UNIVERSITY OF CAPE COAST

EXPERIENCES OF FAMILY CAREGIVERS OF PATIENTS WITH STROKE IN THE CAPE COAST METROPOLIS: A DESCRIPTIVE QUALITATIVE DESIGN

GODWIN KWAME FIANU

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BY

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Thesis submitted to the School of Nursing and Midwifery, College of Health and Allied Sciences, University of Cape Coast in partial fulfilment of the Requirements for the award of Master of Nursing Degree.

MAY 2023

DECLARATION

Candidate's Declaration

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

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

Name…………………………………………………………………………...

Supervisors' Declaration

We hereby declare that the preparation and presentation of the thesis were supervised per the guidance on supervision of the thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature……………………... Date…………………......

Name…………………………………………………………………………

Second Supervisor's Signature…………………… Date……………………...

Name ……………………………………………………………………….

ABSTRACT

This study explored the experiences of informal caregivers of stroke survivors in the Cape Coast Municipality of the Central Region of Ghana. In order to achieve this purpose, a purposive sampling technique was endorsed and used to select twelve caregivers who participated in the study. Data collection which was driven by a semi-structured interview guide was done by the use of tape-recorded interviews which lasted for 45 minutes. Thematic content analysis was used to analyze transcribed data. Three major themes with each having sub-themes were derived. These included challenges caregivers faced, strategies for managing disease-related tasks associated with stroke care and the support system available to caregivers. Findings from the study indicated that challenges that confronted informal caregivers mostly in the discharge of their duties included financial constraint, the health of the caregiver being affected and emotional challenges. It was further revealed that caregivers employed strategies for bathing the patient, strategies for medication, communication strategies and feeding strategies. It was finally revealed that support systems that were available for caregivers of stroke patients included support from families, communities, religious organizations and health professionals. It was, therefore, recommended that a well-designed program aimed at equipping the caregivers with requisite skills that will enable them effectively care for their patients should be organized. Also, there must be follow-up activities in which nurses and doctors who attended to the caregivers and their patients could visit caregivers in their home to ascertain their challenges as well as that of the patients. The study further recommended that there should be workshops or conferences on home care to enhance nurses' interest and potentials. In addition, it was recommended that clinicians who have specialized in the care and treatment of stroke are brought to the hospital or if possible trained.

KEY WORDS

Experiences

Family Caregiver

Patients

Stroke

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DEDICATION

To all family caregivers of patients with stroke and my wife for her enormous support, encouragement, and prayers throughout the periods of schooling and writing this thesis.

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CHAPTER ONE

INTRODUCTION

Stroke is a condition with debilitating effects on affected patients, carers and families. Nurses have an important role in supporting patients and families to deal with the impact of stroke. However, in the current literature, there has been limited publication on concerns and needs of carers of stroke patients, especially in developing countries such as Ghana. This thesis explored the experiences of family or informal caregivers of stroke patients to better understand their concerns and needs. The study greatly contributes to the approach used to managing stroke patients and their carers as formal care providers will focus their attention not only on stroke patients but the carers as well. Pre and post-stroke programmes could be designed so that effective care could be implemented to support them. In addition to this introductory section, the remaining part of this study will focus on the background of the study.

Background of the Study

A stroke is defined as an obstruction in brain blood flow resulting from a blockage in an arterial blood vessel or bleeding into the brain (Green & King, 2009). It is an illness with a sudden onset that affects physical, cognitive and behavioural functioning (American Stroke Association, 2015). Globally, stroke was reported to have resulted in an estimated 6.7 million deaths in 2012 (World Health Organisation, 2014) and is the second leading cause of death and the third most important cause of disability burden (Feigin, Forouzanfar. Krishnamurthi, Mensah, Connor & Bennett, 2014). Stroke-related disability burden is on the rise with a 12% increase worldwide since 1990 (Pindus et al., 2018). Nearly one-fifth (17%) of stroke survivors experience post-stroke spasticity (PSS), a disorder of the sensorimotor system characterized by a velocity-dependent increase in muscle tone (Lundstrom, 2008). Post-stroke spasticity frequently causes pain and interferes with hand and arm positioning, which affects grasping, self-care and other activities of daily living of the stroke survivor (Doan, Brashear & Gillard, 2012; Zorowitz & Gillard, 2013). Spasticity-related stiffness and discomfort can interfere with physical activities such as ambulation, hygiene and dressing in addition to psychological consequences on mood and self-esteem (Graham, Dibonaventura,& Gillard, 2015).

Since stroke is sudden and often results in a disability, the caregiver is often unprepared to undertake the related caring responsibilities such as feeding, hygiene and daily living activities (Camak, 2015; Gbiri, Olawale & Isaac, 2015). This, therefore, raises the significance and the involvement of informal caregivers in the caring process.

Informal caregivers are non-medically trained persons (relatives, friends or neighbours) who provide unpaid practical support either daily or at least twice a week to an older adult or person who has a medical condition that affects their ability to carry out basic activities of daily living (Gupta, 2009; Lethin et al., 2016; Shiba, Kondo & Kondo, 2016). Family members caring for patients can have profound effects on all aspects of everyday life. Therefore, many caregivers endure a significant burden of caring for loved ones. Family caregivers may become active members of the healthcare team without preparation or with very little preparation and sometimes they experience severe conditions (Glajchen, Kornblith, Homel, Fraidin & Mauskop, 2005). These caregivers may not have the resources or skills needed to play this complex and new role, which may include activities related to daily life, giving medication and financial and psychological support (Kavi, Bazrafshan, Taleghani, Abolhasani, & Akbari, 2019). Also, informal caregivers of stroke patients in the acute phase of stroke care experienced increased burden that bothered on the immediate health status and medical interventions required for the recipients (Hafsteinsdóttir, Vergunst, & Lindeman, 2011; O'Connell & Baker, 2003). They reported to health care managers in the acute care facilities certain limitations impacting on their caring roles. These included limited communication, use of unfamiliar medical terms by health professionals and hospital environment issues (Clarke, et al., 2014; Grant & Hunt, 2014; Scarafia, 2012).

Family caregivers frequently express concerns regarding inadequate preparation and lacking the knowledge and skills to support the patient (Jullamate, De Azeredo & Paul, 2006; Oupra, Griffiths & Pryor, 2010). Studies have shown that informal caregivers are vulnerable to physical and psychological distress (Thrush, 2014; Camak, 2015; Gott, Allen & Moeke-Maxwell, 2015). A recent survey by the Stroke Association of the United Kingdom in 2013 found that 64% of informal carers suffer from the emotional impact of stroke, over two-thirds experience stress, and approximately 80% experience anxiety or frustration. The experience of stress and negative effects can lead to a breakdown in family relationships and neglect of a caring role. Two-thirds of informal carers report experiencing difficulties in their relationship with a stroke survivor and 1 in 10 breakup with their partner (United Kingdom Stroke Association., 2013). Even if the caregiver has had previous experience caring for individuals with disabilities, the demands and expectations of vigilance for adequate care at home are often overwhelming and exhausting (Lutz, Young & Kim, 2011). Despite the negative experiences that are linked with care-giving, there are positive aspects as well (Cameron, Stewart, Streiner & Coyte, 2014; Kruithof & Visser-Meily, 2012). These positive experiences include; strengthened relationships, feeling appreciated and increased self-esteem (Greenwood & Mackenzie, 2012). Also, caregivers' feeling of being appreciated and gaining more meaning to life, feeling needed, useful and good about themselves were reported in a study by more than 80% of stroke family caregivers (Haley, Allen, Grant & Clay, 2012).

Descriptions of the experiences of stroke caregivers have focused on specific experiences and populations, and have considered varied time intervals from the initiation of caregiving (Simeone et al., 2016). Studies 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 (Ellis-Hill et al., 2009; Gustafsson & Bootle, 2013; Hunt & Smith, 2004; Wallengren, Friberg, & Segesten2008). Research on experiences of stroke caregivers reflects certain demographics of the population including female caregivers (Saban & Hogan, 2012) and older caregivers (Gosman-Hedstrom & Dahlin-Ivanoff, 2012; Greenwood, Mackenzie, Cloud, & Wilson, 2010; Cecil et al., 2011).

Other studies that have been done mainly investigated informal caregiver experiences with incontinence, utilization of primary and community health care and stroke crisis (Aziz, Pindus, Mullis, Walter & Mant, 2016; Barbara Lutz, Mary Ellen Young, Kim Cox,2013; Ghazzawi, Kuziemsky & Sullivan, 2016; Kerr & Smith, 2001; Tseng, Huang, Yu, & Lou, 2015).

Furthermore, most of the studies were conducted in Europe, China, Thailand, Taiwan, United Kingdom, Brazil, Peru and America (~~Barbara Lutz, Mary Ellen Young, Kim Cox, 2013~~ Lutz, Ellen Young, Cox, Martz, & Rae Creasy (2011).; Ghazzawi, Kuziemsky & Sullivan, 2016; Kerr & Smith, 2001; Tseng, Huang, Yu, & Lou, 2015) but limited studies in Africa.

In Africa, studies related to stroke carers have been reported only in Nigeria and South Africa (Ademola, Ayinla, & Oghenekewe, 2015; Hassan, 2011; Ogunlana, Dada, Oyewo, Odole & Ogunsan, 2014). However, in the Ghanaian context, Boakye, Nsiah and Bello (2017) explored the burden of care and quality of life among caregivers of stroke survivors: influence of clinical and demographic variables. In the same vein, Sanuade (2016) also studied the burden of stroke in Ghana with attention to prevalence, experience and care-giving. Similarly, Adzovie (2016) also worked on formal social support for caregivers of elderly stroke survivors.

In these few studies, none concentrated on the experiences of informal caregivers of stroke patients with a focus on experiences with management of disease-related tasks, strategies for managing disease-related tasks which are inherent in chronic diseases and the support system available to informal caregivers. This study seeks to explore the experiences of informal caregivers in the home environment**.** The drive to conduct this study is ignited by the absence of studies relating to this particular topic in the Cape Coast metropolis. A better understanding of stroke caregiver experience would improve knowledge on the stroke trajectory from the caregivers’ perspective, which is needed to tailor interventions for caregivers.

Statement of the Problem

Stroke is among the leading cause of death and one of the major causes of disability worldwide. (Gbiri, 2013; Murray, Vos, Lozano, Naghavi, Flaxman & Shibuya, 2012). It is claimed that informal caregivers experience life after stroke as “lives turned upside down (Bulley & Shiels, 2010). Due to the abrupt and often unpredictable nature of stroke, caring for stroke survivors often puts a considerable burden on informal family caregivers (Bhattacharjee, Vairale & Gawali, 2012; Costa, Costa & Martins, 2015).

Informal caregivers in sharing their experiences of caring indicated that their style of life has drastically changed since their loved ones were taken ill (Masuku, Mophosho & Tshabalala, 2018). Many of these family caregivers have recounted moments or periods of sleeplessness because they have to keep watch in the night to monitor any changes with the patient. Others have indicated feelings of fear and lack of control over situations around them (Das, Hazra, Ray, Ghosal, Bernejee, Roy, Chaudhuri, Raut & Das, 2010; Jullamate, De Azeredo & Paul, 2006b; Oupra, Griffiths & Pryor, 2010b). They attributed this to the fact that family members of their sick spouse have neglected their responsibilities and are ready to blame them in case of the demise of the stroke patients. The majority of these informal caregivers face several challenges. These challenges include financial burdens where they have emptied their accounts to only facilitate treatment especially physiotherapy, altered job schedules because they do not report to work on time and difficulty communicating with their patients (Asiret & Kapucu, 2012).

The issue of communication challenges they indicated was frustrating as they are not able to make meaning out of what their patients say. They have to spend time bathing, feeding and giving medications which consume so much time. The reason is that their loved ones have a mobility impairment and swallowing difficulties which demand a lot of patience in providing care. Another thorny challenge they encounter concerns the state in which loved ones are discharged from the hospital. In their interactions with the nurses on the wards where their patients have gone on admission, they indicated a lack of confidence and boldness in rendering care sometimes. It was disclosed that they have not been trained or educated enough to fully assume the caregiving role. One of the family caregivers during the review of her husband, requested periodic visits by the nurses to their home because they felt neglected and lonely. Since the care of stroke patients is complex, the need for strategies to managing their patients has become imperative and caregivers (informal) have looked up to the formal caregivers to impact them with the requisite skills for their caring roles.

Furthermore, other challenges include poor adherence to medication based on difficulties associated with swallowing and increased stress on caregivers and these can result in increased rates of readmission. It is anticipated that the high readmission rate could be attributed to improper care the patients receive at home. However, in the Ghanaian context, Boakye, Nsiah and Bello (2017) explored the burden of care and quality of life among caregivers of stroke survivors: influence of clinical and demographic variables. In the same vein Sanuade, (2016) also studied the burden of stroke in Ghana with attention to prevalence, experience and care-giving. Similarly, Adzovie, (2016) also worked on formal social support for caregivers of elderly stroke survivors.

In these few studies, none focused on the experiences of informal caregivers of stroke patients with a focus on experiences with management of disease-related tasks, strategies for managing disease-related tasks and the support system available to these informal caregivers at home where there is no influence of trained health personnel. Also, in Ghana and Cape Coast specifically, there is lack of long-term care for stroke patients, poor social support for patients and limited stroke rehabilitation services thereby increasing the burden of family caregivers and hence, the need to conduct this study. This study seeks to discover the experiences of informal caregivers in their home settings.

Purpose of the Study

The purpose of the study is to explore the experiences and challenges of informal caregivers of stroke patients in the Cape Coast metropolis.

Specific Objective

1. To explore the informal caregivers' challenges in the care of stroke patients.
2. To explore caregivers' strategies for managing the "disease-related tasks" associated with stroke care among informal carers.
3. To explore the support systems made available to informal stroke caregivers in the Cape Coast metropolis.

Research Questions

1. What are the challenges informal caregivers of stroke patients encounter?
2. How do informal caregivers manage the disease-related tasks associated with stroke care?

3. What are the support systems available to informal stroke caregivers?

Significance of the Study

It is expected that the findings of this study will provide an understanding of the challenges that confront stroke caregivers, the specific stroke care strategies in domestic settings including safe and unsafe practices and the support they receive in caring for stroke patients. This information will then be utilized to design educational interventions for stroke caregivers to promote safer care for stroke patients in domestic settings. In the area of nursing education, the findings of this study will provide or increase the knowledge of the nurses in academia regarding home management practices of stroke by carers. This will help to tailor teaching and learning among staff and students in nursing schools. The findings will serve as the basis for further research by students in nursing schools and care providers in clinical settings. The findings from this research also contribute to theory development in nursing to guard stroke management in the homes and communities.

Delimitations

The study will focus on caregivers of patients who were diagnosed with stroke (cerebrovascular accident), unable to perform any activity, went on admission, discharged home to continue treatment and are dependent. It will not include caregivers of stroke patients who are outside the Cape Coast metropolis or caregivers of patients who were not diagnosed in the Cape Coast Teaching Hospital. In this instance, the experience of the caregiver will capture the challenges that these informal caregivers are confronted with, strategies for managing these patients, and the support system available to these informal caregivers in their quest to cater to these patients.

Limitations

This study had a few limitations. First, the selection of participants to be interviewed was limited to caregivers who understood and spoke English language, thereby neglecting other caregivers who have had rich experiences that the researcher could have used.. The busy schedules of caregivers were limitations because even in their home setting, they had to be met several times to complete the interviews**.** Some of the caregivers in the course of the interview became emotional with sensitive issues which did not permit them to given details**.** Finally, the retrieval of caregivers` addresses and contacts from the admission and discharge books was difficult because of improper documentation on the part of the nurses in the ward. As a result, some caregivers eligible for selection could not be reached. This created deficiencies in the findings in terms of the rich information these unreached caregivers could have given. So, nurses who had a personal relationship with these caregivers during the period of admission were contacted for their contact numbers and direction to where they reside. Thus, the majority of these caregivers were reached to reduce the impact on the findings of this study. Those who got emotional in the cause of the interview were visited again to get detailed information.

Operational Definition

Stroke patient: A person suffering from a condition in which there is an interrupted or reduced blood supply to part of the brain preventing brain tissue from getting oxygen and nutrients resulting in brain cell death.

Caregiver: A person who manages a stroke patient at home to ensure that the stroke patient's activities of daily living, health and other needs are met daily.

Experience: It is the feelings, challenges or difficult situations encountered by informal caregivers in the course of caring for stroke patients. It involves management of feeding tubes at home, sleeplessness which is associated with observing patients throughout the night and purchasing of expensive medications.

Disease-related tasks: **T**hey are activities such as bathing, feeding, giving of medication, dressing of pressure sores, preventing pressure sores, contractures and maintaining patient's hygiene which care givers perform for stroke patients.

Organization of the Study

The study is 11nderpin11 into five chapters. Chapter one which presents the introduction of the study shelters background of the study, problem statement, purpose of the study and specific objectives, research questions, the significance of the study, delimitations, limitations and operational definition. Chapter Two dealt with the theoretical and conceptual review and empirical review relevant to experiences of family caregivers of stroke patients. The Third Chapter was dedicated to research design, study area, study population, sampling procedure, inclusion criteria, exclusion criteria, data collection instrument, data collection procedure, ethical consideration, data processing analysis and rigor. The Fourth Chapter looked at the findings and discussions of the objectives which are to explore the experiences of caregivers. Chapter five covered the summary of the main findings, conclusions, contribution to knowledge, recommendation, limitations and suggestion for further research.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This study focuses on exploring the experiences and challenges of caregivers of stroke patients and also examines how they deal with health-related challenges that arise from care-giving. The previous chapter explained the background of the study, the research problems, and gave justification for the necessity of the study. This chapter aims at reviewing literature that is relevant and related to this study.

The literature for this study was accessed from electronic databases and other internet-based resources including CINAHIL, EBSCOHOST, PUBMED, HINARI, and GOOGLE SCHOLAR. Only English Language papers with full texts available, published from 2007 to 2017 were reviewed. Key search terms for the search included informal caregivers and synonyms such as carers, stroke, and synonyms such as cerebrovascular accident (CVA) and experience and synonyms such as strategies, skills and “know-how”. Other print resources such as books, print articles and journals were sourced through the University of Cape Coast Library. Other grey literature was sourced from the Ministry of Health, Ghana, Ghana Health Service, and the Cape Coast Teaching Hospital. The data was stored in Mendeley. The review covers stress Process Model of Family Caregivers, the self-care deficit theory (Orem, 1991) and Watson’s nursing theory (Watson, 1999). The conceptual review focuses on stroke and caregiving. The empirical review looks at the experiences of caregivers, challenges of informal caregivers of stroke patients, strategies for managing the health-related task associated with stroke care and the support system available to informal caregivers. The evidence derived from reading the literature was summarized and reported narratively.

Theoretical Review

This aspect of the study focuses on outlining the various theoretical models that underpin this area of inquiry. The theories in focus are Stress Process Model of Family Caregivers, Orem's theory of self-care deficit and Watson's nursing theory.

Stress Process Model of Family Caregivers

Researchers in the area of mental health have been interested in understanding the processes involved in the translation of the stressors that individuals experience into outcome symptoms of distress or other health problems. A variety of stress process models have been proposed and developed primarily to examine the nature of stressors and their associations with various health outcomes. One of these models is Pearlin's stress process model (Pearlin, 1999). This model begins by locating stressors in their broader social context: the structural positions, statuses and roles that shape exposure and response. Stressors come in many different forms, including major life events, chronic strains, daily hassles and traumas. The effects of stressors on outcomes depend on the extent to which stressors proliferate as well as social and personal resources to which people have access, including social support and the self-concept. These moderating resources may themselves be affected by stressors, as when a job loss diminishes one's access to supportive social relations and may therefore mediate as well as moderate stressors' effects.

This model has motivated two major lines of sociological research. In the first, researchers use the stress process framework to analyze the process through which people respond to challenging life circumstances. For example, Aneshensel et al. (1995) used the stress process framework to conceptualize the experiences of family members caring for a person with Alzheimer's disease. The14nderpinns they asked centered on the stress process itself: GIven the presence of a stressor (caregiving), what processes determine its outcomes? Stress proliferation, stress containment, social support and mastery were among the experiences and resources that predicted variation in physical and mental health in their sample. Other scholars have evaluated variation in the association of summated measures of stressors with outcomes based on these same factors. Although different in the specifics, these studies share an interest in what distinguishes people who adapt successfully to stressors from those who do not.

In the second line of inquiry, researchers use the components of the stress process model to analyze the social origins of distress. For example, Turner, Wheaton, and Lloyd (1995) evaluated the extent to which group differences in depression were attributable to group differences in stress exposures. Similarly, Williams et al. (1997) evaluated the extent to which race differences in health were attributable to race differences in exposure to discrimination. The questions these researchers asked included the following: Do stress exposure and access to social and personal resources vary on the basis of important social statuses, such as race, socioeconomic position and gender? Do these variations explain group differences in distress? In this line of research, the focus is less on the stress process itself and more on its components as proximate manifestations of stratification. A central tenet of psychological and sociological stress research is that the effects of stressors on outcomes depend on their meanings to the person (Lazarus & Folkman, 1984; Pearlin, 1989). This tenet implies that the resources and actions that modify stressors' effects (e.g., social support and coping) do so in part by altering meanings. It further suggests that (1) we cannot understand how the stress process operates without taking meaning into account and that (2) social arrangements may produce distress not only by influencing objective life circumstances but also by influencing how those circumstances are interpreted. Dominant approaches to analyzing meaning in the stress process do not give systematic attention to either.

A general stress paradigm has also been developed in the study of health and illness. In comparison to caregivers of stroke patients, they experience a greater number of stressors in their lives (Hoffman et al., 1992). The stress process model allows the researcher to examine this issue because the model incorporates factors that influence the ways in which stressful experiences are translated into outcomes. These factors are regarded as resources that might intervene, acting as moderators, in the stress-outcome relationship. As such, it is argued that the stress process model is a useful tool for assessing the complex relationships associated with informal caregivers of stroke patients.

There are three key components to the stress process model: sources of stress, intervening factors and the manifestations of stress. Life experiences do not occur in a vacuum, but are influenced by the social structure and the status and roles individuals occupy. A central assumption of this paradigm is that stress is a process encapsulating a variety of factors. These may culminate in a range of outcomes including mental and physical health problems (Pearlin, Monton, Lieberman, Menaghan & Mullan, 1981; Pearlin & Schooler, 1978).

In general, the stress process model describes the interplay between potentially stressful occurrences, as well as personal and environmental resources that may influence the effects of stress on health outcomes.

Self-care deficit theory

The study is grounded in a larger theoretical framework based on the self-care deficit theory by Dorothea Orem (1991). The self-care deficit nursing theory is a grand nursing theory that was developed by Dorothea Orem (Hartweg, 1991). The theory is also referred to as Ore''s Model of Nursing. This theory originates from the totality paradigm based on human beings able to adapt to one's environment (Younas, 2017). It is widely used in nursing literature and has displayed the improved quality of care based on results from various randomized controlled trials in the nursing discipline (Younas, 2017). It is particularly used in rehabilitation and primary care settings, where the patient is encouraged to be as independent as possible (Denyes, Orem & Bekel, 2001).

The Self-care deficit theory was developed as a result of Dorothea Orem working toward her goal of improving the quality of nursing in general hospitals in her state (Hartweg, 1991). The model inter-relates concepts in such a way as to create different ways of looking at a particular phenomenon. The theory is relatively simple, but generalizable to apply to a wide variety of patients. It can be used by nurses to guide and improve practice but it must be consistent with other validated theories, laws and principles (Younas, 2017).

According to Hartweg (1991), the major assumptions of Orem's Self-care deficit theory are: individuals should be self-reliant, and responsible for their care, as well as others in their families who need care. People are distinct individuals. Nursing is a form of action. It is an interaction between two or more people. A perso''s knowledge of potential health problems is needed for promoting self-care behaviours. Self-care and dependent care are behaviours learned within a socio-cultural context. Orem's theory comprises three related parts: theory of self-care; theory of self-care deficit and theory of nursing system. These are explained below:

Theory of self-care

The theory of self-care includes self-care, which is the practice of activities that an individual initiates and performs on his or her own to maintain life, health and well-being; self-care agency, which is a human ability that is "the ability for engaging in self-care", conditioned by age, developmental state, life experience, socio-cultural orientation, health and available resources; therapeutic self-care demand, which is the total self-care actions to be performed over a specific duration to meet self-care requisites by using valid methods and related sets of operations and actions; and self-care requisites, which include the categories of universal, developmental and health deviation self-care requisites (Denyes et al., 2001). Universal self-care requisites are associated with life processes, as well as the maintenance of the integrity of human structure and functioning (Denyes et al., 2001). According to Hartweg (1991), Orem identifies these requisites, also called Activities of Daily Living (Denyes et al.,2001), which includes: maintenance of sufficient intake of air, food and water; provision of care associated with the elimination process; balance between activities and rest, as well as between solitude and social interaction; prevention of hazards to human life and well-being and promotion of human functioning.

Again, developmental self-care requisites are associated with developmental processes (Shah, 2015). They are generally derived from a condition or associated with an event. Health deviation self-care is required in conditions of illness, injury or disease (Denyes et al., 2001). These include: seeking and securing appropriate medical assistance; being aware of and attending to the effects and results of pathologic conditions; effectively carrying out medically prescribed measures; modifying self-concepts to accept oneself as being in a particular state of health and specific forms of health care and learning to live with the effects of pathologic conditions.

Theory of self-care deficit

The second part of the theory, self-care deficit, specifies when nursing is needed. Nursing is required when an adult is incapable or limited in the provision of continuous, effective self-care (Orem, 1991 as cited in Hartweg, 1991). The theory identifies five methods of helping: acting for and doing for others; guiding others; supporting another; providing an environment promoting personal development to meet future demands and teaching another (Denyes et al., 2001).

Theory of nursing systems

The theory of nursing systems describes how the patient's self-care needs will be met by the caregivers and the patient (Shah, 2015). Orem identifies three classifications of the nursing system to meet the self-care requisites of the patient: wholly compensatory system, partly compensatory system and supportive-educative system (Hartweg, 1991). Orem recognized that specialized technologies are usually developed by members of the health care industry (Hartweg, 1991). The theory identifies two categories of technologies.

The first is social or interpersonal. In this category, communication is adjusted to age and health status (Hartweg, 1991). The nurse helps maintain interpersonal, intra-group or inter-group relations for the coordination of efforts. The nurse should also maintain a therapeutic relationship in light of psychosocial modes of functioning in health and disease (Denyes et al., 2001). In this category, human assistance adapted to human needs, actions, abilities and limitations are being given by the nurse. The second is regulatory technologies, which maintain and promote life processes. This category regulates psycho-physiological modes of functioning in health and disease (Hartweg, 1991). Nurses should promote human growth and development, as well as regulating position and movement in space (Denyes et al., 2001).

Application of Orem's Self-care deficit theory

Ore''s approach to the nursing process provides a method to determine the self-care deficits and then to defines the roles of the patient or nurse to meet the self-care demands. The steps in the approach are thought of as the technical component of the nursing process. Orem emphasizes that the technological component“"must be coordinated with interpersonal and social pressures within nursing situations.” The nursing process in this model has three parts. First is the asses“ment, which collects data to determine the problem or concern that needs to be addressed. The next step is the diagnosis and creation of a nursing care plan. The third and final step of the nursing process is the implementation and evaluation. The nurse sets the health care plan into motion to meet the goals set by the patient and his or her health care team, and, when finished, evaluates the nursing care by interpreting the results of the implementation of the plan.

Orem’s theory of self-care is a very important as far as this study is concerned. Because the purpose of this current study is to explore the experiences and challenges of caregivers, understanding this theory will give caregivers insight on how to regulate and meet the demands of stoke patients. Caregivers can base on the theory of self-care to train the patients on how to be independent in case of an absence of caregivers and this can be done through the theory of nursing systems where all the needs of patients are provided. Systems can be put in place to ensure that things needed to practice self-care theory by patients are provided.

Watson’s nursing theory

Jean Watson began developing her theory while she was an assistant dean of the undergraduate program at the University of Colorado, and it evolved into the planning and implementation of its PhD nursing programme. The Philosophy and Science of Caring addresses how nurses express care to their patients (Watson, 1999). Caring is central to nursing practice and promotes health better than a simple medical cure (Watson, 2007).

The Philosophy and Science of Caring have four major concepts: human beings, health, environment/society and nursing. Watson (1999) refers to the human being as “a valued person in and of him or herself to be cared for, respected, nurtured, understood and assisted; in general, a philosophical view of a person as a fully functional integrated self. Human is viewed as greater than and different from the sum of his or her parts.” According to Watson (1999), “health is defined as a high level of overall physical, mental, and social functioning; a general adaptive-maintenance level of daily functioning; and the absence of illness, or the presence of efforts leading to the absence of illness.”

Watson's definition of environment/society addresses the idea that nurses have existed in every society, and that a caring attitude is transmitted from generation to generation by the culture of the nursing profession as a unique way of coping with its environment (Watson, 1999).

The nursing model states that nursing is concerned with promoting health, preventing illness, caring for the sick and restoring health. It focuses on health promotion, as well as the treatment of diseases. Watson (1999) believed that holistic health care is central to the practice of caring in nursing. The nursing process outlined in the model contains the same steps as the scientific research process: assessment, plan, intervention, and evaluation (Watson, & Woodward, 2010). The assessment includes observation, identification, and review of the problem, as well as the formation of a hypothesis. Creating a care plan which helps the nurse determine how variables would be examined or measured and what data would be collected. Intervention is the implementation of the care plan and data collection. Finally, the evaluation analyses the data, interprets the results and may lead to an additional hypothesis (Watson, 2007).

Assumption of Watson nursing theory

Watson's (1999) model makes some assumptions:

1. Caring can be effectively demonstrated and practised only interpersonally. Caring consists of curative factors that result in the satisfaction of certain human needs.
2. Effective caring promotes health and individual or family growth.
3. Caring responses accept the patient as he or she is now, as well as what he or she may become.

4. A caring environment is one that offers the development of potential while allowing the patient to choose the best action for him or herself at a given point in time.
5. The science of caring is complementary to the science of curing.
6. The practice of caring is central to nursing.

Curative factors of Watson's nursing theory

Jean Watson devised ten caring needs specific curative factors critical to the caring human experience that need to be addressed by nurses with their patients when in a caring role (Watson, 2007). As curative factors evolved within an expanding perspective, and as her ideas and values evolved, Watson offered a translation of the original curative factors into clinical Caritas processes that suggested open ways in which they could be considered (Watson, 2007). The first three curative factors are the "philosophical foundation" for the science of caring, while the remaining seven are derived from that foundation (Watson, 2007). According to Watson (1999), the ten primary curative factors are: the formation of a humanistic-altruistic system of values begins at an early age with the values shared by parents. The system of values is mediated by the nurs''s life experiences, learning gained and exposure to humanities. It is perceived as necessary to the nurse's maturation which in turn promotes altruistic behaviour toward others. The installation of faith-hope is essential to the curative and curative processes. When modern science has nothing else to offer a patient, a nurse can continue to use faith-hope to provide a sense of well-being through a belief system meaningful to the individual.

The cultivation of sensitivity to one's self and to others, which explores the need of nurses to feel an emotion as it presents itself. The development of a nurs’'s feelings is needed to interact genuinely and sensitively with patients. By striving to become more sensitive, the nurse is more authentic. This encourages self-growth and self-actualization in both the nurse and the patients who interact with the nurse. The nurses promote health and higher-level functioning only when they form person-to-person relationships. The development of a helping-trust relationship includes congruence, empathy and warmth. The strongest tool a nurse has is his or her mode of communication, which establishes a rapport with the patient, as well as caring by the nurse. Communication includes verbal and nonverbal communication, as well as listening that connotes empathetic understanding.

The promotion and acceptance of the expression of both positive and negative feelings need to be considered and allowed in a caring relationship because of how feelings alter thoughts and behaviour. The awareness of the feelings helps the nurse and patient understand the behaviour it causes. The systematic use of the scientific method for problem-solving and decision-making allows control and prediction and permits self-correction. The science of caring should not always be neutral and objective. The promotion of interpersonal teaching-learning should focus on the learning process as much as the teaching process. Understanding the person’s perception of the situation assists the nurse to prepare a cognitive plan.

The provision for a supportive, protective, and/or corrective mental, physical, socio-cultural and spiritual environment, which Watson divides into interdependent internal and external variables, manipulated by the nurse to provide support and protection for the patien’'s mental and physical health. The nurse must provide comfort, privacy and safety as part of the curative factors.

Assistance with satisfying human needs is based on a hierarchy of needs similar to Maslow's. Each need is equally important for quality nursing care and the promotion of the patien''s health. Also, all needs deserve to be valued and attended to by the nurse and patient. The allowance for existential-phenomenological forces, which helps the nurse to reconcile and mediate the incongruity of viewing the patient holistically while at the same time attending to the hierarchical ordering of needs. This helps the nurse assist the patient to find strength and courage to confront life or death. Phenomenology is a way of understanding the patient from his or her frame of reference (Watson, 2007). Existential psychology is the study of human existence.

Watson's Hierarchy of Needs

Based on the model, Watson (1999) created a hierarchy of needs. Watson's hierarchy of needs consists of four levels and begins with lower-order biophysical needs to higher-order intrapersonal-interpersonal need or growth-seeking need. Watson's hierarchy of needs is:

1. **Lower order biophysical needs (survival needs):** These include the need for food and fluid, elimination and ventilation.
2. **Lower order psychophysical needs (functional needs):** These include the need for activity, inactivity and sexuality.
3. **Higher-order psychosocial needs (integrative needs):** The higher-order psychosocial needs or integrative needs include the need for achievement and affiliation.
4. **Higher-order intrapersonal-interpersonal need (Growth-seeking needs):** The higher-order intrapersonal-interpersonal need or growth-seeking need is the need for self-actualization.

Application of Watson's nursing theory

The nursing process in Watson's theory includes the same steps as the scientific research process: assessment, plan, intervention and evaluation. The assessment includes observation, identification and review of the problem, as well as the formation of a hypothesis. Creating a care plan helps the nurse determine how variables would be examined or measured, and what data would be collected. Intervention is the implementation of the care plan and data collection. Finally, the evaluation analyses the data, interprets the results,and may lead to an additional hypothesis (Clarke, Watson & Brewer, 2009). It is undeniable that technology has already been part of nursing's whole paradigm with the evolving era of development. Watson's suggestion of purely "caring" without giving much attention to technological machinery cannot be solely applied but then her statement is praiseworthy because she dealt with the importance of the nurse-patient interaction rather than a practice confined to technology.

Also, the theory is logical in that the causative factors are based on broad assumptions that provide a supportive framework. The curative factors are logically derived from the assumptions and related to the hierarchy of needs. Watson's theory is best understood as a moral and philosophical basis for nursing. The scope of the framework encompasses broad aspects of health-illness phenomena. Also, the theory addresses aspects of health promotion, preventing illness and experiencing peaceful death, thereby increasing its generality. The curative factors provide guidelines for nurse-patient interactions; an important aspect of patient care.

Influence of theory on the study

The theory of self-care deficit is specifically developed to guide and improve the quality of nursing care. Some aspects of the theory were adopted to help develop a conceptual framework for this study. The adoption of the two theories became necessary because informal caregivers who are not nurses are expected to directly play the roles of nurses in their home environment. The aspects of the theory borrowed are;

1) Universal self-care requisites which focus on life processes as well as maintenance of the integrity of human structure and functioning. These requisites are also called activities of daily living. These activities of daily living include, according to Orem, maintenance of sufficient air, food and water (food and water was captured by the researcher as **nutrition**). The issue of nutrition was paramount to the researcher because people with stroke for a long time suffer from the inability to swallow food and water. Since stroke patients have this deficit, it is very clear that the administration of **medication** at home will certainly be challenging. Hence the informal care-giving in the area of nutrition and medication is investigated.

2) Another activity of daily living raised in the theory by Orem was the provision of care that is associated with the elimination process. The elimination processes include defaecation and urination which is a major problem for people with stroke because they develop incontinence in this area. If this aspect of care-giving by informal caregivers is not managed or catered for skillfully and knowledgeably, complications develop.

Prevention of hazards to human life mentioned as one of the activities of daily living is very relevant to the study. Hazards to human life and well-being from the researcher’s perspective include patients’ inability to observe hygiene, prevent bedsores and contractures (complication prevention). These hazards to human life and well-being are common in stroke patients who have been bedridden and have received poor care at home.

The balance between activities and rest, as well as between solitude and social interaction was identified by Orem as an activity of daily living. Of interest to the researcher is the issue of solitude and social interaction. The solitude and social interaction was considered an issue of communication which is very crucial in the provision of care appropriate to meet the needs of the stroke patient. This is because stroke patients have speech impairment which makes communication very difficult. Research to explore the experiences of caregivers who care for patients who cannot communicate easily is important to improve and appreciate the efforts of these informal caregivers.

The theory of self-care deficit stipulates when nursing (formal or informal) is needed. Orem indicated that care is required when an adult is incapable or limited in the provision of effective self-care. Orem identified five methods of helping; notable amongst them is “doing for others”. This method of helping is very imperative in the provision of care to stroke patients because they are incapacitated and caregivers have to do almost everything for them. This implies that caregivers would have to assume patients` roles in performing activities of daily living. This is challenging as it affects both caregivers and care recipients. The experiences of the informal caregivers as far as care-giving challenges are concerned are of paramount interest to the researcher. Hence the researcher looked at the emotional, financial and personal health challenges of the informal caregiver. Another area the researcher explored to fully understand caregiver experience was the support system available to these informal caregivers. A relevant theory to address the above is an aspect of Watson`s nursing theory.

Watson (1999) believed that holistic health care is central to the practice of caring in nursing. Holistic care from the researcher`s perspective looks at the effect of care-giving on the caregiver and not only patients. The researcher identified challenges with the caregiver`s health, emotions and finance. The next curative factors of Watson`s theory considered was the cultivation of sensitivity to on''s self and to others, which explores the need for nurses to feel an **emotion** as it presents itself. Since it is very apparent from the theory that care-giving is interlaced with emotions, this aspect of the theory was adopted to discover the emotional challenges these informal caregivers go through. The provision of support was not lacking in the ten curative factors of the theory. The researcher, therefore, sees it very significant to look at the **support system** available to the caregivers to enhance care. The above became a guide to the development of a conceptual framework upon which the literature review was constructed. It also served as the basis for the development of interview guidelines.

Definition of concepts

- Stroke: A medical condition that affects people and causes weakness or paralysis in the human body
- Nutrition: This refers to caregivers` experiences and strategies in feeding patients, mode of feeding of the patient (whether tube feeding or feeding through the mouth), kinds of food given to the patient and ability of the patient to swallow or drink without aspiration.

- Medication: refers to the mode of administration of prescribed drugs and how caregivers manage to get patients with difficulty in swallowing to take their medications.
- Hygiene: Hygiene refers to caregivers` experiences and strategies for maintaining the cleanliness of patients through a bath, mouth care, changing of soiled linens and patient's clothing.
- Communication: The caregivers' experiences as they interact with patients, how they understand patients' speeches, gestures and responses to those gestures to accurately meet the needs of the patient.
- Elimination refers to caregivers' experiences in handling a patient's bowel movement and urination which is altered in stroke patients (faecal and urinary incontinence).
- Prevention of complication: prevention of complication refers to the caregiver's experiences in caring for the patient such that complications such as pressure sores and contractures due to immobility do not occur.
- Challenges: these are difficulties encountered by caregivers as they care (Disease-Related Tax). It looks at difficulties with financial obligations, caregivers' emotions and health.
- Informal caregiver: A person without formal medical training who cares for stroke patients. These persons include family members, friends, etc.
- Family: A relative who is in charge or takes care of patients with stroke

Conceptual Review

The conceptual review of this study outlines and explains the various concepts in the study. This study is founded on two concepts; thus, stroke and care-giving. The conceptual review provides definitional issues and explanations, characteristics as well as treatment and management of health conditions where applicable.

Concept of stroke

Stroke also is known as cerebrovascular accident (CVA) is a medical condition in which poor blood flow to the brain results in focal or global cell death in the brain (National Heart, Blood and Lung Institute (NHBLI), 2014). The occurrence of a stroke can lead to mild to severe forms of disability. Stroke was the second most frequent cause of death worldwide in 2011, accounting for 6.2 million deaths (11% of the total) (WHO, 2013). Between 1990 and 2010 the number of strokes decreased by approximately 10% in the developed world and increased by 10% in the developing world (Feigin, Forouzanfar, Krishnamurthi, Mensah, Connor, Bennett, & O'Donnell, 2014). Overall, two-thirds of strokes occurred in those over 65 years old (Feigin et al., 2014) South Asians are at particularly high risk of stroke, accounting for 40% of global stroke deaths.

Classification of stroke

Stroke can be classified into two major areas:

1. Ischemic stroke**:** In an ischemic stroke, blood supply to part of the brain is decreased, leading to a dysfunction of the brain tissue in that area (Shuaib & Hachinski, 1991). This is sometimes due to thrombosis (obstruction of a blood vessel by a blood clot forming locally), embolism (obstruction due to an embolus from elsewhere in the body), systemic hypoperfusion (general decrease in blood supply, e.g., in shock) (Shuaib & Hachinski, 1991) or cerebral venous sinus thrombosis (Stam, 2005). Ischemic stroke is caused by focal cerebral ischemia due to arterial occlusion (Hinkle, 2007; Kleinschnitz, 2008; Lee, 2014; Osama, Aziz & Saeed, 2014; Stoll &

Kleinschnitz, 2008) or stenosis or occurs when the blood supply to a part of the brain is suddenly interrupted by occlusion (Aggarawal, Aggarwal & Khata, 2010; D'souza, 2008; Lakhan et al., 2009). In other words, Ischemic stroke is defined as acute onset (minutes or hours) of a focal neurological deficit consistent vascular lesion that persisted for more than 24 hours (Osama, Aziz & Saeed, 2014). Ischemic cerebrovascular disease is mainly caused by thrombosis, embolism, and focal hypoperfusion, all of which can lead to a reduction or an interruption in cerebral blood flow (CBF) that affect neurological function due to deprivation of glucose and oxygen (Guo, 2013; Hinkle, 2007; Stankowski, 2011). Ischemic stroke can further be classified into (1) large-vessel atherothrombosis (12.9 % of ischemic strokes), (2) cardioembolism (36.5 %), (3) small-vessel disease (18.4 %), (4) other determining causes (6 %), and (5) undetermined causes, which includes cases invoking more than one primary mechanism (26.4–42.3 %) (Gao, Wang, Xu & Li, 2011).

a. Haemorrhagic stroke: This kind of stroke occurs when there is a burst of rapture in an artery in the brain (National Stroke Association, 2014). This causes blood to seep into the cortical parts of the brain (National Stroke Association, 2014). There are two main types of haemorrhagic stroke: intracerebral haemorrhage, which is bleeding within the brain itself (when an artery in the brain bursts, flooding the surrounding31nderpue with blood) due to either intraparenchymal haemorrhage (bleeding within the brain tissue) or intraventricular haemorrhage (bleeding within the brai''s ventricular system). The other type is subarachnoid haemorrhage, which is bleeding that occurs outside the brain tissue but still within the skull and precisely between the arachnoid mater and pia mater(Al-Shahi, Labovitz & Stapf, 2009).

b. The third type of stroke called a transient ischemic attack or TIA is a minor stroke that serves as a warning sign that a more severe stroke may occur.

Signs and symptoms of stroke

Stroke symptoms typically start suddenly, over seconds to minutes, and in most cases do not progress further. The symptoms depend on the area of the brain affected (National Stroke Association, 2014). The more extensive the area of the brain is affected, the more functions that are likely to be lost. Some forms of stroke can cause additional symptoms. Most forms of stroke are not associated with a headache, apart from subarachnoid haemorrhage and cerebral venous thrombosis and occasionally intracerebral haemorrhage. Other associated symptoms of stroke include loss of consciousness, headache and vomiting. These usually occur more often in haemorrhagic stroke than in thrombosis because of the increased intracranial pressure from the leaking blood compressing the brain (National Stroke Association, 2014). Stroke survivors may experience muscular problems (difficulty walking, instability, paralysis with weak muscles, problems with coordination or paralysis of one side of the body), visual difficulties (blurred vision, double vision, sudden vision loss, or temporary loss of vision in one eye), speech difficulty, whole body fatigue and reduced sensation of touch (National Stroke Association, 2014).

Risk factors of stroke

1. **Blood pressure:** High blood pressure accounts for 35–50% of stroke risk (Sierra, Coca & Schiffrin, 2011). Individuals with high blood pressure levels are at risk of developing a stroke because high blood pressure can

lead to the rapture or burst of arteries in the brain thereby causing a haemorrhagic stroke (Sierra et al., 2011).

2. **High cholesterol:** High cholesterol levels have been inconsistently associated with (ischemic) stroke (Peters, Singhateh, Mackay, Huxley & Woodward, 2016). Though cholesterol is good for the body, excess and used cholesterol that flows in the bloodstream can form plagues along the arterial wall and hence cause occlusion of the artery, thereby leading to an ischemic stroke (Peters et al., 2016).
3. **Lifestyle:** Unhealthy diet, cigarette smoking, drug use and lack of physical activity can lead to the development of hypertension and/or diabetes which also has the potential of causing a stroke (Hackshaw, Morris, Boniface, Tang & Milenković, 2018; Hankey, 1999; Westover, McBride & Haley, 2007).

Previous stroke or Transient Ischemic Attack (TIA): A transient ischemic attack is like a stroke, producing similar symptoms but usually lasting only a few minutes and causes no permanent damage (Lewandowski, Rao & Silver, 2008). Known as a mini-stroke, a transient ischemic attack may be a warning sign of stroke. Individuals who have experienced a TIA are at risk of developing a full stroke ((Lewandowski et al., 2008).

Managing stroke

Thrombolysis: Thrombolysis, also called fibrinolytic therapy, is the breakdown (lysis) of blood clots formed in blood vessels, using medication (Emberson, Lees, Lyden, Blackwell, Albers, Bluhmki & Grotta, 2014). It is used in treating myocardial infarction, stroke and very large pulmonary embolisms. This is used in acute ischemic stroke when given within three hours of symptom onset results in an overall benefit of 10% concerning living without disability (Emberson et al., 2014). It does not, however, improve the chances of survival (Wardlaw, Murray, Berge & del Zoppo, 2014). Individuals who have suffered an intracerebral haemorrhage require supportive care, including blood pressure control if required. They are monitored for changes in the level of consciousness and their blood sugar and oxygenation are kept at optimum levels. Some patients may benefit from neurosurgical intervention to remove the blood and treat the underlying cause. however, this depends on the location and the size of the haemorrhage as well as patient-related factors (Vespa, Martin, Zuccarello, Awad & Hanley, 2013).

Rehabilitation: Stroke rehabilitation is the process by which those with disabling strokes undergo treatment to help them return to normal or near-normal life as much as possible by regaining and relearning the skills of everyday living (Langhorne, Bernhardt & Kwakkel, 2011). It also aims to help the survivor understand and adapt to difficulties, prevent secondary complications and educate family members to play a supporting role (Langhorne et al., 2011). A rehabilitation team is usually multidisciplinary as it involves staff with different skills working together to help the patient. These include physicians trained in rehabilitation medicine, clinical pharmacists, nursing staff, physiotherapists, occupational therapists, speech and language therapists and orthotists. Some teams may also include psychologists and social workers since at least one-third of affected people manifest post-stroke depression (Long, Kneafsey, Ryan & Berry, 2002).

Preventing stroke

1. **Lifestyle modifications:** According to literature and health professionals, the most effective way of preventing stroke is through making healthy lifestyle choices (Chiuve, Rexrode, Spiegelman, Logroscino, Manson & Rimm, 2008). This includes physical activity (exercise), a healthy diet, avoiding the use of drugs such as cocaine and nicotine as well as reducing alcohol intake.
2. **Medical approaches:** Since high blood pressure, diabetes mellitus, and atrial fibrillation (irregular heartbeat which causes a blood clot in the heart) are medical conditions that could trigger a stroke, it is recommended that patients who have these conditions seek treatment as early as possible to reduce the risk of developing a stroke (Abbott, 2009).

Concept of care-giving

Care-giving is providing care and assistance for the physical and emotional needs of an individual; it could be a family member or friend (Heard, 2018). Care-giving may involve: assisting with meals, personal care, and transportation and helping with medical procedures and therapy. Care-giving is most commonly used to address impairments related to old age, disability, a disease or a mental disorder (Heard, 2018). A caregiver or carer is an unpaid or paid member of a person's social network who helps them with activities of daily living (Heard, 2018).

Basic principles of care-giving

According to Kindersley (2013), there are certain basic principles in care-giving, they are

1. **Good communication:** A fundamental part of giving care is being a good communicator with the person getting care. Care is given with respect for the dignity of the person receiving it. The carer remains in contact with the primary health care provider, often a doctor or nurse, and helps the person receiving care make decisions about their health and matters affecting their daily life (Kindersley, 2013 p.144).
2. **Hygiene management:** In the course of giving care, the caregiver is responsible for managing hygiene of themselves, the person receiving care, and the living environment. Hand washing for both caregivers and persons receiving care happens often (Kindersley, 2013 p.144).
3. The caregiver manages the organization of the person's agenda since helping the person meet medical appointments is of special importance. Also, routine daily living functions are scheduled, like managing hygiene tasks and keeping health care products available (Kindersley, 2013 p.144).

Duties of caregivers

Monitoring: The caregiver is in close contact with the person receiving care and should reasonably monitor their health. In some cases, people receiving care require that someone take notice of their breathing, body temperature or blood pressure. Thus, it is expected that a caregiver would notice changes in breathing, temperature or blood pressure and relay that information to the doctor or appropriate medical professional (Kindersley, 2013 p.148).

a. **Keeping the patient mentally alert:** There is a link between mental health and physical health and mind-body interventions may increase physical health by improving mental health. These practices to improve a patient's quality of life by helping them socialize with others, keep friendships, enjoy hobbies and enjoy whatever physical exercise is appropriate. Caregivers have to encourage patients to leave their homes for the health benefits of the resulting physical and mental activity (Kindersley, 2013 p.66).

b. **Eating assistance:** Caregivers help patients have a healthy diet. This help might include giving nutrition suggestions based on the recommendations of dietitians, monitoring the body weight, addressing difficulty swallowing or eating, complying with dietary restrictions, assisting with the use of any dietary supplements and arranging for pleasant mealtimes (Kindersley, 2013 p.45).

c. **Managing medications:** Caregivers have a vital role in supporting people with managing their medications at home. A person living with chronic illness may have a complex medication regimen with multiple medications and doses at different times of the day. Caregivers may assist in managing medications in many ways. This may range from going to the pharmacy to collect medications, helping with devices such as medication boxes, or administering the medications at home.

d. **Providing emotional support:** Provision of emotional support can greatly affect the physical health of the patient. Thus, the greatest gifts a caregiver can provide is human contact, loving support and reassurance. This could also involve helping the patient develop a more positive outlook on life (Gbiri, Olawale & Isaac, 2015). Caring has both positive and negative dimensions.

Positive aspects of care-giving

Studies by the National Opinion Research Center (2014) found that 83% of caregiver's care-giving as being a positive experience. Many family caregivers report positive experiences from care-giving, including a sense of giving back to someone who has cared for them, the satisfaction of knowing that their loved one is getting excellent care, personal growth and increased meaning and purpose in one's life. Some caregivers feel that they are passing on a tradition of care and that by modelling care-giving, their children will be more likely to care for them if necessary.

Many caregivers also report that they find benefits in their roles and activities. This is increasingly seen as a positive form of coping with stressful circumstances and situations. Benefit-finding may be a product of the ability to find meaning through positive reappraisals, spiritual beliefs or other adaptive coping mechanisms in the face of stress. Caregivers who perceive more benefits from care-giving report lower levels of depression (Haley, LaMonde, Han, Burton & Schonwetter, 2003). This sense of satisfaction and well-being can have important benefits for caregivers well after care-giving has ended.

Problems in care-giving

Care-giving exerts a tremendous toll on caregivers' health and well-being and accounts for significant costs to families and society (Lou, Kwan, Chong & Chi, 2013). Care-giving has been associated with increased levels of depression and anxiety as well as greater use of psychoactive medications, poorer self-reported physical health, compromised immune function and increased mortality. Over half of caregivers indicate that their decline in health compromises their ability to provide care (Lou et al., 2013).

Care provided for family members, especially partners who are mentally challenged/with non-physical disorders, the degree of mental strain is high to the point where the caregivers themselves are at risk of being psychologically broken due to the high demanding situations of both physical toll complicated with non-professional work environment (lack of institutional care-giving equipment both in terms of work-safety equipment and care providing equipment), safety concerns and behavioural issue (Lou et al., 2013). The physical, emotional and financial consequences for the family caregiver can be overwhelming. Caregivers responsible for an individual with a psychiatric disorder can be subjected to violence (Labrum & Solomon, 2017).

Empirical Review

This review covers various empirical studies that are related to this study. The empirical review was conducted on the research question that guides this study. The empirical review helps to understand various perspectives of the researcher and also aid in the discussion of findings from this study

Experiences of caregivers

Various empirical studies have outlined certain experiences that caregivers of stroke patients have in their line of work. For example, to evaluate caregivers' experiences concerning the care of a terminally ill loved one at home, and to compare the death experiences of caregivers with and without access to home care programs, Singer, Bachner, Shvartzman and Carmel (2005) interviewed a total of 159 caregivers in a mixed research study in Beer-Sheva (Israel). Singer et al. (2005) found that even though caring for a loved one at home was a greater financial and emotional burden, there was a greater overall satisfaction with the caring experience of those whose loved ones died at home and had access to the home care programme. Thus, the experience was mixed in nature (positive and negative). The researcher concluded that positive outcomes and reduction in negative outcomes appear to be dependent upon the availability of adequate support systems to meet both the physical and emotional needs of caregivers.

Also, a phenomenological study by (Kaan, Young, Cockell and Mackay (2010) to describe the emotional and lived experience of caregivers of patients who were discharged home with a ventricular assist device found interesting results. The researchers sampled and interviewed 13 caregivers of 9 patients discharged to go home with a ventricular assist device between March 2004 and June 2007 in Vancouver hospital (Canada). Four themes emerged during the interviews: anxiety initially exhibited as a profound shock; loss of a loved one of their lives, freedom and independence; burden, bothoth physical burden and the burden of responsibility, and finally coping through faith, acceptance, empathy and social support. Kaan et al. (2010) concluded that caregivers of patients experienced significant pressures that changed throughout support provided and also argued that understanding the fluctuating needs of caregivers will enable teams to provide interventions based on the situation.

Furthermore, to examine the experiences of Singaporean people caring for those with Parkinson’s disease (PD), Tan, Williams and Morris (2012) interviewed 21 participants in a mixed-method sequential explanatory study. From the analysis of their data, 11 sub-themes were identified, which were organized into four key themes. These themes were coping and adaptation, challenges of care-giving, effects of care-giving on the caregivers and the need for better caregiver support. About experiences, the majority of the respondents

(14) reported that they had uncomfortable and bad experiences when discharging their duties as caregivers while the rest stated that they had mixed experiences in their line of duty. The results of this study have provided insights into the issues of caregivers of people with Parkinson`s disease (PD). The findings of their study underscore the need for formal caregiver support and education to reduce strain in caregivers targeted at every stage of PD as there is no clear pattern of disease progression (Tan et al., 2012).

Siddiq, Wilson, Graham, Lamoureux, Khangura, Tingley & Potter (2016) also sought to understand the experiences of parents and caregivers of children with Inherited Metabolic Diseases (IMD) to inform strategies for supporting patients and their families. Siddiq et al (2016) investigated their experiences regarding the management of disease, its impact on children and family life and interactions with the health care system. From four Canadian IMD centers, the researchers also conducted 21 semi-structured telephone interviews with caregivers of children with an IMD who were born between 2006 and 2015 and who were participating in a larger cohort study. Most caregivers reported that they and their families had adapted well to their child’s diagnosis. Caregivers used proactive coping strategies to integrate complex disease management protocols into routine family life. An important source of stress was concerned about the social challenges their children face,. Participants reported positive interactions with their most involved health care providers within the metabolic clinic. However, they reported challenges associated with the health care system outside of disease-specific metabolic care, when encountering systems and providers unfamiliar with the child’s disease. Siddiq et al. (2016) concluded that the successful use of proactive coping strategies among parents of children with IMD in this study suggests the potential value of promoting positive coping and is an important direction for future study. Parents' social concerns for their children were important stressors that warrant consideration by health care providers positioned to support families.

In a more recent qualitative descriptive study to explore family caregivers' emotional experiences while caring for patients with advanced cancer and navigating distressing information, awareness of dying and difficult decisions, Rodenbach, Norton, Wittink, Mohile, Prigerson, Duberstein and Epstein (2019) conducted semi-structured interviews with 92 bereaved caregivers of patients with advanced cancer in the USA. Interviews explored caregivers' experiences as patients transitioned out of active cancer treatment and neared the end of life. Included in caregivers' characterization of this transition time were three particularly emotional experiences. The first occurred when caregivers felt jolted into awareness that patients were dying. They were startled to realize that patients would die sooner than expected; some expressed frustration that they had not been adequately warned. In the second, caregivers felt conflicted when involved in decisions that did not favour patients' preferences against what caregivers felt patients needed, resulting in ambivalence, guilt, and grief. Thirdly, caregivers who felt they did their best for patients expressed fulfilment and gratitude.

Kavi, Bazrafshan, Taleghani, Abolhasani & Akbari (2019) explored the experiences of Strokes' Caregivers in a large hospital in Iran. The purpose for which the researchers conducted the study was to investigate the experiences of caregivers of patients with stroke. Their study employed qualitative descriptive phenomenology, in which the participants included seven caregivers of stroke patients. Data were collected through semi-structured interviews. Data analysis was performed based on Colaizzi. The results in the study were summarized in three main categories: anxiety (tension and stress, concern about the economic future), care consequences (fatigue, reduced family interactions) and neglected needs (psychological needs, educational needs). The study concluded that nurses and physicians should pay more attention to the needs and concerns of patients and their caregivers and try to resolve with them the consequences of the disease.

The work of Gertrude, Kawuma, Nalukenge, Kamacooko, Yperzeele, Cras and Seeley (2019) investigated the caring for a stroke patient: The burden and experiences of primary caregivers in Uganda—a qualitative study. The study purposively assessed the burden and experiences of caregivers looking after stroke patients in Kampala, Uganda. It was a qualitative cross-sectional study between May 2018–July 2018 among primary caregivers of stroke patients. Purposive sampling was used to consecutively recruit primary caregivers. In-depth interviews were conducted and audiotape recorded and observations were also made. Data were managed using NVIVO 12.0 following a thematic approach. In the study, twenty-five caregivers were included in the analysis with a mean age of 39.3, SD 10.7. Four themes were identified from th43nderpitative analysis on caregivers' experiences of looking after stroke patients: taking on new responsibilities, factors that protected caregivers from breaking down, limited resources and experiences with patient outcomes. The findings of the study highlighted the need for interventions to support stroke patients and their caregivers.

In the same vein, Wagachchige, Muthucumarana, Samarasinghe and Elgán (2018) researched on caring for stroke survivors: experiences of family caregivers in Sri Lanka—a qualitative study. This study aimed at exploring family caregivers' experiences of providing informal care for dependent stroke survivors in the Sri Lanka context. The sample was chosen by purposive sampling with a maximum variation by age, ethnicity, religion, educational level, relationship and monthly income. Ten informal family caregivers to stroke survivors with hemiplegia who had been treated at the National Hospital of Sri Lanka participated in in-depth interviews analyzed using conventional content analysis. The findings of the study revealed that although the increased workload, restricted social life, physical problems and knowledge and financial deficits were challenging for the family caregivers, self-strength and supportive social networks helped them to compassionately care for their stroke survivor.

In summary, the review on the experiences of caregivers of stroke shows that a lot has been written in that field. The above research works predominantly employed a qualitative approach in their investigation. In a few instances, a mixed approach was employed. Again, a work has been conducted on informal caregivers of stroke in the Ghanaian context. My study seeks to explore informal caregivers' experiences in the Ghanaian context, and employing an exploratory qualitative approach will enrich the scanty literature on this subject. The findings of the above-reviewed points to challenges of care-giving.

Challenges of caregivers

It is a fact that caregivers of the elderly, as well as patients with chronic health conditions, have challenges that can affect both their physical health and mental health status. An empirical phenomenological study that focused on exploring the challenges, experience and perception of stroke among stroke caregivers by Thomas and Greenop (2008) outlined certain challenges of stroke caregivers in South Africa. Thomas and Greenop (2008) interviewed 6 caregivers with the aid of a semi-structured interview guide. The data were analysed qualitatively using thematic and content analysis. Prominent themes associated with care-giving challenges included: role changes and relationship disruptions within the family, occupational and social implications, fatigue, anxiety, depression, loneliness, frustration as well as financial problems. The finding revealed that there are many challenges that caregivers face but these challenges are not attended to because they are considered less important than the patients' health.

Studies by Greenwood, Mackenzie, Cloud and Wilson (2009) to summarize the challenges of caregivers of stroke survivors in the USA found that commonly described difficulties and challenges included emotional responses, lack of understanding of the patient's condition, uncertainty and associated information and training needs. Greenwood et al. (2009) suggested that caring for stroke survivors is often challenging but focusing on the difficulties and not drawing attention to successful management strategies and satisfaction reported by caregivers limits understanding and reduces the chances of providing appropriate support. The study further suggested that future qualitative research should consider the implications of the timing of collection more carefully and should move away from simple content or thematic analysis which tends to emphasize similarities amongst carers and should now focus on understanding carer diversity. Acknowledging this diversity should maximize the chances of providing appropriate support (Greenwood et al., 2009).

King, Ainsworth, Ronen and Hartke (2010) using a mixed research approach also found similar results. Intending to identify the types and frequency of care-giving problems and associated stress and coping effectiveness, the researcher purposively sampled 58 caregivers during the first four months of care-giving. Three problem-related themes emerged from the results: interpersonal disruptions, sustaining the self and family and stroke survivor functioning. Although sustaining the self and family challenges were most frequent, interpersonal disruptions were rated most stressful and lowest in coping effectiveness. King et al. (2010) argued that caregivers may deal with these challenges by identifying potential support system resources (efor instance, family members, religious or community organizations) and specific tasks that helpers could assume. Given the stress associated with changes in relationships and with interpersonal concerns, forming caregiver support groups (or other systems) to help caregivers form connections with one another may be beneficial (King et al., 2010).

In a descriptive study to document the challenges associated with the transition to caregiver role following diagnostic disclosure of Alzheimer disease, Ducharme, Lévesque, Lachance, Kergoat and Coulombe (2011) recruited a sample in Quebec (Canada) cognition clinics comprising 122 caregivers of an elderly relative diagnosed with Alzheimer’s disease in nine months. Findings reveal the context of care to be marked by several challenges for caregivers. The majority of caregivers receive little informal support, have poor knowledge of available formal services and have difficulty planning for the relative’s future care needs. Caregivers themselves report a lack of preparedness to provide care. Compared with men caregivers, women seem to have more problems controlling disturbing thoughts about their new caregiver role and to experience more family conflicts and psychological distress. Compared with offspring caregivers, spouse caregivers are less able to respond to the relative's disruptive behaviours, make less use of problem-solving strategies and report fewer family conflicts.

Finally, to describe the challenges and experiences of caregivers managing incontinence in stroke survivors in Taiwan, Tseng, Huang, Yu and Lou (2015) found consistent results. Tseng et al. (2015), using a qualitative approach selected 10 family caregivers and conducted interviews using semi-structured interview guide. Data analysis identified four themes: chaos, hyper-vigilance, exhaustion and creating a new life. There were nine related subcategories: fluster, dirtiness, urgency, fear of potential health-hazard, physically demanding and time-consuming, mentally draining, financial burden, learning by doing and attitude adjustment. The research highlighted unique caring challenging experiences of family caregivers of stroke patients, which focused solely on the 'incontinence issue'. Understanding these challenges may help nurses provide better support and resources for family caregivers when caring for stroke survivors with incontinence.

The empirical review of the challenges of caregivers of stroke patients reveals some difficulties that caregivers of stroke patients face. Greenop (2008) suggest that role changes and relationship disruptions within the family, occupational and social implications, fatigue, anxiety, depression, loneliness, frustration as well as financial problems. Other challenges include interpersonal disruptions, sustaining the self and family and stroke survivor functioning (King et al., 2010). Tseng et al. (2015) also state that fear of potential health-hazard, physically demanding and time-consuming, mentally draining, financial burden, learning by doing and attitude adjustment are some challenges of caregivers of stroke patients.

Strategies for managing health-related problem among caregivers

Caregivers are more often than not taxed with taking care of health-related issues that may arise in the patients they care for. Thus, caregivers must be able to manage or cope with the health care issues as and when they arise. Chow, Wong and Poon (2007) focused on assessing coping and support in caregivers of stroke survivors, and thus they sampled 47 family caregivers in Korea. The participants pointed out that they deal with health-care problems by contacting the appropriate medical personnel to take the patient to the emergency room for medical attention. Chow et al. (2007) stated that though caregivers may not have the adequate skills and competencies to deal with medical issues related to stroke patients, they are however important because they can provide valuable information to the medical professional who is taking care of the patient.

Assessing emergency psychiatric services for individuals with intellectual disabilities from the caregivers' perspective, Weiss, Lunsky, Gracey, Canrinus and Morris (2009) conducted focused group discussions with one group of unpaid caregivers and two groups of paid caregivers from Ontario, Canada. Caregivers identified some issues centering on a lack of services, respect, knowledge and expertise. Diagnostic overshadowing and over-medication were also prevalent concerns. Also, the caregivers stated that in the case of medical emergencies, they provide first aid by administering the prescribed medication for the patients. Caregivers also pointed out that the medical professionals who are contacted during medical emergencies are often able to provide that needed care without the need to take the patient to the hospital. The researcher concluded that input from caregivers' points to deficiencies in the system that lead them to use the emergency unit when other options have been exhausted. Some recommendations can be implemented to improve the emergency psychiatric care of adults with intellectual disabilities in the emergency unit (Weiss et al., 2009).

To describe the caregiver's health-care task difficulty and involvement and explore the association between and caregiver well-being, a cross-sectional study was conducted by Giovannetti, Wolff, Xue, Weiss, Leff, Boult & Boyd (2012). The study sampled a total of 308 caregivers from the USA and assessed their health-related task performance quantitatively. The finding pointed out that the number of health-care tasks performed were positively associated with increased health-care task difficulty. The quality of the caregiver's relationship with the patient and self-efficacy were inversely associated with increased health-care task difficulty. Also, caregivers revealed that when health-care problems arise they consider the needs of the patient before taking any action, and thus all actions that are taken care of in the interest of the patient. The study concluded that caregiver self-efficacy was strongly associated with how they would react when health-related issues arise in the patients they care for. Giovannetti et al. (2012) also assert that a caregiver's action concerning the health-care issues of a patient could either be helpful or worsen the patient's condition.

Ahl and Nyström (2012) aimed to interpret and explain the experiences of caregivers providing caring in pre-hospital care situations that are not defined as traumatic or life-threatening. Twenty participants sampled from Sweden were interviewed. The design of the study was exploratory and it used an interpretative approach to understand the meaning of pre-hospital caring among caregivers. The findings show that pre-hospital caring can be understood and explained as a matter of interplay between carer(s) and patient with potentials for positive as well as negative outcomes. Most caregivers reported that they provide first aid to the patients, contact appropriate medical professionals and then take the patient to the hospital in that order. Ahl and Nyström (2012) concluded that the initial meeting for patients' needs by their caregivers is of vital importance in how patients experience pre-hospital care.

Strategies for managing specific health-related problem among stroke caregivers

Nearly 50% of post-stroke patients who have moderate to severe impairment have developed paralysis and are not able to take care of themselves (Ovbiagele, Kautz & Feng, 2015) or have developed other physical complications such as aspiration pneumonia, joint contracture and pressure ulcer, as well as various psychological conditions such as anxiety, stress or depression (Kuptniratsaikul, Kovindha, Suethanapornkul & Archongka, 2013) Many stroke caregivers lack basic information about stroke, strategies for caring for stroke survivors and the ways to prevent complication and future attacks of stroke (Kumar, Kaur & Reddemma, 2016).

Due to the above, the strategies employed by informal caregivers in the management of stroke patients at home concerning bathing, feeding, medication, prevention of pressure sores, contractures, fecal and bladder incontinence and communication difficulties were explored. It is very difficult to assess informal caregiver management strategies for health-related problems. Therefore, management strategies within the formal domain would be looked at to appreciate what should be done in the home or community.

Communication strategies

A stroke occurs as a sudden and unexpected life event often with a severe impact on all aspects of life including cognition and communication. Living wills can be helpful here, but they are not always available. Therefore, determining the will of the patient when communication and/or decision-making capacities have been lost is particularly challenging and often relies on narratives by proxies. Limitations in experience, resources and self-perceived qualifications present additional barriers for health care professionals to successfully elicit the patient's point of view. Communication problems that arise from aphasia make nursing difficult. However, several strategies can be applied.

Use of language For a start, everyone should think carefully about the language they use. For example, most people with aphasia struggle to comprehend long or complex sentences. They also understand concrete words better than abstract ones. Concrete words refer to things that can be seen and touched, examples being 'pillow' and 'trolley'. Abstract words refer to concepts that cannot be experienced by the senses, examples being 'idea' and 'diagnoses'. Therefore, short simple speech, constructed mainly from concrete words is easier. Many people with aphasia are helped by slowed speech, although this must not sound patronizing (Steigleder, Kollmar, Ostgathe & Martin, 2019).

a) Clues

Clues about what is being said can also accompany speech. So, if a nurse wants to tell a man with aphasia that they are going to give him an injection, it would be a good idea to show him the syringe or make a simple gesture. Many people with aphasia find written words and pictures helpful. So if the patient is being taken for a scan, it would be a good idea to show him the written sign and a picture of the equipment. It can be difficult to know whether a person with aphasia has understood. In some cases, they may even repeat what you say, but without comprehension. Therefore, important information should be conveyed several times with the support of pictures, written words and symbols (Steigleder et al., 2019).

b) Group therapy

Group therapy and conversation groups can be used for people with aphasia and should be available in the longer term for those with chronic and persisting aphasia. People with chronic and persisting aphasia should have their mood monitored (Ulaan, 2013).

Pressure ulcer prevention strategies

A pressure ulcer occurs when the skin and underlying tissue gets damaged by unrelieved pressure. Essentially the skin, its blood supply and underlying tissue are squashed between the hard surface (the cause of pressure) and the underlying bone. In 95% of cases, pressure ulcers are completely preventable with good care and therefore they are classified as ‘avoidable harm’. Every resident (patient) should have their risk of developing pressure ulcers assessed using a validated tool such as the Waterlow risk assessment scale. This should be completed within 6 hours of admission to the care home (NICE, 2014). The risk should also be reassessed as frequently as required and when there is a clinical concern or change in the person's mental or physical status. The strategies for the prevention of pressure ulcers in home care employ the Surface, Skin, Keep moving, Incontinence (SSKIN) preventive guidance.

Surface

This refers to the surface that residents are sitting or lying on, in other words, the chair cushion and bed mattress. The surface underneath the resident needs to provide the right amount of support and comfort and no resident at risk of pressure ulcers should be nursed on anything less than a high-specification foam mattress (National Institute for Health and Care Excellence (NICE),2014). Patients are at greater risk of pressure damage when seated than they are when lying in a bed due to the distribution of their body weight. Carers must continue to move residents frequently whatever the type of support surface is used and make sure bedclothes and clothing are smooth under the resident when repositioning. Support surfaces may also be described as pressure-relieving equipment that works by either spreading out the pressure (redistribution) or removing pressure regularly from different parts of the body (alternating).

Skin

Routine skin inspection plays a role in decreasing the incidence of pressure ulcers. All patients should have their skin assessed on admission as part of a holistic assessment and then checked at least every day. Inspection of all areas of the skin regularly, with particular attention paid to bony prominences and areas of skin that come into contact with devices such as catheters, compression stockings, etc. is recommended. A compact mirror is helpful to visualize difficult to see areas such as the heels when the resident is in a chair. Skin inspection should look for reddened areas of skin on light-skinned people, blue/purple patches on dark-skinned people, blisters, hot or cool areas, swelling, signs of irritation, or scratches and patches of hard skin (Sutton Homes of Care, 2020).

Keep patient moving

Prevention of skin damage and pressure ulcers is achieved through the regular movement of patients as much as possible and immobile residents are at the highest risk of developing pressure ulcers. Regular movement or repositioning will redistribute pressure and help prevent pressure damage. Residents who are being cared for on a support surface still need to be repositioned. Patients who can get out of bed or their chair should be encouraged to do so whenever possible. These movements need only be small but may give a significant pressure difference. Changing position can be incorporated into everyday activities such as standing up to get a drink, walking/transferring to the toilet. For patients who need help, reposition at least every 1-2 hours when sitting in a chair or bed, for instance; on their left side, then on their back, then on their right side. Patients who have actual damage to their sacral area should only sit out for 45 mins–1 hour at a time (depending on severity). When deciding how frequently repositioning is required, consider the wishes of the patients and what they can tolerate. Manual handling aids must be used when moving residents, for example; sliding sheets to avoid dragging the resident along the mattress. To help residents maintain their position when in bed, use a wedge/pillow to maintain a 30-degree side-lying position (Sutton Homes of Care, 2020).

Incontinence

Both urine and feces are highly irritating to the skin, making it more susceptible to pressure damage. It is therefore important to maintain continence and actively manage incontinence. Incontinence is not a normal or inevitable part of aging and has many different causes. Always check whether your resident has a urinary tract infection (UTI) as this can be a cause of incontinence in the elderly or make incontinence worse. Where continence problems are identified, the resident should have a full continence assessment to identify the cause and develop a management plan (Sutton Homes of Care, 2020).

Nutrition

Adequate nutrition and hydration are important for preventing as well as healing pressure ulcers. A nutritional assessment is needed to identify patients who are not receiving enough nutrition. Patients should be encouraged to eat a healthy balanced diet and have regular drinks, ensuring patients have a choice and variety available. Encouraging participation in the activities surrounding preparing and serving meals will also keep your patients moving. Assist patients who find eating meals difficult and ensure those at risk of malnutrition are referred to a dietician. If a patient develops a pressure ulcer, it is good practice to refer them to the dietician to ensure their diet is sufficient to enable the ulcer to heal (Sutton Homes of Care, 2020).

Strategies for maintaining hygiene and comfort (fecal and bladder incontinence)

Incontinence of urine and feces is drastically increased following stroke and is likely to impact heavily on the quality of life of the patient and their carers and family. Dysfunction of the bladder and/or bowel may be caused by a combination of stroke-related impairments (some examples areweakness, cognitive or perceptual impairments). Available evidence suggests that behavioural strategies currently used in non-stroke patients can be effective in some stroke patients. For example, toileting assistance programs such as timed voiding or prompted voiding for stroke patients unaware of their bladder status or those with cognitive impairment.

All stroke survivors with suspected urinary continence difficulties should be assessed by trained personnel using a structured functional assessment. The use of indwelling catheters should be avoided as an initial management strategy except in acute urinary retention. A community continence management plan should be developed with the stroke survivor and family or carer before discharge and should include information on accessing continence resources and appropriate review in the community. For people with urge incontinence, anticholinergic drugs can be trialed. Prompted or scheduled voiding regime program or bladder retraining should be trialed. If continence is unachievable, containment aids can assist with social continence (Ulaan, 2013).

Fecal incontinence

Fecal incontinence after stroke can be improved in most patients after fecal loading and infective diarrhea (due to Clostridium difficile) have been treated. Some management strategies can help achieve continence. These include: bowel habit retraining using type and timing of diet, helping the patient to sit on the toilet after meals and ensuring correct positioning to use the toilet, in exceptional circumstances, regular use of a constipating agent, and bowel care with an enema (Ulaan, 2013).

Contracture Prevention Strategy

After stroking with hemiparesis, 60% of patients will develop joint contracture on the affected side within the first year, with wrist contractures occurring most commonly in patients who do not recover functional hand use (Malhotra, Pandyan, Rosewilliam & Roffe 2011; Sackley, Brittle, Patel, Ellins, Scott & Wright, 2008). The occurrence of elbow contractures within the first year after stroke is associated with the presence of spasticity within the first 4 months (Ada & O'Dwyer, 2006). These contractures can cause pain and make self-care, including dressing and hygiene, difficult. Many clinicians recommend daily stretching of the hemiplegic limbs to avoid contractures and patients and families should be taught proper stretching techniques to avoid injury and to maximize effectiveness. Resting hand splints are often applied to prevent contractures in hemiplegic wrist and fingers but their effectiveness is not well established (Harvey, de Jong & Goehl, 2006; Lannin, Cusick & McCluskey, 2007).

Early after stroke, positioning of the hemiplegic shoulder in maximum external rotation for 30 minutes each day either in bed or in a chair can be useful for preventing shoulder contracture (Ada, Goddard, McCully & Stavrinos, 2005; de Jong & Nieuwboer, 2010). Ankle plantarflexion contractures after stroke can affect gait quality and safety. The use of an ankle-foot orthosis (AFO) can improve gait in patients with active plantarflexion during the swing phase of gait but may also be beneficial in preventing ankle contracture (de Jong & Nieuwboer, 2010; Robinson, Smith & Aung, 2008).

Bathing Strategies

According to Yadav, Gera and Yadav (2018), the strategy for bathing stroke patients involves the use of a soap-on-a-rope to hang around the neck or put soap in a pocket washcloth. It is recommended to use bath or shower bench to help him or her get into a shower or bath, to sit on and to help him or her get out again. The provision of grab rails and a long-handled brush to wash back and feet are needed to facilitate bathing. Placing a non-slip mat in the tub or shower to prevent falls is highly endorsed. Traditionally and historically, washbowls/basins, towels and soap have been well known and often used utensils. In recent times, however, these items have been challenged by several innovative single-use products consisting of skin-cleansing towels/wet wipes that are warmed before and disposed of after use. The bag bath developed by Susan M. Skewes in 1994 is now well known in international nursing practices (Pia & Larsen, 2014).

Feeding Strategies

Dysphagia (difficulty swallowing associated with foods, fluids and saliva) is a common complication of stroke, with about 50% of patients affected acutely (Smithard, Smeeton & Wolfe, 2007). However, 13% of patients are left with persistent dysphagia with attendant risks of malnutrition and dehydration (Smithard et al., 2007). Swallowing problems are managed by a modification of diet and fluids and if this does not suffice to reduce the risk of aspiration by replacement of oral intake with enteral nutrition and hydration (Cohen, Roffe, Beavan, Blackett, Fairfield, Hamdy, Havard, McFarlane, McLauglin & Randall, 2016; Smithard, 2016).

Support systems for caregivers

Grant, Elliott, Giger and Bartolucci (2001) aimed to investigate the unique contributions of social problem-solving abilities and social support in the prediction of aspects of caregiver adjustment. Correlational procedures were used to determine the unique contributions of social problem-solving abilities and social support in the prediction of caregiver depression, health and life satisfaction. Caregivers of individuals who had a stroke were 40 (20 African Americans and 20 Caucasians). Social support was the best predictor of caregiver life satisfaction. Perceived control over emotions when solving problems was the best predictor of caregiver depressive behaviour and health. Social problem-solving abilities were associated with caregiver depressive behaviour and health; social support did not mediate these relationships. Grant et al. (2001) concluded that social support and problem-solving interventions may be most appropriate for the treatment and prevention of caregiver depression and health problems. Social support programs may be indicated for caregiver life satisfaction.

In a related study to determine the assessment support systems and contributions of social support and social problem-solving abilities in the prediction of adjustment of family caregivers of stroke survivors, Grant, Elliott, Weaver, Glandon, Raper and Giger (2006) conducted a descriptive study in two rehabilitation facilities in the South-eastern United States and sampled 52 family caregivers of stroke survivors. Participants complained of the lack of adequate support systems in their line of duty. Also, trajectory analysis indicated that higher levels of social support were associated with lower levels of caregiver depressive symptomatology and higher levels of well-being and general health were independent of social problem-solving. A greater negative problem orientation was associated with higher levels of depressive symptomatology and lower levels of well-being. A more positive problem orientation was associated with greater increases in general health. The strength or slope of this positive relation lessened over time. Grant et al., (2006), in conclusion stated that social support and the emotion-focused component of social problem-solving and problem orientation independently contribute to caregiver adjustment. Interventions that provide social support and assist caregivers to develop more adaptive abilities toward problem-solving may be beneficial.

In a related qualitative inquiry which focused on family caregivers and the support they need as they provide supports for stroke survivors, the researchers': Cameron, Naglie, Silver and Gignac (2013) main objectives of this qualitative study were to explore the support needs over time from the perspective of caregivers, explore the support needs over time from the perspective of health care professionals and also compare and contrast caregivers' and health care professionals perspectives. The population of the qualitative study involved stroke family caregivers (n = 24) and health care professionals (n = 14). Three main themes emerged from the data collected. They were concerned with the types and intensity of support needed, who provide support and the method of providing support and the primary focus of care. The results suggested that family caregivers had little or no support from others while health care professionals did. Researchers suggested that Caregivers need for support and the individuals most suited to provide support change across the stroke survivor's recovery trajectory. Changes to service delivery to better support caregivers may include: addressing caregivers' changing needs across the care continuum, implementing a family-centered model of care and providing 7-day per week inpatient rehabilitation.

Finally, to improve support outcomes for pregnancy caregivers, Anders, Aaron, Jackson and Novak (2019) conducted interviews with 29 pregnancy caregivers. Interview transcripts were analyzed inductively, resulting in a coding scheme of actions and roles that pregnancy caregivers perform. The most common actions and roles included; searching for information (97%), accompanying patients to medical appointments (69%) and being a source of emotional support (76%). Caregivers also reported a lack of support from the family as well as other individuals who may be able to assist. Ander et al. (2019) stated that the patient work framework can be employed to describe the activities and roles of pregnancy caregivers. It can also be used as a guide to provide the needed support for caregivers.

Chapter Summary

This chapter reviewed related literature that is relevant to this study. This chapter defined the theoretical review of this study emphasizing Stress model process for family caregivers (1999), the Self-care deficit theory (Orem, 1991) and Watso''s nursing theory (Watson, 1999). The chapter also defined the variables in the study and how they are related to each other. It also revealed varying empirical findings of studies done in Africa, Asia and Europe. The empirical evidence pointed out that some experiences of caregivers are guilt and grief, anxiety and loss of freedom, emotional and financial burden as well as feelings of anxiety. Also, some challenges of caregivers that were outlined in the review include the lack of support and inability to cope with difficulties associated with care-giving. About strategies that help in coping, it was outlined that most caregivers rely on social support, others also learn more about caring for stroke patients while others tend to self-medicate. It was noted that support systems are not readily available for stroke patients' caregivers. However, social support is the most common avenue for caregivers seeking support. The findings from the review are considered relevant in discussing the findings from this study. I anticipate that this study help fill the gaps in terms of methodology, geography and content. The next chapter presents the Research Method.

CHAPTER THREE

RESEARCH METHODS

Introduction

The previous chapter reviewed the literature that is relevant to this study. This chapter presents the research methodology used for the study. It consists of the research design, population, sample size and sampling procedure, instruments for data collection, data collection procedure and data processing and analysis.

Research Design

The research methodology is defined by Leedy and Ormrod (2001) as "the general approach the researcher takes in carrying out the research project." There are two main approaches to research, quantitative and qualitative methods, however, in 2003, a third approach emerged which is the mixed-method approach. Quantitative research involves the collection of data so that information can be quantified and subjected to statistical treatment (Creswell, 2003, p.153). Quantitative research is defined as a systematic investigation of phenomena by gathering quantifiable data and performing statistical, mathematical or computational techniques. Quantitative research collects data from existing and potential participants using sampling methods and sending out online surveys, online polls, questionnaires amongst others, the results of which can be expressed in the form of numerical presentation. Qualitative research involves asking participants about their experiences of things that happen in their lives. It enables researchers to obtain insights into what it feels like to be another person and to understand the world as another experiences it (Austin & Sutton, 2014).

In addition to strictly qualitative and strictly quantitative analysis approaches, mixed methods of research have recently been recognized as the third mainstream research designs. Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms (Creswell, 2009). It involves both quantitative and qualitative data processing and interpretation (Creswell, 2007). Mixed method designs provide researchers with a systematic approach to address research questions through research disciplines. This is a valid approach in the case of the holistic study of dynamic structures, such as the mega-project. It is novel to bring together all types of data (qualitative and quantitative) as a distinct research design. Mixed methods can be used to achieve a deeper interpretation of qualitative and quantitative data connections or contradictions; they can offer opportunities for participants to provide a clear voice and express their perspectives in the study process and they can encourage numerous discovery avenues that expand the facts and encourage questions to be asked more thoroughly (Wisdom & Creswell, 2013). Despite the different assertions of the other approaches, this study will employ a qualitative approach to uncover the experiences of informal caregivers of stroke patients in the Cape Coast Metropolis.

Creswell (2013, p.48) suggests that qualitative research is preferred when health science researchers seek to: (a) share individual stories (b) write in a literary and flexible style (c) understand the context or set of issues (d) explain mechanisms or linkages in causal theoriesI) develop theories and (f) when traditional quantitative statistical analyses do not fit the problem at hand. Typically, qualitative textbooks present learners with five approaches for qualitative inquiry: narrative, phenomenological, grounded theory, case study, and ethnography. Yet, eminent researcher, Margarete Sandelowski argues that "in the now vast qualitative methods literature, there is no comprehensive description of the qualitative description as a distinctive method of equal standing with other qualitative methods, although it is one of the most frequently employed methodological approaches in the practice disciplines'' (Sandelowski, 2000). Despite the various approaches to qualitative study, this study specifically made use of descriptive qualitative design. Descriptive research explores and describes a person, a community or a situation. The researcher deems it appropriate to use this design because caregivers' experiences in the area of the specific disease-related tasks such as caregivers of stroke patients have not been investigated.

The research parad65nderpinpinning this study is constructivism. This paradigm assumes that every individual seeks understanding of the world and that every individual has its own notion of objects and subjects. Researchers therefore seek to understand concepts from the perspective of participants and thereby understanding different dimensions and facets of a single phenomenon. Due to this, all studies that adopt this paradigm are qualitative study and this attests to the reason for which constructivism paradigm is also employed in this current study.

Study Area

Cape Coast is the only Metropolis out of the Twenty (20) districts in the Central Region. The projected population of Cape Coast in 2017 was 182,236 (Metro Health Directorate, Cape Coast). The Metropolis is endowed with a good number of health facilities to facilitate access to health care. These include hospitals, clinics, CHPS compounds, etc. Some are public owned while others are private. Notable among these facilities are the Cape Coast Teaching Hospital, Cape Coast Municipal Hospital and University Hospital which receive referral cases from other health centers in the municipality. The district, in 2017, recorded 8894 cases of under-five malaria, 42,746 malaria cases, 13,570 diabetic cases, 28,056 cases of hypertension and 15,311 cases of anaemia. There was no record of the number of people living with stroke in the district (Metropolitan Health Directorate, Cape Coast). The setting of the study is relevant because it has a teaching hospital or a tertiary health institution that sees all categories of patients. It is easily accessed by people in and outside the metropolis. It has high cases of hypertension which is a risk factor for the development of stroke. There was a total number twelve stroke cases reported in Cape Coast Teaching Hospital at the time the research was conducted.

Study Population

A research population is generally a large collection of individuals or objects that is the main focus of a scientific query. It is also known as a well-defined collection of individuals or objects known to have similar characteristics (Creswell, 2013). The population of the study included informal caregivers of patients diagnosed with stroke and living in their homes and communities in the Cape Coast Metropolis. The population covered both male and female caregivers of both male and female stroke patients. This study included all informal caregivers of stroke patients who have been diagnosed and discharged by a physician from the Cape Coast Teaching Hospital and live within the Cape Coast metropolis. The total population of informal caregivers of patients diagnosed with stroke at the Cape Coast Teaching Hospital was twelve. To be eligible, the caregiver should have cared for the stroke patient for at least one month.

Sampling Procedure

A sample is a subset of the population selected, which is an unbiased representative of the larger population (Karthik & Suresh, 2011). The process or method of choosing a sub-group from a population to participate in a study is the sampling procedure or technique (Bryman, 2012). Various sampling techniques include probability and non-probability approaches. In probability sampling, participants are selected based on probability (Bryman, 2012). The most popular types of probability sampling are simple random sampling and stratified sampling. On the other hand, non-probability sampling does not rely on probability theory. Non-probability sampling techniques are not intended to be used to infer from the sample to the general population in statistical terms (Bryman, 2012). Instead, for example, grounded theory can be produced through iterative non-probability sampling until theoretical saturation is reached. Major types are purposive sampling and convenience sampling procedures.

The study, however, employed the purposive sampling technique to select informal caregivers of stroke patients who are in the Cape Coast Metropolis. Purposive sampling (also known as a judgment or subjective sampling) is a sampling method in which researchers rely on their judgment when selecting members of the population to participate in a research study (Cohen et al., 2011).

This sampling technique was utilized to deliberately choose participants that possess the qualities needed; in this case, the informal caregivers of stroke patients. They are the participants who fit the study and can provide valid and reliable source of information.

Purposive sampling is a non-probability sampling method and it occurs when “elements selected for the sample are chosen by the judgment of the researcher. The units of a purposive sample have the same characteristics (Kothari, 2004). In this study, the researcher used a homogeneous purposive sampling technique to choose the participants. This required the researcher to do some exploratory work to determine the nature of the variation of the situation under study, then sampling intense examples of the phenomenon of interest (Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood, 2015). All 12 participants were selected for the study. Creswell (2007) recommends that the sample size should be between 5 and 25 for qualitative study which implies the sample size chosen for this study falls in line. A stepwise approach was used to select the participants who were involved in the study.

Firstly, the admission and discharge books of both the male and female medical wards of Cape Coast Teaching Hospital were used to gain access to clients’ out-patient department numbers. Secondly, the out-patient department numbers were used to retrieve stroke patients’ folders to access particulars such as a home address, telephone numbers of patients and next of kin. This helped identify primary caregivers to select the right participants for the interview. Finally, after negotiation, the homes of selected participants were visited and caregivers who have cared for these patients for at least a month were interviewed. Sampling continued till saturation was reached. This was based on a guiding principle in qualitative research where the researcher is to sample until data saturation has been achieved. Data saturation means the collection of qualitative data to the point where a sense of closure is attained because new data yield redundant information (Polit & Beck, 2017). This suggests that all participants selected for the interview were identified and all information needed were been retained.

Inclusion criteria

The study included informal caregivers of stroke patients who have been diagnosed and discharged by a physician from the Cape Coast Teaching Hospital and lived within the Cape Coast metropolis. To be eligible, the caregiver should have cared for the stroke patient for at least one month. Also, all the participants selected were above 18 years old. In addition, both paid and unpaid family caregivers were involved in the study. Finally, because the study was done in Cape Coast, the spoken language of caregivers was restricted to Fante and English Language.

Exclusion criteria

Caregivers with less than a month of experience in stroke care did not participate in the study. This was because less than one-month duration in the care of stroke patients was not adequate for a caregiver to understand the condition of stroke and gain rich experience. Caregivers of stroke patients who were not resident in the Cape Coast Metropolis were not included. This was to enable the researcher to focus on a sample that is easy to work with.

Data Collection Instrument

A semi-structured interview guide was developed from the research questions to guide the interview. The purpose of semi-structured interviews was to ascertain participants' perspectives regarding their experiences on the research topic. The semi-structured interview was designed to ascertain subjective responses from persons regarding a particular situation or phenomenon they have experienced (Partridge, Edwards & Thorpe, 2010). The semi-structured interview guide was used to allowed participants to express themselves without stringent restrictions (Creswell, 2013).

The instrument was developed by the researcher and was based on the research questions of the study. The questions explored topics to reflect the objectives of the study and included questions that focused on 1) the challenges of the informal caregivers regarding stroke patient's care or the stroke patients from the perspective of the caregivers 2) strategies for managing the health-related task associated with stroke care 3) the support systems available to informal stroke caregivers. These questions were typically posed to each interviewee but there was freedom to diverge from the script. Probes such as "In whatIy...?" or "Il me...?" were included to elicit further responses beyond the participants' initial response.

Data Collection Procedures

Before the collection of the data, an introductory letter was sent to the Cape Coast Teaching Hospital to seek approval. After it was approved, the researcher was educated on the incidence of stroke cases at the hospital. The researcher was then introduced to the stroke patients in the hospital and informed consent was sought from them. After this, each of the caregivers was scheduled for an interview. The researcher then conducted face to face interviews in the homes of informal caregivers to gain an in-depth perspective of the experiences of caregivers of stroke patients. The interviews were semi-structured around guided questions that reflect the objectives of the study. The interview was audio-taped with the permission of all the respondents involved in the study. There were varieties of method of data collection in qualitative research, including observations, textual or visual analysis (e.g., from books or videos) and interviews (individual or group) (Silverman, 2000). Individual interviews were conducted in this study and each interview took approximately 45 minutes. The interview took place in the homes of the participants and the medium of communication was Fante and English. Twelve participants were approached and all of them agreed to participate in the research.

The interviews were semi-structured around guided questions that reflect the objectives of the study including challenges and strategies for 1) meeting nutritional needs of stroke patients 2) prevention of complications 3) administration of medication in a stroke patient at home 4) communication with stroke survivors at home 5) meeting elimination needs of stroke patients 6) meeting the hygiene of stroke patients and 7) facilitators and barriers to providing

The audio taped interview was transcribed verbatim by the principal researcher. A file was created to store all information from the interview and was password-protected to prevent unauthorized access. The hard copies of the transcript and audio taped recorder will be kept for six months before destroying it by burning. The electronic data will be preserved for at least a year after the defence of this thesis before finally destroying it.

Ethical Considerations

Ethical considerations in research are critical. Ethics are the norms or standards for conduct that distinguish between right and wrong. Ethics helps to determine the difference between acceptable and unacceptable behaviours. Ethical considerations are important in research because ethical standards prevent the fabrication or falsifying of data and therefore, promote the pursuit of knowledge and truth and prevent physical and psychological harm to the participants which is the primary goal of research (Creswell, 2013a). Firstly, ethical clearance was sought from the University of Cape Coast Institutional Review Board (UCC IRB) An introductory letter from the School of Nursing and Midwifery, Completed UCC IRB forms, copies of the proposal and other relevant documents were sent to the IRB to seek for clearance to undertake the study.

The clearance letter from the university and a copy of the proposal were submitted to Cape Coast Teaching Hospital (CCTH) research board to seek approval and permission to undertake the study in the hospital. Thereafter, strategies were implemented to ensure respect and care of participants including voluntary participation as well as protection from physical and psychological harm. These were formalized in participants' informed consent forms which outlined the information about the nature of the research and steps taken to ensure confidentiality and voluntary participation (Appendix I). For the interview, consent was assumed when respondents completed and returned the consent form. Participation in the research was voluntary and participants were given full autonomy to withdraw from the study at any time or decline to answer any question. Identities of the participants were kept anonymous and information acquired from respondents was kept confidential to protect participants from harm. In relation to confidentiality, all the information received from participants were used solely for this research and none of the data was compromised.

Data Processing Analysis

When data collection is complete it is important to subject the data to analysis and interpretation. To analyze data, all audio taped interviews collected were transcribed manually. The transcribed data was organized to reduce a large amount of information to a smaller one. This was done by going back to the research objectives or questions and then organizing the collected data according to these objectives or questions. The organized data was then coded into easily understandable concepts for a more efficient data analysis process.

There are various approaches to qualitative data analyses. They include content analysis, thematic analysis, narrative analysis, template analysis and discourse analysis. Thematic analysis was considered more appropriate because the researcher aimed to organize the responses of the participants and determine which pattern of response stands out. Thematic analysis was done by following the six phases of thematic analysis laid down by Braun and Clarke (2006). First of all, the researcher became familiar with the data collected. This involved the repeated reading of the data and actively reading the data, hence searching for meanings and patterns that existed in the data and making a list of ideas about the data. The second step was to generate initial codes from the repeated reading of the transcribed data. Generating these initial codes involved identifying features of the data (semantic content or latent) that appeared interesting to the researcher and referred to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon”.

After generating these codes from the data, the researcher searched for themes that were in the data. For example, through the search for themes,

themes such as ***support systems, availability of informal stroke caregivers,*** etc. emerged. At this phase, the researcher focused the analysis at the broader level of themes, rather than codes, involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes. Also, the researcher tried to establish the relationships that existed in the themes. The fourth step was to review the themes that were found. It involves the refinement of emerging themes. During this phase, it became evident that some candidate themes are not themes, while other themes collapsed into each other (separate themes forming one theme). Also, others were broken down into separate themes. In a way, it was easy to identify and categorize major themes and sub-themes. For example, after some themes were collapsed and merged, the theme, ***support systems available to informal stroke caregivers*** emerged.

The fifth phase involved defining and naming the themes that were present or found in the data. At this point, there was a need to then define and further refine the themes that were presented for analysis. This meant identifying the essence of what each theme is about (as well as the overall themes) and determining what aspect of the data each theme captures. For example, using this step, three major themes were finally arrived at; ***challenges faced by caregivers, strategies for managing the health-related task associated with stroke care, support systems available to informal stroke caregivers***. The final phase of this approach involved producing the report on the data. The report of the thematic analysis was written to outline the salient information gathered from the data. The report provides a concise, coherent, logical, nonrepetitive and interesting account of the information in the data within and across the themes.

Rigor

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

Credibility ensures the study measures what is intended and is a true reflection of the social reality of the participants. There are many strategies to address credibility that include “prolonged engagement” and member checks (Maher, Hadfield, Hutchings & Eyto, 2018). The researcher ensured credibility by recruiting only participants that were willing to take part in the study and those who meet the inclusion criteria. The researcher established a good relationship with the participants from the beginning and encouraged participants to be honest and give accurate information about their experiences. Piloting of the study was also done to ensure the meaningfulness of interview questions and help to identify researcher bias and minimize error. The pilot study was done at the University of Cape Coast Hospital where four caregivers were identified and after agreed consent, scheduled an interview session. After the pilot study, the instrument was seen to be credible and trustworthy, hence used for the main study. Member checks were done by verifying all patterns and statements observed by the researcher from participants.

Transferability is the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents. The researcher facilitates the transferability judgment by a potential user through the thick description. Detailed descriptions and verbatim quotations were presented so that a person who wants to use the findings of this research could judge the appropriateness of transferring the study findings to another group (Korstjens & Moser, 2018).

Confirmability of findings means that the data accurately represent the information that the participants provided and the interpretations of those data are not invented by the inquirer (Polit & Beck, 2012). To ensure confirmability, it is recommended that the analysis be performed by more than one person to increase comprehensiveness and provide a sound interpretation of the data (Burla, Knierim, Barth, Duetz & Abel, 2008). In this study, the work was frequently given to supervisors and reviewers for directions to deal with possible biases. This action continuously reflected on personal characteristics and examined how they influenced data gathering and analysis. Triangulation of data sources was done to sidestep biases from a single data source.

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

Chapter Summary

This chapter deals with all the procedures employed in the entire study. The chapter discussed the research designs and the research paradigm (constructivism) that underpined the study, the study area and population, sampling procedure and the technique used, inclusion and exclusion criteria. Data collection instrument as well as data collection procedures used.Ethical consideration and rigor of the study were also captured in this study .

CHAPTER FOUR

RESULTS AND DISCUSSIONS

Introduction

The previous chapter captured the research methods for the study. This chapter presents the results and discussions of the study. The study is to explore the experiences of informal caregivers of stroke patients in the Cape Coast metropolis. The interviews were transcribed verbatim and analyzed in response to the research questions. In all, three major themes were obtained from the coded interviews;

- Challenges faced by caregivers
- Strategies for managing the health-related task associated with stroke care
- Support systems available to informal stroke caregivers

Biographic Information of the Respondents

Gender, Age, and Education Qualification of respondents

The gender, age and educational qualification distribution of respondents in the study is shown in the Table below.

Table 1: Gender, age, and education qualification distribution of respondents

Gender	Frequency	Percentage (%)
Male	3	25.0
Female	9	75.0
Total	12	100.0
Age range		
26-30	3	25.0
31-35	4	33.3
36-40	2	16.7
41-50	2	16.7

Table 1 continued

51 and above	1	08.3
Total	12	100.0
Educational Level		
SHS	5	41.7
Tertiary	7	58.3

Source: Field survey (2020)

Table 1 part 1: shows that majority of the respondents were female, representing more than half the total sample size. The results in part 2 show that 3(25.0%) respondents were between the ages of 26 and 30. Again 4 (33.3%) were between the ages of 31 and 35. However 4 (33.4%) of the respondents were between 36 and 50 and a respondent was above 51 years. The age of respondents was thought to be important to the study so the researcher sought to establish the mean age of the respondents. The age range of the respondents is shown in the Table 1. In the last part, all twelve (12) participants were interviewed which comprised three (3) males and nine (9) females. Five (5) participants were aged between 24 to 43 years and seven (7) participants were between the ages of 44 and 73 years. Seven of the participants were married and the rest were made up of sisters, brothers and daughters of the patients. Six of the participants had served as caregivers for a maximum of 12 years and the remaining six had been serving the same role from one year to ten-year period. Five of the participants had received formal education at the secondary school level and seven of them had had formal education at the tertiary level.

Analysis of Main Findings

Table 2: Themes and Sub-themes derived from analysis.

Themes	Sub-Themes
Theme One: Challenges faced by caregivers	Financial challenges caregivers experience Caregiver`s health challenge Emotional challenges of care-giving
Theme two: Strategies for managing health-related task associated with stroke care	Bathing strategies Medication strategies Communication strategies Feeding strategies
Theme three: Support system available	Family support Community members Religious organization Health professionals

Source: Field survey (2020)

This section presents the findings of the key research questions guiding the study. The results have been presented in major themes and sub-themes emerging from the coded data. For easy identification and references, the participants were given codes as P1, P2, P3, P4…………P12

Challenges faced by caregivers

The researcher was interested in finding out from the participants their views on challenges that confronted them in the care of stroke patients. In this regard, various challenges are described below:

Financial Challenge

In this instance, the researcher was interested in exploring from the participants or the informal caregivers the financial constraint in caring for these patients. From the majority of the responses, participants were of the view that they were financially constrained in giving the best of care to their patients. For instance, some participants were of the view that money for transportation to the hospital for review was a challenge. Excerpts from participants are below:

> *"Financially, I have been challenged because each time we [patient and carer] go for a review, I have to chatter a taxi and pay forty Ghana cedis for the in and out. Due to this, I have not been able to continue with review and physiotherapy on account of financial difficulty (P2)."*

> *"At times, like today when we were coming to physiotherapy, I have to go round and look for some coins for transportation because when the condition started, his [stroke patient] money was in the bank, unless he goes nobody can go for money (P9)."*

Another participant also added that money for medication was even a big challenge to him as a caregiver. Participant 4 had this to say:

> *"For that one, we struggle to buy drugs, to pay for bills. You know some of the drugs are expensive and sometimes not available and you struggle to get them. A caregiver also reiterated that everything about taken care of stroke patients is expensive with emphases on drug purchase. And his drugs were very expensive. Everything about the sickness was very expensive, and you know that the use of the executive ward is very expensive (P6)."*

Caregivers' Health Challenge

Caregivers' health challenge looks at the impact of care-giving on the caregiver. Almost all the caregivers who responded to the interview had serious challenges with their health as a result of the services they rendered to the stroke patients they were caring for. Below are excerpts from participants' comments:

> *"Even now I am well but initially, I have been feeling headaches, waist pains and others. But if I take pain killers*

> *and rest a while, I become sound. Yesterday like this, if I walk it was difficult. Last when I came to the physiotherapy, they saw that I have a problem with my knees. My knees were paining me so they applied hot water and taught me what to do the next time I have pain* (**P9**)."

A caregiver added that all those taking care of their patient are also sick as a result of the assistance they were offering to the sick. They do not have enough time for themselves.

> *"All of us taking care of him have issues with our health. Our back and waist have been affected so we even go for physiotherapy and the hospital for treatment. Others are complaining of chest and leg pain. We have informed the physiotherapist treating us. I have gone for an x-ray. His condition has affected all of us* (**P5**)."

Participant **3** could not hold her side of the story but also added that her patient was on the 3rd floor of the flat and therefore had to be carrying him up and that has had implications on her health as a caregiver.

> *"Eee yes, in the beginning, we were on the third floor and sometimes I have to carry him. So I have been having pains in my back and waist, but now the pain has reduced."*

Some caregivers also said that their roles as caregivers have affected their sleep. They do not get adequate sleep and that has had implications on their health. For example, participants 11 and 8 had these to say respectively.

> "*…I have realized that waking up early all the time to do the type of work I do is weakening me and I feel tired. I do not sleep adequately- by five am I have to rise. During the daytime if I*

> *sleep, by 11:00 am I have to get up and prepare for supper* (**P11**)."
>
> *"Eeee yes in the night I sleep with her at the initial stage, the problem lies at the initial stage she said to take my hand raise me up and so I felt pain in my left hand and waist, to be honest, but now that she is improving, I am also a bit relieved* (**P8**)."

A caregiver narrated her ordeal when she said she has been taking care of the sick for the past five years and within these past years the patient has not been sleeping so she too has not been sleeping. For instance, **Participant 6** said:

> *" I had taken care of him for about five years. He was not sleeping and so I was also not sleeping. So, I realized that everyday around 4 pm, I started feeling dizzy, my walking you know I will stagger.*

Emotional challenges

Caregivers further revealed the emotional difficulties that they have to go through as a result of their roles as caregivers to their stroke patients. Excerpts from participants' comments are below:

> *"Emotionally, I was challenged. Initially, I felt sorry for him when he was not able to do certain things for himself because he could not walk and bath, I have to be lifting him. Although we are three children, two of my siblings are not here so I have to do everything. I sometimes ask if I am the only child of this man. So emotionally, I feel challenged and pray that God will heal him. Now he is progressing very well and now I am emotionally stable* (**P3**)."

A participant said as a result of her role as a caregiver sometimes she weeps and it affects her emotionally. **Participant 5** said:

> *"Emotionally I am worried and challenged, sometimes I weep because my husband is a preacher and suddenly, he could not talk and do anything again."*

A caregiver lamented further by saying that her patient had become troublesome and that is making her emotionally challenged.

> *"Emotionally I am challenged because he has become troublesome and complains a lot when he is offended by the children (P2)"*

In the same vein, a caregiver also said that the patient she was taking care of had become bedridden and makes her think a lot. For example, **Participant 10** had this to say:

> *"I think a lot because he is bedridden and I can't go anywhere at all. You have to focus your attention on him every day. If he is not sick, I would not suffer like this, this makes me think."*

From the above, it may be said that the main challenges that confronted the caregivers of stroke were financial constraints, negative health impact and emotional imbalance as a result of their role as caregivers. Financially, caregivers narrated how financial constraints made their work in taking care of the sick so difficult. Some of these constraints were encountered in the area of purchasing drugs, payments of other hospital bills. As a result of this, caregivers and their sick patients are moved to different healthcare centers in search of alternative cheap care. The health of the caregivers was in turn impacted negatively as a result of serving as a caregiver. Caregivers could not have enough sleep and this has affected the health of caregivers as reiterated by caregivers. Emotionally, caregivers were severely troubled, some had to cry overnight. These challenges have affected the caregivers psychologically and socially.

Strategies for managing health-related task associated with stroke care

The researcher wanted to know from the caregivers the strategies that they use in managing the health-related task associated with stroke. In this regard, various strategies are used by caregivers.

Bathing strategies

Strategies in caring for the patients centered on areas such as bathing. A lot of different ways of bathing these sick people emerged. Excerpts from some caregivers are below:

> *"I informed you that at the start of the sickness I was bathing her in bed because I could not carry her to the bathroom. Now I assist her to the bathroom, she sits on a chair and she baths. I support with the scratching of the back* (**P1**)."

Another caregiver added that:

> *"...she could not bathe on her own, I used warm water, add a little Dettol because at the hospital I was asked to buy Dettol. So when I got home too I was applying it. I used Dettol and the way they treat her at the hospital I studied it – the bed bath and all those things I studied it at the hospital. So when I went home, I remembered everything on the bed- I just applied it and bath her nicely* (**P8**)."

A participant narrated that when they were in the hospital, they were using a sponge to bathe him but when they went home, they decided to use a towel to clean his body instead of the sponge.

> *"…they were using a sponge at the hospital but when we went home, the mother was using a towel to bath him because he complains of bodily pain. He was bathed in bed and later we have to sit him on a chair in the bedroom and bath him. We feared he will slip into the bathroom if we send him there. But now I send him to the bathroom to bath him* (**P9**)."

A caregiver said she sits the patient in a wheelchair and then baths him. She goes on to describe the process involved as captured

> *"…I sit him in the wheelchair, I wash the back, hands, and legs. I try to lift him to stand, support him with my left hand at the back, wash the buttocks still holding with my left hand so that he would not fall (P11)."*

A caregiver corroborated what previous caregivers had said with regards to bathing strategies they employed in taking care of their patients. **Participant 10** had this to say:

> *"I bath him in bed and because at that time he could turn in bed, anytime I got to wash his back I say brother turn a little and he turns for me to wash the back. These two weeks that he is not talking and is weak, I have to turn him in bed myself to bath the back."*

Medication strategies

Medication strategy focuses on the techniques employed by these untrained informal caregivers to give their stroke patients the medications prescribed.

Caregivers, again, narrated the strategies that they used in giving medications to their stroke patients. Many were the views shared by the caregivers who were interviewed. For instance, **Participant 9** said:

> *"I crashed all the tablets, mix it with water, and give it to him. This also takes a long time for him to swallow. Occasionally, he aspirates some of the food and drugs. Another participant also employed a similar strategy as participant 9 did. The caregiver said: Medication too we were crashing the tablets and mix it with water so she can drink. This demands a great deal of patience anytime you are medicating (P1)."*

A participant said sometimes he has to use the favorite sports of his patient' to serve as bait for the intake of the medicine. **Participant 3** said:

> *"I often use sports and favorite programs to influence him to take. I give him options and because he likes sports, he would at all costs swallow or take his medication."*

Communication strategy

The medium of communication between the caregiver and the stroke patients is key for the services to be rendered. However, the stroke condition sometimes makes it difficult to have a free flow of communication. In this regard, the caregivers gave the means or strategies in communicating with patients.

> *"I initially did not have a problem with communication with him because he could talk effectively. It was about three weeks before his death that when he talked, we could not hear. So the strategy we used was to listen carefully to him when he talked. Even though it was difficult hearing him talk, we managed most of the time* (**P6**)."

A caregiver said ever since they were discharged from the hospital, his patient has never been able to speak, and therefore has to listen carefully each time his patient is trying to say something to him. For example, **Participant 12** said:

> *"Since we left the hospital, his speech has not come, so when he talks, I cannot hear what he says. I have to sit by him and listen over and over before I can know what he is saying. You must have patience if you want to understand what he is saying."*

A participant said she wishes to have used signals in communicating with the patients she is taking care of. However, the patient could not signal so she has to pay attention each time he requires anything.

> *If he is capable of signaling me, I would ask him to signal me when he needs something-but he cannot. I have to stay closer to him and use my discretion **(P10)**.*

A caregiver added that she had to ensure extreme quietness.

> *"When communication was not clear, I have to listen to him carefully, and sometimes I have to ensure quietness around to hear him well (P2)."*

Feeding strategies

Feeding stroke patients as a caregiver can sometimes be worrying for caregivers. In this regard, the researcher inquired from the caregivers how they feed their patients. A caregiver said she learned how to feed her patient from the hospital.

> *"We learned how to feed through the nasogastric tube at the hospital and since we came home, we have been doing it perfectly. When it blocks, I call one of the nurses to come and help. We know the length of the tube that has to be out and we use plaster to keep it in position. The last time it came out and we secured it in place. After feeding, we use water to flush it so that it will not block. We were taught not to keep the tube open because air will enter and make the stomach bloat* (**P4**)."

> *"The doctors have passed a tube to help us feed. We are going home and the nurses have taught me how to feed through the tube and take care of it. I think I can do it since I have observed them doing it each time, I come to visit him* (**P10**)."

A caregiver reiterated that she has to use a teaspoon to feed their patient. Given that she has to exercise great patience in feeding the patient.

> *"We were giving him liquid diets and have to exercise great patience in feeding him. Some of the foods given are porridge, light soup, and tea. I use a spoon to fetch the food and introduce it into his mouth. I wait till he swallows before another one is given* (**P5**)."

Participant 9 also gave her side of the story:

> *"I have been assisting with introducing food into his mouth because he was weak in the dominant hand. I have to wait for*

> *some time before following up with another spoonful of food (P9).”*

A caregiver added that she mostly gives liquid food to her patient, however, she sometimes requests fufu where she makes it soft to enable her to swallow it easily. For instance, **Participant 8** said:

> *“I was giving her a liquid diet. At times she requests for fufu, so I have to make it very soft so that she can swallow. She also takes much of soups.”*

It is evident from the above that strategies used by caregivers in the discharge of their duties included strategies in bathing the sick, medication strategy, communication strategies, and feeding strategies. It could be said that patients with stroke conditions mostly became immobile and had to be bathed on a bed and sometimes even in wheelchairs. Some had to be carried from one place to another before they could be bathed. Caregivers in their quest to give medication to patients had to go into various ordeals before the patients could take their medication. Caregivers had to use sporting activities and other means before they get their patients to take the medication. In their efforts to meet the nutritional needs of patients, caregivers were faced with the task of food modification while preparing food to facilitate swallowing. Communicating with the patients was difficult as caregivers found it challenging to talk to their patients. Patients had lost communication ability and therefore made it difficult for caregivers to understand the exact services patients needed.

Support system available

The researcher was interested in knowing from the caregivers the available support in caring for their stroke patients. It was of interest to explore caregivers’ family support, community support, religious organization and health professionals. Therefore caregivers, family, community, religious organizations and health professionals' support were explored.

Family support

To this end, caregivers narrated the various support from family members in taking care of the patient. Excerpts from the comments of caregivers are below:

> *"Family members, they did well and brought support. Anybody who hears he is sick came and brought contribution because he is the type who cares about the family. everything he does it in the family. So anybody who hears that he was sick came. They only brought money and could not bath or feed him because the mother would not allow them. Even if you are not a very close friend, the woman will not allow you to see him. That is why the church members did not come to visit him, because of the mother`s attitude* (**P9**)."

Another caregiver added that she got support from family members:

> *"He is being supported financially by his two children, one is a teacher, and the only one employed. The family does help occasionally and their support is mainly finance and prayers (**P2**)."*

Furthermore, a caregiver said she does not get any support from any family member but a friend supports them in taking care of the sick

> *"…Once in a while they come and talk but do not support anything. A friend in London sends me something small and my wife also supports me (**P4**)."*

Not all, a caregiver also emphasized that apart from the nuclear family that do support her in taking care of the sick, the extended family members only come around but do not support her in taking care of the patient.

> *"Apart from myself and the children who support me financially, the extended family comes and has nothing to give to me especially in the area of finance (**P5**)."*

Community members

The researcher again explored from caregivers if there was any way the community gives them any form of support. Some caregivers said truly they receive support from the community in the form of visitation.

> *"The people he worked with- the former vice-chancellor, the new vice-chancellor, the registrar, welfare a whole people they were coming. Those he taught in 1972 were all here and they display their German language skills. People came and I was always grateful because the interaction was more healing than the medication. So it is like they still love you treasure you for things you did for them* (**P6**)."

A caregiver added that:

> *"Oooh they know him and they always come to visit him, he is nana oo. Even though he does not come from here, the denkyira people have made him nana because of his good behavior and comportment (**P12**)."*

Other caregivers also said the community members were supportive in terms of given financial assistance to the upkeep of the patients

> *"…Yes, apart from his master, some people also come to help him in terms of finance-his friends, and those who know him come and if they have money, they give him (**P11**)."*

Participant **10** could not hide the support she receives from the community members but added that

> *"…Oooh, those in the community (crying and voice have changed…), those whom he is nice with coming to visit him and offer little support."*

Another caregiver said they received financial support and in addition to that the community members

> *"…Financially, they give him nothing. They however help to carry him each time we are going to the hospital (**P5**)."*

Religious organization

Still on the issue of support systems available for caregivers of stroke patients, the researcher was interested in probing further to ascertain the support they received from the religious organization since most of the patients were affiliated with a religious denomination. For instance, **Participant 3** said the pastor of the church and some elders' have been visiting the patient.

> *"From the church, he has been visited by our pastor and prayed for. Some elders of the church had been here. Some women leaders have also been here. So basically, it has been prayer support. Some of them who came gave him some money. Some come from the workplace every four-month with money* (**P3**)."

> *"Yes, he attends Anglican and they come periodically, they come to have church service with him at home. The same church they do in the church premise, the same is done here in the house when they come. He has a position in church but for five years since he has been sick, I don't think the position is vacant. Someone may occupy it at all cost* (**P12**)."

A caregiver said the patient is not serious with church activities and therefore, does not receive many visitors and any help from the church however, the young priest sometimes comes over to pray for him

> *…He is not serious with a church so no member comes but the young priests sometimes come to pray for him **(P10)**.*

Financial and spiritual support comes from the pastor of the church as reiterated by a caregiver

> *…My pastor comes with little financial and spiritual support **(P7)**.*

Evidence from the caregivers showed that religious organizations to a large extent assisted caregiver in taking care of their stroke patients. Assistance from the visitation to financial support was received by these caregivers.

Health professionals

Health professionals' assistance could not be ignored, because of this, the researcher inquired from the caregivers the support they received from health professionals. The majority of the participants said they do not receive any assistance from the health professionals. Excerpts from the participants' comments are below:

> *"No nobody comes here; do you nurses do this? No doctor has walked here to visit us. You have come here because you want to interview me. When you came, I am happy you came. So, I will be happy if a doctor comes here to check on us* (**P12**)."

Participant 10 added that:

> *"None of them has come to visit before. I am now looking for a nurse to take over because I am not healthy again to continue caring. Another caregiver also reiterated that they do not*

> *receive any help from neither doctors nor nurses. There is no support from the doctors and the nurses (***P7***).”*

A caregiver could not also hide her frustration as a result of her inability to receive any form of help from health professionals. For instance, **Participant 11** said:

> *“No none of them have come to visit us. They only see us when we come for review and they (nurses and doctors) tell him eee you are looking fine too.”*

Even though it could be said that health professionals were not mandated to visit patients at home, nevertheless, caregivers ultimately expected that health professionals should have been visiting them, however, that did not happen.

In summary, it may be said that support systems available to caregivers were support from family members, the community and religious organizations, however, there was not much support from the health professionals as reiterated by caregivers. Family support went a long way in easing the burden on the patients and the caregivers at large. The immeasurable support from the community and religious organizations could not be underestimated. Prayers and financial support from religious bodies brought great relief to patients and caregivers. The visitations received from the community members also raised the hopes of patients and caregivers immensely. However, health professionals could not provide the assistance caregivers expected from them.

Discussions of Findings

This study presents findings that highlight the experiences of stroke patients’ caregivers in a Ghanaian home setting. The three thematic areas identified in this study were similar to those from previous studies (Thomas &

Greenop, 2008; Greenwood et al., 2009; King et al., 2010; Tseng et al., 2015; Ae-Ngibise et al., 2015; Masuku et al., 2018; Simeone et al., 2016; Namale et al., 2019). Generally, the process of caring described by the caregivers in this study illustrates challenging experiences and difficulties in caring for stroke patients. The high number of women caregivers in the current study is similar to previous literature (Ae-Ngibise et al., 2015; Salama, 2012; Namale et al., 2019). This finding shows the African cultural burden on women; having to bear care-giving 's a woman's role irrespective of their employment status. Women are known to be commonly devoted to caring for their family members and for managing household chores unlike male caregivers even though the evidence from this study showed they also undertook the challenge of caring for their patients. Both male caregivers were providing care by themselves and did not depend on other people as in Namale et al. (2019). According to Uemura, Sekido & Tanioka (2014), male caregivers learned how to provide care independently without support.

The major challenges that confronted informal caregivers in their discharge of duties included financial constraints, the health of the caregiver being affected and emotional challenges. A study to investigate informal caregivers' burden and strains of caring for stroke patients showed that caring for stroke survivors put social, emotional, health and financial burdens and strains on the informal caregivers. These burdens and strains increase with the duration of a stroke, intimacy, a smaller number of caregivers and other significant factors (Gbiri, Olawale and Isaac, 2014). The changes in the stroke patients caregivers' lives are in line with study findings in the existing literature (Ang et al., 2013; Bulley, Shiels Wilkie & Salisbury, 2010). According to Ang et al. (2013), the changes in the lives of caregivers may differ depending on the caregivers’ relationship with the stroke patient.

Financing the medication bills and other necessities for stroke patients by informal caregivers was a big challenge. It became a major constraint that emerged from the ’aregivers' point of view as in Dewey et al. (2001); Ae-Ngibise et al. (2015); Salama (2012) and Namale et al. (2019). The health of the caregivers was also affected. Caregivers at some point became sleepless as a result of the services been rendered to the stroke patients. Others ended up also being ill as a result of their work as caregivers. These findings are similar to literature from other studies (Bulley et al., 2010; Masuku et al., 2018; Wagachchige et al., 2018 and Namale et al., 2019). The study could not stand alone but underpin studies such as Grant et al., (2001), Grant et al. (2006) Cameron et al. (2013), and Anders et al. (2019). These studies explored the support needs over time from the perspective of health care professionals and also assessed support systems and contributions of social support and social problem-solving abilities. In contrast, a research evidence from Japan has reported less stress and a lower sense of care burden among caregivers due to available support systems (Uemura et al., 2014). Even though the support system available in this study context has a level of impact, an enormous impact could be expected if a well-structured system as shown in the mentioned study was implemented. Optimistically, this information would prove useful to healthcare professionals in prioritizing efficacious interventions. This is based on the emphasis that there is a need for strong institutional and professional support for caregivers of stroke patients in the country to reduce their caregiver burden.

Emotional instability and psychological trauma became a hindrance to caregivers. Some caregivers had to be weeping because of the conditions they saw their patients in. These caregivers were mostly women and the sudden life changes may have important aspects of balancing care-giving with other demands including relationships and household chores. Findings from recent studies show that life at home for caregivers had to be done alongside the stroke crisis and the demands of looking for school fees, feeding, treatment, and transport to the health facility (Simeone et al., 2016 and Namale et al., 2019). These empirical studies revealed the challenges caregivers face in the management of stroke. There is however a pressing concern since these aforementioned challenges are not prioritized and treated as a public health crisis in Ghana.

Another critical area of the study was the strategies that were employed by informal caregivers in their line of duties. Feeding a stroke patient was a difficult issue in caring for them. However, informal caregivers had to learn how to feed their patients through the nasogastric tube, some were being given liquid diets and caregivers have to exercise a great deal of patience to feed them. This implies that caregivers spent a lot of time in caring for such patients. The flow of speech by stroke patients is another difficulty that confronts informal caregivers. Nevertheless, informal caregivers had to pay rapt attention whenever they were communicating with patients. Caregivers at a point have to be using signals to communicate with patients. This could affect the clarity of the message being communicated to patients. This can intend to affect medication and other salient issues about taking care of stroke patients. The stress of bathing stroke patients was a nightmare to caregivers. They sometimes had to bath these patients in bed. Some had to sit in their wheelchair for bathing to take place. Another worrying revelation is that most of the caregivers were bathing patients alone. The challenges experienced by these caregivers are similar to most literature (Bulley et al., 2010; Cecil et al., 2011; Ae-Ngibise et al., 2015; King, Ainsworth, Ronen & Hartke, 2010; Masuku et al., 2018; Namale et al., 2019). According to evidence in Namale et al. (2019), the need for information support, skills and active listening to caregivers' concerns to feel confident about care-giving was a very crucial part of stroke care-giving. In line with the study findings, evidence of a systematic review (Greenwood et al., 2009) reveals the educational needs of caregivers. These caregivers experienced a lot of difficulties in care and family and friends were an important source of support. The family relationships and support in this study are similar to Namale et al. (2019) in Uganda, Ae-Ngibise et al. (2015) in Ghana and South Africa (Mashau et al., 2016). Although all these works of literature point to the need for an organized education structure for caregivers, a study by Uemura, Sekido, & Tanioka (2014) reveals caregivers can independently acquire knowledge to aid them to discharge their duties.

Finally, medication or medicine had to be crashed; all the tablets mixed with water before giving it to patients. This revelation is confirmed by Chow et al. (2007), Weiss et al. (2009) and Giovannetti et al. (2012), which focused on assessing coping and support in caregivers of stroke patients. Contrary to existing studies, evidence from this study shows limited supporting systems in place to educate caregivers on bathing, feeding, communication and medication for stroke patients by caregivers.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

This chapter looks at the summary of the research process as well as the key findings that surfaced from the research. The chapter also outlines the conclusions and recommendations that were made based on the findings of the study. Areas suggested for further research are also presented in this final chapter of the study.

Summary

The focus of the study was to explore the experiences of informal caregivers of stroke patients in the Cape Coast metropolis. The study sought to investigate the informal caregivers' experiences with challenges associated with the care of stroke patients, explore caregivers' strategies for managing the "disease-related tasks" associated with stroke care among informal carers and to explore the support systems available to informal stroke caregivers in the Cape Coast metropolis**.** The research was a qualitative study that was based on a descriptive qualitative design. The population of the study was informal caregivers. The purposive sampling procedure was used to select 12 participants which comprised 3 males and 9 females. All participants were met in their various homes for the interviews. The main instrument for data collection for the study was a semi-structured interview guide. The interview data were transcribed, coded and analyzed thematically. Braun and Clark's (2006) six phases of qualitative data analysis were employed in analyzing the data. Findings were discussed concerning the research questions.

Key Findings

1. The finding on the challenges of informal caregivers of stroke patients showed that the challenges that confronted informal caregivers mostly in their discharge of duties included financial constraint, the health of the caregiver being affected and emotional challenges. Financing the medication bills and other necessities for the stroke patients by informal caregivers was a big challenging moment.
2. The finding of the strategies for managing the health-related task of caregivers revealed that caregivers employed strategies for bathing the patient, strategies for medication, communication strategies and feeding strategies. Feeding a stroke patient was a difficult issue in caring for them.
3. The study showed that support systems that were available for caregivers of stroke patients included support from families, communities and religious organizations. Family support in terms of visitations, giving financial assistance and helping to take the sick to the hospital when the need arose could not be underestimated by caregivers.

Conclusion

The study has shown the experiences of informal stroke caregivers and some of the strategies they adopt in managing patients. These caregivers experienced care-giving burden mainly due to financial difficulties, emotional distress, high care-giving demands and a resulting health effect. Even though existing community systems like families, friends, churches, etc. provided some form of support, the absence of community rehabilitation support services presented a lasting emotional burden like stress in their care-giving roles with subsequent impact on their lives. Many caregivers experienced a hard-financial toll with no existing support system in place to aid this effect. Also, the required skills in bathing, feeding, giving medications and active communications to patients which were crucial during their care-giving duties were self-learned without support from health professionals.

Recommendations

The subject of recommendation will be discussed with attention centered on the following sub-headings; nursing practice, nursing education, nursing or hospital administration and nursing research.

Nursing practice

In the area of nursing practice in Cape Coast Teaching Hospital, nurses should focus attention on caregivers while caring for patients with stroke or other chronic conditions. It should be appropriate that from the day of admission of stroke patients to the ward, a well-designed program aimed at equipping the caregivers with requisite skills that will enable them effectively care for their patients be put in place. One important skill demanding immediate attention is the skills of lifting patients from the bed. Most of the caregivers have problems with their waist and shoulders as a result of lifting. Caregivers should be given automatic recommendations to electronic lifting devices and allowed to decide if they can afford it. Training in this area will curb the development of health problems on the part of caregivers. In addition to the above, there must be follow-up activities in which nurses and doctors who attended to the caregivers and their patients could visit caregivers in their home to ascertain their challenges as well as that of the patients. This will help monitor progress made by patients and caregivers as to whether they are effectively implementing the requisite skills imparted by the nurses.

Nursing education

Furthermore, the recommendation for nursing education is vitally important and cannot be trivialized. The nursing institutions have only majored in the training of nurses for the wards and none of them has considered the training of nurses from the public schools or universities who can specialize in home care with much emphasis on the care of the elderly with chronic conditions. There should be workshops or conferences on home care to enhance nurses' interest and potentials

Nursing/ hospital administration

Not all hospital administration takes the care of stroke patients very seriously. This is because stroke affects the family of sufferers and even stops some of the caregivers from working to support the home. It is therefore very essential that clinicians who have specialized in the care and treatment of stroke are brought to the hospital or if possible trained. These specialists can quickly handle stroke patients from the onset to prevent devastation or the development of complications which directly increases the burden of caregivers. The nursing administration should in their capacity appoint nurses who attended to caregivers and their stroke patients to extend care to the homes of caregivers. Again, the psychology units of the hospital must also be involved in the follow-up visits to caregivers' homes. Since most of the caregivers are emotionally traumatized in the provision of care at home, psychological counseling is needed from time to time to relieve caregivers from emotional stress. The hospital administration can also play an advocacy role by calling for support from the various organizations' caregivers work to earn a living. This will help caregivers obtain time allocation for rendering care until they can resume work and not to quit work. The government must also ensure every drug needed in the treatment of stroke is available and covered by insurance in the various hospitals. This will result in reduced financial burdens on caregivers when it comes to purchasing expensive medications.

Nursing research

Finally, this study can be conducted in other hospitals in Ghana to know if findings will be similar or different. The need for a quantitative study into the experiences of informal caregivers of stroke patients is highly recommended. Research can also be conducted to investigate the lack of well-structured programs in the hospitals tailored to meet the needs of caregivers to enhance caring skills and capacities. Similar qualitative research can be carried out to explore the experiences of stroke patients. Also, further studies can be conducted to investigate the experiences of stroke patients themselves to understand what they go through when they go home from the hospital.

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APPENDICES

APPENDIX A

DATA COLLECTION INSTRUMENT

INFORMATION FOR PARTICIPANTS

STUDY TITLE: EXPERIENCES OF INFORMAL CAREGIVERS OF STROKE PATIENTS IN THE CAPE COAST METROPOLIS: A DESCRIPTIVE QUALITATIVE DESIGN

General Information about Research

This study is being undertaken for a Masters in Nursing at the University of Cape Coast. The research is purely for academic purpose and is undertaken to explore the experiences of informal caregivers of stroke patients in the Cape Coast Metropolis. The researcher was driven by the desire to know the skills employed by untrained caregivers in the management of stroke patients at home. The care of stroke patients is very difficult and challenging. Provision of good care at home can improve the quality of life of a stroke patient and it is therefore necessary to investigate what informal caregivers go through.

Procedures

To find answers to some of these questions, we invite you to take part in this research project. If you accept, you will be required to participate in an interview with Godwin Kwame Fianu. You were selected because you have been on admission with a stroke patient at the Cape Coast Teaching Hospital and since your discharge from the hospital, you have been caring and have gained experience needed for a study of this nature. You are expected to share with us every experience you have gained in the care of your patient. If you do not wish to answer any of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place in your home and no one else but the interviewer will be present. The information recorded is considered confidential and no one else except Godwin Kwame Fianu name will have access to the information documented during your interview. The expected duration of the interview is about 60–105 minutes.

Possible Risks and Discomforts

There is nothing risky or discomforting by agreeing to participate in this study except the discomfort of taking time off your busy schedule to grant us an interview. The team will manage to decrease this discomfort by going straight to the point so as not to consume more than necessary time.

Possible Benefits

There are no financial or material benefits by taking part in this study. However, the research is expected to provide us with a picture about experiences of caregivers of stroke patients in order to promote patient`s safety. The findings of the research will also inform the formal caregivers of stroke patients about what educational programme to develop in order to equip informal caregivers with skills. It can also lead to the formulation of policy that will ensure the provision of follow-up care by medical professional after the discharge of stroke patient from the hospitals of admission.

Confidentiality

This study is anonymous and we will not be collecting or retaining any information about your identity. Information provided in this study will not be accessed by any person outside the research team. The audio recordings made will be kept under lock and key and finally destroyed after publication of the research work.

Voluntary Participation and Right to Leave the Research

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the investigators of this study or the School of Nursing, University of Cape Coast. You have the right to withdraw completely from the interview at any point during the process. Additionally, you have the right to request the interviewer not to use any of your interview material.

Contacts for Additional Information

If you have any enquiry or clarification about this research, please kindly contact Mr Godwin Kwame Fianu through this contact number 0243685474.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCC IRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 pm through the phones lines 0332133172 and 0244207814 or email address: irb@ucc.edu.gh.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title "Experiences of informal caregivers of stroke patients in the Cape Coast Metropolis" has been read and explained to me.

I have been given an opportunity to have any questions about the research answered to my satisfaction.

I agree to participate as a volunteer.

_____________________________ ____

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 Consent.

SECTION A. BIOGRAPHICAL INFORMMATION

The purpose of this study is to explore the experiences of caregivers of stroke survivors and you are invited to participate. If you accept to participate, an interview will be conducted with you. The interview will include questions about the care you give to your stroke patient and what your experiences are. The interview will be completed between 30–45 minutes. With your permission, the interview will be taped. Any question you do not want answer can be skipped. The records of this study will be kept confidential and destroyed after the study.

1) Date of birth …………………

2) Sex: -

a) Female

b) Male

3) Relationship with the stroke patient

a) Spouse………

b) Sister…………

c) Brother………

d) Son………….

e) Daughter…….

f) Others (please specify) ………………….

4) How many years have you been caring for your patient?............................

5) What is your level of education?

a) None…………

b) Primary…………..

c) JHS/Middle School……

e) Secondary……

f) Polytechnic/Vocational…………

g) University………..

h) Other (please specific) …………………………

SECTION B. SEMISTRUCTURED INTERVIEW GUIDE

1) What has been your experience since you started caring for your patient?

Probe for:

a) How long have you been providing care?

b) Is there something you like about caring for your patient?

c) What do you hate about caring for a stroke patient?

d) What skills have you acquired since you started caring?

2) What are the barriers or challenges you have encountered in the care of your patient?

Probe for challenges with careers well-being

i) Emotional challenges?

ii) Financial challenges?

iii) Challenges with the personal life and work of the carer?

iv) Challenges with the carer's health status?

Also probe for challenges with disease related care, including challenges with:

i) Bathing patient

ii) Feeding patient

iii) Giving medication

iv) Preventing pressure sores

v) Preventing contractures

vi) Communicating with the client

vii) Maintaining the hygiene and comfort of patients (urine elimination and defaecation)

3) What strategies have you used in performing the disease related task for your client: in the care of your patient?

Probe for strategies used in:

i) Bathing patients

ii) Feeding patient

iii) Giving medication

iv) Preventing pressure sores

vi) Preventing contractures

vii) Communicating with patient

viii) Maintaining the hygiene and comfort (urine and faeces)

4) What support do you receive in caring for the stroke patient?

Probe for support from:

i) Religious organizations?

ii) Family members?

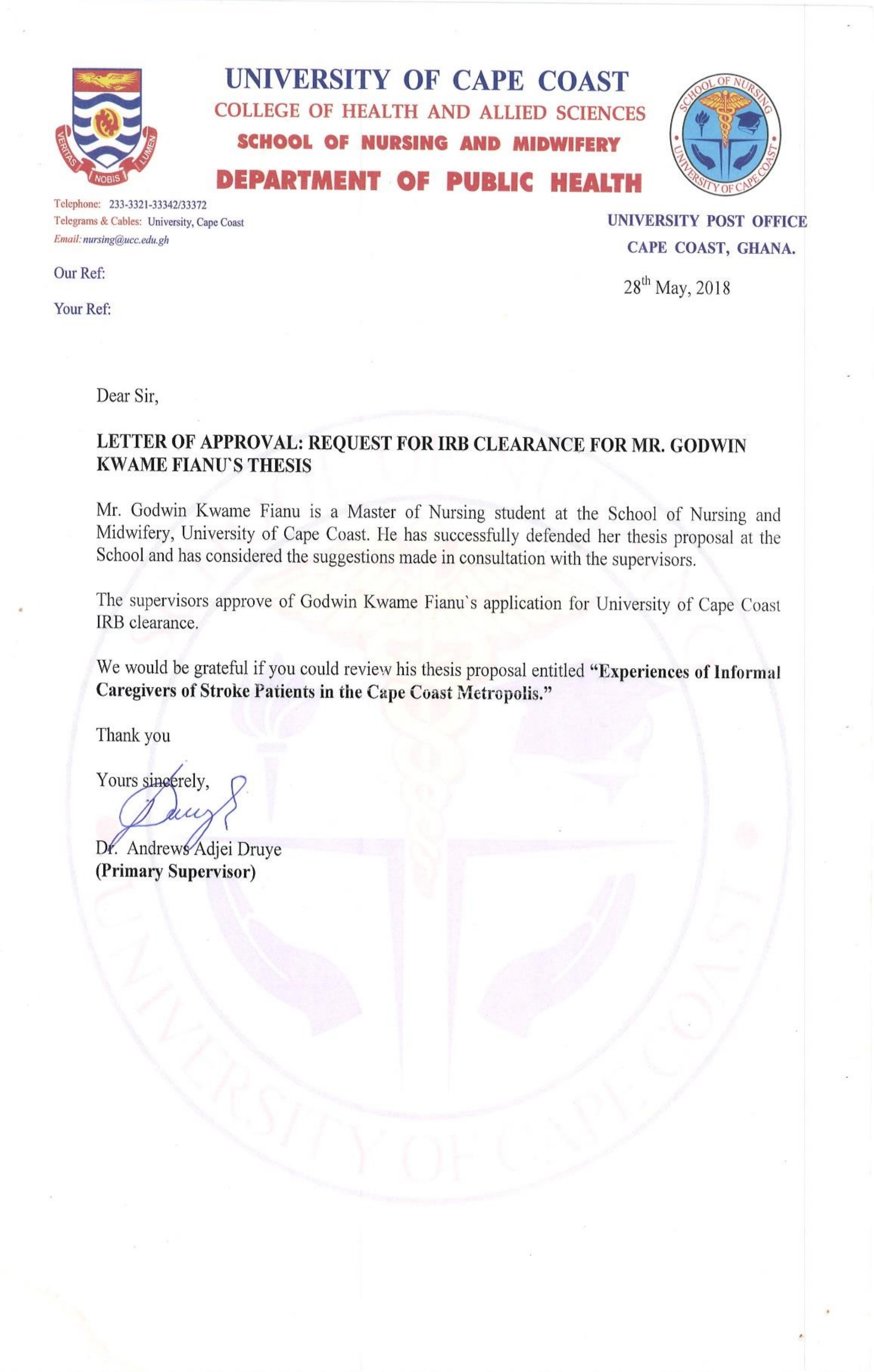
iii) Health professionals?

iv) Community members?

v) Community based organization (NGOs)?

5) Are there any other things you would like to share with me concerning the care of your patient?

APPENDIX B
LETTER OF APPROVAL



UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEPARTMENT OF PUBLIC HEALTH

Telephone: 233-3321-33342/33372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref:

Your Ref:

28th May, 2018

Dear Sir,

LETTER OF APPROVAL: REQUEST FOR IRB CLEARANCE FOR MR. GODWIN KWAME FIANU`S THESIS

Mr. Godwin Kwame Fianu is a Master of Nursing student at the School of Nursing and Midwifery, University of Cape Coast. He has successfully defended her thesis proposal at the School and has considered the suggestions made in consultation with the supervisors.

The supervisors approve of Godwin Kwame Fianu`s application for University of Cape Coast IRB clearance.

We would be grateful if you could review his thesis proposal entitled **"Experiences of Informal Caregivers of Stroke Patients in the Cape Coast Metropolis."**

Thank you

Yours sincerely,

Dr. Andrews Adjei Druye
(Primary Supervisor)

APPENDIX C
LETTER FOR ETHICAL CLEARANCE

UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEAN'S OFFICE

Telephone: 233-3321-33342/33372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref: SNM/I/4/Vol.1/49
Your Ref:

1st January, 2018

The Chairman
Institutional Review Board
UCC

Dear Sir,

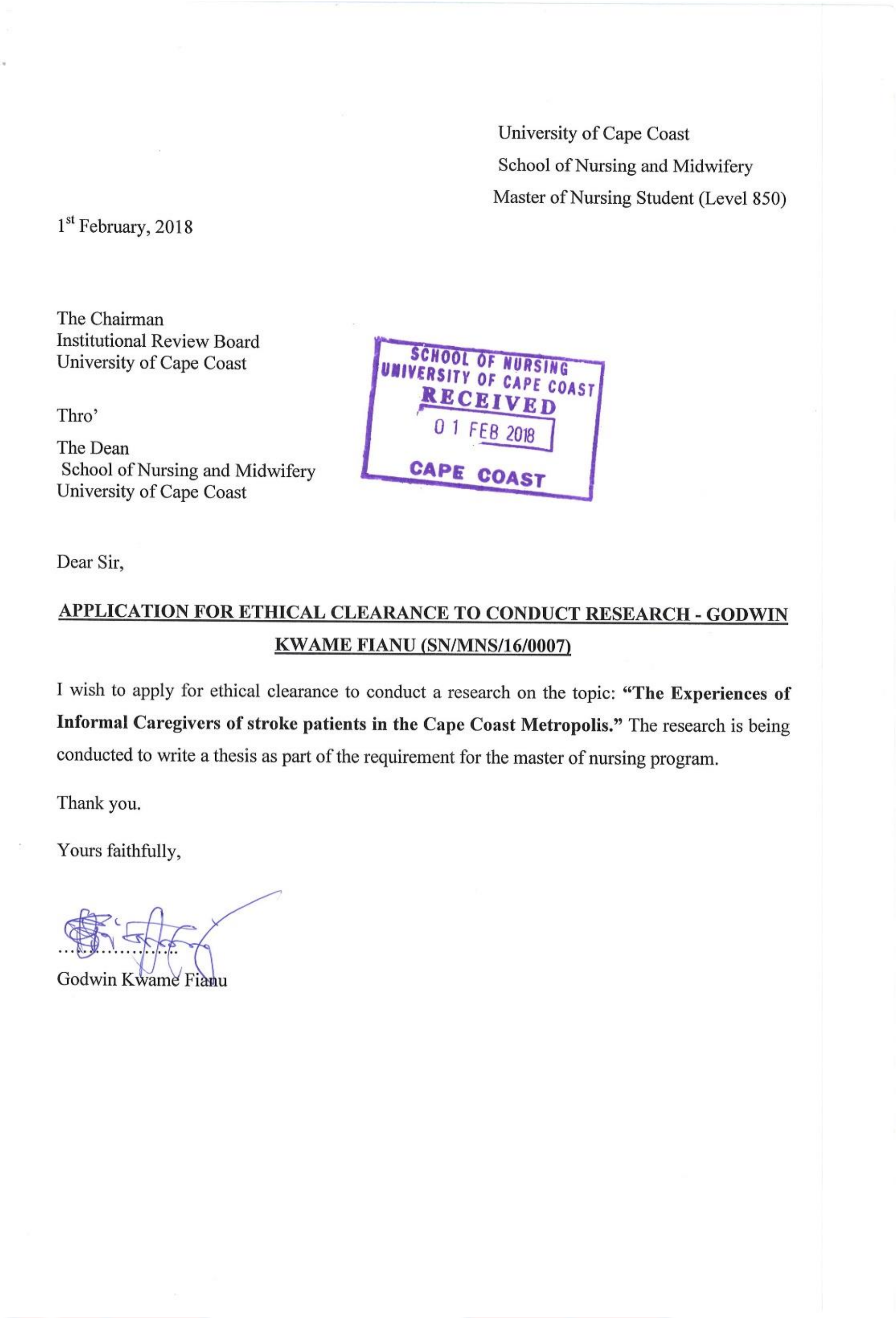
RE: APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT A STUDY: MR. GODWIN KWAME FIANU

We forward herewith the attached application for ethical clearance from the above-mentioned Post-Graduate student of the School of Nursing and Midwifery for your consideration, please.

Thank you.

Yours faithfully,

Dr. Samuel Victor Nuvor
VICE-DEAN



University of Cape Coast
School of Nursing and Midwifery
Master of Nursing Student (Level 850)

1st February, 2018

The Chairman
Institutional Review Board
University of Cape Coast

Thro'

The Dean
School of Nursing and Midwifery
University of Cape Coast

SCHOOL OF NURSING
UNIVERSITY OF CAPE COAST
RECEIVED
01 FEB 2018
CAPE COAST

Dear Sir,

APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT RESEARCH - GODWIN KWAME FIANU (SN/MNS/16/0007)

I wish to apply for ethical clearance to conduct a research on the topic: **"The Experiences of Informal Caregivers of stroke patients in the Cape Coast Metropolis."** The research is being conducted to write a thesis as part of the requirement for the master of nursing program.

Thank you.

Yours faithfully,

……………………

Godwin Kwame Fianu

APPENDIX D
LETTER OF INTRODUCTION

UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEAN'S OFFICE

Telephone: 233-3321-33342/33372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref: SNM/R/2/Vol.2/69
Your Ref:

23rd May, 2018

………………………………………………………
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………………………………………………………
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………………………………………………………

Dear Sir,

LETTER OF INTRODUCTION: MR. GODWIN KWAME FIANU: SN/MNS/16/0007

The above named student of the School of Nursing and Midwifery, University of Cape Coast is undertaking a research as part of the requirements for her Mater of Nursing program.

She would like to collect data in your institution, Cape Coast Teaching Hospital.

Her topic is: **Assessing the Practices of palliative and end of life care among nurses: A study at Cape Coast Teaching Hospital.**

We would be grateful, if you could offer her the necessary assistance and support she may need to enable her collect the data for the research.

Counting on your cooperation.

Thank you.

Yours faithfully,

SCHOOL OF NURSING
UNIVERSITY OF CAPE COAST
CAPE COAST

Dr. Samuel Victor Nuvor
VICE-DEAN