UNIVERSITY OF CAPE COAST

EXPERIENCES OF INFORMAL CAREGIVERS OF PATIENTS WITH STROKE IN CAPE COAST METROPOLIS, GHANA

BY

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DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university elsewhere.

Candidate's Signature: ....… Date: ....

Name………………………………………………………………………………

Supervisors' Declaration

We hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature: .... Date: ....

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ABSTRACT

Many stroke survivors experience long-term impairments in physical, psychosocial, and cognitive functions that are formidable challenges to informal caregivers. During the period leading up to and including the stroke survivors’ discharge, the informal caregiver will face immense uncertainties and new challenges. A qualitative phenomenological design was used to explore the experiences of informal caregivers of persons living with stroke in the Cape Coast Metropolis. Thirteen respondents were purposively selected from the Cape Coast Teaching Hospital and University of Cape Coast Hospital. Face-to-face interviews were conducted using a semi-structured interview guide. The interviews were audio recorded with each interview lasting between 25 and 45 minutes. Thematic content analysis was used to analyse the transcribed data and three major themes were derived namely: nature of caregiving, coping strategies and impact of caregiving. Informal caregivers’ experiences were characterized with increased daily task, which was time-consuming, stressful, frustrating and financially demanding. However, caregiving for stroke patients strengthened the relationship between caregivers and patients. Coping strategies such as watching television, sleeping, acceptance, patience, tolerance and hope in God further self-encouragement were employed by these participants. The study also revealed that generally, caregiving for stroke patients negatively affects the caregivers’ work, finances, social life and health. Thus, the study recommends that proper psycho-educational and counselling services should be given to informal caregivers to properly adapt to their situation.

KEYWORDS

Cape Coast

Informal Caregivers

Stroke

Caregiving

Coping

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DEDICATION

To my Lovely Husband, Daughter, and Family.

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LIST OF ACRONYMS

CCM	Cape Coast Metropolis
CCTH	Cape Coast Teaching Hospital
CVA	Cerebrovascular Accident
CVI	Cardiovascular Injury
DM	Diabetes Miletus
ICP	Increase Intracranial Pressure
LMIC	Low- and Middle-Income Country
LVO	Large Vessel Occlusion
NINDS	The National Institute of Neurological Disorders and Stroke
QOL	Quality of Life
SSA	sub-Saharan Africa
TIA	Transient Ischemic Attack
UCCH	University of Cape Coast Hospital
ZBIS	Zarit Burden Interview Schedule
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

Background to the Study

Stroke, sometimes called brain attack, occurs when a clot blocks the blood supply to the brain or when a blood vessel in the brain bursts. Stroke can result mostly through high risk lifestyle behavioural changes and, in some cases, medications (Feigin et al., 2016). Stroke can be understood as when a blood vessel that carries oxygen and nutrients to the brain either bursts, ruptures or is blocked by a clot. As a result, the brain cannot get the blood and oxygen it needs and pieces of the brain start to die.

Stroke can occur at different spots or parts of a person's anatomy and physiology, therefore leading to the different types of stroke. An Ischemic Stroke occurs when a clot or mass, often a fatty plaque deposit, clogs a blood vessel cutting off the blood flow to brain cells. A Hemorrhagic Stroke results from a weakened vessel that ruptures and bleeds into the surrounding brain tissue. Transient Ischemic Attack (TIA) produces stroke-like symptoms and is caused by a clot; but unlike a stroke, the blockage is temporary and usually causes no permanent damage to the brain. TIAs are often called "mini-strokes" (Mozaffarian, et al., 2015). Transient Ischemic Attack (TIA) produces stroke-like symptoms and is caused by a clot; but unlike a stroke, the blockage is temporary and usually causes no permanent damage to the brain. TIAs are often called "mini-strokes" (Mozaffarian et. al., 2015)

Several factors can increase a person's risk for stroke, these include: age, sex, ethnicity and unhealthy habits such as; smoking, drinking too much alcohol, not getting enough exercise and having high cholesterol, high blood pressure, or diabetes (Feigin et. al., 2016). Stroke is one of the leading causes of death in industrialized countries (Go et al., 2014). Stroke is a disabling illness that is prevalent (Mozaffarian et al., 2015), it is the third leading cause of mortality worldwide (Hsieh, & Chiou, 2014) and the second leading cause of mortality in Ghana (Agyemang & Sanuade, 2013). Stroke is a serious neurological event primarily affecting older people, and its consequences include mobility problems, cognitive impairment, urinary/fecal incontinence, speech and communication difficulties, and personality changes that often require lifelong assistance hence, the need for a caregiver (Lloyd-Jones et al., 2010; Saban & Hogan 2012).

Each year, about 5.5 million people die because of stroke worldwide (Mendis, Davis, & Norrving, 2015). The incidence and prevalence of stroke increases exponentially with increasing age, with a peak in people aged 85 years and over; 75% of strokes occur in people over the age of 65 (Di Carlo et al., 2003; Heuschmann et al., 2009). In Europe, the prevalence of stroke ranges from 4.6 to 7.3 per 1000 and the annual incidence ranges from 7.5 to 10.1 per 1,000 after 65 years of age (Truelsen et al., 2006). Stroke is the leading cause of disability in the adult population (Adams et al., 2007) and has a significant impact on patients and their informal caregivers (Zorowitz, Gillard, & Brainin, 2013).

Stroke rehabilitation has concentrated successfully on patient-focused interventions to reduce severe disability and institutionalization, which has resulted in increasing the number of disabled patients being managed at home (Anderson, Linto, & Stewart- Wynne, as cited by McCullagh, Brigstocke, Donaldson, & Kalra ,2005). Recent years have seen increasing awareness of the role of caregivers in the long-term management of patients with stroke (McCullagh et al., 2005). It is also becoming clear that the emphasis in stroke rehabilitation needs to shift from a patient-focused approach (Blake, Lincoln & Clarke, 2003) to a combined patient- and caregiver-focused approach because these individuals are central in preserving rehabilitation gains and the long-term well-being of stroke survivors.

However, the success of early attempts to support caregivers has been limited, largely because the determinants of caregiving burden and the needs of caregivers remain poorly understood (McCullagh et. al., 2005). Little research has been devoted toward understanding the complex and multi-layered phenomenon of caregiving, beyond patient dependence and the emotional or psychological aspects of caregiving after stroke. Thus, it is important to study caregiver experiences and the effect it has on caregivers and stroke survivors (McCullagh et. al., 2005).

Stroke symptoms can be very stressful for family caregivers (Haley, Roth, Howard, & Safford, 2010), but much knowledge and awareness of the stressfulness of stroke-related patient problems is not given attention. A little is known about the perceived problems and difficulties that stroke caregivers' experience. Many stroke survivors experience long-term impairments in physical, psychosocial, and cognitive functions that are formidable challenges to family caregivers (Haley et al., 2009). Caregiving demands in the home can place care recipients at risk for subsequent institutionalization. Caregivers of stroke survivors tend to have elevated levels of depression during both acute and chronic phases of care (Powers et al., 2018).

Recent health policy is shifting its focus from professional institution care to informal/home-based care (LeSeure & Chongkham-ang, 2015). An escalating trend is the early discharge of hospital patients. Having a high and continuous growth in the percentage of the elderly group, associated with an increased prevalence of chronic diseases has made family members and informal/home-based persons to have a form of substantial part of the care system (LeSeure & Chongkham-ang, 2015).

A study by Marsella (2009), has shown that informal caregivers already provide an average of 55% of the care needed. Caregivers play an important role throughout the post-stroke recovery process starting from day one. A caregiver can be a family member, friend, neighbour and/or an official/unofficial healthcare professional. Caring for stroke survivors can cause high levels of emotional, mental, and physical stress for both the stroke survivor and caregiver. In addition to distress, disruption of employment and family life makes caregiving very challenging. Caregivers can promote positive post-stroke recovery outcomes; however, they need to care for themselves as well (Caregiving for persons who have had a stroke differs from caregiving related to other chronic conditions, such as Alzheimer's Disease or cancer (Glasdam, Timm, & Vittrup, 2010). In other chronic conditions, caregiving may start and increase gradually, which may allow for adaptation to caregiving. However, in the case of stroke, caregiving begins suddenly and does not allow family members sufficient time to prepare for the complex responsibilities of caregiving. Patients with stroke with residual functional limitation typically transition from being cared for by formal caregivers in acute care and inpatient rehabilitation- 24 hours a day, 7 days a week- to relying fully on informal caregivers (most often a spouse or adult child). Even if the caregiver has had previous experience caring for individuals with disabilities, the demands and vigilance required for adequate care at home are often overwhelming and exhausting (Lutz, Young, Cox, Martz & Creasy, 2011).

In addition, the duration of hospital stays for persons who have had a stroke has significantly decreased in the last few years (Hall, Levant, & DeFrances, 2012; Morris et al., 2014), which consequently increases the burden for caregivers who begin to take care of their loved ones very soon after the stroke event (Lutz, et al., 2011). Caregivers of patients with stroke have been found to have poor quality of life, and frequently develop depression, anxiety, sleep disorders and health problems (McCarthy, Powers, & Lyons, 2011). A large proportion of stroke survivors are therefore dependent on family caregivers who must assume multiple responsibilities, and this can lead to frustration, depression and other forms of stress, particularly with those tasks that are most time-consuming (Hayder & Schnepp, 2008; Tseng, Huang, Yu, & Lou, 2015).

Support from family or informal caregivers is important in meeting the needs of the majority of survivors of stroke, and frequently involves the provision of practical help such as assistance with activities of daily living (ADLs) and emotional support (Sumathipala, Radcliffe & Sadler, 2011). The use of informal support such as family and friends have also been reported as an invaluable and key component in facilitating recovery following stroke

(Ch'ng & French, 2008). However, this can be at a significant personal and financial cost to caregivers. For example, caregiver time costs have been estimated to be between 14% and 23% of the lifetime cost of a first-ever stroke or AUS$42.5 million (replacement cost approach), with most of this care (90%) provided during caregiver's leisure time (Turner, Fleming & Ownsworth, 2011). Primary caregivers have also been reported to spend a median of 17–32 hours a week performing caregiver-related tasks, such as assistance with self-care, driving the survivor to appointments or other community-based activities, or performing domestic duties previously performed by the survivor (Turner et al, 2011). Personal costs or consequences frequently experienced by caregivers include impacts on quality of life (Tooth, McKenna & Barnett, 2005) as well as increased frequency of anxiety and depression compared to those not in caregiver roles (Denno, Gillard & Graham, 2013). For the caregiver, this can also have detrimental effects on relationships both inside and outside the family and their ability to participate in work and leisure activities (El Masry, Mullan, & Hackett, 2013).

In the word of long-term services and supports policies and programs, caregiving tends to be thought of as a dichotomy of family care versus paid care, with little coordination across programs for both family caregivers and professional (paid) caregivers (Seavey, 2005). However, both family and paid caregivers are vital to ensuring access to quality service and supports for people of all ages with disability/illness, and both groups experience similar rewards as well as challenges (Nortey, Aryitey, Aikins, Amendah & Nonvignon, 2017). In the western world, home care agencies hire, train, supervise, pay and are responsible for services provided by caregivers in people's homes (Seavey, 2005). However, family caregiving duties in Ghana are often unremunerated and their care-related economic burden is often overlooked (Nortey et al., 2017).

Statement of the Problem

Descriptions of the experience of stroke caregivers have focused on specific experiences and populations and have considered varied time intervals from the initiation of caregiving. Studies of specific experiences have investigated the caregiver's experience of the patient's transition from hospital to home (Lutz et al., 2011; Plank, Mazzoni, & Cavada, 2012) and the experience of caregivers during the acute phase of the stroke (Gustafsson & Bootle, 2013; Hunt & Smith, 2004; Wallengren, Friberg, & Segesten, 2008). Most Western Studies focused on specific populations of stroke caregivers have been conducted on female caregivers (Saban & Hogan, 2012) and older caregivers (Gosman-Hedstrom & Dahlin-Ivanoff, 2012). However, their studies were gender and age biased where men and younger caregivers were not considered. Also, researchers often focus on specific caregiver burden and also certain psychological or stressful problems that caregivers may encounter (Cameron, et al., 2006).

During the period leading up to and including the stroke survivors' discharge, the informal caregiver will face immense uncertainties and new challenges. The caregiver must learn to cope with their loved ones' stroke, their concurrent grief, and an uncertain future. Thus, the sudden need to care for a stroke survivor can be emotionally difficult and physically challenging for an informal caregiver (Cameron et al., 2006). Caregivers are often unsure of their new role and are unfamiliar with the disease, its progression, and the kinds of supports that are available to them. Caregivers who lack accurate information on how to care adequately for a stroke survivor are likely to have more negative experiences due to nature of the patient's condition and inability to deal effectively with changes in mood, behavior and personality of the stroke patient.

Most studies on stroke caregivers conducted in Ghana were done in Accra and Kumasi Metropolis. These studies touched on some aspects of caregivers' experiences without looking at the total experiences of caregivers in the country. For example, a study conducted by Sanuade (2016) focused on the burden of stroke in Ghana. Although the researcher touched on prevalence and caregiving, he did not focus much on the experiences of caregivers. Another study conducted by Boakye, Nsiah, Bello, and Quartey (2017) also focused on the burden of caregivers and quality of life.

It appears that most of the studies done in Ghana looked at specific burdens and not total experiences of caregivers of patients with stroke. Due to the growing elderly population, the high cost of care in Ghana and low coverage of the National Health Insurance Scheme, demand for family caregiving has become more imperative in Ghana than ever before. Many caregivers experience high burdens, yet literature on caregiving in Ghana is lacking (Sanuade & Boatemaa, 2015).

On this premis that this study seeks to describe the lived experiences of stroke caregivers in Cape Coast Metropolis (CCM).

Purpose of the Study

The main purpose of this study is to examine informal caregivers' experiences in taking care of persons with stroke. Specifically, it is to investigate:

1. The experiences of informal caregivers of patients with stroke in Cape Coast Metropolis (CCM).
2. The various ways in which informal caregivers of patients with stroke cope with their experiences in caring for patients with stroke in CCM.
3. How caregiving affects informal caregivers of patients with stroke in CCM.

Research Questions

The following research questions were designed to guide the study.

1. What are the experiences of informal caregivers of patients with stroke in Cape Coast Metropolis (CCM)?
2. What are the various ways in which informal caregivers of patients with stroke cope with their experiences in caring for patients with stroke in CCM?
3. How does caregiving affect informal caregivers of patients with stroke in CCM?

Significance of the Study

The study will inform professionals and stakeholders such as clinical psychologist, medical practitioners and family relatives on the various caregiver experiences and how they affect their personal lives. This will go a long way to provide information on how to help informal caregivers cope with their experiences and to be integrated properly.

It is imperative to assess caregiver experiences and how they can be integrated into society to improve the physical and mental health of both caregivers and patients.

It also adds to the existing literature on caregiver experiences in caring for patients with stroke. This is mainly because literature in the area is limited; and thus, this study will be relevant in increasing literature for future studies.

Delimitations

The study was delimited to Cape Coast Metropolis; hence, findings may not be applicable to other contexts. Also, though other studies have focused on caregiver's burden and the impact on patient recovery from conditions such as cancer and other mental health problems, this study focused only on caregiver experiences in caring for patients with stroke, meaning it has nothing to do with patients' recovery. Participants were selected from the Cape Coast Teaching Hospital (CCTH) and the University of Cape Coast Hospital.

Limitations

Due to the fact that the study was a phenomenological study, responses of the participants may not have been objective, but rather subjective since some participants may have exaggerated their responses. Biases associated with responding to questions by some the participants could not be ruled out completely and that may likely have affected the validity of the research finding.

Operational Definition of Terms

Caregiver: A person who takes daily care of a patient with stroke.

Informal caregivers: A person offering care to an individual with stroke

Experiences: An event(s) or occurrence(s) which leave(s) an impression.

Care: The provision of what is necessary for the health of a person.

Organization of the Study

The study was divided into five main chapters. Chapter one dealt with the introduction, which included the background, the problem and scope of the study. Chapter two dealt with the review of related literature. It included what authors from various disciplines have written about caregivers' experiences and how they influence the recovery of patients with stroke. It also presented theoretical, conceptual and empirical review of literature that backs this study. Chapter three presented the research methodology used for the study. This consisted of the research design, population, sample and sampling procedure, research instruments, and data collection procedure and data analysis. The analysis of the data collected from the field is found in chapter four. This is where the data gathered was subjected to synthesis, analysis and discussion. Chapter five which is the final chapter presented the summary, conclusions and recommendations based on the research findings.

CHAPTER TWO

LITERATURE REVIEW

This study focuses on exploring caregiver experiences in caring for stroke patients. The previous chapter gave an in-depth description of the phenomenon under study and also gave justification for the need to conduct this study. The purpose of this chapter is to discuss the theoretical, conceptual and empirical basis of the study. This review is organized under three main headings: theoretical review, conceptual review and empirical review.

The theoretical review discusses the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), and the Middle Range Theory of Caregiver Stress (Tsai, 2003). The conceptual review looks at the concept of stroke, caregiving and coping strategies, while the empirical review looks at experiences of caregivers of patients with stroke in the areas of coping mechanisms employed by caregivers of patients with stroke, and the effect of caregiving on caregivers.

Theoretical Review

In this section, theories that are deemed relevant for this study are reviewed and explained. These theories include the Transactional theory of stress and coping by Lazarus and Folkman (1984) and Middle range theory of caregiver stress by Tsai (2003).

Transactional Theory of Stress and Coping

The overarching theoretical framework for this research is the Transactional theory of stress and coping (Lazarus & Folkman, 1984). This theory suggests that a stress reaction occurs under situations where the demands of the environment exceed the individual’s resources. In the presence of a threat, the individual will engage in both primary and secondary appraisals of the perceived threat (Wilborn-lee, 2015). Primary appraisal is set into action when the individual appraises the encounter as harmful, a threat, or a challenge. The person makes a secondary appraisal or judgment regarding his or her available coping resources for managing the potential threat. Stress is the interaction between the person and the environment that is burdening to the person's coping resources or taxing to the extent that it threatens his or her physical and psychological well-being (Wilborn-lee, 2015). The individual makes a cognitive assessment of his or her ability to cope with the situation. In turn, the individual copes with the stress by engaging in cognitive and behavioural efforts to manage the physical and emotional demands that are beyond the individual's resources to manage the stressful event. The more negative or threatening the individual perceives the stressful situation; the more unfavourable the stress reaction. For example, the demands of caregiving can create stress that involves an increased number of caregiving activities that conflict with other responsibilities. The caregiving demands can cause a loss of opportunity to regenerate from caregiving activities, obtain adequate rest, or engage in social activities. The caregiver’s stress may be exacerbated by inadequate caregiving skills to care for the patient and inadequate coping strategies to manage the caregiving stresses (Pearlin, Mullan, Semple, & Skaff, 1990). Therefore, stress will become a negative self-reinforcing process.

The transactional theory of stress and coping has been fundamental in conceptualizing the dynamic and interactional process of caregiver stress. Researchers have expanded Lazarus and Folkman’s (1984) Transactional theory of stress and coping to articulate the occurrence of stress among caregivers of individuals with chronic health conditions (Pearlin et al., 1990). Various formulations of the stress process have been created to examine the influence of stress on informal caregiving (Pearlin et al., 1990). In Lazarus and Folkman’s transactional model of stress, “transaction” implies a process in which stress is not caused by personal or environmental factors; rather, it reflects conjunction of both factors (Lazarus, 1990). This model demonstrates that the stress relationship is consistently changing because of continual interaction between personal and environmental factors, which have a dynamic, mutually reciprocal, bidirectional relationship. In addition, cognitive appraisal processes provide a common pathway through which personal and environmental variables change the psychological response and as a result, emotions and their biological modification follow. Thus, this model implicates a biopsychosocial model of stress. Therefore, the key premise of Lazarus and Folkman’s transactional model is that appraisal (psychological distress) and coping strategies (cognitive coping) mediate the relationship between stressor (caregiving) and the individual’s stress outcomes (stroke patient).

In summary, based on Lazarus and Folkman's (1984) Transactional Theory of Stress and Coping, researchers have formulated theories on the nature, cause, and management of stress among informal caregivers. This theory gives a clear explanation and backing to the various experiences of caregivers who care for not only the chronically ill but also patients with other health conditions that require attention and continuous care.

Application of the Transactional Theory of Stress and Coping

According to Lazarus and Folkman's (1984) Transactional Theory of Stress and Coping, stress is a product of a transaction between a person and his environment. This approach conceptualises coping as the cognitive and behavioural efforts of the individual to manage (reduce, minimize, master or tolerate) specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. The demands of caregiving can break down a person's coping ability as well as cause both physical and psychological harm to the caregiver. This emanates from the fact that caregiving can lead to either a reduction or loss of opportunity to regenerate from caregiving activities, receive sufficient rest, and also engage in social activities. The demands of caregiving could be more than a caregiver's coping strategy to manage a patient with stroke. A family caregiver who is the sole provider for the patient as well as the family experiences much more burden. With no financial support for that caregiver, caregiving could be very stressful.

Middle-range theory of Caregiver stress

The Middle range theory developed by Tsai (2003), aims to predict caregiver stress and its outcomes from demographic characteristics, the objective burden in caregiving, stressful life events, social support and social roles. This theory has four assumptions of the caregiver which include that the caregiver can respond to environmental change; the caregivers' perceptions will determine how they will respond to the environmental stimuli; the caregivers' adaptation is a function of their environmental stimuli and adaptation level; and lastly the caregivers' effectors are results of chronic caregiving such examples include marital satisfaction and self-esteem. The structure of the Middle-range theory is explained in three sections: the input, control and output section. These sections are further explained into details:

Input section

The input section of is made up of an objective burden that is a focal stimulus of the caregivers' situation which means that it is the tasks or responsibilities that are associated with the caregiving of a person with a chronic condition. These responsibilities may include hours of care or the management of care arrangement thus initiating coping mechanisms. These responsibilities may interfere with other aspects of the caregiver's life which include interpersonal relationships or finances in which are defined as contextual stimuli. Contextual stimuli also include social supports, social roles and stressful life events. Stressful life events are defined in this theory as changes in living conditions that challenge the individual and result in distress. When a caregiver has unresolved stressful life events, they will experience higher levels of stress than caregivers who do not (Tsai, 2003).

Another aspect that composes the contextual stimuli is social support. This theory views social support as how the individual (caregiver) perceives that they are cared and loved, respected and involved in mutual obligations within their network. The theory of caregiver stress proposes that if the quality of social support is seen to be high, that can be a buffer to the caregiver's stressors by increasing their abilities to cope with the stress in an effective manner. This can enhance the well-being of the caregiver. The last aspect that composes the contextual stimuli is the social role. The social role in this theory is defined as the function in which the caregiver has towards other individuals in other aspects of their life such as being a parent, sister, or supervisor. This theory suggests that the multiple roles that a caregiver has, the better mentally and physically equipped they are at handling stress. However, if the caregiver was not married, was unemployed or had no children that this was not true. Multiple social roles give caregivers an avenue for them to express their feelings and vent whereas a limited number of roles may not; thus the more roles a caregiver tends to possess, the better they are at handling stress (Tsai).

Residual stimuli include the caregiver's race, age, gender and relationship to the caregiving recipient. Residual stimuli have their effects on the objective burden through the individual's cognitive appraisal of the stress that is influenced by many factors such as cultural beliefs and values. This theory of caregiving has defined race as a group of individuals that share a common relationship through common descent, by blood or by heredity. The race is one common indicator of culture and influence on personal beliefs and values. Stress may be viewed differently by one culture versus another and better equipped to handle it.

Age is another characteristic that composes residual stimuli. Age is defined in this theory as the caregiver's chronological age that includes both the developmental stage as well as the length of time since birth. As one age, it can change an individual's perspective on many things. The theory of caregiving explains that younger caregivers will experience more stress than older caregivers. Another reason could be that older caregivers have more life experiences and have had more opportunities to use and fine-tune their coping skills.

Gender is another aspect that influences an individual's cognitive appraisal of stress. Gender is defined and the functional and structural difference between men and women. The theory of caregiving hypothesizes that women will experience higher levels of stress than men do. This may be because more women than men are more likely to become major caregivers than men and are more involved with caregiving activities.

Lastly, the relationship of the caregiver to the individual receiving the care can influence stress. The relationship is defined as individuals being related either by blood, marriage, adoption or by other means regardless of formalities. The theory of caregiving proposes that the relationship between the caregiver and the individual receiving care can influence the stress level of the caregiver(Tsai, 2003).

Control Process

The Control process of Tsai's theory links the Input or Environmental Stimuli to the output section or adaptation responses through perceived caregiver stress and depression. The control process is the link that encompasses the coping mechanisms of the caregivers. Depression is also seen as a coping mechanism in this theory as well as being associated with the adaptive modes to different degrees.

Output Section

The final section which is the Output portion of Tsai's Theory of Caregiver Stress is compiled of the responses that the caregivers will experience stress. These responses fall into four categories that include physical function, self-esteem/mastery, role enjoyment, and marital Satisfaction. To begin with, the physical function response in the output aspect is manifested by physiological functions such as activity, rest, nutrition, and neurological functioning. If the physical function of an individual is not operating appropriately, then this indicates an ineffective response to the stress. If physical function is maintained, then the individual is demonstrating an adaptive response to the stress. In these scenarios, the individual represents the caregiver.

The second category that is included in the structure of this theory is self-esteem/mastery. In the theory of caregiver stress, self-esteem is defined as the perception of how important the caregiver is in relation to themselves and to others. This theory states that low self-esteem is indicative of a maladaptive response to stress as where high self-esteem is an adaptive response to the stress. Mastery is also included in this category and is defined by the ability of the caregiver to control things in life. Thus low mastery represents an ineffective response to stress while high mastery represents an adaptive response.

The third category that is described in this theory of caregiver stress is role enjoyment. Role enjoyment is described in this theory as the" caregiver's expressive behavior in their major social role, may be used as role function". If the adaptive responses fail, then the caregiver will demonstrate low role enjoyment however if adaptive responses are adequate then the caregiver will demonstrate high role enjoyment. The last aspect of the adaptive modes of the theory of caregiver stress is marital satisfaction. Marital satisfaction is seen as the caregiver's most important relationship with their significant other in which they are loved, valued and respected. If marital satisfaction is low, then this reflects a maladaptive response to stress. If there are high levels of marital satisfaction, then there is an effective adaptive response.

The Middle range theory was modified from the Roy Adaptation Model in order to offer a better applicable model for caregivers of chronic ill relatives. This theory is broken down in structure and identifies the objective burden being the most influential stimulus for caregiver stress. The theory proposes that, if the caregiver perceives high stress, he or she will experience ineffective responses in the four adaptive modes in the output section of the theory structure. Depression can either be a direct outcome of caregivers' stress or may influence the stress on the four adaptive modes.

In summary, a caregiver's perception concerning his/her new role as a caregiver could cause stress for the caregiver. If a caregiver feels loved, respected, and is involved in mutual obligations within their network, it serves as a buffer to the caregiver's stressors by increasing his/her ability to cope with the stress in an effective manner. Caring for a stroke patient may require that a caregiver spends more time with the patient as he/she may need help with daily living such as bathing, dressing, eating and using the toilet. This could be quite exhausting for the caregiver. If the caregiver perceives his or her efforts not appreciated, this could affect his/her ability to cope with the stress of caring for the stroke patient which could invariably affect the care being provided for the stroke patient.

Based on this theory, participants in this study who have friends, family members, as well as the church supporting them will be able to cope better in their caregiving role than those who perform the caregiving role alone without support.

Conceptual Review

The conceptual review provides information on the various concepts under study. It considers definitional issues and explanation, characteristics, causes and risk factors, effects, treatment and management of stroke, and also explain the main variables in the study.

Stroke

Stroke, a form of cardiovascular disease is seen as the most common serious neurological disorder in the world (Robinson, 1998). It is sometimes also referred to as cerebrovascular accident (CVA), cardiovascular injury (CVI), brain attack or apoplexy. To better understand the effects of stroke for the life-world of stroke families, knowledge about stroke grounded in natural sciences provides important background. The brain cells need continuous supply of blood, oxygen, and glucose (blood sugar) to function properly (World Health Organization, 2007). Unfortunately, this supply can be interrupted, caused by a blockage, infarct or a rupture in a vessel supplying blood to the brain (Indredavik, 2004). Depending on the severity of the impairment, the functioning of the brain may be affected temporarily or permanently.

Stroke is the second leading cause of death and the third leading cause of disability worldwide (Feigin et al., 2015; Murray et al., 2012). It is one of the leading causes of death in industrialized countries (Go, Mozaffarian, Roger, Benjamin, Berry & Blaha, 2014). Globally as per an estimate of WHO, every year about 15 million of the world population suffers from stroke out of which 33 % (5 million) become disabled permanently. Of the people who survive stroke, only 10% are able to recover almost completely, 31 % are completely dependent, 71% have problems with speech and 20% are partially dependent regarding mobilization (Mol & Baker, 1991). Again, estimates suggest that 8% of all first-ever strokes occur in Africa and that 5% of the 30 million stroke survivors worldwide live in Africa. The prevalence of stroke might increase in the near future because of changes in exposure to major stroke risk factors and improved prevention and control of infectious diseases (WHO, 2010). Sadly, a scarcity of data from stroke studies in Africa (Agyemang et al., 2012) severely limits our understanding of the burden of stroke in Africa.

In low- and middle-income countries (LMICs), stroke incidence is increasing and research has precisely shown that stroke mortality will triple in Latin America, the Middle East, and subSaharan Africa between 2002 and 2020 (Beaglehole & Yach, 2003; WHO, 2004). Community-based studies in sub-Saharan Africa (SSA) show that stroke is the cause of 5-10% of all deaths partly because of inadequate health systems and increasing rates of hypertension (Agyemang et al., 2012; Van Der Sande et al., 2005). Also, the impact of stroke is estimated to go up in this region as a result of urbanization, poor socioeconomic status and change in the demographic structure of the population from young to an ageing population. By 2025, it is anticipated that about half of the populations in Sub-Saharan Africa will be living in urban areas and the number of people who are aged 60 years and above will be more than twice over in countries like Ghana, Cameroon, Democratic Republic of Congo, and Mozambique (Kengne & Anders, 2006; Help Age International, 2015; Haub, 2012). This projected demographic transition may increase stroke-induced disability in the region in the near future if serious measures are not put in place.

In Ghana, stroke is among the top three causes of death and constitutes more than one-tenth of all causes of deaths in the country (Donkor et al., 2014). Stroke moved from being the 11th cause of premature death in 1990 to the 7th cause of premature death in 2010 (Feigin et al., 2015). Further, stroke is the leading cause of premature death among the non-communicable diseases between 1990 and 2010. There is also a high case fatality rate of stroke in the country and between 60% and 90% of stroke in the country are haemorrhagic. The main risk factors of stroke in Ghana are hypertension, diabetes, obesity, ageing and plasma level of homocysteine (Hcy) (Agyemang et al., 2012; Sanuade & Agyemang, 2013).

Stroke is a recurrent cause of admission to hospitals in Ghana, and causes a high level of disability which poses a huge burden on the stroke survivors and their families, healthcare staff, and the country’s health system (Sanuade & Agyemang, 2013). According to Aikins (2007), stroke is a developmental issue because it affects the elderly, young people and poor communities are disproportionately affected. Also, it can push individuals and households further into poverty and drain government health budget. Notwithstanding, stroke is not on the list of priority health interventions outlined by Ghana's Ministry of Health and stroke burden has been under-researched and under-funded. Hence, there is no national action plan on stroke in Ghana. A study by Birabi, Oke, Dienye and Okafor (2012) have shown that many of the people diagnosed with stroke die in the first year after the diagnosis. Some of the reasons for this include: lack of a good follow-up plan after the stroke survivors are discharged from the hospitals; lack of proper caregiving; high cost of stroke management; inadequate knowledge of the disease (Donkor et al., 2014), and; psychosocial conditions of stroke survivors and family caregivers (Carney & Freedland, 2002).

It is a serious neurological event primarily affecting older people, and its consequences include mobility problems, cognitive impairment, urinary/faecal incontinence, speech and communication difficulties, and personality changes that often require lifelong assistance hence, the need for a caregiver (Lloyd-Jones et al., 2010; Saban & Hogan, 2012). Incidence of stroke is higher in men (30-80%) as against women, and blacks have a 50-130% higher incidence than whites.

The incidence of stroke, a cardinal complication of cardiovascular risk factors, appears to be rising in Africa and other low- and middle-income country (LMIC) settings (Moran et al., 2010) and approximately 87% of all deaths by stroke occur in these countries (Strong, Mathers & Bonita, 2007). A retrospective study of in-patients with stroke at the Komfo Anokye Teaching Hospital over a two year period yielded a mean age of 63.7 years (Agyemang et al, 2012). Stroke accounts for approximately 4% of the total annual National Health Service expenditure in the United Kingdom (Mc Govern & Rudd, 2003), costs over $1.3 billion per annum in Australia (National Stroke Foundation, 2005) and $34 billion annually in the United States (Mozaffarian et al, 2015).

Risk Factors of Stroke

Several factors can increase a person's risk for stroke, these include modifiable and non-modifiable risk factors. Modifiable risk factors are of great importance, as intervention approaches aimed at reducing these factors can later reduce the risk of stroke (Roger et al., 2012). Non-modifiable risk factors include age, sex, race/ethnicity and family history (Pathak, Kanth & Pant, 2006). Modifiable risk factors include hypertension, diabetes mellitus, hyperlipidemia and unhealthy habits such as; smoking, drinking too much alcohol, not getting enough exercise and having high cholesterol, (National Stroke Association, 2018).

Hypertension is the most important modifiable risk factor for stroke, with a strong, direct, linear, and continuous relationship between blood pressure and stroke risk (Howard et al., 2016). Maintaining a blood pressure of 130/90mmHg or less is desirable in an average population. High blood pressure damages the arteries, putting a person at risk for haemorrhages or blockages in the blood vessels supplying your brain (Lindholm, 2002).

Diabetes mellitus (DM), commonly known as diabetes, is a group of metabolic disorders characterized by high blood sugar levels over a prolonged period. Diabetes mellitus is an independent risk factor for stroke with a 2-fold increased risk in stroke for diabetic patients (Shou, Zhou, Zhu & Zhang, 2015). Uncontrolled blood sugar levels have been shown to damage blood vessels, particularly capillaries. It causes destructive changes not only in the body but to the brain as well (Vaidya, Gangan & Sheehan, 2015).

High cholesterol increases the risk of blocked arteries. If any artery leading to the brain becomes blocked, a stroke can result (Amarenco, Labreuche, & Touboul, 2008)

Classification and Pathophysiology of Stroke

Strokes can be classified into two major types: ischemic and hemorrhagic (National Institute of Neurological Disorders and Stroke (2015). Ischemic strokes are caused by the disruption of the blood supply to the brain, while hemorrhagic strokes result from the rupture of a blood vessel or an abnormal vascular structure. About 87% of strokes are ischemic, the rest being hemorrhagic (Donnan, Fisher, Macleod & Davis, 2008). In a study involving 39484 post-stroke patients Andersen, Olsen, Dehlendorff and Kammersgaard (2009) reported nearly a 90% ischemic stroke incidence as against hemorrhagic stroke.

Ischemic stroke occurs due to a loss of blood supply to a portion of the brain, initiating the ischemic cascade (Deb, Sharma & Hassan 2010). Brain tissue ceases to function if deprived of oxygen for more than 60 to 90 seconds, and after approximately three hours will suffer irreversible injury possibly leading to death of the tissue (infarction). Atherosclerosis may disrupt the blood supply to a portion of the brain by constricting the lumen of blood vessels leading to a reduction of blood flow, by instigating the formation of blood clots within the vessel or by releasing bursts of small emboli through the disintegration of atherosclerotic plaques (Snell, 2006).

At the cellular level of the brain, ischemia has the following effects:

1. Reduction of cellular energy reserve due to mitochondrial dysfunction and subsequent cell death by apoptosis (Karaszewski et al., 2009).

2. Rapid engorgement of neurons and glia due to loss of membrane ion pump function (Deb et al, 2010).
3. Release of excitatory neurotransmitters which further deplete cell energy and activation of deleterious enzyme systems that lead to cell death (Nakanishi et al., 2009).

In addition to the direct harmful effects of ischemia on brain cells, it also has an effect on the overall structural integrity of the brain. The discharge of proteases causes the collapse of blood-brain barrier which eventually causes cerebral edema, damaging the structural integrity of the brain (Adibhatla & Hatcher, 2008).

Hemorrhagic strokes arise from bleeding within the parenchyma of the brain or intra-ventricular spaces, and are classified based on their underlying pathology. Its harmful effects are a resultant of;

1. Hypoxia due to disrupted blood supply.
2. Direct irritant effect of unconfined blood on brain parenchyma and vascular structures.
3. Increased intracranial pressure (ICP) due to continued bleeding.

Some examples of hemorrhagic stroke are hypertensive hemorrhage, ruptured aneurysm, ruptured arteriovenous fistula, drug induced bleeding and transformation of prior ischemic infarction (Longo, 2012). They result in direct brain tissue injury by causing compression of surrounding tissue. This direct injury is further exacerbated by expanding hematoma or hematomas (Eastwood, Engelter, MacFall, Delong, & Provenzale, 2003). Additionally, the pressure leads to a loss of blood supply to adjacent tissue with subsequent infarction. The blood released by brain hemorrhage tends to have direct noxious effects on brain tissue and its associated blood vessels (Wang, 2010).

Signs and symptoms of stroke

The National Institute of Neurological Disorders and Stroke (NINDS, 2015) lists the signs and symptoms of an acute stroke as follows

1. Sudden numbness or weakness around the face, arm or leg, usually on one half of the body.
2. Sudden confusion, difficulties in speaking or perceiving speech.
3. Sudden difficulty with vision in one eye or both.
4. Difficulties with walking, dizziness, lack of coordination or loss of balance.
5. Sudden severe headache with no known cause.

Other signs and symptoms include double vision, drowsiness, nausea and vomiting.

Stroke Management

Management of stroke involves a multidisciplinary team approach (Clarke, 2010) and consist of stroke physicians, physiotherapists, occupational therapists, speech and language therapists, nurses, healthcare assistants, dieticians, clinical psychologists, social workers and case/disability managers. Reported benefits of effective multidisciplinary team work include more patient-centered decision making (McCallin & BA, 2009), a lessening in the fragmentation of care (Kilbride, Meyer, Flatley & Perry 2005), increased staff satisfaction (Clarke, 2010) as well as more effective and efficient use of resources.

Treatment Modalities of Stroke

Emergency treatment depends on the type of stroke. To treat an ischemic stroke, doctors must quickly restore blood flow to your brain. The treatment for ischemic stroke is clot removal. Doctors can accomplish this with medication and mechanical treatments (Lisa, Jughters, & Kerckhofs, 2013).

Medication treatment with Alteplase IV r-tPA

Considered the gold standard, tissue plasminogen activator – r-tPA (otherwise known as alteplase) is approved by the Food and Drug Administration to treat ischemic stroke, which is caused when a vessel supplying blood to the brain is blocked. Doctors administer Alteplase IV r-tPA through an IV in the arm, dissolving the clot and improving blood flow to the part of the brain being deprived (Lewandowski et al., 1999).

Mechanical Treatment to Remove the Clot

An endovascular procedure or a mechanical thrombectomy is a strongly recommended option to remove a clot in eligible patients with a large vessel occlusion or LVO. In this procedure, doctors use a wire-cage device called a stent retriever. They thread a catheter through an artery in the groin up to the blocked artery in the brain. The stent opens and grabs the clot. Special suction tubes may also remove the clot. The procedure should be done within six hours of the onset of acute stroke symptoms. It can benefit patients under certain conditions if done within 24 hours of onset (Bose et al., 2008)

Hemorrhagic stroke treatment

Emergency treatment of hemorrhagic stroke focuses on controlling bleeding and reducing pressure in the brain. One might also need surgery to help reduce future risk (Rasler, 2007).

Mechanical Treatment

A small tube called a catheter can sometimes be threaded up through a major artery in an arm or leg and guided into the brain tissue, allowing the surgeon to use cameras to see the problem. Once the catheter is guided to the source of the bleeding, it deposits a mechanical agent, such as a coil, to prevent further rupture. This type of procedure is endovascular, meaning that the surgeon gains access through the vascular system, making it less invasive than conventional surgical treatment (Heck, & Brown, 2015).

Stroke Recovery and Rehabilitation

After emergency treatment, stroke care focuses on helping patients recover as much function as possible and return to independent living. The impact of stroke depends on the area of the brain involved and the amount of tissue damaged. If the stroke affected the right side of the brain, movement and sensation on the left side of the body may be affected. If the stroke damaged the brain tissue on the left side of the brain, movement and sensation on the right side of your body may be affected. Brain damage to the left side of the brain may cause speech and language disorders. In addition, if this is as a result of stroke, you may have problems with breathing, swallowing, balancing and vision (Harvey, Macko, Stein, Winstein, & Zorowitz, 2008).

Most stroke survivors receive treatment in a rehabilitation program. A doctor will recommend the most rigorous therapy program a patient can handle based on his/her age, overall health and degree of disability from the stroke. A doctor will take into consideration the lifestyle, interests and priorities, and the availability of family members or other caregivers. The rehabilitation program may begin before the patient leaves the hospital. After discharge, the patient might continue the program in a rehabilitation unit of the same hospital, another rehabilitation unit or skilled nursing facility, an outpatient unit, or his/her home (Langhorne, Bernhardt, & Kwakkel, 2011)

Caregiving

Caregiving refers to the act of looking after a child, sick, elderly, chronically ill or disabled person. An informal caregiver is anyone who provides care without pay and who usually has personal ties to the care recipient and helps them with activities of daily living (Larsen & Lubkin, 2006). Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder. Typical duties of caregivers might include taking care of someone who has a chronic illness or disease; managing medications or talking to doctors and nurses on someone's behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone.

Demographically, 66 percent of family caregivers are women, and remarkably, 65 percent of care recipients are women (National Family Caregivers Association, 2012). In addition, the typical caregiver spends approximately 20 hours per week in caregiving duties (Pandya, 2012). Caregiving for a loved one with a chronic condition can be very fulfilling, as individuals often move closer together when challenges arise. However, caregiving can also be daunting, emotionally and physically challenging, and isolating. At times caregiving results in caregiver burden, which Buhse (2008), referred to as a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience.

The challenges of caregiving are widespread and encompass much more than the care of the recipient. One of these challenges is isolation. Caregivers can often feel cut off from the outside world. So much time and energy are spent caring for someone else, caregivers often don't have time to take care of themselves. Another challenge of caregiving is stress. Taking care of a loved one and being responsible for their health can be very stressful. There are a lot of tasks to juggle, from managing medications to helping with getting dressed or bathing. All these tend to take a toll on the caregiver. Financial burden also tends to be another challenge to caregiving. Informal care of persons with serious chronic conditions such as stroke provides many benefits to patients but can be costly to family members and friends both in monetary terms and in terms of the value of time spent in caregiving and learning new caregiving skills (Carmichael & Charles, 2003). Researchers have found that caregiving leads to reduced working hours or wage penalties (Heitmueller & Inglis, 2007), significant outlays for medical treatment (Grunfeld et al., 2004) as well as other direct costs such as hiring of home health workers.

Despite the challenges in caregiving, it also has benefits not only to the recipient, but also to those who provide the care (Wagner, Das, Bigatti & Storniolo, 2011). One of these benefits is a sense of accomplishment. Taking care of someone else presents unique challenges and obstacles to overcome. Dealing with the difficult scenarios caregiving presents can be stressful, but working through the tough times can be very rewarding, thereby giving you a sense of accomplishment. No one ever thinks of helping others and bringing joy to their lives as a waste of time. Additionally, caring for others makes caregivers feel loved and build strong Relationships with the people they provide care for. The act of caring for another is so powerful because it creates deeper bonds as individuals lean on each other for emotional support. Also, caring for others gives caregivers a sense of value and experience personal growth. Caregivers gain a variety of skills from their experiences. Taking care of someone else forces caregivers to learn about the proper ways to do things, whether it's preparing finances, or planning for the future. It also teaches important virtues such as patience, understanding and loyalty that benefit them in both their personal and professional lives. Lastly, caring for others provides benefits that most people often don't experience at their day jobs. Everyone has a desire to feel needed and the role of caregiver does that, which is a great feeling. It also gives greater meaning and purpose to the lives of caregivers, helping them to refocus on more important things in life – their relationships with the people they care about (Elmore, 2014)

Types of Caregivers

There are two types of caregivers; formal and informal caregivers. Formal caregivers are the trained caregivers with professional qualifications for that kind of work and usually are paid for services rendered. On the other hand, informal caregivers are not paid or trained by statutory bodies (Smith, Lawrence, Kerr, Langhorne & Lees 2004). Informal caregivers refer to family members such as spouses or their offspring or friends who take the role of looking after someone when they are afflicted with some ailment (Blake, Lincoln & Clarke, 2003). This study will solely concentrate on informal caregivers.

Role of Informal Caregivers

Informal caregivers more often than not are responsible for taking care of the patient with stroke after discharge. They play a very important supporting role in the rehabilitation process and it is believed that this role will increase with the growing trend of providing stroke rehabilitation in survivors' own homes once they have been discharged from hospital (Low, Paynee & Roderick, 1999). Caregiving duties can involve administering medicines, assisting with physiotherapy exercises and performing medical procedures with little or no training (Pierce, Steiner, Hicks, & Holzaepfel, 2006). Caregivers often enter into their roles unexpectedly, with little or no preparation (Kerr & Smith, 2001). Such responsibility can be very challenging, affecting the health and psychosocial functioning of the caregiver. The presence of the informal caregivers allows the stroke survivor to be in the community instead of a nursing home (Patel, Knapp, Evans, Perez & Kalra, 2004). It is however important to realise that it is the early period at home after return from hospital and rehabilitation, that feelings of desolation and isolation are usually the strongest among carers (Pierce et al., 2006; Smith et al., 2004). In their efforts to ensure that the person with stroke is taken care of, the impact of that process on the caregivers often results in a burden that can negatively affect the well-being of the caregivers.

Coping

Coping is defined as thoughts and behaviours that people use to manage the internal and external demands of situations that are appraised as stressful (Lazarus & Folkman, 1984). Stroke causes considerable distress in caregivers who are continuously required to deal with the daily care of patients.

Types of Coping Strategies

Coping strategies play a fundamental role in modulating the psychological impact of the disease. Although there is some disagreement about how coping strategies may be categorized (Cooper, Katona, Orrell & Livingston, 2008), coping may be classified into three broad main types, that is, task-focused, emotion-focused, and avoidance-focused strategies (Li, Cooper, Bradley, Shulman & Livingston, 2012). Task-focused coping seeks to actively perform a task that will remove the problem or make the problem better; typically, if the frequency of task-focused coping increases, the distress decreases (Li et al., 2012). Emotion-focused coping seeks to regulate distressing emotions and can include emotional expression, fantasizing, and reflecting on positive or negative thoughts (Bauman, Haaga & Dutton, 2008). Avoidance-focused coping involves avoiding the adverse situation and includes social diversion (Thompson, 2014). According to Thompson, emotion-focused and avoidance-focused coping strategies may be dysfunctional, since they divert from understanding or managing requests, with the consequence of increased psychological distress. This study explored both task-focused and emotion-focused coping strategies as participants in this study made use of the following coping strategies: sleeping, watching television, acceptance, hope in God and self encouragement, patience and tolerance.

Empirical Review

This aspect comprises literature review on experiences of stroke informal caregivers, coping mechanisms employed by informal caregivers of stroke patients, and the effect of caregiving on informal caregivers patients with stroke. It covers studies that other researchers have done in relation.

Experiences of Caregivers of Patients with Stroke

A phenomenological study conducted by Simeone (2016) described the lived experiences of stroke caregivers three months after patients were discharged home from a rehabilitation hospital. A total of 25 participants were purposefully sampled for the study. Thematic analysis of the data gathered revealed seven themes that relate to caregiver experiences. The seven themes that emerged include; deeply changed life; re-appreciation of the relationship with patient and family members; increased workload; difficulties in getting support from the national health-care system; lack of preparation for caregiving; difficulties in coordinating caregiving, family and personal life; relief after patient's recovery. Simeone (2016) concluded that becoming a caregiver of a stroke survivor is a sudden event that marks and profoundly changes the lives of these individuals. Hence their results indicated that caregivers need emotional support, explanations concerning the physical assistance and bureaucratic procedures to be implemented. The researcher also recommended that interventions aimed at improving caregiver knowledge before patient discharge may be very effective in improving caregiver knowledge and in reducing their needs of help from others.

A study by Greenwood, Mackenzie, Cloud and Wilson (2009), found a similar theme emerging, that is caregivers experienced a life change that they referred to as uncertainty. A phenomenological study conducted by Bulley, Shiels, Wilkie and Salisbury (2010) investigated the experiences of nine stroke survivor-caregiver dyads from two to seven years after the stroke who were all married women. An overarching theme emerged, entitled: 'lives turned upside-down', which is similar to a theme in Simeone (2016) study known as "deeply changed life". Hunt and Smith (2004) also conducted a phenomenological study using a sample size of four and found a theme they called "strength of relationships" in stroke caregivers which is also similar to an emerging theme in Simeone (2016) study known as re-appreciation of family relationships. The researcher must be commended on his methodology. However, the sample for this study included mainly female informal caregivers and this aspect may have influenced the experiences reported in the study. This current study will therefore include both male and female informal caregivers in order to ascertain a more indepth and rich experiences from them.

A study conducted by Wigginton (2016) in Kentuckey, described the lived experiences of informal caregivers of chronic stroke patients. Four caregivers of clients with chronic stroke were conveniently sampled for the study. The study utilized a descriptive qualitative method, specifically, transcendental phenomenology. Three themes emerged from the analysis. These are; loss of control, role shift and occupational deprivation. Data collected were analysed using the thematic approach. Evidence also suggests that caring for stroke survivors at home leads to emotional distress and burden in informal caregivers as exhibited by disruption of employment, leisure, social participation and quality of life (Greenwood, Mackenzie, Cloud & Wilson, 2009). The study revealed that caregivers experienced a significant role shift. In the long-term, caregivers experienced their shift into the caregiving role as a loss of free time and control over how they spend their time. Additionally, the study found that the caregivers were deprived of time to engage in valued occupations, specifically for leisure. It was a good attempt by the researcher to describe the lived experiences of informal caregivers. However, this study had a limited sample size with only four participants and all caregivers interviewed were married women. Thus, saturation may not have been reached. This current study will therfore include unmarried females as well as males.

To investigate and understand the experiences of caring for someone after stroke, El Masry (2010) conducted a study at the George Institute for International Health. The study made use of a qualitative research approach, specifically, phenomenology. Twenty informal caregivers participated in the study. A semi-structured interview was used to elicit information from participants. Data analysis and interpretation were primarily thematic (Braun & Clarke, 2006; Willig, 2001), with a generation of an integrative set of themes. The purposive sample of twenty was recruited based on saturation. Five inter-related master themes with various subcategories emerged from the analysis. These are; Relationships and Support, Caregiver Factors, Survivor Factors, External Stressors and Positive Outcomes. The study revealed that stroke caregivers undergo a series of psychological, emotional, interpersonal, social, health and occupational changes as a result of undertaking their role.

The researcher did good work in describing the experiences of caregivers of patients with stroke; however, the sample of caregivers in the study consisted of a small percentage of people who were invited to participate in the study. It is, therefore, possible that the caregivers who volunteered to participate may be different in some way to those that did not participate.

A critical review of the above studies revealed that almost all of them employed phenomenological study and run thematic analysis which might seem much more appropriate. However, the sample sizes were relatively very small; as small as four (4) participants. Again, the studies focused more on female caregivers. Thus this study will try and use a relatively large sample and again include males. The reviewed studies above also showed that there were inconsistencies in the findings. This could have been as a result of differences in the study areas as well as differences in sample sizes.

Coping mechanisms employed by caregivers of patients with stroke

To assess and investigate the caregiver experience of stress and coping, Ye (2016) conducted a study at the University of Texas Health Science Center at Houston. The study made use of descriptive, mixed-method triangulation approach (Cresswell & Plano-Clarke, 2011). Data were collected using questionnaires and semi-structured interviews. Thirty participants were purposively sampled for the study. Quantitative data were analysed using a paired t-test, repeated measure analysis and linear mixed models while qualitative data were analysed using content analysis. Themes related to coping that emerged from the analysis were family/ social support, spiritual/ faith in God/prayer, problem-solving coping approach, emotion-focused coping approach, being active, let go of worries, learning to deal with difficulties, being positive, having a break from caring situation and pragmatism. Coping with stress is critical for caregivers of stroke survivors (Minnes, Graffi, Nolte, Carlson & Harrick, 2000) in terms of adjustment to the caregiver role and improving or maintaining their own quality of life (Larson et al,. 2005; Van den Heuvel, Witte, Schure, Sanderman & Meyboom-de Jong, 2001). The study revealed that there was a significant association between stress and coping variables (p=.01) that did not change over time (p=.90), indicating that caregivers with positive coping skills consistently experienced less stress over the stroke survivor recovery trajectory. The study above employed a mixed method of analysis. However, this current study will make use of qualitative analysis, specifically, thematic analysis.

Similarly, findings of Ye’s study also showed that there was a significant inverse association found between coping and stress scores where higher coping scores (F-COPEs) were correlated with lower perceived stress scores. Findings reported by Adriaansen, van Leeuwen, Visser-Meily, van den Bos, and Post. (2011) revealed a significant decrease in social support at three years after stroke reflecting reduced social activities outside the home, decreased visitors when stroke recovery was prolonged (Green & King, 2009; Forsberg-Warleby, Moller, & Blomstrand, 2004), and decreased involvement of others as family members return to their own routines. The researchers should be commended for the methodology of the study, however, the sample size for the study limited generalisation. Also, participants for the study were primarily females, hence the coping strategies that emerged from the study. An equal representation of male and female participants might have generated other coping skills by the study.

Kumar, Kuar and Reddemma (2015), conducted a study in India to investigate the burden and coping strategies in caregivers of stroke survivors. A descriptive correlation design was used for the study. The sample comprised 100 caregivers of stroke survivors who were purposively selected. Information Data Sheet, Zarit Burden Interview Schedule (ZBIS) and Coping Checklist were used for the study. They reported that caregivers employed an array of coping strategies but the most widely used coping strategies by caregivers of stroke patients were solving the problem, positive distraction, seeking social support, identifying a couple of solutions and help of religious things while the least coping strategies used were denying/blaming own's fate and distracting negatively. Similarly, a study conducted by Ma, Lu, Xiong, Yao and Yang (2014), on caregivers reported that problem-solving or problem-focused coping strategy was most commonly used and others used emotion and task-focused coping strategies. Likewise, problem-solving, acceptance, religion and seeking social support are common while denying/blaming and distracting negatively are least commonly used coping styles by relatives to overcome stressful caregiving experiences as this is consistent with findings from Nishio et al. (2015). The coping checklist was administered to caregivers to identify coping strategies used by caregivers to overcome burden of caregiving. The analysis revealed that problem-focused coping (68.50%) is most commonly used coping strategy followed by mix of problem and emotion-focused coping strategies (72.33%) and least used is emotion-focused coping (46.48%) by caregivers of stroke survivors. This study also showed a statistical positive significant relationship between denial as a coping style and different spheres of burden among caregivers. The findings were also in agreement with research conducted by Lavarone, Ziello, Pastore, Fasanaro and Poderico (2014) on caregivers which reported that increasing burden leads to more use of denial or start feeling responsible for other present problem. The study concluded that caring for patients with stroke presented increased burden to caregivers which manifested at increased rate of varied physical and psychological consequences among them, however, caregivers adopted varied types of coping strategies to overcome the burden and maintain a balance between different spheres of life. Despite the resourceful nature of the study, the findings, however, cannot be generalized in another context due to the cross-section design used for the study.

Mourad, Zaki and Ali (2014) research on the perceived stress and stressors facing caregivers of patients with cerebrovascular stroke and their coping abilities. The study was carried out at the Outpatient Clinic of Neuropsychiatry in Ain Shams University Hospitals. A quasi-experimental design was utilized to conduct the study. A sample of convenience of 50 caregivers accompanying their patients with cerebrovascular stroke (males & females) to Clinic was selected for the study. The study revealed that coping strategies used by caregivers of patients with cerebrovascular stroke were; increased social activities which reduced their level of depression, rest, exercise, reward and satisfaction. The findings of the study showed that there were improvements in coping abilities from the low percentage in pre-program to high in post-program, which showed statistically significant differences. Coping abilities upgraded enormously post-intervention. Mourad, Zaki and Ali (2014) opine that coping with caring can be considered a cognitive and behavioral balancing process to achieve equilibrium between internal and external physical and emotional demands. Social support is an extremely important means of coping as it satisfies the need for attachment, relieves stress and bolsters a sense of self-worth, trust and life direction. Likewise, informational interventions alone are not as effective in meeting the complex needs of stroke caregivers as interventions that combine information with other supportive guides may be helpful for caregivers' coping. Lastly, another study conducted by Hai, Hui, Xiao, Jain, and Zhen (2104) among caregivers of the spinal cord injury patients, found out that most caregivers employed several types of coping strategies such as active and negative coping styles. The result of their study is most likely to be dipicted in the current study due to similar coping strategies that are employed by caregivers that attend to the health need of patients with chronic diseases. The findings of study may slighty differ from the results of current study due to differences in methodology that is spefically sample size difference and difference in study design (quantitative survey approach).

Effects of Caregiving on caregivers of patients with stroke

Karakurt, Unsal and Tanriverdi (2018) conducted a descriptive study to determine the care burden and quality of life of the caregivers of the patients with stroke at Neurology Clinics of a state hospital. One hundred and twenty-one caregivers of patients with stroke were conveniently sampled for the study. Data was collected using questionnaires. It was found that participants demonstrated poor health on the SF36 which is a questionnaire for self-evaluation of physical and mental health. A significant negative correlation was found between Quality of Life (QOL) and Caregiver burden, indicating lower QOL with higher burden intensity. Similarly, a study conducted by

Kalav (2011), showed that the quality of life of the caregivers of patients with stroke decreased as their burden increased. A study conducted by Karabuga-Yakar and Pınar (2013), also showed that quality of life was rather low among caregivers of patients with stroke in the family. Jonsson, Lindgren, Hallstrom, Norrving and Lindgren (2005) also asserted from their study that emotional and mental domains of quality of life among the caregivers were low. The study concluded that the role of caregiving decreases the life quality of caregivers to a great extent. A meta-analysis study conducted by Roth, Fredman and Haley (2015) on informal caregiving and its impact on health, also reported that caregiving is associated with poorer physical health. Roth and colleagues again stated that caregivers have poorer physical health when compared with various samples of noncaregivers due to the stressful nature of the caregiving role. The results of this meta-analysis study is most likely to be demonstrated by caregivers of patients with stroke due to similarities of role played by all caregivers of chronic diseases.

Chow, Wong and Poon (2007), conducted a descriptive comparative study at Hong Kong hospital to examine the physical and emotional health of caregivers of stroke survivors using a sample of 47 participants who were conveniently sampled. Data was collected through interviews. The study revealed that caregivers of stroke patients demonstrated high levels of anxiety and depression than non-stroke caregivers. The hospital anxiety and depression scale was used to assess caregivers. Caregivers reported that their health was worse than one year prior to becoming primary caregivers. The result indicated that stroke caregivers did not appear to cope with the unexpected caregiving roles over the period of investigation. This finding is consistent with several studies conducted on caregivers' experiences, with their risk of burn out arising from caregiving in the post-acute phase of stroke (Anderson, Linto, & Stewart-Wynne, 1995; Kotila, Numminen, Waltimo, & Kastse, 1999; Hacke et al., 1998; Han & Haley 1999). The result also confirmed Palmer and Glass (2003), that depression during the first phase of stroke predicts depression later on. Caregivers with greater depressive symptoms soon after beginning to care for stroke survivors were more likely to be at risk for future depression. The study concluded that stroke caregivers experienced significantly higher emotional distress than non-stroke caregivers at three and six months after the stroke survivor had been discharged from the hospital.

To determine the impact of caregiving on the primary caregivers of patients with stroke, Hassan (2009) conducted a descriptive study at the Western Cape Rehabilitation (WCRC) using 57caregivers of stroke survivors. The study employed both qualitative and quantitative methods of data collection. Quantitative data were analysed statistically while qualitative data were analysed thematically. The findings of the study revealed that caregiving had a major financial impact on caregivers. In addition to financial difficulties, physical dependence of patients also caused great strain on caregivers. Areas that were found to cause the most strain were the emotional cognitive and perceptual problems with behaviour changes, other demands on the person's time, having to adapt one's own plans and changes in one's family life, loss of employment, financial problems and the confining nature of caregiving duties. Caregivers also tend to develop hypertension, migraine, bleeding duodenal ulcers, depression and may become the "hidden patient." This was reemphasized by Thompson, Bundek and Sobolew-Shubin (1990), Coyne, Mares and Clarke (1995), Bressick and Harvey (1997), Mayo and Wood-Dauphinee (2004) and Teasell and Kalra (2005). The study concluded that caring for a stroke patient caused high levels of strain and decreased life satisfaction in caregivers. Another study conducted by Dadson, Annor, Salifu-Yendork (2018) on the burden of care, revealed that stress was common with family caregivers which impacted on their physical health. The study further found that Caregivers were being stigimatized. Family caregivers were seen also using emotional-focused coping to deal with the psychological distress. The current study is most likely to record similar findings due to similarities in methodology, specifically qualitive design and study settings (Ghana). The result of current study may also deviate from the finidings of previous study because of difference in the medical condition and differernces in sample sizes of both study.

Lastly, A study conducted by Ae-Ngibise, Doku, Asante and Owusu-Agyei (2015) on the exprinces of caregivers of people living with serious mental disorders also reorded results that were noteworthy. The study reported that caregivers experience various degrees of burden which included financial, social, exclusion, emotional,depression and inadequate time for other social responsibilities. Religious prayers and the anticipation of cure were the main coping strategies that were adopted by caregivers, with expectation of new treatments being discovered. The results of their study is most likely to be demonstrated in current study findings due similar research design employed by both studies and similarities in culture settings with respect to caregivers burden. The study may deviate from previous findings because of differences in the conditions.

Experiences of Family Caregivers of patients with stroke

Marsella (2009), conducted a qualitative study on experiences of family caregivers of stroke survivors throughout a weekend pass from a rehabilitation facility. Fifteen family caregivers of stroke survivors were purposefully recruited for the study with 13 participants being females. Data was collected using a semi-structured interview guide. Data were analysed thematically. Five themes emerged from the analysis of the study: caregivers feel overwhelmed throughout the weekend pass, access to supportive resources influence caregiving experiences, caregivers adjust to the weekend pass throughout it subsequent use, caregivers feel a responsibility and need to be included by health professionals in the care of their family stroke survivors and caregivers described their weekend pass as a means towards recovery.

Franzén-Dahlin, Larson, Murray, Wredling, and Billing (2007), asserted that an overwhelmed stroke caregiver will result in increased utilisation of healthcare resources, and a premature institutionalisation of the patient. In the study, access to supportive resources (such as social support from family members, friends, and health professionals, as well as access to tangible supports, such as home modifications and assistive devices) was perceived as increasing the positive experiences of caregivers throughout the weekend pass. This observation is supported by previous research studies conducted by Friedland and McColl (1987), that described the buffering effect social support may have in preventing the negative health outcomes, which would otherwise have been predicted. Similarly, Grant, Elliot, Weaver, Glandon, Raper, and Giger (2006), emphasized that supportive resources may contribute to positive caregiver adjustment, as well as higher levels of well-being and general health in stroke family caregivers.

The findings of Franzén-Dahlin et al. study revealed that caregivers expressed an increase in anxiety and fears before their first-weekend pass. However, these feelings subsided through repeated engagement. The researcher must be commended on the methodology and findings of the study however, the sample for the study was primarily females hence, the experiences that were revealed. Equal representation of male and female participants may have revealed other experiences. Also, the findings of the study cannot be generalized for all family caregivers of stroke survivors since experiences of family caregivers of stroke survivors at home may be different.

In a qualitative study to explore the lived experience of family members of stroke survivors, Olivier (2015), selected three-stroke family members to conduct the study in New Zealand. Three main themes emerged from the study which were; ‘Being prepared’, ‘Where you stand changes the view’ and ‘Relinquishing and reclaiming’. Being prepared revealed how family members anticipated the stroke and drew on personal and professional experience in facing the phenomenon. The second theme showed the influence of expectation and location on family members’ experiences. Relinquishing and reclaiming identified loss, grief and a quest for equity in the synthesis of competing stroke survivor and caregiver desires.

Findings showed that participants were better prepared than most. Participants in Wallengren, Friberg, and Segesten (2008), study described their health professional experience as rendering the stroke more comprehensible.

The study also revealed that participants were familiar with the hospital environment as well as medical management of their family member, hence they knew where to obtain information and resources, differing from experiences reported by families in other stroke research who described the hospital environment as strange and frightening (Wallengren, et al., 2008).

A comparative study by Greenwood, Mackenzie, Cloud and Wilson (2009), found that established caregivers were sooner able to identify coping strategies than first-time carers, indicating perhaps that prior experience, knowing what to expect, and being able to plan, may help stroke families manage their situation, corroborating findings of the study.

The findings of the study showed that participants experienced various losses of self-identity, self-priority, autonomy, and routines. Losses occurred before, during and after the stroke. For some family members, loss was coupled with the insidious transitioning to the caregiving role. For others, it was more acutely experienced at the time of the stroke as lost roles and rituals became apparent. Green and King (2009), Hogan and Saban (2012) portray loss as originating with the stroke event but this may be a more gradual process for established caregivers. The researcher's sample for the study was quite small hence saturation might not have been reached. The study can therefore not be generalized to all family caregivers of stroke survivors in that setting. This current study will try to use arelatively large sample.

Irfan, Irfan, Ansari, Qidwai and Nanji (2017) assessed the impact of caregiving on the lives of the informal caregivers in Pakistan. The researchers made use of the cross-sectional research design. Participants were individuals who were offering caregiving to a family member and were above 18 years of age. A total of 400 caregivers were sampled through the use of the consecutive sampling procedure. All participants were interviewed. However, the researcher used a pretest structured questionnaire for data collection. Their finding showed that 57% of the participants were between 18-30 years while 60% of the caregivers were unmarried. The findings again showed that the majority of the participants were students. Also, 48% of the participants responded that caregiving has an overall negative impact on various aspects, such as physical (40.8%), psychological (47.8%), and professional aspects (51.8%) of their lives. The study concluded that caregiving had a negative impact on caregivers as a result of the extensive demands of caregiving and limited resources. They recommended that health care providers should explore, identify and support caregivers to cope in a better way to the challenging task of caregiving.

Summary of Literature

In this literature, the researcher explored an overview of certain aspects of stroke. The literature on the transactional theory of stress and coping and Middle range theory of caregiver stress provided the framework to explain the connection that exists between the various variables used in the study.

In the entire literature reviewed, three main issues were very prominent that provided the basis for this current study. Firstly, the literature reviewed showed that comparatively, the sample sizes that were used in majority of the studies were relatively very small. Secondly, the majority of the caregivers that were involved in most of the studies were females. And finally, findings of the studies were inconsistent. Scarcely did any of the literature reviewed focus on Ghana. It is based on this premise that this study seeks to address these issues by conducting the study to cover both males and females with relatively larger sample size in the Cape Coast Metropolis of Central Region, Ghana.

CHAPTER THREE

RESEARCH METHODS

Understanding the experiences of caregivers while caring for stroke survivors require a strategy that not only acknowledges the details and complexities of caring for a loved one, but also recognises the subjectivity and humanness of caregivers' experiences. As Upton and Reed (2006), suggest that a past preoccupation with typically narrow research approaches has delayed the essential development of an accurate understanding of the lived caregiving experience. A gap in our understanding of caregiving experiences is therefore highly problematic and warrants a study with a methodology specifically aimed at understanding such lived experiences. This chapter presents the research methodology used for the study. It consists of the research design, population, sample and sampling procedure, instruments, data collection procedure and data processing and analysis

Research Design

A research design is generally considered as the structure of research, or the "glue" that holds all of the elements in research together (Saunder, 2012). In addition, the research design is used to form a methodical construction of the entire research procedure and explains all of the major parts and tasks to be carried out in a research project. Research design is the general plan of how the researcher will go about answering the research questions (Saunder, 2012). There are various methods of qualitative research and these include ethnography, narrative, phenomenological, and grounded theory. These methods generally use similar data collection techniques such as observation, interviews, and reviewing text.

When faced with a number of methodological options within the qualitative paradigm, the method of choice is that which provides the researcher with the most complete picture of the developing phenomenon, and thus elicits the greatest gain in understanding (Giorgi, 2012). Phenomenology is a qualitative research method that is used to describe how human beings experience a certain phenomenon (Giorgi, 2012). A phenomenological study attempts to set aside biases and preconceived assumptions about human experiences, feelings, and responses to a particular situation. It allows the researcher to delve into the perceptions, perspectives, understandings, and feelings of those people who have actually experienced or lived the phenomenon or situation of interest. Therefore, phenomenology can be defined as the direct investigation and description of phenomena as consciously experienced by people living those experiences (Creswell, 2009).

As with any research method, phenomenology has strengths and limitations. One of the strengths of phenomenology is that it seeks to find the universal nature of experience and can provide a deeper understanding. Also, phenomenology helps to understand a lived experience and brings meaning to it. This may contribute to the development of new theories, changes in policies or changes in responses. However, phenomenology has some limitations and one of them is that the research participants must be able to articulate their thoughts and feelings about the experience being studied but it may be difficult for them to express themselves due to language barriers, age, cognition, embarrassment and other factors. Also, phenomenology requires researcher interpretation, making phenomenological reduction an important component to reduce biases, assumptions, and preconceived ideas about an experience or phenomenon. Researcher bias is difficult to determine or detect. Since the main objective of this study is to understand and describe the experiences of caregivers caring for stroke survivors, a phenomenological methodology was chosen.

Phenomenology best suited this study because there was no attempt to generate a theory (as in grounded theory methodology), or interpret a cultural or social group (as in an ethnography), or the experiences of one individual (as in a case study). Instead, the focus was to gain rich descriptions of experiences of caregivers of patients with stroke in their own world. Phenomenological research is a design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants (Creswell & Poth, 2017). It is employed when the study is about the life experiences of a concept or phenomenon experienced by one or more individuals. A phenomenological researcher investigates subjective phenomena (Creswell, 2009). This type of research is used to study areas in which there is little knowledge (Donalek, 2004). Phenomenology attempts to understand how participants make sense of their experiences. Additionally, phenomenology was found to be appropriate for this study because it aimed to gain rich descriptions of caregivers' experiences, in their own words, without external interpretations. Phenomenology holds these goals in high regard. Phenomenology above all other methods, honours human experiences (Creswell & Poth, 2017)). It is because of this core value, that phenomenology has become one of the dominant qualitative perspectives employed by health researchers today (Dowling, 2005). Its aim is to illustrate the world of the participant to help researchers interpret and understand the experiences under investigation (Creswell & Poth, 2017).

Study Area

This study was conducted in the Central Region of Ghana, specifically Cape Coast in the Cape Coast Metropolitan Area. Cape Coast Metropolitan Area is one of the seventeen (17) districts in the Central Region of Ghana. With the last population census conducted in 2010, the population of Cape Coast was 169,894 for both sexes. It is projected to be 183,937 as of now. There are three major hospitals in the Cape Coast Metropolis which are Cape Coast Metropolitan Hospital, Cape Coast Teaching Hospital (CCTH) and University of Cape Coast Hospital. The rest are urban clinics, Community Health Promotion Services (CHPS) Compounds and private hospitals. Out of the three major hospitals, only CCTH and the University of Cape Coast Hospital have physio units that have the necessary facilities to cater for persons with stroke, hence were selected for the study.

Population

The research population is the largest group of potential participants in a research study. Banerjee and Chaudhury (2010), defined research population as an entire group about which some information is required to be ascertained. Participants in the general population must share at least a single attribute of interest (Bartlett et al., 2001; Creswell, 2013). According to Krause and Corts (2012), there are two types of population in research namely target population and accessible population. The target population refers to the entire group of individuals or objects to which researchers are interested in generalising the conclusions. The target population usually has varying characteristics and it is also known as the theoretical population (Krause & Corts, 2012). The accessible population is the population in research to which the researchers can apply their conclusions. This population is a subset of the target population and is also known as the study population. It is from the accessible population that researchers draw their samples (Krause & Corts, 2012). The target population for this research was all informal caregivers of patients with stroke in the Cape Coast Metropolis (CCM), while the accessible population was all informal caregivers of stroke survivors receiving treatment at CCTH and University Of Cape Coast Hospital. Based on the records from the hospitals, there were 50 and 30 stroke patients in Cape Coast Teaching Hospital (CCTH) and University of Cape Coast hospital (UCCH), respectively. The population consisted of both males and females, spouses, parents, and adult children caregivers of stroke survivors.

Participants

Caregivers who brought their stroke survivors to the Out Patient Department (OPD) of the Stroke and Physiotherapy Units of the hospitals were contacted and screened to find out if they met the inclusion criteria.

Participants’ Eligibility

Inclusion Criteria: Participants were included if they were 18 years and above and were primary caregivers who assisted the stroke survivor in activities of daily living (ADL) as well as other things like taking the stroke survivor to the hospital.

Exclusion criteria: Participants were excluded if they cared for patients with other chronic conditions aside from stroke. Caregivers of stroke survivors outside Cape Coast accessing health care in CCTH and University of Cape Coast Hospitals (UCCH) were excluded. Participants were also excluded on refusal to willingly participate or offer consent.

Sample and Sampling Technique

In statistics and qualitative research methodology, a data sample is a set of data collected and/or selected from a statistical population by a defined procedure (Peck, Olsen & Devore, 2008). The elements of a sample are known as sample points, sampling units or observations. This study aimed to recruit 20 informal caregivers providing care to stroke survivors from CCTH and UCC Hospital. For phenomenological studies, Creswell (1998) recommends 5 – 25 and Morse (1994) suggests at least six participants. Based on these recommendations, the researcher chose the sample size. The sample size was proportionately calculated. Seven participants were selected from UCCH and 13 from CCTH. Proportionate stratified sampling was used to share the selected sample size among the two hospitals.

Formula = $\frac{Strata\ Size}{Total\ Population} \times Sample\ Size$

This helped the researcher to gain information and perspectives from a broad range of caregivers, including male and female informal caregivers, spouses and parents. Such a strategy challenges the investigators' own preconceived understanding of the phenomenon being studied as a variation in responses is likely to be obtained (Crabtree & Miller, 1999). Purposive sampling was used to select the two hospitals for the study, while convenience sampling was used to select participants from the hospitals.

Purposive sampling technique is a form of sampling method in which a researcher selects participants based on the inclusion criteria and purpose of the study (Saunders, Lewis, & Thornhill, 2012). Purposive sampling was used in selecting the two hospitals because they met the inclusion criteria for the study. Convenience sampling is also a type of sampling technique where members of the target population that meet certain practical criteria, such as easy accessibility, geographical proximity, availability at a given time, or the willingness to participate are included for the purpose of the study (Etikan, Musa, & Alkassim, 2016). This sampling technique was most appropriate for the present study because it enabled the researcher to undertake the study in a less researched area and understand the caregivers' experiences. Convenience sampling was employed in recruiting respondents sample because of their proximity and availability at the both hospital and also not many of them came to the physiotherapy clinic on a given day, hence it became difficult to randomly select them for the study. The concept of saturation was used to determine the actual sample size for the study. Data saturation is reached when there is enough information to replicate the study (Saunders et al., 2018) when the ability to obtain additional new information has been attained, and when further coding is no longer feasible (Guest, Bunce & Johnson, 2006). Therefore, the actual sample size used in this study was thirteen which was based on saturation.

Data Collection Instrument

Data collection is directly associated to sampling and is best viewed as complementary to it (Whitehead & Whitehead, 2016). Data, therefore, are collected directly from the identified and selected sample population.

Dependent on the kind of data of interest for the research at hand in particular qualitative research, numerous approaches of data collection can be employed, either singularly or in combination to obtain direct data. For direct data, data collection methods may include interviews, observations, open-ended questionnaires, journaling (diary accounts) or ‘think aloud’ sessions (Whitehead & Whitehead, 2016). The most appropriate data collection strategy for interpretive phenomenological analysis research is the experiential interview. However, present literature (Marshall & Rossman, 2010) accords that the phenomenological interview should be open or semi-structured. These two types of interviews allow the researcher to address the phenomenon profoundly, providing the participants enough room to express their experiences in detail and approaching reality as faithfully as possible. The detailed descriptions or interpretations brought by the participant in the profound-phenomenological interview should be as representative of experienced reality as possible.

The data collection instrument for this study was a semi-structured interview. Data collection instrument was made up of an audio recording of the job experiences of the caregivers which were then transcribed by the researcher. An interview guide was designed to allow caregivers to discuss their experiences openly, without being influenced by the researcher. The guide was based on the study’s objectives. To accomplish this, the interview guide was designed with a minimal number of broad questions, and a series of open-ended probes, which were used to clarify the meaning of responses and encourage in-depth discussions. Such a guide allowed participants to discuss what they deemed as important, while still remaining focused on the goals of the study. Questions focused on participants' experiences on their caregiving role, effect of their caregiving role as well as coping strategies used by caregivers in dealing with their experiences. The interview guide was made up of four sections (See Appendix A). The section I was designed to address demographic background of participants and duration of caregiving role. For example, gender, age, marital status and occupation. Section II focused on exploring participant's caregiving experiences. For example, can you share with me your experiences from your caregiving role? Section III focused on exploring participant's coping strategies used in dealing with their caregiving roles. For example, what are the various ways you cope with your experiences in caring for your patient? The last section focused on effect of caregiving on participants. For example, how has your caregiving role affected you? A one-on-one interview was conducted for each caregiver at the Physiotherapy Units of CCTH and UCC hospital. Throughout the interviews, the researcher maintained a level of reduction, refraining from outside interpretations by bracketing preconceived notions. As Upton and Reed (2006) suggest, phenomenological reduction does not involve an absence of presumptions, but a consciousness of one's own assumptions. This open awareness was practiced not only throughout the interview process but also in the data analysis phase as well. Interviews were digitally audio recorded after seeking the consent of participants and transcribed verbatim by the researcher. Field notes were also taken during the interview session.

Pilot Testing

A pilot-test was conducted prior to the main study. It was conducted by interviewing five informal caregivers at the C4C Hospital. The aim of the pilot-test was to ascertain the appropriateness, reliability and validity of the interview guide. It was also conducted to ascertain whether participants would have any difficulty responding to the interview and also to determine an estimated time for the study. This led to the reconstruction of the items on the interview guide. The outcome of the pilot test showed that caregiving had a negative effect on informal cargivers of patients with stroke as it affected their social lives, finances and health. Below are some of the comments from participants.

Nature of Caregiving

The finding relating to nature of caregiving showed indicated:

> *“I cook for her and bath her and make sure she takes her medications” (Kakra)*
>
> *“...because he can not walk, every morning, I have to bath her and brush her teeth and feed her and help her take her drugs before I do the cleaning in the house…” (Rich)*
>
> *“He cannot walk properly so I have to help him do almost everything. I help him with his food and drugs” (Rob)*

Time Draining

The participants expressed that:

> *“This work takes all my time” (Kakra)*
>
> *“… going to the hospital with her and taking care of her through out the day takes a lot my time” (Rich)*
>
> *“I commit almost everyday taking care of him…” (Rob)*

Financially Demanding

> *"It is expensive to take care of a stroke person because of the transportation to and from hospital almost every day…" (KaKra)*
>
> *"I have spent almost all my saving on him. It is expensive my sister." (Rich)*
>
> *"…paying for the medication and transportation has consumed all money…" (Rob)*

Coping Strategies

The interview data revealed that participants employed varied means of coping with their role of as caregivers. Some participants explained that:

> *"I watch television when she is sleeping and I also don't have anything to do. I cannot leave her and go out so just watch television" (Kakra)*
>
> *"Sometimes I think about her situation and they only thing I do is to pray for her to get better…" (Rich)*
>
> *"I usually sleep during the day when he is sleeping" (Rob)*

Impact of Caregiving

Participants revealed that their caregiving role have impacted their lives in serval way. They indicated that it impacted on their work and social life. The following are comments from participants' interview.

DeWork

Participants revealed that providing care for stroke patients impacted negatively on their work. Some participant commented:

> *"I have stop working because I have to stay here and take care of her" (Kakra)*
>
> *"I have to tell my customers about the situation at hand and plead with them to come home if they need to buy something and those who cannot come, I ask them to call me and I would deliver it to them. But sometime I delay with the delivery because sometimes there is no one to deliver or take care of him so that I will do the delivery." (Rich)*
>
> *"…my work is affected because now I can't open my shop regally and so the business is going down" (Rob)*

Social Life

Participants indicated how providing caregiving for stroke patient affected their social life. Some participants said:

> *"…now it is difficult for me to attending parties or funerals" (Kakra)*
>
> *"I am part of my church's singing group but since I started taking care of my father, I have not been able to attend any of our meetings nor have I been able to go to church either" (Rich)*
>
> *"I am someone who likes going out with friends but now I don't go anywhere and that makes me sad sometimes but I cannot do anything about it." (Rob)*

Data Collection Procedure

An introductory letter (see Appendix B) was taken from the Department of Education and Psychology to the Cape Coast Teaching

Hospital and the University of Cape Coast Hospital to seek permission to conduct the research. Also, an ethical clearance form was obtained from the Institutional Review Board (IRB) of the University of Cape Coast to enable the researcher conduct the study in these hospitals. After permission (see Appendix D) was granted, a one-on-one interview was conducted for each caregiver at the Physiotherapy Units of both hospitals. The researcher personally conducted the interview using an interview guide (see Appendix A). On days during which data was collected, the researcher was introduced to patients waiting for their turn for physiotherapy or waiting to see a doctor (at the Stroke Unit). Though the focus of the study was not the stroke survivor, they were crucial in identifying who their caregivers were. Those who were identified as primary caregivers and were willing to participate in the study were given consent form to fill and to sign their signatures to indicate their voluntary participation. Those who could not sign gave verbal consent before the commencement of the interview.

Prospective participants were briefed by staff at the Physiotherapy Unit in the hospital. Additionally, further detailed explanation was given to participants with regards to the purpose of the study. Participants of the research were informed of the likely physical and psychological risks associated with their participation, as well as benefits of the exercise. A suitable time and venue were discussed after prospective participants had fully consented to participate in the study. However, participants agreed to have the interview session in the hospital on appointment days at the physiotherapy unit. Additionally, consent of each participant was sought to record the interview session via an audiotape recorder. For the sake of ethical considerations, names of respondents were not recorded rather participants were given pseudonyms. Participants were made aware that they were at liberty to withdraw from the study any time they wished to do, without any consequences. Data was collected personally between May 2018 and July 2019, at the premises of the hospitals. Face-to-face interviews were conducted for all participants. Each interview lasted between 25 and 45 minutes. Twenty participants were interviewed at both hospitals. However, saturation set in from the thirtheen participants which makes the actual sample size for the study thirteen. Data collection was quite challenging as one session was not enough for a participant. Hence, researcher had to book other sessions with participants based on their appointments dates at the physiotherapy unit since they all preferred the interview session being done at the physiotherapy unit.

Ethical Consideration

The researcher obtained ethical clearance from Ethical Review Board at the University of Cape Coast (see Appendix C).

Participants were assured of confidentiality, privacy, anonymity and voluntary participation. Informed consent was sought from participants before the commencement of the interview.

Data Analysis

In qualitative research, data analysis consists of preparation and organising the data for analysis, then reducing the data into themes through a process of coding and condensing the codes; and finally representing the data in tables for discussions (Braun & Clarke, 2006). Data collected was analyzed using Braun and Clarke’s (2006) thematic data analysis technique. Thematic analysis is a qualitative data analysis procedure that enables the researcher to identify patterns or themes within a specific qualitative dataset. This technique is often used to analyze, classify and to present themes (patterns) that relate to the data. It enables the researcher to demonstrate the data in great detail and deals with diverse subjects via interpretations (Boyatzis, 1998).

Procedure

Familiarizing yourself with the data:

This is the first stage of data analysis where one familiarises him or her self with the data collected. The recorded tapes were played and listened to carefully; this helped the researcher to transcribe the data verbatim. The data was transcribed. The transcribed data was read and re-read over a period of time to ensure familiarity with the data. This conforms to Bogdan and Biklen (2007), proposition that in thematic analysis, data must be read at least twice so that the researcher obtains a rich feel of the data. Furthermore, re-reading the transcribed data allowed the researcher to gain the full picture and make connections between the participants' thoughts, ideas and the data collected through observations.

Generating Initial Codes

This is the second stage of data analysis which is also known as the building blocks of data analysis. At this stage, the researcher started highlighting and organising data in a meaningful and systematic manner, significant to the objectives of the study. These initial codes helped in the organization of the participants' data into small chunks of meaning. The researcher coded each segment of data that was pertinent to or captured something fascinating about the research questions. The researcher worked through each transcript coding every segment of texts that appeared to be relevant to or specifically address the research questions. Having done this, the codes were compared, discussed and modified before moving on to the rest of the transcripts. As the researcher worked through the remaining transcripts, new codes were identified and modified. The researcher generated the initial set of codes by hand, working through hard copies of the transcripts with pens and highlighters.

Searching For Themes

The third stage is characterised by the identification of themes. Themes are patterns of information that capture something significant about the data in relation to a specific research question. At the end of the procedure of identifying themes, the originally generated codes were organised into broader themes that seemed to say something specific about the research questions. This phase involved reviewing the coded data to identify areas of similarity and overlap between codes. The researcher generated themes and subthemes, (subcomponents of a theme) by clustering codes that seem to share some unifying feature together so that they reflect and describe a coherent and meaningful pattern in the data.

Reviewing Potential Themes

This process followed the identification of themes. During the review stage, the researcher reviewed, modified and developed the initial themes that were identified earlier. All data that were relevant to each theme were gathered. The researcher read the data associated with each theme to determine whether the data really did support the themes they were associated with. Data that did not match the themes, with which they had been associated, were removed. This exercise ensured coherence between the themes and associated data. At this phase, the researcher's final objective was to generate a set of themes that captured the most important and relevant elements of the data, and the overall tone of the data, in relation to the research question.

Definition and Naming of Themes

The various themes were appropriately defined. This was the final alteration of the themes and the aim was to identify the essence of what each theme is about, as opined by Braun and Clarke (2006). At this stage, the researcher questioned the meaning of the themes and further discovered the existence of sub-themes and how they interacted and related to the main themes and the other sub-themes. To ensure good thematic analysis, the researcher ensured that the developed themes:

(i) ideally had a singular focus;

(ii) are related but do not overlap, so they are not repetitive, although they may build on previous themes; and

(iii) directly addressed the research questions.

Reporting

This phase comprised of producing a report of the data. Writing and analysis are thoroughly interwoven in qualitative research; from informal writing of notes and memos to the more formal processes of analysis and report-writing. The purpose of the report is to provide a compelling 'story' about the data, based on the analysis. The story should be convincing and clear, yet complex and embedded in a scholarly field by providing scholarly evidence. Here, the researcher reported the findings from the data by quoting verbertim what the participants said in line with the research questions in such a way that, the themes were connected logically and meaningfully, and built on previous themes to tell a coherent story about the data.

Ensuring Trustworthiness and Rigor in Qualitative Research

In every qualitative study, it is imperative to explain that the requirements for establishing rigor in qualitative data analysis differ from those required in quantitative studies. Requirements of reliability, replication, and validity generally associated with establishing rigor in quantitative studies are less applicable to qualitative studies. This is because, they were originally developed for quantitative studies and their focus is primarily on measurement and the adequacy of the measures (Maher, Hadfield, Hutchings, & Eyto, 2018). Trustworthiness is considered a suitable criterion for evaluating qualitative studies. For qualitative process to be trustworthy, Guba and Lincoln (1989), proposed that four principles should be satisfied. These are credibility, transferability, dependability, and confirmability.

Credibility

This principle ensures that the study measures what is intended and is a true likeness of the social reality of the participants (Maher, Hadfield, Hutchings & Eyto, 2018). Also, it comprises the accurate and truthful depiction of a participant’s lived experiences. This concept was reached by extended interaction with the research participants. Before the interview process, rapport was effectively built, followed by peer debriefing to offer the participants a better understanding of the purpose of the study. Investigator triangulation was also applied, where an expert in qualitative research was contacted to help with the analysis and interpretation of the data.

Transferability

This criterion relates to the ability of the findings to be transferred to other contexts or settings. Because qualitative research is specific to a particular context, it is important a thick description of the particular research context is provided allowing the reader to assess whether it is transferable to their situation or not (Maher, Hadfield, Hutchings & Eyto, 2018). A purposive sampling was adopted to select appropriate participants for the study who were willing to offer detailed accounts of their lived experiences with stoke caregiving.

Dependability

This criterion ensures that the research process is described in adequate detail to assist another researcher to repeat the work (Maher et al., 2018). This, on the other hand, determines how reliable the study's findings will be. This was ensured by engaging the services of experts to assist in the review of transcribed materials in order to authenticate the identified themes and descriptors. Emergent themes were considered and were compared to the results developed from the thematic analysis.

Comfirmability

Confirm ability is comparable to objectivity in quantitative studies. Here, the goal is to reduce investigator bias by recognizing researcher predispositions (Maher et al., 2018). This was sustained by keeping a reflexive journal during the entire data collection process, to keep daily notes and documents, introspections that would be beneficial to the study.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

This chapter presents the core findings from the study that was conducted in the Cape Coast Metropolis. The phenomenological qualitative study design was used. A total of 13 informal caregivers were involved in the study based on saturation.

The face-to-face interview method of data collection was employed by the researcher. The purpose of the study was to examine informal caregivers' experiences in taking care of persons with stroke. The themes presented in this chapter were derived from the research questions. The researcher adopted Braun and Clarke's (2006) thematic data analysis technique. The chapter ends with a summary of the findings. Table 1 shows participants characteristics

Results

Table 1: Participant's Characteristics

Scale	Sub-Scale	Frequency
Gender	Male	2
	Female	11
Age	20	1
	24	1
	25	1
	26	1
	28	3
	35	1
	39	1
	52	2
	69	1
	72	1
Level of Education	Tertiary	3
	Secondary Education	7
	Basic education	3
Marital Status	Married	4
	Single	6
	Divorced	2
	Widow	1
Occupation	Food vender	1
	Taxi driver	1
	Media house intern	1
	Pensioner	1
	Student	1
	Trader	3
	Sales Attendant	1
	Nurse	1
	Health assistant	1
Patient's relation with caregiver	Children	9
	Sister	1
	Daughter-in-law	1
	Wife	2
Duration of Caregiving	2-10 months 8	8
	1-5 years 3	3
	1 and half-year to 2	2

Filed Data, 2019

Table one presents the demographic characteristics of the 13 participants involved in the study. The findings showed that most of these participants were females. These findings were not in line with that of Irfan et al. (2017) who found that in Pakistan most of the informal caregivers were males. Three of these participants were 28 years, while one was 69 years and another was 72 years. That is most of the participants were between the ages of 28 and 39. However, Irfan et al. (2017) found that most informal caregivers were between the ages of 18 and 30 years. It is evident from Table 1 that all the participants had received some formal education. Seven of the participants had had secondary education, while three had tertiary education. Six of the participants were not married, four were married, two were divorced and one was a widow. The findings are similar to that of Irfan et al. (2017) who found out that most of the informal caregivers were unmarried. Also, table 1 shows that most caregivers were related to the patient. Nine of the caregivers were the children of the patient while two of the caregivers were providing care for their husbands. Most of the participants in the study had worked as caregivers between a period of 2 to 10 months.

Themes and sub-themes for Caregivers

The researcher first familiarised herself with the data collected by listening to the audiotapes. After which she transcribed it verbatim as participants gave their accounts. The transcribed data was read and re-read over a period of time to ensure familiarity with the data. The second stage of the data analysis was the generation of initial codes. The researcher did this in order to organise the data in a systematic manner relevant to the research objectives. The researcher generated the major themes and sub-themes based on the objectives and the meaning derived from the data. Table 2 shows the major and sub-themes derived from the data.

The findings were supported by some comments from participants. The researcher ensured anonymity and confidentiality by assigning individual participant with pseudonyms.

Table 2: Themes and Sub-themes

Themes	**Sub-themes**
Nature of Caregiving	Increased Daily Tasks
	Stressful
	Frustrating
	Time-consuming
	Strengthen family bond
Coping Strategies	Watching television
	Sleeping
	Acceptance
	Hope in God and self-encouragement
	Patience and tolerance
Impact of caregiving	Work
	Health effect /Poor health
	Sleep
	Education
	Social life
	Financially
	Emotionally

Source: Filed Data 2019

Research Question One: What are the experiences of caregivers of patients with stroke in Cape Coast Metropolis (CCM)?

Theme 1: Nature of Caregiving

The nature of participants' role as caregivers was a prominent feature of participants' interviews. Participants' described the nature of their role as caregivers to involve: daily tasks of which they described as stressful, frustrating, time-consuming and financially draining. Also, these daily tasks left them with some minor health impacts though it strengthened family ties or bond.

Increased Daily Task

All the caregivers interviewed reported that their role as caregivers involved daily task such as bathing the stroke patient, cooking their meals, feeding them (if the stroke has affected their hands), taking him or her to the hospital and assisting them in taking their drugs as prescribed by the doctor. Caregivers explained that the daily task also involved lifting or raising the patient to sit-up when they had to eat or take their drugs and help them with daily exercises. Some participants said:

> *"Initially when she had the stroke, she could not do anything for herself. She could not even lift herself so every morning, I would look for someone to help me take her to the bathroom before I can bath her. Then I would dress her, feed her and give her medication. I had to wear her diapers as well". (Bryan)*
>
> *"…I cook for her, bath her, clean her up when she uses the toilet, take her to hospital for her regular visit to the physiotherapy unit and give her medication…" (Love).*
>
> *"…I care for my dad together with my younger sister. She does the cooking, cleaning while I do the bathing. I also take him to the hospital to see the physiotherapist for his regular exercise…" (Acqua)*

> *"…From the hospital, when she was brought home, I was the one caring for her. I bath her, clean her up when she uses the toilet, I cook for her, feed her and wash her clothes…" (Perry)*

Another participant described her daily task as

> *"In the morning, I heat water then my husband will help bath my mother in law because I also don't feel so well. I then help her get dressed and smear or rub her with her balm. I also make sure she takes her medication in the morning, afternoon and evening".* ***(Agyeiwaa)***

Stressful

Caregivers described their roles and experiences as demanding. They explained that their daily tasks were physically demanding. Especially, when they were to carry the patient to the washroom and back each day, raise them up to take their drugs and help them when going to the toilet. Caregivers added that they work throughout the day. Some participants said:

> *"…for me, caring for my mother-in-law is quite stressful…" (Agyeiwaa)*
>
> *"In terms of my health, I can say that it has been quite stressful because I had to lift her sometimes and that gave me back pains". (Waters)*
>
> *"…the only thing that was stressful in caring for her was bathing her, feeding her and lifting her. (Bryan)*

Another caregiver who catered for her husband (stroke patient) said:

> *"…caring for a stroke person is very stressful. Aside from caring for him, I also have to care for the children. Sometimes after attending to all of them, time will be far gone in the evening so I sleep without eating" (Araba)*

Frustrating

The third subtheme related to the nature of caregiving had to do with the frustrating nature of it. Caregivers explained that their work was frustrating because the patients do not allow them to take care of them as they are supposed to. They added that sometimes patients prvented them from carrying out their duties such as helping them with their exercises. A caregiver said:

> *Caring for my dad is quite frustrating because he does not allow you to do the things that are necessary for him. This makes caring for him quite frustrating. For example, when I want to do his regular exercises with him, he is always reluctant to do it. (Ama)*

Another participant said:

> *"…aside helping with activities of daily living such a bathing cleaning and the like, you also have to help him with his daily exercise. This is quite frustrating because he does not allow you to do the exercise that will help him get well…" (Acqua)*

Time-consuming

The result of the analysed data showed that all caregivers described their caregiving role as time-consuming. The caregivers explained that they spent almost the whole day and night on caring for the stroke patient. The caregivers added that they are always worked or did something to ensure that the stroke patient was catered for properly. Also, carers expressed that they were not able to go anywhere even when the stroke patient was sleeping because they did not know when he or she would call for assistance. A caregiver said:

> *"Caring for a person with stroke is time-consuming and so leaves you with very little time for yourself…" (Love)*
>
> *"I take him to the hospital for his regular check-up and psychotherapy session which takes a lot of time…" (Acqua)*

Strengthen Family Bond

In spite of the challenges involved in caring for stroke patients, participants indicated that it strengthened their family bond. The analysis revealed that caregivers and stroke patients had time to discuss various issues they would not have spoken about if they were not their caregivers. The caregivers explained that it had strengthened the bond between them as family members. A participant explained:

> *"...before my sister had stroke, we use to just talk on the phone, once in a while because I was busy working in the village while she also busy with her business in Cape Coast. My younger sister too who helps with caring for our sister was also living elsewhere doing her business. But my sister's condition has brought all three of us together to live in the same house for the past 6 months. It has brought us together in terms of our relationship. We can now sit and*

> *talk about various issues. We share jokes and watch the television to entertain ourselves". (Adepa)*

Another participant who took care of her mother-in-law said:

> *"…my mother-in-law and I were not so close but since I started taking care of her due to the stroke, we have become more like sisters because we are always chatting. The bond between us has become stronger than before. Sometimes I go and sleep on her bed in a room while we chat…" (Agyeiwaa)*

Similarly, another participant said:

> *"… now that he has a stroke and cannot go anywhere, we get to talk a lot about issues unlike before when he was sick". (Ama)*

Research Question Two: How do caregivers of patients with stroke cope with their experiences in caring for patients with stroke in CCM?

This research question sought to explore how caregivers of stroke patients coped with their role. The major theme that answered this research question was theme two. It is supported with sub-themes.

Theme Two: Coping Strategies

The participants gave varied explanations to explain how they coped as caregivers. Watching television, sleeping, hope in God and self-encouragement, tolerance and patience were the strategies adopted by participants as their coping mechanisms.

Watching Television

Some participants explained that in their attempt to cope with their role as caregivers, they watched television to entertain themselves when they were less busy or bored. This was because they could not go anywhere.

A participant expressed:

> *"…I watch television when am less busy or bored. I also listen to music on the radio to relax sometimes. …" (Love)*
>
> *''….Well, I watch television to entertain myself when I am bored. I also try to sleep as much as I can in the day when am less busy…''(Adepa)*

Sleeping

Sleeping was an approach some caregivers adopted as their coping mechanism. Due to the nature of their work, some participants indicated that they would have to wake up at night to attend to the stroke patient. The participants expressed that in order to cope with the stressful nature of their role as caregivers, they had to sleep during the day.

> *"… I try to sleep as much as I can when I having nothing doing or when my care recipient is asleep…" (Love)*
>
> *"Well, there is not much to cope with but sometimes I usually sleep during the day when am less busy or would listen to the radio…" (Waters)*
>
> *"…there was nothing I could do about it so I mostly get to sleep in the day when she is watching the television…" (Bema)*

Acceptance

Another recurrent theme under coping strategies was acceptance. The participants dealt with the stressful nature of their role as caregivers by accepting the situation as it is because they could not do anything about it. These participants acknowledged the fact that their role as caregivers had negative effects on their finances, social life and health, it was therefore expedient to just accept it as it is. Some caregivers said:

> *"Well, as I said earlier, my only challenge is the delay in starting work on days that I take my dad to the hospital for his physiotherapy sessions but there is nothing I can do about it so I've accepted it as it is.....''* (Acqua)
>
> *''....Caring for my dad has affected my job at the media house but I've told my boss at work about my dad's situation so he understands me when I am late or unable to make it work. However, there is really nothing I can do about it than to bear it''.* (Ama)
>
> *"...despite the stress involved in caring for her, there is really not much I can do about it so I am just managing it for now..."* (Agyeiwaa)

Hope in God and Self-encouragement

For some caregivers, their hope in God and self-encouragement was an essential coping strategy that kept them going. These caregivers expressed their reliance on self-encouragement and belief in God that their stroke patients would be healed. The caregivers expatiated that their belief in God and self-encouragement were sources of strength that enabled them to care for the stroke patient. The following is one of the participants' account:

> *"…like I said, sometimes I feel sad but I encourage myself that it will be well. Also, my faith and hope in God give me the strength to keep caring for her. She is the only mother I have, so I will do anything to keep her alive for me and my siblings…" (Cardinal)*

Similarly, another participant said:

> *"…Well, there's really nothing I can do about my mum's condition than to pray and believe that she will get better soon. My faith in God gives me hope that everything will be fine…" (Perry)*

Another participant added:

> *"Sometimes too I encourage myself with the Lord, that it shall be well. Now that I see a change in her condition, it has given me hope to keep caring for her. If that was not the case, I would have been discouraged by now but I thank God for her gradual recovery" (Woode).*

Patience and Tolerance

Few caregivers viewed patience and tolerance as a source of strength that helped them to cope with their caregiving role. These caregivers were of the view that taking care of a stroke patient was stressful, however, they were able to cope because they had patience and were able to tolerate the stroke patients when they were acting in an unusual way.

> *"To care for a stroke person, you need to have a lot of patients and tolerance else you cannot do the job and that has sustained me till now". (Bryan)*
>
> *"Caring for a stroke person requires a lot of patience and love because without them you will not be able to care for them so I think these two have sustained me till now". (Araba)*

Research Question Three: How does caregiving affect caregivers of patients with stroke in CCM?

Impact of Caregiving on the Caregiver

There were four sub-themes in the major theme which depicted clearly the impact of caregiving on caregivers. These sub-these were: decline in work, financial drain, sleep disturbance, health effect and decline in social activities.

Decline in Work

Almost all participants involved in the study were workers, but their role as caregivers of stroke patients had significant impact on their work. Participants were unable to carry out the day to day activities that would ensure the growth and productivity of their work. Where these activities were performed, they were delayed. In some cases, participants had to quit their work to be able to care for stroke patients. This is because they spent most of their time with the stroke patient either in the home or in the hospital. Below are some sentiments shared by their caregivers:

> *"Caring for my mum has also affected my job because I had to quit my job to be able to care for her and even now, I still*

> *cannot work because she is still not fully recovered". (Perry)*
>
> *"…also affected the time I spend in taking him to the hospital for his regular check-up and physiotherapy session has affected me. I spend half of the day at the hospital which also affects my sales for the day…". (Acqua)*
>
> *"… since I started caring for my mum, my business has also been affected because am not able to go and sell anymore. I sell natural spicies as well but I have not been able to make sales since I started caring for my mum …". (Waters)*

Other participants indicated that:

> *"Caring for my dad has affected my job. For instance, I am supposed to be at work today but I am here with him at the hospital. This has really affected me because as an intern in the media house I have to gain experience but most of the time I am absent from work which is not helping me at all". (Ama)*
>
> *"Well, as I said earlier, I used to work for a factory in my village but because of my sister's illness, I had to quit my job to come and take care of her. Also, as you can see, am quite old so lifting my sister here and there has given me somebody pains but once I apply some ointment, I get better". (Adepa)*
>
> *"Caring for my husband has also affected my work because I am not able to open my shop until my children come back*

> *from school in the afternoon. Today, for instance, I closed my shop to be able to bring him to the hospital. When we go home too, I have to make sure he takes his meals and his medication before I can leave him for the children and then go and sell at the shop".* (Araba)

Financial Drain

Most participants were emphatic that caring for a stroke patient was financially burdensome. This is because treatment, management and medication for stroke patients are expensive. This had caused them to use up their savings. Participants said that the financial burden was severe if the stroke patient was the breadwinner for the family. Some of the participants' experiences are presented below:

> *"Caring for a stroke patient is also financially draining because their medication is quite expensive but you have to buy them. This affected not just my dad and brother financially but me too. I had to use up all my savings to care for the family. Even as at now, the family is still going through financial hardship. Sometimes, we are unable to come for review because we can't afford transportation and medication".* (Perry)
>
> *"… I can say it has really affected us because he was the breadwinner of our family but since he became ill, I had to bear all the financial responsibilities from the money I make from selling provision items…"* (Araba)

> *"… my mother's condition really affected the family. My dad and brother bore all the financial responsibilities during the period until now. My mum was working before she fell ill, afterward, she could not work anymore so the financial burden also increased. My elder brother is a student but he had to also work to support my dad financially. Sometimes, my mum will miss her medication for two weeks because we did not have the money to buy her medication. She was also placed on a different diet and all these involve money so the financial drain was more".* (Bema)

Sleep Disturbance

Majority of the caregivers in this study indicated that their role as caregivers had a significant impact on their sleep at night. Their sleep was interrupted at night by the stroke patient either to assist them to urinate or take their drugs. Below are some caregivers' experiences they shared with the researcher:

> *"…caring for my mum has affected my sleep. I cannot sleep for the number of hours that I want because at night she would call me to get her water or help her use the washroom". (Perry)*
>
> *"…my sister's situation has also affected my sleep because I cannot sleep like the way I used to. My sleep is always interrupted at night because I have to wake up and attend to her needs". (Adepa)*

> *"… taking care of my mum has affected my sleep because, at night, she would wake me up that she was having pains in her body and will be crying. I have to assure her that everything will be fine before she goes back to sleep. At times too, she will wake me up to drink water or ease herself and that really interrupted my sleep. Sometimes I had sleepless nights".* (Bema)

> *"It affected my sleep because I had to wake up in between sleep to care for her".* (Bryan)

> *"It has affected my sleep because she wakes me up at night for one reason or the other".* (Woode)

> *"When she wants to sleep or urinate, I help her with that so this makes me sleep in bits because I have to wake up in between sleep to attend to her. If I sleep too deep, I may not be able to hear her when she calls".* (Agyeiwaa)

Health effect

Another impact of caregiving on caregivers was body pains. This was a common issue they shared. They explained that their role as caregivers had left them with unbearable body pain due to the continuous lifting of stroke patients. The only way they could deal with the body pains was to apply an ointment and take some painkillers. A participant explained:

> *"Well, due to the constant lifting of my mum, I developed back pain which was unbearable. Yet, there was nothing I could do about it than to rub it with ointment from time to time".* (Perry)

Similarly, some participants said:

> *"I constantly have body pains but not much can be done about it because I still have to care for him". (Araba)*
>
> *"…my health but then I constantly had this back pain from always lifting her". (Bema)*
>
> *"…because I had to lift her sometimes and that gave me back pains…" (Waters)*
>
> *"I was constantly having headache and body pains…" (Bryan)*
>
> *"…lifting my sister here and there has given me somebody pains but once I apply some ointment, I get better". (Adepa)*
>
> *"…I can say the constant lifting of my dad gives me body pain…". (Acqua)*

Decline in Social Activities

Caregivers reported that taking care of stroke patients had significant effect on their involvement in social activities. Caregivers indicated that they were not able to attend social functions such as church services, funerals and wedding ceremonies. Caregivers in their interview revealed that this impact was strong within the first ten months the individual was diagnosed of stroke. Some caregivers explained their experiences:

> *"Since I started caring for my mum, I am unable to go to church and other social functions. I am always at home which is quite boring". (Perry)*

> *"Even when there is a funeral that I have to attend, I cannot because I have to stay and care for her. I cannot also attend church service because of my sister". (Adepa)*
>
> *"Caring for my husband has also affected my social life in many ways. For instance, I am unable to go for weddings or parties but for some funerals, I make my eldest daughter attend to him so that I will quickly go for the funeral and come back. For church service, now we are all able to go on Sunday because he can walk a bit but initially when he had the stroke, I especially, could not go to church because there will be no one to care for him. I am unable to travel for a family function or meeting". (Araba)*
>
> *"Caring for my mum really affected my social life as I could not leave her to go to church or other places. During the first 9 months of her illness was really bad so I could not leave her alone to go anywhere because I didn't know when she might need something in my absence. As at that time she was completely dependent on us for everything so we could not leave her at any point in time. I had to stop church for some time and also at school, I had to come home from time to time in between lectures to attend to her. During the first nine months, I had to miss lectures to come home to attend to my mum". (Bema)*
>
> *"…my social life has been affected because I am unable to go to church for a while now…". (Waters)*

Summary of Findings

In summary, three major themes emerged from the analysis and these are nature of caregiving, coping strategies,and impact of care giving. There were five sub-themes emeriging from the nature of caregiving(increased in daily task, stress, frustrations, time consumption and strengthen of family bond) as a one of the major themes. Again, there were five sub-themes(watching television, sleeping, acceptance, hope in God and self encouragement, patience and tolerance) emerging from coping strategies as also one of the major themes. Finally, the last major theme being impact of caregiving(work, health effect, sleep, education, social life, finances, and emotions)

Discussion

This study was conducted to examine informal caregivers' experiences in taking care of persons with stroke. This section presents the discussion of the findings that emerged from the participant's interviews. These discussions are the reflections of the purpose of the research questions which were to investigate:

1. What are the experiences of caregivers of patients with stroke in Cape Coast Metropolis (CCM)?
2. How do caregivers of patients with stroke cope with their experiences in caring for patients with stroke in CCM?
3. How does caregiving affect caregivers of patients with stroke in CCM?

Nature of Caregiving

It came out of the findings that caregivers' experiences were characterised by work throughout the day. This finding is consistent with the findings of Simeone et al (2016). They found out that caregivers involved in their study experienced work overload throughout the day to ensure that the stroke patient is catered for appropriately. Similarly, the finding of this current study is in line with the findings of Bulley, Shiels, Wilkie, and Salisbury (2010) that caregivers experienced work overload due to the fact that they have to take care of the stroke patient and children. According to Simeone et al (2016), the caregivers experienced work overload because caregivers did not receive assistance from the National Health Service. However, in this current study, it was evident that caregivers experienced work overload because they were the only family members who were available to take care of the stroke patient.

Also, the finding of this study shows that caregivers experienced stress due to their numerous daily tasks as well as other responsibilities of caring for other family members such as children. This finding confirms the findings of El Masry (2010) who found out that caregivers of stroke survivors admitted to the Royal Prince Alfred Hospital (RPAH) reported that their work was stressful. El Masry explained that the caregivers experienced stress because they had to manage and adjust to their increased daily tasks as well as competing duties of caring for stroke patients and other family members.

In addition, caregivers reported their frustration resulting from the behaviour of stroke patients during the performance of tasks or catering for the stroke patient. In the same way, El Masry (2010) found out that caregivers of stroke patients experienced frustration resulting from the performance of their day-to-day activities of catering for the stroke patient.

Furthermore, the findings of this study confirm that of Greenwood et al. (2009) that carers of stroke patients experienced time constraints and expressed their need for time for themselves. Like the findings of this study, Greenwood et al's study revealed that caregivers are constantly with the stroke patient throughout the day. Caregivers expressed that taking care of a stroke patient denies them freedom since they have to be with the stroke patient constantly. Also, the lack of time deprives caregivers of engaging in activities they value or even take leisure. Although caregivers expressed the need for time for themselves, they felt this is an impossibility because the stroke patient depends on them for their needs to be met. The implication of this finding is that caregivers recognise their importance in the life of stroke patients.

Additionally, the account of participants is consistent with the findings of Simeone (2016) who found out that caregivers' relationship with the stroke patient improved. That is, caregivers and stroke patients, developed mutual affection for each other. Simeone et al (2016) attributed the affection caregivers and stroke patients had to the fact that caregivers experienced a lot of challenges in caring for the patient. However, in this current study, the findings showed that the strengthening of the bond between the stroke patient and caregivers was as a result of spending most of their time together in the home or in the hospital. This created an opportunity for caregivers and stroke patients to talk about personal issues as described by Ama. Also, the finding of this current study is consistent with that of Hunt and Smith (2004), who found out that caregivers experienced strengthening of relationships with patients. They added that caregivers described their relationship with stroke patients as more solid and closer.

Coping Strategies

The findings of this study revealed that caregivers employed several coping strategies. Earlier studies (Hai et al., 2014; Kumar, Kuar, & Reddemma 2015; Ye 2016) had identified the following as coping strategies: solving problem, positive distraction, seeking social support, help of religious things, family/ social support and spiritual/ faith in God or prayer. Caregivers of stroke patients also employed emotion-focused coping approach which were being active, let go of worries, learning to deal with difficulties and being positive. However, this current study found out that most of the coping strategies employed by caregivers of stroke patients differed from what had been identified by previous studies. The findings of this study showed that caregivers of stroke patients resorted to watching television, sleeping, acceptance, patience and tolerance as well as hope in God and Self-encouragement as means of coping. The difference in the coping strategies employed by the caregivers in this study and previous studies could be attributed to the differences in the geographical settings and culture. However, hope in God and self-encouragement as a coping strategy identified by this study is in line with the findings of some previous studies (Hai & Hui, 2014; Kumar, Kuar & Reddemma, 2015; Ye, 2016).

Impact of Caregiving

All participants involved in this study were workers except those who were on an internship. The findings showed that caring for the stroke patient affected the work of caregivers in one way or the other. This resulted in their reporting to work late which in turn affected their productivity and sales. This finding is consistent with the findings of Irfan et al. (2017) who found out that 51.3% of caregivers reported that their work was negatively affected as a result of giving care to stroke patients.

Financial difficulty was a major theme that emerged from the study. This finding showed that most participants experienced financial constrains as a result of medication, treatment and management. Similarly, a study conducted on impact of caregiving on various aspects of the lives of caregivers in a teaching hospital in Karachi, Pakistan, found out that half of 400 caregivers reported financial difficulties (Irfan et al., 2017). The result of current study was also demonstrated in the study of Ae-Ngibise et al. (2015). It was reported that caregivers experienced financial difficulties which in turn affected them in caring for their patients. This financial difficulties were due to high cost of treatment and management of patients.

Furthermore, the findings of this study revealed that caring for stroke patients affected the sleep of caregivers. It was evident that the participants' sleep was interrupted at night. Caregivers explained their sleep was affected because they had to wake up between sleep and attend to the stroke patient. Also, the participants added that they were unable to sleep for the number of hours they wanted. This finding is in line with the findings of Irfan et al. (2017) who reported that 65% of caregivers who were involved in their study reported that their sleep pattern had been altered as a result of caring for stroke patients.

Equally, evident from other studies (Roth, Fredman, & Haley, 2015; Irfan et al., (2017) is the fact that caregivers' health is compromised as a result of physically challenging tasks such as bathing, dressing and lifting of the stroke patient. This is consistent with the results of this current study. In this recent study, caregivers reported body pains resulting from their daily tasks such as bathing and lifting the stroke patient. Caregivers explained that this affects their health. However, Chow, Wong and Poon (2007) found out that caregivers of stroke patients demonstrated high levels of anxiety and depression. This finding is also consistent with the study of Dadson et al., (2015). According to Dadson and colleagues they found out that stress was common among family caregivers and it impacted negatively on their physical health. The burden (financial, time consuming and others) of caregiving was responsible for their increase in stress which impacted negatively on their physical health.

Additionally, the findings of this study revealed that caregivers' involvement in social activities declined due to caregiving. Caregivers explained that they were unable to attend church services, funerals or parties of their loved ones. This finding is consistent with a previous study conducted by (Greenwood et al., 2009) who found out that caregivers were deprived of time to engage in valued occupations, specifically for leisure. This finding then suggests that taking care of a stroke patient could deny the caregiver freedom. This may affect other individuals' desire to provide care for stroke patients.

Chapter Summary

In this chapter, the researcher explored informal caregivers' experiences in taking care of persons with stroke. The findings were supported by the work of other researchers who had investigated the experiences of caregivers. The key themes identified were:

1. Nature of Caregiving
2. Coping Strategies
3. Impact of caregiving

The findings of this study may lack transferability and generalisation to some other population in different locations since it is a purely qualitative study.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, RECOMMENDATIONS

Introduction

This chapter provides a summary of the study. It presents the key findings and conclusions. It proposes some recommendations towards improving on the work of caregivers of stroke patients.

Summary

The main purpose of this study was to examine informal caregivers' experiences in taking care of persons with stroke. The researcher sought to answer the following research questions:

1. The experiences of caregivers of patients with stroke in Cape Coast Metropolis (CCM).
2. The various ways in which caregivers of patients with stroke cope with their experiences in caring for patients with stroke in Cape Coast Metropolis.
3. How caregiving affects caregivers of patients with stroke in Cape Coast Metropolis.

In order to provide answers to these research questions, the researcher employed the phenomenological method of inquiry. Data was gathered using face-to-face interviews. The purposive sampling method was used in selecting participants for the study. The sample consisted of 13 caregivers. The researcher adopted Braun and Clarke's (2006) thematic data analysis technique

Key Findings

1. Caregivers experiences were characterized with increased daily task which is time-consuming, stressful, frustrating and financially demanding. However, caregiving for stroke patients strengthened the relationship between caregivers and patients.
2. Caregivers made use of different coping strategies such as watching television, sleeping, acceptance, patience and tolerance as well as hope in God and self-encouragement. These were the techniques that kept caregivers going.
3. Generally, caregiving for stroke patients negatively affects the caregivers' work, finances, social life and health.

Conclusions

The study concludes that the nature of caregiving for stroke patients is identified with the daily task which is time-consuming, frustrating, and stressful. Also, caregiving promotes and improves family relationships. Again, the study concludes that caregivers employ several coping strategies most especially hope in God and self-encouragement. Findings indicate that participants' work, social life and finances were affected greatly.

To sum it up, informal caregivers of patients living with stroke must pay more attention to their environmental factors that are more likely to lead to stress or challenges in their caregiving. They should also fully accept their role and find better ways of managing the situation.

Recommendations

Based on the findings of the study, the researcher recommends the following:

1. Family members should come together as a group to offer caregiving to their stroke patient instead of leaving it to an individual family member. This would help reduce the burden on individuals.
2. Professionals and stakeholders such as clinical psychologists, medical practitioners should provide education for informal caregivers on how to blend caregiving and manage their work as well as their social life so as to achieve balance.
3. Professionals and stakeholders such as clinical psychologists, medical practitioners should provide education for informal caregivers on the possible health effects due to their role as caregivers and how to manage it.
4. Non-Governmental Organisations that are interested in supporting stroke patients should provide some financial support for informal stroke caregivers to reduce their financial burden.
5. Friends and family members of informal caregivers of patients with stroke should pay regular visits to them in order to serve as a buffer to the effect of caregiving stressors and also not to feel isolated from society.

Suggestions for Further Research

1. Considering that this study employed only qualitative methods of data collection, the study can be replicated within the same metropolis or another using the mixed method approach of data collection.
2. Comparative research is needed to examine the experiences of informal caregivers and formal caregivers.

3. There is also the need to investigate people’s perceptions of giving care to stroke patients.

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APPENDICES

APPENDIX A

INFORMED CONSENT

UNIVERSITY OF CAPE COAST

DEPARTMENT OF EDUCATION AND PSYCHOLOGY.

CAREGIVER EXPERIENCES SEMI-STRUCTURED INTERVIEW GUIDE Title: Experiences of Informal Caregivers of Patients with Stroke in Cape Coast Metropolis, Ghana

Principal Investigator: Phyllis Hyde

Address: University of Cape Coast, College of Education studies, Department of Educational foundation, Department of Education and Psychology.
hydephyllis@yahoo.com

General Information about Research

This consent form is a request for you to take part in a research study on your experiences as informal caregivers of stroke patients. The purpose of this study is to find out your experiences as an informal caregiver providing care for a person 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 caregiver's of stroke patients. It is important that you read this form carefully before deciding to take part in this study and for you to be able to ask all pressing questions of which the necessary clarifications will be given. In case you agree to take part in this study, you will be taken through an interview, which will last between 35 minutes to an hour and will be tape- recorded with your permission. You will be interviewed at a time and place which is suitable for you. The interview will centre on questions relating to your experiences on how caregiving has affected your health, finances, marriage and social life and well-being, how you are coping with your caregiving role and the effects that caregiving has had on you.

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 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 some 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. 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 the hospital or 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, Phyllis Hyde on the mobile number, 0249087048 or via email on hydephyllis@yahoo.com. You can also contact the research supervisor, Professor Emmanuel Kofi Gyimah on 0245698750.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title ‘’Experiences of Informal Caregivers of Patients with Stroke in Cape Coast Metropolis, Ghana’’ has been read and explained to me. I have been given an opportunity to ask any question about the research and answered to my satisfaction. I agree to participate as a volunteer.

……………………….. ……………………………………………..

Date 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.

……………………….. …………………………………….

Date 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.

……………………….. …………………………………………

Date Name Signature of Person Who Obtained Interview

Appendix A

INTERVIEW GUIDE

A. CAREGIVER DEMOGRAPHICS

1. Gender
2. Age (in years)
3. Marital Status
4. Educational level
5. Occupation
6. Religious affiliation
7. Relationship with care recipient
8. How long have you been taking care of the patient?

I. EXPERIENCES OF CAREGIVERS OF PATIENTS WITH STROKE

9. Can you share with me your experiences from your caregiving role
10. What are some of the good experiences or moments in your caregiving role?

III. EFFECT OF CAREGIVING ON CAREGIVERS

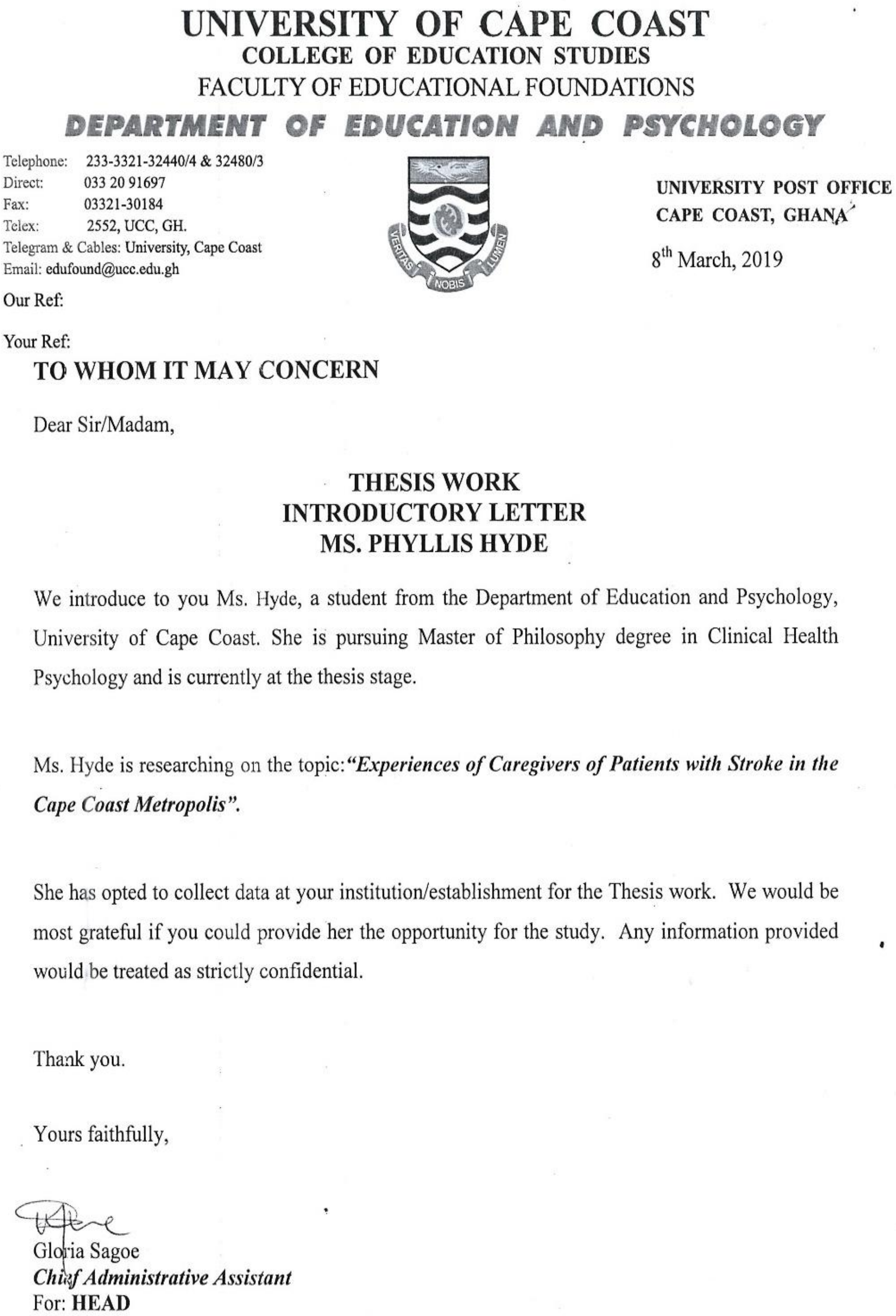
11. How has caregiving affected your health?
12. How has caregiving affected your finances?
13. How has caregiving affected your work?
14. How has caregiving affected your social life?
15. How has care giving affected your marriage?

II. COPING STRATEGIES USED BY STROKE CAREGIVERS IN DEALING WITH THEIR EXPERIENCES

16. What are the various ways you cope with the experiences in caring for the patient?

APPENDIX B

UCC INTRODUCTORY LETTER



UNIVERSITY OF CAPE COAST
COLLEGE OF EDUCATION STUDIES
FACULTY OF EDUCATIONAL FOUNDATIONS
DEPARTMENT OF EDUCATION AND PSYCHOLOGY

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UNIVERSITY POST OFFICE
CAPE COAST, GHANA

8th March, 2019

Our Ref:

Your Ref:

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

THESIS WORK
INTRODUCTORY LETTER
MS. PHYLLIS HYDE

We introduce to you Ms. Hyde, a student from the Department of Education and Psychology, University of Cape Coast. She is pursuing Master of Philosophy degree in Clinical Health Psychology and is currently at the thesis stage.

Ms. Hyde is researching on the topic: ***"Experiences of Caregivers of Patients with Stroke in the Cape Coast Metropolis".***

She has opted to collect data at your institution/establishment for the Thesis work. We would be most grateful if you could provide her the opportunity for the study. Any information provided would be treated as strictly confidential.

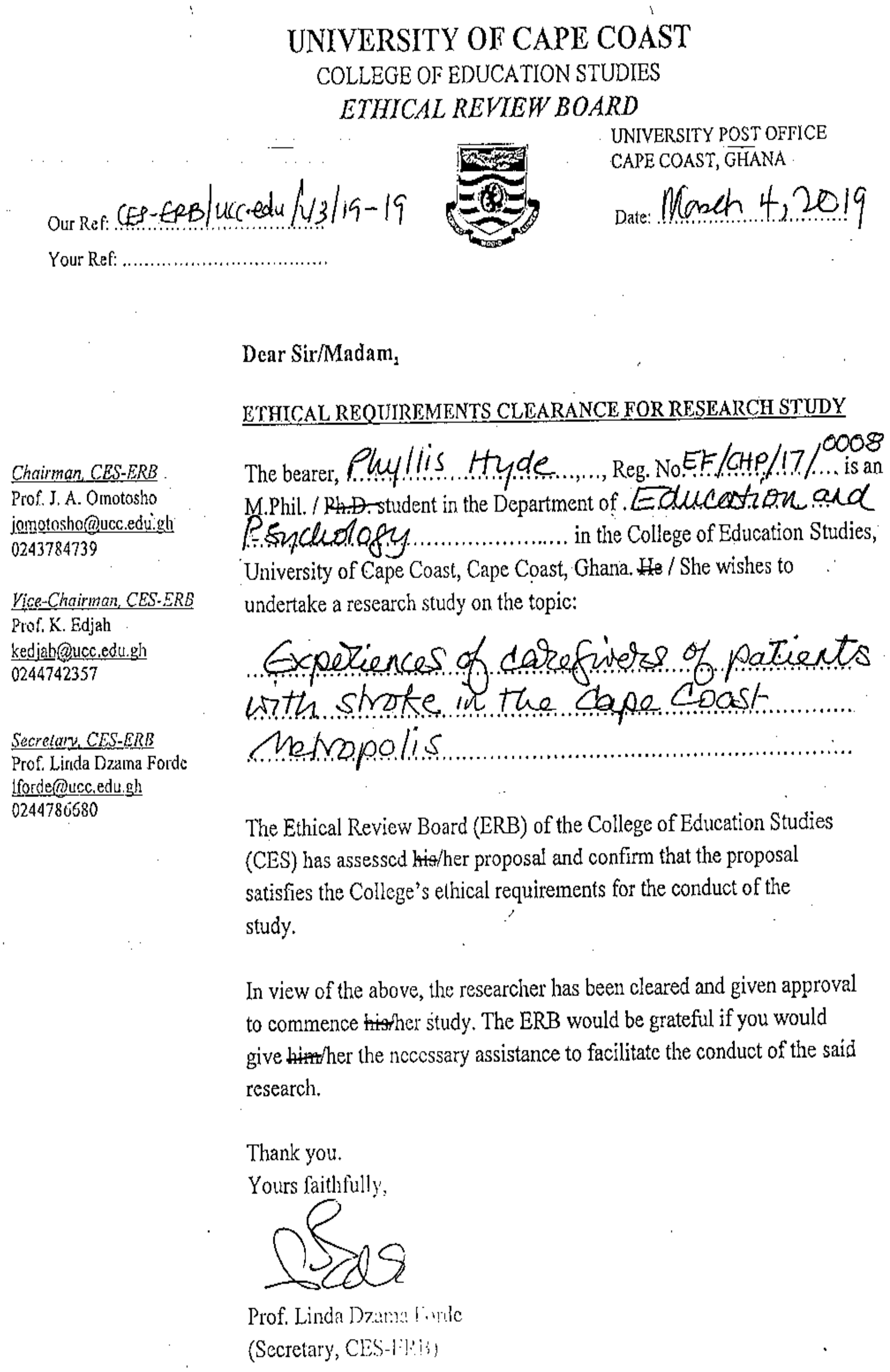
Thank you.

Yours faithfully,

Gloria Sagoe
Chief Administrative Assistant
For: **HEAD**

APPENDIX C

UCC ETHICAL CLEARANCE



UNIVERSITY OF CAPE COAST
COLLEGE OF EDUCATION STUDIES
ETHICAL REVIEW BOARD

UNIVERSITY POST OFFICE
CAPE COAST, GHANA

Our Ref: CES-ERB/ucc.edu/v3/19-19

Your Ref: ....

Date: March 4, 2019

Chairman, CES-ERB
Prof. J. A. Omotosho
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Vice-Chairman, CES-ERB
Prof. K. Edjah
kedjah@ucc.edu.gh
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Secretary, CES-ERB
Prof. Linda Dzama Forde
lforde@ucc.edu.gh
0244786680

Dear Sir/Madam,

ETHICAL REQUIREMENTS CLEARANCE FOR RESEARCH STUDY

The bearer, Phyllis Hyde, Reg. No. EF/CHP/17/0008 is an M.Phil. / ~~Ph.D.~~ student in the Department of Education and Psychology in the College of Education Studies, University of Cape Coast, Cape Coast, Ghana. ~~He~~ / She wishes to undertake a research study on the topic:

Experiences of caregivers of patients with stroke in the Cape Coast Metropolis

The Ethical Review Board (ERB) of the College of Education Studies (CES) has assessed ~~his~~/her proposal and confirm that the proposal satisfies the College's ethical requirements for the conduct of the study.

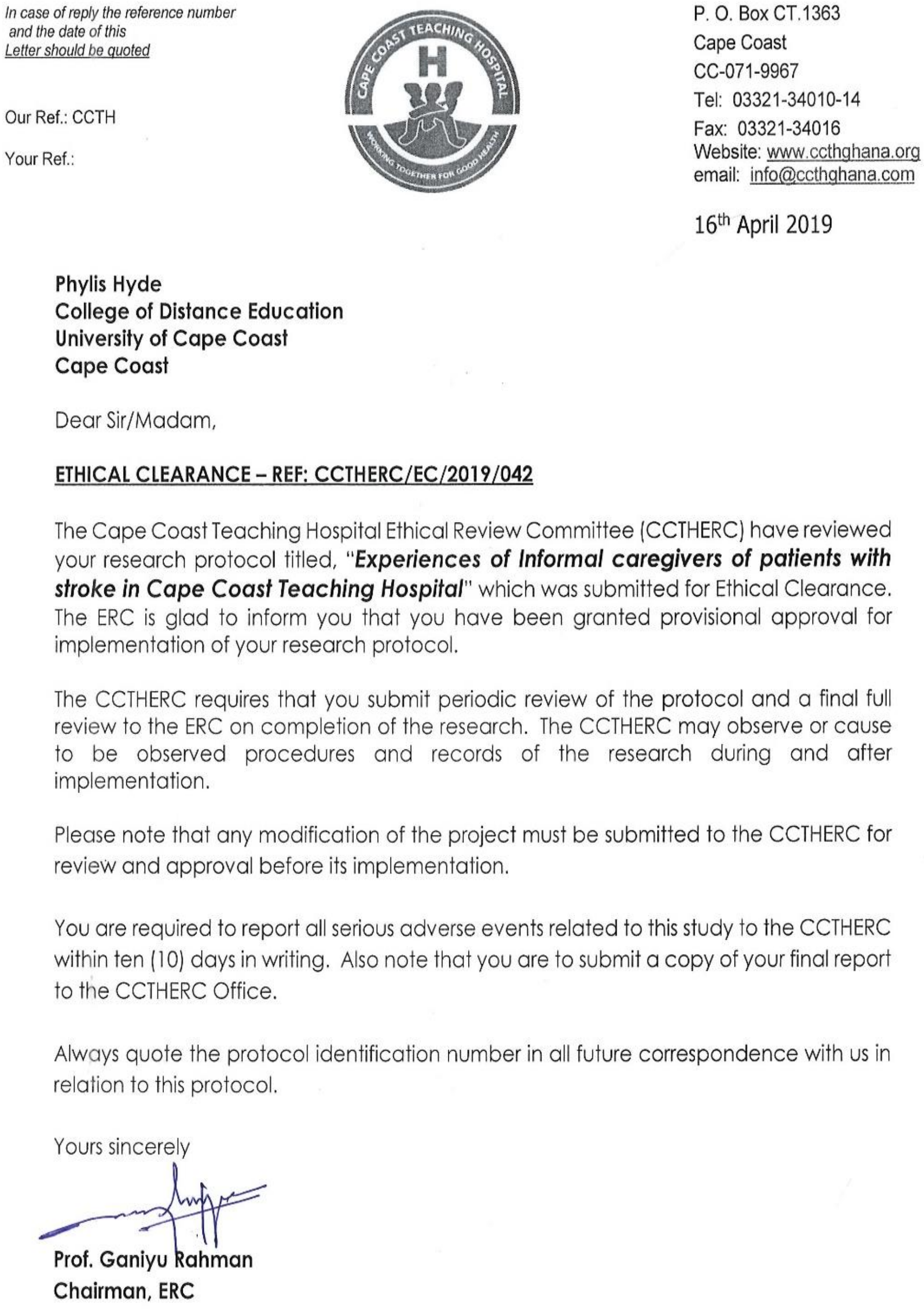
In view of the above, the researcher has been cleared and given approval to commence ~~his~~/her study. The ERB would be grateful if you would give ~~him~~/her the necessary assistance to facilitate the conduct of the said research.

Thank you.
Yours faithfully,

Prof. Linda Dzama Forde
(Secretary, CES-ERB)

APPENDIX D

CCTH ETHICAL CLEARANCE



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

Our Ref.: CCTH

Your Ref.:

P. O. Box CT.1363
Cape Coast
CC-071-9967
Tel: 03321-34010-14
Fax: 03321-34016
Website: www.ccthghana.org
email: info@ccthghana.com

16th April 2019

Phylis Hyde
College of Distance Education
University of Cape Coast
Cape Coast

Dear Sir/Madam,

ETHICAL CLEARANCE – REF: CCTHERC/EC/2019/042

The Cape Coast Teaching Hospital Ethical Review Committee (CCTHERC) have reviewed your research protocol titled, "***Experiences of Informal caregivers of patients with stroke in Cape Coast Teaching Hospital***" which was submitted for Ethical Clearance. The ERC is glad to inform you that you have been granted provisional approval for implementation of your research protocol.

The CCTHERC requires that you submit periodic review of the protocol and a final full review to the ERC on completion of the research. The CCTHERC may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the CCTHERC for review and approval before its implementation.

You are required to report all serious adverse events related to this study to the CCTHERC within ten (10) days in writing. Also note that you are to submit a copy of your final report to the CCTHERC Office.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours sincerely

Prof. Ganiyu Rahman
Chairman, ERC