

**UNIVERSITY OF GHANA**

**COLLEGE OF HEALTH SCIENCES**



**EXPERIENCES OF YOUNG ADULTS LIVING WITH STROKE IN THE  
ACCRA METROPOLIS**

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## DECLARATION

I, Sussana Opoku certify that, this thesis is the result of a research undertaken towards the award of the Master of philosophy Degree in Nursing from the School of Nursing, University of Ghana, Legon. This research has been undertaken with the guidance and supervision of Mrs. Cecilia Eliason of the School of Nursing, University of Ghana, Legon and Dr. Albert Akpalu, Head of the Stroke Unit at the Korle-Bu Teaching Hospital.

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INTEGRI PROCEDAMUS

## ABSTRACT

Stroke has a devastating effect on young adults between the ages of 18-45years. In Ghana, there is paucity of research in stroke among young people, but stroke is said to be increasing among younger age groups of adults less than 45 years; forming greater than 30% of strokes seen and at a higher mortality rate. This research was conducted in Accra, Ghana, to explore the experiences of Young Adults (18-45years) living with stroke. A qualitative explorative descriptive design was used to explore the experiences of the young adults who participated in the study and purposive sampling technique was employed to recruit ten participants. Data was collected using tape recorded interviews which lasted between 45minutes to 1hour 30 minutes and guided by a semi-structured interview guide which was informed by the research objectives and literature review. Thematic content analysis was used to analyze the transcribed data and six major themes were derived namely; Disruption to body-self, disruption to social identity, disruption to personal agency, disruption to economic circumstances, illness action and lack of continuity of care. Young Adults living with stroke were affected physically by various signs and symptoms which negatively impacted their physical health. They were unable to work and perform simple tasks. They experienced social isolation, fear, anxiety, depression, guilt and had suicidal ideations. They coped with their condition through spiritual practices and beliefs, self-determination, support from family, friends, employers and co-workers and some took to herbal medicine. Stroke Survivors lacked information about the cause of their stroke and about stroke and its related signs and symptoms. Provision of continuity of care for young adults living with stroke and further research as well as public education on stroke amongst young adults was highly recommended.

## DEDICATION

To my husband, Dr. Albert Hammond, for being there for me from the very beginning and to my daughter, Frances-Alberta Norley Keenor Hammond. I love you both to bits.



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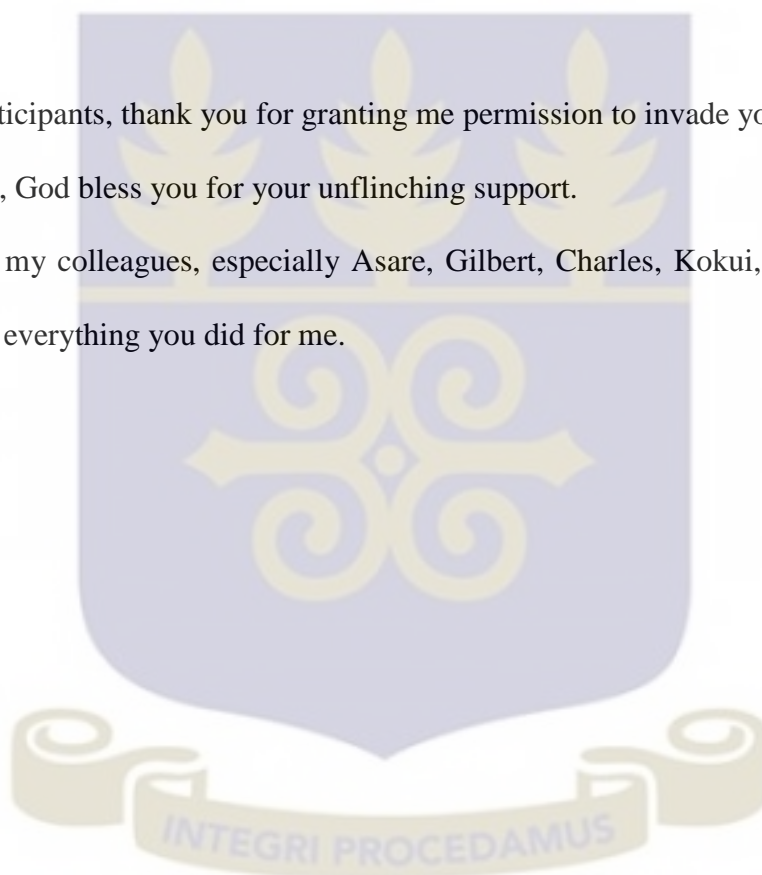
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## LIST OF ABBREVIATIONS

AVM	:	Arteriovenous Malformation
CDC	:	Centre for Disease Control
CNS	:	Central Nervous System
CVA	:	Cerebrovascular Accident
CVD	:	Cardiovascular Disease
DCI	:	Delayed Cerebral Ischemia
ICH	:	Intracranial Haemorrhage
KBTH	:	Korle-Bu Teaching Hospital
SAH	:	Subarachnoid Haemorrhage
TIA	:	Transient Ischaemic Attack
WHO	:	World Health Organization



## CHAPTER ONE

### INTRODUCTION

Chapter one of this study gives a detailed presentation of the background of the study, problem statement, purpose of the study, objectives, significance of the study and operational definitions.

#### 1.1 Background of the study

The W.H.O. (World Health Organization) defines stroke as a rapidly developing clinical sign of focal or global disturbance of cerebral function, with symptoms that last for 24 hours or longer or leading to death with no apparent cause other than a vascular origin (Sacco et al., 2013). A recent definition describes it as a neurological deficit attributed to an acute focal injury of the Central Nervous System (CNS) by a vascular cause, including cerebral infarction, intracerebral hemorrhage (ICH), and subarachnoid hemorrhage (SAH). In other terms, a stroke is said to have occurred, when the interruption of the blood supply to the brain, (usually because a blood vessel bursts or is blocked by a clot) cuts off the supply of oxygen and nutrients, causing damage to brain tissue (WHO, 2016).

The two main types of stroke are Haemorrhagic stroke and Ischaemic stroke. Haemorrhagic strokes form 20% of all strokes and can either be intracerebral or subarachnoid. Ischaemic strokes on the other hand form the remaining 80% and may include large artery disease, cardio-embolism, and small vessel disease” (Howard, 2014; Markus, 2012). These types of stroke primarily originate from two main types of risk factors; non modifiable risk factors such as age, gender, race, ethnicity, heredity and modifiable risk factors such as hypertension, atrial fibrillation, other cardiac diseases, hyperlipidemia, diabetes, cigarette smoking, physical inactivity, carotid stenosis, and Transient Ischemic Attack (TIA) (White et al, 2005; Pinto, Tuttolomondo, Di, Fernandez & Licata, 2004).

Once affected with stroke, clinical features vary and include hemiparesis, hemisensory loss, hemianopia, dysphasia, inattention (both visual and sensory) neglect, activity limitations (disability), and participation restriction (handicap) (Markus, 2012).

Stroke was first discovered by Hippocrates from 460 to 370 before the Common Era, and was initially known by its symptoms of convulsions and paralysis as apoplexy. As the years advanced and new technology evolved, a more pathophysiological approach of dealing with the condition emerged. The term apoplexy also faded with time making room for the term stroke to be used (Nilsen, 2010).

In recent times, Stroke is the third most common cause of death worldwide and the major cause of adult neurological disability. It accounts for approximately 5.5 million deaths annually and remains common amongst the aging population, 65 years and above (Mukherjee & Patil, 2011). Globally and in the United States, approximately 795, 000 people continue to experience a new or recurrent stroke (ischemic or hemorrhagic) each year. Approximately 610, 000 of these are first events and 185, 000 are recurrent stroke events. On average, every 40 seconds, someone in the United States has a stroke, and someone dies of one approximately every 4 minutes (Go et al., 2013). In a lifetime, it is estimated that about 25% of men and 20% of women who live to 85 years of age can expect to suffer a stroke with 25% of strokes occurring in individuals of working age (Markus, 2012).

Although stroke occurs in developed countries, its incidence is said to be decreasing, with a gradual increase in developing countries (Ovbiagele, 2015; BeLue et al., 2009; Feigin, 2005). In sub-Saharan Africa, it is a leading cause of death, disability, dementia, and depression (Ovbiagele, 2015; BeLue et al., 2009; Feigin, 2005) and a quarter of stroke patients die within a month with poor prognosis for those with intracerebral and

subarachnoid haemorrhage (Johnny & Gupta, 2006). Significant mortality is gradually shifting from infectious diseases such as Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome and malaria to non-communicable ones such as stroke (Ogbole, Owolabi & Yusuf, 2013; Ntsekhe & Damasceno, 2013; Danesi, Okubadejo, Ojini & Ojo, 2013).

In Greater Accra, stroke mortality is second only to that from malaria, and is a major burden not only on patients and family, but also on staff and the health-care system (Henriques, Henriques & Jacinto, 2014; Morris, 2011). A study by Agyemang et al (2012), which involved in-patients with stroke admitted to the Komfo Anokye Teaching hospital (KATH), from January 2006 to December 2007 revealed that; stroke constituted 9.1% of total medical adult admissions and 13.2% of all medical adult deaths.

Paucity in stroke studies among young adults has made it difficult, to estimate the percentage of young people affected by stroke worldwide (Smajlović, 2015). However, several lines of evidence now show that stroke is on the increase in young adults (Renna et al., 2014; Sultan & Elkind, 2013). Whilst developed countries are recording less than 5% of stroke in young adults; higher proportions, between 19% and 30%, are reported in developing countries (Marini, Russo & Felzani, 2011; Ogbole, Owolabi & Yusuf, 2013; Ntsekhe & Damasceno, 2013; Danesi, Okubadejo, Ojini & Ojo, 2013).

The causes of stroke among young adults have also been identified not to be limited to hypertension and diabetes. Some other permanent or transient risk factors such as smoking, use of oral contraceptives, migraine, trauma, use of illicit drugs and pregnancy or puerperium have also been identified (Renna et al., 2014). These causes have further worsened the prognosis of stroke in the young in relation to mortality and psychosocial consequences (Schaapsmeeders et al., 2013).

Stroke survivors are left with physical impairments that limit functional abilities and the devastating effects of stroke impact on individuals and their family members, robbing them of their independence. (Obembe, Mapayi, Johnson, Agunbiade & Emechete, 2013).

The inability to meet basic fundamentals of care like eating, bathing and elimination, worsen the psychological and emotional impact of the condition (Kitson, Dow, Calabrese, Locock & Athlin, 2013) consequently leading to a negative effect on relationships and wider social participation, including the ability to return to work and to enjoy an active social life (Lawrence, 2010). Stroke caregivers are also often overwhelmed and find it difficult to cope with the short length of time available to deal with the stroke crisis and its subsequent responsibilities (Lutz, Ellen Young, Cox, Martz & Rae Creasy, 2014).

Furthermore, most young adults are left with the burden of having to foot huge hospital bills, and have to deal with meeting the financial needs of their immediate family (Ellis, 2010). Evidently, stroke affects young adults in many ways, yet very few studies have been done in relation to the experiences of young adults in respect to stroke. This therefore forms the basis for this study.

## **1.2 Problem Statement**

Stroke has a devastating effect on young adults between the ages of 18-45 years (Lawrence, 2010). Suffering from it at a young age impacts significantly on family relationships and functioning (Kristensen et al., 2014; Eriksson & Tham, 2009; Wood, Connelly & Maly, 2010; Kitzmüller, Asplund & Häggström, 2012). The ability to meet specific needs such as parenting, family finances, sexual function and issues related to the sense of self (i.e. self-confidence and self-esteem) is often greatly affected (Lawrence, 2010; Rowat et al, 2009).

Sub-Saharan Africa is currently recording a rapid rise in the incidence of stroke in young adults who are been affected mainly in their reproductive years (Bevan, Sharma t& Bradley, 1990; Felipe Varona, Manuel Guerra & Bermejo, 2004; Ogbole, Owolabi & Yusuf, 2013; Ntsekhe & Damasceno, 2013; Danesi, Okubadejo, Ojini & Ojo, 2013).

Specific studies have not been conducted in Ghana to ascertain whether or not stroke occurrence is on the increase among young adults aged 18-45years, but an expert in the field has indicated that stroke is an epidemic which is increasing among younger age groups of adults less than 45 years; forming greater than 30% of strokes seen and at a higher mortality rate. Uncontrolled hypertension is present in more than 80% of these cases, putting overall average mortality between 20-30 % of total mortality and positioning stroke consistently, among the top three causes of death” (Hammond, 2014).

My three years of practice as a general nurse, has also seen several young adults who have been affected by stroke, many of whom did not recover but passed on mainly after a sudden collapse. The patient I used for my care study as a prerequisite for the award of a license to practice as a nurse also died at the age of 45 years from a subarachnoid hemorrhage.

Rehabilitation after stroke provides a multidisciplinary supportive service for survivors and their caregivers, but the proportion of patients who sign up for these services are few (Langhorne, Bernhardt & Kwakkel, 2011; Lange et al., 2015). Ghana currently has a stroke unit, which is equipped with a multidisciplinary team and equipment to see to patients and those from other West African countries, but the unit faces a unique challenge of limited staff and equipment due to the vast number of patients in need of acute stroke care (Hammond, 2014).

The concern here is that the individualized need for skill acquisition for continuity of care among patients and their caregivers may be lost, posing an issue of major concern because these younger people are still part of the economically active population and live longer to face the impact of stroke on their quality of life (Ellis, 2010). There is therefore need to gain an in-depth understanding into the experience of young adults living with stroke, serving as the basis for this study.

### **1.3 Purpose of the study**

The purpose of this study was to explore the experiences of young adults living with stroke in the Accra Metropolis.

#### **1.3.1 Research objectives**

The specific objectives were;

1. To explore the psychosocial impact of stroke on young adults.
2. To identify the effect of stroke on the physical health of young adults.
3. To explore how young adults cope with stroke



### 1.3.2 Research Questions

1. What is the psychosocial impact of stroke on young adults?
2. What is the effect of stroke on the physical health of young adults?
3. How do young adults cope with stroke-related disability?

### 1.4 Significance of the study

The study is aimed at providing needed information which will serve as a basis for the development of interventions by health professionals, to help decrease the negative impact of stroke on the quality of life of young adults.

It will also provide information for educating the general public about the need for regenerative health which is jeered towards reducing the alarming increase in stroke incidence among young adults. Health training institutions will also receive information that will encourage the development and improvement of their curriculum for training health professionals to better care for stroke affected persons.

Policymakers will also be provided with the needed information for developing policies that will go a long way to improve upon the general wellbeing of young people living with stroke.

### 1.5 Operational definitions

**Stroke** – “rapidly developing clinical sign of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death with no apparent cause other than vascular origin”

**Young adults** – Individuals between the ages of 18 and 45 years as adopted from a study by Ellis (2010).

**Stroke affected persons** – a person who has been diagnosed with stroke and is receiving treatment or undergoing rehabilitation.

**Stroke incident** – the initial occurrence of the stroke disease.

**Stroke experience** – all the circumstances surrounding the stroke incident and its impact on the affected person.

**Disruption to body-self** - refers to the relatedness between the physical and the psychological body.

**Disruption to social identity** - refers to the direct effect of stroke on the social status of the affected individual bringing into play how one sees him or herself or is viewed by people in the community or social group body.

**Disruption to personal agency**- refers to the effect of stroke on the ability of the affected person to work and interact socially.

**Disruption to economic circumstances**- refers to the effects of stroke experience on the financial stability of affected persons.

**Illness action**- refers to the practical routines that participants initiate and manage in order to cope with or overcome the negative psychosocial and psychological impact of the stroke experience.

**Lack of continuity of care**- refers to the absence of a lifelong plan for continuous care after the stroke experience

## CHAPTER TWO

### THEORETICAL FRAMEWORK OF THE STUDY/LITERATURE REVIEW

#### 2.1 Theoretical Framework of Biographical Disruption and Illness Action (Aikins, 2003)

The concept of biographical disruption was first introduced by Michael Bury in 1982 with a focus on the experience of living with chronic illness which he conceptualized as a particular type of disruptive event (Bury, 1982). In describing the experience of the onset and development of rheumatoid arthritis, Bury suggested a perspective which views chronic illness as a particular kind of disruptive experience. He observed that chronic illness included a “disruption, a discontinuance of an ongoing life”. His concept of ‘biographical disruption’ refers mainly to the disruptions that illness causes to “the physical body and the life trajectory of the sufferer” where that illness, especially chronic illness, disrupts the structures of everyday life and the knowledge which underpin (Bury, 1982)

According to Bury, Chronic illness also involves identifying the worlds of pain and suffering and possibly death which are “normally only seen as distant possibilities or the plight of others”. In his qualitative study on rheumatoid arthritis, Bury linked three dimensions of disruption to the occurrence of a chronic illness. The first dimension he called taken-for-granted assumptions and behavior focused on the insidious occurrence of the chronic ailment which leaves sufferers shocked and in a state of disbelief that they have been affected with the condition. The second which he called more profound disruptions delved into the aspect of the chronic illness occurrence where the affected person comes face to face with reality and has to rethink about who he or she is and develop a new self-concept. The third which he called response to disruption identified the

state where the affected person “mobilizes resources in facing the altered situation” (Bury, 1982).

A study by Pound et al (1998) which uses the biographical disruption framework seems to depend more on the unspoken assumption that illness enters lives which until then have been untouched by struggles indicating that illness presents an individual with an extreme crisis, irrespective of other mitigating factors (Pound, Gompertz, & Ebrahim, 1998).

Faircloth et al (2004) submit in their qualitative research that the lives of individuals who have a particular illness that is notably known by sudden onset are unavoidably disrupted with a split between self and body (Faircloth, Boylestein, Rittman, Young, & Gubrium, 2004).

The concept of biographical disruption has dominated studies into the experience of chronic illness in recent times (Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2009; Wilson, 2007; Williams, 2000). In a study by Asbring, (2001) which was conducted in Sweden, the interviews 25, 12 with the diagnosis of Chronic Fatigue Syndrome and 13 diagnosed with fibromyalgia discovered that, the illnesses involved a radical disruption to the life of the women involved and had a clear consequences for their identity, particularly in relation to work and social life (Asbring, 2001)

Another study in the UK which sought to “operationalize the idea of disruption to one's life trajectory in quantitative analysis by examining the social, economic and emotional disruption associated with Multiple Sclerosis” provided evidence on how multiple sclerosis impacts on and disrupts the entire life of the sufferer along with his family in respect to income and employment. (Green, Todd, & Pevalin, 2007).

The concept was reviewed and critiqued by Simon Williams (2000) who identified that the model failed to mention the impact of genetic illnesses (Williams, 2000). A Study by

Carricaburu and Pierret (1995) also however, challenged the study by Burry and explored that the biographical disruption concept could be applied to situations of asymptomatic HIV-positive men's lives.

The theory of biographical disruption has been used in some stroke studies (Greenwood & Mackenzie, 2010; Faircloth, Boylstein, Rittman, & Young, 2004). In a study by Pound, Gompertz & Ebrahim (1998) on "Illness in the context of older age: the case of stroke"; stroke was popularly conceived as an illness which shatters lives. The idea of shattered lives, articulated more generally within the sociological literature on chronic illness as 'biographical disruption' (Pound, Gompertz & Ebrahim, 1998). A cross-sectional comparison study on the perceived changes in the self-concept of stroke respondents and +6hospital volunteers, reported a negative sense of self, reduced social activity and psychological morbidity despite inpatient and outpatient rehabilitation. It concluded that most people after developing stroke may result to a restricted future because of their expectations of life with a disability (Kaufman, 1988).

Living with stroke however has a lifelong effect on young adults since they are more likely to live longer with the experience (Krishnamurthi et al., 2015). In a study by Aikins (2003) on "Living with Diabetes in Rural and Urban Ghana: A Critical Social Psychological Examination of Illness Action and Scope for Intervention" Prof. Ama De.-Graft Aikins further elaborated on the concept of biographical disruption and illness action adopted by chronic illness sufferers in dealing with their condition (Aikins, 2003). She defined biographical disruption in the light of five interrelated dimensions of everyday life: body-self, social identity, personal agency, economic circumstance and nutrition. She further went on to describe how these dimensions are disrupted in the face of a chronic illness and further expatiates on the illness action employed to deal with the physical disruptions of chronic illness (Aikins, 2003). These dimensions were defined as follows:

### **Disruption to body-self**

Body-self is defined here as the inter-relationship between the physical and psychological body Aikins (2003). It highlights those symptoms both minor and major that affect a person suffering from a chronic illness and how it impacts their physical health. It also includes the emotional responses which are attributed to these body disruptions such as fear of death.

### **Disruption to social identity**

Social identity bothers on a person's sense of who they are based on the social group they belong to. These groups are an important source of pride and self-esteem, a sense of identity and belongingness (Tajfel, 1979). In her study a disruption to social identity impacted from three dimensions; the negative impact of physical symptoms on social identity, social perceptions of chronic illness sufferers and the impact of physical disability (Aikins, 2003)

### **Disruption to personal agency**

Personal agency refers to the role of the body-self in fulfilling social and work roles. According to Aikins (2003) disruption to personal agency affects physical strength and impacts on illness experience at the levels of inability to work and to carry out social roles.

### **Disruption to Economic circumstance**

Disruption to economic circumstances impacts the chronic illness sufferer by causing a loss of earnings and increased expenditure. Most often than not, when disruption of economic circumstance is prolonged, alternative means of treatment are sought no matter how inappropriate (Aikins, 2003).

## **Nutrition**

According to Aikins (2003) nutrition refers to diet modification for optimal health after suffering from diabetes. Her study further discovered the impact of low income on the ability to effectively make these modifications.

## **Model modifications and justification for use in this study**

In relation to research in Ghana, the theoretical framework of biographical disruption and illness action by De-graft Aikins (2003) was first identified in her work on “Living with Diabetes in Rural and Urban Ghana: A Critical Social Psychological Examination of Illness Action and Scope for Intervention”.

The researcher does not know of any other researchers that have adopted this framework. The framework was adopted for this current study because its constructs are clearly outlined and provide themes which effectively organize the experiences of young adults living with stroke under various themes. For this study the dimension of nutrition was not adopted.

After thematic content analysis data gathered in this study;

- Disruption to body-self focused on minor disruptions, major disruptions and psychological disruptions
- Disruption to social identity focused on social perceptions and social isolation.
- Disruption to personal agency focused on inability to work and inability to perform simple tasks.
- Disruption to economic circumstances focused on financial constraint.
- Illness action focused on spiritual practices and beliefs, self-determination, support and herbal medicine.

## **2.2 Literature Review**

The remaining aspects of this chapter highlights the literature review of relevant literature on stroke in young adults. The literature search was performed using the following electronic databases: PUBMED, MEDLINE, Science Direct, Sage, Willey online Library, Ebsco host, Elsevier and Google Scholar. The keywords used for the search were ‘stroke’, ‘young adults and stroke’, ‘coping with stroke’ and effects of stroke’

Literature review was done and captioned under the following headings;

- Overview of stroke and stroke in young adults
- Disruption to body-self
- Disruption to social identity
- Disruption to personal agency
- Disruption to Economic circumstances
- Illness Action
- Lack of continuity of care

### **2.2.1 Overview of stroke and stroke among young adults**

Stroke refers to a cardiovascular incident that occurs in the brain. It is the principal cause of adult disability and the third foremost cause of death in most of the developed countries in the world like the United States of America (WHO, 2016; Yoon, Heller, Levi, Wiggers, & Fitzgerald, 2001; Eaves, 2000; Hux, Rogers, & Mongar, 2000).

According to Sacco et al. (2013), stroke is naturally characterized as a neurological deficit credited to an acute focal injury of the Central Nervous System (CNS) by a vascular cause. This includes; cerebral infarction, Intracerebral Haemorrhage (ICH), and Subarachnoid Haemorrhage (SAH), and is a main cause of disability and death globally. Sacco further indicated that, the name “stroke” was first introduced into medicine in 1689 by William

Cole in his work “A Physico-Medical Essay Concerning the Late Frequencies of Apoplexies” (Cole,1995). Afore Cole, the mutual term used to label very acute non traumatic brain injuries was “apoplexy.” Apoplexy was also used by Hippocrates circa 400 BC (Akinyemi, 2014). For more than 2000 years, physicians have struggled to define the term “stroke.” In the course of the 1950s, physicians felt the need to also introduce a term for momentary vascular-related episodes of brain dysfunction that would not qualify as stroke, and that was how “Transient Ischemic Attack” came into use. Currently , the W.H.O has defined stroke as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin.”

#### **2.2.1.1 Types of stroke**

Hademenos & Massoud, (1997) have indicated that, there are two main types of stroke that have been identified and recognized clinically. They are ischemic stroke and hemorrhagic stroke. Ischemic stroke, accounts for 80% of strokes. It is caused by the impediment or clogging of the major arteries in the cerebral circulation. Ischemic stroke occurs as a result of an obstruction within a blood vessel supplying blood to the brain. In the works of Ringleb et al (2010), it is indicated that some symptoms of Ischemic stroke comprise decreases in tissue X - ray attenuation, tissue swelling with effacement of cerebrospinal fluid spaces, and arterial hyper attenuation, which indicates the presence of intraluminal thrombus with high specificity (von Kummer et al.,1994). Hemorrhagic stroke, on the other hand accounts for 20% of all strokes. It occurs as a result of rupture of vascular lesions within the cerebrovasculature, typically due to an aneurysm or a weakened blood vessel within an Arteriovenous Malformation. (American Stroke Association, 2012)

Hemorrhagic stroke occurs when a weakened blood vessel rips. Two types of weakened blood vessels usually cause hemorrhagic stroke: aneurysms and Arteriovenous Malformations (AVMs). However, the most common cause of hemorrhagic stroke is uncontrolled hypertension (high blood pressure). Blood vessels are typically structurally skilled to withstand the dynamic quantities required to maintain circulatory role. For reasons that are not completely understood, the vessel wall can become fatigued and abnormally weak and probably rupture. With vessel rupture, hemorrhage occurs with blood seeping into the surrounding brain tissue. As the blood accrues within the brain, the displaced volume causes the blood, now thrombosed, to ultimately compress the surrounding vessels. The density of vessels translates into a reduced vessel diameter and a corresponding reduction in flow to surrounding tissue, thereby enlarging the insult. Among the vascular lesions that can lead to hemorrhagic strokes are aneurysms and AVMS (Hademenos & Massoud, 1997).

According to the American Stroke Association there is the third type of stroke called TIA (transient ischemic attack). TIA (transient ischemic attack) is caused by a temporary clot. It's often called a "mini stroke" these warning strokes are taken very seriously (Connolly et al., 2012)

#### **2.2.1.2 Causes of stroke**

According to the Centre for Disease control (CDC, 2014), the various types of stroke have their different specific causes. Ischemic strokes occur when arteries that connect to the brain become blocked or narrowed, resulting in ischemia, severely reducing blood flow. These obstructions are often caused by blood clots, which can form either in the arteries joining to the brain, or further away before being swept through the bloodstream and into

narrower arteries within the brain. Clots can be caused by fatty deposits within the arteries called plaque. (Perry et al., 2006).

The medical news today indicates that hemorrhagic strokes are caused by arteries in the brain that either drip blood or burst open. Blood vessels can burst or spill blood in the middle of the brain or near the surface of the brain, sending blood into the space between the brain and the skull. The ruptures can be triggered by circumstances such as hypertension, trauma, blood-thinning medications and aneurysms (weaknesses in blood vessel walls) (van Gijn & Rinkel, 2001). Transient ischemic attack (TIA) is caused by blood clots or other debris. They serve as warning signs for future strokes and indicate that there is a partially blocked artery or clot source in the heart (Nilsen, 2010). Reinstein indicated in his experience of stroke that stroke is caused by blocked blood vessels restricting the flow to the brain or foreign particles entering the brain, disturbing its proper function.

Generally, stroke outcomes appear to be more unfavourable for women than men, specifically in the following areas: pre-stroke physical functioning, managing of risk by patients and their physicians, medical treatment of women who have had a stroke, and outcomes of stroke treatment. Women's pre-stroke physical operation is poorer than men's. Likened to male stroke patients, female stroke patients incline to be older, live alone or are institutionalized, and have a greater level of functional impairment prior to a stroke occurrence (Di Carlo et al., 2003; Lai, Duncan, Dew, & Keighley, 2005).

Furthermore, women tend to have higher frequency of hypertension, atrial fibrillation, and antihypertensive treatment; whereas men on the other hand, tend to have a history of myocardial infarction, smoking, alcohol consumption, and antiplatelet therapy (Holroyd-Leduc, Kapral, Austin, & Tu, 2000; Lai et al., 2005; Di Carlo et al., 2003;).

### **2.2.1.3 Stroke in young adults**

Stroke is a growing public health problem worldwide. There is a rising burden in the less developed and developing regions of the world because of epidemiologic and demographic transition and rising cardiovascular risk profile resulting from nutritional and lifestyle changes (Strong, Mathers & Bonita, 2007 ; Putaala, 2016).

According to Ellis (2010), young adults are group of people between the ages of 18 to 44. This group of people include college students, young people seeking full time employment, the unemployed, married, single, and divorced, among others (Ellis, 2010)

In the past, stroke in young adults was uncommon and was said to be more prevalent among the middle-aged and elderly but in recent times, the trend is changing (Krishnamurthi et al., 2015). An European study which included 3548 participants (less than 44 years of age and with a lower age limit not higher than 20 years) identified that the incidence rates, of stroke among young adults ranged between 8.63 and 19.12 for crude rates and between 8.70 and 21.02 for standardized rates indicating that Stroke in subjects under 45 years of age is not such a rare disease and requires specific preventive programs (Marini, Russo & Felzani, 2011). Since the occurrence of stroke has increased considerably in young adults the impact of it has been unique and varies widely depending on the injury and the essential functions which are affected such as cognition, communication and physical abilities (Kumlien, 2005).

Experiencing a stroke and its repercussion can be devastating for patients and their families, especially young adults. It may be related with severe physical, social and psychological consequences (Dowswell et al. 2000). Many of those who are discharged from hospital after a stroke have tenacious impairments, including weakness, balance difficulty, cognitive impairment, immobility and dependency in activities of daily living

(Perry et al. 2006). Stroke also amends the individual's capability for social role functioning and can render a vulnerable self-concept in the sense of autonomy and mastery (Palmer & Glass 2003).

The outcome of a stroke tends to be extremely difficult with an abundance of adjustments and variations in young adults' physical abilities and family roles (Eaves, 2000; Hux et al., 2000).

### **2.2.2 Disruption to body-self**

Disruption to body-self delves into the interrelationship between the physical and psychological body (Aikins, 2003). World Health Organization (W.H.O) informs that the most prevalent symptom of stroke occurrence is usually a sudden weakness or numbness of the face, arm or leg, which is often experienced on one side of the body. Further indicated are symptoms of fainting or unconsciousness, confusion, blurred vision, imbalance, intense headache with no known cause, difficulty walking and speaking as well as understanding speech (Nishikawa et al., 2016; WHO, 2016; Kothari et al., 1997). The most common problems associated stroke acquisition have to do mostly with some form of paralysis on one or both sides of the body and difficulties in the extent to which one can control and in ability to control and co-ordinate movements. There are impairments in vision, memory sensation and affect which mostly pronounced after the acute phase of stroke (Hackett, Yapa, Parag, & Anderson, 2005). These symptoms, when one is affected with stroke, tend to affect the activities of daily living like self-care physical It may affect activities of daily life such as self-care, employment and leisure (Lawrence, 2010). Five years after getting a stroke, most stroke survivors are likely to have severe physical impairments. Amongst these impairments are inability to walk as before which affects the self - esteem of stroke survivors and limits their ability to perform simple tasks (Barnsley,

McCluskey, & Middleton, 2012). In a study done to compare “health-related quality of life (HRQoL) in young adults with ischemic stroke on long-term follow-up with controls and to evaluate HRQoL in clinically relevant patient subgroups” found that a low level of health –related quality of life among young adults with ischemic stroke was most pronounced in regard to physical functioning. The study further went to suggest that early diagnosis and treatment of physical disability and fatigue could go a long way to improve upon the health related quality of life of young adults with stroke (Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006).

Lawrence (2010) reports that young adults who experience stroke are usually shocked at the onset of the condition. They are unable to relate to the disease and need a while to accept their predicament (Lawrence, 2010). This state of surprise and shock has been reported by many studies to be a result of lack of knowledge about stroke and its related signs and symptoms. This lack of knowledge causes young adults with stroke to be unable to relate their signs and symptoms to the advent of stroke (Mc Sharry et al., 2014; Faiz, Sundseth, Thommessen, & Rønning, 2014; Mackintosh et al., 2012)

Studies have shown that fear and anxiety usually occur after stroke affected persons are discharged from the hospital setting (Campbell Burton et al 2012; Murtizani et al, 2009). Fear most commonly reflects in a state of anxiety and becomes heightened in the face of severe functional disability (Murtizani et al, 2009; House et al 2001; Morris et al 1993). A study by Kishi et al (1996) on “suicidal plans of patients with acute stroke has established that stroke affected persons who get depressed and contemplate suicide usually do so as a result of self-blame.

Studies have shown that post-stroke depression is more common among young adults with affected (Varona, 2010; Kim; Naess, Waje-Andreassen, Thomassen, et al., 2006). A study in Zambia by Mapulanga et al. (2014), showed depression as one of the main social

impacts after stroke. A study by Kuluski, Dow, Locock, Lyons & Lasserson (2014). Studies have also found that young adults experience an “altered sense of self,” including loss of identity, family disruption, and/or loss of valued activities which throw them in a state of depression (Kuluski, Dow, Locock, Lyons & Lasserson, 2014). The total stroke experience leaves young adult sufferers feeling limited and shut out of the world (Secret & Thomas, 1999).

Stroke is considered as a risk factor for suicide. However, there are very few population-based studies investigating the risk for suicidal contemplation in patients with stroke (XA, 2016; Tang et al., 2015; (Batterham, Calear, Mackinnon, & Christensen, 2013). A study by Chung, Kim, & Kim (2016) found that stroke aside from other factors increases a person tendency to consider suicide (Sareen et al., 2005).

### **2.2.3 Disruption to social identity**

In the Seminal work by Tajfel (1979) social identity bothers on a desire to belong to a group; a desire that stems from the fact that these associations has a direct boost on self-esteem Tajfel (1979).

Stroke affected persons who are young are perceived differently in society. Owing to the fact that stroke has been apportioned as a disease of the elderly (Stone, 2007) possibly because, in past years stroke affected the elderly populace and was uncommon among younger persons. As a result, stroke in young persons below 45 years is considered strange (Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk, & de Leeuw, 2014). Sampane-Donkor (2014) also indicates that in Ghana many believe that stroke is a spiritual illness caused by evil spirits and witches. Moorley, Cahill and Corcoran (2016) also indicates that the causes of stroke is believed to include witchcraft (mostly among African societies), lack of control over the ailment, hypertension and diabetes. Young adults with stroke tend

to feel socially isolated and as a result are unable to interact socially. Affected persons with stroke even find it difficult to make friends and speaking to people in areas such as market places, schools among others becomes a challenge. Speaking on telephone even becomes problematic. Some persons suffering with stroke want to be treated as normal but they are not treated so (Dickson et al, 2008).

According to O'Connell et al (2001) despite the need for "help and comfort" a high percentage of broken relationships, social isolation as well as reduced social interaction exist amongst stroke sufferers because of varied physical disabilities (O'Connell et al., 2001). Needs associated with recovery sexuality, sexual function, employment, driving, self-confidence, and self-esteem seem to be a priority to stroke survivors ahead of social interaction (Hamzat, Olaleye, & Akinwumi, 2014 ; Obembe, Mapayi, Johnson, Agunbiade, & Emechete, 2013; Cacioppo, Hawkley, Norman, & Berntson, 2011). Studies however show that there is a high level of expectation among young stroke survivors pertaining to community reintegration although it is difficult for them to openly disclose that they have suffered stroke for fear of been stigmatized (Obembe et al 2013; Hanney, 2012; Pang, Eng, & Miller, 2007).

#### **2.2.4 Disruption to personal agency**

Stroke impedes the productive life years of affected young (Towfighi, Ovbiagele, & Saver, 2010). Stroke survivors have some degree of disability and mostly need help from care givers to meet their needs (Lutz, Ellen Young, Cox, Martz & Rae Creasy, 2014). A study by Frank (2016) showed that having an employment affects the self- esteem of a person and helps them to better associate with society (Frank, 2016). Survival after stroke is largely dependent on the stroke survivor to work and earn a living (Vestling, Tufvesson, & Iwarsson, 2003; Treger et al., 2007). Furthermore, been employed shows that a person is physically fit and has also fit well into society (Gilworth et al, 2009). Unfortunately, with

individuals who are affected with stroke, the ability to return to work becomes very difficult. This is because of neurological and physical impairments that have a negative impact on a person's ability to return to work. Apart from these neurological disruptions which affect the ability of the person affected with stroke to work, employers also would like to employ persons who are medically fit at the workplace (Lock et al, 2005).

“Personal activities of daily living are necessary for survival and include “those tasks which all of us undertake every day of our lives in order to maintain our level of care such as feeding, dressing, toileting, grooming, transferring, and mobilizing” (Sulter, Steen, & Jacques De Keyser, 1999). The main goal of stroke rehabilitation is to improve a patient's level of disability in order for them to function independently and fit in better into society (Won, 2008; Howard et al., 2001)

Aside from physical and neurological impairments, Saeki (2000) asserts that post-stroke depression also makes it difficult for a stroke sufferer to perform basic activities. In many instances for an individual to perform simple tasks, he or she must be able to receive, remember, and process information more quickly. A person affected with stroke, lacks concentration, speech impediments and the inability to perform multiple task regularly (Alaszewski et al, 2007).

#### **2.2.4 Disruption to Economic circumstances**

Stroke is linked with harsh economic consequences. In Africa it is more difficult for those affected with stroke to stand the severe economic conditions as compared to other developed countries. Essue et al (2012) defined economic hardship associated with stroke as the inability of a household to make the necessary payment, resorting to borrowing or use of savings after stroke. They further showed in their study that with their 414

respondents, majority were not having health insurance, couldn't pay hospital bills, and afford common drugs to deal with their ailment (Essue et al., 2012).

Glozier et al (2008) have indicated that about 20 percent of stroke cases emanate from high income countries and in these countries the economic implications include low employment pay, unemployment, changes in career of persons affected with stroke among other hardships. There are also unprepared out of pocket cost, medical equipment, medications, transportation costs associated with individuals affected with stroke (Wozniak & Kittner, 2002). These hardships as results of post stroke confirm previous study by Piette et al (2004) which has submitted that patients with chronic illnesses suffer various financial difficulties. Stroke in young adults does not impact them only but also has a negative effect on a nation because it occurs within the productive age group (Galobardes, Lynch, & Smith, 2004) and on the individual, the loss of employment and financial insecurities which in turn lead to the inability to meet needs such as food provision, payment of school fees, accommodation is established (Mapmaulanga, Nzala, Zyaambo, & Mweemba, 2014).

### **2.2.5 Illness Action**

Darlington et al. (2009) observes that coping strategies among young adults are grouped into Tenacious Goal Pursuit and Flexible Goal Adjustment. Tenacious Goal Pursuit refers to the coping strategy intended for adjusting circumstances actively to personal preferences, and thus determined to maintain life as it was before the stroke (Darlington et al, 2009; Lloyd, Roberts & Freeman, 2014). Flexible Goal Adjustment on the other hand refers to the coping strategy whereby the patient attempts to accept the consequences of the stroke by adjusting personal preferences and goals (Darlington et al, 2009; Brandtstädter, 2009).

According to Rochette, Tribble, Desrosiers, Bravo & Bourget (2006), the most effective way of coping is changing how a situation is perceived, in order to reach a state of acceptance favourable to an optimal quality of life. (Rochette, Tribble, Desrosiers, Bravo & Bourget, 2006)

Saad and de Medeiros (2012) suggest that spiritual well-being is connected with physical and mental health in relation to the psycho-neuro-immune models of health. Spiritual or religious coping refers to where religious practices and beliefs or attitude are adopted by individuals with physical or mental ailments to reduce the emotional suffering caused by painful events of life, for instance loss or transformations which brings more suffering .

Spiritual practices and beliefs help patients affected with stroke, relations associated with the patients and caregivers helping out the patient to cope with the experience. Pargament (2004) suggests that one's connection of physical health with religious beliefs is appropriate in the sense that it brings about good health and prolonged existence.

Family and friends support is another coping strategy for stroke patients. Niemi et al (1988) in this seminal work argues that relevant policies and rehabilitation institutions should be established to deal with stroke in the form of encouragement to persons affected with stroke, psychological aid, adaptation programmes and adequate neuropsychological data to help with the coping of stroke. Stroke sufferers who have such support are more likely to live healthier so as to enable them fulfil their dreams. Kirkevold et al (2014) indicated in their study that individuals who had issues with stroke valued the opportunities to tell people their stories based on the experiences they have had through stroke. The researchers revealed that, respondents narrating their stories to people have increased their understanding on their situation and have helped them see opportunities out of their problems by setting realistic goals for themselves.

“Perceived self-efficacy is concerned with people's beliefs in their ability to influence events that affect their lives. This core belief is the foundation of human motivation, performance accomplishments, and emotional well-being” (Bandura, 2010). A self-determined mind will enable those affected with stroke to engage in meaningful self-selected social activities. Self – determination urges people to be positive, hopeful, courageous and resilient. These attitudes and behaviours according to Woodman et al (2014) would enable stroke survivors to live healthier and stronger. Sharing with people their stories has also helped them reflect on their conditions, experiences and moved them towards a new situation. In stroke related cases, self-efficacy has been seen as a major contributing factor to the achievement of positive rehabilitation outcomes and improvement in overall quality of life (Jones & Riazi, 2010; Robinson-Smith, Johnston, & Allen, 2000).

Sampane-Donkor (2014) asserts that there have been proliferation in recent times of herbal services that provide non-orthodox medical assistance for wide range of diseases such as stroke. However there is concern about the proliferation of unsafe herbal treatments as well as the possible interactions between herbal support and prescriptions given by medical officers (Chan, 2003; Best, 1993).

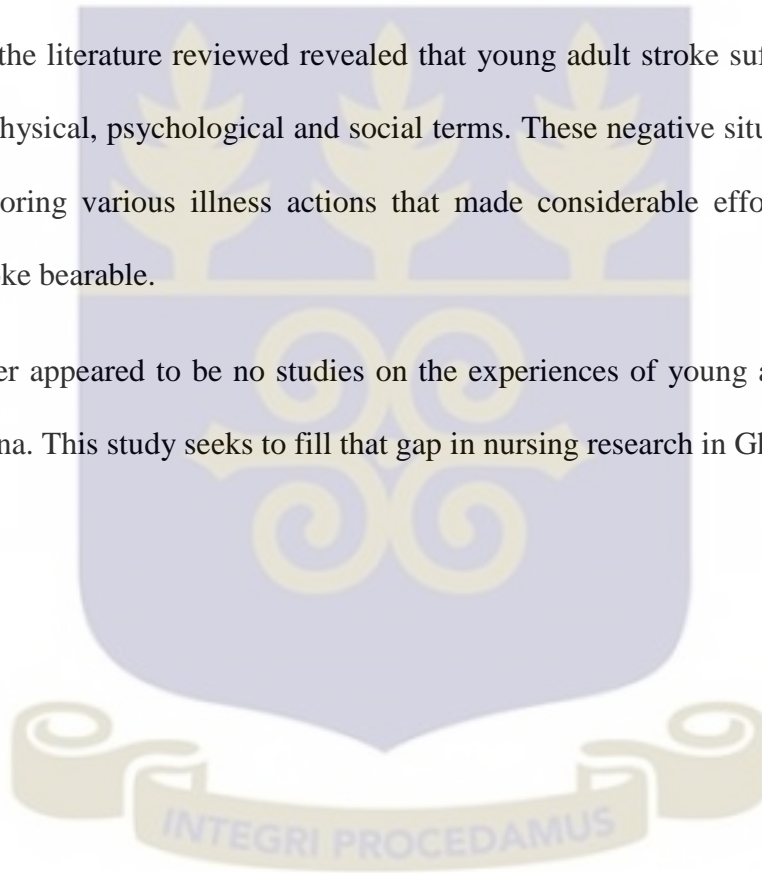
#### **2.2.6 Lack of continuity of care**

Continuity of care is regarded as a primary requisite of care particularly for those physically and mentally ill. Alazri et al (2007) have indicated some factors that affect continuity of care such as demographic factors, patients and healthcare officials, inter-professional factors and organizational factors. Continuity of information is a major function of consistency and central to the continuity of care of patients. Problems in communication among various services cause discontinuity of care at health services and the relay of information to patients (Freeman, 2001). Cameron et al (2008) indicate in their

study that health officials find it difficult in accessing the information of patients once they have been discharged to their various communities. Patients and caregivers report that they are not routinely provided with information on how to access the next step in the sequence of care (Jane Elizabeth & Smith, 2000). In a survey conducted by the Stroke Association in the United Kingdom half of the individuals recruited mentioned that they had been assessed only once after being discharged from hospital, and coordination of care had fallen largely on the shoulders of family (Stroke Association, 2016).

In summary, the literature reviewed revealed that young adult stroke sufferers are impacted diversely in physical, psychological and social terms. These negative situations were dealt with by imploring various illness actions that made considerable effort in making the impact of stroke bearable.

There however appeared to be no studies on the experiences of young adults living with stroke in Ghana. This study seeks to fill that gap in nursing research in Ghana.



## CHAPTER THREE

### METHODOLOGY

This chapter highlights a comprehensive description of the research methodology that was used for the study in the following order; the research design, research setting, target population, inclusion and exclusion criteria, sample size, sampling technique, inclusion criteria, exclusion criteria, method of data collection, procedure for gathering data, data management, data analysis, methodological rigor and ethical consideration.

#### 3.1 Research design

A qualitative research design was used for the study. This design was appropriate because it allowed for the study of human experiences in a naturalistic way and helped to provide a 'deeper' understanding into the phenomenon under study (Hollway & Jefferson, 2000).

An exploratory descriptive design was used specifically to explore the experiences of young adults living with stroke. This design studies what has not initially been studied and seeks to highlight new knowledge, new insights, new understandings, and new meanings and to explore factors related to the topic (Brink & Wood 1998). It also provides a precise and concise account of the nature of a particular individual, event or group in a real-life situation (Polit & Hungler, 1992).

#### 3.2 Study setting

The Greater Accra Region is the smallest of the 10 administrative regions in terms of area, occupying a total land surface of 3,245 square kilometres or 1.4 per cent of the total land area of Ghana. In terms of population, however, it is the second most populated region, after the Ashanti Region, with a population of 4,010,054 in 2010, accounting for 15.4 per cent of Ghana's total population. It has a coastline of approximately 225 kilometres,

stretching from Kokrobite in the west to Ada in the east. The age structure of the five districts is characteristic of populations experiencing rapid growth. The proportion of persons under 15 years varies from 31.6 per cent in AMA to 42.4 per cent in Dangme East, while that of the aged (65 years and older) ranges from 3 per cent in the Ga District to 8.2 per cent in Dangme East. The sex ratio varies from 90.4 males to 100 females in Dangme East to 100.9 in the Ga District. The relatively low sex ratio for Dangme East can be attributed to several factors including male out-migration and higher male mortality. The age structures in the five districts have given rise to two patterns of dependency ratios (Lartey, 2016).

The Korle Bu Teaching Hospital is a tertiary hospital in the Southern part of Ghana, affiliated to the University of Ghana. It is currently the third largest hospital in Africa and the leading national referral centre in Ghana. Since its inception on October 9, 1923, it has grown from an initial 200 bed capacity to 2,000 with 17 clinical and diagnostic Departments/Units. The Korle Bu Teaching Hospital through a partnership with Wessex and a grant from the Tropical Health Education Trust (THET UKAID), has set up a stroke unit which is managed by a multi-disciplinary team of experts. The stroke unit sees to patients from Ghana and other West African countries. It has 20 beds which can be manoeuvred, a hoist that helps in the lifting of patients and wheel chairs. More importantly, it reduces back injuries for both the patient and the caregiver. The unit is also equipped with a ripple bed that prevents bedsores. The washrooms in the unit are fitted in a way that makes it easier for the patient to use and for caregivers to attend to the patient. Within the unit is a physiotherapy section equipped with a parallel bar and a wall. The unit has a team of doctors, nurses, a physiotherapist, occupational therapist, speech and language therapist, dietician, clinical psychologist, pharmacist and housekeeping staff who attend to patients.

The physiotherapy Department of the Korle-Bu Teaching Hospital also provides preventive, curative and rehabilitative services to its clientele. The clinical department offers services on out-patient and in- patient basis. It also runs paediatric Services, teaching introductory physiotherapy to medical students, teaching/supervising physiotherapy students during clinical postings and supervising physiotherapy interns. Conditions treated at the unit are vast and vary in relation to musculoskeletal disorders, neuro rehabilitation, cardiorespiratory disorders and paediatric cases like Cerebral palsy and Spina bifida (Korle Bu Teaching Hospital, 2016).

Participants were recruited from the stroke and physiotherapy units of the hospital. These units in the hospital were chosen because Korle-Bu Teaching hospital is the biggest referral hospital in Ghana and sees a wide number of cases from the Accra Metropolis.

### **3.3 Target population**

The target population for this study were young adults between the ages of 18-45 years who were living with Stroke in the Accra Metropolis.

### **3.4 Inclusion criteria**

#### **The study included;**

- a. Male and female Young Adults aged 18-45 years who had lived with stroke for at least 1 year and are undergoing rehabilitation or recovering at home.
- b. Young adults, who had the ability to communicate verbally in, understand and speak English and Twi.
- c. Young adults who were able to give informed consent.

### **3.5 Exclusion criteria**

The study excluded;

- a. Individuals who were below the ages of 18 and above 45
- b. Individuals who were still on admission and had not lived with stroke for at least a year
- c. Individuals who were unable to communicate verbally or express themselves in English or Twi.
- d. Individuals who could not give informed consent.

### **3.6 Sampling size and Sample technique**

A nonprobability sampling technique, specifically purposive sampling technique, was used for the study. This technique was chosen because it focused on gathering information from persons who had firsthand information and could provide needed data in the field of study. The stroke and physiotherapy units of the Korle-Bu Teaching Hospitals were used to recruit participants for the study. An introductory letter was sent from the School of Nursing, University of Ghana, Legon, to the central administration of the Korle-Bu Teaching Hospital, then to the stroke and physiotherapy units. At these units, the researcher got some of the staff, in addition to herself, to tell the patients about the study and leave their contacts. Those who were interested in participating in the study were identified by the researcher who further explained the purpose of the research to the participants, ensuring that they met the inclusion criteria and took their contacts. The researcher then contacted these persons by phone and explained further what was expected in the study. Those who were willing to be interviewed were asked to choose a convenient time and place when the researcher could interview. All participants were interviewed in the privacy homes. For this study, recruitment continued until data saturation was

reached. Data saturation is reached when new themes, categories or explanations stop emerging from the data been gathered by a researcher (Polit & hungler, 1992; Marshall, 1996). A sample size of 10 young adults took part in the study.

### **3.7 Data collection tool and procedure**

Data was collected through interviews which were guided by a semi-structured interview guide designed with focus on the objectives of the study. The purpose of the research interview was to explore the views, experiences, beliefs and/or motivations of individuals on specific matters (Hollway & Jefferson, 2000). The Semi structured interview guide also allowed the researcher to delve into the opinions and perceptions of participants and include significant questions that help to define the areas to be explored (Gill, Stewart, Treasure & Chadwick, 2008; Louise Barriball & While, 1994).

The semi-structured interview had two main aspects. The section A portion had the demographic and the section B portion of the guide included open ended questions and probing questions that helped the researcher gain in-depth information into to the psychological, social and physical experiences as well as coping strategies of the young adults living with stroke. Piloting was done using two young adults living with stroke at the Korle-Bu Teaching Hospital. Questions were then reorganized to ensure that data rich information was collected.

The proposal for the study was reviewed by the Noguchi Memorial Institute for Medical Research and given ethical approval. Permission was then sort from the Stroke and physiotherapy units of the Korle-Bu Teaching Hospital before the research was conducted. The researcher was then allowed to speak to the young adults living with stroke on their clinic days on Tuesdays. After participants had consented to the interview by signing the consent form, the researcher conducted one interview each with participants, varying from

45 minutes to an hour and half. A second interview was only scheduled in situations where further probing was required.

The interview commenced after rapport had been established and permission had been given by the participant for the interview to be audiotaped. The interviews were conducted confidentially in either Twi or English based on the preference of the participant. The participant was assured that all information given was to be kept private for at least 5 years and their identity was not to be disclosed. Only the researcher and her supervisors would have access to the data. The data was also to be kept under password and in a locked file.

Interviews were audiotaped and transcribed verbatim after each session. Field notes were also taken during and after the interview session in order to ensure that data gathered through environmental observation, verbal and nonverbal cues were not lost.

### **3.8 Data management**

Recorded data was downloaded onto the researcher's laptop and transcribed verbatim after every interview session. Each participant was given a number starting from one (1). After transcription, each participant's data was kept in a separate file, under password and in code names. Notes taken on the field were typed and kept together with the transcribed data under password in Microsoft word. Hard copies were used to serve as back up for printed copies of transcripts and field notes which was kept in a locked cabinet at the School of Nursing, University of Ghana, Legon. Each participant had their own file with their code names indicated on them.

### **3.9 Method of Data Analysis**

Thematic content analysis was used to analyze data gathered and was done by identifying and distinguishing the main themes and sub-themes as deduced from the information given by the participants. Thematic analysis searches for themes that arise as being important to the description of a phenomenon (Daly, Kellehear, & Gliksman, 1997). It involves identifying patterns in data and developing themes that serve as categories for analysis (Boyatzis, 1998).

Audio taped data, collected through the interviews were transcribed word for word. The tape was played repeatedly and cross-checked with the transcribed data to ensure accuracy. The researcher familiarized herself with the transcribed data studying it repeatedly, in order to identify and pinpoint outstanding patterns in the form of phrases, sentences and paragraphs for the generation of codes. Themes and sub-themes were then grouped out of these codes and taken through series of reviews. The themes were then clearly defined and named and used in describing the experiences of young adults with stroke.

### **3.10 Methodological Rigor**

Methodological rigor is the standard by which all research is measured. In qualitative research it also refers to trustworthiness and determines the confidence with which conclusions can be drawn from the results of a study (Shenton, 2004). A qualitative research should satisfy these four criteria in order to be considered a trustworthy study; credibility, transferability, dependability and confirmability (Harrison, MacGibbon, & Morton, 2001).

Credibility refers to the ability of a study to measure what is actually intended and how consistent findings are with reality (Merriam 1998; Lincoln & Guba, 1985). The

researcher ensured credibility by recruiting only participants that were willing to take part in the study and those who meet the inclusion criteria. The researcher established rapport from the onset and encourage participants to speak frankly and give accurate information about their experiences. Piloting of the study was also done to ensure the meaningfulness of interview questions and help to identify researcher bias and minimize error. Member checks were done by verifying all patterns and statements observed by the researcher from participants. Field notes were added to transcribed data to ensure triangulation.

Transferability determines the degree to which the results of a study can be applied to other situations (Merriam, 1998). To ensure this, a clear and accurate description of the phenomenon under study was given in order for other researchers to make meaning of it. The researcher also gave a thick description of study setting, sample size, study design, inclusion and exclusion criteria.

Dependability addresses the issue of reliability. It focuses on whether or not similar results would be generated if the study is repeated under the same circumstances, participants and methods alike (Shenton, 2004). The researcher made sure that the research process especially the research design and the data gathering procedure was documented in detail to make repetition of the research easy. The same interview guide was used for all the interviews and the same method for data analysis was used to ensure consistency.

Confirmability reflects the objectivity of the researcher and his or her ability to conduct a research free of bias (Shenton, 2004). This was done by leaving an audit trail which will help other researchers to identify the stepwise process involved in conducting the study. The researcher also kept a field diary to ensure that all needed information was collected both verbal and non-verbal. Random cross checks of transcripts with audiotapes was done

by a neutral person to ensure that the verbatim quotes were a true reflection of data provided by the participants.

### **3.11 Ethical Considerations**

Ethical approval was sought from the Institutional Review Board (IRB) of the Nogouchi Memorial Institute, University of Ghana. An introductory letter was sent from the School of Nursing, University of Ghana, Legon, to the central administration of the Korle-Bu Teaching Hospital, stroke and physiotherapy units, seeking permission to carry out the study. Consent forms were given to participants to fill and sign after all their concerns had been addressed. All potential risks and benefits were made known and further clarifications about the study were given. Participation in the study was voluntary and confidential. Participants were allowed to choose a setting that was most convenient for them to ensure privacy. All the participants chose to be interviewed in the privacy of their homes.

Participants who were emotionally disturbed during the interviews were allowed to grieve and the interview was paused and continued when they gave the go ahead. The researcher was prepared to help participants herself and to direct those confronting difficult emotional issues to qualified professionals, and by providing participants with relevant references/information. There were no other significant risks to participating in this study. Discretion was used throughout the data collection process and code names and pseudonyms were used in identifying participant information.

The researcher and her supervisors were the only ones with access to the tapes and transcripts from the interviews. Hardcopies of these have been kept in a locked cabinet and softcopies under password.

## CHAPTER FOUR

### FINDINGS

This chapter highlights the findings of the study. The findings were classified based on the dimensions of the theoretical framework of biographical disruption and illness action (Aikins, 2003) and also in line with the objectives of the study. The chapter first presents the demographic characteristics of the participants followed by the themes and subthemes.

#### 4.1 Demographic characteristics

Ten (10) young adults living with stroke were recruited in all, comprising of eight (8) men and two (2) women. The youngest participant was 26 years old whilst the oldest participant was 45 years old. All participants had received some level of formal education with the lowest been at the Junior Secondary School (JSS) level and the highest been at the Tertiary level. All participants could speak and understand English but only six (6) could speak it fluently, the others preferred to communicate in Twi. Eight (8) participants were Christians whilst two (2) were Muslims. Five (5) of the male participants were unemployed and solely dependent on their family members for financial support; three (3) were unemployed as a result of varied forms of physical disability whilst the remaining two (2) who had no extensive physical disabilities were finding it difficult to secure jobs. The remaining three (3) male participants were employed. One (1) was a banker, another was a teacher and the other was a building drafts man. The only female participants were both self-employed. One (1) was a hairdresser and the other was a trader. Out of the ten (10) participants, seven (7) were married, two (2) were single and one (1) was a widower. Details of the demographic characteristics of participants are shown in table 4.1. (See Appendix C)

## 4.2 Organization of themes

Six (6) major themes and thirteen (13) subthemes were identified after thematic content analysis. Five (5) of these themes were derived from the biographical disruption and illness action theoretical framework but one (1) emerged from the data. Details of the themes and subthemes are shown in table 4.1 below.

**Table 4. 1:** Themes and subthemes

Themes	Subthemes	Categories
<b>Disruption to body-self</b>	▪ Minor body disruption	- Headache/muscle weakness unconsciousness/facial palsy/memory loss/blurred vision/sexual dysfunction
	▪ Major body disruption	- Hemiparesis/contracture
	▪ Psychological disruption	- Surprise/fear/anxiety/depression guilt/suicidal ideation
<b>Disruption to social identity</b>	▪ Social perceptions	- Disease of the elderly/witchcraft Punishment/bewitchment
	▪ Social isolation	- Loneliness
<b>Disruption to personal agency</b>	▪ Inability to work	- Pain/lack of strength
	▪ Inability to perform simple tasks	- Physical disability
<b>Disruption to economic circumstances</b>	▪ Financial constraint	- High cost of treatment/increased expenditure/ unemployment
<b>Coping/illness action</b>	▪ Spiritual practices and beliefs	
	▪ Support	

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	<ul style="list-style-type: none"> <li>▪ Self-determination</li> </ul>
	<hr/> <ul style="list-style-type: none"> <li>▪ Herbal medicine</li> </ul>
<b>Lack of continuity of care</b>	<ul style="list-style-type: none"> <li>▪ Lack of information</li> </ul>

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*Source: Transcribed data*

### **4.3 Disruption to body-self**

Disruption to body-self refers to the relatedness between the physical and the psychological body. It delves into all the signs and symptoms experienced by the participants, that impacted their physical health, from the onset of the stroke episode through to recovery and the psychological and emotional responses that evolved as a result of those disruptions. From the findings of the study, all ten participants reported to have experienced certain signs and symptoms which resolved after recovery from the acute stages of their stroke. These signs and symptoms were headache, muscle weakness, unconsciousness, facial palsy, memory loss, blurred vision, sexual dysfunction and hallucinations; termed as minor disruptions. Some participants also experienced certain signs and symptoms which were either not present during the initial stages or have persisted after recovery from the acute stage of their stroke. These signs and symptoms were hemiparesis, contracture, pain and dizziness; termed as major disruptions. In response to these physical effects of stroke on the physical health and activities of participants, they revealed having experienced varied degrees of psychological impact. They experienced surprise, fear and anxiety, depression, guilt and suicidal ideation. The subthemes that emerged under this theme are: minor body disruption, major body disruption and psychological disruption.

#### 4.3.1. Minor body disruption

All ten participants experienced certain signs and symptoms in the initial stages of the stroke which resolved with time. Some of these signs and symptoms like headache, muscle weakness, facial palsy and unconsciousness occurred sequentially and immediately they were affected with stroke. However, memory loss, blurred vision, hallucinations and sexual dysfunction were discovered after those immediate signs as stated before elapsed. The immediate signs occurred suddenly, without warning and the participants who were affected confessed that they could not explain what was happening to them. Atakora and Kojo who experienced sudden inability to move parts of their body shared their experience:

*“I couldn’t move my hand and leg... then I called my wife and told her to come because something was happening to me”*. **Kojo**

*“From one day you are very healthy looking and then the next day you are sick, all of a sudden, just like that”* **Atakora**

Majority of the participants experienced *headache* as the first indication of stroke. From their narrations, they revealed that the pain was sudden and very severe. According to Sulley and Rufinah:

*“I had a severe headache... it was severe and that was the pain I felt”*  
**Sulley**

*“I felt a sharp pain in my head... the pain was very severe.”* **Rufinah**

In addition to the headache which occurred suddenly, majority of the young adults alleged that they had muscle weakness with some describing it as a loss of sensation at the affected side. They explained that they experienced inability to move some parts of their body and ended up falling. Sulley shared his experience as follows:

*“I couldn’t walk, I kept falling each time I tried to stand...I couldn’t move my left, so they took me to the hospital”* **Sulley**

In a similar manner, some participants explained that their inability to move was accompanied by loss of sensation of the affected side. According to Lokko he could not stand to his feet when he had the stroke;

*“I couldn’t stand on my feet... I had no sense of feeling anymore in the body”.* **Lokko**

Two male participants who experienced facial palsy said their speech was impaired.

*“My speech was a bit slurred because I had palsy and the stroke had affected my left. So my mouth tilted a bit and I couldn’t speak like I’m doing now”.* **Atta**

*“I realized my mouth had shifted to one side... it shifted to the left”.* **Lokko**

Some of the participants indicated that they fell *unconscious*. They were not aware of their immediate surroundings when the stroke occurred. From the narratives, they couldn’t remember how it happened or the number of days they were in coma. They only got to know from their family members when they woke up. Rufinah and Bonsu who had been unconscious for some time said:

*“When I gained consciousness, I was at the stroke unit... My sister told me that I was lying there for long... but I don’t remember anything”.* **Rufinah**

*“I don’t really know what happened. I was in a comatose state for two weeks”* **Bonsu**

Atta who was also unconscious for some time said he developed bedsores.

*“My back was all bed sores... I had a stroke and I was in a coma”* **Atta**

Some of the participants reported that the stroke experience affected their *memory*. Particularly they could not recollect names and were disoriented to time and place. Joojo the youngest participant recounted the difficulty he had with his memory and his inability to remember names in this quote:

*“I couldn’t remember names, I couldn’t remember those who were close to me I mean I couldn’t remember their names”*. **Joojo**

For a few of the participants although they couldn’t remember names and faces they indicated that they could remember numbers. Bonsu said with amazement how he forgot everything but could remember phone numbers:

*“I forget everything, but one thing that amazes me ... all the numbers that are told me ... some phone numbers as you speak now I still remember them”*. **Bonsu**

In respect to *blurred vision* and *hallucinations* some of the young adults mentioned that it happened for a period of time after they regained consciousness. Serwaa who experienced blurred vision had this to say;

*“When I came to myself I was weak, my vision wasn’t clear. Everything was dark. Visitors had to come closer before I could see them”*. **Serwaa**

Lokko who experienced hallucinations said it made him aggressive and had to be tied to his bed.

*“It got to a point too now I started having these hallucinations and I became very aggressive so they had to tie me to the bed”*. **Lokko**

In relation to *sexual dysfunction*, two male participants out of the eight who participated in the study revealed that in the earlier stages of their stroke they have difficulties with sexual intercourse. Delali who had problem with ejaculation and Bonsu who couldn’t have an erection recounted:

*“Initially when I was having sex, it became difficult for me to release the sperm”*. **Delali**

*“I didn’t know I could even sustain an erection because throughout my sickness I see my wife and I wasn’t excited I don’t know whether it was a state of mind”*. **Bonsu**

#### 4.3.2 Major body disruption

Three participants were paralysed on one side of their body. They could not move both their arm and leg on the affected side. They all had difficulty walking and two were managing with walking sticks. The last person who didn't have a walking stick managed to move by dragging the affected foot on the ground. Aside from the limitation in movement, the three participants felt pain at the affected side. This painful experience made it difficult for some of them to sleep. Two participants out of the ten also experienced dizziness which disorganized their way of walking.

Delali who was *paralyzed* on his left gave this account:

*“When I was discharged that is when I realized that this my side (the left side) could not actually work... and even as I talk to you now it is not working so”*. **Delali**

Bonsu who was paralyzed on his right side mentioned that he felt a lot of *pain* and could not sleep at night. He lamented:

*“I feel pains down at the side so I always have to sleep on my side... I feel a sharp pain so I'm always awake”*. **Bonsu**

One participant who had a contracture in his left arm also shared his painful experience during physiotherapy:

*“It used to be difficult but I went through physiotherapy. I still have a lot of pain on my left”*. **Atta**

The two young adults, Lokko and Kojo who mentioned *dizziness* as a problem they were encountering, indicated that the dizziness was accompanied by an imbalance which affected their way of walking.

*“It's the dizziness and the imbalance that is worrying me”*. **Lokko**

*“I also have this ringing sound in my right ear that comes with dizziness...it lasts for about three minutes and I feel dizzy...and it distorts my balance”*. **Kojo**

### 4.3.3 Psychological disruption

The data gathered suggested that all the participants were impacted psychologically as a result of the overwhelming nature of the physical effects of the condition on their daily lives. All ten participants shared that they were surprised when they discovered that they were affected with stroke. The condition occurred without warning and they could not relate the signs and symptoms to the disease process. From the narratives, it was evident that they became afraid because they had a lot of uncertainties about their recovery and wondered what the outcome of their situation would be. The fear of dying and disability led to feelings of regret, depression and eventually thoughts of suicide.

#### 4.3.3.1 Surprise

The young adults mentioned that they were surprised when they were diagnosed with stroke. They were surprised because they were not sick in any way before they started having the signs and symptoms of the disease so it was difficult to believe that they actually had the condition.

Remembering how physically active he was before the stroke incident made it difficult for Bonsu to believe that he had stroke and mentioned that it came as a surprise. He said:

*“Like I said initially it came as a surprise. I was a physically active person ...I had to argue a little with the doctors because I didn’t believe that I had stroke.”. **Bonsu***

Similarly, another participant, Atakora, mentioned that he was caught off guard by the stroke incident. He expressed his surprise at the condition because he recollected that he was not sick before the stroke.

*“It wasn’t like I was sick... I thought it was something like numbness and it would go, not knowing this is something serious, very serious”.*  
**Atakora**

In diversion, Lokko, another participant said that he wasn't surprised when he starting experiencing the signs and symptoms because he knew he had high blood pressure.

*“I knew what was happening to me before I was taken to the hospital...because sometimes I used to check my pressure at the pharmacy... they have all been telling me that if I don't take care I will get stroke so I wasn't surprised”.* **Lokko**

#### **4.3.3.2 Fear and anxiety**

Fear of death and disability run through all ten narratives. Participants were afraid because they didn't know what the aftermath of their condition would be. Their fear was also heightened because people who also had stroke were dying and they felt that the same faith would the befall them. Sulley who thought he was going to die confessed saying:

*“I felt I was going to die...I was wondering how the disease was going to go away”.* **Sulley**

Lokko who recollected that he had to be tied to his hospital bed because he was so afraid of dying shared this experience:

*“They used this gauze to tie me because I said no I wanted to go home because people were dying. All around me people were dying...I now started becoming scared that I don't know what will happen to me”.* **Lokko**

Some of the participants also expressed their fear through anxiety. They had uncertainties and were worried about how long the recovery process would take and whether they would be able to recover fully. Lokko shared his sentiments:

*“Being unable to go about my normal duties is my main problem... something that you've been doing before and you know you can do it. But now because of your disability you can't do it. You tend to be thinking”.* **Lokko**

#### 4.3.3.3 Guilt

Guilt always took the form of blame. Some participants had a sense of guilt because they held themselves responsible for their stroke. Whilst some indicated that they felt responsible for their stroke because of their bad lifestyles, others felt that it was because they failed to go to the hospital for regular checkup. Lokko and Bonsu blamed themselves for getting the stroke as follows:

*“I blame myself .... If I had not put myself into certain habits I don't think such a thing would have happened to me.”. Lokko*

*“I never knew I was hypertensive so the whole stroke thing is a disappointment ... I have let myself down by not going for regular checkups”. Bonsu*

One participant, Atakora expressed regret for not listening to advice when he was told to quit his bad habits and get married. He felt that if he had listened, he wouldn't have drunk so much to get stroke.

*“I'm still not married you know, I'm a bad boy... if I had listened more... maybe things would be different”. Atakora*

#### 4.3.3.4 Depression

From the narratives it was identified that most of the participants had experienced some form of depression at various stages of the disease process. It was evident from data gathered that they were taken aback by the stroke diagnosis and all the signs and symptoms they were experiencing. Events surrounding the stroke experience made them feel like their lives had come to an end and that friends were advancing in life whilst they were stagnant. Some participants mentioned that they felt embarrassed whenever they came into contact with friends who knew about their condition and this added to their depression. Delali who was physically handicapped said he felt depressed:

*"I feel embarrassed, depressed...I feel ashamed of myself and sometimes I might meet any of my old girlfriends and I feel shy". Delali*

Atakora on the other hand said he felt like less of a man because of his condition. He was depressed about how he had moved from been so active to not been able to do certain things. He explained saying:

*"A full able bodied man like me, and I can't do some of the things...It changed my life...I was feeling like less a man". Atakora*

Atta who had a contracture and was paralysed on the left side also said he was depressed because he felt a huge setback in his life. His friends had advanced in their careers and he had been left behind.

*"I felt the world had left me... I felt cheated because my colleagues had all left me, some were managers, general managers, here was me still been a clerk". Atta*

Some of the participants expressed their depression through sadness. Serwaa who was depressed because she wasn't as physically active as before the stroke occurred and remarked sadly:

*"I am not that active anymore and I'm not like I used to be. I attended a wedding recently and I went to cry there because I saw a lady who is like I used to be so I was very sad... I used to like dressing a lot, I liked wearing heels; look at what stroke has done to me. This disease has destroyed me. It really made me cry". Serwaa*

Some of the participants were also depressed because they were frustrated. Simple tasks had become so tedious and certain activities could not be performed anymore. Two participants expressed their frustration. Atta and Bonsu lamented that they could not do the things they used to do before and felt frustrated:

*"I miss my legs because I'm a sports person, work out, play tennis a lot but I couldn't do that. It was very frustrating for me". Atta*

*“My hand is so ridged and static it will never move. Every task is a herculean one.”. **Bonsu***

#### **4.3.3.5 Suicidal ideation**

It was evident from the narrations that some participants had thoughts of committing suicide at some point in their stroke experience. They felt that they could not cope with their disabilities and that death would have been a better option. Delali stated frankly that he wanted to kill himself:

*“I wasn’t feeling comfortable. I really feel like ending it all...just to kill myself...because I sometimes felt if I had even died it would have been better”. **Delali***

#### **4.4 Disruption to social identity**

Disruption to social identity refers to the direct effect of stroke on the social status of the affected individual bringing into play how one sees him or herself or is viewed by people in the community or social group. The findings of the study revealed that some members of the community had negative perceptions about young people living with stroke. Aside from the fact that some considered the disease as a condition for older people, some were either perceived to be witches or to be paying for a sin they have committed. Some of the participants also mentioned superstitiously that they had been bewitched. All these negative perceptions made participants feel stigmatized and unable to interact with other people. Most of the participants disclosed that they were no longer able to do the things they used to do before such as sporting activities, taking walks and travelling as result of various forms of physical disability. The subthemes that were identified were: social perceptions and social isolation.

#### 4.4.1. Social perceptions

The data revealed that some people in the community considered stroke amongst young adults to be strange and viewed it as a disease for the elderly. Sulley who was told that he was too young to get a stroke shared his encounter:

*“I can meet someone and they would ask what has happened to me and I will say stroke and they will say you young boy and you have had a stroke”.* **Sulley**

Other people considered stroke survivors as witches and didn't want to be associated with them.

*“It is the kind of disease that makes your friends abandon you. Some think you are a witch or that you are paying for a particular sin... They think we have gone to do something bad or gone for something from a fetish priest”.* **Serwaa**

Two participants didn't want to disclose their condition for fear of stigmatization. Joojo believed that the fact that he had had a stroke could ruin his chances of finding a job and Serwaa was concerned that her children would not find suitors.

*“I won't go for an interview and tell them I am a stroke victim I can't do that”.* **Joojo**

*“Sometimes I wonder if my daughter has a boyfriend... since the stroke affected us I have observed that some people are scared. Some of the boys might even say this family has stroke cases and that if you marry from it the person might get a stroke”.* **Serwaa**

A participant, Delali mentioned that he later discovered that he had been bewitched and felt that he was paying for a sin he had committed. He revealed that:

*“Later on certain things unfolded pointing to the fact that some people were behind ... because my mum had a call and then the person told my mum that he is a chief priest and I was actually brought there to him to kill me... Well I'm not saying I'm paying for anything, I also wouldn't know... this sickness attacked me, maybe it's a way of paying”.* **Delali**

The youngest participant also indicated that his father also believed that he had been bewitched and shared how this perception led to overprotection and lack of privacy. He said angrily:

*“My dad felt like some spirit came to cause it so I couldn’t go out. He seized my phones so I couldn’t call people. I mean he was just being over protective. I had no privacy”.* **Joojo**

#### **4.4.2 Social isolation**

Majority of the young adults indicated that they had to keep to themselves because they could no longer mingle with people. They could not go out to interact with people because of their physical disabilities. Most of them ended up feeling very lonely.

One male participant who was physically incapacitated because of his contracture mentioned that he could no longer go out with friends or to play sports. He stated that:

*“I cannot swing my racket and play tennis... I’m the kind who would say let’s go clubbing, let’s go partying, let’s go swimming. I miss that life. I now cannot do things that would make me walk too much or that will involve both hands”.* **Atta**

Another participant who could walk but was experiencing dizziness and imbalance said:

*“I don’t go out at all...I’m always up there. If I come down I just walk around the house and I go back upstairs. I don’t go out unless I’m coming to the hospital”.* **Lokko**

For most of the participants, being socially isolated made them feel lonely mostly because they were usually home alone. Lokko who wished that he had someone to talk to confessed saying:

*“Loneliness is there... mostly I feel like if I had somebody by my side to be chatting with to keep me company, it would be better”.* **Lokko**

#### **4.5 Disruption to personal agency**

Disruption to personal agency refers to the effect of stroke on the ability of the affected person to work and interact socially. The findings of the study revealed that most of the participants were unemployed, mainly because some did not have the strength to work and some were also limited because of their physical disabilities which included imbalance, paralysis and pain at the affected side. A few who could work also explained that they faced a lot of difficulties because it was difficult for them to move around. Some also reported that they could no longer perform certain simple tasks such as bathing. They could no longer meet their share of family roles and responsibilities such as parenting and home management. The subthemes that emerged under this theme were inability to work and inability to perform simple tasks.

##### **4.5.1 Inability to work**

Majority of the participants per the findings of the study revealed that they could no longer work like before. The findings of this study revealed that most of the participants couldn't work like before due to their condition and for varied reasons. They mentioned pain and lack of strength as the main reason for their inability to work.

Sulley, who said that he was not strong enough to work after he was discharged, revealed how he had to relocate to the village with his family to live with his mother after he was discharged. According to him:

*“I don't think I can work like before... when I was discharged I didn't have any strength to work here and I have a wife and children so I went to my mum in the village”.* **Sulley**

Another participant who could walk said she couldn't work because she had pain in her back and couldn't stand for long.

*“I can walk but because of the pain in my back I am unable to do anything else. I should have been able to sell at my shop...if it wasn't the stroke that affected me I would have been able to work”.* **Serwaa**

Lokko who had been receiving salary initially from his work place was asked to go on early retirement because he wasn't fit to return to work. He accounted that:

*“They take care of me from the office, but the whole of this year it hasn't been so. So when I made my enquiry my boss was telling me that its better I go on early retirement, because he doesn't know when I'll be well to come back”.* **Lokko**

A male participant alleged that even though his movement was limited because of his condition, he wasn't given any special assistance at work. He had to work like everyone else and couldn't make time for physiotherapy as a result. According to him:

*“I had this condition and they didn't make me special... Physiotherapy means I would have to take time off work and go, but work will not permit that”.* **Atta**

#### **4.5.2 Inability to perform simple tasks**

Some of the participants had difficulty performing simple everyday tasks. Simple tasks like walking had become tedious and almost impossible without assistance. Atakora who couldn't walk straight stated that:

*“I was really down... I couldn't walk straight, so I was limping”.*  
**Atakora**

Bonsu, who was paralyzed on his left side also reported that he had to make a conscious effort to support his weight and walk. He could not read or talk for long due to easy fatigability. Every simple thing had become so difficult for him. In his account he mentioned that:

*“I can’t talk for long, I can’t read for long ... every simple thing becomes so difficult and mechanical because of the inability to use my left hand ... when I am standing I have to cautiously position myself well ... to support my weight so I will be able to stand straight... to stand is even a conscious thing”.* **Bonsu**

He further went on to reveal that his family members were at a loss as to what to do to help when it came to certain tasks. The sudden nature of the condition gave them no time to prepare to meet certain needs of the affected participants. Bonsu recollected when he needed an enema and his family members could not do it for him. He said:

*“When I was sick and I couldn’t pass stool and pass urine, I needed enema, but my wife couldn’t do it and all those around me couldn’t do it they were afraid and they don’t have the skill to do it”.* **Bonsu**

One female participant mentioned that even turning her whole body whilst crossing the street had become a difficult task.

*“It’s difficult for me to turn my whole body when crossing the street. I have to ask someone to help me”.* **Serwaa**

In relation to meeting family roles and responsibilities, some participants were sad because they could not even hold their children or play with them. Atta shared his experience:

*“I’m unable to carry my babies...now when they are playing I can’t play with them”.* **Atta**

It also became apparent from the findings that some participants had to switch roles with their spouses and other family members to ensure the smooth running of the home. Atta whose wife had to drive him to work also confirmed by saying:

*“My wife runs the home now. She drives me to work, takes the boys to school and picks us after work and school... So basically she’s not really working now”.* **Atta**

#### **4.6 Disruption to economic circumstances**

Disruption to economic circumstances refers to the effects of stroke experience on the financial stability of affected persons. It was evident from the findings of the study that

majority of the participants had been greatly affected by the huge financial burden that was brought upon them by the diagnosis and treatment of their stroke. Majority of them were unemployed and as a result could not afford the high cost of treatment. Their living expenses also increased because they had to spend so much on transportation in order to get around. The subtheme that emerged after analyzing the data was financial constraint.

#### **4.6.1 Financial constraint**

The narratives revealed that most of the participants were financially constrained. The factors that influenced this financial instability were unemployment, high cost of treatment and increased expenditure.

##### **4.6.1.1 High cost of treatment**

Most of the participants mentioned that the drugs needed for their treatment were very expensive. Joojo revealed how much he had to be spend on drugs alone.

*“The money involved is just too much! We used to spend a lot. I remember we used to spend like GH¢2000 every 3 months just for drugs”.* **Joojo**

In a similar situation, Delali mentioned that stroke is an expensive disease.

*“Stroke is serious and an expensive disease...the drugs are very expensive”.* **Delali**

##### **4.6.1.2 Increased expenditure**

Most of the participants lamented about the increase in their standard of living because they had to spend a lot of money on transportation whenever they had to go for review and for the review itself: coupled with family expenses like money for rent and feeding.

Sulley and Atta said:

*“I’m struggling financially...it’s difficult because of my rent, my hospital checkups and drugs”.* **Sulley**

*“My cost of living had become quite high...now anytime I wanted to move, because of my stroke I had to charter a taxi ...standard of living was more expensive”. Atta*

#### **4.6.1.3 Unemployment**

Some of the participants who were unemployed said that it was difficult for them to meet their financial obligations. They were living from hand to mouth; depending on the benevolence of friends. Serwaa whose husband was also unemployed because of stroke said she had to beg her friends for money to pay her children’s school fees. She recounted sadly:

*“Things are not good now ...I’m not working, my husband is also not working and two children are in school. It’s not easy at all...if I hadn’t mastered courage and called my friends for some money, my children would have had to stop school and come and sell. It would have affected my family a lot”. Serwaa*

One participant explained how he had to stop doing his physiotherapy because his spouse who also wasn’t gainfully employed, could no longer afford it. He shared his experience:

*“We did the physiotherapy for at least 2 months or so. Then my wife said she could not continue to afford so we had to stop. My wife is not fully employed”. Delali*

#### **4.7 Illness action**

This refers to the practical routines that participants initiate and manage in order to cope with or overcome the negative psychosocial and psychological impact of the stroke experience. From the study it was evident that most of the participants had developed certain coping strategies to deal with their stroke and its related issues. All the ten participants expressed a deep sense of belief in God. They were convinced that he was the only one who could help them and expressed gratitude to him for how far they had recovered and were looking forward to been healed completely at his own time and according to His will. Most of the participants received support from family, friends,

colleagues at work and their employers. They also made their own efforts to enhance their recovery by motivating themselves to live a healthy lifestyle and some resorted to herbal medicine for treatment. The study identified the following subthemes namely: spiritual practices and beliefs, self-determination, support and herbal medicine.

#### **4.7.1 Spiritual practices and beliefs**

All participants both Christians and Muslims alike attributed their recovery, source of encouragement and hope to the worship of God or Allah whom they expressed their gratitude to. Praying, reading the bible or the Quran along with the encouragement they got from people from their faith gave them courage and a reason to keep on living. Some mentioned that the experience had brought them closer to God and were of the belief that only God could take them out of their predicament. In some narratives they acknowledged that:

*“As Muslims, Allah has thought us that in everything whether good or bad we should give it to Him. If He wills he will allow me to be strong again. He will take care of me for everything to go on well”*. **Sulley**

*“One thing I know for sure is that the sickness has attacked me and I’m just praying to God that he will take me out of it... with the encouragement from my fellow Christians...with the help of the bible I really got this courage to keep trusting in Jehovah than ever.”*. **Delali**

Atta went to the extent of visiting a church because he believed God would heal him through the Pastor in charge of that church.

*“I watched TV saw some of the miracles that maybe God was doing through Pastor Chris so my mum and I decided to go to Christ embassy”*. **Atta**

#### **4.7.2 Support**

Support in the form of financial assistance and special assistance at work from friends, colleagues and employers was evidently a great source of support for participants.

Participants were able to cope with high cost of treatment and work fatigue as a result. Some colleagues were understanding and were willing to allow some of the participants to close early so they could go home and rest. Some participants were also still receiving their salary from their employers and had been told to just relax and focus on their recovery. Family members of participants were also revealed from the narratives to be a great source of support for participants. They helped in diverse ways, especially by paying for medical bills, drugs, and going to stay with and allowing some of the participants to come and stay with them so they could take proper care of them.

According to Bonsu, his directors from his workplace were giving their support by paying his salary and taking care of his medical bills, including drugs. He had also been asked to take his time to recover and return to work when he is better. He stated that:

*“ I have been assured by my directors that I should recover fully I shouldn't worry myself ... my salary is paid me and they take care of my medical costs the drugs, chartering taxi from here to Korle-Bu for physiotherapy or for review, it is my employers who do that”.* **Bonsu**

Atta also revealed that he had understanding colleagues who allowed him to close early from work. He reported with joy:

*“I have understanding colleagues and I take on what I can. I don't do more than I can.”.* **Atta**

He went on to add that when he was in hospital it was his friends that came to donate blood for him because he had his stroke through a head injury he had from a road traffic accident.

*“I had too many friends and everybody wanted to come...So I quickly got blood”.* **Atta**

Serwaa, a petty trader acknowledged that it was her friends who helped her financially to establish her business which now helps to cater for her family.

*“It was my friends who helped me financially to establish this business... and that’s what we use to take care of ourselves.”. **Serwaa***

In relation to family support, Atta disclosed that he had to go and live with his mother after discharge. His mother paid for private nurses to take care of him and assist him to eat, bath and take his drugs.

*“I was living with my mum... she was taking care of me...she took these private nursing, care people and assigned them to come in the morning, to help bath me and clean me up”. **Atta***

Lokko also shared that his family supported by paying his medical bills.

*“The hospital bills, drugs, my senior brother took care of that, it was not a problem. Everybody was fighting for me to survive so then everybody was ready to do everything for me”. **Lokko***

Spousal support was also mentioned by some participants as very key to their recovery and they emphasized the need for every stroke patient to have a companion. They stressed that having a companion eases the burden of the condition and provides a good remedy for recovery. According to Bonsu and Rufinah:

*“Every stroke patient should have a companion, if you have a wife or husband...they should be there for each other. It’s a big relief and a big remedy” **Bonsu***

*“My husband was at Korle-Bu 24/7...the family support was there so I didn’t really feel the impact of the condition”. **Rufinah***

However, some participants didn’t receive any help from their family during the acute stages of their condition and beyond. They had to depend completely on their spouses for their upkeep. They narrated their stories with sadness;

*“My wife is the only one who has helped me in my medications, feeding and everything... Since I was discharged no one has come to look for me or visit till date”. **Kojo***

*“Later on when things started getting bad my mum started to pull out and then brainwashed my sister to also pull out.”. **Delali***

### 4.7.3 Self-determination

Self-determination refers to the ability of the stroke affected person to self-motivate him or herself through the recovery process. Some insisted that it was important for the stroke affected person to realize and accept the state they are in and take the necessary steps to recover. They were of the view that only the person suffering from the stroke knows what he or she is going through and as such knows what to do to hasten recovery and make the condition bearable.

Some of the participants motivated themselves physically to exercise and make the effort to do most of the simple tasks they were finding difficult to perform. Others developed a positive attitude towards the condition and encouraged themselves to move on. According to Lokko:

*“ With stroke when it affects you initially that is where the problem is but if you are out of danger the rest of the recovery almost 80% is with you the person suffering from stroke. I realized ... I have to help myself”. Lokko*

Joojo also motivated himself by having a positive attitude about his condition:

*“ I know this will not be like this forever, by all means there will be a breakthrough so that is what moves me forward. If I don't find work I will do my masters, having that in mind I know life goes on. People have it worse”. Joojo*

A participant shared how he had decided to pursue higher education so he could use his brain more. He wanted to avoid having to move around a lot since his mobility was impaired.

*“I was determined to move on so I pursued a master's degree and I'm currently doing a professional course in banking...I would rather be trained and use my brain than do operations and move around because moving around is a problem”. Atta*

Some participants were also motivated to make the necessary adjustments to live healthy and complete their physiotherapy which they found to be very helpful. These adjustments

included diet management, exercise and strict adherence to treatment regimen. Rufinah revealed that she decided to eat correctly, exercise and take her medication religiously. She accounted that:

*“I eat correctly and I’ve stopped eating late. I jog, take walks... and take my medications”.* **Rufinah**

The young adults who were able to go through physiotherapy found it to be very beneficial. They were able to regain some use of their affected side and this improved their well-being and gave them a sense of hope. Bonsu mentioned with joy:

*“Now I am doing marvelous when I go for physiotherapy.”.* **Bonsu**

#### **4.7.4 Herbal medicine**

A few participants also resorted to herbal medication for treatment. Some indicated that they went in for herbal treatment because they believed that it would help them recover faster and some also considered it because they couldn’t afford their drugs and physiotherapy. Some tried it but didn’t continue because of the side effects they experienced. Sulley who had experienced some weakness in his right side and found herbal treatment to be useful revealed that:

*“I used to limp initially but I started to train and did herbal treatments and within three months I improved...when I was discharged my hand wasn’t strong but the treatments helped”.* **Sulley**

In divergence, some of the participants alleged that they refused to go for herbal treatment because they had been advised by their doctors that the medication could bring about some complications in later life. Atta revealed:

*“I’ve been warned by the doctor because all these Chinese herbs and Chinese things you may not see the effect now, it’s slow”.* **Atta**

A few of the participants also narrated that they did not benefit from herbal medicine. They rather ended up disappointed. Lokko stated that:

*“I tried the herbal medicine, but it never worked. My recovery was through my own efforts”.* **Lokko**

Serwaa on the other hand, had to stop taking the herbal medicine because she experienced some dizziness when she starting taking the drugs.

*“The herbal gave me medicine, each time I took it I felt dizzy and cold. So after studying it for a while I was like no I won’t do it again”.*  
**Serwaa**

#### **4.8 Lack of continuity of care**

Lack of continuity of care is the only major theme that emerged from the content analysis of transcribed data which refers to the absence of a lifelong plan for continuous care after the stroke experience. Continuity of care refers to effective and quality continuous care between a patient and a particular health professional. It creates a platform for patients to receive information and help for unidentified and unmet needs which need to be addressed. From the narrations of all the ten participants, it was identified that there was a deficit of knowledge about stroke itself and a lot of unanswered questions about what caused theirs in the first place. Most of them alleged that this inadequate flow of information began at the hospital. They alleged that they were not informed about the likely symptoms they would experience after discharge from hospital and how to deal with those symptoms. They also insinuated that they did not know that the stroke recovery was going to be so slow and that a year after stroke survival they would still experience certain symptoms that were not present at the beginning of the disease. The subtheme that emerged under this theme is lack of information.

#### 4.8.1 Lack of information

Most of the participants revealed that they did not know what caused their stroke. They alleged that the health professionals who took care of them at the hospital didn't tell them what they needed to know. Joojo and Delali who mentioned that they did not know the cause of their stroke stated that:

*“Upon all the tests as we speak now they still haven't told me the actual cause. They only said that I had a mild stroke”.* **Delali**

Joojo the youngest participant revealed that he also didn't know what caused his stroke.

*“I honestly up till now don't know how it started or what caused it”.*  
**Joojo**

Serwaa also alleged that she was not told anything at the hospital. She was just treated and discharged. She blamed this on the fact that she wasn't given one doctor to take care of her.

*“They didn't tell me anything. They just took care of me and I came home... when you go to Korle-Bu and you don't get one doctor to take care of you they don't take good care of you”.* **Serwaa**

Some participants also revealed that they lacked information about stroke in general and would have taken better care of themselves to prevent the stroke had they known. Joojo the youngest participant shared his sentiments:

*“I had information about a whole lot of sicknesses; stroke was the only one that I didn't pay attention to. I had heard of it, but I didn't really know what it was”.* **Joojo**

It was evident that most of them couldn't relate their symptoms at the acute stage to the stroke because they lacked information about the disease and its related symptoms. One participant shared his ignorance.

*“When the thing happened I did not know what had happened to me. Even when we got to the hospital I didn't know it was stroke, I think it was after two days or three days that I got to know that I had stroke”.*  
**Sulley**

Some of the participants expressed worry about the fact that they still had symptoms from the stroke even after a whole year had elapsed. This made it evident that they lacked information about the long term effects of stroke. According to Atakora:

*“Every day you see something new is happening to you. I kind of look alright but there are things I can’t do”.* **Atakora**

In summary, the findings of this study indicated that participants had varied degrees of physical effects of stroke which greatly affected their physical health both at the onset and through to recovery. All participants were psychologically impacted to a certain degree at various stages of the disease process. Amongst these psychological reactions were surprise, fear and anxiety, depression, guilt, suicidal ideation.

These physical disruptions left participants with different physical disabilities which caused them to be socially isolated and unfit to work to be able to meet family roles and responsibilities.

The study findings also revealed that young adults with stroke were either seen as witches or seen as been punished by a deity for a sin they had committed. Stroke amongst young adults was also considered as strange since it was perceived as a disease for the elderly. Participants also felt displaced in society and felt their lives had come to a standstill.

The effects of stroke were evidently overwhelming but participants coped through spiritual practices and beliefs, self-determination, external and family support, lifestyle modification, physiotherapy and herbal medicine.

Although most of the participants had recovered to an extent from the stroke they expressed concern about a lack of continuity of care in the area of flow of information about the major disruptions or persisting symptoms they were experiencing and the actual cause of their stroke.

## CHAPTER FIVE

### DISCUSSION OF FINDINGS

This chapter highlights a discussion of the findings of the study with relevant and existing literature. The demographic characteristics are first discussed, followed by the themes.

#### 5.1 Demographic characteristics

Stroke among young adults in recent times is said to be on the increase especially in developing countries (Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk, & de Leeuw, 2014; Bejot et al., 2013). This young population is known to be amongst the productive age group and live longer to deal with the challenging effects of stroke on life in general (Krishnamurthi et al., 2015). The ages of all the young adults who took part in this study were between 18 -45years (Ellis, 2010) with the youngest participant been 26 years old and the oldest participant been 45 years old.

In this study only three of the participants were employed and even out of these three, only two were physically present at work. The other participant was still receiving salary from his workplace and had his name on the staff list but was not fit to go to work because of a left sided hemiparesis which he was now recovering from. The five young adults who were unemployed was as a result of certain physical disabilities such as imbalance, dizziness and heaviness in the affected side. Other reasons were lack of strength and easy fatigability. Coupled with these issues, some were also finding it difficult to find jobs because of the length of time spent in the recovery process. The two women who participated in the study were the ones who were self-employed and were managing their own small scale businesses; that is a hairdressing salon and a provisions shop. Though self-employed, only one, the hairdresser , was able to work, the other was unable to work because of pain in her back whenever she stood for long or attempted to lift certain items. Studies have shown congruence with this finding and have indicated that inability to return

to work and unemployment are directly linked to stroke and occur by virtue of the accompanying emotional, social, or physical impairments that associate with stroke acquisition; which tend to impede employment or reduce the quality of life of affected persons (Wolfenden & Grace, 2009; Kappelle et al., 1994). Several studies indicate that most young adults do not return to work or are limited in productivity due to limitations that are placed on their functionality (Varona, 2011; Koch, Egbert, Coeling, & Ayers, 2005; Wozniak & Kittner, 2002).

Most of the young adults in this study were married. Seemingly, these married participants were happier and felt like they really had the needed support to get through their predicaments. The unmarried participants conveyed that they wished they had spouses and emphasized the importance of spousal support and companionship as key features and remedies for recovery. This finding is in line with a study done in Norway which compared “health-related quality of life on long-term follow-up amongst young adults with Ischemic stroke”. The results indicated that those who were unmarried had lower health-related quality of life as compared to married patients (Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006).

## **5.2 Disruption to body-self**

Disruption to body-self refers to the relationship between the physical body and the psychological body (Aikins, 2003). It attempts to find a common ground between the physical impact of stroke on the affected person and the emotional interpretation as well as response attributed to those physical effects and dynamics. From the findings of the study, all ten participants reported to have experienced certain signs and symptoms which resolved after recovery from the acute stages of their stroke. According to the World Health Organization (W.H.O) and other related literature, the most prevalent symptom of

stroke occurrence is usually a sudden weakness or numbness of the face, arm or leg, which is often experienced on one side of the body. Further indicated are symptoms of fainting or unconsciousness, confusion, blurred vision, imbalance, intense headache with no known cause, difficulty walking and speaking as well as understanding speech (Nishikawa et al., 2016; WHO, 2016; Kothari et al., 1997). This elaboration of signs and symptoms by W.H.O confirms the signs and symptoms identified by the young adults in this study. Majority of them mentioned sudden severe headache as the first symptom they experienced prior to the stroke. Headache was followed closely by muscle weakness, facial palsy and unconsciousness. Upon awakening from the comatose state, these young adults discovered that their memory had been impaired, that they had blurred vision, sexual dysfunction and brief periods of hallucination. Invariably, these signs and symptoms elapsed, as progress was made in recovering from the acute stages of the stroke. They were then termed minor body disruptions because of the brief period of occurrence. The other signs and symptoms experienced, which were termed as major disruptions, were paralysis, pain and dizziness which as at the time of interaction were happening and deteriorating the quality of life of the affected participants. Most of the young adults confessed that when they were initially struck by the immediate signs of the stroke incident they could not interpret what was happening to them or associate the symptoms they were encountering with the condition in any way. Studies have shown that lack of knowledge about stroke and its related signs and symptoms result in an inability for affected persons to identify that they have gotten the disease when it first occurs and as such fail to report early for treatment (Mc Sharry et al., 2014; Faiz, Sundseth, Thommessen, & Rønning, 2014; Mackintosh et al., 2012). A study by Le Bonniec et al (2016) which was done amongst members of the general public in France, on “why patients delay their first contact with health services after stroke”, revealed that, aside from

not having knowledge about stroke, other factors that caused delays in contacting the emergency service were difficulties in identifying symptoms and understanding that those symptoms needed emergency attention. Awareness creation about stroke must therefore be done to enhance the knowledge base of the general public about the condition.

Glass & Maddox (1992) describe the “stroke experience” as a “psychological transition” owing to the fact that stroke occurs suddenly and within a short time frame. It also changes the ability of the affected person to function effectively in a social setting and requires a re-evaluation of the meaning one equates to who they are in the face of possibly losing their functional independence (Glass & Maddox, 1992). In this study, it was evident that the young adults faced different psychological disruptions from the very onset of the disease process. Although the intensity of these psychological disruptions had reduced overtime because of adopted coping strategies, traces of such emotional responses were identified as these young adults had to come face to face with existing physical impairments that they had to contend with on a daily basis. This finding is consistent with a study by Kuluski et al (2014) where it was identified that the emotional impact of stroke was difficult to predict because many people were likely to pendulate from a state of grieve to normality throughout the disease process; more consistently in individuals with persisting impairments.

In this study, young adults admitted to been surprised about their stroke diagnosis, particularly because they were not sick before the incident and considered themselves physically active. Some remained in a state of denial for a while and silently or confrontationally challenged health personnel about the accuracy of their diagnosis. Studies confirm that stroke survivors, particularly young adults are taken aback by the sudden nature of the stroke event and shaken to the core in a state of shock (Lawrence, 2010; Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006). However, some of

the participants who had prior knowledge about their state of health and the risk of developing stroke were not at all surprised about their diagnosis. They could also relate their symptoms to the beginning stages of the stroke event so were able to accept their predicament much easily. This finding is at power with other related studies which reveal that having a good knowledge base reduces the state of shock and denial among first time stroke sufferers (Lawrence 2010; Wellwood, Dennis, & Warlow, 1994)

Fear and anxiety which was experienced by most of the participants was in relation to death and disabilities. They were afraid because they were not sure of what next to expect after been diagnosed with stroke and feared that the end result would be death. Some also feared that they would never be themselves again or recover fully. This state of fear and anxiety was probably because young adults live longer, have more responsibilities and obligations and in the advent of physical impairments may remain impacted over a longer period of time (Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk, & de Leeuw, 2014). This fear of death and disability caused heightened feelings of anxiety amongst these survivors, which manifested in constant states of worry. An array of studies have also reported in confirmation of the findings that fear and anxiety are common occurrences in stroke which tend to peak mostly after discharge from the hospital (Campbell Burton et al 2012; Murtizani et al, 2009). Anxiety is reflected upon as the response due to fear from disease; the intensity of which depends on the extent to which a person is affected intellectually, and the extent to which the person is limited in terms of mobility (Murtizani et al, 2009; House et al 2001; Morris et al 1993) which may in turn lead to depression. In the light of the preceding submissions, persons affected with stroke will need to be assessed and monitored for these signs of fear and anxiety which could lead to much devastating complications like depression and suicidal ideation.

Another finding that was identified in this study was in relation to guilt which represented as blame. Most of the young adults blamed themselves for causing their disease. The reason being that they had involved themselves in certain habits like excessive drinking and smoking which are known risk factors for hypertension and subsequently stroke. Another source of guilt was from the fact that they felt they had let themselves down by not going for regular hospital checkups because they were involved in regular exercise, related physical activities, and as a result felt that they were exempted from having stroke. There is paucity of studies to assess the prevalence of self-blame amongst stroke survivors, however a study by Kishi et al (1996) on suicidal plans of patients with acute stroke has established a direct link between self-blame and depression which may lead to suicide.

In relation to depression, the young adults revealed directly and indirectly, that they had suffered or were still suffering from depression. Those participants who showed the most signs of depression were those who had hemiparesis of either the left and right sides of their body and were physically handicapped. Other participants who were also confined to the four walls of their homes due to dizziness and imbalance also showed some signs of depression. Deductively, this manifestation of depression was probably because they were lonely and felt like they had been left alone to face their challenges by themselves. In some studies it has been disclosed that depression is common amongst stroke survivors as a result of social, cognitive and physical dysfunction (Lees, Stott, Quinn, & Broomfield, 2014; Dafer, Rao, Shareef, & Sharma, 2008; Hackett et al 2005; Berg, Palomaki, Lehtihalmes, Lonnqvist, & Kaste, 2002; Andersen, Vestergaard, & Lauritzen, 1994; Sinyor et al., 1986) decreasing the quality of life of affected persons (Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006; Andersen, Vestergaard, & Lauritzen, 1994). The direct link between physical impairment and depression probably explains why

those participants, in this current study who showed signs of depression, also showed signs of frustration. This argument corresponds with a study done by Dafer et al (2008) which found that depression is rooted in extreme feelings of frustration. Depression among young adults living with stroke must therefore be evaluated and treated to avoid the exaggeration of negative impact of already existing disabilities, to prevent the slowdown of functional recovery and to reduce the risk of death (House, Knapp, Bamford, & Vail, 2001).

Another dimension of psychological disruption which was identified in this study was suicidal ideation. A few of the participants made insinuations about contemplating suicide. Most of them attributed these thoughts of suicide to anticipating an inability to cope with physical disabilities, pain and depression. In consistence with these findings, studies have shown that stroke is a risk factor for suicide (XA, 2016; Tang et al., 2015; (Batterham, Calcar, Mackinnon, & Christensen, 2013). A study done in Korea which sought to “compare the risk of suicidal ideation and attempts between patients with stroke and population without stroke” found that “stroke increased the risk for suicidal ideation and attempts, independent of other factors that are known to be associated with suicidality, suggesting that stroke per se may be an independent risk factor for suicidality” (Chung, Kim, & Kim, 2016)

Further studies have attempted to discover the factors that lead to thoughts of suicide and have counted depression as one (Dou, Tang, Lu, Jiang, & Wang, 2015; Pompili et al., 2012). Other studies have also related factors like pain to suicidal contemplation (Tang, Liang, Mok, Ungvari, & Wong, 2013; Tang et al., 2011); just as was discovered amongst participants in this study.

### 5.3 Disruption to social identity

Disruption to social identity focuses on the impact of stroke on the social status of the affected individual whilst delving into how one sees him or herself or is perceived by people in the community or social group. In this current study, participants mentioned instances where they were confronted by friends, family and other members of society with certain perceptions that they had about stroke in young adults and chronic illness sufferers in general. Some of the participants recollected been seen by some members of the society as being too young to suffer from stroke since it was considered as a disease for the elderly. Others also mentioned been considered as witches, or to be receiving punishment for a sin they have committed. Some young adults even considered themselves as been bewitched. Stroke has been apportioned as a disease of the elderly (Stone, 2007) possibly because, in past years, stroke affected mainly the elderly populace and was uncommon among younger persons. This perception seems to have long caught up with society and rendered stroke among young persons, below the age of 45 years as unheard of, even in the light of recent studies that indicate a rise in young stroke (Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk, & de Leeuw, 2014). This further buttresses the need for education amongst the general populace about new trends in stroke, from the experiences of affected young individuals; a gap in research in the Ghanaian context, for which this study seeks to fill.

Again, studies done by Aikins (2003) and Atobrah (2012) support the findings related to superstitious beliefs regarding suffering from chronic illness. In the study by Atobrah (2012) it was discovered that young adults diagnosed with certain chronic illnesses ascribe supernatural interpretations to their disease condition and this may account for the reason why young adults in this study attributed their condition to supernatural occurrences. The study by Aikins (2003) also highlighted findings in relation to society members seeing

chronic illness sufferers as bringing their condition upon themselves through their own powers of witchcraft ; giving some weight to the social perceptions society members hold with regards to chronic illness sufferers. There is paucity of research regarding the meanings stroke sufferers ascribe to their condition. The little research that exists focuses on the meanings ascribed in relation to chronic illness sufferers in general, particularly in the African context. Could it be that the need to ascribe supernatural and superstitious meanings to chronic illness is basically an African concept? There is need for further research which will seek to compare perceptions and meanings that are ascribed to chronic illnesses on local and international fronts.

Social isolation is another finding that emerged from this study. Young adults explained that they were inevitably isolated from society due to obvious disabilities like paralysis and imbalance to hidden ones like dizziness and pain. There were also some indications, however small, about feelings of they or their family members been stigmatized because of the social perceptions that were attributed to stroke among young adults. Studies consistent with these findings indicate that despite the need for assistance and solace, a high rate of broken relationships, social isolation as well as reduced social interaction was observed in stroke survivors because of physical limitations to the ability to function (O'Connell et al., 2001). Though human interaction is necessary for human growth and development , stroke survivors desire to regain functional normality before they can fully attain satisfaction in integrating with people ( Hamzat, Olaleye, & Akinwumi, 2014 ; Obembe, Mapayi, Johnson, Agunbiade, & Emechete, 2013; Cacioppo, Hawkley, Norman, & Berntson, 2011). The concerns raised by young adults in view of social isolation were not devoid of the fact that they desired a means of interacting more meaningfully with society. Congruent with a study by Obembe et al (2013), which revealed that younger stroke survivors were less restricted in their community integration as compared to older

stroke survivors, probably because they were more educated and had greater expectation of their recovery (Pang, Eng, & Miller, 2007).

With regards to stigma amongst young stroke survivors, some findings report that young stroke survivors are likely not to disclose their condition because of the likelihood of been viewed in a negative manner (Hanney, 2012). This supports the findings in this study that mentioned stigmatization in young stroke because the condition is viewed as one for the elderly. Further research is required to look into whether young adults living with stroke feel stigmatized due to the meanings ascribed to chronic conditions in our local setting.

#### **5.4 Disruption to personal agency**

Disruption to personal agency focuses on the effect of the stroke experience on the ability of the affected person to work and interact socially as well as perform simple tasks. “Work is important for one's self-esteem, social standing and ability to participate in the community as well as for the material advantages it brings to individuals and their families” (Frank, 2016). A person’s ability to work after stroke incident directly influences their quality of life, well- being and overall satisfaction (Vestling, Tufvesson, & Iwarsson, 2003). Ability to return to work is of great importance to young stroke survivors ultimately because they have a lot of responsibilities and require a stable flow of income to meet their financial obligations. In a study done in Russia to assess the long-term survival in working-age patients after cerebrovascular accident (CVA) and to identify basic medical and social factors determining their survival rates it was unveiled that unemployment was also a factor in determining the long-term survival rates of patients at the working-age. Most of the time, many stroke survivors do not return to work and this is as a result of varied reasons, pertaining to their inability to function physically as before (Treger et al., 2007; Leys et al., 2002; Howard et al., 2001). They are affected cognitively, physically

and affectively and all these come together to reduce their productivity (Plummer et al., 2007). In this study, most of the young adults revealed that they could not work like before. Most of them were unemployed because of different physical disabilities that had rendered them unfit to go back to work. These included paralysis, contracture, dizziness, and imbalance. According to Vestling, Tufvesson, & Iwarsson (2003) it can be presumed that a person's inability to return to work is due to a more severe disability which has rendered the person dependent and has lowered life satisfaction and well-being. Others were also unemployed because they were unable to find jobs because of the length of stay at home due to the extensive period spent on recovery. Individuals who were employed also lacked the strength to take on other tasks that were likely to bring in more income and some also had to find new jobs that were less tedious. A seminal study by Kaste (1998) supports these findings by instigating that stroke costs are not just direct pertaining to medical costs only but are also indirect and include loss of time from work and movement into less productive jobs (Kaste, 1998).

The performance of activities of daily living is important and includes basic and simple tasks such as feeding, grooming, transferring, dressing, toileting and mobilizing (Sulter, Steen, & Jacques De Keyser, 1999) forming the primary basis for treating persons who have had a stroke in order to bring them back to the point where they can perform these activities independently (Won, 2008; De Wit et al., 2006). Treatment in this regard is essential, mainly because all other activities and many social roles are predicated upon adequate mobility (Party, 2012). Pertaining to the current study, not all the participants had recovered physically and could perform some simple activities of daily living. Owing to their disabilities, there was a limitation to what they could do for themselves and their families. Those who had physical impairments like paralysis and contracture found it difficult to bath, eat, read, and move around. Though they had gotten used to performing

these tasks by adopting aiding mechanisms such as the use of a walking stick and holding on to walls and other objects to walk, a lot of energy was used in performing these tasks which was not so before the stroke. These limitations also put a halt to certain parenting roles such as playing with their children, carrying them, amongst others. They expressed that to them, their recovery could only be complete if they could perform these basic activities. Kim et al (2014) confirms that to patients with stroke, been able to perform living activities independently was the main criteria for their quality of life.

### **5.5 Disruption to economic circumstances**

Disruption to economic circumstances focuses on the effects of stroke experience on the financial and economic stability of affected persons. In this study, Young adults faced a lot of financial difficulties because most of them were unemployed and their spouses were also unemployed and as a result didn't have a regular flow of income to meet financial obligations. This is in line with a study by Draper & Brocklehurst (2007) which concluded that after suffering a stroke, the patient may be unable to work because of impaired function, but the partner may also have to stop working to provide care (Draper & Brocklehurst, 2007).

The high cost of medical treatment put a huge strain on the finances of these young adults and their families, who due to the sudden occurrence of the stroke did not have time to plan for these added expenses. Studies have shown that stroke sufferers are economically burdened by cost of treatment (Jennum, Iversen, Ibsen, & Kjellberg, 2015; Lopez-Bastida et al., 2012; Taylor et al., 1996) and a cross-sectional retrospective study of 448 patients in Spain concluded that stroke has a deteriorating effect on the health related quality of life of sufferers because of the high societal costs it incurs (Lopez-Bastida et al., 2012). Other studies have also revealed that the costs of hospitalizations following stroke are high and

vary amongst stroke subtypes (Wang et al., 2014; Persson, Ferraz-Nunes, & Karlberg, 2012). Catering for medical treatment coupled with meeting financial obligations pertaining to rent, feeding and general upkeep of both themselves and their families is a herculean task due to the increase in expenditure. Young Adults also experienced an increase in expenditure because of the cost of transportation to and from hospital reviews. These findings call for cost-effective strategies to reduce the impact of stroke especially on economic circumstances.

### **5.6 Illness action**

This refers to the practical routines that participants initiate and manage in order to cope with or overcome the negative psychosocial impact of the stroke experience (Aikins, 2003). From the study it was evident that most of the participants had adopted certain coping strategies to deal with their stroke. There was a deep sense of faith in God. They attributed their recovery to His help and prayed for complete healing. According to Giaquinto et al (2007) “the strength of religious beliefs influences the ability to cope after a stroke event, with stronger religious beliefs acting as a possible protective factor against emotional distress” (Giaquinto, Spiridigliozzi, & Caracciolo, 2007). Providing a culture conscious care for patients to needs for spiritual affiliation is essential to them and must be taken seriously by nurses (Mohamed, Nelson, Wood, & Moss, 2015). However in contrast, some studies assert that alternative meanings attributed to the causes of stroke that include witchcraft or wishing wrong for someone suggests a lack of perceived control over stroke and take the focus off less visible risk factors such as hypertension, familial history or diabetes. Stroke affected persons can stick to these beliefs if it does not interrupt their medical management, treatment or risk factor management of stroke. Health promotion training modules should emphasize on obesity through diet and physical activity to

prevent stroke occurring (Moorley, Cahill, & Corcoran, 2016; Theis, Biordi, Coeling, Nalepka, & Miller, 2003)

Most of the participants received support from family, friends, colleagues at work and their employers. Family members contributed immensely to paying of medical bills. Employers gave encouragement and continued to pay the salary of some of the young adults. Friends also gave donations that helped some to establish their businesses in order to be able to cope with financial demands. In contrast, young adults seemed not to have gained a lot of support from health personnel after discharge from hospital and completion of the 6 months stipulated review. In the seminal work by Niemi et al (1988) it was reported that it is important for self-help programs and rehabilitation institutions to make sure that stroke patients have the needed encouragement, psychological support, adaptation training, and sufficient neuropsychological information. Such social support would enable patients who are discouraged by stroke to assess themselves more realistically and to live healthier and fuller lives (Niemi, Laaksonen, Kotila, & Waltimo, 1988). Health professionals must team up and develop follow-up strategies for meeting extended needs of patients.

Participants also made their own efforts to enhance their recovery by motivating themselves. Self-determination in this study delves into the ability and the different ways by which the stroke affected person motivates him or herself through the recovery process. This self –determination can be achieved through self-efficacy. Perceived self-efficacy is concerned with people's beliefs in their ability to influence events that affect their lives. This core belief is the foundation of human motivation, performance accomplishments, and emotional well-being” (Bandura, 2010). In this regard, it takes the actions and beliefs of an individual to cause a change in his or her circumstances. In stroke related cases, self-efficacy has been seen as a major contributing factor to the achievement of positive

rehabilitation outcomes and improvement in overall quality of life (Jones & Riazi, 2010; Robinson-Smith, Johnston, & Allen, 2000). In this study, young adults hammered on the need for the stroke sufferer to gain control of him or herself and be actively involved in those activities jeered towards recovery. They indicated that it is only the person affected with stroke that can clearly know and explain what he or she is going through and as a result is the only one that knows what can be done to speed rehabilitation outcomes. With this in mind they were able to motivate themselves to live healthier lifestyles through diet management and exercise, sticking strictly to treatment regimen as well as developing a positive attitude towards their condition. The onus lies on health professionals to encourage individuals to gain a sense of control over their lives and make decisions that will affect their lives positively (Western, 2007). A person's ability to adapt their behaviour and attitude by being positive, hopeful, determined, resilient and courageous is an essential part of pursuing their self-selected valued activities. Recognizing and encouraging the importance of these behaviours and attitudes should be promoted in rehabilitation (Woodman, Riazi, Pereira, & Jones, 2014).

Amongst the coping strategies adopted by some of the participants to help deal with the dynamics of their condition was the use of herbal medicine. Some of the participants reported to have benefited immensely from the herbal treatment which helped them regain some use of their affected side. A study by Yu et al (2015) gave evidence that showed good efficacy, and safety in patients affected by ischemic stroke (Li et al., 2012) In contrast, some participants reported that they did not benefit at all from these treatments. While some had side effects, others felt it was sheer waste of money. Sampane-Donkor's (2014) assertion supports these findings by evidently revealing that there have being in recent times, proliferation of herbal services that provide non-orthodox medical assistance for wide range of diseases such as stroke. In this regard, it is necessary for the safe

management of stroke patients and for further research to be carried out on factors that influence the use of herbal treatment in order to avoid unwarranted complications.

### **5.7 Lack of continuity of care**

Lack of continuity of care highlights the absence of a lifelong plan which is geared towards maximizing the wellbeing of stroke sufferers. Stroke patients require continuous care to serve as a platform for identifying needs that were nonexistent in the initial stages of the disease condition but may appear in later life, mainly because the effects of stroke span over a lifetime (Kuluski, 2014). Although the average post stroke assessment period for participants was 6 months, young adults in this study desired more contact with health personnel who were skilled enough to give them the necessary assistance. A survey conducted by the Stroke Association in the United Kingdom found that essential services are lacking after individuals leave hospital (Stroke Association, 2012). Half of the individuals surveyed (53%) had been assessed only once after being discharged from hospital, and coordination of care had fallen largely on the shoulders of family (Stroke Association, 2016).

In this study, stroke survivors displayed their ignorance about stroke in general. As a result they made mention that they could not identify themselves with stroke when they first started experiencing their symptoms. Young adults also indicated that they were unaware of the cause of their stroke because they weren't informed by the health personnel that took care of them. They showed an eagerness to know what the actual cause of their stroke was even though a whole year had passed. Their desire to know somewhat gave the impression that they would be at peace if they were to know exactly what happened to them. Lawrence (2010) confirms that following a stroke, young adults usually are preoccupied with finding what happened to them in order to prevent reoccurrence. This

might be the reason why these young adults were so much interested in knowing what caused their stroke even after a whole year of living with the condition. The reasons why young adults may not be informed about the actual cause of their stroke is because studies have shown that due to the uncommon nature of stroke among this group of persons, diagnosis tend to be a bit challenging and require a concise diagnostic workup (Kefi et al., 2016; Bevan, Sharma, & Bradley, 1990; Kristensen et al., 1997; Felipe Varona, Manuel Guerra, & Bermejo, 2004) the most important thing however is to make sure that services provided for stroke patients are tailored to meet their long term needs (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015; Burton, 2000)

In conclusion, it was evident that the young adults in this study had various disruptions to body-self ranging from paralysis to dizziness and pain; that limited their ability to function and perform certain tasks like before. They were psychologically affected, evidently because the sudden nature of the condition, surprised them and gave them no time to prepare for what was ahead. They experienced fear of death and disability which was sometimes expressed in anxiety. They felt responsible for their condition and ended up depressed with thoughts of suicide.

The social perceptions of community members about stroke in young people which ranged from seeing them as witches, the disease been a disease of the elderly and thinking that they were been punished for a sin made them feel socially isolated and lonely. Their economic circumstances changed and they were burdened with high costs of drugs, increased expenditure and were financially constrained mainly because most of them were unemployed and didn't have a stable flow of income.

In order to cope, they employed various illness actions, like praying, reading the Quran and finding inspiration from God whom they looked up to to heal them. They were also

self-motivated to get well and had some support from family, friends, colleagues from work and their employers.

Notwithstanding, they lacked knowledge about their condition and desired a closer relationship with their health professionals for continuity of care.



## CHAPTER SIX

### SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

This chapter presents the summary, implications, limitations, conclusion and recommendations of the study.

#### 6.1 Summary of the Study

This study explored the experiences of young Adults, 18-45years, living with stroke in the Accra Metropolis. It employed the De-graft Aikins (2003) theoretical framework of biographical disruption and illness action as its framework. A total of ten (10) young Adults were recruited for the study from the Accra Metropolis, using the stroke unit and physiotherapy departments of the biggest referral hospital that is the Korle-Bu Teaching Hospital (KBTH) as the recruitment site. Data was collected after the needed approval was given by the Noguchi Institutional Review Board and the authorities of the stroke unit of the Korle-Bu Teaching hospital. One on one interviews were conducted with participants after verbal and written consents were obtained. These interviews were audiotaped and transcribed verbatim between November, 2015 and February, 2016, after which thematic content analysis was conducted for analysis of the data. Six (6) major themes and thirteen (13) subthemes were identified after thematic content analysis. Five (5) of these themes were derived from the biographical disruption and illness action theoretical framework but one (1) emerged from the data.

It was identified from the data gathered that young adults at the onset of their stroke were affected by certain signs and symptoms which occurred suddenly and without warning. Although most of these signs and symptoms resolved with time, these young adults experienced different set of signs and symptoms which persisted, after recovering from the acute stages of stroke. Amongst these major disruptions were paralysis, pain and dizziness.

These disruptions to the physical health of participants led to inability to work and perform simple tasks, social isolation and financial constraint.

The overwhelming nature of the effect of the stroke condition on the physical and socioeconomic aspects of the lives of the affected persons had a negative psychological impact which took the form of surprise, fear and anxiety, guilt, depression and suicidal ideation.

In order to cope with these difficulties , young adults resorted to spiritual beliefs and practices such as prayer and reading of the bible or Quran, family and external support, self-determination lifestyle modification and herbal medicine. It was however revealed that young adults lacked information about stroke, the cause of their stroke and its related signs and symptoms. Predominantly they lacked information about how to cope with the aftermath of the condition after recovery from the acute stages and as a result they had a lot of unanswered questions.

## **6.2 Implications**

The study findings have certain implications for nursing education, practice, research and policy formulation.

### **6.2.1 For Nursing Education**

The findings of the study revealed that young adults living with stroke lacked adequate information about the cause of their stroke and its related long term signs and symptoms and as a result lacked the necessary information on how to cope with those signs and symptoms and what to do in case they occur. There is therefore the need to re-educate nurses for them to be able to effectively give patients the needed education about their disease condition. The stroke survivors also lacked information about stroke in general and

as a result couldn't relate signs and symptoms to the stroke experience at the onset and after recovery from the acute stages. It is therefore imperative for nurses to be trained to serve as nurse educators who will spearhead the education of patients on the prevention, treatment and management of cardiovascular diseases. It has also become necessary per the findings of this study for the Ghana College of Nurses and Midwives to develop or adopt a curriculum that will train cardiac nurses to cater for the comprehensive and holistic needs of stroke sufferers especially Young Adults and their families.

### **6.2.2 For Nursing Practice**

The study findings also revealed that the family members of stroke patients, both nuclear and extended were also affected due to the emotional and physical strain the stroke event put on them during the care of their affected loved ones. This strain posed a threat on the health of these caregivers and further exposed them to hypertension and possibly stroke. It is therefore imminent for nurses to cater for the wellbeing of these caregivers too by regularly monitoring their blood pressure, counselling them to allay their fears and reduce their anxiety, and also educating them in order to equip them with the needed skills for caring for the stroke affected person upon discharge. There is need also for nurses across the nation to equip themselves with the needed knowledge through continuous professional development in order to stay abreast with new trends in cardiovascular health care geared towards providing holistic care and improving patient education.

### **6.2.3 For Research**

This study calls for further research into the psychosocial effects of stroke on spouses and children of young adults living with stroke, in order to gain in-depth understanding into what these spouses and children go through during the stroke experience especially when the affected person is the breadwinner of the family. It further calls for research into the

prevalence and incidence of stroke amongst young adults living with stroke in Ghana using a quantitative approach.

#### **6.2.4 For Policy Formulation**

The study findings revealed that the cost of treatment and management of stroke was high which put a strain on the finances of young adults living with the condition as well as their families. Some stroke survivors were not able to afford their drugs and finish their physiotherapy which together are vital for recovery and rehabilitation. It is necessary then for a policy to be instated to cater for the subsidization of the overall cost of treatment and management for stroke.

#### **6.3 Limitations**

The researcher admits limitations of the study in that the study was conducted using a qualitative approach with a sample size of ten (10); therefore the findings of the study cannot be generalized. However transferability still holds for studies in which the context is the same.

#### **6.4 Conclusion**

The constructs of the biographical disruption and illness action theoretical framework were consistent with findings of this study. These constructs formed the themes, disruption to body-self, disruption to social identity, disruption to personal agency, disruption to economic circumstances and illness action. The theme, lack of continuity of care emerged from the data gathered and revealed that the young adults who participated in this study lacked information about stroke and its related symptoms in general as well as the cause of their own stroke. They also lacked information about persisting symptoms that they had discovered after recovering from the acute stages of the stroke.

The findings also revealed that the physical effects of stroke on the physical health of the participants had a negative psychosocial impact on them and threw them into a state of shock, fear, anxiety, guilt, depression and suicidal ideation.

Socially, most of the participants had to isolate themselves from society because they could no longer do the things they used to do because they had various forms of disability and also because of the diverse social perceptions by members of the community such as they been perceived to be witches or perceived to be paying for a sin they had committed.

Most of them were unemployed as a result of these physical disabilities and couldn't fully meet their family roles and responsibilities such as parenting and providing financially for the general upkeep of the family.

These young adults found their strength and ability to cope from spiritual practices and beliefs, self-determination, external support, family support, and herbal medicine.

To conclude, there is need for the stroke experience to be viewed from a broader perspective by health professionals so that they are able to adequately cater for the needs of stroke affected persons and their families holistically; taking into account the dimensions of the physical, psychological and social needs of persons involved.

## **6.5 Recommendations**

The following recommendations, per the findings of the study are made to the ministry of health, Ghana College of Nurses and Midwives, Korle-Bu Teaching Hospital, Young Adults living with stroke and the general public.

### **6.5.1 To Ministry of health**

- ❖ Assess the cost of treatment for stroke and lobby government to subsidize the cost of treatment and management for stroke.

- ❖ Liaise with Government and other NGOs to set up more stroke units with extensive, comprehensive and multidisciplinary stroke rehabilitation services.
- ❖ Liaise with hospitals and other NGOs to set up associations and support groups for stroke survivors.
- ❖ Employ more doctors and nurses at the current stroke unit to cater for the increasing number of stroke patients.
- ❖ Liaise with the media and intensify campaign for regenerative health to educate and sensitize young adults about risk factors and signs and symptoms of stroke.
- ❖ Organize training for nurses, doctors and other members of the multidisciplinary team to equip them and enhance their knowledge on the care of persons with stroke and also improve patient education.

#### **6.5.2 To Ghana College of Nurses and Midwives**

- ❖ Develop or adopt a curriculum for cardiac nursing to train nurses to provide specialist care for patients with various cardiovascular diseases including stroke.

#### **6.5.3 To Korle- Bu Teaching Hospital (Stroke unit)**

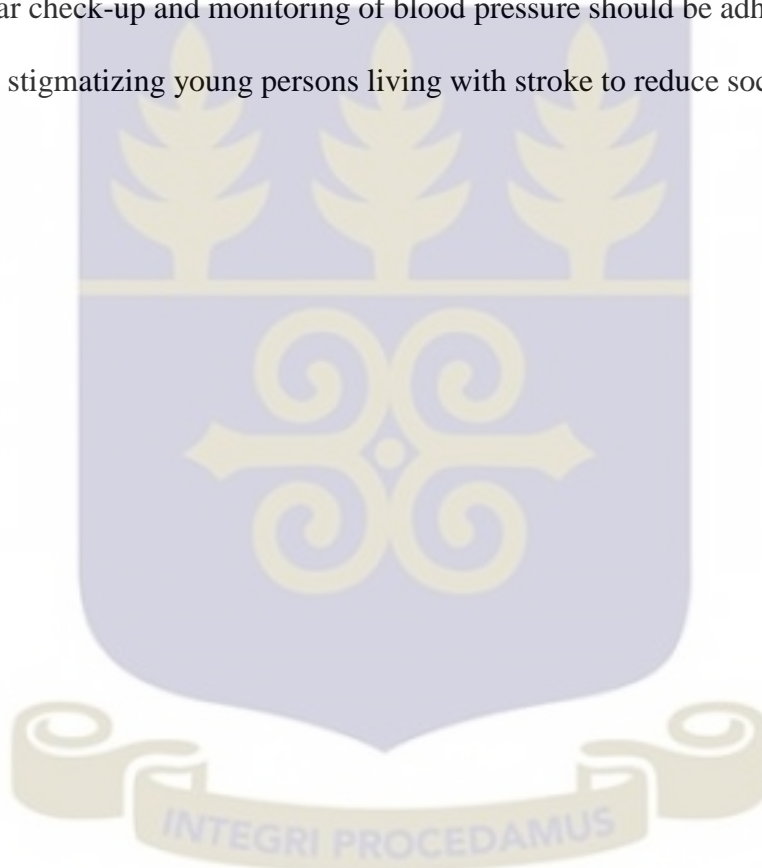
- ❖ Liaise with community health nurses to follow up on stroke affected persons after discharge
- ❖ Make the effort to assign specific doctors to specific patients to ensure continuity of care and also do random checks to ensure that both NHIS and cash paying clients are treated equally.
- ❖ Do regular blood pressure checks, counselling and education for stroke family caregivers during the acute stages of stroke.
- ❖ Assess and upgrade the test element for assessing stroke survivor recovery to avoid repeating the same tests for patients at advanced stages of recovery.

#### **6.5.4 To Young Adults affected with stroke**

- ❖ Keep contact with health professionals in order to communicate and enquire about progress after discharge.
- ❖ Register with NHIS which will cater for basic health needs when financially constrained.

#### **6.5.5 To the general public**

- ❖ Regular check-up and monitoring of blood pressure should be adhered to.
- ❖ Avoid stigmatizing young persons living with stroke to reduce social isolation.



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## APPENDICES

### Appendix A: Ethical Clearance



## Appendix B: Interview Guide

In this interview I would like you to share with me your experiences as a young adult living with stroke. I would like you to share your feelings, thoughts, emotions, ideas, and experiences with me. Please feel free to open up. All information you give will be confidential.

### SECTION A (Demographic data)

1. Name
2. Age
3. Sex
4. Religion
5. Occupation
6. Tribe
7. Educational level

### SECTION B

1. Please tell me about your stroke?

Probing

- When did you get the stroke?
- What was the cause of your stroke?
- Can you tell me what happened when you first started experiencing symptoms, what were they?

2. How do you feel as a young adult living with stroke?

Probing

- How do you see yourself now in your condition?
- How has the stroke affected your life?
- How did your friends and family react to your symptoms or your stroke?
- How has it affected your relationships?

3. What are the physical effects that stroke has had on your health?

Probing

- Did your symptoms stop you from doing anything?
- Are you able to go to work and participate in social activities?

4. How are you managing in your condition now?

Probing

- How are you coping with your symptoms?

- Are you undergoing rehabilitation or have you undergone rehabilitation?
  - What are some of the challenges you have been able to overcome since you had the stroke?
5. What do you think can be done to improve the wellbeing of young adults living with stroke?
  6. Is there anything important you want to share with me?
  7. Do you have any questions?
- Thank you for your time



## **Appendix C: NMIMR-IRB Consent Form**

Title: Experiences of Young Adults living with stroke in the Accra Metropolis

Principal Investigator: Sussana Opoku

Address: School of Nursing, College of Health Science, University of Ghana, Legon-Accra,  
Ghana. Maabena2010@gmail.com

### **General Information about Research**

This consent form is a request for you to take part in a research study on your experiences as a young adult living with stroke. The purpose of this study is to find out your experiences as a young adult living with stroke. You will benefit by knowing that the information you provide will be useful to health care professionals, in developing interventions for the care of young adults living with stroke. It is important that you read this form carefully before deciding to take part in this study and also for you to be able to ask all pressing questions of which the necessary clarifications will be given. You qualify to share your experiences if you have been living with stroke for at least 1 year and are going through rehabilitation or recovering at home. In case you agree to take part in this study, you will be taken through an interview, which will last between 45 minutes to an hour and will be tape-recorded with your permission. You will be interviewed at a time and place which is convenient for you. The interview will center on questions relating to your physical health and well-being, how you are coping with stroke and the effects that stroke has had on your emotional and social life.

### **Possible Risks and Discomforts**

As a participant in this study, you will be required to reflect on your experiences and emotions in order to give meaningful information during your interviews. As a result you are likely to find the interview uncomfortable.

The researcher is prepared to help participants herself and to direct those confronting difficult emotional issues to qualified professionals, and by providing participants with relevant references/information. There are no other significant risks to participating in this study.

### **Confidentiality**

The information that is collected will be kept in a secure area. All information collected during this study will be kept confidential for at least 5 years and will not be shared with anyone outside the study unless required by law. Your identity will not be revealed in any reports and all records, only the researchers and supervisory team will have access to these records. Tapes bearing interviews will also be destroyed upon transcription. Codes and pseudonyms will be attached to your data so that no information can be traced to you.

### **Possible Benefits**

You may benefit emotionally and psychologically by sharing your experiences with an attentive listener and trained nurse. You will also benefit to know that the information you provide will be useful to health care professionals in developing interventions for the care of young adults living with stroke.

### **Compensation**

There are no costs associated with participation in this study. You will be given a snack after the interview. A token will be given as transportation if the interview is not conducted at your home.

### **Voluntary Participation and Right to Leave the Research**

Participation in this study is completely voluntary. You will not be treated any differently from those who agree to take part in this study. You can choose not to participate or refuse to answer a question, or withdraw at any time without penalty.

### **Termination of participation**

The researcher reserves the right to terminate your participation if you become so emotionally affected that you cannot continue with the interviews.

### **Contacts for Additional Information**

If you have any questions related to the study later, you can contact the researcher, Sussana Opoku on the mobile number, 0545229949 or via email on [maabena2010@yahoo.com](mailto:maabena2010@yahoo.com). You can also contact the research supervisor, Mrs. Cecilia Eliason on 0244638716 or the School of Nursing on 0244967807 in case of research- related injury. You will be given a copy of this form to keep. If you also want to know your rights as a participant, please contact the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB) on the contacts stated below.

### **Your rights as a Participant**

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: [nirb@noguchi.mimcom.org](mailto:nirb@noguchi.mimcom.org)

## VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title “**Experiences of Young Adults Living with Stroke in the Accra Metropolis**” has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

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Date

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Name and signature or mark of volunteer

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.

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Date

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Name and signature of witness

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.

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Date  
Consent

---

Name Signature of Person Who Obtained

**Appendix D: Demographic characteristics**

<b>PSEUDONYM</b>	<b>AGE</b>	<b>SEX</b>	<b>MARITAL</b>	<b>LEVEL OF</b>	<b>OCCUPATION</b>	<b>EMPLOYMENT</b>	<b>RELIGION</b>
	<b>(YRS.)</b>		<b>STATUS</b>	<b>EDUCATION</b>		<b>STATUS</b>	
<b>Kojo</b>	40	Male	Married	Form four	Baker	Unemployed	Christian
<b>Sulley</b>	31	Male	Married	JSS	Mason	Unemployed	Muslim
<b>Rufinah</b>	45	Female	Married	Sixth form	Hairdresser	Self employed	Muslim
<b>Joojo</b>	26	Male	Single	Tertiary	University graduate	Unemployed	Christian
<b>Delali</b>	28	Male	Married	Tertiary	Engineer	Unemployed	Christian
<b>Bonsu</b>	39	Male	Married	Tertiary	Teacher	Employed	Christian
<b>Atta</b>	40	Male	Married	Tertiary	Banker	Employed	Christian
<b>Serwaa</b>	45	Female	Married	Form four	Trader	Self employed	Christian
<b>Lokko</b>	45	Male	Married	Tertiary	Engineer	Unemployed	Christian
<b>Atakora</b>	38	Male	Single	Tertiary	Building draftsman	Employed	Christian

