SCHOOL OF PUBLIC HEALTH

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BURDEN OF CAREGIVING ON INFORMAL CAREGIVERS OF STROKE SURVIVORS IN THE WESTERN REGION.

BY

RHODALINE OKAI

10701036

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DECLARATION

I, Rhodaline Okai hereby declare that, with the exception of cited literature, this dissertation is the result of my own original research carried out under the supervision of Dr Reginald Quansah, School of Public Health. This research has not been presented elsewhere either in part or in whole for purposes of the award of another degree.

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Rhodaline Okai Date

(Principal Investigator/Student)

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Dr. Reginald Quansah Date

(Academic supervisor)

DEDICATION

I dedicate this dissertation to all stroke survivors and their informal caregivers. May the joy of the Lord, continue to be your strength.

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ABSTRACT

Background: Stroke is a life-changing event which leaves the stroke survivors with varied degrees of disability requiring a lot of assistance from their informal caregivers who require substantial amounts of uncompensated time and energy to carry out their activities of daily living over a prolonged duration of time. The informal caregivers are therefore exposed to physical, psychological, social and financial problems, commonly reported as burden which affects their quality of life and may further compromise the stroke survivor's recovery.

Objectives: This study sought to give a deeper understanding of the burden of caregiving on informal caregivers of stroke survivors and the possible factors that contribute to the burden.

Method: This facility based cross sectional study involved 118 pairs of stroke survivors and their informal caregivers over a 2 month period. Structured questionnaires were used to obtain quantitative data on socio-demographic and background characteristics, caregiver burden and level of disability whiles focus group discussion was used to obtain qualitative data. Descriptive analysis was done for socio-demographic data whiles Chi-square and logistic regression were used for inferential analysis at a significance level of $p<0.05$ and 95% confidence interval. Recorded discussions were transcribed verbatim and analysed by content thematic analysis.

Results: One hundred and eighteen (118) pairs of informal caregivers and stroke survivors were surveyed in this study. Prevalence of caregiving burden was 74.6%, 66.9%, 63.6%, and 51.7% in the financial, physical, psychological and social domains respectively. Caregiving burden was significantly ($p\leq0.05$) influenced by caregiver's sex, number of tasks performed, level of stroke survivor's disability, caregiver's level of income, presence of comorbidities, employment status of caregiver and infrastructure at the physiotherapy department.

Conclusion: A greater proportion of the informal caregivers reported to be burdened, with high moderate-severe burden in the financial domain. Caregiver factors; sex, number of tasks performed, employment status, level of income, comorbidities, stroke survivor factors; level of disability, comorbidities and health care facility factors; infrastructure at the physiotherapy facility contributed to the burden of care. These findings suggest the need for further research focused on the needs of informal caregivers and interventions to address their challenges.

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LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
BADL	Basic Activities of Daily Living
BI	Barthel Index
CT scan	Computerized Tomography scan
CVA	Cerebro Vascular Accident
DALYS	Disability Adjusted Life Years
FGD	Focus Group Discussion
GHS	Ghana Health Service
IADL	Instrumental Activities of Daily Living
MRI	Magnetic Resonance Imaging
MRS	Modified Ranking Score
OPD	Out Patient Department
PI	Principal Investigator
QoL	Quality of Life
SPH	School of Public Health
TIA	Transcient Ischaemic Attack
WHO	World Health Organization
ZBI	Zarit Burden Interview

OPERATIONAL DEFINITION OF TERMS

Physical stress: A state resulting from situations characterised by physical trauma or injury, pain or discomfort and over exertion leading to fatigue, musculoskeletal imbalances and physical illness such as headaches.

Physical burden: Problems pertaining to the body as a result of physical activities which includes fatigue, strain, musculoskeletal disorders, and health problems such as sleeplessness and headaches.

Psychological burden: Problems pertaining to emotional stress such as fears, frustration, sadness and anger as well as cognitive stress such as worry, anxiety, not feeling like yourself and a sense of not being in control.

Social burden: Problems pertaining to relationship difficulties with partner, siblings, children, family, friends, employer, co-workers or employer, lack of social support, and isolation which is one's inability to interact with their social environment.

Financial burden: Problems pertaining to one's finances in terms of constraints, increasing expenditure and work adjustments.

Stroke survivors: Stroke victims who survive the acute phase of the stroke attack and move on to the rehabilitation phase.

Informal caregivers: Closest family members or friends who are living with the stroke survivor in the same house, taking care of and giving the most assistance to the survivor.

Activities of daily living (ADLs): Refers to people's daily self-care activities. Common ADLs include feeding oneself, bathing, dressing, grooming, and cleaning oneself after defecating.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Stroke happens to be the third leading cause of death and adult disability worldwide (Hampton, Armstrong, Ayyar, & Li, 2014) but in Ghana, it is one of the most important causes of adult disability (Owolabi et al., 2015). The majority of stroke survivors live with various degrees of disability which could either be permanent or temporal affecting the stroke survivors' function and therefore may require assistance in the performance of their activities of daily living (Joo, Wang, Yee, Zhang, & Sleet, 2017). Informal caregivers would have to provide all the needed assistance for these stroke survivors and this can be particularly burdensome in areas like Ghana, where options of institutionalized care scarcely exist as indicated by Camak, (2015). These caregivers are also required to continue the rehabilitation process at home as a study by Feigin, Norrving, & Mensah, (2017) has indicated that such gestures increased post stroke recovery and function. Several studies have reported that the burden experienced by the informal caregivers could be physical, social, financial, or psychological and may affect their quality of life (Boakye, Nsiah, Bello & Quartey, 2017; Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014). The informal caregiving burden has been associated with many factors including stroke survivor factors such as age and level of disability; caregiver factors such as gender, duration of care and employment status; and health care factors such as education. Other health care facility factors such as early referral for physiotherapy, survivor-therapist ratio, available infrastructure and relationship between the therapist and caregiver/ survivor, may also influence the caregiving burden.

1.2 Problem statement

According to Ilse, Feys, de Wit, Putman, & de Weerdt, (2008) in their research in Europe, between 29% and 43% of caregivers experience strain related to the caregiving duties and that one out of every three caregivers experienced burden. Another survey in the United States in 2009, reported that out of an estimated 65.7 million unpaid informal caregivers, 51% had high-medium caregiving burden and had spent an average of 20.5 hours giving care in a week, with 20% of them spending more than 40 hours weekly (Gibson Hunt et al., 2009). This burden is reported to reduce their quality of life and threaten sustainability of the home care and recovery of the stroke survivors (Hung et al., 2012). Though there is no comparable data in Ghana it is reasonable to presume that the situation here could be similar or even worse. This may be due to the absence of social support systems and respite care services that have been reported in other studies to reduce the burden of informal caregiving in developed countries (Hawranik & Strain, 2000; Lyons, Zarit, Sayer, & Whitlatch, 2002). In addition, most informal caregivers in Ghana provide care in homes and communities that are rarely adapted for specialized care thus leading to challenges in adjusting to their new roles. The burden of informal caregiving which includes physical, psychological, financial and social stress as well as some degree of morbidity is however, frequently overlooked by clinicians in this part of the world who focus primarily on the stroke survivor. Bakas et al., (2014) in their study indicated that because of the caregiver’s role in the preservation of the long term wellbeing of the stroke survivor, neglecting to address their burden may eventually lead to increased morbidity and mortality for the survivor as well as the caregiver. This view adds credence in investigating the impact of stroke on caregivers and their inclusion in health care delivery models, as caregiving burden may differ across cultures and countries. This study therefore seeks to give a deeper understanding of the caregiving burden among informal caregivers of stroke survivors and the factors that significantly contribute to the burden.

1.3 Conceptual framework

The conceptual framework below was designed by the researcher based on existing literature and it illustrates how various factors may possibly influence the burden of informal caregivers of stroke survivors. The caregiving burden in this study, would be looked at in four domains derived from Zarit's definition; "the physical, psychological, financial and social problems and disruption experienced by the principal caregiver of a family member" (Zarit, Reever, & Bach-Peterson, 1980). Several studies have indicated that, informal caregivers can experience burden due to both survivor and caregiver factors (Sacrey & Parmar, 2016).

Most studies have associated caring for male stroke survivors, who are advanced in age, are unmarried and have lower educational status with a higher caregiving burden compared to younger male or female survivors with higher educational status (Baumann et al., 2012; Delcourt et al., 2011; Dayapoglu & Tan, 2010). Stroke survivor comorbidities may have a negative impact on the outcomes of the patient's rehabilitation and thus increase informal caregiver burden (Ellis, Grubaugh, & Egede, 2013; Van Puymbroeck, Sberna Hinojosa, & Rittman, 2008). In addition, the level of disability which affects the stroke survivor's activities of daily living may influence caregiving burden (RouillardI, De WeerdtII, De WitIII, & JelsmaIII, 2012; Sussman & Regehr, 2009).

On the other hand, caregiver factors such as being female has been found to increase burden (Brajković, Godan, & Godan, 2009) as well as the duration of caregiving (Lurbe-Puerto, Leandro, & Baumann, 2012). In addition, caregivers with higher educational level have been found to adapt better to their new role of caring for the stroke survivor and so have less burden (Jeong, Jeong, Kim, & Kim, 2015; Vincent-Onabajo, Ali, & Hamzat, 2013). White, Mayo, Hanley, & Wood-Dauphinee, (2003) in their study, reported that unemployed female caregivers who consistently reported higher burden scores and lower overall QOL were found to be more likely unemployed than employed. Informal caregivers may experience higher levels of burden when they have little or no social support and this has been found to increase depression (Kruithof et al., 2016) and exhaustion level (Tuna & Olgun, 2010) as well as the overall caregiving burden (Karahan et al., 2014) on the informal caregiver.

This study therefore seeks to determine how these factors and other factors such as adherence to medication/exercise, previous caregiving experience, physical demands of care, early referral for rehabilitation, survivor/caregiver-therapist relation, therapist-survivor ratio and rehab infrastructure affect the caregiving burden as highlighted in the framework below.

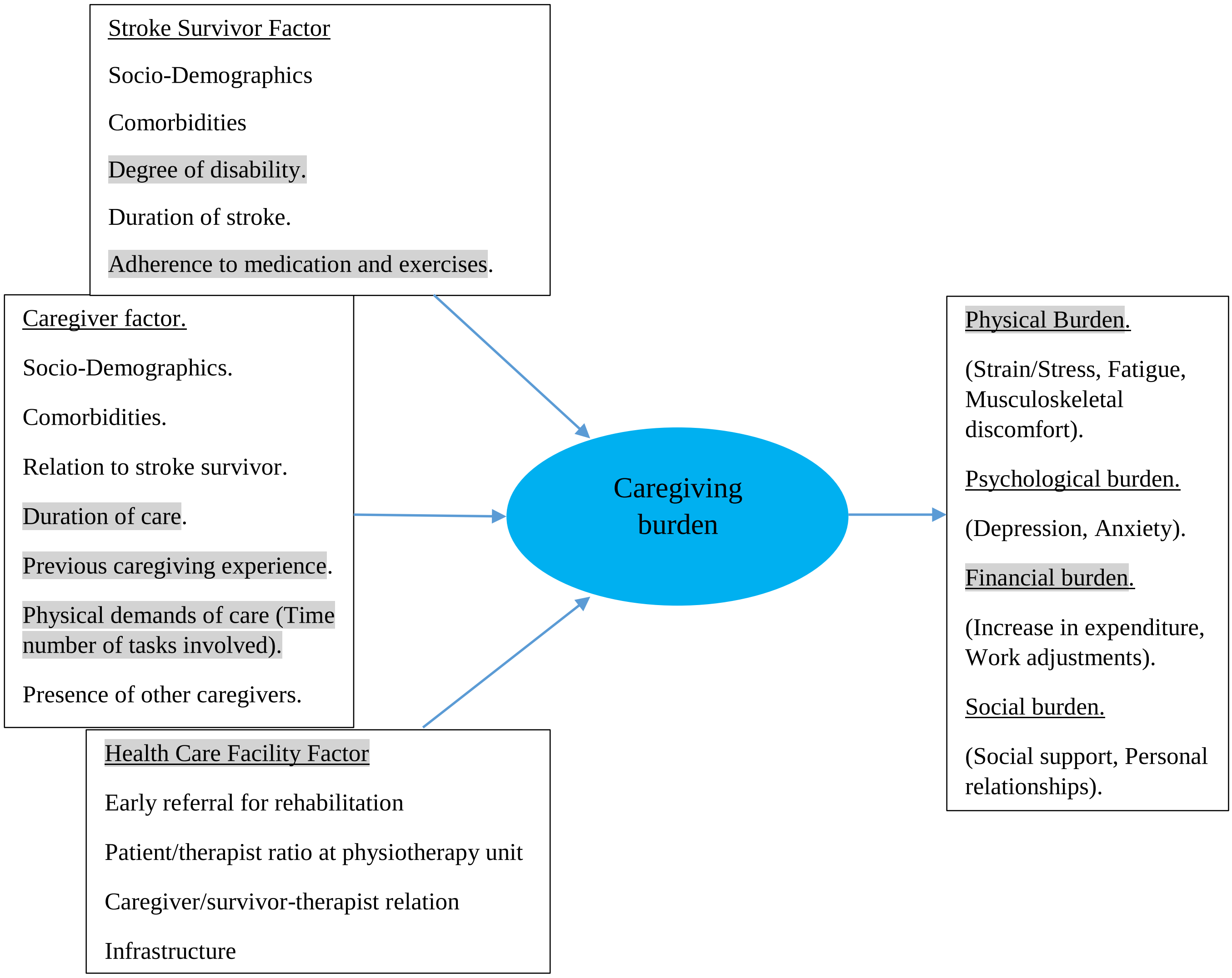


Figure 1. 1: Conceptual framework of the determinants of burden on caregivers of stroke survivors.

1.4 Justification

The chronic nature of stroke and the projected increase in its incidence as a result of demographic and epidemiological transitions are expected to increase the burden on the individual, the family and the country at large. Recent studies among other populations have identified informal caregivers as major stakeholders in the rehabilitation process of stroke survivors, especially, in countries where special rehabilitation homes are limited or absent like Ghana. In order to plan optimal interventions or implement healthcare policies that will alleviate the burden of caregiving and its negative impact on informal caregivers of stroke survivors in this country, there is the need for further research across different settings and the care continuum as highlighted by Cameron, Naglie, Silver, & Gignac, (2013). However, there is paucity of such research in Ghana. The only published research, conducted in the Komfo Anokye Teaching Hospital, by Boakye et al., (2017) on the "Burden of Care and Quality of life among Caregivers of Stroke Survivors", indicated that functional limitation was the single major determining clinical factor of burden experienced by the caregiver.

This current study happens to be the first attempt of assessing the burden of caregiving, in the physical, psychological, social and financial domains, among informal caregivers of stroke survivors and all the possible determinants using both quantitative and qualitative methods in Ghana. The findings of this study will be novel adding to the knowledge on stroke survivors and their informal caregivers. Data on the caregiving burden and its impact on the informal caregiver as well as the recovery of the stroke survivor from this study, will inform clinicians, rehabilitation specialists, researchers and policy makers to develop and put in place intervention strategies that will focus not only on the stroke survivor but also the informal caregiver. Such interventions will ensure an improved Qol of caregivers, improved recovery process for the survivor and an improvement in economic status because both the informal caregiver and stroke survivor will more likely return to work and be productive again.

1.5 Objectives

1.5.1 General Objective

To assess the burden of caregiving and its determinants among informal caregivers of stroke survivors.

1.5.2 Specific Objectives

1. To identify the physical, psychological, social and financial domains of burden experienced by the informal caregivers.

2. To determine the association between the stroke survivor factors and the burden of caregiving on informal caregivers.

3. To find the relationship between caregiver factors and the burden of caregiving on informal caregivers.

4. To investigate any connection between health care facility factors and the burden of caregiving on informal caregivers.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Focus of the literature

The literature review of this research focuses on stroke and its impact on the informal caregiver. It also focuses on the caregiving burden and its association with determining factors such as socio-demographics and other survivor/ caregiver related factors. Tools for assessing the caregiving burden and the level of disability will also be looked at.

2.2 Definition of stroke

Markus in 2012 defined stroke as “a clinical syndrome characterized by the rapid onset of focal neurological signs, lasting more than 24 hours or leading to death, with a presumed vascular cause” (Markus, 2012). The progression of a stroke and the reversibility of its symptoms differ based on the type of stroke.

2.3 Types of stroke

There are two major types of stroke, haemorrhagic and ischaemic. A haemorrhagic stroke occurs as a result of the rupture of a blood vessel or an abnormal vascular structure in the brain tissue (Bamford, Sandercock, Dennis, Warlow, & Burn, 1991) which occurs as a result of a sharp rise in blood pressure, the rupture of an aneurysm and impaired blood clotting (Robbins, Kumar, & Cotran, 2010). The incidence of the haemorrhagic type of stroke is reported to be around 10% -20% of all reported stroke cases (Lennon & Blake, 2009).

Ischaemic stroke also referred to as cerebral infarction, occurs when there is an interruption of blood supply to the brain resulting in a sudden loss of function (Bamford et al., 1991). This mostly happens when an embolus or thrombus gets stuck in a blood vessel hampering blood flow to the area below the blockage (Robbins et al., 2010). Generally, ischemic strokes have been reported to account for between 80% and 85% of stroke cases (Lennon & Stokes, 2009). Transient Ischaemic Attack is a mini-ischaemic stroke caused by tiny embolic substances such as pieces of calcium and fatty plaque lodging in a brain artery and thus blocking the supply of blood to parts of the brain temporarily (Stokes, 2004).

2.4 Epidemiology of stroke

According to the 2008 world health statistics, stroke was the second leading cause of death globally and out of the 56 million deaths that occurred annually, 10.8% were due to stroke (WHO, 2008). In 2016, almost 14 million incidences of first-time strokes was recorded worldwide in the (Global Burden of Disease Result tool., 2016). Globally, about 70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years were reported to have occurred in low and middle income countries (Feigin et al., 2014). Stroke is widely believed to be a disease of the elderly, yet in recent times almost two thirds of the global burden of stroke is seen to occur mainly in people younger than 70 years (Strong, Mathers, & Bonita, 2007). This implies that stroke nowadays affects the majority of people at the peak of their productive life. Seshadri et al., (2006) in their study, reported that women had a higher risk of stroke than men with roughly one in five women suffering a stroke in their lifetime.

2.5 Risk factors for stroke

A variety of factors often grouped into modifiable risk factors such as high blood pressure, diabetes, high cholesterol, alcohol intake, cigarette smoking and atrial fibrillation (Boehme et al., 2017; Markus, 2012) and non-modifiable risk factors such as age, sex, hereditary and race (Stokes, 2004; Warlow, 2001) have been implicated to lead to stroke.

2.6 Clinical presentations of stroke

The human brain needs a continuous supply of oxygen and glucose, which can only be secured through the blood stream and therefore, a few minutes of interruption of blood supply can cause the cells in that area of the brain to die. Gund, Jagtap, Ingale, & Patil, (2013) have indicated in their study that the death of the affected brain cells will lead to the loss of functional abilities controlled by that area of the brain. Clinical presentation of a stroke therefore is dependent on the region of the brain to which blood supply has been compromised thereby leading to extreme variation in the signs and symptoms among stroke survivors. These signs and symptoms can also be influenced by the size and severity of the brain lesion according to Porter & Tidy, (2008) and may include: abrupt onset of one-sided paralysis, one-sided sensory loss, visual loss, one-sided facial paralysis, inability to coordinate voluntary muscle movements and loss of speech loss (Jauch, 2018). Even though these symptoms can occur alone, they are mostly found to occur in varying combinations among the stroke survivors.

2.7 Prognosis of stroke

A wide variety of factors influence the prospect of recovery from stroke. These may include age of survivor, severity and mechanism of the stroke, location of the infarct, presence of comorbidities, other related clinical findings, and associated complications (Karaahmet et al., 2018). Usually one cannot tell the exact prognosis for a stroke survivor because the stroke may differ from one survivor to the other. The most rapid period of recovery according to Lennon & Stokes, (2009), has been reported to occur in the first 8-12 weeks with about 40-50 % residual disability, 30 % full recovery and 20% death within the first four weeks after stroke and a 30 % likelihood of death within the first year.

2.8 Stroke Prevention and Management

Generally the best way to prevent a stroke is to diagnose and treat as early as possible, the risk factors such as high blood pressure and cholesterol level (Goldstein et al., 2011) as well as adapting some essential lifestyle modifications like eating fruits, vegetables, fish oil, exercising regularly and avoiding cigarette smoking (Lennon & Blake, 2009).

Management of stroke involves a multi-disciplinary approach which comprises medical, surgical, rehabilitation and psychological interventions (Bruno-Petrina, 2018). Medical management usually is conservative after diagnosing the type of stroke and may differ from one type of stroke to another (Lloyd-Jones et al., 2009). Bruno-Petrina, (2018) in his research article indicated that there have been reports of successful cases involving surgical bypass or endarterectomy but these procedures have been largely experimental. The same article also indicated that psychological interventions involving psychological adjustments and coping mechanisms have also been found to influence stroke survivor and informal caregiver wellbeing (Bruno-Petrina, 2018). In addition, many studies have also shown that stroke rehabilitation is essential for the improvement of functional ability in stroke survivors who have had severe neurologic and functional deficits (Jauch, 2018).

2.9 Importance of informal caregivers

An informal caregiver according to Martínez-Martín et al., (2007) can be defined as any person, mostly family, friend and loved one who usually lives with the patient and is directly involved in giving care to the patient. This person is neither a professional nor a member of any social support network. Global studies over the years have revealed that informal caregiving is an essential extension of the formal health care system and they contribute immensely to care of stroke survivors in the community (Hanson, Magnusson, Nolan, & Nolan, 2006) . Informal caregivers have also been found to reduce the costs of caring for chronically ill patients like stroke survivors and improve their wellbeing as well as their survival rates (Zarit, 2004). This caregiving role may include all assistance given in the home to the survivor, ranging from help with activities of daily living such as bathing, toileting, dressing and mobility to transportation services and administration of medication depending on the severity of the stroke as also indicated by Gräßel & Adabbo, (2011). Previous studies like that of Harris & Eng, (2010), have reported that an increased therapy time by informal caregivers positively influenced post stroke recovery and functional performance of the survivor. These findings attest to the significant impact of informal caregiving on stroke survivors' wellbeing. Informal caregivers indisputably provide the bulk of care to these stroke survivors and must be recognized as part of the stroke rehabilitation team at all times.

2.10 Informal Caregiving Burden

Informal caregiving burden has been defined by H. Kim, Chang, Rose, & Kim, (2012) as "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual". It has been realised from previous studies that, in other chronic conditions such as Alzheimer's disease or cancer, the caregiving experiences often increased gradually with time and may have allowed the informal caregivers the opportunity to adapt appropriately to the caregiving role (Glasdam, Timm, & Vittrup, 2010). However, according to Morris, (2016), caregiving for stroke survivors unlike the other chronic diseases, begins suddenly possibly because of the abrupt nature of the disease incidence and this leaves the caregivers with no room for preparation or adaptation to the new role. This suddenness is most likely to make the caregiving role more burdensome in recent times when the duration of hospital admissions has also reduced significantly according to Hall, Levant, & Defrances, (2012). The high levels of residual functional disability after the stroke makes majority of the survivors partially or permanently dependent for the rest of their lives. This dependency may also result in an increased negative impact on their informal caregivers (Caro, Costa, & Da Cruz, 2018) as well as increasing health expenditures (Zorowitz, Gillard, & Brainin, 2013). Stroke survivor needs vary and may include; physical care such as help with walking, and transfers, communication using verbal and nonverbal cues, nursing involving feeding, and personal hygiene, and emotional support such as handling disruptive behaviour and depression. Meeting all these needs along with the overarching financial responsibilities according to Ain, Dar, Ahmad, Munzar, & Yousafzai, (2014), can undoubtedly increase the informal caregiving burden. Also, assisting with these activities may require a lot of physical exertion from the informal caregiver. Caring for the stroke survivor genuinely can be very demanding because most of the time, the informal caregiver has to look after the survivor as well as make adjustments to his/ her own life with respect to other responsibilities. Making such adjustments have been reported by Gbiri, Olawale, & Isaac, (2015) to most likely lead to some man-hour losses in terms of productivity, physical, mental, and emotional burden.

2.11 Caregiving outcomes

Caregiving burden in some instances have often been investigated as caregiving outcomes (Casado & Sacco, 2012) which has been measured in several domains by researchers. Studies on the informal caregiver have indicated that extensive caregiving impacts negatively on the physical and psychological health of caregivers and exposes them to a lot of social and financial stresses which can ultimately compromise their wellbeing and the quality of care they provide.

2.11.1 Physical burden

Caregiving can have negative impacts on the informal caregiver’s health in terms of physical strain which may be experienced as a result of the frequent bending, lifting, moving and transfers that the informal caregiver is exposed to daily because of the survivor's functional disability. McGarry & Arthur, (2001), in their study indicated that, caregiving could sometimes be extremely difficult when the informal caregiver was older compared to the younger ones. White et al., (2003) examined quality of life in 97 informal caregivers of stroke survivors, whiles Teel, Duncan, & Lai, (2001) assessed the health of 83 stroke informal caregivers during their first 6 months of caring. Results from both studies revealed that informal caregivers reported physical symptoms which included fatigue, headaches, joint pain and sleep problems. Similarly in another study conducted by Sit, Wong, Clinton, Li, & Fong, (2004) in which the physical health of 102 informal caregivers of stroke survivors was examined, 83% reported fatigue and stress, with approximately 40% reporting somatic symptoms that echoed the earlier stated findings.

2.11.2 Psychological burden

Schulz & Sherwood, (2008) in their study, reported that informal caregivers are most likely to experience poorer mental health and this according to Kang et al., (2016) can affect their emotional and psychological wellbeing. Other literature over the years have also supported this notion by indicating that informal caregivers, were generally more likely to report symptoms of depression and other indicators of psychological distress than non-caregivers (Roth, Perkins, Wadley, Temple, & Haley, 2009; Pinquart & Sörensen, 2003).

2.11.3 Social burden

Informal caregivers are often responsible for providing physical and emotional support to their sick relative and this can greatly limit them from participating in their regular social activities causing them to miss out on many usual family experiences due to the increased demands of caregiving (Edwards Daryl Higgins Matthew Gray & Alan Hayes, 2008). This can really affect their wellbeing negatively. However, when informal caregivers are supported by family, friends and even the community, it can offset the challenges they experience. Stephens et al., (2004) in agreement to this, indicated in their research that a good social support will lead to the provision of higher quality care which will translate into better functional recovery and community re-integration of the disabled individual. Alternatively social isolation and decreased social activity are reported as risk factors for, as well as outcomes of caregiver burden (Rodakowski, Skidmore, Rogers, & Schulz, 2012). Holland, (2008), also added that in the case where the stroke survivor is a spouse, the informal caregiver's isolation was compounded because of the loss of companionship.

2.11.4 Financial burden

Financial stress can be viewed as a risk factor for caregiver burden in instances where meeting daily financial needs is a problem (Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005) and can also be seen as an outcome when the current expenditure as a result of the caregiving role exceeds the caregiver's income and mounts pressure on the household savings (Silver & Wellman, 2002). Adding to this view, Tilden, Tolle, Drach, & Perrin, (2004) in their study reported that there was some association between perceived economic hardship measured in terms of limited financial resources and caregiver burden. Also, caring for a co-residing elderly stroke survivor, has been reported not to have only influenced the daily life of the family but also decreased their well-being especially the informal caregiver (Amirkhanyan & Wolf, 2006). The informal caregiver's exposure to high morbidity may also lead to an increase in financial resources being devoted to the caregiver as well as the survivor, thus aggravating the existing financial burden of the family. When the informal caregiver also happens to give up a job or reduces his/her work hours in order to care for the stroke survivor, there is going to be some loss of income and other benefits which may add to the financial burden of the caregiver as reiterated by Kingson, (1996).

2.12 Impact of caregiving burden

Choi-Kwon et al., (2005) and Grant & Bartolucci, (2000) in their studies, indicated that an informal caregiver's stress may negatively affect their QoL which may potentially affect the rehabilitation outcome of the stroke survivor. Other studies including that of Garcia-Perez et al., (2011) have also shown that poor QoL among informal caregivers can be associated with the readmission of the stroke survivors which will consequently increase the health expenditure. On the other hand, caregiver burden has also been identified as a leading cause of increased mortality for the informal caregivers (Bakas et al., 2014). This may be because informal caregivers are generally more likely to concentrate solely on the health of the stroke survivor and shelf their own health issues. Such behaviours according to Hoffman, Lee, & Mendez-Luck, (2012), can cause an increase in low self-care behaviours. Caregiver burden can predispose informal caregivers to serious health conditions and was reported as an independent predictor for caregiver mortality with a 63% increased risk of death by Schulz & Beach, (1999).

2.13 Determinants of caregiving burden

In response to the various health concerns of informal caregivers, researchers and clinicians have identified that the extent of caregiver burden depends on several caregiver/ survivor-related factors which may include socio-demographic characteristics, stroke survivor's disease progressions and the perceived stress resulting from the caregiving role (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Etters, Goodall, & Harrison, 2008).These factors are mostly referred to in literature as determinants of burden.

Some socio-demographic characteristics reported to be associated with caregiving burden include sex, age, relation to survivor, socio-economic status, employment and social support (Sanuade & Boatemaa, 2015; Y. Kim & Given, 2008). Older female caregivers who reside with the stroke survivor have been found to experience greater burden than younger male caregivers (Campbell et al., 2008). In terms of relation to survivor, several studies have reported that spousal caregivers experienced the highest level of burden (Conde-Sala et al., 2010; Andrén & Elmståhl, 2008). In addition, the level of disability of older stroke survivors which influences their ability to perform their activities of daily living has also been associated with greater informal caregiver burden (Casado & Sacco, 2012; H. Kim et al., 2012). There exist however some inconsistencies, in that, whiles some studies suggest that moderate to severe disability affecting basic daily activities in stroke survivors was related to higher caregiver burden (Sussman & Regehr, 2009) others found weak or no association between the two (Campbell et al., 2008; Thommessen et al., 2002).

Some caregiver factors found to be associated with significant increase in caregiver burden, included the type of tasks, time and effort needed to perform the care giving role, the level of support and caregiver's ability to cope with the situation (Rigby et al., 2009). An increase in informal caregiver burden may also come about as a result of poor health of the informal caregiver or the presence of comorbidities (Andrén & Elmståhl, 2008).

2.14 Informal Caregiver Needs

The needs of informal caregivers vary due to differences in the caregiving setting such as the availability of support, relationship with the stroke survivor and the resources available throughout the various phases of the stroke (Visser-Meily et al., 2009). Caregiving roles or responsibilities during the first month of the stroke incidence will most likely be different from that for 6 months or over a year because the survivor's needs may change over time. Among the most commonly reported needs of informal caregivers are information and education about the condition and also regarding proper lifting and transferring techniques to help stroke survivors overcome their functional deficits without any consequences as much as possible (Northouse, Williams, Given, & McCorkle, 2012).

Informal caregivers manage their time between stroke survivors, themselves and other family members and so require a lot of psychological support such as counselling (Silva-Smith, 2007) and social support groups (Pierce, Steiner, Khuder, Govoni, & Horn, 2009). Another major need is physical support. Informal caregivers of stroke survivors have reported in several studies on their need for assistance with the physical aspects of care, such as helping with mobility, preventing falls, and assisting with bathing and toileting (Bakas & Burgener, 2002). Some studies have also indicated the need for social support after finding out that higher levels of social support could lead to lower caregiver burden (Wilks & Croom, 2008).

Advanced technology like the hoist used for lifting and electronic wheel chairs used for moving immobile stroke survivors around, can facilitate the functional independence of the stroke survivors and reduce dependency on the informal caregivers. Some studies have suggested that, the use of respite services which are support systems put in place to provide temporary relief from the caregiving role can help reduce caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). This service affords the informal caregiver some time to deal with other obligations and have some quite time with self. Such services are however very rare in Ghana.

2.15 Zarit Burden Interview Questionnaires

The Zarit Burden Interview is a caregiver self-report measure which originated as a 29-item questionnaire by Zarit et al., (1980) and was originally used for caregivers of dementia patients. The revised version containing 22 items is either self-administered or interviewer administered. The ZBI tool is reported to have a high internal consistency ranging from 0.85 to 0.94 and a test-retest reliability with Cronbach's alpha coefficient of 0.92. Because scores were unrelated to age, gender, location, language, living situation, marital status or employment status it is reported to be appropriate for use in a variety of populations (Hébert, Bravo, & Préville, 2000). In previous African studies, the tool was used to survey informal caregivers of cancer patients in Nigeria by Akpan-Idiok & Anarado, (2014) and assess informal caregiver burden in the care of stroke patients in Nairobi by Mahinda, (2016).

2.16 Modified Rankin Scale (MRS) questionnaires

The Modified Rankin Scale (MRS) is a clinician-reported measure of global disability for evaluating recovery from stroke (Rankin, 1957). There is ample evidence supporting the validity, reliability and sensitivity of the MRS from previous literature (Banks & Marotta, 2007). As a global disability measure, the broad categories of the MRS entails both instrumental activities of daily living (IADL) such as meals preparation and shopping (de Haan, Limburg, Bossuyt, van der Meulen, & Aaronson, 1995) and basic ADLs (BADL) such as walking and grooming with emphasis on compromised motor function (Bonita & Beaglehole, 1988) as well as other nonphysical characteristics unlike other BADL-specific measures like the Barthel Index (Mahoney & Barthel, 1965).

2.17 Conclusion

The burden of stroke is rising as well as its impact on informal caregivers, yet there is paucity of literature in Africa about these caregivers who play such an essential role in supporting the wellbeing of the stroke survivors. The informal caregivers' burden has been shown to have adverse effects on the physical, psychological, social and financial wellbeing and ultimately negatively affect the care and recovery of their stroke survivors. Clinicians therefore need to recognize the importance of informal caregiving, their challenges and intervene appropriately in a timely manner to ease their burden. This study aims at providing a deeper understanding of the burden that informal caregivers of stroke survivors in the Western region experience and the factors that significantly influence the burden as a result of the caregiving role.

CHAPTER THREE

3.0 METHODS

3.1. Study design

This study was conducted using a descriptive cross sectional design, which employed both quantitative and qualitative methods of collecting and analysing data. A structured questionnaire was used to collect quantitative data on burden of caregiving and socio-demographics as well as clinical background characteristics of stroke survivors and their informal caregivers. Qualitative data was obtained through focus group discussions on caregiving burden and the factors that influence it. The qualitative data was used to complement and further elaborate the figures obtained in the quantitative and also bring to the fore other focal areas not included in the questionnaires.

3.2 Study location

The hospital based surveys were carried out at the Physiotherapy departments of Effia-Nkwanta Regional Hospital and Tarkwa Municipal Hospital in the Western Region.

i. Effia-Nkwanta Regional Hospital is the major referral health centre for the entire Western Region and is located at Efia in the Sekondi Metropolis. It is situated at the junction between the Sekondi and Adiembra roads branching from the main Sekondi-Takoradi road. The 330-bed capacity hospital is believed to have been opened in 1938. The Hospital is a public health institution that provides optimum secondary health care services to people living in Sekondi-Takoradi and beyond with referral cases from other health facilities. It is National Health Insurance Scheme (NHIS) accredited and has several departments for the effective execution of its duties. These departments include but not limited to Pharmacy Department, Medical Stores, Out-Patient

Department (OPD), Paediatric Unit, X-ray Department, Laboratory Department, Ear, Nose and Throat Department, Comprehensive Care Centre (CCC), Family Planning Department, Obstetrics and Gynaecology Department, TB department, Central Supplies and Surgical Department (CSSD), Accident and Emergency, Psychiatric Department, Public Health, Administration and the Physiotherapy Department. The physiotherapy out-patient department sees an average of 90 stroke patients on monthly basis. This comprises an average of 65 continuing/ old cases and 25 new cases.

ii. Tarkwa Municipal Hospital is located at Tarkwa Nsuaem in the Wassa West District. The hospital is situated along the K.M. Steven Street, Nsuta. It is the highest order facility in the municipality and the second biggest hospital in the region. The 120-bed capacity hospital started operations in 2013, offers general primary health services and is NHIS accredited. For the effective execution of its duties, the hospital has the following departments; Out-patient department, Laboratory, X-ray, ENT, Eye clinic, Dental clinic, Maternity, Obstetrics and Gynaecology, and the Physiotherapy department. The physiotherapy out-patient department sees an average of 45 stroke patients on monthly basis. This comprises an average of 40 continuing/ old cases and 5 new cases.

The two study sites happen to be the only government NHIS accredited facilities with well -established and licensed physiotherapy departments in the Western region. Most of the stroke cases in the western region that report to a hospital or clinic pass through one of these departments and thus data collected from these two facilities can be representative of stroke survivors and their caregivers in the region.

3.3 Study population

The study population included all stroke survivors and their informal caregivers who accompanied them for treatment at the physiotherapy departments of Effia-Nkwanta Regional Hospital and Tarkwa Municipal Hospital during the data collection period from May to June, 2019. All one hundred and forty-five (145) pairs of stroke survivors and their caregivers who reported for treatment at the physiotherapy department of both Effia-Nkwanta regional hospital and Tarkwa government hospital were contacted. Twenty-seven (27) stroke survivors and their caregivers were excluded because they did not meet the inclusion criteria as described in section 3.3.1. In all, 118 pairs of stroke survivors and their informal caregivers participated in the study as shown in figure 3.1 below. Ninety-three (93) were recruited from Effia-Nkwanta Regional Hospital and twenty-five (25) from Tarkwa Municipal hospital.

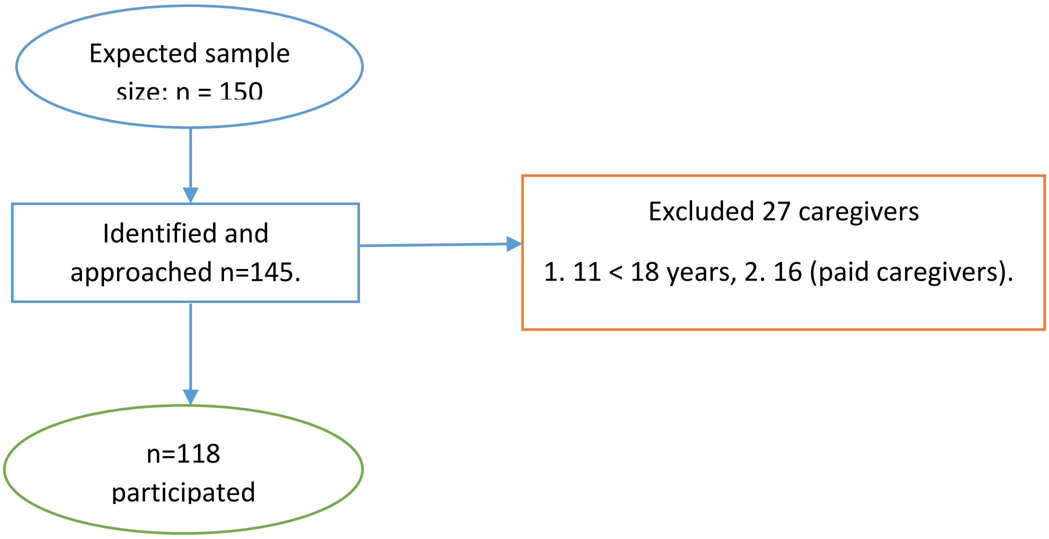


Figure 3. 1: Flow diagram for the number of participants of this study.

3.3.1 Inclusion and exclusion criteria for informal caregivers

i. The study included only the primary informal caregivers living with the stroke survivors. This is because in the Ghanaian setting where the extended family system is mostly practiced, primary caregivers may get some assistance from others living with or away from the stoke survivor. Such people will be excluded from this study.

ii. Informal caregivers who had been playing the caregiving role for at least one month prior to data collection were recruited. This was due to the fact that at one month and above the burden of caregiving is perceived to have been significantly felt by the caregiver. Informal caregivers who had played the role for less than one month were excluded from this study.

iii. Informal caregivers 18years and above, who were not being paid for the caregiving role and who communicated well were recruited. Informal caregivers who were receiving monthly salaries for the caregiving role and those with any form of communication impairments were excluded from this study.

iv. Only the informal caregivers who gave their consent to participate in the study were included. Those whose did not agree to participate were excluded from this study.

3.3.2 Inclusion and exclusion criteria for stroke survivors

i. Stroke survivors who had been clinically diagnosed with stroke at least one month prior to time of data collection and were receiving treatment at the out-patient physiotherapy departments were included in this study. Those who had suffered the stroke less than a month were excluded.

ii. Only stroke survivors who gave their consent to participate in the research were recruited. Those who did not agree to participate were excluded from this study.

3.4 Study variables

Dependent Variables

The dependent variable is caregiving burden, which was measured in four domains using the Zarit Burden Interview questionnaire.

i. Physical domain measured (strain/tiredness, disturbed sleep, feeling physically ill, musculoskeletal disorders)
ii. Psychological domain measured (anxiety, fear, mood, depression)
iii. Social domain measured (personal relationship, family support)
iv. Financial domain measured (increase expenditure, work adjustments).
v. Overall domain measured the overall burden the informal caregivers felt in caring for their relative.

Independent Variables

i. Stroke survivor factor included; age, sex, educational level, employment status, marital status, presence of comorbidities, level of disability, adherence to medication and exercise.
ii. Caregiver factor included; age, sex, educational level, employment status, average monthly income, marital status, number of dependants, presence of comorbidities, duration of care, previous caregiving experience, physical demands of care, presence of other care givers.
iii. Health care facility factor included; early referral for rehabilitation, survivor to therapist ratio, relation between therapist and caregiver/survivor, infrastructure.

3.5 Sampling

3.5.1 Sampling Method

Quantitative:

As at June 2018, the number of stroke survivors who were receiving treatment at the physiotherapy departments of Effia-Nkwanta Regional Hospital and Tarkwa Municipal Hospital were 90 and 60 respectively. This study assumed that the same total population of 150 stroke survivors would be receiving treatment at the two study areas by June 2019 when data was to be collected. In view of the fact that this population was not so large, a total population of 150 pairs of stroke survivors and their informal caregivers was targeted in order not to miss out on any relevant information. For this reason, there was no need for sample size calculation. A total population sampling was therefore used in this study. This involved considering all stroke survivors and their informal caregivers reporting for physiotherapy in the two study locations over the data collection period and who also met the inclusion criteria.

Qualitative:

Literature has varied opinions with respect to an ideal focus group size. Different researchers have indicated ranges in size from 4 to 23 with 8 to 12 participants as common practice in the USA (Falco et al, 1998 cited in (Prince & Davies, 2001) while 5 or 6 participants is widely used in the UK and other countries (Marketing news, 1995 cited in (Prince & Davies, 2001). In view of this the current study selected 8 informal caregivers for the first focus group discussion and 9 physiotherapists and assistants for the second focus group discussion.

The 8 informal caregivers were purposively drawn from the 93 informal caregivers who participated in the quantitative study at Effia-Nkwanta Regional hospital. The caregivers were selected such that there was some dynamics in age, sex, relationship to stroke survivor, duration of care and employment status. Thus efforts were made to ensure that informal caregivers between 18-40 years and 41 years and above, males and females, employed and unemployed and those who had played the caregiving role for less than 6 months and more than 6 months were fairly represented. This helped to ensure a fair representation of the informal caregivers and to capture their multiple life experiences.

A total population sampling was used to select all the physiotherapists and assistants present at work on the day of data collection after working hours. However there was a fair representation of qualification and years of experience to capture multiple views on the health care facility factors that may contribute to the informal caregiver's burden.

3.6 Data collection

This study employed both quantitative and qualitative methods of data collection. Questionnaires were used for the quantitative data collection and focus group discussions was used for the qualitative with the help of two research assistants. The qualitative method was employed to obtain the real life experiences and opinions of the participants.

3.6.1 Quantitative data collection

Stroke survivors and their informal caregivers who met the inclusion criteria were approached by the PI or the research assistants and the objectives of the study was explained to them. Their consent was sought and those who consented were taken to one of the offices to fill the questionnaires. The stroke survivor's questionnaire was filled first to allow him or her go for treatment whiles the informal caregiver was being engaged. This also allowed the informal caregiver to answer freely without any intimidation from the stroke survivor. Questionnaires were filled by face to face and sometimes phone interview was used for informal caregivers who could not make it with their survivor on the data collection day. Thorough explanation of questions within each section of the questionnaire was given with oral translation into local dialect for participants who did not understand English by the PI. Averagely twenty-five minutes was used to fill the questionnaires. The data collection for the study took place over a period of 2 months (from May to June, 2019). Informal caregivers and their stroke survivors who took part in questionnaire survey were not remunerated in any way as they were engaged during their normal clinic visits. The two research assistants helped in coding, administration and filling of questionnaires and entering of data into Microsoft Excel (version 2013). Samples of the questionnaire can be seen at appendices C and D for informal caregiver and stroke survivor respectively.

Questionnaire

The questionnaire was two in one, one part for informal caregivers and the other for their stroke survivor. The informal caregiver questionnaire had six sections, A to F, whiles that for the stroke survivor had two sections, A and B.

The first section, A, of the caregiver questionnaire made up of open and close ended questions was used to collect data on the socio-demographic and background characteristics of the informal caregivers such as age, gender, educational status, employment status, marital status, monthly income, number of dependants, co-morbidities, relationship, duration of care, previous caregiving experience and presence of another caregiver. Section B, was used to assess the physical demands of the caregiving role and was made up of a table which contained a list of activities of daily living that caregivers provided for the patient, how many minutes or hours in total involved in performing them and the degree of demand (light, moderate, high). Section C, was made up of four Likert scaled questions and one closed ended question for assessing caregiver perception of stroke survivor's exercise / medication adherence. Sections D and E were made up of tables that had four and three Likert scaled questions respectively for measuring caregiver/stroke survivor and therapist relation. The last section, F, is the Zarit burden interview questionnaire, a 22 item version modified into a 24 item questionnaire in order to measure more of the physical domain than it originally does. Each item on the interview is a question which the caregiver was asked to answer using a 5-point Likert scale ranging from "0" for never burdened and "4" for nearly always burdened.

The section A of the stroke survivor questionnaire is also made up of closed and open ended questions for assessing their socio-demographics and background characteristics. Section B is the Modified Ranking Scale, an ordinal scale with six (6) categories ranging from "0" (no symptoms) to "5" (severe disability/complete physical dependence) and was used to measure the survivors' level of disability.

3.6.2 Qualitative data collection

Focus Group Discussions (FGD)

The PI along with the 2 research assistants met the 8 informal caregivers and the 9 physiotherapists and assistants on two different occasions in one of the departmental offices away from the stroke survivors or any form of interference. FGD guidelines comprising open-ended questions which gave participants the opportunity to describe their experiences using their own words and in as much detail as possible was used. The guidelines can be seen at appendices E and F for informal caregivers and physiotherapists respectively. Every participant was given a unique number before the discussions began. The discussions were recorded using a smart phone voice recorder as well as a portable Homder recording device. It was later transferred unto a laptop and secured with a password by the PI for later transcription.

The discussions with the informal caregivers focused on their experiences in playing the caregiving role, physical demands of care, challenges, level of support they get and some recommendations on how their burden can be alleviated and this lasted for a period of one hour and forty-five minutes. On the other hand, discussions with the physiotherapists and assistants focussed on health facility factors that may contribute to the informal caregiver's burden and this also lasted for fifty-five minutes. Opinions of the ideal length of sessions in literature fluctuate between half an hour to two and a half hours per focus group (Stewart and Shamdasani, 1990 cited in (Masadeh, 2012). Participants and research assistants for both FGDs were refreshed with lunch and water for their time and commitment.

3.7 Data storage and protection

Completed questionnaires were kept safe under lock and key by the Principal Investigator (PI) only in order to protect against inappropriate use, disclosure and accidental loss or destruction and also to protect the confidentiality of the participants. Recorded discussions from both FGDs were secured with a password by the PI on her personal laptop and routine electronic back up was done during data collection. Hard copies will however be destroyed after the study has been concluded and results have undergone review.

3.8 Data processing and analysis

Quantitative:

Raw scores of data collected were directly entered into Microsoft excel (version 2013), cleaned and later exported and coded by the statistical product and service solutions (SPSS) version 23 software for data analysis. Descriptive analysis of socio-demographic data was carried out. Frequencies, percentages, mean and standard deviation (SD) were calculated. This was presented in the form of frequency distribution tables, pie chart and bar graph. The age was originally in continuous data and later converted into categorical variables [≤ 40 and >40 years] for the caregivers' age and [30-49, 50-59 and 60 and above] for the stroke survivor. The relationship to patients was grouped into six variables [daughters and sons=child, wife and husband=spouse, brothers and sisters=Siblings, niece/nephew together, cousins maintained and formal employee, tenants= others].The marital status was initially classified into four categories [unemployed, private sector, public sector, self-employed and retired) on the questionnaire and later re-categorized into three (unemployed, employed and retired). The level of education was also initially classified into six levels (no education, primary, middle, secondary, technical/vocational and tertiary) and later re-categorized into three (none/primary, Middle/secondary, technical/tertiary). In addition, the monthly income which was initially classified into four levels (<GHc100, GHc100-999, GHc1000-1999, GHc2000-2999) was later re-categorized into levels two levels (<GHc1000, ≥ GHc1000). The number of dependents was also in continuous data and later grouped into categorical [≤4 dependents and >4dependents] variables.

The physical demands of the caregiver’s roles were initially broken down individual activities; bathing, toileting, shopping, feeding, meal preparation, housework, dressing, giving medications, dealing with incontinence, getting in and out of bed and transportation. These activities were later grouped into tasks; no task, 1-4 tasks and >4 tasks and the associated time were categorized into; <30 minutes, 30-60minutes and >60 minutes. The degree of demand was also categorised into light, moderate and high.

The exercise adherence section was formally grouped into [>10 times, 6-10 times, 3-5times, 1-2 times and no exercise]. This was later put into three categories [6-10 times, 1-5 times and no exercises. The caregiver-physiotherapist relation (CPR) and caregiver perception of survivor-physiotherapist relationship (CSPR) was initially on 4-Likert scale [disagree, slightly disagree, slightly agree and agree] and later dichotomized into [disagree and agree].

For the caregivers' burden section the overall burden was scored by adding all the numbered responses of the individual items which were graded on a scale of "0" (never) to "4" (nearly always). A higher score was indicative of higher caregivers' burden and was interpreted into no burden, little burden, moderate burden and severe burden. Little and no burden was later merged as no burden with a score of (0-24) and whiles moderate and severe burden was also merged as burden with a score (>24) for purposes of analysis. The questions were grouped into four domains; physical (had 5 questions), psychological (had 10 questions), social (had 5 questions) and financial domain (had 3 questions). The last question measured the overall burden.

For inferential analysis, chi-square was initially used to test for association between caregiver factors, stroke survivor factors, health facility factors and caregiver burden. Fisher exact test was reported in instances where the 2x2 cells contained less than 5 items. Further analysis using logistic regression was employed to test the strength of association between the significant factors and the caregiver burden. Factors such as age, though not significant from the chi-square test, was also analyzed on the logistic regression model because of the fact that it carries some biological possibility of influencing burden. A p-value of less than 0.05 was interpreted as significant at 95% confidence interval.

Qualitative:

The recorded interviews from the two FGDs were transcribed verbatim from the Homder voice recorder and translated into the English language from Fante by the researcher who is well-versed in that dialect prior to coding, content and thematic analysis. The individual transcript was entered into a Microsoft word file, printed in hard copy and read severally times to obtain the overall sense of the data. Broad notes were made in the margins. The major themes were developed from the objectives of the study. The coding of the responses to each question was done by identifying persistent words, phrases and concepts and these were achieved with the help of the major themes identified. The importance of this was to provide structure and conceptual clarity in the analysis process. The words, phrases and concepts were classed under the major theme as sub-themes which were identified by colours; red, orange, yellow and blue. The coloured codes were put into themes and sub-themes with all associated colours together and summary done for each category. Each transcript and the field notes were analysed thematically in order to cover all transcripts precisely and accurately.

3.9 Quality control and pretesting of questionnaire

A total of 10 informal caregivers and their stroke survivors were recruited at the physiotherapy department of Effia-Nkwanta Regional Hospital for a pilot study. None of the participants in the pilot study was unable to, or refused to, complete the Questionnaire after the objectives of the research were explained to them. The average time for completing a questionnaire for both stroke survivor and informal caregiver was between 25 minutes and 45 minutes.

The results of the pilot study in terms of the Cronbach's alpha for the various components of the questionnaire, revealed a good internal consistency for Zarit Burden Questionnaire (α=0.84), Exercise/medication adherence assessment (α=0.78), caregiver-physiotherapist relation (α=0.70), and caregivers' perception of physiotherapist-patient relation (α=0.81). However, the functional limitation as a result of the physical burden which was previously part of the questionnaire, had very low internal consistency (α=0.25), and thus was removed from the final questionnaire.

The two-week intra-class correlation coefficient (absolute agreement) of the modified ranking scale was good (ICC=0.691) and there was also a good positive correlation between the Zarit Burden Questionnaire and Modified Ranking Scale (r=0.78) indicating good validity and reliability of the instruments for the study.

Research assistants were physiotherapy interns who had requisite knowledge about the topic of study and were given a two-day training on the research topic, inclusion/exclusion criteria and the procedure for collecting and recording.

3.10 Ethical issues

Ethical clearance was sought from The Ghana Health Service Ethics Review Committee. Approval was sought from my supervisor at the School of Public Health (SPH). A written permission to carry out the study at Effia-Nkwanta Regional Hospital and Tarkwa Municipal Hospital were sought from their respective Medical Directors. An informed consent was signed by all informal caregivers and stroke survivors who consented to take part in the survey after an in-depth explanation of the aims and processes of the study had been given. Participants were also given the opportunity to ask questions for clarity and were at liberty to withdraw at any stage. Interview was conducted in the consulting rooms of the physiotherapy departments on their clinic days either before or after their therapy. FGDs was conducted in the absence of the stroke survivors. Names of participants were neither written on questionnaires nor recorded in any write up. The data collected was used for the intended academic and research purpose.

3.11 Conflict of interest

There is no conflict of interest in this study.

3.12 Funding/Sponsorship

This research was funded by the principal investigator. Incentives such as lunch and water were given to participants and research assistants who took part in the FGDs as a form of appreciation for their time and commitment. On the other hand, participants who took part in the survey, were not given any incentives.

3.13 Risk

There were minimal risks involving the time spent in answering questionnaires and provision of answers to questions about age and level of education which might have made some of the respondents feel uncomfortable.

3.14 Expected Outcome

Findings are expected to provide unique insights into the burden of care among informal caregivers of stroke survivors in the Western Region. Knowledge about the extent of burden and the factors that predispose informal caregivers will inform the development of interventions to reduce the burden such as providing appropriate and effective coping mechanisms. With this knowledge health promotion and policy makers can plan services that address these burdens and provide the needed social support for the informal caregivers. Findings will be disseminated widely to clinicians and researchers through journal publications and conference presentations.

CHAPTER FOUR

4.0 RESULTS

4.1 Socio-demographic and background characteristics of stroke survivors.

All the 118 stroke survivors and their informal caregivers who met the inclusion criteria participated in the study representing a 100% response rate. Table 4.1 below, presents the stroke survivors' socio-demographic and background characteristics. Out of the 118 stroke survivors surveyed, 55.1% were females and 44.9% males. Their ages ranged from 32 years to 78 years and with a mean age of 60.12±10.33 years. Majority, (63.0%) were 60 years and above. A combined majority (44.9%) had attained middle/ secondary school education, comprising 22.9% middle school and 22.0% secondary school. A greater portion of 84.0% were married and 80.5% were employed prior to the attack. Majority (34.7%) presented with moderate disabilities whiles 11.0% had moderate-severe disabilities. The most reported comorbidity was hypertension (77.1%). About 80.5% and 89.9% of the stroke survivors were reported to have adhered to their home exercises and medications respectively.

Table 4.1: Socio-demographic and background characteristics of stroke survivors (N=118).

Characteristics	Frequency (n)	Percent (%)
Sex		
Male	53	44.9
Female	65	55.1
Age		
30-49	17	14.4
50-59	29	24.6
60 and above	72	61.0
Employment status		
Employed	11	9.3
Unemployed	95	80.5
Retired	12	10.2
Marital status		
Married	99	83.9
Not Married	19	16.1
Education		
≤Primary	24	20.3
Middle	27	22.9
Secondary	26	22.0
Tertiary/ Technical	41	34.7
Disability level		
No symptoms	4	3.4
No significant disabilities	25	21.2
Slight disabilities	35	29.7
Moderate disabilities	41	34.7
Moderate-severe disabilities	13	11.0
Adherence to exercise (monthly)		
No exercise	14	11.9
1-5	24	20.3
6-10	80	67.8
Adherence to exercise (weekly)		
No exercise	61	51.7
1-5	42	35.6
6-10	15	12.7
Adherence to exercise (daily)		
No exercise	95	80.5
1-5	7	5.9
6-10	16	13.6
Adherence to medication		
Yes	106	89.9
No	12	10.1

4.2 Socio-demographic and background characteristics of informal caregivers.

Table 4.2 below, presents findings on the socio-demographic and background characteristics of the 118 informal caregivers surveyed in this study. The data revealed that 68.6% of the informal caregivers were females aged from 18 to 75 years and with a mean age of 40.52±15.68 years. Majority (53.4%) were below 40 years, 56.8% were married and a greater proportion (49.0%) had middle/secondary education. About 61.0% earned below GHc1000 and 72.9% had less than 4 other dependents. Approximately 77.0% had no previous care giving experience, 74.6% had other family members assisting in the caregiving role, and 44.1% had caregiving duration of 6 months or less. Majority (66.1%) performed more than 4 tasks and 66.9% spent a duration of 30 – 60 minutes performing these tasks on a daily basis. The most reported comorbidities were lower back pain (29.0%) and shoulder pain (27.0%). Majority were 38.1% children and 36.4% spouses as presented in Figures 4.1 and 4.2 below.

Out of the 8 informal caregivers who were engaged in the focus group discussion, 2 were males and 6 females, ages ranging from 23 to 57 years. Three (3) of them were children, 3 sisters, 1 spouse and 1 grandchild. The second focus group discussion involved 4 physiotherapists, 3 physiotherapy technicians and two assistants making 9 in all, with ages ranging from 25 to 59 years. Working experience also ranged from 1 to 30 years. A summary of this data is shown in Appendix I. Table 4.2b, which is presented at the end of this thesis (pg. 115).

Table 4.2: Socio-demographic and background characteristics informal caregivers (N=118).

Characteristics	Frequency (n)	Percent (%)
Sex		
Male	37	31.4
Female	81	68.6
Age		
<40	63	53.4
≥40	55	46.6
Employment status		
Employed	36	30.5
Unemployed	72	61.0
Retired	10	8.5
Marital status		
Married	67	56.8
Not Married	51	43.2
Education		
≤Primary	20	17.1
Middle/Secondary	58	49.6
Tertiary/Technical	39	33.1
Monthly income		
< GHc1000	72	61.0
≥ GHc1000	46	39.0
Number of dependents		
<4	86	72.9
≥4	32	27.1
Previous Care experience		
Yes	27	22.9
No	91	77.1
Family assisting in care	88	74.6
Yes		
No	43	36.4
Duration of care so far		
≤6 months	52	44.1
7-12 months	27	22.9
>1 year	39	33
Number of Tasks		
None	6	5.1
1-4	34	28.8
>4	78	66.1
Time for task		
<30minutes	23	19.5
30-60minutes	79	66.9
>60minutes	16	13.6

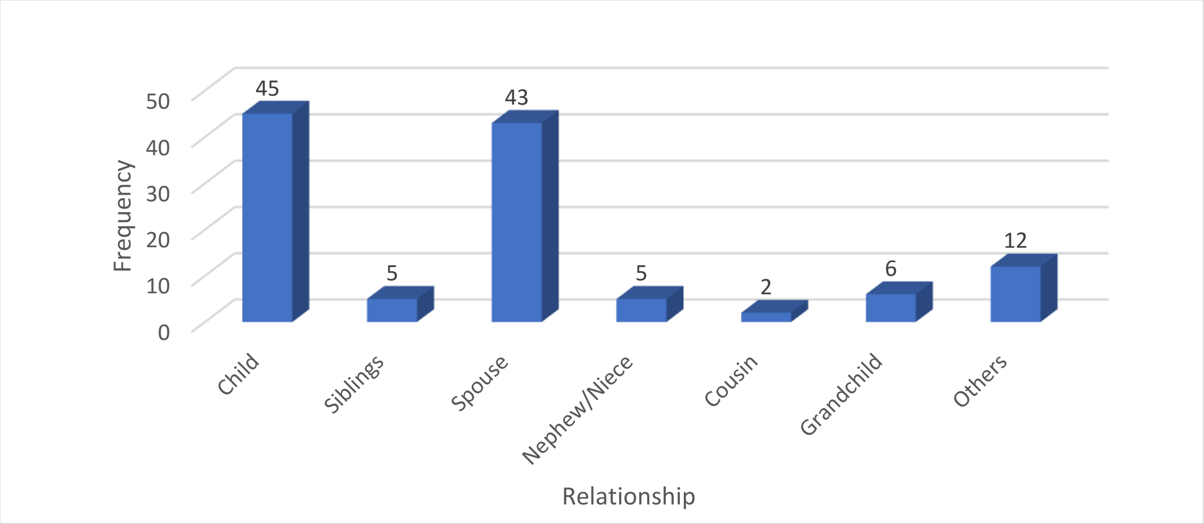


Figure 4.1: Relationship of informal caregiver with stroke survivor

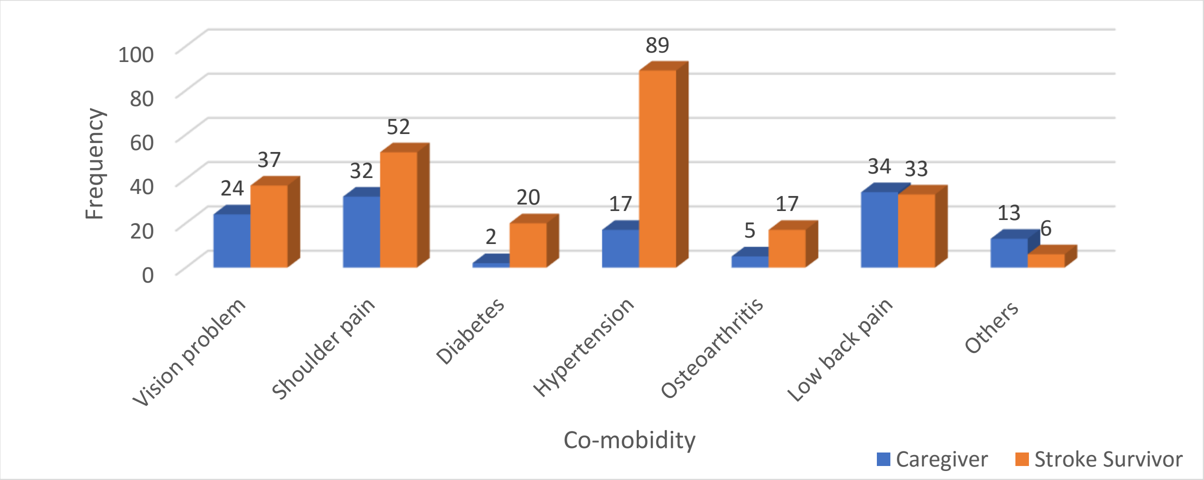


Figure 4.2: Comorbidities of informal caregivers and stroke survivors.

4.3 Background characteristics on health care facility factors.

About, 89.8% of the informal caregivers agreed to the fact that therapist understood their situation and gave them the necessary support and encouragement, 90.7% agreed that their stroke survivors were well taken care of by the physiotherapist/assistants in their absence and 89.8% believed that they as well as their stroke survivors got the necessary attention from their therapists all the time. Majority of the caregivers (63.6%) perceived that the two physiotherapy departments were well-equipped whereas 65.3% reported that their stroke survivors were referred for physiotherapy within one month of the stroke attack (Table 4.3).

Table 4.3: Distribution of health care facility factors (N=118)

Characteristics	**Disagree n (%)**	**Agree n (%)**
Caregiver-physiotherapist relationship		
I know this therapist/ assistant very well	42 (35.6)	66 (64.4)
This therapist/ assistant knows me as a person	40 (34.0)	78 (66.0)
I know what to expect with this therapist/ assistant	35 (29.7)	83 (70.3)
They understand my situation and gives me all the necessary support and encouragement.	12 (10.2)	106 (89.8)
Caregiver perception of survivor-physiotherapist relationship		
Stroke survivor will be well taken care of in my absence	11 (9.3)	107 (90.7)
Stroke survivor is assisted throughout his treatment	17 (14.4)	101 (85.6)
Stroke survivor and I get the necessary attention all time	12 (10.2)	106 (89.8)
Other health care facility characteristics	**n**	**%**
Physiotherapy facility well-equipped		
Yes	75	63.6
No	43	36.4
Referral		
≤1 month	77	65.3
>1month	41	34.7

n=frequency, %=percent

4.4 Prevalence of physical, psychological, social, financial and overall caregiving burden.

Table 4.4 below presents the level of caregivers' burden in the four domains and categorized into no burden and burden. The results reveal that the informal caregivers were mostly financially burdened (74.6%), followed by physical burden (66.9%), psychological burden 63.6% and social burden 51.7% in that order. The prevalence of overall burden was 67.8%.

Table 4.4: Prevalence of physical, psychological, social, financial and overall caregiving burden (N=118).

Caregiving burden	No burden n (%)	Burden n (%)
Physical	39 (33.1)	79 (66.9)
Psychological	43 (36.4)	75 (63.6)
Social	57 (48.3)	61 (51.7)
Financial	30 (25.4)	88 (74.6)
Overall	38 (32.2)	80 (67.8)

n=frequency, %=percentage

Exploring further into the psychological, physical, financial and social experiences of the informal caregivers during the focus group discussion, themes and subthemes that emerged were consistent with and complemented these findings. Under the various domains of burden representing the major themes, the informal caregivers described their experiences as follows;

Physical burden

The informal caregivers described their physical burden in terms of physical stress, fatigue, headache and sleepless nights.

Physical stress

Majority of the informal caregivers indicated that, they experienced a lot of physical stress as a result of the caregiving role they perform especially, in the early stages of the stroke incidence.

This is what they had to say;

> *"…having to lift her up all the time was another issue especially when there is no one around to help. She has had the stroke since last year July till now, and in the first three months it was not easy… "I was lifting her up, moving her here and there and practically doing everything for her". (35- year-old son)*
>
> *''I lift him up, put him on the wheel chair to the bathroom and then put him in the bath to bath him. Then I bring him back to the bedroom and dress him up. It is a very difficult task…like I said earlier, because of when I lift him up, I said my son used to help. Because he is a male child and tall, I presumed he was very strong, and he too whenever he was lifting my husband up, he would use all his strength and was later complaining…'' (55-year-old spouse)*
>
> *''It's been long and we have really suffered, it has been very stressful because in her case she almost lost her life but by the Grace of God, she is still alive. Even if she wants to go to toilet and the toilet is not coming, we have to hold her buttocks and use a small spoon to scoop the feces from her anus little by little, plus urine. If she has to go to the bathroom it's not possible so we have to put her on the mat, bath and clean her up…''. (50-year-old sister)*

Another caregiver mentioned how she combined caregiving with nursing her baby;

> *"…her eating, her bathing, whatever she has to do all lies on you and so whatever you do, it is a burden but you cannot say so, so you just have to take it like that. "Sometimes when baby is breastfeeding, I have to leave her to go and attend to my mother because she wants to ease herself or something….."I will be the only one to lift her up. And she doesn't also like the idea of someone else outside the family to help in lifting her. When she doesn't really know you, she wouldn't allow you to hold her, so it has to be me most of the time". (34-year-old child)*

Fatigue

A cross section of the caregivers also indicated that caring for their stroke survivors was very tiring and exhausting, for instance some caregivers mentioned that;

> *"…you have to do everything for her so by the time you are done, you are exhausted". (23-year-old sister)*
>
> *"I have to massage her and also in the evenings and her arm too was quite stiff so you have to use a lot of pressure so even before you are done you will be tired". (31-year-old granddaughter)*

Musculoskeletal pain

Majority of the caregivers reported to have experienced bodily pains one time or the other. In describing these experiences, the caregivers had this to say;

> *"I have so much pain in my shoulder and back, I sometimes even have to report at the hospital to be treated. I sometimes use hot ointment to rub my shoulder and back. I have a son who is seventeen years who used to help with the lifting but also started complaining of severe pain at the back of his neck so I asked him to stop helping". (55-year-old spouse)*
>
> *"…even sometimes I have severe pain in my leg which extends to the lower back". (50-year-old sister)*

Another female caregiver complained that;

> *"The back of my neck, my waist, sometimes even whiles holding her up I feel severe pain in my waist and back, when I leave her too she will fall so I have to hold her like that, force and go through whatever I was doing and put her down safely before I can take a rest so truthfully, it's made me feel very unwell, I'm not well at all, my right shoulder, my waist, my back is very painful… As I sit here right now, it feels like someone has grabbed me and beaten me very well with a log". (57-year-old sister). (57-year-old sister)*

A male caregiver also indicated;

> *"...sometimes because you have to lift her up, it affected my right shoulder, because it's the right hand that I used most of the time so that I can lift her up properly". (36-year-old son)*

Headaches

Quite a number of the caregivers went further to indicate having experienced headaches most of the time because of the stress they go through. Their opinions were as follows;

> *"In the beginning when it all started, because of the sleepless nights and the thinking made me experience slight headaches most of the time". (36-year-old son)*
>
> *"Because of the lack of enough rest, I experience slight headaches. As for me whenever I don't get enough rest, I will experience headaches and both eyes will all become red. It's something that is with me whenever I don't get enough rest… having my mother's issue too in addition makes me have a lot of headaches". (34-year-old daughter)*

Sleepless nights

Some caregivers narrated their sleepless night experiences as follows;

> *"It was not easy, especially in the night, sometimes even you have sleepless nights because you will have to share the same room with the patient in order to attend to her because you don't know what may happen". (36-year-old son)*
>
> *"Sometimes at night around 12/1:00 am, she will wake up because she needs to ease herself, so it is you who has to wake up and assist her gradually to the washroom and back… the early stages of the disease it wasn't easy at all". (35-year-old son)*
>
> *"Sometimes at dawn, when baby is breastfeeding, I have to leave her to go and attend to my mother because she wants to ease herself or something…." (34-year-old daughter)*

Psychological burden

The informal caregivers shared their experiences on the impact the caregiving role has on them psychologically in terms of worry and mood changes.

Worry

A caregiver explained her dilemma;

> *"In fact, it is a big worry, it's been just about a month now since she had the stroke, it hasn't been that long but what I have passed through this short while''… Her stroke affected her left side and so it is very worrisome… In fact, if not for the fact that she happens to be my own sister I would leave, but if I say I want to leave too then I'm sad because her own children are not with her, they have now acquired some jobs and so I don't have to make them leave or lose their jobs". (57-year-old sister)*

Mood changes

Other caregivers reported on the fact that the stress in the caregiving role affected their mood;

> *"Yes it has affected my mood so much that my grandmother even sometimes complains that I have changed towards her and that it's not like before. At first I was very close to her but now it looks as if I don't care about her. The stress is overwhelming and it's like she always gets me angry and that has really affected the mood". (31-year-old granddaughter)*
>
> *"Honestly, my mood changes are on and off, but I think it's normal, despite the fact that when she is getting on my nerves I shout at her, we fight small but when*

> *that is over, we become paddies again and move on. So the mood is like "network" comes on and off "laughter".* (35-year-old son)

The same caregiver gave an example by saying;

> "*…her feeding, even yesterday I asked her severally and she said she will eat rice, we have put rice on fire and prepared everything only for her to now say that she wants yam, meaning we have to prepare yam so I got angry and left to sleep whiles my little sister prepared the yam for her".* (35-year-old son)

Another added;

> *"As for the mood sometimes when you are with him, because this is not how he was before the illness, sometimes the mood will change but you have to try and control yourself. Because of his illness if you don't control your mood too it's likely that his BP might go up".* (36-year-old son)

Social burden

The informal caregivers had also expressed certain experiences that highlighted the impact of care on their social life in terms of disruption in church attendance and loss of relationship.

Disruption of church attendance

Some of the caregivers mentioned that there was a disruption in their church attendance;

> *"We are Adventist and we could not go to church initially but now that the physio has helped, she suggested that if we come for therapy on one Saturday then we go to church on the next".* (35-year-old son)

> *"In the beginning going to church was not possible. We both attend the same church and so when there is no one to leave the patient with, you have to stay with him and so for about three weeks or a month I hadn't been to church".* (36-year-old son)

> *"As for me I wasn't able to go to church at all. About a month passed without going to church, but church members came by including my pastors and also prayed with us".* (55-year-old spouse)

Loss of relationships

The caregiving role affected some of their relationships;

> *"It has affected most of our relations especially some friends".* (36-year-old son)

> *"I have even lost a relationship because of my mother's illness. My partner was always complaining that I didn't have time for him because I was always with my mother".* (31 year-old-granddaughter)

Limited time for self

Some of the caregivers expressed how they had limited time for themselves by saying;

> *"When the stroke started, there was no chance for anything. It made my life miserable, everything was off. I am unemployed at the moment and at the early stages of the stroke, I didn't even have the time to go out and look for job"* (35-year-old son)
>
> *"You will have to stay with him to the extent that sometimes even in a week or more those that you need to see you wouldn't have been able to see".* (36-year-old son)
>
> *"The caregiving role is so time consuming that I am unable to even go to the saloon because I have to be with her all the time. Because of that I had to cut my hair".* (23-year-old sister)

Financial burden

With the exception of the youngest caregiver, all the rest complained about how the caregiving role had greatly impacted on their finances in terms of increased expenditure and work adjustments. The following were some of their opinions;

Increased expenditure

> *"As for financial issues, "sigh" it's very tough. It is very worrisome. When the illness started, we could even buy medication worth 1,000GHc, it wasn't easy. Also, whenever we reported for physiotherapy, the cost of dropping in and out and also reporting for Saturday rehab sessions. This illness looks like that for the rich, because it is very cost intensive…. Physiotherapy is very good and if you are not consistent it affects recovery and so when you don't have enough money to continue it becomes a major problem. So, buying medications and transport and other things is a problem".* (35-year-old son)
>
> *"Financially, we have been really drained. At times when you don't even have the money, you have to force no matter what and wherever you need to go and get the money. Sometimes a day before physio, you need to try very hard to look for money for the next day's therapy session and dropping fare. When he needs medications, you need to buy".* (36-year-old son)

A female participant described her financial predicaments;

> *"As for financial problems it's very true. It's very difficult. For me where we live, the driver who will bring us for physio and back will take 40GHc so you can imagine how much we spend when we have to report three times weekly. We started physiotherapy only about two weeks ago and the cost is building, when we go to Takoradi hospital for review, they will take money. In fact, monetary cost involved is really a problem, it is very difficult. And since it has already happened*

> *there is not much that can be done. You have to look for all means possible to get money to support her care, so when it becomes difficult". (57-year-old sister)*

Another caregiver described her ordeal;

> *"I remember when we were on admission at Takoradi hospital if you are supposed to move from one place to the other and you are given assistance, you pay, if you receive visitors you pay, if they carry your patient up the building on the staircase you pay. Some day they wanted 50GHc for taking my husband down the stairs, I had to plead for them to reduce to 40GHc. They are the same people who assisted in bringing my husband to be put in the machine (CT scan). If you don't pay you cannot do anything because I didn't have any male around who could help. That aside, buying the medications, transportation to and from physiotherapy because you have to pick dropping. You can spend 50GHc a day. So sometimes when you don't have money then you have to be indoors and see the patient deteriorating when indeed he would be better if he reported to the hospital. This illness demands a lot money". (55-year-old spouse)*

Work adjustments

Some of the caregivers have had to make some adjustments in their work. This is what some of them had to say;

> *"It also affects our work input and output for instance I have to report to work around 7 / 7:30 but because of the situation I get there after 9am and so I miss a lot of customers". (50-year-old sister)*
>
> *"I'm out of job at the moment and it is not easy for me. Sometimes you need to go and hustle for some jobs here and there, the little you get you have to spend on the patient plus the little support you get from other siblings". (35-year-old son)*
>
> *"when I go to work, there is no one at home to care for her so I schedule my work such that I come back home in the afternoon and evening to prepare her meals before I go back and close for the day, it is really affecting my output at work".(31-year-old granddaughter)*

4.5 Association between determinants of interest and caregiving burden (physical, psychological, social, financial and overall).

4.5.1 Caregiver Factors

4.5.1.1 Test of association between caregiver factors and caregiving burden.

Physical burden.

The results from the Chi-square analysis revealed a significant relationship between physical burden and the number of tasks performed by the caregiver [X^2 (N=118) =18.47, p=.00], sex [X^2 (N=118) =5.926, p=.015] and income level [X^2 (N=118) =6.752, p=.009]. Physical burden had no significant association with the age, duration of care, time, education, employment status, marital status, previous caregiving experience, comorbidities and number of dependents. The results are presented in Table 4.5.1.1a below.

Psychological burden:

The results of the Chi-square analysis, indicate that there was significant relationship between the number of tasks performed [X^2 (N=118) =6.39, p=.04], income level [X^2 (N=118) =6.752, p=.01] and psychological burden. The age, sex, duration of care, education, employment status, marital status, caregiving experience, comorbidities, time and number of dependents had no significant association. The results are presented in Table 4.5.1.1a below.

Social burden.

The results from the Chi-square analysis indicate that there was significant relationship between the employment status [X^2 (N=118) =7.52, p=0.04], sex [X^2 (N=118) =4.15, p=0.04], previous caregiving experience [X^2 (N=118) =4.89, p=0.03], income [X^2 (N=118) =5.84, p=0.02] and social burden. The age, duration of care, number of tasks performed, time, education, marital status, comorbidities and number of dependents had no significant association. The results are presented in Table 4.5.1.1a below

Table 4.5.1.1a: Test of association between caregiver factors and physical, psychological and social burden (N=118).

Characteristics	Physical burden				Psychological burden				Social burden			
	No burden	Burden	X^2	p-value	No burden	Burden	X^2	p-value	No burden	Burden	X^2	p-value
Age/years				.10				.12				.19
<40	25	38	2.69		27	36	2.40		34	29	1.74	
>40	14	41			16	39						
Duration of care				.46				.47	23	32		
≤6 months	15	38	1.55		17	36	1.50					.62
7-12 months	11	15			12	14			23	30	.97	
>12 months	13	26			14	25			14	12		
Number of Tasks				**.00***				**.04***	20	19		.06
No task	5	1	18.47		5	1	6.39		6	0	2.29	
1-4 tasks	18	16			13	21			25	9		
>4 tasks	16	62			25	53			26	52		
Time				.93				.06				.50
<30 minutes	7	16	.14		7	16	4.39		13	10	1.37	
30-60 minutes	27	52			31	48			38	41		
>60	5	11			5	11			6	10		
Sex				**.02***				.30				**.04***
Male	18	19	5.93		16	21	1.08		23	14	4.15	
Female	21	60			27	54			34	47		
Employment status				.72				.07				**.02***
Employed	13	23	.66		20	52	5.46		29	43	7.52	
Unemployed	23	49			18	18			24	12		
Retired	2	7			4	5			4	6		
Marital status				.08				.15				.33
Unmarried	21	30	3.12		22	29	2.06		27	24	.93	
Married	17	49			20	46			29	37		
Income level				**.01***				**.01***				**.02***
<Ghc1000	19	53	6.75		19	53	6.75		27	45	5.84	
>GHc1000	11	8			10	9			13	6		

Table 4.5.1.1a continued.

	Physical burden				Psychological burden				Social burden			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
PCE**				.07				.40				**.03***
No	34	57	3.34		35	56	.70		49	42	4.89	
Yes	5	22			8	19			8	19		
Family Assistance				.19				.64				.29
No	7	23	1.72		12	18	.22		12	18	1.11	
Yes	32	56			31	57			45	43		
Education				.69				.25				.09
None/primary	6	14	.75		4	16	2.75		6	14	4.74	
Middle/Secondary	21	37			22	36			33	25		
Tertiary/Technical	11	28			16	23			17	22		
Dependents				.19				.41				.07
<4	26	60	1.71		30	56	.68		38	48	3.26	
≥4	13	17			13	17			19	11		
Vision problem				.65				.19				.24
No	32	62	.21		37	57	1.70		48	46	1.41	
Yes	7	17			6	18			9	15		
Shoulder pain				.12				.62				.16
No	33	53	4.22		33	53	.95		45	41	3.67	
Yes	6	26			10	21			12	20		
Diabetes**				.32				.28				.96
No	39	77	1.00		43	73	1.17		56	60	.02	
Yes	0	2			0	2			1	1		
Hypertension				.83				.33				.35
No	33	68	.05		35	66	.97		47	54	.88	
Yes	6	11			8	9			10	7		
Low back pain				.16				.47				.52
No	32	67	.05		29	55	.46		39	45	.41	
Yes	7	12			14	20			18	16		
Osteoarthritis**				.11				.08				.59
No	39	74	2.58		43	70	2.99		54	59	.29	
Yes	0	5			0	5			2	3		

*significant at $p<0.05$, X^2=Chi-square, **Fischer Exact test, PCE=Previous caregiving experience

Financial burden.

The results from the Chi-square analysis indicated that there was significant relationship between age [X^2 (N=118)=17.90, p=0.00**], number of tasks performed [X^2 (N=118)=19.28, p=0.00], sex [X^2 (N=118)=11.97, p=0.01], marital status [X^2 (N=118)=16.33, p=0.00], income [X^2 (N=118)=23.67, p=0.00], number of dependents [X^2 (N=118)=5.31, p=0.02**] and financial domain where (**) represents values from the Fisher's exact test. The duration of care, education, family assisting in caregiving role, and time had no significant association. The results are presented in Table 4.5.1.1b below.

Overall burden.

The Chi-square analysis results showed a significant relationship between the previous caregiving experience [X^2 (N=118) =4.85, p=0.00**], marital status [X^2 (N=118)=7.59, p=0.00], sex [X^2 (N=118) =9.05, p=0.00], tasks [X^2 (N=118) =19.89, p=0.00], income [X^2 (N=118) =10.83, p=0.00] comorbidities like [hypertension (X^2 (N=118)=3.91,p=0.05, lower back pain (X^2 (N=118)=4.64,p=0.03] and overall burden where (**) represents values from the Fisher's exact test. The duration of care, education, family assisting in role, and time had no significant association. The results are presented in Table 4.5.1.1b below.

Table 4.5.1.1b: Test of association between caregiver factors and financial and overall caregiving burden (N=118).

	Financial burden				**Overall burden**			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
Age/years**				**.00***				.06
<40	26	37	17.90		25	38	3.46	
>40	4	51			13	42		
Duration				.11				.65
≤6 months	14	39	4.43		15	38	.86	
7-12 months	10	16			10	16		
>12 months	6	33			13	26		
Number of Tasks				**.00***				**.00***
No task	3	6	19.28		5	1	19.89	
1-4 tasks	17	17			18	16		
>4 tasks	10	68			15	63		
Time				.89				.46
<30 minutes	5	18	.22		8	15	1.54	
30-60 min	21	58			27	52		
>60 min	4	12			3	13		
Sex				**.01***				**.00***
Male	17	20	11.97		29	18	9.05	
Female	13	68			19	62		
Work				.58				.26
Employment	18	54	1.08		22	50	2.67	
Unemployed	10	26			14	22		
Retired	1	8			1	8		
Marital				**.00***				**.01***
Unmarried	22	29	16.33		23	28	7.59	
Married	7	59			14	52		
Income				**.00***				**.00***
<Ghc1000	10	62	23.67		17	55	10.83	
>GHc1000	13	6			12	7		

*significant at $p<0.05$, X^2=Chi-square, **Fischer Exact test, Tasks=bathing, dressing, feeding, meal preparation, housework, toileting, shopping, dealing with incontinence and transportation. No tasks=does not perform any of the activities, 1-4tasks=performing between 1 to 4 of any of the activities, >4=more than 4 of any of the activities

Table 4.5.1.1b continued.

	Financial domain				**Overall domain**			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
PCE				.95				**.03***
No	23	68	.05		34	57	4.85	
Yes	7	20			4	23		
Family Assistance**				.08				.77
No	4	26	3.10		9	21	.09	
Yes	26	62			29	59		
Education				.24				.35
None/primary	2	18	2.83		5	15	2.12	
Middle/Secondary	16	42			22	36		
Tertiary/Technical	11	28			10	29		
Dependents**				**.02***				.59
<4	27	59	5.31		27	59	.28	
≥4	3	27			11	19		
Vision problem				.27				.72
No	26	68	1.22		31	63	.13	
Yes	3	20			7	17		
Shoulder pain				.09				.08
No	24	62	4.63		31	55	5.03	
Yes	6	26			6	25		
Diabetes**				.41				.33
No	30	86	.69		38	78	.97	
Yes	0	2			0	2		
Hypertension **				.16				**.05***
No	28	73	1.94		29	72	3.91	
Yes	2	15			9	8		
Low back pain				.21				**.03***
No	24	60	1.52		32	52	4.64	
Yes	6	28			6	28		
Osteoarthritis**				.44				
No	28	85	.59		37	76	.36	.55
Yes	2	3			1	4		

*significant at p<0.05, X^2=Chi-square, **Fischer Exact test, PCE=Previous caregiver experience

4.5.1.2 Association between caregiver factors and caregiving burden.

Physical burden

Results from the logistic regression showed significant association between the number of tasks performed and physical burden [Adjusted OR=2.14, CI=1.28-20.7, P=0.01]. This indicates that an informal caregiver who performed more than 4 tasks was approximately 2 times more likely to have physical burden compared to one who performed no task at all. Even though there was a significant relationship, the wide Confidence Interval implies that the point estimate was not precise possibly due to the small sample size. Sex and income level had no significant association with physical burden. This is shown in Table 4.5.1.2a below.

Psychological burden.

The results of the logistic regression showed that there was a significant association between the level of income [Adjusted OR=1.26, CI=1.22-13.95 P=0.02], number of tasks performed [Adjusted OR=1.19, CI=1.18-11.57, P=0.03] and psychological burden. This means that informal caregivers who earned less than GHc1000 had a 26% chance of increased psychological burden compared to those who earned greater than GHc1000. Informal caregivers who performed more than 4 tasks a day, had a 19% chance of increased psychological burden compared to caregivers who performed no task at all. This is shown in Table 4.5.1.2a below.

Social burden.

Logistic regression results indicated that informal caregivers who were employed aside giving the care, were approximately 8 times more likely to have increased social burden compared to those who were unemployed [Adjusted OR=7.51, CI=1.43-39.32, P=0.02]. Even though there was a significant relationship, the wide Confidence Interval implies that the point estimate was not precise possibly due to the small sample size. Sex, previous care experience and level of income had no significant association with social burden. This is shown in Table 4.5.1.2a below.

Table 4.5.1.2a: Association of caregiver factors and physical, psychological and social burden (N=118).

	Physical burden				Psychological burden				Social burden			
	Crude		Adjusted		Crude		Adjusted		Crude		Adjusted	
Characteristics	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**
Age		.10		.64		.12		.99		.19		.44
<40	1.00		1.00				1.00		1.00		1.00	
>40	1.92 [.88-4.24]		.77 [.27-2.25]		1.83 [.85-3.95]		.99 [.37-2.69]		1.63 [.77-3.38]		1.55 [.51-4.70]	
Sex		.02		.10						.04		.75
Male	1.00		1.00						1.00		1.00	
Female	2.71 [1.19-6.11]		2.41 [.84-6.93]		-	-	-	-	2.27[1.02-5.04]		1.20 [.18-3.77]	
Income level		.01		.07		.01		**.02***		.02		.19
<Ghc1000	1.26 [1.09-2.75]		1.33 [.10-1.09]		1.84 [1.34-10.97]		1.26[1.22-13.95]		.28 [.22--.10.62]		.39[.09-2.59]	
>GHc1000	1.00		1.00		1.00		1.00		1.00		1.00	
Number of Task		.01		**.01***		.04		**.03***				
No task	1.00		1.00		1.00		1.00		-	-	-	-
1-4 task	1.44[.47-4.21]		1.53 [.52-5.80]		1.07[.84-7.70]		1.42[1.24-1.64]		-	-	-	-
>4task	1.93[1.21-2.78]		2.14[2.28-20.7]		1.06[1.18-9.55]		1.19[1.23-11.57]		-	-	-	-
PCE										.03		.23
Yes	-	-	-	-	-	-	-	-	1.00		1.00	
No	-	-	-	-	-	-	-	-	2.77 [1.10-6.97]		2.05 [.63-6.65]	
Employment status										.01		**.02***
Unemployed	-	-	-	-	-	-	-	-	1.00		1.00	
Employed	-	-	-	-	-	-	-	-	2.96 [1.28-6.85]		7.51 [1.43-39.32]	
Retired	-	-	-	-	-	-	-	-	4.0 [.85-18.84]		4.21 [1.39-45.15]	

*significant at p<0.05, OR=Odd Ratio, CI=Confidence Interval, -Not applicable, PCE=Previous caregiver experience, Tasks=bathing, dressing, feeding, meal preparation, housework, toileting, shopping, dealing with incontinence and transportation. No tasks=does not perform any of the activities, 1-4tasks=performing between 1 to 4 of any of the activities, >4=more than 4 of any of the activities

Financial burden.

The results from the logistic regression indicates that there was significant association between the financial domain and level of income [Adjusted OR=1.15, CI=1.03-2.61, p=0.00] as well as the number of tasks performed [Adjusted OR=3.44, CI=1.72-4.68, p=0.00]. This implies that caregivers who earned less than GHc1000 were 15% more likely to experience financial burden compared to those who earned more than GHC1000. Informal caregivers who performed more than 4 tasks daily, were approximately 3 times more likely to experience financial burden compared to those who performed no tasks. Age, sex, marital status and number of dependents had no significant association with financial burden. This is shown on Table 4.5.1.2b below.

Overall burden

The logistic regression results showed that female caregivers were approximately 3 times more likely to experience overall burden compared to their male counterparts [Adjusted OR=3.31, CI=1.17-9.34, p=0.02]. Informal caregivers who had hypertension were 9% more likely to experience overall burden compared to those who did not have [Adjusted OR=1.09, CI=1.02-2.43, p=0.00]. Additionally, informal caregivers who had Low back pain were approximately 4 times more likely to experience overall burden than those who did not have [Adjusted OR=4.31, CI=1.16-15.97, p=0.03]. Informal caregivers who performed more than 4 tasks daily, were approximately 5 times more likely experience overall burden compared to those who performed no tasks at all [Adjusted OR=5.10, CI=1.92-23.0, p=0.01]. Age, marital status and level of income had no significant association with overall burden. This is presented in Table 4.5.1.2b below.

Table 4.5.1.2b Association of caregiver factors and financial and overall caregiving burden (N=118).

	Financial domain				Overall domain			
	Crude		Adjusted		Crude		Adjusted	
Characteristics	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**
Age		.00		.39		.07		.59
<40	1.00		1.00		1.00		1.00	
≥40	8.95 [2.88-27.86]		1.92 [.43-8.58]		2.13[.95-4.73]		1.46 [.36-5.93]	
Sex		.00		.56		.00		**.02***
Male	1.00		1.00		1.00		1.00	
Female	4.44[1.85-10.69]		1.45 [.39-5.84]		3.44[1.51-7.86]		3.31 [1.17-9.34]	
Income level		.00		**.00***				
<Ghc1000	1.07 [1.02-2.24]		1.15 [1.03-2.61]		-	-	-	-
≥GHc1000	1.00		1.00		-	-	-	-
Number of dependent		.03		.71				
<4	1.00		1.00		-	-	-	-
≥4	4.12 [1.15-14.77]		1.41 [.23-8.47]		-	-	-	-
Marital status		.00		.13		.00		.07
Unmarried	1.00		1.00		1.00		1.00	
Married	6.39 [2.44-16.69]		2.84 [.73-10.95]		3.05[1.36-6.84]		2.82[.92-8.58]	
Number of Task		.03		**.00***		.00		**.01***
No task	1.00		1.00		1.00		1.00	
1-4 task	1.01[.18-5.67]		5.87[.47-7.31]		4.44[.47-4.21]		4.57[.38-5.39]	
>4task	6.8[1.20-3.84]		3.44[1.72-4.68]		5.21[2.28-19.32]		5.10[1.92-2.30]	
PCE						.04		.17
Yes	-	-	-	-	.43[1.09-10.76]		.42[.68-.8.56]	
No	-	-	-	-	1.00		1.00	
Hypertension						.05		**.00***
Yes	-	-	-	-	1.35[1.13-2.02]		1.09[1.02-2.43]	
No					1.00		1.00	
Lower back pain						.04		**.03***
Yes	-	-	-	-	2.87[1.07-7.69]		4.31[1.16-15.97]	
No	-	-	-	-	1.00		1.00	

*significant at p<0.05, OR=Odd Ratio, CI=Confidence Interval, -Not applicable, PCE=Previous caregiving experience, Tasks=bathing, dressing, feeding, housework, toileting, shopping, dealing with incontinence, transportation. No tasks=no activity performed, 1-4tasks=between 1 to 4 of any of the activities, >4=more than 4 of any of the activities

The qualitative aspect of the study in an attempt to explore further into how physically demanding the caregiving role is during the focus group discussion, unearthed findings that were consistent with the significant association of the number of tasks performed and burden. The informal caregivers in expressing how physically demanding their role is, described the types of activities or tasks they performed on a daily basis for the stroke survivors. The subthemes that emerged included; bathing, feeding/meal preparation, giving medications, toileting and home exercise supervision.

Daily tasks performed

Bathing

Bathing for the stroke survivor was one of the key activities of daily living performed by most of the informal caregivers. Some of their narrations were as follows;

> *"When she is lying down on the floor or flat, getting up is very difficult, so when we manage to lift and hold her to the bathroom, one person holds the sponge so when she baths her front then I bath her back". (50-year-old sister)*

> *"As for mine, he cannot walk without support so when he has to visit the toilet, he will tell me then I put him on the wheel chair and take him there close to the water closet, then little by little we get him on it, and then when he is done I bring him back. Also when he is going to bath it's the same process". (55-year-old spouse)*

> *"In the morning, I wake up very early and prepare to clean her up in bed using warm water and dettol, because of the pampers and her inability to get up". (57-year-old sister)*

Feeding/meal preparation

The caregivers narrated their experiences on feeding the stroke survivors by saying;

> *"As for me from beginning up till now I still feed her. And she also does not like food that has been prepared and stored for later, so even if I go to work, in the afternoon, I have to come home and prepare her meals for her to eat because her right hand is not working… it's just the feeding". (31-year-old granddaughter)*

> *"I prepare both breakfast and lunch because I close from work in the evening around 7pm, so my mum who is very old, takes care of her when I'm away, when I come back in the evening then I continue". (50-year-old sister)*

> *"She doesn't like to eat very heavy food like rice in the morning so I ask her what she wants to eat, and if she wants oats or tom brown, I prepare for her. If I decide*

> *what food to prepare for her, she will not eat unless she tells you herself". (57-year-old sister)*

Giving Medication

Some of the informal caregivers also had this to say about administering medications;

> *"I ensure that she eats and takes her medications, then she will go to sleep". (23-year-old sister)*
>
> *"After the breakfast and I give her medications", (57-year-old sister)*

Toileting

Some also commented on how they assisted with toileting;

> *"He cannot walk without support so when he has to visit the toilet, he will tell me then I put him on the wheel chair and take him there close to the water closet, then little by little we get him on it, and then when he is done I bring him back". (55-year-old wife)*
>
> *"She is unable to visit the toilet on her own, so I assist her in everything". (57-year-old sister)*

Home exercise program supervision

Exercise supervision which was not part of the questionnaire emerged as a very relevant part of their role as informal caregivers. These were some of their narrations;

> *"I also assist him with the exercises we were taught at the physio department, especially the Saturday ones". (35-year-old son)*
>
> *"In the morning after eating I make him do his exercises and then I can leave him". (36-year-old son)*
>
> *"I massage her and take her through her exercises. Everything that we do at the physiotherapy department I do with her at home". (57-year-old sister)*
>
> *"After everything, we go and do our exercises, and go for a walk around the house". (23-year-old sister)*

4.5.2 Stroke survivor factors

4.5.2.1 Test of association between stroke survivor factors and caregiving burden.

Physical burden

The association among the stroke survivor factors and physical burden were tested using Chi-square. There was no significant relationship between physical burden and age, marital status, education, employment status, medication and exercise adherence and comorbidities. Significant association existed between the level of disability and physical burden [X^2(N=118) =19.91, p=0.00]. This is shown in Table 4.5.2.1a below.

Psychological burden.

Results from the Chi-square analysis showed that, there was no significant relationship between physical burden and age, marital status, employment status, medication and exercise adherence. There was however, significant association between psychological burden and the level of disability [X^2(N=118) =16.04, p=0.00], education X^2(N=118) =7.85, p=0.02], shoulder pain X^2(N=118) =3.79, p=0.05], and hypertension X^2(N=118) =7.87, p=0.00] as shown in Table 4.5.2.1a below.

Social burden.

The results from the Chi-square analysis showed no significant relationship between social burden and age, marital status, education, medication and exercise adherence. However, there was significant association between the social burden and level of disability [X^2(N=118) =17.37, p=0.00], employment status [X^2(N=118) =7.99, p=0.02] and shoulder pain [X^2(N=118) =6.52, p=0.02] as shown in Table 4.5.2.1a below.

Table 4.5.2.1a: Test of association between stroke survivor factors and physical, psychological and social burdens (N=118).

	Physical burden				Psychological burden				Social burden			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
Age				.60				.76				.87
30-49	4	13	1.01		6	11	.56		9	8	.29	
50-59	11	18			9	20			13	16		
60 and above	24	48			28	44			35	37		
Disability level				**.00**				**.00**				**.00**
NS	1	3	19.91		1	3	16.04		0	4	17.37	
NSD	16	9			16	9			17	8		
MD	13	22			12	23			20	15		
MSD	9	32			14	27			19	22		
SD	0	13			0	13			1	12		
Sex				.33				.08				.85
Male	22	37	.96		26	33	2.96		29	30	.03	
Female	17	42			17	42			28	31		
Marital status				.88				.28				.16
Unmarried	6	13	.02		9	10	1.16		12	7	2.00	
Married	33	66			34	65			45	54		
Employment status				.19				.13				**.02**
Unemployed	1	10	3.38		2	9	4.08		3	8	7.99**	
Employed	33	62			34	61			44	51		
Retired	1	10			7	5			10	2		
Education				.07				**.02**				.47
None/primary	9	14	5.26		10	13	7.85		9	14	1.52	
Middle/Secondary	11	39			13	37			25	25		
Tertiary/Technical	16	20			20	16			20	16		

Table4.5.2.1a continued.

	Physical burden				Psychological burden				Social burden			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
Vision problem				.09				.06				.51
No	21	55	2.83		23	53	33.51		35	41	.43	
Yes	18	24			20	22			22	20		
Shoulder pain				.27				**.05**				**.01**
No	19	47	1.23		19	47	3.79		25	41	6.52	
Yes	20	32			24	28			32	20		
Diabetes				.73				.48				.62
No	34	66	.64**		35	65	1.49		49	51	.96	
Yes	5	13			8	10			8	10		
Hypertension				.97				**.00**				.99
No	9	18	0.01		16	11	7.87		13	14	.01	
Yes	30	61			27	64			44	47		
Osteoarthritis				.46				.93				.69
No	35	67	.54**		37	65	.09		50	52	.16	
Yes	4	12			6	10			7	9		
Low back pain				.21				.39				.39
No	31	54	1.61		33	52	.75		39	46	.71	
Yes	8	25			10	23			18	15		
Exercise Adherence				.51				.42				.09
No exercise	5	13	4.29		11	7	4.96		9	12	9.58	
1-5 times	9	23			9	17			13	13		
6-10 times	30	43			31	43			40	34		
Medication adherence				.34				.38				.25
No	2	8	.91**		5	5	.78		3	7	1.33	
Yes	37	69			38	68			52	54		

NS=No symptoms, NSD=No significant disability, MD=Moderate Disability, MSD=Moderate-Severe Disability, SD=Severe Disability, **Fischer's exact test

Financial burden.

There was no significant relationship between financial burden and age, marital status, education, medication and exercise adherence on the chi-square. Significant association was however found between the financial burden and level of education [X^2(N=118) =7.07, p=0.03], shoulder pain [X^2(N=118) =6.06, p=0.01] as shown in Table 4.5.2.1b below.

Overall burden

The Chi-square analysis indicated that there was significant relationship between the employment status [X^2 (N=118) =6.46, p=0.00], level of disability [X^2 (N=118) =14.07, p=0.00] and overall burden. The, age, sex, marital status and comorbidities showed no significant association with the overall burden. The results are presented in Table 4.5.2.1b below.

Table 4.5.2.1b: Test of association between stroke survivor factors and financial and overall caregiving burden (N=118).

Characteristics	Financial domain No burden	Burden	X^2	p-value	Overall domain No burden	Burden	X^2	p-value
Age				.45				.31
30-49	4	13	1.59		4	13	2.37	
50-59	5	24			7	22		
60 and above	21	51			27	45		
Disability level				.06				**.00***
NS	0	4	8.98		0	5	14.07	
NSD	9	16			13	12		
MD	12	23			14	21		
MSD	9	32			11	30		
SD	0	13			0	13		
Sex				.98				.97
Male	15	44	.1		18	38	.04	
Female	10	49			20	42		
Marital status				.50				.64
Unmarried	6	13	.45		7	12	.22	
Married	24	74			31	68		
Employment status				.07				**.04***
Unemployed	1	10	5.44		1	10	6.46	
Employed	23	72			30	65		
Retired	6	6			7	5		
Education				**.03***				.11
None/primary	6	17	7.07		9	14	4.37	
Middle/Secondary	8	42			11	39		
Tertiary/Technical	15	21			15	21		

Table4.5.2.1b continued

	Financial burden				Overall burden			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
Vision problem				.56				.85
No	18	58	.34		24	52	.04	
Yes	12	30			14	28		
Shoulder pain				**.01***				.16
No	11	55	6.06		17	49	3.61	
Yes	19	33			21	31		
Diabetes				.82				.55
No	26	74	.39		31	69	1.17	
Yes	4	14			7	11		
Hypertension				.11				.88
No	10	17	2.49		9	18	.02	
Yes	20	71			29	62		
Osteoarthritis				.51				.22
No	27	75	.44		35	67	1.53**	
Yes	3	13			3	13		
Low back pain				.77				.25
No	21	64	.08		30	55	1.33	
Yes	24				8	25		
Exercise Adherence				.08				.31
No exercise	9	12	9.78		5	12	5.98	
1-5 times	8	18			12	14		
6-10 times	21	53			24	49		
Medication adherence				.70				.39
No	2	8	.15		2	8	.71	
Yes	27	79			35	71		

*significant at $p<0.05$, X^2=Chi-square, **Fischer Exact test, NS=No symptoms, NSD=No significant disability, MD=Moderate Disability, MSD=Moderate-Severe Disability, SD=Severe Disability

4.5.2.2 Association between stroke survivor factors and caregiving burden.

Physical burden.

The logistic regression showed that there was a significant relationship between the level of disability and physical burden [Adjusted OR=2.26, CI=1.46-3.49, p=0.00]. Stroke survivors with greater disability level were approximately 2 times more likely to cause the informal caregiver to experience physical burden than those with no disability. Age, presence of comorbidities and employment status had no significant association with overall burden. This is shown in Table 4.5.2.2a below.

Psychological burden.

The logistic regression showed a significant relationship between the level of disability, hypertension and psychological burden. Stroke survivors with greater disability levels were approximately 2 times more likely to increase psychological burden of their informal caregivers compared to those with no disability [Adjusted OR=2.08, CI=1.31-3.29, p=0.00]. Also, a stroke survivor with hypertension was approximately 5 times more likely to increase their informal caregivers' psychological burden [Adjusted OR=4.68, CI=1.62-13.53, p=0.00]. Age, presence of shoulder pain and employment status had no significant association with overall burden. This is presented in Table 4.5.2.2a below.

Social burden.

Results from the logistic regression showed a significant relationship between shoulder pain and social burden. Informal caregivers of stroke survivors with shoulder pain had a 44% increased chance of experiencing social burden [Adjusted OR=1.44, CI=1.20-1.94, p=0.00]. Age, presence of hypertension, level of disability and employment status had no significant association with overall burden. This is shown in Table 4.5.2.2a below.

Table 4.5.2.2a: Association of stroke survivor factors and physical, psychological and social burden (N=118).

	Physical burden				**Psychological burden**				**Social burden**			
	Crude		**Adjusted**		**Crude**		**Adjusted**		**Crude**		**Adjusted**	
Characteristics	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**	**OR [95%CI]**	**P-value**
Level of disability	2.24[1.45-3.46]	**.00***	2.26 [1.46-3.49]	**.00***	1.82[1.22-2.72]	**.00***	2.08[1.31-3.29]	**.00***	1.51[1.05-2.19]	.03	1.4[.96-2.05]	.08
Age		.32		.56		.77		.62		.59		.32
30-49	1.00		1.00		1.00		1.00		1.00		1.00	
50-59	.50[.13-1.94]		.64[.14-2.91]		1.21[.34-4.31]		1.96[.45-8.67]		1.39[.42-4.60]		2.04[.49-8.39]	
60 and above	.62[.18-2.09]		.52[.13-2.05]		.86[.29-2.58]		1.30[.42-3.75]		1.19[.41-3.43]		1.54[.44-5.38]	
Hypertension						.49		**.00***				
No	-	-	-	-	1.00		1.00					
Yes	-	-	-	-	1.01[.98-1.05]		4.68[1.62-13.53]		-	-	-	-
Employment						.26		.75				
Unemployed	-	-	-	-	1.00		1.00		-	-	-	-
Employed	-	-	-	-	.39[.08-1.95]		.76[.13-4.41]		-	-	-	-
Retired	-	-	-	-	.16[.02-1.08]		.26[.03-2.11]		-	-	-	-
Shoulder pain										.01		**.04***
No	-	-	-	-	-	-	-	-	1.00		1.00	
Yes	-	-	-	-	-	-	-	-	1.38[.18-81]		1.44[1.20-1.94]	

*significant at p<0.05, OR=Odd Ratio, CI=Confidence Interval

Financial burden.

The logistic regression results showed a significant relationship between shoulder pain and financial burden. Stroke survivors with shoulder pain were 31% more likely to increase their informal caregivers' financial burden [Adjusted OR=1.31, CI=1.12-1.79, p=0.02]. Age, presence of hypertension, level of disability and employment status had no significant association with overall caregiving burden. This is shown in Table 4.5.2.2b below.

Overall burden

Results from the logistic regression, indicated that there was a significant relationship between the disability level and overall caregiving burden. Stroke survivors with greater level of disability were 63% more likely to increase their informal caregivers' overall burden [Adjusted OR=1.63, CI=1.06-2.52, p=0.03]. Age, presence of comorbidities and employment status had no significant association with overall burden. This is presented in Table 4.5.2.2b below.

Table 4.5.2.2b Association of stroke survivor factors and financial and overall caregiving burden (N=118).

	Financial burden				**Overall burden**			
Characteristics	**Crude**		**Adjusted**		**Crude**		**Adjusted**	
	OR[95%CI]	**P-value**	**OR [95%CI]**	**P-value**	**OR[95%CI]**	**P-value**	**OR[95%CI]**	**P-value**
Age		.61		.60		.61		.99
30-49	1.00		1.00		1.00		1.00	
50-59	1.48[.34-6.47]		1.55[.30-7.88]		1.48[.34-6.47]		.99[.23-4.33]	
60 and above	.75[.22-2.56]		.92[.22-3.69]		.74[.22-2.59]		.27[.13-1.75]	
Education		.31		.18				
None/primary	1.00		1.00		-	-	-	-
Middle/Sec	1.85[.56-6.15]		2.39[.66-8.61]		-	-	-	-
Tertiary/technical	.49[.15-1.55]		.57[.17-1.92]		-	-	-	-
Shoulder pain		.02		**.02***				
No	1.00		1.00		-	-	-	-
Yes	1.35[.15-.82]		1.31[1.12-1.79]		-	-	-	-
Disability level	-	-	-	-	1.64[1.10-2.43]	.02*	1.63[1.06-2.52]	**.03***
Employment						.15		.33
Unemployed	-	-	-	-	1.00		1.00	
Employed	-	-	-	-	.22[.03-1.77]		.34[.04-3.03]	
Retired	-	-	-	-	.07[.07-.75]		.11[.01-1.22]	

*significant at p<0.05, OR=Odd Ratio, CI=Confidence Interval

These findings on the stroke survivor factors that contribute to the caregiver's burden were consistent with the qualitative findings unearthed during the focus group discussion held with the informal caregivers. Further interactions on the issue of the physical demands of caregiving, revealed some major challenges they experienced in relation to some of the stroke survivor factors such as level of disability and presence of comorbidities. The subthemes that emerged included; feeding/meals, lifting and time restraint.

Major challenges

The informal caregivers indicated that they had encountered some major challenges whiles playing the caregiving role. These were some of their narrations;

Feeding/Meal preparation

The informal caregivers described how feeding/ meal preparation was a challenge as a result of stroke survivor comorbidities like hypertension and diabetes. They had this to say;

> *"...concerning her feeding, she is diabetic and hypertensive and so feeding her is quite a struggle. Sometimes she the patient does not even know what to eat and so those of us around find it difficult to decide. Also because of the diabetes she is not supposed to be hungry, when she is hungry then she becomes someway. At first, she was even on insulin injection, so sometimes you see her sweating all over". (35-year-old son)*

> *"Her eating is very worrying. She is also diabetic and hypertensive and on insulin injection. Sometimes you will find out from her what she wants to eat, but ever since she came back from the hospital, the only food she likes is plantain. When you give her vegetable stew, she will say she is tired, it feels someway in her mouth and so, when you do it she won't eat, she likes grounded tomatoes and garden eggs with palm oil. We have also been told that the palm oil too is not good so should be taken in small quantities. When you do without the palm oil there is trouble, this has made feeding her very difficult". (34-year-old daughter)*

Lifting

Other caregivers further indicated that lifting of their stroke survivor because of the level of disability was a major problem by saying. They described their experience by saying;

> *"As for me my major challenge is lifting him up, that is what worries me. If he has to go to toilet, I have to put him on the wheel chair, if he has to bath too, I have to lift him to the bathroom. At least if he were a little independent and could move by himself for instance to the bathroom, it would be a great relief". (55-year-old spouse)*

> *"One major challenge is that when she is sitting down on the floor, getting her up is difficult. We have to lift her up and that is what leads to the back pain we experience". (50-year-old sister)*

Time restraint

The caregiving role was described by most of the informal caregivers as very time consuming especially at the early stages when the level of disability was high. They had this to say;

> *"I will say that I lost a relationship because of this caregiving role. Because I wasn't getting time for my partner it was always her. And in work too it's like I feel that what I'm supposed to do, I don't get enough time to do it. Because I have to include her in my schedule it makes me draw back and that is a major challenge for me". (31-year-old granddaughter)*

> *"My challenge is that I cannot leave her and go out to any place, because she needs me to be around all the time. Sometimes even going to do your hair is an issue, it has to be fast so because of that I had to cut my hair "laughter". So, it takes a lot of time". (23-year-old sister)*

4.5.3 Health care facility factors.

4.5.3.1 Test of association between health care facility factors and caregiving burden.

Physical burden

The association between the caregiver-physiotherapist relation, caregiver perception of survivor-therapist relationship, whether the physiotherapist facility was well-equipped or not, early referral and physical burden were analyzed using Chi-square. There was no significant ($p>0.05$) association between all the variables and physical burden as shown in Table 4.5.3.1a below.

Psychological burden.

The results of the Chi-square analysis showed a significant association between how well the facility was perceived to be equipped by the informal caregiver and psychological burden [X^2(N=118) =8.73, P=0.00]. However, no significant associations were found with caregiver-physiotherapist relation, caregiver perception of survivor-therapist relationship and early referral as shown in Table 4.5.3.1a below.

Table 4.5.3.1a: Test of association between health care facility factors and physical and psychological burden (N=118)

	Physical burden				Psychological burden			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
CSPR				.55				.16
DA	1	5	1.19		2	4	3.72	
Agree	38	72			43	67		
CPR				.43				.31
DA	8	11	2.73		4	15	3.61	
Agree	31	61			37	55		
Well-equipped				.16				**.00***
Yes	17	47	1.99		15	49	8.73	
No	17	26			22	21		
Referral				.40				.45
<1month	28	49	.67		31	46	.55	
>1month	19	22			16	25		

DA=Disagree, CPR= Caregiver-Physiotherapist Relation, CSPR= Caregiver Perception Survivor-Physio Relation, X^2=Chi-square, *significant at p<0.05

Social burden

The results of the Chi-square analysis showed no significant (p>0.05) association between social burden and caregiver-physiotherapist relation, caregiver perception of survivor-therapist relationship, whether the physiotherapist facility was well-equipped or not and early referral. This is shown in Table 4.5.3.1b below.

Financial burden.

The Chi-square results also showed no significant (p>0.05) association between financial burden and the caregiver-physiotherapist relation, caregiver perception of survivor-therapist relationship, whether the physiotherapist facility was well-equipped or not and early referral. This is also shown in Table 4.5.3.1b below.

Table 4.5.3.1b: Test of association between health care facility factors and social and financial burden (N=118)

	Social burden				**Financial burden**			
Characteristics	**No burden**	**Burden**	**X^2**	**p-value**	**No burden**	**Burden**	**X^2**	**p-value**
CSPR				.19				.73
DA	5	3	3.29		2	5	.62	
Agree	52	58			28	82		
CPR				.35				.75
DA	8	9	3.26		4	13	1.21	
Agree	49	43			25	66		
Well-equipped				.72				.55
Yes	29	35	.13		8	35	.36	
No	21	22			15	49		
Referral				.18				.78
<1month	39	38	1.77		21	56	.08	
>1month	17	24			14	27		

DA=Disagree, CPR= Caregiver-Physiotherapist Relation, CSPR= Caregiver Perception Survivor-Physio Relation, X^2=Chi-square

Overall burden

The overall informal caregiving burden was also found to have no significant (p>0.05) association with the caregiver-physiotherapist relation, caregiver perception of survivor-therapist relationship, whether the physiotherapist facility was well-equipped or not and early referral using the Chi-square. This is shown in Table 4.5.3.1c below.

Table 4.5.3.1c: Test of association between health care facility factors and overall caregiving burden (N=118).

	Overall burden			
Characteristics	**No burden**	**Burden**	X^2	**p-value**
Caregiver Perception Survivor-Physiotherapist Relation				.47
Disagree	2	2	1.51	
Agree	36	74		
Caregiver-Physiotherapist Relation				.46
Disagree	4	15	2.59	
Agree	33	58		
Physiotherapy facility Well-equipped				.81
No	13	30	.06	
Yes	18	46		
Referral				.53
<1month	27	50	.42	
>1month	25	26		

X^2=Chi-square.

4.5.3.2 Association between health care facility factors and caregiving burden.

Psychological burden.

With the exception of psychological burden, there was no significant association between health care facility factors and physical, financial, social and overall caregiving burden. Further analysis using logistic regression showed significant relationship between well-equipped facility and psychological burden. A perceived under equipped facility was more likely to increase the informal caregiver's psychological burden by 42% [OR=1.42, CI=1.40-7.86 p=0.00]. This is shown in Table 4.5.3.2 below.

Table 4.5.3.2: Association of health care facility factor and psychological burden (N=118).

Characteristic	**Psychological burden**	
	OR (CI 95%)	p-value
Facility well-equipped?		**.00***
Yes	1.00	
No	1.42[1.40-7.86]	

OR=Odds Ratio, CI=Confidence Interval, *=significant at p<0.05

CHAPTER FIVE

5.0 DISCUSSIONS

5.1 Main findings of the study

This study sought to assess the burden of caregiving experienced by the informal caregivers of stroke survivors who reported for physiotherapy at the Effia-Nkwanta Regional and Tarkwa Municipal Hospitals in four domains; physical, psychological, social and financial. The study also sought to find the determinants of their burden. Findings from the study revealed that about 68% of the informal caregivers experienced overall caregiving burden with 74.6% reporting moderate-severe burden in the financial domain followed by, physical, psychological and social domains in that order. Caregiver factors that were found to influence burden were sex, the number of tasks performed, employment status, level of income and presence of comorbidities such as hypertension and low back pain whiles stroke survivor factors influencing burden included level of disability and presence of comorbidities such as hypertension and shoulder pain. The only health facility factor found to influence caregiver burden was infrastructure.

5.2 Methodological validity.

This study has a number of strengths which includes the fact that it is the first hospital based research on informal caregiving burden that has been carried out in the Western region.

The study also happens to be the first research on the burden of caregiving on informal caregivers of stroke survivors using both qualitative and quantitative methods in the Western region and in Ghana at large. The addition of the qualitative methods improved the understanding of the findings from the quantitative aspect of the study.

It also happens to be among the very few studies that has looked at caregiving burden in four different domains especially the physical domain which is hardly reported compared to the psychological domain.

This study was a cross-sectional study involving all stroke survivors and their informal caregivers reporting for treatment over the data collection period at the two major physiotherapy facilities in the western region which are NHIS accredited and serves the entire region. Effia-Nkwanta regional hospital is the main referral centre for the whole region. This ensured that selection bias was minimal and that the data would be representative of all stroke survivors who report to the hospital and their informal caregivers in the region.

The study also included all the possible determinants of caregiving burden from literature and practice and ensured that during data analysis all confounders were controlled for. Thus ensuring that all possible confounding bias was very minimal.

One major limitation of this study was the fact that, factors influencing caregiving burden was self-reported and thus the study may have suffered some recall bias but then, the extent to which the bias affected the outcome will warrant further research. However, in order to reduce the information bias, this study used the Zarit burden interview which is a structured questionnaire that has been used extensively in several countries and has been reported to have a high internal consistency ranging from 0.85 to 0.94 and a test-retest reliability with Cronbach’s alpha coefficient of 0.92 (Hébert et al., 2000).

Another limitation was the inclusion of informal caregivers who reported little or no burden into no burden, and those with moderate or severe burden into burden which might have led to possible misclassifications. This was however necessary because of the limited data as a result of the sample size. It was also sometimes difficult to differentiate between those who had no or little burden and also for most of the caregivers who had adapted to the caregiving role, they reported no burden even though they had.

5.3 Contextual analysis and Comparison with other studies.

5.3.1 Prevalence of caregiving burden.

Majority of the informal caregivers in this study were burdened on the whole and in all the domains. The most prevalent among the domains were financial burden followed by physical. This finding is in agreement with several studies conducted previously including that of Achilike et al., (2019) in his survey of 71 caregivers in the USA which indicated a very high level of caregiving burden (34%). Jaracz et al., (2014), in his study on level of caregiver burden among 150 caregivers in Poland, also indicated that 47% of the participants reported significant burden. Comparatively, this study recorded a much higher burden among the informal caregivers. The differences may be explained by the variations in culture which might have affected the way and manner in which the informal caregivers perceive burden. It is also possible that the availability of support systems for caregivers in countries such as US and Poland could have accounted for their slightly lower caregiving burden perception as indicated by Tosun, Temel, Kemal Mahallesi, & Caddesi, (2017), who reported that informal caregivers who receive financial support for care had perceived lower caregiving burden. Other recent studies like those of Menon, Salini, Habeeba, Conjeevaram, & Munisusmitha, (2017) conducted among 201 caregivers in Indian and Kumar, Kaur, & Reddemma, (2015) among 100 caregivers in Punjab indicated that the pattern of burden experienced was higher in the financial domain as compared to the other domains, as the participants reported a decrease in financial status after they had assumed the caregiving role. Menon et al, also added that more than half of the informal caregivers of their study reported physical burden.

5.3.2 Caregiver factors associated with caregiving burden.

Majority of the informal caregivers in this study were females and younger than the survivors, with majority below the age of 40 years. This agrees with a previous study among 66 caregivers by Boakye et al., (2017) in Kumasi, which reported that a majority of the caregivers were females (65.0%) aging between 31 and 49 years. This may be as a result of the fact that majority of the informal caregivers were children of the stroke survivors and so were relatively young.

The caregiver socio-demographic factors found to influence caregiving burden in this study were sex, employment status and average monthly income. The female informal caregivers were more likely to experience increased overall burden than their male counterparts. This finding is consistent with the findings of Sreedharan et al., (2013) from his study in south India which involved 150 stroke patients and their caregivers. Their findings indicated that female caregivers, were more likely to experience worse quality of life as a result of caregiving burden. Menon et al., (2017) also reiterates this view by indicating that the caregiving burden was predominantly shouldered by female informal caregivers and that they also experienced more physical and psychological stress. In trying to explain why the female caregivers in their study experienced more burden, Jennifer Klinedinst et al., (2009) reported that female caregivers were less likely to ask for help and assistance in caring for their patient and thus spent more time giving care compared to their male counterparts. In addition, females are generally found to actively play the role for almost all the time at the expense of their own health especially in this part of the world, where the caregiving role is mainly considered a woman’s job. The high proportion of female informal caregivers who participated in this study may have also contributed to this finding.

This study also found out that caregivers who were employed aside their caregiving role, compared to the unemployed were more likely to experience social burden. Caring for the stroke survivor whiles being employed, may imply that the caregiver had an increased responsibility of not only caring for the stroke survivor but also making efforts to adjust his/ her own life as well as work responsibilities. Gbiri et al., (2015) in their study among 157 caregivers in Lagos state, Nigeria, further explains the impact of being employed by indicating that these adjustments by the informal caregiver could cause man-hour losses, physical, mental, and emotional strain. Sometimes the informal caregivers might even quit their job because of the stress in playing the caregiving role. Menon et al., (2017) reported that 81.0% of the 201 caregivers he surveyed had left their work for caregiving. This finding is also consistent with the narratives of some of the informal caregivers during the focus group discussion in terms of leaving their jobs in order to perform the caregiving role. Contrary to this finding however was the report that female informal caregivers who consistently reported higher burden as well as lower overall QoL were more likely to be unemployed than employed in a previous research by White et al., (2003).

Informal caregivers who earned more than GHC1000 in this study were less likely to have financial and psychological burden. This makes logical meaning in that, the financial resources needed to pay the medical bills and buy the needed medications and other care items to make caring for the stroke survivor easy, will be available and thus there will be less worries.

This study revealed also that informal caregivers who performed more than 4 tasks in a day for their stroke survivors had an increased chance of experiencing physical, financial, psychological and overall burden than those who performed no task at all. This finding is consistent with previous studies like that of Snyder, (2000) who worked on “the impact of caregiver-receiver relationship quality on burden and satisfaction”. He reported that caregiving-related factors associated with burden, included the type of tasks that the informal caregiver performed for the stroke survivor. Performing an increasing number of tasks on a daily basis, may lead to a build-up of the stress and fatigue from these tasks overtime and this may also increase their physical burden. This is also consistent with the findings of the qualitative aspect of this study in which the informal caregivers narrated their ordeal in relation to the demands of care especially at the early stages of the stroke when the level of dependency was high and when there was no one else to assist. Bakas & Burgener, (2002) also support this in their study in the US, which indicated that informal caregivers who participated in greater and very involving dependent care such as toileting and bathing had experienced greater emotional distress and greater caregiving burden.

Findings from this study also indicated that informal caregivers with hypertension or low back pain were more likely to have increased overall burden compared to those who had no comorbidities. In line with this finding, Aşiret & Kapucu, (2013) posited in their study that the informal caregiver's health status was an important determinant of the care burden. Another study from Andrén & Elmståhl, (2008) reiterates the fact that caregiver burden may be as a result of the informal caregiver's poor health or the presence of some comorbidities.

Duration of care, previous caregiving experience, number of dependents and family assisting in the caregiving role in this study did not influence the caregiver's burden. These findings are however inconsistent with other studies. One of such is a study carried out in Turkey by Aşiret & Kapucu, (2013) who reported that the informal caregiver's burden may increase after longer care durations, because of the continuous experience of fatigue, exhaustion, or accumulation of health problems. The non-significance of duration of care in this study could be due to the fact that most of the informal caregivers after a long period of caregiving began to accept and adapt to their circumstance as was revealed during the focus group discussion with the informal caregivers. It could also be due to the fact that majority of the informal caregivers in this study had giving the care for less than 6 months. Another study inconsistent with the finding on family assistance is that of Reinhard, Given, Petlick, & Bemis, (2008), who indicated that caregivers were found to experience a higher level of burden when they had lower levels of social support from their study on supporting family caregivers in providing care in US. The study also reported that the temporary care provided by other family members, may reduce some of their burden in terms of physical, emotional and financial assistance. The non-significance in this study may be due to the fact that most of the informal caregivers who participated in the study had no family assistance as was revealed through the narrations from the focus group discussion. Whiles some informal caregivers acknowledged the little support they got from their immediate family members, others also had received no support at all except for the occasional support they got from friends and well-wishers.

There is not much literature to support or contradict the non-significance of previous caregiving experience and the number of dependents. The no significance found in this study however, could be attributed to the fact that majority of the informal caregivers were children of the stroke survivors and were relatively younger. There is therefore the need for further studies to compare the burden of informal caregivers with previous caregiving experience and other dependents aside the stroke survivor and those who do not have.

5.3.3 Stroke survivor factors associated with caregiving burden.

Results from this study, indicate that majority of the stroke survivors surveyed in this study were females. On the contrary, previous studies done in Ghana suggested that most of the stroke survivors were males. One of such in the Greater Accra region, is a current study that explored the barriers to accessing physiotherapy for stroke survivors which found that 57% of the stroke survivors were male (Nketia-Kyere, Aryeetey, Nonvignon, &

Aikins, 2017). Since this current study was conducted in the Western Region, there is a possibility that there could be a regional disparity as to which gender forms the greatest majority of stroke survivors and possibly, which gender suffers stroke the most.

This study found level of disability of the stroke survivor to be significantly associated with an increase in the caregiver's overall burden as well as the physical and psychological burdens. A high level of disability meant that the stroke survivor would have a reduced functional ability and thus would need more physical assistance from their informal caregivers in performing their basic ADLs. This finding is consistent with that from the focus group discussion in which the informal caregivers described how their burden reduced with time as the level of disability improved and survivor became more independent. Some of their major challenges was lifting and spending so much time with the survivors because they could not do much for themselves and needed assistance in almost all their activities of daily living because of their level of disability. This finding is also consistent with that of RouillardI et al., (2012) in Rome, which indicated that the ability of stroke survivors to perform activities of daily living which serve as indicators of their functional ability was related to high caregiver burden. Other studies like that of Achilike et al., (2019) in USA and Boakye et al., (2017) in Kumasi also support this finding by indicating that caregiving burden was strongly associated with the stroke survivor's physical disability. There are however some inconsistencies in literature with other studies like Morimoto et al., (2003) in Japan and Thommessen et al., (2002) in Norway reporting a weak or no association between caregiver burden and level of disability.

Another finding from this study was that, the presence of comorbidities like hypertension significantly influenced psychological burden, whiles shoulder pain significantly influenced social and financial burden. This is consistent with the study of Edwards Daryl

Higgins Matthew Gray & Alan Hayes, (2008). Their findings indicated that the informal caregiver was likely to miss out on many usual family experiences due to the increased demands of being the primary caregiver as a result of the presence of stroke survivor comorbidities which may impact their level of disability and dependence. Similar, to this finding again is that of Ellis et al., (2013) in their study among 666 US adults with a history of stroke, reported that comorbid conditions had a negative impact on patient rehabilitation outcomes and their social reintegration which increased the burden of their caregivers. Previous studies by Adey-Wakeling et al., (2015) among 301 stroke patients over a 12 month period, added some meaning by indicating that the frequency of post stroke shoulder pain was almost 30% and it slowed down recovery. Prolonged recovery is most likely to warrant prolonged duration of physical, psychological and financial support from the informal caregiver. Financial burden may also increase as a result of increased health expenditures. Controlling hypertension will also reduce the tendency of the stroke survivor suffering another attack as well as reduce the informal caregiver’s fear and anxiety about that possibility.

There was no significant association between adherence to exercise/medication and the caregiver’s burden. This finding is however inconsistent with the study of Harris et al., (2010), which assessed caregiver involvement in the upper limb treatment of individuals with sub-acute stroke in USA. Their findings indicated that involvement of caregivers in supervision of patient’s adherence to home exercises is positively associated with post stroke recovery and functional outcome which can reduce caregiver burden. The physiotherapists and assistants during their focus group discussion, highlighted the impact of non-adherence to exercise on the recovery. They narrated how from experience, they had seen delays in recovery of stroke survivors who did not adhere to their home exercises compared to those who were very committed. The delay also meant prolonged dependency on the informal caregiver and prolonged therapy sessions which increased their health expenditure.

None of the stroke survivor socio-demographic factors was found to be significantly associated with the caregiver's burden. This finding is however inconsistent with other findings such as that from the study of Greenwood & Mackenzie, (2010) who explained that informal caregivers male survivors are more likely to experience burden. Akosile et al., (2018), in their study among 91 Nigerian stroke caregivers contradicts this by indicating that caregiver burden increased in those caring for female stroke survivors compared to male stroke survivors.

5.3.4 Health care facility factors associated with caregiving burden

Findings from this study showed that the informal caregiver's perception of how underequipped the physiotherapy facility was, had a significant association with an increase in the psychological burden of the informal caregiver. Not much studies have been done on the influence of health facility factors on caregiver burden. However in a study by Hung et al., (2012) which sought to find out the factors associated with strain among 89 informal caregivers of stroke patients in India, it was indicated that help from formal caregivers was associated with a considerable increase in caregiver burden whereas the use of out-patient rehabilitation services had no association. This can be explained considering the fact that the severity of the stroke may require more use of formal caregiver services and more visits to the rehab centres which may mean an increase in financial burden which could translate into a high overall caregiving burden irrespective of any decrease in the other domains. Mahinda, (2016) also in her research on informal caregiver burden in the care of stroke patients at Kenyatta national hospital in Nairobi, indicated that there was little preparation of caregivers in terms of education by the health providers, prior to discharge of their patient and that may have led to high caregiver burden. McCullagh et al., (2005) also in their studies on determinants of caregiving burden and quality of life in caregivers of stroke survivors indicated that caregiver training by the health professionals could reduce informal caregiving burden.

Caregiving burden, was not influenced in any way by the early referral of the stroke survivors for rehabilitation, caregiver/survivor-therapist relation and the physiotherapist-survivor ratio in this study. However, exploring further into the caregiver burden qualitatively, the focus group discussion with the physiotherapists and assistants revealed that the delay in referral for physiotherapy affects functional recovery of the stroke survivor. They narrated how the stroke survivors who report for rehabilitation late, come with spastic joints or very flaccid limbs for which there is not much to be done. There is therefore a prolonged dependency on caregiver which increases their burden. In relation to the physiotherapist-survivor ratio was the physiotherapists and assistants described how the low staff numbers affected their ability to offer effective therapy to the survivors because of the limited time they had for each of the many stroke survivors that reported and the possibility of that delaying recovery and increasing the caregiving burden. These findings posits that, there is the need for further studies on all possible health care factors that may influence caregiver burden, to help structure the needed interventions and aid in the formulation of policies to reduce informal caregiving burden.

CHAPTER SIX

6.0 CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The overall caregiving burden was high with more than half of the study population reporting moderate-severe burden. This depicts that informal caregivers of stroke survivors in the western region are really burdened as a result of the caregiving role. The domain of burden which recorded the highest prevalence of moderate-severe burden was the financial domain, followed by physical, psychological, and social which also depicts that the informal caregivers are more financially and physically burdened compared to the other domains. Caregiver factors that contributed to burden were being female, performance of multiple tasks daily, being employed, earning an income level of less than GHC1000 and having comorbidities like hypertension and low back pain. Stroke survivor factors that also contributed to the burden were the level of disability and the presence of comorbidities like hypertension and shoulder pain. The only health facility factor that contributed to caregiving burden was infrastructure at the physiotherapy facility which affected only the psychological burden.

Because of the importance of informal caregivers in providing the bulk of care towards the recovery and wellbeing of the stroke survivors, it is imperative that their well-being is given adequate attention by Clinicians and other professionals of the rehabilitation team, in order to alleviate their burdens. This study therefore paves way for further research into interventions that can help caregivers to prevent or effectively deal with the burden of caregiving.

6.2 Recommendations

i. Health care providers especially those on the rehabilitation team like the physiotherapists should develop and implement educational and supportive programs for stroke survivors and their informal caregivers through health promotion and public education on the challenges that they face. Especially in the areas of lifting, feeding/meal preparations and how to manage their time to minimise their restraints as revealed during the focus group discussion.

ii. Clinicians, especially physicians, nurses and community health officers at the primary health delivery levels should improve the preparation of stroke survivors' informal caregivers towards the caregiving role they perform by intensifying education on the management of stroke, relative to its prognosis, expectations and interventions available such as physiotherapy as well as the need to seek early medical treatment for the stroke risk factors. This in turn will promote early commencement of rehabilitation which will help reduce the stroke survivor's level of functional disability and dependency on the informal caregiver which will also help reduce the physical burden on the caregiver.

iii. Since the survivor's functionality as a result of his/her level of disability has been found in most of the literature to significantly influence caregiving burden, it is needful to research into and implement strategies that will effectively deal with stroke related disability in order to curb the burden of the informal caregiver. Research into early interventions that can prevent or reduce the incidence of shoulder pain which is one of the stroke survivor factors that contribute to burden, is also needed to improve patient recovery and thus reduce caregiver burden.

iv. Because financial burden happens to be the most prevalent of all the domains in this study, policy makers can also ensure that the national health insurance scheme is expanded to cover all the medical and rehabilitation expenses of the stroke survivor. This will help reduce the financial burden that the informal caregivers who are mostly children of the survivors, are exposed to after the stroke incidence as a result of increased health expenditures.

v. Government can also ensure an equitable distribution of well-equipped rehabilitation units with experts like the physiotherapists, occupational and speech therapists across the nation, so that every stroke survivor can have the opportunity of improving functionality and reduce the effect of the survivor's level of disability on the informal caregiving burden.

REFERENCES

Achilike, S., Sanner, J. E., Okpala, M., Payen, S., Baldridge, L., Okpala, N., … Savitz, S. (2019). Abstract WP239: Caregiver Burden Among Informal Caregivers of Stroke Survivors. *Stroke*, *50*(Suppl_1). https://doi.org/10.1161/str.50.suppl_1.WP239

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA - Journal of the American Medical Association*. https://doi.org/10.1001/jama.2014.304

Adey-Wakeling, Z., Arima, H., Crotty, M., Leyden, J., Kleinig, T., Anderson, C. S., … SEARCH Study Collaborative. (2015). Incidence and associations of hemiplegic shoulder pain poststroke: prospective population-based study. *Archives of Physical Medicine and Rehabilitation*, *96*(2), 241-247.e1. https://doi.org/10.1016/j.apmr.2014.09.007

Ain, Q. U., Dar, N. Z., Ahmad, A., Munzar, S., & Yousafzai, A. W. (2014). Caregiver stress in stroke survivor: data from a tertiary care hospital -a cross sectional survey. *BMC Psychology*, *2*(1), 49. https://doi.org/10.1186/s40359-014-0049-9

Akosile, C. O., Banjo, T. O., Okoye, E. C., Ibikunle, P. O., & Odole, A. C. (2018). Informal caregiving burden and perceived social support in an acute stroke care facility. *Health and Quality of Life Outcomes*, *16*(1), 57. https://doi.org/10.1186/s12955-018-0885-z

Akpan-Idiok, P. A., & Anarado, A. N. (2014). Perceptions of burden of caregiving by informal caregivers of cancer patients attending University of Calabar Teaching Hospital, Calabar, Nigeria. *Pan African Medical Journal*, *18*, 159. https://doi.org/10.11604/pamj.2014.18.159.2995

Amirkhanyan, A. A., & Wolf, D. A. (2006). Parent Care and the Stress Process: Findings From Panel Data. *The Journals of Gerontology: Series B*, *61*(5), S248–S255. https://doi.org/10.1093/geronb/61.5.s248

Andrén, S., & Elmståhl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, *17*(6), 790–799. https://doi.org/10.1111/j.1365-2702.2007.02066.x

Aşiret, G. D., & Kapucu, S. (2013). Burden of Caregivers of Stroke Patients. *Turkish Journal of Neurology*, *19*, 5–10. https://doi.org/10.4274/Tnd.60234

Bakas, T., & Burgener, S. C. (2002). Predictors of Emotional Distress, General Health, and Caregiving Outcomes in Family Caregivers of Stroke Survivors. *Topics in Stroke Rehabilitation*, *9*(1), 34–45. https://doi.org/10.1310/GN0J-EXVX-KX0B-8X43

Bakas, T., Clark, P. C., Kelly-Hayes, M., King, R. B., Lutz, B. J., Miller, E. L., & American Heart Association Council on Cardiovascular and Stroke Nursing and the Stroke Council. (2014). Evidence for Stroke Family Caregiver and Dyad Interventions. *Stroke*, *45*(9), 2836–2852. https://doi.org/10.1161/STR.0000000000000033

Bamford, J., Sandercock, P., Dennis, M., Warlow, C., & Burn, J. (1991). Classification and natural history of clinically identifiable subtypes of cerebral infarction. *The Lancet, 337(8756), 1521–1526.* , *337*(8756), 1521–1526.

https://doi.org/10.1016/0140-6736(91)93206-o

Banks, J. L., & Marotta, C. A. (2007). Outcomes validity and reliability of the modified rankin scale: Implications for stroke clinical trials - A literature review and synthesis. *Stroke*. https://doi.org/10.1161/01.STR.0000258355.23810.c6

Baumann, M., Couffignal, S., Le Bihan, E., & Chau, N. (2012). Life satisfaction two-years after stroke onset: The effects of gender, sex occupational status, memory function and quality of life among stroke patients (Newsqol) and their family caregivers (Whoqol-bref) in Luxembourg. *BMC Neurology*. https://doi.org/10.1186/1471-2377-12-105

Boakye, H., Nsiah, A., Bello, A. I., Quartey, J. N. A., & Bagriacik,) E Umit. (2017). Article no.BJMMR.31903 Reviewers: (1) Olufemi O. Oyewole, Olabisi Onabanjo University Teaching Hospital. *British Journal of Medicine & Medical Research*, *20*(6), 31903. https://doi.org/10.9734/BJMMR/2017/31903

Boehme, A. K., Esenwa, C., Elkind, M. S. V, Fisher, M., Iadecola, C., & Sacco, R. (2017). Stroke Risk Factors, Genetics, and Prevention Stroke Risk Factors, Genetics, and Prevention Effects of Neurologic Injury on Cardiovascular Function Vascular Cognitive Impairment. https://doi.org/10.1161/CIRCRESAHA.116.308398

Bonita, R., & Beaglehole, R. (1988). Recovery of motor function after stroke. *Stroke*, *19*(12), 1497–1500. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3201508

Brajković, L., Godan, A., & Godan, L. (2009). Quality of Life After Stroke in Old Age: Comparison of Persons Living in Nursing Home and Those Living in Their Own Home. *Croatian Medical Journal*. https://doi.org/10.3325/cmj.2009.50.182

Bruno-Petrina, A. (2018). Motor Recovery In Stroke: Recovery Considerations, Theories of Recovery, Mechanisms of Recovery. Retrieved February 7, 2019, from https://emedicine.medscape.com/article/324386-overview

Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of Clinical Nursing*, *24*(17–18), 2376–2382. https://doi.org/10.1111/jocn.12884

Cameron, J. I., Naglie, G., Silver, F. L., & Gignac, M. A. M. (2013). Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. *Disability and Rehabilitation*, *35*(4), 315–324. https://doi.org/10.3109/09638288.2012.691937

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P., … Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry*. https://doi.org/10.1002/gps.2071

Caro, C. C., Costa, J. D., & Da Cruz, D. M. C. (2018). Burden and Quality of Life of Family Caregivers of Stroke Patients. *Occupational Therapy In Health Care*, *32*(2), 154–171. https://doi.org/10.1080/07380577.2018.1449046

Carretero, S., Garcés, J., Ródenas, F., & Sanjosé, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*. https://doi.org/10.1016/j.archger.2008.05.004

Casado, B., & Sacco, P. (2012). Correlates of Caregiver Burden Among Family Caregivers of Older Korean Americans. *The Journals of Gerontology Series B:*

Psychological Sciences and Social Sciences, *67B*(3), 331–336. https://doi.org/10.1093/geronb/gbr115

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. *Archives of Physical Medicine and Rehabilitation*. https://doi.org/10.1016/j.apmr.2004.09.013

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & Secundino López-Pousa. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies.*, (47), 1262-1273.

Dayapoglu, N., & Tan, M. (2010). Quality of life in stroke patients. *Neurology India*, *58*(5), 697–701. https://doi.org/10.4103/0028-3886.72165

de Haan, R., Limburg, M., Bossuyt, P., van der Meulen, J., & Aaronson, N. (1995). The Clinical Meaning of Rankin 'Handicap' Grades After Stroke. *Stroke*, *26*(11), 2027–2030. https://doi.org/10.1161/01.STR.26.11.2027

Delcourt, C., Hackett, M., Wu, Y., Huang, Y., Wang, J., Heeley, E., … Anderson, C. S. (2011). Determinants of quality of life after stroke in China: The ChinaQUEST (QUality Evaluation of Stroke care and Treatment) study. *Stroke*. https://doi.org/10.1161/STROKEAHA.110.596627

Edwards Daryl Higgins Matthew Gray, B., & Alan Hayes, P. (2008). *Inquiry into Better Support for Carers Submission from the Australian Institute of Family Studies*.

Ellis, C., Grubaugh, A. L., & Egede, L. E. (2013). Factors Associated with SF-12 Physical and Mental Health Quality of Life Scores in Adults with Stroke. *Journal of Stroke and Cerebrovascular Diseases*, *22*(4), 309–317. https://doi.org/10.1016/J.JSTROKECEREBROVASDIS.2011.09.007

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20*(8), 423–428. https://doi.org/10.1111/j.1745-7599.2008.00342.x

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., … Murray, C. (2014). Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. *The Lancet*, *383*(9913), 245–255. https://doi.org/10.1016/S0140-6736(13)61953-4

Feigin, V. L., Norrving, B., & Mensah, G. A. (2017). Global Burden of Stroke. *Circulation Research*, *120*(3), 439–448. https://doi.org/10.1161/CIRCRESAHA.116.308413

Garcia-Perez, L., Linertova, R., Lorenzo-Riera, A., Vazquez-Diaz, J. R., Duque-Gonzalez, B., & Sarria-Santamera, A. (2011). Risk factors for hospital readmissions in elderly patients: a systematic review. *QJM*, *104*(8), 639–651. https://doi.org/10.1093/qjmed/hcr070

Gbiri, C. A., Olawale, O. A., & Isaac, S. O. (2015). Stroke management: Informal caregivers' burdens and strians of caring for stroke survivors. *Annals of Physical and Rehabilitation Medicine*, *58*(2), 98–103. https://doi.org/10.1016/j.rehab.2014.09.017

Gibson Hunt, G., Barrett, L., Management Susan Lutz, K., Stein, R., Vuckovic, N., Donna Wagner, I., … Weber-Raley, L. (2009). *National Alliance for Caregiving in collaboration with AARP*.

Glasdam, S., Timm, H., & Vittrup, R. (2010). Support Efforts for Caregivers of Chronically Ill Persons. *Clinical Nursing Research*, *19*(3), 233–265. https://doi.org/10.1177/1054773810369683

Global Burden of Disease Result tool. (2016). GBD Results Tool | GHDx. Retrieved January 30, 2019, from http://ghdx.healthdata.org/gbd-results-tool

Goldstein, L. B., Bushnell, C. D., Adams, R. J., Appel, L. J., Braun, L. T., Chaturvedi, S., … Council on Peripheral Vascular Disease, and Interdisciplinary Council on Quality of Care and Outcomes Research. (2011). Guidelines for the Primary Prevention of Stroke. *Stroke*, *42*(2), 517–584. https://doi.org/10.1161/STR.0b013e3181fcb238

Gräßel, E., & Adabbo, R. (2011). Perceived Burden of Informal Caregivers of a Chronically Ill Older Family Member. *GeroPsych*, *24*(3), 143–154. https://doi.org/10.1024/1662-9647/a000042

Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature. *Maturitas*, *66*(3), 268–276. https://doi.org/10.1016/J.MATURITAS.2010.03.017

Gund, G.-M. B. M., Jagtap, M. P. N., Ingale, M. V. B., & Patil, R. Y. (2013). *Stroke: A Brain Attack. IOSR Journal Of Pharmacy* (Vol. 3).

Hall, M. J., Levant, S., & Defrances, C. J. (2012). *Hospitalization for Stroke in U Key findings*. Retrieved from https://www.researchgate.net/profile/Carol_DeFrances/publication/225056140_Hospitalization_for_stroke_in_US_hospitals_1989-2009/links/5422b7240cf290c9e3ab1d10.pdf

Hampton, S., Armstrong, G., Ayyar, M. S., & Li, S. (2014). Quantification of Perceived Exertion During Isometric Force Production With the Borg Scale in Healthy Individuals and Patients With Chronic Stroke. *Topics in Stroke Rehabilitation*, *21*(1), 33–39. https://doi.org/10.1310/tsr2101-33

Hanson, E., Magnusson, L., Nolan, J., & Nolan, M. (2006). Developing a model of participatory research involving researchers, practitioners, older people and their family carers: An international collaboration. *Journal of Research in Nursing*. https://doi.org/10.1177/1744987106065829

Harris, J. E., & Eng, J. J. (2010). Strength Training Improves Upper-Limb Function in Individuals With Stroke. *Stroke*, *41*(1), 136–140. https://doi.org/10.1161/STROKEAHA.109.567438

Harris, J. E., Eng, J. J., Miller, W. C., & Dawson, A. S. (2010). The Role of Caregiver Involvement in Upper-Limb Treatment in Individuals With Subacute Stroke. *Physical Therapy*, *90*(9), 1302–1310. https://doi.org/10.2522/ptj.20090349

Hawranik, P. G., & Strain, L. A. (2000). *Health Of Informal Caregivers: Effects Of Gender, Employment, And Use Of Home Care Services The Prairie Women's Health Centre of Excellence*.

Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, Validity and Reference Values of the Zarit Burden Interview for Assessing Informal Caregivers of Community-Dwelling Older Persons with Dementia. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *19*(04), 494–507. https://doi.org/10.1017/S0714980800012484

Hoffman, G. J., Lee, J., & Mendez-Luck, C. A. (2012). Health behaviors among Baby Boomer informal caregivers. *Gerontologist*. https://doi.org/10.1093/geront/gns003

Holland, K. E. (2008). *Carers' perspectives on caring: A qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index survey 2007*. Retrieved from www.carersaustralia.com.au

Hung, J.-W., Huang, Y.-C., Chen, J.-H., Liao, L.-N., Lin, C.-J., Chuo, C.-Y., & Chang, K.-C. (2012). *Factors Associated with Strain in Informal Caregivers of Stroke Patients*. *Chang Gung Med J* (Vol. 35). Retrieved from https://pdfs.semanticscholar.org/9c15/59ff3df48fa83ef435ffa1a910a5cc889ed1.pdf?_ga=2.170308320.1990080363.1562139939-774726774.1537922693

Ilse, I. B., Feys, H., de Wit, L., Putman, K., & de Weerdt, W. (2008). Stroke caregivers' strain: prevalence and determinants in the first six months after stroke. *Disability and Rehabilitation*, *30*(7), 523–530. https://doi.org/10.1080/09638280701355645

Jaracz, K., Grabowska-Fudala, B., Górna, K., & Kozubski, W. (2014). Caregiving burden and its determinants in Polish caregivers of stroke survivors. *Archives of Medical Science*, *5*, 941–950. https://doi.org/10.5114/aoms.2014.46214

Jauch, E. C. (2018). ischemic stroke. Retrieved November 19, 2018, from https://emedicine.medscape.com/article/1916852

Jennifer Klinedinst, N., Gebhardt, M. C., Aycock, D. M., Nichols-Larsen, D. S., Uswatte, G., Wolf, S. L., & Clark, P. C. (2009). Caregiver characteristics predict stroke survivor quality of life at 4 months and 1 year. *Research in Nursing and Health*, *32*(6), 592–605. https://doi.org/10.1002/nur.20348

Jeong, Y.-G., Jeong, Y.-J., Kim, W.-C., & Kim, J.-S. (2015). The mediating effect of caregiver burden on the caregivers' quality of life. *Journal of Physical Therapy Science*. https://doi.org/10.1589/jpts.27.1543

Joan S. Grant, Alfred A. Bartolucci, A. A. B. T. R. E. J. N. G. (2000). Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury*, *14*(12), 1089–1100. https://doi.org/10.1080/02699050050203586

Joo, H., Wang, G., Yee, S. L., Zhang, P., & Sleet, D. (2017). Economic Burden of Informal Caregiving Associated With History of Stroke and Falls Among Older Adults in the U.S. *American Journal of Preventive Medicine*. https://doi.org/10.1016/j.amepre.2017.07.020

Kang, D.-W., Han, M.-K., Kim, H.-J., Sohn, H., Kim, B. J., Kwon, S. U., … Warach, S. (2016). Silent new ischemic lesions after index stroke and the risk of future clinical recurrent stroke. *Neurology*, *86*(3), 277–285. https://doi.org/10.1212/WNL.0000000000002289

Karaahmet, O. Z., Umay, E., Gurcay, E., Serçe, A., Gundogdu, I., & Cakci, A. (2018). The effect of premorbid features on post-stroke rehabilitation outcome. *Iranian Journal of Neurology*, *17*(1), 38–46. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/30186558

Karahan, A. Y., Kucuksen, S., Yilmaz, H., Salli, A., Gungor, T., & Sahin, M. (2014). EFFECTS OF REHABILITATION SERVICES ON ANXIETY, DEPRESSION, CARE-GIVING BURDEN AND PERCEIVED SOCIAL SUPPORT OF STROKE CAREGIVERS. *ACTA MEDICA (Hradec Králové)*, *57*(2), 68–72. https://doi.org/10.14712/18059694.2014.42.

Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, *68*(4), 846–855. https://doi.org/10.1111/j.1365-2648.2011.05787.x

Kim, Y., & Given, B. A. (2008). Quality of life of family caregivers of cancer survivors. *Cancer*, *112*(S11), 2556–2568. https://doi.org/10.1002/cncr.23449

Kingson, E. R. (1996). Ways of Thinking About the Long-Term Care of the Baby-Boom Cohorts. *Journal of Aging & Social Policy*, *7*(3–4), 3–23. https://doi.org/10.1300/J031v07n03_02

Kruithof, W. J., Post, M. W. M., van Mierlo, M. L., van den Bos, G. A. M., de Man-van Ginkel, J. M., & Visser-Meily, J. M. A. (2016). Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. *Patient Education and Counseling*. https://doi.org/10.1016/j.pec.2016.04.007

Kumar, R., Kaur, S., & Reddemma, K. (2015). Burden and Coping Strategies in Caregivers of Stroke Survivors. *Journal of Neurology and Neuroscience*, *06*(s1). https://doi.org/10.21767/2171-6625.S10005

Lennon, O., & Blake, C. (2009). Cardiac rehabilitation adapted to transient ischaemic attack and stroke (CRAFTS): a randomised controlled trial. *BMC Neurology*, *9*(1), 9. https://doi.org/10.1186/1471-2377-9-9

Lennon, S., & Stokes, M. (2009). *Pocketbook of Neurological Physiotherapy*. *Pocketbook of Neurological Physiotherapy*. https://doi.org/10.1016/C2009-0-37172-X

Lloyd-Jones, D., Adams, R., Carnethon, M., De Simone, G., Ferguson, T. B., Flegal, K., … Hong, Y. (2009). Heart Disease and Stroke Statistics—2009 Update. *Circulation*, *119*(3). https://doi.org/10.1161/CIRCULATIONAHA.108.191261

Lurbe-Puerto, K., Leandro, M. E., & Baumann, M. (2012). Experiences of Caregiving, Satisfaction of Life, and Social Repercussions Among Family Caregivers, Two Years Post-Stroke. *Social Work in Health Care*. https://doi.org/10.1080/00981389.2012.692351

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*. https://doi.org/10.1093/geronb/57.3.P195

Mahinda, L. W. (2016). Evaluation of the Informal Caregiver Burden in the Care of Stroke Patients At Kenyatta National Hospital.

Mahoney, F. I., & Barthel, D. W. (1965). FUNCTIONAL EVALUATION: THE BARTHEL INDEX. *Maryland State Medical Journal*, *14*, 61–65. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/14258950

Markus, H. S. (2012). Stroke genetics: Prospects for personalized medicine. *BMC Medicine*. https://doi.org/10.1186/1741-7015-10-113

Martínez-Martín, P., Forjaz, M. J., Frades-Payo, B., Rusiñol, A. B., Fernández-García, J. M., Benito-León, J., … Catalán, M. J. (2007). Caregiver burden in Parkinson's disease. *Movement Disorders*, *22*(7), 924–931. https://doi.org/10.1002/mds.21355

Masadeh, M. A. (2012). Focus group: Reviews and Practices. *International Journal of Applied Science and Technology*, *2*(10). Retrieved from http://ijastnet.com/journals/Vol_2_No_10_December_2012/9.pdf

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of Caregiving Burden and Quality of Life in Caregivers of Stroke Patients. *Stroke*, *36*(10), 2181–2186. https://doi.org/10.1161/01.STR.0000181755.23914.53

McGarry, J., & Arthur, A. (2001). Informal caring in late life: a qualitative study of the experiences of older carers. *Journal of Advanced Nursing*, *33*(2), 182–189. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11168701

Menon, B., Salini, P., Habeeba, K., Conjeevaram, J., & Munisusmitha, K. (2017). Female caregivers and stroke severity determines caregiver stress in stroke patients. *Annals of Indian Academy of Neurology*, *20*(4), 418. https://doi.org/10.4103/aian.AIAN_203_17

Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing*, *32*(2), 218–223. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12615568

Morris, M. (2016). *Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper*. Retrieved from https://www.researchgate.net/publication/237412393

Nketia-Kyere, M., Aryeetey, G. C., Nonvignon, J., & Aikins, M. (2017). Exploring barriers to accessing physiotherapy services for stroke patients at Tema general hospital, Ghana. *Archives of Physiotherapy*, *7*(1), 1–8. https://doi.org/10.1186/s40945-017-0037-5

Northouse, L., Williams, A., Given, B., & McCorkle, R. (2012). Psychosocial Care for Family Caregivers of Patients With Cancer. *Journal of Clinical Oncology*, *30*(11), 1227–1234. https://doi.org/10.1200/JCO.2011.39.5798

Ogunlana, M. O., Dada, O. O., Oyewo, O. S., Odole, A. C., & Ogunsan, M. O. (2014). Quality of life and burden of informal caregivers of stroke survivors. *Hong Kong Physiotherapy Journal*. https://doi.org/10.1016/j.hkpj.2013.11.003

Owolabi, M., Akarolo-Anthony, S., Akinyemi, R., Arnett, D., Gebregziabher, M., Jenkins, C., … Ovbiagele, B. (2015). The burden of stroke in Africa: a glance at the present and a glimpse into the future: review article. *Cardiovascular Journal Of Africa*, *26*(2), S27–S38. https://doi.org/10.5830/CVJA-2015-038

Pierce, L. L., Steiner, V. L., Khuder, S. A., Govoni, A. L., & Horn, L. J. (2009). The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services. *Disability and Rehabilitation*, *31*(20), 1676–1684. https://doi.org/10.1080/09638280902751972

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, *18*(2), 250–267. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12825775

Porter, S. B., & Tidy, N. M. (Noël M. (2008). *Tidy's physiotherapy*. Churchill Livingstone/Elsevier. Retrieved from https://books.google.com.gh/books?hl=en&lr=&id=qYbgp7eZkgsC&oi=fnd&pg=PA364&dq=stroke,+OR+TIA+Rigby&ots=WWaSaMfj0Y&sig=oAeLgdChBgZY_dV5kHAYh7AcMeU&redir_esc=y#v=onepage&q&f=false

Prince, M., & Davies, M. (2001). Moderator teams: an extension to focus group methodology. *Qualitative Market Research: An International Journal*, *4*(4), 207–216. https://doi.org/10.1108/EUM0000000005902

RANKIN, J. (1957). Cerebral vascular accidents in patients over the age of 60. III. Diagnosis and treatment. *Scottish Medical Journal*, *2*(6), 254–268. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/13432842

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). *Supporting Family Caregivers in Providing Care*. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Agency for Healthcare Research and Quality (US). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/21328765

Rigby, H., Gubitz, G., Eskes, G., Reidy, Y., Christian, C., Grover, V., & Phillips, S. (2009). Caring for Stroke Survivors: Baseline and 1-Year Determinants of Caregiver Burden. *International Journal of Stroke*, *4*(3), 152–158. https://doi.org/10.1111/j.1747-4949.2009.00287.x

Robbins, S. L. (Stanley L., Kumar, V., & Cotran, R. S. (2010). *Robbins and Cotran pathologic basis of disease*. Saunders/Elsevier. Retrieved from https://www.worldcat.org/title/robbins-and-cotran-pathologic-basis-of-disease/oclc/212375916/viewport

Rodakowski, J., Skidmore, E. R., Rogers, J. C., & Schulz, R. (2012). Role of Social Support in Predicting Caregiver Burden. *Archives of Physical Medicine and Rehabilitation*, *93*(12), 2229–2236. https://doi.org/10.1016/J.APMR.2012.07.004

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research*. https://doi.org/10.1007/s11136-009-9482-2

RouillardI, S., De WeerdtII, W., De WitIII, L., & JelsmaIII, J. (2012). Functioning at 6 months post stroke following discharge from inpatient rehabilitation. *SAMJ: South African Medical Journal*, *102*(6), 545–548. Retrieved from http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S0256-95742012000600073

Sacrey, L.-A. R., & Parmar, J. (2016). *A Framework to Assist Family Caregivers in Acute Care*. ca. Retrieved from http://seniorsnetworkcovenant.ca/wp-content/uploads/2017/01/1.-Resources-Caregivers-Framework-to-Assist-Family-Caregivers-in-Acute-Care-Framework-FINAL-20160817.pdf

Salmon, J. R., Kwak, J., Acquaviva, K. D., Brandt, K., & Egan, K. A. (2005). Transformative Aspects of Caregiving at Life's End. *Journal of Pain and Symptom Management*, *29*(2), 121–129. https://doi.org/10.1016/J.JPAINSYMMAN.2004.12.008

Sanuade, O. A., & Boatemaa, S. (2015). Caregiver profiles and determinants of caregiving burden in Ghana. *Public Health*, *129*(7), 941–947. https://doi.org/10.1016/J.PUHE.2015.05.016

Schulz, R., & Beach, S. R. (1999). Caregiving as a Risk Factor for Mortality. *JAMA*, *282*(23), 2215. https://doi.org/10.1001/jama.282.23.2215

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, *108*(9 Suppl), 23–27; quiz 27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

Seshadri, S., Beiser, A., Kelly-Hayes, M., Kase, C. S., Au, R., Kannel, W. B., & Wolf, P. A. (2006). The Lifetime Risk of Stroke Estimates From the Framingham Study. https://doi.org/10.1161/01.STR.0000199613.38911.b2

Silva-Smith, A. L. (2007). Restructuring Life. *Journal of Family Nursing*, *13*(1), 99–116. https://doi.org/10.1177/1074840706297425

Silver, H. J., & Wellman, N. S. (2002). Family caregiver training is needed to improve outcomes for older adults using home care technologies. *Journal of the American Dietetic Association*, *102*(6), 831–836. https://doi.org/10.1016/S0002-8223(02)90185-9

Sit, J. W., Wong, T. K., Clinton, M., Li, L. S., & Fong, Y. (2004). Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing*, *13*(7), 816–824. https://doi.org/10.1111/j.1365-2702.2004.00943.x

Snyder, J. R. (2000). Impact of Caregiver-Receiver Relationship Quality on Burden and Satisfaction. *Journal of Women & Aging*, *12*, 1–2. https://doi.org/10.1300/J074v12n01_10

Sreedharan, S. E., Unnikrishnan, J. P., Amal, M. G., Shibi, B. S., Sarma, S., & Sylaja, P. N. (2013). Employment status, social function decline and caregiver burden among stroke survivors. A South Indian study. *Journal of the Neurological Sciences*, *332*(1–2), 97–101. https://doi.org/10.1016/j.jns.2013.06.026

Stephens, S., Kenny, R. A., Rowan, E., Allan, L., Kalaria, R. N., Bradbury, M., & Ballard, C. G. (2004). Neuropsychological characteristics of mild vascular cognitive impairment and dementia after stroke. *International Journal of Geriatric Psychiatry*, *19*(11), 1053–1057. https://doi.org/10.1002/gps.1209

Stokes, M. (2004). *Physical management in neurological rehabilitation*. Elsevier Mosby. Retrieved from https://books.google.com.gh/books?hl=en&lr=&id=DQquLSXL8e4C&oi=fnd&pg=PR7&dq=Baer,+G+and+Durward,+B+(2004)+/+stroke&ots=U71fI7VGie&sig=ZAnrVWUsT0Mj3Hd8hY5989rHCoU&redir_esc=y#v=onepage&q=Baer%2C G and Durward%2C B (2004) %2F stroke&f=false

Strong, K., Mathers, C., & Bonita, R. (2007). Preventing stroke: saving lives around the world. *The Lancet. Neurology*, *6*(2), 182–187. https://doi.org/10.1016/S1474-4422(07)70031-5

Sussman, T., & Regehr, C. (2009). The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health and Social Work*. https://doi.org/10.1093/hsw/34.1.29

Teel, C. S., Duncan, P., & Lai, S. M. (2001). Caregiving experiences after stroke. *Nursing Research*, *50*(1), 53–60. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19785245

Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A. R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry*, *17*(1), 78–84. https://doi.org/10.1002/gps.524

Tilden, V. P., Tolle, S. W., Drach, L. L., & Perrin, N. A. (2004). Out-of-Hospital Death: Advance Care Planning, Decedent Symptoms, and Caregiver Burden. *Journal of the American Geriatrics Society*, *52*(4), 532–539. https://doi.org/10.1111/j.1532-5415.2004.52158.x

Tosun, K. Z., Temel, M., Kemal Mahallesi, N., & Caddesi, K. (2017). *Burden of Caregiving for Stroke Patients and The Role of Social Support Among Family Members: An Assessment Through Home Visits*. *International Journal of Caring* (Vol. 10). Retrieved from www.internationaljournalofcaringsciences.org

Tuna, H. M., & Olgun, N. (2010). *The Role of Perceived Social Support on Stroke Patients' Caregivers who have the Burnout Syndrome*. Retrieved from http://www.hacettepehemsirelikdergisi.org/pdf/pdf_HHD_92.pdf

Van Puymbroeck, M., Sberna Hinojosa, M., & Rittman, M. R. (2008). Influence of Sense of Coherence on Caregiver Burden and Depressive Symptoms at 12 Months Poststroke. *Topics in Stroke Rehabilitation*, *15*(3), 272–282. https://doi.org/10.1310/tsr1503-272

Vincent-Onabajo, G., Ali, A., & Hamzat, T. (2013). Quality of life of Nigerian informal caregivers of community-dwelling stroke survivors. *Scandinavian Journal of Caring Sciences*, *27*(4), 977–982. https://doi.org/10.1111/scs.12017

Visser-Meily, A., Post, M., van de Port, I., Maas, C., Forstberg-Wärleby, G., & Lindeman, E. (2009). Psychosocial Functioning of Spouses of Patients With Stroke From Initial Inpatient Rehabilitation to 3 Years Poststroke. *Stroke*, *40*(4), 1399–1404. https://doi.org/10.1161/STROKEAHA.108.516682

Warlow, C. (2001). *Stroke : a practical guide to management*. Blackwell Science. Retrieved from https://trove.nla.gov.au/work/35606132?q&versionId=45739752

White, C. L., Mayo, N., Hanley, J. A., & Wood-Dauphinee, S. (2003). Evolution of the caregiving experience in the initial 2 years following stroke. *Research in Nursing and Health*. https://doi.org/10.1002/nur.10084

WHO. (2008). *WORLD HEALTH STATISTICS*. Geneva. Retrieved from https://www.who.int/gho/publications/world_health_statistics/EN_WHS08_Full.pdf?ua=1

Wilks, S. E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging & Mental Health*, *12*(3), 357–365. https://doi.org/10.1080/13607860801933323

Zarit, S. H. (2004). Family care and burden at the end of life. *CMAJ : Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, *170*(12), 1811–1812. https://doi.org/10.1503/CMAJ.1040196

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden 1. *Oxford Journal*, *20*(6), 649–655. Retrieved from http://gerontologist.oxfordjournals.org/

Zorowitz, R. D., Gillard, P. J., & Brainin, M. (2013). Poststroke spasticity: Sequelae and burden on stroke survivors and caregivers. *Neurology*. https://doi.org/10.1212/WNL.0b013e3182764c86

APPENDICES

APPENDIX A: Participant information sheet.

Study Title: Burden of caregiving among informal caregivers of stroke survivors.

Introduction: My name is Rhodaline Okai, I am currently the head of the physiotherapy department at the Effia-Nkwanta Regional Hospital. I have enrolled as an MPH student at the School of Public Health, University of Ghana.

Background and purpose of research: This is an academic research aimed at finding out the burden experienced by informal caregivers of stroke survivors as a result of their caregiving role. The objective of this study is to measure the physical, psychological, social and financial domains of the informal caregiver burden and identify the factors that contribute to it. This will be achieved by measuring the four domains of burden in the informal caregivers, degree of disability in the stroke survivor, exploring socio-demographic determinants (age, sex, marital status, employment and educational status) of stroke survivors and their informal caregivers, stroke survivor factors(duration of stroke, comorbidities and adherence to medication and exercises), caregiver factors (duration of care, previous caregiving experience, comorbidities and presence of other caregivers. This will enlighten heath professionals responsible for stroke care and rehabilitation about the challenges of informal caregivers and inform inclusion of the caregivers in their intervensions.

Nature of research: The study seeks to interview stroke survivors and their informal caregivers at Effia-Nkwanta Regional Hospital and Tarkwa Municipal Hospital using questionnaires. There will also be a focus group discussion with some informal caregivers and physiotherapists/assistants.

Participants' involvement: This study will be done within the months of April and June, 2019. The participants will be expected to fill questionnaires with the help of the principal investigator or research assistant. Filling of the stroke survivor questionnaire will take about 10 minutes while that of the informal caregiver may last for 30 minutes. There will also be a audio recorded focus group discussion with some informal caregivers and physiotherapists/assistants. Ten participants from each group will be recruited for the focus group discussion and is expected to last for about one hour.

Potential Risks: There are no known risk or harm associated with participating in this study.

Benefits: The information provided will help the clinical and rehabilitation team understand the burden of informal caregivers and identify the factors that can lead to it so as to plan interventions to minimise or prevent the negative impact of the caregiving role. The information will be beneficial to policy makers and the health professionals involved in the stroke rehabilitation process to plan interventions that will improve the overall quality of life of informal caregivers and stroke survivors.

Compensation: There will be no compensation for participating in the study, however, focus group discussion participants will be refreshed during the discussions.

Confidentiality: Study participants will be assured that the information collected will be kept confidential and will not be divulged to anyone. Participant names will not be mentioned in any study outputs. Also, in order to minimize participant's discomfort about the issues being discussed, all interviews will be conducted in a private place and questionnaires will be coded. During training, field staff will be made aware of the importance of protecting interviewee's privacy and confidentiality of information obtained from them.

Voluntary participation/withdrawal: Informed consent will be read out in the appropriate language (local or English) to all respondents outlining the risks and benefits of being interviewed and giving them the opportunity to decline to be interviewed or to discontinue the interview at any time. Participation will be completely voluntary. Those who give their consent will be asked to sign or put their thumbprint on the consent form to indicate their willingness to participate in the study.

Outcome and Feedback: All the information gathered will be put together in a report. The findings of the study will be shared with all stakeholders including the study participants

Appropriate alternative Procedures and Treatment: This study does not involve any treatments

Feedback to participant: The findings of the study will be shared with all stakeholders including the study participants.

Funding information: This study will be self-sponsored.

Sharing of participants Information/Data: The data generated from participants will be used solely for the purpose of research and will not be shared.

Storage of samples (where applicable): The questionnaires will be kept for five (5) years before discarding appropriately. In case there is the need to use participant information for any other purpose aside what has been stated, consent will be sought from participants

Provision of Information and Consent for participants: A copy of the Information sheet and Consent form will be given to you after it has been signed or thumb-printed to keep. In addition, a consent form requesting for focus group discussion participants consent to tape record discussion will be sought.

Who to Contact for Further Clarification/Questions:

PI – Rhodaline Okai	**ERC Administrator - Hannah Frimpong**
Tel: 0244959888	Tel: 0507041223
Email: rhodalineo@gmail.com	Email: Hannah.frimpong@ghsmail.org

APPENDIX B: Consent form.

Study Title: Burden of caregiving among informal caregivers of stroke survivors

PARTICIPANTS' STATEMENT

I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and satisfactorily explained to me in a language I understand (English /Fante/Twi). I fully understand the contents and any potential implications as well as my right to change my mind (i.e. withdraw from the research) even after I have signed this form.

I voluntarily agree to be part of this research.

Name or Initials of Participant………………………….. ID Code …………………………..

Participants' Signature ………OR Thumb Print……….. OR Mark (Please specify)…………

Date…………………………

INTERPRETERS' STATEMENT

I interpreted the purpose and contents of the Participants' Information Sheet to the afore-named participant to the best of my ability in the (Fante/Twi) language to his understanding.

All questions and appropriate clarifications sort by the participant were also duly interpreted to his/her satisfaction.

Name of Interpreter……………………………

Signature of Interpreter……………………….. Date: ……………………

STATEMENT OF WITNESS

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the language he/she understood (English/Twi/Fante).

I confirm that he/she was given the opportunity to ask questions/seek clarifications and same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Name:…………………………

Signature……………. OR Thumb Print ……….... OR Mark (please specify)………………..

Date:……………………………

INVESTIGATOR STATEMENT AND SIGNATURE

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed.

Researcher's name……………………………………….

Signature ………………………………………………….

Date……………………………………………………….

APPENDIX C: Informal caregiver questionnaire.

SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF GHANA

DEPARTMENT OF BIOLOGICAL, ENVIRONMENTAL AND OCCUPATIONAL HEALTH

This questionnaire is designed to measure the physical, psychological, social and financial burden of informal caregivers, assess caregiver factors that affect caregiver burden including socio-demographics, and determine the association between caregiver and caregiver perceived health care facility factors and the caregiver burden.

Your opinions and experiences are important to us. We want you to be honest and truthful in answering our questions. If you decide to participate in the study, your answers will be kept confidential and will not be shared with anyone who is not part of the study team.

A. SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF CAREGIVER

1. Age (completed years) ………

2. Gender Male [ ] Female [ ]

3. Relationship to patient……………………

4. Employment status

Unemployed ( ) Formal Public sector ( ) Formal Private sector ( ) Self-employed ( ) Retired ( ) Other (specify)………......................

5. Marital status

Never married ( ) Married ( ) Widowed ( ) Divorced ( ) Separated ( )

6. Educational qualifications

No education ( ) Primary ( ) Middle ( ) Secondary ( ), Technical/Vocational ( ), University degree ( )

7. Average monthly income in Ghanaian cedi

<100 ( ) 100-999 ( ) 1,000-1,999 ( ) 2,000-2,999 ( ) >/= 3,000

8. Average monthly cash inflows from gifts or donations in Ghanaian cedi

<100 ( ) 100-999 ( ) 1,000-1,999 ( ) 2,000-2,999 ( ) >/= 3,000

9. Apart from this patient, how many other dependants do you have at home? ………….

10. Co-morbidities **(Tick all apply)**

Vision problem ( ) Shoulder pain ( ) Diabetes ( ) Hypertension ( ) Osteoarthritis ( ) Low back pain ( ) Other (specify) ……………………

11. Have you ever had any previous caregiving experience before this stroke incident?

Yes [ ] No [ ]

12. Duration of caring for patient? …………...years………months…………weeks

13. Do you have other family members assisting with the caregiving role? Yes [ ] No [ ]

14. How long did patient stay at home before reporting to the hospital after the stroke incident? …………...years………months…………weeks

15. How long did patient stay home after hospital discharge before starting physiotherapy?

…………...years………months…………weeks

16. In your opinion, do you think this physiotherapy facility is well equipped for all exercises? Yes [ ] No [ ]

B. PHYSICAL DEMANDS OF THE CAREGIVING ROLE

1. The table below shows a list of activities of daily living. Kindly tick all the ones you have provided for the patient within the last one month and for each of these indicate how many minutes or hours in total it takes you to perform in a day as well as the degree of demand (light, moderate, high).

ACTIVITY	TICK (IF YES)	MINUTES/ HOURS	DEGREE OF DEMAND
Bathing(include undressing)			
Getting Dressed (pomading, combing hair, buttoning)			
Grocery shopping			
Preparing meals			
Feeding			
Dealing with incontinence or diapers			
Help with toileting			
Getting in and out of beds or chairs			
Housework (such as dishes, laundry, or straightening up)			
Giving medicines, pills or injections			
Transportation (driving, helping arrange transportation)			

C. CAREGIVER PERCEPTION OF STROKE SURVIVOR'S EXERCISE / MEDICATION ADHERENCE

1. On average, how many times does the patient do the home exercises in a month?

A. Greater than 10 [ ]

B. 6-10 [ ]

C. 3-5 [ ]

D. 1-2 [ ]

E. Patient does not exercise [ ]

2. On average, how many times does the patient do the home exercises in a week?

A. Greater than 10 [ ]

B. 6-10 [ ]

C. 3-5 [ ]

D. 1-2 [ ]

E. Patient does not exercise [ ]

3. On average, how many times does the patient do the home exercises in a day?

A. Greater than 10 [ ]

B. 6-10 [ ]

C. 3-5 [ ]

D. 1-2 [ ]

E. Patient does not exercise [ ]

4. How many times in a day is patient expected to take his medications?

A. Once [ ]

B. Twice [ ]

C. Thrice [ ]

D. None of the above. [ ]

5. Does patient take his medications as prescribed? Yes [ ] No [ ]

D. CAREGIVER -PHYSIOTHERAPIST RELATIONSHIP.

1. Did you see your usual or regular therapist/ assistant today? Yes [ ] No [ ]

Thinking about the therapist/assistant you have just seen, please answer the following questions as honestly as possible by ticking the box that best fits with your opinion.

Questions	Disagree	Slightly Disagree	Slightly Agree	Totally Agree
	0	1	2	3
I know this therapist/ assistant very well				
This therapist/ assistant knows me as a person				
I know what to expect with this therapist/ assistant				
I feel the therapist/ assistant understands my situation and gives me all the necessary support and encouragement.				

E. CAREGIVER PERCEPTION OF PATIENT – PHYSIOTHERAPIST RELATIONSHIP

Please answer the following questions as honestly as possible by ticking the box that best fits with your opinion.

Questions	Disagree	Slightly Disagree	Slightly Agree	Totally Agree
	0	1	2	3
I feel my patient will be well taken care of in my absence				
I feel my patient is assisted throughout his/her treatment regimen				
I feel my patient and I get the necessary attention all the time				

F. CAREGIVER BURDEN

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

Please circle the response the best describes how you feel.

QUESTION	SCORE
Physical Domain	
1. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4

2. Do you feel your sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)	0 1 2 3 4
3. Do you feel your health has suffered because of your involvement with your relative? (e.g., feeling physically ill, musculoskeletal discomfort)	0 1 2 3 4
4. Do you feel inconvenienced? (e.g., because helping takes so much time or it's a long drive over to help)	0 1 2 3 4
5. Do you feel physically strained / tired (e.g., because of lifting in and out of a chair; effort or concentration is required)	0 1 2 3 4
Psychological domain	
6. Do you feel angry when you are around your relative?	0 1 2 3 4
7. Are you afraid what the future holds for your relative?	0 1 2 3 4
8. Do you feel your relative is dependent on you?	0 1 2 3 4
9. Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
10. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
11. Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
12. Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
13. Do you feel uncertain about what to do about your relative?	0 1 2 3 4
14. Do you feel you should be doing more for your relative?	0 1 2 3 4
15. Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
Social domain	
16. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
17. Do you feel that you don't have as much privacy as you would like	0 1 2 3 4

because of your relative?	
18. Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4
19. Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
20. Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
Financial domain	
21. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
22. Do you feel that you will be unable to take care of your relative much longer?(financially)	0 1 2 3 4
23. Do you feel that there has been work adjustments (e.g., because of having to take time off)	0 1 2 3 4
24. Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

THANK YOU FOR PARTICIPATING.

APPENDIX D: Stroke survivor questionnaire.

SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF GHANA

DEPARTMENT OF BIOLOGICAL, ENVIRONMENTAL AND OCCUPATIONAL HEALTH

This questionnaire is designed to assess stroke survivor factors that affect caregiver burden including socio-demographics, and to determine the association between stroke survivor factors and the caregiver burden.

Your opinions and experiences are important to us. We want you to be honest and truthful in answering our questions. If you decide to participate in the study, your answers will be kept confidential and will not be shared with anyone who is not part of the study team.

A. SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF STROKE SURVIVOR.

1. Age (completed years) ………

2. Gender M/F……….

3. Relationship to caregiver……………………

4. Employment status before stroke

Unemployed ( ) Formal Public sector ( ) Formal Private sector ( ) Self-employed ( ) Retired ( ) Other (specify)……….....................

5. Marital status

Never married ( ) Married ( ) Widowed ( ) Divorced ( ) Separated ( )

6. Educational qualifications

No education ( ) Primary ( ) Middle ( ) Secondary ( ), Technical/Vocational ( ), University degree ( )

7. Co-morbidities

Vision problem ( ) Shoulder pain ( ) Diabetes ( ) Hypertension ( ) Osteoarthritis ( ) Low back pain ( )

B. DEGREE OF DISABILITY

QUESTIONS	SCORES
No symptoms at all	0
No significant disabilities despite symptoms able to carry out all usual duties and activities	1
Slight disabilities unable to carry out all previous activities but able to look after own affairs without assistance	2
Moderate disability requiring some help but able to walk without assistance	3
Moderate severe disability unable to walk without assistance unable to attend to own bodily needs without assistance	4
Severe disability – bedridden incontinent requiring constant nursing care and attention	5

THANK YOU FOR PARTICIPATING.

APPENDIX E: Focus group discussion probes for informal caregivers.

1. Can you please describe in as much detail as possible how your experiences as an informal caregiver have been?
2. Does the caring impact on your health and wellbeing in any way?
3. Can you describe your caregiving role activities on an ordinary day?
4. What are some of the major challenges in caring for the stroke survivors?
5. In what ways does the caregiving role impact your life financially?
6. In what ways does your role impact on your time management and engagement in social activities?
7. What level of support do you get from family members?
8. What level of support do you get at the physiotherapy department?
9. Do you think your role affects your mood?
10. What do you think about the information and advice given when taking stroke survivor home after discharge?
11. How have you been managing your situation so far? Any coping mechanisms?
12. What are your reasons for default from physio treatment if any?
13. Do you believe more respite services and facilities are needed to reduce your burden?
14. Have you had any positive experiences so far?
15. Do you have any recommendations to help relief you of your burden?
16. Additional comments?

APPENDIX F: Focus group discussion probes for physiotherapists and assistants.

Kindly answer from experience and your continuous interaction with caregivers and stroke survivors.

1. What are your major challenges in caring for stroke survivors as a professional?

2. Do you have all you need to rehabilitate stroke survivors at your disposal?

3. What are some of the things needed that you don’t have?

4. How have you been managing without them?

5. How best do you think you can help relief informal caregivers of their burden?

6. What is the relationship between you and informal caregiver/ survivor like?

7. Can the relationship be improved and in what way?

8. Are the stroke survivors referred on time and how does that translate in their recovery and informal caregiver burden?

9. In what ways do you think the caregiving role has impacted on informal caregivers?

10. What are some of the factors that you think can lead to or contribute to the informal caregiver’s burden?

14. Any suggestions on coping mechanisms for the informal caregiver?

15. Additional comments?

APPENDIX G: Budget for the study.

The budget for the study was Three Thousand, One Hundred and Fifteen Ghana Cedis (GH₵ 3,115.00)

Budget Category	**Unit Cost (GH₵)**	**Quantity**	**Total Cost (GH₵)**
Transportation	40.00	20	800.00
Communication Cost	100.00	-	100.00
Research assistance allowance	350.00	2	700.00
Incentives	15	21	315.00
Training and pre- testing	200.00	1	200.00
Stationary and printing	800.00	-	800.00
Miscellaneous	200.00	-	200.00
Grand Total (GH₵)			**3,115.00**

G. 1. Justification for the Budget.

Research assistants: Two (2) research assistants were recruited to assist in data collection and received some remuneration at the end of their work.
Stationery and printing 1. Buying paper, files and envelopes 2. Typing 3. Printing and binding 4. Photocopying
Communication cost: money for buying data and air time for communication.
Incentives: small package (lunch, water) for participants of the study

APPENDIX H: Timelines.

ACTIVITY	TIME FRAME
Proposal Presentation	October, 2018
Writing up proposal	October – November, 2018
Submission of proposal for ethical clearance	February, 2019
Training of research assistants	January, 2019
Data Collection	May – June, 2019
Data analysis and write up of dissertation	June, 2019
Submission of dissertation	July, 2019

APPENDIX I: Focus group discussion participant characteristics.

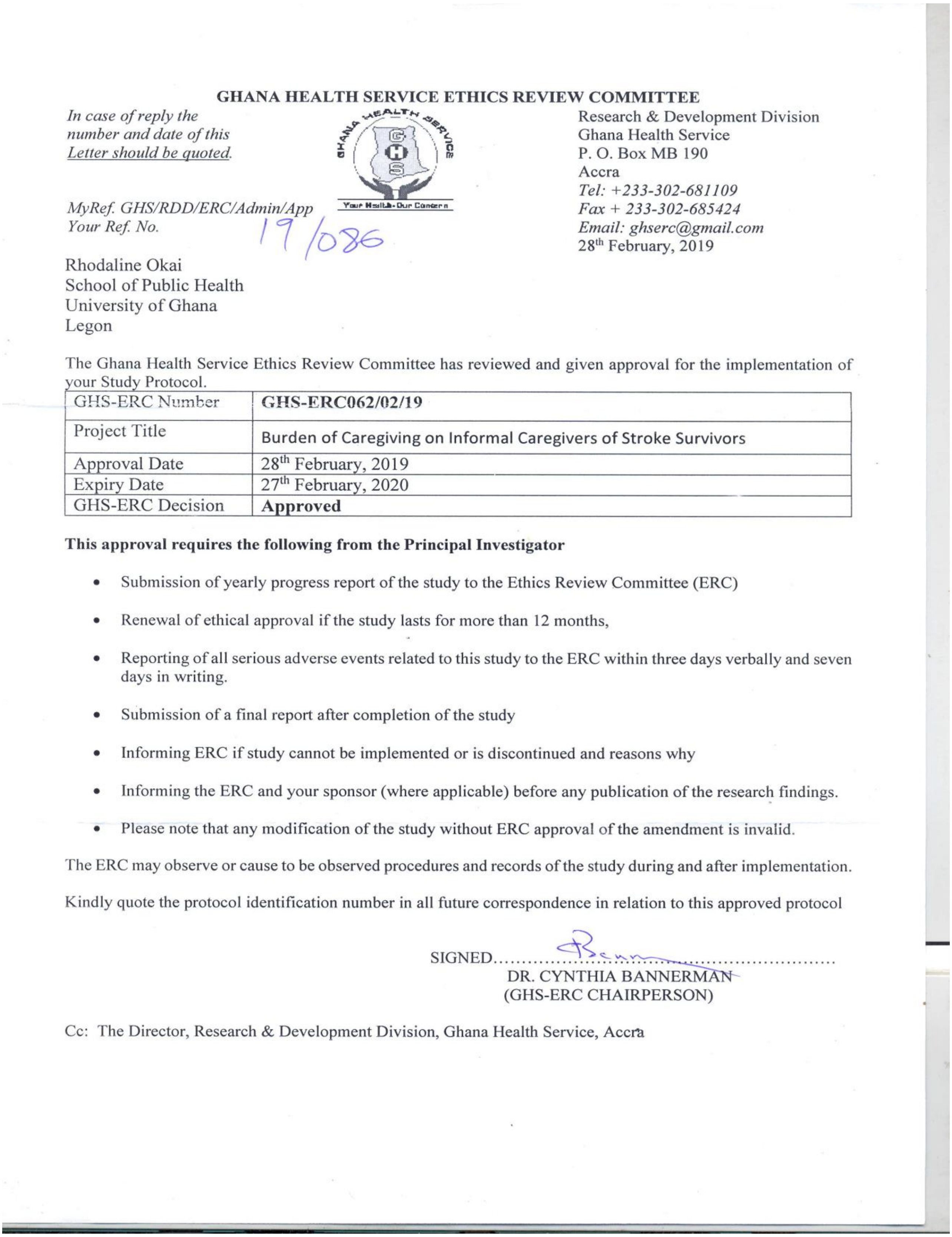
Caregiver	**Sex**	**Age(years)**	**Relation to survivor**	**Caregiving Duration**	**Employment Status**
1	Male	36	Child	>6 months	Unemployed
2	Female	57	Sibling	<6 months	Employed
3	Female	31	Grandchild	>6 months	Employed
4	Male	35	Child	>6 months	Employed
5	Female	34	Child	<6 months	Employed
6	Female	55	Spouse	<6 months	Unemployed
7	Female	50	Sibling	>6 months	Employed
8	Female	23	Sibling	>8 months	Unemployed
Therapists	**Sex**	**Age**	**Qualification**	**Experience(Years)**	
1	Female	34	PT	8	
2	Female	31	PTT	8	
3	Male	26	PT	1	
4	Male	25	PTT	1	
5	Female	31	PTA	4	
6	Male	35	PT	8	
7	Male	33	PT	8	
8	Male	30	PTT	1	
9	Female	59	PTA	30	

PT=Physiotherapist, PTA=Physiotherapist Assistant, PTT=Physiotherapist Technician

APPENDIX J: Summary of themes and subthemes.

Themes	**Subthemes**
Informal caregiver Experiences	
Physical burden	Physical stress Fatigue Musculoskeletal pain Headache Sleepless night
Psychological burden	Worry Mood change
Social burden	Disruption of church attendance Loss of relationships Limited time for self
Financial burden	Increased expenditure Work adjustments
Physical demands of care	Bathing Feeding/meal preparation Giving medication Toileting Home exercise supervision Lifting
Physiotherapist/Assistants Experiences	
Stroke survivor factor	Non-adherence to exercises
Health facility factors	Stroke survivor-therapist ratio Late referral for physiotherapy

APPENDIX K: Ghana health service ethics review committee approval.



GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

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

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

MyRef. GHS/RDD/ERC/Admin/App 19/086
Your Ref. No.

28th February, 2019

Rhodaline Okai
School of Public Health
University of Ghana
Legon

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

GHS-ERC Number	**GHS-ERC062/02/19**
Project Title	Burden of Caregiving on Informal Caregivers of Stroke Survivors
Approval Date	28th February, 2019
Expiry Date	27th February, 2020
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.
- Please note that any modification of the study without ERC approval of the amendment is invalid.

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

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

SIGNED……………………………………………………
DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

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