consistency of the instrument was determined using Nigerian samples; Cronbach alpha and split-half reliabilities were computed. A Cronbach alpha of 0.91 and a split-half coefficient of 0.82 were obtained (Oshodi et al., 2012).

Also, for this study, the reliability of the BOC items was investigated using the Cronbach alpha coefficient. The reliability measures the internal consistency of the scale, thus the degree to which the items that make up the scale 'hang together'. A Cronbach alpha coefficient value of 0.89 was found for the BOC items indicating that the scale was internally consistent. The BOC schedule is a 5-point Likert response scale with 22 negatively phrased questions/statements for participants to respond to. The Burden Interview has been specially designed to reflect the stressors experienced by caregivers of mentally ill persons. It can be completed by caregivers themselves or as part of an interview. Caregivers were asked to respond to a series of 22 questions about the impact of their patient's disabilities on their life. For each item, caregivers were to indicate how often they felt that way (never=0, rarely=1, sometimes=2, quite frequently=3, or nearly always=4).

The Burden Interview is scored by adding the numbered responses of the individual items. Higher scores indicate greater caregiver distress. The Burden Interview, however, should not be taken as the only indicator of the caregiver's emotional state. Clinical observations and other instruments, such as General Health Questionnaire-12 (GHQ12), which is a measure of the level of psychological distress should be used to supplement this measure (Seng et al., 2010; Cummings et al., 2002). In a study among 238 Singapore residents, Seng et al. (2010) found a positive relationship between subjective burden and psychiatric and psychological disturbances, and a strong correlation between BOC and GHQ scores. The estimates of the degree of burden are as follows; 0-20: Little or no burden; 21-40: Mild to moderate burden; 41-60: Moderate to severe burden; and 61-88: Severe burden.

3.6.3 General Health Questionnaire-12 (GHQ-12).

The General Health Questionnaire version 12 (GHQ-12) in appendix 3, was used to screen for probable psychiatric morbidity in the participants. The GHQ-12 was adopted for use in this study as a back-up to the Zarit burden scale in order to screen the respondents for probable psychiatric morbidity. This is because, according to Cummings et al., (2002), the Burden Interview scale should not be used as the only indicator of the caregiver's emotional state, but clinical observations and other instruments, such as General Health Questionnaire-12 (GHQ-12), which is a measure of the level of psychological distress should be used as a compliment to this measure (Cummings et al., 2002). It was designed as a self-administered screening instrument, sensitive to the presence of psychiatric disorders in individuals presenting in primary care settings and non-psychiatric clinical settings (Goldberg, 1972). It has been used extensively by several authors, and locally in Ghana (Glozah & Pevalin, 2015), and also among Nigerian samples (Aloba et al., 2019), and therefore validates the tool for use in Ghana. Although most of its use was among primary care and general population subjects, it has also been found useful in screening other special groups for psychiatric morbidity (Oshodi et al., 2012). The GHQ-12 has been found to be a reliable screening tool, and scores of 13 and above on the GHQ is indicative of psychiatric morbidity (Goldberg & Williams, 1988). The reliability of the GHQ-12 items was investigated for this study, using the Cronbach alpha coefficient. A Cronbach alpha coefficient value of 0.69 was found for the GHQ items indicating that the scale was internally consistent.

The GHQ-12, developed by Goldberg, (1972), is one of the most popular and widely used screening instruments for recognition and measurement of psychological distress. The original GHQ consists of 60 items, and now there are multiple versions, including GHQ-1, GHQ-12, GHQ-20, GHQ-28 and GHQ-30. The GHQ-12 is the most popular due to its brevity, and it consists of 12 items, each of which is evaluated by four indices. The two most commonly used scoring types are the bi-modal (0-0-1-1) and Likert scoring methods (0-1-2-3) (Liang et al., 2016).

This questionnaire includes 12 items (six positively worded items (e.g., Have you been able to concentrate on whatever you are doing?) and negatively worded items (e.g., Have you lost much sleep over worry?). The study adopted the four-point Likert scale, with each item ranging from 0 to 3. For negatively worded items, ‘0’ indicated Not at all, ‘1’ indicated Seldom, ‘2’ indicated Usual and ‘3’ indicated More than usual, while positively worded items were reversely scored. All items were added to obtain the total score, making the score range 0-36 (with a higher score indicating worse mental health). A score of 12 is the cut-off point score, and any figure over and above the cut-off point of 12 being classified as cases (Hankins, 2008; Liang et al., 2016).

3.6.4 Family Stigma Scale (FSS)

The Family stigma scale in appendix 4, is a 14-item instrument from the Family Interview Schedule (WHO developed psychiatric assessment), was used in the study to assess the affiliate stigma among caregivers. The original version of the FSS was developed for relatives of people with schizophrenia and was therefore adopted for use in this study to focus on caregivers of individuals with mental disorders. An adopted version of the FSS has previously been used in Ethiopia to assess stigma in relatives of children with developmental disorders (Tilahun et al., 2016). A score ranging from 0 to 3 for each item indicates how frequently caregivers experience stigma, higher scores indicate that one experienced stigma more frequently. FSS questionnaire in this survey was rated on a four-point scale whereby experiencing stigma in the community 'a lot' was given a score of 3, 'often' a score of 2, 'sometimes' a score of 1, and 'not at all' a score of 0. To assess the distribution of responses between groups, a total score was computed by summing the item scores, with a minimum score of 0 and a maximum score of 42. The internal consistency of this adopted FSS scale was good (Cronbach's Alpha = 0.92). Also, for this study, the reliability of the FSS items was investigated using the Cronbach alpha coefficient. The reliability measures the internal consistency of the scale, thus the degree to which the items that make up the scale 'hang together'. A Cronbach alpha coefficient value of 0.85 was found for the FSS items indicating that the scale was internally consistent.

3.7 Data Management and Analysis

All the questionnaire that was duly filled and completed by participants were taken by the principal researcher for verification and certification. All certified questionnaires were put in a safe until they were all collected. Prior to data entry, all cases were verified and certified, and subsequently entered into IBM SPSS-22 for analysis.

Correlational and hierarchical multiple regression analysis was employed to investigate the extent of association between the independent and dependent variables, representing background characteristics, social support resources, and caregiver burden as the outcome variable respectively. Demographic data was summarized using frequency distribution and cross tabulation. Chi square analysis and Pearson's correlation coefficient was employed to test for the validity of the research findings. Assumptions of normality and collinearity was examined prior to developing the model, by checking the normal probability plots of residuals and scatter plots of residuals against the predicted residuals, and no breaches were found. The exhibits of the normality and scatter plots are in appendices 7 and 8 respectively.

3.8 Qualitative Research Method

3.8.1 Study Design

Interpretive phenomenology was used as the most suitable technique of query for the investigation. This is because interpretive phenomenology is interested in how individuals make sense of their feelings of a particular situation (Cohen, 2000), and therefore it is the well-suited technique or instrument of inquiry and examination for the research. The use of diverse qualitative techniques was contemplated over in this study, but phenomenological studies require that lived-experiences should be probed into. Interpretive phenomenology does not endeavour to remove the investigator from the body of the study. The doctrine of interpretive phenomenology believes that predisposition is irrepressible, and therefore to endeavour to remove bias is actually seeking to do rather somewhat that, we as humans are not capable of (Schwandt, 2000). Life describes the fact of our existence, and to refuse that our experience has an impact on our behaviour is to refuse that we are alive (van-Mane, 1990). Interpretive phenomenology as an approach defined by van-Manen (1990), as descriptive-interpretive, conforms with my ideology of the significance of going farther than the narratives of the research respondents to grasping the contextual meaning of the narratives by means of interpretation.

Van-Manen (1990), gave no ideal approach (template) to the pursuance of the concept, but he simply demonstrated with some sample tracks for the investigator to follow and to uncover the lived-experience of the research respondents. This is an approach which endeavours to avert any inclination toward conceiving a predefined sets of rigid protocols or methods that would control and direct the research programme (van-Manen, 1990). Investigators should engage in episodes of significance through the lived-experience instead of predetermined concepts. Considerations of episodes through staying with the data and writing and rewriting are fundamental elements of the research methodology (van-Manen, 1990).

3.8.2 Study Population

The study population for the qualitative research were made up of male and female community members in the Tamale environs who were caring for their relatives diagnosed with mental illness and registered as part of the Tamale Health and Demographic Surveillance System (THDSS).

3.8.3 Selection of Study Participants

Purposive sampling technique was used to recruit participants for this research. This is a non-probability method in which participants are selected to a study on the basis of their level of expertise or experience on issues or matters that are of relevance to the investigation (Green & Thorogood, 2004). According to Patton (2002), this method is used in identifying experts who are knowledgeable in the subject matter which is of interest to the research community.

The selection was therefore informed by the lived-experience of participants in the care of their mentally-ill relatives. Ten (10) participants were selected for this research after saturation was deemed to have been reached by the principal investigator after the eighth participant interview, and the two additional interviews were conducted to be double-sure that no relevant information was left out. The participants included six (6) females and four (4) males.

3.8.4 Participants Inclusion Criteria

To be eligible for selection, the following requirements were strictly observed;

Informants' mentally ill relatives should have been diagnosed with a mental health condition using the International Classification of Diseases (ICD) criteria, 10th edition, primary care version for mental disorders (ICD-10, PCV) such as, schizophrenia, depression or bipolar disorder, etc.

Participants should have been living with and/or actively involved in the care of the patient for at least one year prior to start of study, and participants should have been at least 18 years' old at the time of recruitment.

3.8.5 Data Collection Method and Tools

In-depth interviews (IDI) guide was used for data collection in this study. IDIs is a qualitative method in which the investigator (interviewer) uses probing questions to solicit for information that are of relevance to the study from the research informant (interviewee) (Plummer. 1983). The interviews were conducted among ten key informant interviewees (KII) with question guides (appendix 5) crafted and modelled along the lines of Kleinman's, (1980) explanatory model interview catalogue (EMIC- scale) that covered phenomena relevant to caregiving to mentally-ill individuals. The 10-key informants were purposively recruited from the sample frame but those were different from the sample for the quantitative study. They included six females and four males; the gender ratio was informed by the proportion of male and female representation in the finite population. The principal investigator therefore chose to engage them further and individually, through in-depth interviews guide, in order to learn from their rich experiences relating to caregiving. Hence, the name 'key-informants' was designated for this group because of their perceived deep-rooted knowledge and experience in caregiving.

EMIC-scale is a set of 8 questions designed by Kleinman, (1980) to elicit caregivers explanatory models of their caregiving roles. A set of ideas about an episode of sickness which attempt to answer questions about: Cause, time and mode of onset, nature of the pathology, severity and course of sickness, and treatment from the point of view of the caregiver. Explanatory models are influenced by culture and hence will be suitable for this study. As a generic scale it can be used for different health conditions (Weiss, 1997), and the interviews were administered to the ten informants.

Each of the informants answered questions from the question guides that covered some major themes bordering on cause of sickness, experience of stigma due to the sickness, experience of burden, coping strategies adopted, and whether they receive support from social network, if they had one. The themes that were used for the question guides to the interview were as follows; (1) ADL, IADL, care demands, bodily pains, worries, sleeplessness, and exhaustion as sources of physical and psychological burden (2) Witchcraft, evil spirits, isolation, neglect, and stigmatisation as sources of social and relationship burden (3) Financial problems and responsibility roles as sources of financial burden (4) Symbolic meaning of care giving to relatives as sources of strength and coping (5) Stress, worries, mental exhaustion, and bodily pains as sources of role strain and burden (6) Absence of NHIS coverage for psychiatric drugs as a source of financial burden and helplessness for caregivers (7) Stress, guilt feeling and financial problems as sources of moral injury for caregivers (8) Worry, anxiety and emotional trauma as sources of feeling overwhelmed by caregivers.

The interviews were audio recorded, and it took about one hour to complete. The venue for interviews were at the discretion the informants, and these were at the facility, work place, or at home. The use of EMIC interviews for cultural epidemiology research focuses on local concepts of illness, rather than professional concepts of disorder. Therefore, it required a systematic and more complex approach to coding, analysis, and presentation of local categories of experience, meanings and help-seeking behaviour (Weiss, 2001).

The EMIC tool, which was developed in 1992, was successfully used to study mental health, leprosy, diarrhea diseases, filariasis, onchocerciasis and tuberculosis (Akogun et al., 2001; Auer, Tanner & Weiss, 2000; Pan-African, 1995; Weiss, 1997). Furthermore, Ahorlu, Koram, Ahorlu, De Savigny, & Weiss, (2005) successfully used the EMIC tool to conduct research on malaria in southern Ghana. The framework of cultural epidemiology arose from efforts to achieve an effective interdisciplinary collaboration, finding appropriate and useful ways of integrating the framework and methods of anthropology and epidemiology. To make this integration possible was the development of a framework and research instruments from insider's perspectives known collectively as EMIC interviews (Weiss, 2001; Weiss, 1997). EMIC interviews are instruments used for assessing representations of illness or specified health problems from the perspective of affected persons, their family members or community members.

3.8.6 Qualitative Data Analysis

For the qualitative data analysis, responses to in-depth interview were transcribed verbatim. The interview transcripts were coded and manually analysed thematically using the method of thematic analysis (Braun and Clarke, 2006). For this study, an essentialist stance was taken, which reports the participants' experiences as a reflection of reality. Initially the interview transcripts were read several times by the researcher in order to become familiar with the data. All transcripts were analysed to derive initial codes, which were applied to segments of the data and closely reflected the raw data (inductive analysis). Following this, all the data extracts relating to the same codes were collated together.

Responses to all the open-ended questions, from one to eight, relating to cause of the mental illness, its severity, and the challenges and difficulties posed by the illness on the caregiving role were analysed using the method of thematic analysis of Braun and Clarke, (2006).

The data was systematically reviewed to establish data segments and initial themes. Similar actions, events and objects were grouped together as categories, from which common themes/categories were extracted for a second level of interpretation. The data analysis process and findings are described in a narrative format and illustrated with tables at the results section in chapter four.

3.9 Ethical consideration

Ethical approval for the study was obtained from the Ghana Health Service Ethical Review Committee with protocol identification number GHS-ERC: 006/11/18 (appendix 12). Permissions were also sought from the Northern Regional Directorate of Health Services, Tamale Metropolitan Director of Health Services, and Management of the Tamale Central

Hospital respectively prior to data collection. Caregivers and their patients were also assured of the privacy, confidentiality, data safety and appropriate data usage by using anonyms, codes and pseudonyms during data analyses and collation. There were no known risks of using the data, and benefits of using the data were of immense importance to providing evidence-based information on the burden of mental healthcare on family caregivers in the Tamale Metropolis on one hand and in Ghana as a whole. Furthermore, there was no conflict of interest.

This research study was in keeping with the Ghana Health Service Ethical Review Committee's protocols (appendix 11), and was therefore reviewed to ensure strict compliance prior to conducting this research. Written informed consent was sought from study participants in a language that they understood, and the purpose of the research was explained to the participants with the support of the psychiatric nursing officers who doubled as the research assistants. The voluntary nature of participation was told to participants, and they could choose to withdraw from the study without consequences. They could decline to answer any question they were not comfortable with, and participants were encouraged to ask questions for clarifications. Anonymity and confidentiality were guaranteed. The detailed protocols and procedure of the ethical principles with research participants were observed by this study and were in compliance with the Ghana Health Service Ethical Review Committees' protocol.

CHAPTER FOUR

RESULTS

4.1 Introduction

The goal of this research was to explore the experiences of family caregivers (in their caregiving roles) in order to determine the impact of giving care to their mentally ill relatives on their lives. Guiding the research process were the following questions; (1) What care experiences exacerbate family caregivers' burden whilst caring for relatives who suffer from mental health disorders? (2) What sociocultural behaviours exacerbate caregiver strain while caring for family with mental health disorders? (3) Does caring for relatives who have mental health problems laden with stigma and discrimination? (4) What sociodemographic factors contribute to the burden of informal caregivers? (5) How do family caregivers cope with the difficulties and obstacles inherent in caring for relatives who suffer from mental health disorders?

The chapter begins with socio-demographic characteristics of study respondents for quantitative and qualitative studies respectively, followed by descriptive statistics, which are used to present frequencies and percentages on the background characteristics of study respondents. Research findings are presented for quantitative data, and qualitative data from in-depth interview transcripts from 10-key informants. Analysis of quantitative data is presented first, followed by analysis of interview transcripts from the 10-key informants.

4.2 Socio-demographic Profile of Caregivers

Table 4.1 revealed that most of the caregivers were between 31- 60 years of age 186 (64%), with 117 (40%) being males and 176 (60%) females. Relatives caring for patients were mainly:

parents 98 (33%), spouse 93 (31%) and household heads 80 (27%). The majority 149 (51%) of caregivers were Secondary/Middle school leavers, 52 (18%) had tertiary education, 20 (7%) had basic school education and 72 (25%) had no education. This implied that 221 (76%) of the caregivers were literate. Also, the far majority 236 (80%) were in some form of employment, whilst 57 (20%) rated themselves as unemployed. Of those employed, 34 (12%) were teachers, 16 (6%) were farmers, four (1%) were nurses, 63 (22%) were in the services sector (e.g., driving, cleaning, etc.), whilst 119 (41%) described themselves as self-employed. About 216 (74%) caregivers in this study rated themselves as not having regular and dependable income and only 22 (8%) described themselves as having regular and dependable income.

The study revealed further that majority 174 (59%) of the caregivers were married with 71 (24%) never married, divorced 34 (12%), widowed, 12 (4%) or remarried, two (1.00%). Most of the caregivers 207 (71%) had children to care for, whilst the rest 86 (29%) had no children to care for. The results further indicated that more than a third of the caregivers were mothers 111 (38%) and siblings 87 (30%), whilst 16 (6%) were fathers. Table 4.1 indicate further that, about half 144 (49%) of the care recipients were diagnosed with depression, 59 (20%) were diagnosed with schizophrenia, 45 (15%) were diagnosed with paranoid disorders, 22 (7%) were diagnosed with anxiety disorders, whilst 23 (8%) were diagnosed with panic disorders. As was expected, most of the caregivers of this study were Muslims 250 (85%) and Christians 43 (15%), reflecting the dominance of these religious denominations in the study area, this is illustrated in Table 4.5.

Table 4.1: Sociodemographic profile of Caregivers and Severity of Caregiver Burden

	Severity of Caregiver Burden				
	Mild to moderate Burden	Moderate to Severe Burden	Severe Burden	Total	Test
CARE GIVER FACTORS					
Age Group					
18-30	2(0.70%)	53(18.10%)	26(9.60%)	81(27.30%)	
31-40	1(0.30%)	43(14.70%)	17(5.80%)	61(20.80%)	
41-50	3(1.00%)	48(16.40%)	19(6.50%)	70(23.90%)	χ^2 = 9.788
51-60	2(0.70%)	39(13.30%)	14(4.10%)	55(18.80%)	P = 0. 306
61-70	0(0.00%)	17(5.80%)	1(0.30%)	18(6.10%)	df = 10
71 and above	0(0.00%)	7(2.40%)	1(0.30%)	8(2.70%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
Gender					
Male	4(1.40%)	101(34.40%)	12(4.13%)	117(39.93%)	χ^2 =24.450
Female	4(1.40%)	106(36.20%)	66(22.47%)	176(60.07%)	P = 0.000
Total	8(2.80%)	207(70.60%)	78(26.60%)	293(100%)	df = 2
Level of Education					
Tertiary	2(0.70%)	35(11.900%)	15(5.10%)	52(17.70%)	χ^2 = 7.87
Secondary/Middle	4(1.40%)	114(38.90%)	31(0.60%)	149(50.90%)	P = 0.248
Basic	0(0.00%)	11(3.80%)	9(3.10%)	20(6.80%)	df = 6
No education	2(0.70%)	47(16.00%)	23(7.8%)	72(24.60%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
Type of employment					
Teacher	1(0.30%)	26(8.50%)	8(2.70%)	34(11.60%)	χ^2 = 5.134
Farmer	0(0.00%)	13(4.40%)	3(1.00%)	16(5.50%)	P = 0.882
Nurse	0(0.00%)	4(1.40%)	0(0.00%)	4(1.40%)	df = 10
Services	2(0.70%)	41(14.00%)	20(6.80%)	63(21.50%)	
Self-employed	4(1.40%)	86(29.40%)	29(9.90%)	119(40.60%)	
Unemployed	1(0.30%)	38(13.00%)	18(6.10%)	57(19.50%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
Marital Status					
Never Married	3(1.00%)	46(15.70%)	22(7.50%)	71(24.20%)	χ^2 = 6.406
Married	5(1.70%)	125(42.70%)	44(15.00%)	174(59.40%)	P = 0.602
Divorced	0(0.00%)	23(7.80%)	11(3.80%)	34(11.80%)	df = 8
Remarried	0(0.00%)	2(0.70%)	0(0.00%)	2(0.70%)	
Widowed	0(0.00%)	11(3.80%)	1(0.30%)	12(4.10%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
Status of the caregiver					
Household head	2(0.70%)	63(21.5%)	15(5.10%)	80(27.30%)	χ^2 =14.400
Spouse	3(1.00%)	55(18.80%)	35(11.90%)	93(31.70%)	P = 0.0012
Parent	2(0.70%)	70(23.90%)	26(8.90%)	98(33.40%)	df = 8
Child	1(0.30%)	18(6.10%)	1(0.30%)	20(6.80%)	
Other	0(0.00%)	1(0.30%)	1(0.30%)	2(0.70%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
Regular and dependable income					
No	4(1.40%)	160(54.80%)	52(17.70%)	216(73.70%)	χ^2 = 13.428
Possible	4(1.40%)	29(9.90%)	22(7.60%)	55(18.80%)	P = 0.009
Yes	0(0.00%)	18(6.10%)	4(1.40%)	22(7.50%)	df = 4
Total	8(2.80%)	207(70.60%)	78(26.60%)	293(100%)	
Do you have Child(ren)					
Yes	4(1.40%)	148(50.50%)	55(18.70%)	207(70.60%)	χ^2 = 1.718
No	4(1.40%)	59(20.10%)	23(7.80%)	86(29.40%)	P = 0.042
Total	8(2.80%)	207(70.60%)	78(26.60%)	293(100%)	df = 2

What are the effects of taking care of your mentally ill patient					
Financial problems	0(0.00%)	5(1.70%)	0(0.00%)	5(1.70%)	$\chi^2 = 9.342$
Psychological/emotional problem	0(0.00%)	0(0.00%)	2(0.70%)	2(0.70%)	
Social problems	5(1.70%)	124(42.30%)	52(17.70%)	181(61.80%)	$P = 0.314$
Physical/bodily pains	0(0.00%)	6(2.00%)	1(0.30%)	7(2.40%)	df = 8
All category of problems (1-4)	3(1.00%)	72(24.60%)	23(7.80%)	98(33.40%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	
What are the motivations (coping strategies) for your continuous care					
Religious duty and obligation	0(0.00%)	7(2.40%)	3(1.00%)	10(3.40%)	$\chi^2 = 0.328$
family duty and responsibility	8(2.70%)	200(68.30%)	75(25.60%)	283(96.60%)	$P = 0.849$
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	df = 2
PATIENT FACTOR					
Relation to the Patient					
Mother	1(0.30%)	65(22.50%)	45(15.40%)	111(37.80%)	$\chi^2 = 27.611$
Father	1(0.30%)	14(4.80%)	1(0.30%)	16(5.50%)	$P = 0.016$
Sister	2(0.70%)	43(14.70%)	14(4.80%)	59(20.10%)	df = 14
Brother	0(0.00%)	24(8.20%)	4(1.40%)	28(9.60%)	
Daughter	3(1.00%)	44(15.00%)	12(4.10%)	59(20.10%)	
Son	1(.30%)	7(2.40%)	1(0.30%)	9(3.10%)	
Wife	0(0.00%)	7(2.40%)	0(0.00%)	7(2.40%)	
Other (husband, nephew, aunt, niece)	0(0.00%)	3(1.00%)	1(0.30%)	4(1.40%)	
Total	8 (2.70%)	207(70.00%)	78(26.60%)	293(100%)	
What type of mental condition is your patient suffering from					
Schizophrenia	1(0.30%)	47(16.00%)	11(3.80%)	59(20.10%)	$\chi^2 = 7.013$
Paranoid disorders	3(1.00%)	29(9.90%)	13(4.40%)	45(15.40%)	$P = 0.535$
Depression	3(1.00%)	99(33.80%)	42(14.30%)	144(49.20%)	df = 8
Anxiety disorders	1(0.30%)	16(5.50%)	5(1.70%)	22(7.50%)	
Panic Disorders	0(00.00%)	16(5.50%)	7(2.40%)	23(7.80%)	
Total	8(2.70%)	207(70.60%)	78(26.60%)	293(100%)	

Source: Field Data, 2020

4.3 Socio-demographic Profile of IDI's Participants

There were ten (10) participants involved in the qualitative study, they were six females (4 married, 1 divorced, and 1 single) and four males (3 married and 1 single). Their ages ranged from 26 to 62 years old respectively, seven were educated and the other three had not been to school. Except for three participants who were in formal employment as civil servants, the rest were engaged in the informal sector doing petit-trading for their livelihood. Ten in-depth interviews were conducted with the participants at their homes and work places. Table 4.2, provide the illustrative details about the study participants.

Table 4.2 Summary of Sociodemographic Characteristics of IDI's Participants

Caregivers	Interview Details	Sociodemographic Details of Respondents/Caregivers	Relationship to Patient	Patient's Age
1	Conducted at healing center (church)	Female, age 26, not married, SHS as highest educational attainment, employed as a cleaner, and lives with patient	Mother	50 years
2	Conducted at work place market (store)	Female, age 27, married with 2 children, employed as a petit-trader, and JHS as the highest educational attainment	Mother	55 years
3	Conducted at work place (hospital)	Female, age 56, divorced single parent with 6 children, employed as a nurse, and highest educational attainment is tertiary level	Daughter	28 years
4	Conducted at home	Female, age 45, married with 4 children, employed as a petit-trader, and has not been to school	Daughter	18 years
5	Conducted at home	Female, age 50, married with 4 children, doing petit-trading as a source employment, and has not been to school	Son	24 years
6	Conducted at home	Female, age 26, married, professional Nurse as source employment, and highest level of education is tertiary.	Mother	56 years
7	Conducted at home	Male, age 45, not married and unemployed, with SHS been highest level of education.	Sister	54 years
8	Conducted at work place	Male, age 62, married and engaged in peti-trade, with MSLC been highest level of education.	wife	45 years
9	Conducted at home	Male, age 55, married and engaged in peti-trade, with no education	daughter	26 years
10	Conducted at home	Male, age 50, married, teaching, and tertiary as highest level of education	daughter	28 years

Source: Field Data, 2020

4.4 Descriptive Statistics of Severity of Caregiver Burden

Table 4.3 presents the results of burden of Care (BOC) assessment on caregivers. The results revealed that there were 293 relatives in this study, with 207 (70%) experiencing moderate to severe burden, 78 (27%) experienced severe burden, whilst only eight (3%) persons experienced mild to moderate burden. This means that, all the participants in this study experienced caregiver burden of varied proportions as a result of caring for a relative suffering from mental illness. Table 4.1 further indicated that, of the 117 male participants in this study, 12 (4%) experienced severe burden, whilst a whooping majority 66 (22%) of the female participants experienced severe burden, and this was statistically significant ($X^2 = 24.450$, $P =$ 0. 000, df = 2), implicating gender disparities in caregiver burden. Also from Table 4.1, it is observed that, 148 (50%) and 55 (18%) of the participants who had children to care for in addition to their caregiving responsibilities, experienced moderate to severe burden and severe burden respectively, and this again was statistically significant ($X^2 = 1.718$, $P = 0.042$, df = 2) at 5% level of significance used for the study.

Furthermore, Table 4.4 assessed the mean scores on individual items of the BOC Schedule ranged between 1- 4 (lowest scores = 1 and highest scores = 4). The highest mean score was found on the item describing ‘Overall burden of caring for your relative’ (item 22), with a mean and standard deviation (SD) of 3.2526 (SD±0.53414) respectively. The results also indicated that (item 7) ‘Being afraid of what the future holds for your relative’ (care recipient) has a relatively high mean score of 3.1945 (SD ±0.58495), whilst the lowest mean score was on (item 5) ‘feeling angry when around the relative’1.9659 (SD±0.74865). The reliability of the BOC items was investigated using the Cronbach alpha coefficient. The reliability measures the internal consistency of the scale – thus the degree to which the items that make up the scale 'hang together'. A Cronbach alpha coefficient value of 0.894 was found for the Zarit Burden Interview Scale (BOC) items, indicating that the scale was internally consistent.

Table 4.3: Severity of Caregiver Burden

Severity	Frequency	Percent
21-40 (Mild to moderate Burden)	8	2.8
41-60 (Moderate to Severe Burden)	207	70.6
61-88 (Severe Burden)	78	26.6
Total	293	100

Source: Field Data, 2020

Table 4.4: Mean Scores on Burden Items

(Score range 1 - 4) Items (all referring to burden due to caregiver role)	Mean	Standard Deviation
Do you feel that your relative asks for more help than he/she needs?	2.8532	0.85746
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	2.9693	0.72793
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	3.1570	0.55757
Do you feel embarrassed over your relative's behaviour?	2.2048	0.74419
Do you feel angry when you are around your relative?	**1.9659**	**0.74865**
Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	2.2867	0.74924
Are you afraid of what the future holds for your relative?	3.1945	0.58495
Do you feel your relative is dependent on you?	2.9590	0.71075
Do you feel strained when you are around your relative?	2.1638	0.69276
Do you feel your health has suffered because of your involvement with your relative?	2.3857	0.66058
Do you feel that you don't have as much privacy as you would like because of your relative?	2.3413	0.61896
Do you feel that your social life has suffered because you are caring for your relative?	2.4744	0.79609
Do you feel uncomfortable about having friends around because of your relative?	2.0853	0.59354
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	2.6212	0.80442
Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	3.1263	0.64194
Do you feel that you will be unable to take care of your relative much longer?	2.1843	0.98976
Do you feel you have lost control of your life since your relative's illness?	2.1433	0.80661
Do you wish you could leave the care of your relative to someone else?	1.9693	0.80818
Do you feel uncertain about what to do about your relative?	2.4437	0.72698
Do you feel you should be doing more for your relative?	2.6485	1.37092
Do you feel you could do a better job in caring for your relative?	2.3720	0.72728
Overall, how burdened do you feel in caring for your relative?	**3.2526**	**0.53414**
Reliability Statistics	Cronbach's Alpha	**0.894**

Source: Field Data, 2020

4.5 Descriptive Statistics of Caregivers' perception of cause of patients' mental illness

Table 4.5 presents a descriptive statistic of the results of caregivers. The results indicated that 193 (66%) of the caregivers believed that the cause of their patient's problems was due to Evil-spirits possession. As to what could be done to help take care of the mentally-ill patients, majority of the caregivers 176 (60%) suggested financial and medical support from philanthropists, whiles 115 (39%) suggested that Government should ensure that National Health Insurance Scheme (NHIS) covered the psychiatric drugs that they buy for their patients (care recipients). Furthermore, 105 (36%) of caregivers thought that their patient's conditions could have been prevented, with 274 (94%) agreeing that early recognition and reporting to hospital could have prevented the problem (mental illness) from occurring in the first place.

On the question of whether their patient's condition required absenting themselves (as caregivers) from work, majority (87%) of the caregivers agreed that their patient's conditions took them out of work most of the time. Furthermore, the result indicated that 192 (66%) of the caregivers used both medical and herbal medications as supplements in managing their patient's conditions at home, whiles 58 (20%) used only herbal medication as supplements to prescriptive drugs from the hospital. However, the worst fear for all caregivers about their patients' illness was self-harm (98%) from the care recipient, especially when there was relapse.

Table 4.5: Descriptive Statistics of Caregivers and Patients

Perceived cause of your patient's problems	Frequency	Percent
Possessed by evil spirits	193	65.9
Self-inflicted	10	3.4
God's creation	20	6.8
Prolong stress	20	6.8
Personality and past experience	50	17.1
Total	293	100
Perceived needs of family caregivers	Frequency	Percent
Social support from family and relatives	2	0.7
Financial and medical support from philanthropists	176	60.1
Government to ensure that NHIS covers the drugs	115	39.2
Total	293	100
Perceived prevention of condition	Frequency	Percent
Early recognition and reporting to hospital	274	93.5
Prayerful	12	4.1
Uncertain	7	2.4
Total	293	100
Views about preventability of patient's condition	Frequency	Percent
Uncertain	178	60.8
Yes	105	35.6
Possibly	7	2.4
No	3	1.0
Total	293	100
Views about absenting oneself from work because of patients condition	Frequency	Percent
Possibly	37	12.6
Yes	256	87.4
Total	293	100
Psychiatric diagnosis of condition of relatives	Frequency	Percent
Schizophrenia	59	20.1
Paranoid disorders	45	15.4
Depression	144	49.2
Anxiety disorders	22	7.5
Panic Disorders	23	7.8
Total	293	100.0
Treatment supplements of relatives at Home	Frequency	Percent
Medical drugs available at home	19	6.5
Herbal medication at home	58	19.8
Medical and Herbal medicine	192	65.5
Spiritual prayer	22	7.5
Other	2	0.7
Total	293	100.0
Perceived behavioural consequences of psychiatric condition	Frequency	Percent
Self-harm	286	97.6
Attacks from patient	5	1.7
Destruction of property	2	0.7
Total	293	100.0

Religious affiliation of Caregivers	Frequency	Percent
Christianity	43	14.7
Islam	250	85.3
Total	293	100.0

Source: Field Data, 2020

4.6 Cumulative and Mean Scores on General Health Questionnaire-12 (GHQ-12) for Caregivers.

The cumulative score of the GHQ-12 for caregivers was assessed in Table 4.6. The highest cumulative score was found to be 32, indicating the presence of psychological distress, while the lowest score was 20, also indicating the presence of psychological distress. This means that, all the respondents experienced psychological distress, but with differences in the level of severity, this is because they all met the requirement for psychological distress as a measure of the General Health Questionnaire-12 as represented in Tables 4.6 & 4.7 respectively. The threshold or cut-off point score for psychological distress is a score of 12, and any figure over and above the cut-off point of 12 are being classified as cases (Hankins, 2008; Liang et al., 2016). For instance, although a score of 32 was recorded as the highest score in this population, only 3 (1%) respondents attained that score as compared to 88 (30%) respondents scoring 22 on the GHQ-12 scale.

The mean scores of the General Health Questionnaire for caregivers' items was assessed in Table 4.6. The highest mean score was found on the item describing 'Been able to concentrate on whatever you are doing' (item 1) with a mean and standard deviation (SD) of 2.2150 (SD±0.42786). The results also indicated that the item 'Lost much sleep over worry' (item 2) has a relatively high mean score of 2.1160 (SD ±0.35139); while the lowest mean score was on the item 'Felt capable of making decisions about things' (item 4) 1.4198 (SD±0.5234). Furthermore, the reliability of the items was also investigated using the Cronbach alpha coefficient. The result from the table indicated that the internal consistency of the scale was moderately reliable with a Cronbach alpha coefficient value of 0.692.

Table 4.6: Cumulative Score of General Health Questionnaire-12 (GHQ-12)

Score	Frequency	Percent (%)
20	3	1.0
21	38	13.0
22	88	30.0
23	44	15.1
24	65	22.2
25	21	7.2
26	12	4.1
27	4	1.4
28	8	2.7
29	6	2.0
31	1	0.3
32	3	1.0
Total	**293**	**100.00**

Source: Field Data, 2020

Table 4.7: Level of Caregiver Psychological Distress (GHQ-12)

Variables	Frequency	Percent (%)
(0 – 12) Mild/ No psychological Distress	0	0
(20 -32) Psychological Distress	293	100

Source: Field Data, 2020

Table 4.8: Mean Scores on General Health Questionnaire-12 of Caregivers

General Health Questionnaire-12	Mean	Std. Deviation
Been able to concentrate on whatever you are doing?	**2.2150**	**0.42786**
Lost much sleep over worry?	2.1160	0.35139
Felt that you are playing a useful part in things?	1.7577	0.47469
Felt capable of making decisions about things?	**1.4198**	**0.52134**
Felt constantly under strain?	2.0751	0.27665
Felt you couldn't overcome your difficulties?	2.0375	0.23834
Been able to enjoy your normal day-to-day activities?	2.0341	0.21628
Been able to face up to your problems?	2.0000	0.26171
Been feeling unhappy and depressed?	2.0444	0.20626
Been losing confidence in yourself?	2.0102	0.24107
Been thinking of yourself as a worthless person?	1.4471	0.55031
Been feeling reasonably happy, all things considered?	2.1741	0.37981
Reliability Statistics	Cronbach's Alpha	**0.692**

Source: Field Data, 2020

4.7 Assessment of Stigma Among Caregivers

The World Health Organization Family Stigma Scale (FSS) was administered to the primary caregivers of patients with mental illness in the study area. The family stigma scale was first subjected to reliability and consistency check using the Cronbach alpha statistic.

From Table 4.8, the highest mean score was found on the item describing ‘Felt grief or depression because of it’ (item 13) with a mean score and standard deviation (SD) of 2.7747 (SD ±0.47875). The results also indicated that (item 1) ‘Worried about being treated differently’ has a relatively high mean score and standard deviation of 2.4232 (SD ±0.71559), while the lowest mean score was on the item ‘Sought out people who also have relatives with similar health problems’ (item 12) 1.4334 (SD ±0.71661). The result from the table indicated that the internal consistency of the scale was very reliable with a Cronbach alpha coefficient value of 0.855.

Table 4.9: Mean Scores on Family Stigma Scale of Caregivers

Stigma Item	**Mean**	**Std. Deviation**
Worried about being treated differently?	2.4232	0.716
Worried other people would find out about it?	1.884	0.979
Felt the need to hide this problem from people?	1.6724	0.911
Helping other people to understand what it is like to have a family member with psychiatric problem?	1.5631	0.798
Have you made an effort to keep this problem a secret?	1.6451	0.931
Worried about being avoided by friends and neighbours?	1.8191	0.706
Explaining to others that your relative isn't like their picture of "crazy" people?	1.7577	0.875
Worried that people would blame you for your relative's problems?	1.6894	0.791
Worried that a person looking to marry would be reluctant to marry into/from your family?	1.9181	2.026
Worried about taking him/her out?	1.6041	0.811
Felt ashamed or embarrassed about it?	1.5563	0.849
Sought out people who also have relatives with similar health problems?	**1.4334**	**0.717**
Felt grief or depression because of it?	**2.7747**	**0.479**
Felt that somehow it might be your fault?	1.7167	0.612
Reliability Statistics	Cronbach's Alpha	**0.855**

Source: Field Data, 2020

Table 4.19 presents the endorsement and prevalence of positive responses for each stigma item. For each of the items, there was an overwhelming endorsement of at least one positive answer on the stigma scale. The most frequently endorsed items were 'Worried about being treated differently' and 'Felt that somehow it might be your fault' (100%), followed by 'Felt grief or depression because of it' and 'Worried about being avoided by friends and neighbours' (99.7% and 96.2%) respectively. Figure 4.2 shows clearly the prevalence of affiliate stigma among the caregivers in the study area.

4.8 Quantitative and Qualitative Findings

4.8.1 Research Objective 1: The extent of perceived burden as measured by ZBS

To examine research objective one, the Severity of Caregiver Burden, Table 4.3 (as a reflection of caregiver's self-rating of the Zarit Burden Interview Scale - appendix 2) was used to investigate the level of perceived burden in the participants. The results indicated that, out of the 293 participants, 207 (70%) experienced moderate to severe burden, and 78 (27%) experienced severe burden, while only eight persons (3%) experienced mild to moderate burden. Thus, all the 293 participants found caring for patients with mental illness to be burdensome. These burdens varied from mild to moderate, moderate to severe and severe respectively. However, of the seventy-eight persons who experienced severe burden, 66 (22%) were women, whilst only 12 (4%) were men, and this result was statistically significant ($X^2 = 24.450$, $P = 0.000$, $df = 2$) with caregiver burden (Table 4.1). This result means that, gender disparities are implicated in caregiving burden among the caregiver population interviewed in this study. This is because, out of a male population of 117 caregivers, only 4% experienced severe burden as compared to 22% of the female caregivers experiencing severe burden out of a population of 176 in the study area; the females were more severely burdened as compared to the males. The reliability of the scale was investigated using the Cronbach alpha coefficient, and this yielded a Cronbach alpha coefficient value of 0.894, indicating that the scale was internally consistent; alpha coefficient value of above 0.70 is considered satisfactory (George & Mallery, 2012). Results of the severity of burden is presented in tables 4.1 and 4.3 respectively.

Narratives from IDI's transcripts also show evidence of some dire situation associated with the caregiving role. Informants were asked to discuss the challenges and difficulties they faced as they were confronted with the task of caring for the mentally ill relative. One informant (caregiver) noted that finance has been a major challenge.

> *The major challenge has been our finances, the cost of treatment has drained us. I used to trade but since the onset of this problem, I have used all my money including the working capital, I am literally surviving on loans that I can't even pay because the business has collapsed, but the father tries to help but it has not been easy because he doesn't have a stable job too* (participant # 4).

The concern of the informant so to be appraised against the fact that in recent times by policy, mental health care has shifted from institutionalisation to home care. The informant explains the implications of this shift for the economic well-being of family members. Family members assuming the role of routine caregiving-fulltime and therefore, in many instances at the detriment of their livelihoods. The enormous burden experienced by caregivers presupposes how mental illness and poverty interact in a vicious cycle. The caregiver and family are more likely to drift into or remain in poverty as shown due to reduced productivity and increased expenditure.

The effect of a family member being mentally ill may affect all members of the immediate family. This is what an informant (caregiver) had to say about the issue:

> *Well, it has caused me a lot because when I was in school, I was always thinking about my mothers' sickness and so I could not concentrate on my studies and so I failed my BECE and I couldn't continue my education. And now money problem and cost of the medication, the problems are so many and there is nobody to help* (informant # 1).

This informant, an adolescent member of the family, explains her lived-experiences even when away from home in a boarding school far away. Indeed, young people are affected because it is a period of key social, emotional and behavioural change, a time when relationships and social capital are crucial for defining one's identity. Unfortunately, as explained by the informant, the challenge at home affected her badly even when far from home, thus limiting her life chances and placing her at even the risk of mental ill health.

Furthermore, when Informants were requested to discuss their experience about the seriousness of the relative's condition, the narratives showed a wide range of difficulties emanating from the severity of their relatives' health condition, especially during relapse. For instance, this is what a 45-year-old mother had to say about her daughter during relapse:

> *Anytime she relapses the situation is so frightening, she experiences hallucinations and aggression, and destructive as well, we will have to tie her up and quickly rush her to the hospital for assistance, but if the father is not home, she destroys things and leave home and it can take us up to several weeks to look for her, sometimes outside of Tamale in some towns and villages. And this experience can be exhaustive, stressful, and loss of control, everything will come to a standstill, including taking care of the rest of the family, sending children to school and picking them back, cooking for the family and sleepless days and nights. This takes a big toll on our finances and breeds family conflicts and sometimes stretches us beyond our limits* (informant # 4).

This is another narration of a 56-year-old single parent about her daughter's condition during relapse:

> *Whenever she relapses, she refuses to eat food and she is very abusive and violent, and so it is difficult to control her. So, I usually will lock her up in the room and be with her myself in the room to force her or persuade her to take food, otherwise she will run away and starve at her hiding place. If left unattended she will run to a far place which will take us several days to find her at her hideout. So, for the whole period during her relapse, I will always be with her without losing guard otherwise she can harm herself, and persuading/forcing her to eat and to administer her drugs to her and cleaning her up all by myself and sometimes with the help of the brother, this worries me a lot* (informant # 3).

As reported by the informants, the ill person may engage in behaviours that are aggressive or disruptive. The caregiver is obliged to control even though sometimes they feel overwhelmed. Self-harm or running away onto the street is cited as a major concern which engages the full attention of the caregivers. As noted, "…this experience can be exhaustive, stressful, and loss of control…" The caregiver in such relapse situation must do little activity related to her own life but focus the full attention on the welfare of the care recipient.

4.8.2 Caregiving Appraisal as a measure of caregiver's self-rating of the ZBS

To do this, factor analysis was used to reduce the Zarit burden scale (which is a multi-item scale) from 22 variables to 5 factors (table 4.13) based on the 293 respondents. The factor structure that emerged was stable as the number of variables were reduced, and a set of principal components analyses with rotation (table 4.12) produced factors with the same critically defining variables. The factor structure that was derived from a principal components' analysis and varimax rotation (Table 4.12) of the 22 appraisal variables are the appraisal dimensions used in this study. These dimensions represent all the experiences relating to the caregiving situation, including background and context variables, care demands, coping strategies and social support, as presented in the conceptual framework in figure 1.1. The care giving appraisal dimensions are also the care providers understanding and conviction about their adaptability to the tasks of care provision, and therefore should have a relationship with caregiver burden. The five caregiving appraisal dimensions were proposed as the key factors to predict the level of burden in caregivers in the study area. The five dimensions include, role strain, low self-efficacy, learned-helplessness, moral guilt and feeling overwhelmed.

After the maximum likelihood estimates of the influencing variables of the level of care burden among caregivers in the regression model was examined, the results suggested that, there is a significant relationship between the level of burden and role strain, low self-efficacy, learned-helplessness, moral guilt and feeling overwhelmed at 5% level of significance as presented in table 4.15. Therefore, a relationship was established, which means that, role strain, low self-efficacy, learned-helplessness, moral guilt and feeling overwhelmed, are all predictive factors to the caregiver burden in the study area. Below are definitions of the predictive variables as well as tables illustrating the statistical analyses used in arriving at the results?

Role strain is defined as the felt difficulty in fulfilling role obligations. Secondary stressors are related to the task difficulties and psychosocial distress which are generated by family disputes that re-emerges from family members (Pearlin et al., 1990). For instance, role and task associated difficulties arising out of disputes among family members regarding the best form of care for the mentally impaired relative about where to go for consultation and treatment for the patient (Duxbury et al., 2011).

Self-efficacy is defined as a person's belief in his or her ability to successfully perform a particular task (Bandura, 1997). Together with the goals that people set, self-efficacy is one of the most powerful motivational predictors of how well a person will perform at almost any endeavour. A person's self-efficacy is a strong predictor of their effort, persistence, strategising, as well as their subsequent training and job performance. Self-efficacy makes a difference in how people feel, think and act. In terms of feeling, a low sense of self-efficacy is associated with depression, anxiety, and helplessness. Such individuals also have low self-esteem and harbour pessimistic thoughts about their accomplishments and personal development (Bandura, 1997).

Helplessness, learned helplessness is the cognitive psychological state that results when an individual who is unable to exercise reasonable control in one situation incorrectly assumes that he or she is then unable to exercise reasonable control in other situations as well. This may complicate the delivery of health interventions since the individual with learned helplessness may assume that no caregiver or treatment intervention can be of any assistance (Flannery, 2002). According to the learned helplessness theory, people exposed to uncontrollable events learn that their responses and outcomes are independent of each other, and that this learning produces the motivational, cognitive, and emotional effects of uncontrollability.

Guilt has been defined as "the dysphoric feeling associated with the recognition that one has violated a personally relevant moral or social standard" (Kugler, Karen; Jones, 1992). Furthermore, the experience of moral guilt has been suggested as a factor potentially contributing to depression and distress in non-dementia caregivers (Boye et al., 2002; Spillers et al., 2008) and non-caregiving samples (Ghatavi et al., 2002); and some scholars even consider it as the main emotion for caregiver outcomes, which may exacerbate their burden levels (Brodaty, 2007). The association between guilt and burden may either be direct or indirect, but these are moderated by other relevant variables in caregiving.

Feeling overwhelmed is a universal human life experience of living quality. From a psychoanalytic point of view, feeling overwhelmed has been variously described as being smothered, engulfed, flooded, drowned, fragmented, and entrapped (Hurvich, 2000). Caregivers often felt overwhelmed by the impact of the experience of care giving and of major disruptions in their established life style and their life goals and dreams (Zegwaard et al., 2011). They also felt overwhelmed by disruptions in their relationship with the ill person and their own emotional responses when confronted with, for instance, difficult behaviour (Rose et al., 2002;Wynaden, 2008).

4.8.3 Factor Analysis

This section focuses on application of factor analysis to the Zarit burden scale variables. Before the data was subjected to factor analysis in order to identify latent structures, correlation analysis of the data was first conducted. This revealed possible groupings that may have existed between the original variables. Variables with high correlation among themselves were identified and grouped together giving a clue as to the number of labels or structures to expect before the data was subjected to further analysis. The table in appendix 9, gives the correlation matrix of the indicator variables. The correlation matrix revealed the presence of many correlation coefficients of 0.3 and above among the variables under study indicating the factorability of the data set (Tabachnick and Fidell., 2001).

The adequacy of the data was further assessed using Kaiser-Meyer-Olkin's (KMO) measure of sampling adequacy (MSA) and the Bartlett's test of Sphericity (table 4.10). The KMO value was 0.843 exceeding the recommended value of 0.6 (Kaiser, 1974), which indicates the degree of common variance in the dataset. The KMO index ranges from zero to one (0-1), with 0.6 suggested as the minimum value for a good factor analysis (Tabachnick and Fidell., 2001). The Bartlett's test of sphericity (Bartlett, 1954) was highly significant (Table 4.10), affirming that the data is adequate for factor analysis. The KMO value and the Bartlett's test altogether confirm the appropriateness of factor analysis.

Table 4.10: KMO and Bartlett's Test

KMO Measure of Sampling Adequacy	0.843
Bartlett's Test of Sphericity	
Approximate Chi Square	4378.081
Degree of Freedom (DF)	231
P-Value	0.000

Source: Field Data, 2020

The eigenvalues and the percentage variation explained by each of the twenty-two possible factors are given in Table 4.11, which shows that the five factors have eigenvalues greater than one. Therefore, based on the rule of eigenvalue-greater-than-one, five factors appear appropriate to estimate the correlation matrix since their eigenvalues are greater than one. The five factors account for about 70.8% of the total variation in the data set. It can be observed that, the first factor accounts for 36.217% of the total variance, the second factor accounts for 11.707%, the third factor accounts for 10.230%, the fourth factor accounts for 6.762% and the fifth factor accounts for 5.884%.

Table 4.12, represent the un-rotated factor matrix of the five factors. From the un-rotated factor solution, there was no definite representation for the fifth factor. This was attributed to the generally low loadings on all the indicators. In order to aid the interpretation of this factor solution, the factor matrix was rotated (Table 4.13) using the Varimax orthogonal approach to obtain a new factor solution. The main motivation for rotation of the factors is that, it offers an opportunity to have simpler factor structure that can be meaningfully interpreted.

Table 4.11: Total Variance Explained

Factors	Initial Eigenvalues		Extracted Sum of Squares Loadings	
	Total	Percent Variance	Total	Cum. Percent Variance
1	7.968	36.217	7.968	36.217
2	2.576	11.707	2.576	47.924
3	2.251	10.230	2.251	58.154
4	1.488	6.762	1.488	64.916
5	1.294	5.884	1.294	70.800
6	0.945	4.295	7.968	
7	0.776	3.527		
8	0.672	3.053		
9	0.575	2.615		
10	0.519	2.360		
11	0.498	2.265		
12	0.367	1.667		
13	0.316	1.436		
14	0.305	1.386		
15	0.278	1.262		
16	0.225	1.025		
17	0.196	0.889		
18	0.191	0.868		
19	0.168	0.762		
20	0.149	0.677		
21	0.134	0.611		
22	0.111	0.504		

Source: Field Data, 2020

Table 4.13 displays the rotated factor matrix. In this study, a cut-off value of 0.35 was used in interpreting the factors. This value is a fairly good measure since according to (Sharma, 1995), a cut-off value as low as 0.3 has been used successfully by many researchers. After rotation, it was observed from Table 4.13 that, factor one loads highly on ZBS3, ZBS8, ZBS2, ZBS14, ZBS15, ZBS22, ZBS19, ZBS1 and ZBS7. These are the set of indicators for the first factor in the rotated factor solution. The first factor reflects the strain experienced as a result of the role the caregiver plays. Hence the first factor can be labelled as "**Role Strain**". The second factor has high significant loading on ZBS12, ZBS10, ZBS13, ZBS11, ZBS5 and ZBS9 thus this factor can therefore be labelled as “**Overwhelmed Factor”.** Three indicator variables, ZBS16, ZBS18 and ZBS17 have high loadings on the third Factor. The third factor is therefore identified as “**Low Self-efficacy Factor**”. Only two indicator variables have very high loadings on the fourth factor, ZBS6 and ZBS4. This represents the feeling of helplessness experienced by the caregiver; thus, this factor was labelled as “**Helplessness**”. The fifth factor has very high loadings on indicator variables ZBS21 and ZBS20. Thus, this factor was labelled as “**Moral-guilt**”. Thus, the factors extracted in this model included, role strain, overwhelmed, low self-efficacy, helplessness, and moral guilt respectively. These factors collectively describe the burden levels experienced by caregivers in the study area. This is explicitly shown in Table 4.13 and 4.14.

Table 4.12: Unrotated Component Matrix

	Components				
Variables	1	2	3	4	5
ZBS1	0.569	-0.572			
ZBS2	0.672	-0.382			
ZBS3	0.764		-0.357		
ZBS4	0.527		0.545		
ZBS5	0.563		0.532		
ZBS6	0.383	0.418	0.457		0.495
ZBS7	0.685				
ZBS8	0.587		-0.525		
ZBS9	0.708				
ZBS10	0.717				
ZBS11	0.575	0.515			
ZBS12	0.689				-0.365
ZBS13	0.594	0.436			
ZBS14	0.714		-0.365		
ZBS15	0.429			0.357	0.570
ZBS16	0.531	-0.530		0.426	
ZBS17	0.714	-0.418			
ZBS18	0.447	-0.416	0.364	0.395	
ZBS19	0.645				
ZBS20		0.377			
ZBS21		0.598		0.523	
ZBS22	0.801				

Table 4.13: Rotated Factor Matrix

	Components				
Variables	1	2	3	4	5
ZBS1	0.796				
ZBS2	0.823				
ZBS3	0.792				
ZBS4				0.851	
ZBS5		0.659			
ZBS6				0.900	
ZBS7	0.712				
ZBS8	0.579				
ZBS9		0.509			
ZBS10		0.588			
ZBS11		0.494			
ZBS12		0.571			
ZBS13		0.665			
ZBS14	0.654				
ZBS15					
ZBS16			0.874		
ZBS17	0.458		0.692		
ZBS18			0.802		
ZBS19	0.609				
ZBS20					0.747
ZBS21					0.889
ZBS22	0.656				

Cut-off value = 0.35

Source: Field Data, 2020

Table 4.14: Psychological Constructs

ZBS FACTOR LOADINGS	FACTOR/CONSTRUCT
ZBS1. Do you feel that your relative asks for more help than he/she needs?	1 Role Strain
ZBS2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	
ZBS3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	
ZBS7. Are you afraid of what the future holds for your relative?	
ZBS8. Do you feel your relative is dependent on you?	
ZBS14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	
ZBS15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	
ZBS19. Do you feel uncertain about what to do about your relative?	
ZBS22. Overall, how burdened do you feel in caring for your relative?	
ZBS5. Do you feel angry when you are around your relative?	2 Overwhelmed
ZBS9. Do you feel strained when you are around your relative?	
ZBS10. Do you feel your health has suffered because of your involvement with your relative?	
ZBS11. Do you feel that you don't have as much privacy as you would like because of your relative?	
ZBS12. Do you feel that your social life has suffered because you are caring for your relative?	
ZBS13. Do you feel uncomfortable about having friends around because of your relative?	
ZBS16. Do you feel that you will be unable to take care of your relative much longer?	3 Low Self-efficacy
ZBS17. Do you feel you have lost control of your life since your relative's illness?	
ZBS18. Do you wish you could leave the care of your relative to someone else?	
ZBS4. Do you feel embarrassed over your relative's behaviour?	4 Helplessness
ZBS6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	
ZBS20. Do you feel you should be doing more for your relative?	5 Moral-guilt
ZBS21. Do you feel you could do a better job in caring for your relative?	

Source: Field Data, 2020

4.8.4 Correlation Analysis

Table 4.15 presents the Pearson's product-moment correlation analysis of the various variables under consideration. This statistic was used to test the strength and direction of the relationship between the variables. The results revealed that there is a weak negative relationship between the Level of burden (LB) and age of caregivers at 5% significant level ($r = -0.188$ and $p < 0.05$). The results also indicated that there is a strong positive relationship between LB, Role Strain (RS), Overwhelmed (OW), Low self-efficacy (LSE) and Helplessness (H) at 5% level of significance ($r = 0.628$, $r = 0.428$ and $r = 0.450$, $r = 0.368$, $P < 0.05$). This result suggest that these variables are closely related to the level of burden of caregivers and might have influenced it positively. The results from Table 4.14 further revealed that there exist a weak positive relationship between Moral guilt (MG) and level of burden, but this relationship between Moral guilt (MG) and LB is not significant at 5% level significance, since the p – value > 0.05 and the correlation coefficients ($r = 0.056$) is very small.

Table 4.15: Pearson Product-Moment Correlation Analysis

Variable	Age	RS	OW	LSE	H	MG
LB	-0.188**	0.682**	0.428**	0.450**	.368**	0.056
Sig. (2-Tail)	0.001	0.000	0.000	0.000	0.000	0.342
Number	293	293	293	293	293	293

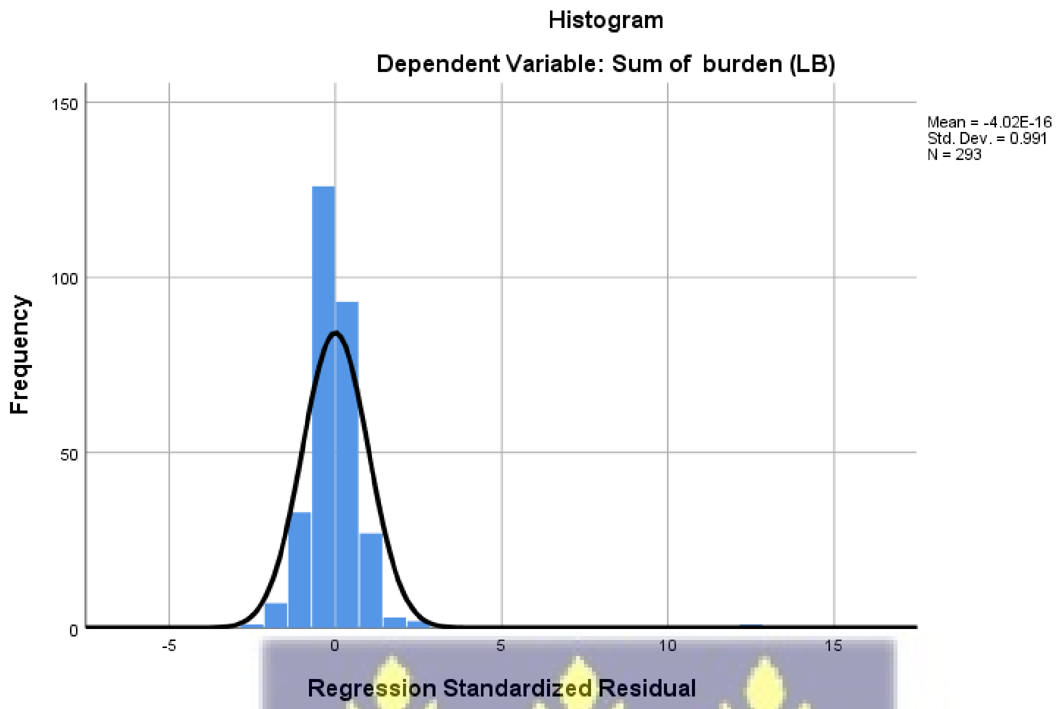
Source: Field Data, 2020

4.8.5 Multiple Regression Analysis

This section seeks to build a model to predict the level of burden for caregivers using age and the factor scores of caregivers' burdens in the study area in the Northern Region of Ghana. Following the explanatory factor analysis of the Zarit's burden scale variables, five factor solutions were found based on eigenvalue rule (Kaiser Criterion). In this regard a model was developed based on the five factor solution scores and age of caregivers. Multiple regression analysis makes some assumptions about the data set, these assumptions were found to be satisfactory (Figures 4.1, 4.2 & 4.3). Following the satisfactory assumptions of multiple regression, a model was fitted to the data using the standard algorithm.

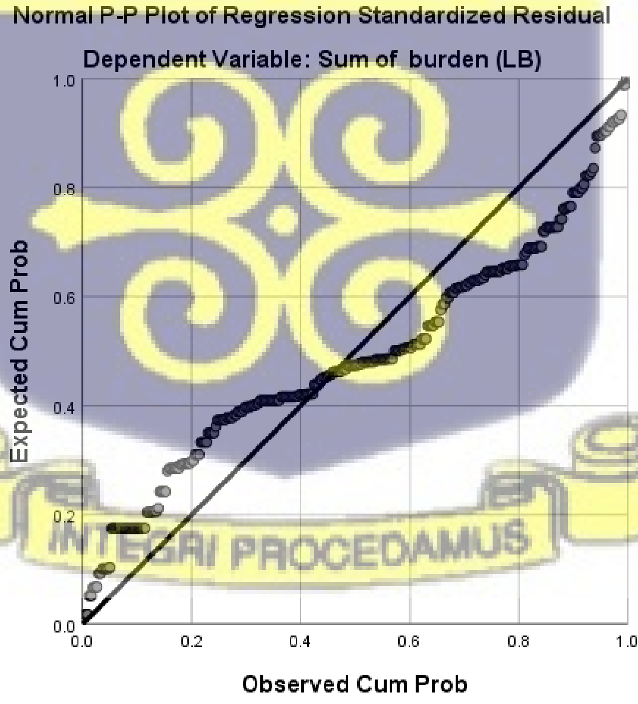
The underlying assumptions of multiple regression analysis especially with respect to the dependent variable is that, it should follow a normal distribution and should be independent of the observations. This was assessed by using a histogram of the regression standardised residuals and normal P-P plot of regression residuals (Figure 4.1). It can be observed from the histogram with normality plot that the scores (Level of burden) are reasonably normally distributed, with most of the scores occurring at the center, and spreading out towards the extremes. In the normal probability plot, it is observed further that, the scores are reasonably diagonally straight line along the normal line from left to the top right supporting normality of the observations (Figure 4.2). Also, the scatterplot of standardised residuals is roughly rectangularly distributed, with most of the scores concentrated at the centre along the zero-line suggesting that the scores are independent of each other (Figure 4.3). The illustrative figures are presented in the following pages.

Figure 4.1: Histogram of the Regression Standardised Residuals



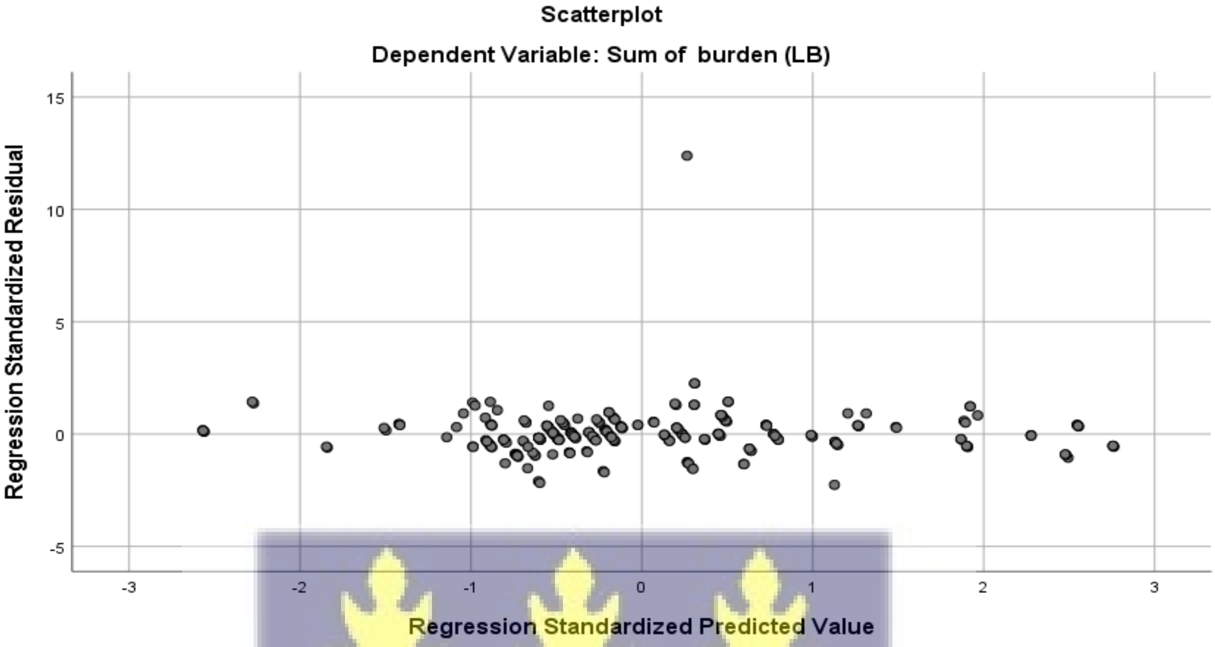
Source: Field data, 2020

Figure 4.2: Plot of Regression Standardised Residuals



Source: Field data, 2020

Figure 4.3: Scatter Plot of Regression Standardised Residuals



Source: Field data, 2020

Table 4.16 present the maximum likelihood estimates of the influencing variables of the level of care burden among caregivers in the regression model. The results revealed that, role strain, overwhelmed, low self-efficacy, helplessness and moral guilt were statistically significant at the 5% significance level in explaining caregivers' burden (level of burden) in the study area. The results showed that these factors positively affected the level of burden in the Northern Region of Ghana, since their coefficients were positive. The results further indicated that caregiver's age does not influence the level of burden. Hence, the reduced model without age implied that, for every unit increase in role strain, the level of burden of a caregiver is increased by 6.404, holding all other variables constant. Again, holding other variables constant, every unit increase in overwhelmed will lead to an increase in the level of caregiver burden by 4.024.

A unit increase in low self-efficacy, when all other variables are held constant will increase the caregiver's level of burden by 4.225. Similarly, for every unit increase in helplessness, caregiver's level of burden will increase by 3.457 given that all other variables remain constant. Likewise, a unit increase in moral guilt will increase the level of burden of caregiver by 0.552.

Table 4.16: Parameter Estimates of Multiple Regression Model

	Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
	B	Std. Error	B	t	Sig.	Tolerance	VIF
Constant	55.678	0.199		279.410	0.000*		
Age	0.003	0.005	0.004	0.653	0.514	0.951	1.051
RS	6.404	0.060	0.682	105.940	0.000*	0.990	1.010
OW	4.024	0.061	0.429	66.498	0.000*	0.988	1.012
LSE	4.225	0.060	0.450	70.143	0.000*	0.997	1.003
H	3.457	0.061	0.368	56.786	0.000*	0.976	1.025
MG	0.522	0.060	0.056	8.679	0.000*	0.999	1.001

*** = Significant at 5% level**

Source: Field data, 2020

The reduced multiple regression model is given by;

$$Y_{LB} = 55.678 + 6.404RS + 4.024OW + 4.225LSE + 3.457H + 0.522MG$$

Where LB = Level of Burden, RS = Role Strain, OW = Overwhelmed, LSE= Low Self-Efficacy, H = Helplessness, and MG = Moral Guilt.

After fitting the model, a diagnostic test for the regression model was performed to assess the adequacy of the model. The statistical significance of the model was assessed using the analysis of variance (ANOVA) table. This tests the null hypothesis that multiple regression in the model equals zero. As observed from Table 4.17, the fit of the model was satisfactory. The estimated coefficients for the likelihood ratio F-statistic was significant (*P*< 0.05), with F-values of 4014.726.

Furthermore, collinearity statistics of tolerance and variance inflation factor (VIF) were used to check whether there were high correlations among the variables (multicollinearity) in the model. The model was found to be free from multicollinearity since the tolerance and VIF values were all greater than 0.6.

Table 4.17: Analysis of Variance (ANOVA)

Model	SS	df	MSS	F	P-Value
Regression	25444.418	6	4240.736	4014.726	0.000
Residuals	302.100	286	1.056		
Total	25746.519	292			

Source: Field Data, 2020

Another way of checking the usefulness of the model was to examine the R square and the adjusted R square values. This provided the amount of variation in the dependent variable explained by the model. The R-Square (Table 4.18) indicated that about 98.8% of the variations in the dependent variable have been explained by the independent variables. Also, the Durbin-Watson statistic value further affirmed that the model was correctly specified. The study found Durbin-Watson statistic value of 1.627, whereas a value between 1.5 and 2.5 indicate no autocorrelation among the variables, whilst values outside this interval suggests the presence of autocorrelation.

Table 4.18: R-Square Model Summary

Model	R-Square	Adjusted R-Square	Std. Error	Durbin-Watson
1	0.988	0.988	1.02776	1.627

Source: Field Data, 2020

4.8.6 Validation of Sample Estimates

Although the minimum sample size (293) obtained for this study was adequate for a quantitative analysis, the study participants were relatively small as compared to the total population (1084) of caregivers of mentally ill patients in the study area. Therefore, there was the need to validate the sample estimates of the regression analysis (table 4.16) to determine whether or not they varied significantly from the true population estimates. Statistically, one sure technique of sample estimate validation is through bootstrapping. Bootstrap technique is a form of pseudo sampling from the original dataset to determine the variability of the dataset, and it is a very robust and statistically sound technique for measuring standard errors (Alhassan & Nokoe, 2016). Consequently, the bootstrap technique was used to validate the results of this study (Table 4.19). The basic idea of the procedure involves sampling with replacement to produce random samples of size ‘n’ from the original data. Each of these samples known as a bootstrap sample provides an estimate of the parameter of interest. Repeating the process for a large number of times provides the required information on the variability of the estimator and an approximate 95% confidence interval can be constructed for the estimates.

Table 4.19 presents the results of the bootstrap estimates. The results show that both parameter estimate and standard errors of the bootstrap samples converged to the estimates of the original data. The bias, defined as the difference between the original data and the bootstrap samples estimates was almost zero indicating non-variability among the two samples. The confidence interval estimates further provides evidence to the adequacy of the original data. This is because when the process or experiment is repeated infinitely many times and the estimates computed, then 95% of the time, the confidence interval derived (6.264 - 6.534) would contain the true parameter estimate of Role strain. At 95% confidence interval for the parameter estimates for overwhelm, low self-efficacy, helplessness and moral guilt are 3.886 – 4.134, 4.099 – 4.364, 3.193 – 3.844 and 0.416 – 0.654 respectively. Thus, if repeated samples of size 293 are drawn 10,000 times from the original data and confidence intervals are constructed, then 95% of the time, the confidence interval derived would contain the true parameter estimates.

Although bootstrapping is asymptotically more accurate than the standard intervals using sample variance and assumptions of normality (DiCiccio & Efron, 1996), the results in Table 4.19 indicates a close approximation between the bootstrap estimates and the empirical data and thus provided a consistency check for the empirical data (DiCiccio & Efron, 1996). The bootstrap results therefore provided a sound statistical basis for the conclusive results on predicting caregiver burden in the study area. Below are the bootstrap results in table 4.19.

Table 4.19: Bootstrapping for Sample Estimate Validation

Model	Estimate (B)		Std Error		P-Value		C.I (95%) Bootstrap		Bias
	Original Data	Bootstrap	Original Data	Bootstrap	Original Data	Bootstrap	Lower	Upper	
Constant	55.678	55.678	0.199	0.180	0.000*	0.001*	55.293	56.006	0.008
Age	0.003	0.003	0.005	0.005	0.514	0.599	-0.006	0.014	0.000
RS	6.404	6.404	0.060	0.066	0.000*	0.001*	6.264	6.534	0.005
OW	4.024	4.024	0.061	0.062	0.000*	0.001*	3.886	4.134	0.003
LSE	4.225	4.225	0.060	0.066	0.000*	0.001*	4.099	4.364	0.003
H	3.457	3.457	0.061	0.177	0.000*	0.001*	3.193	3.844	0.005
MG	0.522	0.522	0.060	0.065	0.000*	0.001*	0.416	0.654	0.005

Source: Field Data, 2020

Findings from the qualitative study related to the impact of caring for their mentally ill relatives showed a dire situation among caregivers. For example, this is the narration of (participant # 2) on the issue:

> *It affects me so much ranging from my finances to my health, my time, and even threatening my marriage because sometimes it leads to family feud between my husband and I over lack of quality time for the children. When I wasn't married it was a bit better than now with all the children and husband, and work, and my sick mother all competing for that one time that I have. That's so difficult for me, I can't concentrate and easily get confused over simple things and very forgetful these days. The last time I was sending my daughter to school and travelled for long on a wrong course until my daughter asked me "mama where are we going, before it dawned on me that I had taken the wrong course unknowingly.*

This is what a 56-year-old mother had to say:

> *Hmm, it has caused me my financial problems, stigma is there, she is always complaining to me I can't do work, I can't marry, I can't do what and what and what, she is always complaining, at times she complains and be weeping and I also will be weeping. So really it is in my heart, it is disturbing me really; and I also brought her up to go to school and she went to the school half way, really there is no work for her to do now at the moment, so it disturbs me and she is grown* (participant # 3).

The informants raised a number of issues that comes with being a family caregiver: financial strain, lack of privacy as well as "quality time" to support other family members; fatigue and symptoms that show depression. However, the situation as presented by the 56-year-old mother caregiver emphasises the fact that individuals with mental illnesses still have identity and aspirations like getting work in order not to be a burden on the family; want to get married, have children and want to feel "normal" again. Such worries and anxieties create empathy in the caregiver "…and I also will be weeping…." This shows helplessness and feeling overwhelmed. The informant's concern is that even though treatment brings relief, reintegration into society is a big barrier because of stigma.

Furthermore, narratives from IDI's pertaining to caregiver fears about their relative's mental health condition revealed mixed feelings of courage, worry, and apprehension in their responses. For example, the narratives below amply demonstrate the situation. A 27-year-old mother of two had this to say about the issue:

> *I have so many fears, now that she has run from home and living in the forest, anybody could do anything to her like rape or even murder, or even to strip her cloth off for everybody to see her nakedness. In fact, she has been raped and impregnated before and the resulting issue is at the orphanage at Nyohini, those are the fears that I can speak to you about, but there are other bigger fears that I cannot mention to you* (participant # 2).

Another female respondent of age 26, had this to say about the issue:

> *Well, I think death…Yes because, my mother could be thinking that her family have neglected her, both her husband side and her father and mother side have all neglected her, and so she can think ahh and contemplate taking poison to end her life and the suffering* (participant # 1).

And yet another female respondent of age 50 and a mother of 4, had this to say about her patient's condition:

> *Well, I have soon gone past the fears to courage and belief that we shall see light at the end of the tunnel, because there are remarkable improvements in his sufferings and our sufferings. We could hardly sleep because of the unbearable pains and suffering we went through, but now we see the relief coming and we can only hope and pray believing that there would be better improvement leading to the restoration of normal health* (participant # 5).

4.8.7 Research Objective 2: Sociocultural issues contributing to caregiver burden?

To examine research objective two, a quick reference was made to responses for question number 16 from the semi structured questionnaire (Appendix 1) pertaining to perceived cause of the care recipients' illness condition (''we would like to know what you think may be the cause of your mentally-ill relative's problem. Each of us may explain health problems in various ways. I would like to know what you think has caused Musah/Aisha's condition?''). The questionnaire is based on the framework of the explanatory model interview catalogue (EMIC) for cultural epidemiology (Weiss, 2001), and it was used to solicit caregivers' perceived views on the cause of mental illness based on their beliefs and cultural orientations. Respondents came up with six possible causes of their relative's illness condition, and these included, possessed by evil spirits, self-inflicted, God's creation, prolonged-stress, personality and past experience, and witchcraft. The results indicated that 193 (66%) of the caregivers believed that, the cause of their relative's problems was due to Evil-spirits possession, 50 (17%) believed that, the cause of their patient's problems was due to Personality and past experience of the care recipient, whilst 20 (7%) believed that, the cause of their patient's problems was due to God's creation.

Several sociocultural issues including perceived cause of patients' illness, treatment options and supplements available to the caregiver as well as possible self-harm to the patient himself or herself are culturally motivated. For instance, on the question of (what do you fear most about the condition of your patient?) in the questionnaire, almost all 286 (98%) respondents said "self-harm" of the relative (care recipient) was their preoccupation. Therefore, all these unpredictable social and cognitive evaluative and introspective processes of caregivers' regarding the mental health conditions of their ill relatives, may have exacerbated their problems and contributed immensely to the burden and moral injury among the study participants as shown in table 4.5.

Narratives from IDI's which relates to the cause of care recipient's mental illness as well as the difficulties experienced by caregivers, also supports the perceived contributory role of sociocultural issues in caregiver burden. Witchcraft, spiritual possession, and evil spirits, came up strongly as the main cause of their relative's mental illness among all the informants. For example, a 26-year-old daughter caring for her 50-year-old mother, explained her situation as follows;

> *…the problem is that I don't know whether it's both physical and spiritual or what, but I know it to be spiritual. Because first she was saying that she can see a man wearing white gown and telling her that if she ate the food the spirit will kill her. So, this is what caused her mental problems* (participant # 1).

The informant's assertion is a very common response from quite a number of caregivers. Like she noted, listening to the mentally ill relative gives impression to the caregiver that spiritual forces are at play. The lay person may interpret present hallucinations, private perceptions and associated phantom vision syndrome as manifestations of spirit-visits. No doubt, the informant concludes "…but I know it to be spiritual…" Her "knowledge" is drawn out of listening to the "interpretations" given by the mentally ill patient. She seems to follow the patient along that path and in this way, she is drawn into the world view of the patient completely.

4.8.8 Research Objective 3: The perceived stigma experienced by family caregivers?

To examine research objective three, the endorsement of stigma items on the FSS, Table 4.20 (as a reflection of caregiver's self-rating of the experience of stigma on the Family Stigma Scale) was used to investigate the level of perceived stigma in the study participants. The results indicated that, there was an overall endorsement of stigma prevalence among study participants as reflected in the positive responses for each of the stigma items. For each of the items, there was an overwhelming endorsement of at least one positive answer on the stigma scale, indicative of a 100% level stigma prevalence among the study participants. The most frequently endorsed items were 'Worried about being treated differently' and 'Felt that somehow it might be your fault' (100%), followed by 'Felt grief or depression because of it' and 'Have you made an effort to keep this problem a secret' (99.7% and 96.2%) respectively. Table 4.20 and figure 4.3 shows clearly the prevalence and distribution of stigma among the caregivers of the study area.

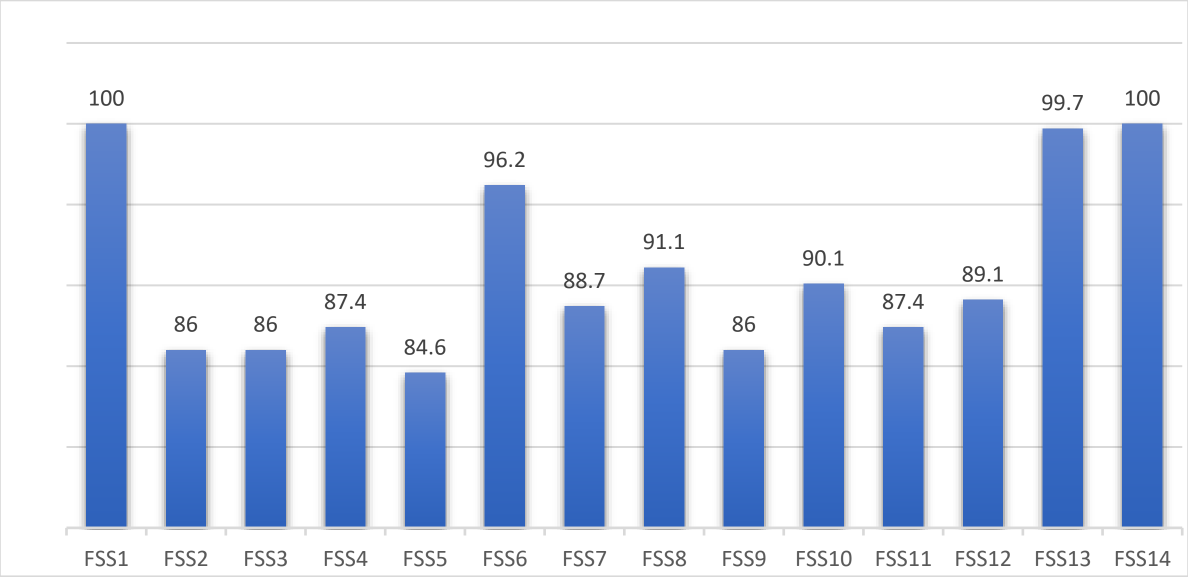
Furthermore, the association between affiliate stigma and the level of caregiver burden among the study participants was investigated (Table 4.21). The family stigma scale was categorized into two groups consisting of low-stigma prevalence (a score of 0 – 12) and high-stigma prevalence (a score of 13 – 42). As clearly demonstrated (Table 4.19), the caregivers with high-stigma prevalence experienced moderate to severe burden 175 (59.9%) and severe burden 78 (26.7%) respectively as compared to those in the low-stigma prevalence category, experiencing only moderate-to-severe burden 31 (11%). Therefore, 259 (89%) participants experienced stigma more frequently as compared to only 33 (11%) participants who experienced stigma less frequently. Pearson's chi-square test further affirmed that there is statistically significant ($P < 0.05$) relationship between perceived stigma and level of burden among caregivers of mental-ill patients in the study area at 0.05 level of significance ($X^2 = 14.321$, P = 0.001, df = 2). These burdens varied from mild to moderate 8 (2.7%), moderate to severe 206 (70.5%) and severe 78 (26.7) respectively, this result is illustrated in table 4.20.

Table 4.20: Endorsement of Each Stigma Item on the FSS

	0 - Not at all		1 - Sometimes		2 - Often		3 - A lot		Any positive endorsement	
Stigma Items	n	%	n	%	n	%	n	%	n	%
Worried about being treated differently	0	0	39	13.3	91	31	163	55.6	293	100
Worried other people would find out about it	41	14	36	12.3	132	45	84	28.7	252	86
Felt the need to hide this problem from people	41	14	62	21.2	142	49	48	16.4	252	86
Helping other people to understand what it is like to have a family member with psychiatric problem	37	12.6	74	25.3	162	55	20	6.8	256	87.4
Made an effort to keep this problem a secret	45	15.4	62	21.2	136	47	48	16.4	248	84.6
Worried about being avoided by friends and neighbors	11	3.8	71	24.2	171	58	40	13.7	282	96.2
Explaining to others that your relative isn't like their picture of "crazy" people	33	11.3	57	19.5	151	52	52	17.7	260	88.7
Worried that people would blame you for your relative's problems	26	8.9	73	24.9	160	55	34	11.6	267	91.1
Worried that a person looking to marry would be reluctant to marry into/from your family	41	14	54	18.4	115	39	83	28.3	252	86
Worried about taking him/her out	29	9.9	90	30.7	142	49	32	10.9	264	90.1
Felt ashamed or embarrassed about it	37	12.6	88	30	136	46	32	10.9	256	87.4
Sought out people who also have relatives with similar health problems	32	10.9	109	37.2	145	50	7	2.4	261	89.1
Felt grief or depression because of it	1	0.3	5	1.7	53	18	234	79.9	292	99.7
Felt that somehow it might be your fault	0	0	108	36.9	160	55	25	8.5	293	100

Source: Field Data, 2020

Figure 4.4 Distribution of Positive Answers on the 14 Stigma Items



Source: Field Data, 2020

Table 4.21: Relationship between Stigma and Level of Burden

	Level of Burden 21 - 40 (Mild to Moderate burden)	41 - 60 (Moderate to severe burden)	61 - 88 (Severe burden)	Total	
0 - 12 (Low-stigma prevalence)	2 (0.70%)	31 (10.6%)	0 (0.0%)	33(11.3%)	$\chi^2 = 14.321$
13 - 42 (High-stigma prevalence)	6 (2.10%)	175 (59.9%)	78 (26.7%)	259(88.7%)	P = 0. 001*
Total	8 (2.70%)	206 (70.5%)	78 (26.7%)	292(100%)	df = 2

Source: Field Data, 2020

Findings from the qualitative study relating to perceived stigma revealed how informants felt about discussing their patient's situation with family members or friends. Of the ten informants, only one informant (informant # 4) said she did not have any problem discussing her patient's condition with family and friends. All the remaining informants said they could not come to terms with discussing their relative's conditions with family members or even friends. This was what informant # 2 had to say:

> *I could easily discuss my mothers' situation with family members if they were caring, but they have simply abandoned her completely, so there is no point. As for my friends and this type of condition, it is difficult and I simply can't. It is difficult because of the back-biting they will do about me and my mother and a whole lot of things. How can I just tell my friends or even outsiders that my mother smoke weed, take alcohol or abuse drugs, or even lives in the forest? That's stigmatising and it will live with me and my children forever, I can't do that* (participant # 2).

The informant alludes to how social stigma brings social distance and affected family-of-orientation within even the larger extended family as well as the community. This is contrary to expectations, and it is an emerging phenomenon. The extended family used to be seen as the carrier of the burden of illness of the individual when the nuclear family was overwhelmed by the challenges. "…how can I just tell my friends or even outsiders that my mother smoke weed…That is stigmatizing… my children forever…" It shows the effect of embarrassment when a close relative is suffering from mental illness. It affects the family and also the stigma is extended to generations yet unborn.

The embarrassment the caregiver feels is even worse because the caregiver may become a direct victim of violence from the sick person. One caregiver explains as follows;

> *Oh, no problem for those who care about us, but for outsiders and friends I can't discuss with them because it's embarrassing and they will call you names. No, I can't, even for some family members I will not. Well, it is sickness and I can't be discussing the way my mother has been behaving or beating and insulting me to others. It is embarrassing to do so* (participant # 1).

The informant feels vulnerable because apart from being isolated as a caregiver, she suffers violence also from the relative. Here personal and family embarrassment is obviously manifest in association with burdensome caregiving to the mentally sick. "…I can't be discussing the way my mother … beating and insulting me to others. It is embarrassing to do so". Apart from the challenges of care, the informant said she experiences shame and violence not only from society but also from the patient (care recipient).

Furthermore, informants mentioned high cost of psychiatric drugs as a major problem worsening their financial situation because of so many responsibilities, hence the call from them to government to make psychiatric drugs free of charge. For example, this is what a 27-year-old mother of two had to say when the issue of support was posed:

> *Any form of support that will reinstall my mother's health is all I pray for so that I can have my own life back on course, there is hardly any passing day that I can be happy and have peace of mind without thinking of my mother. That is my prayer for people everywhere with this type of condition, for we are suffering so much. It will help us if NHIS can cover the drugs too, so government should help us* (participant # 2).

Another 56-year-old mother gave the following narration:

> *Me, now that my daughter is getting better with the help of the drugs, I want the government to get some work for her so that she will also be doing small, small, because if she is taking the drugs no relapsing will occur. But because she is always lying in the room and doing nothing, she also thinks and that is why she always questions me. So, I won't do any work? I have nothing to do? So, me, I just came to the world like that? I can't help you? I can't get something for myself? She will be*

> *complaining and I'm also worried. So, to me I want the government to help and then get some work for her to also be doing and it will help me too, because at times you won't get the drugs, you have to buy. The government should also make NHIS to cover all psychiatric drugs to help us, because the drugs are expensive* (Participant # 3).

The issue of getting work for those affected by mental health illness is seen generally as part of the therapy. Both informants noted that there are several work barriers impacting persons with severe mental illness. In the case of the 56-year-old informant, the situation is even worse of when the rehabilitated person finds it difficult to fit into the working force because of such barriers like unavailability of jobs and the unwillingness of people to employ such people even though they have been treated. It clearly shows also how care giving duties act as secondary role strain conflicting with other domains of life.

4.8.9 Research Objective 4: Socio-demographic variables that contribute to caregiver burden?

To examine research objective four, chi square test was conducted to assess whether there was any relationship between socio-demographic and context variables and the level of burden experienced by caregivers. The caregiver stress variables analysed in this study included but not limited to background characteristics like age, gender, income, employment, marital status, education, relationship to patient, and care provider status. Therefore, chi square was employed to examine the extent of association between demographic factors and care provider burden. Chi square is the ideal analytical tool to use if the goal was to measure the association between two categorical variables (Sharpe, 2015). Chi square was employed to identify the association between the composite scores of demographic factors and care provider outcome.

With respect to sex, findings from the chi square demonstrated significance (X^2 =24.450, P =0.000, df =2) with caregiver burden.

Furthermore, the findings also indicated that, 176 (60%) of the caregivers were women, whilst 117 (40%) were men; and of those who experienced severe burden, women constituted 66 (22%) as compared to only 12 (4%) men experiencing severe burden.

For education, employment and marital status, the finding did not indicate significance {(X^2 = 7.87, P = 0.248, df = 6), (X^2 =5.134, P = 0.882, df = 10) and (X^2 = 6.406, P = 0.602, df = 8)} with caregiver burden respectively.

For caregiver status, result of the chi square indicated significance (X^2 = 14.400, P = 0.001, df = 8) with caregiver burden. With 98 (33%) of the caregivers being parents, whilst 93 (31%) and 80 (27%) were spouses and household heads respectively. Furthermore, of those who experienced severe burden, spouses (12%), parents (9%), and household heads (5%) respectively were severely burdened as compared to the rest.

For income, the chi square result showed significance (X^2 = 13.428, P = 0.009, df = 4) with caregiver burden. For issues in marriage, results of the chi square indicated significance (X^2 = 1.718, P = 0.042, df = 2) with caregiver burden. The results further indicated that, 207 (71%) of the caregivers had children whiles 86 (29%) were childless; also, 18% of those with children were severely burdened as compared to only 8% of those who did not have children.

For relationship to patient, results of the chi square indicated significance (X^2 = 27.611, P = 0,016, df = 14) with caregiver burden. The results further indicated that majority of the caregivers were mothers 111 (38%), siblings 87 (30%), children 68 (23%) and fathers 16 (6%); with 45 (15%) of mothers experiencing severe burden while 18 (6%) of siblings experienced severe burden. Of the siblings, 14 (5%) sisters experienced severe burden whilst 4 (1%) brothers experienced severe burden.

For age, Pearson's product-moment correlation analysis was used to test the strength and direction of the relationship between age and caregiver burden. The results revealed that there is a significant relationship between age and caregiver burden (LB) at 5% significant level (r = -0.188, p = 0.001) as represented in table 4.14.

Therefore, the results have demonstrated significant relationship between socio-demographic variables (age, gender, caregiver status, income, issue (children) in marriage, and relationship to patient) with caregiver burden in this study. However, socio-demographic variables like education, employment and marital status were not found to be significantly related to caregiver burden in this study as shown in tables 4.1, and 4.14 respectively.

Narratives from IDI's transcripts show support for the contributory role of socio-demographic variables to caregiver burden, especially relating to gender and being a woman, having a child, in addition to caring for a mentally-ill person who doubles as a relative (mother). This is what a 27-year-old married woman, a mother of 2, and caring for her 55-year-old mother had to say;

> *...in the morning I give her food and her medication, clean the room and also wash her clothing, and any other thing she wants me to do for her, in addition to taking care of her baby. All these, added to caring for my own children and the house chores as well. That is very difficult to do, you know... (Sobbing in tears),* (participant # 2).

The informant explains her challenges including; worries, sleeplessness, and exhaustion, in addition to the bodily pains experienced from the care demands. These care demands included, cooking, cleaning, washing, bathing patient, feeding patient, lifting patient to-and-from bird to sofa, administration of medication, transportation to clinic and healing centres, and transportation to-and-from market. The challenge is also aggravated by the fact that some female mentally ill may still be sexually active. The informant explains the peculiar situation of not only caring for her own household, but also caring for the sick as well as the burden of the child of the sick.

4.8.10 Research Objective 5: Coping strategies employed by family caregivers?

To examine research objective five, participants responses to question 19 in the semi-structured questionnaire (Appendix 1) was investigated to determine their informed opinions on the subject matter relating to coping with caregiving (during the past months, what has been your motivation or sources of strength to continue to provide care to your mentally ill relative in spite of the difficulties that you face?). A total of two hundred and ninety-three (293) participants responded to this question, and of this number, 283 (97%) indicated that, their source of strength and motivation for the continuous care for their relative was from family duty and responsibility. In other words, that sense of “familism” was their main source of support and motivation. And the remaining 10 (3%) respondents indicated that, their main source of support and motivation for their continuous care for their ill relative was due to religious duty and responsibility (religiousity) towards family members.

Furthermore, chi square was used to examine if there was any association between coping strategies and caregiver burden. The chi square analytical tool was adopted for this purpose because it was the ideal tool to use, especially because they were categorical variables (Sharpe, 2015). The results indicated that, of the 283 respondents who used familism as a coping strategy, 8 (3%) had experienced mild to moderate burden, 200 (68%) experienced moderate to severe burden, whiles 75 (26%) experienced severe burden respectively; and of the ten (10) respondents who used religiosity as a coping strategy, 7 (2%) experienced moderate to severe burden, whilst the other three (1%) experienced severe burden respectively. Therefore, for coping strategies, the chi square result did not show significant relationship ($X^2 = 0.328$, $P = 0.849$, df = 2) with caregiver burden. This result is illustrated in table 4.1 under the caption coping strategies.

Transcripts from IDI's revealed informants (caregivers) use of family duty and responsibility as motivation and coping strategy for the continuous care of their relatives corroborate the finding of the quantitative study on coping strategies. This was what a 56-year-old single parent with 4 children narrated:

> *Ehh! Because she is my daughter, she is my daughter. I became pregnant, carried the pregnancy from day one to 9 months, delivered her, took care of her even to secondary school and she completed SHS. It was only mathematics she could not pass well. She said she wanted to register and do that again. Then this problem happened, so she couldn't write the paper. She has only mathematics problem and she is in the house with me, and so because of that I can't say I won't take care of her. If I refuse to take care of her, if the father has refused and I also refuse where is she going? So, for me, I pity her and I can never even refuse to take care of her because posterity will not spare me and the law of Karma will haunt me even generations after me. So, I have to accept my responsibility and my duty to care for her* (informant # 3).

The informant exhibits what many family members show in relation to the emotional aspects that motivates devotion to providing care. "ehh!... because she is my daughter… she is my daughter….". The statement rings a positive, and supportive note which, all things being equal, should give the necessary backing to the mentally ill person. The sense of "familism" becomes the main stay and motivation. However, the caveat here is that taken to its extremes, the care recipient is usually expected to assume a passive role, may not ask or protest and must obey all the mandates "…because she is my daughter…". This conjures an assumed passive role which may become a form of paternalism, which means the care recipient is seen as a child always, who must be limited to comply. Clearly, such caregivers may over work themselves instead of helping the sick to have her identity and the voice.

A similar situation is presented by another informant- a 45-year-old mother of 4:

> *Hmm, that's my child, that's my blood, that's my family, that's my responsibility. In fact, Karma and posterity will haunt me if I were to abdicate my responsibility, life will be meaningless without values, he is a part of me, and I cannot cut away any part of my body whether good or bad. You know, life comes in pairs; male/female, positive/negative, happiness/sadness, good/bad; and so, we must accept our responsibility and stand up to the challenge in the face of difficulties when it comes. That is our brand, those are our values, and that is my motivation* (informant # 5).

Again, the issue raised by the informant shows very emotional and supportive parenthood. It shows that mental illness impacts on parenting skills, calling for dedication and motivation drawn from commitment. It however registers the fact that holistic family centred approach to care and rehabilitation should necessarily provide support to parents in order to prevent negative outcomes for the family caregivers. An exhibition of all the extraction processes as well as interview transcripts have been displayed in Table 4.22 and Appendix 10 respectively.

Table 4.22: Extraction and Thematic Analysis of IDI's Transcripts of Caregivers

Question Summaries	Extraction for Questions from the IDI's Transcripts	First theme	Second theme
(1) Caregiving roles and difficulties	Cooking, cleaning, washing, bathing patient, feeding patient, lifting patient to-and-fro bird to sofa, administration of medication, transportation clinic and healing centers, and transportation to-and-fro market.	ADL, IADL, care demands, bodily pains, worries, sleeplessness, and exhaustion	Physical and psychological burden
(2) Cause of mental illness and its associated problems, and issues of disclosure to neighbours	- Witchcraft, spiritual possession, evil spirit, evil eye, etc. - The way people gaze at you, name calling, back-biting, avoidance, neglect, finger pointing, isolation, gossips, etc	Witchcraft, evil spirits, isolation, neglect, and stigmatization	Social and relationship burden
(3) Challenges and needs	High cost of medication, money problem, no time for socialization and visitation of friends, school dropout, no adequate time for self and work, several things competing for once time, etc.	Financial problems, responsibility burden, etc.	Financial burden
(4) Source of strength (motivation) for continuous care giving	Family duty and responsibility, religious duty and responsibility, karma, etc	Meaning (source of strength and coping strategy)	Moral obligation, moral guilt, etc.
(5) Severity of illness and its effects	- Can be very serious especially during relapse - Insults, beating, blames for her condition and name calling (ashawo), violence, embarrassment and guilt feeling, etc.	Stress, worries, mental exhaustion, bodily pains, etc.	Role strain
(6) Support from community/government	High cost of drugs, poverty, needy, etc.	NHIS coverage of psychiatric drugs	Financial burden and helplessness
(7) Impact of mental illness	Bodily pains, worries, sadness, sleeplessness, exhaustion, self-blame, financial problems, etc.	Stress, guilt feeling, financial problems, etc.	Moral injury
(8) Fear/concerns about patient's condition	Thinking about death, suicide, neglect, murder, rape resulting in pregnancy, relapse, courage, etc., the preoccupation of caregivers about impending calamities that could befall their patients.	Worry, anxiety, emotional trauma, etc.	Overwhelmed

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the study findings in line with the research objectives and the theories that provided the foundation upon which the study was built. These are Lazarus & Folkman (1984), Transactional theory of stress and coping and Pearlin et al., (1990) caregiver stress theory.

5.2 Perceived Caregiver Burden and Appraisals

This section discusses findings from research objective one, which relates to perceived caregiver burden.

5.2.1 Burden Experienced by Family Caregivers

This study demonstrates unequivocally that caregiver burden is widespread among caregivers of mentally ill patients. The study discovered that all participants had medium to severe caregiver burden when the Zarit burden assessment scale was used to assess respondents' perceived caregiver load. The implication of this finding is that, whilst all respondents found caring for patients with mental illness to be burdensome, the burdens varied from mild to moderate (3%), to moderate to severe (70%) and severe burden was experienced by 27%, indicating that caregiver burden exceeded the "caseness" threshold. As a result, these individuals were referred to the psychiatric unit's management for additional assessment and appropriate action.

The findings of this study corroborate those of Walke et al. (2018), who found that 40.9 percent of caregivers reported experiencing severe load, while 59.1 percent reported experiencing moderate burden. Additional support for this conclusion comes from an Iranian study that examined caregiver burden among caregivers of schizophrenic patients. The Zarit Load Interview Schedule was used to determine the amount of burden experienced by the majority of primary caregivers (Hajebi et al., 2019). Although it should be noted that carers in the Hajebi et al., (2019) study were exclusively caring for schizophrenic patients, in contrast to the current study, which examined caregiver stress among caregivers of patients with a variety of mental disorders.

The findings of this study shed light on the situation of carers who shoulder the primary responsibility for caring for a mentally ill individual and are subjected to unacceptably high levels of hardship. Additionally, the link can be identified using Pearlin et al (1990)'s stress process model, in which caregiver responsibilities operate as secondary role strains, culminating in conflict with other domains of life and thereby affecting caregivers' mental well-being (Pearlin et al., 1990). These caregivers require the assistance and understanding of the individuals and communities they serve.

5.2.2 Predictors of caregiver burden: role strain, feeling overwhelmed, low self-efficacy, helplessness, and moral guilt

The study's findings indicated that role strain, feeling overwhelmed, low self-efficacy, helplessness, and moral guilt were all significant predictors of caregiver burden at the 5% level of significance in the study region. These predicted indicators included sentimental and emotional overtones, indicating the psychological pain and caregiver burden experienced by respondents as a result of their daily caregiving obligations and responsibilities. This conclusion implies that all factors represent caring experiences, including background and context variables, care demands, coping mechanisms, and social support. The caregiver burden predictor variables are also appraisal dimensions of caregivers' perceptions and beliefs about their ability to cope with the demands of caregiving, and thus should have a relationship with caregiver burden as determined by the study area's key factors predicting caregiver burden.

This finding is consistent with Pearlin et al (1990)'s study of the stress process model in the context of caring, which found that secondary stressors operate as antecedents to caregivers' experiences of stress and burden. They implied that life events can result in the formation of new strains or the intensification of pre-existing strains, and that these new or intensified strains eventually manifest as stress. They discovered increased tensions in marriage, parenthood, and among caregivers, particularly those caring for mentally ill individuals who doubled as relatives (Pearlin et al., 1990).

The finding sheds light on the caregiving circumstances faced by family carers of those living with mental illness. Not only were caregivers presented with the onerous work of caregiving, but they also developed new ideas about caregiving. The qualitative study discovered that carers felt helpless, overwhelmed, and lacked self-efficacy due to a lack of knowledge about how and where to seek support for their mentally ill relatives. As a result, they felt they were unable to offer proper care for their family as much as they desired and so lost control over their relatives who suffered from mental illness, which eventually instilled in caregivers a sense of moral guilt.

5.3 Evil-spirit possession Contributing to Caregiver Burden

According to the findings of this study, 193 (66 percent) of caregivers believed that their relative's problems were caused by Evil-spirits possession, 50 (17 percent) believed that their relative's problems were caused by the care recipient's personality and prior experiences, and 20 (7 percent) believed that their relative's problems were caused by God's creation. The implication of this study is that cultural ideas significantly influence behaviour, and so one cannot discuss the causes of mental health illness without considering culture, as culture shapes people's perceptions of normalcy and abnormality. Thus, an individual's cultural predisposition toward and experience with spirits as a causative component in mental illness may have influenced their choice of evil-spits as the cause of their family's mental illness.

This conclusion corroborates a previous study conducted among carers of mentally ill patients, which discovered evidence of supernatural and mystical beliefs related with mental illness (Mohd et al., 2014). They discovered that the majority of study participants attributed their patients' mental illness to a "curse from God" or the punishment for previous sins (karma), loss of mental strength, incitement of "Jin," an imbalance of "chi," or the incitement of evil spirits. These beliefs were observed across ethnic groups (Mohd et al., 2014).

This study's findings also corroborate those of Byaruhanga et al. (2008), who observed that over 90% of their study respondents who went to the hospital first consulted with indigenous healers; and that during hospitalization, some patients and caregivers continue to consult with indigenous healers, while others express an interest in consulting with them after discharge to perform certain rituals or ceremonies (Byaruhanga et al., 2008). Numerous indigenous healing modalities are ingrained in local, social, and cultural contexts, forming a bond amongst individuals who share same cultural background.

5.4 The experience of stigma among family caregivers

The study's findings provided significant evidence of participants experiencing stigma, with around 89 percent of caregivers experiencing stigma more frequently. Additionally, the study established a clear connection between perceived stigma and caregiver burden ($X^2 = 14.321$, $P = 0.001$, $df = 2$). According to the qualitative analysis, carers faced social isolation and neglect from their neighbours as a result of their affiliation with those who suffer from mental illness, resulting in increased social and relationship strain. The relevance of this finding is that it emphasises the huge scale of the issue that family stigma offers to family members caring for relatives who are mentally ill. This is because they are labeled, discriminated against, and even abused, despite the fact that they do not have a known diagnosis of mental illness, but their mere association with relatives who do suffer from these disorders expose them and their relatives to isolation, neglect, and violence, all of which make access to mental health care services difficult.

This study corroborates earlier research on stigma and prejudice associated with mental illness among people diagnosed with mental illness and their carers in Ghana (Tawiah et al., 2015a). On the one hand, the study discovered a positive association between mental illness and stigma; on the other hand, it discovered a negative relationship between mental illness and discrimination (Tawiah et al., 2015a). Economic, psychological, and social stigma were all identified as manifestations of stigma among the participants. 72% of reported stigma was social in nature, ranging from familial blame to derision to mockery. Economic stigma was mostly induced by a lack of food access (14%), whereas psychological stigma was caused by a loss of self-esteem (13%). Discrimination against people with mental illness was mostly economic (46%) and social (54%). (Tawiah et al., 2015a).

Another study that corroborates the current study's findings is a Singaporean study in which a significant number (94.5 percent) of main caregivers reported experiencing affiliate stigma after their care recipient experienced psychiatric issues (Zhang et al., 2018). The study discovered that parents of people with mental illness felt more stigmatised than siblings and spouses (Zhang et al., 2018). According to studies, parents are held more accountable for their children's mental health development, and hence, their children having a mental illness can reflect adversely on the person's family and cause the family shame (Zhang et al., 2018).

The findings of this study demonstrate that when family members share the stigma and practical challenges associated with having a family member with mental illness, they experience psychological discomfort and burden. Additionally, stigma and discrimination towards people with mental illness, as well as their caregivers who may not have diagnosable mental health disorders, are connected with negative health outcomes such as decreased psychological well-being. The findings add to the growing body of evidence that stigma may play a role in the etiology of health problems and may be considered a social determinant of health inequities.

Additionally, it is argued that stigma may impose a financial strain on health services as a result of frequent contact with health personnel. Stigma may decrease adherence to treatment, resulting in an insufficient response to treatment and a delay in recovery for individuals, which may also result in increased service costs. Additionally, some individuals may refuse to accept services that they require. Psychological distress has a role in the consequences of stigma on these health outcomes. It is critical, then, that agencies improve their ability to recognize individuals enduring psychological distress as a result of stigma.

5.5 The sociodemographic variables' effect on caregiver burden

This section examines the sociodemographic factors that contribute to caregiver burden. Age, gender, income, relationship to patient, caregiver status, marital status, issues (children) in marriage, education, and employment were the sociodemographic variables evaluated in this study.

5.5.1 The relationship between caregiver burden and sociodemographic parameters

The findings of this study established a strong association between family caregiver burden and caregiver age, gender, caregiver relationship to the patient, caregiver status, income, and issues (children) in marriage. The results indicated that the majority of caregivers, 176 (60%) were female, while 117 (40%) were male, and that 66 (22%) of female caregivers suffered severe burden compared to only 12 (4%) of male caregivers. The finding re-emphasises the role of demographic variables on caregiver load. This is because being a working mother with the traditional responsibilities of looking after children and providing for their basic needs, including cooking for your husband and the rest of the household, is already taxing; adding the additional burden of caring for a mentally ill relative can be overwhelming.

This finding is consistent with previous research (Swinkels et al., 2019; Marks et al., 2002; McDonnell & Ryan, 2013; Penning & Wu, 2016; Pinquart & Sorensen, 2006; Yee & Schulz, 2000). The caregiving literature has consistently demonstrated that female caregivers face greater burdens than male caregivers; and that caregivers are more likely to be women than men in many parts of the world (World Federation of Mental Health, 2010).

According to Pearlin et al. (1990), there are two possible explanations for gender disparities in caregiver burden. To begin, women and men live in structurally distinct environments, and the unequal distribution of rewards, privileges, opportunities, and responsibilities results in stressors of varying types and intensities to which people are exposed (Pearlin et al., 1990).

Additionally, the survey discovered that more than a third (38%) of caregivers were mothers, 30% were siblings, and 6% were fathers; with 45 (15%) of moms having severe burden and 18 (6%) of siblings experiencing severe hardship. Among the siblings, 14 (5%) sisters reported significant burden, while 4 (1%) brothers did. The data imply that moms are more likely than fathers to have caregiver burden, and that sisters are more likely than brothers to experience caregiver burden among carers in the research area.

The study discovered that 98 (33 percent) of caregivers were parents, while 93 (31 percent) and 80 (27 percent) were spouses and household leaders respectively. Additionally, spouses (12%), parents (9%), and household heads (5%) were significantly burdened in comparison to the others. Concerning marriage with children, the survey discovered that 207 (71%) of carers had children, while 86 (29%) did not; also, 18% of caregivers with children were extremely stressed, compared to just 8% of caregivers without children. The finding implies that spouses are more likely to face caregiver strain than parents and other family caregivers. As a result of the additional stress involved with caring for children, caregivers with children are also more likely to experience severe burden than caregivers without children.

Jeyagurunathan et al. (2017)'s investigation of the interaction between caregiver and patient and caregiver burden corroborate the present study's findings. While individuals who cared for their son/daughter had a decreased chance of burden symptoms, those who cared for their spouses (i.e. spousal carers) had a higher risk of psychological load (Jeyagurunathan et al., 2017). They proposed an explanation for the disparities noticed between the two groups. They suggested that, in comparison to parents, spouse carers may have lost their confidant, economic support, co-manager of the household, and child-rearing aid, which may have contributed to the higher psychological stress scores (Jeyagurunathan et al., 2017). Sato et al. (1996) examined the relationship between age and caregiver load in a study involving 58 caregivers. They discovered a correlation between age and burden. They implied that there was a good risk that an aged caregiver will develop health difficulties as a result of providing care to a person with a compromised health state (Sato et al., 1996). Another study (Kim et al., 2012) examined the demographic variables that influenced care provider load after providing care to 1,218 individuals for five years. Age of the carer was revealed to be a significant predictor of caregiver burden five years after diagnosis with a mental illness. These findings corroborate the conclusions of the current investigation.

However, the current study discovered no significant relationship between caregiver strain and marital status, education, or employment. Although the quantitative findings indicated no significant association between marital status and caregiver burden, the qualitative analysis revealed a worrisome relationship between marital status and caregiving, particularly for married caregivers with children. The caregivers found it exceedingly challenging to balance marriage duties, such as child care and other family demands, with being a working mother and caring for a mentally ill relative, especially if they resided in different locations and involved a parent.

Siddiqui and Khalid's (2019) findings on the association between caregiver marital status and caregiver burden among 120 Pakistani citizens corroborate the qualitative findings. Siddiqui & Khalid (2019) discovered that married caregivers experienced considerably more caregiver burden than unmarried caregivers ($t=-2.98$, p 0.01). They implied that marriage is already a full-time job with multiple duties and obstacles, on top of one's professional career as a source of income; and adding caregiving to a relative with a mental health issue might be overwhelming, contributing to the psychological strain experienced.

However, another study's finding (Jeyagurunathan et al., 2017) contradicts Siddiqui & Khalid's (2019). They discovered that carers who were single or widowed had a much lower quality of life and a greater psychological load than married caregivers. They implied that carers had additional difficulties in the absence of a spouse who could offer support and share some of the burden (Jeyagurunathan et al., 2017).

Additionally, in a study involving 350 caregivers of mentally ill relatives, Jeyagurunathan et al. (2017) discovered a strong relationship between demographic characteristics (education and occupation) and psychological stress. Caregivers with lower education levels were substantially more likely to report experiencing a greater psychological load. They implied that highly educated carers tended to have better occupations with higher salaries, which allowed for more resources to be spent on caring for their ailing relatives, possibly contributing to their superior quality of life. Employment was also found to be associated with psychological distress. Employed individuals reported a higher quality of life than unemployed individuals. They stated that one reason for this could be that employed individuals had a larger social network, which enabled them to communicate with other people, thereby alleviating their mental pain. Similarly, increased wages from employment could have benefited in reducing their financial misery (Jeyagurunathan et al. 2017).

The outcome of this study reveal unequivocally that caregiver burden is associated with the sociodemographic features of family caregivers. Certain demographic characteristics of the caregiver, such as age, gender, relationship to the patient, and socioeconomic status, can have a substantial impact on and increase the level of burden experienced by the family caregiver. As a result, developing social support networks and educating family caregivers may help ease some of these responsibilities.

5.6 Use of familism and religiousity as coping strategies among family caregivers

The study discovered that the vast majority of family caregivers 283 (97 percent) utilised "familism" as their primary coping mechanism when caring for a mentally ill relative. In other words, their primary source of support and inspiration in the face of adversity was their feeling of "familism." While the remaining ten (3%) respondents utilised "religion" as a coping mechanism when caring for mentally ill individuals. Yang's (1995) study of caregivers' and care-recipient relatives' utilisation of familism as a social capital corroborates this current conclusion. According to Yang (1995), familism refers to a condition in which individuals are accustomed to prioritising family honour, survival, prosperity, and stability over their petty individual interests.

Twigg & Atkin's (1994) earlier research on family duty and responsibility as a coping mechanism corroborate this finding. According to them, the position of family caregivers is not always enjoyable; rather, it is one of duty and sharing one's life with another person. Thus, the nature of this form of care is providing a home, interacting with financial or public authorities, handling crises or periodic hospitalisation, and keeping the family member from succumbing to lethargy and self-neglect (Twigg & Atkin, 1994). Additionally, Endrawes et al. (2007) discovered that Egyptian families tended to continue caring for mentally ill relatives despite feelings of powerlessness, a lack of support, isolation, embarrassment, and stigma. Additionally, they discovered that Egyptians have a strong feeling of duty and obligation to uphold family bonds and keep the family intact despite the hardships caused by their relatives' illness (Endrawes et al., 2007).

The findings show that when family load threatens their well-being, family members are more inclined to take action or participate in adaptive coping techniques. As such, family caregivers may be characterised as seeking external solutions to perceived external difficulties. Additionally, family members may have felt that they possessed additional resources and talents to deal with family burdens. Because they "felt fulfilled," all carers in this study engaged cultural and religious coping methods, which can contribute to a pleasant caring experience. While the satisfaction associated with caring may not be readily evident to others, it may serve as a coping mechanism for the family caregiver.

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

This chapter summarises the study's primary findings in relation to the research objectives and draw pertinent conclusions for each of the study's five research objectives. Additionally, it discusses the novel discoveries from this work as a contribution to knowledge. It finishes by discussing the study's consequences for public health decision-making, its recommendations, and proposals for additional research and policy makers.

6.2 A Synthesis of the Study's Findings

To evaluate reported family caregiver load, this study used a mix of quantitative and qualitative methodologies. The study surveyed 293 carers of relatives living with mental illness in the Tamale Metropolis, capital city of the Northern region. Respondents were recruited from the Tamale Central Hospital's psychiatric unit. The majority of caregivers (64%) were between the ages of 31 and 60, with 176 (60%) females and 117 (40%) males.

The study's major findings include the following:

1. When the Zarit burden measurement scale was used to assess respondents' reported caregiver burden, all family caregivers in this study met the threshold for caregiver burden.
2. At a 5% level of significance, role strain, low self-efficacy, helplessness, moral guilt, and feeling overwhelmed were revealed to be predictors of family caregiver burden in the research area.
3. In terms of sociocultural issues, the study discovered that the majority (66%) of caregivers believed that their patient's problems were caused by Evil-spirits

possession, 17% believed that their patient's problems were caused by the care recipient's personality and prior experiences, and 7% believed that their patient's problems were caused by God's creation.

4. There was substantial evidence of perceived stigma among family caregivers in the study location, which accounted for around 89 percent of the caregiver population investigated.
5. Age, gender, income, relationship to patient, caregiver status, and issues (children) in marriage were found to significantly contribute to caregiver burden among research respondents.
6. The vast majority (97 percent) of family caregivers in the research area utilised "familism" as their primary coping mechanism when caring for their mentally ill patient.

6.3 Conclusion

The purpose of this study was to determine the predictive ability of multidimensional characteristics for assessing caregiver burden in caretakers of people with mental illness, utilising a sample of 293 caregivers from a community in the Northern region. The findings indicated that two distinct categories of predictors, caregiver demographic variables (age, gender, income, relationship status, caregiver status, education, marital status, issues in marriage and employment), and caregiver appraisal reflecting care demands and active coping, explained caregiver burden uniquely. The ADL/IADL dependency of care recipients, which reflects care demands and coping, explained the highest variance in caregiver load, followed by caregiver demographic characteristics.

Specifically, the best predictors of caregiver stress in the research region were role strain, overwhelm, low self-efficacy, helplessness, and moral guilt. The findings suggested that these factors had a favourable effect on the burden level in Ghana's Northern Regions, as their coefficients were positive.

6.4 Contribution to the Advancement of Knowledge

6.4.1 Study Novelty

While numerous researches have been conducted on family caregiver burden in mental health disease, these scholarly works have focused on the relationship between caregiver sociodemographic factors and caregiver burden on the one hand, and the kind and severity of mental disorder on the other. The current study is the first to employ multiple regression analysis to construct a model for predicting caregiver burden among family caregivers of mental health patients (against a review of the literature). The study discovered that role strain, feeling overwhelmed, low self-efficacy, helplessness, and moral guilt were all statistically significant predictors of caregiver burden at the 5% significant level. The five factors explained more than 70% of the variation in the data set.

6.4.2 High Burden Scores Found Among Family Caregivers

Attention of staff of the psychiatric unit of TCH was drawn to the plight of 78 participants who recorded higher scores (61-88) on the ZBS, which were indicative of severe burden, for further assessment and necessary action.

6.5 Observations and Recommendations

6.5.1 Practice Recommendation

Ghana Health Service should scale-up the community psychiatrists advocacy campaign towards selfcare among caregivers through the provision of health information, education and resources.

6.5.2 Policy Recommendation

As part of their protocols, Ghana Health Service via community psychiatric nurses (CPN) should investigate the presence of "burden markers" among family caregivers when they come for review with their patients at the facility and when CPN visit communities for review.

6.5.3 Research Recommendation

Future research addressing attrition as an outcome variable could be helpful in the quest to understanding why participants leave studies midway.

References

(ABS), A. B. of S. (1998). *Disability, Ageing and Carers, Australia: Summary of Findings* (Issue 02).

Adefunke, S. E. & I. M. (2015). Preservation and Use of Indigenous Knowledge in Primary Healthcare Among the Alternative Healthcare Practitioners in Oyo State , Nigeria. *Afr. J. Lib. Arch. & Inf. Sc.*, *25*(1), 59–68.

Ahorlu, C. K., Koram, K. A., Ahorlu, C., De Savigny, D., & Weiss, M. G. (2005). Community Concepts of Malaria-Related Illness with and without Convulsions in Southern Ghana. *Malaria Journal*, *4*(47), 1–12. https://doi.org/10.1186/1475-2875-4-47

Akogun, O. B., Audu, Z., Weiss, M. G., Adelakun, A. O., Akoh, J. I., Akogun, M. K., Remme, H., & Kale, O. O. (2001). Community-Directed Treatment of Onchocerciasis with Ivermectin in Takum, Nigeria. *Tropical Medicine and International Health*, *6*(3), 232–243. https://doi.org/10.1046/j.1365-3156.2001.00696.x

Alhassan, A., & Nokoe, K. S. (2016). Modelling the Transitional Dynamics of Mycobacterium Tuberculosis Strain. *Journal of Medical and Biomedical Sciences*, *5*(2), 13–23.

Alloh, F. T., Regmi, P., Onche, I., Teijlingen, E. Van, & Trenoweth, S. (2018). Mental Health in Low-and Middle Income Countries (LMICs): Going Beyond the Need for Funding. *Journal of Public Health*, *17*(Special Issue).

Aloba, O., Opakunle, T., & Ogunrinu, K. (2019). Alternative Models Examination and Gender Measurement Invariance of the 12-item General Health Questionnaire among Nigerian Adolescents. *Psychiatry Research*, *16*(11), 808–815.

Amirkhanyan, A. A., & Wolf, D. A. (2003). Caregiver Stress and Noncaregiver Stress: Exploring the Pathways of Psychiatric Morbidity. *Gerontologist*, *43*(6), 817–827. https://doi.org/10.1093/geront/43.6.817

Anokye, M. A. (2020). Sample Size Determination in Survey Research. *Journal Scientific Research and Reports*, *26*(5), 1–9.

Aranda, M., & Knight, B. G. (1997). The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: A Sociocultural Review and Analysis. *The Gerontologist*, *37*(3), 342–354.

Ashworth, M., & Baker, A. H. (2000). "Time and Space": Carers' Views About Respite Care. *Health & Social Care in the Community*, *8*(1), 50–56. https://doi.org/10.1046/j.1365-2524.2000.00221.x

Auer, C., Jr, J. S., Tanner, M., & Weiss, M. (2000). Health Seeking and Perceived Causes of Tuberculosis Among Patients in Manila, Philippines. *Tropical Medicine and International Health*, *5*(9), 648–656. http://onlinelibrary.wiley.com/doi/10.1046/j.1365-3156.2000.00615.x/full

Avison W R, Turner R J, N. S. & S. K. N. (1993). *The Impact of Caregiving: Comparisons of Different Family Contexts and Experiences', in S H Zarit, L I Pearlin & K W Schaie (eds) Caregiving systems. Informal and formal helpers,* (P. L. I. &Schaie W. K. Zarit, Steven H (Ed.)). Lawrence Erlbaum Associates.

Bandura, A. (1997). *Self-efficacy : the exercise of control*. W.H. Freeman.

Baronet, A.-M. (1999). Factors Associated with Caregiver Burden in Mental Illness: A Critical Review of the Research Literature. *Clinical Psychology Review*, *19*(7), 819–841. https://doi.org/10.1016/S0272-7358(98)00076-2

Bartlett, M. S. (1954). A Note on the Multiplying Factors for Various Chi Square Approximations. *Journal of the Royal Statistical Society*, *16*, 296–298.

Bernard, H. R. (2006). *Research Methods in Anthropology: Qualitative and Quantitative Approaches.: Vol. Four*. Rowman & Littlefield Publishers.

Bigby, C., & Ozanne, E. (1999). *Older Carers of Adults with Intellectual Disability, Characteristics and Service Provision Issues. A Literature Review.*

Blanco, C., Compton, W. M., Saha, T. D., Goldstein, B. I., Ruan, W. J., Huang, B., & Grant, B. F. (2017). Epidemiology of DSM-5 bipolar I disorder: Results from the National Epidemiologic Survey on Alcohol and Related Conditions – III. *Journal of Psychiatric Research*, *84*, 310–317. https://doi.org/10.1016/j.jpsychires.2016.10.003

Bowling, A. (2014). *Research Methods in Health: Investigating Health and Health Service* (Fourth Edi). Open University Press.

Boye, B., Bentsen, H. and Malt, U. F. (2002). Does guilt proneness predict acute and long-term distress in relatives of patients with schizophrenia? *Acta Psychiatrica Scandinavica, 106*, 51-57.

Braithwaite, V. A. (2000). Contextual or General Stress Outcomes: Making Choices Throught Caregiving Appraisals. *Gerontologist*, *40*(6), 706–717.

Braun, V. and Clarke, V. (2006). *Using thematic analysis in psychol-ogy. Qualitative Research in Psychology. 32*, 77–101.

Bridges Barbara J. (1998). *Therapeutic Caregiving: A Practical Guide for Care- givers of Persons with Alzheimer's and Other Dementia-Causing Diseases.* (Second Edi). BJB.

Brodaty, H. (2007). Meaning and measurement of caregiver outcomes. *International Psychogeriatrics*, *19*, 363–381.

Calabrese, R. S. M. & J. R. (2019). Bipolar Depression: The Clinical Characteristics and Unmet Needs of a Complex Disorder. *Current Medical Research and Opinion*, *35*(11), 1993–2005.

Calasanti, T. (2010). Title Gender Relations and Applied Research on Aging. *The Gerontologist*, *50*(6), 720–734.

Cannon, T. D. (2022). Psychosis, Schizophrenia, and States vs. Traits. *Schizophr. Res.*, *242*, 12–14.

Carruth, A. K., Tate, U., Moffett, B., & Hill, K. (1997). Reciprocity, Emotional Well-Being, And Family Functioning as Determinants of Family Satisfaction In Caregivers of Elderly Parents. *Nursing Research*, *46*(2), 93–100.

Chang, B., Brecht, M., & Carter, P. (2001). Predictors of social support and caregiver outcomes. Women Health. *Women Health*, *33*(1–2), 39–61.

Chaturvedi, S. K. (2021). *Hand Book of Clinical Depression*.

Cohen, S. (2004). Social Relationships and Health. *Am. J. Psychol.*

Correll, C. U., Solmi, M., Croatto, G., Schneider, L. K., Rohani-Montez, S. C., Fairley, L., Smith, N., Bitter, I., Gorwood, P., Taipale, H., & Tiihonen, J. (2022). Mortality in people with schizophrenia: a systematic review and meta-analysis of relative risk and aggravating or attenuating factors. *World Psychiatry*, *21*(2), 248–271. https://doi.org/10.1002/wps.20994

Covinsky, Kenneth E.; Goldman, L. (1994). The Impact of Serious Illness on Patients' Families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *American Medical Association*, *727*, 1839–18344.

Cox, C., & Monk, A. (1993). Hispanic Culture and Family Care of Alzheimer's Patients. *Health and Social Work*, *18*(2), 92–100. https://doi.org/10.1093/hsw/18.2.92

Creswell, J. W. (2009). (2009). *Research design: Qualitative, quantitative, and mixed methods Approaches* (Third Edit).

Cummings, J. L., Angeles, L., Frank, J. C., Cherry, D., Kohatsu, N. D., Kemp, B., Hewett, L., & Mittman, B. (2002). Guidelines for Managing Alzheimer ' s Disease : Part I Assessment. *American Family Physician*, *65*(11), 2263–2272.

Del Barrio, V. (2016). Diagnostic and statistical manual of mental disorders. In *The Curated Reference Collection in Neuroscience and Biobehavioral Psychology* (5th ed.). American Psychiatric Association: https://doi.org/10.1016/B978-0-12-809324-5.05530-9

DiCiccio, T.J & Efron, B. (1996). *Bootstrap confidence intervals. Statistical Sciences. 11*, 189–228.

Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of Race on Cultural Justifications for Caregiving. *Journals of Gerontology*, *60*(5), 257–262. https://doi.org/10.1093/geronb/60.5.S257

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of Race, Ethnicity, and Culture in Caregiving Research: A 20-Year Review (1980-2000). *Gerontologist*, *42*(2), 237–272. https://doi.org/10.1093/geront/42.2.237

Douglas, A., L . & Robert, D., M. (1996). *Basic Statistics for Business and Economics.* (Second Edi). Richard D Irwin.

Drake, R. E., Xie, H., & McHugo, G. J. (2020). A 16-year follow-up of patients with serious mental illness and co-occurring substance use disorder. *World Psychiatry*, *19*(3), 397–398. https://doi.org/10.1002/wps.20793

Dupuis, M., Baggio, S., M ohler-Kuo , M ., & Gmel, G. (2015). (2015). *The benefits of online Swiss, questionnaires to prevent from attrition in longitudinal surveys: The example of the Congress, cohort on substance use risk factors (C- SURF). Paper presented at the 2nd European for Social Psy- chiatry: Social Psychiatry in .*

Dupuis, M., Preisig, M., Strippoli, M.-P., Vandeleur, C., & Gholam-Rezaee, M. (2019). Mental Disorders, Attrition at follow-up, and Questionnaire Non-Completion in Epidemiologic Research. Illustrations from the ColauslPsyColaus Study. *International Journal of Psychiatry*, 1–10.

Duxbury, L., Higgins, C., & Smart, R. (2011). Elder care and the impact of caregiver strain on the health of employed caregivers. *Work and Health*, *40*, 29-40.

Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding Economic and Other Burdens of Terminal Illness:Tthe Experience of Patients and Their

Caregivers. *Annals of Internal Medicine*, *132*(6), 451–459. https://doi.org/10.7326/0003-4819-132-6-200003210-00005

Fanner, M., Locke, B., Liu, I., & Moscicki, E. (1994). Depressive Symptoms and Attrition: the NHANES I Epidemiologic Follow-Up Study. *Int J Methods Psychiatr Res*, *4*, 19–27.

Flannery, R. B. (2002). Treating Learned Helplessness in the Elderly Dementia Patient: Prelimenary Inquiry. *American Journal of Alzheimer's Disease and Other Dieentias*, *17*(6).

Flick, S. (1988). Managing attrition in clinical research. *Clinical Psychology Review*, *8*, 499-515.

Freedman Vicki A. & Spillman Brenda C . (2014). Disability and Care Needs Among Older Americans. *Population Health and Health Policy*, *92*(3), 509–541. https://doi.org/10.1111/1468-0009.12212

GE, S., EJ, L., & Unutzer J. (2008). Severity of Mood Symptoms and Work Productivity in People Treated for Bipolar Disorder. *Bipolar Disord.*, *10*, 718–725.

Geddes, J. (2005). Bipolar disorder. *Clinical Evidence*, *387*(13), 1561–1572.

George, D., & Mallery, P. (2012). *IBM SPSS statistics 19 step by step: A simple guide and reference* ((12th edit). Pearson.

George, L. K., & Gwyther, L. P. (1986). Caregiver Well-Being: A Multidimensional Examination of Family Caregivers of Demented Adults. *The Gerontologist*, *26*(3), 253–259. https://doi.org/10.1093/geront/26.3.253

Ghana Statistical Service. (2012). *2010 Population and Housing Census Final Results*. http://www.statsghana.gov.gh/docfiles/2010phc/2010_POPULATION_AND_HOUSING_CENSUS_FINAL_RESULTS.pdf

Ghana Statistical service (GSS). (2014). *Ghana Demographic and Health Survey*.

Ghatavi, K., Nicolson, R., MacDonald, C., Osher, S. and Levitt, A. (2002). No TitleDefining guilt in depression: a comparison of subjects with major depression, Chronic Affective, medical illness and healthy controls. *Journal of Disorders*, *68*, 307–315.

Given, B., Keilman, L., Collins, C., & Given, C. (1990). Strategies to Minimize Attrition in Longitudinal Studies. *Nursing Research*, *39*(3), 184-186.

Given Barbara, Wyatt Gwen, Given Charles, Gift Audrey, Sherwood P., DeVoss Danielle, R. M. (2005). Burden and Depression Among Caregivers of Patients with Cancer at the End-of-life. *Oncology Nursing Forum*, *31*(6), 1105–1117.

Glozah, F. N., & Pevalin, D. J. (2015). Factor structure and psychometric properties of the General Health Questionnaire (GHQ-12) among Ghanaian adolescents. *JOURNAL OF CHILD & ADOLESCENT MENTAL HEALTH*, *27*(1), 53–57. https://doi.org/10.2989/17280583.2015.1007867

Glozman, J. M. (2004). Quality of life of caregivers. *Neuropsychology Review*, *14*(4), 183–196. https://doi.org/10.1007/s11065-004-8158-5

Gnambs, T., & Kaspar, K. (2016). *Socially Desirable Responding in Web-based Questionnaires: A meta-Analytic Review of the Candor Hypothesis. Assessment*. *24*, 746–762.

Goldberg, David P and Williams, P. (1988). *A user's guide to the General Health Questionnaire*. NFER-Nelson.

Goldberg, D. P. (1972a). *The detection of psychiatric illness by questionnaire; a technique for the identification and assessment of non-psychotic psychiatric illness,*. Oxford University Press,.

Goldberg, D. P. (1972b). *The Detection Of Psychiatric Illness By Questionnaire*. Oxford University Press.

Goldberg JF, H. M. (2011). A 15-Year Prospective Follow-Up of Bipolar Affective Disorders: Comparisons with Unipolar Nonpsychotic Depression. *Bipolar Disord*, *13*, 155–163.

Green, M. F. ., Lee, J. ., & Wynn, J. K. (2020). Experimental Approaches to Social Disconnection in the General Community: Can We Learn from Schizophrenia Research? Worl Psychiatry Off. *J. World Psychiatr. Assoc.*, *19*, 177–178.

Gur, R. E. (2022). Considering alternatives to the schizophrenia construct. *Schizophrenia Research*, *242*, 49–51. https://doi.org/10.1016/j.schres.2021.12.027

Haley, W. E., Gitlin, L. N., Wisniewski, S. R., Mahoney, D. F., Coon, D. W., Winter, L., Corcoran, M., Schinfeld, S., & Ory, M. (2004). Well-being, Appraisal, and Coping in African-American and Caucasian Dementia Caregivers: Findings From the REACH Study. *Aging and Mental Health*, *8*(4), 316–329. https://doi.org/10.1080/13607860410001728998

Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of Depression and Life Satisfaction Among Spousal Caregivers in Hospice: Application of a Stress Process Model. *Journal of Palliative Medicine*, *6*(2), 215–224. https://doi.org/10.1089/109662103764978461

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, *2*(4), 323–330. https://doi.org/10.1037/0882-7974.2.4.323

Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A. C., Collins, R. P., Isobe, T. L., & Al, H. E. T. (1996). Appraisal , Coping , and Social Support as Mediators of Well-Being in Black and White Family Caregivers of Patients With Alzheimer ' s Disease. *Journal of Consulting and Clinical Psychology*, *64*(1), 121–129. https://doi.org/10.1037/0022-006X.64.1.121

Hankins, M. (2008). *The Factor Structure of the Twelve item General Health Questionnaire(GHQ-12): The Results of Negative Phrasing*. *4*(10). https://doi.org/10.1186/1745-0179-4-10

Hebert, R. S., & Schulz, R. (2006). Caregiving at The End of Life. *Palliative Medicine*, *9*(5), 1–15.

Hong, S., & Coogle, C. (2016). Spousal Caregiving for Partners With Dementia: A Deductive Literature Review Testing Calasanti's Gendered View of Care Work. *Journal of Applied Gerontology*, *35*(7), 759–787.

Hunt, G. E. ., Large, M. M. ., Cleary, M. ., Lai, H. M. X. ., & Saunders, J. B. (2018). *Prevalence of Comorbid Substance Use in Schizophrenia Spectrum Disorders in*

Community and Clinical Settings, 1990- 2017: Systematic Review and Meta-Analysis. Drug Alcohol. Depend. 191, 234–258.

Hurvich, M. (2000). Fear of being overwhelmed and psychoanalytic theories of anxiety. *Journal of Psychoanalytic Review*, *87*(5), 615–649.

Insel, T. . (2010). Rethinking Schizophrenia. *Nature*, *468*, 187–193.

Johnson, B. (2015). *Caregiving and Caregiver Burden. In: Loue S, SajatovicM, editors. Encyclopedia of Immigrant Health* (Vol. 49, Issue 0).

K, J., A, T., & S., M. (2016). Is Treatment for Bipolar Disorder More Effective Earlier in Illness Course? A Comprehensive Literature Review. *Int J Bipolar Disord*, *4*(19), 1–51.

Kaiser, H. (1974). An Index of Factorial Simplicity. *Psychometrik*, *39*, 31–36.

Kaunonen, M., Tarkka, M. T., Hautamäki, K., & Paunonen, M. (2000). The Staff's Experience of The Death of a Child and of Supporting The Family. *International Nursing Review*, *47*(1), 46–52. https://doi.org/10.1046/j.1466-7657.2000.00003.x

Keck PEJ, Dewan N, N. H. (2005). Bipolar Disorder: The Clinician's Guide to Pharmacotherapy for Patients with Co-occurring Medical Conditions. *Curr Psychiatry. 2005;4:1–51.*, *4*, 1–51.

Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the national quality of life survey for caregivers. *Psycho-Oncology*, *21*(3), 273—281.

Kleinman, A. (1978). Concepts and Models for the Comparison of Medical Systems as Cultural Systems. *Social Science and Medicine*, *12*, 85–93.

KR, M., HS, A., & Angst J. (2007). Lifetime and 12-Month Prevalence of Bipolar Spectrum Disorder in the National Comorbidity Survey Replication. *Arch Gen Psychiatry.*, *64*, 543–552.

Kramer, B. J., & Lambert, J. D. (1999). Caregiving As a Life Course Transition Among Older Husbands: A Prospective Study. *Gerontologist*, *39*(6), 658–667. https://doi.org/10.1093/geront/39.6.658

Kristjanson JL, A. S. (2004). Palliative Care for Families: Remembering the Hiden Patients. *Can J Psychiatry*, *49*(6), 359–365. https://doi.org/10.1177/070674370404900604

Kristjanson LJ, Nikoletti S, Porock D, Smith M, Lobchuk M, P. P. (1998). Congruence Between Patients' and Family Caregivers' Perceptions of Symptom Distress in Patients with Terminal cancer. *Palliative Care*, *14*(3), 24–32.

Kugler, Karen; Jones, W. H. (1992). On conceptualizing and assessing guilt. *Journal of Personality and Social Psychology*, *62*(2), 318–327.

Labonté, B. ., Engmann, O.; Purushothaman, I.; Menard, C. ., Wang, J. ., Tan, C. ., Scarpa, J. R. ., Moy, G. ., Loh, Y. E. ., & Cahill, M. . (2017). *Sex-Specific Transcriptional Signatures in Human Depression. Nat. Med. 2017, 23, 1102–1111*. *23*, 1102–1111.

Lancet. (2016). *Disease and Injury Incidence and Prevalence Collaborators. Global, Regional, and National Incidence, Prevalence, and Years Lived with Disability for 310 Diseases and Injuries, 1990–2015: A Systematic Analysis for the Global Burden of Disease Study* (Vol. 388).

Lawton, M. P., Brody, E. M., & Saperstein, A. R. (1989). *A Controlled Study of Respite Service for Caregivers of Alzheimer's Patients*. Oxford University Press.

Lazarus, Richard S & Folkman, S. (1984). *Stress, Appraisal and Coping*. Springer.

Levine, C. (2000). *Always On Call; When Illness Turns Families into Caregivers. United Hospital Fund Book.*

Liang, Y., Wang, L., & Yin, X. (2016). The factor structure of the 12-item general health questionnaire (GHQ-12) in young Chinese civil servants. *Health and Quality of Life Outcomes*, *14*(1), 1–9. https://doi.org/10.1186/s12955-016-0539-y

Lim, J. W., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes*, *2*(50), 1–9. https://doi.org/10.1186/1477-7525-2-50

Lundh, U. (1999). Family Carers. 3: Coping Strategies Among Family Carers in Sweden. *The British Journal of Nursing*, *8*(11), 1–7. https://doi.org/10.12968/bjon.1999.8.11.6591

Marcellus, L. (2004). Are we missing anything? Pursuing research on attrition. *Canadian Journal of Nursing Research*, *36*(3), 82–98.

McDonnell Eilis, R. A. (2013). Male caregiving in dementia: A review and commentary. *Dementia*, *12*(2), 238–250.

Menon, V. (2020). Brain Networks and Cognitive Impairment in Psychiatric Disorders. *World Psychiatry*, *19*, 309–310.

Miller, J. G. (1994). Cultural Diversity in the Morality of Caring: Individually Oriented Versus Duty-Based Interpersonal Moral Codes. *Cross-Cultural Research*, *28*(1), 3-39.

Miller, S., Dell'Osso, B., & Ketter, T. A. (2014). The prevalence and burden of bipolar depression. *Journal of Affective Disorders*, *169*(S1), S3–S11. https://doi.org/10.1016/S0165-0327(14)70003-5

Misiak, B., Stańczykiewicz, B., Wiśniewski, M., Bartoli, F., Carra, G., Cavaleri, D., Samochowiec, J., Jarosz, K., Rosińczuk, J., & Frydecka, D. (2021). Thyroid hormones in persons with schizophrenia: A systematic review and meta-analysis. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, *111*. https://doi.org/10.1016/j.pnpbp.2021.110402

Mitchell, P. B., Goodwin, G. M., Johnson, G. F., & Hirschfeld, R. M. A. (2008). Diagnostic guidelines for bipolar depression: A probabilistic approach. *Bipolar Disorders*, *10*(1 PART 2), 144–152. https://doi.org/10.1111/j.1399-5618.2007.00559.x

Mor, V., Allen, S., & Malin, M. (1994). The Psychosocial Impact of Cancer on Older Versus Younger Patients and Their Families. *Gerontology and Health Care*, *74*(7), 2118–2127. https://doi.org/10.1002/1097-0142(19941001)74:7+3.0.co;2-n

NAC. (2009). *Caregiving in the U.S.*

National Academies of Sciences, Engineering, A., & Medicine. (2016). *Providing Sustainable Mental and Neurological Health Care in Ghana and Kenya: Workshop Summary.* The National Academies Press.

Nielsen, R. E., Banner, J., & Jensen, S. E. (2021). Cardiovascular disease in patients with severe mental illness. *Nature Reviews Cardiology*, *18*(2), 136–145. https://doi.org/10.1038/s41569-020-00463-7

Nolan, Mike , Grant, Gordon & Keady, J. (1996). *Understanding Family Care : A Multidimensional Model of Caring and Coping*. Open University Press.

Nortey, S. T., Aryeetey, G. C., Aikins, M., Amendah, D., & Nonvignon, J. (2017). Economic Burden of Family Caregiving for Elderly Population in Southern Ghana : the Case of a Peri-Urban District. *International Journal for Equity in Health*, *16*(16), 1–9. https://doi.org/10.1186/s12939-016-0511-9

Okpalauwaekwe, U., Mela, M., & Oji, C. (2017). Knowledge of and Attitude to Mental illnesses in Nigeria: A Scoping Review. *Integrative Journal of Global Health.*

Opoku-Boateng, Y. N., Kretchy, I. A., Aryeetey, G. C., Dwomoh, D., Decker, S., Agyemang, S. A., Tozan, Y., Aikins, M., & Nonvignon, J. (2017). Economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana. *BMC Health Services Research*, *17*(Suppl 2). https://doi.org/10.1186/s12913-017-2642-0

Oshodi, Y., Adeyemi, J., Aina, O., Suleiman, T., Erinfolami, A., & Umeh, C. (2012). Burden and Psychological Effects : Caregiver Experiences in a Psychiatric Outpatient Unit in Lagos, Nigeria. *African Journal of Psychiatry*, *15*(2), 99–105. https://doi.org/10.4314/ajpsy.v15i2.13

Pan-African, S. G. (1995). *The Importance of Onchocercal Skin Disease: Report of a Multi-Country Study. Applied Field Research.*

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990a). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist*, *30*(5), 583–594.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990b). Caregiving and the Stress Process: An Overview of Concepts andTheir Measures. *The Gerontologist*, *30*(5), 583–594. https://doi.org/10.1093/geront/30.5.583

PhD Ahorlu. (n.d.).

Phillips, L. R., de Ardon, E. T., Komnenich, P., Killeen, M., & Rusinak, R. (2000). The Mexican American Caregiving Experience. *Hispanic Journal of Behavioral Sciences*, *22*(3), 296–313. https://doi.org/10.1177/0739986300223002

Pinquart, M., & Sörensen, S. (2005). Ethnic Differences in Stressors , Resources , and Psychological Outcomes of Family Caregiving: A Meta Analysis. *The Gerontologist*, *45*(1), 90–106.

Pinquart M, S. S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging.*, *18*(2), 250–267.

Pinquart Martin and Sorensen Silvia. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES, 61B*(1), 33–45.

Polak, M. ., Nowicki, G. J. ., Naylor, K. ., Piekarski, R. ., & Slusarska, B. (2022). The Prevalence of Depression Symptoms and Their Socioeconomic and Health Predictors in a Local Community with a High Deprivation: A Cross-Sectional Study. *Int. J. Environ. Res. Public Health*.

Porter, G., Hampshire, K., Kyei, P., Adjaloo, M., Rapoo, G., & Kilpatrick, K. (2008). Linkages Between Livelihood Opportunities and Refugee - Host Relations: Learning

From The Experiences of Liberian Camp-Based Refugees in Ghana. *Journal of Refugee Studies*, *21*(2), 230–252. https://doi.org/10.1093/jrs/fen015

RC, K., HS, A., & Ames M. (2006). Prevalence and Effects of Mood Disorders on Work Performance in a Nationally Representative Sample of U.S. Workers. *Am J Psychiatry*, *163*, 1561–1568.

Roberts, M., Asare, J. B., Mogan, C., Adjase, E. T., & Osei, A. (2013). *T he mental health system in Ghana* (Issue June).

Roberts, M., Mogan, C., & Asare, J. B. (2014). An overview of Ghana ' s Mental Health System : Results from an Assessment Using the World Health Organization ' s Assessment Instrument for Mental Health Systems (WHO-AIMS). *International Journal of Mental Health System*, *8*(16), 1–13. https://doi.org/10.1186/1752-4458-8-16

Robinson, E., Rodgers, B., and Butterworth, P. (2008). *Family Relationships and Mental Illness: Impacts and Service Responses*.

Rosa, A. R., Reinares, M., Michalak, E. E., Bonnin, C. M., Sole, B., Franco, C., Comes, M., Torrent, C., Kapczinski, F., & Vieta, E. (2010). Functional impairment and disability across mood states in bipolar disorder. *Value in Health*, *13*(8), 984–988. https://doi.org/10.1111/j.1524-4733.2010.00768.x

Rose, L., Mallinson, R., & Walton-Moss, B. (2002). A Grounded Theory of Families Responding to Mental Illness. *Western Journal of Nursing Research, 24*, 516–536.

Rudnick, A. (2004). Burden of Caregivers of Mentally Ill Individuals in Israel: A Family Participatory Study. *International Journal of Psychosocial Rehabilitation.*, *9*(1), 147–152.

Ruiz-Pérez, I. ., & Bermúdez-Tamayo, C.; Rodríguez-Barranco, M. (2017). Socio-economic Factors Linked with Mental Health During the Recession: A Multilevel Analysis. *Int. J. Equity. Health*, *16*(45).

Saiepour, N., Najman, J. M ., Ware, R., Baker, P., Clavarino, A. M., & Williams, G. M. (2019). Does Attrition Affect Estimates of Association: A Longitudinal Study. *Journal of Psychiatric Research*, *110*, 127-142.

Sanuade, O. A., & Boatemaa, S. (2015). Caregiver Profiles and Determinants of Caregiving Burden in Ghana. *PUBLIC H EA L T H*, *129*, 941–947.

Sato, A., Ricks, K., & Watkins, S. (1996). Needs of Caregivers of Clients With Multiple Sclerosis. *Journal of Community Health Nursing*, *13*(1).

Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review*, *27*(1), 111. https://doi.org/10.1071/AH042710111

Schofield, H., Bloch, S., Herrman, H., Murphy, B., Nankervis, J. &, & Singh, B. (1998). Family Caregivers : Disability , Illness and Aging. *Australian Journal of Social Issues*, 287–289.

Schulz, R., Mcginnis, K. A., Zhang, S., Martire, L. M., Hebert, R. S., Beach, S. R., Zdaniuk, B., Czaja, S. J., & Belle, S. H. (2008). Dementia Patient Suffering and Caregiver Depression. *Alzheimer Dis Assoc Disord*, *22*(2), 170–176. https://doi.org/10.1097/WAD.0b013e31816653cc.Dementia

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes. *The Gerontologist, Volume 3*, *35*(6), 771–791.

Seng, B. K., Luo, N., Ng, W. Y., Lim, J., Chionh, H. L., Goh, J., & Yap, P. (2010). Validity and reliability of the zarit burden interview in assessing caregiving burden. *Annals of the Academy of Medicine Singapore*, *39*(10), 759–763.

Sharma, S. (1995). *Applied Multivariate Techniques.*

Sharpe, D. (2015). *Chi-Square Test is Statistically Significant: Now What, Practical Assessment, Research, and Evaluation. 20*(8).

Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, B. A. (2008). Family caregivers and guilt in the context of cancer care. *Psychosomatics*, *49*, 511-519.

Stephens, M. A. P., Townsend, A. L., Martire, L. M., & Druley, J. A. (2001). Balancing Parent Care with Other Roles: Interrole Conflict of Adult Daughter Caregivers. *Journals of Gerontology*, *56*(1), 24–34. https://doi.org/10.1093/geronb/56.1.P24

Stetz, K. M., Brown, M., KM, S., & Brown, M. (2004). Physical and Psychosocial Health in Family Caregiving: A Comparison of AIDS and Aancer Caregivers. *Public Health Nursing*, *21*(6), 533–540. http://search.ebscohost.com/login.aspx?direct=true&db=jlh&AN=106566081&site=ehost-live%5Cnhttp://search.ebscohost.com/login.aspx?direct=true&db=jlh&AN=2005021503&site=ehost-live

Tabachnick B. G. and Fidell L. S. (2001). *Using Multivariate Statistics* (Seventh Ed).

Tawiah, P. E., Adongo, P. B., & Aikins, M. (2015a). Mental Health-Related Stigma and Discrimination In Ghana : Experience Of Patients And Their Caregivers. *Ghana Medical Journal*, *49*(1), 30–36.

Tawiah, P. E., Adongo, P. B., & Aikins, M. (2015b). Mental Health-Related Stigma and Discrimination in Ghana: Experience of Patients and Their Caregivers. *Ghana Medical Journal*, *49*(1), 30–36. https://doi.org/10.4314/gmj.v49i1.6

Teddlie, C. & Tashakkori, A. (2010). *Overview of contemporary issues in mixed methods esearch. In C. Teddlie & A. Tashakkori (Eds.), Handbook of Mixed Methods in Social and Behavioural Research* (C. Thousand Oaks (Ed.); Second Edi). SAGE Publications.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma , Explanatory Models And Unmet Needs of Caregivers of Children with Developmental Disorders in a Low-Income African Country : A Cross-Sectional Facility- Based Survey. *BMC Health Services Research*, *April*. https://doi.org/10.1186/s12913-016-1383-9

Turner, A., & Findlay, L. (2012). *Informal caregiving for seniors* (Vol. 23, Issue 3).

Unützer, J., & Park, M. (2012). Strategies to Improve the Management of Depression in Primary Care. *Primary Care - Clinics in Office Practice*, *39*(2), 415–431. https://doi.org/10.1016/j.pop.2012.03.010

van der Sanden, R. L. M., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. R. (2016). Stigma by Association and Family Burden Among Family Members of People with Mental Illness: The Mediating Role Of Coping. *Social Psychiatry and Psychiatric*

Epidemiology, *51*(9), 1233–1245. https://doi.org/10.1007/s00127-016-1256-x

Vitaliano, P. P. (1997). Physiological and Physical Concomitants of Caregiving: Introduction to Special Issue. *Annals of Behavioral Medicine : A Publication of the Society of Behavioral Medicine*, *19*(2), 75–77. https://doi.org/10.1007/BF02883322

Vitaliano, P. P., Ustundag, O., & Borson, S. (2017). Objective and Subjective Cognitive Problems among Caregivers and Matched Non-caregivers. *Gerontologist*, *57*(4), 637–647. https://doi.org/10.1093/geront/gnv690

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is Caregiving Hazardous to One's Physical Health? A Meta-Analysis. *Psychological Bulletin*, *129*(6), 946–972. https://doi.org/10.1037/0033-2909.129.6.946

Weber, A. Joseph and Fournier, G. D. (1985). Family Support and a Child ' s Adjustment to Death. *Family Relations*, *34*(1), 43–49.

Weiss, M. (1997). Explanatory Model Interview Catalogue (EMIC): FrameworK for Comparative Study of Illness. *Transcultural Psychiatry*, *34*(2), 235–263. https://doi.org/10.1177/136346159703400204

Weiss, M. G. (2001). Cultural Epidemiology: An Introduction and Overview. *Anthropology and Medicine*, *8*(1), 5–29. https://doi.org/10.1080/13648470120070980

Werner, S., & Shulman, C. (2015). Does Type of Disability Make a Difference in Affiliate Stigma Among Family Caregivers of Individuals with Autism, Intellectual Disability or Physical Disability? *Journal of Intellectual Disability Research*, *59*(3), 272–283. https://doi.org/10.1111/jir.12136

WHO. (2014). *Social Determinants of Mental Health*.

WHO. (2018). *Key Factors and Publications Concerning Schizophrenia*.

WHO (World Health Organization). (2017). *Depression and Other Common Mental Disorders: Global Health Estimates*.

Wolff, J. L., & Jacobs, B. J. (2015). Chapter 7 – Chronic Illness Trends and the Challenges to Family Caregivers: Organizational and Health System Barriers. In *Family Caregiving in the New Normal*. Elsevier Inc. https://doi.org/10.1016/B978-0-12-417046-9.00007-6

World Federation of Mental Health, (WFMH). (2010). *Caring for the caregiver: Why your mental health matters when you are caring for others*.

World Health Organisation. (2012). *Risks To Mental Health: An Overview of Vulnerabilities and Risk Factors*.

World Health Organization. (2007). *New Data on Male Circumcision and HIV Prevention : Policy and Programme Implications* (Issue March).

World Health Organization. (2013). Comprehensive Mental Health Action Plan 2013 – 2020. In *Sixty-Sixth World Health Assembly* (Issue 13.3).

Wynaden, D. (2008). The experience of caring for a person with a mental illness: A grounded theory study. *International Journal of Mental Health Nursing*, *16*.

Yamane Taro. (1967). *Statistics: An Introductory Analysis* (Second Edi). HARPER & ROW, NEW YORK.

Yates, M. E., Tennstedt, S., & Chang, B. (1999). Contributors to and Mediators of

Psychological Well-Being for Informal Caregivers. *Journal of Gerontology: Psychological Sciences*, *54B*(1), 12–22. https://doi.org/10.1093/geronb/54B.LP12

Yee, J. L., & Schulz, R. (2000). Gender Differences in Psychiatric Morbidity Among Family Caregivers : A Review and Analysis. *The Gerontologist*, *40*(2), 147–164.

Zarit, S.H., Reever, K.E., Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feeling of Burden. *Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Zegwaard, M. I., Aartsen, M. J., Cuijpers, P., & Grypdonck, M. H. (2011). Review: A conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour. *Journal of Clinical Nursing*, *20*(15–16), 2233–2258. https://doi.org/10.1111/j.1365-2702.2010.03524.x

Zwanzig, S. (1997). On L_1 norm estimators in nonlinear regression and in nonlinear errors in variables models. In Y. Dodge (Ed.), *L_1-Statistical Procedures and Related Topics*.

APPENDICES

Appendix 1: EMIC Questionnaire

The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis:

1. **Respondent Study No:**

					Date:	**Day**	**Month**	**Year**

2. **Community Name**

FUO **1**	**TISHIGGU** **2**

3. **Resp. Name:**

First	**Last**	**Resp. Age:**		**Resp. Sex:**	**M**	**F**

4. **"Is there any mentally-ill relation/patient in your home, whom you have been caring for on a regular basis for at least in the past 6 months?"**

Tick one only (highest number)

Yes **3**	**Occasional care** **2**	**No Care** **1**	**No** **0**

Narrative

____

____

4.1. **If there is any such person(s), 'What is your relationship to that person(s)?'**

Tick all that apply

Mother **1**	**Father** **2**	**Sister** **3**	**Brother** **4**	**Other specify** **5**

____

Narrative ____

____

Introduction

Thank you for agreeing to talk to me about a health problem that affects many people in this community. Before we continue, I would like to ask you a few questions about your background.

Social and Demographic Information

5. **House Number:**

					{O.B} {G.S}

6. **Religion**

1. Traditional Religion	**2. Muslim**	**3. Christian**	**4. Other: …………………**

7. **Marital status**

1. Never married	**2. Married**	**3. Separated/Divorce**	**4. Remarried**	**5. Widowed**

8. **Household Head**

Relationship:	**Self** **1**	**Spouse** **2**	**Parent** **3**	**Child** **4**	**Other(specify)** **5**	**M**

9.1 **Do you have children? Tick appropriately.**

Yes	**No**

Elders

9.2 **Children & Elders**

Sons				Daughters				
<5 Yrs		≥5 Yrs		<5 Yrs		≥5 Yrs		≥18yrs
Alive	Dead	Alive	Dead	Alive	Dead	Alive	Dead	

10. **Education:** Years

If no school: **Functional Literacy?**

No 0	Yes 1

11. **Occupation**

"What is your main source of income and livelihood?"

If married, **"What about your husband/wife, what is her/his occupation?"**

12. **Is your household income usually regular and dependable?** (Tick one only)

Yes **3**	**Possibly** **2**	**Uncertain** **1**	**No** **0**

Narrative ____

____

Introduction to vignette

I appreciate your willingness to share with me about the experiences you go through at the healing center in the course of taking care of your patient. I want to know how you feel and think about it; how it affects your health, your social life, your career and finances, and your leisure, both positively and negatively. You should know that it is about your feelings and experiences that I am interested in knowing, so please there is no right or wrong answers to the questions I will ask you. Please do not be shy to tell me what you feel or go through as a result of your care giving role at the healing center, for I know some of it can be difficult, emotional and challenging, but I assure you that it is confidential. So then let me tell you about the story/experience of a man/woman called Musah/Aisha looking after his/her mental patient at a healing center.'

MALE	FEMALE
Musah is a 45 years oldman, happily married with 3 children who are all in school. Musah is gainfully employed as a teacher, while his wife (Aisha) is a nurse at a nearby clinic. Musah does some part-time teaching to supplement his salary making him a busy person. One morning Musah wakes up to find his wife behaving abnormally with the eyes widely opened without blinks and aggressively talking to somebody that nobody sees and claiming that person wants to harm her. Musah calls for help only to be told by family elders that his wife Aisha had been possessed by spirits, and so he had to rush her to a religious healing center nearby for treatment, where they say is the right place for the illness. The wife could not eat, bath, or wear clothes by herself. From now on everything changed for Musah, he had to take care of the wife who was admitted at the healing center and the home, including sending and picking the children to and from school, and managing his two jobs as well. Musah had to divide himself among these tasks and before long he started having problems (problems with his sick wife, problems with school management over the children's school fees and lateness to school, and problems with his employers among others). Musah was now forgetful, absent minded, and temperamental with the least provocation'.	Aisha is a 35 years oldwoman, happily married with 3 children who are all in school. Aisha is gainfully employed as a nurse, while her husband (Musah) is a teacher at a nearby school. Aisha operates a chemical drugs-store in the neighbourhood to supplement her salary making her a busy person. One morning Aisha wakes up to find her husband behaving abnormally with the eyes widely opened without blinks and aggressively talking to somebody that nobody sees and claiming that person wants to harm him. Aisha calls for help only to be told by family elders that her husband Musah had been possessed by spirits, and so she had to rush him to a religious healing center nearby for treatment, where they say is the right place for the illness. The husband could not eat, bath, or wear clothes by himself. From now on everything changed for Aisha, she had to take care of the husband who was admitted at the healing center and the home, including sending and picking the children to and from school, and managing her two jobs as well. Aisha had to divide herself among these tasks and before long she started having problems (problems with her sick husband, problems with school management over the children's school fees and lateness to school, and problems with her employers among others). Aisha was now forgetful, absent minded, and temperamental with the least provocation'.

13. **Name of Problem**

"What do you think is the problem with your patient (Musah/Aisha), how do you call it in your language?"

Specify name, summary term, or short description in the patient's words.

Narrative ____

____

		Yes	No
Specify exact term used: ________________	Identified as mental illness?	1	0

13.1 **Typical symptoms**

"What are the most typical symptoms that affect people like Musah/Aisha with this condition?"

Narrative ____

____

13.2 Tick appropriately about the illness diagnosis from hospital.

What is their illness/condition?	
1	Schizophrenia
2	Paranoid disorders
3	Depression
4	Anxiety disorders
5	Panic disorders
6	Eating disorders
7	Others

14. **Effect on you (family caregiver)**

"How does Musah/Aisha's condition affects you as a family caregiver, does it create any problem for you? What kind of problem?"

Narrative ____

____

____

____

Tick the cells for physical, psychological, social, or financial problems based on the respondent's account.

Effect on Family Caregiver
1. Loss of income
2. Sadness, anxiety or worry
3. Concern about course of illness
4 Disbelief, shock
5 Confusion, grief, denial
6 Guilt/anger
7 Despair
8 Exhaustion
9 Lack of confidence
10 Depression
11 Frustration
12 Lack of sleep
13 Searching for cure

14.1. **Most troubling problem for you (family caregiver)**

''What is the single most troubling problem for you as caregiver?"

Code single most troubling symptom problem for the family from the above list of effect on family ☐

15. **Perceived Seriousness**

"Do you think this is a serious problem?" 'How serious is your condition?'

Usually fatal	**Sometimes fatal**	**Serious but not fatal**	**Cannot say**	**Not serious**
4	**3**	**2**	**1**	**0**

Narrative ____________________

____

____

16. **Open-Ended Query**

''We would like to know what you think may be the cause(s) of your mentally-ill patient's problem. Each of us may explain health problems in various ways. I would like to know what you think has caused Musah/Aisha's condition?''

Summarize respondent's ideas about cause in the respondent's own words (first-person account).

Narrative ____________________

____

____

Continue by probing for any perceived causes not yet mentioned from the major subgroups listed below. Screening each item, mark additional perceived causes reported in response to "probe".

Perceived Cause	
1	Possessed by evil spirits
2	Self-inflicted
3	Chemical imbalances in brain
4	Witchcraft
5	God's creation
6	Evil eyes or sorcery/charm
7	Severe, prolonged stress
8	Personality and past experience
9	Other

16.1 **Most Important Perceived Cause**

If respondent has mentioned more than one cause of the problem, inquire further:

"Which of these causes that you have mentioned (or perhaps something else) do you now consider the most important cause of Musah/Aisha's problem?"

Code single most important perceived cause from the above list of perceived causes ☐

Narrative ____

____

____

17. **Absence from work or school:**

"Do you think that it will be necessary for someone in Musah/Aisha's family to stay away from work or school to take care of Musah/Aisha''?

Yes **2**	**Possibly** **1**	**No** **0**

Narrative ____

____

____

18. **If yes or possibly, "who is that person likely to be?''**

Mother **1**	**Father** **2**	**Sister** **3**	**Brother** **4**	**Other specify** **5**

19. **Stigma and discrimination**

"During the past 4 weeks, how concerned have you been about people treating you differently because of the illness/condition of your mentally-ill patient".

Narrative ____

20. **Positive care giving experiences**
During the past month, how often have you felt satisfied or happy about caring for a mentally-ill patient?

Narrative ____

21. **Your own safety**
During the past 4 weeks how concerned have you been accidentally doing something that puts you at risk (e.g. smoking/taking drugs)?

Narrative ____

22. **The safety of the person you cared for**
During the past 4 weeks how concerned have you been about your patient relapsing or deteriorating, such that it puts their safety at risk?

Narrative ____

23. **For each of the following sources of home remedy, mark either considered effective, uncertain or ineffective**

Help Seeking	
1	Leftover drugs available at home
2	Leftover Chloroquine & other antimalarials at home
3	Drug/chemical shops to purchase drugs
4	Home prepared herbal medications for drinking
5	Home prepared herbal medications given as enema
6	Home prepared herbal medications for bathing
7	Home prepared herbal medications for other uses
8	Showering/bathing with ordinary cold water
9	Other Actions
10	Cannot say/Don't know

24. **Prevention and Control**

‘‘Do you think that Musah/Aisha’s condition could have been prevented or controlled? Could anything have been done so that your patient would not have had this problem?”

Tick one only

Yes **3**	**Possibly** **2**	**Uncertain** **1**	**No** **0**

Narrative

24.1. **‘‘Can anything be done so that other people in this village will not have this problem? Tell me about what could be done”**

Tick one only

Yes **3**	**Possibly** **2**	**Uncertain** **1**	**No** **0**

Narrative

25. **Concluding advice from respondent**

“Is there anything else you can tell me about this condition from your experience? Any further comments, advice, or suggestions will be appreciated?’’

Narrative

Interviewer:

Rater:

Interviewer Signature:

Rater Signature:

Interview Date: ☐ ☐ ☐ **Day/Month/Year**

Additional Comments

Notes concerning subject's interest and the quality of the interview. Include any noteworthy features and details of this interview

The Zarit Burden Interview

0 : NEVER
1 : RARELY
2 : SOMETIMES
3 : QUITE FREQUENTLY
4 : NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question		Score
1	Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4	Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5	Do you feel angry when you are around your relative?	0 1 2 3 4
6	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7	Are you afraid what the future holds for your relative?	0 1 2 3 4
8	Do you feel your relative is dependent on you?	0 1 2 3 4
9	Do you feel strained when you are around your relative?	0 1 2 3 4
10	Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11	Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12	Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Question		**Score**
13	Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15	Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16	Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17	Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18	Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19	Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20	Do you feel you should be doing more for your relative?	0 1 2 3 4
21	Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22	Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Patient last name: . . . . Date of birth: . . . . / . . . . / . . . .
Patient first name: . . . . Date: . . . . / . . . . / . . . .

GENERAL HEALTH QUESTIONNAIRE

GHQ-12

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1 -	**been able to concentrate on whatever you're doing?**	Better than usual	Same as usual	Less than usual	Much less than usual
2 -	**lost much sleep over worry?**	Not at all	No more than usual	Rather more than usual	Much more than usual
3 -	**felt that you are playing a useful part in things?**	More so than usual	Same as usual	Less useful than usual	Much less useful
4 -	**felt capable of making decisions about things?**	More so than usual	Same as usual	Less so than usual	Much less capable
5 -	**felt constantly under strain?**	Not at all	No more than usual	Rather more than usual	Much more than usual
6 -	**felt you couldn't overcome your difficulties?**	Not at all	No more than usual	Rather more than usual	Much more than usual
7 -	**been able to enjoy your normal day-to-day activities?**	More so than usual	Same as usual	Less so than usual	Much less than usual
8 -	**been able to face up to your problems?**	More so than usual	Same as usual	Less able than usual	Much less able
9 -	**been feeling unhappy and depressed?**	Not at all	No more than usual	Rather more than usual	Much more than usual
10 -	**been losing confidence in yourself?**	Not at all	No more than usual	Rather more than usual	Much more than usual
11 -	**been thinking of yourself as a worthless person?**	Not at all	No more than usual	Rather more than usual	Much more than usual
12 -	**been feeling reasonably happy, all things considered?**	More so than usual	About same as usual	Less so than usual	Much less than usual

Appendix 4: Family Stigma Scale (FSS)

Questions about your family and your mentally ill relative

Can you please tell me whether any of the following things have happened to you since your relative developed the problem?

Question	**Score**			
	Not at all (0)	**Sometimes (1)**	**Often (2)**	**A lot (3)**
1. Worried about being treated differently?	0	1	2	3
2. Worried other people would find out about it?	0	1	2	3
3. Felt the need to hide this problem from people (i.e. that your relative has problems)?	0	1	2	3
4. Helping other people to understand what it is like to have a family member with psychiatric problem?	0	1	2	3
5. Have you made an effort to keep this problem a secret?	0	1	2	3
6. Worried about being avoided by friends and neighbours?	0	1	2	3
7. Explaining to others that your relative isn't like their picture of "Crazy" people?	0	1	2	3
8. Worried that people would blame you for his or her problems?	0	1	2	3
9. Worried that a person looking to marry would be reluctant to marry into/from your family?	0	1	2	3
10. Worried about taking him or her out?	0	1	2	3
11. Felt ashamed or embarrassed about it?	0	1	2	3
12. Sought out people who also have relatives with similar health problems?	0	1	2	3
13. Felt grief or depression because of it?	0	1	2	3
14. Felt that somehow it might be your fault?	0	1	2	3

Appendix 5: In-depth Interview Question Guide

1. What is the problem with your relative? (mother/father/son/daughter)
   - How long has he/she been living with the condition?
   - What difficulties if any does it pose to you?
   - Can you describe your caregiving role to him in a day and how long?

2. What do you think is the cause of the problem?
   - How will you feel discussing the condition with other family members?
   - How will you feel discussing the condition with friends or neighbours?

3. How long have you been caring for your relative?
   - What are your needs/challenges as a caregiver?

4. What do you think the sickness does to you?
   - What motivates you to continue to give care to your relative in spite of the difficulties that you face?

5. How serious is the sickness?
   - Will it have a short or long life course?
   - How will it affect your life whether short/long term?

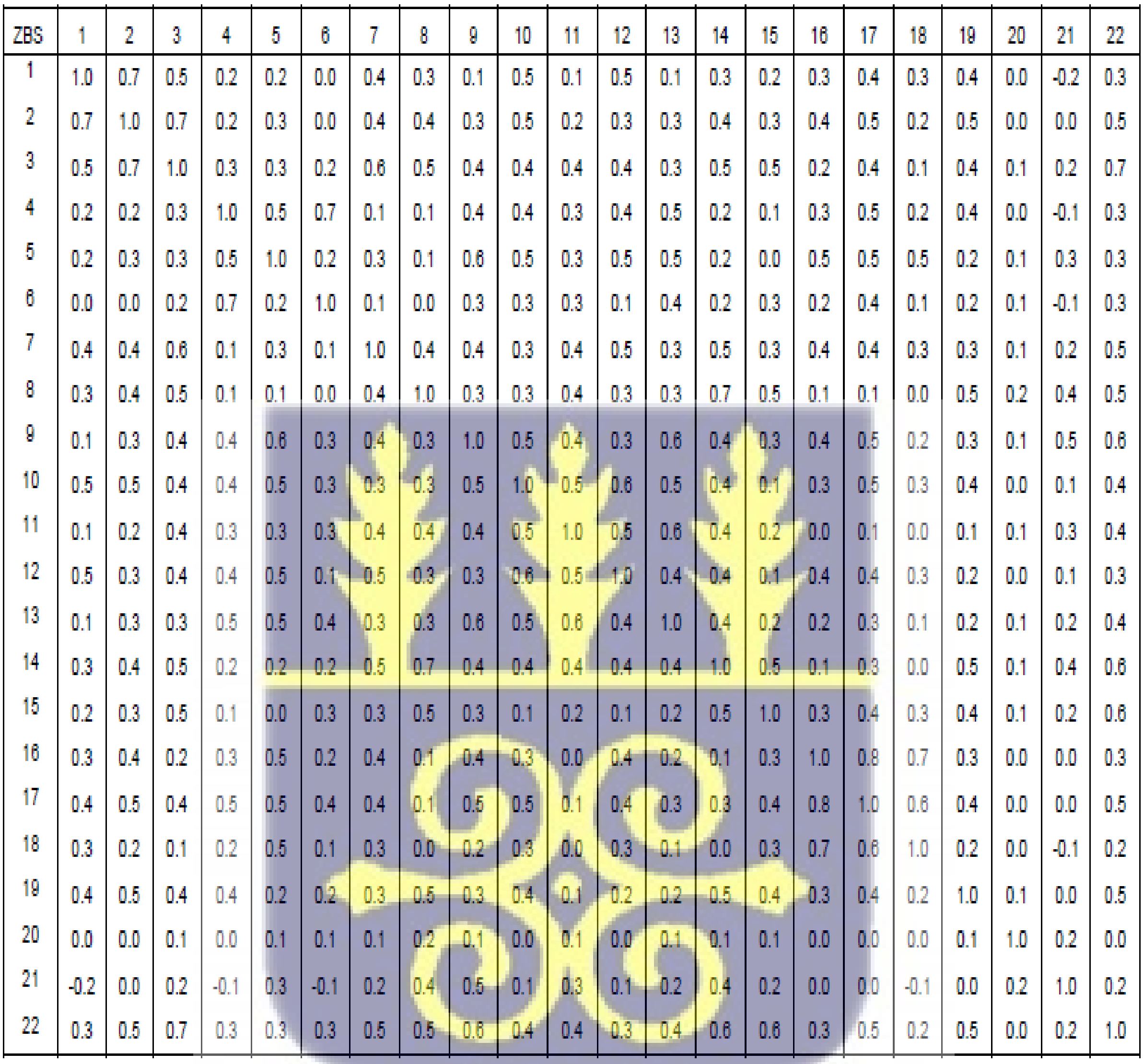
6. What kind of treatment do you think you should receive?
   - What kind of support do you need from government?
   - What kind of support do you receive from family members?
   - What kind of support do you receive from community members?

7. What are the chief problems the sickness has caused you?
   - Has anybody from the community related to you negatively as a result of your relative's condition? And how do you feel about that?
   - What are the chief problems the sickness has caused the family?

8. What do you fear most about the sickness?
   - Happening to him or to family members?

Appendix 6: Zarit Burden Scale Correlation Matrix

Table B1: Zarit Burden Scale (ZBS) Correlation Matrix



ZBS	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
1	1.0	0.7	0.5	0.2	0.2	0.0	0.4	0.3	0.1	0.5	0.1	0.5	0.1	0.3	0.2	0.3	0.4	0.3	0.4	0.0	-0.2	0.3
2	0.7	1.0	0.7	0.2	0.3	0.0	0.4	0.4	0.3	0.5	0.2	0.3	0.3	0.4	0.3	0.4	0.5	0.2	0.5	0.0	0.0	0.5
3	0.5	0.7	1.0	0.3	0.3	0.2	0.6	0.5	0.4	0.4	0.4	0.4	0.3	0.5	0.5	0.2	0.4	0.1	0.4	0.1	0.2	0.7
4	0.2	0.2	0.3	1.0	0.5	0.7	0.1	0.1	0.4	0.4	0.3	0.4	0.5	0.2	0.1	0.3	0.5	0.2	0.4	0.0	-0.1	0.3
5	0.2	0.3	0.3	0.5	1.0	0.2	0.3	0.1	0.6	0.5	0.3	0.5	0.5	0.2	0.0	0.5	0.5	0.5	0.2	0.1	0.3	0.3
6	0.0	0.0	0.2	0.7	0.2	1.0	0.1	0.0	0.3	0.3	0.3	0.1	0.4	0.2	0.3	0.2	0.4	0.1	0.2	0.1	-0.1	0.3
7	0.4	0.4	0.6	0.1	0.3	0.1	1.0	0.4	0.4	0.3	0.4	0.5	0.3	0.5	0.3	0.4	0.4	0.3	0.3	0.1	0.2	0.5
8	0.3	0.4	0.5	0.1	0.1	0.0	0.4	1.0	0.3	0.3	0.4	0.3	0.3	0.7	0.5	0.1	0.1	0.0	0.5	0.2	0.4	0.5
9	0.1	0.3	0.4	0.4	0.6	0.3	0.4	0.3	1.0	0.5	0.4	0.3	0.6	0.4	0.3	0.4	0.5	0.2	0.3	0.1	0.5	0.6
10	0.5	0.5	0.4	0.4	0.5	0.3	0.3	0.3	0.5	1.0	0.5	0.6	0.5	0.4	0.1	0.3	0.5	0.3	0.4	0.0	0.1	0.4
11	0.1	0.2	0.4	0.3	0.3	0.3	0.4	0.4	0.4	0.5	1.0	0.5	0.6	0.4	0.2	0.0	0.1	0.0	0.1	0.1	0.3	0.4
12	0.5	0.3	0.4	0.4	0.5	0.1	0.5	0.3	0.3	0.6	0.5	1.0	0.4	0.4	0.1	0.4	0.4	0.3	0.2	0.0	0.1	0.3
13	0.1	0.3	0.3	0.5	0.5	0.4	0.3	0.3	0.6	0.5	0.6	0.4	1.0	0.4	0.2	0.2	0.3	0.1	0.2	0.1	0.2	0.4
14	0.3	0.4	0.5	0.2	0.2	0.2	0.5	0.7	0.4	0.4	0.4	0.4	0.4	1.0	0.5	0.1	0.3	0.0	0.5	0.1	0.4	0.6
15	0.2	0.3	0.5	0.1	0.0	0.3	0.3	0.5	0.3	0.1	0.2	0.1	0.2	0.5	1.0	0.3	0.4	0.3	0.4	0.1	0.2	0.6
16	0.3	0.4	0.2	0.3	0.5	0.2	0.4	0.1	0.4	0.3	0.0	0.4	0.2	0.1	0.3	1.0	0.8	0.7	0.3	0.0	0.0	0.3
17	0.4	0.5	0.4	0.5	0.5	0.4	0.4	0.1	0.5	0.5	0.1	0.4	0.3	0.3	0.4	0.8	1.0	0.6	0.4	0.0	0.0	0.5
18	0.3	0.2	0.1	0.2	0.5	0.1	0.3	0.0	0.2	0.3	0.0	0.3	0.1	0.0	0.3	0.7	0.6	1.0	0.2	0.0	-0.1	0.2
19	0.4	0.5	0.4	0.4	0.2	0.2	0.3	0.5	0.3	0.4	0.1	0.2	0.2	0.5	0.4	0.3	0.4	0.2	1.0	0.1	0.0	0.5
20	0.0	0.0	0.1	0.0	0.1	0.1	0.1	0.2	0.1	0.0	0.1	0.0	0.1	0.1	0.1	0.0	0.0	0.0	0.1	1.0	0.2	0.0
21	-0.2	0.0	0.2	-0.1	0.3	-0.1	0.2	0.4	0.5	0.1	0.3	0.1	0.2	0.4	0.2	0.0	0.0	-0.1	0.0	0.2	1.0	0.2
22	0.3	0.5	0.7	0.3	0.3	0.3	0.5	0.5	0.6	0.4	0.4	0.3	0.4	0.6	0.6	0.3	0.5	0.2	0.5	0.0	0.2	1.0

Appendix 7: Interview Transcripts of Key Informants

Case Study Transcription 1

Study Title: The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis
Method: EMIC IDI's
Category: Primary Caregiver Interview (26 year old Daughter)
Region: Northern
District: Tamale Metropolis
Rural/Urban: Urban
Language of Discussion: English
Moderator: Adam Yussif Hamdan
Note-Taker: Eckow
Transcriber: Adam Yussif Hamdan
Date Conducted: 05/15/2019
Date Transcribed: 05/16/ 2019
Length of Discussion (minutes):
Number of Participants: 1
Location/Venue of interview: Prayer camp

Key:
M=Moderator
P= Participant

M: Permit me to engage you in a discussion and questions about your relative
P: You are welcome, go ahead please
M: How are you related to the patient?
P: She is my biological mother
M: What is the problem with your mother?
P: The problem is that I don't know whether it's both physical and spiritual or what, but I know it to be spiritual. Because first she was saying that she can see a man wearing white

gown and telling her that if she ate the food the spirit will kill her. So this is what caused her mental problems.

M: And who is that man that she is talking about?
P: Nobody sees him, she is the only person seeing him, and maybe that is a spirit
M: How does she behave when the spirit comes to her?
P: When it comes like that she is not feeling comfortable, she will be shouting and insulting people.
M: How long has she been living with the condition?
P: It's a long time, since 2014
M: How old is your mother?
P: For her age I don't know
M: Are you the only child?
P: No, we are 2 myself and my younger brother.
M: And how old are you (yourself)?
P: I am 26 years old now.
M: Can you describe your caregiving role to your mother in a day?
P: In the morning I give her food and her medication, clean the room and also wash her clothing, and any other thing she wants me to do for her.

M: What about bathing?
P: As for bathing she is able to do it herself unless it is critical
M: The way your mother is lying down, what is happening?
P: Well, she is just resting
M: What about the other patients in the camp, are they suffering from the same health condition like your mother?

P: No, everybody and his or her problem. Some people came here with similar health conditions but they got their healing and they are gone

M: How will you feel discussing your mother's health condition with outsiders or even friends?

P: Oh, no problem for those who care about us, but for outsiders and friends I can't discuss with them because it's embarrassing and they will call you names. No I can't even for some family members I will not.

M: Why can't you discuss it with your friends and some family members?

P: Well, it is sickness and I can't be discussing the way my mother has been behaving or beating and insulting me to others. It is embarrassing to do so.

M: Does your mother beat you and for what?

P: When she relapse, she can be very violent, she will be hitting me, insulting me, and accusing me that I'm a prostitute. And she thinks you are the cause of her problems.

M: Do you think your mothers' sickness is serious?

P: Yes, it is very serious, sometimes she is restless, she can't sleep, she won't eat and accusing me of poisoning the food and she grows very lean and that worries me a lot. And when you want to force her small, she will be insulting you and calling names like "ashawoo", and even at the hospital she will be insulting the nurses and doctors, and this can be very embarrassing to me.)

M: What kind of treatment do you think your mother needs?

P: Well, at first when the sickness started, we send her to the mallam people for treatment, but after sometime we came to the hospital for treatment, but now we are using the hospital medication and the prayer camp. That I think is ok.

M: What problems has your mothers' sickness caused you?

P: Well, it has caused me a lot because when I was in school, I was always thinking about my mothers' sickness and so I could not concentrate on my studies and so I failed my BECE and

I couldn't continue my education. And now money problem and cost of the medication, the problems are so many and there is nobody to help.

M: Do you have work?

P: Yes I'm a cleaner at the prayer camp, but the pay is not enough to take care of me and my mother

M: What problems and challenges do you have?

P: Well, financial problems, food and medicine to take care of my mother

M: What do you fear most about your mother's sickness?
P: Well, I think death

M: Can this kind of sickness cause death?
P: Yes because, my mother could be thinking that her family have neglected her both her husband side and her father and mother side have all neglected her, and so she can think ahh and contemplate taking poison to end her life and the suffering.

M: Why do you continue to take care of her when other family members have neglected her?
P: Well, she is my mother, the one only, she gave birth to me and took care of me when she was well. When my father died I didn't worry that much because he didn't take care of me. But if my mother dies I will feel it so much because who will I call my mother?

Case Study Transcription 2

Study Title: The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis

Method: EMIC IDI's

Category: Primary Caregiver Interview (27-year-old Mother)

Region: Northern

District: Tamale Metropolis

Rural/Urban: Urban

Language of Discussion: Dagbanli

Moderator: Adam Yussif Hamdan

Note-Taker: Eckow

Transcriber: Adam Yussif Hamdan

Date Conducted: 05/15/2019

Date Transcribed: 05/16/ 2019

Length of Discussion (minutes):

Number of Participants: 1

Location/Venue of interview: Work place (Store)

Key:

M=Moderator

P= Participant

M: Permit me to engage you in a discussion and questions about your relative

P: You are welcome, go ahead please

M: How are you related to the patient?

P: She is my biological mother

M: How old is your mother?

P: She should be over 50 years old

M: And how old are you (yourself)?

P: I am 27 years old now.

M: What is the problem with your mother?

P: She is suffering from mental illness

M: How long has she been living with the condition?

P: It's a long time, that's about 13 years now

M: What do you think is the cause of the problem?

P: It's frustration. She started having problems with her husband (my step father) who was abusing her physically and psychologically which ended in a divorce at a time my mother was not prepared for. That is what caused her problem because we don't have it in our family and we have never known our mother with this kind of problem until she got married again after my father's death.

M: What kind of abuse do you mean?

P: I mean physical molestation and beating and womanizing and neglect all combined

M: What difficulties does it pose to her?

P: It is characterized by restlessness, lack of sleep, hallucination, abusive and violence. With the least challenge she will hit you if you are standing close by

M: You said she has been living with the condition for 13 years now, so what have you been doing with her until now?

P: Well, we used to live in Accra then, so we send her to Accra psychiatric hospital then for attention where she was diagnosed with the condition for the first time. And so they treated her and gave some medication, and due to non-adherence and abuse she relapse several times until we relocated to Tamale.

M: Can you describe your caregiving role in a typical day?

P: In the morning I give her food and her medication, clean the room and also wash her clothing, and any other thing she wants me to do for her in addition to taking care of her baby. In addition to caring for my own children and the house chores as well. That is very difficult to do, you know (Sobbing in tears).

M: How will you feel discussing your mothers' situation with other family members and friends especially?

P: I could easily discuss my mothers' situation with family members if they were caring, but they have simply abandoned her completely, so there is no point. As for my friends and this type of condition, it is difficult and I simply can't.

M: Why not your friends please?

P: It is difficult because of the back biting they will do about me and my mother and a whole lot of things. How can I just tell my friends or even outsiders that my mother smoke weed, take alcohol or abuse drugs, or even lives in the forest? That's stigmatizing and it will live with me and my children forever, I can't do that.

M: Does your mother live at the forest and abuse drugs?

P: Unfortunately, yes (uncontrolled sobbing and tears running following response), she abandoned home and run into the forest claiming she wants to live alone and not at the family house any longer. And you know at the forest there is no control, and I am married with children in my matrilineal home and I can't keep tracking her and so gradually we are losing control.

M: Sorry about that, but what do you think can be done?

P: Well, I don't know but I have been thinking of sending her to the traditional healers where they could mechanically restrain her with chains so that this loitering about could stop for we no longer know what to do with her.

M: Does that condition have short or long time course?

P: I think it has a short time course only if we had the money to send her back to Accra psychiatric hospital where she will be admitted and treated, but it all takes money to do so, but we don't have the money.

M: How does her condition affect your life?

P: It affects me so much ranging from my finances to my health, my time, and even threatening my marriage because sometimes it leads to family feud between my husband and I over lack of quality time for the children. When I wasn't married it was a bit better than now with all the children and husband, and work, and my sick mother all competing for that one time I have. That's so difficult for me, I can't concentrate and easily get confused over simple things and very forgetful these days. The last time I was sending my daughter to school and travelled for long on a wrong cause until my daughter asked me "mama where are we going before it dawned on me that I had taken the wrong course unknowingly".

M: What kind of support do you need?
P: Any form of support that will reinstall my mother's health is all I pray for so that I can have my own life back on course, there is hardly any passing day that I can be happy and have peace of mind without thinking of my mother. That is my prayer for people everywhere with these types of conditions, for we are suffering so much. It will help us if NHIS can cover the drugs too, so government should help us.

M: What do you fear most about your mother's condition?
P: I have so many fears, now that she has run from home and living in the forest, anybody could do anything to her like rape or even murder, or even to strip her cloth off for everybody to see her nakedness. In fact, she has been raped and impregnated before and the resulting issue is at the orphanage at Nyohini, those are the fears that I can speak to you about, but there are other big fears I cannot mention to you.

Case Study Transcription 3

Study Title: The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis

Method: EMIC IDI's

Category: Primary Caregiver Interview (56 year old Mother)

Region: Northern

District: Tamale Metropolis

Rural/Urban: Urban

Language of Discussion: English

Moderator: Adam Yussif Hamdan

Note-Taker: Eckow

Transcriber: Adam Yussif Hamdan

Date Conducted: 05/15/2019

Date Transcribed: 05/16/ 2019

Length of Discussion (minutes):

Number of Participants: 1

Location/Venue of interview: Work place (Hospital Facility)

Key:

M=Moderator

P= Participant

M: Permit me to engage you in a discussion and questions about your relative

P: You are welcome, go ahead please

M: How are you related to the patient?

P: She is my daughter

M: how old is she?

P: She is now 28 years

M: How old are you yourself as the mother?

P: I am 56 years old

M: What is the problem with her?

P: Well, she is suffering from psychosis

M: How long has she been living with the condition?

P: About 6 year's now

M: What difficulties or challenges does her condition pose to her?

P: At times she sits down and be complaining to me that now she cannot do anything for herself, and she keeps questioning me whether she can do something. So she is just out of everything, she cannot go to school, she cannot get any work, she cannot get a husband to marry, and is she_always going to be with me? And I say no, you can still go to school if it is better, and you can still marry if they understand you, and the government can still employ you with this, because if you are taking the drugs you will be fine and if you are fine you will be able to go back to school. And so I also explain to her like that and she will look happy.

M: So can you describe your typical role as caregiver when the condition relapse?

P: Whenever she relapses, she refuses to eat food and she is very abusive and violent, and so it is difficult to control her. So I usually will lock her up in the room and be with her myself in the room to force her or persuade her to take food, otherwise she will run away and starve at her hiding place. If left unattended she will run to a far place which will take us several days to find her at her hideout. So for the whole period during her relapse I will always be with her without losing guard otherwise she can harm herself, and persuading/forcing her to eat and to administer her drugs to her and cleaning her up all by myself and sometimes with the help of the brother.

M: And how long does this usually take?

P: Eh when she relapses it can time, sometimes up to 2 weeks or more before she feels better. The last time she relapsed she didn't eat for 13 days and she will grow very lean and she will also refuse to take her medication, sometimes too, we have to look for a car to transport her to the clinic for the injections to calm her down, and whenever this happens she will be sleeping all the time.

M: So what do you think is the cause of the problem?

P: I think it's all God, or what am I going to say, because with her case it was after laparotomy, one week after her laparotomy that she had the case.

M: What is laparotomy?

P: She had operation, they said she had ovarian cyst, she was bleeding and then with severe abdominal pains, so they discharged us 3 days after the operation and said everything was ok. But 7 days after the discharge from the hospital that she started hallucinating and insulting everybody, refused to eat, and behaving violently. Some few days' time she run to Bimbilla with the sores to her pastor and loitering about in Bimbilla town.

M: But why Bimbilla, does she have any relations there?
P: Yes we have lived there before, I have been married there before. So when she disappeared we were asking around until we got the information that she was at Bimbilla, and so we hired a car to Bimbilla to transport her back to Tamale again and to the Tamale Teaching Hospital where they referred us to the psychiatric unit of the Tamale Central Hospital where the condition was diagnosed. Before she relapses she will stop taking the drugs, she will say she is now ok. And whenever she goes to church and the pastor is preaching "you are healed.in Jesus name nothing will happen to again, you are healed in Jesus name nothing will happen to you again", she will take it that she won't take the drugs again, I'm healed, and she will by all means relapse. But if she is taking the drugs she will be the best person, she likes people, she likes reading, she cooks, she will do everything, and there is nothing she can't do. And even she teaches her junior brothers and the sisters, but immediately she relapses eh.

M: How will you feel discussing her condition with other family members or friends?
P: To discuss it with them, well sometimes they ask of her and I tell them that she is fine but not fine, my senior brothers and sisters for instance, I tell them she is not well. Sometimes they visit us and she will refuse talking to them and everybody will be weeping. And I tell them they should go, it will be ok, I will take care.

M: That is your side of the family, what about her father's side?
P: Hmm, hmm, her father's side, at times she will relapse and I will be struggling with her and if I tell the father he says he has no money to come, but at times too he will come, and if he comes too he won't give us anything. I am the only one suffering with her, even the last time she relapsed she refused to eat for 13 days, and when she started eating and gained strength small she run to the father. And the father has a wife, we divorced, I divorced with the father, they are 3 in number but the father left all of them for me and so I'm doing

everything for them, even the children themselves can swear that we never wear our father's chalewati or uniform to school. But some of them are gainfully employed now, so at times they tell me that they want to visit their father and I tell them they can go and say hello: so she also run there and her father's wife refused to give her food, no food for her and wouldn't allow her to sleep in her room but instead kept her in the kitchen. Ah so I called them and made a follow up, at times I buy the drugs and send it to them, and if I tell the father to buy the drugs he always complains that he has no money but the girl also refused to come to me because I'm forcing her to take the drugs. So at times I buy the drugs go and hide somewhere and call the father to come for the drugs, and at times she will take the drugs from the father, she was taking it small, small until one day she complained of rips pains. She couldn't eat again, she couldn't stand and she can't do anything and so the father quickly…, so I called them and said they should give the phone to her which they did, I greeted her and asked if she wanted to come back to me and she agreed. Because I looked at where they went and kept her, her room it is a kitchen, they even cook inside and what and what and what, so she cannot be there like that and at times the father's wife refuse to give her food, and so finally the father brought her back to me, so she became fine now, she is better with the drugs.

M: So this kind of problem, how do you feel your neighborhood and friends knowing about it?

P: Hmm I don't want them to know really because of the stigma, some of them if they know it that way they point fingers at her and some of them too they will say eh Ajara's daughter she is mad so they don't want to come to her again if they come she will wound them, at times even their children they stop them from coming to my children to play that if they come the girl will wound them. But she is not that type, she just sees somebody and then be wounding that person, so the stigma is there.

M: The father has denied her but you continue to provide care to her, what is your motivation?

P: Ehh because she is my daughter, she is my daughter, I became pregnant carried the pregnancy from day one to 9 months, delivered her, took care of her even to secondary school and she completed SHS. It was only mathematics problem that she had and she said she wanted to register and do that and this problem happened, so she couldn't do anything again, she has only maths problem and she is in the house with me, and so because of that I can't say I won't take care of her. If I refuse to take care of her, if the father has refused and I also refuse where is she going? So me I pity her and I can never even refuse to take care of her because posterity will not spare me and the law of Karma will haunt me even generations after me. So I have to accept my responsibility and my duty to care for her.

M: Do you think it is a serious problem?
P: Yes, it is serious.

M: Do you think it has a short or long term course?
P: In my estimation because she has now started taking the drugs, she is now taking it herself even if I have forgotten to say she should take it, she will tell me that oh have taken the drugs, so just put it here I will know where it is, if I want I will take it. So she is now better, so I think with the drugs she will be healed, I don't think she will be with this forever and ever.

M: So do you think the drugs is enough or you need other alternative medicines to support her?
P: Hmm, the drugs she is taking I think is ok for her because she is getting better with the drugs, now that she start to ask me she want work to do, she wants to do some trade, m hmm, that is my problem now. And she is not the only one, they are 6 in number, 3 from one father and 3 from another man.

M: What about the other father/step father how is he taking it?
P: He is taking care of his children, he takes care small, not all.

M: Does he see it as a burden?
P: Hmm, yes

M: Does he talk in some ways and you see it and feel it?
P: Oh no, if he doesn't have he always say oh I don't have this but time to come they should come, so if they go there he always gives them some yams, he is a farmer, some food stuffs and give them some GHS100 [some giggles] to come. And where we are we always border truck in & out to their school, you know Vittin barrier there and then SDA School that is

where they come. But only GHS 100 can it do for a full term? But I take it that that is my luck so I'm prepared to take care of them, or if somebody can help me.

M: What is the biggest problem that her sickness has caused you?
P: Hmm, it has caused me my financial problems, stigma is there, she is always complaining to me I can't do work, I can't marry, I can't do what and what and what, she is always complaining, at times she complains and be weeping and I also will be weeping. So really it is in my heart, it is disturbing me really; and I also brought her up to go to school and she went to the school half way, really there is no work for her to do now at the moment, so it disturbs me and she is grown.

M: So what do you fear most about her condition?
P: The relapsing that I don't want it to come, the relapsing is my problem, if she is not relapsed it is better; and one thing too if she takes the drugs she will sleep ahhh even she can decide to sleep from ehh 8 o'clock in the night till 10 o'clock in the morning or even 11 o'clock, so that thing disturbs me. At times I will wake her up she will get up and look at me like this and say ehh mama let me sleep small and lie down again, it's the drugs and so everything in the house I have to do it. She would have helped but because of that, at times I will leave her and at times I will force her to get up and do it; at times if you force her she will wake up and be sleeping and doing, sleeping and doing [giggles].

M: What kind of support will you need from government?
P: Me, now that my daughter is getting better with the help of the drugs, I want the government to get some work for her so that she will also be doing small, small, because if she is taking the drugs there is no any relapsing and because she is always lying in the room doing nothing she also thinks and that is why she always questions me, so I won't do any work? I have nothing to do? So me I just came to the world like that? I can't help you? I can't get something for myself? She will be complaining and I'm also worried, so to me I want the government to help and then get some work for her to also be doing and it will help me too, because at times you won't get the drugs, you have to buy. The government should also make NHIS to cover all psychiatric drugs to help us, because the drugs are expensive.

M: The last time did you say she has a daughter?

P: Yes, somebody impregnated her and she delivered that child, the one who impregnated her too is also poor like me [giggles]. When I asked him to take care of her, he came and knelt down and beg me that he had nothing and I tried to make the girl to go and stay with him, when the girl went the following day she couldn't even get food to eat so my daughter came back to me. And the man also came that Mama I beg you it's just a mistake but take care of her for me, I have nothing and if I say she should come and stay with us we will all be suffering because she can fall sick and she won't get to eat but if it is me alone even if I go to friends and they are eating I can also put my hands or something like that. So I took care of her ahhh she delivered they did cesarean section, she was a baby girl. So when the girl was 2 years she relapse again, I was carrying this girl up & down, I was backing the girl and doing everything for the girl. I will buy clothing for the girl and buy for my daughter too, everything I'm doing, and up till now the boy is not doing anything, but the boy rather came and took the child to the sister at Accra without my notice. So it's these days that I became serious, that they saw that I became serious that I will come there see where they are and if I see that they cannot take care of the child, I will bring the child home, I will suffer it no problem.

M: But how did they get the child was she not living with you?

P: She was living with me, but at times the father will come and take the child at the time the mother was better, at times she relapsed and at times she became fine, so at time he took the child to his house and they will sleep together, get up and bath the child, feed the child and bring her back. So when he came I thought it is like that, and he took the child 2 days I called this boy is not picking me, 1 week I searched for him but I couldn't get him and even up to 2 good months I was crying going round and not knowing what to do. But when he eventually picked my call he said he had sent the child to the sister, and that the sister was in Tamale town and that he will come and send me to the place to see where the child is. And I said did I say I cannot take care of the child after 2 years, how can somebody take care of your child like that for you, I used to back the child to work and at my work side they are my witness. But the child is still with them in Accra.

Case Study Transcription 4

Study Title: The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis

Method: EMIC IDI's

Category: Primary Caregiver Interview (45 year old Mother)

Region: Northern

District: Tamale Metropolis

Rural/Urban: Urban

Language of Discussion: Dagbanli

Moderator: Adam Yussif Hamdan

Note-Taker: Eckow

Transcriber: Adam Yussif Hamdan

Date Conducted: 05/15/2019

Date Transcribed: 05/16/ 2019

Length of Discussion (minutes):

Number of Participants: 1

Location/Venue of interview: (Home Nyohini)

Key:

M=Moderator

P= Participant

M: Permit me to engage you in a discussion and questions about your relative

P: You are welcome, go ahead please

M: How are you related to the patient?

P: She is my daughter

M: What is the problem with your daughter?

P: As for this problem if not God nobody can really tell exactly what it is. In fact it all started one rainy day when our daughter got soaked in the rain and refused to get out of the rain and behaving strangely in a bizarre manner experiencing auditory and visual hallucinations. We quickly rushed her to a traditional healer at Gumani when it was still raining heavily and this was at midnight. The traditional healer attended to us with my daughter verbally abusing him with all manner of insults and we finally left for home with little changes and her conditions even got worse and she was now violent and aggressive. We couldn't handle the situation and we had to lock her up in the room because this was still midnight, and by the next morning when we opened her up much to our surprise she had destroyed so much of our property. The situation hadn't changed and so we had to visit another traditional healer for assistance, but again with little improvement. And so we kept moving from one traditional healer to the other until somebody advised us to visit the hospital for assistance. All this while, we were literally begging, for we had run out of resources looking for cure for her. So without much hesitation we went to the hospital and we have been there ever since with much improvements. Before the start of treatment at the hospital, the doctors asked whether we have a history of mental illness in our family, and we said no neither the mother's family nor the father's family.

M: How long has she been suffering from this condition?
P: It is exactly one year today, it was during the month of Ramadan

M: What has been the major challenge to you?
P: The major challenge has been our finances, the cost of treatment has drain us. I used to trade but since the onset of this problem, I have used all my money including the working capital, I am literally surviving on loans that I can't even pay because the business has collapsed, but the father tries to help but it has not been easy because he doesn't have a stable job too.

M: How old are you?
P: I am 45 years old

M: Are people treating you or relating to you differently because your daughter is mentally challenged.

P: Not exactly in the sense of stigma, because in my experience people are rather empathizing and trying to support in the best way that they can by providing you with information regarding treatment options for the condition.

M: Do you feel ashamed that people know you have a daughter with such a condition?
P: Not at all, otherwise I wouldn't be sending her from one place to the other looking for cure, in fact we should be hiding in our home if that were the case.

M: What coping strategies do you employ and what motivates you to continue to care in the face of the difficulties?
P: What can I do my brother, she is my daughter and I cannot abandon her; she is just a victim, she is innocent and she is not responsible. I brought her into this world without her consent, she is my blood and so she is my responsibility whether good or bad, in good health and in sickness and it does not matter what kind of sickness, it is my responsibility and I accept it …..sobbing and sobbing and sobbing.

M: If she relapses, what difficulties does she go through and what challenges do you face?
P: Anytime she relapses the situation is so frightening, she experiences hallucinations and aggression and destructive as well, we will have to tie her up and quickly rush her to the hospital for assistance, but if the father is not home, she destroys things and leave home and it can take us up to several weeks to look for her, sometimes outside of Tamale in some towns and villages. And this experience can be exhaustive, stressful, and loss of control, everything will come to a standstill, including taking care of the rest of the family, sending children to school and picking them back, cooking for the family and sleepless days and nights. This takes a big toll on finances and breeds family conflicts and sometimes stretches us beyond our limits.

M: What are your fears if any, and what kind of support will your need towards her treatment and up keep?
P: Now not so much of fears for there is tremendous improvement in her situation, but we are appealing for medical and financial support from government and benevolent organisations, especially if government could absorb all psychiatric drugs under the NHIS.

Case Study Transcription 5

Study Title: The Burden of Mental Health Care on Family Caregivers in the Tamale Metropolis

Method: EMIC IDI's

Category: Primary Caregiver Interview (50 years old Mother)

Region: Northern

District: Tamale Metropolis

Rural/Urban: Urban

Language of Discussion: Dagbanli

Moderator: Adam Yussif Hamdan

Note-Taker: Eckow

Transcriber: Adam Yussif Hamdan

Date Conducted: 05/15/2019

Date Transcribed: 05/16/ 2019

Length of Discussion (minutes):

Number of Participants: 1

Location/Venue of interview: (Home Kpalsi)

Key:

M=Moderator

P= Participant

M: What health condition is your son suffering from?

P: He is suffering from mental illness resulting from a spiritual possession

M: How old is your son?

P: He is about 24 years old

M: What about you, how old are you yourself?

P: I am about 50 years old

M: How long has he been living with the condition?

P: He has been living with this condition for the past 2 years or so.

M: What has been the most difficult and challenging caregiving experience to you relating to your son's health condition during periods of relapse?

P: Hmm as for the difficulties and challenges they are just so many. Typical among them is sleepless nights for us and even our immediate neighbours. He experiences visual and auditory hallucinations and this becomes very serious at nights, talking and wailing throughout the night and destroying and burning of property. And at these moments, we cannot control him and neither can we leave him alone, it's just a difficult situation to live with. He will not eat, he will not wash or bath.

M: What was the cause of this problem?

P: Well, it's a bit complicated because some attribute it to spiritual possession and witchcraft, but I think its God's creation because we have been to malams and traditional healers but there was little improvements until we came to the hospital.

M: What has been the role of the family, are they supportive?

P: The family is not supportive at all, you know the father is not around, and so there was an occasion that I needed financial help from one of the uncles only to be disappointed, and this was so shocking to me that it left me thinking and crying for such a long time that I still find it difficult to belief and to think that if the father is not around we can't lean on anybody. In fact this was so shocking for me because it was my husband who asked me to go to the brother for help because he was not at home with us.

M: So why do you think the family is not supportive?

P: Hmm, it's difficult to tell, but you know some people are so pretentious and they are never predictable and that is exactly the situation that we find ourselves; nowhere to go for help even among your family members who naturally should provide you with the social buffering at least for the sake of the family have left you with no choices but to carry your physical, emotional, spiritual, and financial problems solitarily.

M: How are you coping and what is the motivation for your continuous care to him in spite of all the difficulties you are going through?

P: Hmm, that's my child, that's my blood, that's my family, that's my responsibility. In fact Karma and posterity will haunt me if I were to abdicate my responsibility, life will be meaningless without values, he is a part of me and I cannot cut away any part of my body whether good or bad. You know, life comes in pairs; male/female, positive/negative, happiness/sadness, good/bad; and so we have to accept our responsibility and stand up to the challenge in the face of difficulties when it comes. That is our brand, those are our values, and that is my motivation.

M: What are your fears about his condition in the long term?

P: Well, I have soon gone past the fears to courage and belief that we shall see light at the end of the tunnel because there is remarkable improvements in his sufferings and our sufferings. We could hardly sleep because of the unbearable pains and suffering we went through, but now we see the relief coming and we can only hope and pray believing that there would be better improvement leading to the restoration of normal health.

M: What kind of support would you need towards alleviating and improving on your son's condition?

P: I will appeal to government and other benevolent organizations to make psychiatric drugs available and for free to such clinical populations, because such drugs are expensive and sometimes unavailable even if you have the money to buy.

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
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Tel: +233-302-681109
Fax + 233-302-685424
Email: ghserc@gmail.com

MyRef. GHS/RDD/ERC/Admin/App 18/460
Your Ref. No.

14th December, 2018

Yussif Adam Hamdan
University of Ghana
School of Public Health
P.O. Box LG 13
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-ERC006/11/18**
Project Title	The Burden on Mental Health Care on Family Caregivers in the Tamale Metropolis
Approval Date	14th December,2018
Expiry Date	13th December 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.

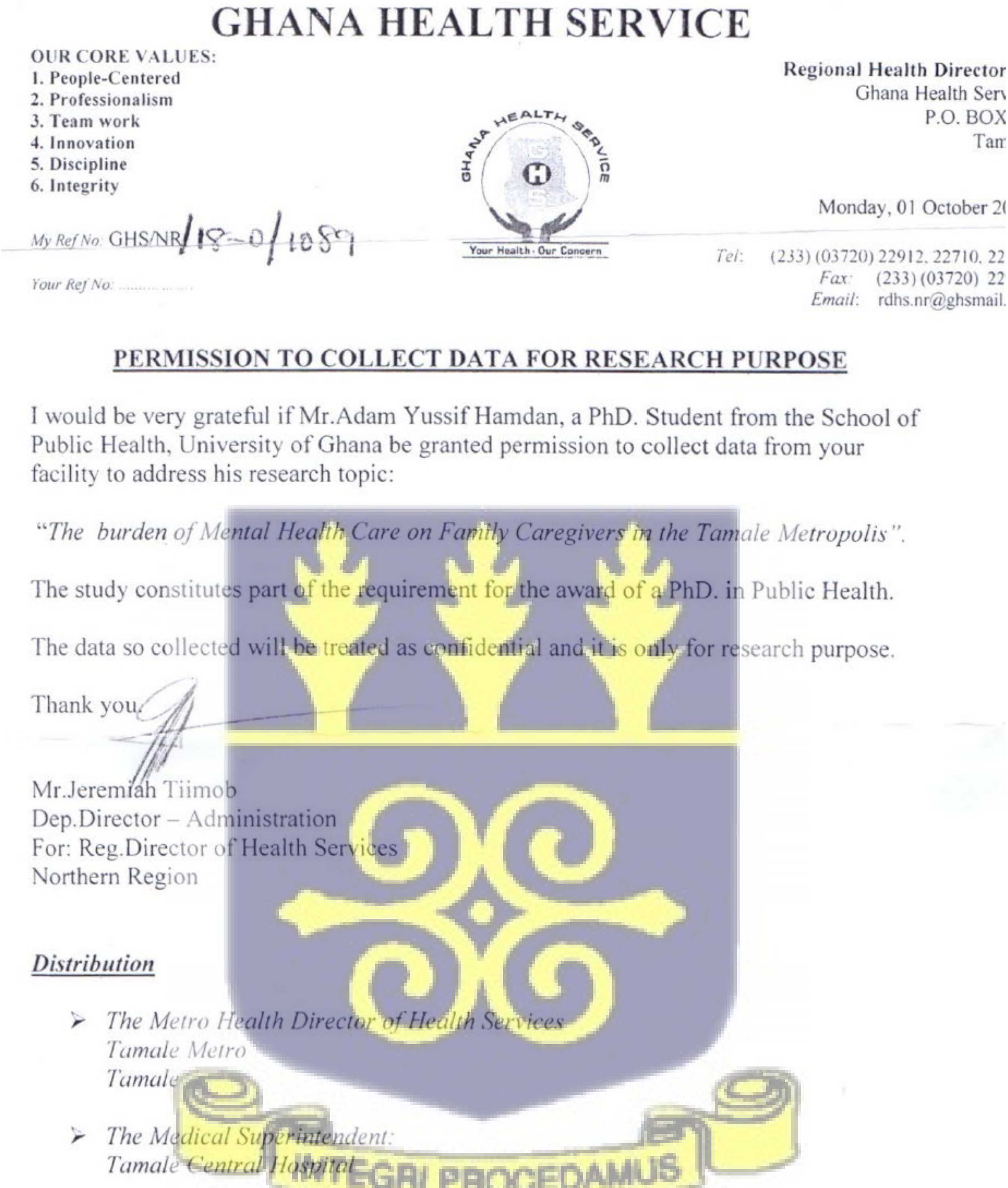
The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

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

Appendix 9: Introductory Letter (GHS)



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Email: rdhs.nr@ghsmail.

Monday, 01 October 2

My Ref No: GHS/NR/18-0/1089

Your Ref No: ....

PERMISSION TO COLLECT DATA FOR RESEARCH PURPOSE

I would be very grateful if Mr.Adam Yussif Hamdan, a PhD. Student from the School of Public Health, University of Ghana be granted permission to collect data from your facility to address his research topic:

"The burden of Mental Health Care on Family Caregivers in the Tamale Metropolis".

The study constitutes part of the requirement for the award of a PhD. in Public Health.

The data so collected will be treated as confidential and it is only for research purpose.

Thank you.

Mr.Jeremiah Tiimob
Dep.Director – Administration
For: Reg.Director of Health Services
Northern Region

Distribution

- *The Metro Health Director of Health Services*
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