

**DEPRESSION AND QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF  
STROKE SURVIVORS IN GHANA**

**BY**

**DOREEN ASANTEWA ABEASI**



**A THESIS SUBMITTED TO THE DEPARTMENT OF PSYCHOLOGY,  
UNIVERSITY OF GHANA IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF  
MASTER OF PHILOSOPHY IN  
CLINICAL PSYCHOLOGY**

**JULY, 2014**

### DECLARATION

This is to certify that this thesis is the result of research undertaken by Doreen Asantewa Abeasi under supervision towards the award of Master of Philosophy in Clinical Psychology Degree in the University of Ghana, Legon.

.....

.....

Doreen Asantewa Abeasi

Date

(Student)

.....



Dr. Joseph Osafo

Date

(Supervisor)

.....

.....

Dr. Paul Doku

Date

(Co-Supervisor)

## ABSTRACT

*The impact on daily lives as a result of stroke is a concern for world health because mostly surviving stroke is an altered life to come for both the survivor and the informal family caregiver. A good proportion of its survivors are left to battle with residual neurological and functional impairment, which often require long term support and care. Mostly after discharge, these stroke survivors depend on family caregivers who are usually ill prepared for their caregiving role. Poor health of the caregiver can in turn affect the general wellbeing of the stroke survivor. Thus, this study examined depression and quality of life among family caregivers of stroke survivors. A sample of one hundred (100) participants was selected purposively using a cross sectional research design at the Korle-Bu Teaching Hospital. The results were analyzed by using Multiple Analyses Of Variance, Multiple Regression Analysis, Independent t-Test, Sobel test and Pearson's r test to identify the relationships between the variables. The findings were that caregivers experienced significant depressive symptoms and low quality of life than the non caregivers. There was a significant relationship between depression and quality of life. The relationship between social support and quality of life was mediated by depression. Severity of stroke, duration of care, age of caregiver and gender were not significant predictors of depression. The significant predictors of quality of life were financial constraint, age and gender of the caregiver.*

## **DEDICATION**

To all stroke survivors and their caregivers



## ACKNOWLEDGEMENT

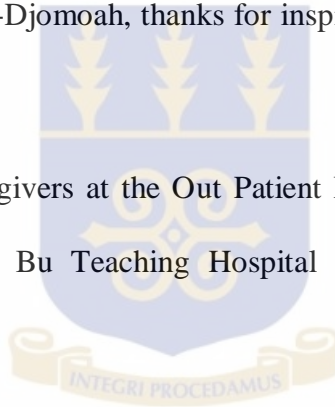
To God be the glory.

First and foremost, I express my sincere gratitude to my supervisors, Dr. Joseph Osafo and Dr. Paul Doku for their patience, constructive criticisms and supervision. Words cannot express my heartfelt gratitude for your encouragement and inspiration. God bless you.

Madam Mary Eduam, thank you very much for single handedly sponsoring me through my education. I love you mum.

To my husband, Mr. Ernest Obese-Djomoah, thanks for inspiring and supporting my decision to continue my education.

Many thanks to the staff and caregivers at the Out Patient Department of the Stroke Unit and Physiotherapy Unit of the Korle Bu Teaching Hospital for their support during my data collection.



Finally but not the least, I am grateful to all my friends and loved ones for their assistance in the course of my programme.

**TABLE OF CONTENTS**

Contents	Page
DECLARATION.....	i
ABSTRACT .....	ii
DEDICATION .....	iii
ACKNOWLEDGEMENT .....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES .....	ix
LIST OF FIGURES .....	x
LIST OF ABBREVIATIONS .....	xi
CHAPTER ONE .....	1
INTRODUCTION .....	1
1.1. Background to the study .....	1
1.2. Post stroke: The survivor and family caregiver .....	4
1.3. Problem statement .....	7
1.4. Relevance of the study .....	9
1.5. Aims and objectives of the study .....	10
CHAPTER TWO .....	11
LITERATURE REVIEW .....	11
2.1. Overview of literature review.....	11
2.2. Theoretical framework .....	12

2.2.1 Stress Process Model .....	12
2.2.2 Transactional Model of Stress and Coping .....	13
2.3. Related studies .....	14
2.3.1 Outcomes of caregiving .....	14
2.3.2 Depression in caregivers .....	15
2.3.3. Predictors of depression .....	21
2.3.3.1. Duration of caregiving .....	21
2.3.3.2. Severity of stroke .....	23
2.3.3.3. Social support .....	24
2.3.3.4. Sex of the caregiver .....	25
2.3.3.5. Caregivers' age .....	26
2.3.4. Quality of life of a stroke survivor caregiver .....	26
2.3.5. Predictors of quality of life .....	28
2.3.5.1. Depression .....	28
2.3.5.2. Caregivers' age .....	29
2.3.5.3. Gender of caregiver .....	30
2.3.5.4. Financial constraint.....	30
2.3.5.5. Severity of stroke/ functional status .....	31
2.3.4.6 Social support.....	31
2.4. Limitations of Reviewed Literature .....	32
2.5 Summary of Literature Review.....	34

2.6. Rationale of the study .....	36
2.7. Statement of hypothesis .....	37
2.8. Operational definition .....	39
CHAPTER THREE .....	40
METHODOLOGY .....	40
3.1 Population .....	40
3.2 Sample size determination.....	40
3.3 Sampling technique .....	41
3.4 Participants.....	41
3.5. Research Design .....	44
3.6. Instruments .....	44
3.6.1. The Beck Depression Inventory.....	44
3.6.2. The WHO Quality of Life- BREF.....	45
3.6.3. The Barthel scale or Barthel ADL index .....	46
3.6.4. Multidimensional Scale of Perceived Social Support .....	47
3.7 Pilot Study.....	47
3.8. Procedure.....	49
CHAPTER FOUR .....	51
RESULTS.....	51
4.1 Introduction .....	51
4.2 Descriptive Statistics.....	52

4.3 Hypotheses Testing .....	53
4.4 Summary of Findings.....	62
4.5. Additional Findings .....	63
CHAPTER FIVE.....	65
DISCUSSION .....	65
5.1 Introduction.....	65
5.2 Discussion of Findings.....	65
5.3. Limitations.....	77
5.4. Recommendations .....	78
5.5 Conclusions.....	80
REFERENCES .....	81
APPENDICES.....	97
Appendix A: Ethical Clearance Letter.....	97
Appendix B: Letter of Introduction .....	98
Appendix C: Additional Findings .....	99
Appendix D: Consent Form .....	100
Appendix E: Questionnaire .....	104

## LIST OF TABLES

Table 1: Descriptive Frequency and Percentages of Caregivers and Non caregiver Control Group.....	43
Table 2: Internal Consistencies of the Scales from a Pilot study of 15 Family Caregivers of Stroke survivors.....	48
Table 3: Means, standard deviation and Cronbach alpha of variables.....	52
Table 4: Correlation matrix representing the relationship among variables.....	52
Table 5: Frequency and chi-square representing level of depression among caregivers.....	53
Table 6: Summary of results on independent t test comparing caregivers and non caregivers on depression.....	54
Table 7: Summary of results on independent t test comparing caregivers and non caregivers on quality of life.....	55
Table 8: Summary of means and MANOVA results on depression and quality of life between the groups.....	56
Table 9: Summary results of mediation effect of depression on the relationship between social support and quality of life.....	57
Table 10: Multiple Regression Analysis of the contribution of financial constraint and gender to QOL.....	60
Table 11: Means, standard deviations and t-test of differences between younger and older caregivers.....	61

## LIST OF FIGURES

Figure 1: Proposed Conceptual Framework.....	39
Figure 2: Mediation model summary.....	58
Figure 3: Revised Conceptual Framework.....	64

## LIST OF ABBREVIATIONS

APA	American Psychiatric Association
BI	Barthel Index
BDI	Beck Depression Inventory
ECH	Ethics Committee for Humanities
CG	Caregiver Group
GHS	Ghana Health Service
MOH	Ministry of Health
MSPSS	Multidimensional Scale of Perceived Social Support
NCG	Non Caregiver Group
QOL	Quality of life
SPM	Stress Process Model
WHO	World Health Organization

## CHAPTER ONE

### INTRODUCTION

#### 1.1. Background to the study

Stroke, a form of cardiovascular disease is perceived as the most common serious neurological disorder in the world (Robinson, 1998) and it is sometimes also referred to as cerebrovascular accident (CVA), cardiovascular injury (CVI), brain attack or apoplexy. To better understand the consequences of stroke for the life-world of stroke families, knowledge about stroke grounded in natural sciences provides an important background. The brain cells need continuous supply of blood, oxygen, and glucose (blood sugar) to function properly (World Health Organization [WHO], 2007). Unfortunately, this supply can be interrupted, caused by a blockage, infarct or a rupture in a vessel supplying blood to the brain (Indredavik, 2004). Depending on the severity of the impairment, the functioning of the brain may be affected temporarily or permanently. Two major forms of stroke exists, which can be ischaemic or haemorrhagic. Ischemic strokes are more prevalent than hemorrhagic making up approximately 87% of all cases and have been the target of most drug trials (Rosamond et al., 2008).

Ischaemic stroke occurs because of loss of blood supply to the part of the brain, initiating the ischaemic cascade (Deb, Sharma & Hassan, 2010). They can be broadly subdivided into thrombotic and embolic strokes. The common pathway of ischaemic stroke is lack of sufficient blood flow to perfuse cerebral tissue, due to narrowed or blocked arteries leading to or within the brain. In thrombotic stroke, narrowing is commonly the result of atherosclerosis (the occurrence of fatty plaques lining the blood vessels). Atherosclerosis may disrupt the blood supply by narrowing the lumen of the blood vessels leading to a reduction in blood flow, by causing the

formation of blood clots within the vessel, or by releasing showers of small emboli through the disintegration of atherosclerotic plaques. In an embolic stroke, blood clots or debris from elsewhere in the body, typically the heart valves, travel through the circulatory system and block narrower blood vessels (Snell, 2006).

On the other hand, haemorrhagic strokes result in tissue injury by causing compression of brain tissue from an expanding haematoma which can distort and injure the tissues. This pressure may lead to a loss of blood supply to affected tissues with resulting infarction, and the blood released by brain haemorrhage appears to have direct toxic effects on brain tissue and vasculature. Intracerebral haemorrhage is caused by rupture of a blood vessel and accumulation of blood within the brain. This is commonly the result of blood vessel damage from chronic hypertension, vascular malformations, or the use medications associated with increased bleeding rates, such as anticoagulants, thrombolytics, and antiplatelet agents. Subarachnoid haemorrhage is the gradual collection of blood in the subarachnoid space of the brain dura, typically caused by trauma to the head or rupture of a cerebral aneurysm (National Institute of Neurological Disorders and Stroke, 1999).

In the past and even now, stroke is a high priority area for world health and social policy makers due to its high prevalence and also to the fact that they cause long term disabilities and substantial socioeconomic and emotional impacts on daily lives with major casualties being its survivors and their caregivers (Fisher & Bogousslavsky, 1998; Caplan, 2000; Oleson & Leonardi, 2003). According to Robinson (1998) nearly half of all acute hospitalizations for neurological diseases are attributed to stroke, which may partially explain why it is a public health concern in high, middle and low income countries. In spite of efforts made to decrease the

incidence of the diseases, statistics show that many people are affected which may partly be as a result of ageing population. But older people are not the only group with disabilities that is growing, as modern medical technology and pharmaceuticals are saving and prolonging more and more lives of people who would not have survived their conditions thirty or forty years ago (Guberman, 2013).

Globally as per an estimate of WHO every year about 15 million of the world population suffers from stroke out of which 33 % (5 million) become disabled permanently. Of the people who survive stroke, only 10% are able to recover almost completely, 31 % are completely dependent, 71% have problems with speech and 20% are partially dependent regarding mobilization (Mol & Baker, 1991). Again, estimates suggest that 8% of all first-ever strokes occur in Africa and that 5% of the 30 million stroke survivors worldwide live in Africa. The prevalence of stroke might increase in the near future because of changes in exposure to major stroke risk factors and improved prevention and control of infectious diseases (WHO, 2010). Sadly, a paucity of data from stroke studies in Africa (Agyemang et al., 2012) severely limits our understanding of the burden of stroke in Africa.

Although comprehensive strokes surveillance data for Africa are lacking, the available data show that the case fatality and prevalence of disability stroke in Africa are similar to or higher than those measures in most high income regions (Mensah, 2008). For over two decades, the burden of stroke is reported to be on the rise in developing countries. Between 1990 and 2010, the number of strokes decreases approximately 10% in the developed world and increased by the same percentage in the developing world (Feigin, Lawes, Bennett, Barker-Collo & Parag, 2010). Similarly, Truelsen, Heuschmann and Bonita (2007) reported that the rate of stroke in these

developing countries including Ghana have exceeded the rate of developed countries by 20% during the period from 2000 to 2008.

Agyemang et al. (2012) conducted a study on stroke in the Ashanti region of Ghana with the aim of determining the morbidity and mortality in adult in-patients with stroke admitted to the Komfo Anokye Teaching Hospital. Results showed that stroke accounted for 9.1% of total medical adult hospital admission. This finding is consistent with the previous unpublished study in Accra, where stroke was responsible directly for 12.7% of medical admissions (Amoah et al. unpublished data). The figures reported in Ghana far exceed those reported in Sokoto, Nigeria where stroke constituted 0.36% of total hospital admission from 1994 to 1998 (Njoku & Adujolu, 2004). This is suggestive of the fact that stroke is a major burden in Ghana, which is worrying because stroke can affect both the survivors and their informal caregivers physically, mentally, emotionally, and economically (Rosamond et al., 2008).

## **1.2. Post stroke: The survivor and family caregiver**

In terms of disability, stroke is found to be the leading cause worldwide and in developing countries it is the second leading cause of disability (Clarke, 2000). Mostly after the incidence of stroke, people who survive have to deal with mild to severe disability increasing the number of individuals who need help to manage their daily lives annually. Stroke may limit the functional and cognitive capacities of its survivors (Rosamand et al., 2008). Again, they are more likely to be dependent in daily living activities. This may be categorized as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (Hackett et al., 2000). Feeding, grooming, bathing, dressing are often classified as ADL. IADL on the other hand include shopping, preparing meals, housework and basic home maintenance. Apart from dependence in

daily living activities, survivors experience emotional difficulties including anxiety, panic attacks, flat affect, mania, apathy, and psychosis. About 30 to 50% of stroke survivors suffer post stroke depression, which is characterized by lethargy, irritability, sleep disturbances, lowered self-esteem and withdrawal (Senelick, Rossi & Dougherty, 1994).

Prompt intervention at the onset of a stroke has been cited as one of the ways to decrease case fatality among people who are affected by stroke. Unfortunately, the lack of such services especially in low and middle income countries may mean that most people may arrive late at health centers to receive the appropriate treatment. Delay in treatment can contribute to the severity of brain injury subsequently leading to serious residual deficits. In spite of these residual deficits survivors cannot forever remain hospitalized and the unavailability of rehabilitation centres in developing countries like Ghana means that care of patients with stroke after discharge falls on family members (WHO, 2010).

The sudden presentation of stroke usually leaves the family with little or no time to prepare for their caregiving roles (Exall, 1999) and they receive little guidance from the formal health care provider. Notwithstanding their unpreparedness, they don't see caregiving as optional. For example, Sawatzkyi and Folwer-Kerry (2003) reported that in Jordan, family caregivers providing care for a relative with a disability is a moral obligation, therefore, institutionalizing a patient with stroke is an unacceptable option for families. Often times, nurses and family caregivers rarely agree about the specific needs or problems during hospital admission and discharge (Bucher et al., 2001). Family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed due to inadequate knowledge and skill. Also, they may not know how to access and best utilize available resources (Given et al., 1994). As a result, caregivers often neglect their own health needs in order to assist their family member who is ill

causing deterioration in the caregivers health. Consequently, inadequate preparation for caregiving role places not only the caregiver at risk but also the care recipient (Ski & O'Connell, 2007). The caregiver literature agrees that providing care for a chronically ill family member can be harmful to the caregiver's physical and emotional health (Berg et al., 2005).

Several studies have demonstrated the multi-faceted impact of providing care since 1988 when the first articles on burden of stroke caregivers were published (Berg et al, 2005; Low, Payne & Roderick, 1999; van Exel et al., 2004). Ross and Morris (1988), one of the early researchers in the study of burden assessed 20 co-resident spouses of aphasic stroke patients. The study showed that the degree of perceived strain had been substantial and comparable to spouses of people with dementia. This was confirmed many years later by Draper, Poulos, Cole, Poulos and Ehrlich (1992) and by Thommessen, Wyller, Bautz-Holter and Laake (2002) who examined family caregivers of the elderly with stroke, dementia and Parkinson's disease. The obtained results showed that the caregivers perceived a similar type and level of psychosocial burden and psychological morbidity, independent of the disease.

Recent studies have reported very specific psychological disorders that are associated with caring for a stroke survivor. In a study conducted by Cohen et al. (1990), the results showed that depression appears to be the most common disorder with 30% to 59% of caregivers reporting depressive disorders or symptoms. Similarly, caregivers have higher levels of depression than non-caregivers and the general populations (Morimoto, Schreiner & Asano, 2003). The above finding is important because a caregiver's physical, social, emotional and cognitive functioning can be impaired by depression (Cannuscio, Jones, Kawachi, Colditz, & Berkman, 2002). In addition, caregivers may avoid asking for health care to manage depression (Nasir & Al-Qutob, 2005).

Besides the reported depressive symptomatology, quality of life (QOL) is also affected in family caregivers of stroke survivors. Quality of life as explained by Maatouk et al. (2012) refer to the state of loss and decline in a person's perception of life's goodness with influences from past and or present life events. It may comprise an individual's physical, functional, psychological and social life. Some studies have reported that increased burden is significantly related to decreased health-related quality of life among stroke caregivers particularly in mental health and social functioning domains (McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Morimoto et al., 2003). Several other determinants and predictors of QOL have been reported, such as: physical disability of the stroke survivor, behavioral disturbances following stroke, personal attributes and depression of the caregiver and social support (Hans & Haley, 1999; Nelson, Smith, Martinson, Kind, & Luepker, 2008; White, Mayo, Hanley & Wood-Dauphinee, 2003).

### **1.3. Problem statement**

Stroke remains a challenge that health care organizations around the globe will need to address for the next several decade because it is one of the major chronic illnesses (Patel, McKeVitt, Lawrence, Rudd & Wolfe, 2007). In Ghana, the projected rise in stroke burden (Agyemang et al., 2012) is estimated to affect the survivor as well as family members who serve as informal caregivers (de-Graft Aikins, 2007). This is because stroke rehabilitation has integrated patient focused intervention which has reduced the level of disabilities and subsequently increased the number of survivors being managed at home (McCullagh et al., 2005). Also, unlike in Western countries, nursing homes and institutes for patients with chronic illness are generally unavailable in Ghana, which could increase the burden of an informal caregiver (Choi, 1996).

Additionally, the residual deficits including neurological and functional impairments suffered by stroke survivors (Chow, Wong & Pong, 2006) poses a challenge to informal caregivers. Professionals worldwide usually discharge their duties within their stipulated training. Health care workers (formal caregivers) are no exception since they have the requisite skills and knowledge needed to provide care and in so doing reduces caregiving burden. In other words, they are mostly prepared to adjust better to their caregiving roles and responsibilities (Glass, Matchar, Belyea & Feussner, 1993). On the other hand, informal caregivers do not have access to the same information, training, or supervision as professionals (Guberman et al., 2005) and also provide care in homes that are rarely adapted for specialized care. This put family caregivers in a difficult situation and may have difficulty adjusting to their new roles.

In the management of stroke survivors, one would think that informal caregivers would also be given priority since they are reported as being hidden patients (Guberman, 2013) but that is not so in Ghana. Several studies have especially reported the deteriorating psychological health as well as poorer quality of life of caregivers though not in Ghana (Akosile, Okoye, Nwankwa, Akosile & Mbada, 2011; Fatoye, Komolafe, Adewuya, & Fatoye, 2006; Ogunlana, Olumide, Olajire, Adesola & Morenike, 2014). Hung et al. (2007) posits that the burden of caregiving affects not only the caregiver but may further compromise the recovery, rehabilitative process and overall health outcome of the stroke survivor. Poor mental health and quality of life apart from its negative effect on the survivor, may threaten the sustainability of home care. This presents a challenge to the health delivery system.

Furthermore, with the projected rise in stroke, it is estimated that the number of survivors as well as informal caregivers would increase. These informal caregivers may have their own way of dealing with the mental health challenges that accompany their caregiving role but the question

is which resources do they use and are these resources likely to buffer the effects of caregiving on their mental health and overall quality of life? Therefore, there is the need to identify the various factors; caregiver, survivor and socio-demographic variables that are likely to have significant influence on the mental health and quality of life of caregiver in order to inform professionals on the way forward for management.

Finally, though studies have investigated the burden of stroke on family caregivers in some sub-Saharan Africa, it is difficult to extrapolate the findings to other sub-Saharan countries due to significant disparities in the findings (Akosile et al, 2011; Fatoye et al., 2006; Ogunlana et al., 2014). Therefore, in countries with increasing burden of stroke like Ghana, there is the need to examine the psychological health as well as the QOL of the informal caregiver since they play the role of major extension to health delivery system.

#### **1.4. Relevance of the study**

This study seeks to provide the Ministry of Health and other stake holders in the health sector, with a clinical aspect of depression and quality of life among family caregivers of stroke survivors. These findings are aimed at emphasizing that the family caregivers who are major extension in providing health services may themselves be secondary or hidden patients with serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and reduced attention to their own health and health care.

Necessary information when acquired can be used to draw up intervention programs for family caregivers. Interventions such as those that assist the family caregiver to build effective buffers against being overwhelmed and distressed with their caregiver roles can be initiated. Other

interventions may include those that assist caregiver to engage in activities that promote their own health.

Caregivers will gain in-depth understanding of factors that are associated with depression as well as poorer quality of life. They will be informed on the caregiver as well as survivor related factors that are associated with depression and poorer quality of life. The documented results of the study will also serve as a reference for related studies in the future.

### **1.5. Aims and objectives of the study**

The aim of this study is to investigate depressive symptoms and quality of life among family caregivers of stroke survivors and also determine the influence of social support, financial constraint, severity of stroke, age of caregiver, and duration of caregiving on these variables.

Specifically this study seeks;

1. To assess the level of depression of family caregivers of stroke survivors and non-caregivers.
2. To examine the quality of life of family caregivers of stroke survivors.
3. To explore the role of social support in depression and quality of life among family caregivers.
4. To investigate the relationship between depression and quality of life of caregivers.
5. To explore the predictors of depression (severity of stroke, duration of care, age of caregiver, gender and financial constraint).
6. To explore the predictors of quality of life (social support, severity of stroke, duration of care, age of caregiver, gender and financial constraint).

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1. Overview of literature review

For some time now, stroke caregiving has been identified as one of the factors leading to depression among family caregivers. Several researches have been conducted on the psychological functioning as well as the quality of life of stroke survivor's caregivers (Fatoye et al., 2006). These studies have shown that caregiving is related to depression, anxiety, fatigue and poorer quality of life (Berg et al., 2005; Cohen et al., 1990). The present study is aimed at examining depression and quality of life among family caregivers of stroke survivors. Also the predictors of depression and quality of life will be explored (social support, financial constraint, severity of stroke, age of the caregiver, sex of the caregiver, and duration of caregiving).

This chapter presents the theoretical framework underlying the study. The aim is to elaborate on theories that explain the various variables in the study by putting them in perspective. The theories that have been included in the study are the Stress Process Model (Pearlin, Mullan, Semple & Skaff, 1990) and Transactional model of stress (Lazarus and Folkman, 1984; Palmer & Dryden, 1995). The reviews of empirical literature on various variables in the study follow the review of the theories. The first section focuses on depression and quality of life among caregivers followed by the predictors of depression and quality of life and caregiving. The reviews of theoretical and empirical literature are followed by the rationale of the present study, the hypothesis to be tested and lastly the operational definition of key terms.

## **2.2. Theoretical framework**

### **2.2.1 Stress Process Model**

The theoretical framework was derived from the Stress Process Model (SPM) developed by Pearlin et al. (1990) and review of the literature. The SPM provides a structure to examine predictors of caregiver outcomes that occur from one phase of the illness trajectory to another (Blum & Sherman, 2010). Providing care to patients who have survived stroke involves several interrelated factors. Each factors taken alone may be stressful, but when combined they can become unmanageable and result in depression and poor quality of life for caregivers.

There are four core components of this model. These are: 1) background and context, 2) stressors, 3) moderating resources, and 4) outcomes. Background and context refer to the characteristics of the caregiver and care recipient (socio-demographic characteristics), the context within which the care is provided (caregiving history), family and network composition, and program availability. In this study, there was a focus on the characteristics of the caregivers as well as the care recipient. The literature revealed that caregiver age, sex, level of dependency of the survivor and duration of care were correlated with depression among family caregivers of stroke survivors.

Pearlin et al. (1990) considered that SPM stressors were conditions that threaten, thwart efforts, and defeat the dreams of people, and those experiences that challenge a caregiver's ability to adjust to the demands of care giving. Family hardiness, coping, and social support are the moderating resources of SPM, that have the capacity to hinder, prevent, or cushion the development of the stress process and its outcomes; moreover, these provide a buffering effect to stressors through direct and indirect pathways (Pearlin, 1999). Coping styles include

management of the following; the situation, meaning of the situation and stress symptoms that result from the situation. Depending on how these are managed, the caregiver can be affected negatively or positively.

The outcomes of stress refer to its consequences. In this study, the focus was on caregiver depression and QOL as an outcome because QOL is a salient aspect of well-being for individuals who are going through stress, and in particular caregivers of stroke survivors. Additionally, QOL is an outcome of caregiver experience and also an important outcome to help maintain the health status. Hence, evaluating caregiver QOL provides information to understand how family caregivers react to their new roles.

### **2.2.2 Transactional Model of Stress and Coping**

The transactional Model of Stress and Coping was developed by Lazarus and Folkman (1984). It is a framework for evaluating the processes of coping with stressful events. Stressful events are construed as person-environment transactions. These transactions depend on the impact of the external stressor. This is mediated by firstly the persons appraisal of the stressor and secondly on the social and cultural resources at his or her own disposal. When faced with a stressor, a person evaluates the potential threat (primary appraisal). Primary appraisal is a person's judgment about the significance of an event as stressful, positive, controllable, challenging or irrelevant. Facing a stressor, the second appraisal follows, which is an assessment of peoples coping resources and options. Secondary appraisals address what one can do about the situation. Actual coping efforts aimed at regulation of the problem give rise to outcomes of the coping process.

The present did not evaluate the perception of stress by the informal caregivers of stroke survivors which can significantly influence the impact of the stressor. However, having a family member surviving an acute illness event such as stroke can be considered to be a stressful life event. The consequences of this stressful life event may be a drastic, unplanned and crucially challenging change in for example interpersonal relationships, roles, financial status and life trajectory. The interactions between the stress of being an informal caregiver and available personal resources can change the course of stress. In as much as the caregiving situation has been construed as stressful, the caregivers' appraisal is very significant. For example, the survivor may be very dependent and the caregiving very stressful but if the caregiver perceives the situation as controllable, he/she is likely to experience less stress and vice versa. Also, the resources available may significantly buffer the stress involved in caregiver. If a caregiver evaluates those resources as adequate, then he/she is likely to experience less stress which will translate into less emotional problems and better quality of life.

## **2.3. Related studies**

### **2.3.1 Outcomes of caregiving**

In a review of caregiver studies, caregiving has been shown to affect the family caregiver positively and negatively. Some researchers have revealed that caregiving role is associated with satisfaction including a sense of fulfillment for the caregiver, increased feelings of closeness between the caregivers and their relatives, and pleasures resulting from day-to-day interaction with the individual receiving the care (Harper & Lund, 1990; Kinney, Stephens, Franks, & Norris, 1995). Satisfaction with caregiving and rewarding appraisals of caregiving may reduce caregiving stress and improve emotional outcomes (Roff et al., 2004). Taking care of a friend or

relative can be a positive and fulfilling activity. It can lead to closer ties with the person requiring support, the development of new competencies and even give meaning to one's life (Farran 1997; Kramer 1997; Nolan, Grant & Keady 1996). However, it can also be difficult, complicated and disturbing.

In a study conducted by Cohen, Colantonio and Vernich (2002) involving 289 Canadian caregivers, results revealed that 73% of caregivers could identify at least one aspect of positive experiences from feeling fulfilled, important, and responsible, to finding a sense of companionship and meaning within the relationship which is associated with less depression, burden, and better subjective health. Cohen and colleagues concluded that the ability to identify positive aspects within the caregiving relationship might serve as a buffer against negative consequences. Notably, this research was cross-sectional, limiting the causal attributions that can be gleaned from the results.

On the contrary to these positive effects associated with providing care to a family member who is a stroke survivor, several other studies have reported the negative consequences that are accompanied with caregiving. Emotional disorders with symptoms of anxiety, stress, depression, and fatigue have been widely documented (Kinney et al., 1995; Pearlin et al., 1990; Stein, Gordon, Hibbard, & Sliwinski, 1992; Williams, 1994). A caregiver's physical, social, emotional and cognitive functioning can be impaired by depression (Cannuscio et al., 2002).

### **2.3.2 Depression in caregivers**

Several studies have reported a significant relationship between caregiving for stroke survivors and depression. No causal relationship has been established between caregiving and depression,

however, most caregivers have been reported to be depressed. There is lack of consistency amongst reviewed studies. Some studies have reported low prevalence of depression among caregivers (Bakas et al., 2006; Fatoye et al., 2006; Haley et al., 2009) whilst others report very high rates (Berg et al., 2005; Khalid & Kauser, 2008).

Haley et al. (2009) investigated the problems and benefits reported by stroke family caregivers. Stroke survivors (n=75) from a prospective epidemiological study of stroke, the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study were identified and their caregivers were followed. The 20 item Centre for Epidemiological Studies-Depression scale (CES-D) was used measure depression at 8-12 months after the onset of stroke among caregivers. The average CES-D score for caregivers was 7.32(SD=9.15) with only 14% scoring at or above the commonly used clinical cut point of 16 which is below levels of depressive symptoms typically reported in studies of stroke caregiving. This may be explained in several ways. The epidemiological nature of the study provides a unique picture of caregiver strains compared with clinically based convenience samples, which tend to over represent more impaired patients. One other reason might be that caregivers appeared to be coping quite well and better than reported previously, as only 16% of caregivers reported high levels of strain. Also, many caregivers reported benefits from caregiving which may be an important psychological resource for the caregiver reflecting in the lower prevalence of depression among caregivers.

Balhara, Verma, Sharma and Mathur (2012) sought to investigate predictors of anxiety and depression levels among caregivers of patients with stroke. Seventy-five consecutive patient-caregiver dyads were recruited from an in-patient setting of a tertiary care hospital. Assessment of the outcome variables was done using the Hospital Anxiety and Depression Scale (HADS).

The study reported that, 18% were found to have clinically significant depression which included mild (14%), moderate (2%) and severe (2%). The low prevalence of depression may be attributed to some reasons. The mean age of caregivers and patients in the study was reported as 45.22 and 52.43 years, respectively. Thus caregivers in the study were relatively younger. Also 67% of caregivers were males. Several researches have established the relationship between depression and being a female (Dennis et al., 1998). The high proportion of male caregivers is likely to account for the low prevalence.

Bakas, Kroenke, Plue, Perkins and Williams (2006) in a cohort study conducted in the USA compared selected outcomes such as perceived task difficulty, depressive symptoms and other negative stroke related outcomes among caregivers of aphasic (n=46) and non aphasic (n=113) stroke survivors. Caregivers were unpaid, a family member or a significant other of a stroke survivor living at home within one month after stroke and could read and write. Also the caregiver should perform a minimum of two caregiving tasks on the Oberst Caregiving Burden Scale (OBCS). Convenience sampling was used select of caregivers recruited from hospital and clinics. These caregivers were assessed for depression at 1 month and 4 months using the Patient Health Questionnaire (PHQ). Findings of the study showed that 18% of caregivers scored above the cut off measure using the PHQ at 1 month and 4 months.

Consistent with the above is a study done by Fatoye et al. (2006) assessing emotional distress and quality of life among family caregivers of stroke survivors in Nigeria using a cross sectional study design. One hundred and three matched pairs of caregivers of stroke survivors and caregivers of mild hypertensive patients and 103 stroke survivors were recruited in the study. One criterion was the family caregiver should have provided care for at least more than 3 months. The participants were assessed using the (HADS) score of less or equal to 8. Out of the

103 participants that were assessed, 25 scored above the cutoff point on the measuring instrument, thus 24% were found to be depressed. The mean age of the primary caregivers was 41.2 years (SD=3.9) which may be accounting for the low depressive rates. Older age of caregivers is correlated caregivers' depression.

In cross sectional study carried out by Dennis et al. (1998) to investigate the emotional outcome of people caring for caring for stroke survivors. As part of a randomized trial to evaluate a stroke family care work, 246 caregivers of stroke patients were recruited. Survivors were made to identify the main caregiver. The mean age of the caregivers was 60 years and majority (79%) was spousal caregivers. The HADS for assessment of depression revealed that 23% caregivers were above the cut-off measure for depression. In this study, caregiver definition did not stipulate that patients required physical help, so some caregivers may not have been responsible for much actual physical caregiving. This may explain why caregiver depressive rate is not as high as reported in other studies.

King et al (2001), assessed depression prior to discharge and 6-10 weeks post discharge from the hospital. The study found that 24% and 20% were reported to be depressed after using the same scale (score > 16). Similarly, Greenwood, Mackenzie, Cloud and Wilson (2008) conducted a cohort study in the UK and the criterion for choosing a participant was that the caregiver had to be looking after stroke survivors either in the stroke survivor's home or the caregivers' home. The timing of assessment was between discharge and 1 month and three months post discharge. Using the HADS on 45 caregivers at the various, 31% and 28.9% were found to be depressed. More so, in a cohort study conducted in Scotland, while stroke patients were in the hospital and when their condition was assessed to be stable, patients were asked by a researcher to identify the person who was most involved in their care at home. Caregivers identified were contacted

then recruited in the study and were assessed 2 weeks and 8 weeks post discharged using the HADS (score > 8). Out of the 138 participants, 76% were women. Scores on the HADS at the various time of assessment were 32% and 30% respectively (Molloy et al., 2005).

Some studies have reported high prevalence of depression among informal caregiver with values ranging from 33% to 59%. Reporting higher rates of depression for caregivers was a study conducted by Berg et al. (2005). The study was aimed at assessing the prevalence of depressive symptoms among caregivers of stroke survivors and to determine which patient or stroke related factor associated with and can be used to predict caregiver depression during an 18 month follow up after stroke. Examination of 98 caregivers of 100 consecutive patients experiencing their first ever ischaemic in Helsinki University Central Hospital was done. The BDI 21 was used to assess depression among caregivers at three different times during the caregiving process. At the acute phase (26 days), 33% of caregivers showed signs of depression. However, at 6 months and 18 months, the results were similar with 30% of caregivers showing signs of depression. In this study, majority of patients (67%) were males whilst 33% were females. Also the patients mean age (55.3) years, relatively older as compared to other studies. The relatively higher prevalence of depression may be attributed to the higher proportion of males and older age of stroke survivors.

Similarly, Grant, Weaver, Elliott, Bartolucci and Giger (2004) in a cohort study used a convenience sample of family members who were primarily responsible for assisting stroke patients with basic and instrumental activities of daily living. The participants were assessed 1-2 days before discharge of the stroke survivor and at 5, 9, 13 weeks. The Centre for Epidemiologic Studies Depression (CES-D) Scale (score of less or equal to 20) was used to assess depression.

The study showed 48 participants scoring above the cut-off point measure of depression were 36.5%, 39.5% and 34% respectively. These values appear consistent with previous study.

Cameron, Cheung, Streiner, Coyte and Stewart (2006) conducted a study using a cross sectional research design involving 94 informal caregivers who were identified from rehabilitation outpatient clinic, tertiary facility outpatient clinic, and community care organizations. The caregiver was described as the person primarily responsible and or coordinating care in the home of the stroke survivor. The time of assessment was a mean of 21.5 (+ 5.82) months after the onset of stroke. The caregivers were assessed using CES-D-20. The findings of the study were that 45% of carers reported depressive symptomatology scoring above 16 on the CES-D-20.

Reporting similarly higher values for depression was a study conducted by Khalid and Kausar (2008). The study was aimed at investigating depression and QOL in caregivers of people affected by stroke. It was hypothesized that caregivers would exhibit high levels of depression and that there was a negative relationship between depression and QOL. A total of 25 caregivers of stroke survivors were recruited and assessed with the HADS. Findings were consistent with studies which reported high prevalence of depression among informal caregivers. Nearly half of caregivers (48%) were depressed, 24% were at the borderline and 28% were normal. Since the sample size in the study was small (25) it is likely that sample is not representative and have produced exaggerated prevalence rate of depression among caregivers. Cohen et al. (1990) and Morimoto et al. (2003) have also reported very high prevalence of depression, 30-59% and 52% respectively.

Berg et al. (2005) argues that data concerning depression among caregivers must be taken early post stroke since other confounding variables can affect the outcomes over time. Moreover, it

must be emphasized that most of the reviewed studies were cohort studies (Bakas et al., 2006; Berg et al., 2005; Cumming et al., 2006; Grant et al., 2004) and differential loss to follow up can introduce bias.

### **2.3.3. Predictors of depression**

Depression in caregivers may be associated with several patient-related and caregiver-related variables. One patient-related variable that is often associated with depression in caregivers is the severity of impairments or the level of dependency of the stroke survivor (Chumbler et al., 2008; Dennis et al., 1998; Kotila, Nummino, Waltimo & Kaste, 1998). Considering the caregiver-related factors, the poorer physical health of the caregiver (Carnwath & Johnson, 1987; Chumbler et al., 2008; Grant, Bartoluci & Elliot, 2000; Hodgson et al., 1996; Schulz et al., 1988), being female caregiver (Jönsson et al., 2005; van den Heuvel et al., 2001) and lack of social contacts or support (Carnwath & Johnson, 1987; Smith et al., 2004) have been found to be associated with caregiver depression.

#### **2.3.3.1. Duration of caregiving**

Previous studies have reported a significant relationship between the duration of caregiving and depression among caregivers of stroke survivors. Berg et al. (2005) argued that as the time spent in caregiving increases, the relationship between caregiving duration and depression is no longer significant. Some studies have been found to be consistent with the findings of Berg et al. (2005) who in his study revealed that at the later stages of stroke survivors' care, caregivers showed lesser signs of depression. For example in a cohort study conducted in Israel, 137 caregivers were conveniently sampled. The Short Geriatric Depression Scale (score of 6 or more) was used

to assess depression. The timing of assessment was at 2 weeks, 3 months and 6 months. Depression was found to be high at the acute stage (37%) and decreased significantly at 3 months and 6 months (31%) (Nir et al., 2009). Consistent with the above is a study which showed that the number of caregivers who were found to be depressed significantly decreased over time. At 1 month and 6 months, 20% and 16% were found to be depressed respectively (Rittman et al., 2006).

Smith et al. (2004) conducted a cross sectional study in the UK using unpaid caregivers of stroke patients identified from the stroke registers in two hospitals. The sampling method was convenience sampling and using the HADS, assessment of depression was done one year after stroke onset, the assumption being that there wouldn't be a statistically significant relationship between prolonged caregiving (>1 year) and depression of caregivers. On the contrary, a significant proportion (19%) were reported to be depressed which is similar to the proportion of caregivers found to be depressed at the acute phase (18%) in Berg's study. The duration of caregiving may not be a significant predictor since both acute and chronic stages of caregiving provided similar prevalence among caregivers. Other factors might be significant predictors of depression compared to duration of caregiving.

Also, there is a significant relationship between increasing number of hours providing care and depression (Legg, 2012). The findings of the study was that, there was a close relationship with those providing highest number of hours of care reporting the highest rates poor health and those providing the least having the lowest. However this may not be applicable in the study as caregivers were family members and stayed in with their care recipients, hence caregiving was ongoing and it was difficult to quantify the number of hours of caregiving.

### **2.3.3.2. Severity of stroke**

Dennis et al. (1998) conducted a qualitative study on the emotional outcome of people caring for stroke survivors. They found that caregivers were more likely to be depressed if the survivors were severely dependent. Similarly, a study by Kotila et al. (1998) found that poor Rankin scale score and severe Scandinavian stroke scale long term score of the patient at 3 months from the onset of stroke were associated with depression of the caregiver at 3 months by univariate analysis. These findings are consistent with a study conducted by Berg et al. (2005) which also showed that the level of dependency of the stroke survivor correlated significantly with caregivers' depression. McCullagh et al. (2005) also found that caregivers of stroke survivors with more disability experienced more emotional problems.

At odds with the above findings, is a study conducted by Anderson et al. (1995) to describe the health and social consequences of caregiving for long term survivors of stroke with residual handicap, there was no significant relationship between the degree of the survivors' physical disabilities and emotional stress among caregivers. However, a limitation of this study was that effects of caregiving were measured only at one year after stroke. At this time, optimal recovery of physical function should have been achieved and both survivors and their caregivers should have adjusted to the acute event and resettlement after a period of rehabilitation. Consistent with the above is a study conducted by Stein et al. (1992) examining depression in the spouses of stroke patients. In this study they examined the prevalence and correlates of depression in the spouses of 41 stroke patients. Results indicated that 44% of the spouses were depressed. However, spouses' depression was not correlated with the severity of the stroke survivors' physical cognitive or language impairment or level of dependency.

Interestingly, Berg et al. (2005) found that the association between stroke severity and caregiver depression was stronger at the acute stage and no longer at 18 months. This study and other longitudinal studies supports the idea that at least a moderate association occurs between stroke severity and caregiver depression soon after stroke, but that this association decreases during longer follow up times.

### **2.3.3.3. Social support**

Although the extant literature suggests social support promotes caregiver adjustments in other populations (De Leeuw et al., 2000), published studies examining the problem in family caregivers of stroke survivors are relatively few and components of clinical interventions remain unclear (Chavalisz & Vaux, 2000). Review of these cross sectional studies suggest that social support is a significant predictor of depression and life satisfaction at the onset of the caregiver's role (Grant et al., 2000). Furthermore these benefits may extend long term, generating better energy, mental health, physical function, general health, quality of life and less pain (Mant, Carter, Wade & Winner, 2000).

Other researchers have observed that caregivers' perceptions of available social support can influence their health (Blake, Lincoln & Clarke, 2003). The absence of social support has been associated with stress in stroke survivors as well as their caregivers (Glass et al., 1993; Jonsson et al., 2000; Secrest, 2000). In a study by Khalid and Kauser (2008), caregivers' depression was best predicted by lack of tangible social support. Choi-Kwon, Kim, Kwon and Kim (2005) compared the perceived burden for caregivers in Korea and the USA using a brief interview method. The primary predictor of overall burden of the caregiver was insufficient social support.

Grant et al. (2006) conducted a quantitative study on social support, social problem solving abilities and adjustment of family caregivers of stroke survivors using 52 family caregivers with majority being females (46). Outcome measures for caregiver adjustment were depressive symptomatology, wellbeing and general health. Consistent with prior research, declines on social support are linked intricately with family caregiver adjustment and these associations are evident soon after their return to the community. In their study, there was a dynamic association between social support and caregiver adjustment the first 3 months after stroke, affecting depressive symptomatology and wellbeing.

#### **2.3.3.4. Sex of the caregiver**

It is a well established fact that females are at higher risk for depression than males (Legg, 2012). Some studies have also reported female caregivers to be more depressed than their male counterparts. Van den Huevel et al. (2001) reported in his study that being a female caregiver was associated with caregiver depression. Studies in patients with traumatic brain injury (TBI), dementia or stroke have reported female caregivers reporting more anxiety and depression than their male counterparts (Kreutzer, Gervasio & Camplair, 1994).

On the contrary, a study conducted by Balhara et al. (2012) on the predictors of anxiety and depression among stroke patient caregivers recruited seventy five consecutive patient dyads. Regression analysis revealed that the sex of the caregivers was only significant predictor of anxiety level among caregiver ( $\beta=0.44$ ,  $\rho < 0.01$ ). However, the sex of the caregiver was not found to be a significant predictor of depression level in caregivers. Similarly a quantitative study by Dennis et al. (1998) reported that female caregivers scored more on the HADS (anxiety subscale) than their male counterpart ( $\rho < 0.01$ ) but not on the depression subscale.

### **2.3.3.5. Caregivers' age**

Some studies have reported a relationship between the age of the caregiver and depression experienced by them. For example the study conducted by Fatoye et al. (2006) showed that depression is predicted by high caregivers' age. Other studies have found no significant relationship between the two variables. In a study by Draper et al. (1992) comparing caregivers for elderly stroke and dementia victims, no significant relationship was found between the age of the caregiver and the depressive symptoms experienced. Other studies have also found that the age of the caregiver was not related to caregivers' depression (Ross & Morris, 1988; Schulz et al., 1988). Studies on the association between caregiver's depression and caregiver's age give controversial results (Jönsson et al., 2004; Smith et al., 2004; van den Heuvel et al., 2001; Visser-Meily et al., 2008).

### **2.3.4. Quality of life of a stroke survivor caregiver**

Several studies have examined the quality of life of caregivers of stroke survivors. White et al. (2003) examined quality of life in 97 stroke caregivers, and Teel, Duncan, and Lai (2001) assessed the health of 83 stroke caregivers during the first 6 months of caring. Results revealed that caregivers reported very little change in their physical health. Despite this stability, they reported physical symptoms, including fatigue, headaches, problems falling asleep, depressive symptomatology, recurrent sorrow, scheduling and finance problems, and difficulties with family support). Similarly, Schulze et al. (1997) postulates that caregiving may compromise the caregivers quality of life and contribute to depression. Caregiving has been found to affect the informal caregivers of stroke survivors and also their quality of life is reportedly poorer as compared to the normal ideals (Bugge, Alexander, & Hagen, 1999).

Additionally, studies have reported that certain domains of QOL were more affected than others in caregivers. Results are not consistent as different researchers have identified different domains as the most affected. Forsberg-Wärleby, Möller and Blomstrand (2001); Gunduz and Erhan (2008) and McCullagh et al. (2005) have reported that the most affected domain of quality of life among caregivers of stroke survivors was the psychological/ mental/ emotional domain. Contrary to the above Khalid and Kauser (2008) reported the social domain as the most affected.

Akosile et al. (2011) reported that the mental domain was the most affected. Scores on the social domain were lower in caregivers with high burden. This may be due to the fact that increasing burden of caregiving may increase the experience of fatigues and undermine their ability to participate in social activities. Also in the physical domain, caregivers with low and high burden differed significantly. Caregivers are not trained and may not have the appropriate skills for lifting, turning and bending while caring for stroke survivors. Consequently this may result in undue strain, bodily pains subsequently poor physical health.

Khalid and Kauser (2008) examined emotional distress and QOL among caregivers of stroke survivors. The mean scores for environmental, physical, psychological and social domain of QOL were 23.88, 23.08, 18.72 and 10.24 respectively. Environmental QOL was the least affected while social domain of QOL was the most affected. Though it was the most affected domain, it was less correlated to depression. This is because in Pakistan there is availability of social support. The affected social life may be as a result of the responsibility of caregiving and time spent on caregiving.

### **2.3.5. Predictors of quality of life**

The studies that report the consequences of chronic diseases in caregivers' lives identify some variables/predictors of their QOL, namely: severity of the impairment; functional disability, cognitive and behavioural disorders, and impaired social interactions of the disabled person; age, gender, educational level and financial status of both; coping strategies, social support, perception of support availability, and type of relationship of the caregiver (Glozman, 2004). Regarding stroke, socioeconomic status, caregivers' health, amount of care hours and social network were additionally identified (Rombough, Howse, Bagg, & Bartfay, 2008).

#### **2.3.5.1. Depression**

A relationship between depression and QOL has been reported previously (Haghoo, Pazuki, Hosseini & Rassafiani, 2013; Suenkeler et al., 2002). In a study conducted by Jonsson et al. (2005), they found that caregivers' QOL was worse than for patients regarding emotional and mental factors at follow-up. Also depression was found to be the most important determinant of QOL. However, one limitation of this study was it lacked detailed assessment of depression as GDS-20 which is a screening scale was used. Though the screening tool would to some extent provide information on the number of caregivers who are depressed, it would be unfair to draw conclusions and use it to predict QOL.

Contrary to expectations, the findings of Fatoye et al. (2006) showed that presence of clinically significant emotional symptoms did not indicate that caregivers would report adverse consequences on their quality of life. Consistent with the above is a study of predictors of

anxiety and depression among stroke patients' caregivers. There was no reported significant correlation between depression and QOL of caregivers (Balhara et al., 2012).

#### **2.3.5.2. Caregivers' age**

Advancing age of the caregiver is found to be related with lower QOL in some studies (Choi-Kwon et al., 2005; Jonsson et al., 2005; McCullagh et al., 2005). Akosile et al. (2011) conducted a study aimed at determining the QOL of caregivers of stroke survivors in a Nigerian population and some patient and caregiver-related variables that may be associated with it. A survey of the QOL of volunteering informal caregivers of stroke survivors in purposively selected tertiary health centres from South-Eastern Nigeria was done using the Short Form-12 questionnaire. The study showed that older age was significantly related to poorer QOL scores.

Consistent with the above was a study by Ogunlana et al. (2014) which showed that caregivers' age affected their quality of life. Older informal caregivers reported significantly lower QOL than their younger counterparts. In a study about the QOL of informal caregivers, the caregivers reported lower levels of QOL on emotional and mental domains and the most important determinant of QOL was their own age (being older)(Jonsson et al., 2005). On the contrary, Gunduz and Erhan (2008) reported there was no relationship between QOL and age of the spousal caregiver. This may be attributed to the fact that the mean age of participants in this study was younger as compared to other studies.

### **2.3.5.3. Gender of caregiver**

The gender of caregivers; being a male or a female is reported in studies to be associated with quality of life. Gunduz and Erhan (2008) conducted a study investigating QOL of stroke patients' spouses living in the community in Turkey. Forty seven spouses of first ever stroke patients living in the community and 26 healthy controls of the same and sex range were included in the study. The clinical status of the patients were evaluated using Brunnstrom's stages of motor recovery and Modified Barthel Index whilst QOL was assessed using Short Form 36 (SF-36). The study showed that spousal caregivers reported lower quality of life. Also being a female as a spouse had a negative effect on the QOL. Ogunlana et al. (2014), conducted a cross sectional study in Nigeria on informal caregivers' burden and quality of life of caregivers of stroke survivors. One of the findings was that caregivers' gender was a significant predictor of QOL. Female gender has also been found to be a significant determinant of QOL (Akosile et al., 2011).

### **2.3.5.4. Financial constraints**

Caregiving has been reported to put considerable amount of strain on individuals involved. This may be due to the fact that mostly the survivors are rendered incapable of returning to active work after the incidence of stroke and may have to depend on others in every aspect of their lives for survival. Caregivers' on the other hand because of their caregiving role may not be fully employed or unemployed. What even worsens the problem is where the survivor was the main bread winner of the family. A study reported that financial constraints were associated with poorer QOL for both carers and care recipients (Morgan et al., 2011). This is consistent with the findings of Larson et al. (2005). Khalid & Kauser (2008) found that income of informal

caregivers is negatively correlated with depression and thus due to financial constraints, QOL also suffer.

#### **2.3.5.5. Severity of stroke/ functional status**

Survivors' functional status as recorded by Modified Rankin score and Barthel index significantly influenced the caregivers' QOL (Ogunlana et al., 2014). Thus survivors with lower scores on the Barthel index and Modified Rankin score depicting greater level of dependency found their caregivers reporting poorer QOL. Similarly, patient poor functional status was found to be a determinant of QOL (Jonsson et al., 2005). On the contrary, severity of stroke as measured by the Barthel index was not correlated with quality of life (Gunduz & Erhan, 2008).

#### **2.3.4.6 Social support**

Choi-Kwon et al. (2005) in a cross sectional study investigated factors affecting the burden on caregivers' of stroke survivors in South Korea. Random selection of 340 stroke patients was done and was evaluated 3 years post stroke. Among them, 147 caregivers and patients were finally interviewed. The finding was that the primary predictor of overall burden and poor quality of life was insufficient social support.

## 2.4. Limitations of Reviewed Literature

Various studies have defined caregivers differently and thus have not been consistent. Cameron et al. (2006) defined informal caregiver as the person's primarily responsible for providing and/or coordinating care in the home for the stroke survivor. Das, Banerjee, Biswas, Dutt and Hazra (2010) used informal caregiver to mean an unpaid person closely involved in physical (feeding, bathing, toileting, walking) and emotional care (empathetic listening, encouragement and motivation to adhere to treatment). Informal caregiver was defined as a family member or friend taking primary responsibility for managing the aftercare of the person with stroke (Teel et al, 2001). While some studies restricted the caregiver to be a family member (Fatoye et al, 2006; Grant et al, 2006; Teel et al., 2001) others focused on only spousal caregivers (Draper et al., 1992; Franzen Dhalin, 2007; Green, 2007). Some studies also did not restrict their conceptual definition of who a caregiver was (Cameron et al., 2006; Das et al., 2010)

There is no widely conventional, obvious, and explicit definition of the informal care. Currently, the unavailability of a detailed definition of an informal caregiver (in stroke or any other disease state which can cause disability) makes it complicated to work out the accurate informal caregivers' prevalence and therefore to obtain a valid and precise estimate of the frequency (incidence rate or proportion) of disease or ill health in those who have been truly exposed. In addition, lack of a clear definition is a major problem in selecting participants for, designing interventions for and applying the results of, randomized controlled trials testing interventions directed towards informal caregivers.

Additionally, different scales were used in measuring for depression, though those included in the reviewed literature were all standardized. Some of the scales included the PHQ, CES-D,

GDS, HADS and BDI. It therefore becomes difficult to compare the depressive symptomatology experienced by these caregivers as reported by the various studies. The consistency of some of the results cannot be attributed to similarity in the used of instruments. The reason being that there are studies that have used similar instruments for measuring depression as well as similar research design yet the results varied widely (Balhara et al., 2012; Dennis et al., 1998; Khalid & Kauser, 2008; Morimoto et al., 2003). Other studies reported significant relationship between the caregiver and depression, however, non standardized rating for depression was used (Brockhurst, 1981; Christopher, 1999). Though results were consistent with previous researches, non standardized instruments can compromise the results of any study.

Furthermore, in evaluating QOL of informal caregivers various scales were used. For example Khalid and Kauser (2008) used the WHO QOL BREF scale which constitutes 26 items. Ogunlana et al. (2014) and Gunduz and Erhan (2008) used the Personal wellbeing index and Short form-36 health Survey Questionnaire (SF-36) respectively. The Short Form 12 item Health Survey Questionnaire (SF-12) was used by Akosile et al. (2011). The SF-36 measures eight concepts while the WHO QOL scale measures four domains. Sometimes, it may be difficult comparing results from different studies which have used different instruments for measuring QOL. Though QOL has being restricted to three main domains (physical, psychological and social), it is a multidimensional and difficult to define.

In addition to the above, there is a well known association between being a female and high risk for depression (van den Huevel et al., 2001). The recruitment of more females in various studies may increase the estimates of depression. Most studies reviewed recruited more females than males. From the reviewed literature the highest proportion of female recruit was a study by Grant et al. (2006) reporting 46(88.5%) as participant and the least by Haley et al (2009) reporting

59(59%). Only few studies have found more men to be informal caregivers (Ogunlana et al., 2014).

## **2.5. Summary of reviewed literature**

The Stress Process Model (Pearlin et al., 1990) and the Transactional Model of Stress (Lazarus & Folkman, 1984) provided the theoretical basis for this study. Each of the models was explained in the light of various variables in the study. The Stress Process Model provides a structure to examine the caregiver outcomes that occur from one phase to the other. In this model, the background and the context in which care is given includes socio demographic characteristics explained as influencing outcome of caregiving. Also certain resources were mentioned to moderate the relationship between the socio demographic variables and caregiving outcomes (depression and quality of life). The transactional model of stress also examines primary and secondary appraisals that mediate stressors. The secondary appraisals include the social and cultural resources.

Some researchers have associated caregiving with positive outcomes (Harper & Lund, 1990; Kramer, 1997; Norris, 1995) whilst others have reported negative outcomes (Cannuscio et al., 2002; Stein et al., 1992). Researchers have mainly focused on caregiver burden (Low et al., 1999; Ross & Morris, 1998), emotional distress (Fatoye et al., 2006), psychosocial burden (Draper et al., 2002; Thommessen et al., 2002), anxiety (Balhara et al., 2002) and depression (Berg et al., 2006; Cameron et al., 2006).

Depression appears to be the mostly widely psychological morbidity investigated by the reviewed studies (Bakas et al., 2006; Haley et al., 2006; Khalid & Kauser, 2008). Few studies

have focused on the quality of life of caregivers of stroke survivors (Teel et al., 2001; White et al., 2003). Some demographic variables have been demonstrated in these studies as significantly predicting depression and quality of life. These variables include age, sex, employment status, relationship to the caregiver, education, financial constraints and duration of caregiving (McCullagh et al., 2005; Gunduz & Erhan, 2008; van den Huevel et al., 2001; DeLeeuw et al., 2000). However, the association between these demographic variables and depression/ QOL is not consistent.

The role of social support in the outcome of the caregiver (depression and quality of life) have been reviewed in some studies (Khalid & Kauser, 2008; Blake et al., 2003; DeLeeuw et al., 2000; Grant et al., 2000) demonstrating a consistent pattern of social support serving as a protective factor against development of depression. In other words, the more a caregiver has social support, the less likely for the person to be depressed. This is due the fact that social support provides caregivers' with better coping resources. However, some studies (Chavalisz & Vaux, 2000) have also not demonstrated such protective ability of social support. Thus the influence of social support on depression and quality of life remain inconclusive.

Finally, studies have observed that a significant relationship exist between depression and quality of life among family caregivers (Jonsson et al., 2005; Suenkeler et al., 2002). This means that caregivers who are depressed are more likely to have poorer quality of life. Interestingly, other studies have not found a significant relationship (Fatoye et al., 2006; Balhara et al., 2002). The relationship between depression and quality of life still remains unclear.

## **2.6. Rationale of the study**

Environmental and contextual factors are critical in determining the behaviour of a particular group. Cuellar (2002) found that cultural variations have been observed to influence the response of caregivers to the burden of caregiving. Indeed, the environmental and contextual factors of Europe may differ considerably from that of Ghana. Thus, the depressive symptoms as well as the quality of life of the caregivers of stroke survivors and non-stroke survivors would be different across the various regions. This study will address the phenomenon as applied in the Ghanaian context.

In addition to the above, few studies have compared caregivers of stroke survivors with other control groups with most of them studying only the caregivers (Das et al., 2010; Bakas et al., 2006; Berg et al., 2006; Cumming et al., 2004). Without the inclusion of non caregivers or other control groups, it is difficult to define the extent of caregiver outcomes beyond or below those found in the general population having demographic status similar to that of stroke caregivers (Ward, Morisky & Jones, 1996). For example Anderson et al. (1995) in their study did not compare caregivers with non caregivers or with other caregivers involved with other disabling illnesses, therefore, it cannot be concluded that stroke related disability has differential effect on caregivers. Han & Haley (1999) posits that it is necessary to compare caregivers and non caregivers in order to differentiate unique stroke caregiving impacts. Therefore, this work will compare the depressive symptoms and the quality of life of both caregivers of stroke survivors and non-caregivers. The non-caregivers will serve as a control for comparing with the caregivers.

It is relevant to note that, the complexity of caregiving cannot be done without the family. Very few studies have concentrated on family caregivers of stroke survivors (Grant et al., 2009;

Fatoye et al., 2006). There is the need therefore for a study that will uniquely consider the family caregiver and see if the results will be consistent with previous studies. Also, most of the studies reviewed either looked at depression among family caregivers (Fatoye et al., 2006; Kamel, Bond & Froelicher, 2011) or quality of life of stroke caregivers (Puymbroeck & Rittman, 2005). Few studies have looked at both variables among family caregivers (Khalid & Kauser, 2008). There is the need for a study which will consider both depression and quality of life of these family caregivers and non-caregivers. This will help establish whether a relationship exists between depression and quality of life of the caregiver. Again, the reviewed literature does not clearly state whether depression affects the quality of life of the caregiver and if it does in which way?

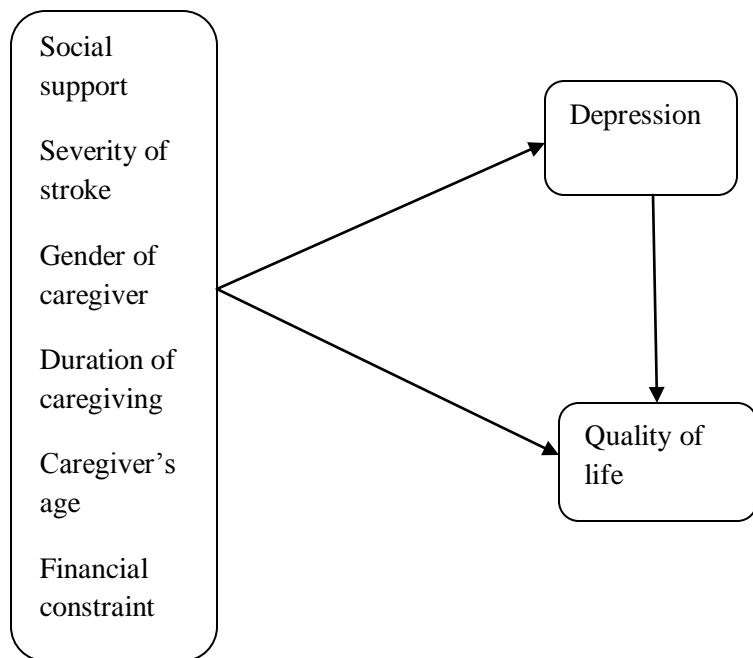
Finally, there is a dearth of data on depressive symptoms and quality of life of caregivers of stroke survivors and non caregivers on Ghana. Only a few studies are available even on Africa (Akosile et al., 2011; Fatoye et al., 2006; Ogunlana et al., 2014). It will therefore be necessary to conduct such a study in Ghana.

## **2.7. Statement of hypothesis**

1. Hypothesis 1 states non caregivers will report lower level of depression than caregivers of stroke survivors. Studies have observed that caring for a stroke survivor places the caregivers in a high risk for depressive symptomatology when measured on depression (Berg et al., 2006; Bakas et al., 2006).

2. Hypothesis 2 states that non caregivers will report better quality of life compared to caregivers of stroke survivors. Stroke caregiving has been described to affect the quality of life of the caregivers as compared to the control group (non caregivers) (White et al., 2003; Schulz et al., 1997).

3. Hypothesis 3 states that caregivers who have high social support will report lower level of depression and better QoL than caregivers who have low social support. Family caregiver's depression is best predicted by the lack of tangible social support (Khalid & Kauser, 2008).
4. Hypothesis 4 states that there will be significantly positive relationship between depression and quality of life of caregivers. Depression has been reported to be one determinant of poorer quality of life (Suenkeler et al., 2002).
5. Hypothesis 5 states that social support; severity of stroke, duration of care, age of caregiver, gender and financial constraint will significantly predict depression among caregivers of stroke patients (Chumbler et al., 2008; Jönsson et al., 2005; Smith et al., 2004).
6. Hypothesis 6 states that severity of stroke, duration of care, age of caregiver, gender and financial constraint will significantly predict quality of life among caregivers of stroke patients (McCullagh et al., 2005).

**Figure 1: Hypothesized Model**

## 2.8. Operational definition

*Family Caregiver:* An individual who is 18 years and above, a family member and the primary caregiver of a stroke survivor.

*Non caregiver:* A person who is 18 years and above and is not a primary caregiver either for a stroke survivor or any other individual with a form of disability.

*Quality of Life:* It is a person's general view on how good their life is.

*Depression:* Unusually prolonged feelings of sadness.

*Stroke survivor:* Any individual alive, post stroke attack.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 Population**

The primary population comprised family caregivers at the Korle-Bu Teaching Hospital (KBTH). It is the main referral point in Ghana and hence it is likely to find people with varying demographic and socioeconomic background. Since this was a maiden study in the country, a varied level of demographic qualities was easier and possible at a tertiary-level health provider like the Korle-Bu Teaching Hospital.

#### **3.2 Sample size determination**

A sample size of one hundred (100) respondents comprising fifty (50) family caregivers and fifty (50) non caregivers were sampled. This sample size was arrived at by using Epi-info TM sample size calculation for unmatched Case-Control Studies Version 3.03.17 (Centers for Disease Control and Prevention, 2012). Using the Kelsey formula, an alpha of 0.05 and a power of 80 gave a calculated sample size forty-four (44) case group and forty-four (44) control group. In order to decrease the chances of non-response case effects on the test outcomes, an additional six (6) respondents were added to each of the groups, thus the sample size was one hundred(100); fifty (50) caregivers of stroke survivors and fifty (50) non caregivers.

### **3.3 Sampling technique**

The purposive sampling method was used to select case samples. This was due to the specialized nature of the study and the selective nature of samples to suit the study. Exclusions of controls was based on any cognitive contra-indications like dementia, central nervous system disease, and unstable medical illness, other Axis 1 disorders (including bipolar disorders), drug or alcohol dependence, head trauma and or refusal to be tested.

### **3.4. Participants**

Family caregivers who brought their stroke survivors to the OPD of the Stroke and Physiotherapy Units of the hospital were contacted and screened to find out if they meet the inclusion criteria. Non caregivers were also identified at the same premises like the caregiver. However, the non caregiver was involved in any primary caregiving role in the last three months.

Participants' selection criteria were based on the following criteria:

#### **Family caregiver group (FCG)**

##### **Inclusion Criteria**

1. The caregiver should be a family member of the stroke survivor
2. The informal caregiver should be 18 years and above.
3. The person should be the primary caregiver who assists the stroke survivor in ADL as well as other things like taking the stroke survivor to the hospital.
4. Should have provided care for at least one month.

#### Exclusion criteria

1. Below 18 years
2. With any past psychiatric illness, severe physical illness or
3. Refusal to willfully participate or offer consent.

#### **Non caregiver group (NCG)**

##### Inclusion criteria

1. The non-caregiver should be 18 years and above.
2. Should not be a primary caregiver providing care for a family member with disability.
3. Not from the same family as the caregivers. This is because in a family with persons with disability, more than one person may be assisting but may not be the primary caregiver.

##### Exclusion Criteria

1. Less than 18 years
2. With any past psychiatric illness, severe physical illness or
3. Refusal to willfully participate or offer consent.

**Table 1***Descriptive Frequency and Percentages of the Family Caregiver and Non caregiver Group*

Variable	Category	FCG (n-50)	NCG(n-50)
		Frequency (%)	Frequency (%)
<b>Sex</b>	Male	12(24%)	16(32%)
	Female	38(76%)	34(68%)
<b>Educational level</b>	Primary	13(26%)	15(30%)
	Junior high	22(44%)	19(38%)
	Secondary school	8(16%)	6(12%)
	Tertiary	7(14%)	10(20%)
<b>Employment</b>	Unemployed	20(40%)	6(12%)
	Employed full time	24(48%)	41(82%)
	Employed part time	4(8%)	2(4%)
	Retired	2 (4%)	1(2%)
<b>Relationship to the stroke survivor</b>	Spouse	23(46%)	
	Child	2(4%)	
	Parent	16(32%)	
	Sibling	7(14%)	
	Aunt/uncle	2(4%)	
<b>Caregiving Duration</b>	1-6 months	39(78%)	
	7-12 months	5(10%)	
	> 12 months	6(12%)	
<b>Social support</b>	Available	27(54%)	
	Unavailable	23(46%)	

### **3.5. Research Design**

The study employed a cross sectional survey design. This is because the study was intended to take place at a single point in time. Again, the researcher was not interested in manipulating variables as well as drawing causal relations.

### **3.6. Instruments**

The tests administered to measure various variables in the study included the Beck Depression Inventory (BDI), WHO Quality of life BREF (WHOQOL BREF), Multidimensional Scale of Perceived Social Support (MSPSS) and Barthel Index (BI).

#### **3.6.1. The Beck Depression Inventory (Beck, Steer & Brown, 1996)**

The BDI is a series of questions developed to measure the intensity, severity and depth of depression. It is composed of 21 questions or items, each with four possible responses. Each response is assigned a score ranging from zero to three, indicating the severity of the symptom. Individual questions of the BDI assess mood, pessimism, sense of failure, self dissatisfaction, guilt, punishment, self-dislike, self-accusation, suicidal ideas, crying, irritability, social withdrawal, body image, work difficulties, insomnia, fatigue, appetite, weight loss, bodily pre occupation and loss of libido.

Items 1 to 13 assess symptoms that are psychological in nature, while items 14 to 21 assess more physical symptoms. The sum of all BDI scores indicates the severity of depression. The test is scored differently for the general population and for individuals who have been clinically diagnosed with depression. For the general population, a score of 21 or over represents depression. For people who have been clinically diagnosed, scores from 0 to 9 represent minimal

depressive symptoms, scores of 10 to 16 indicate mild depression, scores of 17 to 29 indicate moderate depression and scores of 30 to 63 indicate severe depression.

The BDI can distinguish between different subtypes of depressive disorders, such as major depression and dysthymia. It takes approximately 10 minutes to complete the items on the BDI. Internal consistency for the BDI ranges from .73 to .92 with a mean of .86. Similar reliabilities have been found for the 13-item short form. The BDI demonstrates high internal consistency, with alpha coefficients of .86 and .81 for psychiatric and non-psychiatric populations respectively.

### **3.6.2. The WHO Quality of Life- BREF (WHOQOL, 2007)**

The WHOQOL-BREF is cross-culturally comparable quality of life measure, developed collaboratively and field-tested across a number of cultural contexts. It assesses the individual's perceptions in the context of their culture and value systems, and their personal goals, standards and concerns. The instrument comprises 26 items which measure four broad domains namely; physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). Two other items measure overall QOL and general health.

Each domain has certain facets incorporated within. For example the facets incorporated within the physical health domain include activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest and work capacity. Social relationship facets include personal relationships, social support and sexual activity. Items are rated on a 5-point Likert scale (low score of 1 to high score of 5) to determine

a raw item score. Cronbach alpha values for each of the four domain scores ranges from .66 to .84.

### **3.6.3. The Barthel scale or Barthel ADL index (O'Suivillan & Schmitz, 2007)**

The index is an ordinal scale that measures the extent to which somebody can function independently and has mobility in their activities of daily living (ADL). It also indicates the need for assistance in care. The Barthel index is a widely used measure of functional disability and was developed for used in rehabilitation patients with stroke and other neuromuscular or musculoskeletal disorders, but may be used for oncology patients as well. It consists of ten (10) items.

Items are rated in terms of whether individuals can perform activities independently, can perform with some assistance or are totally dependent. Each performance item is rated on this scale with a given number of points assigned to each level or ranking. Higher scores reflect greater independence. A score of 91-99 suggests slight dependence, 61-90 moderate dependence, 21-60 severe dependence and 0-21 total dependence. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital.

The amount of time and physical assistance required to perform each item are used in determining the assigned value of the item. External factors within the environment affect the score of each item. If adaptations outside the standard home environment are met during assessment, the participant's score will be lower if these conditions are not available. If adaptations to the environment are made, they should be described in detail and attached to the

Barthel index. The Barthel index has demonstrated high interrater reliability (0.95) and test re-test reliability (0.89) as well as high correlations (0.74–0.8) with other measures of physical disability.

#### **3.6.4. Multidimensional Scale of Perceived Social Support (Zimet et al., 1988; 1990)**

This is a short 12 item social support scale that assesses the adequacy of a person's perceived social support from family, friends and significant others. The items are easy to understand and it is therefore suitable for use with populations that may experience limited literacy levels. Respondents use a Likert-type scale to rate each item from Very Strongly Agree to Very Strongly Disagree (Levin, 2004). The questions are all positively worded but it has been reported that MSPSS is relatively free from social desirability bias (Cheng & Chan, 2004; Kazarian & McCabe, 1991).

Levin (2004) claims the MSPSS has demonstrated adequate reliability and validity. For the Significant Other, Family and Friends subscales, the internal are .91, .87 and .85 respectively. The reliability of the total scale is .88.

#### **3.7. Pilot Study**

A pilot study was conducted prior to the main study. It was conducted by administering the scales to 10 family caregivers at the out-patient department of the Ridge Regional Hospital. The aim of the pilot study was to ascertain the appropriateness, reliability and validity of the adopted tests on Ghanaian clinical samples. It was also conducted to ascertain whether participants would

have any difficulty responding to the measures and also to determine an estimated time for the study. The Cronbach alpha (Internal Consistency) was run for each scale and their respective sub-scales. The results of the internal consistency measures are summarized in the Table 2 below;

**Table 2**

*Internal Consistencies of the Scales from a Pilot study of 10 Family Caregivers of Stroke Survivors*

<b>SCALE</b>	<b>Internal consistency(Cronbach alpha)</b>
<b>Beck Depression Inventory (BDI)</b>	0.87
<b>Barthel Index (BI)</b>	0.81
<b>Multidimensional Scale of Perceived Social Support (MSPSS)</b>	0.92
<b>WHO QOL BREF</b>	0.93
<b>Physical domain</b>	0.77
<b>Psychological domain</b>	0.81
<b>Social domain</b>	0.68
<b>Environmental domain</b>	0.76

From Table 2 above, the Beck Depression Inventory has a Cronbach alpha value of .87, the WHO QOL BREF has a Cronbach alpha value of .93, the Barthel Index has a Cronbach

alpha value of .81 and the Multidimensional Scale of Perceived Social Support has a Cronbach alpha of .92.

### **3.8. Procedure**

Ethical clearance to carry out the research was sought from the Ethical Committee for Humanities (ECH), University of Ghana, Legon (Appendix A). After approval from the ECH, an introductory letter from the Psychology Department (Appendix B) together with the ethical clearance were sent to the Korle Bu Teaching Hospital (KBTH) more specifically the department heads of the Stroke and the Physiotherapy Units for introduction as well as permission to carry out the study.

After permission was granted, a date was fixed for the commencement of data collection. One research assistant was recruited for the data collection and was trained on the administration of the questionnaires. The Out Patient Departments of the Stroke and Physiotherapy Units were used for the data collection. On days during which data was collected, the researchers were introduced to patients waiting for their turn for physiotherapy or waiting to see a doctor (at the stroke unit).

Though the focus of the study was not the stroke survivor, they were key in identifying who their primary caregiver was. Family members who were identified as primary caregivers and were willing to participate in the study were given consent form to write their names (for confidentiality initials were permitted) and then sign or make a mark to indicate their voluntary participation. The respondents who could read and write were administered the questionnaires in pen and paper form. On the other hand, those who could not write were interviewed following

the questionnaire format. During the data collection, those who were not able to complete were not forced to do so, however, their uncompleted questionnaires were not included in the analysis. The data collection lasted for six weeks. The completed questionnaires were then sorted out for analysis.

## CHAPTER FOUR

### RESULTS

#### 4.1 Introduction

This chapter contains results of the analyses done with the data collected. To test the stated hypotheses, the SPSS version 21.0 was used to analyze the data. Following all the assumptions required for parametric test selection and usage, the hypotheses were tested with Independent t-test, One-way Multivariate Analysis of Variance (MANOVA), Multiple regression, Sobel test and Partial correlation.

The Independent t Test was used to access the differences between the caregiver group and the non caregiver control group on depression and quality of life levels. MANOVA establish the difference after the participants were divided into two groups based on their overall mean score on social support and measured on depression and quality of life. The Sobel test was used to test for the mediation effect of depression. Multiple regression analysis was used to identify the predictors of quality of life among the respondents.

The data was further screened for possible missing data and outliers in the data. In addition, other data transformations which included calculation of grand and subscale scores of the behaviour measures were done before continuing with the hypothesis testing. The chapter contains descriptive statistics, correlation matrix, hypotheses testing and summary of findings.

## 4.2 Descriptive Statistics

The summary of the means, standard deviations of scores on Severity of stroke/dependence index, Social support, Depression, Quality of life and age, and Cronbach alpha ( $\alpha$ ) of their respective scales are presented in Table 3.

**Table 3**

**Means, standard deviation and Cronbach alpha of variables**

Variable	Mean	SD	$\alpha$
Severity of stroke/dependence index	54.90	20.29	.83
Social support	45.28	13.47	.92
Depression	6.21	5.75	.83
Quality of life	84.11	12.45	.93
Age	41.69	9.76	-

Pearson product moment correlation was also used to find out if relationships exist among the variables. Results are presented in table 4.

**Table 4:**

**Correlation matrix representing the relationship among variables**

Variables	1	2	3	4	5	6	7
<b>1. Social support</b>	-						
<b>2. Severity of stroke</b>	.05	-					
<b>3. Duration of care</b>	-.21	.11	-				
<b>4. Age of caregiver</b>	-.12	.08	.35*	-			
<b>5. Financial constraint</b>	-.90**	-.01	-.08	-.38**	-		
<b>6. Depression</b>	-.60**	.01	.16	.09	.58**	-	
<b>7. Quality of life</b>	.56**	.08	-.27	-.28	.66**	-.66**	-
<b>8. Gender</b>	.14	.27	-.09	-.40**	.45**	-.16	.37**

\*Significant at the .05 level of significance (2-tail) \*\*significant at the .01 level of significance (2-tail)

Table 4 presents correlation matrix representing the relationship among variables. Financial constraints and social support were correlated to depression. Social support, financial constraint, gender and depression were significantly related to QOL.

### 4.3 Hypotheses Testing

Chi-square Goodness of fit test was used to assess the level of depression among caregivers of stroke survivors.

Table 5 represents chi-square statistics of level of depression among caregivers of stroke patients.

**Table 5**

*Frequency and chi-square representing level of depression among caregivers*

<b>Level of depression</b>	<b>Observed frequency</b>	<b>Expected frequency</b>	<b><math>\chi^2</math></b>	<b><math>\rho</math></b>
<b>Normal</b>	42	16.7	58.24	.000
<b>Mild</b>	6	16.7		
<b>Moderate</b>	2	16.7		
<b>Total</b>	50			

Table 5 shows that a significant number of caregivers (42) did not show clear signs of clinical depression representing about 84 % of the participants. Mild depression was found in 12 % of caregivers. Only 4 % had moderate depression and none of the caregivers reported severe depression [ $\chi^2(1, N = 50) = 58.24, \rho < .05$ ] and the differences were significant at the .05 level of significance. This shows that level of depression is low among caregivers of stroke survivors.

**H1:** *Non-caregivers will report lower level of depression than caregivers of stroke patients.*

To analyze this hypothesis, the Independent t-test was used. Results are presented in Table 6.

**Table 6:**

*Summary of results on independent t-test comparing caregivers and non-caregivers on depression.*

<b>Groups</b>	<b><i>n</i></b>	<b>Mean</b>	<b><i>SD</i></b>	<b><i>t</i></b>	<b><math>\rho</math></b>
<b>Caregivers</b>	50	8.94	5.34	5.37	.000
<b>Non-caregivers</b>	50	3.48	4.81		

From Table 6, it was found out that a significant difference exist between caregivers of stroke patients and non-caregivers on their depression scores [ $t(97) = 5.37, \rho < .05$ ; equal variances not assumed]. Further analysis of the means of the two groups reveal that caregivers of stroke patients reported higher levels of depression [ $M = 8.94, SD = 5.34$ ] than non-caregivers [ $M = 3.48, SD = 4.81$ ] which was statistically significant at the .05 level of significance. This means that the stated hypothesis that “non-caregivers will report a significant lower level of depression than caregivers of stroke patients” was supported.

**H 2:** *Non-caregivers will report better quality of life compared to caregivers of stroke patients.*

The Independent t-test was used to compare caregivers of stroke patients and non-caregivers on quality of life (QOL). Summary of findings are presented in Table 7.

**Table 7:**

*Summary of results on independent t-test comparing caregivers and non-caregivers on QOL*

<b>Groups</b>	<b><i>n</i></b>	<b>Mean</b>	<b><i>SD</i></b>	<b><i>t</i></b>	<b><i>p</i></b>
<b>Caregivers</b>	50	79.52	12.04	-3.95	.000
<b>Non-caregivers</b>	50	88.70	11.19		

Table 7 shows that a significant difference exist between caregivers of stroke patients and non-caregivers on their quality of life [ $t(98) = -3.95, p < .05$ ; equal variances assumed]. Examination of means shows that caregivers of stroke patients reported poorer quality of life ( $M=79.52, SD=12.04$ ) compared to non-caregivers ( $M = 88.70, SD = 11.19$ ) which was significant at the .05 level of significance. This implies that the hypothesis which states that “Non-caregivers will report better quality of life compared to caregivers of stroke patients” was supported.

**H 3:** *Caregivers who have high social support will report lower level of depression and better quality of life (QOL) than caregivers who have low social support.*

This hypothesis was analyzed using MANOVA after the participants were divided into two groups based on their overall mean score on social support (~45). The multivariate test shows that a significant difference exists between the groups [ $F(2, 47) = 14.90, p < .05, \eta^2 = .39$ ;

Wilk's Lambda = .612,  $\rho < .05$ ]. The summary of MANOVA results and means of the groups on depression and quality of life scores are presented in Table 8:

**Table 8**

**Summary of Means and MANOVA Results of depression and QOL between the groups**

<i>Dependent variable</i>	<i>Low SS</i> ( <i>n =24</i> )	<i>High SS</i> ( <i>n = 26</i> )	<i>df</i>	<i>F</i>	<i>ρ</i>	<i>η<sup>2</sup></i>
Depression	12.25	5.88	1, 48	27.24	.000	.36
Quality of life	72.75	85.77		20.37	.000	.30

The MANOVA table in Table 8 clearly shows that a significant difference exists between the two groups being compared on both depression and quality of life [ $F(1, 48) = 27.24, \rho < .05; \eta^2 = .36$ ]; [ $F(1, 48) = 20.37, \rho < .05; \eta^2 = .30$ ] for depression and quality of life respectively. The results show that caregivers of stroke patients with high social support reported lower level of depression ( $M = 5.88 < M = 12.25$ ) and better quality of life ( $M = 85.77 > M = 72.75$ ) than those with low social support and these differences were significant at the .05 level of significance.

**H 4:** *The relationship between depression and quality of life among caregivers of stroke patients will be statistically significant.*

Table 4 showing result from Pearson correlation reveal that a strong relationship exists between depression and quality of life [ $r(48) = -.66, \rho < .05$ ] which is significant at the .05 level of significance. The hypothesis was therefore supported.

Also, results from the Pearson correlation (Table 4) shows that a strong relationship exists between social support (Independent variable) and depression (mediator) [ $r(48) = -.60, \rho < .05$ ] which is statistically significant at the .05 level of significance. Again, social support also had a significant relationship with quality of life (outcome) ( $r(48) = .56, \rho < .05$ ). This means that the conditions for mediation analysis have been met. Multiple regression analysis and Sobel test were used. Results are summarized in Table 9.

**Table 9**

*Summary results of Mediation effect of depression on the relationship between social support and QOL*

Variables	$R^2$	$\Delta R^2$	SEB	B	$\beta$	$t$	$\rho$
Depression on QOL	.52		.23	-1.63	-.72	-7.21	.000
Social support on depression	.36		.05	-.24	-.60	-5.19	.000
Step 1	.31						
Social support			.11	.50	.56	4.65	.000
Step 2	.55	.23					
Depression			.28	-1.36	-.60	-4.91	.000
Social support			.11	.18	.20	1.59	.118

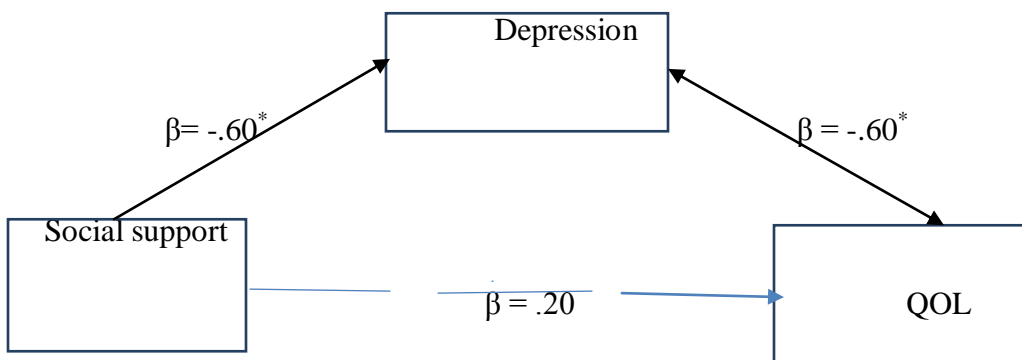
Table 9 shows that depression (disregarding the effect of social support) accounted for about 72% variance in quality of life which was statistically significant at the .05 level of significance ( $\beta = -.72; t = -7.21, \rho < .05$ ), social support also accounted for 60% variance in depression which was also statistically significant at the .05 level of significance ( $\beta = -.60; t = -5.19, \rho < .05$ ). Social support alone, disregarding the effect of depression (mediator) when put in the model in

step 1 accounted for 56% of variance in quality of life which was statistically significant at the .05 level of significance ( $\beta = .56, t = 4.65; \rho < .05$ ). However in step 2, after controlling for depression, the variance accounted for by social support in quality of life reduced drastically and was not statistically significant ( $\beta = .20, t = 1.59; \rho > .05$ ) while the relationship between depression and quality of life continued to be statistically significant (despite a reduction) after controlling for the effect of social support ( $\beta = -.60, t = -4.91; \rho < .05$ ).

Sobel test was used to ascertain the significance of the mediation effect of depression. The Sobel test revealed that the mediation effect of depression on the relationship between social support and quality of life is statistically significant at the .05 level of significance ( $Z = -1.63; \rho = .05$ ). This finding indicates that depression significantly mediated the relationship between social support and quality of life among caregivers of stroke patients.

Figure 2 represents summary of mediation model

**Figure 2: Mediation Model Summary**



**H 5:** *Severity of stroke, caregiver's age duration of care, gender and financial constraint will significantly predict depression among caregivers of stroke patients.*

Results from Pearson correlation presented in Table 4 shows that only financial constraint had a significant relationship with depression ( $r(48) = .58; \rho < .05$ ), severity of stroke, duration of care, and gender had no significant relationship with depression [ $r(48) = .01; \rho > .05; r(48) = .16; \rho > .05; r(48) = -.16; \rho > .05$  respectively] therefore there was no need for further analysis to ascertain the predictive ability of these variables. This means that the stated hypothesis was not supported. However since financial constraint had a significant relationship with depression, partial correlation was used to explore the relationship between financial constraint and depression while controlling for social support. Results reveal that controlling for social support resulted in a significant reduction in the strength of relationship between financial constraint and depression, and the relationship was no longer statistically significant after controlling for social support ( $r(47) = .12; \rho > .05$ ). This implies that the observed relationship between financial constraint and depression is due to social support.

**H6:** *Severity of stroke, caregiver's age, duration of care, gender and financial constraint will significantly predict quality of life among caregivers of stroke patients.*

From the correlation matrix (Table 4), only financial constraint and gender had significant relationships with quality of life, so only these two variables were used in further analysis. To test this hypothesis, the variables were re-coded into dummy variables and the multiple regression analysis was used to find out their predictive ability. For financial constraint, those who reported no financial constraint were used as a reference group, and for gender, females

were used as the reference group. A significant model emerged; [ $R^2 = .34$ ;  $F = 12.32$ ,  $\rho < .05$ ] and the model accounted for about 34% of the variance in quality of life.

The results of the individual contributions of financial constraint and gender are presented in Table 10.

**Table 10**

*Multiple Regression Analysis of the Contributions of financial constraint and gender to QOL*

<b>Variable</b>	<b><i>B</i></b>	<b><i>SEB</i></b>	<b><math>\beta</math></b>	<b><i>t</i></b>	<b><math>\rho</math></b>
<b>Constant</b>	82.50	2.16		38.28	.000
<b>Financial constraint</b>	-10.95	2.85	-.46	-3.84	.000
<b>Gender</b>	8.57	3.33	.31	2.57	.013

$R^2 = .34$ ;  $\rho = .000$  Adjusted  $R^2 = .32$

Table 10 shows that financial constraint contributed about 46% of the variance in quality of life which was significant at the .05 level of significance ( $\beta = -.46$ ;  $\rho < .05$ ) and the relationship was negative which means that the more a person has financial constraint the poorer his or her quality of life. Gender contributed about 31% of the variance in quality of life which was also significant at the .05 level of significance ( $\beta = .31$ ;  $\rho < .05$ ). This means that a change in the gender of a caregiver of stroke patients from being female (since female is the referent group) to male predicts a significant variation in quality of life. It can also be seen that financial constraint predicted more variance in quality of life than gender ( $\beta = -.46 > \beta = .31$ ).

Age was only found to be a significant predictor of QOL when categorized thus younger and older caregivers. The independent t-test was used to test for the differences between the two groups on depression and quality of life in both hypotheses. Results are presented in Table 11.

**Table 11**

*Means, standard deviations and t-test of differences between younger and older caregivers*

<b>Variable</b>	<b>Younger</b>	<b>Older</b>	<b><i>t</i></b>	<b><i>ρ</i></b>
	<b>M(SD)</b>	<b>M(SD)</b>		
<b>Depression</b>	7.96 (5.37)	9.92 (5.24)	-1.31	.197
<b>QOL</b>	83.00 (11.42)	76.04 (11.84)	2.12	.040

Results from Table 11 indicate that though younger caregivers reported less depression than older caregivers ( $M = 7.96 < M = 9.92$ ), the difference between the two groups was not statistically significant at the .05 level of significance ( $t = -1.31, \rho > .05$ ). However a statistically significant difference existed between the two groups when it comes to quality of life, at the .05 level of significance ( $t = 2.12, \rho < .05$ ). Younger caregivers reported better quality of life than older caregivers ( $M = 83.00 > M = 76.04$ ).

#### 4.4 Summary of Findings

1. Level of depression among caregivers of stroke survivors is low in the present sample. However, non-caregivers reported a significant lower level of depression than caregivers of stroke patients.
2. Non-caregivers reported better quality of life compared to caregivers of stroke patients. The differences in quality of life between the two groups was however not significant for environmental domain of quality of life but was significant for physical, psychological and social.
3. Caregivers of stroke patients who have high social support reported lower level of depression and better quality of life than those who have low social support.
4. The relationship between social support and quality of life was significantly mediated by depression.
5. Severity of stroke, duration of care, and gender did not significantly predict depression, but financial constraint had a significant positive relationship with depression.
6. The relationship between financial constraint and depression was found to be no longer statistically significant after controlling for social support, which shows that the relationship between the two variables was due to social support.
7. Severity of stroke and duration of care did not predict quality of life significantly, but gender and financial constraint did. Financial constraint also predicted more variance in quality of life than gender.
8. Younger and older caregivers did not differ significantly on their level of depression. However younger caregivers reported better quality of life than older caregivers. In

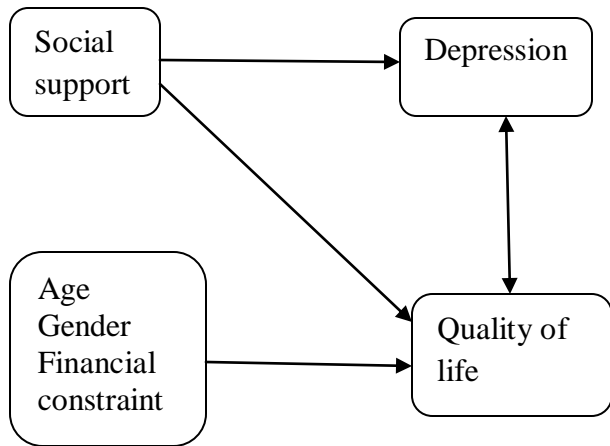
addition the differences in quality of life were only significant for psychological and environmental domains of quality of life.

#### 4.5. Additional Findings

Further analysis was done to find out how caregivers and non-caregivers differed on the various domains of quality of life; physical, psychological, social and environmental using MANOVA. Results revealed that caregivers reported poorer quality of life on all domains than non-caregivers except environmental domain of quality of life [ $F(1, 98) = 9.05; \rho < .05$ ]; [ $F(1, 98) = 23.45; \rho < .05$ ]; [ $F(1, 98) = 33.61; \rho < .05$ ]; [ $F(1, 98) = 2.74; \rho > .05$ ] for physical, psychological, social and environmental respectively. It was also found out that the social domain of quality of life was the most affected as it had the highest effect size ( $\eta^2 = .26$ ), followed by psychological domain ( $\eta^2 = .19$ ) and then physical ( $\eta^2 = .09$ ) See appendix Ca for table.

In addition, it was also found out that though younger caregivers reported better quality of life than older caregivers, the two age groups did not differ significantly in all domains of quality of life. Result from MANOVA shows that the groups did not differ significantly in physical and social domains ( $F(1, 48) = 2.20; \rho > .05$ ;  $F(1, 48) = .04; \rho > .05$ ). Significant differences existed in the psychological and environmental domains ( $F(1, 48) = 8.54; \rho < .05$ ;  $F(1, 48), \rho < .05$ ). See appendix Cb for table.

**Figure 3: Observed Model**



## **CHAPTER FIVE**

### **DISCUSSION**

#### **5.1 Introduction**

The aim of this study was to investigate depressive symptoms and quality of life among family caregivers of stroke survivors. The specific objectives of the study included: To assess the level of depression among family caregivers of stroke survivors and non-caregivers; to examine the quality of life of family caregivers of stroke survivors; to find out whether severity of stroke, financial constraints, social support, caregivers' age, duration of caregiving, gender can influence family caregiver depression and quality of life. Lastly, to investigate the relationship that exists between depression and quality of life of caregivers. This chapter contains discussion of findings, implications of the study, recommendations, limitations, and conclusions.

#### **5.2 Discussion of Findings**

##### **Level of Depression among Family Caregivers of Stroke Survivors**

The study sought to assess the level of depression among family caregivers of stroke survivors. It was hypothesized that non-caregivers will report lower level of depression than caregivers of stroke survivors. It was found out that depression level among the caregivers was generally low with a significant number of the participants reporting minimal level of depression. This finding suggests that the prevalence of clinical depression may not be very high among family caregivers of stroke survivors in the present sample. This may be due to the fact that Ghana is a collectivist country hence, though one individual may be the primary caregiver of the stroke survivor, other family members might help out with the care. In the present study for instance, more than half of

the caregivers reported having other sources of support in giving care to the patient (refer to Table 1). The impact of the burden of care on the caregiver is therefore less compared to perhaps individualistic cultures. This is consistent with studies which reported low prevalence of depression among caregivers of stroke survivors (Bakas et al., 2006; Fatoye et al, 2006). Some studies however reported high prevalence of depression among caregivers of stroke survivors (Berg et al., 2006; Grant et al., 2004; Khalid & Kausar, 2008).

Even though the level of depression was generally low in both groups, non-caregivers reported lower level of depression than caregivers of stroke survivors. This may be because stroke usually has a sudden onset and so caregivers are mostly unprepared but still have to take on the care of survivors and cope with the situation. As most survivors become dependent on their family caregivers for their day to day activities depending on the severity of the stroke, it puts strain on the physical and psychological well-being of the caregivers which non-caregivers do not experience. It is therefore not surprising that caregivers reported higher level of depression than non-caregivers. Sometimes the stress level could be overwhelming and result in other serious psychological problems including depression. Caregivers of stroke patients would therefore have elevated level of depression compared to the general population, the severity however may depend on other factors (Pearlin et al., 1990). Depression is one of the most reported psychological outcomes of caregiving of stroke survivors in the literature (Khalid & Kausar, 2008; Haley et al., 2009). The finding of the present study is consistent with other studies who reported higher rates of depression among caregivers than non-caregivers (Han & Haley, 1999).

### **Quality of Life among Family Caregivers of Stroke Survivors**

Another objective of the study was to examine the quality of life of family caregivers of stroke survivors. It was hypothesized that caregivers of stroke patients will have a poorer quality of life compared to non-caregivers. Findings revealed that caregivers of stroke patients reported poorer quality of life compared to non-caregivers. As mentioned earlier, the burden of taking care of sick persons who are highly dependent on another for their daily living can be quite challenging and act as a high source of stress to the individual. This can pervade into all aspects of the individual's life and affect his/her quality of life. According to the stress process model, when the several factors surrounding caregiving is not managed properly, it could result in some negative outcomes and the present study has found decline in quality of life as one of such outcomes. Caregiving burden may include emotional distress, financial, occupational and social disruptions which have the potency to affect quality of life of the caregiver (Greenwood et al., 2008). Quality of life in this study included physical, psychological, social and environmental domains.

It was also found out that environmental domain of quality of life did not differ significantly between caregivers and non-caregivers which is quite understandable because the environmental quality of life is not particularly linked to stroke caregiving but the general living conditions of the caregivers. Consequently the environmental experiences of a caregiver may not differ significantly from a non-caregiver. However physical, psychological and social domains of quality of life differed significantly between the two groups with non-caregivers reporting better quality of life in those domains.

Activities of caregiving may include bathing, feeding, dressing, and grooming which may put a burden on the physical health of caregivers and hence affect their physical quality of life

negatively. Caregivers may experience increased workload, fatigue, or exhaustion, sleep disturbance, headaches and body pains and sometimes already existing medical conditions such as hypertension and diabetes may be exacerbated as a result of the demands of caregiving (Teel et al., 2001; Thrush & Hyder, 2014). This would interfere in their daily functioning and lead to poor physical quality of life.

In addition, caregiving in disabling conditions may come with certain psychological burdens which mostly result from burdens in other domains of a person's life such as social and physical. Caregivers may experience psychological distress associated with caregiving such as depression, anxiety, stress, frustration, feelings of helplessness, despair among others (Denno, Gillard, Graham, Dibonaventura, Goren et al., 2013; Thrush & Hyder, 2014) which may impact their psychological quality of life negatively. Caregivers would therefore have a poorer psychological quality of life compared to non-caregivers.

Finally, social domain of quality of life was found to be the most affected by caregiving in the present study. This is because the stroke survivor is dependent on the caregiver for most of his or her needs, there is much burden on the time and the finances of the caregiver, therefore the caregiver may lose his or social networks which may translate into reduced quality of life in the social domain. The caregiver may not be able to go to social functions or spend time with people who matter in his or her social circles. This may lead the individual caregiver to experience a restricted social life, withdrawal from social activities, stigma, family conflicts, dissatisfaction and instability in social relationships, limited family mobility, and rejection (Khalid & Kauser, 2008; Thrush & Hyder, 2014). The physical and psychological impact of caregiving can also affect an individual's social life. For instance an individual experiencing depression, hopelessness, frustration and poor physical health may lose interest in his/her social life and

would want to dedicate the time in staying at home to take care of the patient as well as to solve his or her own problems of daily living. With time social relationships may begin to strain and they feel isolated.

Contrary to the findings in the present study, Akosile et al. (2011) reported in their study that emotional well-being was the most affected domain of quality of life among caregivers of stroke survivors. It is possible that among the sample used in the present study, social relationships are more important to them than emotional or psychological needs hence their quality of life is most affected by social burdens compared to the others. However it could also be because the participants are more aware of their social difficulties compared to the other domains of quality of life.

### **Social support, Depression and Quality of life among Family Caregivers of Stroke Survivors**

The study also sought to assess whether social support influence depression and quality of life among caregivers of stroke survivors and to find out the relationship between depression and quality of life. The findings revealed that caregivers who had high social support reported lower levels of depression and better quality of life compared to caregivers who had low social support. It was also found out that depression had a significant negative relationship with quality of life and also mediated the relationship between social support and quality of life.

According to both the stress process model (Pearlin et al., 1990) and the transactional model of stress and coping (Lazarus & Folkman, 1984; Palmer & Dryden, 1995), the outcomes of a stressful event depends highly on the coping resources available. It is plausible in this case

therefore that social support serves as one of the effective coping mechanisms caregivers may use in coping with the stressors associated with caregiving. This may in turn influence their mental health and quality of life positively. This explains why people with high social support reported less depression and better quality of life than those with low social support. It has been shown that the perception of availability of social support has the potency to make a person perceive a stressful situation as less stressful (Lakey & Cohen, 2000) and the actual supportive acts of significant others may boost a person's coping ability (Lazarus & Folkman, 1984). This implies that a caregiver of a stroke survivor who perceives that social support is available would interpret the burden of care as less stressful. This enhances the individual's capacity to cope with the situation and in turn has beneficial effects on both physical and psychological well-being. Khalid and Kausar (2008) for instance found social support as the best predictor of depression among caregivers of stroke survivors.

The influence of caregiving among caregivers of stroke survivors is found to have both direct and indirect impact on quality of life (White et al., 2003). As found in this study, one of the indirect pathways through which caregiving could influence quality of life of caregivers is through depression or emotional distress (Khalid & Kausar, 2008). As level of depression increases in caregivers, their quality of life is bound to be affected. Studies have reported that depression is a major predictor of quality of life in both patients and caregivers of stroke survivors (Haghoo et al., 2013; Jonsson et al., 2005; Suenkeler et al., 2002). Fatoye et al. (2006) however reported that the mere presence of clinically significant emotional symptoms is not indicative of reduced quality of life which is inconsistent with the findings of the present study.

In the present study also, depression was found to mediate the relationship between social support and quality of life significantly. This implies that social support influences a caregiver's

quality of life by buffering the effect of caregiving on psychological burden such as depression. However once depressive symptoms already exists in the person, the influence of social support on quality of life minimizes and become less significant. A person with heightened level of depression is less likely to perceive the availability of social support hence the available social support may not have any significant impact on their quality of life. Chiou, Chang, Chen and Wang (2009) reported that caregivers who had high social support also reported lower caregiver burden which could translate positively into better quality of life compared to those who have low social support. Emotional support such as, being able to talk to someone about your emotional problems from sources of social support can go a long way to reduce emotional distress and lead to a better quality of life (Kruithof, van Mierlo, Visser-Meily, van Heugten & Post, 2013).

### **The Role of Caregiver Variables and Caregiving Circumstances in Depression and Quality of life among Family Caregivers of Stroke Survivors**

Part of the objectives of the study was to find out whether severity of stroke can influence family caregiver depression and quality of life, to assess the influence of caregivers age on depression and quality of life, to determine whether duration of care provided contributes to caregivers' depression and quality of life, to find out the influence of gender on depression and quality of life among caregivers of stroke survivors and to find out whether financial constraint influenced depression and quality of life among caregivers.

### **Severity of stroke**

Contrary to predictions, severity of stroke did not influence both depression and quality of life in caregivers. The occurrence of stroke in itself whether mild or severe still poses stress to the caregiver and would predict depression and quality of life regardless of its severity. Studies have reported that what matters most to the caregiver is not the level of impairment of the patient but the burden of caregiving, which is mostly subjective (Denno et al., 2013; Isaac, Stewart & Krishnamoorthy, 2011; Thrush & Hyder, 2014). This signifies that different caregivers giving care to patients with the same level of severity may perceive the burden posed to them differently. A caregiver may perceive the burden associated with giving care to someone with less severe stroke or impairment as greater than someone who is giving care to a person with a greater impairment or severity. Consequently what might really matter in predicting depression and quality of life among caregivers of stroke survivors may not be the severity of the stroke per se but the caregiver's perceived burden associated with the severity. Severity of stroke or level of dependence may be more crucial for the patient's depression and quality of life than the caregiver (Haghgoo et al., 2013). The present study did not look at the perceived caregiving burden associated with the stroke but rather looked at the level of dependence of the stroke survivor as a measure of severity which may explain why the severity of stroke had no significant relationship with both depression and quality of life. This finding nonetheless is consistent with Anderson et al's (1995) study which found no significant relationship between the degree of the survivors' physical disabilities and emotional stress among caregivers. Stein et al. (1992) also reported that spouses' depression was not correlated with the severity of the stroke survivors' physical, cognitive or language impairment. The finding however contradicts studies which reported significant relationship between severity of stroke and depression and

quality of life among caregivers (Berg et al., 2005; Dennis et al., 1998; McCullagh et al., 2005; Ogunlana et al., 2014).

### **Age of caregiver**

The findings also reveal that age of caregiver did not have any significant relationship with depression. This implies that caregiving in stroke survivors has similar impact on the emotional/psychological health of the caregiver across the various age groups. Some studies have found no significant relationship between the two (Draper et al., 1992) which is consistent with the present finding. Other studies also found caregiver age to be predictive of depression in the patient but not the caregiver (Khalid & Kausar, 2008). Fatoye et al. (2006) reported that older age of the informal caregiver was correlated to depression. Moreover the findings on the relationship between age and depression among caregivers of stroke survivors have been quite inconsistent (Jönsson et al., 2004; Smith et al., 2004; van den Heuvel et al., 2001; Visser-Meily et al., 2008).

It was however found that younger caregivers reported better overall quality of life than older caregivers. Older caregivers may be saddled with more burden as they are more likely to be playing other roles in society in addition to giving care than the younger caregivers. They are also more likely to give up other aspects of their lives such as job in order to devote themselves to taking care of the patient than the younger caregivers would be willing to. They may therefore perceive a decline in their quality of life compared to younger caregivers. Even though studies have found a significant relationship between caregiver age and quality of life, the domains of quality of life which are most affected by age have not been consistent across studies. In the present study, psychological and environmental domains are what seem to be affected by

caregiver's age which is contradictory to Khalid and Kausar's (2008) findings. They found social domain as the aspect of quality of life that is affected by age. On the other hand, McPherson, Wilson, Chyurlia and Leclerc (2011) found that the physical component of quality of life is rather the aspect predicted by caregiver age.

The finding from the present study may suggest that caregivers used in the present study regardless of their age are physically healthy or perceive themselves to be and also enjoy some support from their social network hence do not perceive any changes in their physical and social quality of life. However the emotional distress associated with the patient's care may have more impact on the psychological quality of life of older caregivers compared to younger ones. Also satisfaction with living conditions or surroundings such as residential and transportation facilities may decline faster in older caregivers than younger caregivers since some of the older caregivers may have retired from active work or may have other economic responsibilities. Isaac et al., (2011) however did not find any association between age and quality of life among caregivers of stroke survivors.

### **Duration of care**

It was found out that duration of care did not have a significant relationship with depression and quality of life. This could be due to the reason that a significant number of the caregivers were providing care for the patient within the first six months which means the duration of care did not vary much across the caregivers hence was found to have no significant influence on depression and quality of life. It could also be as a result of the fact that the impact of caregiving does not really depend on the duration of time that elapse since the beginning of care, as studies have revealed that the impact of care giving starts right from the onset of care and continues for

about 15-18 months, whether the impact will increase or reduce is dependent on other variables rather than the mere period of time that elapsed (Byun & Evans, 2014; Simon, Kumar & Kendrick, 2009). Other researchers suggest that the number of hours actually spent on taking care of the patient in a day is what is predictive of quality of life (Byun & Evans, 2014; Legg, 2012) not necessarily the number of weeks, months or years.

## **Gender**

Gender was found to predict quality of life significantly but was not significantly related with depression. The results suggest that male caregivers have a better quality of life compared to female caregivers. This may be due to the fact that females are typically the caregivers of stroke survivors and they usually give care without much assistance from other family members (McCann & Christiansen, 1996) because it is viewed as their normal responsibility to care for sick family members (Ogunlana et al., 2014). This increases the burden of care on the female caregiver and leads to decline in quality of life. On the other hand, when males happen to give care, they may arouse sympathy in other family members who would be willing to share the burden of caregiving because the man is seen as going too much out of his way to take care of the patient, as society does not really expect caregiving from men. Consequently the burden of care on male caregivers may be less compared to females. Women are already burdened with other major role demands such as being a mother, wife, employer etc. therefore taking care of a stroke survivor only increases those demands and leads to role strain and increased burden. However with men, they may feel that they voluntarily took on the role of caregiving which may result in male caregivers feeling needed, useful and appreciated and the caregiving experience rather adds more meaning to their lives hence and increases in quality of life instead of a decline

(Larson et al, 2008). Some studies have actually suggested that caregiving may be linked to a sense of fulfillment for the caregiver and increased feelings of closeness between the caregivers and their relatives (Harper & Lund, 1990; Kinney et al., 1995). The finding from the present study signifies that this assertion is mostly true for men than women. The finding is consistent with previous studies which found female caregivers to report lower quality of life than males (Larson, et al, 2008). This means that females are more affected by the caregiving role than males.

### **Financial constraint**

Financial constraint also had a significant positive relationship with depression and significant negative relationship with quality of life and predicted quality of life significantly. However, after controlling for social support, the relationship between financial constraint and depression was no longer significant. Caregivers of stroke survivors may experience economic hardships as a result of the expenses they incur in taking care of their family member including hospital bills and the upkeep of the home. Most stroke survivors are unable to go back to their jobs after they suffer stroke; it may take a long while for them to be productive again and so both the patient and the caregiver and other dependents have to rely on either the savings or investments of the patient which may deplete over time or rely solely on what the caregiver can afford. This may increase the burden on the caregiver and result in emotional distress and decreased quality of life. Studies have revealed that economic burden is one of the predictors of caregiver burden among caregivers of stroke patients (Isaac, Stewart & Krishnamoorthy, 2011).

However when there is available social support, the financial burden reduces and consequently the negative impact of financial constraint on emotional/psychological health reduces. For

instance if a caregiver knows that even though he or she has no money, they could talk to another family member, friend or colleague who would be willing to help, then that caregiver is less likely to be worried or feel sad.

### **5.3. Limitations**

The present study bears the limitations that it is characterized by cross-sectional research, therefore one cannot derive any conclusions on the causality of the associations observed between the variables. Also the study employed self-reported measures which relied solely on the accuracy of the information provided by respondents. The study is also limited to caregivers of stroke survivors who report to Korle-bu Teaching hospital for medical care. Caregivers who are at home and are unable to report for reviews with the patients and those who seek medical care in other hospital settings are not represented in the present study.

The sample size (100) used is also not very large for findings to be generalized to all caregivers of stroke survivors in Ghana. Finally, the comparison group used in the study (non caregivers) makes it difficult to attribute the differences observed in the stroke family as solely to stroke and not just caring for any illness. It is therefore difficult to tell if caring for a stroke survivor confers additional effect beyond caring for any illness. These notwithstanding, the study makes important contributions to our understanding of the impact of caregiving among caregivers of stroke survivors in the present sample and population at large and also add to the body of research on stroke and its related issues.

## **5.4. Recommendations**

The recommendations are categorized under (i) future studies (ii) health professionals (iii) family caregiver of stroke survivors (iv) health sector

### **Future Studies**

As a recommendation for future studies, the sample selection should be done using the probability sampling technique to ensure only caregiver characteristics that was examined in this study was found the representativeness of the sample of the population of family caregivers. This present study examined the negative outcomes of caregiving on the survivor. Future studies should explore on the positive outcomes of caregiving since a lot more needs to be explored in that dimension. The study limited itself to only one survivor characteristic (level of dependency/severity of stroke), future studies should explore more survivor characteristics since they are likely to predict depression and poorer quality of life in informal caregivers. Finally, the study did not categorize survivors based on the type of stroke suffered by the survivor. Different types of stroke may present with different challenges both for the survivor and the caregiver.

### **Health Professionals**

The outcome of this study does not limit itself to future studies but also health professional especially mental health professionals. This is because caregivers have been found as being at risk for psychiatric morbidities and poor quality of life. The Stress Process Model explains that when coping resources are available, it buffers the effect of stress on the caregivers. Health care professionals can be one significant group to provide resource on information and education.

It was also found that caregivers and non caregivers differ significantly in their depressive symptomatology as well as quality of life, therefore, the former deserve attention in delivery of mental health services. Females and older caregivers should have the necessary attention since they are more susceptible to poorer quality of life. Thus female and older individuals who have a history of caregiving should be identified and well attended to.

### **The Caregiver**

Caregivers of stroke survivors are at risk of becoming hidden patients. They should identify factors that predict depression and QOL. For example, social support had a significant relationship with depression. Caregivers should seek for support in managing their new roles. Support can be in many forms and also sought from different categories of people. One way of support is to be informed about their caregiving roles.

### **Health Sector**

The findings that caregivers are depressed and have a poorer QOL, has several implications for the health sector. The Ministry of health and Ghana health service should take a holistic approach with respect to the health of caregivers since they serve as a major extension to the formal caregiving. Target intervention to decrease depression and improve their QOL should focus on caregivers' social support, finance and age. Social support groups can be formed where caregivers can obtain the necessary assistance they need in the course of their caregiving role. Also caregivers' fund can be created by which financial support will be given to caregivers. In addition, caregivers' social domain of QOL was found to be the most affected. Consequently, centres should be established where caregivers can leave their survivors for some hours to pave

the way for them to engage in necessary social activities. In doing this caregiver will not feel too isolated as a result of their caregiving responsibilities which will translate into improved social QOL.

## **5.5. Conclusions**

Being an informal caregiver has been shown to be associated with psychological morbidities such as anxiety, depression, and psychological distress among others. However, in our Ghanaian context little research is available to identify factors or variables that could predict these mental health related problems. This study examined depression and QOL among family caregivers of stroke survivor as well as caregiver/survivor related variables associated with them. The outcome demonstrated that caregivers were more depressed than non caregivers and reported poorer quality of life. Significant predictors of QOL and depression was social support, however, depression mediated the relationship between social support and QOL. Caregivers' age, gender and financial constraints were significant determinants of QOL. Another determinant of depression was financial constraint but was no longer significant when social support was controlled for. In conclusion, the study outcomes serve as the basis for future studies.

## REFERENCES

- Agyemang, C., Attah-Adjepong, G., Owusu-Dabo, E., De-Graft Aikins, A., ... Addo, J. (2012). Stroke in the Ashanti region of Ghana. *Ghana Medical Journal*, *46*(2), 12-17.
- Akosile, C. O., Okoye, E. C., Nwankwo, M. J., Akosile, C. O., & Mbada, C. E. (2011). Quality of life and its correlates in caregivers of stroke survivors from a Nigerian population. *Qual Life Res*, *20*(9), 1379-1384.
- Anderson, C. S., Linto, J., & Stewart-Wynne, E. G. (1995). A population based assessment of the impact and burden of care-giving for long-term stroke survivors. *Stroke*, *26*, 843-849.
- Balhara, Y. P. S., Verma, R., Sharma, S., & Mathur, S. (2012). A study of predictors of anxiety and depression among stroke patient-caregivers. *J Midlife Health*, *3*(1), 31-35.
- Bakas, T., Kroenke, K., Plue, L. D., Perkins, S. M., & Williams, L. S. (2006). Outcomes among family caregivers of aphasic versus non aphasic stroke survivors. *Rehabilitation Nursing*, *31*(1), 33-42.
- Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation.
- Berg, A., Psych, L., Palomaki, H., Lonnqvist, J., Lehtihalmes, M., & Kaste, M. (2005). Depression among caregivers of stroke survivors. *Stroke*, *36*, 639-643.
- Blake, H., Lincoln, N. B., & Clarke, D. D. (2003). Caregiver strain in spouses of stroke patients. *Clinical Rehabilitation*, *17*(3), 312-317.
- Blum, K., & Sherman, D. W. (2010). Understanding the Experience of Caregivers: A Focus on Transitions. *Seminars in OncolNurs*, *26*(4), 243-58.
- Brocklehurst, J. C., Morris, P., Andrews, K., Richards, B., & Laycock, P. (1981). Social Effects of Stroke. *Social Science & Medicine Part A-Medical Sociology*, *15*(1), 35-39.

- Bucher, J. A., Loscalzo, M., Zabora, J., Houts, P. S., Hooker, C., & Brintzenfeszoc, K. (2001). problem solving cancer care education for patients and caregivers. *Cancer Pract.* 9(2), 66-70.
- Bugge, C., Alexander, H., & Hagen, S. (1999). Stroke patients' informal caregivers: Patient, caregiver, and service factors that affect caregiver strain. *Stroke*, 30, 1517-1523.
- Byun, E., & Evans, L. K. (2014). Concept analysis of Burden in caregivers of stroke survivors during the early Poststroke period. *Clinical Nursing Research*, 1-19.
- Cameron, J. I., Cheung, A. M., Streiner, D. L., Coyte, P. C., & Stewart, D. E. (2006). Stroke survivors' behavioral and psychological symptoms are associated with informal caregivers' experiences of depression. *Archives of Physical Medicine and Rehabilitation*, 87(2), 177-183.
- Cannuscio, C., Jones, I., Kawachi, I., Colditz, G., Berkman, L., & Rimm, E. (2002). Reveberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the nurses' health study. *American Journal of Public health*, 92(8), 1305-11.
- Caplan L. (2000). *A Clinical Approach*. Butterworth Heinemann; Caplan's Stroke.
- Carnwath, T. C. M., & Johnson, D. A. W. (1987). Psychiatric morbidity among spouses of patients with stroke. *BMJ*, 294, 409-411.
- Centers for Disease Control and Prevention. (2002). National diabetes fact sheet: National estimates and general information and national estimates on diabetes in the United States, 2000. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

- Cheng, S. T., & Chan, C. M. (2004). The multidimensional scale of perceived social support: dimensionality and age and gender differences in adolescents. *Personality and Individual Differences, 37*, 1359–1369.
- Chiou, C. J., Chang, H., Chen, I. P., & Wang, H. H. (2009). Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Archives of Gerontology and Geriatrics, 48*, 419-424.
- Christopher, A. B. (1999). *The caregivers of stroke patients: the evolution of health status over the first three months after the patient returns home*. Thesis/dissertation. McGill University
- Choi, S. J. (1996). The family and ageing in Korea (a new concern and challenge). *Ageing Society, 16*, 1–25.
- Choi-Kwon, S., Kim, H. S., Kwon, S. U., & Kim, J. S. (2005). Factors affecting the burden on caregivers of stroke survivors in South Korea. *Arch Phys Med Rehabil, 86*, 1043–1048.
- Chow, S. K. Y., Wong, F. K. Y., & Poon, C. Y. F. (2006). Coping and Caring: Support for family caregivers of Stroke survivors. *J. Clin. Nurs. 16(76)*: 133-143.
- Chumblor, N. R., Rittman, M., Van Puymbroeck, M., Vogel, W. B., & Qin, H. (2004). The sense of coherence, burden, and depressive symptoms in informal caregivers during the first month after stroke. *Int J Geriatr Psychiatry, 19(10)*:944-953.
- Chwalisz, K., & Vaux, A. (2000). Social support and adjustment to disability. In: Frank RG, Elliott T, editors. Handbook of rehabilitation psychology. Washington (DC): *American Psychological Association*, p 537-52.
- Clarke, P. J., Lawrence, J. M., & Blacke, S. E. (2000). Changes in Quality of life over the first year after stroke. *Stroke 9(3)*: 121-7.

- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry, 17*(2), 184-188.
- Cohen, D., Luchins, D., Eisdorfer, C., Paveza, G., Ashford, J. W., Gorelic, P., Hirshman, R., Freels, S., Levy, P., Semla, T., & Shaw, H. (1990). Caring for relatives with Alzheimer's Disease: The Mental Health Risks to Spouses, Adult Children and other members caregivers. *Behaviour Health and Ageing, 1*, 171-182.
- Cuellar, N. G. (2002). Comparison of African American and Caucassian American Female Caregivers of Rural, Post Stroke, Bedbound Older Adults. *Journal of Gerontological Nursing, 28*, 36-45.
- Cumming, T. B., Cadilhac, D. A., Rubin, G., Crafti, N., & Pearce, D. C. (2008). Psychological distress and social support in informal caregivers of stroke survivors. *Brain Impairment, 9*(2), 152-160.
- Das, S. K., Banerjee, T. K., Biswas, A., Dutt, A., & Hazra A. (2010). A community-based stroke study of Stroke in Kolkata, India. *Stroke, 38*, 906-910.
- De Leeuw, J. R., De Graeff, A., Ros, W. J., Hordijk, G. J., Blijham, G. H., & Winnubst, J. A. (2000). Negative and positive influences of social support on depression in patients with head and neck cancer: a prospective study. *Psychooncology, 9*, 20-28.
- Deb, P., Sharma, S., & Hassan, K. M. (2010). Pathophysiologic mechanisms of acute ischemic stroke: An overview with emphasis on therapeutic significance beyond thrombolysis. *Pathophysiology : the official journal of the International Society for Pathophysiology, 17*(3), 197-218.
- de-Graft Aikins, A. (2007). Ghana's neglected chronic disease epidemic: a developmental challenge. *Ghana Med J, 41*, 154-159.

- Dennis, M., O'Rourke, S., Lewis, S., Sharpe, M., & Warlow, C. A. (1998). A Quantitative Study of Emotional Outcome of People Caring for Stroke survivors. *Stroke*, *29*, 1867-1872.
- Denno, M. S., Gillard, P. J., Graham, G. D., DiBonaventura, M. D., Goren, A., Varon, S. F., & Zarowitz, R. (2013). Anxiety and Depression Associated with Caregiver Burden in Caregivers of Stroke survivors with Spasticity. *Archives of Physical Medicine and Rehabilitation*, *94*, 1731-1736.
- Draper, B. M., Poulos, C. J., Cole, A. M, Poulos, F. G., & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc*, *40*, 896-901.
- Exall, K. (1999). Caring for carers coping with stroke. *Nursing Times*, *95*(11), 50-51.
- Farran, C. J., Miller, B. H., Kaufman, J. E., & Davis, L. (1997). Race, finding meaning and caregiver distress. *Journal of Aging & Health*, *9*(3), 316-333.
- Fatoye, F. O., Komolafe, M. A., Adewuya, A. O., & Fatoye, G. K. (2006). Emotional distress and self-reported quality of life among primary caregivers of stroke survivors in Nigeria. *East Afr Med J*, *83*(5), 271-279.
- Feigin, V. L., Lawes, C. M., Bennett, D. A., Barker-Collo, S. L. & Parag, V. (2010). Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. *Lancet Neurol*, *8*, 355-369.
- Fisher M, Bogousslavsky J, (1998). Further Evolution Toward Effective Therapy for Acute Ischemic Stroke. *JAMA*, *279*(16), 1298-1303.
- Forsberg-Wärleby, G., Möller, A., & Blomstrand, C. (2001). Spouses of first-ever stroke patients: Psychological well-being in the first phase after stroke. *Stroke*, *32*, 1646-1651.

- Franzen-Dahlin A, Larson J, Murray V, Wredling R, Billing E. (2007). Predictors of psychological health in spouses of persons affected by stroke. *J Clin Nurs*, 16(5), 885-891.
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S. & Franklin, S. (1994). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health*, 15(4), 271-283.
- Glass, A., Matchar, D. B., Belyea, M. & Feussner, J. R. (1993). Impact of social support on outcome in first stroke. *Stroke*, 24(1), 64–70.
- Glozman, J. M. (2004). Quality of life of caregivers. *Neuropsychol Rev*, 14(4), 183-196.
- Grant, J. S., Bartolucci, A.A., Elliot, T.R. & Giger, J.N. (2000). Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Inj*, 14, 1089–1100.
- Grant, J. S., Elliott, T. R., Weaver, M., Glandon, G. L., Raper, J. L. & Giger, J. N. (2006). Social Support, social problem-solving abilities and adjustment of family caregivers of stroke survivors. *Archives of Physical and Medical Rehabilitation*, 87, 343–350.
- Grant, J. S., Weaver, M., Elliott, T. R., Bartolucci, A. R. & Giger, J. N. (2004). Sociodemographic, physical and psychosocial factors associated with depressive behaviour in family caregivers of stroke survivors in the acute care phase. *Brain Inj*, 18(8), 797-809.
- Green, T. L. (2007). *An examination of male patient, wife-caregiver, and marital dyad outcomes over a three-month period following minor stroke*. The University of Calgary.

- Greenwood, N., Mackenzie, A., Cloud, G. C. & Wilson, N. (2008). Informal carers of stroke survivors--factors influencing carers: a systematic review of quantitative studies. *Disability & Rehabilitation*, 30(18), 1329-1349.
- Guberman, N., Gagnon, E., Côté, D., Gilbert, C., Thivièrge, N. & Tremblay, M. (2005). How the trivialization of the demands of high-tech care in the home is turning family members into para-medical personnel. *Journal of Family Issues*, 26(2), 247-272.
- Guberman N. (2013). *Caregivers: Their Role in Rehabilitation*. In: JH Stone, M Blouin, editors. International Encyclopedia of Rehabilitation.
- Gündüz, B. & Erhan, B. (2008). Quality Of Life of Stroke Patients' Spouses Living in The Community in Turkey: Controlled Study with Short Form-36 Questionnaire. *J Neurol Sci [Turk]*, 25, 226-234.
- Hackett, M. L., Duncan, J. R., Anderson, C. S., Broad, J. B. & Bonita, R. (2000). Health-related quality of life among long-term survivors of stroke: results from the Auckland Stroke Study, 1991-1992. *Stroke*, 31, 440-447.
- Haghgoo, H. A., Pazuki, E. S., Hosseini, A. S. & Rassafiani, M. (2013). Depression, Activities of daily living and Quality of life in patients with stroke. *Journal of Neurological Sciences*, 328, 87-91.
- Haley, W. E., Allen, J. Y., Grant, J. S., Clay, O. J., Perkins, M., & Roth, D. L. (2009). Problems and benefits reported by stroke family caregivers: Results from a prospective epidemiological study. *Stroke*, 40(6), 2129-2133.
- Han B. & Haley W. E. (1999). Family caregiving for patients with stroke. Review and analysis. *Stroke*, 30(7), 1478-1485.

- Harper, S. & Lund, D. (1990). Wives, husbands, and daughters caring for institutionalized and non-institutionalized dementia patients: Toward a model of caregiver burden. *International Journal of Aging and Human Development*, 30(4), 241-262.
- Hodgson, S. P., Wood, V. A., & Langton-Hewer, R. (1996). Identification of stroke carers “at risk”: a preliminary study of the predictors of carers’ psychological well-being at one year post-stroke. *Clin Rehabil*, 10, 337–346.
- Hung, J. W., Huang, Y. C., Chen, J. H., Liao, L. N., Lin, C. J., ... Chuo, C. Y. (2012). Factors associated with strain in informal caregivers of stroke patients. *Chang Gung Med J*, 35, 392–401.
- Indredavik, B. (2004). Slag [Stroke]. In L. Lande Wekre & K. Vardeberg (Eds.), *Lærebok i rehabilitering, når livet blir annerledes*[*Rehabilitation textbook, when life becomes different*] (pp. 125-146). Bergen: Fagbokforlaget.
- Isaac, V., Stewart, R., & Krishnamoorthy, E. S. (2011). Caregiver burden and quality of life of older persons with stroke: A community Hospital study in south India. *Journal of Applied Gerontology*, 30(5), 643-654.
- Jonsson, A. C., Lindgren, I., Hallstrom, B., Norrving, B., & Lindgren, A. (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*, 36(4), 803–808.
- Kamel, A. A., Bond, A. E., & Froelicher, E. S. (2011). The Centre of Epidemiologic Studies of Depression and the caregiver strain. *Int J Nurs Pract*. 18(2), 147-154.
- Kazarian, S. S., & McCabe, S. B. (1991). Dimensions of social support in the MSPSS: factorial structure, reliability, and theoretical implications. *Journal of Community Psychology*, 19, 150–160.

- Khalid, T., & Kausar, R. (2008). Depression and quality of life among caregivers of people affected by stroke. *Asia Pacific Disability Rehabilitation Journal, 19*(2), 103-110.
- King, R. B., Carlson, C. E., Shade-Zeldow, Y., Bares, K. K., Roth, E. J.,..., Heinemann, A.W. (2001). Transition to home care after stroke: depression, physical health, and adaptive processes in support persons. *Research in Nursing & Health, 24*(4), 307-323.
- Kinney, J. M., Stephens, M., Franks, M. M., & Norris, V. K. (1995). Stress and satisfactions of family caregivers to older stroke patients. *J Appl Gerontol, 14*, 3–21.
- Kinney, 1. M., & Stephens, M. A. P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging, 1*(4), 402-408.
- Kotila, M., Numminen, H., Waltimo, O., & Kaste, M. (1998). Depression after stroke: results of the FINNSTROKE Study. *Stroke, 29*(2), 368-372.
- Kramer, B. J. (1997). Gain in the caregiving experience: where are we? What next? *Gerontologist, 37*, 218-232.
- Kreutzer, J. S., Gervasio, A.H., & Camplair, P.S. (1994). Primary Caregivers' psychological status and family functioning after traumatic brain injury. *Brain Inj, 8*, 197-210.
- Kruithof, W. J., von Mierlo, M. L., Visser-Meily, J. M. A., von Heugten, C. M., & Post, M.W.M. (2013) . Associations between social support and stroke survivors' health-related quality of life: A systematic review. *Patient Education and Counselling, 93*, 169-176.
- Lakey, B., & Cohen, S. (2000). Social support theory and selecting measures of social support. In S. Cohen, L. U. Gordon & B. H. Gottlieb (Eds.) *Social support measurement and interventions: A guide for health and social scientists*. New York: Oxford.

- Larson, J., Franzen-Dahlin, A., Billing, E., Arbin, M., Murray, V., & Wredling, R. (2005). Predictors of quality of life among spouses of stroke patients during the first year after the stroke event. *Scand J Caring Sci*, 19(4), 439-445.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York, NY: Springer Publishing Co Inc.
- Legg, L. A. (2012). Informal carers of stroke survivors. PhD thesis. <http://theses.gla.ac.uk/3123/>
- Levine, C. (2004). *Always on call: When the illness Turns Families into Caregivers* (2<sup>nd</sup> ed.). Vanderbilt University Press for the United Hospital Fund.
- Low, J. S. T., Payne, S., & Roderick, P. (1999). The impact of stroke on informal carers: a literature review. *Soc Sci Med*, 49(6), 711-725.
- Maatouk, I., Wild, B., Herzog, W., ... Wesche, D. (2012). Longitudinal predictors of health-related quality of life in middle-aged and older adults with hypertension: Results of a population-based study. *Journal of Hypertension*, 30(7), 1364-1372.
- Mant, J., Carter, J., Wade, D. T., & Winner, S. (2000). Family support for stroke: a randomized controlled trial. *Lancet*, 356, 808 – 813.
- McCann, J., & Christiansen, K. (1996). Home Care. In: Luecckenotte, A. G. (Ed.), *Gerontologic Nursing*. St. Louis: CV Mosby.
- McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*, 36, 2181-2186.
- McPherson, C. J., Wilson, K. G., Chyuria, L., & Leclerc, C. (2011). *Health and Quality of Life Outcomes*, 9, 29.
- Mensah, G. A. (2008). Epidemiology Of Stroke And High Blood Pressure In Africa. *Heart*, 94, 697-705.

- Mol, V.J., & Baker, C.A. (1991). Activity intolerance in the geriatric stroke patient. *Rehabil Nurs*, 16(6), 337-343.
- Molloy, G. J., Johnston, D. W., Johnston, M., Morrison, V., Pollard, B., ..., Bonetti, D. (2005). Extending the demand-control model to informal caregiving. *J Psychosom Res*, 58(3), 243-251.
- Morgan, M. A., Small, B. J., Donovan, K. A., Overcash, J., & McMillan, S. (2011). Cancer Care recipients with Pain: The Spouse/Partner Relationship and Quality of Life. *Cancer Nursing*, 34(1), 13-23.
- Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age Ageing*, 32(2), 218–223.
- Nasir, L., & Al-Qutob, R. (2005). Barriers to the diagnosis and treatment of depression in Jordan; A national qualitative study. *The Journal of the American Board of Family Practice*, 18, 125–131.
- National Institute of Neurological Disorders and Stroke (NINDS). (1999). *Stroke: Hope Through Research*. National Institutes of Health.
- Nelson, M. M., Smith, M. A., Martinson, B., Kind, A. J. H., & Luepker, R. V. (2008). Declining patient functioning and caregiver burden/health: The Minnesota Stroke Survey-Quality of Life after Stroke Study (MSS-QLASS). *Gerontologist*, 48, 573-583.
- Njoku, C. H., & Adujolu, A. B. (2004). Stroke in Sokoto, Nigeria: A Five Year Retrospective Study. *Ann Afr Med*, 3(2), 73-76
- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care*. Buckingham : Open University Press.
- Odusote, K. (1996). Management of Stroke. *Nig Med Pract*, 32:56-62.

- O'Sullivan, S. B., & Schmitz, J. (2007). *Physical Rehabilitation* (5<sup>th</sup> ed.). Philadelphia, P.A: F.A. Davis Company. P.385.
- Ogunlana, M. O., Dada, O. O., Oyewo, O. S., Odole, A. C., & Ogunsan, M. O. (2014). Quality of life and burden of informal care caregivers of stroke survivors. *Hong Kong Physiotherapy Journal*, 32, 6-12.
- Oleson, J., & Leonardi, M. (2003). The burden of brain disease in Europe. *Eur J Neurol*, 10(5): 471-7.
- Palmer, S., & Dryden, W. (1995). *Counseling for Stress Problems*. London: Sage.
- Patel, M. D., McKeivitt, C., Lawrence, E., Rudd, A. G., & Wolfe, C. D. A. (2007). Clinical determinants of long-term quality of life after stroke. *Age Ageing*, 36, 316–322.
- Pearlin, L. I. The stress process revisited. In: Aneshensel, C. S., Phelan, J. C., (1999). *Handbook of the Sociology of Mental Health*. New York: Kluwer Academic/Plenum Publishers, p. 395-415.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 583-591.
- Rittman, M., & Sberna, M. (2006). *Racial/Ethnic Variation in Recovery From Stroke: The Role of Caregivers*. American Sociological Association.
- Robinson, R. G. (1998). Treatment issues in poststroke depression. *Depress Anxiety*, 8(1), 85-90.
- Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *J Gerontol B Psychol Sci Soc Sci*, 59, 185–190.

- Rombough, R. E., Howse, E. N., & Bartfay, W. J. (2006). Caregiver strain and caregiver burden of primary caregivers of stroke survivors with and without aphasia. *Rehabilitation Nursing, 31*(5), 199–209.
- Rosamond W, Flegal K, Furie K, Go, A., Greenlund, K., & Haase, N. (2008). Heart disease and stroke statistics—2008 update: A report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation, 117*, 25–146.
- Ross, S., & Morris, R. G. (1988). Psychological adjustment of the spouses of aphasic stroke patients. *Int J Rehabil Res, 11*(4), 383 - 386.
- Sawatzky, J., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing, 10*, 277–286.
- Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving. The caregiver health effects study: An ancillary study of the cardiovascular health study. *Annals of Behavioral Medicine, 19*, 110–116.
- Schulz, R., Tompkins, C. A., & Rau, M. T. (1988). A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychol Aging, 3*, 131–141.
- Secrest, J. (2000). Transformation of the relationship: the experience of primary support persons of stroke survivors. *Rehabil Nurs, 25*(3), 93–99.
- Senelick, R. C., Rossi, P. W., & Dougherty, K. (1994). *Living with Stroke: A Guide For Families*. Contemporary Books, Chicago.
- Shanmugham, K., Cano, M. A., Elliott, T. R., & Davis, M. (2009). Social problem-solving abilities, relationship satisfaction and depression among family caregivers of stroke survivors. *Brain Injury, 23*(2), 92-100.

- Simon, C., Kumar, S., & Kendrick, T. (2009). Cohort study of informal carers of first-time stroke survivors: Profile of health and social changes in the first year of caregiving. *Social Sciences & Medicine*, *69*, 404-410.
- Smith, L. N., Norrie, J., Kerr, S. M., Lawrence, I. M, Langhorne, P., & Lees, K. R. (2004). Impact and influences on caregiver outcomes at one year post-stroke. *Cerebrovasc Dis*, *18*(2), 145-153.
- Snell, R. S. (2006). *Clinical neuroanatomy*, (6<sup>th</sup> ed.). Lippincott Williams & Wilkins, Philadelphia. pp. 478–485.
- Stein, P. N., Gordon, W. A., Hibbard, M. R., & Sliwinski, M. J. (1992). An Examination of Depression in the Spouses of Stroke Patients. *Rehabil Psychol*, *37*(2), 121-130.
- Suenkeler, I.H., Nowak, M., Misselwitz, B., Kugler, C., Schreiber, W., Oertel, W.H. (2002). Time course of health-related quality of life as determined 3, 6 and 12 months after stroke. Relationship to neurological deficit, disability and depression. *Journal of Neurology*, *249*, 1160–1167.
- Teel, C., Duncan, P., & Lai, S. (2001). Caregiving experiences after stroke. *Nursing Research*, *50*(1), 53-60.
- The WHOQOL Group. (1997). An approach to response scale development for cross-cultural questionnaires. *European Psychologist*, *2*, 270-276.
- Thommessen, B., Wyller, T. B., Bautz-Holter, E., & Laake, K. (2001). Acute phase predictors of subsequent psychosocial burden in carers of elderly stroke patients. *Cerebrovasc Dis*, *11*(3), 201-206.
- Thrush, A., & Hyder, A. (2014). The neglected burden of caregiving in low and middle-income countries. *Disability and Health Journal*, *7*, 262-272.

- Truelsen, T., Heuschmann, P., & Bonita, R. (2007). Standard method for developing stroke registers in low and income countries. Experiences from feasibility study of a stepwise approach to stroke surveillance (STEPS Stroke). *Lancet Neurol*, *6*, 134-9.
- van den Heuvel, E. T., de Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation*, *15*, 669–677.
- van Exel, N. J. A., Brouwer, W. B. F., van den Berg, B., Koopmanschap, M. A., & van den Bos, G. A. M. (2004). What really matter: An inquiry into the relative importance of dimensions of informal caregiver burden. *Clinical Rehabilitation*, *18*, 683–693.
- van Heugten, C., Visser-Meily, A., Post, M., & Lindeman, E. (2006). Care for carers of stroke patients: evidence-based clinical practice guidelines. *J Rehabil Med*, *38*, 153–158.
- van Puymbroeck, M., & Rittman, M. R. (2005). Quality of life predictors for caregivers at 1 and 6 months poststroke. *J Rehabil Res Dev*, *42*(6): 747-760.
- Visser-Meily, A., Post, M., Gorter, J., Berlekom, S. B. V., van den Bos, T., & Linderman, E. (2006). Rehabilitation of stroke patients needs a family centred approach. *Disabil Rehabil*, *28*(24), 1557-1561.
- Ward, H., Morisky, D. E., & Jones, D. (1996). Prevention of multi-infarct dementia and stroke in ethnicity diverse population. In: Yeo G, Gallagher-Thompson D, eds. *Ethnicity and the Dementias*. Washington, DC: Taylor & Francis, 207–224.
- White, C., Mayo, N., Hanley, J., & Wood-Dauphinee, S. (2003). Evolution of the Caregiving Experience in the initial 2 years following stroke. *Research in Nursing and Health*, *26*, 177-189.

WHO. Disease and injury regional estimates for 2004.

[http://www.who.int/healthinfo/global\\_burden\\_disease/estimates\\_regional/en/index.html](http://www.who.int/healthinfo/global_burden_disease/estimates_regional/en/index.html).

(accessed June 24, 2010).

Williams, A. (1994). What bothers caregivers of stroke victims? *Journal of Neuroscience Nursing*, 26, 155-161.

World Health Organization; The Atlas of Heart Disease and Stroke. Erişimtarihi: 2010 July 20.

Available from:

[http://www.who.int/cardiovascular\\_diseases/en/cvd\\_atlas\\_16\\_death\\_from\\_stroke.pdf](http://www.who.int/cardiovascular_diseases/en/cvd_atlas_16_death_from_stroke.pdf)

World Health Report (2007). Geneva: World Health Organization

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52, 30–41.

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric properties of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 55, 610–617.

**APPENDICES  
APPENDIX A****Ethical Clearance Letter****UNIVERSITY OF GHANA  
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)**

---

*P. O. Box LG 74, Legon, Accra, Ghana*

My Ref. No.....

14th March, 2014

Ms. Doreen A. Abeasi  
Department of Psychology  
University of Ghana  
Legon

Dear Ms. Abeasi,

**PROTOCOL ECH 032 13-14: DEPRESSION AND QUALITY OF LIFE AMONG FAMILY CARE GIVERS OF STROKE SURVIVORS**

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities and the following actions taken subject to the conditions and explanation provided below:

Expiry Date: 11/03/15  
On Agenda for: Initial Submission  
Description: 15/01/14  
ECH Action: Approved

Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y Mante  
ECH Chair

CC: Director, ISSER

Tel: +233-303933866

Email: [ech@isser.edu.gh](mailto:ech@isser.edu.gh)



**APPENDIX B****Letter of Introduction****UNIVERSITY OF GHANA  
DEPARTMENT OF PSYCHOLOGY**

Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: psychology@ug.edu.gh  
028 955 04 63

Our Ref. No. PSYC 2/33/02.....

2<sup>nd</sup> April, 2014

The Korle-Bu Teaching Hospital  
Accra.

Dear Sir/Madam,

**LETTER OF INTRODUCTION**  
**MS. DOREEN A. ABEASI**

The above-named is an M.Phil Clinical Psychology student at the University of Ghana, Legon.

In partial fulfillment of the requirement for the award of the M.Phil degree Ms. Doreen A. Abeasi has to write and submit an original thesis. She has selected the topic: "*Depression and Quality of life Among Family Care Givers of Stroke Survivors.*"

To enable her collect data for her work she would need to administer questionnaires and/or conduct interviews. She has selected your institution as suitable for her data collection. Attached is her institutional approval/clearance to enable her carry on with her research work.

Any assistance you may give her would be greatly appreciated.

Yours sincerely,

(Prof. C. C. Mate-Kole )  
**HEAD OF DEPARTMENT**

## APPENDIX C

## Additional Findings

*a. Summary of MANOVA results for the difference between caregivers and non-caregivers on the domains of quality of life.*

Variable	Caregivers	Non-caregivers	<i>F</i>	<i>P</i>	$\eta^2$
Physical	23.18	25.72	9.05	.003	.09
Psychological	20.74	23.76	23.45	.000	.19
Social	8.82	11.04	33.61	.000	.26
Environmental	26.78	28.18	2.74	.101	.03

*b. Summary of MANOVA results for the difference between younger and older caregivers on the domains of QOL*

Variable	Younger	Older	<i>F</i>	<i>P</i>	$\eta^2$
Physical	24.08	22.28	2.20	.144	.04
Psychological	22.04	19.44	8.54	.005	.15
Social	8.88	8.76	.04	.834	.00
Environmental	28.00	25.56	5.00	.030	.09

**APPENDIX D**

UNIVERSITY OF GHANA



Official Use only Protocol number
--------------------------------------

OFFICE OF RESEARCH, INNOVATION AND DEVELOPMENT  
**Ethics Committee for Humanities (ECH)**

PROTOCOL CONSENT FORM
-----------------------

Section A- BACKGROUND INFORMATION
--------------------------------------

Title of Study:	Depression and quality of life among family caregivers of stroke survivors
Principal Investigator:	Doreen Asantewa Abeasi
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN RESEARCH
--

**General Information about Research**

You are invited to participate in an academic research project which is aimed at investigating depression and quality of life among family caregivers of stroke survivors in Ghana. The aim of this study is to investigate depressive symptoms and quality of life among family caregivers of stroke survivors and also determine the influence of severity of stroke, age of caregiver and duration of caregiving on these variables. You will be required to answer questionnaires, a pencil will be provided which will be used to fill the questionnaires. You may be required to circle or tick answers which you think will be appropriate. There are no wrong or right answers.

**Benefits/Risk of the study**

**Possible risks:** You may experience fatigue as a result of long period of test administration. You will be given ample time in the form of periodic breaks to prevent fatigue during testing. Some of the tests may be easy, while others may be difficult. You are not required to answer all the questions correctly or to perform all the tasks perfectly.

**Possible Benefits:** This study was not planned to benefit you directly. Nonetheless, your participation in this research will enrich the understanding of the depression and quality of life among family caregivers of stroke survivors. It will also provide relevant information which can be used to educate you to help you in future caregiving roles.

**Confidentiality**

The information and responses you provide will be treated with utmost confidentiality. Only the researcher and approved research assistants will have access to the individual data you will provide. The results will be reported in an aggregated format (e.g., as averages, etc.), and under no circumstances will any individual participant be identified in a publication or presentation describing this study.

**Compensation**

This study will not include any compensation apart from a verbal appreciation of your valued time and efforts.

**Withdrawal from Study**

Your participation in this study is entirely voluntary and may refuse to participate in this research at any time without any penalty. You may at any time, for any reason, discontinue your participation without any negative consequences after having begun as a participant. Deciding

not to be in the study or leaving the study before it is finished will not affect your relationship with the researcher, your health care provider or the University of Ghana. It will also have no impact on the person that you care for, the health service they receive or the amount of time that they will spend in hospital.

### Contact for Additional Information

The following numbers can be contacted in case of any discomfort, explanation or further information.

Researcher: Doreen Asantewa Abeasi (Tel: 0242808985)

Supervisor: Dr. Joseph Osafo (Tel: 0244296435)

Section C- VOLUNTEER AGREEMENT
-----------------------------------

**"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."**

\_\_\_\_\_  
Name of Volunteer

\_\_\_\_\_  
Signature or mark of volunteer

\_\_\_\_\_  
Date

### If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

---

Signature of witness

---

Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

---

Name of Person who Obtained Consent

---

Signature of Person Who Obtained Consent

---

Date

**APPENDIX E**  
**QUESTIONNAIRE**

**SECTION A**

**DEMOGRAPHIC DATA**

1. How old were you on your last birthday? \_\_\_\_\_
2. What is the age of the survivor?
3. What is your gender?            (a) Female            (b) Male
4. What is your relationship to the care recipient?  
(a) Spouse                            (b) Child                            (c) Step-Child  
(d) Grandchild                        (e) Other (please specify): \_\_\_\_\_
5. What is the highest educational level you achieved?  
(a) Primary School                        (b) Junior High  
(c) Senior High School                        (d) Tertiary  
(e) Other (please specify) \_\_\_\_\_
6. What is your employment status?  
(a) Employed Full-Time                        (b) Employed Part-Time                        (c) Retired  
(d) Retired due to disability                        (e) Unemployed
7. How long have you been a caregiver for this care recipient? \_\_\_\_\_
8. Do you have any other form of social support? Yes/No
9. Do you have financial constraints catering for your stroke survivor? Yes/No

**SECTION B**

**Choose the one statement, from among the group of four statements in each question that best describes how you as a caregiver have been feeling during the past few days. Circle the number beside your choice.**

1	<p>0 I do not feel bad.</p> <p>1 I feel sad.</p> <p>2 I am sad all the time and I can't snap out of it.</p> <p>3 I am so sad or unhappy that I cannot stand it.</p>
2	<p>0 I am not particularly discouraged about the future.</p> <p>1 I feel discouraged about the future.</p> <p>2 I feel I have nothing to look forward to.</p> <p>3 I feel that the future is hopeless and that things cannot improve.</p>
3	<p>0 I do not feel like a failure.</p> <p>1 I feel I have failed more than the average person.</p> <p>2 As I look back on my life, all I can see is a lot of failure.</p> <p>3 I feel I am a complete failure as a person.</p>
4	<p>0 I get as much satisfaction out of things as I used to.</p> <p>1 I don't enjoy things the way I used to.</p> <p>2 I don't get any real satisfaction out of anything anymore.</p> <p>3 I am dissatisfied or bored with everything.</p>
5	<p>0 I don't feel particularly guilty.</p> <p>1 I feel guilty a good part of the time.</p> <p>2 I feel guilty most of the time.</p> <p>3 I feel guilty all of the time.</p>
6	<p>0 I don't feel that I am being punished.</p> <p>1 I feel I may be punished.</p> <p>2 I expect to be punished.</p> <p>3 I feel I am being punished.</p>

7	<p>0 I don't feel disappointed in myself.</p> <p>1 I am disappointed in myself.</p> <p>2 I am disgusted with myself.</p> <p>3 I hate myself.</p>
8	<p>0 I don't feel I am worse than anybody else.</p> <p>1 I am critical of myself for my weaknesses or mistakes.</p> <p>2 I blame myself all the time for faults.</p> <p>3 I blame myself for everything bad that happens.</p>
9	<p>0 I don't have any thoughts of killing myself.</p> <p>1 I have thoughts of killing myself but I would not carry them out.</p> <p>2 I would like to kill myself.</p> <p>3 I would kill myself if I had the chance.</p>
10	<p>0 I don't cry anymore than usual.</p> <p>1 I cry more now than I used to.</p> <p>2 I cry all the time now.</p> <p>3 I would kill myself if I had the chance.</p> <p>4</p>
11	<p>0 I am not more irritated by things than I ever am.</p> <p>1 I am slightly more irritated now than usual.</p> <p>2 I am quite annoyed or irritated a good deal of the time.</p> <p>3 I feel irritated all the time now.</p>
12	<p>0 I have not lost interest in other people.</p> <p>1 I am less interested in other people than I used to be.</p> <p>2 I have lost most of my interest in other people.</p> <p>3 I have lost all my interest in other people.</p>
13	<p>0 I make decisions about as well as I ever could.</p> <p>1 I put off making decisions more than I used to.</p> <p>2 I have a greater difficulty in making decisions than before.</p> <p>3 I can't make decisions at all anymore.</p>
14	<p>0 I don't feel I look any worse than I used to.</p> <p>1 I am worried that I am looking old or unattractive.</p> <p>2 I feel that there are permanent changes in my appearance that make me look unattractive.</p> <p>3 I believe that I look ugly.</p>
15	<p>0 I can work about as well as before.</p> <p>1 It takes an extra effort to get started at doing something.</p> <p>2 I have to push myself very hard to do anything.</p> <p>3 I can't do any work at all.</p>
16	<p>0 I can sleep as well as usual.</p> <p>1 I don't sleep as well as I used to.</p> <p>2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.</p> <p>3 I wake up several hours earlier than I used to and cannot get back to sleep.</p>

17	<p>0 I don't get more tired than usual.</p> <p>1 I get tired more easily than I used to.</p> <p>2 I get tired from doing almost anything.</p> <p>3 I am too tired to do anything.</p>
18	<p>0 My appetite is no worse than usual.</p> <p>1 My appetite is not as good as it used to be.</p> <p>2 My appetite is much worse now.</p> <p>3 I have no appetite at all anymore.</p>
19	<p>0 I haven't lost much weight, if any, lately.</p> <p>1 I have lost more than five pounds.</p> <p>2 I have lost more than ten pounds.</p> <p>3 I have lost more than fifteen pounds trying to lose weight.</p> <p><i>Score 0 if you have been purposely trying to lose weight.</i></p>
20	<p>0 I am no more worried about my health than usual.</p> <p>1 I am worried about my physical problems such as aches and pains or upset stomach.</p> <p>2 I am very worried about physical problems and it's hard to think of much else.</p> <p>3 I am so worried about my physical problems that I cannot think about anything else.</p>
21	<p>0 I have not noticed any recent change in my interest in sex.</p> <p>1 I am less interested in sex.</p> <p>2 I am much less interested in sex.</p> <p>3 I have lost interest in sex completely.</p>

**SECTION C**

The following questions ask how you as a caregiver feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither good or poor	Good	Very good
1.	How would you rate your quality of life	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you about your health	1	2	3	4	5

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

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

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

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5

24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

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

**SECTION D**

**Instructions: The items tended to divide into factor groups relating to the source of the social support, namely family, friends or significant other. Read each statement carefully and indicate how you feel.**

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **strongly disagree**

Circle the “3” if you **mildly disagree**

Circle the “4” if you are **Neutral**

Circle the “5” if you **mildly agree**

Circle the “6” if you **strongly agree**

Circle the “7” if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

**SECTION E**

**Instruction: The following questions are about the extent to which you (caregiver) assist your family member who is ill in the activities of daily living such as feeding, bathing, grooming among others.**

**FEEDING**

0 = unable

5 = needs help cutting, spreading butter, etc., or requires modified diet

10 = independent \_\_\_\_\_

**BATHING**

0 = dependent

5 = independent (or in shower) \_\_\_\_\_

**GROOMING**

0 = needs to help with personal care

5 = independent face/hair/teeth/shaving (implements provided) \_\_\_\_\_

**DRESSING**

0 = dependent

5 = needs help but can do about half unaided

10 = independent (including buttons, zips, laces, etc.) \_\_\_\_\_

**BOWELS**

0 = incontinent (or needs to be given enemas)

5 = occasional accident

10 = continent \_\_\_\_\_

**BLADDER**

0 = incontinent, or catheterized and unable to manage alone

5 = occasional accident

10 = continent \_\_\_\_\_

**TOILET USE**

0 = dependent

5 = needs some help, but can do something alone

10 = independent (on and off, dressing, wiping) \_\_\_\_\_

**TRANSFERS (BED TO CHAIR AND BACK)**

0 = unable, no sitting balance

5 = major help (one or two people, physical), can sit

10 = minor help (verbal or physical)

15 = independent \_\_\_\_\_

**MOBILITY (ON LEVEL SURFACES)**

0 = immobile or < 50 yards

5 = wheelchair independent, including corners, > 50 yards

10 = walks with help of one person (verbal or physical) > 50 yards

15 = independent (but may use any aid; for example, stick) > 50 yards \_\_\_\_\_

**STAIRS**

0 = unable

5 = needs help (verbal, physical, carrying aid)

10 = independent \_\_\_\_\_

**TOTAL (0–100):** \_\_\_\_\_