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BURDEN OF STROKE IN GHANA: PREVALENCE, EXPERIENCE AND CAREGIVING

BY

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ACCEPTANCE

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DECLARATION

I, OLUTOBI ADEKUNLE SANUADE, hereby declare that, except for references to other people's work, which have been duly acknowledged, this is the result of my own research and it has neither in part nor in whole been presented for another degree.

OLUTOBI ADEKUNLE SANUADE   DATE

DEDICATION

This work is dedicated to my lovely wife, Adetutu Sanuade, for all her support during my PhD Programme.

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ABSTRACT

Background: Stroke has been named as one of the public health priorities in sub-Saharan Africa (SSA) because of its impact on mortality, morbidity and quality of life. Despite this, there is limited population-based information on prevalence and correlates of stroke, and there is limited information on knowledge and experience of stroke from the perspectives of the stroke survivors and their caregivers in SSA.

Objectives: This thesis examined the prevalence, correlates, knowledge and experience of stroke in Ghana. It drew on three main concepts and theories: Health Related Quality of Life; explanatory models, and; biographical theories (biographical disruption, biographical transformation, biographical flow and biographical reinforcement). These concepts and theories were subsumed under social determinants of health.

Methodology: This study adopted a triangulation mixed method approach using both quantitative and qualitative data. The wave 1 data of the World Health Organization (WHO) Survey on Global Ageing and Adult Health (SAGE) (Ghana) was used for the quantitative data and the sample size was 4,279 Ghanaian adults aged 50 years and above. The SAGE data was used to examine stroke prevalence and correlates as well as Health Related Quality of Life (HRQoL) of stroke survivors. While binary logistic regression was used to determine the correlates of stroke, multiple linear regression was used to determine the predictors of HRQoL of stroke survivors. For the qualitative data, a total of 22 stroke survivors and 29 caregivers were purposively selected from Ga Mashie and Korle-Bu Teaching Hospital (Physiotherapy and Stroke Units), Accra. Individual semi-structured interviews were used to explore the knowledge and experience of stroke from the perspectives of the stroke survivors and their caregivers. Data were analysed using thematic approach with the aid of Atlas ti.

Results: Stroke prevalence was 4.6% and the correlates of stroke were being never married, unemployed, and living with hypertension and diabetes. This study showed that the HRQoL of stroke survivors was low in the physical health (body-self), functional, psychological, social and environment domains. The predictors of HRQoL of the stroke survivors were: unemployment, lower wealth status and living with hypertension. Particularly, the HRQoL was lower for stroke survivors who were unemployed; those in the poorest wealth quintiles, and; those living with hypertension. Further, participants' knowledge on stroke causal theories, complications and prevention was eclectic and their sources of knowledge were mostly based on lived experiences of the stroke survivors and post-diagnosis information from health professionals. The impact of stroke on the stroke survivors centered on seven broad interrelated themes: body-self disruption; disruption to economic; disruption to social relationships; disruption to family relationships; cognitive disruption; nutrition disruption, and; lifestyle disruption. On the other hand, the impact of stroke on the caregivers centered on seven broad categories: disruption to physical body; disruption to economic circumstances; disruption to social relationships; nutrition disruption; psychological disruption; lifestyle disruption, and; disruption to life circumstances.

Conclusion: This study showed high stroke prevalence among Ghanaian adults and the health of the stroke survivors affected that of their caregivers. The participants' illness actions indicate that dual use of pharmaceutical and herbal treatments are adequate for stroke management. Further, the impact of stroke on stroke survivors and their caregivers was multifaceted. This indicates that interventions need to adopt a combined patient-and caregiver-focused approach in stroke survivor rehabilitation by adopting the Innovative Care for Chronic Conditions Framework, developed by World Health Organization.

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CHAPTER ONE

INTRODUCTION

1.1   Background

Stroke is the second leading cause of death and the third leading cause of disability worldwide (Feigin et al., 2014; Murray et al., 2012). It is estimated that 15 million people suffer from stroke every year. Out of this number, about six million people die and another five million people are left permanently disabled (World Heart Federation, 2014). Specifically, a total of 44 million disability-adjusted life-years (DALYs) are lost to stroke every year and this is projected to increase to 61 million by 2020 (Mukherjee and Patil, 2011; WHF, 2014). The prevalence is projected to increase throughout the world because the number of persons aged 60 years and above is expected to more than double by 2050 and more than triple by 2100, increasing from 901 million in 2015 to 2.1billion in 2050 and 3.2 billion in 2100 (United Nations, 2015).

 In low- and middle-income countries (LMICs), stroke incidence is increasing and research has specifically shown that stroke mortality will triple in Latin America, the Middle East, and sub-Saharan Africa between 2002 and 2020 (Beaglehole et al., 2003; WHO, 2004). Community-based studies in sub-Saharan Africa (SSA) show that stroke is the cause of 5-10% of all deaths partly because of inadequate health systems and increasing rates of hypertension (Agyemang et al., 2012; Van Der Sande et al., 2001; Walker et al., 2000; Kahn and Tollman, 1999). Further, the impact of stroke is projected to go up in this region as a result of urbanization, poor socio-economic status and change in the demographic structure of the population from young to an ageing population. By 2025, it is projected that about half of the populations in SSA will be living in urban areas and the number of people who are aged 60 years and above will more than

double in countries like Ghana, Cameroon, Democratic Republic of Congo, and Mozambique (Muna, 1993, Kengne and Anders, 2006; Help Age International, 2015). This projected demographic transition may increase stroke-induced disability in the region in the near future if serious measures are not put in place.

In Ghana, stroke is one of the top three causes of death and constitutes more than one-tenth of all causes of deaths in the country (Sampane-Donkor et al., 2014). Stroke moved from being the 11th cause of premature death in 1990 to the 7th cause of premature death in 2010 (Feigin et al., 2014). Further, stroke is the leading cause of premature death among the non-communicable diseases between 1990 and 2010. Also, there is a high case fatality rate of stroke in the country (Agyemang et al., 2012; Sanuade and Agyemang, 2013). Research has further shown that the main risk factors of stroke in Ghana are hypertension, diabetes, obesity, ageing and plasma level of homocysteine (Hcy) (Agyemang et al., 2012; Sanuade and Agyemang, 2013) and between 60% and 90% of stroke in the country are haemorrhagic (Sanuade and Agyemang, 2013).

Stroke is a frequent cause of admission to hospitals in Ghana, and causes a high level of disability which poses a huge burden on the stroke survivors and their families, healthcare staff, and the country's health system (Sanuade and Agyemang, 2013). Stroke is a developmental issue because it affects the elderly, young people and poor communities are disproportionately affected (de-Graft Aikins, 2007). Also, it can push individuals and households further into poverty and drain government health budget (de-Graft Aikins, 2007). Despite this, stroke is not on the list of priority health interventions outlined by Ghana's Ministry of Health and stroke burden has been under-researched and under-funded. Hence, there is no national action plan on stroke in Ghana. Studies have shown that many of the people diagnosed with stroke die in the

first year after the diagnosis. Some of the reasons for this include: lack of a good follow-up plan after the stroke survivors are discharged from the hospitals; lack of proper caregiving; high cost of stroke management (Birabi et al., 2012); inadequate knowledge of the disease (Sampane-Donkor et al., 2014), and; psychosocial conditions of stroke survivors and family caregivers (Carney, 2002). This indicates that addressing stroke burden requires clear understanding of the prevalence and correlates of the condition and also knowledge on the experience of stroke survivors and their caregivers. This study aims to address the gap by examining the prevalence, correlates and experiences of stroke in Ghana.

1.2 Conceptualisation of burden of stroke

In this thesis, burden of stroke is conceptualised as prevalence, experience and caregiving. Prevalence of a disease is the proportion of a population that is living with a particular disease at a point in time. Illness experience focuses on how an individual living with a particular illness lives with and responds to the condition on a daily basis (Pieret, 2003). Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs (Collins et al., 2011). In the context of this study, prevalence will be limited to the study population as defined and stroke prevalence will be derived from there. The lived-experience of stroke will focus on the impact of the illness on the quality of life of an individual living with stroke (stroke survivor) as well as the illness actions and the coping strategies adopted by such individual in managing the illness. Caregiving will focus on the kinds of support that stroke caregivers provide for the stroke survivors and the kinds of support the caregivers received from family members, friends and other significant others. This will also focus on the impact of caregiving on the quality of life of the caregivers.

1.3   Statement of Problem

The burden of stroke has been increasing in sub-Saharan Africa. The disability adjusted life years (DALYs) due to stroke in the region is about seven times higher than that of the high income countries (Sampane-Donkor et al., 2014). It is projected that the burden of stroke will increase in sub-Saharan Africa in the next few decades due to epidemiological transition (Agyemang et al., 2010). As a result, stroke has been named as one of the public health priorities in the region (Beaglehole et al., 2011). Consequently, addressing the burden of stroke should be a priority to individuals, government, politics and policy in all the countries in the sub-region. Even though the impact of stroke on mortality, morbidity, disability and quality of life in Ghana is high, it is not being prioritised in the country. In 2012, Ghana's Ministry of Health developed a national policy for the prevention and control of chronic non-communicable diseases; however, information on the burden of stroke is not explicit in the policy (Ghana Ministry of Health, 2012).

Studies have shown that stroke is the third leading cause of death in Ghana and a major cause of disability in the country (Sampane-Donkor et al., 2014). Stroke mortality has increased from 2% in 1921 to 13.2% in 2007 (Edington 1954; Agyemang et al. 2012). Also, hypertension prevalence is already high in the country and is projected to increase even further (Addo et al., 2012). This has serious implication on the burden of stroke unless urgent measures are taken to control this (Bosu, 2010; Addo et al., 2012). In addition, stroke prevalence in Ghana may be on the increase because of poor community knowledge of stroke risk factors and their warning signs (Sampane-Donkor et al., 2014). Research has shown that high awareness of stroke risk factors improves compliance with stroke prevention. On the other hand, lack of recognition of stroke warning signs causes delay in hospital reporting of stroke (Cossi et al., 2012).

Stroke is fast becoming a major cause of medical admissions in Ghana (Agyei-Mensah & de-Graft Aikins, 2010). Stroke accounted for 8% of medical admissions between 1960 and 1968, and 9.1% between 2006 and 2007 (Agyei-Mensah & de-Graft Aikins, 2010; Agyemang et al., 2012). The case fatality rate for stroke is high in the country partly due to weak health system and late reporting to the hospital. A study has shown that about 69% of stroke deaths in Accra occurred in less than 24 hours after the onset of the illness (Wiredu & Nyame 2001). In Kumasi, the case fatality rate of stroke was 5.7% at 24 hours, 32.7% at 7 days and 43.2% at 28 days (Agyemang et al., 2012). In addition, for stroke survivors who are being discharged from the hospital, they mostly depend on caregivers for practical and emotional support due to the physical, psychological and cognitive disabilities associated with the illness. The quality of life of such individuals deteriorates over time due to older age, stroke severity, long stroke duration, higher frequency of stroke, and negative emotions (Sampane-Donkor et al., 2014). Stroke also has serious effect on the working population because most of the stroke cases in Ghana occur around 50 years (Sanuade and Agyemang, 2013). Hence, an individual diagnosed with stroke in early years has not only lost years of productive life, but has also lost his/her means of livelihood. Coupled with this, the financial demand for managing the condition is huge.

The burden of stroke on caregivers is also high and this reduces their quality of life. Studies have shown that the burden of caring for stroke survivors is high due to the level of physical, cognitive, and behavioural disabilities of stroke survivors and availability of social support (Lauren et al., 2011; Cameron et al., 2011). Caregivers also experience loss of income due to job absenteeism, adjustment of work schedules, and reduced work hours as a result of care responsibilities. This may place a huge 'double financial burden' on the whole family. This double financial burden indicates that the stroke survivors may no longer be able to engage in

economic activities and even the caregivers who are supposed to work may not have enough time to work and so there is a 'two-way' blockage in household income flow. This may thereby results in reduction in the caregivers' quality of life. The implication of this is that as the caregivers' quality of life declines, the ability to provide good care for stroke survivors may also decline. This therefore places both dyads (stroke survivors and their caregivers) at risk of poor health (Ostwald et al., 2009).

Even though several studies have been conducted on stroke in Ghana (Sanuade and Agyemang 2014; Sampane-Donkor et al., 2014), there is no information on stroke prevalence and correlates at the national level. Also, there is limited information on experiences of stroke survivors and no information exists on experiences of stroke caregivers in Ghana. Further, there is no study in sub-Saharan Africa that has looked at stroke knowledge and experiences from the perspectives of the stroke survivors and their caregivers. This therefore raises important questions that this thesis intends to address.

1.4   Research Questions

  i.   What are the prevalence and correlates of stroke in Ghana?

 ii.   What is the quality of life of people living with stroke in Ghana?

iii.   What are the knowledge and experience of stroke from the perspectives of the stroke survivors and their family caregivers at the community and institution level?

1.5   Rationale of the Study

Even though the burden of stroke is rising in Ghana, there is limited information on stroke prevalence, correlates and experience. Presently, no study exists on knowledge of stroke from the perspectives of the stroke survivors and their caregivers. The few studies on stroke in Ghana had

focused on risk factors, mortality, case fatality rates, knowledge, and quality of life (Table 1.1). No study has investigated the experiences of stroke survivors and their family caregivers and stroke prevalence at the national level.

The first reason for undertaking this study is to understand the burden of stroke by providing data on prevalence and experiences of living with and caring for stroke survivors in Ghana. Understanding the experiences of stroke survivors and that of their caregivers can improve prognosis. Studies have shown that many of the people diagnosed with stroke die in the first year after the diagnosis. Plausible reasons include: stroke survivors' attitudes and lifestyles after diagnosis, poor management, lack of good follow-up plan after discharge from the hospitals; lack of proper caregiving, and; high cost of stroke management (Birabi et al., 2012; Thorogood et al., 2004; Ogungbo et al., 2005).

In many previous studies, stroke rehabilitation has concentrated largely on patient-focused interventional approaches in reducing the stroke survivor disability, but not many studies have focused on the roles of caregiving in stroke rehabilitation. Recently, there is increasing awareness of the roles that caregivers play in the long-term management of stroke survivors and how the caregiver burden can affect the health outcomes of stroke survivors in the community (Das and Hazra, 2010; Balhara et al., 2012). This means that there is need to shift focus from concentrating only on patient-focused approach to a combined patient-and caregiver-focused approach in stroke survivor rehabilitation by adopting the Innovative Care for Chronic Conditions Framework, developed by WHO (WHO, 2002; Coast et al., 2016). The Innovative Care for Chronic Conditions Framework acknowledges both the patients and their caregivers as active participants in care. This study will address this by looking at the dyadic relationship

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between stroke survivors and their caregivers in Ghana. This is because while the level of depression experienced by the stroke survivors may affect the psychosocial health of the caregivers, the reverse is also true. This interconnectedness between the stroke survivors and their caregivers therefore necessitates understanding the dynamic and multidimensional relationship between the psychosocial conditions of both the stoke survivors and their caregivers in stroke rehabilitation.

Table 1.1 Stroke research in Ghana

Themes	Authors
Risk factors	Agyemang et al., 2012 Agyei-Mensah and de-Graft Aikins, 2010 Akpalu and Nyame, 2009 Wiredu and Nyame, 2001 Acheampong, 2001
Mortality	Wiredu and Nyame, 2001 Nyame et al., 1994 Anim, 1984 Edington, 1954
Morbidity	Roberts, 1994 Obajimi et al., 2002 Bello et al., 2012 Amosun et al., 2013 Agyemang et al., 2012
Case fatality rates	Agyemang et al., 2012 Wiredu and Nyame, 2001
Rehabilitation	Hamzat and Kobiri, 2008 Bello, Oduro and Adjei, 2012
Knowledge of stroke	Sampane-Donkor et al., 2014
Quality of life	Sampane-Donkor et al., 2014

Source: Adapted from Sanuade and Agyemang, 2013

1.5.1 Significance of the study

Research has shown that in order to improve the wellbeing of individuals who are ill, it is important to understand how they conceptualise their illness in terms of: onset of the illness, its perceived causes, symptoms, duration, severity, expected consequences, appropriate treatment and anticipated outcomes (de-Graft Aikins et al., 2014; Kleinman et al., 1978). This is because

individuals' representations and experiences of illness particularly influence whether they are receptive to health information, willing to change health behaviours or adhere to medications and whether they will experience improvement in their health condition (McSweeney et al., 1997).

Understanding individuals' representations and experiences of an illness provides insight into what is most important to them, their beliefs about health and illness and what they think can get them better (Kleinman et al., 1978). Even though some studies had been done on stoke representation globally (Mshana et al., 2008; Wilson, 2010), no study had focused on patients' and their caregivers' explanations of stroke. It is important to look at this because while the health of the stroke survivors affects that of the caregivers, the reverse is also true. In addition, stroke survivors do not manage their illness in isolation, their illness practices are also being influenced by their caregivers, thus necessitates concentration on these dyads (i.e., stroke survivors and their caregivers). This study will therefore contribute theoretically to the literature by providing systematic explanations of stroke from the perspectives of the stroke survivors and their caregivers. This understanding is important as it can help improve health care quality and outcomes and bridge the gap between health professional expertise and what matters most to the stroke survivors and their caregivers.

Further, this study will be significant at several levels. Firstly, this study will be beneficial to stroke survivors and their family caregivers in Ghana by providing systematic explanations of the ways in which stroke survivors and their caregivers experience and respond to the condition. This will help to facilitate the development of practical interventions on stroke in Ghana.

This study will also provide information to fill the gap between the policy recognition of the burden of stroke in Ghana and the development and implementation of stroke policy. In

addition, this study will help to provide insights for Demography and Population Studies by detailing illness practices and coping strategies of the participants which can help to minimise stroke–induced premature mortality. This is because stroke is a major cause of mortality in Ghana and one of the key components of population change is mortality. This study will also reveal the coping strategies used by stroke survivors and their caregivers in managing the condition. Recommendations from this understanding can help to come up with measures to enhance survival and thereby minimise the morbidity from this condition.

The findings from this study will be relevant to four categories of people. Firstly, this study will be relevant to the stroke survivors and their caregivers by providing ways to minimise stroke-induced premature mortality. This study will also help lay individuals understand what they can do to prevent stroke occurrence. The third group of people is the health professionals; this study will help health professionals understand the domains of quality of life of stroke survivors to focus on in facilitating stroke rehabilitation and improvement in stroke care. This understanding may help to improve doctor-patient relationship. Finally, this study will provide useful information for policy makers to guide the development of national guidelines on stroke in Ghana.

1.6   Objectives of the Study

16.1   General objective

The general objective of this study is to understand the burden and knowledge of stroke in Ghana with a view to developing primary and tertiary prevention strategies for the illness.

1.6.2   Specific Objectives

1.   To examine the prevalence and correlates of stroke in Ghana.

2.   To examine the health related quality of life (HRQoL) of stroke survivors in Ghana.

3.   To explore the knowledge and experience of stroke from the perspectives of the stroke survivors and their caregivers in community and institutional contexts.

1.7   Study Organization

This study is divided into eight chapters. Chapter one focuses on the introduction of the study. This includes background of the study, statement of the problem, research questions, rationale of the study, significance of the study and objectives. Chapter two focuses on literature review of studies on stroke. This chapter also focuses on the theoretical and conceptual framework for the study. Chapter three provides details of the study areas and methodology. In chapter four, prevalence and correlates of stroke are provided. Chapter five focuses on the Health Related Quality of Life of stroke survivors in Ghana. In chapter six, knowledge and experiences of stroke survivors are examined. Chapter seven explores the knowledge and experience of stroke from the perspectives of stroke caregivers. Chapter eight provides summary of findings and interpretation, recommendations and conclusion.

CHAPTER TWO

LITERATURE REVIEW

2.1   Introduction

This chapter focuses on review of literature on stroke burden and identifies the gaps in literature. The review of literature focused on five broad sections: 1) prevalence and correlates of stroke; 2) stroke mortality; 3) health related quality of life of stroke survivors; 4) experience of stroke survivors, and; 5) experience of stroke caregivers. In addition, this chapter outlines the theoretical framework guiding this thesis based on a synthesis of theories and concepts used by relevant studies. Three broad categories of theories and concepts are used: 1) health related quality of life; 2) explanatory models, and; 3) biographical theories. These concepts and theories are subsumed under social determinants of health framework.

2.2   Prevalence and correlates of Stroke

Stroke prevalence, as defined earlier in chapter one, refers to the proportion of a population that is living with stroke at a point in time. In Africa, stroke prevalence generally ranged from 15/100,000 population in Ethiopia in 1988 to 963/100,000 population in Egypt in 2010. The pooled prevalence rate of stroke in Africa between 1970 and 2013 was 387.93/100,000 population. In sub-Saharan Africa, the highest stroke prevalence (500/100,000 population) was reported in Cotonou, Benin (Cossi et al, 2012) (Appendix 1). Two studies from Nigeria showed that stroke prevalence was higher among males than females (Danesi et al., 2013; Sanya et al., 2015). As at 2009, the number of stroke survivors in Africa was estimated to be 1.89 million (990,000 for males and 898,000 for females) for people aged 15 years and above (Adeloye et al., 2015). In 2010, the number of stroke survivors in Africa was estimated as 1.94 million and 2.09 million in 2013 (Adeloye et al., 2015). This indicates that there was an increase of 20% in stroke

prevalence between 2009 and 2013. Plausible reasons for the increase in stroke prevalence between 2009 and 2013 include population growth and ageing (Adeloye et al., 2015).

Further, a review of stroke prevalence in southern Asian countries showed that stroke prevalence was 900/100,000 population in Sri Lanka and 300/100,000 population in Bangladesh (Wasay et al., 2014). In India, studies have shown that stroke prevalence varied from 47/100,000 population in 1999 to 545/100,000 population in 2007 (Wasay et al., 2014). In South America, stroke prevalence reduced from 651/100,000 population in 1983-1992 to 174/100,000 population in 1994 (Saposnik et al., 2003).

The reviewed studies on stroke prevalence showed that the highest stroke prevalence (963/100,000 population) was reported in Africa. This rate is higher than the ones reported in high income countries and some other LMICs (Kaul et al., 2009; Awuah et al., 2016). Despite the relatively high rate of stroke prevalence in Africa, there is evidence of stroke under-estimation in this region because there are many non-presentations of stroke cases at the hospital (Bonita and Truelson, 2003).

Several studies have examined the correlates of stroke in SSA (Appendix 2). The most common risk factor of stroke identified from these studies was hypertension, followed by type-2 diabetes. For instance, in Ethiopia and Nigeria, hypertension accounted for 65.6% and 77.8% of stroke cases respectively (Zenebe et al., 2005; Onwuchekwa et al., 2009). A hospital-based study in Ghana showed that diabetes accounted for 26% of stroke cases (Asefa, 2010). Other correlates of stroke identified in these studies included: older age, atrial fibrillation, heart disease, dyslipidemia, high cholesterol, excessive alcohol intake, cigarette smoking, obesity, high ratio of

total to HDL cholesterol, high level of homocysteine, previous history of stroke, right intracrania stenosis, thromboembolism, and metabolic syndrome (MetS) (Appendix 2).

Based on the reviewed studies on stroke in SSA, the most common factor associated with stroke was hypertension, followed by diabetes. This is not surprising because it has been shown that about 54% of stroke worldwide is attributable to hypertension (Lawes et al., 2008), and WHO (2014) estimates show that Africa has the highest prevalence of elevated high blood pressure globally. This may explain why stroke burden is high in the region. Also, diabetes has been shown to be on the rise in SSA (Mbanya et al., 2010; Awuah et al., 2016). For instance, Awuah et al. (2016) showed that diabetes (type 2) prevalence ranged from 0.4% in a rural community in Uganda, to 26.3% in an urban community in South Africa. Consequently, minimizing stroke burden in sub-Saharan Africa demands tackling elevated blood pressure, diabetes and other associated risk factors (Mukherjee and Patil, 2011).

2.3   Stroke mortality in sub-Saharan Africa

Ten studies were retrieved on stroke mortality (Appendix 3). While many studies in sub-Saharan Africa have shown an increase in stroke mortality over time, two studies from Seychelles and Tanzania showed a decrease in trends of stroke mortality (Stringhini et al., 2012; Walker et al., 2000). The studies showed that stroke mortality varied from 1.9% in Usmanu Danfodiyo University Teaching Hospital, Sokoto (Nigeria) to 75.0% in Royal Victoria Hospital, Gambia (Njoku and Aduloju, 2004; Walker et al., 2003). With regard to the rate of death, a study in Ghana showed that majority of deaths (62.1%) which occurred within the study periods occurred within the first seven days of stroke onset (Agyemang et al., 2012).

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On the other hand, stroke mortality in Seychelles decreased from 0.25% in males and 0.14% in females in 1989-1991 to 0.14% in males and 0.09% in females in 2008-2010 (Stringhini et al., 2012). In Tanzania, stroke mortality decreased from 0.07% in males in 1992-1993 and 0.09% in females to 0.04% population in males and 0.03% females in1994-1995 (Walker et al., 2000). The two studies from Seychelles and Tanzania showed that stroke mortality was higher among males. The determinants of stroke mortality from the reviewed studies included: age (young), sex (male), low socio-economic status (SES), being a migrant, ischemic stroke, heart rate (100 bpm), age (60+), systolic BP (>160 mmHg) and fibrinogen (400 mg/dl and above) (Appendix 3).

In addition, some studies examined the case fatality rate (CFR) of stroke and different periods were examined in these studies (Table 2.3). The 7-day CFR ranged from 32.7% in Ghana to 35% in Zimbabwe (Agyemang et al., 2012; Matenga, 1997). Studies which examined 28-day mortality showed that CFR varied from 23.8% in Tanzania to 49.6% in Mozambique. Further, three-month CFR varied from 25.5% to 30% in South Africa (Mudzi et al., 2012; Wasserman et al., 2009). A community-based study in Tanzania showed that the three-year CFR was 60% (Walker et al., 2011). The predictors of case fatality rate identified from these studies include hypertension, obesity, smoking (Mudzi et al., 2012), stroke severity, hyperglycaemia, level of consciousness of the stroke survivors, presence of complications during hospitalization (Wahab et al., 2008), older age, and ischemic stroke (Longo-Mbenza et al., 2008).

Many of the reviewed studies showed high stroke mortality. This is consistent with what Feigin et al (2013) found that stroke mortality has increased significantly between 1990 and 2010 globally, and the main contributors are low-income and middle-income countries. However, studies from Seychelles and Tanzania showed decrease in stroke mortality over time. A plausible

reason for decrease in stroke mortality in Seychelles over time may be that compared to many of the other SSA countries, the programmes on non-communicable diseases in Seychelles may have been effective. As a result, this may mean that the national programme for the prevention and control of cardiovascular disease (CVD) which was launched in the country in 1991 has been effective (Gervasoni et al., 1991). Particularly, the main aim of this programme was to establish community-based program that focused on the promotion of healthy lifestyles and control of risk factors of chronic diseases in the population (Gervasoni et al., 1991). This programme had three overlapping areas of intervention: 1) Training of health workers; 2) health policies, and; 3) intervention in the population. Firstly, the program aimed at improving the knowledge of health workers on cardiovascular disease as well as providing basic medical materials (scales, mercury, sphygmomanometers, glucometers, etc) in all hospitals and clinics in the country. The provision of these medical materials was partly to ensure diabetes and hypertension control in the country. Secondly, this programme aimed at lobbying policy makers to develop health oriented policies which targeted reduction in smoking and alcohol consumption and promotion of good diet and physical activity. Thirdly, this programme intended to develop and disseminate attractive, health related education material (on diet and physical activity) on the television and other media sources; schools; clubs and working places (Gervasoni et al., 1991). Consequently, this programme may have enhanced the life expectancy of people living with stroke in this country, thereby reducing stroke mortality over time.

This review further showed decline in stroke mortality in Tanzania. It is important to note that Tanzania is one of the earliest countries where the burden of stroke was first described; it may be that the programme on Non-Communicable Diseases (NCDs) in the country has been effective in slowing down the burden of stroke. For instance, the health sector in Tanzania has included the

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prevention and control of NCDs as their main target (Metta et al., 2014); the government has also signed and approved the WHO's framework Convention for Tobacco (FCTC) in 2004, thus reducing the demand and supply of tobacco and alcohol (Halabi, 2010). Excise taxation on tobacco and alcohol has also been put in place to lower the consumption of these products (Metta et al., 2014; Osoro et al., 2001). Further, the government has introduced zero tolerance policy for drinking and driving; regulations of alcohol advertising and sponsorships, and restrictions for on- and off-premise sales of alcoholic beverages (Metta et al., 2014). A National Nutrition Strategy that seeks to ensure the nutritional status of all citizens of Tanzania throughout their life cycle is in place in the country (Tanzania Ministry of Health and Social Welfare, 2013). The decline in stroke mortality in Seychelles and Tanzania therefore indicates that with effective programmes on NCDs being initiated and implemented in sub-Saharan Africa, the rising levels of stroke can actually be halted.

2.4   Health related quality of life of stroke survivors

Health Related Quality of life (HRQOL) is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997; Oort, 2005; Meeberg 1993). This definition focuses on the subjective approach of quality of life (QoL) and it is based on the realist view that posits that there is no objective reality beyond our subjective experiences. This means that "perception is reality" or "life is how one perceives reality" (Milgram et al., 1995). Consequently, measuring the HRQoL of stroke survivors using their subjective experiences is a good way to adequately capture their HRQoL.

There are many definitions of HRQoL globally (Farquhar, 1995). These include: global definition; component definitions; research-specific definitions; focused definitions; and combination definition (Farquhar, 1995). Global definitions are general definitions which omit the possible components of HRQoL. Component definitions break down HRQoL into different domains considered necessary to measure HRQoL. Further, research-specific definitions are tailored to meet the objective of a particular study. Focused definitions refer to just one domain, or a minority of components of HRQoL. Finally, combination definitions include the global definitions and the domain specific aspect of HRQoL. Even though different definitions of HRQoL of stroke survivors had been used in different studies globally, all of these definitions measured the subjective wellbeing of individuals living with stroke; these studies generally showed that the impact of stroke on HRQoL is multifaceted and the highest impact is in the physical domain (Owolabi and Ogunniyi, 2008).

Studies which have explored the relationship between the HRQoL of stroke survivors and healthy individuals showed that stroke survivors had poorer HRQoL than healthy individuals. For instance, a comparative study by Owolabi (2011) showed that stroke survivors in Nigeria and Germany had poorer HRQoL in the physical, psycho-emotional (the state of the mind), cognitive and ecosocial interaction domains compared to healthy individuals. However, stroke survivors had better HRQoL in the spiritual domain in the two study sites. Plausible reason for high HRQoL of stroke survivors in the spiritual domain is that religious beliefs play pivotal role in re-establishment of continuity of self, self-rediscovery and self-rejuvenation after stroke (Owolabi, 2011). In addition, Hackett et al. (2000) showed that in New Zealand, stroke survivors had poorer HRQoL than healthy individuals. Another study in Turkey showed that HRQoL was poorer for stroke survivors than healthy individuals (Gokkaya, 2005).

On the other hand, one study in the United States showed that the HRQoL of the stroke survivors was comparable with that of the healthy individuals (King, 1996). This indicates that many of stroke survivors in the study area were probably coping well with the disabilities of stroke. The relatively high HRQoL reported by King (1996) is consistent with other studies in the United Sates and Sweden that showed that many long-term stroke survivors were satisfied with their lives (King, 1996).

Further, results on the determinants of HRQoL of stroke survivors are inconclusive partly because of the different measures used in assessing this concept. In some studies, age (Rochette et al., 2001; Sturm et al., 2004), sex (Carod-Artel et al., 2000), dependency on activities of daily living, lack of social support (Carod-Artel et al., 2000), depression (Sturm et al., 2004; Carod-Artel et al., 2000; Suenkeler et al., 2002), and diabetes (Rochette et al., 2001; Sturm et al., 2004)) have been associated with poorer HRQoL. Studies from Nigeria showed that functional status of stroke survivors, depression, and lack of social support from family members were determinants of HRQoL of stroke survivors (Abubakar, 2012 Hamza, 2014; Owolabi, 2008). In addition, a study from the United States also showed that depression, low social support, lower functional status, presence of cardiovascular disease, younger age and unemployment were determinants of poorer HRQoL (King, 1996). Further, in New Zealand, Hackett (2000) showed that HRQoL was poorer for women, older patients, and those with poor functional status. This study contradicts that of King (1996) with reference to age. While King (1996) showed that HRQoL was poorer for those in the young age groups, Hackett (2000) showed that HRQoL was poorer for older patients. These contradictory findings may be due to different measure of HRQoL used for different context in which this was examined.

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2.5   Experience of stroke survivors in sub-Saharan Africa

The experience of stroke survivors focuses on the management of the illness and the coping strategies employed by stroke survivors (Appendix 4). With regard to stroke management, a study in South Africa showed that nearly all of the studied population managed stroke by seeking allopathic health care (seeking medical practice that aims to combat stroke by use of remedies such as drugs or surgery which produce effects different from those produced by the stroke being treated) (Thorogood et al., 2004). In addition, the study showed that 40.8% of the stroke survivors healer-shopped (the sequential use of a range of treatments within and across medical systems) from traditional healers and churches. The five studies which focused on stroke survivor experience showed that the factors that impede stroke management in Africa included: limited resources, lack of organised stroke unit, lack of neuro-imaging facilities, health seeking behaviour of survivors, cost of treatment, non-adherence to medications, difficulties with access to drugs and lack of equipment to measure the blood pressure of the survivors.

The only study which examined the cost implication in stroke management in SSA showed that an average of N95,100 (approximately $600) in the government hospitals and N767, 900 ($4,845) in a private hospital were required to access care within the first 36 weeks of post stroke affectation in Nigeria (Birabi et al., 2012). However, one study in Tanzania showed that the beliefs of patients with respect to the best treatment informed patients' management practices more than cost of care (Mshana et al., 2008).

The reviewed studies on stroke survivors' experiences showed that stroke management is poor in sub-Saharan Africa. The first challenge in ensuring appropriate stroke management was shortage of drugs (Thorogood et al., 2004). Many of the drugs needed for stroke treatment were not

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available at the health clinics (Thorogood et al., 2004). Coupled with this, many of the stroke patients in South Africa and Nigeria could not afford the drugs (Bryer et al., 2010; Birabi et al., 2012). For instance, one of the reviewed studies showed that the cost of stroke treatment, especially in private hospitals was too high for an average Nigerian (Birabi et al., 2012). These high costs may have forced some of the stroke survivors to seek help from traditional healers and churches. It has been shown that a larger proportion of the direct cost incurred in stroke management is spent on physiotherapy; an amount that is too high for people who live on per capital income of less than \$2 per day (Bryer et al., 2010). Further, stroke units are not well developed in sub-Saharan Africa and this has implications for proper stroke management at the institutional level. For instance, neuro-imaging centers are very few and access to these facilities is limited by cost and distance (Thorogood et al., 2004; Ogungbo et al., 2005). In addition, there are few neurologists in the region which means many of the patients are being attended to by non-Neurologist and general practitioners and this leads to poor stroke prognosis. Further, multidisciplinary rehabilitation team management is difficult in sub-Saharan Africa because of dearth of paramedical staff, physiotherapists, occupational therapists and stroke nurses (Ogungbo et al., 2005).

Another factor which impedes proper stroke management in sub-Saharan Africa is the cultural beliefs of the patient. Some of the stroke patients in South Africa had the beliefs that stroke can be cured and as a result healer shopped within the ethnomedical and faith healing systems (Thorogood et al., 2004). This belief system has also been reported in the study of Ghanaian diabetes experiences (de-Graft Aikins, 2007). This study showed that some of the people living with diabetes who had the belief that their diabetes could be cured persistently healer shopped between ethnomedical and faith healing systems. de-Graft Aikins (2007) however observed that

those who mainly have these beliefs were those who lived in rural areas, had low income and were recently diagnosed with diabetes or experienced acute disruption. Other studies in Africa have shown that healer shopping within ethnomedical systems is the primary and dominant response for chronically ill people in Africa (Green, 1992; Kirby, 1993; Nkwi, 1994; de-Graft Aikins, 2005).

2.6 Experience of Stroke caregivers in sub-Saharan Africa

Two studies (one study from Nigeria and one from South Africa) focused on the experience of stroke caregivers (Appendix 5). The study showed that stroke caregivers experienced anxiety, depression, caregiving burden (the strain or stress of providing care which impact on the well-being of caregivers), poor physical health (difficulty with sleep, inability to rest well and experience of pain, discomfort and fatigue), poor social relationships and low environment quality of life domains (QOL) (Fatoye et al., 2006; Gbiri et al., 2015). The factors associated with poor caregivers' psychosocial condition include low socio-economic status, older age of stroke survivors, depression of stroke survivors, closer intimacy with stroke survivors, few number of caregivers for stroke survivors, long duration of caregiving and high number of hours of caregiving per day. The study from Nigeria showed that high quality of life of stroke caregivers was associated with intimate relationship with survivor, female gender of caregivers, longer duration of caring, higher education of survivor and higher age of survivors (Fatoye et al., 2006).

The two studies which examined the experience of stroke caregivers showed that caregivers experienced anxiety, depression, caregiving burden, poor physical health, poor social relationship and low environment quality of life. This review showed that there is limited

information on experiences of stroke caregivers in SSA. However, global studies have generally shown that stroke caregivers experience poor psychosocial conditions such as anxiety, depression, fear, worry, pain, stress, financial burden, inability to work, reduction in work output, restrictions in social activities and social isolation. Many of the studies outside sub-Saharan Africa showed that the poor psychosocial condition of the caregivers is predicted by the characteristics of both the stroke survivors and their caregivers (Cameron et al., 2010; Ostwald et al., 2009).

The stroke survivor characteristics which determine poor psychosocial conditions of stroke caregivers include: functional and cognitive status; slow improvement in condition; poor psychosocial state, and; co-morbidity of hypertension and diabetes and dementia (Cameron et al., 2010; Thommessen et al., 2002). On the other hand, the caregivers' factors include: knowledge on caregiving; availability of social supports (Secrest, 2000; Pierce et al., 2004); and poor physical health (Cameron et al., 2011); younger age; preparation for caregiving responsibilities; high level of mutuality with stroke survivors (Ostwald et al., 2009); low education (Family Caregiver Alliance, 2011); lack of collaboration with health care team, intensity of caregiving role (White et al., 2007), and; amount of hours of providing care (Lutz et al., 2011). In essence, stroke caregivers may have little choice but to take on the roles of caregiving and depending on the severity and impact of stroke, such roles could be for a short or long period of time. These additional roles can be a source of burden for caregivers who have to fulfil their 'normal roles' as well as provide care for a stroke survivor.

2.7 Gaps identified from stroke studies in sub-Saharan Africa

Even though several studies had been done on the burden of stroke in sub-Saharan Africa, the following information is still missing in the literature. Firstly, the reviewed studies showed that there is no information on nationally representative data on stroke prevalence and correlates in SSA; this limits country generalization. Secondly, there is limited information on HRQoL of stroke survivors in SSA and only one study has been done on HRQoL in Ghana. Thirdly, there are limited data on stroke experience with regard to impact of stroke on stroke survivors and coping strategies employed by stroke survivors. Further, there is limited information on the experience of stroke caregivers with respect to impact of stroke, coping strategies, and psychosocial conditions. In addition, there is no study that has examined the experiences of stroke survivors and their caregivers in a single study. This study intends to fill all these gaps.

2.8 Theoretical Framework

2.8.1 Introduction

This thesis draws on three different theories and concepts: 1) Health Related Quality of Life (HRQoL); 2) Explanatory models, and; 3) Biographical theories. These concepts and theories are subsumed under the social determinants of health framework. Social determinants of health therefore formed the overarching basis within which these concepts and theories are being examined. The concept of HRQoL provides the basis for understanding the impact of stroke on the stroke survivors and their caregivers. Explanatory models reveal how people perceive, experience and cope with their illness. Finally, biographical theories provide explanations on post-diagnosis experiences from the perspectives of the stroke survivors and their caregivers.

2.8.2 Social determinants of health

According to the World Health Organization, social determinants of health (SDH) are the conditions in which people are born, grow, work, live, and age and the fundamental drivers of these conditions (WHO, 2015). The social determinants include: 1) Social context such as: economic policies and systems, development agendas, social norms, social policies and political systems and other resources at global, local and national levels, and; 2) individual characteristics such as: income and social status, education, physical environment, social support networks, genetics, health services, sex, etc.

The social context creates social stratification and assigns individuals to different social positions. These social positions engender differential exposure and vulnerability to the risk or causes of an illness. Exposure to risk therefore determines the likelihood of living with the illness. Living with a particular illness has social and economic consequences. While the social consequences focus on the individual's seclusion from the society, the economic consequences focus on inability to work as well as cost of health care. These consequences depend on the extent of disability from the illness and on society's environment and social policies. The social and economic consequences may further feed back into the etiological pathways and contribute to the further development of disease in an individual or they can cause reduction in the socio-economic status of an individual (Figure 2.1). The process by which the social and economic consequences feeds back to the development of disease in an individual or reduce the socio-economic status of an individual will be explained by the concept of Health Related Quality of Life (HRQoL) and the biographical theories.

Figure 2.1 Social determinants of health
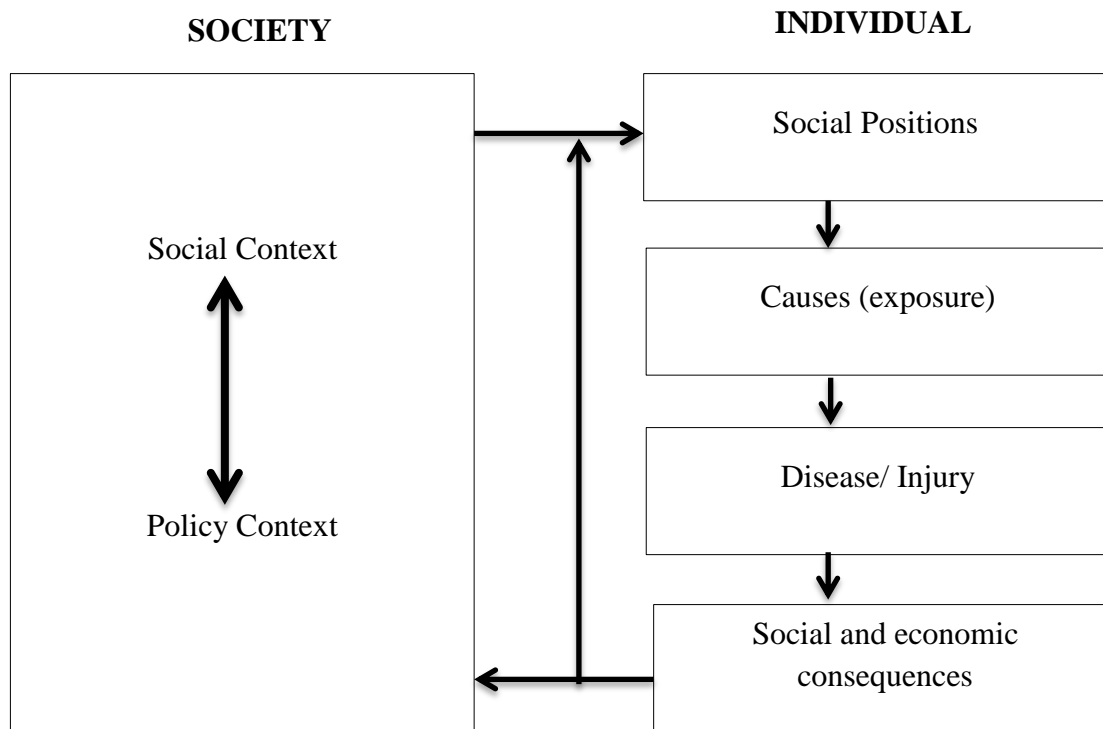
Source: Diderichsen et al (2001)

2.8.3 The concept of Health Related Quality of Life

According to the World Health Organization, Quality of life (QoL) is defined as "individuals' perception of their positions in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1998). It also refers to a person's subjective well-being and life satisfaction which includes mental and physical health, material well-being, interpersonal relationships within and outside the family, work and other activities in the community, personal development and fulfilment of active recreation (Vincent-Onabajo et al., 2013).

Health Related Quality of Life (HRQoL) has been widely used in the literature and it is a concern for policymakers, researchers and health practitioners (Bakas et al., 2012). This concept

is commonly conceived as dynamic, subjective and multidimensional. The different domains of HRQoL include physical, functional, social, psychological, spiritual, and environment (Sampane-Donkor et al., 2014; WHO, 1997). Research has shown that there is no unified measure of HRQoL in the literature; this therefore makes comparison across studies difficult.

The concept of Health Related Quality of Life has been used to determine the multifaceted impact of disease in a population (Sampane-Donkor et al., 2014; Owolabi and Ogunniyi, 2009). It can be used as a measure for assessing post-stroke outcomes from the perspectives of an individual living with this illness. Also, knowledge of HRQoL can help to improve patient care (Bakas et al., 2012). Health Related Quality of Life can be used to indicate areas of need for supportive interventions for a stroke survivor. Since there are different treatments available for stroke, HRQoL can help clarify harms and benefits of a treatment. Adequate understanding of this concept among stroke survivors is necessary for stroke rehabilitation. Studies have also shown that HRQoL is an effective concept that can be used to determine the probability that an individual will survive a particular illness (Montazeri, 2009).

Research has shown that measures of HRQoL could be generic or disease-specific (Owolabi and Ogunniy, 2009). While generic measures assess and compare HRQoL across different populations or different diseases, disease-specific measures are designed to assess HRQoL with questions and scales that are specific to a disease or population. Examples of generic HRQoL include SF-36, EuroQol and World Health Organization Quality of Life (WHOQoL-BREF) (Sampane-Donkor et al., 2014; WHO, 1998). Among the generic measures of HRQoL, WHOQoL is the most culturally sensitive because it was developed as a measure that can be used to assess the quality of life in different cultures. This measure assesses the individual's

perceptions in the context of their culture and value systems, and their personal goals, standards and concerns (WHO, 1998). The WHOQoL has six (6) different domains. These domains include: physical health, functional, psychological, social relationships, environment (economic circumstances), and spirituality/religion/personal beliefs. In this thesis, WHOQoL will be used as a measure of HRQoL. The domains that will be examined include physical, functional, psychological, social, environment and overall QoL.

2.8.4   Explanatory models

An explanatory model reveals how people make sense of their illness. It emphasizes understanding of an illness from the perspectives of an individual. According to Kleinman (1980), individuals' explanations of illness are shaped by how they perceive, experience and cope with the illness (Kleinman, 1980). Explanatory models are often used to explain how people view their illness in terms of: how it happens (illness onset); what causes it and how it affects them (causal theories of illness and illness complications), and; what will make them feel better (illness actions) (Kleiman, 1980; de-Graft Aikins et al., 2014).

With regard to the causal theories of illness and illness complications, Moscovici (1961/1976) suggests that people draw on different sources of knowledge in making sense of their illness. He used the concept of 'cognitive polyphasia' to explain the sources, content and functions of knowledge (de-Graft Aikins, 2003). In the cognitive polyphasia model, even though individuals are seen to have a large 'degree of agency' over their ideas, they do not think alone. Provencher (2011) used the concept of 'social individuals' to emphasize that individuals do not produce ideas, knowledge and beliefs in isolation, but these are developed through interpersonal interactions and communication. de-Graft Aikins (2003) has used the concept of cognitive

polyphasia in the analysis of diabetes experience in Ghana and mentioned that some of the sources and content of knowledge that people draw on in making sense of their illness are: common sense knowledge, scientific knowledge and scientized knowledge. She referred to common sense knowledge as a knowledge that is rooted within the socio-cultural explanations of health, illness, life and death. This knowledge is drawn from social observations and interactions. de-Graft Aikins (2003) referred to scientific knowledge as technical biomedical knowledge that is used in the domain of specialist medical practice alone and is used by medical practitioners during clinical encounters with patients. Scientized knowledge (or practical biomedical knowledge) was defined as 'simplified technical themes used in public health campaigns and during clinical encounters to inform lay people and patients on appropriate methods of health maintenance, the nature of diseases, treatment profiles and self-care' (de-Graft Aikins, 2003).

Further, the concept of explanatory models emphasized that people engage in different practical routines in order to cope with their illness; this is referred to as 'illness action'. Illness action is therefore a form of coping strategy that an individual adopts in dealing with the disruption caused by a chronic illness. Charmaz (1987) explained that individuals with chronic illness do not remain in the permanent position of not doing anything about the 'loss of self' and 'loss of participation in social life' which results from a chronic illness; rather, individuals actively look for ways and means to reconstruct their lives. These ways and means constitute the practical response to lessen the impact of a chronic illness. The concept of illness action has been used by de-Graft Aikins (2003) in the study of experiences of people living with diabetes in Ghana. de-Graft Aikins (2003) used the concepts of 'healer-shopping' (the sequential use of a range of treatments within and across medical systems) and 'dual-use' (the simultaneous use of different treatments) to indicate the different forms of illness actions of individuals. In addition, de-Graft

Aikins (2003) mentioned that prolonged disruption of an illness may lead to 'illness inaction (not doing anything to treat the illness).

In this thesis, the concept of explanatory models is used to understand: stroke onset; causal theories of stroke and stroke complications; sources of the causal theories (common sense, scientized, indigenous religious beliefs), and; illness actions (practical routines individuals engage in to cope with stroke).

2.8.5 Biographical theories

Studies have shown that stroke is an illness that people live with over time. As a result, there are physical, cognitive, psychological, emotional and behavioural consequences involved. The immediate post-diagnosis process of psychological adjustment for stroke shifts to a long-term process of adjustment and adaptation (Carel, 2007). Medical sociologists and social psychologists have developed a number of useful concepts that can help explain chronic illness experiences over time. These concepts focus on the changes in the biography of an individual living with a chronic illness and how the illness experience influences the relationship such individual has with his/her social world.

Theorists have suggested that the biographical impact of chronic diseases can take one or more of four courses: biographical disruption, biographical transformation, biographical reinforcement and biographical flow. Biographical disruption theory was developed by Michael Bury in 1982 and the theory focused on people living with rheumatoid arthritis. The theory of biographical flow, developed by Faircloth et al. (2004) focused on people living with stroke. Biographical transformation was developed by Charmaz (1983) and the theory was developed from the study of different chronic conditions including: cardiovascular disease, cancer, diabetes, multiple

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sclerosis and lupus erythematosus. Finally, Carricaburu and Pierret (1995) developed the theory of biographical reinforcement and their study focused on men living with HIV.

2.8.5.1 Biographical disruption theory

Bury (1982) introduced the concept of biographical disruption to describe the way in which chronic illness can disrupt the physical body and the life trajectory of the sufferer. Bury (1982) sees chronic illness as a major kind of disruptive experience or critical situation that disrupts the structure of everyday life and the forms of knowledge that underpins them. He identified three aspects of disruption that can result from chronic illness. The first aspect of disruption is called 'the disruption of taken-for-granted assumptions and behaviours'. This is a situation where an individual with chronic illness is down with the shock of 'what is going on'. This occurs as a result of the sudden change in the bodily state to which such individual is not familiar with.

The second aspect of the disruption is when an individual with chronic disease begins to re-think his/her biography and self-concept because of the profound disruptions that is being experienced. The third aspect of disruption comes in the form of how to mobilize resources in facing the altered situation. These resources can be cognitive (sympathy from friends, neighbors and work places) and/or material (financial and physical support from friends, neighbours and work places).

The concept of biographical disruption has been used to explain illness experiences of people living with diabetes and other chronic diseases in Ghana (de-Graft Aikins, 2003; Tagoe, 2012). For instance, de-Graft Aikins (2003) showed that diabetes disrupted the lives of individuals in five areas: body-self (interrelationship between the physical and psychological body such as weakness, dizziness, sexual dysfunction, headaches, persistent wounds and physical disability);

social identity (the negative impact of weight loss, social perceptions of chronic illness sufferers as witches, and the impact of physical disability); personal agency (the role of the body-self in fulfilling social and work roles); economic circumstance (loss of earning and increased expenditure due to high cost of pharmaceutical drugs), and; nutrition (adoption of recommended diet changes prescribed by health practitioners).

On the other hand, Tagoe (2012) distinguished between direct and indirect cost of chronic disease. While the direct cost focused on the healthcare expenses incurred in the management of the chronic illness, indirect cost was conceptualised as the disruptions an individual experiences as a result of living with a chronic disease. Tagoe (2012) found that chronic diseases disrupt the economic activity of individuals with chronic diseases (and their caregivers) and many of them had to rely on household members, friends and social groups for support. The two studies identified the interrelated disruptions of chronic disease and the need for social support in managing this condition.

2.7.8.2 Theory of biographical flow

This theory was developed by Faircloth et al. (2004) and the aim was to find out whether experience of stroke is a biographical disruption or not and whether the onset of stroke is part of an ongoing 'biographical flow' of the person. The authors argued that a sudden illness like stroke does not always serve as a disruptive event, but may become part- and parcel of an individual's biography.

The first theme Faircloth et al. (2004) looked at focuses on stroke as a normal component of age. This indicates that the stroke, as a sudden event, may not suddenly disrupt the life of an individual, but instead fit into the social clock of such individual. For instance, old age provides

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a framework by which stroke can be seen as something to be expected. Based on this framework, an elderly individual with chronic illness may normalise the illness as 'part-and -parcel of the old age experience'.

Faircloth et al. (2004) discussed the role of pre-existing knowledge of stroke in minimizing the biographical disruption. This means that if a stroke survivor has pre-existing knowledge of stroke, he/she becomes familiar with the effects and impact of the illness on daily life and activities. In essence, the direct effects of stroke are not constructed as life altering; rather, they give meaning within 'a social context that places narrative importance on other challenges and social contingencies'. Also, they noted that having a social relationship with others who have survived stroke provides a useful way of understanding and expecting changes in the body that occur after stroke which in the long run helps to minimize the biographical disruption. In essence, previous knowledge of stroke may reduce depression or psychological stress that comes with stroke and this may make an individual move from the disruptive state to making the illness become part-and-parcel of life.

2.8.5.3 Biographical transformation

Charmaz (1983) explained that many people living with chronic illness experience 'loss of self'. This is a situation where an individual with chronic illness frequently experience 'a crumbling away of their former self-images without simultaneous development of equally valued new ones'. As a result of the loss of self, Charmaz (1983) explained that individuals living with chronic illness suffer from: 1) living restricted lives; 2) social isolation, and; 3) becoming a burden to others.

Living restricted lives is a situation where people living with chronic illness experience restrictions in their day-to-day activities compared to other adults, due to the disruptions which result from the illness. Charmaz et al. (1983) see social isolation as loss of self as well as a consequence of living a restricted life. As chronically ill individuals no longer participate in shared activities such as work, community organizations and leisure activities such as games, sports, etc, earlier friendships reduce over time and this leads to social isolation. The feeling of isolation by such individual may be compounded by experiences of being discredited, embarrassed, ignored or devalued by relatives, friends or others. The sense of becoming a burden comes into play when people living with chronic conditions lose hope and experience loss of recapturing positive-images of the past (Charmaz, 1983). This involves becoming more dependent and immobilised. This dependence may not be limited to physical, but can also be economical, psychological, emotional, etc.

According to Charmaz (1983), even though individuals living with chronic illnesses suffer from living restricted lives, experience of social isolation, and, becoming a burden to others, those who see improvement in their condition can experience biographical transformation. For those who experience improvement in their conditions, such periods become the foundation for re-evaluation and change of self. Their illness therefore becomes a tool of self-discovery and a fundamental source of later self-development. These kinds of people are those who have had several events of serious illness in the past but later improved. Charmaz (1983) explained that such individuals speak of earlier crises as periods of time when they were free from the ordinary bonds of routine existence. This freedom consequently heightens the consciousness of who they are and who they wished to become.

2.8.5.4 Theory of biographical reinforcement

The theory of biographical reinforcement was developed to explain how post-diagnosis biographical reconstruction may reinforce previously-existing components of identity. With regard to the experience of the People Living With HIV (PLWH), Carricaburu and Pierret (1995) found that many of these people were disturbed by the illness because of the difficulty in keeping it a secret. Managing the secret of living with HIV formed the basis for which they re-organised their lives. Since the immune status of the participants was not directly seen, they could decide whether or not to reveal their status to others. This secrecy was built upon the stigma on AIDS. Some of the participants therefore kept their illness as a secret because they did not want to lose their jobs, be pitied or hurt those they loved.

Further, Carricaburu and Pierret (1995) found that being HIV positive brought uncertainty about the future. Hence, management of the illness was determined by how the PLWH interpreted the illness, age of infection, and causes of infection. These people experienced changes in their biography and so the ability to continue living necessitates fitting their immune status into their biographies. Being HIV-positive was therefore seen as a biographical disruption. In an attempt to mobilise resources in managing the illness, the PLWH had to depend on their significant others. Carricaburu and Pierret (1995) found that the reason why mobilization of resources was important to these people was because they need to re-organise their everyday lives and increase their capacity to deal with an uncertain future.

In order to gain control of their lives, the PLWH developed coping strategies for the illness such as: development of new eating habits, vitamin therapy, psychotherapy or even spirituality. All these kept them from being passive and helped them take responsibility for themselves so as to

go on living like everyone else. Even though many of them lost their jobs due to their condition, they became inventive and took on personal jobs. They adopted several strategies to keep some control over their lives. They see this as a way to project their lives into the future rather than being taken prisoner by the illness. This helped them to live well with this illness. The introspective work they did about their life stories allowed them to approach the new life with meaning. In this way, they tried to find new identity and continuity in their biographies. This is what Carricaburu and Pierret (1995) called "biographical reinforcement".

2.9 Conceptual framework for burden of stroke in Ghana

This thesis uses the concept of social determinants of health as a framework for understanding the concepts of HRQoL, explanatory models and biographical theories. A conceptual framework was developed based on these (Figure 2.2). Based on social determinants of health, several variables have been shown to determine health; these are referred to as social positions. The correlates of stroke examined in this thesis include: 1) socio-demographic factors such as: sex, age, place of residence, marital status, level of education, wealth status, religion, current work status, and ethnicity; 2) lifestyle behaviours such as: smoking, alcohol consumption, physical activity, and body mass index; 3) co-morbidities such as hypertension and diabetes.

Social positions can determine exposure to the risk of stroke. For instance, socio-demographic factors determine to a great extent one's risk of stroke. With regard to sex, research has shown that the risk of stroke is higher in men than in women (Kengne and Anders, 2006). An explanation for this is that hypertension prevalence, which is the most common risk factors of stroke, is higher in men than in women. Increasing age has been shown to be associated with stroke. Specifically, two-thirds of all strokes occur in people older than 65 years (Feigin et al.,

2014). In Ghana, the risk of stroke also accelerates after the fifth decade of life. Education has been shown to be associated with stroke. Stroke prevalence is higher among those with low level of education at lower ages, however, beyond age 75 years, stroke rate is higher among those with higher education (Avendano et al., 2006). A plausible explanation for this is that a higher proportion of stroke survivors with low education may have died before getting to age 75 years. Similarly, higher education correlates with longer life expectancy among persons with higher education hence contributing to a higher proportion of stroke cases beyond age 75 years.

The relationship between wealth and stroke is inconclusive. Some studies have shown that stroke is higher among those with higher wealth status because they have access to resources that predispose them to risky behaviours leading to stroke (Kaplan and Keil, 1993). Other studies have argued that even though those with higher wealth status are more likely to engage in risky behaviours leading to stroke, they are also the first to respond to health messages and recognize more quickly that their lifestyles are not conducive to a healthy life (Cox et al., 2006; Engels et al., 2014). Those with higher wealth status also have more resources to change their risk.

Lifestyle behaviours such as smoking, alcohol consumption, obesity and lack of physical activity have been shown to be major risk factors of stroke. This indicates that engagement in these behaviours creates different exposure and vulnerability to the risk of stroke. For instance, strong relationship exists between alcohol intake and stroke (Emberson et al., 2006). The risk of stroke in those who smoke tobacco is about 2-4 times the risk of non-smokers (Shah and Cole, 2010). Obesity can also increase the risk of stroke because of the inflammation caused by excess fatty tissue (Kurth et al., 2002). Co-morbid conditions such as hypertension and diabetes have been

seen as major causes of stroke. Specifically, studies have shown that hypertension is the leading cause of stroke in Ghana, followed by diabetes (Sanuade and Agyemang, 2013).

After stroke diagnosis has been confirmed, individuals involved are confronted with many challenges that they have to deal with in their everyday lives due to the changes in their biographies. These challenges start from the immediate reaction of the stroke survivors and their caregivers after the stroke diagnosis. The immediate post-diagnosis reaction may go a long way in determining the illness action adopted by the stroke survivors and their caregivers in managing the condition (Carricaburu and Pierret, 1995). The concept of HRQoL shows that the impact of stroke can be multifaceted. Stroke can affect an individual in the following areas: physical health, functioning ability, social, psychology and economic circumstances. HRQoL therefore shows how self-perception of health mediates experiences and illness action.

Further, as stroke survivors experience change in bodily state, limitations in their daily activities or reduction in HRQoL, the desire to get back to their 'former self' may drive them to seek different forms of treatment. This may even be encouraged by the stroke caregivers in their desire to re-work the biographies of the stroke survivors to the former self. In addition, the sudden nature of stroke may generate problem of uncertainties; a situation where stroke survivors and their caregivers are unsure of the stroke prognosis. At this stage, medical knowledge becomes important because it will help the stroke survivors and their caregivers understand the condition and provide guidance on how to re-adjust the 'critical situation'. Also, Faircloth et al. (2004) explained that pre-existing knowledge and interactions with people who have survived stroke can help to minimise these uncertainties.

The theory of biographical flow is used to explain whether stroke survivors and their caregivers move from the disruptive state of the stroke condition to making the condition become part- and parcel of their biography. This explanation is predicated on stroke survivors' and their caregivers' knowledge on stroke causes, prevention and complications. This is because if there is adequate knowledge on stroke, stroke survivors and their caregivers may become familiar with the effects and impact of the disease on daily life and activities. They may also become familiar with appropriate treatment to seek in managing the condition. This may therefore help them in moving from seeing stroke as a disruptive event to making the illness become part of their lives and activities.

While it is possible for some of the stroke survivors and their caregivers to only see stroke as a biographical disruption, for others, the stroke condition can fit into their social blocks (biographical flow). Some of the stroke survivors may also experience a transformation of life in a positive way (biographical transformation) because of improvement in their condition. Moving beyond this, some of the stroke survivors and their caregivers may go through periods of introspection about their life stories and try to find new identity and continuity in their biographies (Carricaburu and Pierret, 1995). These kinds of people will refuse to be victim of the illness but will rather determine to gain control of their lives and will experience "biographical reinforcement". Moving from the disruptive state to biographical flow, or biographical transformation or biographical reinforcement therefore depends on stroke severity, age, sex, cultural beliefs, pre-diagnosis knowledge, prior experience of another condition as well as the resources available to an individual. These resources can be: psychological (e.g cognition, emotions, advice), material (e.g money, food, access to healthcare, purchase of pharmaceutical

drugs, etc), and symbolic (metaphysical understandings in terms of an individual's personal meanings of life, death and the unknown) (Faircloth et al., 2004).

In conclusion, the findings from this study will provide understanding on whether stroke disrupts individual biography, or; whether both the stroke survivors and their caregivers allow the illness to fit into their social block, or; whether the illness experience allows the stroke survivors and their caregivers re-interpret their individual and collective pasts. This understanding will help to come up with ways on how to move from the disruptive state of the illness to minimising stroke-induced premature death.

Figure 2.2 Conceptual framework showing determinants of stroke and experiences of stroke survivors and their caregivers

Source: Author's construct
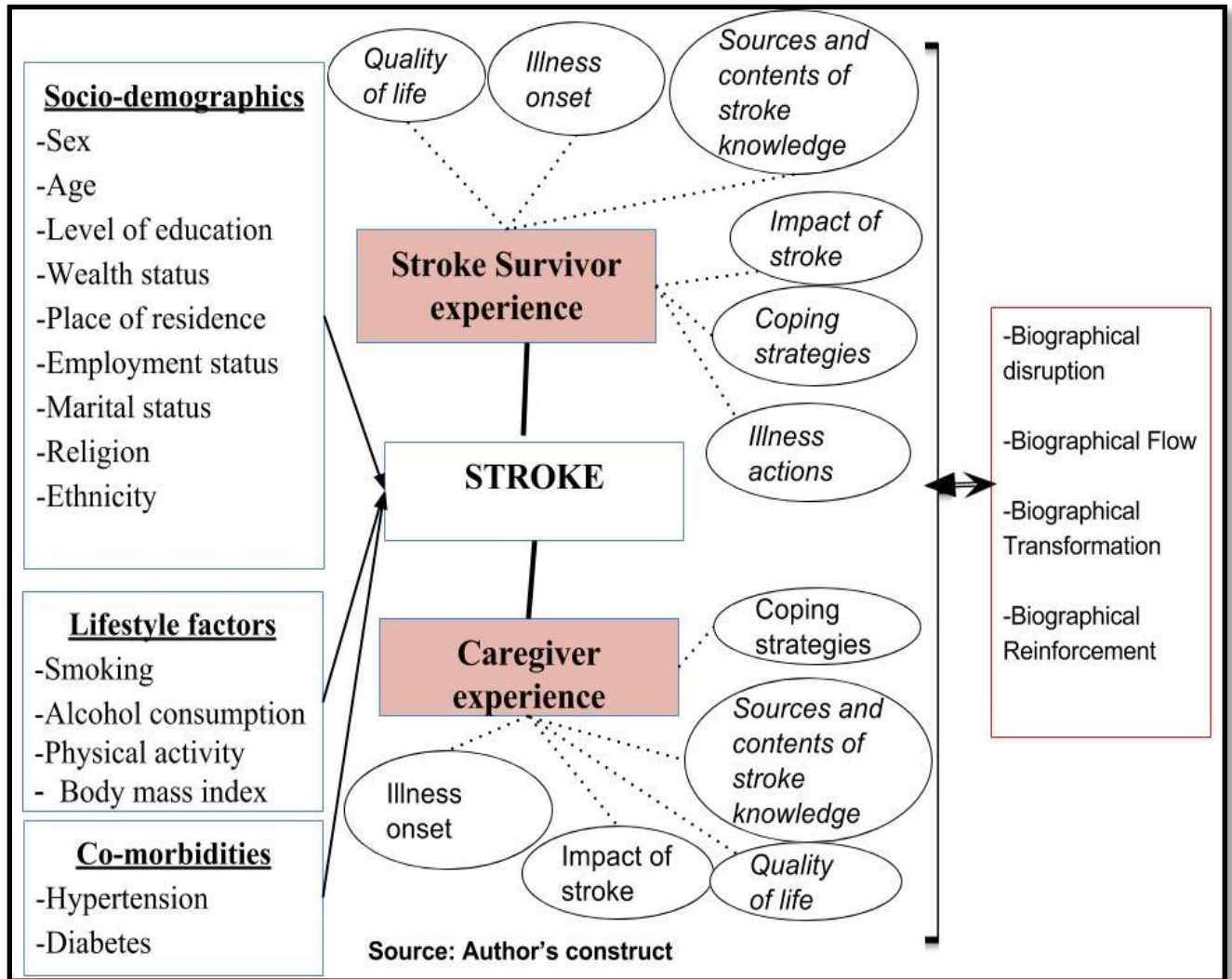
CHAPTER THREE

METHODOLOGY

3.1   Introduction

This chapter gives details of the methodology of the study. This will cover: study area, study design, data and methods, and methods of data analysis. The quantitative methodology is discussed first and this is followed by the qualitative methodology.

3.2   Study Design

This study adopted a triangulation, mixed-method approach (quantitative and qualitative) (Cresswell et al., 2003). The quantitative part used the World Health Organization (WHO) Survey on Global Ageing and Adult Health (SAGE) data while the qualitative part of the study made use of interviews collected in two urban poor communities in Accra (James Town and Ussher Town) and Korle-Bu Teaching Hospital (Stroke Unit and Physiotherapy Unit).

3.3   Quantitative Data

3.3.1   Study Area: Ghana

The 2010 Population and Housing Census showed that Ghana had a population of 24,658,823, and a larger proportion (51.2%) were females (Ghana Statistical Service, 2013). The sex ratio is 95.2 males per 100 females. There are ten regions in the country (Figure 3.1). Out of the ten regions in the country, the most populous is Ashanti Region, which made up 19.4% of the total population; this is followed by Greater Accra (16.3%) and the least populated region is Upper West (2.8%). With regard to the age structure, 38.3% of Ghana's population is less than 15 years; 49.5% are 15-49 years, and; 12.2% are aged 50 years and above (GSS, 2013). Further, a

little over half of the populations (50.9%) is living in urban areas (GSS, 2013). More than 70% were Christians, 17.6% were Muslims, 5.2% were traditional religious worshippers and 5.3% did not have any religious affiliations. In terms of occupation, a larger proportion was engaged in agricultural related activities. Specifically, 41.2% of the economically active population is made-up of skilled agricultural, forestry and fishery workers; about 21% is also engaged as service and sales workers while 15.2% is craft and related trade workers.

Figure 3.1 Map of Ghana showing the region of study location
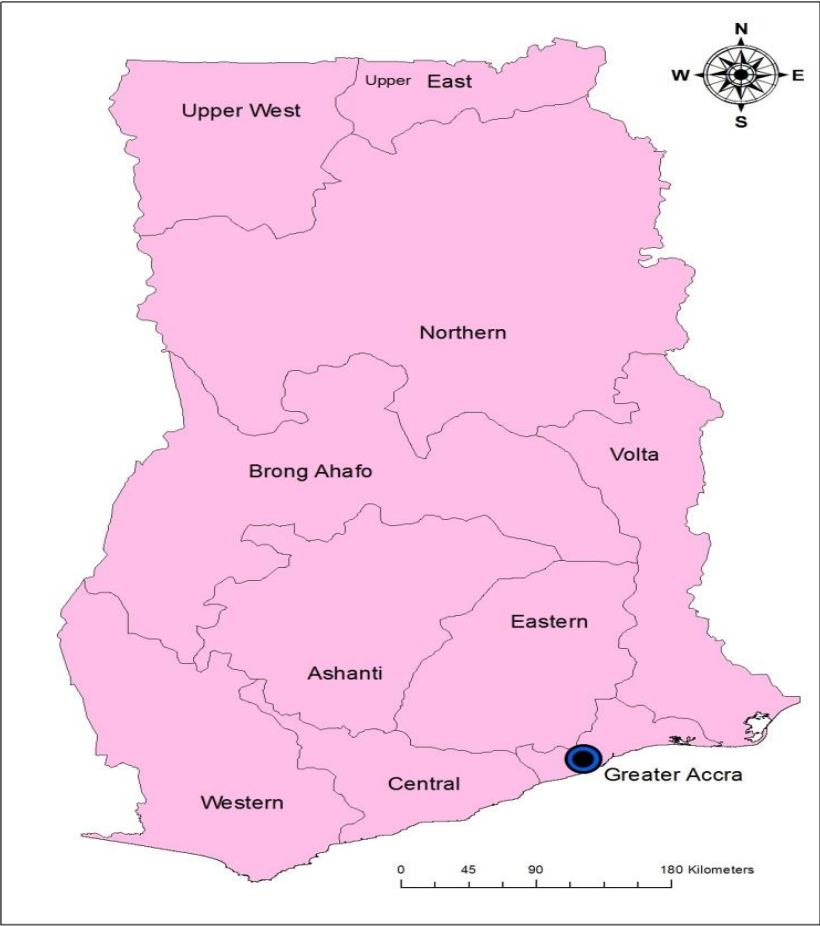
Ghana is a lower-middle income country with average per capita income of GH¢5,347 (about US$1,353) (Ghana Statistical Service, 2014). The health system is structured to mainly treat infectious diseases (de-Graft Aikins, 2007). The health care system in Ghana faces inadequate investment in health system and health workforce generally. The health spending as a percentage of GDP was 5.4% in 2013 (WHO, 2016), higher than the WHO recommendation of 5% (WHO, 2003).The most recent statistics indicate that there are three teaching hospitals (Korle-Bu in Accra, Komfo Anokye in Kumasi and Tamale Teaching Hospital); 9 regional hospitals; 96 government hospitals; and 1106 health centres and clinics (Ghana Health Service 2010). In terms of the distribution of health professionals, there are 2,033 medical officers, 24,974 nurses, 1,129 pharmacists and 41 health research officers. The doctor population ratio was 1:11,929 and the nurse to population ratio was 1:971 (Ghana Health Service 2010).

3.3.2 Data

The study retrieved data from the Wave 1 of the World Health Organization (WHO) survey on Global Ageing and Adult Health (SAGE) conducted between 2007 and 2008. The sample size was 4,279 respondents aged 50 years and above.

3.3.3 Sampling design

Ghana SAGE Wave 1 used a stratified, multistage cluster design which was based on the design for the World Health Survey (Biritwum et al., 2013), and this was nationally representative. The primary sampling units were stratified by administrative region (Ashanti, Brong Ahafo, Central, Eastern, Greater Accra, Northern, Upper East, Upper West, Volta, and Western) and type of locality (urban/rural). Based on this, a total of 20 strata were developed (Biritwum et al., 2013; Minicuci et al., 2014). From each of the strata, a total of 10-15 Enumeration Areas (EA) were

selected according to the population size. Household listings were done for each selected EA. Twenty households with persons aged 50 years and above and four households with persons aged 18-49 years were then selected for interview (Biritwum et al., 2013). All persons aged 50 years and above in 'older' households (households with at least one person aged 50 years and above) were invited to participate, whereas only one person was randomly selected in 'younger' households (households with no person aged 50-plus years). Further, for those who were incapable of completing an interview for reasons of health or cognition, a proxy questionnaire was completed (Biritwum et al., 2013). Standardized training in all aspects of the interview was provided to all interviewers. The questionnaires were translated into respective local languages, following a translation protocol, and modified to take into account the local context where needed (Minicuci et al., 2014). The interview response rate was 86% (Biritwum et al., 2013).

3.3.4   Measures

3.3.4.1 Stroke

Those who had been diagnosed of stroke and /or had ever suffered from sudden onset of weakness in arms or legs and/or experienced loss of feeling on one side of the body, for more than 24 hours were regarded as stroke survivors. The prevalence of stroke in this study was determined as the proportion of Ghanaians aged 50 years and above who had been diagnosed with stroke or had ever suffered from sudden onset of weakness in arms or legs and/or experienced loss of feeling on one side of the body, for more than 24 hours, between 2007 and 2008.

3.3.4.2 Hypertension

Respondents who had been diagnosed with hypertension, and/or had the mean of the three blood pressure (BP) measurements to be 140mm/g and above, and/or diastolic BP of 90mm/g and above, were regarded as people living with hypertension.

3.3.4.3 Physical activity

Physical activity was measured as the number of days respondents spent doing moderate-intensity activities like sports, fitness, or recreational leisure activities. This was re-categorized into three namely: not physically active; partially active (those who engaged in physical activities less than 3 times a week) and; fully active (those who engaged in physical activities 3 or more times a week.

3.3.4.4 Smoking and alcohol consumption

Two questions were used to categorize smoking status. These included whether the respondents had ever smoked and if they currently smoke. These were recategorized into: non-smokers, previous smokers and current smokers. Those who responded 'No' to the two questions were referred to as 'non-smokers'; those who responded 'Yes' to ever smoked and 'No' to currently smoking were referred to as 'previous-smokers' and; those who responded yes to the two questions were categorised as 'current smokers'. Alcohol consumption was divided into three categories: non-drinkers (those who have never consumed alcohol), occasional drinkers (those who take alcohol once in a while), and; regular drinkers (those who take alcohol regularly).

3.3.4.5 Body mass index

BMI was categorized according to WHO criteria (34): BMI < 18.5, underweight; BMI = 18.5–24.99, normal weight; BMI = 25–29.99, overweight; and BMI ≥ 30, obese.

3.3.4.6 Chronic diseases

The co-morbid conditions examined in this study were: diabetes, angina and arthritis. The question asked concerning these was whether the respondents had been diagnosed with any of these conditions. The responses were "Yes" and "No".

3.3.4.7 Other independent variables

The other independent variables included in this study were: sex, age, place of residence, marital status, level of education, wealth status, religion, employment status and ethnicity (Table 3.1).

Table 3.1 Measurement of other independent variables

Variable	Categories
Age	50-59 years; 60-69 years; 70-79; 80+
Sex	Male; female
Place of residence	Rural; urban
Marital status	Never married; currently married; separated/divorced; widowed
Level of education	No education; primary; secondary; higher
Wealth Quintiles	Poorest; poorer; middle; richer; richest
Religion	No religion; Christianity; Islam Traditional
Employment status	Employed; not employed
Ethnicity	Akan; Ewe; Ga-Adangbe; Gruma; Grusi; Mande Busanga; Mole Dagbani; Others

3.3.4.8 Health related quality of life

Health Related Quality of Life (HRQoL) was measured using 33 items. This scale was divided into five different domains and two individually scored items on stroke survivors' overall perception of quality of life and health. Thirty-one (31) items were used to construct the five domains and they were scaled in a positive direction with higher scores indicating higher quality of life. The scores for each of the items ranged from 1 to5 (Table 3.2). The domain scores were transformed (based on WHOQoL scoring) into a scale of 0 to 100, with 0 indicating worst health and 100 best health (WHO, 1997).

The quality of life domains examined were: physical health, functional, psychological, social relationship, environment and overall quality of life (Table 3.2 and 3.3). The physical health domain was computed using four items. These included whether respondents have enough energy for everyday life; how satisfied the respondents were in their ability to perform their daily living activities; how often they felt that they were unable to control the important things in their lives, and; how often they have found that they could not cope with all the things that they had to do. The questions which assessed the functioning abilities of the stroke survivors centered on how much difficulty an individual had in doing the activities listed in Table 3.3. The item score ranged from 1 to5 with higher scores indicating high functioning ability.

The psychological domain was computed using two questions. This domain focused on how satisfied respondents were with themselves and whether the respondents were happy with the way they are these days. One question was used in computing the social relationship domain and this focused on how satisfied respondents were in their relationship with other people. The environment domain focused on whether respondents thought they have enough money to meet

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their needs and how satisfied they are with the conditions of their living place. The overall

quality of life focused on how satisfied respondents were with their health and how they would

rate their quality of life.

Table 3.2 Scoring domains of the quality of life (QoL)

Domains	Direction of scaling	Raw domain score	Raw item score
Overall Quality of Life and General Health 1. How would you rate your quality of life?	-(reverse)	2-10	1-5
2. How satisfied are you with your health	-(reverse)		1-5
Physical Health 1. How satisfied are you with your ability to perform your daily living activities?	-(reverse)	4-20	1-5
2. Do you have enough energy for everyday life?	-(reverse)		1-5
3. How often have you felt that you were unable to control the important things in your life?	-(reverse)		1-5
4. How often have you found that you could not cope with all the things that you had to do?	-(reverse)		1-5
Psychological 1. How satisfied are you with yourself?	-(reverse)	2-10	1-5
2. Taking all things together, how would you say you are these days?	-(reverse)		1-5
Social Relationship 1. How satisfied are you with your personal relationships?	-(reverse)	1-5	1-5
Environment 1. Do you have enough money to meet your needs?	-(reverse)	2-10	1-5
2. How satisfied are you with the conditions of your living place?	-(reverse)		1-5

3.3.4.9 Transformation of scale scores

Since the raw domain scores differ for each of six domains of HRQoL, comparison becomes

difficult. In order to address this, it is important to transform the raw domain scores so as to

make them comparable. The first step involved in the transformation of the scale was that a raw

score was calculated for each facet and each domain. After this, each raw score was transformed to a 0-100 scale using the formula below:

$$\text{Transformed Scale} = \frac{\text{Actual raw score} - \text{lowest possible raw score}}{\text{Possible raw score range}} * 100$$

Where "Actual raw score" is the value achieved through item summation; "lowest possible raw score" is the lowest possible value that could occur through item summation, and; "Possible raw score range" is the difference between the maximum possible raw score and the lowest possible raw score. This transformation converts the lowest and highest possible scores to zero (0) and 100, respectively.

Table 3.3 Scoring of the functional domain Quality of Life

S/N	Items	Direction of scaling	Raw domain score	Raw item score
1	Sitting for long periods	-(reverse)		1-5
2	Walking 100 metre	-(reverse)		1-5
3	Standing up from sitting down	-(reverse)		1-5
4	Standing for long periods	-(reverse)		1-5
5	Climbing one flight of stairs without resting	-(reverse)		1-5
6	Stooping, kneeling or crouching	-(reverse)		1-5
7	Picking up things with fingers (such as coin from a table)	-(reverse)		1-5
8	Taking care of household responsibilities	-(reverse)		1-5
9	Joining community activities (festivals, religious) in the same way as anyone else	-(reverse)		1-5
10	Extending arms above shoulder level	-(reverse)		1-5
11	Concentrating on doing something for 10 minutes	-(reverse)	22-110	1-5
12	Walking a long distance such as a kilometer	-(reverse)		1-5
13	Bathing/washing whole body	-(reverse)		1-5
14	Getting dressed	-(reverse)		1-5
15	Day to day work	-(reverse)		1-5
16	Carrying things	-(reverse)		1-5
17	Moving around inside home	-(reverse)		1-5
18	Eating (including cutting up food)	-(reverse)		1-5
19	Getting up from lying down	-(reverse)		1-5
20	Getting to and using the toilet	-(reverse)		1-5
21	Getting where one want to go, using private or public transport if needed	-(reverse)		1-5
22	Getting out of home	-(reverse)		1-5

3.3.5   Methods of data analysis

3.3.5.1 Stroke prevalence and correlates

Descriptive statistics such as frequency tables and means were used to describe the socio-demographic characteristics of the respondents (age, sex, level of education, wealth status, place of residence, marital status, religion, ethnicity, and employment status); lifestyle behaviours (smoking status, alcohol consumption status, level of physical activity and BMI status) and; co-

morbidities (hypertension and diabetes). At the bivariate level, cross tabulations and Chi-Square tests were used to determine the variation in stroke by the socio-demographic characteristics, lifestyle behaviours and co-morbidities. Further, binary logistic regression was used to examine correlates of stroke in Ghana.

3.3.5.2 Health related quality of life of stroke survivors

Descriptive statistics were used to present the socio-demographic characteristics of the stroke survivors and that of the other elderly. After this, t-tests and one-way ANOVA were used to examine the factors associated with each of the HRQoL domains. A multiple linear regression was used to examine the determinants of each of the HRQoL domains.

3.4   Qualitative data

The quantitative data focused on what happened at the broader level in Ghana with regard to prevalence and determinants of stroke and quality of life of stroke survivors. On the other hand, the qualitative data explored the lived experiences of stroke survivors and their caregivers in two communities in Accra and Korle-Bu Teaching Hospital, Accra, Ghana. While the quantitative data provided explanations on the factors that predisposed individuals to stroke, the qualitative data provided explanations on post-diagnosis experiences from the perspectives of the stroke survivors and their caregivers.

3.4.1   Research design

Based on the nature of the empirical and theoretical questions of the study, the individual interview was used to explore stroke experiences from the perspectives of the stroke survivors (and family caregivers). This focused on the source and content of knowledge on stroke causes, risk factors, complications and prevention. The stroke experiences focused on the stroke

survivors and caregivers' discussion of how the illness started; immediate reaction when diagnosed with stroke; impact of stroke; health seeking behaviour, and; coping strategies/social support. A four-week participant observation was also conducted in order to understand the structure of treatments at the Physiotherapy and Stroke Units, KBTH. Two weeks were spent at each of the Units and this provided context for the interviews that were conducted at these Units.

3.4.2   Study areas

There were two broad study areas: Ga Mashie (James Town and Ussher Town) and Korle-Bu Teaching Hospital.

3.4.2.1 Ga Mashie

Ga Mashie is located on the Atlantic Coast of the Greater Accra Region of Ghana. The area is referred to as Old Accra because it is the place where the original Ga ethnic group first settled. This makes Ga Mashie the oldest community in Accra (Mahama et al. 2011). Ga Mashie, constituting James Town and Ussher Town, covers an area of 100 hectares along the southwest coast of Accra. Ga Mashie is home to the Ga people who speak the Ga language. The Ghana Statistical Service reports that the population of Ga Mashie to be about 125,000 (GSS, 2010). The population of Ga Mashie has grown rapidly and it is currently one of the most densely populated communities in Accra (GSS, 2010). The population growth has been attributed to natural growth and in-migration (Quartey-Papafio, 2006).

Participants were recruited from Ga Mashie because the community is characterised by low income, low level of education, lack of access to improved sanitary facilities, low access to healthcare services and double burden of communicable and non-communicable diseases (AMA-UN-Habitat 2011). There is also evidence of high prevalence of hypertension and diabetes in this

community (Awuah et al., 2014; de-Graft Aikins et al., 2014). An analysis of longitudinal data gathered by the Regional Institute for Population Studies, University of Ghana, with support from the Secretariat of the African Caribbean and Pacific Group of States – ACP-EU Cooperation Programme in Higher Education (EDULINK) and IDRC, from 2010 to 2013, showed that Stroke prevalence in Ga Mashie has increased from 0.4% in 2010 to 2.3% in 2013. Further, while the average monthly income in Greater Accra is GHC544 (US$138.43), the average monthly household income in Ga Mashie is GHC126.13 (US$32.09) (GSS, 2008; AMA-UN-Habitat 2011). Three-quarters of the population have attained up to Junior High School (or middle school) education and above (de-Graft Aikins et a., 2014).

The current livelihoods in Ga Mashie are based on different small scale economic activities with fishing being a major source of livelihood. There are few schools in these communities. The water and power supplies are in deplorable state and the area is characterised by poor sanitation conditions and poor housing structures. Drainage is virtually non-existent, with existing drains being frequently choked with solid waste. The Korle Lagoon, which borders the community to the west, is contaminated with sediments, especially garbage. Government has made effort to dredge the lagoon through the Korle Lagoon Ecological Restoration Project (KLERP). However, this project has stalled and the environmental pollution caused by the lagoon is enormous (Mahama et al., 2011). The number of educational institutions set up to serve the community is not enough compared to the population. There are about three quarters of the population who have attained up to Junior High School (or middle school) education and above. Most of the schools are in deplorable state and inadequate facilities to support the numbers of students (de-Graft Aikins, 2014).

Many of the Ga Mashie residents have low access to healthcare services (AMA-UN-Habitat 2011). There are two government-run clinics in these communities: 1) Ussher Polyclinic, and; 2) James Town Maternity Home. Ussher Polyclinic deals with all manner of cases, from malaria, complex deliveries, to sex education. James Town Maternity Home, on the other hand, deals exclusively with maternity and post-natal cases. Both public facilities, which are managed by the Accra Metro Health Directorate, face serious resource challenges. In addition, there are four privately run clinics (Sea View Clinic, Cathedral Clinic, Post Office Clinic and Charlton Clinic), two chemist's shops (Ansong Chemist and St. Michael's Chemist) and four pharmaceutical stores (Jamestown Pharmacy, Bukom Pharmacy, Dart Pharmacy and Sea View Pharmacy), in these communities. Major medical cases from these health centres are referred to the Korle-Bu Teaching Hospital, which is less than one kilometre from the western border of Ga Mashie (Mahama et al., 2011).

3.4.2.2 Korle-Bu Teaching Hospital

The Korle-Bu Teaching Hospital is the primary health care facility in Ghana. It is the largest tertiary hospital in Ghana and it is also a teaching hospital affiliated with the medical school of the University of Ghana. The hospital was founded in 1923 as the Gold Coast Hospital and it is located in Accra. The then Governor, Gordon Guggisberg laid the foundation for Korle-Bu Hospital in 1921, and it was finally opened on 9th October, 1923. The hospital has expanded in phases and now has 1,600 beds. Three centres of excellence, the National Cardiothoracic Centre, the National Plastic and Reconstructive Surgery and the Radiotherapy Centre are all located within it. In 2007, funded by the World Bank and the Ministry of Health, Ghana the standby power system to Korle-Bu was replaced after three years of no central backup supply. The expanded system of 3mVA provides power to the whole of Korle-Bu Hospital and was opened

by the Minister of Health, Major Courage Quashigah (retd) and Mr G Asiedu of G&J Technical Services on June 6, 2007.

Participants were recruited from two units at Korle-Bu Teaching Hospital (Physiotherapy and Stroke Units). The rationale for choosing hospital as part of the recruitment site is because it is expected that the experiences of stroke survivors and caregivers from the hospital will be different from those in the communities. Those from the hospital may have more serious stroke condition compared to those in the communities. In addition, it is expected that those at the Stroke unit will probably have more serious complications compared to those at the Physiotherapy unit. This is because many of the stroke cases at the Stroke Unit are acute in nature; many of the people admitted in this Unit are unable to restrain natural discharges or evacuations of urine or faeces. Some of the patients in this unit are on oxygen and are unconscious. Further, while none of the stroke survivors who came for physiotherapy at the Physiotherapy Unit was admitted at the hospital, many of those at the Stroke Unit were on admission. This indicates that some of the caregivers for those from the Stroke Unit have to sleep around the hospital to provide care for their care recipients.

3.4.3   Sample and sampling strategy

Due to the nature of the study population, purposive and snow-ball sampling strategies were adopted. Stroke survivors (and their family caregivers) were recruited from two communities in Accra (James Town and Ussher Town) as well as Korle-Bu Teaching Hospital (KBTH), Accra (Physiotherapy and Stroke Units). Some of the participants recruited from the Physiotherapy Unit were interviewed in their houses because of lack of time at the hospital. The houses were located in: Dansoman, Korle Gonno, Spintex and Mamprobi (Figure 3.2). Respondents were

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included in the study once they give their informed consent. The process involved reading the general information about the study and potential benefits/risk (in the consent form) to people with stroke in the research community (see Appendix 3). The consent form also outlined the rights of participants including confidentiality and the right to withdraw from the study or from answering a question. Participants gave their verbal consent before starting the interviews and this was tape-recorded. Further, for two of the stroke survivors from Ga Mashie (R4 and R5-Appendix 4) who could not talk, their caregivers were interviewed. A total of 22 stroke survivors and 29 caregivers were recruited in this study (Table 3.4). Further, out of this number, seven stroke dyads (stroke survivors and their corresponding caregivers) were recruited from Ga Mashie and Physiotherapy Unit while two stroke dyads were recruited from the Stroke Unit (Table 3.4).

Figure 3.2 Map of Accra showing the study areas
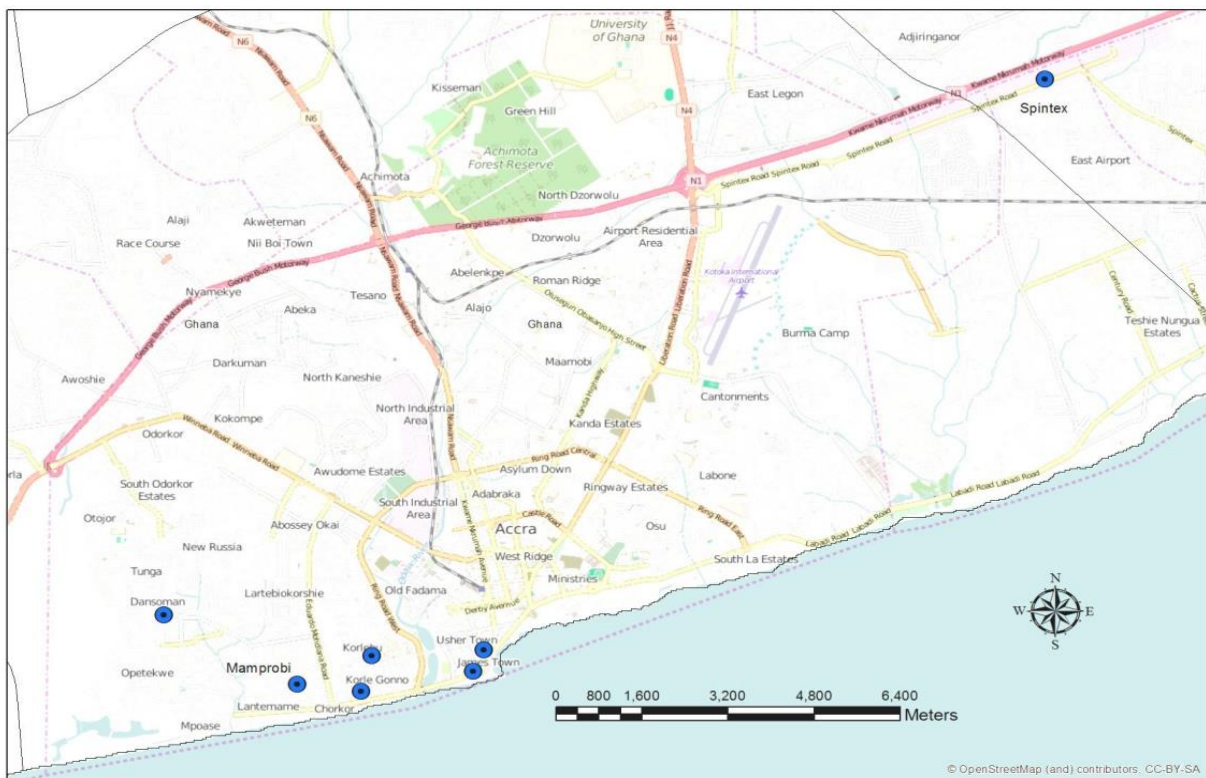
Table 3.4 Number of interviews completed

Study Sites	Number of Interviews		
	Stroke Survivors	**Caregivers**	**Dyads**
Ga Mashie	8	8	7
Physiotherapy	9	10	7
Stroke Unit	5	11	2
Total	**22**	**29**	**16**

Note: Dyads refer to stroke survivors and their corresponding caregivers

3.4.4   Data collection/data collection tool

The fieldwork was carried out between March 2014 and December 2015. This period can broadly be categorized into three. The first part of the data collection took place between March, 2014 and May, 2014. The aim of this was to pilot the interview guide at Ga Mashie (James Town and Ussher Town) to see how valid the instrument was. Pilot participants were recruited into the main study because of limited number of people living with stroke condition. Eight (8) stroke survivors and eight (8) caregivers were interviewed in the two communities. Two interview guides were developed for stroke survivors and their family caregivers (Appendices 6 and 7) . The interview guide for the stroke survivors and that of their family caregivers was divided into 5 broad sections. The key areas are presented in Boxes 3.1 and 3.2. Detailed interview guides are presented in appendix 1 and 2. Ethical approval was provided by the Ethics Committee for the Humanities (ECH), University of Ghana.

Box 3.1 Key interview areas for people living with stroke

(1) General life history
(2) Nature of illness experience, management and health seeking behaviour
(3) Stroke self-care
(4) Knowledge of chronic diseases
(5) Sources and content of health, illness and medical pluralism

Box 3.2 Key Interview areas for family caregivers of stroke survivors

(1) General life history
(2) Nature of coping strategies
(3) Knowledge of chronic diseases
(4) Impact of stroke
(5) Sources and content of health, illness and medical pluralism

Three research assistants helped in the data collection. Each of the research assistants helped at each of the three sites (Ga Mashie, Physiotherapy Unit and Stroke Unit). The one who assisted in Ga Mashie was fluent in English and 4 local languages (Ga, Twi, Ewe and Hausa). The second and third research assistants who worked during data collection at Physiotherapy Unit and Stroke Unit respectively were fluent in English, Twi and Ga. All the research assistants received training on the interview guide so that they could get familiar with the questions. All the interviews at the community except one was conducted in Ga, This was because the communities were predominantly Ga. The last interview was conducted in Twi because the stroke survivor was Akan. About half of the interviews at the Physiotherapy Unit and Stroke Unit were conducted in local languages (Twi and Ga) and the rest were conducted in English language.

3.4.5   Transcribing and translating

The interviews lasted between 45 minutes and 2 hours. All the interviews were transcribed verbatim into English by a team of transcribers with Ga, Twi and English competence. The transcription was done between July and September, 2015.

3.4.6   Data analysis

For the qualitative data analysis, the data were analysed using the thematic approach (Attride-Stirling, 2001) with the aid of Atlas ti. The first stage in the analysis was to develop low-

inference descriptors by recording and transcribing the interviews. After this, the transcripts were read in order to gain familiarity with the text. The next stage was the coding process where codes were attached to unit segments of a record. The importance of this was to provide structure and conceptual clarity to the analysis process. A mix of deductive and inductive codes was employed. The deductive codes were derived from the theoretical framework and previous studies on chronic illness in Ghana (de-Graft Aikins, 2003, 2005; de-Graft Aikins et al., 2014; Tagoe, 2013). The inductive codes included unexpected themes that emerged from the transcripts. Using the principle of constant comparison, the emerging themes were compared against each other to describe the depth and coverage of themes across transcripts. A coding frame describing the relationship between codes and frequency was generated to explore the knowledge and experience of people living with stroke as well as that of their family caregivers. Linkages to existing models and concepts were drawn by comparing and contrasting results with similar studies in order to establish consensus, conflict and absence (Hsieh & Shannon, 2005). In addition, thematic networks were also constructed to show the relationship between basic themes, organising themes and the global themes.

CHAPTER FOUR

PREVALENCE AND CORRELATES OF STROKE IN GHANA

4.1   Introduction

This chapter examines the prevalence and correlates of stroke in Ghana. The factors explored in this chapter include socio-demographic characteristics (age, sex, level of education, wealth status, place of residence, marital status, religion, ethnicity, and employment status); lifestyle behaviours (smoking status, alcohol consumption status, level of physical activity and BMI status) and; co-morbidities (hypertension and diabetes).

The results in this chapter are presented at three levels. The socio-demographic characteristics, lifestyle behaviours and co-morbidities are presented using descriptive statistical analyses procedures. After this, the variation in stroke prevalence by the socio-demographic/economic characteristics, modifiable risk factors and co-morbidities are presented using cross-tabulations and Chi-Square tests. The determinants of stroke are examined using binary logistic regression.

4.2   Individual characteristics

4.2.1   Socio-demographic characteristics of respondents

The socio-demographic/economic characteristics of the respondents are shown in Table 4.1. The respondents' age ranged from 50 to 114 years with an average age of 64.3 years (SD=10.7). More than one-third (39.3%) were 50-59 years, 38.0% were 60-69 years and the least proportion (9.9%) was 80 years and above. More than half (52.3%) were females, and close to 60.0% lived in the rural areas. The highest proportion was currently married (56.8%), more than one-fourth (27.9%) were widowed and the least proportion (1.2%) were never married.

Further, more than half (55.0%) had no education and about one-fifth (19.9%) had tertiary

education. With regard to wealth status, almost equal proportions were in the middle, richer and

richest categories (20.0%, 20.2% and 20.1% respectively). More than six out of ten (68.7%) were

Christians, about 16.0% were Muslims and 5.0% had no religion. In terms of the employment

status, close to 70% were working. The largest proportion (48.8%) was Akan, followed by Ga-

Adangbe (10.4%), and the least proportion (1.0%) was Grusi.

Table 4.1 Percentage distribution of the respondents by socio-demographic/economic characteristics

Characteristics	Number (n=4279)	Percentage
Sex		
Male	2043	47.7
Female	2236	52.3
Age Group		
50-59	1682	39.3
60-69	1197	28.0
70-79	975	22.8
80+	425	9.9
Place of residence		
Rural	2531	59.2
Urban	1748	40.8
Marital status		
Never married	50	1.2
Currently married	2431	56.8
Separated/divorced	606	14.1
Widowed	1192	27.9
Level of education		
No education	2362	55.2
Primary	891	20.8
Secondary	173	4.1
Higher	853	19.9
Wealth status		
Poorest	852	19.9
Poorer	842	19.8
Middle	854	20.0
Richer	868	20.2
Richest	863	20.1

Table 4.1 continued

Characteristics	Number (n=4279)	Percentage
Religion		
No religion	214	5.0
Christianity	2939	68.7
Islam	673	15.7
Other	453	10.6
Employment status		
Not working	1325	31.0
Working	2954	69.0
Ethnicity		
Akan	2052	48.8
Ewe	289	6.9
Ga- Adangbe	436	10.4
Gruma	215	5.1
Grusi	42	1.0
Guan	65	1.5
Mande Busanga	63	1.5
Mole Dagbani	105	2.5
Others	939	22.3

Source: Computed from SAGE survey data, 2008

4.2.2   Lifestyle behaviours

The lifestyle behaviours of the respondents are shown in Table 4.2. The Table shows that while more than seven out of ten (74.2%) had never smoked, 13.3% and 12.5% were previous and current smokers respectively. More than 40% had never consumed alcohol, 28.5% were occasional consumers and 30.1% were regular consumers of alcohol. While a large proportion were not physically active (86.5%), 5.2% were partially active and 8.3% were fully active.   With regard to the BMI status, more than half of the respondents (51.8%) had normal BMI, close to one-fifth (19.6%) were underweight and 28.6% were overweight or obese.

Table 4.2 Percentage distribution of respondents by Lifestyle Behaviours

Lifestyle behaviours	Number (n=4279)	Percentage
Smoking Status		
Non smoker	3166	74.2
Current smokers	533	12.5
Previous smokers	570	13.3
Alcohol consumption status		
Non consumer	1773	41.4
Occasional consumers	1221	28.5
Regular consumers	1285	30.1
Physical Activity		
Not physically active	3702	86.5
Partially active	224	5.2
Fully active	353	8.3
BMI Status		
Underweight	816	19.6
Normal	2157	51.8
Overweight	786	18.9
Obese	407	9.7

Source: Computed from SAGE survey data, 2008

4.2.3 Stroke prevalence and co-morbidities

The prevalence of stroke and other co-morbidities are shown in Table 4.3. The results showed that stroke prevalence was 4.6%. More than half of the respondents (57.8%) were living with hypertension and 4.2% were living with diabetes.

Table 4.3 Percentage distribution of respondents by stroke and co-morbidities

Characteristics	Number (n=4279)	Percentage
Stroke		
No	4071	95.4
Yes	195	4.6
Hypertension		
No	1804	42.2
Yes	2475	57.8
Diabetes		
No	4099	95.8
Yes	180	4.2

Source: Computed from SAGE survey data, 2008

4.3   Univariate analysis

4.3.1   Variation in stroke prevalence by socio-demographic characteristics

Table 4.4 shows the variation in stroke prevalence by the socio-demographic characteristics of respondents. The table shows that stroke significantly varied by age, place of residence, marital status, and employment status. On the other hand, stroke prevalence did not vary by sex, level of education, wealth status, religion and ethnicity. Specifically, stroke prevalence was higher among the older age groups. The prevalence of stroke among those who were 50-59 years, 60-69 years and 70-79 years were 3.2%, 5.0%, and 6.3% respectively. Stroke prevalence was significantly higher among those who lived in urban areas compared to their rural counterparts (5.8% and 3.7% respectively).

In addition, stroke prevalence was highest among respondents who had never been married and lowest among those who were currently married (10.0% and 3.6% respectively). With regard to education, stroke prevalence was higher among those with higher level of education. Concerning variation in stroke prevalence by employment status, the results showed that stroke prevalence

was significantly higher among those who were not working (9.8%) compared with those who were working (2.2%).

Table 4.4 Association between stroke and socio-demographic characteristics of Ghanaians aged 50 years and above

Socio-demographic Characteristics	Stroke		Chi-Square	df
	No	Yes		
Sex				
Male	96.0	4.0	2.974	1
Female	94.9	5.1		
Age Group				
50-59	96.8	3.2	14.901**	3
60-69	95.0	5.0		
70-79	93.7	6.3		
80+ (RC)	95.1	4.9		
Place of residence				
Rural	96.3	3.7	10.115**	1
Urban	94.2	5.8		
Marital status				
Never married	90.0	10.0	13.757**	3
Currently married	96.4	3.6		
Separated/divorced	93.9	6.1		
Widowed	94.5	5.5		
Level of education				
No education	95.8	4.2	6.308	3
Primary	94.9	5.1		
Secondary	91.9	8.1		
Higher	95.5	4.5		
Wealth status				
Poorest	96.6	3.4	4.606	4
Poorer	95.0	5.0		
Middle	95.0	5.0		
Richer	95.8	4.2		
Richest	94.8	5.2		

Source: Computed from SAGE survey data, 2008
*p<0.05, **p<0.01, ***p<0.001; df- degrees of freedom

Table 4.4 continued

Socio-demographic Characteristics	Stroke		Chi-Square	df
	No	Yes		
Religion				
No religion	97.2	2.8	6.603	3
Christianity	96.7	3.3		
Islam	94.5	5.1		
Other	96.4	3.6		
Current working status				
Not working	90.2	9.8	121.623***	1
Working	97.8	2.2		
Ethnicity				
Akan	95.0	5.0	9.971	8
Ewe	94.1	5.9		
Ga- Adangbe	94.0	6.0		
Gruma	97.2	2.8		
Grusi	100.0	0.0		
Guan	96.9	3.1		
Mande Busanga	95.2	4.8		
Mole Dagbani	95.2	4.8		
Others	96.5	3.5		

Source: Computed from SAGE survey data, 2008
*p <0.05, **p < 0.01, ***p < 0.001 df- degrees of freedom

4.3.2   Variation in stroke prevalence by lifestyle behaviours

Table 4.5 shows that none of the lifestyle behaviours was significantly associated with stroke. However, there was a pattern seen with regard to physical activity. The results showed that stroke prevalence reduced with higher level of physical activity, although this was not statistically significant. Stroke prevalence was 4.6%, 4.5% and 4.0% respectively for those who were inactive, partially active and fully active.

Table 4.5 Association between Stroke and lifestyle behaviours of Ghanaians aged 50 years and above

Lifestyle Behaviours	Stroke		Chi-Square	df
	No	Yes		
Smoking Status				
Non smoker	95.4	4.6	0.231	2
Current smokers	95.7	4.3		
Previous smokers	95.1	4.9		
Alcohol consumption status				
Non drinkers	95.5	4.5	4.41	2
Occasional drinkers	94.5	5.5		
Regular drinkers	96.3	3.7		
Physical Activity				
Not physically active	95.4	4.6	0.337	2
Partially active	95.5	4.5		
Fully active	96	4.0		

Source: Computed from SAGE survey data, 2008
*p <0.05, **p < 0.01, ***p < 0.001 df- degrees of freedom

4.3.3 Association between stroke and other co-morbidities

From Table 4.6, hypertension and diabetes were significantly associated with stroke. While 5.8%

of those living with hypertension had stroke, 16.2% of those living with diabetes had stroke.

Table 4.6 Association between stroke prevalence and health status of Ghanaians aged 50 years and above

Co-morbidities	Stroke		Chi-Square	df
	No	Yes		
Hypertension				
No	97.1	2.9	20.257***	1
Yes	94.2	5.8		
Diabetes				
No	95.9	4.1	53.583***	1
Yes	83.8	16.2		

Source: Computed from SAGE survey data, 2008
*p <0.05, **p < 0.01, ***p < 0.001 df- degrees of freedom

4.4   Correlates of stroke

Table 4.7 shows the correlates of stoke in Ghana. The Table shows that being single, being separated, not working, living with hypertension and diabetes, were the correlates of stroke in Ghana. However, lifestyle factors such as physical activity, smoking status and alcohol consumption status did not have any significant effect on stroke. Also, stroke prevalence was not significantly related to BMI status and other socio-demographic characteristics.

The results showed that those who were never married and those separated were more likely (2.8 times and 0.7 times respectively) to be living with stroke compared with those who were currently married. Those with secondary education had higher odds of living with stroke compared with those with no education (Odds Ratio= 2.303, p<0.05). In addition, those who were not working were 2.4 times more likely to be living with stroke compared with those who were currently working. Diabetes and hypertension were also factors associated with stroke. Specifically, those who were living with hypertension were 1.6 times more likely to be living with stroke while those living with diabetes were 1.9 times more likely to be living with stroke, compared with their respective counterparts.

Table 4.7 Correlates of stroke among Ghanaians aged 50 years and above

Characteristics	Odds Ratio	s.e	95% CI
Sex			
Female (RC)			
Male	1.345	0.310	0.856 - 2.113
Age Group			
50-59	1.54	0.540	0.774 - 3.062
60-69	1.708	0.562	0.896 - 3.256
70-79	1.504	0.483	0.801 - 2.821
80+ (RC)	-	-	-
Marital Status			
Currently married (RC)	-	-	-
Never married	3.837**	1.991	1.387 - 10.611
Separated	1.652*	0.419	1.005 - 2.715
widowed	1.332	0.323	0.829 - 2.141
Place of residence			
Rural (RC)	-	-	-
Urban	0.948	0.183	0.649 - 1.383
Level of education			
No education (RC)	-	-	-
Primary	1.151	0.269	0.728 - 1.820
Secondary	2.182	0.814	1.050 - 4.533
Higher	1.043	0.272	0.626 - 1.739
Wealth Status			
Poorest	1.084	0.346	0.580 - 2.027
Poorer	1.329	0.386	0.752 - 2.350
Middle	1.518	0.408	0.896 - 2.570
Richer	0.956	0.26	0.562 - 1.626
Richest (RC)	-	-	-
Religion			
No religion (RC)	-	-	-
Christians	1.499	0.716	0.588 - 3.821
Islam	1.578	0.87	0.536 - 4.648
Other	1.431	0.786	0.487 - 4.200
Employment status			
Currently working (RC)	-	-	-
Not currently working	3.444***	0.054	2.374 – 4.998

Table 4.7 continued

Characteristics	Odds Ratio	s.e	95% CI
Ethnicity			
Akan (RC)	-	-	-
Ewe	1.206	0.364	0.667 - 2.179
Ga- dangbe	1.043	0.273	0.625 - 1.741
Gruma	0.447	0.216	0.174 - 1.153
Guan	0.781	0.583	0.180 - 3.376
Mole Dagbani	0.994	0.593	0.309 - 3.200
Others	0.946	0.28	0.530 - 1.689
Smoking Status			
Non-smoker (RC)	-	-	-
Current smokers	1.182	0.331	0.682 - 2.046
Previous smokers	1.053	0.273	0.633 - 1.749
Alcohol consumption status			
Non-drinkers (RC)	-	-	-
Occasional drinkers	1.196	0.181	0.889 - 1.608
Regular drinkers	0.837	0.124	0.626 - 1.120
Physical Activity			
Fully active (RC)	-	-	-
Partially active	1.079	0.485	0.447 - 2.606
Inactive	1.022	0.317	0.557 - 1.877
BMI Status			
Normal (RC)	-	-	-
Underweight	0.73	0.171	0.461 - 1.156
Overweight	0.687	0.163	0.431 - 1.093
Obese	0.921	0.254	0.536 - 1.582
Hypertension			
No (RC)	-	-	-
Yes	2.614***	0.533	1.754 - 3.897
Diabetes			
No (RC)	-	-	-
Yes	2.863***	0.778	1.681 - 4.876

Source: Computed from SAGE survey data, 2008

RC- Reference Category   s.e.: standard error   N=4279   CI- Confidence Interval

$*p < 0.05$, $**p < 0.01$, $***p < 0.001$

4.5   Discussion

The aim of this chapter was to examine the prevalence and correlates of stroke in Ghana among people aged 50 years and above. The findings showed that stroke prevalence was 4.6%. This rate is higher than the ones reported in the reviewed studies on stroke in sub-Saharan Africa but lower than the ones reported in Brazil and Spain (Cossi et al., 2012; Boix et al., 2006; Copstein et al., 2013). The prevalence of stroke among older adults was 7.3% and 8.4% in Brazil. This study showed that being single, being employed, living with hypertension and diabetes, were correlates of stroke among older adults in Ghana.

4.5.1   Stroke and socio-demographic factors

At the bivariate level, the findings showed that stroke prevalence was highest among those who were 70-79 years, those in urban areas, those who were never married and those who were not working. At the multivariate level, employment status was the only socio-demographic correlate of stroke. Specifically, those who were not working had higher odds of living with stroke. One plausible explanation for this is that a large proportion of those with stroke probably may have stopped working as a result of the illness. This is likely because among those who were not working, the mean age at which they stopped working was 41.5 years. Further, about one-third (33.6%) of these people stopped work because of health issues or disabilities. In addition, when those who were not currently working were asked if they were looking for work, 85.5% said they were not actively looking for work. This may suggest that they were not actively looking for work probably because of the stroke. Studies have particularly shown that stroke usually comes with physical, cognitive and behavioural disabilities that limit one's ability to be independent or engage in productive activities (Lai et al., 2002).

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On the other hand, sex, age, level of education, wealth status, religion and ethnicity were not significantly related to stroke. Even though some studies have shown that stroke is associated with high socio-economic status (SES), the findings from this study show otherwise. This finding is consistent with the systematic review on stroke burden in SSA because none of the reviewed studies reported SES as a correlate of stroke. However, the finding is contrary to that of Xu et al. (2008) which showed that income was associated with stroke in rural and urban China. In addition, the study shows that stroke prevalence was higher among those in the highest and middle income groups compared to those in the lowest income group. Conversely, some studies have shown that those with lower SES are at higher risk of stroke (Cox, McKevitt, Rudd and Wolfe, 2006). An explanation for this is that those with lower socioeconomic status have inadequate access to and use of health care service that can help prevent stroke. These contradictory findings may either be as a result of the different conceptualisations of socio-economic status or different populations examined. Some studies have rather shown that socio-economic status may matter with regard to stroke management and care and not necessarily with prevalence (Birabi et al., 2012). The argument from these studies is that there is no difference between those with higher SES and those with low SES concerning exposure to the risk factors of stroke. However, these studies showed that those with higher socio-economic status have more resources to manage the condition compared to those with low socio-economic status. Many of the studies suggest that living with stroke has the tendency to drive any household into poverty due to the high cost required in the management of the illness (Birabi et al., 2012).

Age has been shown to be an important risk factor of stroke in many studies. Research has shown that the risk of stroke doubles after age 55 (American Heart Association, 2015). Even though stroke prevalence was 3.2%, 5.0%, 6.3% and 4.9% for older adults aged 50-59 years, 60-

69 years, 70-79 years and 80+ respectively, age was not significantly associated with stroke in this study. This may be because this study only considered people who were 50 years and above and so the risk of developing stroke is the same for all age groups after 50 years in Ghana. In addition, review studies in Ghana have also shown that the risk of stroke is high in the fifth decade of life (Sanuade and Agyemang, 2013).

With regard to sex, this study showed that the likelihood of stroke is the same for men and women. The finding from this study contradicts what some studies have shown (Petrea et al., 2009). Many studies have shown increasing evidence of gender-specific differences in stroke symptoms, diagnosis, treatment, and preventive interventions (Petrea et al., 2009). Two of the reviewed studies on the burden of stroke in SSA showed that stroke prevalence is higher among males than females (Danesi et al., 2013; Sanya et al., 2015). An explanation for this is the selection bias which privileges males to have higher likelihood of being admitted to the hospital due to cultural and/or financial reasons (Kengne and Anders, 2006). Another explanation is that women are more likely to use the health care services than men and therefore may have higher chance of detecting the risk factors at the earlier stage (Connor et al., 2007).

On the other hand, some studies have shown that stroke prevalence is higher among women than men (American Heart Association, 2015). Plausible explanations for this include: use of birth control pills, pregnancy, history of preeclampsia/eclampsia or gestational diabetes, oral contraceptive use, post-menopausal hormone therapy, systemic delays in the recognition and insufficient treatment of conventional stroke risk factors in women (American Heart Association, 2015; Petrea eta l., 2009). It is clear from these studies that the association between sex and stroke is inconclusive. This therefore calls for further studies, in order to fully understand the

impact of sex on stroke prevalence. This is important because recognition of gender differences may help with appropriate treatment of stroke.

4.5.2   Stroke and lifestyle behaviours

The analysis showed that none of the lifestyle behaviours was a correlate of stroke. With regard to smoking, the findings from this study contradict those of earlier studies. Many studies suggest that the risk of stroke is higher among those who smoke compared with non-smokers and previous smokers (Obiako et al., 2011; Wahab et al., 2008; Harmsen et al., 2006; Feigin et al., 2005 Myint et al., 2008). Conversely, some studies have shown that the association between smoking and stroke depends on age. A study has shown that smoking increases the risk of stroke among those who were 40-64 years. However, the risk of stroke was the same for those aged 65 years and above irrespective of whether they smoke or not (Nakayama et al., 2000). Another study reveals that while the risk of stroke for smokers was three times that of the non-smokers at age 35 years, the risk decreases with age (Boysen et al., 1988; Sha and Cole, 2010). An explanation for why this study showed no significant association between smoking status and stroke may be because this study used a cross-sectional data. Even though a study in Ashanti Region showed that current smoking is higher among the older adults (Owusu-Dabo et al., 2009), it is possible that the effect of smoking on stroke does not differ significantly after the age of 50 in Ghana. There is need for further investigations on the relationship between smoking and stroke in Ghana.

The insignificant association between alcohol consumption and stroke found in this study contradicts what others have shown. A study has shown that taking more than two alcoholic beverages a day in middle-age increases stroke risk in early old age than traditional risk factors

such as hypertension and diabetes (Kadlecova et al., 2015). Kadlecova et al. (2015) further showed that the risk of stroke for individuals who consumed more than two alcoholic drinks a day during midlife doubles between ages 60 and 75 years compared with those who consume an average of half an alcoholic drink per day. Kadlecova et al (2015) further showed that heavy drinking is a more important risk factor for stroke before age 75 years. However, the risk of stroke is more affected by hypertension and diabetes after 75 years. Other studies have shown that current but not previous alcohol consumption is a risk factor for stroke (Hillborn, Numminen an Juvela, 1999; Wolf, Abbott and Kannel, 1991; Hart, 1992). However, some studies have shown that alcohol is not a risk factor for stroke among the elderly people. One plausible reason is that elderly people do not usually drink alcohol for intoxication (Gorelick et al., 1989). Also, other plausible reason has been that the number of people who consume alcohol in this age group is usually small to achieve statistically significant results (You et al., 1997; Henrich and Horwitz, 1989).The findings from this study may be due to inappropriate measurement of alcohol consumption. It will be important to consider the length of alcohol consumption, the number and types of alcohol consumed and quantity of alcohol consumed in further studies.

This analysis showed that there was no significant relationship between physical activity and stroke. On the contrary, a meta-analysis of cohort and case-control studies has shown that partially and fully active individuals had lower risk of stroke compared with low active individuals (Do Lee, Folsom and Blair, 2003). An explanation for the finding from this study may be time-sequence based.

4.5.3   Stroke and co-morbidities

The findings from this study showed that hypertension and diabetes were correlates of stroke. This is not surprising because hypertension may lead to bursting of fragile capillaries in the brain leading to a stroke. Studies in sub-Saharan Africa have shown that hypertension is a major risk factor of stroke. For instance, in Ethiopia, hypertension accounted for 52% to 65.6% of stroke cases (Alemayehu and Birhanesilasie, 2013; Alemayehu and Oli, 2002). In Mozambique, 86.6% to 96.0% of stroke patients had hypertension before admission (Damasceno et al., 2010). A study in Nigeria showed that hypertension was responsible for 77.8% of stroke cases (Onwuchekwa, Onwuchekwa and Asekomeh, 2009). It has been shown that about 54% of stroke worldwide is attributable to hypertension (Lawes, Vander Hoom and Rodgers, 2008), and by appropriate blood pressure control measure, up to 45% of stroke cases can be prevented (Richard, 2013).

Further, the association between diabetes and stroke is not surprising because diabetes can lead to deposition of plaques in arterial walls and this may predispose patients to stroke (ischemic type) as the vessels stiffen up and may completely occlude blood supply to specific areas of the brain. Studies in Nigeria, Ethiopia and Senegal have shown that diabetes account for 11.1%-26.0% of stroke cases (Alemayehu and Birhanesilasie, 2013; Eze et al., 2013; Toure et al., 2008). This indicates the need to tackle hypertension and diabetes with a view to reducing the burden of stroke in Ghana.

CHAPTER FIVE

HEALTH RELATED QUALITY OF LIFE OF STROKE SURVIVORS IN GHANA

5.1   Introduction

This chapter examines the Health Related Quality of Life (HRQoL) of stroke survivors in Ghana. Six domains of HRQoL are examined in this chapter. These include: physical health, functioning, psychological, social relationships, environment and overall quality of life. Specifically, this chapter examines the differences in the HRQoL domains (physical, functional, psychological, social, environment and overall QoL) between stroke survivors and other elderly, and; examines the determinants of HRQoL of stroke survivors in Ghana.

Two levels of analysis were performed in this chapter. Independent sample t-tests were used to show the mean differences in HRQoL domains between the stroke survivors and the other older adults. Independent sample t-tests and ANOVA were used to describe the factors associated with the quality of life domains. Further, multiple linear regression was used to examine the determinants of quality of life domains.

5.2   Health Related Quality of Life

Table 5.1 shows the comparison of the mean scores of the Health Related Quality of Life (HRQoL) between the stroke survivors and those without stroke. The table shows that there was a significant difference between the stroke survivors and those without stroke with respect to all the HRQoL domains. Among stroke survivors, the HRQoL scores ranged from 30.9% (physical health) to 62.10% (social relationship) (Figure 5.1), while HRQoL scores for those without stroke ranged from 45.2% (physical health) to 82.0% (functional status). In general, the mean

HRQoL was significantly lower for the stroke survivors in all the domains (Figures 5.2-5.7). The most affected HRQoL of stroke survivors were the physical and psychological domains.

Table 5.1 Mean differences in HRQoL between stroke survivors and other Ghanaian adults

Domains	Stroke Survivors		Other older adults		P-value
	Mean	Std Deviation	Mean	Std Deviation	
Physical	30.91	17.38	45.24	14.27	<0.0001*
Functional status	60.66	24.87	81.95	16.56	<0.0001*
Psychological	39.02	18.14	48.98	14.69	<0.0001*
Social relationship	62.10	25.66	70.14	20.22	<0.0001*
Environment	40.43	19.04	45.33	18.27	<0.0001*
Overall QoL	40.23	22.05	57.79	18.50	<0.0001*

Source: Computed from SAGE survey data, 2008
p value is significant

Figure 5.1 Box plots showing the mean HRQoL domains for the stroke survivors
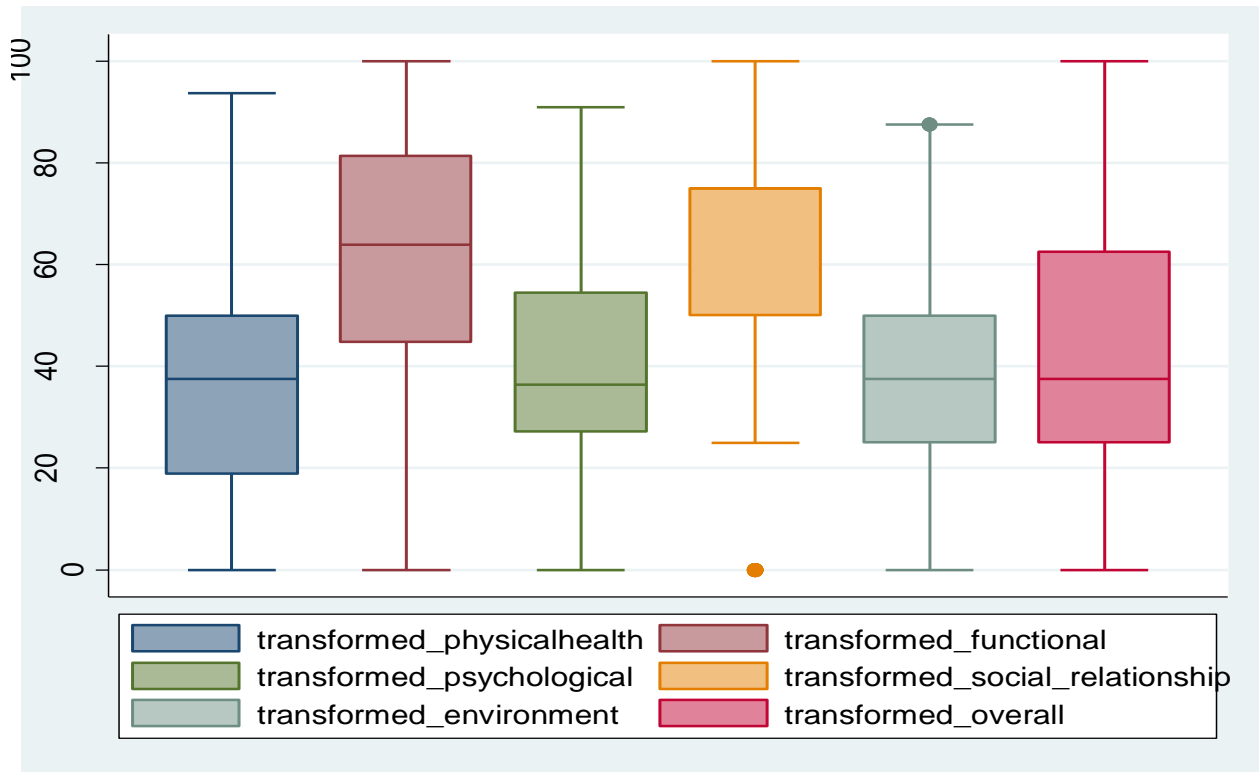
Figure 5.2 Difference in HRQoL between stroke survivors and other older adults (Physical health domain)
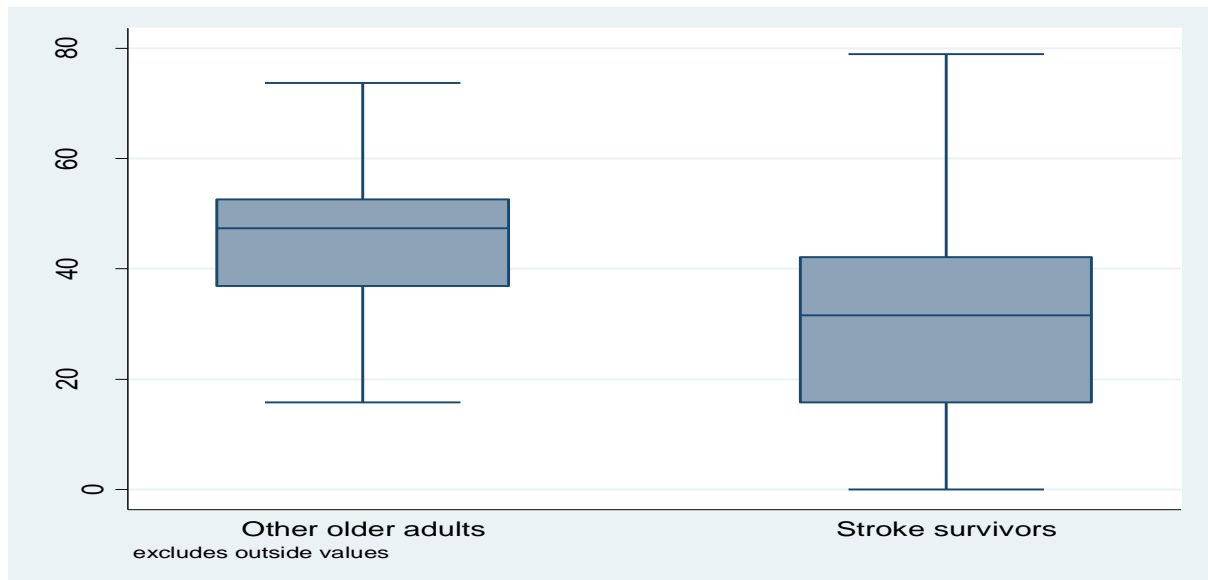
Figure 5.3 Difference in HRQoL between stroke survivors and other older adults (Functional domain)
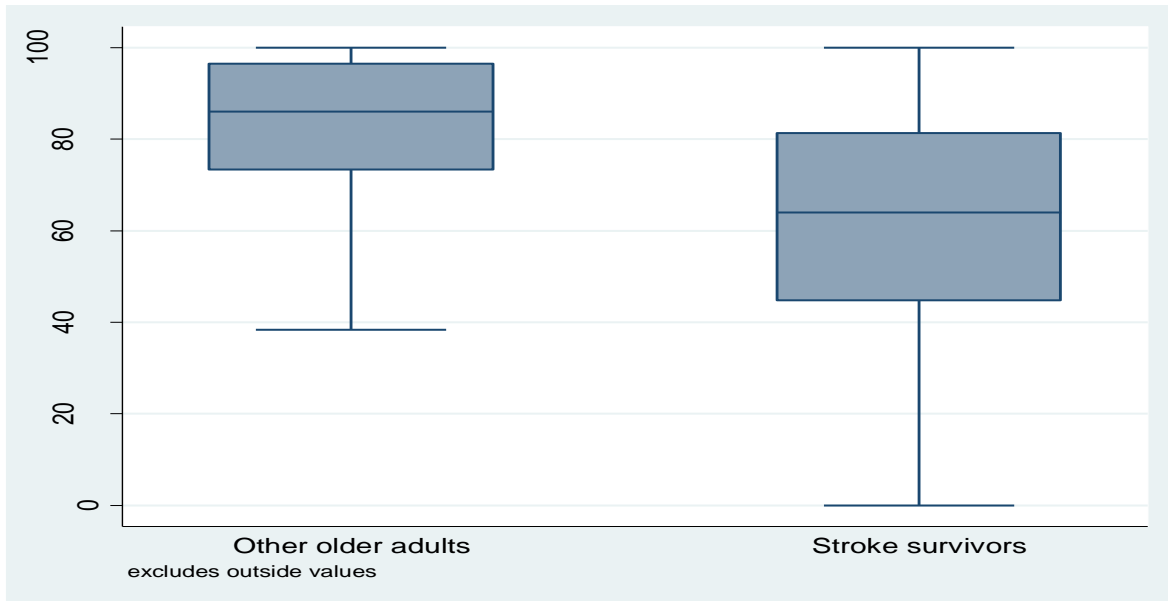
Figure 5.4 Difference in HRQoL between stroke survivors and other older adults (Psychological domain)
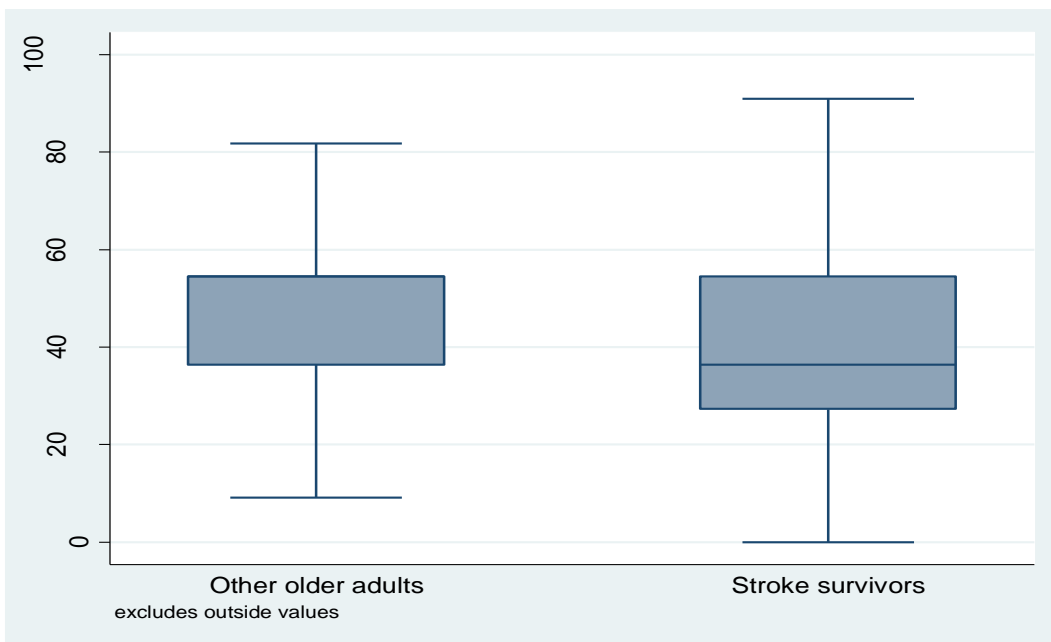
Figure 5.5 Difference in HRQoL between stroke survivors and other older adults (Social relationship domain)
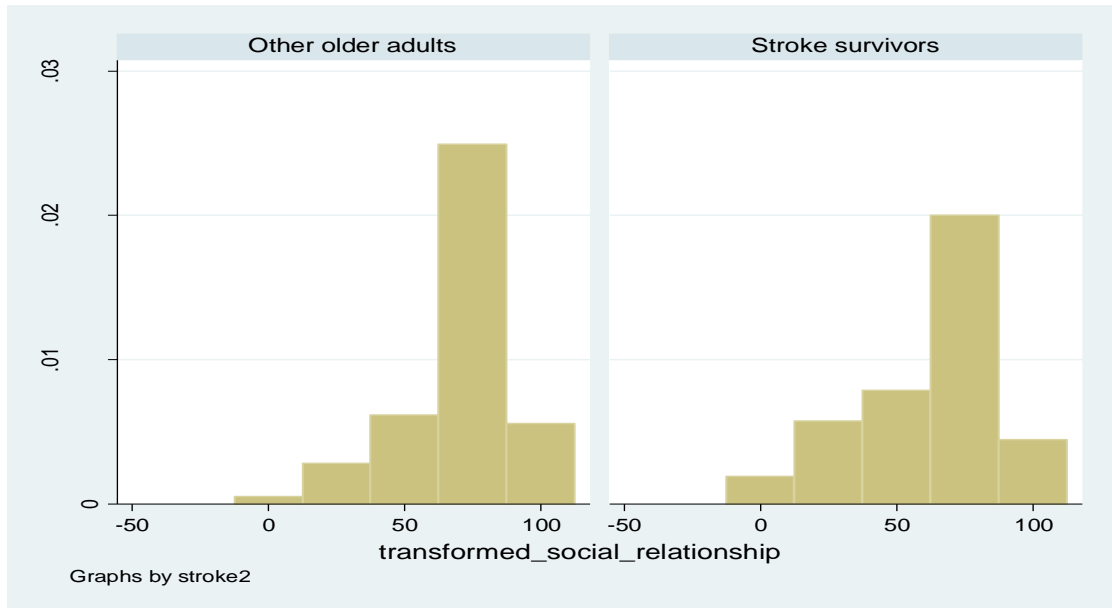
Note: Box plot was not shown for the social relationship domain because the third and first quartiles are the same. Hence, histogram is more appropriate to show this difference

Figure 5.6 Difference in HRQoL between stroke survivors and other older adults (Enviroment domain)
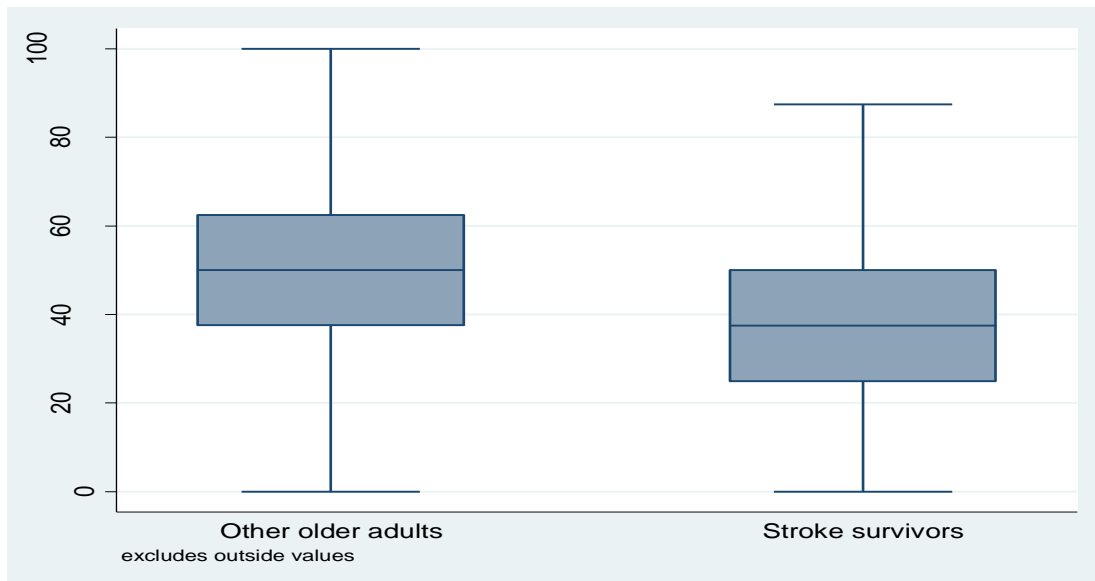
Figure 5.7 Difference in HRQoL between stroke survivors and other older adults (Overall QoL domain)
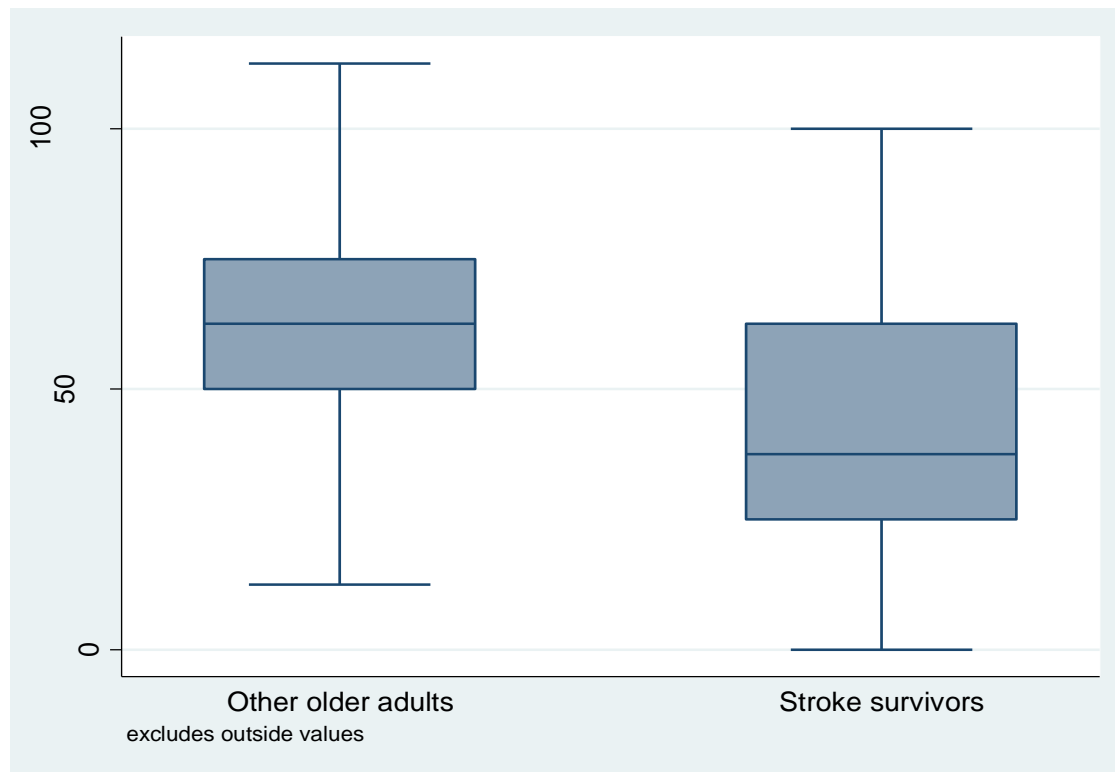
5.3   Association between background characteristics and Health Related Quality of Life

The association between the background characteristics of the respondents and each of the HRQoL domains showed that age was associated with all the domains of HRQoL except the environment domain (Table 5.2). The general pattern observed was that HRQoL was lower among people in the older age groups. The HRQoL domains did not differ by sex, marital status, religion and ethnicity. Stroke survivors who lived in urban areas significantly had higher HRQoL in the physical health domain compared with those in the rural areas. However, place of residence was not significantly associated with the psychological, social and environment domains. Level of education and wealth status were significantly associated with the physical and environment domains. The physical health and environment HRQoL were higher among

those with higher level of education and those with higher wealth status. Employment status was significantly associated with all the HRQoL domains; those who were working had higher mean scores in all the HRQoL domains.

With regard to the lifestyle factors, alcohol consumption was significantly associated with functional HRQoL (Table 5.3). Those who were non-consumers of alcohol had better functional health status compared with those who were current and previous consumers. BMI status was also significantly associated with the physical health, psychological and environment domains. While physical and psychological HRQoL was lowest among those who were obese, those who were underweight had the lowest environment HRQoL. The only co-morbid condition associated with stroke survivors' HRQoL was hypertension (Table 5.4). Stroke survivors who were living with hypertension had lower functioning HRQoL.

Table 5.2 Background characteristics and Health Related Quality of Life of stroke survivors

Characteristics	Physical health		Functional		Psychological		Social relationship		Environment		Over QoL	
	Mean	t/F	Mean	t/F	Mean	t/F	Mean	t/F	Mean	t/F	Mean	t/F
Sex												
Female	34.64	-1.62	61.6	-0.91	54.17	0.29	38.48	-0.16	40.69	0.45	38.92	-0.90
Male	39.26		64.72		53.09		38.89		38.13		41.94	
Age Group												
50-59	40.38	2.77*	70.37	3.75*	57.21	2.93*	38.39	3.42*	43.27	0.52	44.58	2.91*
60-59	39.8		64.55		58.99		31.15		46.43		43.96	
70-79	30.61		58.68		47.46		44.05		42.38		34.43	
80+	36.25		52.87		47.5		45.24		39.58		36.31	
Marital Status												
Never married	31.25	0.12	53.41	0.72	35	1.06	65	2.23	40.00	0.69	37.5	0.15
Currently married	36.85		62.58		54.17		37.24		39.19		39.91	
separated	36.49		67.49		52.36		41.45		36.18		39.19	
widowed	37.08		62.02		55.3		37.1		41.73		41.73	
Place of residence												
Rural	33.42	-2.15*	63.57	0.26	52.72	-0.5	41.25	1.45	37.25	-1.64	38.3	-1.2
Urban	39.84		62.66		54.56		36.14		41.58		42.2	
Level of education												
No education	32.18	3.93**	64.61	1.02	50.93	0.93	41.02	0.69	34.83	7.09***	36.86	1.64
Primary	37.79		58.76		518.43		37.5		47.44		43.06	
Secondary	45.09		57.47		55.36		35.71		50.89		43.75	
Higher	43.75		66.02		54.39		35.00		38.44		44.74	

Source: Computed from SAGE survey data, 2008
*p<0.05, **p<0.01, ***p<0.001

Table 5.2 Cont'd

Characteristics	Physical health		Functional Status		Psychological		Social relationship		Environment		Overall QoL	
	Mean	**t/F**	**Mean**	**t/F**	**Mean**	**t/F**	**Mean**	**t/F**	**Mean**	**t/F**	**Mean**	**t/F**
Wealth Quintiles												
Poorest	31.7	2.79*	63.41	0.90	50.89	0.67	43.33	0.83	27.08	8.83***	36.21	1.91
Poorer	32.97		67.05		52.19		36.05		35.47		37.50	
Middle	33.04		57.58		51.19		42.86		38.69		36.05	
Richer	39.77		62.07		56.82		36.49		41.55		45.83	
Richest	44.18		65.13		56.82		36.46		50.00		45.17	
Religion												
No religion	36.45	1.33	55.68	1.18	45.83	1.04	39.29	0.07	30.36	3.10*	37.50	1.08
Christianity	37.97		61.86		55.17		38.98		41.45		30.83	
Islam	34.97		62.23		51.63		36.54		36.54		41.00	
Other	26.79		70.8		44.64		39.06		28.91		42.71	
Current working status												
Not working	31.4	-5.24***	54.09	-7.77***	48.29	-4.30***	42.72	3.06**	37.6	-1.82	33.46	-6.74***
Working	46.97		78.59		64.06		31.76		42.57		54.04	
Ethnicity												
Akan	39.23	1.3	63.82	0.7	54.38	0.62	39.08	0.93	41.02	1.37	40.93	1.61
Ewe	37.87		59.02		58.82		29.41		41.18		40.44	
Ga- Adangbe	39.5		62.36		56		37		43.5		48.08	
Gruma	41.67		53.41		58.33		29.17		45.83		39.58	
Others	30.33		63.11		53.93		41.94		34.62		34.30	

Source: Computed from SAGE survey data, 2008
*p<0.05, **p<0.01, ***p<0.001

Table 5.3 Lifestyles and Health Related Quality of Life of stroke survivors

Characteristics	Physical health		Functional		Psychological		Social relationship		Environment		Overall QoL	
	Mean	F	Mean	F	Mean	F	Mean	F	Mean	F	Mean	F
Smoking Status												
Non smoker	38.00	2.1	65.55	3.16*	56.07	2.47	63.54	-0.16	41.06	2.69	41.41	0.73
Current smoker	28.53		57.46		47.28		56.52		32.07		35.87	
Previous smoker	37.04		54.29		54.29		56.25		36.57		38.39	
Alcohol consumption status												
Non consumers	37.01	1.12	68.14	5.48**	56.41	1.08	63.44	0.39	38.62	0.15	40.94	1.13
Occasional	39.98		55.20		50.2		59.7		40.04		37.31	
Regular consumers	39.84		65.32		53.9		61.46		40.1		43.49	
Physical activity												
Non actives	36.02	0.9	63.04	0.01	52.42	2.48	61.11	0.46	39.11	0.3	39.69	1.83
Partially active	38.75		63.86		55.0		62.5		40		36.25	
Fully active	43.75		63.54		68.27		67.86		43.27		50.89	
BMI Status												
Underweight	33.17	3.26*	61.41	2.62	49.52	3.21*	62.96	1.09	32.87	4.27**	39.35	-1.2
Normal	38.06		65.97		54.78		64.01		40.97		42.31	
Overweight	45.37		69.44		64.81		71.3		48.21		50.93	
Obese	30.98		56.17		47.28		60.23		35.71		42.61	

Source: Computed from SAGE survey data, 2008

*p<0.05, **p<0.01, ***p<0.001

Table 5.4 Chronic Diseases and Health Related Quality of Life of stroke survivors

Characteristics	Physical health		Functional		Psychological		Social relationship		Environment		Overall QoL	
	Mean	t	Mean	t	Mean	t	Mean	t	Mean	t	Mean	t
Hypertension												
Yes	36.69	0.03	60.72	2.30*	51.88	0.92	60.51	0.47	38.46	0.57	37.32	1.40
No	37.76		69.61		54.35		62.3		40.04		41.96	
Diabetes												
Yes	36.3	0.74	69.49	-1.82	51.44	0.49	62.96	-0.28	39.1	0.12	36.57	0.94
No	36.77		61.57		54.44		61.45		39.51		40.92	
Angina												
Yes	37.85	-0.25	59.91	0.30	59.03	-0.96	62.50	-0.15	39.58	0.20	43.75	-0.68
No	36.58		61.73		53.09		61.58		40.51		39.97	
Arthritis												
Yes	34.94	0.60	58.54	0.87	48.72	1.39	56.88	1.34	36.54	1.44	37.19	1.00
No	37.16		62.35		54.95		62.90		41.44		41.13	

Source: Computed from SAGE survey data, 2008

*p<0.05, **p<0.01, ***p<0.001

5.6   Determinants of Health Related Quality of Life of stroke survivors

The determinants of Health Related Quality of Life are shown in Table 5.5. Only significant variables were presented in the table. Wealth status, employment status and living with hypertension were significant determinants of physical HRQoL. The physical HRQoL was lowest among those with poorest wealth status compared with those with richest wealth status. Those who were working had better physical HRQoL compared to those who were not working. Physical HRQoL was lower among those who were living with hypertension. The only variable that was significantly associated with functional HRQoL among the stroke survivors was employment status. Those who were employed had better functional HRQoL compared with their counterparts.

The determinants of psychological HRQoL were employment status and living with hypertension. While those who were employed had better psychological HRQoL, those who were living with hypertension had lower psychological HRQoL, compared to their respective counterparts. For the social relationship domain, employment status was the only determinant of HRQoL and those who were working had better HRQoL in this domain. Wealth status and employment status determined environment HRQoL and overall QoL. Those who were working and those with higher wealth status had better HRQoL in these domains compared with their counterparts.

Table 5.5 Determinants of health related quality of life of Ghanaian elderly identified through regression analysis

HRQoL domain	Determinants	t	p	β	95% CI
Physical health	**Wealth status**				
	Poorest	-2.46	0.004	-14.687	-26.517 - -2.858
	Poorer	-3.47		-16.897	-26.543 - -7.251
	Middle	-3.63		-17.452	-26.972 - -7.932
	Richer	-2.64		-12.201	-21.351 - -3.051
	Richest (RC)	-	-	-	-
	Employment status				
	Currently working	4.34	0.000	14.5	7.885 - 21.120
	Not currently working (RC)	-	-	-	-
	Hypertension				
	Yes	-3.26	0.001	-12.328	-19.800 - -4.847
	No (RC)	-	-	-	-
Functional Status	**Employment status**				
	Currently working	4.46	0.000	16.946	9.430 - 24.460
	Not currently working (RC)	-	-	-	-
Psychological	**Employment status**				
	Currently working	3.55	0.001	15.357	6.799 - 23.914
	Not currently working (RC)				
	Hypertension				
	Yes	-2.18	0.031	-10.637	-20.298 - -0.976
	No (RC)	-	-	-	-

B-coefficient, p-probability value, t- t statistic (coefficient divided by standard error), CI- Confidence Interval

Table 5.8 Cont'd

HRQoL domain	Determinant	t	p	b	Confidence Interval
Social relationship	**Employment status**				
	Currently working	2.9	0.004	13.038	4.130 - 21.946
	Not currently working (RC)				
Environment	**Wealth status**				
	Poorest	-4.78	0.000	-26.575	-37.565 - -15.584
	Poorer	-4.13		-18.692	-27.654 - -9.730
	Middle	-4.15		-18.538	-27.383 - -9.693
	Richer	-3.08		-13.231	-21.732 - -4.730
	Richest (RC)	-	-	-	-
	Employment status				
	Currently working	2.1	0.037	6.376	0.390 - 12.686
	Not currently working (RC)	-	-	-	-
Overall QoL	**Wealth status**				
	Poorest	-1.16	0.044	-7.442	-20.146 - 5.262
	Poorer	-1.85		-9.712	-20.071 - 0.647
	Middle	-3.01		-15.577	-25.801 - -5.353
	Richer	-1.11		-5.534	-15.362 - 4.291
	Richest (RC)	-	-	-	-
	Employment status				
	Currently working	5.67	0.000	20.359	13.252 - 27.466
	Not currently working (RC)	-	-	-	-

B-coefficient, p-probability value, t- t statistic (coefficient divided by standard error), CI- Confidence Interval

5.7   Discussion

Apart from the study by Sampane-Donkor et al (2014), this is the second study that has been done on HRQoL of stroke survivors in Ghana. This is however the first study which used a nationally representative data to examine the HRQoL of stroke survivors aged 50 years and above in Ghana. Hence, the findings from this study can be generalized to all persons aged 50 years and above in the country. Further, this is the first study that has included co-morbid conditions such as hypertension, diabetes, angina and arthritis in the study of HRQoL among stroke survivors in Ghana. The results from this study showed that stroke survivors had poorer HRQoL in all the domains than other adult Ghanaians without stroke. This is not surprising because other studies have shown that the quality of life of stroke survivors is worse than that of the general population (Sampane-Donkor et al., 2014; Owolabi and Ogunniyi, 2009; Owolabi, 2008; Gurcay et al., 2009). The findings from this study however contradict that of King (1996) which showed that the HRQoL of stroke survivors is comparable to that of healthy individuals because stroke survivors were probably coping well with the disabilities of stroke.

In this study, the mean HRQoL of the stroke survivors was lowest in the physical health (36.7% ± 20.64%) and many of the stroke survivors (65.2%) had a score that was lower than 50% in the physical health domain. This indicates that many of the stroke survivors felt that: they did not have enough energy for everyday life; they were not satisfied with their ability to perform their daily living activities; they were unable to control the important things in their lives, and; they could not cope with what they had to do on a daily basis. This is not unexpected because of the physical disabilities that come with stroke. Owolabi and Ogunniyi (2009) also showed that the HRQoL of the stroke survivors in a teaching hospital in Nigeria was low in the functional, psychological, environment and overall QoL domains. Since HRQoL is a concept that is used to

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assess the impact of an illness on individuals, the findings from this chapter indicate that the wellbeing of the older adults living with stroke in Ghana is poor.

The socio-economic factors associated with HRQoL were wealth status and employment status. This study showed that employment status was a determinant of all the domains of HRQoL. This is consistent with what other studies have shown (Naess et al., 2006; Singhpoo et al., 2012). Employment is important to HRQoL of stroke survivors because being employed is an important aspect of life that ensures the livelihood of an individual (Vincent-Onabajo, 2013). Being employed not only provides financial security, it also guarantees social contacts outside of the family and enhances one's social identity. On the other hand, being unemployed can have serious effects on wellbeing and this may cause dissatisfaction with life in general. For a stroke survivor who is unemployed, especially when he/she has not reached the retirement age, the person is faced with the challenge of living with stroke disabilities as well as the fear of how to mobilise resources for the treatment of the illness.

Even though age was a determinant of HRQoL in the study by Sampane-Donkor et al (2014), age was not a statistically significant determinant of HRQoL in this study. This finding is consistent with what other studies have shown (Owolabi, 2008; Gurcay et al., 2009). The only co-morbid determinant of HRQoL in this study was hypertension and stroke survivors living with hypertension had lower mean scores in the physical HRQoL. This finding is consistent with what other studies have shown (Trevisol et al., 2011).

CHAPTER SIX

KNOWLEDGE AND EXPERIENCE OF STROKE: PERSPECTIVES OF THE STROKE SURVIVORS

6.1   Introduction

This chapter focuses on knowledge and experience of stroke from the perspectives of the stroke survivor. The analysis is presented under four broad themes: 1) knowledge about stroke; 2) experience of stroke survivors; 3) responses to illness (illness action), and; 4) sources and content of social support. The narratives of the stroke survivors on knowledge of stroke are presented under five categories: (i) pre-diagnosis awareness of stroke; (ii) general causes of stroke and causes of participants' stroke; (iii) groups affected by stroke; iv) stroke complications, and; v) stroke prevention. The experience of stroke survivors is presented under the following themes: (i) illness onset; (ii) immediate reaction after stroke diagnosis, and; (iii) impact of stroke. With regard to the illness action, stroke survivors' dual and sequential use of pharmaceutical drugs and herbal medicines is explained. The sources and content of support received by the stroke survivors are presented under three themes: i) psychological support; ii) material support, and; iii) symbolic support.

6.2   Participants' socio-demographic and economic characteristics

Table 6.1 presents the socio-demographic and economic characteristics of twenty-two (22) stroke survivors interviewed for this study. The detailed profiles of the participants are presented in appendix 6. More than half of the stroke survivors (14 participants) were male and 15 participants (68.2%) were fifty years and above (mean age=55.3 years). Seventeen of the participants had secondary education or lower and more than half were unemployed. With regard to marital status, 15 participants were currently married at the time of interview, five were

divorced or separated, and one was never married. Majority of the stroke survivors (20 participants) were Christians. Eleven participants had been living with stroke for 1-5 years and the median year of stroke onset was 1 year.

Table 6.1 Socio-demographic characteristics of stroke survivors

| | | KBTH | | |
Characteristics	Ga Mashie (N=8)	Physiotherapy Unit (N=9)	Stroke Unit (N=5)	Total Participants (N=22)
Sex				
Female	6	1	1	8
Male	2	8	4	14
Age				
31-40	1	0	0	1
41-50	4	3	1	8
51-60	2	4	2	8
61-70	1	2	1	4
> 70	0	0	1	1
Education				
No education	0	0	0	0
Primary	4	0	0	4
JHS	2	4	0	6
SHS	2	4	1	7
Tertiary	0	1	2	3
No response	0	0	2	2
Occupation				
Unemployed	6	7	0	13
Trader	2	0	1	3
Civil Servant	0	0	0	0
Retired	0	0	2	2
Driver	0	1	1	2
Other	0	1	1	2
Monthly Income				
No income	7	7	0	14
< GHC300	1	0	0	1
GHC301-GHC500	0	2	0	2
No response	0	0	5	5

Table 6.1 Continued

| | | KBTH | | |
Characteristics	Ga Mashie (N=8)	Physiotherapy (N=9)	Stroke Unit (N=5)	Total Participants (N=22)
Marital Status				
Never Married	0	0	1	1
Currently married	3	9	3	15
Divorced/Separated	4	0	0	4
Widowed	1	0	0	1
No response	0	0	1	1
Religion				
Christian	6	9	5	20
Muslim	1	0	0	1
No religion	1	0	0	1
Ethnicity				
Akan	2	3	2	7
Ewe	0	1	2	3
Ga	6	4	0	10
Other	0	0	0	0
Other Nationals	0	1	0	1
Duration of Illness				
<1 month	0	0	1	1
1-6 months	0	2	2	4
6-11 months	0	1	0	1
1-5 years	4	4	2	11
6-10 years	3	1	0	4
>10 years	1	0	0	1

6.2 Knowledge of stroke

Five key questions were asked concerning knowledge of stroke. The first one was related to pre-diagnosis awareness of stroke. The second question focused on general post-diagnosis social knowledge (causes of stroke) and post-diagnosis subjective knowledge (causes of participants' stroke). Other contents of knowledge explored included groups affected by stroke, stroke complications and prevention.

6.2.1 Pre-diagnosis awareness of stroke

This focused on participants' awareness of stroke before their diagnosis. Five participants, mostly from the hospital facility, had pre-diagnosis awareness of stroke. However, many of the participants from Ga Mashie did not have pre-diagnosis awareness of stroke. While some of the participants who had pre-diagnosis awareness of stroke knew the causes of stroke, some did not and others had misconceptions about stroke. For instance, a stroke survivor recruited from the Physiotherapy Unit particularly mentioned that even though he had prior awareness of stroke, he did not know it could happen to someone younger than 50 years old.

I: Before the doctor told you that you had stroke, have you heard of stroke?
P: NO, NO, NO. I didn't even know that there was any illness like that [R3]

I: Before your condition, have you heard about stroke?
P: I have heard about it, but I didn't expect it to happen to someone of my age. I expected it to happen to old men and women. I am not even 50 years old [R1]

6.2.2 Causes of stroke

This section focuses on the general social knowledge (causes of stroke) and post-diagnosis subjective knowledge (causes of participants' stroke). Eleven (11) causal theories of stroke were identified and these include: 1) dietary practices; 2) poor lifestyle; 3) high blood pressure (hypertension); 4) family history; 5) psychological disruption; 6) contagion; 7) spiritual disruption; 8) predestination; 9) stress; 10) other chronic diseases (diabetes and high cholesterol), and; 11) delay in treatment of symptoms (Figure 6.1). A significant number of the stroke survivors from Ga Mashie and the Stroke Unit did not know the causes of stroke as well as what

caused their stroke. The contents of stroke knowledge and spread of views of participants are provided in Table 6.2.

> **I:** *So please what would you say made you get stroke?*
>
> **P:** *I have been thinking about it a lot and I still don't get it because I am not that old. No one in my family has it so don't know. So when I went to the mosque they advised me to just take good care of myself*
>
> **(Adult female, Ga Mashie)**

Figure 6.1 Thematic network showing causal theories of stroke

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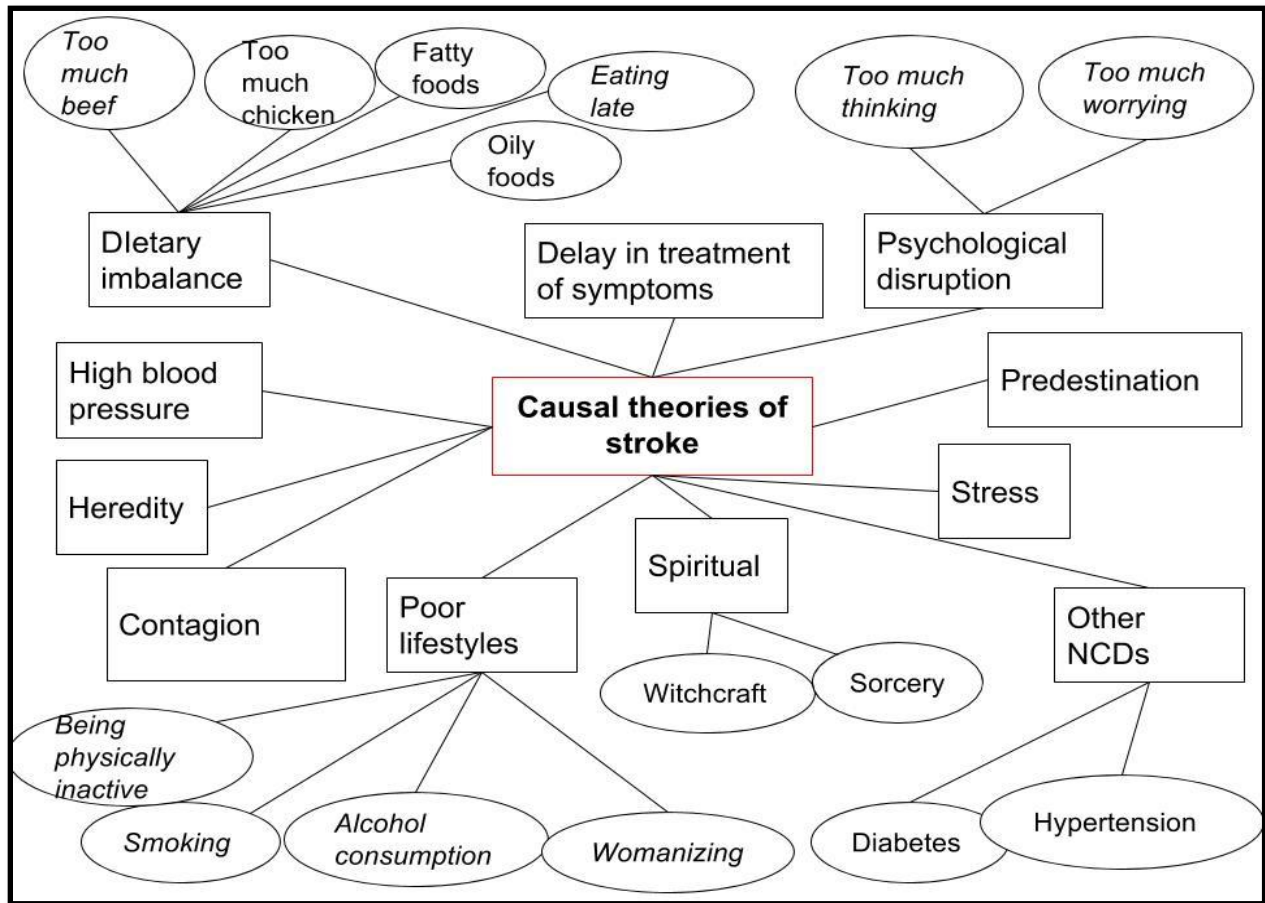
Table 6.2 Content of stroke knowledge and spread of views

	Content of Knowledge	Spread of views
1	Poor lifestyle practices	Thirteen (13) participants in the three research sites
2	High blood pressure	Nine (9) participants from Physiotherapy and Stroke Unit
3	Unhealthy diet/dietary practices	Six (6) participants in the three research sites
4	Spiritual disruption	Four (4) participants mostly from Ga Mashie
5	Stress	Four (4) participants from the three sites
6	Heredity/Family history	Two (2) participants from Ga Mashie and Physiotherapy Unit
7	Psychological disruption	Two (2) participants from Ga Mashie
8	Other chronic diseases	Two (2) participants from Physiotherapy Unit
9	Contagion	One (1) participant from Ga Mashie
10	Predestination	One (1) participant from physiotherapy Unit
11	Delay in treatment of symptoms	One (1) participant from Physiotherapy Unit

Study sites: Ga Mashie, Physiotherapy unit (KBTH) and Stroke unit (KBTH)
Note: Eight stroke survivors did not know the causes of stroke

6.2.2.1 Unhealthy diet/dietary practices

Six participants from the three study sites mentioned unhealthy diets as causes of stroke. This theme focuses on two dimensions: 1) unhealthy foods, and; 2) unhealthy dietary practices. With respect to the unhealthy foods, participants mentioned that intake of fatty and oily foods can lead to stroke. With regard to the dietary practices, participants mentioned that poor timing of meal (eating late), eating too much of chicken and beef can result in stroke.

> *I: Which kind of people would you say get stroke easily?*
> *P: As for stroke, those who usually get it are those who like eating oily foods a lot*
> *(R1)*
> *…it (stroke) can affect anybody, but it usually affects people from 40 years and above, because of their eating habits…. (R8)*

6.2.2.2 Poor lifestyle practices

Poor lifestyle practices were the dominant causal theory of stroke mentioned and discussed by 13 participants. Participants identified lifestyle practices such as smoking, alcohol consumption, being physically inactive and 'womanizing' as causes of stroke, as shown by some of the quotes below. This explanation was drawn from common sense knowledge (practical social knowledge) and scientized knowledge from health professionals.

> *...people claim drinking, smoking, or womanizing cause stroke. I hardly drink. I don't smoke and womanize [R12]*
>
> *... hmm, elderly people have stroke. When I went to the hospital they told me that when you are drinking alcohol and smoking and a lot of things you can get stroke. I know at the hospital [R13]*

6.2.2.3 High blood pressure/hypertension

Nine participants from Physiotherapy and Stroke Units associated stroke with high blood pressure/hypertension. Some of them were already living with hypertension before they were diagnosed with stroke and so they were able to link their stroke condition to high blood pressure. Some further said that untreated hypertension or non-adherence to anti-hypertensive medications can lead to stroke. The participants' narratives were drawn from lived experiences and information from health professionals.

> *I: So why do you think you got the stroke?*
>
> *P: They said my BP (hypertension) had gone up. They said it was because of the blood pressure.*
>
> *I: Okay, so what do you think causes stroke apart from the blood pressure that you mentioned? What do you think are the causes of stroke?*
>
> *P: I don't know so much about stroke but what I think I know is only the BP. That is all I know [R11]*

6.2.2.4 Family history

Two participants mentioned family history as a cause of stroke. They drew their narratives from lived experience of family history of stroke as well as scientized knowledge from health professionals. For a participant who had experienced family history of stroke, she mentioned that her mother and aunt had stroke before she got hers. She particularly stated that her mother got stroke two months before hers.

> *...I know because as for hypertension even in my mother's side a lot of them have the hypertension. Even this stroke they normally get it. Even my mother had the stroke two months before me [R11]*

6.2.2.5 Psychological disruption

The participants mentioned that psychological disruptions such as thinking and worrying can cause stroke. These explanations were mainly drawn from participants' experiences.

> *I: Okay, in your opinion, what brings about stroke?*
> *P: As for me, I think stroke is brought about by thinking or worrying. Maybe life is not going the way you plan it therefore, when think too much, it can trigger stroke. [R6]*

6.2.2.5 Contagion

Participants were asked whether stroke can be contagious or infectious. Some of the participants from Ga Mashie mentioned that stroke can be contagious; however, majority of the stroke survivors from the three study sites said that stroke is not contagious.

> *No, I don't think so, because as I have stroke now, there are people around me, but none of them has had it. So, I know that stroke is not contagious [R6]*
>
> *..the reason why I think so is that, it's not a cough or anything of that sort. Stroke is a matter of inability of the blood to penetrate the veins properly. That's what I know brings about stroke [R1]*

6.2.2.6 Spiritual disruption

Spiritual disruption causal theory reflects across the narratives from Ga Mashie and Physiotherapy Unit but was mostly dominant in Ga Mashie. There were two sub-themes to this: 1) witchcraft, and; 2) spiritual means. While some of the stroke survivors said that stroke can be caused by witchcraft, others mentioned that it can be invoked on an individual through spiritual means. The narratives of these participants were drawn from lived experiences and common sense knowledge.

> *…some people say it is transferred to a person through spiritual means, others say it is the disease in town now [R5]*
>
> *At first, elderly people used to have it a lot, but now it is different, young people and little children are also getting it. Where is this coming from, it is all the work of the devil. Even if you don't think evil of anyone, someone is wishing evil for you [R6]*

6.2.2.7 Stress

Four participants mentioned stress as a cause of stroke. The dimension of stress included: hard work and lack of sleep. According to the participants, involvement in a lot of hard work and lack of sleep can lead to stroke. The narratives of these participants were based on lived experiences. For instance, a Pastor who was recruited from the Physiotherapy Unit mentioned that his condition was caused by too much stress. He regretted his limited knowledge about the

association between stress and stroke. As a result, he had made a decision to educate his fellow

Pastors not to indulge in too many activities but rather take resting very seriously.

> *I think it is stress (respondent referring to causes of stroke). It is stress because I must confess, I am always stressed due to the nature of my work. We pastors, we don't know that sometimes we can be in this condition. They will call you to go here and you will go and they will call you to go there and you will go. That day I wanted to travel to the village where I do missionary work and I got the sickness, since that day I have not gone again [R9]*

6.2.2.8 Other chronic diseases

Even though 16 participants had co-morbid conditions (hypertension, diabetes, high cholesterol

and kidney failure), only two participants associated stroke with diabetes and high cholesterol.

These narratives were based on the lived experiences of the participants.

> *For mine, it is a complication. I know I had diabetes, then pressure came in (BP), but the pressure is on and off. So I went to the hospital, they said I have cholesterol. So finally I had it (respondent referring to stroke) [R15]*

6.2.2.9 Predestination

One stroke survivor from Physiotherapy Unit mentioned that stroke can be caused by life's own

determination. This theme came out of the fact that the respondent could not identify or explain

the cause of his stroke condition.

> *I: Do you know what causes stroke?*
> *P: It can be caused by life's own determinations [R14]*

6.2.3 Groups affected by stroke

When the stroke survivors were asked to mention the groups that were mostly affected by stroke, the list which came up included: aged/elderly, obese/fat people, people who do hard work, people who take oily foods, people who do not adhere to anti-hypertensive medications, people who are stressed, and "anybody". Many of the stroke survivors recruited from the hospital facility mentioned that anyone can develop stroke. Their narratives were based on their observations at the hospital facility where they had seen all kinds of people with stroke. On the other hand, many of the stroke survivors from Ga Mashie identified the "aged" as the group mostly affected by stroke.

> *...those who are from 50, 60, 70 and above. But these days, people from 40 years get stroke* **[R2]**
>
> *... why is it that when stroke affects people who are obese, it is difficult to fight it than when it affects people who are not obese* **[R1]**

6.2.4 Complications of stroke

Stroke complications focus on the disabilities that could result from living with stroke. Participants from the two study sites were asked to list the complications of stroke as well as the complications they have experienced as stroke survivors. Their knowledge on stroke complications fell under two interrelated themes: 1) Physical disability, and; 2) Stigmatization (Figure 6.2).

Figure 6.2 Thematic Network showing knowledge on stroke complications
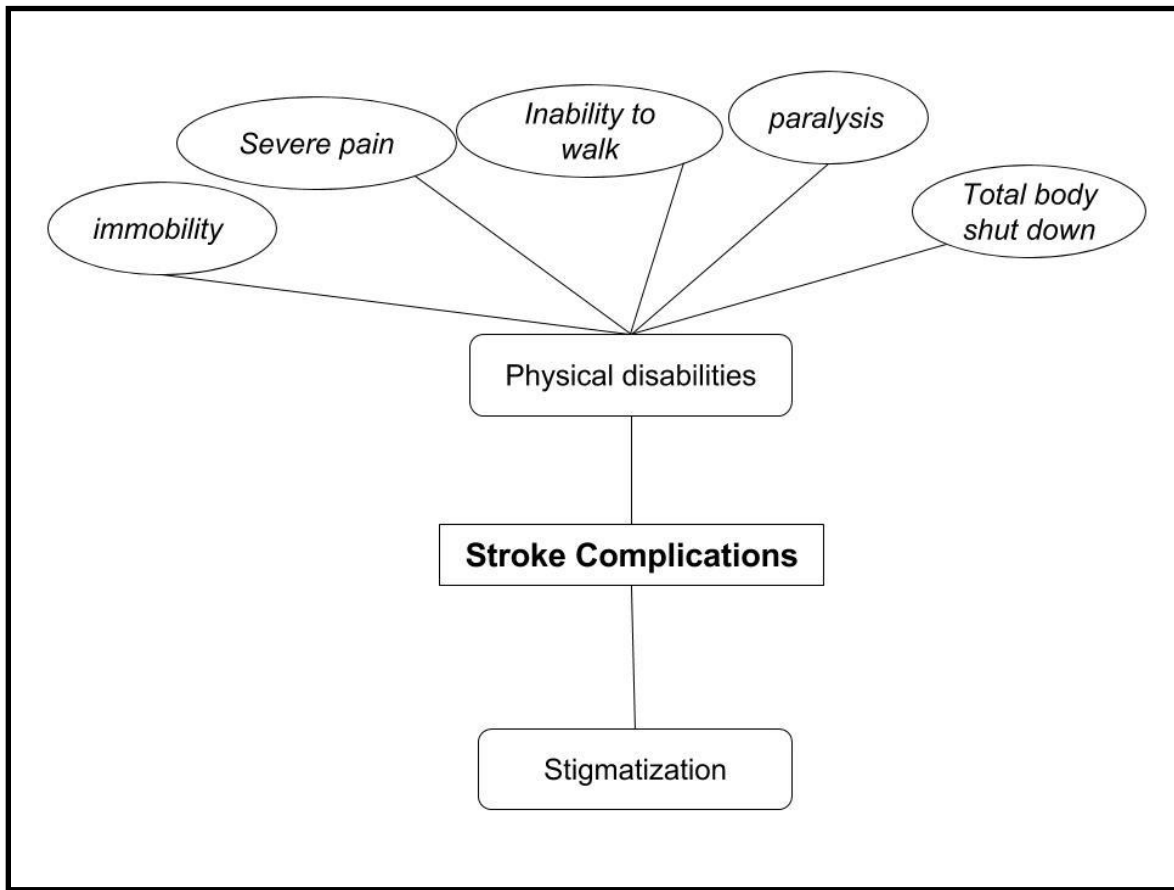
Participants from Physiotherapy and Stroke Units mentioned that stroke can cause physical disabilities such as immobility, severe pain, inability to walk properly, total body shut down, and paralysis. A participant from the Physiotherapy Unit mentioned that stroke can lead to stigmatization as a result of the physical disabilities associated with the illness. Two out of the three participants that could not identify the complications of stroke were from the Physiotherapy Unit.

...as you are sitting down and you can't move your leg, those are some of the things and the changes it brings to your life..because of this now I cannot walk properly. I cannot move out. Even when I am staying out I don't feel okay. When I am among people I cannot stay with the people. It is a lot of things [R11]

I: okay, so sir, do you know some of the complications that can result from stroke?
P: no, no [R10]

6.2.5 Knowledge on stroke prevention

This section focuses on stroke survivors' knowledge on how an individual can prevent stroke occurrence. The narratives of the participants centered on five major themes: 1) spiritual; 2) psychological balance; 3) good lifestyles practices; 4) good dietary practices and; 5) adherence to health issues (Figure 6.3).

Figure 6.3 Thematic Network showing knowledge on stroke prevention
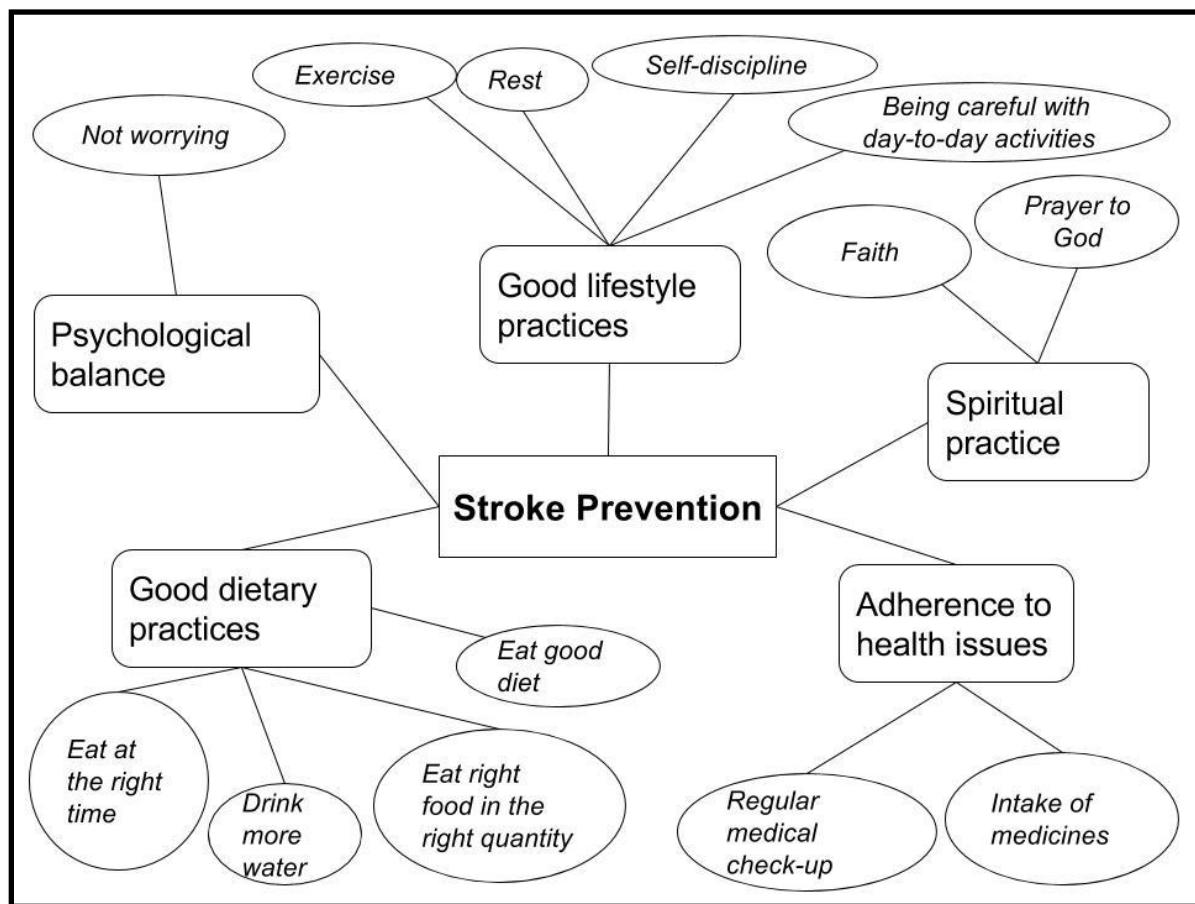
With respect to spiritual prevention, stroke survivors mentioned that consistent prayers, faith and self-discipline can help an individual to prevent stroke. Further, a stroke survivor from Ga Mashie mentioned that not worrying too much can help to prevent stroke occurrence.

> *I: please what can we do to prevent stroke?*
> *R: prayer and service to God [R6]*
>
> *…there is only one thing you can do to protect yourself. My belief is that… that's my belief, is that apart from God and your own discipline, there isn't any protection anywhere else. You should be careful with your day to day activities. You shouldn't worry too much [R1]*

Stroke survivors, mostly from Physiotherapy Unit, mentioned that stroke can be prevented if an individual maintains good lifestyle practices such as regular exercise, enough sleep at night, rest, self-discipline and being careful with day-to-day activities. Participants further explained that engaging in good dietary practices such as intake of proper diet, eating on time and taking a lot of water can help to prevent stroke. In addition, stroke survivors from the Physiotherapy Unit KBTH explained that stroke can be prevented through adherence to health issues such as regular medical check-up and intake of medicines.

> *…Yes, eat the right food in the right quantity [R15]*
>
> *…I feel when you take your medicine and you are praying [R11]*

6.3   Experience of stroke

This section focuses on stroke experience from the perspectives of the stroke survivors. Participants' experiences focused on five broad interrelated categories: (1) illness onset (2) immediate reaction after stroke diagnosis; (3) Impact of stroke; (4) Illness action- health seeking behaviour; (5) content and sources of support-coping strategies.

6.3.1   Illness onset

Participants were asked to narrate how their illness started. Two categories of people emerged based on this. For the first category of people, the illness started when they were doing their regular day-to-day activities.

I: ...I want you to tell us a little about yourself before you got the sickness….

P: I went to the market and came back. I went to prepare 'klakla akala'

I: you finished preparing it?

P: yes I finished preparing it and I went to call my friends to come and eat with me. When I got to the veranda, I got struck by the sickness and fell to the ground and they came to lift me up [R3]

The second category of people was those who experienced the illness at the middle of the night when they wanted to wake up to either urinate or do something else.

I am a pastor. I pastor in the church before the sickness came. One day as I just came back from my work and I decided to have a little rest at home. It was in the evening like this around 6 or 7 so when I woke up from sleep, I saw that my body has changed and I could not understand. That time my wife was lying by my side. She was very surprised, to see me that way. She said what is the problem and I told her I don't know what was happening to me, my body was twisting [R9]

6.3.2 Immediate reaction after diagnosis

Participants in the three study sites had more or less similar emotional responses after they were diagnosed with stroke. The emotional responses included: worry ('*naagba*'), sadness ('*aweleho*'), crying/weeping ('*yaafo*'), fear ('*gbeye*'), shock ('*tsui famɔ*'), and dismay ('naakpe'). For participants who experienced worries, the worries were on what to eat and how they will take care of their families. Some of the participants felt sad because they knew they could not do the things they used to do any longer.

> *hmm, I feel very sad. Even the first time I was crying every day… [R11]*
>
> *I was a bit worried. Because I thought I wouldn't be able to do anything again [R13]*

In addition, many of the participants from the Physiotherapy Unit mentioned that they were shocked about the diagnosis because they did not expect someone of their age to have stroke. That is, they felt they were too young to have stroke. One participant from the Stroke Unit had a contrary emotional response when diagnosed with stroke. When she was diagnosed, she said she wasn't sad because she had the belief that God would heal her.

> *…instantly, I didn't feel any sadness, but with time, I started feeling sad, knowing I couldn't do some of the things I could do earlier on [R18]*

6.3.3   Impact of stroke

Stroke disrupted seven interrelated dimensions of everyday life: 1) disruption to body-self; 2) disruptions to economic circumstances; 3) social disruptions; 4) disruption to family relationship; 5) cognitive disruptions; 6) nutrition disruption, and; 7) disruption to lifestyles (Figure 6.4). It is important to note that each of these disruptions had significant impact on the emotional wellbeing of the participants as well as their illness actions. Also, many of the participants experienced multiple impact of stroke. On the other hand, stroke brought about positive changes in the dietary and lifestyle practices of some of the stroke survivors.

Figure 6.4 Thematic Network showing the impact of stroke
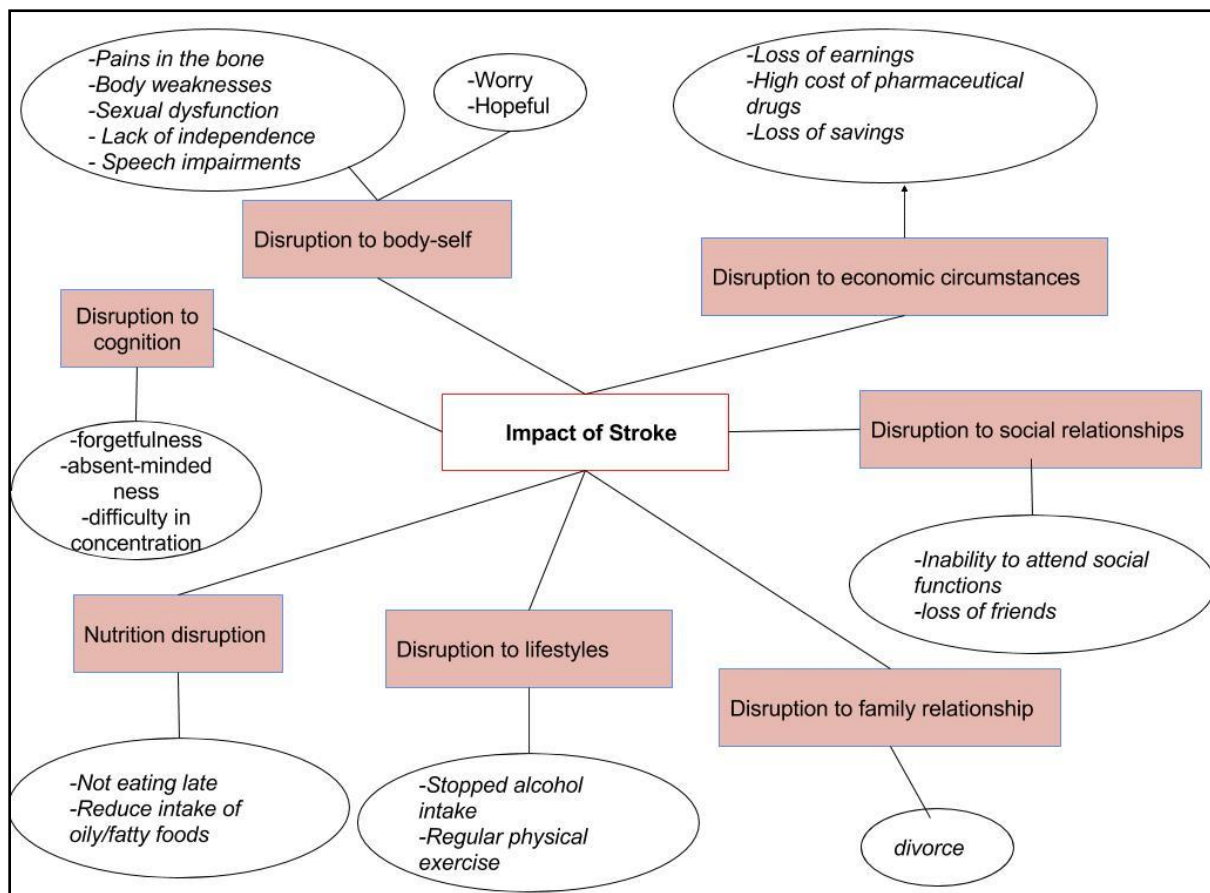
6.3.3.1 Disruption to body-self

Body-self refers to the inter-relationship between the physical and psychological body (de-Graft Aikins et al., 2014). In this analysis, body-self disruption refers to the physical-psychological impact of stroke. All the participants interviewed experienced different forms of disruptions to body-self. These included: pains in the bone, body weakness, sexual dysfunction, sharp pains, lack of independence, inability to stand upright, inability to move around, inability to walk properly, immobility and speech impairments (inability to talk loud and slowness of speech). Some of the participants lived with other serious chronic conditions such as hypertension and liver problems. For most of the participants, being dependent on other people and inability to do what they used to do constituted a lot of worry to them. Hence, the predominant response of many of the stroke survivors to this disruption was high level of uncertainties and it centered on fear of not being able to do what they usually did before they were diagnosed of the illness. Further, participants who had been living with the illness for relatively shorter periods were afraid of neglect by family members in case their conditions did not improve. On the other hand, a participant from Ga Mashie who had been living with the illness for a relatively longer period mentioned that she had experienced neglect by family members compared to when she was first diagnosed with stroke.

Honestly, within three years I realized a lot had changed about my body, a lot of drugs... When it started at first, I couldn't get up; if I wanted to do something, I will tell my mother (the old lady you met the first time) and my sister would carry me. If I am going to the hospital, I am carried [R6]

All the participants experienced different forms of psychological disruptions. However, their abilities to manage these varied depending on their socio-economic status and the social supports networks available to them. While some experienced a lot of worries because of how they will get by each day due to their disabilities, others were hopeful that the illness will disappear "one day". One particular woman said that she was depressed because she could not take proper care of her baby due to her physical disability. Some of the participants felt sad because the illness has 'shattered their dreams'.

Very much I always need somebody to be around me, to chat with me. Sometimes when people come around, I like it than being alone because in my condition it is not good to be alone **[R14]**

…first time I feel sad so I was crying. I was crying because the time I gave birth in two weeks we should name our baby and we should do our blessing at the same time. When this thing happened I was feeling so bad. So I am thinking about it and I am always crying. The doctor also made me know that I should not cry and I should not think about it. When I am thinking the more the sickness is there. It will not go so I should stop thinking about it. I should not cry because sometimes when my baby is laying down and she is crying I can't pick it. So when he is crying then I am sitting down and looking at him. So I am feeling so much pain and I am crying **[R11]**

6.3.3.2 Disruptions to economic circumstances

Disruptions to economic circumstances occurred at three interrelated levels: 1) loss of earnings due to inability to work; 2) increased expenditure due to cost of pharmaceutical and herbal medicines, and; 3) inability to save due to financial demand of stroke management. More than half of the stroke survivors in the three study sites were not currently working and so did not earn any income. For those who used to engage in trading activities, they mentioned that the illness had affected their trade because they could no longer pursue their trade. For participants who still

worked, they could not engage in full-time economic activities due to disruptions to body-self. After diagnosis, some of the participants expressed negative emotions because of the projected impact of stroke on their economic circumstances.

Also, the challenges stroke survivors had to face included the high cost of the pharmaceutical drugs and the fact that the expensive drugs recommended by doctors were not covered by health insurance. The participants, most especially those from Ga Mashie, mentioned that the impact of stroke on their economic circumstances was enormous. This was because the lack of money undermined any practical attempt to overcome the ongoing body-self disruption. Disruption to economic circumstances formed key reason for non-adherence to medications and healer shopping, most especially among participants from Ga Mashie. While some had resorted to herbal treatment in order to minimize body-self disruption, some were practising illness inaction because both biomedical and herbal treatments were too expensive for them.

At the third level of disruption to economic circumstances, a stroke survivor from Ga Mashie mentioned loss in savings due to inability to work and increased cost of pharmaceutical drugs. A woman interviewed at the Physiotherapy Unit particularly mentioned that she had used all her savings on the stroke treatment and this had disrupted the education of her children. According to her, the children had experienced disruption in their education because she had used the money she saved for the children's education on drugs.

> *...hmm, it cost me a lot because before that, I have some money. The money I have put down for my girl who sells the food right now for her to go to WASS (secondary school)... So I keep some money for her which she will use to start the school but because of this sickness, we have used all the money to buy medicine, medicine. So it has cost me a lot but (...) [R11]*

> *Formerly I used to take only the orthodox drugs, but they are expensive. There is this drug from Germany which was prescribed for me; cebrotonin, it is very expensive. In the store just here, one goes for Ghc75.00, so it isn't easy. So I decided to start taking the herbal medicines because it is also good. So now I have resorted to the herbal medicines [R1]*

6.3.3.3 Disruptions to social relationships

Participants mentioned that stroke had disrupted their social relationships. This had different dimensions including: inability to attend social functions, inability to go out with friends, loss of friends, vulnerability to being cheated by others and stigmatization. Many of the stroke survivors mentioned that they could no longer attend social functions such as "outdooring" (naming ceremonies) and funerals because of the illness. The dynamics that were observed showed that while some of the participants could not attend these functions due to their physical disabilities, others deliberately refused to attend these functions because of the stigma associated with stroke. As a result of this disruption, some of the participants experienced loneliness, sadness and depressive symptoms.

> *...it hasn't been easy. It isn't a sickness (referring to stroke) you should even wish for your enemy. All my dreams have been shattered. You can't go anywhere. You can't eat, walk or do anything without help. At first I couldn't even talk like I am talking now. It takes you away from the society. If you don't have a family to take care of you, you may even die before your time. It's a sickness that may even cause people to neglect you. Even if you have people to support you, with time, the people may even draw back.... [R12]*
>
> *... yes, I am feeling if I went out people (...) even now when we went out to Korle Bu to come back, a lot of people when they see me they are looking at me. That is why I can't go anywhere [R11]*

6.3.3.4 Disruption to family relationship

Participants also experienced family breakdown as a result of the illness. One participant from Ga Mashie had experienced divorce as a result of the condition. The divorce was attributed to the

inability of the 'ex-wife' to deal with the physical demands and socio-economic burden of her husband's condition. For those that had not experienced disruption in family relationship, they were afraid of experiencing family abandonment or neglect if their conditions did not improve over time.

> *....well I will refer to my own personal experience. When I was going through my hard times and my wife realised that I didn't have any family members to offer a helping hand she also left me. This got me thinking [R1]*

6.3.3.5 Disruption to cognition

Participants experienced disruption to their cognitive abilities. While some of them could no longer remember things that they normally would remember before the illness, others also experienced absent-mindedness and difficulty in concentration. This cognitive disruption brought about depression, anger and sadness for some of the participants because of their inability to continuously engage in meaningful conversation with people.

> *Because what I see is that when you think so much about the disease it makes you forgetful concerning a lot of things. Even when you are holding glass, you may let go of it for it to crash on the ground without noticing it [R1]*

> *I: what about forgetfulness, are there certain things you forget?*
> *P: yes, but when I'm speaking and it comes to me I say it*
> *I: so if it doesn't come to you what do you do?*
> *P: I don't say anything [R3]*

6.3.3.6 Nutrition disruption

Many of the stroke participants noted a positive change in their dietary practices due to their illness. This change can be grouped based on timing of diet consumption and types of food consumed. With regard to timing of diet consumption, the participants mentioned that they had

adopted not eating late as they used to do before, based on the doctors' advice. Some particularly

mentioned that they no longer ate after 6:00pm. Concerning the types of foods consumed, many

had stopped or reduced the consumption of certain foods (e.g groundnut soup, cakes and milo)

that they believed are high in oil, fat or sugar, while others have had to resort to eating more

fruits and vegetables based on the doctors' recommendations. Participants from Ga Mashie could

not consume fruits and vegetables as they should due to finances, even though they wish they

could consume more of these. On the other hand, participants from the hospital site did not report

this challenge.

.....because this time I cannot eat salt, I cannot eat pepper and oil food. Even palm nut soup and ground nut soup I eat it in once a month. I cannot drink Milo tea but I like Milo tea. I can drink only tea, morning, afternoon and evening **[R11]**

6.3.3.7 Disruption to lifestyles

Some of the participants mentioned that they had experienced changes in their lifestyles because

of the illness. Some of the participants had stopped consumption of alcohol and many had started

doing physical activities as a result of the illness. Some of the participants from Ga Mashie

however had not changed their lifestyles due to their socio-cultural practices (consumption of

alcohol during funerals).

As I mentioned earlier, I was only drinking occasionally. But now, I don't even go to occasions, to even be compelled to drink. So I now I don't even drink at all **[R12]**

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6.3.4 Illness action

Dominant health seeking behaviours among the stroke survivors centered on the dual and sequential use of pharmaceutical and herbal medicines. With the exception of one participant from Ga Mashie, most of the participants accessed biomedical care as their first point of call after noticing symptoms (Figure 6.5). Initial biomedical treatment choices were influenced by two major factors: the sudden nature of physical symptoms of stroke and advice by significant others. The main reason for seeking biomedical treatment was to ensure appropriate diagnosis and understanding of the sudden physical symptoms of stroke. For the participant who sought herbal treatment as his first choice of treatment, he was influenced by his brother as well as lack of finance.

> *I got up to go and pray around 3am but I couldn't get up, so I was wondering "what is wrong with my leg?" so I went to a brother's place and when he saw me, he told me it was a stroke. So he went to buy coke, the big bottle and prepared medicine for me with it* **[R2]**
>
> *Fortunately, I was in traffic when it happened, so I wasn't on a tough speed. The neck and the right hand ceased to move. So the people around came to my aid, thinking I was having a problem with the car. But when they realized what the problem was, they took me from the driver's seat, to the passenger's seat, and drove me to the ridge hospital* **[R12]**

Most of the participants engaged in healer shopping due to disruption to body-self, economic disruption and "hope for a cure". Even though some of the participants did not believe in herbal treatment, they had no say in the kinds of treatment sought because of their "state of helplessness".

> *....well I was taken to Korle Bu hospital. Yes Poly clinic. I got to poly clinic. When I went there and they were able to lower my BP (blood pressure)(3.18) my people were getting scared that something may happen so it will better for them to take me to a herbalist to take care of me. So they discharged me from the hospital and took me to the herbalist where I got treatment* **[R9]**

With regard to the health-seeking behaviours of the participants, six interesting dynamics were observed (Figure 6.5). Firstly, two stroke survivors (from Ga Mashie) started with biomedical treatment, and thereafter moved to herbal treatment due to their inability to afford the biomedical treatment. Secondly, one participant at Ga Mashie started with herbal treatment, moved to biomedical treatment, went back to herbal treatment and currently not actively seeking for cure because of lack of finances. Further, one stroke survivor from Ga Mashie started with biomedical treatment and is currently using home remedies and herbal medicines due to the expensive nature of pharmaceutical drugs.

Figure 6.5 Illness actions among participants
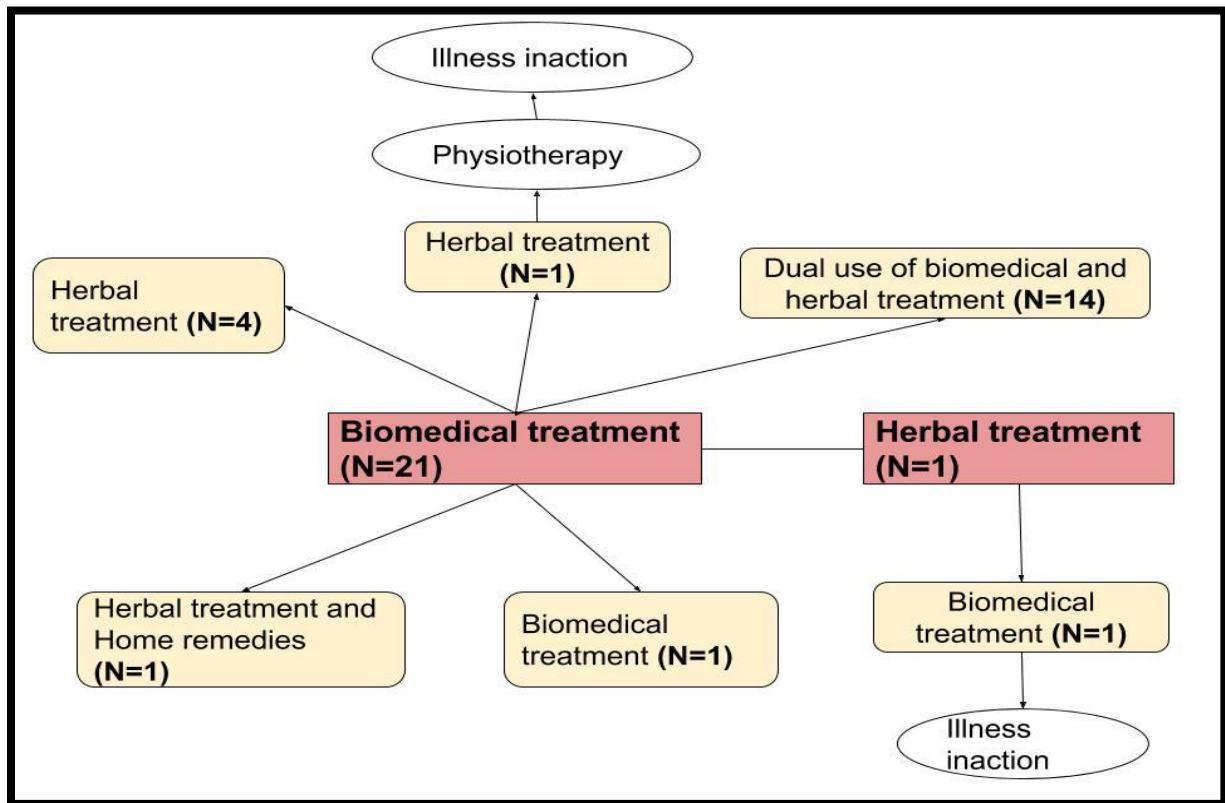
Nearly all the stroke survivors from physiotherapy and stroke Units who started with biomedical treatment were currently practising the dual use of biomedical and herbal treatments. These participants had the belief that both biomedical and herbal treatments were complementary. While they mostly used herbal treatments as primary form of treatment, they used biomedical treatment to verify if the herbal medicines were working for them. One participant from Ga Mashie started with biomedicine and moved to herbal treatment. When there was no improvement in condition, he was taken for physiotherapy for some time and when there was no notable change, he is currently practising illness inaction. Lastly, one stroke survivor from the Stroke Unit sought biomedical treatment for diagnosis and still currently seeking only biomedical treatment in managing the illness.

The determinants of participants' illness actions included: cost of pharmaceutical drugs such as prolonged physical disruption, and hope for a cure. Cost of pharmaceutical drugs such as Bisoprolol, Somazina Citicoline, Cholesrastin and Nifin mostly influenced those from Ga Mashie who were practising illness inaction. Prolonged physical disruption mostly influenced participants from the hospital facility who engaged in the dual use of biomedical and herbal treatment. Further, hope for a cure cut across the narratives of all the participants but mostly influenced those who sought herbal treatment. Generally, caregivers played major role in participants' illness actions and prayer formed an integral aspect of illness actions for all the participants.

6.3.5 Content and sources of social support

This section describes the resources that stroke survivors drew on in coping with their illness. Three different kinds of resources were identified by the stroke survivors: Psychological,

material and symbolic resources. These resources formed important part of the recovery process for the participants. It was observed that those who had access to these resources reported faster rate of.

6.3.5.1 Material resources

Participants drew on two types of material resources: financial and physical resources. Financial resources formed the dominant resources that stroke survivors drew on in coping with their illness. Many of the stroke survivors from the hospital sites reported financial support from family members, friends and previous places of work. The financial support was either in the form of buying drugs for the participants or giving money that could take care of the day-to-day needs of the participants. However, some of the participants from Ga Mashie complained of lack of financial support from family members. Financial support was mainly from participants' family members (brothers, sisters, friends, sons/daughters, parents) and church members.

> *I: So in terms of financial support, who usually provide financial support for you?*
>
> *P: I have my own. I have my own and my brothers and sisters too they are doing their best. They bring some money because the hospital medicines I use ….there is one we buy for GHC410 every week…GHC 410 every week. [R11]*

> *..there is this phone contact I have, anytime I call, they would then invite me over. If my son doesn't get the time then I would have to go by myself. My brother is a pastor there, so when I go they help me financially. Sometimes they give me Ghc500.00 and at times Ghc600.00. I don't feel comfortable doing that though, but I have no option because I don't have [R6]*

Some of the participants received physical support in terms of assistance on things they could not do on their own due to their physical disabilities. These include: assistance in bathing, cooking, taking care of baby and other forms of physical support. One participant from Physiotherapy

mentioned that her family members assist in bathing her and to take care of her baby because of her physical disability.

> *...as for my sisters the first time I can't bath so they came here to take me to bath, bathing me, taking care of the baby. But now, I can bath myself so they normally come here. This place is my in-laws place, my husband's mother's place. So when I will go and bath they take my water into the bath room. When I want to eat they will cook some of the food for me because they say I will not eat salt, pepper and those things. So they always cook my food separate. They will cook that food that everybody will eat but they cook my own different* **[R11]**

6.3.5.2 Psychological resources

Psychological resources that stroke survivors drew on were in the form of advice, encouragement, visitations and phone calls from significant others. Most of the participants received this emotional support from family members, friends, church members and health workers. The goal of the psychological resources was to encourage participants to "be hopeful for a cure" or to adhere to medications. These resources had helped some of the participants get by each day while deficiency of this has been of great concern to others.

> **..***oh okay. When I have such problems I go to one of my nephews and I will say "Yaw, this is what's on my mind". Then he'd tell me not to worry too much that all would be fine* **[R1]**
>
> *...well they have been coming to encourage me. They have been coming to encourage me. Even I am in pastor's association and most of them know that I am not well. So they have been coming to encourage me. Even the school that sometimes I go and preach at, they ask me why I don't come again. I told them I am sick with this problem. Oh they sent some people to come and visit me and they give me some help also* **[R9]**
>
> *when this sickness came, Samuel has finished his school so he is always here with me so sometimes I will start crying and Samuel will come say oh mummy don't cry it will be okay. When I start crying he will say don't cry because when I cry it will not go. It won't go so stop crying. Then he will be talking to me* **[R11]**

6.3.5.3 Symbolic resources

The symbolic resources that participants drew on were in the form of prayer and to get the assurance that God will heal them. This support was either from Pastors, church members, Muslim friends or significant others. Some also drew on symbolic resources to encourage themselves because they see people they are better than despite their physical disabilities.

I: okay, what about your friends do they know about your condition?

P: yes.

I: and what have been their responses?

P: they all came here. They always come here. The food I sell, I was selling it to a lot of the Lighthouse pastors. They come to eat at my place. So every day they were here. They come to my place to come and pray for me and encourage me saying it will be okay [R11]

oo… I know some friends who always pray for me, err sometimes I call them. Yesterday for instance I call somebody, I was talking to him and he said "oh, we always pray for you". Err…he has err…how do you call it….prayer warriors group where they normally pray. He says he can't promise to visit me but anytime he finds time, he will visit me. I have other friends when I call they just tell me they are praying for me. I have some Muslim friends we call them, this morning somebody call me, he's called Mallam Issah, he said oo, I always pray for you, I said thank you. I have a friend also at Bolga (a cock crows in the background) he's a Muslim, I tell him and he said oo, I pray for you, God will do it. So they have been encouraging me as a Christian and I also encourage myself because at the end of the day when I go to the hospital, I see people that I'm better than them, I know people are…I don't know their problem they, maybe theirs is different from mine [R15]

6.4   Discussion

This discussion focuses on four key findings: 1) the knowledge of stroke (causal theories of stroke and stroke complications; 2) the experience of stroke from the perspectives of the stroke survivors; 3) illness actions, and; 4) social support received by stroke survivors.

6.4.1   Knowledge of stroke

The findings from this study showed that many of the stroke survivors, most especially from Ga Mashie, did not have pre-diagnosis knowledge of stroke. This may be due to low level of education among the stroke survivors recruited from Ga Mashie. The participants from the two study sites attributed the causes of stroke to eleven (11) causal theories: unhealthy diets/dietary practices; poor lifestyle practices; hypertension; family history; psychological disruption; contagiousity; spiritual causal theory; predestination; stress; other chronic diseases, and; delay in treatment of symptoms. This study showed that these causal theories were shaped by cultural, scientized and religious knowledge, as well as subjective experiences of the stroke survivors.

Even though the contents of participants' knowledge were eclectic, they placed greater emphasis on practical biomedical knowledge. For example, the dominant themes for the causes of stroke were: unhealthy diet/dietary practices, poor lifestyles and hypertension. This is also similar to the findings on causal theories of diabetes in Ghana where participants attributed the causes of diabetes to unhealthy diet/dietary practices, poor lifestyles, family history, psychological stress and supernatural factor (de-Graft Aikins et al., 2014). de-Graft Aikins et al. (2014) showed that four out of these five causal theories of diabetes aligned with biomedical models. However, in this study, seven out of the eleven causal theories of stroke aligned with biomedical models (de-Graft Aikins et al., 2014).

Few participants drew on supernatural theories (such as witchcraft) and this aligned with socio-cultural beliefs which had been reported in the study of causal theories of diabetes in Ghana and other countries in SSA (de-Graft Aikins et al., 2014; Hjelm and Mufunda, 2010; Awah et al., 2008). Participants drew on the spiritual causal theories because they thought that their practices

should not predispose them to stroke. This finding contradicts what literature has shown. Literature suggests that drawing on spiritual causal theory will lead to seeking herbal treatment or faith healing. On the contrary, three out of four of the participants who drew on spiritual causal theory sought immediate biomedical treatment after stroke onset.

Another important causal theory mentioned by a participant and which is missing in the stroke literature was predestination or fate. Based on this causal theory, stroke may not be caused by one's actions or by someone's influence, it may be a matter of life's determination or fate in which no one has influence on. This knowledge was drawn from the religious belief and subjective experience of the stroke survivor. It was expected that attributing the cause of stroke to predestination may trigger illness inaction or use of faith healing in managing the illness, but the participant who drew on this causal theory rather sought biomedical treatment. This indicates that there is a distinction between drawing on cultural beliefs as causal theories and applying them to everyday illness practices. Even though contagiosity as causal theory of stroke is new in stroke study, this has been mentioned in other chronic diseases study such as diabetes. For instance, de-Graft Aikins (2012) found that people living with diabetes mentioned disclosure of their diabetes as an infectious agent. She referred to this as "social infection"- a situation where people think that diabetes can be passed on to others through speech and interaction.

6.4.2 Experience of stroke

The experiences of the stroke survivors focused on: the sudden nature of the illness; immediate reaction after stroke diagnosis, and; impact of stroke on participants. The findings showed that many of the stroke survivors expressed different forms of emotions (sadness, worry, shock, fear, etc) when they were diagnosed with stroke. The main reason for these emotional responses was

because the stroke survivors thought they will not be able to do what they would ordinarily do if they don't have the illness. These expressions are not unexpected because at the point of diagnosis, participants see stroke as being a "strange condition" which can bring about changes in their biographies.

Since many of the stroke survivors did not have pre-diagnosis knowledge of stroke, this may also explain why the stroke survivors expressed high level of uncertainties immediately after the stroke diagnosis because they were unsure of the stroke prognosis. This is because pre-diagnosis knowledge of stroke can help to minimise uncertainties after diagnosis (Faircloth et al., 2004).

With regard to the impact of stroke on participants, this study was guided by the biographical disruptions explained by Bury (1982) and the impact of a chronic event explained by Charmaz (1983). The findings from this study showed that stroke brought about multifaceted disruptions to individuals living with stroke. The various disruptions experienced by the participants in this study included disruptions to: body-self; economic circumstance; cognition; social relationships; family; diet, and; psychological wellbeing of the participants. These findings confirm what other studies have shown that stroke brings about limited mobility, inability to perform usual daily activities, decreased leisure activities, and limitations on meaningful life roles (Gillen, 2006). Some of the participants from Ga Mashie and Physiotherapy had experienced biographical flow because the illness has become more or less part-and-parcel of their lives. This was mainly due to the fact that many of them have been living with the illness for some time. However, many of the stroke survivors from the Stroke Unit still experience biographical disruption because of the recent stroke diagnosis as well as the acute nature of the stroke condition which they are not familiar with.

In addition, from these interrelated disruptions, body-self disruption constituted the basis for the other forms of disruptions (economic, psychological wellbeing, diet, family breakdown, social relationships). Another major disruption caused by stroke was disruption in economic circumstances. Most of the participants lost their physical strength and so could no longer work. Apart from the inability to work, the participants found it difficult to cope with the high cost of purchasing the pharmaceutical drugs and use of physiotherapy services. Some of the participants (from Ga Mashie) had resorted to illness inaction as a result of this. Many of the stroke survivors are faced with the fear of how to mobilise resources in managing the illness and how to get by financially on a daily basis.

Prolonged body-self disruption also had influence on the health seeking behaviours of the participants. The desire to get well and be able to do things that they usually do before influenced many of them to engage in the dual and sequential use of biomedical and herbal treatments. In essence, rather than the illness practices being shaped by stroke causal theories as suggested in the literature, it was being shaped by the prolonged body-self disruption, hope for a cure and influence of significant others. In addition, the findings bring to light the social dimension of biographical disruption of stroke and the creation of dysfunctional families due to the physical and economic burden of stroke. One of the participants in this study experienced divorce due to burdening on spouse. Marital disruption has also been mentioned in a study on breast cancer in Ghana (Bonsu et al., 2014). In the study, women living with breast cancer experienced marital disruption because their current situation did not attract their husbands' affections and this led to neglect. Other social disruptions experienced by the participants in this study included: abandonment (due to social isolation) and stigmatization (which caused living restricted lives) as a result of stroke. The participants experienced living restricted lives, not only because of their

disability, but also because of the embarrassment which such disabilities create. Hence, the initial taken-for-granted world of everyday life becomes a burden of conscious and deliberate action. As a result, individuals began to restrict their terrain to local and familiar territory where they are least likely to be exposed to the questions of friends and strangers.

6.4.3 Illness action

With regard to illness action, the findings showed that most of the participants engaged in the dual use of biomedical and herbal treatments, and this was common among participants recruited from the health facility. Generally, the dual use choice was based on the belief that both biomedical and herbal treatments were complementary. As a result, the stroke survivors used herbal medicines as the primary form of treatment while they went to the hospital to verify if the herbal medicines were working for them. Many of the stroke survivors also said that they will advise anyone living with stroke to practice the dual use of biomedical and herbal treatments as this can facilitate stroke recovery process. The participants were confident about the dual use of biomedicines and herbal medicines because they have personally experienced improvement in their conditions as a result of this. This indicates that the role of herbal medicine in the management of chronic non-communicable diseases in African and global contexts cannot be overemphasized. This is because herbal medicine has been part-and-parcel of the Primary Healthcare System in Africa and it is also one of the assured alternative means to achieve total health care coverage of the world's population (Antwi-Baffour et al., 2014).

6.4.4 Contents and sources of social support

Participants mentioned that they have received different forms of support (such as financial, spiritual, emotional/psychological, and physical) and these supports were mostly from their

significant others. The findings indicate that the participants recruited from the health facility were able to cope more with the illness as a result of these supports compared to those from Ga Mashie. Due to the inability to work and lack of financial support, some of the participants from Ga Mashie found it difficult to cope with the illness. Even for participants who were receiving these supports, some of them were afraid of abandonment and discontinued support by family members if their recovery process is being delayed.

CHAPTER SEVEN

KNOWLEDGE AND EXPERIENCE OF STROKE: PERSPECTIVES OF STROKE CAREGIVERS

7.1   Introduction

This chapter focuses on the knowledge and experience of stroke from the perspectives of the stroke caregivers. The profiles of the caregivers are discussed first. After this, the narratives of the caregivers on knowledge of stroke are presented under five broad themes: 1) pre-diagnosis awareness of stroke; 2) general causes of stroke and causes of care recipients' stroke; 3) groups at risk of stroke; 4) complications of stroke and; 5) stroke prevention. The experiences of the caregivers are presented under four broad categories: 1) immediate reaction after diagnosis; 2) impact of stroke on caregivers; 3) support provided for stroke survivors, and: 4) social support received-coping strategies.

7.2   Caregivers' socio-demographic and economic characteristics

Table 7.1 presents the socio-demographic and economic characteristics of twenty-nine (29) caregivers interviewed for this study. Detailed profiles of the participants are shown in the appendix 12. The table shows that many of the caregivers (20 participants) were females and many were 50 years and below. With regard to education, all the caregivers have received some formal education. All the participants with secondary education were from Ga Mashie. Out of the nine participants with tertiary education, seven were recruited from the Stroke Unit. Four participants were not working while others had different forms of occupations such as trading and civil service. Two of the caregivers had retired from active service and one was a student.

When the participants were asked about their income, some of them refused to disclose their income and many of these people were recruited from the Stroke Unit. Among those who

disclosed their monthly income, five caregivers received less than GHC300; three received GHC300- GHC500 and four received more than GHC500 every month. A significant number of the participants were Christians, Ga and married. With respect to duration of caregiving, many of the caregivers have been involved with caregiving for an average of two years. Ten of the caregivers were spouses of the stroke survivors; thirteen (13) were children and the rest were mothers, nieces/nephews and a cook.

Table 7.1 Socio-demographic and economic characteristics of caregivers

| Characteristics | Ga Mashie (N=8) | KBTH | | Total Participants (N=29) |
		Physiotherapy (N=10)	Stroke Unit (N=11)	
Sex				
Female	6	6	8	20
Male	2	4	3	9
Age				
≤30	2	5	2	9
31-40	2	0	0	2
41-50	2	1	2	5
51-60	1	4	2	7
61-70	1	0	2	3
>70	0	0	1	1
No response	0	0	2	2
Education				
No education	0	0	0	0
Primary	3	0	0	5
JHS	2	4	1	7
SHS	2	4	1	6
Tertiary	0	1	2	9
No response	0	0	2	2
Occupation				
Unemployed	2	1	1	4
Trader	3	3	2	8
Manual worker	1	0	0	1
Civil Servant	0	0	1	1
Business (private)	0	2	2	4
Student	1	0	0	1
Retired	0	0	2	2
Other occupations	1	4	3	8
No response	0	0	0	0

Table 7.1 Continued

		KBTH		
Characteristics	**Ga Mashie (N=8)**	**Physiotherapy (N=10)**	**Stroke Unit (N=11)**	**Total Participants (N=29)**
Income status				
No income	3	1	0	4
< GHC300	3	2	0	5
GHC301- GHC500	0	2	1	3
> GHC500	1	2	1	4
No response	1	3	8	12
Marital Status				
Never Married	3	4	3	10
Currently married	3	5	8	16
Divorced/Separated	1	1	0	2
Widowed	1	0	0	1
Religion				
Christian	8	10	10	28
Muslim	0	0	0	0
No religion	0	0	1	1
Ethnicity				
Akan	1	2	6	9
Ewe	1	1	3	5
Ga	6	6	0	12
Other Nationals	0	1	0	1
No response	0	0	2	2
Duration of caregiving				
<1 month	0	0	2	3
1-6 months	0	1	6	7
7-11 months	0	2	0	2
1-5 years	5	5	3	13
6-10 years	1	1	0	2
>10 years	1	0	0	1
No response	1	1	0	1
Relationship with SS				
Husband/wife	1	4	5	10
Mother	1	0	0	1
Son/daughter	5	4	4	13
Nephew/niece	1	1	1	3
Other (cook, friend)	0	1	1	2

7.3 Knowledge of stroke

Participants were asked five key questions concerning knowledge of stroke. These included: 1) pre-diagnosis awareness of stroke; 2) general causes of stroke and causes of care recipients stroke; 3) groups affected by stroke; 4) complications of stroke and; 5) stroke prevention (Figure 7.1).

7.3.1 Pre-diagnosis awareness of stroke

Many of the participants mentioned that they had pre-diagnosis awareness of stroke before their care recipients were diagnosed with the illness. Out of the six participants who did not have pre-diagnosis awareness of stroke, four participants were from Ga Mashie. Among those who had pre-diagnosis awareness of stroke, some had comprehensive knowledge of stroke while others did not until it happened to their care recipients.

> *Uhhh…. Yeah I know a little bit about stroke and because I am a nurse, I know* **[R20]**
>
> *I... have a limited knowledge but I didn't know so much about it until it happened to my wife* **[R27]**

7.3.2 Causes of stroke

Participants attributed stroke to nine causes: 1) dietary imbalance; 2) poor lifestyle practices; 3) high blood pressure (hypertension); 4) family history; 5) spiritual causes; 6) other chronic diseases (diabetes and multiple sclerosis); 7) stress; 8) non-adherence to health care, and; 9) other factors (such as lack of knowledge about health issues, not being social and not paying attention to stroke symptoms). Out of the nine participants who did not know the causes of stroke

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and the causes of their care recipients' stroke, seven were from Ga Mashie. The spread of views

on content and sources of participants' knowledge on causes of stroke are presented in Table 7.2.

> *I really can't tell. I don't know what makes one to get it, so I can't tell what to do in order to prevent it [R3]*

Table 7.2 Content of stroke knowledge and spread of views

	Content	**Spread of views**	**Sources of knowledge**
1	Poor lifestyle practices	Eight (8) participants in the two study sites	Care recipients' experiences
2	High blood pressure	Eight (8) participants in all the study sites	Care recipients' experiences; scientized
3	Non-adherence to health care	Five (5) participants in all the study sites	Care recipients' experiences; scientized
4	Stress	Four (4) participants in all the study sites	Care recipients' experiences
5	Spiritual disruption	Three (3) participants in all the study sites	Cultural
6	Other factors	Three (3) participants from Stroke Unit	Care recipients' experiences
7	Unhealthy diet/dietary practices	Two (2) Participants from Ga Mashie and Physiotherapy	Scientized
8	Other chronic diseases	Two (2) participants from Stroke Unit	Care recipients' experiences; scientized
9	Family history	One (1) participant from the Stroke Unit	Observations; care recipients' experiences

7.3.2.1 Unhealthy diet/dietary practices

Participants from Ga Mashie and Physiotherapy Unit associated the cause of stroke to dietary

imbalance such as poor diet and poor eating habits. The narratives of the participants on this

knowledge were drawn from scientized information from health professionals.

> *...they say it's partly caused by our eating habits. So we have to watch our eating habits [R1]*

7.3.2.2 Poor lifestyle practices

Participants in all the three study sites linked the causes of stroke to poor lifestyle practices such as: alcohol consumption, smoking, and physical inactivity. The participants' narratives were drawn mainly from the experiences of the care recipients (stroke survivors). The participants particularly laid emphasis on smoking as a poor lifestyle that put their care recipients at risk of stroke.

> *The doctor told her not to drink alcohol but she continued to take it. If the doctor advises you to refrain from something and you don't listen, you will face the consequences [R5]*

> *I: do you think your father could have prevented the stroke?*
>
> *P: I can't really say, because I wasn't living with him. But he was smoking both cigarettes and marijuana. He wasn't going to the hospital too [R8]*

> *I: so what do you think can be the causes of stroke?*
> *P: drinking, smoking, not being physically active… [R28]*

7.3.2.3 High blood pressure/hypertension

Hypertension formed the dominant theme on the narratives of the stroke caregivers on causal theories of stroke. Since many of the stroke survivors had high blood pressure before stroke diagnosis, the participants were able to identify hypertension as a cause of stroke. Hence, the participants' narratives were based on care recipients' experiences and information from the health professional.

> *In my mother's case, it was the BP (hypertension) that caused her to get stroke. So if someone has BP, the person should take care of him/ herself so that it doesn't affect other things which could bring the stroke [R4]*

7.3.2.4 Family history

Family history appeared within the narratives of participants from the Stroke Unit. The participants mentioned that the existence of stroke in a family can put an individual at risk of stroke. Participants' knowledge was drawn from personal observations as well as lived experiences of their care recipients.

> *I: You said stroke exists in his family. Amongst his siblings, is he the only one with stroke?*
> *P: No. some of them have even passed on*
> *I: How many siblings has he got?*
> *P: Two*
> *I: And they have both passed on?*
> *P: Yes [R25]*

7.3.2.5 Spiritual causal theory

Three participants in all the three study sites mentioned that stroke can occur through spiritual attack or it can be invoked on an individual by someone else. Some of the participants drew on this knowledge because they could not offer explanation to the cause of their care recipients' illness (stroke). Some also mentioned that stroke can be spiritually caused as a way of implying that living with stroke is not based on individual's actions.

> *However, sometimes, it may be given to you spiritually [R8]*
>
> *I don't know. I feel it is an attack (spiritual attack I guess) because we have gone to check for any heart problem, kidney, liver, all are normal. He is not diabetic [R12]*
>
> *I think it is somebody who sent it to him because how can somebody who came back and went to sleep in the evening time as siesta come out like this [R12]*

7.3.2.6 Other chronic diseases

Participants mentioned that other chronic diseases such as diabetes and multiple sclerosis can result in stroke. They also mentioned that untreated diabetes, non-adherence to medication and indulgent in poor lifestyles as a diabetes patient can lead to stroke. Their narratives were drawn mostly from the experiences of their care recipients as well as scientized knowledge from the health professionals.

> *If you have diabetes and you're not checking it, it leads to stroke. You're having diabetes but you're taking alcohol, which has sugar in it. When you come back, then you also go and buy 'hausa koko' which also has sugar in it. After that, then you sleep. So I feel the diabetes is what caused the stroke [R25]*

7.3.2.7 Stress

Some of the caregivers mentioned stress as the cause of their recipients' stroke. The dimension of stress included lack of rest or not having enough rest after involvement in too much work. This knowledge was based on the experiences of the care recipients.

> *My mom is a trader and works very hard. She brought us up single-handedly and she wasn't having enough rest. You know most of these traders work so much and just take a little rest when they feel headache from too much working [R18]*

7.3.2.8 Non-adherence to health care

Non-adherence to health care entails not following scientized advice on health issues. Participants mentioned that irregular blood pressure check, non-adherence to anti-hypertensive medications, non-intake of drugs when sick, and not seeking biomedical treatment early after notice of symptoms can result in stroke. The narratives of these participants were based on their care recipients' experiences and scientized knowledge from encounters with health professionals.

> *Since it is BP which causes it, so if you don't take medications and check your BP you can get stroke [R1]*
>
> *My father's friend is a doctor, he used to tell us that if you're the kind who doesn't go to the hospital to check your blood pressure, you can get stroke [R1]*
>
> *...and she not taking her medicine. According to her, it was only on that day that she failed to take her medicine on time [R15]*

7.3.2.9 Other causes

Participants mentioned that stroke can be caused by other factors such as: lack of knowledge about health issues, not being sociable, predestination and not paying attention to patients' complaints.

> *...to some extent, I think it is lack of knowledge about certain health issues [R21]*

A participant from the Stroke Unit mentioned that stroke can be caused by 'non-sociability'. This narration was based on the experience of a care recipient who is living with stroke. According to the participant, the sister liked to be alone all the time and that was why it was difficult for anyone to help her when she experienced the stroke symptoms because she always locked herself in the room. Hence, when she (care recipient) fell down in the room, she was helpless for four days before she could get to open the door for people to come to help out. By that time, her condition had become worse. The caregiver mentioned that the stroke could have been prevented if his care recipient was more sociable.

> *If you ask me, where I think she can help herself is that she needs to change her lifestyle and be 'socially inclusive' (interact with people) [R21]*

Further, another participant from the Stroke Unit mentioned that her mother's illness could have been prevented if the health professionals had paid more attention to her. This participant also attributed her mother's stroke to predestination and acknowledged that the illness will happen irrespective of health professionals' actions.

...at the moment she's 90 and when it started she was 88 so she was already an old lady. But I remember one Friday morning, she was bathing and she called the young lady who was looking after her to call me and said that her legs had become very 'heavy' and she could not move them. So I quickly went there and affirmed what she said. It was a weekend and I didn't want her to remain in the condition over the weekend and it was very difficult going to the hospital over a weekend, so we took her to her doctor. But when we went, the doctor measured her sugar level and said it was the sugar level that had dropped. So he gave her some Coca-Cola and it came back up, so we returned home. We used a wheel chair when we were going there, but when she was attended to, the doctor asked her to get up on her own, which she did so we all thought she was okay. But the following Sunday, she had a stroke. So I think maybe if the doctor had done more and rather not consider that she's an old lady so it was nothing, maybe the stroke could have been delayed or checked or stopped or something of that sort. I keep saying though that we're not God so I think this is how it had to be. But these things do happen, where the words of the elderly are taken lightly by doctors because of their age. Before then, my mother was functionally independent and all of a sudden the stroke comes in and everything just changed [R26]

7.3.2.10   Groups at risk of stroke

Participants were asked to indicate the groups who are at risk of stroke. The categories which came were segmented by: sex, age, lifestyle, and specific diseases. With regard to sex, equal number of participants mentioned that men and women are at risk of stroke. While some of the participants mentioned that the elderly are more at risk of stroke, others (especially from Physiotherapy and Stroke Units) mentioned that both young people and the elderly are at risk of stroke. The narratives of participants from the Physiotherapy and Stroke Units were based on observations at the hospital.

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> *...the very elderly people around the ages of eighty years old. But these days you see very young people also getting the disease [R3]*

Further, participants mentioned that people who sleep immediately after eating, people who consume a lot of alcohol and are obese or overweight, are more at risk of stroke. Some of the participants mentioned that anyone can get stroke. Two participants from Ga Mashie and Stroke Unit mentioned that they did not know the groups at risk of stroke.

> *I think we are all at risk of getting it, even the young ones. Both men and women [R16]*
>
> *Oh, I can't tell. I honestly can't tell because this is my first close experience with someone having stroke [R23]*

.

7.3.3 Complications of stroke

The participants were asked to list the complications of stroke as well as the complications of their care recipients. The knowledge of the participants centered on four main themes: 1) physical disability; 2) behavioural and psychological changes; 3) cognitive disability; and; 4) death.

7.3.3.1 Physical disability

Physical disability formed the dominant theme on the knowledge of caregivers on stroke complications. The participants mentioned that anyone living with stroke will experience physical disabilities such as: inability to eat alone; immobility; loss of limbs; numbness in limbs; inability to work; inability to do things; not being active as before; pain in "manhood", and; other forms of physical disabilities. Participants' narratives came from their care recipients' experiences.

> *...yes, sometimes when he urinates he experiences pains in his manhood [R11]*
>
> *It affects a lot of things, there are things you wish you could do yet you cannot do them again [R4]*

7.3.3.2 Behavioural and psychological changes

Participants mentioned that stroke can bring about behavioural and psychological changes in an individual living with stroke. The behavioural changes mentioned by four participants included: being easily annoyed, getting angry easily and not wanting to be helped. These narratives were based on caregivers' experiences with their care recipients.

> *She gets angry very quickly, she is very quick tempered. But when she is angry, I am the only one who can calm her [R4]*
>
> *...he doesn't calm down to be helped. He wants to do everything on his own [R8]*

Psychological disability refers to the effect of stroke on the thinking pattern of the stroke survivors. Only two participants mentioned that stroke could result in psychological disability such as consistent thinking and worry.

> *He is always been thinking more than he should. Thus, worries a lot about things he shouldn't even be bothered about[R4]*

7.3.3.3 Cognitive disability

According to the participants, stroke could result in cognitive dysfunctions such as: inability to remember things, forgetfulness and brain damage. The explanations of the participants were drawn from their care recipients' lived experiences. These complications were mentioned by caregivers recruited from the Stroke Unit.

He forgets what he has been doing in the church. Sometimes he forgets to do it. If I remind him then he will do it **[R12]**

He cannot even remember anything. All he remembers is the meetings concerning his business and other appointments **[R15]**

7.3.3.4 Death

One participant from Ga Mashie mentioned death as one the complications of stroke. The participant saw this complication as the end point of stroke prognosis.

The end result of such a case is that you will die. Because you would also think a lot; and with this kind of situation, you don't have to think a lot. Because when you have stroke, it comes with BP, so you don't have to think too much...[R6]

7.3.4   Stroke prevention

Participants were asked to explain how stroke can be prevented. Their narratives fell under five (5) broad categories: 1) Good dietary practices; 2) Good lifestyle practices; 3) Psychological balance; 4) Adherence to health care, and; 5) other factors.

7.3.4.1 Good dietary practices

Participants mentioned that engaging in good dietary practices can help prevent stroke occurrence. Good dietary practices formed the dominant theme in the explanations of the participants on how stroke can be prevented. Several codes were listed under this but this can be broadly re-categorised into five: 1) being observant about what one eats; 2) reduction in intake of some foods, and; 3) consuming more of some foods; 4) eating a balanced diet, and; 5) not eating late.

Firstly, the caregivers mentioned that an individual has to watch what he/she eats in order to prevent stroke occurrence. This includes not eating sugar and not taking a lot of fufu most especially for those who are old. Secondly, the caregivers explained that every individual has to reduce intake of some foods such as fat, meat, sugar and salt in order to avoid stroke. Further, the participants identified some foods that have to be consumed more often to help prevent stroke. These include plantain, foods rich in iron, fruits and vegetables. Participants also emphasized eating well or eating balanced diet in order to avoid stroke. Timing of food also came out from the narrative of one of the caregivers. He emphasized that not eating late can help prevent stroke occurrence.

> *We must limit meat in-take and rather focus on vegetables and other fruits that can prevent some of the sicknesses [R12]*
>
> *Well, the little I know is that you are not supposed to eat late [R17]*
>
> *I will tell the person watch the food they eat and things they do so that they don't get it [R7]*

7.3.4.2 Good lifestyle practices

Adoption of behaviours that are healthy to the body is seen as one of the ways of preventing stroke. The caregivers' narratives centered on six interrelated areas. These include: 1) taking a lot of water; 2) non-consumption of alcohol; 3) not smoking; 4) regular exercise; 5) adequate rest, and; 6) taking care of oneself properly. This knowledge was mostly drawn from scientized information from health professionals.

> *Exercising more reduces your chances of getting a stroke [R11]*
>
> *Not everyone can get it. If you take care of yourself properly, you might not get it [R8]*

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7.3.4.3 Psychological balance

Participants mentioned that there is need to maintain a psychological balance in order to avoid stroke. This includes not being quick tempered, not taking anything too serious, not getting angry and not thinking too much.

> *I: how do you think stroke can be prevented?*
>
> *P: don't think too much. Try to be sincere. Don't take anything too serious, let your life be as light as anything [R29]*

7.3.4.4 Adherence to health care

According to the participants, adherence to health care such as regular hospital check-up and regular blood pressure check can help prevent stroke occurrence.

> *What I will tell them is that if they are advised not to do certain things they should abide by it. Otherwise you will experience complications in a lot of things. It could even go on to affect your family [R3]*

7.3.4.5 Other factors

Participants mentioned that not working with vibrating machine and increased regular blood pressure monitoring can help in stroke prevention. According to one participant from the Stroke Unit, working with vibrating machines can raise an individual's blood pressure and this can lead to stroke. His explanation came from what he believed to be the cause of his care recipient's stroke.

When you go outside, the government actually spends a lot of money on educating the people because they believe it's a proactive form of applying medication. Thus, teaching somebody to take care of himself and check his BP and stuff like that… the likelihood of that person developing stroke is not high [R20]

As for that I don't know (participant referring to stroke prevention). If you know can you please teach me [R17]

Figure 7.1 Thematic Network showing knowledge of stroke from the perspectives of the caregivers
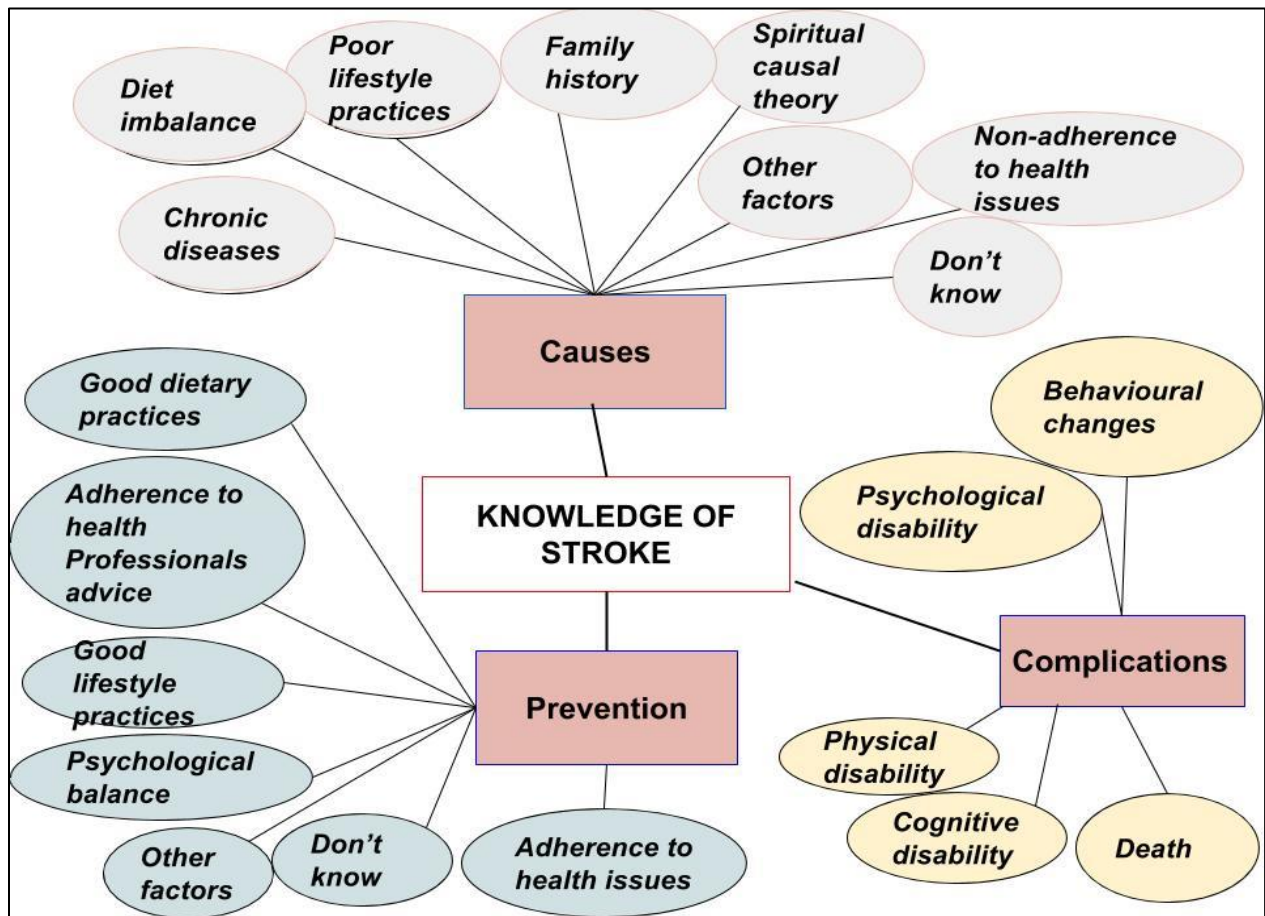
7.4 Experience of stroke caregivers

The experience of stroke from the perspectives of the stroke caregivers is organised into four themes: 1) Immediate reaction after diagnosis; 2) Impact of stroke; 3) Types of support provided

for stroke survivors, and; 4) Types of social support received (These refer to the resources that caregivers drew on in coping with their caregiving duties).

7.4.1   Immediate reaction after stroke diagnosis

Participants were asked to explain how they felt after their care recipients were diagnosed with stroke. Majority of the caregivers expressed different forms of emotions such as sadness, worries, fear, etc. Three categories of emotional responses emerged from their narratives. Firstly, for some of the participants, the emotional responses were as a result of the sudden nature of stroke. For others, they expressed those emotions because they were aware of the numerous disabilities associated with stroke.

> *Honestly I was really sad, because someone with whom we were living normally, he just complained of malaria and went to buy the drugs himself then all of a sudden getting stroke, it was really disturbing* **[R1]**
>
> *Well, initially because I haven't experienced it, I only heard of it and I didn't know what it is. I was a bit afraid that my wife is going to be bed ridden. It was a bit difficult for me and more importantly for people around who used to see her as someone who was strong and going about her business…all that they see now is that she is in her wheelchair and all that. It was something difficult for me to bear* **[R24]**

In addition, some of the participants expressed different emotions because they felt their care recipients were too young to be diagnosed with stroke. One participant from Ga Mashie particularly mentioned that she cried because her care recipient still had little children to take care of and despite the fact that his wife has left him.

> *It disturbed me that he had stroke, because he is not old, and his children are still very small. When the doctor broke the news that day, honestly, I cried because his children are very small* **[R1]**

Some of the female caregivers were worried because with the household head being diagnosed with stroke means a disruption in the families' livelihood. One participant from the Stroke Unit was so devastated to the extent that she could not describe the extent of her devastation.

> *I was worried. I was worried because a man who was heading the house, now look at him. So I told myself that the Lord is my strength* **[R9]**
>
> *I was so devastated, everything…everything was…, I don't know the words to use* **[R23]**

Due to the sudden nature of the illness as well as lack of knowledge of stroke symptoms, some of the participants denied the diagnosis when their care recipients were diagnosed with stroke. Conversely, some of the caregivers believed the diagnosis because the physical disabilities of their care recipients were evident.

> *…it depended on how the nurse said it that maybe it has entered into his head. So she told me in front of him, so I went there and I told him that he should not mind them and that nothing will happen to him. Nothing has entered into him. He is normal* **[R9]**
>
> *I didn't really believe that, because the first day it happened, it was his mouth that had tilted* **[R27]**

> *I know for stroke when you have it you cannot walk so I believed it was stroke* **[R17]**
>
> *I believed it, because of the way the hand has become, and mostly this is how stroke starts* **[R14]**

7.4.2   Impact of stroke on caregivers

Participants were asked to state the impact stroke has had on them. Their narratives can be divided into seven (7) broad categories: 1) disruption to physical body; 2) nutrition disruption; 3)

disruption to economic circumstances; 4) lifestyle disruption; 5) psychological disruption; 6) social disruption, and; 7) disruption to life circumstances (Figure 7.2).

7.4.2.1 Disruption to physical body

Many of the participants mentioned that as a result of caring for the stroke survivors, they do experience pains all over their bodies as well as tiredness. Disruption to physical body occurred as a result of the physical disabilities of the stroke survivors, the physical demands of caregiving and the stress of getting medications for care recipients. One elderly woman from the Physiotherapy Unit expressed tiredness in the search for the stroke survivor's medication considering the fact that she is also hypertensive.

> *It hurts, sometimes (m hmm) this hand (pointing to one of her hands) I feel pains in it as if there is a wound in it. And also I feel pains around my waist, my thighs I feel pains. Sometimes this part of my body hurts [R17]*
>
> *Yeah. Saturday this is the only time I'm sitting beside him to rest. I've been moving from one pharmacy to the other. You'll get one drug here and you wouldn't get the other there. I'm very tired and I myself I have pressure (hypertension) [R12]*

With regard to the extent of physical pains experienced by the participants, some of them mentioned that they experienced pains because they were the only one taking care of the stroke survivors. One participant from the Physiotherapy Unit expressed that he had not been feeling well because of the caregiving duties and he expressed dissatisfaction with the prolonged nature of the illness despite all his efforts.

> *I am worn out because I am the only one taking care of him [R12]*
>
> I'm not feeling okay but the sickness too isn't going so there's nothing I can do about it *[R10]*

7.4.2.2 Nutrition disruption

Some of the participants mentioned that caring for the stroke survivors has caused them to experience changes in their diet practices. They have either stopped consumption of some foods or they are being cautious of the foods they eat due to the stroke experience. Two participants from the Stroke Unit mentioned that they have not experienced change in diet because they have always been cautious of what they eat.

> *Now I'm very cautious when I'm eating something most especially taking of alcohol* ***[R14]***
>
> *About the food I eat, it hasn't changed much because my diet has always been extremely simple. So in that regard, it hasn't changed* ***[R26]***

7.4.2.3 Disruption to economic circumstances

The disruption to economic circumstances took two different dimensions. These include: 1) effect of stroke on the jobs of the caregivers, and; 2) the financial demand of caregiving. Disruption to economic circumstances formed the major dominant theme under the impact of stroke. Participants' narratives regarding the effect of stroke on the job of the participants focused on inability to take up job opportunities, reduction in job outputs, and resignation from work as a result of caregiving demands.

> *It has really affected my output at the workplace but my employers understand. As we are talking now, I have to attend the finance committee meeting…I have to deliver a presentation on that. Here, I am to make sure she gets the deserved care. So in terms of my work it has affected me* ***[R24]***
>
> *After SHS, I had the opportunity to go and teach in a certain school but because of the sickness I couldn't accept it. Otherwise, there would have been nobody at home to take care of my mom* ***[R11]***
>
> *…very much. The money I'm spending to take her to the hospital, I could have rather saved it and used it for something else* ***[R7]***

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The narratives of the caregivers with respect to the financial burden focused on expenditure on drugs and other associated cost on stroke treatment.

> *...Not really but financially, it has , financially it has really affected it but my social life and all that I know it is one of those things so it really didn't affect in those parts but financially it has [R23]*
>
> *Financially, I will say it has had a lot of impact on me because aside the medication which are very expensive because on daily basis I have to spend about 100 Ghana Cedis on some of the medicine and the up keep; buying of diapers, the food the kind of food that she will have to eat. So financially it has had a lot of impact on me [R24]*

7.4.2.4 Lifestyle disruption

Participants mentioned that they have experienced lifestyle disruption as a result of their caregiving duties. Firstly, the participants have been experiencing lack of deep sleep as a result of their caregiving responsibilities. Further, one participant from the Stroke Unit mentioned that she has become more organised than before.

> *....they aborted the seizure upon getting there. Because of such unforeseen occurrences I don't sleep deep because I still have such fears [R18]*
>
> *...rather, it has forced me to take another look at certain things. I know that I have to be organised because one day you're very okay but the next day, functionally you cannot do anything [R26]*

7.4.2.5 Psychological disruption

Participants from the three study sites experienced psychological disruptions as a result of caring for the stroke survivors. These disruptions include: worry, thinking about care recipients' condition, fear, feeling worn out, and experience of emotional difficulties.

> *Yes, I really think about it and people tell me not or else if I should die as a result, who will take care of her? [R7]*
>
> *Yes, I was thinking about it if she will recover. Initially, I will even cry the whole day because I know about the stroke and all that [R23]*

7.4.2.6 Social disruption

Participants had experienced social disruption as a result of caring for stroke survivors. This included inability to attend social functions and not being able to go out anymore due to caregiving duties.

> *At times, sometimes I have to go somewhere but I can't. Just last week, I had to travel but I could not go. Sometimes he feels that when I am not around, he does not feel happy, even at home I'm so busy [R14]*
>
> *I used to visit friends and go out. But ever since he fell sick I've not been able to go anywhere because there's no one else to take care of him [R13]*

7.4.2.7 Disruption to life circumstances

One participant from the Physiotherapy Unit mentioned that the family has experienced change in place of residence because of lack of toilet in the previous place of residence.

> *I: hmm, so you left the house because of the condition*
> *P: I left because that place has no toilet. [R9]*

Figure 7.2 Thematic Network showing impact of stroke on stroke caregivers
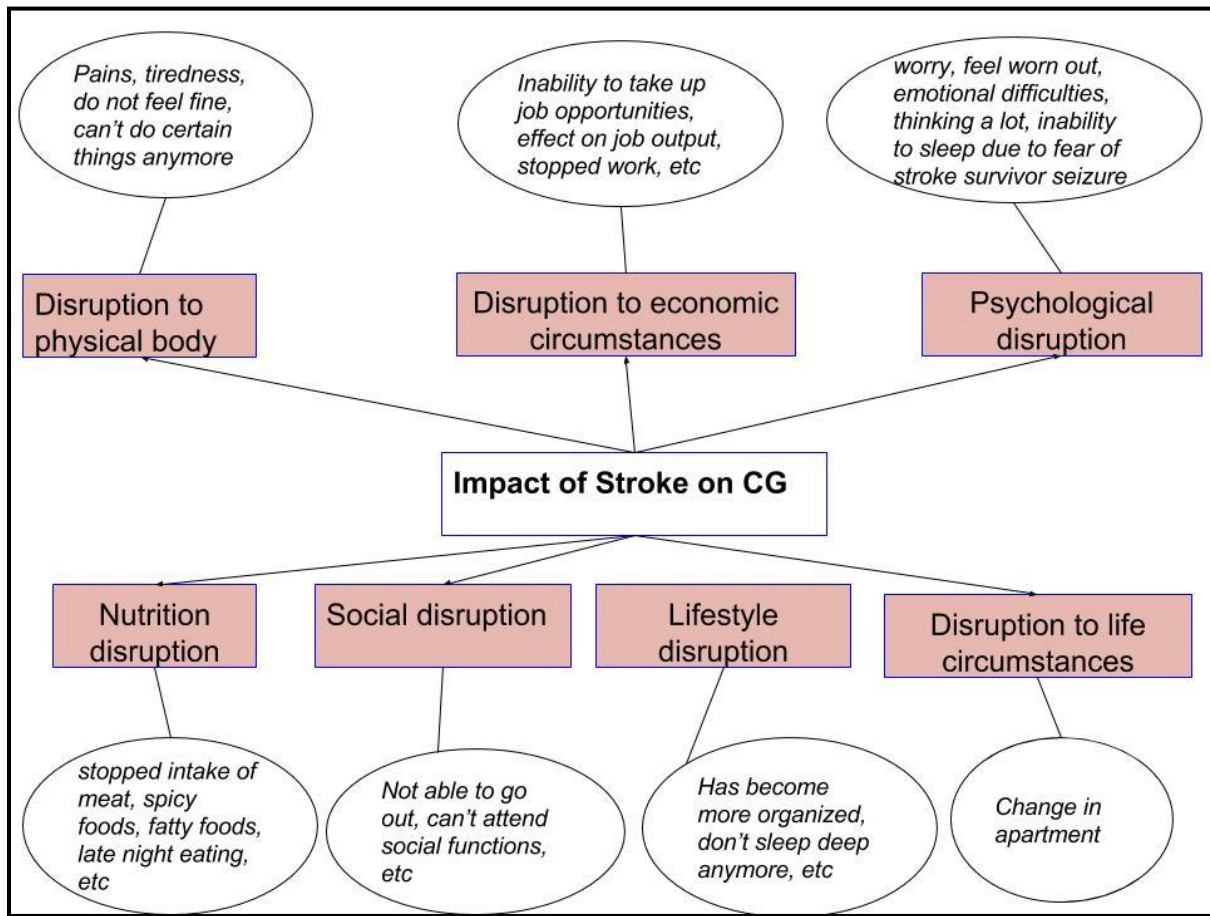
7.4.3 Types of support provided to the stroke survivors

The participants were asked to outline the types of support they provided for the stroke survivors.

Their narratives centered on three themes: 1) physical support; 2) financial support, and; 3)

emotional support.

> *when he needs money, I have to give him fast, because there is no one here to take care of him apart from me]R8]*

With regard to the physical support, the participants helped the stroke survivors in bathing, cooking, fetching of water, washing of clothes, and running of errands. Physical support formed the dominant support provided by the caregivers to the stroke survivors.

...as at now we have accepted the fact that she is sick, so we're taking care of her. I bath her and wash her clothes [R5]

I am the one who takes care of her in every aspect. Excuse me to say even if she wants to visit the toilet. I get tired but there's no one to do it in my stead [R4]

The financial support provided by caregivers to the stroke survivors focused on provisions of money for the purchase of drugs and to take care of other needs of the stroke survivor. The

emotional support given by caregivers included giving of encouragement and advice to stroke survivors.

Financially, I don't make her to know I am financially down, no, so whenever there is the need to buy any medicine I make sure the medicine she takes are there [R24]

I give him so much love right now, so that he will be able to heal on time. He usually gets angry sometimes, but I give it a blind eye, and return it with love [R28]

7.4.4 Coping strategies/social support received

This section focuses on the types of support received by the participants in coping with their caregiving duties. These supports centered on three categories: 1) physical; 2) financial, and; 3) psychological.

7.4.4.1 Physical support

The physical support received by caregivers focused on the help they received with bathing the stroke survivors and in moving him/her around.

> *I: who else has been of help to uncle apart from you?*
> *P: his wife and his niece.*
> *I: what kind of support do they give?*
> *P: they help physically [R24]*

7.4.4.2 Financial support

Some of the caregivers received financial support from significant others in order to take care of the stroke survivors. This helped them to cope better as caregivers.

> *Mmm… Not really, I do things myself aside a friend who helps financially, psychologically, I mean every … (giggles), he is really helping me [R23]*

7.4.4.3 Psychological support

The psychological support received was in the form of encouragement, advice and other forms of emotional support.

7.5   Discussion

This section discusses the findings on knowledge and experience of stroke from the perspectives of the stroke caregivers. The discussion is organised around these three themes; 1) Awareness and knowledge of stroke; 2) Experience of stroke caregivers, and; 3) Social support.

7.5.1   Knowledge of stroke

The findings showed that many of the caregivers had pre-diagnosis awareness of stroke. However, many of those with no pre-diagnosis awareness were from Ga Mashie and they were people with Junior High School education and below. The stroke caregivers attributed stroke to nine causal theories: dietary imbalance, poor lifestyle practices, high blood pressure

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(hypertension), family history, spiritual causal theory, non-adherence to health issues, stress, other chronic diseases (diabetes and multiple sclerosis), and other factors (such as lack of knowledge about health care, not being sociable and not paying attention to stroke symptoms). The dominant themes in the causal theories of stroke were hypertension and poor lifestyle practices and this knowledge was drawn from stroke survivors' experiences. Generally, the findings showed that participants placed emphasis on practical biomedical knowledge concerning stroke causal theories.

With regard to knowledge on stroke complications, participants identified different interrelated disabilities of stroke (physical, behavioural, cognitive and psychological) in line with what literature suggests (Charmaz, 1983; Cameron et al., 2010). With respect to knowledge on stroke prevention, participants placed more emphasis on good dietary and lifestyle practices. This shows that participants attributed more importance to biomedical knowledge because these modes of stroke prevention have been identified in the literature as well (Chiuve et al., 2008). These narratives cut-across the different level of education. This is not surprising because the stroke caregivers mostly drew their knowledge from scientized information from health professionals. In addition, participants stated that stroke can be prevented through government's sensitizations on the need for regular blood pressure monitoring in the population.

 This is important considering the fact that a significant number of participants from Ga Mashie did not have pre-diagnosis awareness of stroke. This gives an indication that there may be low awareness of stroke among the members of the community. This is not surprising because Sampane-Donkor et al. (2014) has shown poor community awareness of stroke in Ghana. Therefore, consistent sensitization on the need for regular blood pressure check in the

community may help to detect elevated blood pressure and this can be tackled early before it progresses to stroke.

7.5.2 Experience of stroke

The experience of the participants on stroke focused on four interrelated themes: immediate reaction after diagnosis, impact of stroke, types of support provided for stroke survivors and types of support received from significant others. The findings showed that many of the participants expressed different forms of emotions after their care recipients were diagnosed with stroke. These expressions were influenced by the sudden nature of stroke, pre-diagnosis awareness of stroke disabilities, younger age of stroke survivors and projected strains on households' means of livelihoods. These emotional responses are not unexpected because research has shown that stroke disrupts the structure of everyday life of both the stroke survivors and their caregivers (Cameron et al., 2010).

The findings further showed that the impact of stroke on the caregivers were multi-faceted. This impact included: disruption to physical body, change in dietary pattern, disruption to economic circumstances, changes in lifestyles, psychological disruption, social disruption and change in place of residence. The findings indicated that the caregivers saw stroke as a disruption in the lives they were used to before their care recipients were diagnosed with stroke.

Further, many of the participants were stressed because they have either stopped working, reduced work hours or could not take up some jobs because of their care recipients. Coupled with this, they expended a lot of money on taking care of the stroke survivors and some have even used their personal savings on this. Since some of the caregivers have either stopped working or used their savings in taking care of the stroke survivors, they were however not able

to adequately provide enough support to the stroke survivors and this led them to experience frequent thinking, feeling worn-out and fear of how to mobilise resources. This is consistent with what literature suggests that one of the major disruptions of a chronic event is the fear of how to mobilise resources for proper management of the illness (Bury, 1982). One participant has however experienced biographical transformation. This participant saw his care recipient's stroke as a blessing in disguise because of the transformation that took place in his economic circumstance.

The participants provided more support for the stroke survivors than they received from significant others; this limited their capacity to cope well with their caregiving duties. Generally, many of the caregivers mentioned that they had experienced stress in their caregiving duties. While some of them perceived their caregiving duties as something that they had to do, others admitted that they were tired of providing care because of the stress involved and because of the behavioural changes in their care recipients. Some of the participants mentioned that their care recipients were difficult to relate with sometimes and one participant said that she was tired of her care recipient. Further, some of the caregivers mentioned that even though they experienced stress, they made their care recipients feel that the caregiving had no impact on them. The impact of caregiving was more for those in the Stroke Unit as they were not familiar with their caregiving duties. Many of these people spent most of their time around the Stroke Unit as they had to visit their care recipients from time to time.

7.6   Causal theories and experience of stroke: perspectives of the stroke survivors and their caregivers

Stroke survivors attributed stroke causes to 11 factors while caregivers mentioned nine causal theories of stroke (Figure 7.3). The dominant theme for both dyads was poor lifestyle practices (such as smoking, alcohol consumption, physical inactivity), followed by high blood pressure. Eight of the factors mentioned by both dyads aligned with biomedical theories (Box 7.1). Spiritual causes, contagion and predestination were factors that did not conform to biomedical models and two of these factors (contagion and predestation) came from the narratives of the stroke survivors.

With regard to stroke complications, discussion around physical disabilities was common to both dyads. Another complication of stroke mentioned by the stroke survivors was stigmatization. The caregivers mentioned behavioural and psychological changes, cognitive disability and death as other complications of stroke. This suggests that the caregivers had more knowledge on stroke complications than the stroke survivors and their narratives on stroke complications aligned with biomedical theories (Box 7.1). The dominant source of stroke survivors' and caregivers' knowledge on stroke and stroke complications was the lived experiences of the stroke survivors. This suggests that many of the stroke survivors may not have known about stroke and its complications if they were not diagnosed with the illness. In the same way, their caregivers may not have had much knowledge about stroke and its complications if they were not providing care.

This study showed poor pre-diagnosis knowledge among the stroke survivors and their caregivers. This is contrary to the situation in a high income country such as Canada and a middle income country such as India (Pandian et al., 2006) where stroke survivors and caregivers

have adequate pre-diagnosis knowledge about stroke symptoms, causes and complications and their main source of knowledge was the media (Schneider et al., 2003). This indicates that it is important to find out the most effective means of enhancing pre- and post-diagnosis knowledge of stroke in Africa.

With regard to the impact of stroke, this study intended to first of all find out the multifaceted impact of stroke on stroke survivors and their caregivers. At the second level of analysis, this study aimed to show how the disruptions experienced by the stroke survivors affect the health of their caregivers. This study showed that stroke survivors and their caregivers experienced: body-self disruptions, disruption to economic circumstances, disruption to social relationships, nutrition disruption, and changes in lifestyles (Figure 7.4). However, while cognitive disruption was unique to the narratives of the stroke survivors, relocation of residence was unique to the narratives of the caregivers. The narratives of both dyads (stroke survivors and their caregivers) showed that while body-self disruption was the dominant disruption experienced by the stroke survivors, disruption to economic circumstances constituted the dominant disruption experienced by the caregivers.

Box 7.1 Established biomedical theories of causes of stroke and stroke complications

Causal theories of stroke	Causal theories of stroke complications
Common causes	1. Recurrent stroke
1. High blood pressure	2. Epileptic seizure
2. Diabetes	3. Urinary tract infection
3. Serum cholesterol	4. Chest infection
4. Fibrinogen	5. Falls with serious injury
5. Smoking	6. Pressure sores
6. Diet	7. Deep venous thrombosis
7. Alcohol consumption	8. Pulmonary embolism
8. Physical inactivity	9. Pains
9. Family history	10. Depression, anxiety, emotionalism, confusion
10. Obesity	11. Incontinence
11. Education	12. Pneumonias
12. Social class	13. Fever
13. Ethnicity	14. Dysphagia
14. Environmental factors that may be physical (temperature, altitude), geographical or psychosocial	
15. Medical conditions such as: hyperlipidemia, thromboembolism, hypercholesterolemia, rheumatic heart disease, Transient Ischemic Attack, Atrial fibrillation	

Sources: Truelson, Begg and Mathers, 2000; Reviewed studies on burden of stroke in SSA (Chapter Two); Langhorne et al., 2010; Kumar et al., 2010

Figure 7.3 Hierarchical causal theories of stroke from the perspectives of the stroke survivors and their caregivers
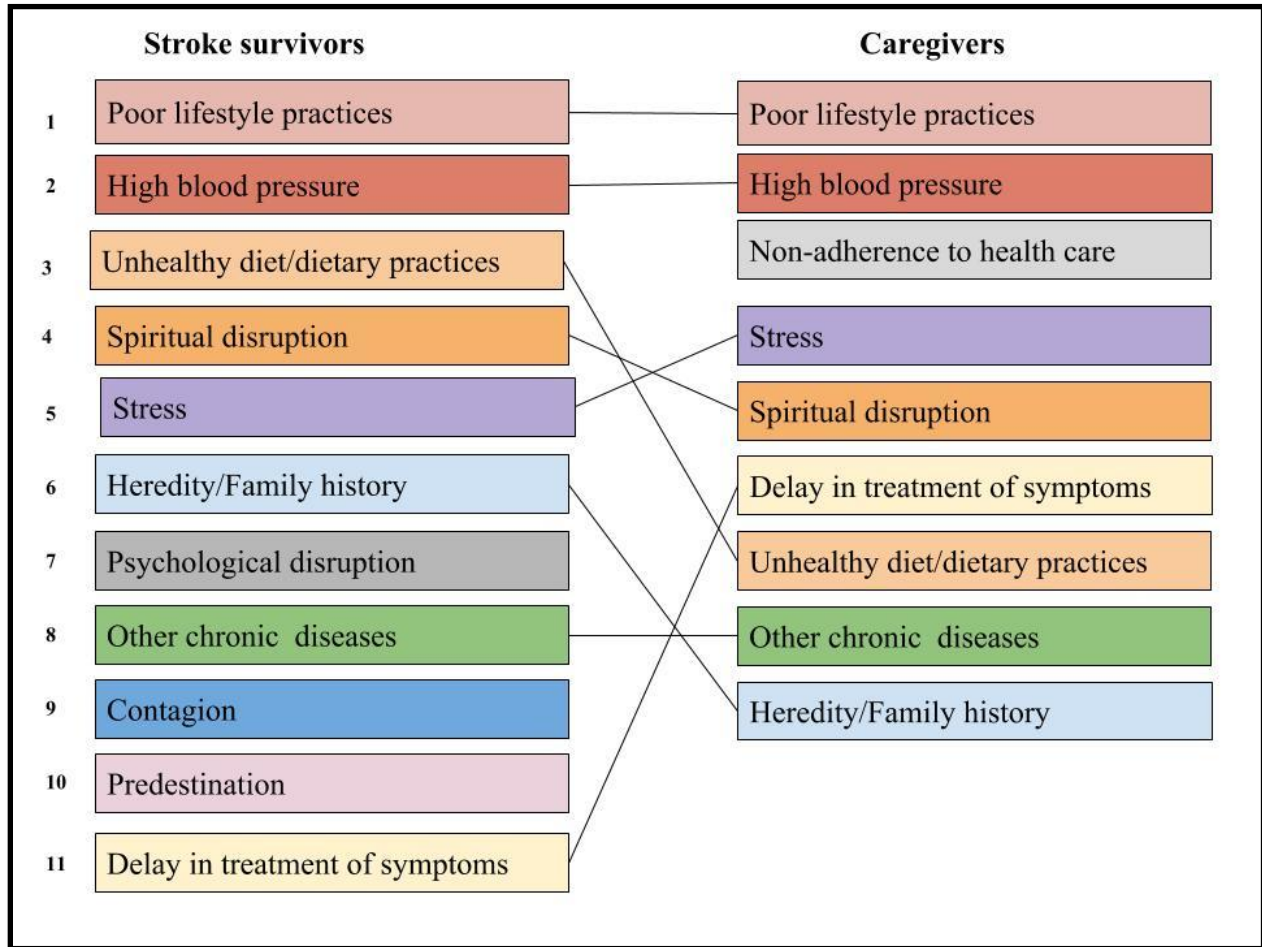
Further, the findings indicate that the disruptions experienced by the stroke survivors affected the caregivers in different areas but the effect was mostly felt in their economic circumstances. This clearly shows the areas that need to be focused on in addressing the impact of stroke on stroke survivors and caregivers in an African context. This finding also alluded to what has been shown in the literature that the impact of stroke is not only on the stroke survivors, but the health of the caregivers is also affected. This indicates that intervention needs to adopt a combined patient-and caregiver-focused approach in stroke survivor rehabilitation rather than patient-focused approach.

Even though stroke survivors and caregivers in high income, middle income and low income countries experience biographical disruption at the initial stage of the illness, many of those in high income countries are able to move from this disruptive state to a transformative state because of the resources (material, psychological, and symbolic) available to them (American Heart Association, 2015; Bury, 1982). However, this study showed that only one caregiver experienced biographical transformation while none of the stroke survivors had experienced biographical transformation. What was clear from this study is that the ability to move from the disruptive state to a transformative state is dependent on the availability of resources (pre and post diagnosis stroke knowledge, material, psychological and symbolic resources).

In a high income country such as the United States of America, stroke survivors have access to community resources such as adult day care, adult foster homes, home health aide service (in-home personal care assistance), homemaker assistance (supervised, trained personnel who help with household duties), respite care (people who come into the house for a limited time to give caregivers a break), and meal programmes (a federally sponsored nutrition program) (American Heart Association, 2015). These resources help to lessen the caregiving burden. Also, training programmes are available for these caregivers for them to become familiar with their caregiving duties. On the other hand, caregivers in an African country do not have access to these community resources. This study also showed that a significant number of the caregivers had low pre-diagnosis and inadequate post-diagnosis knowledge of stroke and no formal training programmes exist for these caregivers; this speaks to the quality of care they can provide for their care recipients. Coupled with this, this study showed that many of the stroke caregivers had experienced loss of income (due to job absenteeism, adjustment of work schedules, and reduced work hours) and other forms of disruptions as a result of their care responsibilities. This shows

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that stroke caregivers in an African setting will potentially experience more caregiving strains than those in a high income country like USA due to lack of established community resources, poor stroke knowledge, unavailability of training programmes and multifaceted and interrelated disruptions of stroke. These have implications on the quality of life of stroke caregivers in Africa and the quality of care they can provide for the stroke survivors as well as the tendency to move from biographical disruptive state to biographical transformation.

Figure 7.4 Hierarchical lists of disruptions experienced by stroke survivors and their caregivers
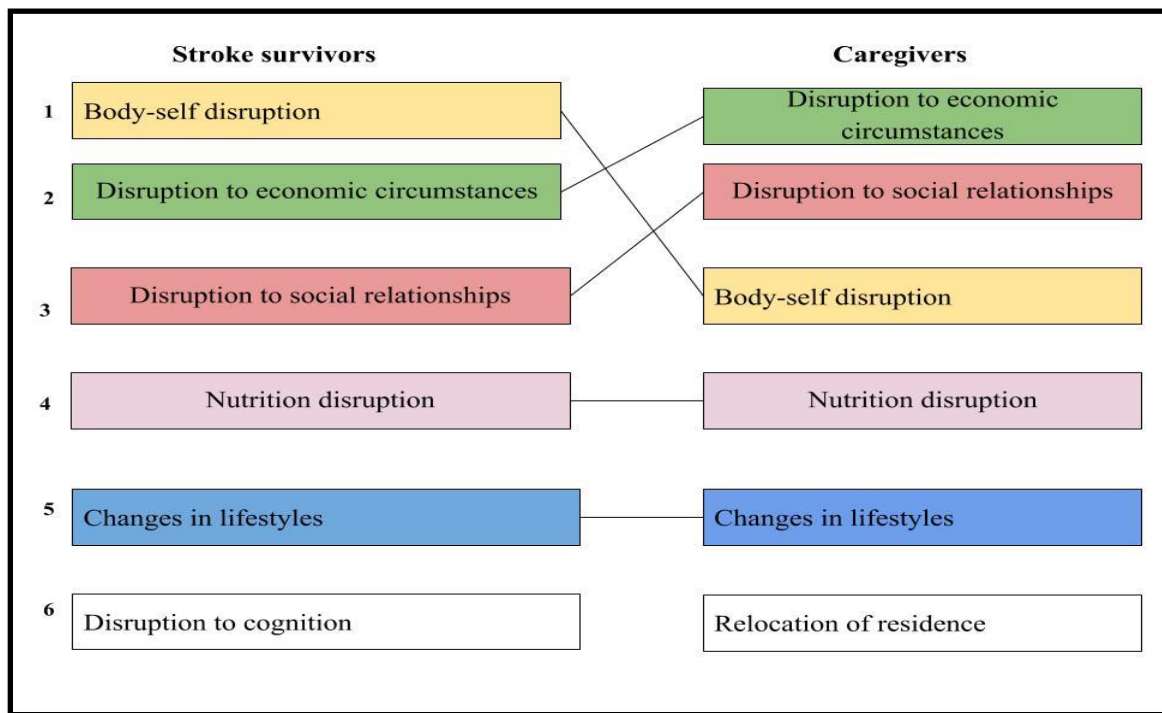
CHAPTER EIGHT

SUMMARY, RECOMMENDATIONS AND CONCLUSION

8.1   Introduction

Stroke is a significant contributing factor to the morbidity and mortality of chronic non-communicable diseases. This however is not being prioritized for control in many African countries partly because of lack of data on the burden of the condition (i.e. prevalence and experience of the condition by survivors and caregivers). Such data are needed in order to develop effective primary and tertiary prevention strategies. Although several studies had been done on stroke burden globally, what is clearly missing in the literature is how stroke survivors and their caregivers conceptualise this condition in terms of: onset of the illness, its perceived causes, symptoms, duration, severity, expected consequences, appropriate treatment and anticipated outcomes. Research has however shown that this information is important because it shows what is most important to the stroke survivors and their caregivers, their beliefs about the illness and what they think can get them better.

This study contributes theoretically to the literature by providing systematic explanations/representations of stroke from the perspectives of the stroke survivors and their caregivers. In addition, this study helps to advance non-communicable diseases' research in Africa by showing that the burden of living with an illness can be understood by interviewing both the sufferers and their family caregivers. What this study has shown is that the impact of stroke on the sufferers affected their caregivers and the reverse was also true. Hence, in order to fully understand the impact of living with a chronic non-communicable disease, the methodology should capture the perspectives of both dyads (i.e. the sufferers and their caregivers). This will help in developing appropriate interventions.

In order to fill this gap, this study sought to investigate the burden of stroke in Ghana with a view to developing primary and tertiary prevention strategies for the illness. Burden of stroke was broadly conceptualized as prevalence and experience. The experience domain focused on: Health Related Quality of Life (HRQoL); immediate reactions of stroke survivors and caregivers after diagnosis; impact of stroke on stroke survivors and their caregivers; health seeking behaviour, and; coping strategies/social supports. Specifically, this study examined stroke prevalence and correlates among Ghanaian adults aged 50 years and above; examined the Health Related Quality of Life of people living with stroke in Ghana, and; explored the knowledge and experience of stroke from the perspectives of the stroke survivors and their caregivers.

In this study, a triangulation mixed method design was adopted using both quantitative and qualitative approaches to answer the research questions. The quantitative aspect focused on stroke prevalence and HRQoL, and the source of data was the wave 1 data of the World Health Organization Survey on Global Ageing and Adult Health (SAGE). On the other hand, the qualitative method was used to explore knowledge and experiences of stroke from participants purposively recruited from Ga Mashie and Korle-Bu Teaching Hospital (Physiotherapy and Stroke units), Accra. This was achieved through semi-structured individual interview with stroke survivors and their caregivers. This study drew on the concepts of HRQoL, explanatory models and biographical theories to explain its concepts and findings. The summary of findings, theoretical implications of findings, policy recommendations and recommendations for future research are presented in this chapter.

8.2   Summary of empirical findings

8.2.1   Prevalence and correlates of stroke

This study showed that the prevalence of stroke in Ghana among people aged 50 years and above was 4.6%. The correlates of stroke included being never married, unemployed, and living with hypertension and diabetes. The findings were consistent with what the reviewed studies on stroke in Chapter 2 showed. Many of the studies in sub-Saharan Africa (SSA) showed that hypertension and diabetes are the two main correlates of stroke in the region.

8.2.2   Quality of life of stroke survivors

This study showed that stroke survivors had low quality of life in the physical health (body-self), functional, psychological, social and environment (economic circumstance) domains of HRQoL. The main predictors of poor HRQoL of stroke survivors were unemployment, lower wealth status and living with hypertension. This finding was also validated in Chapter 6. In Chapter six, the results showed that the impact of stroke on the sufferers was multifaceted and interrelated and this confirmed what previous studies have shown (Sampane-Donkor et al., 2014; Owolabi and Ogunniyi, 2009).

8.2.3   Explanatory models of stroke

Generally, a significant number of stroke survivors and caregivers with low level of education in Ga Mashie did not have pre-diagnosis awareness of stroke. The participants (stroke survivors and caregivers) related stroke to several causal theories such as unhealthy diet/dietary practices; poor lifestyle practices; hypertension; family history; psychological disruption; contagion; spiritual causal theory; predestination; stress; other chronic diseases, and; delay in treatment of symptoms. Contrary to emphasis on the dominance of spiritual causal theories to chronic illness in Africa

(Green, 1992; Kirby, 1993; Nkwi, 1994), this study showed that spiritual causal theory constituted a "peripheral" secondary causal theory. The social determinants of participants' knowledge of stroke were: level of education, lived experiences of the stroke survivors and post-diagnosis information from health professionals. The fact that participants' sources of knowledge were mostly based on lived experiences of the stroke survivors and post-diagnosis information from health professionals indicates that there is probably low knowledge of stroke causes, complications and preventions among healthy individuals in the community. This is not unlikely because a previous study has shown low knowledge of stroke in a Ghanaian community (Sampane-Donkor et al., 2014).

Compared to previous studies conducted on stroke experience in sub-Saharan Africa, as shown in Chapter 2, this study provides a more holistic understanding of stroke experience. This was achieved by providing a clearer picture of participants' reactions after diagnosis, kinds of treatment sought/illness actions, impact of stroke on HRQoL (of sufferers and their caregivers) and the coping strategies available for the stroke survivors and their caregivers.

With respect to the immediate reactions after diagnosis, the findings showed that nearly all the participants (stroke survivors and their caregivers) expressed different forms of emotional responses after stroke diagnosis. For the stroke survivors, the reasons for expressing high level of uncertainties included the sudden nature of stroke, physical disabilities of stroke and low pre-diagnosis awareness. On the other hand, the expression of uncertainties by caregivers was influenced by the sudden nature of stroke, low pre-diagnosis awareness of stroke disabilities, younger age of stroke survivors and projected impact of stroke on households' means of livelihoods. The findings from this study suggest that the prolonged body-self disruption of

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stroke can be minimised by financial support or improvement in the economic circumstances of the stroke survivors and their caregivers.

In the African literature, it has been shown that illness actions are shaped by illness causal theories (Green, 1992; Kirby, 1993; Nkwi, 1994; de-Graft Aikins, 2005). As a result, recommendations have been made along this line. For instance, the dominant assumption in the literature is that individuals who attribute the cause of chronic illness to natural causes will seek biomedical treatment, and those who attribute the cause of chronic illness to supernatural and social causes will seek treatment from ethnomedical systems. Within this framework, poor illness practices have been attributed to faulty cultural beliefs and practices and interventions have been made in addressing the cultural beliefs by promoting public awareness of chronic illnesses (de-Graft Aikins, 2005).

This study showed that contrary to what the literature suggests, participants' illness actions were not shaped by illness causal theories but was rather shaped by a myriad of factors. The immediate illness actions of the participants were shaped by the sudden nature of stroke and pre-diagnosis awareness. With respect to the long-term illness practices, the findings showed that stroke survivors from Ga Mashie mostly practiced illness inactions and sequential use of biomedical and herbal medicines because of high cost of pharmaceutical drugs, cultural beliefs and influence of significant others. On the other hand, participants from the hospital facility mostly practised the dual use of biomedical and herbal medicines due to the prolonged body-self disruption, hope for a cure, personal experiences and influence of significant others. In essence, illness actions with respect to stroke management should not be attributed to faulty cultural

beliefs, but it should be viewed in terms of complex biophysical and psychosocial responses to biographical disruption.

8.3   Theoretical implication of findings

This study drew on the social determinants of health developed by Diderichsen et al (2001) as an overarching concept under which the concepts of HRQoL, explanatory models and biographical theories were subsumed. The findings imply that social positions of adults in Ghana did not really matter with regard to stroke occurrence. However, stroke was rather predicted by other chronic diseases (hypertension and diabetes) which have been regarded as the proximal risk factors of stroke (Alemayehu and Birhanesilasie, 2013; Iadecola and Gorelick, 2004).

This study drew on the biographical theories in explaining stroke experience from the perspectives of the stroke survivors and their caregivers. These included- biographical disruption theory (Bury, 1982), biographical transformation theory (Charmaz ,1983), theory of biographical reinforcement (Carricaburu and Pierret, 1995) and biographical flow theory (Faircloth et al., 2004). These theories have been used by medical sociologists to explain the impact of chronic diseases on sufferers and caregivers. In providing explanation for the immediate reactions of participants after stroke diagnosis, this study drew on the first aspect of disruption (the disruption of taken-for-granted assumptions and behaviours) explained by Bury (1982). The findings for this study confirmed this aspect of disruption because the participants in this study experienced different forms of emotional expressions immediately after their diagnosis. Also, many were shocked because of the sudden change in their bodily state to which they were not familiar with. However, this study moves beyond what was explained by Bury (1982).

This study showed that the emotional expressions of the participants were not only based on the sudden change in the bodily state of the sufferers as suggested in the above theories. For the stroke survivors, the findings indicated that the expression of shock or different emotions immediately after stroke diagnosis was determined by a myriad of factors such as: the sudden nature of stroke, physical disabilities of stroke and low pre-diagnosis awareness of stroke. On the other hand, for the caregivers, the expression of different emotions was influenced by the sudden nature of stroke, pre-diagnosis awareness of stroke disabilities, younger age of stroke survivors and projected impact of stroke on households' means of livelihoods. Pre-diagnosis knowledge of stroke has been identified in the literature as a cause and 'preventer' of uncertainties. Faircloth et al (2004) particularly explained that medical knowledge of stroke is important in dealing with the level of uncertainties.

With regard to the impact of stroke on stroke survivors and caregivers, this study drew on the third aspect of disruption by Bury (1982) (how to mobilize resources in facing the altered situation) and three consequences of a chronic event explained by Charmaz (1983) (living restricted lives, social isolation and burdening others). The findings from this study confirmed the multifaceted impact of stroke as shown by the biographical disruption theory and theory of biographical transformation. This study moved beyond these theories by showing that even though the impact of stroke on participants was multifaceted, they were also interrelated. For instance, for the stroke survivors, this study showed that the disruption to body-self formed the basis for the other forms of disruptions experienced by the stroke survivors. On the other hand, the data on the caregivers suggest that disruption to the economic circumstances was the basis for the other forms of disruptions they experienced.

Further, with respect to the economic implications of living with a chronic illness, Bury (1982) only focused on mobilisation of resources and Charmaz et al (1983) did not directly examine the economic impact of a chronic illness. This study seems to suggest that the economic impact of stroke on both dyads is not limited to mobilization of resources as Bury (1982) suggests, but it extends to impact on economic source of livelihood. In this study, unemployment was a major cause of low quality of life of stroke survivors while impact of stroke on the jobs of the caregivers was a major source of worry for them.

Additionally, in order to see whether stroke survivors and their caregivers move from the disruptive state of the stroke condition to making the condition become part- and-parcel of their biography, this study drew on biographical flow theory developed by Faircloth et al (2004). One of the things that Faircloth et al (2004) mentioned as pre-requisite for becoming familiar with the effects and impact of the disease on daily life and activities was adequate knowledge of the illness. This study revealed that even though many of the participants drew on practical biomedical knowledge on the causes, complications and prevention of stroke, the prolonged disruptions of stroke undermine the benefits of knowledge in managing the illness. For instance, even though participants knew that biomedical treatment is beneficial, those from Ga Mashie could not use this treatment because of finances. On the other hand, participants from the health facility engaged in the dual use of biomedical and herbal treatment despite their high level of knowledge. This indicates that moving from the disruptive state to becoming familiar with the impact of stroke is not dependent on knowledge alone.

From this study, it was evident that changes in participants' biographies were dependent on the resources available to the participants. Based on the findings, this study showed that stroke was a

biographical disruption for few participants who have been living with stroke for less than a year, most especially for those recruited from the Stroke Unit, KBTH. Many of the participants who have been living with stroke or providing care for stroke survivors for two or more years have experienced biographical flow- they have moved from the disruptive state of stroke to making the stroke part-and-parcel of their biographies. Only one stroke survivor (a Pastor) has experienced biographical reinforcement. The Pastor had gone through a period of introspection about his life story and the cause of his stroke; he had decided to refuse to be victim of the illness but decided to be an advocate of change in explaining to his fellow pastors on the need to rest well so as to avoid stroke. One stroke caregiver has also experienced biographical transformation in his economic activities. Prior to his father developing stroke, he was more or less unemployed. But after his father was diagnosed of stroke, a door of job opportunities was opened for him. This caregiver claimed that this transformation in his life history came because God decided to compensate him for taking good care of his father. It is clear from this study that many of the stroke survivors and their caregivers have experienced biographical flow.

The illness practices of the participants have implications for stroke premature death. This study has shown that with the current illness practices among the participants, pre-mature mortality from stroke in the study sites may go up. This study showed that while some of the participants from Ga Mashie practised illness inactions and sequential use of biomedicine and herbal medicines, those from Korle-Bu engaged in the dual use of biomedicine and herbal medicines. These practices have been shown to predict stroke premature deaths. For instance, during follow-up of participants in Ga Mashie, two of the stroke survivors were dead and the conditions of many have deteriorated because of the illness inactions. Therefore, adherence to medications may help to reduce premature deaths among these participants.

8.4   Recommendations

8.4.1   Policy recommendations

Since information about stroke is missing in the national policy on NCDs in Ghana, this study recommends that Ghana's Ministry of Health (MOH) should include stroke in the National Policy for the Prevention and Control of Chronic Non-Communicable Diseases (NCDs). Further, in addressing the burden of chronic non-communicable diseases (NCDs) in Ghana, the country's Ministry of Health (MOH) developed a national policy on NCDs in the country in 2012. The goal of this policy is *"to ensure that the burden of NCDs is reduced to the lowest possible level as to render it of little public health or clinical consequences. This involves reducing avoidable morbidity and premature mortality related to major NCDs".* Even though the goal of this policy seems laudable, the measures put in place in the policy on how the burden of NCDs could be reduced seem unrealistic.

For instance, the policy aims to promote knowledge of fruit and vegetable intake, and good dieting; even though the Ministry of Health has done a lot by sensitizing the population on the need to consume fruits, vegetables and good diet, information on how to make them accessible and affordable is missing in the policy document. This study showed that even though participants from Ga Mashie knew that intake of fruits and vegetables was good for them, they could not afford them. Hence, the challenge for these participants is not knowledge but rather affordability and accessibility. There is need for the Government to come up with programmes that can increase affordability and accessibility of fruits and vegetables in this community.

This study showed that hypertension and diabetes were correlates of stroke in Ghana. Even though part of the aim of the National Policy on NCDs in Ghana is to routinely screen all adults

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aged 25 years and above for high blood pressure, as well as to institute national awareness months for diabetes and hypertension by promoting 'know your blood pressure, know your blood sugar, and know your blood cholesterol'; there is no record that these have been carried out by the Ministry of Health. This study recommends that tackling hypertension and diabetes should be treated as topmost priority by Ghana's Ministry of Health. At the first level, individuals above the age of 25 years should be sensitised by Ghana's Ministry of Health on the need to routinely check their blood pressure and blood sugar level. At the second level, the Ministry of Health needs to consciously engage in regular nationwide screening of individuals aged 25 years and above for high blood pressure and blood sugar. This will help in early detection of hypertension and diabetes in the population before the age of 50.

Further, this study showed the areas of HRQoL that need to be improved upon in order to enhance the health of the stroke survivors and their caregivers. For the stroke survivors, this study showed that improvement in their physical health can enhance rehabilitation in other areas of their lives. On the other hand, the economic circumstances of the caregivers were the most affected areas. The findings also suggest that improvement in the physical health of the stroke survivors can in turn improve the economic circumstances of the caregivers. Therefore, it is important that the health professionals target improving the physical health of the stroke survivors as this can improve their quality of life as well as the health of their caregivers.

As shown in Chapter Two, there are few neurologists in sub-Saharan African. This suggests that many of the stroke patients are being attended to by non-neurologists and general practitioners (physicians who do not specialise in one particular area of medicine) and this leads to poor stroke prognosis within the sub-region. In order to improve the physical health of the stroke survivors,

there is need for a multidisciplinary rehabilitation team to be established in all health facilities in the country. Based on two-week long systematic observations during the fieldwork, the current members of the stroke management team at the Stroke and Physiotherapy Units (KBTH) are too few to handle the influx of stroke cases at the hospital.This means that there is need for more trained neurologists, paramedical staff, physiotherapists, occupational therapists and stroke nurses at the KBTH for proper improvement in the physical health of the stroke survivors. In addition, there is need to expand the gym section at the Physiotherapy Unit as well as increase the equipment used in the gym. This will improve access for the stroke patients and reduces the time they spend at the Out-Patient Department.

This study showed that the immediate health seeking behaviour of the participants was shaped by the sudden nature of stroke as well as pre-diagnosis awareness of stroke. This study recommends the need to promote stroke knowledge in Ghanaian communities so as to increase the knowledge on the warning signs of stroke in order to ensure early detection and diagnosis. After stroke diagnosis at the hospital, there is need for the health professionals to take time to explain the course of stroke prognosis to the stroke survivors and their caregivers by emphasising that rehabilitation can occur with proper management. This will go a long way to influence proper illness actions for stroke management and in the long run help in reducing stroke-induced mortality.

Further, the findings showed that the healer shopping practices among participants from Ga Mashie was mostly influenced by high cost of pharmaceutical drug. Although hope for a cure was held by all participant, it mostly influenced the behaviour of participants from KBTH. This is not surprising because hope for a cure is more acute during the earlier phase of chronic illness

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experience. Therefore, for those from Ga Mashie, there is a need to include some of the key medications mentioned by the participants [such as Bisoprolol and nifedipin (for treatment of hypertension), Somazina Citicoline (for treatment of head trauma, stroke, and neurodegenerative disease - to improve memory, attention span, focus, concentration, etc)] in the National Health Insurance Scheme (NHIS). Currently, out of the 20 pharmaceutical drugs listed in the National Health Insurance Authority (NHIA) 2015–18 Strategic plan, six are anti-malarial drugs, five are analgesics and antipyretics (e.g. paracetamol) and four are cardiovascular drugs (e.g. amlodipine), despite high burden of NCDs in the country (de-Graft Aikins and Koram, 2017). Government's inclusion of these key medications (Bisoprolol, Somazina Citicoline, and Nifedipin) in the NHIS can enhance adherence and proper stroke management. Since many of these participants have functional National Health Insurance cards, this can increase access to these medications.

In addition, participants suggested that one of the ways of preventing stroke occurrence is government's sensitizations on regular blood pressure check. Since the main sources of stroke knowledge for many of the participants were lived experiences of stroke survivors and post diagnosis knowledge from health professionals, these groups can be used as a medium for public education on stroke. This may help to detect and tackle elevated blood pressure before it graduates to stroke.

8.4.2   Recommendations for future studies

Based on the findings from this study, the following recommendations are made for future studies. Firstly, since the sources of stroke knowledge for many of the participants were stroke survivors' experiences and post diagnosis knowledge from health professionals, this may

indicate that there is still low level of stroke knowledge in Ga Mashie. Based on this, there is need for future studies to explore comprehensive knowledge of stroke among Ga Mashie residents. This will help to assess the population knowledge on stroke and help to see areas that need to be improved upon in preventing stroke.

Secondly, in order to fully understand the impact of stroke on stroke survivors and their caregivers, future studies need to focus on using a longitudinal approach. This will help to understand the course of stroke over time in order to come up with evidence-based intervention. This will also help to understand the factors accounting for changes in the biophysical and psychosocial state of the dyads. Since this study was cross-sectional in nature, the participants may have experienced a recall bias in recounting their experiences. As a result, future studies can monitor the lived experiences of the dyads right from the time of diagnosis. This will give a clearer picture of the impact of stroke as well as reveal how the dyads navigate their day-to-day activities.

Thirdly, future studies need to examine the impact of biomedicines, herbal medicines or dual use of both medicines on stroke rehabilitation. This recommendation is based on the responses of the participants who claimed that they have experienced improvement in their condition due to the herbal medicines. There should be increased research into these claims from pre-clinical to clinical stages; including studying the toxicology of any treatment used by stroke patients. This will help to properly come out with evidence-based treatment approach for stroke in Ghana.

In addition, since many of the stroke survivors in Ga Mashie mentioned cost as a major reason for non-adherence to medications and non-visits to the hospital; future studies should look at the feasibility of setting up a 'wellness center' in this community and examine how this can enhance

stroke rehabilitation. This wellness center can be a 'mini-rehabilitation' centre where the biophysical and psychosocial needs of the stroke survivors can be addressed. In achieving this, there may be need to train local physiotherapists and make use of community health nurses in this endeavor.

8.5   Limitations of the study

The findings from this study may have been influenced by some limitations that are worth noting. Firstly, the findings from the survey may have suffered from a time-sequence challenge in determining the factors associated with stroke. Some of the socio-demographic characteristics of the stroke survivors may have changed after diagnosis. Hence, these characteristics may not determine stroke but may rather be consequences of stroke. For instance, the relationship between employment status and stroke found in this study may be a time-sequence factor. It is possible that those who have been diagnosed of stroke stopped working and that was why those who were unemployed had higher odds of stroke. It would have been good to know the employment status of the stroke survivors before and after the stroke diagnosis; this would have revealed the true effect of employment status on stroke. Secondly, the findings from the qualitative data cannot be generalized to any area (Ga Mashie or KBTH). However, these findings provided in-depth understanding of knowledge and experience of stroke.

Another limitation was the problematic nature of measurements for some of the lifestyle factors. For instance, the measure of physical activity in this study was based on the number of days respondents spent doing recreational activities such as sports, fitness, or recreational leisure activities. Based on this measure, 86.5% of Ghanaians adults were not physically active. This may be erroneous because recreational activities were used as proxies for physical activities and

this may have led to over-estimation of Ghanaian adults who were not physically active. In addition, using recreational leisure as a proxy for physical activity also ignores other forms of physical activity such as blue collar work, hawking, mechanics, etc.

Further, the measures for smoking and alcohol consumption may have contributed to the non-significant associations between smoking, alcohol consumption and stroke prevalence. The questions on smoking and alcohol consumption focused on whether an individual had ever smoked/consumed alcohol and/or currently smoking/consuming alcohol. However, there were no questions on the frequency of smoking/consumption of alcohol or types of alcohol consumed. These may be better measures of smoking or alcohol consumption to capture the effect of smoking/alcohol on stroke prevalence.

8.6   Conclusion

This study showed that there is a high burden of stroke in Ghana. It is clear from this study that the health of the stroke survivors affected that of their caregivers. Further, participants' illness actions indicate that dual use of pharmaceutical and herbal treatments are adequate for stroke management. This indicates that the role of herbal medicines in stroke management in Ghana should not be downplayed because the use of herbal medicine is embedded in the country's socio-cultural environment. It is important that studies focus on understanding the efficacies of herbal medicines in stroke management and how to strengthen its quality.

In addition, this study showed that the impact of stroke on the stroke survivors and their caregivers are multifaceted. Thus, intervention need to adopt the WHO Innovative Care for Chronic Conditions Framework which focuses on combined patient-and caregiver-focused approach in stroke survivor rehabilitation.This study also provided information that is relevant to

the field of Demography and Population Studies. Demography and Population Studies focus on the study of mortality which is one of the components of population change. This study has particularly shown the illness practices adopted by stroke survivors and how these can potentially reduce their life expectancies. This study recommended that there is need to pay attention to the complex biophysical and psychosocial disruptions of stroke through subsidising stroke medications and dialogue between health professionals and stroke patients in coming up with the best treatment strategy for stroke. This will help to minimize stroke-induced mortality in this population.

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Appendix 1: Summary of studies on stroke prevalence in Africa

Country	First Author	Year of Publication	Setting	Sample Size	Key findings
Nigeria	Osuntokun	1987	Community	18954	Stroke prevalence across all age groups was 58/100,000 in 1982
Ethiopia	Tekle-Haimanot	1990	Community	60820	Stroke prevalence across all age groups was 15/100,000 in 1988
Tunisia	Romdhane	1993	Community	34874	Stroke prevalence across all age groups was 42/100,000 in 1985
Benin	Connor	2004	Community	724	Crude prevalence rate was 30/100,000
Egypt	Kandill	2006	Community	25000	Stroke prevalence across all age groups was 508/100,000 in 1993
Egypt	Kandill	2006	Community	8464	Stroke prevalence across all age groups was 410/100,000 in 1993
Egypt	Kandill	2006	Community	11228	Stroke prevalence across all age groups was 540/100,000 in 1993
Nigeria	Danesi	2007	Hospital	13,127	Crude prevalence rate in urban Nigeria was 100/100,000
Benin	Cossi	2012	Community	15155	Crude prevalence rate was 500/100,000.
Egypt	Farghaly	2013	Community	62583	Stroke prevalence across all age groups was 560/100,000
Egypt	Farghaly	2013	Community	44600	Stroke prevalence across all age groups was 580/100,000
Egypt	Farghaly	2013	Community	17983	Stroke prevalence across all age groups was 520/100,000
Egypt	Tallawy	2013	Community	19848	Stroke prevalence across all age groups was 655/100,000 population
Egypt	Khedr	2013	Community	5920	Stroke prevalence across all age groups was 963/100,000 in 2010
Nigeria	Danesi	2013	Community	189	Crude prevalence rate was 30/100,000. It was 30/100,000 and 20/100,000 for males and females respectively.
Tanzania	Dewhurst	2013	Community	976	Stroke prevalence among those aged 70 years and above was 2300/100,000 population and it was higher among men.
Nigeria	Sanya	2015	Community	12,992	Stroke prevalence was 200/0100.000 for males and 100/100,000 for females

Appendix 2: Summary of studies on correlates of stroke in sub-Saharan Africa, 1990-2015

Country	First Author	Year of Publication	Setting	Sample Size	Key findings
Burkina Faso	Zabsonre	1997	Hospital	193	The risk factors of stroke were: poor hypertension control, obesity, hyperlipidemia, thromboembolism, smoking, hypercholesterolemia and diabetes
Cameroon	Balti	2013	Hospital	57	Metabolic syndrome was a major risk factor of stroke mortality at 1 year and 5-year follow-up.
Ethiopia	Zenebe	2005	Hospital	128	Hypertension was the most common risk factor (65.6%), followed by cardiac disease (22.7%).
Ethiopia	Alemayehu	2013	Hospital	114	Hypertension, diabetes mellitus, and atrial fibrillation, were the main risk factors of stroke.
Ethiopia	Alemayehu	2002	Hospital	259	Hypertension and Rheumatic heart disease were the most common risk factors among the youth.
Gambia	Garbusinski	2005	Hospital and community	162	Hypertension and smoking were the prevalent risk factors. Fever, lung infection, swallowing difficulties at admissions, and no aspirin treatments were risk factors for a lethal outcome.
Ghana	Akpalu	2009	Hospital	160	Significant relationship between a high level of homocysteine and stroke. Mean homocysteine level in stroke cases was higher than the one measured in controls.
Ghana	Asefa	2010	Hospital		Main risk factors of stroke were hypertension (52%) and diabetes (26%)
Mozambique	Damasceno	2010	Hospital	651	Hypertension was mostly present in hemorrhagic stroke patients; atrial fibrillation was more frequent among ischemic patients.
Nigeria	Eze	2013	Hospital	108	The risk factors identified were: hypertension, diabetes mellitus, previous stroke and dyslipidaemia.
Nigeria	Wahab	2007	Hospital	81	Predictors of stroke mortality include level of consciousness at stroke onset and presence of complications.
Nigeria	Onwuchekwa	2009	Hospital	611	Hypertension accounted for 77.8% of stroke cases, followed by excessive alcohol intake (27.8%).
Nigeria	Maduagwu	2012	Hospital	236	Stroke was associated with hypertension, diabetes mellitus and HIV.
Nigeria	Karaye	2007	Hospital	81	The most common risk factor of stroke was hypertension. Dyslipidemia

					was the most common risk factor among those who were <45 years, and; systemic hypertension was the main risk factor among those who were > 45 years
Nigeria	Desalu	2011	Hospital	101	Hypertension, diabetes mellitus and tobacco smoking were the main risk factors
Nigeria	Obiako	2011	Hospital	66	The risk factors were: systemic hypertension, obesity, alcohol and diabetes mellitus.
Nigeria	Komolafe	2007	Hospital	293	Uncontrolled hypertension is the most common risk factor.
Nigeria	Obembe	2013	Hospital	90	Age, motor function and depression were associated with stroke.
Nigeria	Wahab	2008	Hospital	100	The risk factors of stroke include hypertension, diabetes mellitus, and cigarette smoking.
Nigeria	Sanya	2015	Community	12,992	Uncontrolled systemic hypertension and transient ischaemic attack were the factors associated with stroke.
Senegal	Toure	2008	Hospital	314	The leading risk factors of stroke were hypertension and previous history of stroke and diabetes
Senegal	Sagui	2005	Hospital	107	Hypertension was the main risk factor for both types of stroke (IS and HS).
South Africa	Thorogood	2004	Community	103	Hypertension was associated with stroke and present in 71% of the survivors.
South Africa	Norman	2007	Community		About 59% of ischemic heart disease and 29% of IS were attributable to high cholesterol (>= 3.8 mmol/l)
South Africa	Bernstein	2008	Hospital	(120)	Prevalence of aspirin resistance and a history of prior stroke was associated with stroke
South Africa	Mudzi	2012	Hospital	200	Hypertension, obesity and smoking were the most common risk factors.
Sudan	Zein	2007	Hospital	128	Hypertension, diabetes mellitus, smoking, heart disease and hypercholesterolaemia were stroke risk factors.
Tanzania	Jusabani	2011	Community	132	1.8% had evidence of right Intracrania stenosis (as a risk of stroke), with a mild degree of right internal carotid artery stenosis.
Tanzania	Walker	2013	Community	201	Hypertension, smoking, previous cardiac event, and a high ratio of total to HDL cholesterol level were associated with stroke in urban and rural Tanzania.
Zambia	Atadzhanov	2012	Hospital	250	Hypertension was the most common risk factor of IS and HS.

Appendix 3: Summary of studies on stroke mortality in sub-Saharan Africa, 1990-2015

Country	First Author	Year of Publication	Setting	Sample Size	Key findings
Ghana	Wiredu EK	2001	Hospital	9760	Stroke accounted for 11% of autopsies carried out at KBTH from 1994 to 1998.
Ethiopia	Asefa G	2010	Hospital		About 5% of all head CT indications were due to stroke. Stroke mortality was 21%.
Ethiopia	Awoke M	2012	Mortality surveillance system	58010	The proportion of stroke mortality from 2006 to 2009 in Addis Ababa was 11%.
Gambia	Walker RW	2003	Hospital	106	75% of the stroke survivors died during the 4-year follow-up. The predictors of death included : initial stroke, further stroke, infection, miscellaneous and 9% of the cause of deaths was unknown
Nigeria	Njoku CH	2004	Hospital	93	Stroke constituted about 0.4% of total hospital admission and 1.9% of total hospital mortality. The highest mortality rate occurred among those who were 21-30 years.
Nigeria	Eze CO	2013	Hospital	108	Stroke accounted for 12% of all medical deaths and 11.6% of medical admission within the period.
Nigeria	Wahab KW	2007	Hospital	81	Peak age of stroke onset in females and males was the seventh and eight decade respectively. The overall mortality within 33 months was 23.5%. Predictors of stroke mortality include level of consciousness at stroke onset and presence of complications.
Seychelles	Stringhini S	2012	Vital statistics	13163	Stroke mortality decreased from 250/100,000 person years in males and 140/100,000 person years in females in 1989-1991 to 141/100,000 person years in males and 86/100,000 person years in females in 2008-2010. The proportionate decrease in stroke mortality was 44% for males and 39% for females.
South Africa	Kahn K	1999	Community		Stroke mortality increased with age and was higher among men compared to women over 35 years. The proportionate mortality ration for stroke between 35-64 years patients was 10.3%.
Tanzania	Walker RW	2000	Surveillance sites	307,820	The age-adjusted rates (15-64) of stroke mortality for three years per 100,000 person years were 65, 44, 35 for men and 88, 33, and 27 for women.

Country	Author	Year	Setting	N	Findings
Congo	Longo-Mbenza	2000	Hospital	1032	Male sex, low SES, migrant tribes, ischemic stroke, heart rate (100 and above), age (60 and above), systolic BP (greater than 160) and fibrinogen (400 and above) were significant predictors of stroke mortality.
South Africa	Maredza	2015	Community		The crude stroke mortality was 114 per 100, 000 person-years in 2007-2011
Nigeria	Ekeh B	2015	Hospital	120	The mortality rate was 35%. The predictors of stroke mortality were: stroke severity and presence of co-morbid condition such as hypertension.
Congo	Longo-Mbenza B	2008	Hospital	212	30-day case fatality rate (CFR) for all stroke types, haemorrhagic stroke ischemic stroke were 44%, 29% and 31% respectively. Predictors of CFR were: older age and ischemic stroke.
Ghana	Agyemang C	2012	Hospital	1050	The rate of stroke mortality was 43.4% for the three years and majority of deaths (62.1%) occurred within the first seven days. The CFR was 5.7% at 24 hours, 32.7% at 7 days and 43.2% at 28 days.
Mozambique	Damasceno A11	2010	Hospital	651	28-day CFR was 49.6%.
Nigeria	Onwuchekwa AC	2009	Hospital	611	Overall CFR was 29.6% and intracerebral haemorrhage had the highest.
Nigeria	Danesi MA	2013	Community	189	30-day CFR was 16.2%.
Nigeria	Wahab KW	2008	Hospital	100	30-day CFR was 28% and was higher among men than women. Predictors of CFR were: stroke severity, hyperglycaemia, level of consciousness, and presence of complications during hospitalization.
Nigeria	Eze CO	2014	Hospital		24-hour, 7-day and 30-day CFR were 5%, 10% and 15% respectively. The factors associated with stroke included: advanced age, female sex, extremes of blood pressure, loss of consciousness and haemorrhagic stroke.
Senegal	Sagui E	2005	Hospital	107	One month CFR for Hemorrhagic Stroke was 56%.
South Africa	Mudzi W	2012	Hospital	200	CFR was 25.5% at 3 months, 35.5% at 6 months and 38% at 12 months. Hypertension, obesity and smoking were the most common risk factors.
South Africa	Wasserman S	2009	Hospital	30	CFR at 3 month was 30%.
Tanzania	Walker RW	2011	Community	353	23.8% of stroke patients died within28 days and 60.0% died within 3 years. Out of the 223 deaths from the verbal autopsy, 28.7% died within 28 days of stroke and 84.3% died within 3 years.
Zimbabwe	Matenga J	1997	Community	273	CFR was 35% within the first week of stroke and 54.1% were women.

Appendix 4: Summary of studies on stroke survivor experience in sub-Saharan Africa, 1990-2015

Country	First Author	Year of Publication	Setting	Sample Size	Key findings
South Africa	Thorogood M	2004	Community	103	91% of survivors had sought help; 42 sought help from traditional healers and churches. Barriers to stroke management included: cost of treatment, reluctance to use pills, difficulties with access to drugs, and lack of equipment to measure BP
Nigeria	Ogungbo B	2005			Stroke management in Nigeria is suboptimal because of deficiencies in the provision of diagnostic, treatment, rehabilitation and support services. There are challenges of limited resources, manpower shortage, lack of organised stroke unit, neuro-imaging facilities, ambulance services, education of patients and general practitioners and impracticable use of thrombolytics.
Nigeria	Birabi BN	2012	Hospital	240	An average of N95, 100 ($600) was required in a government hospital and N767, 900 in a private hospital to access care within the first 36 weeks of post stroke affectation in Nigeria.
South Africa	Bryer A	2010	Hospital		Protocol-driven multidisciplinary stroke unit care within a hospital improves recovery from stroke and reduces mortality and dependency after stroke. Stroke care should be promoted in the community.
Tanzania	Mshana G	2008	Community	80	Stroke in urban Dar es Salaam was more linked to supernatural causes while it was more linked to natural causes (hypertension, fatty foods, stress) in rural area (Hai). Hence, the first option in stroke treatment in Hai was the hospital while in the urban area, it was traditional healer.

Appendix 5 Summary of studies on experience of stroke caregivers in sub-Saharan Africa, 1990-2015

Country	First Author	Year Published	Setting	Sample Size	Key findings
Nigeria	Fatoye FO	2006	Hospital	103	Stroke caregivers experienced higher mean anxiety and depressions. Also, they had lower physical health, psychological health, social relationships and lower quality of life in the environmental domain.
South Africa	Gbiri CA	2015	Hospital	157	Closer intimacy with stroke survivors, few number of caregivers for stroke survivors, long duration of caregiving and high number of hours of caregiving per day were factors associated with caregiver burden.

Appendix 6: Individual and Group Interview Guide – People With Stroke

Introduction: – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

Socio-demographic details to be gathered on standardised form.

1. General Life History

1.1 Could you tell me a little bit about yourself?

*Prompts***:** Life before stroke; social dynamics (social activities, friends, etc)

2. Stroke

2.1. I would like us to discuss your stroke. Can you recount how the illness started?

*Prompts***:** How did you first notice that 'something was wrong'?

How did you discover it was stroke?

Did you know about stroke prior to your getting the illness?

Why do you think you got stroke?

What causes stroke?

Do you think stroke is infectious/contagious? Why? / Why not?

Which group of people are most likely to get stroke and why?

 2.2. At which stage of your illness did you seek medical treatment?

Prompts: If at late stage, what were reasons for waiting?

What concerns or expectations did you have with respect to the illness and its treatment?

Who/what influenced your decision to seek medical treatment?

2.3. Did you try alternative forms of treatment before you sought medical treatment?

*Prompts***:** What/who influenced the decision to try alternative forms of treatment?

What sorts of treatments did you try?

Were these treatments successful or unsuccessful?

2.4 What was your immediate reaction when you were diagnosed with stroke?

*Prompts***:** Were you worried? Did you believe the diagnosis?

How did you feel about the life long nature of the illness?

2.5. How do you feel about your stroke now?

Prompts: How do you cope with managing stroke?

Do you feel adequate health services are available to you?

How do health professionals and others perceive or treat you?

Explore experience of the following emotions: sadness, anxiety, depression, anger, loneliness, helplessness, hope, faith and others mentioned by participant.

2.6. Let's talk a bit now about your support system.

Prompts: Does your family know you have stroke? What has been their response?

Do your friends know you have stroke? What has been their response to this?

Does your employer know you have stroke? What has been their response to this?

Do you have a support system (family/friends who help you manage your condition)?

Who do you go to for emotional support?

Who do you go to for financial support?

Who do you go to for spiritual support?

What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about your illness?

2.7. How has stroke made an impact on your everyday life?

Prompts: Has the illness affected your diet?

Has the illness affected your social life?

Has the illness affected your economic situation?

Have you had to make lifestyle changes?

Have you experienced any other problems as a result of your stroke?

How often do you think about your illness?

What strategies do you use to simply 'get by' on a daily basis?

2.8. Do you think stroke is a life threatening illness?

Prompts: What are some of the complications that could result from stroke?

(Ask respondent to list at least 3 complications of stroke)

Which of these complications do you think are most threatening to your health?

Can these complications be prevented and how?

Have you had any complications yet? If yes, list the complications and probe

cognitive, emotional and practical responses.

2.10. Could we talk a bit about your experience of stroke treatment? What kind/kinds of treatment do you use for your stroke?

*Prompts***:** Do you use biomedical treatment? List medicines and cost.

Do you use herbal medications? List medicines and cost.

Do you use spiritual treatment (church, traditional religious healer)?

Do you use home and/or traditional remedies?

If you were advising a friend to seek treatment for stroke what would you advise them to do? Explore reasons for any order of treatment chosen.

3. Self-care

3.1. How do you tell whether your stroke is well controlled or not?

3.2. Do you do the following at home? [Probe how often the following are done]

Test your blood pressure?

Check your weight?

Smoke?

Drink alcohol?

3.3. I will ask you a few questions about stroke/high blood pressure, generally.

What is the ideal blood pressure?

What causes blood pressure levels to decrease? [List 2 reasons]

What causes blood pressure levels to increase? [List 2 reasons]

What are the symptoms of low blood pressure?

What are the symptoms of stroke?

What should you do when you fall ill (e.g cold, malaria) and you cannot eat properly for a few days?

3.4. Have you been educated on the appropriate diet?

3.5. Are you adhering to the appropriate diet?

Prompts: How are you adhering to the diet?

What are the barriers to adhering to the diet?

3.6. Have you been advised on regular exercise?

3.7. Are you keeping to the exercise routine?

Probe: kinds of exercise: walking, dancing, farming, housework, other everyday physical activity.

3.8. Have you been advised on the advantage of maintaining or losing weight?

3.9. What are you doing to maintain or lose weight?

4. Chronic illness

4.1. How would you define chronic illness? (explore causes)

4.2. What types of chronic illness do you know? Can you describe any of these illnesses?

Prompt: with names – hypertension, asthma, arthritis, epilepsy, sickle cell, cancer, etc.

(*When list is obtained conduct sorting exercise to grade most severe – least severe illness, on a scale of 1 to 10, 1 being least severe, 10 being most severe*)
Explore: why illnesses have been graded the way they have been.

4.3. Do you live with any of these illnesses?

4.4. What group of people are most likely to get chronic illness and why?

4.5. Can chronic illness be cured? (Explore reasons)

4.6. What is the best treatment for chronic illness? (Explore opinion of traditional vs biomedicine in treating chronic illness or spiritual/psychological/physical forms of treatment)

4.8. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about chronic illness?

5. Medical Pluralism

5.1. Which one of these treatment methods would you use if you were ill?

    (1) Mobile herbalist with cure-all medicines

    (2) Specialist traditional healer group practice using modern methods

    (3) Traditional religious healer

    (4) Medical centre which uses scientifically tested herbal drugs (e.g Mampong Centre)

    (5) Health post or clinic or hospital

    (6) Foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)

    (7) Religious/spiritual healing (prayer camp, regular church, private prayer)

    (8) Home remedies (bitter leaf, bitters, other)

(Explore reasons given for choices – what influences choices? Type of illness? Treatment offered? A mixture of both? Which preferred? Which trusted? Which have benefits? Which don't.)

6. Perceptions of health and illness

6.1. Generally how would you define health?

6.2. Would you say you were in good or bad health generally?

Prompts: What are your major problems (apart from stroke)?

     Note co-morbid problems for follow up discussion.

6.3. What do you normally do to keep healthy or to avoid being ill in everyday life?

Prompts: Food as prevention and treatment

     Smoking, exercise, medical check-ups

     Holistic health/lifestyle

6.4. What would you define as illness?

6.5. What would you say causes illness?

Prompts: Physical, Psychological, Spiritual factors / examples.

6.6. Can one do anything at all to prevent illness?

Appendix 7: Individual Interview Guide- Caregivers of People with Stroke

Introduction: – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

Socio-demographic details to be gathered on standardised form.

1. General Life History

1.1.Could you tell me a little bit about yourself?

*Prompts***:** Life before being a caregiver stroke; social dynamics (social activities, friends, etc)

2. Stroke

2.1 I would like us to discuss your (relative's/friend's) stroke. Can you recount how the illness started ?

Prompts: How did you first notice that something was wrong ?

　　　Why do you think your relative got stroke ?

　　　Which Group of people are most likely to get stroke and why?

2.2 At which stage of your your (relative's/friend's) illness did he/she seek medical treatment ?

2.3 What or who influenced the decision to seek medical treatment?

2.4 Did your (relative) try alternative forms of treatment before he/she sought medical treatment?

Prompts: What/who influenced the decision to try alternative forms of treatment?

　　　What sorts of treatments did he/she try?

　　　Were these treatments successful or unsuccessful?

2.5 How did you feel when your (relative) was diagnosed with stroke?

Prompts: Were you worried? Did you believe the diagnosis? Why? Why not?

　　　How did you feel about the life long nature of the illness?

2.6 How do you feel about your (relative's) stroke now?

Prompts: How have you adjusted to the condition/situation?

　　　Is there a support system for your relative? (explore –carers and their roles)

　　　How do you feel about the lifelong nature of the illness now?

2.7 How has your relative's stroke made an impact on your everyday life?

Prompts: Has the illness affected your family life?

　　　Has the illness affected your social life ?

Has the stroke affected your economic situation ?

Have you had to make lifestyle changes?

Have you experienced any other problems (health, career, etc) as a result of your relative's stroke?

2.8. How do you cope as your relative's carer?

Prompts: Economic, physical, emotional dimensions.

Relationship with healthcare providers.

2.9. Do you think stroke is a life threatening illness?

Prompts: What are some of the complications that could result from stroke?

Which complications do you think are most threatening to your relative's health?

Can these complications be prevented and how?

Has your relative had any complications yet? (If yes, ask respondent to list complications and probe cognitive, emotional and practical responses by respondent and relative with stroke).

2.10. Let's now focus on prevention. How can one avoid getting stroke?

Prompts: What advice would you give others to prevent getting stroke?

Do you think or believe your relative could have avoided getting stroke?

2.11. Could we talk a bit about your relative's current experience of stroke treatment? What kind/kinds of treatment does he/she use for his/her stroke?

Prompts: Does he/she use biomedical treatment?

Does he/she use herbal medications?

Does he/she use spiritual treatment (church, traditional religion)?

What about other home and/or traditional remedies?

What are his/her your reasons for using alternative medicine?

2.12. Could you talk about your relative's experience of using these forms of treatment?

Prompts: What kind or kinds of treatment have been effective for controlling his/her stroke?

What kind or kinds of treatment does he/she prefer? Why?

What kind or kinds of treatment do you prefer?

List of positives and/or negatives of each form of treatment.

2.13. If you were advising a friend to seek treatment for stroke, what would you advise them to do?

Prompts: Explore reasons for any order of treatment chosen

2.14. What kinds of ideas or beliefs do people around you (in your neighbourhood/village/town) have about stroke?

2.15. Does this affect the way you and your relative handle his/her experience of stroke?

3. Chronic illness

3..1How would you define chronic illness? (explore causes)

3.2.What types of chronic illness do you know? Can you describe any of these illnesses?

   Prompt: with names – hypertension, asthma, arthritis, epilepsy, sickle cell, cancer, etc.

   (*When list is obtained conduct sorting exercise to grade most severe – least severe illness, on a scale of 1 to 10, 1 being least severe, 10 being most severe*)

   Explore: why illnesses have been graded the way they have been.

3.3. Do you live with any of these illnesses?

3.4.What group of people are most likely to get chronic illness and why?

3.5. Can chronic illness be cured? (Explore reasons)

3.6.What is the best treatment for chronic illness? (Explore opinion of traditional vs biomedicine in treating chronic illness or spiritual/psychological/physical forms of treatment)

3.7. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about chronic illness?

4. Medical Pluralism

4.1. Which one of these treatment methods would you use if you were ill?

   (1) Mobile herbalist with cure-all medicines

   (2) Specialist traditional healer group practice using modern methods

   (3) Traditional religious healer

   (4) Medical centre which uses scientifically tested herbal drugs (e.g Mampong Centre)

   (5) Health post or clinic or hospital

   (6) Foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)

   (7) Religious/spiritual healing (prayer camp, regular church, private prayer)

   (8) Home remedies (bitter leaf, bitters, other)

(Explore reasons given for choices – what influences choices? Type of illness? Treatment offered? A mixture of both? Which preferred? Which trusted? Which have benefits? Which don't.)

5. Perceptions of health and illness

5.1.Generally how would you define health?

5.2.Would you say you were in good or bad health generally?

Prompts: What are your major problems (apart from stroke)?

   Note co-morbid problems for follow up discussion.

5.3.What do you normally do to keep healthy or to avoid being ill in everyday life?

Prompts: Food as prevention and treatment

   Smoking, exercise, medical check-ups

   Holistic health/lifestyle

5.4.What would you define as illness?

5.5.What would you say causes illness?

Prompts: Physical, Psychological, Spiritual factors / examples.

5.6.Can one do anything at all to prevent illness?

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	Official Use only
	Protocol number

Ethics Committee for Humanities (ECH)

PROTOCOL CONSENT FORM

Section A- BACKGROUND
INFORMATION

Title of Study:	Burden of stroke in Ghana: Prevalence, Experience and Caregiving
Principal Investigator:	Olutobi Adekunle Sanuade
Certified Protocol Number	ECH 006/15-16

Section B– CONSENT TO PARTICIPATE IN
RESEARCH

General Information about Research

The proposed study aims to explore the knowledge and experience of stroke from the perspectives of the stroke survivors and that of their caregivers in three urban poor communities in Accra and Korle-Bu Teaching Hospital (KBTH). The study aims to recruit stroke survivors (and their family caregivers) from Gamashie, Agbogbloshie and Korle-Bu teaching Hospital. Your experience of stroke will focus on discussion of how the illness started; immediate reaction when diagnosed with stroke; current reaction about stroke; kinds of treatment sought at the early stage of the illness and current treatments being used for stroke. At two months interval, you will be followed up so as to understand the change in your stroke experience. The interview is expected to last for at most two (2) hours.

Benefits/Risk of the study

This study will help improve your health outcomes by providing useful information that can assist you and your family caregivers manage the stroke condition well. Hence, you will learn how to take more active role in your personal health care decisions. Further, some of the issues that will be discussed will help lay individuals in your community understand what they can do to prevent stroke occurrence. In addition, the study will help the health professionals see how and where they need to facilitate stroke rehabilitation and improve stroke care.

Some of the issues that will be discussed may make you a little uncomfortable because they involve questions about how your stroke condition started; the complications of your stroke condition; how you have been managing the condition, and; the challenges involved in proper management of your condition. These questions may cause some emotional pains. Apart from this, we do not think there are any other risks associated with participation in this study.

Confidentiality

The information you will provide in this study will be protected to the best of our ability. The audio recordings will be protected and kept securely at the Regional Institute for Population Studies. Your name or address will not be mentioned in any public communications, documents or reports.

Compensation

You will be given a token in appreciation for your time. The household will be given a collection of household items which may include any items ranging from buckets, soap to other toiletries. The gifts will be given at the end of the study.

Withdrawal from Study

In this study, you are free to decide if you want to be interviewed. Participation is entirely voluntary. In the course of the interview, you may choose not to answer a question or even stop participating in the discussion altogether. Further, you will not be adversely affected if you declines to participate or later stops participating. Also, you or your legal representative will be informed in a timely manner if information becomes available that may be relevant to your willingness to continue participation or withdraw.

Contact for Additional Information

If you have any concerns regarding the study you may contact Mr. Olutobi Sanuade (0267543244) or Prof Ama de-Graft Aikins (+233277089599), P.O.BOX LG 96, University of Ghana, Legon.

If you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@isser.edu.gh / ech@ug.edu.gh or 00233- 303-933-866.

Section C- VOLUNTEER AGREEMENT

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

_____

Name of Volunteer

_____   _____

Signature or mark of volunteer   Date

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

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

_____

Name of witness

_____   _____

Signature of witness   Date

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

_____

Name of Person who Obtained Consent

_____   _____

Signature of Person Who Obtained Consent   Date

Appendix 9: Detailed profiles of the stroke survivors

Ga Mashie

Identifier	Sex	Age	Religion	Marital Status	Duration of illness	Education	Ethnicity	Occupation	Income
R1	M	44	Christian	Divorced	1 year	JHS	Akan	Trader	GHC 260
R2	M	51	Muslim	Co-habitation	1 year	Primary	Ga	Unemployed	No income
R3	F	46	Christian	Widowed	5 years	Primary	Akan	Unemployed	No income
R4	F	86	Christian	Divorced	3 years	SHS	Ga	Unemployed	No income
R5	F	68	No religion	Divorced	13 years	Primary	Ga	Unemployed	No income
R6	F	57	Christian	Divorced	8 years	JHS	Ga	Unemployed	No income
R7	F	32	Muslim	Separated	1 year	SHS	Akan	Unemployed	No income
R8	F	50	Christian	Married	10 years	Primary	Ga	Trading	No response

Physiotherapy

Identifier	Sex	Age	Religion	Marital Status	Duration of illness	Education	Ethnicity	Occupation	Income
R9	M	52	Christian	Married	11 months	Standard 5	Igbo	Unemployed	No income
R10	M	63	Christian	Married	3 years	Form 4	Akan	Unemployed	No income
R11	F	43	Christian	Married	5 month	Form 4	Akan	Unemployed	No income
R12	M	45	Christian	Married	2 years	Technical school	Akan	Unemployed	No income
R13	M	69	Christian	Married		Modern school	Ewe	Unemployed	No income
R14	M	42	Christian	Married	1 year	Diploma	Ga	Unemployed	No income
R15	M	52	Christian	Married	18 months	JHS	Ga	Commercial driver	GHC400
R16	M	51	Christian	Married	2 months	JHS	Ga	Business man	GHC300
R17	M	58	Christian	Married	6 years	JHS	Ga	Unemployed	No income

Stroke Unit

Identifier	Sex	Age	Religion	Marital Status	Duration of illness	Education	Ethnicity	Occupation	Income
R18	M	58	Christian	Married	1 year	Tertiary	Akan	Lab Technician	No response
R19	M	63	Christian	Married	2 months	SHS	Ewe	Retired	No response
R20	F	48	Christian	Single	1 month	No response	Ewe	Trader	No response
R21	M	81	Christian	Married	1 year	Msc	Akan	Retired	No response
R22	M	57	Christian	No response	two weeks	No response	No response	Driver	No response

Appendix10: Basic themes, and codes for Knowledge and experience of stroke from the perspectives of the stroke survivors

Themes and codes	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	Frequency
KNOWLEDGE OF STROKE																							
[A] Pre-diagnosis awareness of stroke																							
Aware	+											+				+		+		+			5
Not aware		+	+	+	+	+	+	+			+		+		+				+				11
[B] Knowledge on causes																							
i. Dietary Imbalance																							
Too much intake of beef	+																						1
Too much intake of meat	+																						1
Too much intake of chicken	+																						1
Intake of oily foods		+																					1
Too much fat intake								+															1
Late night eating												+											1
ii. Spiritual causal theory																							
Witchcraft	+									+				+									3
Transfer through Spiritual means				+																			1
iii. Predestination																							
Life's own determination									+														1
iv. Poor lifestyle practices																							
Smoking												+	+										2
Womanizing												+											1
Alcohol intake				+								+		+							+		4
Lack of sleep			+																				1
Physical inactivity									+														1

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	Total
v. Stress																									
Stress			+						+										+		+				4
vi. Psychological disruption																									
Thinking							+																		1
worrying						+																			1
vii. Contagious																									
Contagious				+																					1
viii. Family history																									
Family history					+								+												2
ix. Hypertension																									
High blood pressure												+	+	+			+		+		+				6
Non adherence to medications																			+						1
Untreated hypertension									+					+											2
x. Other chronic diseases																									
Diabetes																	+								1
High cholesterol																	+								1
xi. Delay in treating symptoms																									
Delay in being attended to by doctors														+											1
xii. Don't know causes																									
Don't know				+	+	+				+						+			+	+			+		8
[B] Complications																									
i. Physical disability																									
Total body shut down								+																	1
Body aches								+																	1
Severe pain												+													1
Inability to move legs														+											1
Inability to walk														+											1

																						Total
properly																						
ii. Other diseases																						
Malaria								+														1
Diabetes																+						1
Cholesterol																+						1
Don't know										+		+						+				3
iii. Social disability																						
Stigmatization												+										1
[C] Knowledge on groups that are affected by stroke																						
Aged/elderly	+		+	+			+	+				+										6
Fat people		+																				1
Those who take oily food			+																			1
Those who do hard work			+																			1
Obese people			+																			1
Anyone				+																		1
Men and women				+	+		+															3
Rich people								+														1
Young and old				+	+	+	+								+							5
People who are stressed								+														1
People who engage in bad lifestyle								+														1
Old men										+												1
Old women										+												1
People who consume alcohol												+										1
People who smoke												+										1
People who are diabetic																+						1

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		Total
Those with high cholesterol	+	1
Those with hypertension	+	1
[D] Stroke prevention		
i. Spiritual		
Prayer to God	+ +	2
ii. Psychological balance		
Not worrying	+	1
iii. Good lifestyle practices		
Exercise	+ + +	3
Sleep at the right time	+	1
Rest	+	1
Maintain a healthy lifestyle	+	1
Being careful with day to day activities	+	1
iv. Good diet practices		
Eat at the right time	+	1
Drink more water	+	1
eat right food in the right quantity	+	1
eat good diet	+ + +	3
v. Adherence to health issues		
regular check-up	+	1
Intake of medicine	+	1
Experience of stroke		
[A] Immediate reaction after diagnosis		
Worries on what to eat	+	1
Worries on physical	+	1

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																							Total
assistance																							
Worries on how to care for family	+		+											+									3
Crying/weeping		+	+	+										+									4
Worried		+		+												+		+				+	5
Sad			+					+					+	+							+	+	6
Took it like that							+																1
Disturbed								+															1
Shock									+														1
Dismay/surprise									+			+											2
Thought it was time to die										+													1
Afraid											+								+				2
Felt bad													+									+	2
Troubled															+								1
Took it as normal																	+	+					2
[B] Impact of Stroke																							
i. Change in dietary practices																							
Diet change					+				+	+	+	+		+	+	+	+			+	+		11
Eat early	+																						1
Stop intake of cake													+										1
Stopped salt intake														+									1
Stopped intake of oily foods														+									1
Stopped intake of milo														+									1
Consume only brown bread													+										1
ii. Psychological disruption																							
worries (due to physical disability)	+			+														+					2

																						Total
changes in way of life	+																					1
Unhappiness							+															1
Loneliness							+			+						+	+				+	5
Thinking													+									1
Sadness																+				+		2
Depression																			+			1
Neglect																			+			1
iii. Economic disruptions																						
Loss of finances		+	+	+					+				+		+							6
Inability to work		+	+				+	+	+	+	+		+	+			+			+	+	12
Disruption to business activities			+																			1
Difficulty in getting daily bread			+																			1
Loss of savings			+																			1
Slowed down business activities			+																			1
Loss of business				+										+								2
Spend a lot on drugs														+								1
iv. Social disruption																						
Inability to attend social functions		+	+	+						+			+	+			+			+		8
Inability to go out with friends due to physical disability			+							+	+	+	+						+	+		7
Lost friends						+																1
Social disruption						+	+								+							3
Stigmatization																			+			1
Vulnerable to cheating	+																					1
v. Cognitive disruption																						

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Symptom	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	Total
Forgetfulness (cognitive disability)		+	+																				2
Absent-mindedness			+																				1
vi. Disruption to body and physical																							
Slowness of walking			+																				1
Physical disability			+		+	+										+							4
Lack of independent (inability to get up and do things alone)	+	+	+							+		+	+	+						+	+		9
Pains in the bone			+																				1
Not being upright as before			+																				1
Sharp pains (arms, joints)			+																+				2
Sexual dysfunction			+																				1
Immobility				+	+						+		+		+								5
Inability to walk properly				+																			1
Speech impairment				+	+				+		+												4
Get tired easily while walking																			+				1
vii. Disruption to Family																							
Family breakdown/divorce			+																				1
Disruption of children's education													+										1
viii. Change in lifestyles																							
Stopped alcohol consumption				+							+	+							+				4
ix. Others																							
Shattered dream											+												1

[C] Immediate treatment option after stroke onset																							
Sought biomedical treatment		+	+	+	+		+		+	+	+	+	+	+	+	+	+	+	+	+	+	+	19
Sought traditional treatment	+					+																		2
Inaction								+																1
[D] Health seeking behaviour																								
Started with herbal, moved to biomedical treatment, then to herbal and currently practising illness inaction because of finances	+																							1
Started with biomedical treatment and moved to herbal because of finances		+				+																		2
Started with biomedicines, and moved to herbal and home remedies due to the expensive nature of orthodox medicines			+																					1
Started with biomedical and concurrently seeking herbal treatment as well				+					+	+	+	+	+	+	+	+	+		+	+	+	+	14
Started with biomedicine, continued with herbal but didn't work, went					+																			1

to physiotherapy but didn't work, currently practising medical inaction																						
Started with biomedicine and still using only biomedicine																+						1

[E] Social Support/coping strategies

i. Spiritual Support

Spiritual	+		+	+	+			+	+	+			+	+			+			+	+	12

ii. Emotional/psychological

Emotional/psychological		+	+	+	+					+	+	+	+							+		9
Visitations				+											+			+	+	+		5
Encouragement not to cry											+		+									2
Encouragement to take medicine													+									1
Phone calls from friends													+									1
Al kinds of support (mother and niece)		+										+										2

iii. Financial

Financial		+	+	+	+			+	+	+			+	+			+	+		+	+	13
Personal savings		+																				1
No financial support	+												+									2
Donations in kinds																						
Salary																				+		1
No support							+															1

iv. Physical

Physical								+						+										2
Assistance in bathing														+										1
Taking care of baby														+										1
Help with cooking														+										1
]F] Sources of Support																								
Brother	+		+																					2
Father	+																						1	1
Daughter		+																						1
Children		+																						1
Mother			+																					1
Family members			+	+																				2
Workplace																		+						1
Wife																						+		1
Friends																			+	+	+			3

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Appendix 11: Global themes, organizing themes and basic themes for knowledge and experience of stroke from the perspectives of the stroke survivors

Global Themes	Organising Themes	Basic Themes	No of responses	Descriptions	Sample quotes
Knowledge of stroke	Pre-diagnosis awareness	Had prior knowledge	5	Had pre-diagnosis knowledge of stroke	*I: before your condition, have you heard about stroke* *P: I have heard about it, but I didn't expect it to happen to someone of my age. I expected it to happen to old men and women. I am not even 50 years old* **(R1)**
		No prior knowledge	11	No pre-diagnosis knowledge of stroke	*I: when you went to the hospital and the doctor told you that had stroke, you started crying* *P: yes* *I: before then, have you heard of stroke?* *P: NO, NO, NO. I didn't even know that there was any sickness like that* **(R3)**
	Causes of stroke	Dietary imbalance	6	Stroke being caused by poor eating habits	*…it (stroke) can affect anybody, but it usually affects people from 40 years and above, because of their eating habits….* **(R8)**
		Poor lifestyle practices	9	Engagement in lifestyle practices such as alcohol consumption, smoking, physical inactivity and stress	*…people claim drinking, smoking, or womanizing causes stroke. I hardly drink. I don't smoke and womanize* **(R12)** *… hmm, elderly people have stroke. When I went to the hospital they told me that when you are drinking alcohol and smoking and a lot of things you can get stroke. I know at the hospital* **(R13)**
		High blood pressure	9	Relating the cause of stroke with hypertension or untreated	*I: Okay, so what do you think causes stroke apart from the blood pressure that you mentioned? What do you think are the causes of stroke?* *P: I don't know so much about stroke but what I*

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			hypertension	*think I know is only the BP. That is all I know* (**R11**)
	Heredity	2	Getting stroke through family history	*...I know because as for hypertension even in my mother's side a lot of them have the hypertension. Even this stroke they normally get it. Even my mother had the stroke two months before me* (**R11**)
	Psychological disruption	6	Stroke being caused by factors such as thinking, worrying, etc	*Interviewer: Okay, in your opinion, what brings about stroke?* *Respondent: As for me, I think stroke is brought about by thinking or worrying. Maybe life is not going the way you plan it therefore, when think too much, it can trigger stroke.* (**R6**)
	Contagion	1	Ability of stroke to spread from one person to another through direct contact	*No, I don't think so, because as I have I have it now, there are people around me, but none of them have had it. So, I know that stroke is not contagious* (**R6**) *..the reason why I think so is that, it's not a cough or anything of that sort. Stroke is a matter of inability of the blood to penetrate the veins properly. That's what I know brings about stroke* (**R1**)
	Spiritual disruption	4	Stroke being caused by witchcraft and spiritual means	*...some people say it is transferred to a person through spiritual means, others say it is the disease in town now* (**R5**) *At first, elderly people use to have it a lot, but now it is different, young people and little children are also getting it. Where is this coming from, it is all the work of the devil. Even if you don't think evil of*

				anyone, someone is wishing evil for you (**R6**)
	Predestination	1	Stroke being caused by life's own determination	*I: Do you know what causes stroke?* *P: It can be caused by life's own determinations* (**R14**)
	Stress	4	Stroke being caused by hard work and lack of sleep	*I think it is stress (respondent referring to causes of stroke). It is stress because I must confess because I am always stressed due to the nature of my work. We pastors, we don't know that sometimes we can be in this condition. They will call you to go here and you will go and they will call you to go there and you will go. That day I wanted to travel to the village where I do missionary work and I got the sickness, since that day I have not gone again* (**R9**)
	Other chronic conditions	2	Stroke being caused by diabetes and high cholesterol	*I: so why do you think you got stroke?* *R: mine. It is a complication. I know I had diabetes, then pressure came in (BP), but the pressure is on and off. So I went to the hospital, they said I'm getting cholesterol. So finally when I had it when I went to the homeopathy, the results is that I have diabetes, I have err…cholesterol* (**R15**)
	Delay in treatment of symptoms	1	Delay in seeing the doctors after noticing symptoms	*…after delivery I even came home. I was at home for two weeks but one midnight when woke up I realized my legs looked different on the floor. So immediately I went to the hospital but I took my babe myself and went to the hospital. When we got down (from a bus) I walked to the hospital and I sat… when I got there they said the doctor was not around. But after sitting for some time I realized my legs and arms were going off.* (**R11**)

	Don't know	8	Inability to identify causes of stroke	*I: so please what would you say made you get stroke?* *P: I have been thinking about it a lot and I still don't get it because I am not that old. No one in my family has it so don't know. So when I went to the mosque they advised me to just take good care of myself(R3)*
Complications	Physical disability	5	Effect of stroke on body-self which causes immobility, pain, inability to work, etc	*as you are sitting down and you can't move your leg, those are some of the things and the changes it brings to your life (R11).* *hmm, I think the complications differ from every individual. I wasn't feeling any pain in the beginning, but now I do. Sometimes I feel severe pain, but I just remain focused (R12)* *I: okay, so sir do you know some of the complications that can result from stroke?* *R: no, no (R10).*
	Stigmatization	1	inability to do things freely in the society without being looked down upon	*Because of this now I cannot walk properly. I cannot move out. Even when I am staying out I don't feel okay. When I am among people I cannot stay with the people. It is a lot of things (R11).*
	Other illnesses	3	Stroke resulting into malaria, diabetes and high cholesterol	*For mine, it is a complication. I know I had diabetes, then pressure came in (BP), but the pressure is on and off. So I went to the hospital, they said I have cholesterol. So finally had it*

					(respondent referring to stroke) **(R11)**
		Don't know	3	Inability to identify complications of stroke	
	Groups at risk of stroke	Aged/elderly	6		
		Fat people	1		
		Those who take oily food	1		
		Those who do hard work	1		
		Obese people	1		
		Anyone	1		
		Men and women	3		
		Rich people	1		
		Young and old	5		
		People who are stressed	1		
		People who engage in bad lifestyle	1		
		Old men	1		
		Old women	1		*those who are from 50, 60, 70 and above. But these days, people from 40 years get stroke* **(R2)**
		People who consume alcohol	1		
		People who smoke	1		*… why is that when stroke affects people who are obese, it is difficult to fight it than when it affects people who are not obese* **(R1)**
		People who are diabetic	1	Attribution of stroke risk to different groups of people.	
		Those with high cholesterol	1		

		Those with hypertension	1		
	Prevention	Spiritual	2	Praying to God to take sicknesses far from individual	*I: please what can we do to prevent stroke?* *R: prayer and service to God (**R6**)*
		Psychological balance	1	Not worrying	*…there is only one thing you can do to protect yourself. My belief is that… that's my belief, is that apart from God and your own discipline, there isn't any protection anywhere else. You should be careful with your day to day activities. You shouldn't worry too much(**R1**)*
		Good lifestyle practices	7	Maintaining healthy lifestyle such as exercise, sleep and rest.	
		Good dietary practices	6	Intake of proper diet, eating on time and consumption of water	*Yes eat that right food in the right quantity (**R15**)*
		Adherence to health issues	2	Regular medical check-up and intake of medicine	*…I feel when you take your medicine and you are praying (**R11**)*
Experience	**Immediate reaction after diagnosis**	Emotional expressions	20	Expression of sadness, fear, worries, etc	*hmm, I feel very sad. Even the first time I was crying every day… (**R11**)* *I was a bit worried. Because I thought I wouldn't be able to do anything again (**R13**)* *instantly, I didn't feel any sadness, but with time, I started feeling sad, knowing I couldn't do some of*

				*the things I could earlier on (**R18**).*
Impact of stroke	Disruption to body self	24	This includes experience of pains, lack of independence, speech impairments, sexual dysfunction, etc	*Honestly, within three years I realized a lot had changed about my body, a lot of drugs... When it started at first, I couldn't get up; if I wanted to do something, I will tell my mother (the old lady you met the first time) and my sister would carry me. If I am going to the hospital, I am carried. (**R6**)*
	Disruption to economic circumstances	20	This includes loss of earnings, increased expenditure of drugs, and inability to save	*...hmm, it cost me a lot because before that, I have some money. The money I have put down for my girl who sells the food right now for her to go to WASS (secondary school)... So I keep some money for her which she will use to start the school but because of this sickness, we have used all the money to buy medicine, medicine. So it has cost me a lot but (...) (**R11**)* *Formerly I used to take only the orthodox drugs, but they are expensive. There is this drug from Germany which was prescribed for me; cebrotonin, it is very expensive. In the store just here, one goes for Ghc75.00, so it isn't easy. So I decided to start taking the herbal medicines because it is also good. So now I have resorted to the herbal medicines [R1]*
	Change in dietary practices	15	Consumption of appropriate diet and at the righttime	*.....because this time I cannot eat salt, I cannot eat pepper and oil food. Even palm nut soup and ground nut soup I eat it in once a month. I cannot drink Milo tea but I like Milo tea. I can drink only tea, morning, afternoon and evening. (**Adult***

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			*…it hasn't been easy. It isn't a sickness (referring to stroke) you should even wish for your enemy. All my dreams have been shattered. You can't go anywhere. You can't eat, walk or do anything without help. At first I couldn't even talk like I am talking now. It takes you away from the society. If you don't have a family to take care of you, you may even die before your time. It's a sickness that may even cause people to neglect you. Even if you have people to support you, with time, the people may even draw back…. **[R12]***
			*… yes, I am feeling if I went out people (...) even now when we went out to Korle-Bu to come back, a lot of people when they see me they are looking at me. That is why I can't go anywhere (**R11**).*
Disruption to social relationship	17	This involves inability to attend social functions and family breakdown	*….well I will refer to my own personal experience. When I was going through my hard times and my wife realised that I didn't have any family members to offer a helping hand she also left me. This got me thinking [R1]*
Disruption to cognition	3	This includes inability to remember things, difficulty in concentration and absentmindedness	*Because what I see is that when you think so much about the disease it makes you forgetful concerning a lot of things. Even when you are holding glass, you may let go of it for it to crash on the ground without noticing it (**R1**)*
Psychological disruption	5	This includes experience of worries and depression due to	*… instantly, I didn't feel any sadness (when diagnosed with stroke), but with time, I started feeling sad, knowing I couldn't do some of the things I could earlier on (**R18**)*

			the stroke condition	
	Other lifestyle changes (stopped intake of alcohols, engaged in physical activities, etc)	5	This includes stoppage of alcohol consumption and engagement in physical activities to prevent further complications	*as I mentioned earlier, I was only drinking occasionally. But now, I don't even go to occasions, to even be compelled to drink. So I now I don't even drink at all (**R12**)*
Immediate Health seeking behaviour	Biomedical care	21	Visiting the hospital immediately after the complications started	*The same day I fell down, and started feeling sick, I went to the hospital. And then I was told that stroke could not be cured in Korle-Bu, in that I should go to "Nipa Hia Mmoa (**elderly woman, Ga Mashie**)*
	Herbal treatment	1	Use of herbal medicines immediately after complications started	*I got up to go and pray around 3am but I couldn't get up, so I was wondering "what is wrong with my leg?" so I went to a brother's place and when he saw me, he told me it was a stroke. So he went to buy coke, the big bottle and prepared medicine for me with it (**R2**)* *Fortunately, I was in traffic when it happened, so I wasn't on a tough speed. The neck and the right all ceased to move. So the people around came to my aid, thinking I was having a problem with the car. But when they realized what the problem was, they took me from the driver's seat, to the passenger's seat, and drove me to the ridge hospital (**R12**)*
Health seeking	biomedical-herbal	2	Started biomedical	

behaviour			treatment and currently using herbal medicines	
	herbal-biomedical-herbal-illness inaction	1	Started with herbal treatment and moved to biomedical treatment and not currently doing anything about the illness	
	biomedical-herbal/home remedies	1	Started with biomedical treatment and currently using herbal medicines and home remedies	
	biomedical-dual use of biomedical and herbal	14	Started with biomedical treatment and currently engaging in dual use of biomedical and herbal treatment	
	biomedical-herbal-physiotherapy-illness inaction	1	Started with biomedical treatment, moved to herbal treatment and then to doing physiotherapy but	

				now practising illness inaction	
	Biomedical-biomedical	1		Started with biomedicine and still using only biomedicine	
Social supports	Financial	12		Receipt help in terms of buying of drugs or receipt of money that can take care of the day-to-day needs of the participants	*...there is this phone contact I have, anytime I call, they'd then invite me over. If my son doesn't get the time then I would have to go by myself. My brother is a pastor there, so when I go they help me financially. Sometimes they give me Ghc500.00 and at times Ghc600.00. I don't feel comfortable doing that though, but I have no option because I don't have.(R6)*
	Emotional	11		Receipt help in the form of advice, encouragement, visitations of phone calls from significant others.	*..oh okay, for that it's one of my nephews. When I have such problems I go to him "Yaw, this is what's on my mind". Then he'd tell me not to worry too much that all would be fine (R1)*
	Physical	3		Receipt of support in the form of assistance on things the stroke survivors could not do due to their physical disabilities	*as for my sisters the first time I can't bath so they came here to take me to bath, bathing me, taking care of the babe but now I can bath myself so they normally come here. This place is my in-laws place, my husband's mother's place. So when I will go and bath they take my water into the bath room. When I want to eat they will cook some of the food for me because they say I will not eat salt, pepper and those things. So they always cook my food*

					separate. They will cook that food that everybody will eat but they cook my own different (**R11**).

Appendix 12: Detailed profiles of stroke caregivers

Ga Mashie

ID	Relationship with SS	Sex	Age	Religion	Marital Status	Duration of caregiving	Education	Ethnicity	Occupation	Monthly Income
R1	Niece	F	41	Christian	Married	1 year	Primary 4	Akan	Trading	GHC120
R2	Wife	F	51	Christian	Married	1 year	Primary 5	Ga	Unemployed	GHC 200
R3	Son	M	31	Christian	Never married	5 years	Primary 2	Ga	Carpentry/Mason	GHC910
R4	Daughter	F	32	Christian	Married	3 years	JHS	Ga	Trading	No response
R5	Daughter	F	48	Christian	Divorced	13 years	Primary 5	Ga	Unemployed	No income
R6	Son	M	20	Christian	Never married	8 years	SHS 2	Ewe	Student	No income
R7	Mother	F	64	Christian	Widowed	1 year	Primary	Ga	Trading	GHC200
R8	Daughter	F	17	Christian	Never married	No response	JHS	Ga	Seamstress/ Apprentice	No income

SS- Stroke survivor

Physiotherapy

Identifier	Relationship with SS	Sex	Age	Religion	Marital Status	Duration of caregiving	Education	Ethnicity	Occupation	Monthly income (GHC)
R9	Wife	F	42	Christian	Married	11 months	SS3	Igbo	Pastor	No response
R10	Son	M	30	Christian	Never married	3 years	BSc	Ga	Videographer	GHC 500
R11	Son	M	17	Christian	Never married	5 month	SS3	Ga	Hotel steward	GHC500
R12	Wife	F	60	Christian	Married	2 years	JHS	Ewe	No occupation	No income
R13	Daughter	F	26	Christian	Married	No response	BSc	Akan	Secretary	GHC 1200-1500
R14	Wife	F	58	Christian	Married	1 year	Form 4	Ga	Trading	GHC130
R15	Cook	M	52	Christian	Divorced	11 months	JHS	Ga	Chef	GHC600
R16	Son	M	24	Christian	Never married	12 months	SHS	Ga	Phone repairer	No response
R17	Wife	F	58	Christian	Married	6 years	JHS	Ga	Petty trader	GHC300
R18	Niece	F	20	Christian	Never married	2 years	SHS	Akan	Petty trader	No response

SS- Stroke survivor

Stroke unit

Identifier	Relationship with SS	Sex	Age	Religion	Marital Status	Duration of caregiving	Education	Ethnicity	Occupation	Monthly income (GHC)
R19	Daughter	F	63	Christian	Married	2 months	JHS	Akan	Retired	No response
R20	Brother	M	No response	Christian	Married	1 month	MSc	Ewe	Business man	No response
R21	Wife	F	82	Christian	Married	1 year	Tertiary	Akan	Retired	No response
R22	Daughter	F	28	Christian	Never married	6 months	Tertiary	Ewe	Nurse	No response
R23	Daughter	F	30	Christian	Never married	2 months	Tertiary	Akan	Nurse	GHC1300
R24	Husband	M	47	Christian	Married	1 year	MSc	Akan	Civil servant	No response
R25	Wife	F	No response	Christian	Married	4 days	No response	No response	unemployed	No response
R26	Daughter	F	66	Christian	Married	20 months	MSc	Akan	Public relation Practioner	GHC3500
R27	Wife	F	53	Christian	Married	6 months	No response	Ewe	Trading	No response
R28	Wife	F	58	Christian	Married	2 weeks	JHS	Akan	Trading	GHC400
R29	Nephew	M	43	No religion	Never married	3 months	MSc	No response	Business man	No response

Appendix 13: Coding Frequencies for Knowledge of stroke from the perspectives of the caregivers

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20	P21	P22	P23	P24	P25	P26	P27	P28	P29	N
KNOWLEDGE OF STROKE																														
Pre-diagnosis Awareness																														
Aware					+	+	+	+	+			+	+	+		+	+	+	+	+	+	+			+	+		+	+	20
Not aware	+	+	+	+						+													+							6
Causes of stroke																														
Chronic Diseases																														
Hypertension			+		+							+				+	+			+	+				+					8
Diabetes																									+					1
Multiple sclerosis																											+			1
Diet Imbalance																														
Poor diet	+																													1
Poor eating habits													+																	1
Poor lifestyle practices																														
Alcohol consumptions				+									+													+		+		4
Smoking								+					+															+		3
Not exercising																												+		1
Stress																														
Lack of rest (stress)							+										+		+			+								4
Family history																														
Family history																									+					1
Spiritual causal theory																														
Spiritual attack								+				+																		2
Being invoked by someone								+																						1
Non adherence to health issue																														

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Irregular BP check	+																		+										2
Non-adherence to BP medications	+											+																	2
Non-intake of drugs												+																	1
Not seeking biomedical treatment early						+				+																			2
Other Factors																													
Lack of knowledge about health issues															+														1
not being social															+														1
Taking the word of the elderly lightly																		+											1
Don't Know																													
Don't' know	+	+	+	+		+		+		+									+			+							9
Complications																													
Behavioural																													
Getting annoyed										+																			1
Getting angry			+									+																	2
Not calming down to be helped						+																							1
Cognition																													
Inability to remember things																							+						1
Forgetfulness										+									+						+				3
Brain damage															+														1
Death																													
Death			+																										1
Physical disability																													
Inability to eat by oneself																							+						1
Immobility		+																					+						2
Loss of limbs															+														1

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	Total
Inability to work													+																	+						2
Inability to do things											+																									1
Not feeling active as before																																			+	1
Pain in "manhood"											+																									1
Numbness in limbs																								+												1
Other forms of physical disability				+																																1
Psychological																																				
Worries																																			+	1
Prevention																																				
Adherence																																				
Adherence to health professional advice					+	+																														2
Good dietary Practices																																				
Watch the food you eat							+		+																											2
Reduce fat intake																		+																		1
Intake of iron													+																							1
Intake of plantain																																				1
Reduce meat intake																+																				1
Not taking a lot of fufu in old age																														+						1
Reduce sugar intake											+																									1
Not eating sugar																																+				1
Eating a well balanced diet																								+						+						2
Eating well																		+						+											+	3
Not eating late											+																									1
Reduce salt intake													+						+																+	3
Consumption of fruits																								+						+						2
Consumption of vegetables																+								+						+						3

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Good lifestyle practices		Freq.
Taking a lot of water	+	1
Not drinking alcohol	+ +	2
Not smoking	+ +	2
Exercise	+ + + + +	5
More sleep	+	1
Rest	+	1
Not stressing oneself	+	1
Taking care of oneself properly	+	1
Psychological balance		
Not being quick tempered		1
Not taking anything too serious	+	1
Not thinking too much	+	1
Not getting annoyed	+	1
Adherence to health issues		
Regular Hospital check up	+ +	2
Regular BP check	+ +	2
Other Factors		
Not working with vibrating machine	+	1
Government sensitization on regular BP check	+	1
Don't' know		
don't know	+	1
Groups at risk of stroke		
Anyone	+ + +	3

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	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	Total
Elderly		+	+	+				+										+		+					+													7
Young people			+					+																	+												+	4
Young and old					+															+							+											3
Women							+																															1
Men									+																													1
People who eat immediately after eating													+																									1
People with diabetes														+																								1
People living with kidney disease														+																								1
People who take a lot of alcohol																+																						1
People who are overweight																									+													1
Don't Know		+																													+							2

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Appendix 14: Coding frequencies for immediate reaction after diagnosis

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20	P21	P22	P23	P24	P25	P26	P27	P28	P29	N
REACTION AFTER DIAGNOSIS																														
Immediate reaction after diagnosis																														
Afraid						+						+															+			3
Devastated																				+							+			2
Troubled			+		+		+				+																			4
Felt bad																				+						+				2
Felt sad	+			+													+						+			+				5
Started crying	+																													1
Worried						+		+				+	+	+	+					+						+			+	9
Not worried when diagnosed																												+		1
Acceptance of diagnosis																														
Believed diagnosis											+		+												+	+				4
Denied diagnosis								+				+						+								+				4

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Appendix 15: Coding frequencies for impact of stroke on caregivers

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20	P21	P22	P23	P24	P25	P26	P27	P28	P29	Total
IMPACT OF STROKE																														
Relocation																														
Change in apartment																														
Change in diet																														
Has changed diet														+											+					2
Hasn't changed diet																							+					+		2
Stopped intake of meat												+																		1
Stopped late night eating																										+				1
Stopped intake of certain foods												+																		1
Stopped intake of fatty foods												+					+													2
Stopped intake of spicy foods																	+													1
Economic disruption																														
Changes in economic situation																									+					1
Could not take up job opportunities															+															1
Not able to work		+				+																								2
Affected job outputs						+																					+			2
Affected business/trading activities										+																		+		2
Stopped work						+						+													+					3
Has affected daily activities								+																		+				2

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																																	Total
Reduce work meetings																											+							1
Job absenteeism																				+											+			2
Financial disruption																																		
High cost of treatment for SS								+																										1
Financial burden			+			+					+												+			+		+			+			7
No steady income		+																																1
High cost of drugs															+			+																2
Employed house help for SS																										+								1
No financial burden																																	+	1
Change in lifestyles																																		
Changed lifestyle													+																					1
Has become more organised																										+								1
Don't sleep deep again																	+																	1
Disruption to physical body																																		
Pains		+																																1
Do not feel fine					+																													1
Feel pains all over body								+																									+	2
Suffer pain from carrying the SS								+																										1
Can't do certain things anymore													+																					1
Stress													+																					1
Waist pains													+																					1
Tiredness from running around																								+										1
No physical impact											+																							1
Psychological disruption																																		

Item																																			Total
Worry		+					+																													2
Think about the condition a lot							+											+															+		3
Frightens a lot							+																													1
Feel worn out													+																							1
Emotional difficulties														+																						1
Social disruption																																				
Not able to go out		+		+	+	+			+		+	+							+																	8
Inability to attend Church									+																											1
Can't go to certain places anymore												+																								1
Had to change schedules																					+															1
Can't attend social functions																								+												1
No social disruption						+																											+	+		3

Appendix 16: Coding frequencies for social support/ coping strategies

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20	P21	P22	P23	P24	P25	P26	P27	P28	P29	Total
SUPPORT GIVEN TO SS																														
Physical																														
Bath for the SS					+		+				+															+				4
Cook for the SS								+					+																	2
Feed the SS							+	+			+														+	+	+			6
Fetch water for the SS								+																						1
Take the SS around for exercise																	+													1
Help the SS to take medication				+																										1
Help the SS in using the toilet			+																											1
Carry the SS around							+																							1
Run errands for SS						+							+																	2
Wash clothes for SS					+	+	+	+																						4
Financial																														
Provide finances to SS				+																							+			2
Emotional																														
Provide much love for SS																									+					1
Keep the company of the SS													+																	1
SUPPORT RECEIVED																														
Physical																														
Received																								+	+			+		3

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physical assistance																															
Financial																															
received money to take care of CG																	+			+			+		3
Psychological support																															
Received psychological help																	+								1
No support																															
received no support		+	+			+																+		4

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Appendix 17: Global themes, organising themes and basic themes for knowledge and experience of stroke from the perspectives of the caregivers

Global Theme	Organising Theme	Basic Theme	No of responses	Description	Sample quotes
Knowledge of stroke	Pre-diagnosis awareness				*Uhhh…. Yeah I know a little bit about stroke because I am a nurse, I know* **(R20)** *I… have a limited knowledge but I didn't know so much about it until it happened to my wife.* **(R27)**
		Aware	20	Had pre-diagnosis knowledge of stroke	
		Not aware	6	No pre-diagnosis knowledge of stroke	*no, no I didn't know. It was when he had it that I started reading about it* (**R24**)
	Causes	Chronic Diseases	10	Relating the cause of stroke with chronic diseases such as hypertension, diabetes and multiple sclerosis	*"…in my mother's case, it was the BP that caused her to get stroke, so if someone has BP, the person should take care of him/ herself so that it doesn't affect other things which could bring the stroke"* **(R4).** *If you have diabetes and you're not checking it, it leads to stroke. You're having diabetes but you're taking alcohol, which has sugar in it. When you come back, then you also go and buy 'hausa koko' which also has sugar in it. After that then you sleep. So I feel the diabetes is what caused the stroke* (**R25**)
		Diet imbalance	2	Getting stroke through poor eating habits	*…they say it's partly caused by our eating habits. So we have to watch our eating habits* (**R1**)
		Poor lifestyle practices	8	Engagement in lifestyle practices	*the doctor told her not to drink alcohol but she*

			such as alcohol consumption, smoking, and physical inactivity	*continued to take it. If the doctor advises you to refrain from something and you don't, you will face the consequences (R4)*
				…I can't really say, because I wasn't living with him. But he was smoking both cigarettes and marijuana. He wasn't going to the hospital too [R8]
				…the doctor told her not to drink alcohol but she continued to take it. If the doctor advises you to refrain from something and you don't, you will face the consequences [R5]
				I: so what do you think can be the causes of stroke? P: drinking, smoking, not being physically active… [R28]
Stress	4	Stroke being caused by hard work and lack of rest		*My mom is a trader and works very hard. She brought us up single handedly and she wasn't having enough rest. You know most of these traders work so much and just take a little rest when they feel headache from too much working (R18)*
Family history	1	Existence of stroke in the family		*I: you said stroke was on his family. Amongst his siblings, is he the only one with stroke? P: no. some of them have even passed on I: how many siblings has he got? P: two I: and they have both passed on? P: yes (R25)*
Spiritual causal theory	3	Being invoked by someone		*However, sometimes it may be given to you, spiritually (R8).*

				*I don't know. I feel it is an attack (spiritual attack I guess) because we have gone to check for any heart problem, kidney, liver, all are normal. He is not diabetic (**R12**).*
				*I think it is somebody who sent it to him because how can somebody who came back and went to sleep in the evening time as siesta come out like this (**R12**).*
				*…yes. So I rushed to the friend's house and brought her the medicine and she took it. She was complaining of numbness in her arm. After she took it I went to bed because it was getting late. During the midnight, I got up and went to the market to do some work and when I came back in the morning I realised there were a lot of people around and a lot seem to be going on. Then I was told what happened. When she took the medicine the night before, she later realised that the dosage wasn't enough so she took the remaining dosage. Her condition became sever around 02:30am so she was rushed to the clinic (**R16**)*
	Non-adherence to health issues	5	Not following advice on health issues	*Since it is BP which causes it. So if you don't take medications and check your BP you can get stroke (**R1**)*
	Other factors	3	This includes lack of knowledge about health issues, not being social and not paying attention to symptoms	*my father's friend is a doctor, he used to tell us that if you're the kind who doesn't go to the hospital to check your blood pressure and take the drugs prescribed for you, you can get it (participant referring to stroke) (**R1**).*

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	Don't know	9	No idea on what causes stroke	*I really can't tell. I don't know what makes one to get it, so I can't tell what to do in order to prevent it (**adult female, daughter, Ga Mashie**)*
Complications	Behavioural changes	4	Changes in behaviour (getting angry, annoyed, etc) due to stroke	*She gets angry very quickly, she is very quick tempered. But when she is angry, I am the only one who can calm her (**R4**).* *he doesn't calm down to be helped. He wants to do everything on his own (**R8**)*
	Cognitive disability	5	Effect of stroke on brain and which can lead to forgetfulness, inability to remember things, etc)	*he forgets what he has been doing in the church. Sometimes he forgets to do it. If I remind him them he will do it (**R12**).* *he cannot even remember anything. All he remembers is the meetings concerning his business and other appointments(**R15**)*
	Physical disability	11	Effect of stroke on body-self which causes immobility, pain, inability to work, etc	*yes, sometimes when he urinates he experiences pains in his manhood (**R11**)* *It affects a lot of things, there are things you wish you could do yet you cannot do it (**R4**)*
	Psychological disability	2	Consistent thinking due to stroke	*he's always been thinking more than he should. Thus, worries a lot about things he shouldn't even be bothered about (**R4**).*
	Death	1	Loss of life as a result of living with stroke	*The end result of such a case is that you will die. Because you would also think a lot; and with this kind of situation, you don't have to think a lot. Because when you have stroke, it comes with BP, so you don't have to think too much...(**R6**)*
Prevention	Adherence to health professional advice	2	Following what health professional advice with regards to living a healthy	*I would say that when one is sick and visits Korle-Bu, whatever advice he or she is given the person should adhere to it (**adult female, daughter, Ga Mashie**)*

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			life	
Good dietary practices	23	Consumption of good foods (such as fruits, vegetables) and eating at the appropriate time	*we must limit meat in-take and rather focus on vegetables and other fruits that can prevent some of the sicknesses (**R12**)* *well the little I know is that you are not supposed to eat late (**R17**)* *I will tell the person watch the food they eat and things they do so that they don't get it (**R7**)*
Good lifestyle practices	14	Adoption of behaviours that are healthy for the body	*Exercising more reduces your chances of getting a stroke (**R11**)* *not everyone can get it. If you take care of yourself properly, you might not get it (**R8**).*
Psychological balance	4	Being emotionally stable, not getting angry, not thinking too much	*There's too much of anger around when you listen to say the politicians on the radio. All these things are not good for the body (**adult male, brother, Stroke Unit**).*
Adherence to health issues	4	This includes regular hospital check-up and regular BP check	*what I will tell them is that if they are advised not to do certain things they should abide by it. Otherwise you will experience complications in a lot of things. It could even go on to affect your family (**R3**)*
Other factors	2	This includes sensitizations by government and taking up jobs which disallow the use of vibrating machine	*When you go outside, the government actually spends a lot of money on educating the people because they believe it's a proactive form of applying medication. Thus, teaching somebody to take care of himself and check his BP and stuff like that. The likelihood of that person developing stroke is not high (**R20**).*
Don't know	1	No knowledge on how stroke can be prevented	*...as for that I don't know (participant refering to stroke prevention). If you know can you please teach me (**R17**)*

		Anyone	3		
		Elderly	7		
		Young people	4		
		Young and old	3		
		Women	1		
		Men	1		
	Groups at risk of stroke	People who sleep immediately after eating	1	Includes people who are most at risk of getting stroke	*I think we are all at risk of getting it, even the young ones. Both men and women (**R16**)* *the very elderly people around the ages of eighty years old. But these days you see very young people also getting the disease (**R3**)*
		People with diabetes	1		
		People living with kidney disease	1		
		People who take a lot of alcohol	1		
		People who are overweight	1		
		Don't Know	2		
Experience of stroke	**Immediate reaction after diagnosis**	Emotional expression	27	Expression of sadness, fear, worries, etc	*Well, initially because I haven't experienced it, I only heard of it and I didn't know what it is I was a bit afraid so my wife is going to be bed ridden or, it was a bit difficult for me and more importantly for her people who are around to see her is someone who was strong going about her business and all that they see now is that she is in her wheelchair and all that. It was something difficult for me to tell (**R24**).*

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					*it disturbed me that he had stroke, because he is not old, and his children are still very small. When the doctor broke the news that day, honestly, I cried because his children are very small (**R1**)* *honestly I was really sad, because someone with whom we were living normally, he just complained of malaria and went to buy the drugs himself then all of a sudden getting stroke, it was really disturbing (**R1**)* *Of course I was devastated ahh given the fact that this is someone who was healthy there wasn't anything like she was going to go down and then the left side was paralyzed she could not lift the legs, lift the hands, initially she could not even sit or even the neck was not stable and all this I am given the fact that we have 5 kids who are between the ages of eer… 8 and 1, it wasn't easy but as a man I had to master courage because it is something that has happened there was nothing that could be done to look up to God than to look for the necessary medication so it wasn't easy, it hasn't been easy on me for the past one year (**adult male, husband, Stroke Unit**)*
		Believed diagnosis	4	Accepted doctors' diagnosis of the condition	*I know for stroke when you have it you cannot walk so I believed it was stroke (**R17**).* *I believed it, because of the way the hand has become, and mostly this is how stroke starts(**R14**)*
		Denied diagnosis	4	Not agreeing with the doctor's diagnosis	*it depended on how the nurse said it that maybe it has entered into his head. So she told me in front of him so I went there and I told him that he should not mind them and that nothing will happen to him. Nothing has entered into him. He is normal (**R9**).*

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					*I didn't really believe that, because the first day it happened, it was his mouth that had tilted (**R27**).*
					*I said that could not be my father, because my father was working. But I was told it was my father. Since I was living with someone, I couldn't leave. So I came around during my free time, only to find out that it was true (**R4**).*
	Impact of stroke				*yeah. Saturday this is the only time I'm sitting beside him to rest. I've been moving from one pharmacy to the other. You'll get one drug here and you wouldn't get the other there. I'm very tired and I myself I have pressure (**R12**)*
					*It hurts, sometimes (m hmm) this hand (pointing to one of her hands) I feel pains in it as if there is a wound in it. And also I feel pains around my waist, my thighs I feel pains. Sometimes this part of my body hurts (**R17**).*
					*it has. Sometimes when I bend down to sweep, I get stuck in the bent position. Also, because I wash a lot, I have feel pains in my hands (**adult female, daughter, Ga Mashie**)*
		Disruption to physical body	10	This includes experience of pains due to caregiving duties	*I am worn out because I am the only one taking care of him (**R12**)*
		Change in diet	10	This refers to stoppage of some foods and being cautious of diet	*Now I'm very cautious when I'm eating something. Especially taking of alcohol (**R14**)*

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				due to stroke experience	
	Disruption to economic circumstance	16	This involves effects of stroke on the jobs/economic activities of the CG	*it has really affected my output at the workplace but my employers understand as we are talking now I have to attend the finance committee meeting I have to deliver a presentation on that here I am to make sure she gets the deserved care. So in terms of my work it has affected me (R24)* *yes. After SHS I had the opportunity to go and teach in a certain school but because of the sickness I had couldn't accept it. Otherwise there would have been nobody at home to take care of my mom (R11)*
	Financial disruption	13	This includes expenditure on drugs and other associated cost on stroke treatment	*Not really but financially, it has , financially it has really affected it but my social life and all that I know it is one of those things so it really didn't affect in those parts but financially it has (R23)* *Financially, I will say it has had a lot of impact on me because aside the medication which are very expensive because on daily basis I have to spend about 100 Ghana Cedis for some of the medicine and the up keep; buying of diapers, the food the kind of food that she will have to eat. So financially it has had a lot of impact on me (R24)*
	Change in lifestyles	3	This involves not being able to sleep deep again and being more organised than before	*....they aborted the seizure upon getting there. Because of such unforeseen occurrences I don't sleep deep because I still have such fears [R18]* *Rather, it has forced me to take another look at certain things. I know that have be organised because one day you're very okay but the next day, functionally you*

				cannot do anything (R26).
	Psychological disruption	8	This includes expression of emotional difficulties, feeling worn out, frequent thinking, etc	*yes, I really think about it and people tell me not or else if should die as a result, who will take care of her (R7)* *Yes, I was thinking about it but I she will recover. Initially, I will even cry the whole day because I know about the stroke and all that.. (R23)*
	Social disruption	15	This includes inability to attend social functions and not being able to go out anymore	*at times, sometimes I have to go somewhere but I cant, just last week I had to travel but I did not go, sometimes he feels that when I am not around, he does not feel happy, even at home im so busy(R14)* *I used to visit friends and go out. But ever since he fell sick I've not been able to go anywhere because there's no one else to take care of him (R13)*
	Relocation	1	Change in place of residence because of lack of toilet in the previous place of residence	*I: hmm, so you left the house because of the condition R: I left because that place has no toilet. (R9)*
Supports given to stroke survivors	Physical	23	Help in bathing, cooking, and moving the stroke survivor around	*as at now we have accepted the fact that she is sick, so we're taking care of her. I bath her and wash her clothes (R5).* *I am the one who takes care of her in every aspect. Excuse me to say even if she wants to visit the toilet. I get tired but there's no one to do it in my stead (R24)*
	Financial	2	Provision of money for the purchase of drugs and to take care of	*Financially, I don't make her to know I am financially down, no, so whenever there is the need to buy any medicine I make sure the medicine she takes are there (R24).*

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			other needs of the stroke survivor	
	Psychological	2	Giving of encouragement, advice to stroke survivor	*..I keep him company, we chat a lot,I always want to chat, Im a nice person (R15)* *I give him so much love right now, so that he will be able to heal on time. He usually gets angry sometimes, but I give it a blind eye, and return it with love (R28)*
Supports received	Physical	3	Receipts of help with bathing the SS and in moving him/her around	*Interviewer: who else has been of help to uncle apart from you?* *Respondent: his wife and his niece.* *Interviewer: what kind of support do they give?* *Respondent: they help physically* *(R24)*
	Financial	3	Receipt of money to help take care of the stroke survivor	*Mmm… Not really, I do things myself aside a friend who helps financially, psychologically, I mean every … (giggles), he is really helping me.(R23)*
	Psychological	1	Receipts of support in terms of encouragement, advice and emotional support	*Mmm… Not really, I do things myself aside a friend who helps financially, psychologically, I mean every … (giggles), he is really helping me (R20).*
	No support received	4	No form of support received	*I am alone, no one helps me. So the little I get is what I used to cater for him (R2).* *when I need money, I have to do it fast, because there is no one here to take care of him apart from me (R8)*